December 2025

Understanding What Direct Payments Really Means to People

Priorities, Choice and Control in Care – Wiltshire

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Acronyms and Key Terms

Acronym	Meaning
ASC	Adult Social Care
BSW ICB	Bath and North East Somerset, Swindon & Wiltshire Integrated Care Board
DP / DPs	Direct Payment(s)
SDS	Self Directed Support
PA	Personal Assistant
VCSE	Voluntary, Community and Social Enterprise
WCIL	Wiltshire Centre for Independent Living
FAB	Financial Assessment and Benefits Team
LPOA	Lasting Power of Attorney
QUAM	Quality User led Assistance and Monitoring

Voice It, Hear It

Community voices inspiring positive change to local support and services.

Voice it, Hear It is an engagement project that works with people aged 18+ living in Wiltshire to get involved in shaping the health and social care services they use.

We work with people with physical disabilities, sensory needs, mental health issues, learning disabilities, neurodiversity, long term conditions, complex needs, older people and people with dementia.

We also work alongside Wiltshire Council and the Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board (BSW ICB) and people living and working in Wiltshire to co-produce, co-design and co-develop health and social care services in Wiltshire.

Voice It, Hear It is a partnership project led by Community First, working with Wiltshire Service Users' Network, Wessex Community Action, Age UK Wiltshire, Beyond Dementia (formerly Alzheimer's Support) and Celebrating Age Wiltshire.

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Executive Summary

This report presents the findings from the first phase of engagement undertaken to inform Wiltshire Council's work on the future direction of Self-Directed Support (SDS), with a particular focus on Direct Payments (DPs) as the main way in which people currently experience self-directed approaches in practice.

Engagement was carried out through a combination of:

- In-depth one-to-one interviews
- Carers' cafés and partner-led conversations
- A lived-experience survey
- Case studies
- Professional system insight

Participants included people using Direct Payments, people who had declined them, unpaid carers (including parent carers and spousal carers), and professionals supporting the delivery of SDS and DPs. Together, this provided a rich and consistent picture of how self-directed support is currently experienced across Wiltshire.

Core Findings

Direct Payments can be life-enhancing when they work well, supporting dignity, independence, continuity and choice. People described being able to shape support around their lives, maintain family relationships, attend medical appointments, remain in work, or take essential breaks. Where relationships with practitioners and support services were strong, Direct Payments enabled genuine personalisation.

However, across Wiltshire, experiences remain highly variable. Outcomes depend strongly on:

- The clarity and timing of information people receive
- Practitioner confidence and consistency
- Access to informal family advocacy to navigate the system
- The accessibility of administrative and financial processes

Across interviews, survey data and professional insight, ten consistent themes emerged:

1. **Lack of clear, accessible information at the outset**, leaving many people unaware of their options or unprepared for the responsibilities involved
2. **Confusion between Self-Directed Support and Direct Payments**, driven by inconsistent terminology and communication
3. **Variable practitioner knowledge and confidence**, leading to mixed messages and unequal experiences
4. **Heavy administrative and employer burden**, particularly for unpaid carers
5. **Variable support from external agencies**, depending on timing, access and personal capacity
6. **Significant difficulties recruiting and retaining Personal Assistants**, especially for specialist, rural areas or unsocial-hours care
7. **Delays and slow financial processes**, creating fear of debt, unspent funds anxiety and disrupted care
8. **High emotional pressure and impact on wellbeing** for carers and individuals
9. **Inconsistent flexibility in practice**, despite flexibility being a core promise of Direct Payments
10. **Reviews and reassessments experienced as intrusive or insensitive** by some participants

Overall Conclusion

Where information is clear, support is timely and relationships are stable, Direct Payments work well. Where systems are slow, processes complex and information fragmented, the burden falls disproportionately on carers and disabled people - often at moments when they have the least capacity to manage it.

At present, people's experience of Direct Payments in Wiltshire is heavily influenced by individual practitioner knowledge, personal resilience and the availability of informal family advocacy, rather than by consistent system design.

Purpose of the Recommendations

All recommendations in this report are grounded in repeated themes across qualitative interviews, case studies, survey responses and professional system insight. They do not represent prescribed solutions, but rather evidence-based areas for consideration to strengthen:

- **Clarity**
- **Equity**
- **Accessibility**
- **Flexibility**
- **Sustainability**

Within Wiltshire's approach to Self-Directed Support and Direct Payments.

Introduction

This report summarises the first phase of engagement undertaken to support Wiltshire Council's work on the future direction of Self-Directed Support (SDS) as part of the Transformation of Adult Social Care programme.

The purpose of this initial phase was to explore what self-directed support means to people who use care and support, and to understand what they consider most important when thinking about increasing or improving choice and control over their lives.

The findings from this initial phase will be used to support Wiltshire Council's ongoing consideration of the future direction of Self-Directed Support as part of the wider Transformation of Adult Social Care programme.

Future phases of the programme may explore further development and co-production opportunities, subject to Wiltshire Council's priorities and programme design.

Engagement included people with a wide range of needs, diagnoses and backgrounds, including unpaid carers and individuals from different protected characteristic groups. This diverse input provides a broad foundation for understanding how Self-Directed Support is currently experienced and what changes could strengthen its effectiveness.

Wiltshire Council's Long-Term Vision for Self-Directed Support

Self-Directed Support aims to offer a more personalised, asset-based and strength-based approach to care and support. This approach increases opportunities for individuals to improve their quality of life by placing greater emphasis on:

- Personal choice and control
- Community connection and mutual aid
- Flexible, creative use of support

It also reflects a strategic shift away from reliance solely on commissioned services towards greater use of community-based support, helping to build resilience at both individual and community levels.

Wiltshire Council's wider business priorities include:

- Empowering people by enhancing their control and involvement in care decisions

- Building a resilient society through stronger, more supportive communities
- Supporting a thriving care economy through innovation
- Promoting sustainability through community-based practice

Why Self-Directed Support Is a Transformation Priority Now

Wiltshire Council recognises that the uptake of Direct Payments (DPs) and Individual Service Funds is currently low. A key strategic driver is therefore to increase the number of people able to access these options by 2026, enabling more residents to exercise genuine choice and control over their support.

Why the Engagement Focused on Direct Payments

Although this engagement focused primarily on Direct Payments (DPs) rather than the broader Self-Directed Support (SDS) model, this approach was appropriate and necessary for the purposes of this phase of work.

Evidence from the engagement shows that most people in Wiltshire experience "self-directed" support through Direct Payments. Very few participants recognised or understood the term SDS. Several people actively receiving DPs told us they had "never heard of SDS", and some frontline staff appeared to use the two terms interchangeably.

Had the engagement been framed around SDS alone, many participants would not have understood the questions or been able to share their experiences in a meaningful way. Using the familiar term "Direct Payments" ensured people could talk openly, clearly and accurately about their real experiences of personalisation, choice and control.

At the same time, the insight gathered extended far beyond the mechanics of DP payments. Through interviews, carers' cafés, surveys, lived-experience conversations and case studies, the engagement captured a wide range of SDS-related issues, including:

- Barriers to genuine choice
- Flexibility of support
- Relationships with practitioners
- Clarity of information
- Emotional impact on carers
- Challenges of managing personal budgets

Robustness of the Evidence

The in-depth interviews generated rich, detailed and highly consistent feedback across participants. In qualitative research, the focus is not on volume but on depth, meaning and pattern. This engagement reached a point of theoretical saturation, meaning that by the later interviews no new themes were emerging and the same issues were being repeated by different participants. This is a recognised methodological principle indicating that the sample was sufficient to generate reliable qualitative insight.

For these reasons, the DP-focused approach successfully captured the lived experience of Self-Directed Support in practice and provided a robust and relevant evidence base for this report.

The engagement also highlighted a significant finding in its own right: many people do not understand what "Self-Directed Support" means, and clearer explanations would be needed in future if Wiltshire wishes to strengthen awareness of the wider SDS model.

All quoted comments have been recorded verbatim as expressed by individuals during the course of this work.

National Context and Comparison with Other Local Authority Findings

Following completion of this Wiltshire engagement, the findings were compared with three recent Direct Payments reports from other local authorities and national improvement bodies, all of which were based primarily in urban or large metropolitan areas and undertaken with direct access to council-held contact lists:

- **Improving Direct Payments Oversight** – Think Local Act Personal (TLAP), LGA & ADASS, March 2022
- **Direct Payments Uptake** – London Borough of Ealing, October 2025
- **Direct Payments and Self-Directed Support** – Medway Council, January 2025
- **Direct Payments: Response to Parent Carers** – Bristol, May 2021

Although these areas differ significantly from Wiltshire in terms of population density, service infrastructure and commissioning scale, the core themes emerging from these reports strongly mirror the findings from Wiltshire.

Areas of Strong Alignment

Across all comparator reports and the Wiltshire engagement, the following issues consistently recur:

Early information and clarity

All reports highlight that access to clear, timely and understandable information at the point of assessment is crucial. Both the TLAP report and the Bristol parent-carer response identify confusion at the start of the Direct Payment journey as a key barrier, directly aligning with Wiltshire findings on poor early information and inconsistent explanations.

Administrative burden and employer responsibility

The Medway and TLAP reports both explicitly identify the complexity and workload placed on individuals and family members acting as employers, including payroll, employment law and financial administration. This directly reflects the Wiltshire evidence showing that administrative burden is a major driver of stress and DP breakdown.

Financial monitoring and unspent funds

The TLAP national report highlights that overly complex auditing and rigid financial monitoring can undermine flexibility and create distress, echoing Wiltshire participants' experiences of fear around unspent funds, delayed assessments and uncertainty about repayments.

Personal Assistant recruitment and market pressures

Both Ealing and Medway identify workforce pressures and recruitment challenges as structural risks to DP sustainability. This aligns closely with Wiltshire's evidence of near-universal difficulty in recruiting PAs, particularly for rural, specialist and unsocial-hours care.

Emotional impact on carers

The Bristol parent-carer review, alongside the Medway report, recognises the emotional strain placed on carers managing Direct Payments, particularly during periods of change or crisis. This directly mirrors the Wiltshire finding that carers frequently operate at or beyond exhaustion point.

Culture, language and relationships with councils

The TLAP report places strong emphasis on the importance of how councils communicate with DP users, identifying that tone, language and co-productive relationships significantly shape people's willingness to engage. Wiltshire participants similarly described how communication style, consistency and trust strongly influenced their experience.

Key Methodological Differences

It is important to note that:

- The Ealing, Medway and Bristol reports were council-led, with access to direct mailing lists, statutory contact routes and internal data systems.
- Wiltshire engagement was delivered independently through VCSE networks, community routes and voluntary participation, without access to council-held contact databases.
- The comparator areas are predominantly urban, while Wiltshire is largely rural, creating additional workforce, transport and recruitment pressures not always reflected in urban models.

Despite these significant differences in geography, methodology and scale, the core lived-experience patterns are strikingly consistent.

Overall Interpretation

The consistency between Wiltshire findings and those from other local and national Direct Payment reviews strongly suggests that the issues identified in this report are not isolated to Wiltshire but reflect wider systemic challenges within Self-Directed Support nationally.

At the same time, the Wiltshire engagement adds important rural-specific insight, particularly around:

- PA recruitment in dispersed communities
- Transport and travel barriers
- Reliance on informal family advocacy where professional infrastructure is stretched

Taken together, this comparison reinforces the robustness of the Wiltshire findings and confirms that the recommendations set out in this report align closely with national improvement priorities already identified across the sector.

Key Findings

Our engagement with people using, attempting to use, or supporting others with Direct Payments (DPs) revealed a clear and consistent picture. Direct Payments can provide life-changing flexibility, dignity and independence, but people's experiences vary widely depending on the information, support and consistency they receive.

Across in-depth interviews, carers cafés, partner-led conversations, survey responses and lived-experience case studies, ten core themes emerged.

1. Lack of clear information at the start

Many people did not receive accessible, upfront information about their options. Some were unaware they had a choice, and others had never heard the term Self-Directed Support even though they were already managing a Direct Payment. This set the tone for confusion later in the process.

> ***"Direct Payments was never discussed. Things were just decided for us."***
>
> *(Interview 10 – dementia carer, commissioned care only)*

> ***"I was in the dark — no one explained Direct Payments."***
>
> *(Interview 2 – not assessed at the time)*

2. Confusion between Self-Directed Support (SDS) and Direct Payments

Terminology is used inconsistently across the system. People repeatedly said they understood "Direct Payments" but not "SDS". Changes in language, particularly without explanation, created uncertainty and made it harder for people to understand what was available or how to navigate the system.

> ***"The language keeps changing and no one explains why."***
>
> *(Interview 16 – long-term DP user)*

> ***"I've had Direct Payments for years and I'd never heard of SDS until now."***
>
> *(Survey respondent)*

3. Inconsistent practitioner knowledge

Experiences were highly dependent on the individual practitioner. Some social workers were described as “wonderful”, while others had limited understanding of DP rules, processes or entitlements. This inconsistency contributed to mistrust, confusion and mixed messages.

“One person tells you one thing, the next tells you something completely different.”

(Interview 15 – working carer)

“It feels like luck of the draw depending on who you get.”

(Survey respondent)

4. Administrative burden and complexity

Carers and individuals described the DP process as time-consuming and overwhelming. Paperwork, recruitment, payroll, DBS checks, training and financial monitoring created significant pressure—especially for carers supporting someone full time. For many, the admin burden overshadowed the potential benefits of SDS.

“It felt like taking on a second full-time job on top of caring.”

(Interview 17 – DP user)

“The paperwork nearly put me off altogether.”

(Interview 9 – dementia carer)

5. Variability in support from external agencies

Experiences of support services varied depending on individual circumstances. At the time of engagement, Wiltshire CIL held the contract to provide Direct Payment support, and many participants described the service as helpful, knowledgeable and supportive when they were able to speak directly to an adviser. Others were unsure what support was available or felt unable to reach out, often due to stress, limited capacity or lack of clarity within the wider system.

“When I finally got through to someone at CIL they were really helpful.”

(Survey respondent)

“At the start I didn’t even know what support WCIL could give me.”

(Interview 13 – DP carer)

6. Difficulty recruiting and retaining Personal Assistants

Almost all participants reported challenges finding suitable PAs - particularly those with dementia training, confidence with personal care, specialist medical needs or availability during evenings and weekends. Fixed or low DP hourly rates made recruitment even harder and sometimes made Direct Payments unworkable.

"Since Brexit, the carers I relied on left the country and I've never recovered that stability."
(20+ year DP user)

"Small packages just aren't attractive to workers anymore."
(Professional feedback – WCIL)

7. Delays, slow processes and limited communication

Many people experienced significant delays in financial assessments. In practice, this sometimes left individuals with unspent DP money accumulating in their bank account, which later had to be repaid. Others avoided arranging care altogether because they feared building up debt they could not predict or control. These situations created real financial and emotional strain, often linked to unavoidable process delays rather than individual actions.

"I didn't arrange the care because I was terrified of getting a massive, backdated bill."
(Interview 15 – working carer)

"Seven months later he got a bill for over £2,000."
(Interview 10 – dementia carer)

8. High emotional pressure and impact on wellbeing

Carers often described feeling overwhelmed and "at breaking point". Some felt judged or excluded from decisions - especially where they lacked Lasting Power of Attorney. People spoke about the emotional toll of managing care, employment, sleeplessness and DP administration simultaneously.

"It just became too much. I was exhausted all the time."
(Interview 8 – dementia and cancer carer)

"If I had to manage Direct Payments, I'd end up depressed."
(Interview 14 – declined DP)

9. Flexibility varies widely in practice

Where well supported, Direct Payments delivered meaningful choice - allowing people to work, attend medical appointments, maintain relationships, or take essential breaks. Where support was limited or inconsistent, people felt constrained by rigid rules or unclear guidance, reducing DP flexibility in practice.

"Direct Payments let me shape support around my life, not the other way round."
(Interview 4 – DP user)

"The rules changed and suddenly I couldn't use it in the same way anymore."
(20+ year DP user)

10. Reviews and reassessments felt intrusive or insensitive

Some participants described reassessments as repetitive, overly personal or lacking understanding of long-term conditions. These processes sometimes felt interrogative rather than collaborative, reducing trust and discouraging engagement.

"Having to prove my needs over and over again feels humiliating."
(Interview 16 – long-term DP user)

"The questions don't change even though my condition never will."
(Interview 17 – DP user)

Overall Conclusion

Direct Payments have the potential to transform people's lives, offering flexibility, dignity and control. However, the current experience in Wiltshire is inconsistent and heavily reliant on practitioner confidence, family advocacy and personal resilience.

The interviews showed that when information is clear, support is timely and processes are smooth, Direct Payments work well. But when information is unclear and systems are slow or complex, the burden falls disproportionately on carers and disabled people - often at moments when they have the least capacity to manage it.

Improving information, consistency, communication and support would enable far more people to benefit from Self-Directed Support and experience genuine choice and control over their care

Overall Engagement and Participant Profile

Participation Numbers

Through our engagement activity, we spoke to a total of **95 people**, comprising:

19	23	43	10
People who took part in in-depth one-to-one interviews	People who participated in an online survey	Carers' cafés and group conversations (43 people in total)	Professionals providing system insight

Carers' cafés and group conversations

- Trowbridge – 17 November 2025: **7 people**
- Marlborough – 25 November 2025: **18 people**
- Chippenham Hub Craft Group – 17 November 2025: **18 people**

This total reflects direct, face-to-face and one-to-one participation. It does not include wider reach achieved through communications activity.

Participant Groups

- People currently using Direct Payments
- People offered Direct Payments who declined
- People receiving commissioned care only
- Unpaid carers (predominantly parent and spousal carers)
- Professionals supporting Direct Payment systems

Demographic Overview

- **Age**: Predominantly 45–79

- **Gender**: Majority female
- **Geography**: Strongest representation from West Wiltshire
- **Needs**: Physical disability, long term illness, dementia, neurodiversity and mental health
- **Carers**: Majority parent carers; several working carers juggling employment and care

This reflects those most actively engaged with Direct Payments in practice, while highlighting geographical and age related engagement gaps to be addressed in later phases.

Communication, Awareness and Wider Reach

Alongside direct engagement, significant effort was invested in raising awareness of the engagement opportunity across Wiltshire through digital and partner-led communications. This activity aimed to reach people who might not otherwise engage in structured interviews or group-based sessions.

This included:

Social media posts designed to promote the engagement and encourage participation (see Appendices). News articles and engagement prompts shared via partner networks and newsletters, including:

- Wiltshire Parent Carer Council (WPCC) newsletters
- Wessex MS Therapy Centre
- Wiltshire Money Forum
- Wiltshire Service Users Network (WSUN)
- Age UK Wiltshire
- Beyond Dementia
- Forward Carers
- Independent Lives
- Wiltshire Sight
- VCSE Leadership Alliance
- Carers Together Wiltshire (Parent Carer newsletter)
- Community First newsletter

In total, social media and newsletter promotion reached over XXXX people.

These communication routes helped extend awareness of the engagement beyond those who took part directly and supported participation from people connected to a wide range of condition-specific, community and carer support networks.

What We Did

How We Gathered Insight into Experiences of Self-Directed Support and Direct Payments

This engagement set out to gather meaningful insight into how people in Wiltshire understand and experience Self-Directed Support (SDS), including Direct Payments (DPs) and Individual Service Funds (ISFs). The engagement specifically explored:

- What Direct Payments mean to people
- What influences whether people take them up
- How choice and control could be strengthened within care and support

Engagement Period

Engagement activity was carried out over a six-month period (June–December 2025).

People Engaged

To ensure a broad and inclusive evidence base, engagement was undertaken with three key cohorts:

1. **People currently receiving Direct Payments:** To understand what works well, what challenges they experience, and how Direct Payments affect their sense of choice, control and independence.
2. **People who were assessed for care but did not take up Direct Payments:** To explore reasons for non-uptake, including confusion, perceived complexity, lack of support or other barriers.
3. **People who have not yet been assessed or who are unaware of Direct Payments:** To gauge levels of public awareness and identify what might make Direct Payments feel more accessible or appealing.

In addition to these three cohorts, we also gathered insight from:

- **Unpaid carers**, both as individuals and as supporters of Direct Payments recipients
- **Professionals**, where their perspectives helped contextualise and clarify system-level issues

Engaging these groups allowed us to build a holistic picture of how Direct Payments are understood, accessed and experienced across Wiltshire.

Our approach remained iterative and participant-led, adapting to what was possible within a very challenging engagement landscape.

Reaching Participants

Reaching individuals receiving Direct Payments - or those closely involved with them - proved extremely challenging. Despite extensive efforts to work through partners and organisations supporting Direct Payments users, carers and people eligible for Direct Payments, engagement opportunities were limited.

Many people had highly personal experiences that they were reluctant to share in group settings. As a result, we shifted to a depth-focused approach, prioritising high-quality insight over high participation numbers.

Given these constraints, we adopted a theoretical saturation model: continuing engagement until recurring themes appeared consistently, ensuring that the core issues were well understood even without large-scale participation.

How We Heard from People

Exploratory Conversations > In-Depth Interviews

We began with exploratory conversations as planned. These quickly evolved into in-depth one-to-one interviews, which provided the richest and most reliable insight into:

- People's lived experiences
- Perceptions of Direct Payments
- Practical and emotional barriers
- The wider impact on wellbeing and daily life

These interviews formed the foundation of our understanding and directly shaped the survey themes and question development.

Survey Development and Testing

Using the themes emerging from the in-depth interviews, we developed a survey designed to test and validate the issues raised.

The interviews made it clear early on that simple yes/no questions or basic rating scales would not be meaningful, as each person's situation and experience of Direct Payments is highly individual and complex.

For this reason, the survey was never intended to be the primary engagement tool, but rather a complementary option for those who:

- Preferred not to meet with us directly, or
- Wanted more time and space to reflect before responding

The draft survey was reviewed with a small number of people with lived experience to ensure the questions were:

- Relevant
- Accessible
- Grounded in real-life scenarios

Their feedback helped refine the language and structure before the survey was released more widely in both online and paper formats, offering a flexible way for people to share their views in a way that suited them.

Analysis and Reporting

We analysed both qualitative and quantitative data together. Because depth was prioritised over scale, we paid particular attention to:

- Recurring issues
- Pattern consistency
- The strength of feeling behind key themes

Where clarification was helpful, we revisited a small number of participants to sense-check interpretation.

Engagement Methods Used

- One-to-one interviews (in-person, phone and video)
- Small exploratory conversations and follow-up discussions
- Online and paper surveys, supported where needed
- Outreach via VCSE organisations, newsletters and forums
- Attendance at relevant community events where opportunities arose
- Flyers circulated with a range of engagement options, including a QR code for easy survey access

Key Principles

- **Inclusivity**: providing accessible formats wherever possible
- **Respect for lived experience**: prioritising depth, nuance and real stories
- **Adaptability**: adjusting methods when initial pathways proved inaccessible
- **Methodological transparency**: using theoretical saturation to ensure robustness despite low participation numbers

Use of Terminology: “Self-Directed Support” vs “Direct Payments”

During the earliest stages of engagement, it became clear that “Self-Directed Support (SDS)” was not a term most people recognised or understood. In contrast, the term “Direct Payments” was familiar, immediately meaningful, and strongly associated with people’s real-life experiences of arranging care.

Because this pattern emerged repeatedly, we adapted our approach and used “Direct Payments” as the primary term in:

- Conversations and interviews
- The survey
- Social media and newsletters

This ensured people could relate the questions to something they already understood, reducing confusion and improving the quality of feedback.

Using Open Questions in This Engagement

Because experiences of Self-Directed Support and Direct Payments are highly individual, complex and often emotionally charged, we deliberately used open questions in both the survey and the lived-experience interviews. This approach reflects best practice in qualitative social care engagement and acknowledges that no two SDS journeys look the same. Experiences vary depending on:

- Disability and health needs
- Family circumstances
- Financial situation
- Practitioner involvement
- Recruitment challenges
- Levels of informal support

Predetermined or closed questions would have risked oversimplifying these differences or steering participants towards predefined categories, rather than the issues that genuinely mattered to them.

Open questions allowed participants to speak in their own words, describing what was working, what was not, and why. This was particularly important given the sensitivity of the topic. Many individuals shared:

- Fears about losing support
- Challenges with capacity
- Emotional strain
- Administrative burden
- Deeply personal caring responsibilities

These insights would not have been captured through tick-box responses.

For these reasons, an open-ended, exploratory approach was the most appropriate and ethically responsible method for this engagement.

Lived Experience Case Study

Case Study 1

A Parent-Carer Navigating 12 Years of Self-Directed Support and Direct Payments

This parent has been caring for her adult daughter, who has a degenerative brain condition, for over twelve years. At the outset of her daughter's care journey, she was offered agency care, which she refused because she did not feel safe with unfamiliar carers supporting her daughter. Only after refusing agency care was she informed about Direct Payments.

Although a payroll management company was used (funded through the Direct Payment), this only covered wage processing. All wider responsibilities - recruitment, training, DBS checks, pensions, insurance, servicing of equipment and HMRC requirements - fell to the parent while she continued to provide full-time care.

Managing the Direct Payment alongside intensive caring responsibilities quickly became overwhelming. Recruitment proved extremely difficult, and carers had to be sourced through informal word-of-mouth routes. As a result of repeated recruitment failures, large sums of unused Direct Payment funding accumulated in the account, with no clear mechanism for returning the money to the council. This created serious financial fear and emotional distress.

Over time, the pressure became unsustainable. She eventually moved back to a care agency, despite knowing this reduced choice and continuity. Even within agency care, instability continued due to staff turnover and limited training capacity for her daughter's specific medical needs. This led to reduced care hours despite higher assessed need and ultimately resulted in the parent being unable to continue employment due to unreliable care cover.

At the time of interview, she was receiving significantly fewer care hours than allocated and was unable to leave the house reliably. She reported having no time to herself and remaining on constant standby to support carers who lacked training and confidence with her daughter's needs.

This case study illustrates how even highly committed, capable carers can be pushed beyond sustainability when administrative burden, recruitment barriers, rate inflexibility and lack of practical system support combine over long periods.

Considerations and Recommendations

All recommendations below are grounded in repeated evidence from interviews, surveys and professional feedback. Each recommendation sets out what is being asked, why, and what good could look like in practice.

1. Co produce a Clear and Accessible SDS / DP Pathway

What is needed: A single, co produced pathway that clearly shows every stage of the SDS/DP journey from first enquiry to review.

Why this is needed: People repeatedly became stuck in the process, did not know who to contact, and misunderstood key steps. Confusion between SDS and DPs created additional barriers.

What this could include in practice:

- A step by step visual pathway from assessment to review
- Clear explanation of all budget options (DPs, managed budgets, ISFs, mixed packages)
- What to expect at each stage and typical timescales
- Who to contact at each point and how escalation works
- What happens during hospital stays, crises, or care breakdown
- Versions in Easy Read, standard print, audio and digital formats

2. Strengthen Early Information and Upfront Conversations

What is needed: Earlier, clearer conversations about all care options before decisions are made.

Why this is needed: Many people felt steered into DPs without fully understanding the responsibilities, while others never realised, they had a choice at all.

What this could include in practice:

- Simple information provided at the assessment stage in plain language
- Real life examples of how DPs can work
- Clear explanation of responsibilities involved in being an employer

- Explicit discussion of alternatives to DPs
- Inclusion of carers in early conversations (with consent)
- Avoiding information overload at point of crisis

3. Improve Practitioner Consistency and Confidence

What is needed: More consistent practitioner knowledge and confidence across Wiltshire.

Why this is needed: People's experiences varied significantly depending on the practitioner they encountered.

What this could include in practice:

- Regular refresher training on SDS/DP rules and flexibility
- Shared guidance across all teams
- Quick reference tools for frontline staff
- Support for respectful, strengths based conversations
- Clear parameters on what practitioners can authorise

4. Reduce Administrative Burden

What is needed: Practical reduction of the administrative load placed on carers and DP users.

Why this is needed: Admin responsibilities were repeatedly cited as overwhelming and damaging to wellbeing.

What this could include in practice:

- Light touch independent DP admin support
- Simplified monitoring and reporting
- Reduced duplication in reviews
- Extra help for digitally excluded individuals
- Practical assistance during crisis, deterioration or bereavement

5. Improve PA Recruitment and Rate Flexibility

What is needed: Better support for recruiting and retaining Personal Assistants and more realistic rate flexibility.

Why this is needed: Recruitment difficulties were near universal and made many DP packages unworkable.

What this could include in practice:

- Review of DP hourly rates in line with local labour markets
- Option to use fewer hours at higher rates
- Support to employ trusted individuals where appropriate
- Simple recruitment packs (job adverts, interviews, contracts)
- Access to basic training pathways for new PAs

6. Streamline Financial Assessments and Unspent Funds Processes

What is needed: Faster, clearer financial assessment processes and transparent handling of unspent funds.

Why this is needed: Long delays caused fear of debt and prevented people from arranging care.

What this could include in practice:

- Reduced FAB waiting times
- Early clarity about personal contributions
- Simple process for returning unspent funds
- Reassurance where delays are system caused
- Named contact for finance queries

7. Create a Single Point of Contact for SDS / DP Queries

What is needed: A consistent, named contact route for DP users and carers.

Why this is needed: People experienced multiple handovers between teams, which sometimes led to inconsistent advice and uncertainty.

What this could include in practice:

- Named SDS/DP contact point
- Logged enquiries and trackable follow ups
- Authority to escalate issues
- Proactive check ins at known pressure points

8. Improve the Quality of Reviews and Reassessments

What is needed: Reviews that feel collaborative, proportionate and trauma informed.

Why this is needed: Many people experienced reviews as repetitive, distressing and insensitive.

What this could include in practice:

- Adapted questions for lifelong or progressive conditions
- Reduced repetition of life history
- Respectful, strengths based review conversations
- Inclusion of carers where appropriate

9. Strengthen Cross Team Communication

What is needed: Better communication between hospital discharge teams, ASC, finance and DP support services.

Why this is needed: Conflicting messages caused confusion, delays and distress.

What this could include in practice:

- Shared definitions and consistent messaging
- Joint working across discharge and community teams
- Continued partnership forums such as DP Champions
- Clear handovers when practitioners change

10. Ensure Accessibility and Inclusion

What is needed: Information and processes that are genuinely accessible for all.

Why this is needed: Digital exclusion and cognitive impairments were significant access barriers.

What this could include in practice:

- Easy Read materials
- Printed and audio formats
- Dementia appropriate guidance
- Support for people with memory, learning and sensory needs

Evidence to Recommendation Matrix

Evidence Theme	Survey	Interviews	Professionals	Linked Recommendation
Poor early information	✓	✓	✓	1,2
Admin burden	✓	✓	✓	4,5
PA recruitment problems	✓	✓	✓	5
FAB delays	✓	✓	✓	6
Lack of named contact	✓	✓	✓	7
Wellbeing impact	✓	✓	✓	4,8

Evidence Integrity Statement

This report draws on triangulated evidence from in depth qualitative interviews, lived experience case studies, survey data and professional system insight. Key findings and recommendations are supported by repeated patterns across more than one evidence source.

Closing Reflections and Next Steps

This engagement has captured a wide range of lived experiences of Self-Directed Support and Direct Payments in Wiltshire. People shared not only practical challenges but also deeply personal stories about care, responsibility, resilience, exhaustion and hope. Many contributed at times of significant emotional and physical pressure, often alongside full-time caring responsibilities.

Across interviews, surveys, group conversations and professional insight, a consistent message emerged: when Self-Directed Support works well, it can be life-enhancing - supporting dignity, stability, independence and meaningful choice. When systems are unclear, slow or inconsistent, however, the burden falls most heavily on those already carrying the greatest responsibility.

This report does not seek to prescribe solutions. Instead, it offers an evidence-based picture of what people experience now, and a set of grounded considerations for what could strengthen clarity, equity and sustainability going forward.

The findings now provide a strong foundation for:

- Ongoing dialogue between Wiltshire Council, partners and residents
- Reflection on how current systems support - or hinder - choice and control
- Future development work shaped by lived experience

Above all, this work reflects the voices of people who took time to share their realities with honesty and courage. Their contributions represent not just feedback, but an act of trust. It is hoped that this report will help ensure those voices continue to shape the future direction of Self-Directed Support in Wiltshire.

Appendices

Appendix 1: Thematic Analysis of All 1-2-1 Conversation Interviews (1–19)

A consolidated picture of people's experiences of Self-Directed Support (Direct payments)/Direct payments. Some excerpts may overlap with the main body of the report, where selected examples are used to illustrate headline themes.

1. What People Value About Direct Payments

Across many case studies, Direct payments enabled choice, control, flexibility and continuity—the core purposes of Direct payments.

1.1. Flexibility and autonomy

Participants consistently valued being able to choose who supports them, when, and how.

> *"I make my DP work for me, not the other way round."*
>
> *"DP gave me the choice to pick my own agency rather than accept whatever brokerage found."*

This flexibility supported carers to maintain essential routines (e.g., Case Study 7, being able to keep playing golf) and enabled people to tailor support around real needs, not rigid service schedules.

1.2. Continuity of care

Long-term relationships with personal assistants (PAs) created emotional safety and stability.

Several described their PA as the single most important factor in successful support:

> *"Our PA has been with us 9 years… that continuity is everything."*

1.3. DS as enabling independence

Where Direct payments worked well, it prevented deterioration, improved wellbeing, and reduced stress

> *"This has completely transformed the experience of being a Mum."*

1.4. Speed and responsiveness in a few cases

A small number of participants (e.g., Case Study 5) experienced very fast set-up due to clinical urgency. This shows that the system can be agile when escalated appropriately.

2. Systemic Challenges Across All Conversational In depth Interviews

Despite positive elements, the majority of participants reported significant challenges - structural, relational, and administrative. These were consistent across age groups, conditions, and parts of Wiltshire.

2.1. Lack of clear information at the start

Across nearly all case studies, people:

- Were not offered Direct payments as a genuine option,
- Did not understand what Direct payments could be used for,
- Felt unprepared for the responsibilities involved, and
- Did not receive written, accessible explanations.

Quotes that illustrate this:

> *"I was in the dark — no one explained Direct payments."*
>
> *"I wasn't aware this was an option."*
>
> *"Where do you find the information?"*

This led to people choosing Direct payments without informed consent, or rejecting it because they were afraid of getting it wrong.

Impact: anxiety, delays in arranging care, unspent funds, and reliance on guesses or family members for decision-making.

2.2. Administrative burden and complexity

People repeatedly described Direct payments as overwhelming, particularly:

- Paperwork
- Record-keeping
- Payroll

- Recruitment
- Fear of making mistakes

Examples:

> *"Completing all the paperwork was the hardest part."*
>
> *"Managing Direct payments added to my stress."*
>
> *"The process is too long and too complicated."*

Carers supporting someone with dementia were particularly stretched, with DP responsibilities added on top of 24/7 emotional labour.

2.3. Delays and inconsistent communication

Many reported long delays that caused distress and blocked timely support:

- Delayed financial assessments (Case Studies 8, 15).
- Months without responses from the Council.
- Unclear or conflicting advice.

Quotes:

> *"The process took too long... I had little contact during this time."*
>
> *"I feared a huge debt because no one completed the financial assessment."*
>
> *"Communication is very difficult — it takes too long to get through."*

2.4. Digital exclusion

Many older carers and participants were excluded by online-only information:

> *"People who are not computer able are being penalised."*
>
> *"I don't really use a computer... I would struggle."*

This included difficulty accessing forms, guidance documents, and communication from the Council.

2.5. Negative practitioner attitudes or assumptions

In several cases, people described feeling:

- Unheard
- Dismissed

- Spoken down to
- Pressured into choosing Direct payments
- Or not treated as capable decision-makers

Example:

> *"They spoke to me like I couldn't make my own decisions."*
>
> *"It was humiliating."*
>
> *"When I asked about commissioned care, it was brushed aside."*

This undermined trust and created fear of the system.

2.6. Carers absorbing system failings

Family members frequently compensated for gaps in Council processes:

- Arranging all support
- Researching options
- Filling forms
- Clarifying misinformation
- Managing payments

Example:

> *"My daughter sorted everything out."*

This reliance on unpaid labour disadvantages those without family advocacy—creating inequality in outcomes.

2.7. Fragmentation and unclear pathways

Several DP users receiving mixed support (DP + commissioned services) reported:

- Confusion about who was responsible for what
- Difficulty requesting changes
- Lack of proactive reviews
- Gaps between services (e.g., respite, domestic support, community access)

2.8. Reassessment processes felt intrusive or insensitive

People described reassessments as:

- Repetitive
- Emotionally exhausting
- Framed as if they needed to “prove” they hadn’t improved

Example:

> *“Having to prove my needs over and over feels insensitive.”*

This creates distress and discourages engagement.

3. Positive Aspects of Commissioned Care

Some participants who declined Direct payments found commissioned care more suitable because:

- They could not manage the admin
- They had their own health conditions
- They lacked digital access
- They preferred structured support

Example:

> *“If I had to manage DP, I would suffer from stress and depression.”*

This highlights that DP is not universally appropriate and should not be treated as the default.

Appendix 2: Lived Experience Case Studies

Case Study 1 - A Parent-Carer Navigating 12 Years of SDS and Direct Payments

(Interview with a parent caring for her adult daughter with a degenerative brain illness)

Background and Initial Offer of Support

This parent has been caring for her daughter for more than a decade. Their original care package was arranged around 12 years ago. At the beginning, they were offered a care agency, but she refused because she did not feel comfortable having "random carers" supporting her daughter.

> *"I wanted to know who they were. I wanted to make sure they were safe to look after my daughter."*

Only after refusing an agency was she told about Direct Payments and Self-Directed Support—something she had to push for herself.

> *"It didn't even seem to exist until I said no to the agency."*

Both the social worker and OT eventually discussed DPs with her, but she felt she had to bring it up rather than being offered it as a genuine option.

Experience of Managing Direct Payments

She describes her experience of SDS/Direct Payments as overwhelmingly difficult.

She used a management company, paid out of her daughter's budget, because she needed help with the mentally demanding parts of DP administration. However, the company only processed wages.

They did not:

- Liaise with the PAs
- Support them onto training
- Manage pensions
- Handle equipment servicing
- Remind her of insurance deadlines

Instead, she was left juggling these tasks—plus DBS checks, recruitment, and HMRC responsibilities - while caring for her daughter full time.

> *"Nobody was helping me. I was trying to look after my daughter and manage all of this. I was on the verge of a breakdown."*

WCIL were supportive to an extent, but there was no practical solution to the pressure she was under.

She did not handle the DP money because the management company controlled the account, but HMRC issues still fell on her shoulders.

Administrative and Financial Difficulties

Some aspects were easy, such as setting up a separate bank account. But most tasks were extremely stressful:

- She worried constantly about large amounts of unused DP money sitting in her name because she could not find carers.
- She asked the council to take some of it back; she was told there was no procedure for doing so.
- She felt responsible for money she could not control.

She described it as "*terrifying*".

Tracking spending was confusing because the management company only allowed her to submit basic carer costs. Reporting back to the council was "almost impossible".

Recruitment was the most challenging aspect:

> *"Finding carers was virtually impossible. Wiltshire CIL had adverts but nothing ever came of them. I had to find people through word of mouth. Vetting everyone felt impossible."*

Impact on Stress, Health and Wellbeing

Managing the Direct Payment pushed her to breaking point.

> *"No one who is looking after someone should have to do all that too."*

After 3–4 years she could no longer sustain the stress and reluctantly switched to an agency.

Poor hourly rates made attracting quality carers impossible:

> *"You could only pay minimum wage after tax. But the council was happy to pay an agency much more."*

Choice, Flexibility and Quality of Care

She had some choice over who supported her, but **no meaningful flexibility** in how the budget could be used:

- DP rates were too low to attract skilled or reliable staff.
- She was not allowed to reduce hours to pay a higher rate for better carers.
- She felt trapped by rigid rules that prevented her from tailoring support to her daughter's real needs.

She sought advice from social workers, OTs and health professionals, but none were able to resolve the issues.

Timescales and Delays

Setting things up took many months, largely because she could not find appropriate carers. They tried to time support around her daughter leaving college, but it took around nine months to prepare due to recruitment difficulties and fitting around carers' availability.

This reduced flexibility and delayed support.

Barriers to Using SDS/DPs

In her view, the biggest barriers are:

- The mental load and emotional exhaustion of caring
- Trying to manage complex admin while sleep-deprived and holding down a job
- Confusing and burdensome paperwork
- Outdated or unrecognised Power of Attorney documents
- Lack of clarity about what DPs can be used for
- No central place where POA details are held or recognised

She emphasised that when carers are already stretched to their limit, they cannot be expected to take on a second job as an employer and administrator.

Understanding of What SDS Funds Could Be Used For

She was only told that DP money could be used for home care.

She personally paid for:

- Continence products
- Therapeutic or wellbeing activities
- Other personal items

She was initially told she could fund therapeutic singing sessions, but this never happened.

Improvements Needed

She identified several areas for improvement:

1. A single point of contact

Someone who can respond quickly to problems and take action—rather than passing carers between services.

2. Meaningful support from management or support organisations

Not just paying wages or sending lists of training, but actively supporting carers and PAs to access training, book courses, and maintain safety and compliance.

3. A mechanism to return unspent funds

Especially when carers cannot be recruited and money sits unused in a bank account under the carer's name.

4. Better training and capacity for agency staff

Her daughter has specific medical needs. Agencies have repeatedly been unable to train staff quickly enough or keep staff long term.

This has led to:

- Two agency changes since October
- Loss of staff who had supported her daughter for over 6 years
- Inconsistent care
- Lack of confidence that paid carers can keep her daughter safe

Present Day: The Impact of System Failures

She currently receives far fewer care hours than the 26 she is allocated. Recent weeks have dropped to 12 hours.

Despite this:

- She cannot leave the house.
- She cannot trust staff to safely care for her daughter without her present.
- She has given up her job because inconsistency in cover made working impossible.
- She receives no time to herself.
- She is constantly on hand to support paid carers who lack training or confidence.

This lack of reliable support has become overwhelming:

> *"I need a break. I get zero time to myself."*

This was witnessed during the interview when the paid carer was unable to manage an issue and called her away mid-conversation.

Case Study 2 - Living with Direct Payments Over 20+ Years

(Interview with a man in his mid-50s who has a lifelong impairment but does not let it define him)

Background and Early Use of Direct Payments

He has been using Direct Payments since 2001, though his care package has changed significantly over time as his physical needs have evolved. He previously worked but eventually had to stop because he could no longer manage both work and daily life due to increasing fatigue and physical changes. He transitioned from using a manual chair to a power chair around the same time.

Because he worked in an organisation connected to social care, he was already aware of personal budgets and saw early on how Direct Payments could support independent living. After attending a meeting about DPs, he approached a support service and was then allocated a social worker. He chose Direct Payments immediately.

Experience Managing Direct Payments

His experience of Direct Payments over the years has been "*varied*":

- It has depended heavily on which social worker or support agency he had at the time.
- Earlier on, he had very good advisors through Wiltshire Centre for Independent Living (WCIL).

- More recently, things have felt more difficult. His benefits were stopped when he moved from historical disability benefits to Universal Credit. He had built up a balance of £9,000 in his account which was due to difficulties recruiting PA's. DWP said they were savings in his own name and therefore he would not be entitled to Universal Credit. Wiltshire Council would not write a letter to explain that the money was from direct payments and could only be used to fund his carers. He had to ask the council to reclaim the money from him which took many phone calls, in order that his benefits were reinstated. This caused him huge amounts of stress and anxiety.

Confusion around Universal Credit led to suggestions that he either move to a direct service or allow WCIL to manage the package - neither of which he wanted.

Despite the variability, he feels confident managing the money himself. He uses a separate account, handles all invoices, and currently uses a micro-provider for support.

Managing the Practicalities

He finds the administrative side manageable:

- Setting up a separate account was fine.
- Online banking and paperwork are not an issue.
- Tracking spending is straightforward because the money is ring-fenced, though disagreements sometimes arise about what counts as a legitimate PA expense.
- Annual council reviews of his care package are routine.

Finding and retaining carers has become significantly harder since the UK left the EU. He previously had long-standing carers who left the country, and now struggles to find people willing to work late evenings or weekends for the council's employed-carer rate of £13 per hour.

He noted that self-employed carers can charge far higher rates to the council, leaving little incentive for them to work for him on employed terms. He currently has to pay agency rates because otherwise he would not receive the support he needs.

Impact on Wellbeing

Managing Direct Payments can sometimes affect his stress levels:

- Conducting disciplinaries or dealing with respect/dignity issues with PAs can be emotionally difficult, especially because relationships often become close.

- He keeps a bank of previous carers he can call on in emergencies.
- Recruiting is challenging, particularly when applicants do not understand the nature of his needs (e.g., hoisting, safeguarding).

He emphasised that training responsibility - manual handling, safeguarding, DBS checks - falls on him, although WCIL provides courses.

Overall, he described the experience as one where *"you are often beholden to other people,"* which can be stressful.

Choice and Flexibility

He does not feel that his care package fully gives him what he needs.

- It covers personal care but not the wider life he wants to live.
- He would love to be able to go to a festival or take a short break with his fiancé, but *"the rules basically say you can't have a life."*
- If he wants to go out socially, he has to fund PA support himself.
- Since moving to a micro-provider model, flexibility has reduced compared with when he employed his own PA directly.

He feels the range of available carers and providers has narrowed.

Clarity About Spending Rules

He feels broadly clear about what Direct Payments can be used for - but that clarity keeps shifting:

- Over a 5-year period, he was told he could use DP funds to pay for PA support when going out.
- Later, the guidance changed and he was told DPs were only for personal care.

This inconsistency has created uncertainty and reduced his quality of life.

Advice and Information Sources

He relies on:

- His own knowledge and experience
- Social media
- Other organisations

He does not rely on family for support with his DP.

He also feels that some agencies have lost sight of the principles of empowerment, the social model of disability, and rights-based approaches. He believes the way DPs are presented by professionals strongly influences whether people feel confident using them.

Barriers to Using Direct Payments

From his perspective, the main barriers others face include:

- Confidence and skill set
- Administrative demands
- Lack of IT confidence
- Variable social worker knowledge and attitudes
- Unclear or inconsistent explanations of what DPs can be used for
- A shift away from rights-based, person-centred framing

Ideas for Improvement

He identified several key improvements:

- **Consistency** in guidance and messaging from Wiltshire Council - particularly around surplus funds and permitted use.
- **A national approach to social care** rather than local variation: *"It's a postcode lottery. I'm not even confident the rules are the same in North and South Wiltshire."*
- **More flexible approaches** that recognise people's whole lives, not just personal care.
- **Recognition of the challenges in recruitment**, especially post-EU exit.

Case Study 3 - Continues on next page

Case Study 3 - Dementia, Carer Stress and Lack of Choice in Adult Social Care

(Interview with the son and main carer of an older man with dementia – August 2025)

Background and Initial Support

PJ, an older man living with vascular dementia, began receiving a council-arranged package of care in March 2024. His son, MJ, had reached a point where he could no longer manage alone and sought help through the GP. Until then, his father had received no care or financial assessment.

MJ was not offered Direct Payments or Self-Directed Support (SDS). A standard agency package was put in place without discussion of alternatives.

> *"I had no idea what help was available. Dad wasn't offered a choice because he was assessed as not having mental capacity."*

Lack of Choice and Difficulty Challenging Decisions

Because MJ did not have a Lasting Power of Attorney (LPOA), he was repeatedly told he had no right to make decisions about his father's care—despite being the sole carer.

He raised concerns about:

- Care workers leaving early
- His father being left without drinks or meals
- Carers sitting in their cars until the end of their shift because they had to "*geo-tag*" their logout

He asked to cancel the care company because the support was unsafe and was told he had **no authority** to request this.

He enquired about Direct Payments but was informed they could not be offered to a carer living in the same household. Instead, he was advised that his father should be referred to the Court of Protection for a deputy to be appointed.

When he asked why he could not be the deputy, he received no answer.

Communication Barriers and Lack of Support

MJ described communication with the council as extremely difficult:

- Calls to the Adult Care helpline were time-consuming and often unanswered.

- Staff appeared to have limited understanding of dementia.
- His attempts to speak on his father's behalf were repeatedly dismissed because he lacked LPOA.

> *"All the questions were directed to Dad, even though he couldn't answer them. I felt invisible."*

Financial Assessment Delays and Distress

The initial care package began in March 2024, but the financial assessment was not done until October 2024 - seven months later.

His father then received an invoice for over £2,000 in back payments, which created significant stress for both of them. MJ believes the delay contributed to his father's deterioration during that period.

The Emotional Burden of Caring Without Authority

MJ described the system as **humiliating** and lacking in empathy.

He felt judged, not supported.

A striking example was the financial assessment process:

- Despite being told he had no right to make decisions without LPOA, he was expected to complete the financial assessment on his father's behalf.
- When he explained that he did not have access to bank statements, he was asked whether his father could *"pop into the bank"* to request them - even though his father's dementia makes busy places frightening and overwhelming.
- MJ drove him to the bank, where staff questioned why he was asking for statements.
- He felt he was coercing his father into a confusing and distressing situation simply to comply with council requirements.

> *"The whole process caused him stress and made me feel like I was doing something wrong."*

Access to Direct Payments

Direct Payments were never discussed at the start.

When MJ later asked, he was told:

- DPs are not given to carers living in the same home

- Since his father lacked mental capacity, only a Court of Protection deputyship would allow changes

No alternatives were offered that would allow SDS to be explored.

He was given no information, no options, and no chance to think through decisions.

Barriers to SDS and Direct Payments

MJ identified several systemic barriers that prevent people - especially those with dementia - from accessing SDS:

- Very poor communication and long wait times
- Limited understanding of dementia by staff
- Rigid adherence to rules around capacity and LPOA
- A process that does not recognise or support the central role of unpaid carers
- Delays in assessments that lead to inappropriate bills and emotional distress
- Over-reliance on open-ended questions (“*What care do you need?*”) that people with dementia cannot answer

He stressed that the system fails to appreciate the vital role of the carer and often sidelines them.

Provider Perspective from the Dementia Support Organisation

The provider who facilitated the interview added:

- Most people with dementia cannot manage SDS or answer capacity-based questions.
- Many elderly carers struggle with computers, forms, and administration.
- Without a supportive family member or clear authority to act, SDS becomes unmanageable.
- Systems do not accommodate the cognitive and emotional realities of dementia.

> “They rely completely on their main carer to advocate for them. The system does not reflect that.”

What Needs to Improve

MJ’s priorities for improvement include:

1. More understanding and empathy for carers of people with dementia

Staff should understand how dementia affects communication, decision-making, and everyday care.

2. Better communication and quicker responses

Delayed assessments and long waits cause distress.

3. More consistent and compassionate staff training

Staff need to recognise that many people with dementia cannot answer open-ended questions and rely entirely on their carers.

4. Inclusion of carers in conversations

When someone lacks capacity, their main carer must be listened to and supported - not dismissed.

Appendix 3 – Survey Findings and Demographic Analysis

Purpose of the Survey

The survey was developed to test and validate the themes emerging from the in-depth interviews, and to provide an additional route for people who preferred not to engage through one-to-one conversations or group settings.

It was designed as a complementary qualitative tool, recognising that experiences of Direct Payments (DPs) are highly individual and not easily captured through closed questions or simple rating scales.

Survey Structure and Routing Design

The survey was intentionally designed for three distinct respondent groups:

- Individuals using **Direct Payments**,
- **Paid and unpaid carers**, and
- **Professionals** supporting or working within Direct Payment systems.

All respondents began with a small number of shared, high-level questions. Based on how they answered these initial questions, they were then automatically routed to tailored sections that asked role-specific questions relevant to their experience.

This adaptive design ensured that:

- Individuals were only asked questions that were meaningful and appropriate to their role,
- Carers were able to reflect on both personal impact and system navigation, and
- Professionals were able to comment on processes, challenges and system-level issues.

This approach reduced respondent burden, improved the relevance and accuracy of responses, and ensured that insights were properly contextualised by lived experience or professional perspective.

Survey Participation

A total of **23 people** completed the survey.

Respondents included:

- People currently using Direct Payments
- Unpaid carers supporting Direct Payment recipients
- People who had declined Direct Payments or experienced difficulties accessing them

Demographic Overview of Survey Respondents

Based on the information shared within survey responses:

- **Age**: Predominantly between 45–79
- **Gender**: Majority female
- **Geography**: Strongest representation from West Wiltshire
- **Primary needs represented:**
  - Physical disability
  - Long-term illness
  - Dementia
  - Neurodiversity
  - Mental health
- **Caring roles:**
  - Predominantly parent carers
  - Several working carers balancing employment and care

These demographics closely mirror the profile seen across the in-depth interviews and group-based engagement.

Key Survey Findings (Validation of Interview Themes)

The survey responses strongly reinforced and validated the themes identified through in-depth interviews and lived-experience case studies. No new contradictory themes emerged through the survey data.

Across responses, the most consistently reinforced issues were:

- Lack of clear, accessible information at the outset, with many respondents unsure what Direct Payments involved or how to access them
- Ongoing confusion between “Direct Payments” and “Self-Directed Support”, with SDS

not widely recognised as a term

- High administrative burden, particularly around payroll, monitoring and employment responsibilities
- Difficulties recruiting and retaining Personal Assistants, especially for specialist care and unsocial hours
- Delays in financial and assessment processes, contributing to anxiety about unspent funds and backdated charges
- High emotional pressure on carers, particularly where informal support was limited
- Variation in flexibility in practice, despite flexibility being the core promise of Direct Payments

The survey therefore served as a confirmation tool, strengthening confidence that the barriers identified through smaller-scale, in-depth engagement are experienced more broadly across participants.

Relationship Between Survey Findings and Interview Data

The survey findings showed strong alignment with the in-depth interviews, demonstrating:

- Consistency of experience across different engagement routes
- Repetition of the same system-level barriers
- Reinforced evidence for the core findings and recommendations presented in the main report

The survey therefore acted as a validation mechanism, confirming that the priority issues identified through smaller, deeper conversations were also being experienced more broadly.

Limitations of the Survey

- The survey was not designed to be statistically representative.
- Participation numbers were modest, reflecting known engagement challenges with Direct Payment users.
- As with all voluntary engagement, responses reflect those who felt able and willing to participate.

However, within a qualitative framework, the survey provided valuable triangulation against interview and case study data.

Conclusion

The survey strengthened confidence in the overall findings of this report. It confirmed that:

- The key challenges are consistent across different engagement methods
- The recommendations are grounded in repeated lived experience
- The barriers identified through interviews are not isolated cases, but part of broader system patterns

Appendix 4 – Professional and WCIL System Feedback

Professionals involved in advising people about Direct payments highlighted a number of system-wide challenges and opportunities for improvement. Much of their feedback reflects pressures experienced across the whole DP pathway—including social workers, finance teams, and advisory services—rather than any single organisation.

1. Confidence and Understanding of Direct payments

Professionals reported that social workers often feel uncertain or under-confident about recommending Direct payments.

This is not due to lack of willingness, but rather:

- High turnover in teams leading to loss of knowledge ("back to square one").
- Variability in experience and familiarity with Direct payments.
- A need for clearer guidance and reassurance when discussing DP with clients.

This lack of confidence sometimes makes the DP process feel "clunky" or inconsistent.

2. Timing and Overload for Clients and Carers

Advisers explained that people can be overwhelmed by the volume of information presented at assessment.

- *"Timing is crucial… earlier conversations work better, especially for carers."*
- People need the option to absorb information gradually, not all at once.

WCIL advisers have responded by sending information ahead of phone calls, so people have time to prepare, which has helped reduce anxiety.

3. Value of Partnership Working

Professionals emphasised the importance of a partnership approach, where social workers, WCIL advisers, and other teams share information and work collaboratively.

- The **DP Champions Forum**, chaired by the Principal Social Worker, was viewed positively.
- It is helping identify barriers, share learning, and feed into the wider transformation of Adult Social Care.

This demonstrates that collaborative structures already exist and could be strengthened further.

4. Barriers Clients Face in Taking Up Direct payments

Professionals identified several reasons people choose not to take up a DP:

- Anxiety about the employment responsibilities, HMRC and pensions.
- The length and complexity of the financial assessment (FAB).
- Fear of getting things wrong or owing money.
- Recruitment challenges - particularly for small packages of support.
- PAs unable or unwilling to become employees.
- QUAM requirements sometimes acting as “gatekeepers”.
- Some families prefer informal arrangements rather than formal care roles.

These barriers make DP feel daunting for many people, even when the flexibility would benefit them.

5. Banking and Payroll Support

WCIL’s banking service supports around 177 people, but advisers noted:

- It is appropriate only for people who need that level of help.
- Many do not know it exists because it is used sparingly and for specific circumstances.
- Anxiety about tax, payroll or pension contributions remains a major concern.

This highlights a need for clearer communication about the support available.

6. Process and Communication Gaps

Professionals observed that once assessments are completed, people sometimes experience a breakdown in communication:

- No clear point of contact.
- Confusion about next steps.
- People feeling they need to “start again”.

There were also comments that Wiltshire Council responses can feel unpredictable, making it hard for advisers to provide certainty.

7. Opportunities for System Improvement

Advisers highlighted several areas that could make the DP process more effective for everyone:

- Better information sharing between teams, so people do not receive conflicting guidance.
- Greater transparency early on about what DPs can and cannot be used for.
- Clearer parameters on spending decisions, reducing ambiguity.
- More direct communication between the Council and clients so people feel supported.
- More flexibility in processes to empower social workers to make appropriate decisions.
- A more personable QUAM process, which currently feels rigid and difficult to navigate.
- Support for social workers so they feel confident to present DP as a genuine option, not a risky one.

Overall Insight

The feedback shows that professionals - including WCIL advisers - are committed to supporting people well, but the current system creates uncertainty for both staff and clients. The challenges identified relate mainly to system processes, communication gaps, and inconsistencies across services rather than to any single organisation.

There is a strong appetite for:

- Clearer information,
- More consistent guidance,
- Improved inter-team communication, and
- A more confident and coordinated approach to Direct payments.

These insights present a constructive opportunity for the Council and partners to strengthen the DP offer together.

Positioning Statement for the Report (and the DP Contract)

At the time these insights were gathered, the Direct payments (DP) support service in Wiltshire was being delivered by Wiltshire Centre for Independent Living (WCIL) under contract with Wiltshire Council. WCIL staff were therefore one of the key professional groups providing information, advice and support to people considering or using Direct payments.

Since this engagement took place, the commissioning arrangements have changed and WCIL no longer holds the contract to provide Direct Payment support. They are not currently delivering this service under a formal agreement with the Council.

The findings presented in this report therefore reflect WCIL's experience and perspective at the time they were contracted to provide DP support and should be understood within that context.

Appendix 5 – Promotional Flyer

SURVEY

Voice It
Hear It

Have you ever received a Direct Payment or Personal Budget?

We'd love to hear about your experience.

Tell us what worked well — and what could work better. Your feedback will help Wiltshire Council shape the future of support for people who use Direct Payments.

Share your story

- Scan the QR code below or visit https://survey.communityfirst.org.uk/zs/3CBZvN
- Or call us on 01380 722 475 to talk to us in person or online.

All stories will be treated **confidentially and anonymously**.
Your voice matters — real experiences lead to better services.

Voice It, Hear It

Working with Wiltshire Council and BSW ICB to improve local health and care services.

voice@communityfirst.org.uk

Appendix 6 – Social Media Posts

Voice It, Hear It · Following

👉 Have you had any experience with Direct Payments / Personal Budgets? We want to hear from you! 🗣️

... See more

Community First - Wiltshire & Swindon

Published by Ellie Davies · 11 November 2025

Matt from the Voice It, Hear It team gives an overview of a new project which aims to understand people's experiences of Direct Payments / Personal Budgets. If you have an experience to share, the Voice It, Hear It team wants to hear from you! 🗣️

Watch the reel for more information or see the post below. You can share your feedback via the online survey here 👉 https://survey.communityfirst.org.uk/zs/3CBZvN

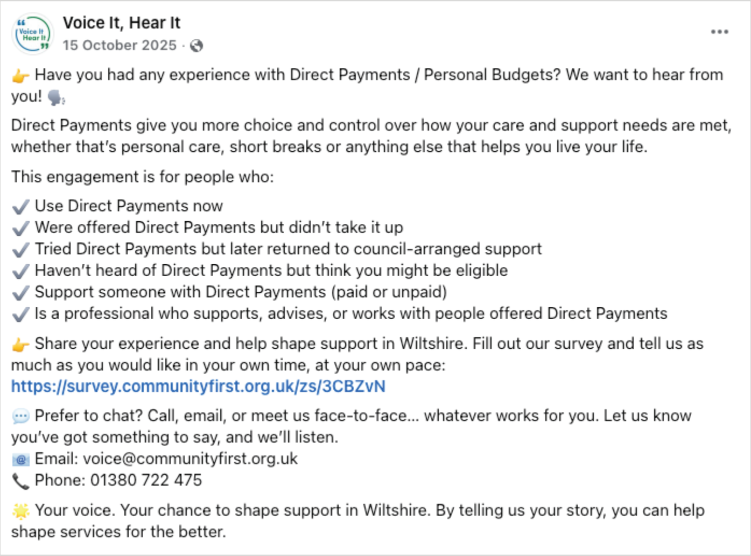
💬 Prefer to chat? Call, email, or meet face-to-face. Let the team know you've got something to say, and they will listen.

📧 Email: voice@communityfirst.org.uk
📞 Phone: 01380 722 475

Beyond Dementia

24 November 2025

Have you had experience with direct payments or personal budgets? Voice It, Hear It would like to hear your lived experiences - the good and the challenging. You can share your views via an online survey, by phone, email, or in person if you would prefer. More details below on how to have your say 👇



Voice It, Hear It

15 October 2025

👉 Have you had any experience with Direct Payments / Personal Budgets? We want to hear from you! 🗣️

Direct Payments give you more choice and control over how your care and support needs are met, whether that's personal care, short breaks or anything else that helps you live your life.

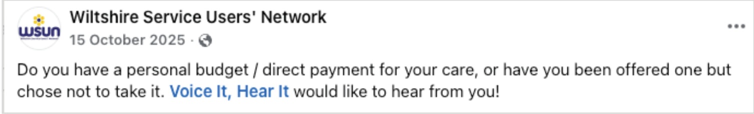
This engagement is for people who:

✓ Use Direct Payments now
✓ Were offered Direct Payments but didn't take it up
✓ Tried Direct Payments but later returned to council-arranged support
✓ Haven't heard of Direct Payments but think you might be eligible
✓ Support someone with Direct Payments (paid or unpaid)
✓ Is a professional who supports, advises, or works with people offered Direct Payments

👉 Share your experience and help shape support in Wiltshire. Fill out our survey and tell us as much as you would like in your own time, at your own pace: https://survey.communityfirst.org.uk/zs/3CBZvN

💬 Prefer to chat? Call, email, or meet us face-to-face… whatever works for you. Let us know you've got something to say, and we'll listen.
📧 Email: voice@communityfirst.org.uk
📞 Phone: 01380 722 475

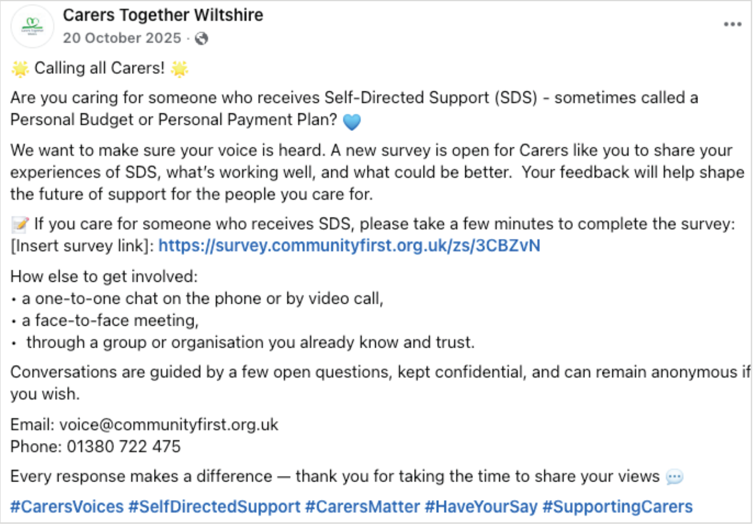
🌟 Your voice. Your chance to shape support in Wiltshire. By telling us your story, you can help shape services for the better.



Wiltshire Service Users' Network

15 October 2025

Do you have a personal budget / direct payment for your care, or have you been offered one but chose not to take it. Voice It, Hear It would like to hear from you!



Carers Together Wiltshire

20 October 2025

🌟 Calling all Carers! 🌟

Are you caring for someone who receives Self-Directed Support (SDS) - sometimes called a Personal Budget or Personal Payment Plan? 💙

We want to make sure your voice is heard. A new survey is open for Carers like you to share your experiences of SDS, what's working well, and what could be better. Your feedback will help shape the future of support for the people you care for.

📝 If you care for someone who receives SDS, please take a few minutes to complete the survey: [Insert survey link]: https://survey.communityfirst.org.uk/zs/3CBZvN

How else to get involved:
- a one-to-one chat on the phone or by video call,
- a face-to-face meeting,
- through a group or organisation you already know and trust.

Conversations are guided by a few open questions, kept confidential, and can remain anonymous if you wish.

Email: voice@communityfirst.org.uk
Phone: 01380 722 475

Every response makes a difference — thank you for taking the time to share your views 💬

#CarersVoices #SelfDirectedSupport #CarersMatter #HaveYourSay #SupportingCarers

Community First - Wiltshire & Swindon

Published by May Young · 16 October 2025

If you have had any experience with Self-Directed Support (SDS) / Personal Budgets, Voice It, Hear It want to hear from you! 🗣️

Acknowledgements

Our thanks to all individuals, carers, professionals and VCSE partners who contributed their time and insight to this work. Your experiences will directly inform the future development of Self Directed Support and Direct Payments in Wiltshire.

This report has been produced by:

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