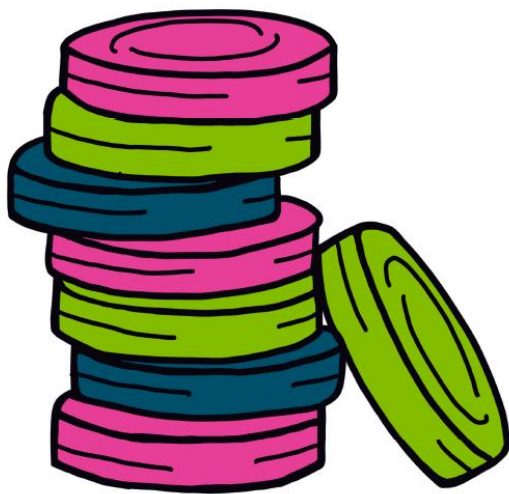


# Personal Budgets



**Report into the lived experience of Personal Budgets within Essex with a particular focus on Direct Payments**

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## 1.0 Introduction

### 1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. We aim to influence decision-makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience. We also provide an information service to help people access, understand, and navigate the health and social care system.

### 1.2 Background

Personal budgets have been rolled out in England since 2008, providing an allocation of funding to users to support and manage their care needs. With a personal budget ‘Government steps back, making the space for people to lead the lives they want, how they want to. In health and social care, that means giving people real choice over their treatment; real control over how money is spent; and real power to hold services to account.’<sup>1</sup>. The Care Act 2014 stated that all local authorities needed to provide a personal budget to anyone who qualified, giving individuals more control over the support they received. A personal budget can be managed in three ways; Arranged by the council on an individual’s behalf, managed and arranged by an independent provider (Individual Service Fund) or as a direct payment to the individual. Whichever way a personal budget is received, local authorities will continually work to produce the support plan most beneficial to the individual. This support plan should set out the eligible needs of the individual, as assessed by the Local Authority, the outcomes and goals important to meet those assessed needs and the solutions the Social Care Worker and individual have agreed would be appropriate to meet those needs. The plan should also identify the Personal Budget amount that has been agreed between the LA and the individual.

Direct Payments were first introduced in Essex in 1997, for disabled adults of working age. By 2001, the criteria had expanded to include older people, carers, parents of disabled children & young adults (16-17). It was in 2003 that regulations changed, which required local councils to make Direct Payments to people who either choose to have them or wished to have them. Essex has currently entered a review and redesign phase of Direct Payments, which, are currently accessed by over 3500 people. It is therefore crucial to ensure that people are getting the best outcome from their Personal Budget and use of a Direct Payment, and we intended to gather this insight by engaging with individuals of all ages, who either directly receive a Direct payment or manage one on someone’s behalf.

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<sup>1</sup> Jones, Karen C. and Forder, Julien E. and Caiels, James and Welch, Elizabeth and Windle, Karen and Dolan, Paul and Glendinning, Caroline and Irvine, Annie and King, Dominic (2011) The cost of implementing personal health budgets. Project report. Personal Social Services Research Unit, University of Kent, Canterbury

We also conducted several conversations with professionals regarding their current thoughts on Personal Budgets, especially Direct payments. These conversations have backed up the themes we have identified, and it is our belief they are the most important topics to focus our analysis on.

## 1.3 Acknowledgement

Healthwatch Essex would like to thank Essex County Council for their continued support throughout this project. We would also like to thank all individuals who took the time to complete the survey and share their lived experience.

## 1.4 Terminology

**Personal Budget (PB)**- Is an agreed amount of money to support an individual's Social Care & support needs.

**Direct payments (DP)**- One way an individual can utilise a Personal Budget to meet their eligible needs. This means they receive the money directly to arrange their own care rather than having the local authority look after their money and arrange care on their behalf.

**Personal Assistant (PA)**- Someone hired by an individual to help with various aspects of their daily life. PA's can also be self-employed, and the individual can enter in to a contract with.

**Support Plan**- Document written between the social worker and Personal Budget receiver, which outlines areas that the Personal Budget can be used for.

**Personalisation of Care**- When people have choice and control over the way their care is planned and delivered

**Advocate**- "An individual who can support people with care and support needs to ensure their rights are upheld and their voice is heard in decisions that impact upon their life"

**Purple**- Disability support service acting on behalf of an individual to manage their direct payment. This can be through many ways, such as providing a payroll service, employer guidance and support to find PAs.

**Individual Service Fund** - The Personal Budget is held by a provider organisation rather than managed by the LA or managed as a Direct Payment. The provider is responsible for arranging care and support against the budget by working closely with person who needs support, their family/wider circle of support and others. They can provide some, all of or none of the care directly. This mechanism enables more choice and control than a managed service but with less administrative and other burdens on the person receiving support and their family than a Direct Payment can sometime entail. It also allows the provider managing the budget to broker other support from local organisations as agreed with the person in receipt of support. An ISF model is in the early stage of development in Essex, the intention is to ensure it is part of the wider Adult Social Care offer in the future.

## 1.5 Disclaimer

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during the engagement visits. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time

## 2.0 Purpose

Healthwatch Essex was asked by Essex County Council to gather insight into the lived experience of people in Essex who receive a personal budget particularly, those who receive this via a direct payment.

With an increasing focus on the personalisation of care, there is a vital need to understand whether the current direct payment scheme is acknowledging the guidelines stated in the Care Act 2014<sup>2</sup>.

We captured lived experience of people living in Essex and ensured we gathered in-depth and real opinions concerning the direct payment scheme. Throughout the project, we spoke to participants who provided a broad overview of the current system, collecting their personal experiences, which had in some cases, unique circumstances.

## 2.1 Engagement methods

A qualitative approach was used to understand peoples' experience of personal budgets and their feelings towards the current direct payment offer. Conversations between Healthwatch Essex and Essex County Council identified the easiest and most practical way to engage with individuals. We decided that data would be collected via two workstreams.

We contacted individuals on the direct payment scheme by putting together a 6-item survey consisting of a mixture of multiple-choice and open-ended questions. Recruitment for participants began in July 2020, with the promotion of the survey via a newsletter and other communications sent by both Essex County Council and Healthwatch Essex social media platforms. In total, we engaged with 27 people of mixed ages, gender, and disability demographics.

The survey invited participants to express their views on a Personal Budget, how they receive a Personal Budget and what could be done to make improvements.

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<sup>2</sup> <https://www.legislation.gov.uk/ukpga/2014/23/section/22/enacted>

To further gather a more in-depth understanding of peoples' lived experience of a Personal Budget, we invited respondents from the survey and networks already established at Healthwatch Essex to take part in a semi-structured interview. Due to Covid-19 restrictions, interviews took place over the phone or via video calling platforms with arrangements made to suit individual needs if requested.

To ensure the anonymity of the participants and confidentiality of the information they provided, names are excluded from the report.

Interviews were then transcribed and analysed, where several key themes were consistently identified by all participants across both areas of engagement.

## 2.2 Summary of Themes

Through our engagement and analysis, we identified the following key findings.

### Personal relationships between social worker and Direct Payment Recipient

When an individual had a consistent and robust relationship with a dedicated social worker who understood their needs, they were positively satisfied with their Personal Budget. When this relationship was “not in place”, feelings differed substantially.

### Knowledge & Interaction with the payment system

Understanding what a personal budget is and how it works can be a challenge for some people. This section focuses on the importance of regular ongoing communication and feedback.

### Choice and control contradiction

Although a direct payment is intended to increase the flexibility of choice and control, numerous factors suggest this is not always the case and has even been described as an ‘inpersonal budget’.

## 3.0 Key Findings and Recommendations

### 3.1 Personal relationships between social worker and Direct Payment Recipient

When engaging with participants both through the survey and interviews, it was necessary to note how experiences and opinions differed depending on the level of personalisation an individual encountered with others.

Important factors contributed to an individual's level of trust in Direct Payments when strong relationships were formed.

However, when someone did not have a continued relationship with dedicated social workers, their experience and opinion differed entirely.

#### 3.11 Understanding of an individual's disability

With everyone we engaged with, it was clear there was a need to feel understood as an individual, as opposed to another person who receives a personal budget. The people we spoke to all had differing needs and, at times, complex needs that should be personally addressed and acknowledged. However, what was intriguing was at what level this individuality was approached and how this influenced the relationships.

Some participants expressed their discomfort at continually speaking about their disabilities with different social workers, especially when it came to their annual review.

**“Feels like an interrogation and they have not read the records in advance. Continuously have to go over the same thing each time”.**

This was further highlighted as an issue by those who act as advocates for a direct payment receiver.

**“The initial social worker was very good. Very thorough and sympathetic to my daughter's needs. However, annual reviews have been undertaken by agency staff who arrive without the questionnaires and don't seem very organised”.**

Furthermore, participants expressed that it was sometimes easy to tell when a social worker had failed to dedicate the time to read notes, which you would consider an essential priority to ensure the individual's needs were being met.

**“But it should be based on the fact that you've read up before you've come out. We can sometimes tell when they haven't. Purely from the fact of the questions they ask”.**

With these factors in mind, it's compelling to see the type of emotion these scenarios caused. Some participants were left feeling upset, having to repeat themselves, which was re-traumatising for the family.

**“Very upsetting. It's quite distressing to repeat everything that's wrong with someone when they're sitting beside you”.**

**“I stress its horrendous because they don't want to keep talking about what's happened to them”.**

For one participant, these situations became so harrowing that they had to seek further support to deal with the aftermath.

**"I get very depressed and have had to have psych support in the past."**

On the other hand, when speaking with individuals who had a good relationship and understanding of their condition with their social worker, the response differed.

**"My mental health social worker dealt with this (annual review), which was good as I often find it hard to explain myself".**

It is interesting to hear that with the support from trained individuals specialising in a particular condition suited to an individual's needs, participants trusted them to advocate on their behalf.

One participant also expressed how having an understanding and trusting relationship helped make the review & assessment processes easier.

**"The process was smooth and implemented quickly through our social worker".**

Therefore, we can assume that when someone understands a person's condition, both processes are less of an 'horrendous' experience, as indicated previously. Still, instead, a smoother process where the individual is listened to and their needs correctly met.

It's important to note that out of the 30+ individuals we engaged with throughout this study, only three mentioned having any relationship with an individual trained or understanding of their condition. Other participants highlighted the countless number of individuals they engaged with over the years.

Interestingly, one participant mentioned engaging with an experienced social worker who knew the ins and outs of the direct payment system. Still, they lacked a genuine understanding of their condition.

**"But she was wonderful. She had lots and lots of experience, and she was an expert in direct payments, but she still lacked that, understanding, and the barriers".**

Therefore, we can conclude that developing a trusting relationship empowers the individual to have confidence throughout the assessment and subsequent reviews, which results in anxiety being decreased during this process.

### **3.12 Consistent Social Worker**

Having a level of trust is seen as necessary between social worker and receiver, particularly the understanding of an individual's needs. When we combine that level of understanding with the consistency of a social worker, participants acknowledged that they were happier with this system.

Individuals who indicated that they received support and guidance from one consistent social worker had a better experience of the DP system. This consistency was especially acknowledged by individuals who received a personal budget as a child, indicating how relationships formed were not only beneficial to the receiver but also their family.

**"They get to know the child or the youngster, and they get to know the family. I mean, we've probably had our social worker, I'd say eight years now".**

Interestingly, participants who acknowledged this consistency have had conversations with others who do not share the same experience. Participants stated that it is very specific to who the social worker is that is put in place, as to how good they are.



**“it all depends on what social worker you've got. We've got a very good social worker. So, I think, speaking to other parents that we know, that's not always the case, you know”.**

Therefore, it can be assumed that other parents/carers have struggled with inconsistency. Although some children with a PB do have consistency, this is not always the case for all receivers.

We continued to see this inconsistency when speaking with individuals who are under adult social care. What was important to see was what emotions were conveyed with these inconsistencies.

**“Stressful. Annual assessments by the social worker and there is no continuity. New social worker every time”.**

Participants expressing that these situations create stress draws focus on the need to have consistency. What was even more compelling was the number of different social workers you can have contact with over a period. One participant, for example, had spoken with between 10 - 12 social workers.

Participants revealed that by speaking to several different social workers, you, in turn, go through the process of disclosing your information and history several times, which leads to frustration due to the lack of understanding of an individual's needs.

One participant also drew focus to conversations they have had with social workers, highlighting that feelings stem beyond the personal budget receiver.

**“I mean, I've spoken to some social workers who say they feel like they are entering the Dragons Den when they go to a panel. I said, well, on our end when you come to us, it is like us entering Donte's inferno because that's how you make us feel”.**

Consistency can, therefore, be highlighted as a need for both receiver and social worker. If social workers feel like they are entering 'dragons den', this tells us that instead of reviews being personal, they are more like a business pitch, which causes the individual to feel like they have entered 'hell'.

Moreover, what is clear from discussions with participants is that understanding & consistency go hand in hand and create a level of trust and empowerment. When listening to individuals, this was something that clearly needed to be changed and was mentioned numerous times by nearly every participant.

**“For review purposes, it would be good to have trained & understanding social workers and to have a named contact”.**

**“Annual assessments and audits of the budget to be carried out by the same person”.**

If this change benefited the welfare of the individual and social workers, it would allow for effective communication, trust, and co-operation across the direct payment system.

## 3.2 Knowledge and Interaction with the payment system

Knowledge of Personal Budgets and the Direct Payment system varied across all participants, which in turn affected an individual's confidence in speaking up and challenging the system. It is said that knowledge gained through experience is vastly superior, and in terms of Personal Budgets, knowledge is at times key to ensuring it is fit for purpose to meet the individual's needs. However, an individual's knowledge is only a small cog in a large machine and problems with organisations involved in Personal Budgets are contributing factors.

### 3.21 Experience = knowledge

When speaking with receivers of a PB, there was a clear indication that some individuals had a good understanding of how they work, whereas others lacked this knowledge due to various reasons.

Some participants and parents of PB receivers acknowledged that their professional backgrounds contributed to their understanding of the system.

**"But one of the reasons why I know is because of the roles that I've always been in and working with Sense, the National Organization for Deafblind people, we did a whole project on Personal Budget's in the early days".**

Participants recognised that having experience benefited them, allowing them to understand when the system was not working as it was initially intended to. Another participant further acknowledged this.

**"I am acutely aware of personal budgets. I have been for a long time. I know how they work, why they work and what the benefit is to people".**

What is quite clear is that participants felt empowered by recognising their knowledge of the system. Interestingly, although these individuals felt confident because of their experience, they still, at times, felt they struggled with understanding certain elements. Therefore, someone with little or no understanding would find it difficult during the process without that 'advantage' of having gained knowledge or experience.

**"You know, obviously, we are quite aware of how the system works; we knew the process. But for a lot of parents that don't understand the system. You know, I'm finding it a little bit frustrating at the moment because I'm sort of saying, well, here's the pot of money who do I give it to?"**

Therefore, it's clear that knowledge can't always make the process easier, but it can contribute significantly to individuals' decision and voices. We need to therefore equip everyone with the most critical information to allow for greater understanding.

### 3.22 Communication with Purple

When speaking with participants, it was clear that most had chosen to use Purple to manage their finances on their behalf, which was easier for them. Participants noted they loved the ethos of the company and what they set out to achieve.

**"Purple, the idea of Purple is brilliant. It's got a lot of people with a disability working there and stuff like that. I think that's absolutely brilliant".**

Participants emphasised how encouraging it was to work with a company actively championing employment for people with a disability and how this made them want to get involved more. However, participants felt discouraged about Purple after raising concerns about the level of Interaction and lack of communication they had encountered.

Participants expressed concerns around some of the problems with services that were part of their support plan that had not been paid on time.

**“Purple, who were supposed to manage my personal budget for me, did not pay my taxi driver for several weeks, so he resigned. I’ve had to pay myself and have had my claim completely ignored”.**

We reached out to Purple who explained they have to follow clear protocols regarding such situations. The payments specified are known as reimbursements and for example, if the individual had insufficient funds in their account or this expenditure is not included within their support plan, Purple is not authorised to make a payment, and this is escalated to ECC for approval.

We can’t speculate exactly the situation which led to these respondents comment but what is clear is communication and education for the direct payment receiver is needed to enable them to understand when the correct circumstance is to contact Purple.

What is interesting to hear is when contact is trying to be made, individuals are being ignored rather than acknowledged. Other participants further evidence this lack of communication.

**“I hate to say it because I really do continually try to work with them (Purple), but you can never get a look in. They do not respond; they do not reply to emails, to calls.”**

Interestingly, Purple’s website stipulates that all individuals should have access to a personal account manager<sup>3</sup>, however, when speaking with individuals, it can be argued otherwise.

**“Purples account managers never stay too long (around six months), so there is never a ‘go to’ person to discuss amount issues”.**

Participants drew attention to this inconsistency and raised concerns about who they could approach to discuss important matters with their direct payment. When a consistent point of contact is not in place, participants opted for the best outcome they could in the situation.

**“I speak to whoever picks up the call. I haven’t got a number for them.”**

We can start to see a pattern emerging in relation to attempting to contact someone directly, and participants stated that they would speak to anyone who will listen.

**“I’ve actually physically before Covid, turned up because I had so many things that weren’t being answered. But actually, I tapped at the door and said please meet with me”.**

It’s alarming how many participants are going to such lengths to have some form of communication with Purple. It raises the question of how many other individual queries are

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<sup>3</sup> <https://wearepurple.org.uk/direct-payment-support/managing-your-personal-budget/payroll-and-payment-services/>

being ignored or unanswered because they don't have the confidence to go above and beyond?

What is also important to acknowledge is that a company specialising in providing a service for individuals with a disability lacks the technology to do so. This was clear when speaking with participants who received digital communication through various channels which did not contain accessible information to meet their needs.

**"I don't find them very helpful in the fact that they used to send a timesheet. But it wasn't accessible using screen readers. My screen reader would read all of that, and it would say '101/02/01/09/06/03/01/05/0289/04/' and that would just be one line. I raised it with them, but they said there's nothing we can do about it" (blind participant)**

When we spoke to Purple, they were disappointed that a service user was told this. As a result, they are putting in place a training plan focused on improving understanding of impairment issues as well as wider customer service responsibilities.

### **3.23 Understanding of payroll**

Communication is also fundamental in relation to payroll. Like many people, it can be challenging to understand how payroll works if you are not familiar with the process. Most participants that we spoke to indicated they had chosen to have their Personal Budget paid through Purple to ease the stress of sorting out payroll.

However, when speaking with individuals in both the survey and interviews, the current payroll system has become challenging to navigate.

One participant indicated that Purple's payroll service had been OK, but they still had to keep track of what was happening.

**"Over a number of years, the service from Purple is adequate but has to be frequently monitored as mistakes do occur".**

Although understandably, mistakes can happen, if these mistakes were rectified quickly and efficiently, the payroll system would likely function quicker.

Participants also indicated that the payroll system, as it used to be, was leaving them short some months, which was difficult to manage.

**"I was just saying they also run a stupid four-week payroll. Which means that we have to hand timesheets in four weekly, which means that one month a year, I have to pay my PA's twice in one month."** Since November 2020, the system was updated to a monthly payroll to avoid such situations as the one previously mentioned. However, one individual indicated they was not made aware of this change.

**"If you're sending in a 4-week time schedule, it's now changed, and it's monthly. So without telling us, they have changed it again. When I phoned them up and said, what's going on? They said you should have had some communication. I said, OK, I haven't?"**

ECC have commented that Purple went to great lengths to make people aware of this change; wrote & emailed out, added it to payslips and sent it out on their autoresponders. This therefore raises questions as to why this specific individual missed this update. It's important to note that this respondent has a visual impairment, which highlights a potential need to investigate what extent communication is adapted to people with accessibility

needs and that by working together with people with accessibility needs, situations like this could potentially be avoided in the future.

Individuals also appreciated the need for communication from Purple when it came to what they can provide as part of their payroll service.

**“For example, I had a PA go on maternity leave, and they refused to help me to work out maternity pay calculations for me. And they said that was my role in doing that”.**

**Purple commented that as part of their service, they do offer advice on forms that need completing and their payrolls system can calculate pay for maternity leave between dates provided.**

What would therefore have been helpful for this participant is an understanding of what is expected from them for Purple to support them. What this comes down to is once again having clear communication from the outset of what Purple is commissioned to do and letting the individual know if they need to provide anything from their end.

We can conclude that communication and feedback are vital for people to feel satisfied, and that Purple can be seen by participants as needing to improve their service in relation to this.

We spoke with Purple prior to publishing the report who accept some of the criticisms, particularly in the past, and we are pleased to learn that they will be implementing some of the proposals in this report.

The organisation may require some improvements; however, Purple was seen as valuable, and individuals felt a need for their support.

### 3.3 Choice and Control Contradiction

If you were to explain to someone what a personal budget was, the word personal would stand out, would it not? One would assume that this budget would be personal to the individual, but when speaking with participants in this project, that was not always the case.

In some cases, where levels of choice were indicated to a degree, this choice was contradicted by feelings of control and loss of flexibility due to several contributing factors.

#### 3.31 Choice in PA's

The hiring of PA/s is a fundamental part of a personal budget, which for many, is essential to living their best lifestyle.

Participants acknowledged that receiving a personal budget via a direct payment allowed them to control who they hired as their PA.

**“It's the freedom to employ who you want and to have the right people you want to come into your home without being dictated to by the county. So you do have that choice”.**

It's this word 'freedom' that really stood out when speaking with individuals having the power to employ people who the participants trusted and felt comfortable with makes a personal budget work well.

**“So, they might have other jobs (PA’s), but they only work in a caring kind of role. They get him, they like him, he’s at the forefront, he rings them when they’re not working, and they’re happy with that, they have a chat with him about their day on facetime, so it’s a real balanced relationship”.**

What’s clear from speaking to participants is that having that control to hire PAs you are comfortable with means you form that strong relationship that is important for the individual and the PA themselves. These relationships can also be tailored to suit an individual, allowing them to work with their PA to find out what works best.

One participant shared how they were told to change their PA because they were a family member but indicated that the trust and reassurance of hiring a family member was beneficial to them due to their disability. Without a PA they trusted, they described the situation as being like them openly handing a stranger their bank card.

**“My PA is my daughter, which they don’t usually allow. When the social worker was sitting there, he said I want you to find another PA. I said, that’s fine, could you give me your bank card your PIN, please. He went no, I went why not? He said because I wouldn’t. I said, that’s what you are expecting me to do, because every time I go to a shop, people can look over my shoulder, work out what my pin is”.**

This respondent has highlighted how having a family member PA is beneficially for them due to their disability. The care act states that the hiring of family PA’s is only allowed in exceptional circumstances<sup>4</sup>, What would therefore be beneficial is education given to Social Workers & the receiver around what constitutes an ‘exceptional circumstance’ and if the individual doesn’t qualify for a family member as a PA, then support put in place to find them a suitable alternative to create a level of trust.

Some participants highlighted that using an agency does not present an opportunity to build a fundamental relationship.

**“I know that if I were using an agency, it would be professionalism, we don’t allow hugs, we have a no hugging policy. That’s why I gave up with agencies in the end because I just thought we needed to have more flexibility to help my son to get in his life, to build relationships, which is what he’s got”.**

What’s clear is that some individuals want to avoid this idea of professionalism and emphasise that every part of a Personal Budget is personal to them, including their choice in hiring PAs.

What was interesting, however, when speaking with individuals, was the discrepancy they raised regarding the cost between care workers employed by an agency and employed PAs.

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<sup>4</sup> 12.35. The previous 2009 Direct Payment Regulations excluded the payment from being used to pay for care from a close family member living in the same household, except in exceptional circumstances. While the Care and Support (Direct Payments) Regulations 2014 maintain this provision regarding paying a family member living in the same household This does not include family members that live elsewhere to the direct payment recipient (i.e. it is allowed to pay a family member to provide care, as long as that member does not live in the same household). 12. Direct payments 171 same household for care, they do allow local authority discretion to give prior consent to pay a close family member living in the same household to provide management and/or administrative support to the direct payment holder- Source [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/315993/Care-Act-Guidance.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/315993/Care-Act-Guidance.pdf)

**“There's a difference between what they pay us and what they pay the care agency down the road, which is absolutely bizarre. They pay them more, and yet our responsibilities are higher than theirs because, if we pay over the PAYE, we have to pay pensions and national insurance”.**

This was also raised by another individual we spoke to, who also questioned why this was the case and found it hard to understand the split between both.

**“But it's become evident to me, this divide. If you are using a care agency, if you had PA carers through a care agency, assessment cost per hour would be £20-£25. For my PA, I only get about £11.78”.**

The fact individuals have picked up on this discrepancy and are questioning it adds to the idea that the Direct Payment scheme is not so personal. This leads to some individuals finding it hard to retain PAs as they can only afford to pay them at much lesser rates than an agency can hire them to work.

**“I can only pay a maximum of ten pounds an hour, which bearing in mind that a PA is an extremely professional role and too hard to retain. People that are employing their own PA's are discriminated against”.**

Participants also acknowledged that if this continued, they could lose valuable workers.

**“So in reality, I've got someone working for an extra eight hours on Peanuts. Because I can't take the rate down any lower, otherwise they walk”.**

What's clear is that developing relationships is extremely important to individuals, and they value the work their PA/s do for them. What needs to be considered once again is putting the individual at the heart of Direct Payments . If we want to encourage individuals to hire their own PA's, then we shouldn't be making this difficult for them by making people work the same level as care agency staff for less money. It needs to be a priority to ensure the right PA's can be retained and create personal relationships with individuals to ensure their Personal Budget is fulfilling its need.

### **3.32 Goalpost's & flexibility**

What was clear from speaking with individuals was that receiving a Personal Budget had allowed for a sense of freedom and given confidence which hadn't existed before. One participant shared their experience of running out of their savings to pay for care and how having a Personal Budget had changed this.

**“It's completely changed our lives. I mean, we had run out of money anyway. You know, we didn't have our savings pot anymore to draw on. It gives me the freedom that I didn't have”.**

What we can tell from this statement is that for this participant, a Personal Budget came at a crucial point in their life, one where they had been relying on their savings to help support their needs. It's interesting to note, however, although this individual felt they had freedom, they also raised concerns around how much actual 'freedom' they got with this budget.

**“It's very hard to explain, but I definitely feel that I'm under the control of someone. Like I am owned by someone, it sounds really weird. I don't feel like I'm free”.**

We can argue that despite this individual feeling a sense of freedom and that a Personal Budget took the pressure off their finances, the constraints of a personal budget could actually make them feel more trapped without control over making decisions.

These queries about freedom were especially prevalent when it came to individuals support plans.

**“I just feel I'm very controlled by my budget because there's so much if you read the document (Support plan), you know, you can't do this. oh, it's just awful.”**

This anxiety around support plans was further noted by other participants who expressed how restricting these plans could be, but more importantly, the uncertainty of them being kept up to date.

**“I mean, his support plan is almost null and void because it's so old. I don't even think anybody uses it as a point of reference now. In my head, it's just in a place where it covers what they say it needs to cover, and that's the end of it. There's no autonomy, no flexibility in it”.**

We can argue that support plans are not changing with an individual; therefore, what's written doesn't reflect a change in an individual's circumstances from one year to the next. One participant even expressed how much dis-attached from personal these plans felt.

**“Everything about it is like a business. The support plan is like a business plan. I hate the fact that we have to work on hours. It just is so demoralising”.**

It's interesting to hear participants speak of their budget in such a way but highlights how un-flexible plans have become for some individuals and the acknowledgement that needs are based on this concept of 'hours' rather than accessing the individual's needs. Participants expressed this idea of a business further by drawing attention to the constant money saving techniques.

**“Because I'm on a restricted level of time. I've got a fixed amount of money, and therefore I haven't got that flexibility. I don't have a contingency budget. So, therefore, if I need to pay somebody extra hours, or I need to pay for, say, my mental health support needs, I don't have any money to do so”.**

What we are seeing is this level of restriction is not only affected by the support plan but also by the allocated hours provided. This comes back to the assumption that an individual's needs don't change, which you can argue they could do from day to day.

Participants also queried about the level of “personalisation” a budget can provide due to the consistent changing of goalposts.

**“They change the criteria for what is and isn't included. So, the goalposts start wide, and they gradually get narrower and narrower and think, OK, what's going on now”.**

These changes in 'goalposts' further strengthens the argument that a Personal Budget is becoming increasingly difficult to make personal. Participants are clearly aware of what is happening, and it can be argued that it's increasingly frustrating for them.

It is appreciated that some of the issues raised would take time to improve, but what's important to remember is that in order for a Personal Budget to work, it needs to be personal for the individual in question. If plans are put in place to ensure individuals



receive the best support to suit their needs, regular communication, updates, and feedback need to be continued to reflect the individual truly.

### 3.33 Lauren & Joe

Lauren's case study represents the support and involvement many parents have in their children's Personal Budget, which is needed to ensure the budget is managed correctly and ensures their child has the best quality of life.

She has experienced first-hand how the Direct Payment scheme has changed over the years through professional and personal scenarios she has been a part of. Lauren's son Joe has been receiving a Personal Budget via a Direct Payment since he was a child and Lauren still supports him, even now when he has reached adulthood. Initially, Lauren opted to use agencies but felt this wasn't the right direction for Joe, so instead changed to use the budget to hire PAs.

"Being honest right from the get-go, I didn't actually opt for hiring my own PA's, and I opted to have two different agencies, neither of which worked out. They worked out, but I could see Joe's quality of life wasn't where it could have been, so I decided to just bite the bullet.

For Lauren, ensuring Joe's budget enabled him to lead a better quality of life than before was the most important outcome from a Personal Budget. As Joe's mum, Lauren knew what suited her son best, so organised many different aspects that play a part in this budget.

This included:

- |  |   |  |
|--|---|--|
| <ul style="list-style-type: none"> <li>• Recruitment</li> <li>• managing staff</li> <li>• supervision</li> <li>• Disciplinary</li> <li>• Grievance</li> <li>• Sickness</li> <li>• Development</li> <li>• staff files</li> <li>• GDPR</li> <li>• health and safety, including fridge temp checks</li> <li>• smoke detector checks</li> <li>• COSHH-Control of substances</li> </ul> | <ul style="list-style-type: none"> <li>hazardous to health</li> <li>• RAs (risk assessments) for individual building and Joe's</li> <li>• Safeguarding</li> <li>• Training</li> <li>• managing a budget</li> <li>• outcome setting including sharing with team</li> <li>• developing paper sets including ABC charts</li> </ul> | <ul style="list-style-type: none"> <li>• incident/accident forms</li> <li>• body charts</li> <li>• linking with employment law advisers</li> <li>• health and safety advisers</li> <li>• awareness of employment law and changes</li> <li>• managing pensions</li> <li>• staff rota</li> </ul> |
|--|---|--|

For Lauren, all these different elements contributed to ensuring that Joe's budget was person-centred while ensuring the team are providing value for money. However, Lauren felt that the work she put in was constantly under-appreciated by Essex County Council. Lauren felt that the money she had saved on PA's was taken away for Joe to be spent elsewhere.

**"It literally is to employ staff, that is what he has his budget for, and that is it, and if they can reduce it all as I say, then they will".**

Because this happened, Lauren viewed Joe's budget as just a business to the council in her eyes, seeing it as an 'impersonal budget'. She questioned why she goes to all this trouble to do this in the first place if they are continually trying to claw back money. Lauren highlighted that without the effort she put in, Joe's care would have cost considerably more.

**"If he were institutionalised in any way, shape or form, then you'd see a different person starting to emerge, and if he had that day after day without being able to get out and about and do the things he wanted to, I know that he would be a good £250,000 a year, plus package. I know he would, without a question of doubt. But like I say, do they want to see that before they believe it".**

Lauren indicates that there needs to be recognition of the level of involvement some parents have in their child's Personal Budget. She emphasises the council needs to work with her as she has the best understanding of what support is suited for Joe. Instead of trying to claw back the money, Lauren states the council need to understand why she handles the budget how she does and recognise its importance.

## 4.0 Conclusion

When we engaged with participants and captured their lived experience, we listened to the thoughts, feelings and opinions of individuals who emphasised that receiving a personal budget as a direct payment had given back their sense of freedom. However, significant steps needed to be taken to allow for full flexibility, empowerment of knowledge and vital relationships.

A personal budget received as a direct payment is more than just an amount of money. For many, it presents opportunities for personal growth and new experience's which otherwise would not have been available.

This report highlights many themes individually, but it seems that one consistent thread underpins them all. Clearly, trust plays a big part in ensuring the success of a direct payment. Without trusting professional relationships, trust in the payment system and trust in choice and control made by the individual, people have become hesitant to explore fully their personal budget and how Direct payments can give control back to the recipient for them for fear of being penalised.

As the NHS website clearly states, “Direct payments give you more flexibility on how your care and support is arranged. It’s your choice as long as you’re spending your personal budget on things that meet your agreed support plan”.<sup>5</sup>Therefore, when individuals expressed an interest in using their budget on something that would benefit an outcome on their support plan, was this flexibility denied?

Participants want to feel that they are being listened to, and this report highlights a snapshot of people receiving a personal budget in Essex. If Direct payments services need improving, then these improvements should reflect issues raised by those who access Direct Payments. We need to ensure that we are empowering individuals and encouraging the right conversations to influence positive change, which will result in improving lives for the people of Essex.

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<sup>5</sup> <https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/personal-budgets/>

## 5.0 Recommendations

Healthwatch Essex has made the following recommendations as ways in which changes can be made to the current Direct Payment system to help receivers.

### Social worker retention scheme

To create personal relationships between social workers and budget receivers, it's important to retain workers. This would involve providing high-quality support, supervision, and training opportunities to equip social workers with specific knowledge in certain disabilities, enabling them to have their own group of direct payment receivers and support them continuously.

### Education & Awareness

We recommend putting together a handbook that explains simply & clearly the most crucial aspect of a Personal Budget and how Direct Payments work. It might include content such as step by step guides, tips on how to employ PA's and how to write a support plan. We believe listening to individuals who are already part of the system will provide valuable insight into the correct content needed to help future Personal Budget users.

### More person-centred approach

Work needs to be undertaken to put the personal back into a Personal Budget. A holistic approach needs to be taken to achieve a person-centred approach, ensuring the individual has control over what they can use their Personal Budget on. It's essential to be open-minded with the approach someone might want to take to meet their social care needs which is stipulated in their support plan and work with them to achieve the best quality of life

### Communication & accessibility

Personal Budget receivers must be kept up to date with any changes or important information from Essex County Council and Purple. Support needs to be put in place to ensure this information is made accessible by everyone. Essex County Council also needs to ensure that Purple and the receiver understand each other's responsibilities regarding payroll and that Purple is communicating on important matters when needed and the individual ensures information such as personal details, is continually kept up to date