What approaches have been used to implement direct payments within health systems, and how do various factors influence the effectiveness of these approaches in supporting personalisation, governance, and equitable access to care: A Rapid Evidence Summary

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Abstract:
Continuing National Health Service Health Care (CHC) is a package of care for adults with significant primary health care needs who live in England or Wales. Currently, direct payments are not available for individuals receiving CHC in Wales. In contrast, in England, individuals in receipt of CHC can access direct payments as part of a broader system of Personal Health Budgets (PHBs), which offer choice and control over how their care is delivered. The *Health and Social Care (Wales) Act 2025* includes provisions enabling the introduction of direct payments for CHC in Wales, with implementation anticipated in 2026, subject to the development of supporting regulations and guidance

This review seeks to explore: what approaches have been used to implement direct payments within health systems, and how effective these approaches are in supporting personalisation, governance, and equitable access to care?

Searches were conducted on bibliographic databases from 2012 onwards to build upon previous work. Important pre-2012 grey literature evidence was also considered. The review included evidence published from 2010 to 2023.

The findings presented are based on the **8 review articles and 16 organisational reports**, some of which cover both health and social care.

The literature lacks clear definitions and consistent use of the terms related to direct payments and Personal Health Budgets (PHBs), often blurring the distinctions between different approaches. Where possible, findings have been drawn from the broader PHB literature, with relevant sections highlighted that directly address the implementation of direct payments.

Many of the **key elements for the successful implementation** of direct payments are similar across the different models of PHB implementation and include: Robust **support** and referral systems, **clear and accessible information** for recipients (patients and families), comprehensive **training and guidance** for staff involved in implementation to enhance knowledge and attitudes.

Policymakers should account for an initial adjustment period when assessing the impact of direct payments, as users and carers, as well as NHS staff, get used to any new arrangements and processes.

Researchers should carefully consider the timing of data collection in evaluations of direct payments, as early-stage data may disproportionately reflect implementation challenges rather than long-term outcomes. Longer-term follow-up (minimum of nine months) is essential to capture the full impact of personalised care, allowing users time to adjust, build confidence, and develop sustainable routines that reflect the intended benefits.

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What approaches have been used to implement direct payments (and other forms of personal health budgets) within health systems, and how do various factors influence the effectiveness of these approaches in supporting personalisation, governance, and equitable access to care: A rapid evidence summary

EXECUTIVE SUMMARY

Report number: RES0054 (July 2025)

What is a Rapid Evidence Summary?

Our Rapid Evidence Summaries (RES) are designed to provide a rapid response product. They are based on a limited search of key resources. Priority is given to studies representing robust evidence synthesis. No quality appraisal or evidence synthesis are conducted, and the summary should be interpreted with caution.

Who is this Rapid Evidence Summary for?

To support the Welsh Government's implementation of direct payments for Continuing National Health Service Healthcare (CHC).

Background / Aim of Rapid Evidence Summary

CHC is a package of care for adults with significant primary health care needs who live in England or Wales. Currently, direct payments are not available for individuals receiving CHC in Wales. However, the *Health and Social Care (Wales) Act 2025*, which received Royal Assent in Spring 2025, includes provisions enabling the introduction of direct payments for CHC in Wales. Implementation is anticipated in 2026, subject to the development of supporting regulations and guidance.

This review seeks to explore: what approaches have been used to implement direct payments within health systems, and how effective these approaches are in supporting personalisation, governance, and equitable access to care?

Results

Recency of the evidence base

- Searches were conducted on bibliographic databases from 2012 onwards to build upon previous work. Important pre-2012 grey literature evidence was also considered.
- The review included evidence published from 2010 to 2023.

Extent of the evidence base

- **2** rapid reviews, **6** systematic reviews, **16** organisational reports and **4** guidance documents.
- Of the 8 reviews included, **6** examined both **health and social care** while **2** focused **exclusively on healthcare.** There was significant variation in terminology, with terms such as 'self-direction', 'individualised budgets', 'personal health budgets' (PHBs), 'direct payments', and 'individualised funding' often used interchangeably across studies.
- Of the 16 organisational reports included, **12 detailed both the pilot phase and the subsequent national rollout of personal health budgets (PHBs)** within the NHS in England. The **remaining 4** provided **additional insights** into the implementation and outcomes of PHBs, both in England and internationally.
- **Four recent guidance documents** published by NHS England are highlighted. These either focus specifically on direct payments for healthcare or take a broader perspective on PHB budgets, with sections directly relevant to the implementation of direct payments.

Key findings:

The findings presented are based on the **8 review articles and 16 organisational reports**, some of which cover both health and social care.

The literature lacks clear definitions and consistent use of the terms related to direct payments and PHBs, often blurring the distinctions between different approaches.

Where possible, findings have been drawn from the broader PHB literature, with relevant sections highlighted that directly address the implementation of direct payments.

- Many of the **key elements for the successful implementation** of direct payments are similar across the different models of PHB implementation and include:
  - Robust **support** and referral systems
  - **Clear and accessible information** for recipients (patients and families)
  - Comprehensive **training and guidance** for staff involved in implementation to enhance knowledge and attitudes.
- Successful implementation requires NHS staff, commissioners and service providers to **embrace cultural and structural change**, including shifting attitudes, adapting traditional service models, and developing infrastructure that supports personalised care.
- Providing **tailored support** to direct payment recipients and the paid carers[1], particularly in the **early stages**, can help build confidence and ensure effective use of budgets.
- **Raising awareness**, improving resource management and streamlining eligibility processes can help encourage **greater uptake**.
- **Training is essential for healthcare staff, personal assistants and local authority leadership,** with recommendations for structured frameworks, competence assessment and peer support mechanisms.
- **Brokerage and independent support services** are critical enablers, helping users navigate budgeting, recruitment and care planning effectively.
- Users **report increased choice, control and empowerment**, and many see direct payments as a valuable route to autonomy of care.
- Direct payments were associated with a range of positive outcomes, **including improved health and well-being** for users and carers[1], particularly when managed by trusted family and friends, which also enhanced living arrangements and supported individuals with dignity.
- **Strengthening governance arrangements** in areas such as accountability, risk management and safeguarding can support individuals to safely and confidently employ their own carer.
- Formal **governance structures support** coherent implementation, clarifying roles and ensuring consistency across regions.
- **Improving clarity** of protocols, access to information and geographic reach, especially in rural and remote areas, can help **ensure more equitable access** to services.
- **Supporting** individuals with **advertising, vetting and employment logistics** can help them successfully recruit suitable carers[1].

Policy and Practice Implications

- Policymakers should account for an initial adjustment period when assessing the impact of direct payments, as users and carers, as well as NHS staff, get used to any new arrangements and processes.

Research Implications

- Researchers should carefully consider the timing of data collection in evaluations of direct payments, as early-stage data may disproportionately reflect implementation challenges rather than long-term outcomes.
- Longer-term follow-up (minimum of nine months) is essential to capture the full impact of personalised care, allowing users time to adjust, build confidence, and develop sustainable routines that reflect the intended benefits.

[1] Carers can be from outside agencies or family members

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Abbreviations

Acronym	Full Description
COPD	Chronic obstructive pulmonary disease
CRB	Criminal records bureau
ICB	Integrated care boards
NHS	National Health Service
PA	Personal assistants
PHB	Personal health budgets

Glossary

Continuing healthcare
"Continuing Health Care is a complete package of ongoing care arranged and funded solely by the NHS through local health boards, where an individual's primary need has been assessed as health-based. Continuing Health Care is one element of a range of services that local authorities and NHS bodies need to have in place to support people with health and social care needs. Continuing Health Care is one aspect of care which people with complex needs may need as the result of disability, accident or illness to address both physical and mental health needs.". (Welsh Government 2022, p.4.)

Direct payments
Direct payments for healthcare are monetary payments in lieu of services. The money is individual (or their representative) receives the money directly and takes full responsibility for purchasing and managing services in line with their agreed care plan. Direct payments give individuals greater choice and control over their care, but they do not remove or alter the NHS's legal duty of care to every person receiving services. (NHS England, 2022b).

Notional budget
Where the NHS retains control of the funds but works with the individual to plan and arrange care based on their choices. This option offers personalisation without the need to handle the money directly (NHS England, 2022b).

Personal assistants
Direct payments for healthcare can be used to pay for a personal assistant to carry out certain healthcare tasks. PAs can only carry out delegated healthcare tasks (e.g. clinical interventions) if these are included in the care plan and they receive proper training, supervision, and competency assessment (Skills for Care, 2023).

Personal health budgets
Personal health budgets as implemented in England, use NHS funding to create an individually agreed personalised care and support plan that offers people of all ages greater choice and flexibility over how their assessed health and wellbeing needs are met (NHS England, 2022b). A PHB can be managed in three ways, via direct payments, a third-party budget, or a notional budget, or through a combination of these.

Third-party budget
Where an independent organisation manages the funds on behalf of the person and arranges care according to their preferences, this allows for choice and flexibility without the administrative burden (NHS England, 2022b).

1. CONTEXT / BACKGROUND

1.1 Background and purpose of the review

Personalised care is increasingly recognised as a cornerstone in the design and delivery of health and social care services in Wales. It reflects a strong policy commitment to ensuring that individuals, particularly those with complex or ongoing needs, have greater voice, choice, and control over how their care is arranged and delivered. One of the key mechanisms for enabling this personalisation in practice is the use of direct payments.

Direct payments involve providing individuals or their representatives with a monetary sum to arrange care in line with an agreed care and support plan. This approach empowers people to tailor their care to what matters most to them, offering greater flexibility, autonomy and control over how services are delivered. Support is often available to help individuals manage the associated responsibilities. Evidence suggests that direct payments can foster more responsive and personalised care that is better aligned with individual's needs, routines, and preferences (Gadsby 2013). By enabling people to shape their care according to what matters most to them, direct payments promote and enable greater dignity, independence, and wellbeing.

In Wales direct payments have long been a central feature of personalised social care, administered by Local Authorities. However, they have not yet been extended into the healthcare system, which in Wales is overseen by Local Health Boards. This lack of continuity can result in a loss of control when individuals transition from social care into continuing healthcare disrupting established support arrangements and undermining person-centred practice (Welsh Government, 2025a; 2025b). This policy divergence has raised concerns among direct payments recipients, carers, and professionals about continuity and equity in service delivery.

To address these concerns, the Welsh Government has committed to introducing direct payments within Continuing NHS Healthcare. Following the passing of the Health and Social Care Act in Spring 2025, implementation of direct payments is anticipated in 2026. Unlike in England, where direct payments are one option within a broader personal health budget (PHB) model, Wales is taking a focused approach by introducing direct payments as a standalone mechanism to enhance personalisation in healthcare.

<u>English approach</u>
In England, Personal Health Budgets, which include as an option the receipt of a direct payment by those wishing to have a greater role in managing their own healthcare package, were piloted from 2009 and formally evaluated in 2012 through a mixed-methods study (Forder et al. 2012). The evaluation found that PHBs could be cost-effective, particularly for people receiving NHS Continuing Healthcare or mental health support, with improvements reported in social care-related quality of life (Forder et al. 2012). Subsequent research has reinforced the positive impact of PHBs on health, wellbeing, choice, and control, though achieving genuine personalisation requires significant shifts in NHS practice (Cooney et al. 2020; Ayoola & Butt, 2021). The NHS Mandate set a target of 50,000–100,000 PHB recipients by 2020/21, and by 2019/20, nearly 89,000 people had received one (NHS England, 2018; NHS Digital, 2020b). Initially restricted to specific groups, eligibility broadened under the NHS Long Term Plan to include individuals with learning disabilities, those under section 117 after-care, and users of bespoke support packages, with an ambition to reach 200,000 recipients by 2023/24 (NHS England, 2019a, 2022).

During the pilot, adults in receipt of NHS Continuing Healthcare (CHC) and living in their own homes were among those who benefited the most from Personal Health Budgets. Pilot sites enabled direct payments under the pilot arrangements, but the formal legal basis for making direct payments in CHC was only established later, through amendments to the NHS Act 2006 in 2014, which secured their availability beyond the pilot sites. Direct payments were also offered during the pilot to individuals with specific needs such as mental health conditions, long-term physical health problems, learning disabilities, or children and young people with complex needs (Irvine et al. 2011; Prabhakar et al. 2011; Jones et al. 2011; Forder et al. 2012; Davidson et al. 2012). In Wales, legislative change has now been made through the Health and Social Care (Wales) Act 2025, which amends the NHS (Wales) Act 2006 to enable the introduction of direct payments within NHS Continuing Healthcare.

Successfully implementing direct payments, whether as part of PHBs or as a standalone option, requires more than simply offering a cash alternative to traditional services. It demands thoughtful planning, supported by robust governance frameworks that ensure accountability, transparency and safeguarding. These frameworks must protect public funds, uphold quality of care and safeguard vulnerable individuals. To promote equity, it is essential to proactively address potential barriers that may affect uptake and implementation. Without appropriate support, individuals with limited capacity, social capital or digital literacy may struggle to navigate complex administrative systems. These considerations should be embedded into the design and planning stages to avoid exacerbating existing inequalities and to ensure that the benefits of direct payments are accessible to all eligible individuals. A clear understanding is therefore needed of how direct payments have been implemented in other health systems and how effective these approaches are in supporting the core aims of personalisation, governance, and equitable access to care. This review seeks to explore:

What approaches have been used to implement direct payments within health systems, and how effective are these approaches in supporting personalisation, governance, and equitable access to care?

While our primary focus is on direct payments, we are also interested in relevant research on other forms of PHBs, including notional and third-party budgets. Including this broader evidence base will help us understand the differences in delivery models and identify transferable learning that may inform the effective implementation of direct payments in the Welsh context.

While this review draws extensively on evidence from the implementation of PHBs in England, it is important to recognise that the policy landscape in Wales is distinct. In Wales, PHBs are not part of the health system, and the focus is solely on the introduction of Direct Payments for Continuing NHS Healthcare. This distinction is crucial, as the legislative and operational frameworks governing direct payments in Wales will be unique and shaped by Welsh policy priorities. With the legislative framework now in place but infrastructure still to be developed, the Welsh approach to implementing direct payments in healthcare will need to be carefully designed to reflect local systems, priorities, and needs, while drawing on lessons from England. Therefore, while learning from PHB implementation in England is valuable, findings must be interpreted with this difference in mind.

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1.2 Research question

To structure the review question and guide eligibility criteria, the SPICE framework was used. SPICE—standing for Setting, Perspective, Intervention, Comparison, and Evaluation (Booth 2006). The table below outlines the scope of the review. A more detailed summary of the methods used for conducting the Rapid Evidence Summary are provided in Section 5.

Review question	
What approaches have been used to implement direct payments (and other forms of PHBs) within health systems, and how do various factors influence the effectiveness of these approaches in supporting personalisation, governance, and equitable access to care?	
Setting	Health systems in England where direct payments (and other forms of PHBs) have been implemented through former Clinical Commissioning Groups and now Integrated Care Boards for individuals eligible for NHS Continuing Healthcare. Comparable systems in other high-income countries that have introduced or piloted direct payment mechanisms within their health systems.
Perspective	Adults with ongoing or continuing health care needs[1] who may be eligible for or are receiving services through direct payments and staff involved in the design, implementation, or delivery of such schemes (e.g. commissioners, care coordinators, and health professionals).
Intervention (phenomenon)	Personal Health Budgets in England, or equivalent schemes elsewhere, including those delivered through direct payments for health care.
Comparison	Not applicable
Evaluation	Approaches to implementation and the factors influencing the effectiveness of direct payments in supporting personalisation, governance, and equitable access to care.
Other Study Considerations 2012 was used as a start date for the databases searches to reflect the fact that this work would be building on the review by Gadsby et al. (2013) and that the researchers' time was limited. However, where particularly useful and important evidence from pre-2012 from the grey literature was identified, this was included.	
Exclusions Studies focused solely on notional budgets or third-party managed budgets where individuals do not receive the funds directly. Interventions where direct payments are used exclusively for social care and not for meeting health or continuing healthcare needs. Studies focused on non-healthcare related budgets models (taken from Welch et al. 2022): including • Individual budget in social care – an amount of money to support an individual's social care needs following an assessment. These budgets in some cases aim to integrate multiple funding streams (e.g., social care funding, integrated community equipment services, access to work, Disabled Facilities Grants, and, historically, the Independent Living Fund).	

- Social care personal budget – allocated by the individual's local authority following an assessment and limited to social care expenditure.
- Integrated budget – an amount of money to support combined social and health care-related needs, allocated by the individual's local care team following an assessment.

Studies that do not involve adults with continuing healthcare needs (e.g., general population, children, or non-healthcare settings).

Research that does not explore implementation or does not address outcomes related to personalisation, governance, or equitable access.

Commentary or opinion pieces without empirical data or detailed description of direct payment models.

Studies published in languages other than English (unless translations are available).

Literature published before 2006, as this predates key legislative changes related to direct payments in health care.

[1.] "Ongoing health needs" refers to the broad range of long-term or complex conditions covered in the evaluation of PHBs in NHS England (2009–2012). These included adults receiving NHS Continuing Healthcare (CHC), individuals with long-term physical conditions (e.g. diabetes, COPD), mental health needs, neurological conditions (e.g. multiple sclerosis), stroke survivors, people at the end of life, children and young people with complex needs, and adults recovering from substance misuse. Select sites also explored use of PHBs in maternity services. This definition has been used to guide inclusion decisions for studies involving comparable populations.

2. SUMMARY OF THE EVIDENCE BASE

2.1 Type and amount of evidence available

The type and amount of evidence retrieved is organised into systematic and rapid reviews, organisational reports and guidance documents and is summarised below. A summary of the findings of the included evidence is provided in Section 3.

2.1.1 Systematic and rapid reviews

- We identified **two** rapid reviews (Health Foundation. 2010, Gadsby. 2013, Gadsby et al. 2013) and **six** systematic Review (Fleming et al. 2019, Lakhani et al. 2018, Micai et al. 2022, Robinson et al. 2022, Tompkins et al. 2018, Webber et al. 2014).
- **Six** of the reviews **examined both health and social care** (Fleming et al. 2019, Health Foundation. 2010, Gadsby. 2013, Gadsby et al. 2013, Lakhani et al. 2018, Micai et al. 2022, Robinson et al. 2022) while **two** focused **exclusively on healthcare** (Tompkins et al. 2018, Webber et al. 2014).
- There was **significant variation in terminology**, with terms such as 'self-direction', 'individualised budgets', 'personal budgets', 'direct payments', and 'individualised funding' often used interchangeably across different studies.
- The Health Foundation collated over 60 articles on **personal budgets across health and social care** in the UK and internationally. The objectives were to examine the international evidence on the impacts of personal health budgets on health outcomes, patient-centred care, and value for money; to explore whether personal health budgets are more effective for some groups of people; to identify where the majority of studies

originate; and to review the UK evidence on individual budgets for social care. The review included studies published up to 2010 (Health Foundation 2010).

- A rapid review across 11 OECD countries that examined how **PHB models and self-directed support** were implemented, focusing on budget allocation, management, and governance. The review identified a range of models, from open to planned[2], with some countries adopting hybrid approaches. The review included studies published up to 2012 (Gadsby 2013; Gadsby et al. 2013).
- A systematic review that synthesised evidence from Europe, the United States, Canada, and Australia to evaluate the effectiveness of **individualised funding** in improving **health and social care** outcomes for people with disabilities. It incorporates findings from 66 qualitative and three mixed-methods studies, examining stakeholder experiences with a particular emphasis on the challenges and facilitators encountered during the initial implementation phase of these interventions. The review covers studies published between 1992 and 2016 (Fleming et al. 2019).
- A systematic review that explored factors that influenced engagement with **self-directed models of health and social support** for people with various disabilities, including intellectual disabilities and degenerative diseases. Additionally, the review investigated how informed decisions were made and people chose services. The systematic review identified 18 reports, 15 primary studies and three review articles. Primary studies were conducted in six countries, six in the UK, five in the USA, and one each in Australia, Finland, New Zealand and Germany. Studies were published between 2012 and 2016 (Lakhani et al. 2018).
- A systematic review that focused on the **use of personal budgets** for people with mental health conditions or intellectual disability and included 29 studies published between 2013 and 2021 in four countries. The studies mainly originated from the UK and the USA, with 11 studies included from each country. Six studies were conducted in Italy and one study was included from Australia. Nineteen studies were qualitative by design exploring people's, their carers and professionals' experiences, whilst 10 studies had a quantitative design (Micai et al. 2022).
- A systematic review that explored the effects and costs of **personalised budgets** for people with **physical disabilities, intellectual and developmental disabilities, and mental health conditions.** The review focused on models where individuals had control over their care decisions, examining various forms of personalised budgeting. The review included a range of study designs, and the studies were conducted in high-income OECD countries, with 16 from the United States, four from England and three from Italy, covering the period from January 1985 to November 2022 (Robinson et al. 2022).
- A systematic review of four programmes across six studies focused on the implementation and delivery of **PHBs** initiatives for **drug and alcohol users** in England and the USA between 1990 and 2017. The review included both qualitative and mixed methods study designs (Tompkins et al. 2018).
- A systematic review that examined the effectiveness of **personal budgets for adults aged 18 to 65 with mental health problems**, including those with additional disabilities.

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[2] *Open model* - Payment for care is provided to those eligible for long-term care services with few strings attached. The cash allowance can be spent however the recipient chooses and the money does not have to be accounted for (Alakeson 2010)

Budgeted or planned models - Programme maintains a more direct connection between a participant's needs and the goods and services purchased to meet those needs. Restrictions are placed on how money can be spent, and the expenditure is audited carefully (Alakeson 2010)

It included nine studies conducted in the United Kingdom and six in the United States, evaluating a range of models such as individual budgets, recovery budgets, personal budgets, **direct payments,** personal health budgets, and cash and counselling programmes. A variety of study designs were used to assess outcomes across different approaches to personalised budgeting (Webber et al. 2014).

2.1.2 Organisational reports

- **Twelve** publications were identified that documented both the pilot phase and the subsequent national rollout of **PHBs within the NHS in England**. These included evaluations of the pilot (Davidson et al. 2012; Forder et al. 2012; Glendinning et al. 2013; Irvine et al. 2011; Jones et al. 2010a, 2010b, 2010c, 2011, 2013; Welch et al. 2013) as well as studies examining the later national implementation (Jones et al. 2017, 2018).
- The PHB pilot programme, launched by the Department of Health in 2009, was a national initiative in England aimed at testing the feasibility and impact of giving individuals greater control over their NHS-funded care.
    - A total of 64 sites participated in the programme, with 20 selected for in-depth evaluation and the remaining sites forming a broader comparison cohort (Jones et al. 2010a, b).
    - Personal health budgets were available for adults with continuing health care, long-term conditions, mental health needs, stroke survivors and parents of children with complex needs (Jones et al. 2010a, b).
- During the pilot, direct payments were not legally available for continuing health care recipients but could be offered to others, such as those with mental health needs, long-term conditions or learning disabilities under existing personalisation frameworks or temporary legal flexibilities.
- The evaluation sought to identify which implementation approaches were most effective in achieving positive outcomes for individuals (Jones et al. 2013; Forder et al. 2012).
- There were several focused studies conducted alongside the national evaluation of the PHB pilot programme. One strand examined the implementation process from the perspectives of organisational representatives (Jones et al. 2010b, 2010c) and budget holders (Irvine et al. 2010; Davidson et al. 2012). Other studies explored specific areas of interest:
    - Jones et al. (2011) assessed the financial costs of planning and delivering PHBs across 20 pilot sites using different models;
    - Welch et al. (2013) examined the use of PHBs in substance misuse services, focusing on outcomes such as impact, satisfaction, relapse, and implementation challenges; and
    - Glendinning et al. (2013) investigated the application of PHBs in maternity care through in-depth case studies and interviews.
- The Department of Health commissioned a further study to explore the continued implementation of PHBs following the national pilot programme. Findings from this study are presented across two reports:
    - The first report focuses on the perspectives of personal health budget leads, commissioners, and budget holders (Jones et al. 2017).
    - The second report explores the views of service provider organisation managers and budget holders (Jones et al. 2018).

- A further **four** organisational reports contributed additional evidence on the implementation and outcomes of **PHBs in England and internationally** (Hatton and Waters 2015; Alakeson and Rumbold 2013; Skills for Care 2016, The Health Foundation 2011).
    - The Health Foundation (2011) examined the implementation of PHBs in the Netherlands through interviews with policymakers, carers, users, and experts. The case study was intended to inform UK policy development during England's PHB pilot phase.
    - Hatton and Waters (2015) evaluated the experiences of personal health budget holders and family carers across 37 areas in England using the POET survey tool.
    - Skills for Care (2016) examined how PHB holders employing personal assistants **via direct payments** are supported across health and care systems.
    - The Nuffield Trust (Alakeson and Rumbold 2013) explored the implementation and implications of PHBs in England based on the data from the evaluation the national pilot programme (described above). The report was intended for commissioners and policy-makers in the UK health system to inform a wider roll-out of PHBs by highlighting practical, financial, and policy challenges.

2.1.3 Guidance documents

We are highlighting **four** of the most recent guidance documents published by NHS England (relevant to the English context) that either focus specifically on direct payments for healthcare or, from the broader perspective of PHBs and **contain sections directly relevant to the implementation of direct payments**.

- A guidance document is intended to support Integrated Care Boards (ICBs) to understand and apply the direct payments for healthcare regulations (NHS England 2022a).
- A guidance document which is designed to help ICBs and other commissioners of health and care services understand the right to have a PHB for eligible groups. These include adults receiving NHS continuing healthcare, individuals receiving after-care under section 117 of the Mental Health Act (1983), people in receipt of NHS wheelchairs, and children and young people receiving continuing care (NHS England 2022b).
- A guidance document that clarifies the three deployment options for personal health budgets (direct payment, notional budget, and third-party budget) and outlines the responsibilities of both the individual and the commissioner. It also reinforces the requirement for ICBs to make all three options available (NHS England 2023a).
- A guidance document that aims to support practitioners and ICBs by outlining the decision-making process for delegating healthcare tasks from registered practitioners to personal assistants. It provides protocols to ensure delegation is safe and appropriate and clarifies roles, responsibilities, and lines of accountability (NHS England. 2023b).

3. KEY FINDINGS

This section draws on findings from both the eight review articles and the 16 organisational reports. Not all sources focused exclusively on healthcare, some addressed both health and social care. The existing review literature lacks consensus on the definitions and applications of key terms associated with direct payments and/or PHBs, often blurring the distinctions between different approaches. Where possible, findings have been drawn from the broader PHB literature, with relevant sections highlighted that **directly address the implementation of direct payments.** Many of the challenges and facilitators identified are similar across the different models of PHB implementation. Key findings are highlighted below, with the full results of relevance presented within Tables 2 to 5 (presented in Section 6).

3.1 Personalisation

This section explores the role of personalised delivery in enhancing choice, control and flexibility through direct payments and/or PHBs and examines how these elements relate to outcomes such as quality of life. It also considers some of the practical challenges that can arise in implementing personalised approaches.

3.1.1 Choice and control

- International evidence shows that well implemented personal budgets for **health and social care** can enhance choice, control, and confidence in managing care (Health Foundation 2010).
- All interventions aimed to enhance user choice and control, though the level of personalisation varied across programmes (Robinson et al. 2022).
- Personal budgets increased choice; individuals appreciated having a wider range of services and more discretion over how time and resources were used (Webber et al. 2014).
- Participants felt more in control of their lives and support, with increased confidence and empowerment (Webber et al. 2014).
- **Direct payments** were widely seen as the most empowering option, with some budget holders and frontline staff viewing them as the only true route to full control (Jones et al. 2010c).
- Some participants viewed **direct payments** as enhancing personalisation and giving individuals greater control over their care (Welch et al. 2013).
- Users valued the control **direct payments** offered (Jones et al. 2017).
- Budget holders experienced greater control over their care arrangements (Jones et al. 2018).
- Funding models that directly allocated budgets to users enabled access to services and activities that might otherwise have been out of reach (Lakhani et al. 2018).
- Self-direction can increase choice and control for disabled people, helping them align services with their needs and aspirations (Lakhani et al. 2018).
- Use of personal budgets by people with mental health conditions has been associated with increased choice and control (Micai et al. 2022).

3.1.2 Outcomes of personalisation

- Personalised budgets were generally associated with improved quality of life and care satisfaction for both service users and carers (Robinson et al. 2022).

- International evidence shows that well implemented personal budgets are associated with improved quality of life and satisfaction with care (Health Foundation 2010).
- Reported benefits included improved quality of life, physical health, mental health, and relationships, though not consistently across all participants (Webber et al. 2014).
- Delivery of PHBs through **direct payments** had a positive impact on carers' well-being (Jones et al. 2010c).
- PHBs were seen to improve quality of life through greater choice, control, and tailoring of services to personal needs and circumstances (Jones et al. 2010c).
- Users reported improved health outcomes from using **direct payments** (Jones et al. 2017).
- Users reported improved independence, dignity, and overall quality of life (Jones et al. 2018)
- Improved responsibility and awareness, quality of life, independent living, employment, and clinical, psychological, social, and daily outcomes have been observed among patients with mental health conditions who utilise personal health budgets. These positive outcomes are associated with increased choice and control, patient empowerment, timely and appropriate access to treatment, active involvement of carers, and collaborative care planning with professionals and stakeholders (Micai et al. 2022).
- **Direct payments** managed by family or friends were more often linked to positive impacts on living arrangements and feeling supported with dignity, compared to those managed by the individuals themselves (Hatton and Waters 2015)
- Some negative effects were reported, including increased cognitive burden among individuals with mental health or cognitive conditions, highlighting the need for more tailored approaches (Robinson et al. 2022).
- Evidence does not clearly support the assumption that greater choice automatically leads to better outcomes or lower costs for PHB recipients (Gadsby 2013; Gadsby et al. 2013).

3.1.3 Flexibility and responsiveness

- International evidence also links personal budgets in **health and social care** to more flexible and responsive services overall (Health Foundation 2010).
- Personal budgets for individuals with mental health problems increased the range of service options and allowed for more flexible use of time and resources (Webber et al. 2014).
- **Direct payments** offered more respite and flexibility, but carers were also concerned about increased responsibility (Jones et al. 2010c).
- **Direct payments** were seen as a way to increase flexibility and improve responsiveness, especially for smaller or ad-hoc purchases (Welch et al. 2013).
- Budget holders experienced greater flexibility over their care arrangements (Jones et al. 2018).
- Flexibility contributed to improved service quality and reduced staff turnover for some users (Lakhani et al. 2018)

- Flexibility was a key benefit, offering greater choice, control and responsiveness to individual needs both in the type and timing of support, and in how funding was used (Flemming et al. 2019).
- Staff delivering personal budgets to people with drug and alcohol problems reported gaining a better understanding of their needs, leading to more trusting relationships, greater flexibility, and increased job satisfaction (Tompkins et al. 2018).

3.1.4 Challenges in personalised delivery

- Evidence on the extent of meaningful choice in self-directed programmes was mixed due to variation in implementation, support, information, and funding controls (Lakhani et al. 2018).
- Reduced service quality was noted as a potential drawback of personal budgets, particularly where unqualified carers were employed in unregulated environments (Lakhani et al. 2018).
- Some individuals, especially those who struggled to express their needs, found directing their own care challenging. Mental health service users often felt less in control than other social care groups despite receiving a personal budget (Webber et al. 2014).
- The assumption that increased choice automatically results in greater autonomy is overly simplistic and not well supported by evidence from recipients of PHBs (Gadsby 2013; Gadsby et al. 2013).
- People with drug and alcohol problems had varied experiences of personalisation, with many unaware of their PHB's value and often having limited control, as budgets were frequently managed notionally or by keyworkers (Tompkins et al. 2018).

3.2 Use of personal health budgets

This section describes the **motivations** for choosing direct payments and/or personal health budgets, followed by a description of **how these are used in practice**, including the types of purchases made and the management arrangements involved.

3.2.1 Motivations for choosing direct payments

- Motivations for choosing **direct payments** included lifestyle fit, greater choice and flexibility, avoiding third-party fees, prior experience, or enjoyment of administrative tasks (Irvine et al. 2011).
- Most people using **direct payments** felt it was the right option for them (Davidson et al. 2012).

3.2.2 Types of purchases and management arrangements

- **Direct payments** enabled personalised care planning, including access to non-traditional services such as complementary therapies (Jones et al. 2018).
- Budgets enabled access to extra-curricular activities aligned with users' interests and aspirations (Lakhani et al. 2018).
- Most people managed their PHB through **direct payments** to themselves or via a family member or friend, while fewer used service providers, brokers, or NHS/council-managed options (Hatton and Waters 2015).
- Some participants reported that the **health and social care** programmes approved by funding agencies were limited in scope (Lakhani et al. 2018).

- Personal health budgets for people with drug and alcohol problems were used not only for core treatment but also for broader lifestyle, educational, and psychosocial supports that individuals felt contributed to their recovery (Tompkins et al. 2018).

3.3 Equitable access

This section examines the extent to which **equitable access** to direct payments and/or PHBs is achieved across different population groups. It includes findings on differential access and benefit, selection bias, barriers to timely and informed access, and challenges in delivering personalised support across diverse populations.

3.3.1 Differential access and benefit

- Self-directed approaches appeared more beneficial for those with family support, middle-class backgrounds, or higher educational resources (Lakhani et al. 2018).
- Some people may benefit more from personal budgets across **health and social care,** especially those with good support, advice, or higher confidence and skills (Health Foundation 2010).
- Concerns about equity in PHB programmes stem from the idea that those with higher education and stronger social networks are better equipped to benefit, while others may struggle. Limited research means the impact on health inequalities remains unclear (Gadsby 2013; Gadsby et al. 2013).
- **Direct payments** were seen as having the potential to improve equity for Black and minority ethnic budget holders by enabling access to more culturally and linguistically appropriate support, including family-led services (Jones et al. 2010c).

3.3.2 Selection bias and underrepresentation

- Evidence from England suggests health professionals may favour younger, more educated individuals for PHBs, with underrepresentation of older adults and minority ethnic groups in the PHB pilot, pointing to potential selection bias in implementation (Gadsby 2013; Gadsby et al. 2013).

3.3.3 Barriers to timely and informed access

- Delays, unclear protocols, and lack of guidance limited timely and fair access to PHBs for people using drug and alcohol services. Service users reported uncertainty about eligible uses and wanted clearer information during care planning (Tompkins et al. 2018).
- Decision-making was affected by access to information, support, location, and socioeconomic factors (Lakhani et al. 2018).
- People in rural or remote areas faced greater barriers—limited services, higher costs (e.g. travel), and difficulties managing care (Lakhani et al. 2018).
- When users were restricted to a list of government-approved providers, informed choice was undermined (Lakhani et al. 2018).

3.3.4 Challenges in personalised delivery

- Staff reported logistical challenges in delivering individualised support, particularly in meeting diverse expectations and accommodating socio-demographic differences (Fleming et al. 2019).

3.4 Implementation challenges

This section describes key implementation challenges associated with direct payments and wider PHBs, including system and cultural change, process complexity, uptake and cost management, and workforce impact.

3.4.1 Structural and cultural change

- Implementation takes time and often requires cultural and structural change within existing systems (Gadsby 2013; Gadsby et al. 2013).
- Successful engagement among service users with self-directed programmes requires a cultural shift across service providers (Lakhani et al. 2018).
- Traditional service models and provider attitudes can resist the shift toward personalised approaches (Gadsby 2013; Gadsby et al. 2013).
- Aligning personal budgets with current processes can be complex (Gadsby 2013; Gadsby et al. 2013).
- The systems in place were often cumbersome and duplicated work. They tended to prioritise targets and cost-efficiency over the actual support provided, creating barriers to personalised care (Flemming et al. 2019).
- The absence of national systems for resource allocation placed a burden on families to negotiate access to funding (Fleming et al. 2019).
- Variation across local areas in what personal health budgets could fund led to confusion and perceived inequities in delivery (Jones et al. 2018).
- Limited awareness of personal health budgets among patients and providers was a barrier to wider service development and uptake (Jones et al. 2018).
- Service users and their families should be central, seen as capable of making care choices, and supported with accessible resources (Lakhani et al. 2018).
- Commissioners must plan for decommissioning services not chosen by PHB holders to prevent duplication and market shrinkage. At the same time, they need to support the growth and diversification of the provider market using strategies that avoid destabilising existing services (Alakeson and Rumbold 2013).
- Infrastructure is needed for budget setting, care planning, and monitoring; using existing systems may support efficiency (Alakeson and Rumbold 2013).
- Integrating PHBs with social care budgets through a coordinated ‘dual carriageway’ model may support service integration without structural merger (Alakeson and Rumbold 2013).
- Risk of a ‘postcode lottery’ highlights the need for consistent national implementation (Alakeson and Rumbold 2013).

3.4.2 Uptake and resource management

- Individual take-up is often slower than expected (Gadsby 2013; Gadsby et al. 2013).
- Costs must be carefully managed, primarily through limits on individual budget allocations, alongside the application of eligibility criteria (Gadsby 2013; Gadsby et al. 2013).
- Policymakers need to plan for the set-up and transition costs of individualised funding models, which are often underestimated (Fleming et al. 2019).
- In many systems, individuals are expected to contribute or cover funding shortfalls (Gadsby 2013; Gadsby et al. 2013).
- Participants experienced financial hardship due to hidden costs associated with managing personal budgets (Fleming et al. 2019).

- All interventions involved a transitionary period and a major challenge during implementation was the lack of national systems for resource allocation which placed a burden on families to negotiate access to funding (Fleming et al. 2019).

3.4.3 Workforce and delivery pressure

- Viewing service users as consumers may motivate providers to improve service standards (Lakhani et al. 2018).
- Some professionals viewed the management of personal budgets as a challenging yet important aspect of their role (Micai et al. 2022).
- It was recognised that there could often be blurring between the positive and the negative, where one person could feel empowered by directly employing support whilst another may find this stressful (Flemming et al. 2019).
- Staff noted that delivering PHBs to people with drug and alcohol problems was time-consuming and often involved extra responsibilities beyond their usual role (Tompkins et al. 2018).

3.5 Factors that enable or hinder successful implementation

This section describes key enablers of successful implementation of direct payments and/or PHBs, including brokerage and support mechanisms, accessible information, effective training and organisational development. It also considers potential challenges such as bureaucracy and administrative burden, recruitment and staffing and communication barriers.

3.5.1 Brokerage and support mechanisms

- Brokerage, which can involve advice, information, and hands-on help, enables individuals to manage their care more effectively (Gadsby 2013; Gadsby et al. 2013).
- Brokerage and signposting support are important and may be most effective when delivered by the voluntary sector or independently of the services being offered (Health Foundation 2010).
- Effective support or signposting mechanisms are key to enabling individuals to understand and manage **direct payments** (Health Foundation 2010).
- independent support services for budget holders are highly valued and are linked to more positive, person-centred outcomes (Gadsby 2013; Gadsby et al. 2013).
- Paid supporters are needed who have strong communication and facilitation skills to help individuals identify their short- and long-term goals and understand the steps needed to achieve them, especially when doing so for the first time (Fleming et al. 2019).
- Strong trusting and collaborative relationships (paid and unpaid) that facilitate information sourcing, staff recruitment, network building and administrative and agency support (Fleming et al. 2019).
- Budget holders greatly valued the support provided from PHB lead officers or support workers including help with advertising, shortlisting, and conducting interviews (Davidson et al. 2012).
- Budget holders for **direct payments** either managed employment[3] tasks such as tax and National Insurance themselves or opted to use an agency. Those who chose to manage the tasks independently sometimes felt daunted and drew on the support from professionals, friends or family (Davidson et al. 2012).

[3] Carers and personal assistants – friends relatives or previous care staff

- It is recommended that procurement and recruitment support be provided for personal health budget holders, particularly those using **direct payments**, as this support is valued by recipients (Forder et al. 2012).
- For those new to managing **direct payments,** ongoing professional support was considered essential. (Jones et al. 2017).
- Independent third-party advisors, such as support brokers and social workers, played a valuable role in supporting individuals to make informed decisions (Lakhani et al. 2018).
- Seeking advice from trusted individuals, such as parents or peers in similar circumstances, was identified as a key factor in supporting choice. However, Internal family conflicts could hinder decision-making, highlighting the need for clear roles and authority within **self-directed support** arrangements. (Lakhani et al. 2018).
- Individuals who received **direct payments** themselves tended to plan more independently, while those whose payments were managed by family, friends, or brokers were more likely to rely on support from those individuals (Hatton and Waters 2015).
- People receiving payments directly found it easier to manage and access support, while those with broker-managed budgets found it easier to make changes to their support (Hatton and Waters 2015).
- A strong network of support, including family, friends, colleagues, and paid coordinators or brokers, was key to sourcing information, recruiting staff, expanding connections, and managing administrative tasks (Fleming et al. 2019).

3.5.2 Employment of personal assistants and carers

- Employed carers or personal assistants were often friends, relatives, or former care staff. (Davidson et al. 2012).
- Holding interviews for carers and personal assistants in professional settings rather than at home was described as a significant relief (Davidson et al. 2012).
- Challenges included recruiting suitable carers and personal assistants locally, covering advertising costs, and finding applicants willing to work on payroll rather than cash-in-hand (Davidson et al. 2012).
- Breakdowns in existing care arrangements of carers and personal assistants and staffing difficulties highlighted the need for accessible back-up and recruitment support (Davidson et al. 2012).
- Budget holders varied in their views on Criminal Records Bureau (CRB – now known as Disclosures and Barring Service - DBS) checks; some felt they were unnecessary when employing relatives or pre-checked staff, while others valued support from professionals in arranging them (Davidson et al. 2012).
- NHS organisations, local authorities, and other CRB holders should work together to address recruitment and retention challenges for personal assistants (Skills for Care 2016).
- National-level work is needed to understand how new models of personal assistant employment may affect current care systems (Skills for Care 2016).
- Core training should be provided to personal assistants, linked where appropriate to the Care Certificate standards (Skills for Care 2016).
- Healthcare systems should plan for increased demand by creating roles to oversee personal assistant training, sign-off, and review of competence (Skills for Care 2016).

- Personal assistants should have access to peer support or, where not feasible, a neutral point of contact for workplace or human resources issues, separate from employer support (Skills for Care 2016).

3.5.3 Information and communication for recipients of direct payments and/or personalised health budgets

- Accessible information for potential budget holders is a key factor in the successful implementation (Health Foundation 2010).
- Recipients of PHBs often encounter unfamiliar systems and responsibilities, making timely access to support and information essential. (Gadsby et al. 2013).
- Positive experiences were associated with support that was knowledgeable, accessible, and responsive to individual needs (Gadsby et al. 2013).
- Effective implementation requires accessible information and tailored assistance, including practical help with managing employment, contracts, and finances (Gadsby et al. 2013).
- Details of **direct payment** options were not always clearly explained, including whether full annual budgets would be paid upfront (Irvine et al. 2011).
- Clear information is needed both during and after care planning, as questions may arise once PHBs are in use (Irvine et al. 2011).
- Limited access to accurate, accessible information and advice is a persistent barrier to informed decision-making (Lakhani et al. 2018).
- Inadequate or misleading information can lead to poor choices and the inefficient use of resources (Lakhani et al. 2018).
- Common concerns included inaccurate, mixed, or inaccessible information, highlighting the need for clearer guidance on available supports, how to access them, and what funding could be used for (Fleming et al. 2019).

3.5.4 Training and support for healthcare staff involved in Implementing direct payments and/or personal health budgets?

- Training and guidance to improve the knowledge and attitudes of frontline healthcare staff and local authority leadership is important (Health Foundation 2010).
- Training for healthcare staff should focus on managing change, improving assessments and promoting equality and challenging assumptions about who is suitable for personal budgets (Gadsby 2013; Gadsby et al. 2013).
- Timely training and education for frontline healthcare are essential to build the knowledge and confidence required to implement **direct payments** effectively (Fleming et al. 2019).
- Healthcare staff felt underprepared to support **direct payments** due to lack of training and guidance (Jones et al. 2010c).
- Clinical commissioning groups (now Integrated Care Boards) should develop local frameworks to support the delegation of healthcare tasks to personal assistants including training and competence assessment (Skills for Care 2016).
- Significant concerns were raised regarding the limited capacity of small local organisations to meet increasing demand with no alternative structures in place. (Flemming et al. 2019).

- Greater investment in education and training is needed to support stakeholder buy-in and understanding of individualised funding and its implementation (Fleming et al. 2019).

3.5.5 Bureaucracy and administrative burden

- Participants often found managing **direct payments** stressful, particularly during early implementation, due to the complexity, bureaucracy, and significant legal and administrative responsibilities involved. This was especially challenging for those without prior managerial experience, who had previously held more passive roles in traditional services (Jones et al. 2017, Jones et al. 2018; Flemming et al. 2019; Micae et al. 2022).
- While individuals with organisational skills, assertiveness, and relative experience found the process more manageable, reduced professional support since the pilot programme left many users less equipped to handle these responsibilities effectively (Jones et al. 2017, Jones et al. 2018).
- Initial issues included setting up bank accounts, managing payments, and delays in funds being deposited or notified (Davidson et al. 2012).
- To help manage the demands of employment administration, some individuals chose to use payroll services, which helped reduce stress and streamline the process (Irvine et al. 2011).

3.6 Eligibility

This section outlines how **eligibility for direct payments and/or PHBs** is determined within health systems. It summarises formal criteria, local variation in assessment practices, staff perspectives and concerns, and considerations specific to safeguarding and the inclusion of particular groups such as people with substance misuse issues.

3.6.1 Formal eligibility criteria and variation in practice

- Eligibility for **direct payments across health and social care** is limited to individuals assessed as needing community care services and who are considered willing and able to manage the payments, with support if needed (Health Foundation 2010).
- However, in practice, local authority teams have sometimes applied eligibility across **health and social care** selectively, with staff perceptions influencing who is encouraged to take up **direct payments**, often favouring younger disabled people (Health Foundation 2010).
- Internationally, the ways people accessed funding varied and was influenced by local policy priorities and infrastructure (Fleming et al. 2019).

3.6.2 Inconsistencies in assessment and budget setting

- Care planning and budget setting for personal health budgets in the UK varied widely across **England's PHB programme** pilot sites. Limited cost data made budget setting difficult, leading to diverse approaches with no clearly superior method (Gadsby 2013; Gadsby et al. 2013).
- Healthcare staff were unsure who to target for PHBs, with inconsistent guidance and differing views on service user readiness and capacity (Tompkins et al. 2018).
- Eligibility assessments often focused not only on the individual's needs but also on the strength of their support network, which can introduce bias and limit access (Fleming et al. 2019).

3.6.3 Staff uncertainty and ethical concerns

- Staff were uncertain about which people with drug and alcohol problems should be offered personal budgets and at what stage in their treatment (Tompkins et al. 2018).
- Staff delivering personal budgets to people with drug and alcohol problems reported moral and ethical concerns about whether this population could make appropriate spending decisions (Tompkins et al. 2018).

3.6.4 Eligibility safeguards and discrimination

- Concerns were raised about offering **direct payments** to people with substance misuse issues, citing risks such as relapse, exploitation, and financial mismanagement (Welsh et al. 2013).
- Suggested safeguards when working with people with substance misuse issues included using care navigators or trusted third parties to manage funds or requiring abstinence before eligibility (Welsh et al. 2013).
- Requiring abstinence or third-party management of budgets was viewed by participants working with people with substance misuse issues as potentially discriminatory (Welsh et al. 2013).
- Those supporting individuals with substance misuse issues argue that, with appropriate safeguards, **direct payments** can promote autonomy and personal responsibility (Welsh et al. 2013).

3.7 Governance

This section outlines a range of accountability and risk management factors that need to be considered to successfully implement direct payments and points to some structural responses and lessons.

3.7.1 Accountability and risk management

- Concerns about accountability and risk management for **personal budgets across health and social care** were raised, particularly when individuals employ their own staff or use unregistered providers (Health Foundation 2010).
- Safeguarding risks were noted in relation to informal care and the employment of family members or unqualified carers through **direct payments** (Gadsby 2013; Jones et al. 2010c; Lakhani et al. 2018).
- Several implementation challenges were highlighted, including the complexity of budget management potentially increasing exposure to risk, concerns that care organisation-led approaches may prioritise cost-efficiency over user choice, and reports of reduced service quality in settings where unqualified carers operated without formal regulation (Lakhani et al. 2018).
- Staff were concerned about the potential for the misuse of funds (Flemming et al. 2019; Jones et al. 2010c).
- In response to issues with **intermediary agencies** in the Dutch PHB system, including fraud and aggressive marketing, the government introduced reforms such as banning **direct payments** to intermediaries and implementing a voluntary code of practice (Alakeson and Rumbold 2013).

3.7.2 Clarity of roles and decision-making

- Governance of PHBs varied widely across sites, with unclear roles and decision-making authority complicating efforts to balance user flexibility with strong oversight and accountability (Gadsby 2013).
- There was a lack of clarity around who approved PHB requests and how decisions were monitored for people with drug and alcohol problems, leading to delays and inconsistencies. Staff highlighted the need for clearer governance structures to support this population (Tompkins et al. 2018).
- There was confusion about appeals processes and who was accountable if things went wrong (Jones et al. 2010c).

3.7.3 Formal governance structures

- Sites with formal governance structures (e.g. boards or steering groups) achieved more coherent implementation by clarifying roles, ensuring consistency, and supporting strategic oversight (Gadsby 2013).

3.8 Areas of uncertainty

- Existing literature lacks consensus on the definitions and applications of key terms associated with PHBs, often blurring the distinction between the different approaches, limiting clarity in interpreting the specific impact of direct payments.
- Despite national guidance, the design and delivery of PHBs can vary widely due to differing local interpretations of roles, responsibilities, and spending rules. This flexibility, while empowering, has led to inconsistent practices across regions, highlighting the need for clearer frameworks to ensure equitable and effective personalised care.
- When evaluating the impact of PHBs and direct payments, it's important for policymakers to consider the initial adjustment period experiences by many users and carers. To capture more accurate outcomes, studies should include follow-ups of at least nine months and, ideally, collect data at multiple time points over an extended period.
- Due to time constraints, this summary does not fully reflect the experiences or outcomes for carers, which remain an important but underexplored aspect of PHB evaluations.

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5. RAPID EVIDENCE SUMMARY METHODS

A list of the resources searched during this Rapid Evidence Summary is provided within Appendix 1. Searches were limited to English-language publications and did not include searches for primary studies as secondary research relevant to the question was found. Searches were limited from 2012 to current date (June 2025) following a review already published in this area by Gadsby et al. 2013. However, where particularly useful and important evidence from pre-2012 from the grey literature was identified, this was not excluded. Search hits were screened for relevance by a single reviewer.

Priority was given to robust evidence synthesis using minimum standards (systematic search, study selection and appropriate synthesis). Quality appraisal was not undertaken as part of this Rapid Evidence Summary and consequently the included research may vary in quality. Citation, recency, evidence type, document status and key findings were tabulated for all relevant secondary research identified in this process.

Our Rapid Evidence Summaries are generally based on key information extracted from the abstracts of included material. However, the nature of the current review question and included material meant that the relevant key information was rarely reported in the abstract. Rather this was frequently embedded in lengthy and complex organisational reports and systematic reviews. Therefore, in light of time constraints of this evidence summary, a single reviewer used artificial intelligence tools Microsoft Co-Pilot or ChatGPT 4.0 to extract the relevant key information included in these documents and then to assist in concisely summarising their content. All extracted and summarised data was subsequently checked for accuracy to ensure clarity, consistency, and reliability.

Date of Search	June 2025
Search Concepts Used	direct payment* OR personal health budget* OR personalisation OR personalization OR individual health budget* (For full search audits see Appendix 1)
Search Completed by	Elizabeth Gillen 10.06.2025

6. EVIDENCE

Table 1: Summary of review evidence identified

Evidence type	Total identified
Systematic reviews (SRs)	6
Rapid reviews (RRs)	2
Organisational reports	16
Guidance Documents	4

A more detailed summary of included evidence can be found in Tables 2 to 5.

Table 2: Summary of included review evidence

Resource	Citation	Recency (Search dates)	Evidence Type*	Status**	Key findings	Reviewer comments
Health and Social Care						
Google search Organisational search	Health Foundation 2010 Personal health budgets The Health Foundation, London https://www.health.org.uk/sites/default/files/PersonalHealthBudgets_EvidenceScan.pdf	Inception to August 2010	RR	Published	Personal budgets in health and social care UK, USA, Germany, the Netherlands, Australia, Belgium, Canada *Eligibility* Eligibility for direct payments is limited to individuals who have been assessed as needing community care services and are considered able to manage the payments, with or without support. However, access is often shaped by professional judgment. In England, local authority teams have been selective in promoting direct payments, while in Scotland, staff have tended to view younger disabled people as the most suitable candidates, which has influenced uptake *Implementation* Research highlights several key factors for successful implementation of direct payments in UK social care. - Effective support or signposting mechanisms - Accessible information for potential recipients - Training and guidance to improve the knowledge and attitudes of frontline staff and local authority leadership Brokerage and signposting support is needed and this may be most successful when it is provided by the	Although some studies focused specifically on direct payments, many combined them with personal or individual budgets, which does blur the distinction between approaches and reduces clarity in interpreting the specific impact of direct payments.

					voluntary sector or is otherwise independent of the services on offer *Personalisation* When implemented effectively, personal budgets have been shown to enhance quality of life, increase users' control over their care, and improve satisfaction with services. Personal health budgets can offer individuals more choice in how healthcare funding is used, making services more responsive and adaptable to their specific needs. *Governance* There are also concerns about ensuring proper accountability for public funds and managing risks to individuals, especially when people hire their own staff or use unregistered care providers. *Equity of Access* Some individuals may be more likely to benefit from personal budgets, particularly those with access to strong support and advice or those who feel more confident and skilled in managing their care	
Database Search	Fleming et al. 2019 Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed methods systematic review. Campbell Systematic Reviews. https://doi.org/10.1002/cl2.1008	Inception to end of 2016	SR	Published	Individualised funding on a range of health and social care outcomes (regardless of name given in the literature) that met the following criteria: • Provided by the state • Recipient able to freely choose how the money is spent • Recipient can avail of services which support them in terms of planning / managing money • Recipient can also independently manage	This review provides examples of terminology used globally – table 1 p9 Qualitative/mixed methods studies 69 unique studies (96 titles) included: Publication years: 1992 – 2016 Included UK studies: 2006-2016 *Direct payments:* McGuigan 2016

					• Fund can be a one-off pilot intervention or more permanent arrangement *Review population:* Focused on people (18+) with a disability specifically people with a lifelong physical, sensory, intellectual, development disability or mental health problems. *Included studies:* 4 quantitative, 66 qualitative, 3 mixed methods. *Countries*: Europe, US, Canada and Australia Qualitative & mixed methods studies (n=69): UK (n=41), US (n=14), Australia (n=7), Canada (n=3), Ireland (n=2), Belgium (n=1) and Germany (n=1) *Implementation* Factors that **enable** & support people with a disability and their carers: • Strong trusting and collaborative relationships (paid and unpaid) that facilitate information sourcing, staff recruitment, network building administrative support, agency support, recognition for voluntary work, appropriate pay, shift in power and thinking creatively. Staff perspectives of what supports: • Involvement of local support organisations • Availability of a network of support, for the person with a disability • Timely training and education for staff • Human resources (intermediary services & community integration)	Fleming 2016 (included 3 brokerage models) O'Brien 2015 Coles 2015 Priestly 2010 (linked to 3) Kinnaird 2010 (Personalisation using DP) Shaw 2008 Adams 2008 Speed 2006 *Indirect payments:* Jepson 2015. (linked to 1: Laybourne) *Personal budgets:* Hamilton 2015b (linked to 5) Glendinning. 2015 (managed by 3rd party) Waters. 2014 England. (self-directed support using pb) Bola 2014 Hatton 2013 Sheikh 2012 Secker 2011 Newbronner 2011 Lambert 2011 Hatton 2011 Wilson 2010 Eost-Telling 2010 *Self-directed support (SDS):* Rummery. 2012 Ridley 2011 Williams 2010 Rogers 2009 Homer 2008 Sanderson 2006 *Support planning & brokerage: using PB or DP:*

					Paid supporters need to have the communication and facilitation skills to guide, for example, when a person (perhaps for the first time) explores what they want to achieve in the short and longer term, and the steps that are required to achieve those goals. Relationships are strengthened by financial recognition for family and friends, appropriate rates of pay and a shift in power from agencies to the individual. Greater investment is needed in education and training in order to facilitate stakeholder buy-in and generate a better understanding of individualised funding and the philosophy, ethos and associated mechanisms required for its successful implementation. The integral role of 'network of support' was highlighted. This network of support typically comprised unpaid supports, such as family, friends and colleagues, but also paid coordinators or support brokers were also strongly associated with the person's network of support. The types of support offered, included sourcing information, recruiting staff, helping to broaden the person's network and finally providing assistance with administrative and management tasks. **Benefits** to participants: • Flexibility (increased choice and control and how funding could be used), improved self-image and	Campbell 2011 *Individual recovery budgets:* Coyle 2009 (linked to 1) *Individual budgets:* Glendinning 2009 Daly 2008

					self-belief, value for money, community integration, freedom to choose, social opportunities, improved family life and needs-led approach • Freedom', was the most cited perceived benefit overall: freedom to choose 'who supports you', as well as, 'how', 'when' and 'where' as well as personal freedoms such as 'perceived autonomy', 'self-determination', 'self-direction', 'self-reliance', 'sense of empowerment', 'space and freedom' and 'freedom to make mistakes' Factors seen to **hinder** implementation include: Disabled people and their carers' perspectives • Lack of trusting working relationships due to previous negative experiences • Complex, rigid and bureaucratic processes delaying access to funds • Lack of clarity around allowable budget use and inconsistent approaches to delivery • Inaccurate and inaccessible information (due to unclear understanding of funding compounded by lack of training) • Finding and retaining suitable staff • Weak support networks • Cumbersome systems duplicating work (focused on targets and costs rather than support provided) • Financial hardship (hidden costs) for participants	

					Participants often reported feeling more burdened with the complexity and level of bureaucracy involved in the new process in comparison to the more passive role in traditional services. This was most prevalent in the early stages of implementation. The most commonly discussed concerns related to 'operational challenges'. Among these, 'information needs' was by far the most cited problem with 'inaccurate information', 'mixed messages' and 'inaccessible information' confounding the issue further. a deeper understanding of individualized funding, what kind of supports were available, where that support could be accessed, and what the money could be used for (amongst other things). The review authors often recognised a blurring between positive & negative which they state "can be explained by the individualized nature of the intervention; thus, for one person, directly employing support workers might be perceived as empowering, whilst for another, it may be stressful". Policy makers need to be aware of the set-up and transitionary costs involved. Investment in education and training will facilitate deeper understanding of individualised funding and the mechanisms for successful implementation. All interventions involved a transitionary period. A major challenge during	

					implementation was the lack of national systems for resource allocation which placed a burden on families to negotiate access to funding. *Eligibility* Across the review it was found that the ways people accessed funding varied by countries and was influenced by local policy priorities and infrastructure. Eligibility assessments often focused not only on the individuals needs but also on the strength of their support network, which can introduce bias and limit access. *Personalisation* Individualised funding was widely seen as a powerful enabler of personalisation: Participants consistently reported that self-directed funding allowed them to shape services around their specific circumstances. Flexibility was a key benefit, including increased choice and control. Aspects frequently mentioned were the extent to which the intervention was seen as 'needs led'; the flexibility of the intervention in terms of type and timing of support; and flexibility in how the funding could be used. The most frequently cited benefit was a sense of freedom and autonomy. This freedom translated into meaningful control over daily life. Having a 'long-term aspirational vision/plan', facilitated by 'achievable short-term goals' was often cited, and	

					was linked with a perceived 'sense of purpose'. *Governance* Staff members were often fearful of misuse of funds or other fraudulent activities by adults with life long disabilityor their network of support. Staff often perceived disabled people to be vulnerable to these kinds of situations and they tended, therefore, to be very risk averse to safeguard their clients. Fears of 'fraud' or 'misuse' (of money) by adults with a life long disability or their representative. *Equitable access* Staff highlighted logistical challenges in accommodating a wide range of support needs in an individualised way including, for example, responding to individual expectations and socio-demographic differences.	
Google search	Gadsby 2013 Personal budgets and health: A review of the evidence. Policy Research Unit in Commissioning and the Healthcare System. Centre for Health Services Studies, University of Kent	Inception to August 2012	RR	Published	Population: Personal budgets in health and social care Included studies: 9 programme evaluation reports, 28 reports of empirical research published in peer-reviewed and 14 articles which offered a cross-national perspective. Countries: 11 OECD countries - England, Belgium, France, Germany, the Netherlands, Austria, the United	*Personal health budgets:* Forder et al. 2012 (England) Jones et al. 2010 (England)

	https://www.academia.edu/22580405/Personal_Budgets_and_Health_a_review_of_the_evidence Gadsby et al. 2013 Personal Budgets, Choice and Health – a review of international evidence from 11 OECD countries: Journal of Public and Private Health care Management and Economics. 3 (3). pp. 15-28 https://doi.org/10.4018/ijpphme.2013070102				States, Canada, Australia, Finland and Sweden. International PHBs range from open models to budgeted or planned models with some countries adopting hybrid approaches. England's PHB programme is more closely aligned with a planned model but has unique features. The budgets are funded by the NHS, spending must be linked to agreed health outcomes, and a broad range of services and items, including complementary therapies, leisure activities, and computers, are allowed without requiring any personal contribution. *Implementation* Key lessons from the implementation of PHBs across programmes: Implementation takes time and requires sustained effort. Personal budgets often challenge existing ways of working and prevailing attitudes among service providers, requiring cultural as well as procedural change. Significant structural changes may be needed, and existing systems do not always align well with personalised approaches. Individual take-up is difficult to predict and is often slower than anticipated. Cost management is essential, often achieved by controlling eligibility or restricting budget levels. In many systems, individuals are required to contribute or cover any shortfall.	

					Staff training and support: Effective training for frontline staff and first-line managers is critical to successful implementation. Training should focus on: • Managing change • Improving assessment practices • Promoting equality Challenging assumptions about risk and suitability, especially for older adults and those with mental health conditions or learning disabilities Staff attitudes significantly influence the success of personal health budget programmes. Ongoing support, reflective supervision, and strong leadership are essential to embedding personalisation in practice. Recipients of PHBs often encounter unfamiliar systems and responsibilities, making timely access to support and information essential. Evidence from several countries highlights the value of tailored assistance, often referred to as brokerage, which may include advice, information, and practical help with managing employment, contracts, and finances. The type and delivery of brokerage vary between programmes, but there is increasing recognition of the benefits of independent support services, especially those not directly linked to service provision. In the English PHB pilot, most recipients were supported by lead professionals, often alongside family members or	

					health and social care staff. These professionals played a crucial role in identifying and exploring creative ways to use the budget. Positive experiences were associated with support that was knowledgeable, accessible, and responsive to individual needs. In some systems, including those in the Netherlands, the United States, and Canada, access to an independent support broker is required. For example, an evaluation of a Canadian programme for people with learning disabilities found that independent planning support was central to the programme's success and user satisfaction. *Eligibility* In the UK, a care planning process is used to identify individual needs and the goods and services required to meet them. However, pilot sites showed wide variation in how this process was carried out. Setting PHBs budgets in England was particularly challenging due to limited data on existing care costs. Sites adopted different approaches, such as outcome-based cost matrices, estimates based on current services, or rough approximations when data were unavailable. The methods used were shaped by how flexibly funds could be reallocated, and no single best approach emerged, though the pilot schemes provided valuable insights. *Personalisation* The assumption that increased choice automatically leads to greater	

					autonomy, better outcomes, and lower costs is overly simplistic and not well supported by evidence. *Governance* Governance of PHBs varied significantly across implementation sites, reflecting differences in local organisational structures and relationships. One of the core challenges was achieving a balance between providing individuals with flexibility and maintaining robust oversight and accountability. In several areas, uncertainty over roles and responsibilities, particularly regarding who held decision-making authority, complicated the implementation process. Safeguarding emerged as a major concern, especially in relation to direct payments and the use of non-traditional or informal care arrangements. Sites that established more formal governance structures, such as dedicated boards or steering groups, tended to experience more coherent and effective implementation of PHBs. These structures helped clarify roles, ensure consistency, and support more strategic oversight *Equitable access* The concern that personal budget programmes might exacerbate existing inequality in the NHS stems from the assumption that those who are able to choose effectively (because of higher levels of education and good social networks) will benefit most from personal budgets, leaving the less well educated to cope with the consequences of poor choices. A	

					paucity of research in this area means that no conclusions can yet be drawn regarding the interrelationships between personal budgets and equity. Research in England suggests that health care professionals, like their social care counterparts, may hold biases about who is suited to personal budgets, often favouring younger, more educated patients. This was reflected in the personal health budget pilot, where certain groups—such as older adults or people from minority ethnic backgrounds—appeared to be underrepresented, indicating potential selection bias in implementation.	
Database search	Lakhani et al. 2018 Perspectives of self-direction: a systematic review of key areas contributing to service users' engagement and choice-making in self-directed disability services and supports. Health and Social Care in the Community, 26(3):295–313 https://doi.org/10.1111/hsc.12386	From 2012 to April 2016	SR	Published	Population: People with developmental or intellectual disabilities (n=4), people with learning disabilities (n=3), people with autism (n=1), people with disabilities with degenerative conditions (n=3), groups with a variability of disabilities (n=7) Included Studies: n=18 (quantitative n=1, qualitative n=12, mixed methods n=2, systematic review n=2, scoping review n=1) Countries: Australia (n=1), Finland (n=1), New Zealand (n=1), Germany (n=1), UK (n=6), the USA (n=5) Reviews focused on UK and Australia *Implementation* Self-directed models of services were implemented in different ways in different settings, with variations in the extent to which service users and their family members or guardians assert	*Included UK studies and interventions:* *Self-directed support:* Mitchell 2012a (children and young people with disabilities) Kendall & Cameron 2014 (adult social care) *Informed choice making:* Mitchell 2012b (children with learning disabilities) Mitchell 2012c (young people with degenerative health conditions) Mitchell 2014a (young people with degenerative health conditions) Mitchell 2014b (young people with degenerative health conditions) *Review articles of self-directed care* Crozier et al. 2013 (focused on Australia)

					complete control over their funding budgets and self-directed services *Factors supporting or hindering implementation:* Successful engagement among service users with self-directed programmes requires a cultural shift across service providers. It is important that service users and their families are regarded as central; that service users are viewed as being able to make choices concerning their health and social care; and that resources used to engage service users are accessible. Professional development or training for service providers and higher level of service user involvement may support cultural shift. Service users and carers indicated need for training and support as planning and budgeting can be a challenging process. Independent third-party advisors concerning budgeting or hiring were viewed as supporting informed decision-making among service users. These could be an advisory board, dedicated officer, administrator, resource consultant, support broker, social worker and/or other professionals. Development of assessment and evaluation tools tailored to service users' unique needs and preferences may ensure that their evaluations are also accounted for Experiential knowledge, such as taking the time to visit service providers, was	Harkes et al. 2014b Sims & Cabrita Gulyurtlu 2014 (focused on UK social care (found via database searches, excluded))

					viewed as strongly informing how service users made decisions concerning their health and social care. Seeking advice from trusted individuals, such as parents or peers in similar circumstances, was identified as a key factor in supporting choice. However, internal conflicts—such as disagreements within families—can hinder quality decision-making. A clear approach to resolving who holds decision-making authority within families using self-directed services is needed. Limited access to accurate, accessible information and advice is a persistent barrier to informed decision-making. Inadequate or misleading information can lead to poor choices and the inefficient use of resources. *Eligibility* Not reported *Personalisation* Findings on the extent to which self-directed programmes enable participants to engage with services of their choice are mixed. Positive experiences were reported in models where funding was directly allocated to service users, who noted that this approach allowed them to access services, supports, and activities they might not have otherwise been able to engage with. Overall, findings suggest that self-direction has the potential to offer people with disability greater choice and control, enabling them to align services	

					with their individual needs and aspirations. Choices included: • More cost-effective choice such as employing family and friends • Extra-curricular activities that align with their interests and aspirations, and a greater choice in these activities For some service users, this flexibility has led to a higher quality of service and reduced staff turnover. For example, re-framing service users as consumers may encourage health and social care providers to deliver support of a higher standard. In contrast, some participants reported that the health and social care programmes approved by funding agencies were limited in scope. Additional literature highlights potential drawbacks of personal budgeting approaches, including reduced service quality due to the employment of uncredentialed or unqualified carers operating in unregulated environments. *Governance* In some cases, the timeframes imposed for spending allocated budgets have been minimal, leading to rushed or ineffective use of funds. Participants in self-directed programmes may also face the risk of personal liability if funds are spent in ways not approved by the agencies distributing payments. The complexity of managing such arrangements can place vulnerable individuals at risk of abuse or	

					exploitation. For instance, some participants reported that budgeting processes managed by care organisations may prioritise cost-cutting, potentially undermining choice and control for service users. *Equitable Access* Self-directed approaches tend to be more beneficial for individuals who have support from family or carers, come from middle-class backgrounds, or possess the educational resources needed to navigate these complex funding systems. Decision-making by service users is inhibited by a variety of factors, including access to accurate information, family and professional support, geographical location, and socioeconomic status. People with self-managed packages living in rural and remote areas face greater barriers and complexities than their metropolitan counterparts, which can significantly impact their ability to make informed decisions. These barriers include limited access to information, a shortage of local service providers, higher costs—such as travel expenses that are not always adequately reimbursed—and the inherent complexity of managing their own care packages. Access is further restricted, and genuine informed decision-making is undermined, when service users are limited to selecting from a government 'approved provider' list.	

Database search	Micai et al. 2022 Benefits and challenges of a personal budget for people with mental health conditions or intellectual disability: A systematic review. *Front. Psychiatry* 13:974621. https://doi.org/10.3389/fpsyt.2022.974621	From 01 April 2013 to 15 September 2021	SR	Published	*Population:* People with mental health conditions and/or people with intellectual disability *Included studies:* n=29 (quantitative n=10 (quasi-experimental n=4, cohort n=3, cross-sectional n=2, unknown design n=1), qualitative n=19) *Countries*: United Kingdom (n=11), USA (n=11), Italy (n=6), Australia (n=1) *Limitation* The authors of this review recognise that the studies included show some limitations that make the generalising of results more difficult, including the differences in healthcare systems and the heterogeneity of personal budget protocols such as differing support and funding mechanisms, particularly in studies older than 2013. *Implementation* Two studies (UK and Australian) highlighted the importance of strong leadership among staff groups and the possibility of increasing power to service providers and commissioners. In one UK study, 64% of personal assistants saw their current roles as congruent with personal budgets, were willing to engage with personal budgets and undertake health-related tasks. At the same time, 74% of personal assistants perceived the need for additional training if enacting PHB. One UK study reported that any conflicts, related to service users' abilities and support needs were most	Although some studies focused specifically on direct payments, many combined them with personal or individual budgets, which does blur the distinction between approaches and reduces clarity in interpreting the specific impact of direct payments. *Included UK studies and interventions:* *Personalisation of the care:* Hamilton et al. 2015 *Personal budgets:* Hamilton et al. 2015 Hamilton et al. 2015 Hitchen et al. 2015 Larkin et al. 2015 Larsen et al. 2015 Mitchell et al. 2015 Norrie et al. 2020 Tew et al. 2015 Williams and Porter 2017 *Personal health budgets:* Welch et al. 2017

					likely to arise during the assessment and support planning of personal budgets. Authorities recognised the importance of involving carers in the service user personalisation processes and support planning. *Personalisation* Positive outcomes for patients with mental health conditions utilising personal budgets include choice and control, patient empowerment, stakeholder engagement, involvement of carers in the personal budgets and timely and suitable access to treatment. Personalisation was shown to have positive outcomes for carers in two UK studies regarding control over their daily lives, quality of life, health, and wellbeing. Personal budgets brought significant changes in the way resources were used and in the personalised intervention approaches. Being in charge of their own care, being able to express and implement their choice and control in their process of care, and jointly sharing the process management with carers and professionals showed improvement in responsibility and awareness, quality of life, independent living, paid work, clinical, psychological and social domains, and everyday aspects of the users' and their carers' life. *Bureaucracy and administrative burden*	

					Concerns and challenges were highlighted in several studies. Users and carers perceived the management procedures of personal budgets to be difficult and stressful, carers perceived difficulties in negotiating personal budgets with professionals and reported feeling less involved in the care processes and professionals perceived the management as an additional burden. One UK study found that some participants did not find it easy to adjust to the opportunity to think and take responsibility for themselves and expressed confusion and frustration at what they saw as inconsistent policies, particularly for purchases that address basic needs like rent, transportation, and household goods. *Enablers and barriers to successful implementation* One UK study showed that some service users felt unsatisfied with health budgets because they believed that they could not manage the budget themselves, felt unable to cope with the monitoring requirements, or perceived themselves to be too out of control in themselves to act consistently responsibly. *Governance* In two UK studies, carers perceived the health budgets as a process not well designed for people with severe mental health conditions to manage.	

					More guidance is required to identify goals and use the personal budgets to take a more active part in society. Two UK studies found that professionals experienced significant stress when trying to manage challenges related to the support provided by their local authorities. This included difficulties in balancing limited resources, budgets, and staffing levels with the need to meet carers identified needs and expectations.	
Databases	Robinson et al. 2022 The effects and costs of personalized budgets for people with disabilities: a systematic review. *Int J Environ Res Public Health*. 2022 Dec 4;19(23):16225. https://doi.org/10.3390/ijerph192316225	Jan 1985 to Nov 2022	SR	Published	*Population*: Physical disabilities, intellectual and developmental disabilities, and mental health conditions where consumers had control of their care decisions, with different models or forms of personalised budgeting. *Study designs:* RCTs (n=10), non-randomised controlled trial (n=1), cross-sectional surveys with a control group (n=6), before–after controlled comparisons (n=4), and pre-post designs without a control group (n=2). *Countries:* OECD high-income countries – US (n=16), England (n=4), Italy (n=3) *Implementation* There was significant variation in terminology (e.g. 'self-direction', 'individualised budgets', 'consumer-directed care') and in delivery models. Of 23 studies, 4 focused on consumer-directed assistance only, while the remaining 19 featured monetary personal budgets of varying structure. Eligibility	"It is important to acknowledge that, in the existing literature, there does not yet appear to be a clear consensus on the use and definition of key terms around 'personalized budgeting'….. We define a personalized budget as an amount of money allocated to or for a person with a disability to pay for their care and support needs. This includes all forms of self-directed or consumer-directed care, as long as service users are in control of their care, being able to choose and direct their services and providers" p.3 *Individual budgets:* Glendinning et al. 2008 (England) Glendinning et al. 2009 (England) *Personal health budgets* Forder et al. 2012 (England) Pelizza et al. 2022 (Italy) Leuci et al. 2021 (Italy) Fontecedro et al. 2020 (Italy)

					Eligibility criteria and scope varied significantly across the 23 studies. Some models placed restrictions on who could be hired (e.g. whether family members were eligible caregivers) and what services or goods could be purchased. The **Individual Budgets Pilot Programme** in England broadened eligibility by integrating multiple funding streams, including social care, housing-related support, and equipment, into a single, flexible budget. In contrast, the **Personal Health Budget Programme** was funded solely by the Department of Health, limiting eligibility to healthcare-related needs but expanding allowable purchases to include social care, well-being, and therapy-related services. Despite variations in study design, populations, and implementation, personalised budgets generally improved quality of life and care satisfaction for both service users and caregivers. Some negative effects, including increased cognitive challenges, were observed among people with mental disabilities, indicating that more tailored approaches may be needed for this group. Certain models also defined eligibility in terms of functional capacity (e.g. ability to self-manage), excluding individuals with more complex needs unless support was provided. *Personalisation*	

					All interventions emphasised increased choice and control, though the degree of personalisation varied. Some programmes restricted what goods and services could be purchased, while others permitted broad discretion. A key distinction was whether the budget was held directly by the service user or managed on their behalf, affecting autonomy. *Governance* Governance mechanisms ranged from highly structured models with support services (e.g. counselling, budgeting help) to less formal arrangements with minimal oversight. Some interventions had safeguards around who could be hired (e.g. exclusion of family or friends in some cases) or limited purchase options, reflecting more centralised control. *Equitable access* Not reported	
Health						
Databases	Tompkins et al. 2018 Implementing and delivering personalised budgets for drug and alcohol users: A narrative systematic review. *Health Soc Care Community*. 2019 Jan;27(1):68-81 https://doi.org/10.1111/hsc.12633	1990 to April 2017	SR	Published	*Population:* Implementation and delivery of PHBs with drug and alcohol users Six records from four studies/programmes of work *Countries:* England (n=5), USA (n=1) *Study designs: Qualitative(n=5), mixed methods (n=1)* *Implementation* Across the studies, staff involved in delivering PHBs reported two key issues affecting implementation.	A personal health budget (PHB) is an allocation of NHS funding given to an individual to support their identified health and wellbeing needs, planned and agreed between the individual (or their representative) and the local NHS team." (p. 2) "PHBs are intended to give people more choice and control over how money is spent on their healthcare,

					First, they identified moral and ethical concerns, such as the belief that individuals with a history of drug and/or alcohol use might be unable to make appropriate decisions about budget use. Second, practical barriers were noted, including uncertainty about who should be offered PBs, when during treatment they should be offered, a lack of clear guidance on eligible purchases, uncertainty around approval processes, and delays in accessing approved purchases. Staff suggested that appropriate training, simplified and integrated assessment protocols, reflective practice, and strong management could help address these challenges. Additionally, staff reported that delivering PHBs to drug and alcohol users often required more time due to coordination and administrative demands, and sometimes involved taking on responsibilities beyond their usual role. *Personalisation* Staff delivering PHBs reported gaining a greater understanding of the needs of drug and alcohol users, which contributed to more trusting and equal relationships, greater flexibility in working, and increased job satisfaction. From the service user perspective, experiences of personalisation varied. Many were unaware of the value of their	enabling more personalised care and support." (p. 2)

					PB and had different levels of control over how their budgets were used, with many budgets managed notionally or by keyworkers. Eligibility Staff raised uncertainty about who should be targeted for PHBs and the appropriate timing within treatment pathways. There was no consistent guidance across studies, and eligibility decision-making was complicated by varying interpretations of service user readiness and capacity. Equitable access Delays in accessing purchases and inconsistent implementation protocols affected timely and equitable delivery of PBs to drug and alcohol users. Some service users expressed uncertainty about how PHBs could be used and wanted more information during the care planning process to assist decision-making. Lack of a definitive list of fundable services contributed to confusion and potential inequities in access. *Governance* There were challenges in determining who was responsible for approving budget requests and how decisions were monitored. The absence of clear guidelines and oversight structures contributed to implementation delays and inconsistencies. Staff expressed the need for clearer governance processes to support delivery.	

					Purchasing People who received personal health budgets used the money in a variety of ways to support their recovery and overall wellbeing. Some used it for traditional treatment options, such as residential or community detox services. Others spent their budgets on alternative therapies like acupuncture or massage, as well as on health and leisure activities including gym memberships, swimming, football, and theatre tickets. Budgets were also used for personal development, such as driving lessons and educational courses aimed at improving life opportunities. In addition, many recipients used the funds for practical, everyday needs like clothing, passports, IT equipment, internet access, diaries, and mobile phone credit. Transport costs were another common use, particularly to attend treatment services or mutual support meetings. Overall, the spending reflected a wide range of individual needs and priorities beyond standard clinical care.	
Databases	Webber et al. 2014 The effectiveness of personal budgets for people with mental health problems: a systematic review. *J Ment Health*. 2014 Jun;23(3):146-55	Inception until April 2013	SR	Published	*Population*: Adults with mental health problems aged 18–65 (irrespective of the presence of other disabilities). Studies evaluated individual budgets (n=2), recovery budgets (n=1), personal budgets (n=5), direct payments (n=1), personal health budgets (n=2) and ‘‘cash and counseling’’ (n=4) as defined by their authors.	The use of personal budgets by people with mental health problems has been consistently lower than for other social care groups. Personal health budgets aim to enhance choice and control over health care but, unlike social care personal budgets, are not means-tested.

	https://doi.org/10.3109/09638237.2014.910642				*Countries*: UK (n=9) and USA (n=6). Study designs: RCTs (n=2), controlled non-randomised studies (n=5), before-and-after studies (n=2), qualitative studies (n=3), and mixed-methods evaluations (n=3). *Personalisation* Personal budgets were generally associated with increased choice and control for people with mental health problems. Participants commonly reported feeling more in control of their lives and support arrangements, and described growing confidence, independence, and a greater sense of empowerment. Some found they had more flexibility in how they spent their time and resources, and appreciated the broader availability of services. However, these benefits were not universal. Some individuals, particularly those who struggled to articulate their needs, experienced uncertainty and found the process of directing their own care challenging. Compared to other social care groups, mental health service users sometimes felt less in control of their support, despite receiving a personal budget. In terms of broader life impact, personalisation was linked to improvements in quality of life, community participation, physical health, goal achievement, and a renewed sense of hope and recovery. Positive effects on mental health and relationships were noted, though not consistently across all experiences.	The evaluation of personal health budgets showed promising findings and they were particularly cost-effective for people with mental health problems (Forder et al. 2012). Consequently, the Government has begun to introduce them into the NHS in England with plans to make them available in mental health services in 2015. *Direct payments:* Spandler & Vick 2004 (UK) *Personal health budgets:* Forder et al. 2012 (UK) Davidson et al. 2012 (UK)

Key: PHB: Personal health budgets; RR Rapid review; SR systematic review

Table 3: Summary of personal health budgets evaluation (pilot)

Citation	Content Summary	Population	Direct Payment Findings
Jones et al. 2010a Evaluation of the personal health budgets pilots. Outline of a research project funded by the Department of Health. Personal Social Services Research Unit, University of Kent. https://www.pssru.ac.uk/publications/pub-1820/	Project outline Sets out the design and methodology for the national evaluation across 70 pilot sites with 20 selected for in-depth evaluation	Adults with CHC, long-term conditions, mental health needs, stroke survivors Children with complex needs, represented by their parents or carers	Does not report findings as this is an outline and one of the aims was to explore the different mechanisms for delivering PHBs, including direct payments, notional budgets, and third-party arrangements.
Jones et al. 2010b Early experiences of implementing personal health budgets. PSSRU Discussion Paper 2726/2. Personal Social Services Research Unit, University of Kent. https://www.phbe.org.uk/documents/interim_report_july_2010.pdf	First interim report Outlines the implementation progress and setup	Adults with CHC, long-term conditions, mental health needs, stroke survivors Children with complex needs, represented by their parents or carers	The report confirms that direct payments were an intended delivery mechanism for PHBs, particularly for non-CHC groups. Notes legal limitations on direct payments for CHC, which had not yet been resolved at this stage. Mentions that some pilot sites were already using direct payments under social care legislation
Jones et al. 2010c. Experiences of implementing personal health budgets: 2nd interim report. PSSRU Discussion Paper 2747/2. Personal Social Services Research Unit, University of Kent.	Second interim report Presents early qualitative findings from the second wave of interviews, conducted between September and October 2010, across the 20 in-depth pilot sites. It explores how personal health budgets were	Interviews with commissioners, managers, and frontline staff. Compared with the first two reports, it includes views from a wider range of staff, not just project leads, and offers a deeper exploration	*Factors that enable or hinder successful implementation* Staff felt underprepared to support direct payments due to a lack of training and clear guidance. *Personalisation* While direct payments could offer more respite and flexibility, some carers were worried about increased responsibility and how it might affect their own lives and benefits. Direct payments were widely seen as the most empowering option, with many frontline staff and some

https://www.gov.uk/government/publications/experiences-of-implementing-personal-health-budgets-2nd-interim-report	being introduced, planned, and delivered	of the positive and negative impacts on carers	budget holders viewing them as the only true way to achieve full choice and control. *Equitable access* Direct payments were seen as having the potential to improve equity for Black and minority ethnic budget holders by enabling access to more culturally and linguistically appropriate support, including the option for family-led services. *Governance* Staff expressed anxieties about risk, especially when direct payments were used to employ family members or unqualified carers. There were concerns about fraud or misuse, such as spending the entire budget early or on non-health-related items. There was confusion about appeals processes and who is accountable if something goes wrong with a direct payment.
Jones et al. 2011. The cost of implementing personal health budgets. Personal Social Services Research Unit, University of Kent. https://www.gov.uk/government/publications/the-cost-of-implementing-personal-health-budgets	Third interim report Examines the financial costs associated with planning and delivering PHBs through different models across 20 of the pilot sites	Adults with CHC, long-term conditions, mental health needs, stroke survivors Children with complex needs, represented by their parents or carers	Four pilot sites reported spending on setting up direct payment services.
Irvine et al. 2011 Personal health budgets: early experiences of budget holders, Fourth Interim Report. DH 2478. Personal Social Services Research Unit, University of Kent .	Fourth interim report Presents findings from in-depth interviews with 58 personal health budget holders (or their representatives) across 17 pilot sites..	Budget holders, i.e., individuals who had already been allocated a PHB People with long-term physical health conditions Individuals with mental health needs Parents of children with complex needs	Direct payments are mentioned throughout as one of the key mechanisms by which individuals accessed their PHB. *Factors that enable or hinder successful implementation* Motivations for choosing direct payments included because they suited their lifestyle, offered greater choice and flexibility, or avoided third-party fees. Others had prior experience or enjoyed the admin. The stress of managing care was already significant for some, leading a few to use payroll services to reduce the administrative burden. Details of the direct payment option were not always clearly explained, such as whether the full annual budget would be paid upfront. Clear

https://www.gov.uk/government/publications/personal-health-budgets-fourth-interim-report			information about the direct payment option is needed both during and after the care planning process, as some questions may only arise once the personal health budget is in use.
Davidson et al. 2012 Personal health budgets: experiences and outcomes for budget holders at nine months, Fifth interim report. DH 2523. Personal Social Services Research Unit, University of Kent. https://www.gov.uk/government/publications/personal-health-budget-pilots-fifth-interim-evaluation-report	Firth interim report Explores what budget holders actually did with their PHBs, once implemented Insights into purchases made How budgets were managed (e.g. direct payments, third-party) Day-to-day outcomes and challenges	Carers of adults receiving PHBs across various pilot sites and health conditions	*Factors that enable or hinder successful implementation* Nearly half of those using direct payments reported initial issues, such as setting up bank accounts, managing payments, and delays in funds being deposited or notified. Some struggled with drafting contracts and used online templates. Most people using direct payments felt it was the right option. About half of budget holders employing staff managed employment tasks like tax and National Insurance themselves, while the other half used an agency. Those managing it alone (employment tasks) often felt daunted and relied on support from professionals, friends, or family. Some did not need recruitment support, having retained staff from previous care packages or using agency carers. Support from PHB lead officers or support workers was highly valued, including help with advertising, shortlisting, and conducting interviews. Many employed their own carer or personal assistant, often friends, relatives, or previous care staff. Holding interviews in professional settings rather than at home was described as a significant relief. **-** Some faced difficulties recruiting suitable staff locally. Challenges included the cost of advertising and finding applicants willing to work on payroll rather than cash in hand. A few experienced problems when existing care arrangements broke down. Some budget holders did not feel CRB checks were necessary, particularly when employing relatives or staff who already had checks in place. Others found support with arranging CRB checks, such as through a support worker to be very helpful. A few faced difficulties with staff, and in one case, a support worker helped dismiss a carer, highlighting the value of back-up support in managing employment issues.
Forder et al. 2012. Evaluation of the Personal Health Budget Pilot Programme. PSSRU Discussion	The final report of the PHB evaluation, using a three-year mixed-methods approach to assess outcomes, service use, and cost-effectiveness across different health groups	Adults with CHC, long-term conditions, mental health needs, stroke survivors	Just under 45% of personal health budgets in the study were deployed as direct payments (as opposed to notional budgets or using third parties). Personalisation

Paper 2840_2. Personal Social Services Research Unit, University of Kent. https://www.york.ac.uk/inst/spru/research/pdf/phbe.pdf	It involved 2,700 participants, with 2,235 in the active sample The study used a controlled trial design with both quantitative and qualitative data over 12 months Qualitative interviews with PHB holders, carers, and professionals (overlap with the findings of the firth interim report from Davidson et al. 2012)	Children with complex needs, represented by their parents or carers	Over two-thirds of carers (68%) reported a positive impact on their well-being when the PHB was delivered through direct payments. The results suggest that the use of a PHB has a direct impact on quality of life via improved choice, control and tailoring of services to personal needs and circumstances. *Factors that enable or hinder successful implementation* Those with direct payments generally felt it was the right choice, despite common initial issues such as setting up bank accounts and delays in PCT payments. Most participants using direct payments employed their own carers or personal assistants. Some required no recruitment help, having existing social care-funded carers or employing friends or family. Others, particularly first-time recruiters, valued support from PCT staff or support workers with tasks like advertising, interviewing, CRB checks, and contracts—relieving significant pressure. However, challenges remained, including difficulty finding suitable carers willing to work on a payroll rather than a cash-in-hand basis. Ongoing support for managing employment arrangements was also seen as essential. **Recommendation: Procurement and recruitment support for personal health budget holders (especially direct payment options) are valued by recipients.**
Jones et al. 2013 Personalisation in the health care system: do personal health budgets have an impact on outcomes and cost? Journal of Health Services Research & Policy, 18(2 Suppl), 59–67. https://doi.org/10.1177/1355819613503152	Summarises key evaluation results with some additional quantitative analysis and outcome data	Adults with CHC, long-term conditions, mental health needs, stroke survivors Children with complex needs, represented by their parents or carers	Overlaps with Forder et al. 2012 and is reported within Fleming et al. 2019

Welch et al. 2013 Implementing personal health budgets within substance misuse services. Final report. PSSRU Discussion Paper 2858. Personal Social Services Research Unit, University of Kent. https://www.phbe.org.uk/documents/substance_misuse_final_report.pdf	Focused evaluation in two of the sites on people with substance misuse issues, reporting on impact, satisfaction, relapse, and implementation challenges in using PHBs	Adults with substance misuse issues The majority of care/support plans were managed notionally. While one of the pilot sites did have approval to offer direct payments, we did not find evidence this deployment was offered during the pilot programme The in-depth interviews with organisational representatives explored the various implementation issues and challenges around offering the direct payment deployment option to this client group	*Personalisation* There was broad support for the potential of direct payments to increase flexibility, reduce administrative burden, and improve responsiveness, particularly for smaller or ad-hoc purchases. Some viewed direct payments as a way to enhance personalisation and give individuals greater control over their care. *Eligibility* Concerns were raised about offering direct payments to vulnerable groups such as people with substance misuse issues. Risks related to relapse, exploitation, and financial management were cited as reasons for caution. Suggestions for safeguards included using care navigators or trusted third parties to manage funds, or requiring abstinence before eligibility. At the same time, some felt that imposing restrictions such as requiring a sustained period of abstinence from drugs or alcohol, or insisting that personal health budgets be managed by a third party rather than the individual, risked being discriminatory. In contrast, others viewed direct payments as a vital tool for promoting autonomy and personal responsibility. They argued that, with appropriate safeguards in place, individuals should be supported to manage their own budgets wherever possible.
Glendinning et al. 2013 Personal Health Budgets and Maternity Care: A Qualitative Evaluation. DH 2541. PSSRU, Personal Social Services Research Unit, University of Kent. https://www.phbe.org.uk/documents/DH2541_maternity_report.pdf	Explores the use of PHBs in maternity care through in-depth case studies and interviews	Pregnant women and new mothers from one PHB pilot site focused on maternity care	No details on direct payments in this report.

Key: PHB: personal health budgets

Table 4: Summary of personal health budgets evaluation (National rollout)

Direct payments were part of the rollout

Citation	Content Summary	Population	Direct Payment Findings
Jones et al. 2017. Personal health budgets: Process and context following the national pilot programme. Working paper 2947. Personal Social Services Research Unit, University of Kent. https://www.pssru.ac.uk/publications/pub-5331/	The report explores how PHBs have been used in England post-pilot, focusing on their effectiveness, influencing factors, and stakeholder perceptions	Twenty-three PHB users who received their budget following the national pilot and evaluation Eight organisational representatives whose work involved the delivery of personal health budgets within clinical commissioning groups	Over half of the 23 interviewed budget holders managed their PHBs via direct payments. *Personalisation* Users valued the **control** and improved health outcomes direct payments offered. *Factors that enable or hinder successful implementation* Managing direct payments was stressful, especially for those without prior managerial experience. It involved significant paperwork and legal responsibilities. Best suited for individuals who are organised, assertive, and have prior experience in managing responsibilities. Budget holders emphasised the importance of professional support in manging their budgets. Pilot participants noted reduced support after the programme ended, while new budget holders reported little to no support. *Conclusion on PHB in general* Many personal health budget holders highlighted the importance of having support and guidance from professionals around how and on what they could use their budget. There were variations in how budgets could be used, reflecting different interpretations of what counts as meeting needs and improving outcomes. Some budget holders faced restrictions on spending, such as on alternative therapies. Interviews suggested that rules had become stricter over time. Balancing flexibility with guidance remains a challenge, with suggestions including allowing some trial and error and recognising broader definitions of wellbeing. Personal health budgets offered potential empowerment, but interviews suggested this depended on the budget holder's commitment, capacity, and willingness.

			The effort involved in managing services and planning care was seen as challenging, making the approach more suitable for those able to take on these responsibilities.
Jones et al. 2018. Personal health budgets: targeting of support and the service provider landscape. Working Paper 2948. Personal Social Services Research Unit, University of Kent. https://www.pssru.ac.uk/publications/pub-5434/	The report evaluates the implementation of PHBs in England following the national pilot, with a focus on service provider perspectives, budget holder experiences, and the evolving policy context	Adults supported through NHS CHC, mental health services, learning disability services, and end-of-life care The population reflected broader eligibility criteria compared to the original pilot phase, aligning with the expansion described in the NHS Five Year Forward View and Long Term Plan	The analysis included forty-two PHB support plans. Of these, thirty-one specified the deployment option, with twenty-six indicating that the budget was managed as a direct payment. *Personalisation* **Greater control and flexibility** for budget holders. Enabled **innovative and personalised care**, including non-traditional services like complementary therapies. Improved **independence, dignity, and quality of life** for users and reduced burden on informal carers. *Factors that enable or hinder successful implementation* Managing direct payments was burdensome, especially without prior experience or adequate support. Professional guidance had declined since the pilot, making it harder for users to manage budgets effectively. Local variation in what PHBs could fund led to confusion and inequity. Limited awareness among patients and providers hindered service development and uptake.

Key: CHC: continuing health care, PHB: personal health budgets

Table 5: Summary of organisational reports that explore direct payments

Citation	Content Summary	Population	Direct Payment Findings
The Health Foundation 2011 Improvement in practice: the personal touch: the Dutch experience of personal health budgets. https://www.health.org.uk/sites/default/files/ThePersonalTouchDutchExperienceOfPersonalHealthBudgets.pdf	Case study report. It includes interviews with policymakers, carers, users, and experts, and is intended to inform UK policy development	It explores the implementation of PHBs in the Netherlands, aiming to supplement formal evidence with real-world insights At the time of publication PHBs were being piloted in England. This case study report was written to inform policy makers using the case study in the Netherlands as an example	Direct payments are a core feature of the Dutch PHB system. Funds are transferred directly to individuals, who then choose and pay for their own care providers *Implementation Challenges* • This model offers freedom and personalisation, but also complexity—users must manage employment law, budgeting, and quality assurance • The system has led to the rise of intermediary agencies, some of which have been problematic (e.g., fraud, aggressive marketing) and as a result the Dutch government has banned direct payments to intermediaries and introduced a voluntary code of practice
Hatton and Waters 2015 Personal Health budget holders and family carers. The POET surveys 2015 http://s557941885.websitehome.co.uk/wp-content/uploads/2018/01/Personal-Health-Budget-Holders-and-Family-Carers-2015-Report.pdf	Evaluation Report. Survey conducted using the Personal Outcomes Evaluation Tool (POET) tool developed by In Control and Lancaster University, and commissioned by NHS England and Think Local Act Personal.	This report evaluates the experiences and outcomes of 302 personal health budget holders and 247 family carers across 31 NHS and council organisations in 37 areas of England The report exclusively examines personal health budgets, which were delivered through direct payments, notional budgets, and third-party arrangements.	*Use of personal budgets* • People most commonly managed their personal health budget through direct payments paid to them (36.7%), followed by direct payments looked after by a friend or family member (26.2%). • Personal health budgets managed by a service provider (13.1%), council or NHS-managed personal health budgets (11.1%) and personal health budgets managed by a broker (11.5%) were less common. *Factors that enable or hinder successful implementation* • People who received a direct payment paid directly to themselves were more likely to plan on their own without any help (p=0.038). • People whose direct payment was managed by a family member or friend were more likely to receive planning support from family or friends (p < 0.001). • People whose direct payment was managed by a broker were more likely to receive planning support from the council (p=0.005). • People who received a direct payment paid directly to themselves were more likely to say it was easy to manage their support (p=0.049) and to get the support they wanted (p=0.004). • People whose direct payment was managed by a broker were more likely to say it was easy to change their support (p=0.028).

			• People with a direct payment paid directly to themselves were less likely to report a positive impact of their budget on where and with whom they lived, and on feeling safe. • People with a direct payment paid to a family member or friend were more than twice as likely to report that their budget had a positive impact on where and with whom they lived, and on being supported with dignity
Skills for Care 2016 Support for personal health budget holders who employ personal assistants https://www.skillsforcare.org.uk/Documents/PHB/PHB-Report-Final-2016.pdf Skills for Care 2016 Support for personal health budget holders who employ personal assistants: Executive summary https://www.skillsforcare.org.uk/Documents/PHB/PHB-Report-Exec-Summary-2016.pdf	Research and case study-based evaluation exploring how personal health budgets using direct payments to employ personal assistants are supported across health and care systems.	This report evaluates the experiences of personal health budget holders who manage their budget via direct payments to employ personal assistants. It draws on 60 survey responses covering approximately 50 clinical commissioning group areas in England, as well as interviews with individuals and teams from 10 participating sites. Detailed evidence from seven of these sites was used for in-depth case study analysis	Recommendations from executive summary *Training* • Clinical commissioning groups should develop local frameworks for delegating healthcare tasks, including training and competence assessment. Clinical commissioning groups should offer core training for personal assistants, linked where appropriate to the Care Certificate standards. • Clinical commissioning groups should plan for increased demand by creating roles to oversee training, sign-off, and review of competence *Support for Personal Assistants* • Personal assistants should have access to peer support or, where not feasible, a neutral point of contact for workplace or human resources issues, separate from employer support *Recruitment and Retention* • National Health Service organisations, local authorities, and other stakeholders should work together to address recruitment and retention challenges • National work is needed to understand how new personal assistant employment models may affect current systems

Alakeson and Rumbold 2013. Personal health budgets: Challenges for commissioners and policy-makers. London: The Nuffield Trust. https://www.nuffieldtrust.org.uk/research/personal-health-budgets-challenges-for-commissioners-and-policy-makers	Research summary using the evidence from the national pilot programme launched in 2009 to test the feasibility and impact of PHB's.	The national evaluation was conducted across 20 sites covering various long-term conditions including mental health, stroke, and NHS continuing healthcare. The report was intended for commissioners and policy-makers in the UK health system to inform a wider roll-out of PHBs by highlighting practical, financial, and policy challenges	Direct Payments: • Direct payment support services are available to help people with the responsibilities of being an employer such as payroll facilities or third-party arrangements can be used for those who cannot or do not want to manage the financial responsibility directly Key points from the research summary: Implementing is the responsibility of clinical commissioning groups: the summary provides important issues for commissioners: *Decommissioning existing services* • Commissioners must plan to phase out services not chosen by PHB holders to avoid duplication and market shrinkage. *Developing and diversifying the provider market* • Efforts are needed to diversify and grow the market of providers needed whilst avoiding destabilising existing providers. • There are a range of transition strategies that commissioners can use to support the provider market. *Funding the necessary infrastructure* • New infrastructure around budget setting, care planning and system monitoring is required with some evidence to suggest that some efficiency can be achieved by 'piggy-backing' systems that already exist • Bringing PHBs together with personal budgets in social care to create integrated individual budgets potentially offers a new route to service integration. The research summary refers to a 'dual carriageway' approach which brings together the referral, assessment, budget setting, planning and monitoring of different budgets without the complexities of structural integration between organisations and government departments Policy-makers need to be aware that there is a risk of a postcode lottery emerging

Key: PHB: Personal Health budgets

7. ADDITIONAL INFORMATION

7.1 Conflict of interest

The authors declare that they have no conflicts of interest

7.2 Acknowledgments

The authors would like to thank Nia Griffiths, Lisa Bridges, Emily Keoghane and Beti-Jane Ingram for their contributions during stakeholder meetings in guiding the focus of the review and interpretation of findings.

8. APPENDIX

APPENDIX 1: – Resources searched during Rapid Evidence Summary

A single list of resources has been developed for guiding and documenting the sources searched as part of Rapid Evidence Summary.

Secondary research resources	Success or relevancy of the retrieval
Medical and health	
Medline (Ovid) https://www.wolterskluwer.com/en/solutions/ovid/ovid-medline-901	Searched, results found
EMBASE (Ovid) https://www.wolterskluwer.com/en/solutions/ovid/embase-903	Searched, results found
Scopus https://www.scopus.com/home.uri	Searched, results found
Key Organisations	
Department of Health & Social Care https://www.gov.uk/government/organisations/department-of-health-and-social-care	Searched, results found
Office for Health Improvement & Disparities https://www.gov.uk/government/organisations/office-for-health-improvement-and-disparities	Searched, nothing found
People Hub https://www.peoplehub.org.uk/	Searched, results found
Personal Health Budgets Evaluation https://www.phbe.org.uk/	Searched, results found
Health Foundation https://www.health.org.uk/	Searched, results found
Personal Social Services Research Unit (PSSRU) https://www.pssru.ac.uk/	Searched, results found
UK Government https://www.gov.uk/	Searched, results found
NHS England https://www.england.nhs.uk/	Searched, results found
National Institute for Health and Care Excellence (NICE) https://www.nice.org.uk/	Searched, nothing found
UK Health Security Agency https://researchportal.ukhsa.gov.uk/	Searched, nothing found
Nuffield Trust https://www.nuffieldtrust.org.uk/	Searched, results found
King's Fund https://www.kingsfund.org.uk/	Searched, nothing found
Care Quality Commission https://www.cqc.org.uk/	Searched, nothing found
Skills for Care https://www.skillsforcare.org.uk/Home.aspx	Searched, results found
Local Government Association https://www.local.gov.uk/	Searched, results found
National Audit Office https://www.nao.org.uk/search/type/report/	Searched, nothing found
Health Education England https://www.hee.nhs.uk/	Searched, nothing found
NHS Confederation https://www.nhsconfed.org/	Searched, nothing found
Skills for Health https://www.skillsforhealth.org.uk/	Searched, nothing found
Think Local	Searched, results found

https://thinklocalactpersonal.org.uk/	
Additional resources searched *(Add in any further resources that have been used, e.g. Scopus, HMIC, Social Care Online)*	
Google Advanced Search https://www.google.co.uk/advanced_search	Not searched, maybe relevant
Google Scholar https://scholar.google.com/	Not searched, maybe relevant

Medline (Ovid): 10th June 2025

#	Query	Results from 10 Jun 2025
1	direct payment*.tw.	243
2	"cash for care".tw.	51
3	(consumer directed care or consumer directed support).tw.	115
4	((person* or patient* or individual*) adj2 (budget* or funds or funding)).tw.	1,461
5	((self-directed or self-managed or user-directed) adj2 (support or care or budget* or funds or funding)).tw.	229
6	((personali#ed or personali#ation) adj2 (budget* or funds or funding)).tw.	21
7	"cash and counsel?ing".tw.	53
8	1 or 2 or 3 or 4 or 5 or 6 or 7	2,112
9	exp "Systematic Review"/	296,091
10	exp systematic review as topic/	15,443
11	(systematic review or review).pt.	3,635,195
12	(systematic adj2 (review* or overview*)).ti,ab,kf.	403,815
13	((umbrella or rapid or scoping) adj review*).ti,ab,kf.	42,989
14	("overview of reviews" or "review of reviews").ti,ab,kf.	1,545
15	9 or 10 or 11 or 12 or 13 or 14	3,740,221
16	exp "Delivery of Health Care"/	1,415,146
17	exp Health Services/	2,569,988
18	exp Health Expenditures/	27,650
19	exp Health Care Costs/	75,181
20	health.tw.	2,921,255
21	16 or 17 or 18 or 19 or 20	5,439,816
22	8 and 15 and 21	192
23	limit 22 to yr="2012 -Current"	**135**

Embase Classic+Embase (Ovid): 10th June 2025

#	Query	Results from 10 Jun 2025
1	direct payment*.tw.	338
2	"cash for care".tw.	49
3	(consumer directed care or consumer directed support).tw.	117
4	((person* or patient* or individual*) adj2 (budget* or funds or funding)).tw.	4,724
5	((self-directed or self-managed or user-directed) adj2 (support or care or budget* or funds or funding)).tw.	331
6	((personali#ed or personali#ation) adj2 (budget* or funds or funding)).tw.	53

7	"cash and counsel?ing".tw.	58
8	1 or 2 or 3 or 4 or 5 or 6 or 7	5,573
9	"systematic review"/	531,403
10	exp "systematic review (topic)"/	37,477
11	(systematic review or review).pt.	3,423,893
12	(systematic adj2 (review* or overview*)).ti,ab,kf.	482,135
13	((umbrella or rapid or scoping) adj review*).ti,ab,kf.	44,157
14	("overview of reviews" or "review of reviews").ti,ab,kf.	1,748
15	9 or 10 or 11 or 12 or 13 or 14	3,815,587
16	exp health care delivery/	5,063,271
17	exp health service/	8,217,162
18	exp "health care cost"/	374,773
19	health.tw.	3,833,989
20	16 or 17 or 18 or 19	10,611,349
21	8 and 15 and 20	359
22	limit 21 to yr="2012 -Current"	241
23	conference abstract.pt.	5,490,612
24	22 not 23	**181**

Scopus: 10th June 2025

#	Query	Results from 10 Jun 2025
1	TITLE-ABS-KEY ("direct payment*" OR "cash for care" OR "consumer directed care" OR "consumer directed support")	1,915
2	TITLE-ABS-KEY ((person* OR patient* OR individual*) W/1 (budget* OR funds OR funding))	5,447
3	TITLE-ABS-KEY (("self directed" OR "self-directed" OR "self managed" OR "self-managed" OR "user directed" OR "user-directed") W/1 (support OR care OR budget* OR funds OR funding))	630
4	TITLE-ABS-KEY ((personali?ed OR personali?ation) W/1 (budget* OR funds OR funding))	86
5	TITLE-ABS-KEY ("cash and counsel*ing")	69
6	OR 1-5	7,859
7	TITLE-ABS-KEY (systematic W/1 (review* OR overview*))	673,884
8	TITLE-ABS-KEY ((umbrella OR rapid OR scoping) W/1 review*)	55,887
9	TITLE-ABS-KEY ("overview of reviews" OR "review of reviews")	1,590
10	OR 7-9	706,634
11	TITLE-ABS-KEY (health*)	8,310,507
12	6 AND 10 AND 11	110
13	12 limited to publication year 2012-2025	**96**

Final Results

Database	Search Results
Medline (Ovid)	135
EMBASE (Ovid)	181
Scopus	96
Total	412
Duplicates identified by Endnote	171
New Total	**241**
Duplicates identified by Raayan	6
New Total	**236**

Health and Care
Research Wales
Evidence Centre

Canolfan Dystiolaeth
Ymchwil Iechyd a
Gofal Cymru

The Health and Care Research Wales Evidence Centre

Our dedicated team works together with Welsh Government, the NHS, social care, research institutions and the public to deliver vital research to tackle health and social care challenges facing Wales.

Funded by Welsh Government through Health and Care Research Wales, the Evidence Centre answers key questions to improve health and social care policy and provision across Wales.

Along with our collaborating partners, we conduct reviews of existing evidence and new research, to inform policy and practice needs, with a focus on ensuring real-world impact and public benefit that reaches everyone.

Director: Professor Adrian Edwards

Associate Directors: Dr Natalie Joseph-Williams, Dr Ruth Lewis, Dr Deborah Edwards

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