communitycatalysts®
unlocking potential effecting change

Growing Personal Health Budget take up and impact

Cheshire and Merseyside

November 2025

NHS
Cheshire and Merseyside

INDEX

1. EXECUTIVE SUMMARY

This report, commissioned by NHS England North West Personalisation and Community Services Team and delivered by Community Catalysts CIC, explores opportunities, challenges and areas for improvement in the expansion of Personal Health Budgets (PHBs) within the Cheshire and Merseyside Integrated Care System. The focus was on Continuing Healthcare and Children's Continuing Care. Work was conducted between November 2024 and May 2025 across five 'Places' in the local system, involving research, data analysis, workshop and interviews with 42 local practitioners, service providers, and people who draw on Personal Health Budgets.

While the work was commissioned and undertaken before the publication of the NHS 10 Year Plan, the insights and recommendations will support the North West region in delivering the new commitments to significantly increase uptake of Personal Health Budgets nationally to 1 million by 2035.

Personal Health Budgets (PHBs) help individuals manage their health and care needs by providing greater choice and flexibility over how their assessed needs are met, through an individually agreed personalised care and support plan. PHBs can be managed as a Notional Budget (NHS holds the money), Third-Party Budget (independent organisation manages the money), or Direct Payment (individual manages the money directly).

Certain groups of people have a legal right to a PHB, including those eligible for NHS Continuing Healthcare (CHC), Children's Continuing Care, individuals under Section 117 of the Mental Health Act (1983), and people who use a wheelchair.

The process for all PHBs involves six key steps: clear information, understanding needs, determining budget, developing a personalised plan, organising care, and monitoring/reviewing.

There is strong local commitment to PHBs in Cheshire and Merseyside ICB, with relatively strong local performance in terms of number of PHBs, compared to national implementation across England.

Key findings from the interviews, desktop research and event that took place:

Positive Impacts:

- PHBs improve people's (patient) experience and offer value for money, with a local analysis showing Direct Payments saved £291,442 per year compared to agency care for 62 PHB holders.
- PHBs enable increased choice and control, allowing individuals to choose other options when traditional care services are not meeting their needs or not working for them. They enable access to a wider range of flexible services, sometimes including employing family members, which can work well when people need support from people who know them well and when family members can't take other employment due to their caring commitments.
- PHBs support people to live "good lives" through activities, therapies, and relationship-based care. The presence of strong, valued advice, support, and brokerage services from third-sector organisations, along with independent advocacy (like in Sefton and Liverpool), significantly enhances PHB effectiveness and confidence

among people who use a PHB and professionals. Creative, hybrid PHB approaches, combining different management methods, are also noted as successful.

Identified Challenges:

- Despite successes, several areas need improvement. Notional Budgets often do not offer true choice and control, frequently defaulting to standard commissioned care services without fully adhering to PHB principles and limiting provider choice due to systemic ties to contractual frameworks and provider lists.
- Restrictions on choice and control are also observed with Direct Payments, where individuals are sometimes told they must use CQC-registered agencies, despite this being at odds with DP legislation[1].
- There's a misconception among professionals that CQC registration is the sole indicator of quality and safety for all care or support services, leading to a bias against non-CQC registered, but potentially effective, wellbeing services and/or care services that are exempt from CQC registration.
- Employing staff (PAs) via PHBs presents challenges due to the workload, difficulties in recruitment and retention (often linked to low pre-defined pay rates), and lack of structured career paths or flexible training.
- An "unbalanced culture of mistrust" sometimes exists among professionals towards families rather than equally scrutinising care providers.

Opportunities and recommendations:

To further scale and improve impact of PHBs, the following actions are recommended:

- Improve information and advice by providing clear, accessible and comprehensive information at early stages, showcasing all PHB options (including Direct Payments, Notional Budgets, and third-party budgets) through real-life stories. Consider peer support programmes and increase knowledge among clinical staff. Expand successful advocacy models.
- Review Notional Budgets through a systemic review to ensure they align with the six PHB principles, clearly distinguishing them from commissioned services and allowing for user scrutiny of invoices. Adapt IT systems to accurately record directly commissioned care services.
- Widen service and support choices by broadening the focus beyond purely clinical tasks to include wellbeing outcomes, accessing diverse commissioning routes and using spot purchasing for Notional Budgets. Develop clearer guidance on using sole traders and approaches to small equipment budgets.
- Maximise creative approaches by actively promoting successful hybrid PHB arrangements and exploring opportunities for budget pooling and more extensive use of third-party budgets.
- Enhance Personal Assistant (PA) recruitment and development by using more ‘relationship based’ methods. Develop creative routes for PA career paths and explore a joined-up, flexible approach to PA training across the ICB area. Conduct a study on PA pay rates and conditions to improve recruitment and retention.
- Address culture of mistrust by implementing training that incorporates the voice of people who hold a PHB.

[1] https://www.england.nhs.uk/long-read/guidance-on-direct-payments-for-healthcare-understanding-the-regulations/

- Evidence financial benefits by undertaking work to collect local and national evidence of the cost-benefit of well-implemented PHBs. Include economic modelling to influence investment in PHB support structures.

2. INTRODUCTION AND BACKGROUND

About this report

This report explores the challenges and areas of improvement for the expansion of Personal Health Budgets (PHBs) in Cheshire and Merseyside Integrated Care System. It was commissioned by NHS England North West Personalisation and Community Services Team and the work delivered by the social enterprise, Community Catalysts. The work took place between November 2024 and May 2025 across five Places within the local system. The focus was on Continuing Healthcare and Children's Continuing Care.

It involved research on local PHB policies and processes in comparison to national policies and expectations for delivery, gathering and analysing available local data and interviews with 42 local practitioners, providers of PHB support services and people who use PHBs. Through this work, the report author sought to understand current delivery opportunities and challenges, the resulting impact on individual choice and lived experiences as well as the local NHS system. The results were analysed into themed areas which form the recommendations of this report. They were shared and tested at a workshop involving 25 people.

This work was commissioned before the new NHS 10-Year Plan was published, but its insights and recommendations will be key to helping the North West region deliver the plan's goals.

Personal Health Budgets (PHBs)

PHBs help people (called patients by the NHS) manage how their health and care needs are met. They follow 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. In their simplest form, a person is told how much money is available to meet their assessed needs and they then work with their care team to decide how to spend it. That might be on home care services, physiotherapy, mobility aids, a choice of wheelchair, or on activities to support them to get out and involved in their community. PHBs can be managed in three ways:

1. **Notional Budget**: The NHS holds the money and arranges care, with the individual actively involved in planning and selecting services.
2. **Third-Party Budget** (also known as an Individual Service Fund or ISF, particularly where there is a link with social care): An independent organisation holds and manages the money, arranging care in partnership with the individual.
3. **Direct Payment**: The individual receives the money directly, allowing control and flexibility. Often used to employ Personal Assistants (PAs) or sometimes to purchase

services. A managed account service can assist people with financial administration e.g. a Direct Payment support service offered by a third sector organisation[2].

Certain groups of people have a legal right to a PHB, including those eligible for NHS Continuing Healthcare (CHC), including people at end of life, defined by the NHS as 'fast-track', or Children's Continuing Care, individuals eligible for support under section 117 of the Mental Health Act (1983) and people who are long term users of a wheelchair. In addition, ICBs are able to consider offering PHBs to wider groups who may benefit from them

There are six key steps that determine what makes a PHB a PHB, and these are detailed in the PHB quality framework developed by NHS England[3] in Appendix G. These apply to all three PHB approaches including Notional Budgets and are:

I. Clear information
II. Understand health and wellbeing needs
III. Determine budget allocation
IV. Develop a personalised care and support plan – with real choice
V. Organise care and support
VI. Monitor and review

This structured process ensures that PHBs are personalised, transparent and effectively managed to enhance individual health and wellbeing.

National policy context and evidence of cost savings

Personal Health Budgets (PHBs) were first introduced in England as a pilot program between 2009 and 2012. Following the pilot's success, which demonstrated improved quality of life and reduced unplanned hospital care, PHBs were rolled out as a mainstream service in October 2014. Nationally there are currently 183,000 Personal Health Budgets being delivered.

The 10-year health plan[4] for England, published in July 2025, recommitted to the continued expansion of PHBs, stating they have a key role in making the NHS more financially sustainable by: *'Expanding personalised, patient-centred care—through the Neighbourhood Health Service—and meeting the new target of offering 1 million personal health budgets by 2030, with a universal offer for everyone who could benefit by 2035'.*

The 10-year plan also briefly summarises the evidence in support for PHBs - in particular citing the growing evidence of 'one-off' PHBs, to prevent hospital admissions and to accelerate hospital discharge, which wasn't explored as part of this project. [5] The 10-year health plan highlights that *'…care plans and personal health budgets both improve outcomes and deliver value. One evaluation in England found they delivered quality of life improvements worth between £1,520 and £2,690 per patient, per episode of care…"*

[2] https://www.england.nhs.uk/long-read/guidance-on-direct-payments-for-healthcare-understanding-the-regulations/
[3] https://www.england.nhs.uk/long-read/personal-health-budget-phb-quality-framework/#steps-of-the-phb-process-and-quality-standards
[4] UK Government, 'Fit for the Future: 10 Year Health Plan for England', July 2025
[5] Discharge-report-2024-final-gc.pdf

There is extensive additional evidence of positive outcomes, impact and cost savings, detailed and referenced below.[6]

NHSE Personalised Care Evidence

[7]The evidence base for personalised care continues to grow, demonstrating a positive impact on people, the system and professionals…Other recent highlights include:

- *In an independent survey 86% of people with a personal health budget said that they had achieved what they wanted…and 77% of people would recommend PHBs to others*
- *PHBs in NHS Continuing Healthcare (CHC) have also been shown to achieve an average 17% saving on the direct cost of home care packages….*
- *From tracking over 9,000 people with long-term conditions across a health and care system, evidence has shown that people who are more confident and able to manage their health conditions…have 18% fewer GP contacts and 38% fewer emergency admissions….*
- *A literature review of over 1,000 research studies found peer support can help people feel more knowledgeable, confident and happy, and less isolated and alone.*
- *A recent systematic review of 73 studies of personal budgets in health and social care across the globe found "positive effects on overall satisfaction, with some evidence also of improvements in quality of life and sense of security…".*

Crucially much of the evidence of impact includes a strong focus on people's wellbeing and 'whole life' outcomes and is not restricted to direct personal care and healthcare tasks.

There is also evidence that Personal Health Budgets (PHBs) can lead to cost savings compared to directly commissioned care services. See Appendix A. This is because of:

- Reduction in other costs
- Cheaper costs than commissioned care services:
- Greater flexibility and personalisation[8]
- Improved outcomes and cost-effectiveness
- System efficiencies over time
- Positive impact on families and carers

Within this context, there is evidence that the way PHBs are implemented matters. The amount of control and flexibility that people have influences both outcomes for the person and cost savings. The less control and flexibility people have the less personal and cost benefit is realised[9].

The role of the ICB in delivering PHBs

The NHSE Quality Framework[10] gives ICBs the key role in expanding numbers and embedding PHB processes and says that ICBs should:

[6]. Jones K and others. 'Personalization in the Health Care System: Do Personal Health Budgets Have an Impact on Outcomes and Cost?' Journal of Health Services Research & Policy 2013: Volume 18, Pages 59-67 (viewed 190625)
[7] https://www.england.nhs.uk/personalisedcare/evidence-and-case-studies/
[8] https://assets.publishing.service.gov.uk/media/5a7c8147ed915d48c2410323/dh_128368.pdf
[9] https://pmc.ncbi.nlm.nih.gov/articles/PMC4768846/
[10] https://www.england.nhs.uk/long-read/personal-health-budget-phb-quality-framework/

- Create the conditions for PHBs to flourish
- Create PHB models for the 'right to have' cohorts and wider groups of people
- Align systems for people supported by health, social care and education
- Ensure there are strong mechanisms for the transfer of PHBs between ICBs
- Provide a system-level approach to quality based on personalised care for all
- Support the enablers of efficient personalised care, including co-production, workforce development and good governance and policy
- Develop a strategic plan to support the implementation and expansion of PHBs.

3. PHBs IN CHESHIRE AND MERSEYSIDE

PHB context in Cheshire and Merseyside

There is a strong local commitment to PHBs in Cheshire and Merseyside and strong local performance within a national context. Quarter 4 2024/25 data[11] shows that Cheshire and Merseyside ICB ranks 11th out of 42 ICBs for PHB numbers.

Local work is underpinned by an extensive exploratory project to survey and report back from staff and people with a PHB. This report has been informed by that existing insight. There is also a new local PHB policy which has been used to underpin this project and report[12].

Cheshire and Merseyside PHB data

Information supplied by Cheshire and Merseyside ICB states that:

Tables 1 and 2 show the numbers of PHBs in the right to have a PHB categories across the ICB in 24/25 using NHSE Digital data.

***The data does not allow for further breakdown of the 'other' category.*

***People can have more than one type of PHB so the numbers of PHB by type do not reconcile back to the number of patients holding PHBs.*

***Due to the way the data is collected there may be some duplication of data within the section 117 category*

The other category includes PHBs for people who are not in the right to have groups e.g. joint funding and learning disability and autism.

Table 1 - Children and young people - total number of PHBs is 601, 24/25

Right to have category	***Number of patients who held a PHB in 24/25***	***Number of Direct Payments held in 24/25***	***Number of Third-party Budgets held in 24/25***	***Number of Notional Budgets held in 24/25***

[11] https://digital.nhs.uk/data-and-information/publications/statistical/personal-health-budgets/2024-25-q4/personal-health-budgets-q4-2024-25
[12] https://www.cheshireandmerseyside.nhs.uk/media/pf2hzgbo/personal-health-budget-and-integrated-budget-policy-version-1-february-2025.pdf

Children's continuing care	*84*	*61*	*9*	*31*
Wheelchair budgets	*490*	*1*	*8*	*481*
Section 117	*2*	*1*		*1*
Other	*25*			
Total	*601*	*63*	*17*	*513*

Table 2 - Adults – total number of PHBs is 3906, 24/25

Right to have category	***Number of patients who held a PHB in 24/25***	***Number of Direct Payments held in 24/25***	***Number of Third-party budgets held in 24/25***	***Number of Notional Budgets held in 24/25***
Continuing healthcare	*974*	*480*	*63*	*553*
Wheelchair budgets	*1841*	*8*	*37*	*1816*
Section 117	*497*	*56*	*10*	*439*
Other	*594*			
Total		*544*	*110*	*2808*

Evidence of local impact and savings

The primary goal of Cheshire and Merseyside ICB in implementing PHBs is to ensure people receive high quality services and support.

…however when the costs of Direct Payments are analysed it is clear that not only do they improve patient experience, but they also offer value for money. **Ruth Hunter, Senior Personalised Care Manager, Cheshire and Merseyside Integrated Care Board (ICB)**

A small-scale local analysis of Direct Payments and value for money was undertaken. Work was done to look at the care and support plans of 62 PHB holders in Cheshire and Merseyside.

The annual total cost to deliver the services in the care and support plan of 62 PHB holders which were taken as a Direct Payment was calculated. The equivalent annual total cost for an agency (£20/h) to deliver the services in the 62 care and support plans was also calculated; this is as a traditionally provided package of care. The two costs were compared. For the 62 PHBs, Direct Payments cost £291,442 less per year than using an agency to deliver a traditional package of care. This equates to a saving of approximately £870k over three years. In addition, people reported increased choice and control over when and how their own care is delivered, improved their outcomes.

Notional Budgets

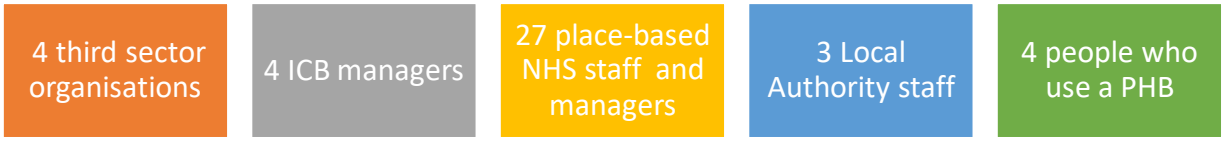
Nationally, there has been a rise in the number of notional budgets. Cheshire and Merseyside ICB want to ensure their local Notional Budgets PHB offers ensure real outcomes for people.

'When done properly, Notional Budgets can give people increased control. However, if we achieve the million PHB target with the majority as notional, then we will have completely missed the whole point' **Angie Boyle, NHSE North West**

Understanding the local picture

To build on the known data and information, the report author sought to find out how PHBs work in practice in Cheshire and Merseyside and learn about local challenges and opportunities. They did this through:

- Interviewing 42 people from Cheshire and Merseyside ICB and Wirral, Warrington, Halton, Liverpool and Sefton places, including:



- Conducting a desktop analysis of local reports, information, and procedures
- Identifying and analysing data sources showing local PHB numbers and statistics to extrapolate trends and indicators
- Capturing stories of PHB holders – directly and via NHS and third sector partners - Appendices C, D and E
- Organising and facilitating an event to test early assumptions, share stories and celebrate great practice and huge impact of PHBs in Cheshire and Merseyside. A report of that event, including a video, is in Appendix B.

This information was then themed and compiled into the learnings, opportunities, challenges and recommendations that now follow.

4. WHAT WE LEARNED

This information is taken from the interviews, desktop research and the event that took place.

Things to celebrate and share

Local systems and processes can enable

- In some areas of the country, research has shown the systems that underpin PHBs do not enable many people to have real choice and control. Conversations with people in the five Places in Cheshire and Merseyside showed that the systems in place can and do enable a creative, motivated person, willing to consider a Direct Payment, to get the care and support of their choice.
- In all the five Places, services are commissioned by the ICB to support, inform and guide people who are interested in taking their PHB as Direct Payment. These services are hyperlocal, well connected and highly valued by the people who use them.
- Many people who take a PHB and who are involved in the system are very positive about nurses and other clinical advisers.
- The research found examples of Notional Budgets that offer people choice and control.

Disability Positive

Wirral Place works with ICB commissioned third sector, User Led Organisation, Disability Positive to provide a personalised brokerage support service to people who take a Personal Health Budget.

Our goal is for the family to live the best life possible. Both partners support and encourage individual choice whilst supporting them to manage risk. We complete the Personalised Support Plan with a holistic view of the whole family. Then we signpost people to activities, accessible holidays, peer support groups, access cards, cinema cards, toilet cards, funding for holidays and equipment and social media groups. We assist in planning for the future for both the cared for person and their family members. We refer for carers assessments, young carer assessments. We offer all the signposting and information available to us, even if the person eventually decides not to take a Direct Payment and have a Notional Budget instead.

Quite often when we attend reviews with a Commissioning Nurse, they comment on how much more a person gains from a Notional Budget taken via the Disability Positive PHB brokerage route rather than a commissioned service without our involvement. The person benefits hugely from a Notional Budget even when the care service they end up using is the same as if they had just used a commissioned service. This highlights a positive difference between a commissioned service and a Notional Budget for people on the Wirral. Nurses also increase their own personal knowledge of local assets and opportunities, and I think that this has really driven the PHB referrals in Wirral.

Notional budget example

A woman approached Disability Positive to explore Personal Health Budgets (PHBs), seeking more flexible and higher-quality care than her current agency provided, without the responsibility of becoming an employer. After discussing PHB options, she chose a Notional Budget, allowing her to use an agency already approved by the ICB. Disability Positive also addressed her concerns about losing valued carers, explaining potential TUPE options or employment transitions. Additional support included information on carers' assessments, accessibility resources, and local inclusive activities. She described the outcome as transformative, saying she felt "part of the community for the first time since diagnosis" and was "really enjoying life." **Annette Gallagher, Disability Positive**

PHBs are offering people control and enabling choice

- People who take a PHB, whose views were gathered for this report, said that it gives them increased choice and control. They can make care choices that work for them and their lives.
- Several people who were interviewed reported that a PHB gave them a chance to choose an alternative when traditional care services were not meeting their needs or not working for them. This created alternatives that work much better. People said this reduces stress and challenges for them and their families. It is likely that it also reduces implementation issues and costs for the system too.
- In some Places, people reported that their PHB allows them to employ family members. This is highly valued by some people. It can work particularly well when people need support from people who know them well and when family members can't take other employment due to their caring commitments.

Jack's experience - family-centred support through a PHB

Jack, a happy and active 2-year-old, lives with his mum, Sarah. He was referred to the PHB Support Service (PHBSS), commissioned by Sefton and Liverpool ICBs and delivered by Sefton Carers Centre in partnership with Sefton Advocacy. Jack had 88 hours of support via a Notional Budget, but Sarah was only using 70 night-time hours, as she was not comfortable with agency care during the day. PHBSS supported Sarah to explore alternatives, including employing her sister—already trained via Alder Hey—as a Personal Assistant (PA). After preparing a PHB budget and gaining panel approval, daytime care was transferred to Sarah's sister. PHBSS arranged the prepaid card and payroll, with no DBS required due to the family relationship. Sarah later chose to end agency support entirely. With PHBSS guidance and clinical input, she began directly employing PAs for all of Jack's support, creating a more personalised and trusted care arrangement. **Appendix E for the full story supplied by Sefton Carers Centre**

- Many people interviewed for this report told us that taking a PHB as a DP and using it to contract services (rather than employ staff):
  - gave them access to a much wider range of services - more choice.
  - gave them the ability to create more flexible and personal care arrangements – days and times, and how this time is used is not dictated - more control.
- Third sector support organisations told us that taking a PHB as a DP and using it to contract services gives people the power to scrutinise the service providers, ensuring that only services used are charged for.

Ali's experience – personalised continuity of care through a PHB

Ali, a young woman, had experienced repeated breakdowns with care agencies until finding stability with a nurse agency and two trusted nurses. Although this option was more expensive, it provided consistency and quality care. When costs became a concern, we explored a Personal Health Budget (PHB) with the family. A PHB was agreed, based on standard agency rates, giving Ali and her mum control over how to use the budget. They chose to continue with the nurse agency, using the PHB to fund four nights a week, with the family providing the rest. This maintained a positive, person-centred arrangement. As Ali approached adulthood, we engaged adult CHC teams early to ensure the support could continue seamlessly beyond transition. **Appendix E for the full story supplied by Sefton Carers Centre**

PHBs are supporting people to live good lives

- The people we spoke to and heard about were clear that their lives are better once they have PHB funded support.
- People shared examples that showed it is possible for people in Cheshire and Merseyside to use a PHB flexibly and creatively to live their life their way and do the things that they enjoy. There are examples of PHBs funding the support people need to go out, join clubs, holiday, enjoy music, support their sports team, swim, walk and keep active. There are also examples of PHBs being used to fund therapies which help people regain, recover and rehabilitate.

- People who take a PHB talk about the importance of relationship-based care. They share examples of PHBs being used to make care and support arrangements based on real relationships, reciprocity and even love. Is this a USP for PHBs?

Meena's experience - creative use of PHB for health outcomes

Meena, a young woman supported by a care agency commissioned by the ICB, was struggling with weight management, posing a medical concern. Her consultant strongly supported a Personal Health Budget (PHB) to fund gym membership, a personal trainer, and hydrotherapy during school holidays. Despite initial questions around outcomes and accountability, the proposal was approved. The PHB has had a significant positive impact on Meena's health and wellbeing. The clear clinical backing was key in enabling this creative, health-focused use of a PHB. **Appendix E for the full story supplied by Sefton Carers Centre**

Good advice and support are having a huge impact

- The five Places involved in the research for this report all have strong advice, support and brokerage services for adults, contracted by Cheshire and Merseyside ICB.
- The third sector organisations contracted by the ICB have a mandate to support people who choose to take their PHB as a DP. These services are valued by people – offering highly personalised support, clear information and advice, help to get creative and a place to ask and get answers to questions.
- Most third sector support organisations also offer general PHB advice.
- People interviewed for the report and who shared their stories, said they valued having a named person, able to help them navigate through decision making and practical PHB arrangements.
- People also said they valued the excellent information, particularly on Direct Payments, on offer to them.
- Evidence would seem to show that this knowledge and expertise creates a strong foundation for creative thinking.
- Independent advocacy for both adult and child PHB/DP holders in Sefton and Liverpool adds an additional, highly personalised, route to advice, information and support. This comes at a time when caseloads are larger, and it is harder to get personalised help from hard-pressed public-sector workers like nurses and social workers. Appendix B for advocacy stories, Appendix F for impact data.
- The NHS Personal Health Budget Quality Framework states that ICBs are expected to consider supporting the development of independent and accessible advocacy services for PHB holders, ensuring people have access to independent support and advice if needed. Despite this expectation, the additional service offered by Sefton Advocacy may be unique.

Strong expertise is valued by professionals

- Third sector organisations that are contracted to support PHBs are often co-located and/or very accessible to CHC/CC nurses and other operational professionals.
- They offer expertise and experience that is highly valued by professionals. Nurses we heard from said they offer a level of knowledge that they and others draw confidence from.

Doing PHBs in creative ways works well

- There are lots of examples of PHBs successfully taken by individuals in more than one way. E.g. Direct Payments used to employ PAs alongside DP pots available to contract an agency and/or a Notional Budget funded arrangement with a care agency. This seems to work well for people, improving lives, adding flexibility and 'back up' which makes all arrangements more attractive and sustainable.
- There are very positive examples of regulated care services and unregulated support services/wellbeing stuff (contracted/Notional Budget purchased) working together – a benefit for the person and saves money.

Olga's experience – personalised end-of-life support through a PHB

Olga, a Polish woman in Merseyside with no close family, was eligible for CHC funding and required intensive palliative care. As her health declined, she relied more on her first language and needed culturally sensitive support. Working with a local third sector PHB support organisation, Olga took a PHB using a Direct Payment. This allowed her to receive personal care from a CQC-registered agency, while also funding wellbeing support from a specialist Polish organisation that could not be commissioned directly by the ICB. The two organisations worked side by side—providing care, language support, and cultural understanding. This creative PHB arrangement enabled person-centred and dignified support at the end of life. **Appendix E for full story - adapted from a true story for anonymity**

Challenges

While there have been some great examples of practice, analysis from the research and interviews in five Places in Cheshire and Merseyside show some areas for action or improvement:

Notional budgets – choice and control

- In some of the five Places, CHC funded care arrangements are often logged as Notional Budgets. This happens even when the six PHB principles are not being fully followed, and the care arrangements are in effect a standard commissioned care service. Notional Budgets of this kind usually offer people no additional choice, control or personalisation, but they are recorded as a PHB, nonetheless.
- In some places, the research and interviews confirmed that there seems to be no way for clinicians to log a commissioned care service as the IT system defaults these to a Notional Budget.
- Notional Budgets we heard about in the research seem to be systemically tied to contractual frameworks and other lists of homecare providers. In practice, this means that people opting for Notional Budget were often only being offered services from a limited range of providers offering a narrow range of services.

Notional budgets - tendering and procurement

- In the areas of Cheshire and Merseyside we researched, the contractual frameworks and lists of homecare services for adults are usually managed by local councils. Health usually uses these frameworks and lists.
- People who hold a PHB talked about the process when these contracts or frameworks are retendered. They told us that when this happens some agencies lose their place on the framework or list. This means that people who are already using these services

and value them are no longer allowed to use them. Conversely, agencies people do not value becoming 'required'.

- People and their families say they have no say in this process, and it can be very disruptive and/or make things worse for people as a result.

Restrictions on choice and control

- Some people who take a DP choose not to use it to employ their own staff. Instead, they elect to use their DP to contract services from a service provider organisation. People in this circumstance are often told they must use a CQC registered homecare agency. Some are told which care agencies they can use too.
- When this happens, people's choices are limited by the system in a way that seems at odds with DP legislation and rules[13].
- Sole traders who provide personal care and who are exempt from CQC registration (sometimes known locally as 'self-employed PAs') are 'allowed' in some places and not others. The local policy does not prohibit their use. In the areas that allow them, they are used and valued.

Quality/not quality

- Locally, some health and social care professionals see CQC registration as the only possible badge of quality and safety for care or support providers.
- This is the case even when the service required to meet people's assessed needs does not come within the scope of CQC 'regulated activity', for example, when personal care is provided in any place that is not the person's home. There is a strong but false perception that all care services are regulatable/should be regulated – including daytime support, help in community settings and support with things that are not personal care/regulated activity.

*The regulated activity of personal care involves providing personal care for people who are unable to provide it for themselves because of old age, illness or disability. The personal care **must** be provided in the place where those people who need it are living at the time when the care is provided*[14]*.*

- CQC registered homecare providers are perceived to be 'safe and high quality' – even when many people had examples of providers that were neither of these. Conversely, services and supports that are not CQC registered (or even registerable) are perceived to be unsafe and low quality, even when many people have working examples where this was not the case.
- For some people, PHBs can be a route to alternatives when traditional care services are not meeting their needs or not working for them. A PHB can be selected to a solve problem rather than because it is attractive in itself. This was a strong theme with most PHB holders we heard from.

Sarah's experience – flexible, person-centred support through a PHB

Sarah, a 24-year-old with complex health needs, was receiving 70 hours of care from an agency, but her family struggled with their inconsistency and had concerns about

[13] https://citizen-network.org/library/direct-payments-and-flexibility.html
[14] https://www.cqc.org.uk/guidance-regulation/providers/registration/scope-registration

professionalism. With support from the PHB Support Service, they explored alternatives. Using a Personal Health Budget (PHB), the family switched to a small, local agency providing reliable, person-centred care. The flexibility of the PHB also enabled Sarah to enjoy family holidays, water-based therapy, and music therapy. She now has greater independence, and her mum, Jane, feels supported and reassured. **Appendix E for the full story supplied by Sefton Carers Centre**

Employing staff

- Some of the people we interviewed, especially the PHB support organisations and nurse advisers, but also PHB holders themselves, talked about the work involved in becoming an employer. For some people, the extra work and hassle is worth the reward of increased choice and control. For other people, it is not. As a result, becoming an employer is not for everyone.
- Nurses and advisers know that PHBs can be used to both employ and contract, but they focus strongly on employing when they introduce the concept to people. This may be because this feels more familiar and usual. This early narrative may mean that people self-select away from a PHB when contracting with a DP might have worked well for them.
- Many people raised the challenge of recruiting employees using a DP. In 3 of the 5 Places, the ICB have set rates that people can pay their employees/PAs. These rates are perceived to be low in comparison with other employers in the area, e.g. supermarkets or food outlets, but also, ironically, NHS funded care agencies.
- There are different approaches in different areas to training PA/employees. One or two areas have a contract with a larger training company that is perceived to be more expensive and less suitable or flexible. Face-to-face training is shifting to online, and this is not felt to be a good thing.
- There are no structures in place to create positive developmental career paths for PAs. This means good PAs are more likely to move on to better work over time.

Unbalanced culture of mistrust

- Professionals often tell stories of people/families that are perverting or 'getting one over' on the system and/or doing things they shouldn't. These examples could be true, but the way they are shared seems to indicate that for some workers, there is a general mistrust of families and a questioning of their motivations and the quality of the care they offer. Poor or fraudulent practice by families obviously needs to be addressed, but there does not seem to be a similar distrust/questioning of care providers – even when people are happy to share stories of their poor or risky practice.

5. OPPORTUNITIES AND RECOMMENDATIONS

Analysis of Cheshire and Merseyside's PHB delivery, including reports from health staff and people in receipt of a PHB, shows further impact and scale could be achieved through a focus on better information and advice; a review of notional budgets; a wider choice of supports; maximising creative approaches; reviewing PA systems and considering the local PHB culture.

5.1 Improve information and advice

Better information at a very early stage, before people express an interest in taking a DP, could be of value. Information needs to clearly show that taking a DP and becoming an employer is only one option from a wide range. It needs to confidently demonstrate the choice and control offered by Notional Budgets. Creating a more detailed and multi-faceted menu of possibilities could result in increased PHB take up and Notional Budgets that offer better choice and control. For this to happen:

- All the PHB options need to be documented and or demonstrated in an accessible way, using practical, real-life stories that clinicians, people and their families can relate to.
- The ICB could consider a peer support programme, linking people with a PHB (taken and used in different ways) with people who are considering it.
- Some clinical staff and advisers need help to increase their knowledge and confidence.
- Extending the successful Liverpool and Sefton hybrid advice/advocacy model could free up more expensive clinical time; ensure PHBs are more sustainable; unlock additional resources and play a prevention role for people and their families. Appendix F.
- Continuing Care (CC) for children is available from birth. At birth, children and their families are connected to maternity and often also paediatric health services. The child's very first hospital discharge is a key information point for CC and linked PHB discussions. For this to happen well, hospital discharge leads may need to increase their knowledge of PHBs and stronger advice and information protocols developed for use at this stage.

5.2 Review and better develop Notional Budgets

Notional Budgets should offer people a level of choice and control that distinguishes them from directly commissioned care services. They should reflect the six PHB principles – Appendix G. To do this successfully:

- Review Notional Budget systems and information against the six PHB principles. Clearly define Notional Budgets against directly commissioned services. Ensure 'real' Notional Budgets are distinguishable and valued. Have information, systems and processes to underpin the distinction.
- Some staff and advisers may need increased knowledge, skills and confidence. IT systems may also need to be adapted to allow directly commissioned care services to be recorded as such (not as a Notional Budget).

Notional Budgets that meet the six principles could offer an additional level of choice and control for people, alongside adding capacity to a stretched system.

- Timesheets/invoices currently go from the provider to the ICB and get paid without checking. People we interviewed said that shifting the power of scrutiny to people/their families could make the Notional Budget better aligned with the six principles and potentially save money for the ICB as discrepancies and overcharges are identified and avoided. Enlisting the 'eye' of PHB holders in this way could add capacity to the system at little or no cost.

People at end of life are unlikely to employ PAs. It is a lot of work when things are difficult, and time is limited.

- Building better approaches to Notional Budgets could offer more choice and control to this group of people.

Please note: opportunities and recommendations that relate to Notional Budgets can also be found in all other sections of this chapter.

5.3 Offer a wider choice of services and supports

Currently in Cheshire and Merseyside, for everyone who chooses not to become an employer, there is a strong focus on CQC registered homecare services. People taking a Notional Budget are almost exclusively directed to use these services. People who take a Direct Payment have more flexibility, but homecare services still seem to predominate. The services and supports people use must be able to meet their assessed needs, but do they always need to be services, designed and regulated to help people with practical physical care and health tasks within their home? Consider:

- Alongside health, wider wellbeing is key in all aspects of the NHS PHB Quality Framework. Sometimes the services and supports on offer to people, especially people taking a Notional Budget, have a strong focus on clinical tasks and less focus on wellbeing. This is supported by the Active Cheshire study outlined below. Could the focus be widened?

Active Cheshire
Work was done in 2024 by Active Cheshire[15] and Disability Positive to see how PHB-funded physical activity could improve people's health and wellbeing. People's support plans were reviewed and there was a strong support for getting fitter and improving mental health through low-cost activities, which could have long-term impact on wider social determinants of health and potentially preventing more costly health interventions. Whilst funding for these initiatives wasn't approved at the time, support for this remains. See Active Cheshire for more detail.

- Whether the ICB has access to other frameworks, lists and commissioning routes, that vet, check and assure the quality of a more varied range of services and supports – those that are CQC registered and those that have more of wellbeing focus. For example, Warrington's Children and Young People team have a 'standard' framework of a wide range of diverse services. Make this wider range of service options available and acceptable to people, both taking a Notional Budget and DP.
- Could spot purchasing be used more extensively for people with a Notional Budget to enable them to gain access to a wider range of more diverse services and supports?
- Do 'sole trader' providers offer opportunities? Is there scope for better guidance on 'sole trader' providers that enables them to be used everywhere in a way that adheres to all legal obligations?
- Equipment and adaptations cause issues and delays, and this is costly whilst also frustrating for people and professionals. Consider:
  - Is there scope to create clearer pathways between community equipment services and PHBs?

[15] https://activecheshire.org/

- Could some people be offered small equipment budgets to enable them to quickly procure what they need, freeing up clinical and procurement time for more complex situations?

5.4 Maximise creative, practical approaches

Hybrid, creative approaches to PHBs, e.g. with one person employing, contracting and receiving commissioned services, appear to work very well in many places, especially for people who take a Direct Payment and get support from a third sector support provider. Despite this success, they do not seem to have a high profile with nurse advisers and other professionals and their potential and impact is not widely acknowledged or maximised.

- Could these experiences and examples be captured, promoted and better maximised?
- Is there potential to create systems that enable people to pool their budgets? For example, a mental health user-run sports and social group was established when members pooled their Direct Payments. The pooled funds paid for setup costs and ongoing activities, including sports and social support in the evenings and weekends. Group and individual assessments ensured the arrangement met both collective and individual need[16]
- Is there potential for a more extensive use of third-party budgets, able to extend more choice and control to people who don't want the responsibility of a Direct Payment[17]?

Simon's experience – enabling choice and stability through a PHB

Simon, 38, has a high-level spinal injury and lives alone. He values time with friends, attending concerts, the cinema, and supporting Manchester United. Referred to the PHB Support Service (PHBSS) in Sefton, Simon was unhappy with his care agency's management and lack of trained staff. With PHBSS support, Simon transitioned most of his care to Personal Assistants (PAs) he trusted, while keeping a small portion with a new, reliable agency for backup. PHBSS provided help with employer responsibilities, training, and DBS checks, and offered advocacy to resolve issues with his former agency. Simon now has a stable, support arrangement that works for him with greater control, trusted carers, and ongoing access to advocacy and advice. **Appendix E for the full story supplied by Sefton Carers Centre**

5.5 Support recruitment and personal development of PAs

Personal Assistants (PAs) are hard to recruit and retain in many areas of Cheshire and Merseyside. Relationship-based recruitment seems to be well used and often successful. Word of mouth, recruiting friends and family and attracting care workers from agencies that already provide support are common. Often, retention relies on strong personal relationships rather than attractive career paths. There is potential to build on this by:

- Acknowledging the power of love and relationships in this space and shifting recruitment methods to better reflect this. Possibly learn from slightly different, relationship focussed, sectors like Foster Care or Shared Lives[18].

[16] www.siryfflint.gov.uk/en/PDFFiles/Social-Services/Adult-Social-Services/SSA-A12PP-Pooling-Direct-Payments-Guidance-English.pdf
[17] https://citizen-network.org/library/thirdparty-personal-health-budgets.html
[18] https://sharedlivesplus.org.uk/what-is-shared-lives-care/

- Developing creative routes to career paths for PAs – find a way to enable PAs to gain skills, qualifications and opportunities for advancement – across the ICB area.

Training of PAs is approached in different ways in different places, with some reported as lower cost and more successful than others.

- Explore whether there is potential to save money and improve quality if an ICB-wide/joined-up approach to training PAs was developed. This should be flexible and personalised rather than online and more corporate.

Some places report that low, pre-defined pay rates make it harder to recruit and retain PAs. The approach to pay rates is different in different places.

- Explore whether there is value in a short analytical study on PA pay and conditions across Cheshire and Merseyside. Investigate whether more flexible and generous rates lead to easier recruitment and better retention. Detail the cost-benefit of different approaches.

Steven's experience – independence and workforce stability through a PHB

Steven, 55, has Multiple Sclerosis and became eligible for Continuing Healthcare. Referred to Sefton Carers Centre's PHB Support Service (PHBSS), he wanted to recognise the commitment of his existing Personal Assistants (PAs) by increasing their pay and to recruit more staff. PHBSS supported Steven through the PHB transition, including budgeting for higher pay and training costs to aid recruitment and retention. They also helped him identify a suitable care agency to provide interim support and supported the purchase of a specialist bed to maintain his independence at night.

5.6 Build a culture of trust

- Could training which includes the voice of PHB holders help address the balance of trust, which sees individuals and families as more in need of scrutiny than larger care agencies? There will be good and bad in both, but this was not reflected in the conversations we had.

5.7 Collect evidence of financial benefits and impact

People we spoke to and who came to the event were clear that the real value of PHBs is not just about the cost. They said that getting it wrong costs money and that we rarely capture evidence of that cost and use it to inform decision-making. People also spoke about the impact of good support, advice and advocacy on their wellbeing and mental health, with a belief that this prevents them from using more costly, and less valued services and interventions.

- Could work be undertaken locally and/or influenced nationally to collect evidence of the cost-benefit of good PHBs? Economic modelling of getting it right, which can influence the freeing up of resources to be invested in PHBs and PHB supporting structures.

6.CONCLUSION

Based on the comprehensive research, analysis of local policy, and insights from 42 interviews with practitioners, providers, and Personal Health Budget (PHB) holders across five places within the Cheshire and Merseyside Integrated Care System (C&M ICS), it is evident that the C&M ICS demonstrates a strong local commitment to PHBs and exhibits good performance within a national context. The report celebrates the significant positive impact PHBs have on individuals' choice, control, and overall wellbeing, offering alternatives to poor care experiences and demonstrating clear value for money, such as Direct Payments saving £291,442 per year compared to agency care for 62 PHB holders.

However, the findings also highlight opportunities for improvement and growth, including the inconsistent application of PHB principles to Notional Budgets, limitations on choice due to a pervasive focus on CQC registration, challenges in Personal Assistant (PA) recruitment and retention, and an 'unbalanced culture of mistrust' towards families.

Through consideration and implementation of the recommendations concerning enhanced information and advice, a systematic review of Notional Budgets, broadening choice of services and supports, maximising creative approaches, optimising recruitment for personal assistants, and fostering a more balanced culture of trust, Cheshire and Merseyside can further enhance the quality, take-up, and impact of PHBs.

This strategic focus will be instrumental in delivering the goals of the new NHS 10-Year Plan, ensuring PHBs consistently support people to manage their health and care needs with greater flexibility and personalisation, ultimately leading to improved outcomes for all.

Acknowledgements

This project was funded by NHS England Northwest, Personalisation and Community Team and was delivered in partnership with NHS Cheshire and Merseyside Integrated Care Board. Particular thanks go to:

- Personal Health Budget holders and their families, across Cheshire and Merseyside
- The late Sharon Lomax and NHS Cheshire and Merseyside staff in Warrington, Halton,
- Wirral, Liverpool and Sefton places
- Annette Gallagher, Disability Positive
- Andrea Holland and Angela Gilmore, Halton Borough Council
- Corinne Barclay and colleagues, Sefton Advocacy
- Helen Vernon, Sefton Carers Centre
- Warrington Council. Direct Payment and Children’s Commissioning teams
- Lorraine Scott, Warrington Disability Partnership
- Angie Boyle, Amy Longson, Jaimee Lewis and Brian Bennett
- Ruth Hunter and Dave Sweeney

APPENDIX A - How Personal Health Budgets can lead to cost savings

There is evidence that Personal Health Budgets (PHBs) can lead to cost savings compared to directly commissioned care services.

- **Reduction in other costs:** PHBs reduce the use of expensive services such as hospital admissions, emergency care, and GP consultations. The national evaluation found that the cost of hospital care was much lower for the PHB group than for the control group, especially for people with mental health problems and those receiving NHS Continuing Healthcare.
- **Cheaper than commissioned care services:** The national pilot evaluation[19] showed a 12% decrease in overall costs for the PHB group.
- **Greater flexibility and personalisation:** PHBs enable people and their families to personalise their care and support, and this often leads to more efficient use of resources. People purchase services that are not on traditional provider lists, and this can be more cost-effective[20].
- **Improved outcomes and cost-effectiveness**[21]: PHBs are cost-effective when measured against care-related quality of life outcomes (ASCOT), particularly for people with higher budgets. Improved quality of life and wellbeing can lead to reduced demand for crisis interventions and acute care, further lowering costs.
- **System efficiencies over time**: As people take more responsibility for their own support planning, demand on NHS staff time for care coordination and assessment is reduced.
- **Positive impact on families and carers:** PHBs can reduce costs by making things easier for family carers. As the health and wellbeing of PHB holders improves and they become more independent, families report less stress and a reduced need for informal care.

There is evidence that the way PHBs are implemented matters. The amount of control and flexibility that people have influences both outcomes for the person and cost savings. The less control and flexibility people have; the less personal and cost benefit is realised[22].

APPENDIX B - The event

Personal Health Budgets – exploring and learning from positive local practice in Cheshire and Merseyside

Took place in May 2025, face-to-face in Warrington. We invited all the people we had met or spoken to, together with additional stakeholders with a role or interest in PHBs. The aim of the event was explained in this way:

Cheshire and Merseyside have a strong commitment to Personal Health Budgets (PHBs) and want to grow their take-up and impact…We would like to invite you to be part of this

[19] https://www.pssru.ac.uk/pub/5433.pdf
[20] https://assets.publishing.service.gov.uk/media/5a7c8147ed915d48c2410323/dh_128368.pdf
[21] https://2020health.org/wp-content/uploads/2020/11/2020healthphbreportMST-ONLINE-9-7-13-1.pdf
[22] https://pmc.ncbi.nlm.nih.gov/articles/PMC4768846/

transformation and join us at an invite only in-person event on 15th May in Warrington. At the event, we will share the results of those conversations and the stories of people who have used a PHB. Together, we will celebrate what is great, offer recommendations and actions for continuous improvement, and pose some positive challenges. We would love you to join us.

About 25 people came along, and there was lots of opportunity for discussion and sharing. The programme covered:

- The strategic context for the project
- Community Catalysts and what we did
- Celebrating PHBs and what they make possible – hearing personal stories from Wirral, Warrington, Sefton and Liverpool. Celebrating the positive impact of PHBs on people and their families
- What we learned in the early stages of the project – testing whether this resonated and felt accurate with people in the room
- What could be better or different?
- What happens next in Cheshire and Merseyside

We filmed the event to allow the lessons and discussions to be disseminated to people who were not able to join us on the day. Video from the event here.

Key quotes from the day

We have had over 10 years of a 'right to have'. But we are only at the end of the beginning for Personal Health Budgets

Sometimes with PHBs we hit the target but miss the point! In Cheshire and Merseyside the quality of PHBs is important

Notional budgets are supposed to offer choice and control for the individual. But I get a sense that they may not always be offering that

Agencies were letting me down. I got in touch with the ICB and said 'I need to take control' That is when our lives changed. It was amazing. Now I have a choice!

Before the PHB I wanted the same people coming to my house but the agency would say that wasn't possible. Now I have a PHB the care for my daughter is better than it has ever been

Systemically if you really want a PHB to help you live your life you way in Cheshire and Merseyside it feels possible

PHBS seem to be often used by people escape more tradtional care services that aren't working

Great things happen...but they are not happening for everyone everywhere

Comments and challenges posed by event participants

- **Information and advice**
  - There is a need to give people better information about all their options much earlier in the process.
  - This would mean that fewer people would have to choose a PHB to get alternatives to traditional arrangements that are not working for them - a positive choice rather than one forced on people by poor circumstances.
  - For this to happen, nurses and other advisers, including those who work in Primary Care, need better information and resources and sometimes better knowledge and confidence.
- **Local focus**
  - Personal Health Budgets work best locally – supported by small local companies that know their communities
- **Real cost and value**
  - The value of PHBs is not just about the cost
  - Getting it wrong costs money – and we rarely evidence that cost or use the evidence to inform decision making
  - Cost, benefit and economic modelling is needed locally and perhaps nationally
- **Relationships**
  - Relationships are key at every stage. They are never written into operating procedures or processes, but their positive impact is reliant on them.
- **Life is more than physical care**
  - People's wellbeing and the support they need to live full lives can get lost in a focus on physical care and health tasks.
  - Wellbeing must be included in care and support plans
- **Extend to more people**
  - In Cheshire and Merseyside we need to extend PHBs to people who are not Continuing Health Care or Continuing Care funded
- **Maximising the impact of limited resources**
  - Times are difficult financially
  - Money is currently tied up in care service contracts. There is a need to free some of this up, so it is available for more and better PHBs

APPENDIX C – Long PHB stories

Please note: These stories are as they have been told, and approved by, the people who feature in them. A lot of work has gone into accurately capturing and reflecting their experiences, as they have wanted to share them. They are all anonymised.

Tim and Mrs Clarke

Tim is in his 20s and lives on the Wirral with his family. He is a fun-loving young man with a wicked sense of humour. He loves music and TV, especially cruder comedy programmes designed to shock. He likes going out and seeing new places. He delights in being part of social interactions, taking glee in gossip.

He wakes up every day with a smile on his face and has to be part of everything that goes on

A medical incident at birth resulted in Tim facing a life of disability, with multiple health conditions including epilepsy, diabetes, cerebral palsy and lung disease. He needs help and support with everything to be able to live his life. He has a tracheostomy and uses a ventilator.

In his early years, Tim's parents supported him with no help. When medical issues increased, it was determined that he needed extra help at school, and this was put in place and funded by the NHS. In recent years, Tim's health deteriorated even further, and he now needs support from 2 staff at any one time.

Over the years Tim and his family have had mixed experiences of care services, with lots of changes. Some services have been really good, building relationships, supporting Tim well and were highly valued as a result.

We moved to another care company, and they were really fantastic. But that only lasted for 2 years and then we had to switch to another.

Other care agencies were inconsistent or unreliable.

It was hit and miss whether the carers turned up or not

Some offered Tim poor care or even worse.

They would send a complete stranger with no training at all

There was an incident in which Tim was injured. There was an investigation, but we never found out what actually happened. We would rather have no one at all than put our son's life at risk

Tim and his family wanted to try and find a better way to get him the help that he needs. They heard about Personal Health Budgets (PHB) and requested one. It took many months for this to be approved, but once it was, the family was able to get support and advice from local third sector organisation Disability Positive. Disability Positive have helped and advised the family at every stage of the process, explaining what could be possible, getting creative and making practical arrangements.

They were unbelievable. They advocated for us when things got difficult at the start

The family now take their budget and uses it to contract with care and support providers rather than to employ their own staff.

Then everything changed. It was amazing

Tim gets help at home and to go out and about from a local care agency.

They employed a staff team just for Tim, so he always has the same, skilled people who know him well. He even has his 'on-call' nurse that we can contact if needed

He also spends time at 2 local social or day services, which he really enjoys and benefits from. Mrs Clarke set up a separate bank account and Tim's Direct Payment is paid into that. Mrs Clarke then receives invoices from the support organisations and she pays them from the bank account. Disability Positive continue to support.

They are still involved now – on the end of the phone if we need help

The family feel strongly that PHBs are a positive thing and should be explained in detail to people at an early stage in their care journey.

It's never explained to you what help is out there or what is possible; you just get little snippets. Full and proper info at the beginning would have really helped

It's early days, but the impact on Tim and the family has already been very positive. The main benefit Mrs Clarke can see is the fact that they are in control and able to make choices that are right for Tim.

I would 100% recommend a PHB to others. The main win is the control and flexibility the PHB gives us. The flexibility to do what is best for Tim. The current agency is working really well, but we know that we can find a new company at any time if that ever changes

William and Mr Jones

Mr Jones' son William is in his 50s, has brain damage and needs total care with everything to live his life. He is very aware of everything around him. He lives at home with Mum and Dad. He likes to go to the theatre, loves music and has a great sense of humour. He enjoys holidays abroad and going out for a walk. He uses a wheelchair to get out and about and has a moulded insert that supports his body in an upright position. He has a car paid for with his mobility allowance, and his PAs drive the car. He has equipment, including a tracking hoist, and home adaptations to make his home accessible. The family have a light/sensory room for William at home.

He had a very low life expectancy and is now in his 50s. We must be doing something right!

William's support was originally funded by the local council but moved to Continuing Health Care (CHC) funding about 20 years ago. William was also awarded some damages, so he has his own funds.

In the past, the family have used care agencies, allocated by the ICB (formerly CCG), but found them to be expensive, inconsistent and didn't give them and William any control.

They come when they can fit you in and not when you need. They are not consistent, and you never know the person who will arrive

Because of this, Mr and Mrs Jones helped their son to take his CHC funds as a PHB using a Direct Payment (DP). The Joneses are supported by Warrington Disability Partnership (WDP). They know they can ring or contact Lorraine at WDP anytime and speak regularly with her. They say:

There is always something happening

They use the DP to employ a team of 8 PAs. They know William values the relationships he has with people, and having consistent PAs enables him and them to form a bond and really get to know each other. Mr and Mrs Jones think this is very important. The family put their PA timesheets into WDP each month, and they do the payroll for the PA team. They have their own bank account, and the system works well in practice.

Mr Jones shared that his family have real difficulties recruiting and retaining good PAs. He thinks this is because the responsibility involved with caring for William is high, the set wage levels are low, do not reflect the immense skill required, and there is no opportunity for career advancement. The job centre also forces people who claim certain benefits to apply, not recognising the commitment and skill needed to support William well. As a result, the family are sometimes put in a position of recruiting people who may not be ideal. This can cause real difficulties for the family.

People take the job and then don't turn up. They are forced to take a job that is too far away from where they live, so travel is difficult for them, and they don't stay. It can be hard to get PAs to do the training, even though there is a certificate.

PAs can ring in sick at the last minute, and the parents end up filling gaps in William's rota. To mitigate against this, a positive arrangement has been made for the family to have a Notional Budget, alongside their Direct Payment budget pot. This Notional Budget enables the family to ring a local care agency, and their bill will be paid by the ICB. They have one local agency they like very much and who do a great job supporting William. They have other agencies that they will not use as they have had poor experiences with them in the past.

Sally and Cathy

Sally is fun loving, lively and engaging teenager who lives with her Mum, Cathy and sibling. She likes going out, shopping and swimming. She is autistic and has very complex health needs. She is tube fed and has intractable epilepsy which means she can fall at any time. She attends a school for the blind, and routine is very important to her. Sally needs a lot of support and practical care to live her life.

We had Direct Payments via the City Council for quite a few years, and then we were approached about Continuing Care. One of the Commissioners said, 'Would you think about Personal Health Budgets?' It was being piloted, and we were one of the first families.

With the support and creativity of Sefton Carers Centre (SCC), Sally and her family were helped to take a PHB as a Direct Payment. Cathy greatly values the support of SCC.

'They put me in contact with SCC and all my questions were answered. For example, I asked about getting a DBS check for a new person and they sorted it all out for me.'

In practice, the Direct Payment means the budget comes directly to Cathy and she puts it in a separate bank account. She uses the budget to employ a small team of PAs. Cathy uses a payroll service, sending them the hours people have worked. They work out things like tax and pensions before sending back the pay slip for each worker.

The team

They now have 11 workers in their team, with a core team alongside people who only work occasionally.

'Some of them have been with us for years and years….they were with Sally when she was younger, but they've grown up themselves now and they've got jobs of their own, but they still come and see us every now and then.

The PHB allows Cathy to pay her PAs a good rate of pay. She thinks this plays a key role in the successful recruitment and retention of good people.

'There were 3 rates, and I didn't think they were enough, so I said no. There was a lot of performance over it. I'm always pushing because I just think if you want to keep these people you have to pay them well. The responsibility that they have is massive.'

It can be difficult for new people to get to know and support Sally well. Cathy sees strong and consistent relationships as essential and draws heavily on word of mouth and established relationships when recruiting PAs for Sally.

'I am very fortunate. We have got some fantastic staff. Really, really good people who love her. And she's not an easy child, there's no doubt about that. So that takes time as well. As gorgeous as she is, she's hard, and I understand that. It's all about relationships.'

Training for PAs is really important. The ICB make arrangements with a local trainer who visits the family and staff at home and works in a really flexible and personal way. Money to pay the trainer is incorporated into the budget.

'So they just put me in touch with a freelance trainer. She's brilliant and will do weekends as well'

Cathy is conscious that all the excellent arrangements for Sally's care and support are fragile and sometimes vulnerable.

'We rely on them so much and I always feel like we're living a little bit on the edge because it doesn't take much. If someone goes on holiday or two people are off sick or something else goes on, everything kind of falls. There's only so much you can protect…It's quite a delicate balance, delicate line to be walking on.'

In addition, Sally has had equipment and home adaptations funded by the PHB, which has been really important to the family.

School
Sally also has additional support at school, arranged by education with a focus on consistency.

'Staff in school are funded through education. Sally has 2 main people who are trained and another 2 who can step in if needed. I could, if I wanted to, incorporate that into the PHB and employ the people at school as well. But I decided not to do that.'

What a PHB enables
Cathy was always conscious that she needed to be around for Sally. Arrangements were made for additional funded hours to enable PAs to work 24/7 over every other weekend. This has enabled her to do important things with her other child.

'I've been able to leave her for 24 hours, which I've never been able to do. So, I've been able to go with him to…. Don't get me wrong, it is a military operation but… it's just so lovely for me to be able to do that…'

Cathy is very positive about the PHB and the impact it has had on Sally and her wider family

'It actually gave me control so that I can actually plan things. I can say to myself that I can do this if I can get the right people.'

The system planning and working together
All of Sally's support is coordinated as part of her Education, Health and Care Plan and the annual reviews of that

'That's when officially everybody comes together. It's usually run by school. School have got medical staff who are important. The community matrons are an excellent link too and they liaise with school, consultants etc. They come to any meetings we have to do with Personal Health Budgets, like the continuing care reviews. They'll sometimes come to the annual reviews at school too.'

The family are also supported by the disabled children's team social care team.

'Every six months we have what's called a child in need meeting. These are held for a child who's on the severely disabled register. They'll usually be some representative there from health and somebody from school too.'

Cathy feels positive about the people within the health system who have helped her to make this happen.

'Claire (CC nurse) has been incredible. She made things move for us and was reliable and responsive. Helen from SCC too. I have to say that I have always found health to be amazing. I feel like they have my back and always do what they say they will. '

Ian, Margaret and Matthew

Ian was in his 50s and lived in Warrington with his Mum Margaret and son Matthew. He was a mischievous people person who loved banter, music, films and football. He loved to spend time outdoors, visiting local places and parks and going for lunch. Sadly, Ian died in April 2025.

Some years ago, Ian had a stroke and two minor strokes, then in 2019, he was found in a hypoglycaemic coma. A combination of these resulted in cognitive difficulties. These and other serious health conditions left him needing care and support to live his life. 6 years ago, Margaret, his Mum, moved into his house and she, alongside Ian's son Matthew, provided Ian with much of the help that he needed – Mum helping mainly during the day and son at night.

After one of many hospital stays, it was determined that Ian needed help 24 hours a day, 7 days a week. He was deemed to be eligible for Continuing Health Care (CHC) funding. Initially, using a Notional Budget, the CCG/ICB made arrangements with a local care agency, and Ian got visits from 2 care workers, 3 times a day. Workers helped him with his personal and physical care and the family continues to fill in the gaps. But Margaret and Matthew were worried that his world was shrinking.

'He was missing out on time with people…on social interaction'

With help from Warrington Disability Partnership (WDP), Ian got a small Personal Health Budget (PHB), taken as a Direct Payment (DP) and Margaret used this to employ staff to sit with Ian at home and/or help him to get out and about. This arrangement ran alongside the care workers from the agency. Some of these workers got on well with Ian and supported him in ways that felt human and relationship-based. Others much less so.

Then, unexpectedly and for different personal reasons, 3 of the agency workers Peter really valued handed in their notice at the same time. Margaret realised she needed to act and supported by WDP she approached the ICB to increase her Direct Payment. She asked the departing staff if they would be willing to work for her and Ian as a Personal Assistant (PA). They all agreed

'We chose people he liked, who had a good relationship with Ian and us as a family'

Ian and his family began to employ the 3 workers themselves, using a payroll service provided by a company called Wired and with continual support from WDP. This worked well. It ran alongside the agency service but started an incremental shift from lots of agency and some DP funded PA time to less agency support and more employed PA hours. The new PAs could offer Ian all the help and support he needed.

'I trusted their standards of care. I knew they would treat him with dignity and respect.'

Crucially, they liked him, and he liked them, connecting on a human level and developing real relationships based on shared interests.

'He knew them and had a relationship with them. They were good company, and all seemed to be on the same page as Ian – sharing an interest in the music he liked or his football team. They spoke to him normally which was important to him and us. They had banter with him but were always kind and caring.'

They were willing and able to work in ways that worked for Ian and his family.

'They worked flexibly, and we could do everything to suit Ian…it was a huge reassurance'

The PA team would help Ian to do things he enjoyed.

'They went to the Beatles Museum, the Football Museum in Manchester, out for lunch, to the park, all sorts of things'

When Ian's health deteriorated even further, the PAs were able to help him in hospital in ways that were highly valued by him and his family.

'Their input was so valued…they went the extra mile. It was them that were with him when he died and that was so reassuring to us. They offered emotional support to all of us and genuinely cared'

They feel strongly that care agencies are not given enough time and do not always have the inclination to support people in ways that really work for them.

'Agencies have strict times and are very task orientated. They don't pay staff for their travel time and workers are often under pressure'

Margaret and Mathew feel that a PHB meant that they were able to move away from these limitations, meaning that Ian got compassionate, respectful care that valued him, right to the end. They are positive about the whole system coming together to support them all, with Ian firmly at the centre.

'Everyone was working together and doing their very best for Ian. The carers, Lorraine at Warrington Disability Partnership and Lyndsey (the CHC nurse). It was a long, hard, rocky road, but we were all on it together.'

APPENDIX D – Long advocacy stories

Please note: These stories are as they have been told to, and approved by, the people who feature in them. A lot of work has gone into accurately capturing and reflecting their experiences, as they have wanted to share them. They are all anonymised.

Tom

I first met Tom when he was 15 years old. He received joint health and local authority funding for his care and support, had heard about Personal Health Budgets (PHBs) and wanted one. Unfortunately, at that time, PHBs were not available to people under the age of 18.

Once Tom turned 18, I met him and his Mum to explain the role of the advocate and what support we could offer him once he had a PHB. They asked for support with Tom's Education and Health Care Plan (EHCP). Tom had enjoyed hydrotherapy sessions throughout his time at high school, and they were beneficial to his health and wellbeing. He had very limited movement in his body and hydrotherapy eased some pain and provided exercise. Tom and his Mum were upset to discover that the local authority joint funding panel had decided to withdraw Tom's hydrotherapy funding (even though it was in his EHCP). I supported them to

complain to the local authority who admitted fault, reinstated the funding and reimbursed Tom for the hydrotherapy sessions he had missed.

The local authority's response and the delay in reinstating the hydrotherapy was not satisfactory. So, I supported Tom and his Mum to write to the Local Government Ombudsman (LGO), who upheld the complaint and ordered the local authority to pay compensation for the distress caused. They also reminded the joint funding panel that changes to EHCPs can only be made through the review process set out in the SEND Code.

In 2021, Tom's shower pump broke, meaning he could no longer shower. It had been fitted using a Disabled Facilities Grant (DFG), but the local authority said that as it was over 12 months old, it wasn't their responsibility to fix. I supported Tom and his Mum to complain, resulting in a long, drawn-out process. Throughout this time, Tom was not able to shower properly. Finally, after many months, the local authority agreed to replace the shower pump.

When Tom transitioned from children to adult services he got CHC funding and a PHB. Initially, he used this PHB to contract directly with a care agency, giving him the chance to check the agency's invoices and ensure he was being charged for the correct hours. Tom had been happy with the care agency but found he was no longer offered the carers that he wanted. So, Tom decided to move away from the agency and employ his own staff instead, building the team he wanted. This was very empowering, but managing staff for the first time can bring challenges and Tom felt he was not offered sufficient training or support. I looked for training courses for him, but we would have had to source funding from Skills for Care, which was an additional barrier. Tom was already busy with his studies and didn't feel he could fit this training in as well. In my research, I found that other ICBs pay for employers' staff management training. Tom feels this should be standard across all ICBs. Tom now has a trachea and is vented 24/7. He requires skilled carers that has found it difficult to attract and retain staff. He feels the hourly rate he can offer them is not enough for the responsibility they have in keeping him alive.

Although the PHB is flexible in some areas, Tom has felt it's restrictive in other areas. As his health deteriorated, he was told by his palliative care team to make plans to fulfil his dreams. Tom has a passion for travel and history, and it has always been his dream to do a short trip to Europe. As he is reliant on carers 24 hours a day, going anywhere involves taking several carers. Tom thought it reasonable that the significant cost of doing this (travel, time and accommodation) should be covered by his PHB. So, I made a request to the ICB on his behalf.

Soon after the funding was agreed and Tom was all set to book his trip. Then the agreement was retracted, which was devastating and frustrating for Tom. I supported Tom and his Mum to challenge the change and 6 weeks later, health agreed they would honour their original decision. It took 4 weeks for the payment to reach Tom's account, and he almost lost the reservation.

Tom and his Mum felt that they had been left in the dark and couldn't find anyone responsible to speak to. This made them feel really disempowered. Tom's Mum is angry that they have spent a lot of precious time worrying about whether Tom would be able to go on his dream trip. Tom would like the autonomy to use the PHB to meet his complex health needs in whatever way he chooses without having to check with health all the time. He thinks this would make his PHB and support truly personalised. Tom and his Mum also feel that it would be more effective to have a single named CHC nurse who is their main contact, so they can

build a relationship with that person. Currently, Tom's reviews are carried out by various nurses. Tom's Mum feels there is a postcode lottery across the country that governs what ICBs allow as regards PHB spending. She finds this unfair and frustrating.

Over the years, Tom's Mum has fought many battles on his behalf to get him the care and support he needs. She is experienced and capable of challenging decisions, but her energy was limited and having the support of an advocate at all stages was helpful.

Tom and I receive support from Sefton Advocacy in different ways. Tom, being the service user, has the full and confidential support as a young adult. He knows he can contact the team, usually Corinne, whenever he needs and the support is there!! This gives him peace of mind that he's not just left alone not knowing where to turn for help. Tom has the support from family, but ultimately as an adult he tries to be as independent as possible.

I receive support as a parent/carer from the team, specifically Corinne and Andrew. I've had their help for many years now and wouldn't survive without them. We have had so many battles over Tom's life. Battles which have drained me and left me exhausted and upset at times, and the support I receive has kept me going, as I know I'm not in it alone. When I can't find the answers, Corinne will go above and beyond to help get the answers and information we need. **Tom's Mum**

Corinne Barclay – PHB Lead Advocate, Sefton Advocacy

Sarah

I first met Sarah and her Mum, and Dad in June 2023 when they moved to the area. Sarah was in her 30s. She has complex health issues that have a huge impact on her daily life. Sarah also has a learning disability and autism. The family was previously living in a supported community, but Mum and Dad wanted to work towards future proofing Sarah's life, in the event that they were no longer able to offer her care and support. They felt that the best way to do this was to move out of the supported community.

Sarah was awarded Continuing Healthcare (CHC) funding and decided to take this as a Personal Health Budget (PHB). This enabled Sarah to attend a local day centre for people with a learning disability. Sarah immediately settled and loves her time there. She describes it as "fantastic" and particularly likes baking there. Mum and Dad are both retired and have felt the pressure of caring for Sarah and managing her fluctuating health. They were often exhausted. A care agency was sourced by the CHC team to provide additional care and support to Sarah outside of the day centre, to give her more independence and give her parents a break.

However, the care agency staff were not suitably trained and couldn't meet Sarah's needs. Mum and Dad felt the staff put Sarah at risk, they were really concerned for her safety and stopped the agency support with immediate effect. The CHC team was informed, but no replacement was found. Mum and Dad supported Sarah for 4 weeks, whilst they tried to recruit Personal Assistants (PAs) to help Sarah. They felt let down and asked for advocacy support to complain. I wrote a letter to the CHC team on their behalf. They received an apology and felt that their concerns had been listened to.

The family used their PHB to employ a small team of PAs that Sarah was able to build strong relationships with and that they could trust to support her well.

Then her parents felt it was the right time to consider Sarah moving into her own property with her own support. This was very hard for Mum and Dad. Together, we discussed various housing options, had an initial meeting with the CHC team and then another which also included Helen at Sefton Carers Centre, a delivery partner of the Personal Health Budget Support Service (PHBSS) alongside Sefton Advocacy.

The nurse was understanding and supportive and agreed to arrange a Best Interest Meeting (BIM) to discuss Sarah's future options. I attended the BIM to ensure Mum and Dad were able to share their views and concerns. The BIM concluded that it was in Sarah's best interest to rent her own property and have 24-hour support from PAs in her new home. Everyone was really pleased that this was agreed.

To help take things forward, I was able to signpost Sarah and her family to the local Welfare Rights service to get benefits advice on the effect of living independently on Sarah's finances. Mum then felt able to make an informed choice about Sarah's options.

With help from her family, Sarah found a lovely flat to rent and she was happy to move in. She loved having her own space and team of PAs around her. Having the flexibility to choose their own PAs has been really beneficial for the family. However, managing staff has had its challenges. Mum and Dad realised that when Sarah had moved into her flat that if she wasn't well enough to go to the day centre, it could be hard to find people to stay at home with her. This led them to consider the need for a 24-hour live-in carer for Sarah. Having a PHB gave them the flexibility to do that, and it has been working well so far.

Mum and Dad are still very involved in Sarah's life and support, making sure everything is working smoothly. Sarah's health issues mean that there will always be a lot for them to do, but Sarah having great carers provides them with some space to live their own lives.

Advocacy and specialist support have been key to the success of this arrangement

We very much appreciate everything that you at the Personal Health Budget Support Service (PHBSS) do for us **Sarah's Mum**

Support from the PHBSS has had such a good impact on our situation and I think it's a huge support for carers **Sarah's Dad**

After 3 months of Sarah having her PHB we talked through how things had gone so far.

If it wasn't for the PHBSS' support, I feel we would have cracked up. You've been a crucial point of communication. We are more than happy with the PHBSS. We wouldn't have known what to do without you. **Sarah's Mum**

Corinne Barclay – PHB Lead Advocate, Sefton Advocacy

John

John was referred to the Personal Health Budget Support Service (PHBSS) at Sefton Carers Centre 5 years ago. PHBSS is commissioned by Sefton ICB and Liverpool ICB . Sefton Carers

Centre and Sefton Advocacy work in partnership to deliver the service. I met with John to introduce myself and the role of the PHB advocate within the PHBSS. He already had a PHB.

John told me about his time as a special constable dealing with road traffic accidents, sudden deaths and suicides. Part of his role was to inform families that loved ones had died. He was unaware at the time but would later be diagnosed with PTSD following a parachute accident and further triggered by his traumatic experiences in the police. John also had physical injuries from his accident, which led to him needing to use a wheelchair and to give up working. Having always been independent, physically active and competitive in sport this was extremely difficult for him and had an additional negative impact on his mental health. In the past when he was in receipt of local authority Direct Payments, the support wasn't enough, it had a really negative impact and John hadn't wanted to carry on living.

When I first met John, his PHB was working well, and he had no issues he wanted advocacy support with. Getting a PHB meant his care had been increased to 24 hours per day, and this was finally meeting his needs and having a really positive effect on his mental health and wellbeing. He found the flexibility of his PHB, being able to employ his own PAs, to really work for him. In the past, he'd had to use care agencies but found having people that he didn't know well in his family home and providing him with personal care to be really stressful. Now he employs people he knows and trusts.

At our next meeting we had a discussion about what was important to him. John identified that he was looking for things to do such as woodwork and kayaking. He was also worried about his teenage daughter, who provided him and others with lots of support. I agreed to do some research into woodwork and canoeing in the area. I also told him about the Young Carers project at Sefton Carers Centre, and he agreed to discuss it with her. A few weeks later I completed the referral and John's daughter was offered support from the service, really benefiting from their support. He also went along to a woodwork group I had found and reignited his confidence in this area.

The advocacy research into canoeing and woodwork is brilliant, I'm made up with it. **John**

We agreed that John could contact me anytime, that I would send him the PHBSS newsletter and be in touch to carry out a review with him every 12 months.

At the first annual review, John told me he'd had a letter from his local council requesting years of past bank statements in relation to Direct Payment. The letter had an intimidating tone with implied financial consequences, and John was extremely worried. The PTSD symptoms John experiences can be exacerbated by stress. I agreed that I would look into the issue on his behalf, contacted the council and then supported John to provide the information required. Then John received an invoice from the council for thousands of pounds for an alleged overspend of his Direct Payments. John had spent the money on his care because he didn't receive enough funding to meet his needs. So, I supported him to challenge the decision, first with the council, then with the Local Government Ombudsman (LGO) and then with his MP, as each stage was unsuccessful. Eventually, the council told John they would write off the debt and clear the invoice.

The process from making the initial complaint to the council to its conclusion was 18 months. During this time John's mental health fluctuated and he would have found it impossible to follow it through to the positive conclusion without the consistent support of one advocate.

John was also contacted by HMRC via the payroll service he uses for the PAs he employs. They highlighted thousands of pounds of unpaid tax from years ago. This tax wasn't paid because John didn't have enough in his Direct Payments account. I supported John to write a challenge to HMRC before contacting the Adjudicators Office regarding HMRC's negative response. The Adjudicator's Office upheld the HMRC decision but ruled their handling of the complaint was too slow and made HMRC pay John some compensation. Finally, I wrote to the ICB to request that they pay the HMRC debt as it was a result of him having insufficient care. The ICB paid and the debt is now cleared.

Thank you for your proactive work. Advocacy is really important to me seeing how it really takes the pressure off the patient/client, enabling them to concentrate on their wellbeing. You have supported me in lots of ways from researching activities to dealing with personal matters, which I could never have done due to my condition. To be honest, I would not be here, if it was not for your support. **John**

Corinne Barclay, PHB Lead Advocate, Sefton Advocacy

APPENDIX E – short stories from partners

Jack

Jack is 2 years old and lives at home with his Mum, Sarah. He is a very happy child who loves exploring. Jack was referred to the Personal Health Budget Support Service (PHBSS) at Sefton Carers Centre. PHBSS is commissioned by Sefton ICB and Liverpool ICB . Sefton Carers Centre and Sefton Advocacy work in partnership to deliver the service. At the point of referral, he had 88 hours of care and support delivered by an agency via a Notional Budget. PHBSS staff offered Sarah and Jack help, advice, support and guidance.

Sarah didn't want to have agency support during the day. There were only a small number of carers that she was happy with, and these were providing overnight support. As a result, she was only using the 70-night hours and not the 18 hours during the day. Sarah had spoken to her Social Care Support Worker about employing her sister as a PA during the day. Her sister had already had training via Alder Hey. PHBSS spoke to Sarah about how the PHB would work in practice and prepared a budget with her that could be taken to panel. Once the PHB had been agreed, Sarah's sister was able to start providing Jack with daytime support. PHBSS set up a prepaid card for Sarah and made all of the payroll arrangements. A DBS wasn't required as Sarah was employing a close relative.

Then Sarah decided that she would like to stop the agency altogether. After discussion, it was agreed that with the support of PHBSS, correct clinical oversight and training, Sarah could employ PAs for all of the allocated hours. **Real story, anonymised, supplied by Sefton Carers Centre**

Ali

Ali, a young lady in Sefton, has been supported by multiple care agencies. Over time, arrangements with each agency broke down for one reason or another. Ali ended up needing support from a nurse agency, which was much more successful but also much more expensive than a standard care agency. When we reviewed Ali's care package, we had a conversation

with her Mum. The family had been working with the nurse agency and 2 particular nurses for over 12 months. They had built strong relationships and had a very positive experience in contrast with what had happened before. Because of the high cost we told Ali and her Mum that we needed to look for a new, cheaper, agency. Mum said no and was adamant that they wanted to keep the nurse agency and the 2 nurses that and her daughter knew well.

So, we started to explore the potential of a PHB. We initiated conversations and creative thinking and brought this to Panel. This took some time. Eventually it was agreed, by Panel, that Ali's PHB budget could be based on her need for overnight and daytime support, costed at the rate of a cheaper agency.

The budget doesn't cover the cost of the full amount of care from the nurse agency. But Ali and her Mum understand that and its implications for the choices they can make. Mum then chooses to use that budget to contract with the expensive nurse agency. This means Ali gets to keep the nurses they know well and value. The budget funds 4 nights a week of nurse support and then that's the budget for that week spent. Mum and the family provide the support Ali needs that is not covered by the nurses. Everyone is happy with that because they know that Ali is getting the care that she wants in ways that work for her. It allows a positive arrangement to continue.

As Ali approached 17, we were starting to consider her transition to adult services and what that would look like. We had conversations with adult CHC leads early to make sure that they were happy with the arrangement and would continue to support it as Ali became an adult. It was important that we didn't set up something now that was going to be taken away. **Real story, anonymised, supplied by Sefton Carers Centre**

Meena

Meena is a young lady who is supported by a care agency, directly commissioned by the ICB. Meena and and her family really value this agency. One of her medical consultants highlighted that Meena was really struggling to manage her weight, which created an issue from a medical perspective. So, he supported the request for a PHB to fund gym membership, a personal trainer, and hydrotherapy for Meena in the school holidays. There were of course lots of questions asked and challenges raised. Things like 'What would the personal trainer be doing?' 'How would we check the outcomes?' But those issues were addressed, and it was all agreed. It has made a massive difference to Meena.

It really helped that it was driven and supported by the medical professional who was clear that it was the only route to try and help Meena to manage her weight. **Real story, anonymised, supplied by Sefton Carers Centre**

Olga

Olga lives in Merseyside, with no close family. She is of Polish origin. Olga's health was very poor, and she was assessed as eligible for Continuing Health Care (CHC) funding. She needed a lot of support, sometimes from 2 people at a time.

Her condition deteriorated rapidly, and she needed palliative care. As her health worsened, she relied more heavily on her first, Polish language and was less able to engage and communicate with other people in English.

Working in partnership with her local third sector PHB support organisation, Olga was helped to take a PHB. Employing her own staff was not appropriate. As the nurse and third sector team considered how best to support Olga, they knew that Polish language and religious and cultural awareness was key to her.

In her area there is an organisation that specialises in culturally sensitive support for people of Polish origin. This organisation used to be registered as a care provider with the Care Quality Commission (CQC) and provide personal care to people. They decided to stop this regulated activity and focus simply on people's wellbeing instead. But local procurement rules meant that because they were not CQC registered, they could not be directly contracted by the ICB to help Olga.

So, the team around Olga got creative and Olga's PHB was split. The third sector organisation helped Olga to take a Direct Payment (DP) and use it to purchase wellbeing services from the specialist Polish focussed organisation. Alongside this the DP was used to purchase care services from a CQC registered care agency.

The arrangement meant that the care agency provided Olga with the personal care that she needed. But they did this alongside the Polish 'wellbeing' organisation, who helped with language and religious and cultural awareness. People from both organisations helped Olga at the same time, fulfilling different needs for Olga and helping each other as they did so. The arrangement enabled Olga to get the help she needed, in ways that worked for her and for all the agencies who played a part. **Adapted from a true story for anonymity**

Sarah

Sarah is 24 years old and lives with her Mum Jane and Stepdad. She loves swimming, regular social clubs, going on holiday, food and eating and music and a disco. Sarah has a rare neurodevelopmental condition, epilepsy, and other health conditions. She uses a wheelchair and has adaptations at home, including a hydrotherapy bath. Sarah and her family say that familiar people, including family and friends are important to them.

Sarah was receiving 70 hours a week of support at home from a local care agency, but the family were finding it hard to work with the inconsistent and unreliable carers they sent. Carers often turned up late, or the agency was unable to cover calls if a carer called in sick. Jane also expressed concerns over the lack of professionalism of some of the workers. Jane wanted to explore the possibility of a PHB and using it to employ Personal Assistants or changing to another agency. They were referred to the PHBSS service which offered help, support, information and guidance.

With support, the family changed to using a small locally based agency and are extremely pleased with the person-centred support provided.

Due to the flexibility of the PHB, Sarah has been able to go on holiday with her family and participate in water-based therapy and music therapy. Sarah has more independence, and Jane has peace of mind that Sarah is cared for. Jane feels supported and said *I no longer had to do everything on my own.* **Real story, anonymised, supplied by Sefton Carers Centre**

Simon

Simon is 38 years old, has a high-level spinal injury and associated complex needs. He lives alone and doesn't have any active involvement from his family. He enjoys going to concerts and the cinema with his friends. He is a Manchester United FC fan and likes going to watch them play.

Simion was referred to the Personal Health Budget Support Service (PHBSS), at Sefton Carers Centre. PHBSS is commissioned by Sefton ICB and Liverpool ICB . Sefton Carers Centre and Sefton Advocacy work in partnership to deliver the service. When he was first referred, Simon was using a care agency. The majority of his care was undertaken by a small team of carers who had worked with him for a long time and who he had brought with him to the agency. Simon was unhappy with the management of the agency; his team of carers had raised concerns about their employment terms, and the agency were not able to recruit more workers to cover sickness/holidays. When new staff were sent to support him, they weren't adequately trained to meet his needs. Simon felt that the agency wasn't behaving in a professional manner towards him.

Staff at PHBSS researched the implications of the PA team moving over from the agency and offered advocacy support to raise a complaint with the agency. Simon wanted to keep a small percentage of his package with an agency, so they researched options and helped him find a new agency. They supported Simon to help him comply with employer responsibilities and offered advice on training and DBS checks for new staff

Simon is now supported at home by people he has chosen and that gives him choice and control over his care. He has the support of an agency in which he has confidence, and they can provide backup if needed. His PA team have access to training and support, and Simon has a point of contact if he has any questions or if he needs to request a review of his package. He has access to advocacy support for a range of issues, not all relating to the PHB. **Real story, anonymised, supplied by Sefton Carers Centre**

Steven

Steven is 55 years old, and he has Multiple Sclerosis. He became CHC eligible and was referred to Sefton Carers Centre PHBSS. Steven wanted to be able to increase the rate of pay for his current PAs to reflect the level of skill they had and to recognise that they had stayed with him through difficult times. He also wanted to recruit additional PAs but was helped to understand this might take time and be challenging, and to consider using an agency in the interim. Steven also wanted to purchase a bed that would help him maintain his independence at nighttime.

PHBSS supported Steven with the transition to PHB and with incorporating training costs into the budget. The rate of pay was increased for the PAs to help him with recruitment and retention of staff. PHBSS also researched agencies with availability and supported Steven to identify a suitable company that could meet his needs. **Real story, anonymised, supplied by Sefton Carers Centre**

APPENDIX F – ADVOCACY IMPACT DATA

Sefton advocacy

June 2019 – April 2025

Currently have 57 cases open to advocacy. We've supported clients with at least **225 issues** (please note there's likely to be some underreporting due to this being a snapshot in time). The categories of issues are:

- Health and wellbeing
- Equipment
- Care and support
- Financial
- Benefits
- Accommodation
- Legal
- Disputes
- Education
- Safeguarding
- Other

People can be supported with more than one issue.

HEALTH AND WELLBEING – SUPPORTED WITH 76 ISSUES

Examples of issues:

- Referral to Affordable Warmth for home energy support.
- Support to add therapies/activities/respite to the care and support plan.
- Referral for Carers' Assessments.
- Support to apply for Blue Badges.
- Support to access tickets for carers to events.
- Support to deal with concerns around residential care.
- Support to deal with issues around hospital visiting during COVID.

Outcomes achieved for clients:	Number of outcomes achieved for clients	One off payment received	Annual amount received
More informed	7		
Rights upheld	2		
Improved health and wellbeing	14		
Enabled access to services	4		
Gained financially	7	£3,017	£2,070
Increased social inclusion	7		

Safer and more secure	5		
Gained in confidence	2		
Views heard	1		

EQUIPMENT – SUPPORTED WITH 53 ISSUES

Outcomes Achieved for clients:	Number of outcomes achieved for clients	One off payment received	Annual amount received
More informed	3		
Rights upheld	2		
Improved health and wellbeing	8		
Enabled access to services	3		
Gained financially	5	£6,587	£2,103
Increased social inclusion	4		
Safer and more secure	5		

CARE AND SUPPORT – SUPPORTED WITH 34 ISSUES

Examples of issues:

- Support to enhance care and support plans with additional care hours, activities and services.
- Securing retrospective CHC funding for unassessed periods of care.

Outcomes Achieved for clients:	Number of outcomes achieved for clients	One off payment received
More Informed	4	
Rights upheld	6	
Views heard	2	
Improved health and wellbeing	10	
Enabled access to services	6	
Gained financially	3	£130,351.30

FINANCIAL – SUPPORTED WITH 25 ISSUES

Examples of issues:

- Debts reduced
- Grants secured to assist with financial hardship
- Amended council tax bills.
- Retrospective CHC funding

Outcomes achieved for clients:	Number of outcomes achieved for clients	One off payment received	Annual amount received
More informed	2		
Rights upheld	4		
Views heard	2		
Gained financially	9	£32, 691.43	£5,650

BENEFITS – SUPPORTED WITH 15 ISSUES

Examples of issues:

- Housing benefit increases due to being unaware of multiple bedrooms policy. One person hadn't had an increase in his housing benefit since 2003.
- Support with Personal Independence Payment (PIP) Review.
- Council tax reduction due to 'Severe Mental Impairment'

Outcomes Achieved for clients:	Number of outcomes achieved for clients	Annual Amount received
More Informed	2	
Rights upheld	1	
Improved health and wellbeing	3	
Gained financially	4	£10,185.28

ACCOMMODATION – SUPPORTED WITH 12 ISSUES

Examples of issues:

- Support to explore housing options
- Support with health & safety issues with accommodation

Outcomes achieved for clients:	Number of outcomes achieved for clients
More informed	3
Rights upheld	1
Improved health and wellbeing	2
Safer and more secure	2
Gained in confidence	1

LEGAL – SUPPORTED WITH 4 ISSUES

Examples of issues:

- Support to find information about court of protection.
- Support to complain about a solicitor.

Outcomes achieved for clients:	Number of outcomes achieved for clients	One off payment received	Annual amount received
More Informed	4		

DISPUTE – SUPPORTED WITH 2 ISSUES

Examples of issues:

- Support to deal with council planning.
- Support regarding omissions from Education & Health Care Plan.

Outcomes achieved for clients:	Number of outcomes achieved for clients	One off payment received
Gained in confidence	1	
Rights upheld	1	
Gained Financially	1	£400

EDUCATION- SUPPORTED WITH 2 ISSUES

Examples of issues:

- Support with Education & Health Care Plan.
- Support to gain funding for educational course.

Outcomes chieved for clients:	Number of outcomes achieved for clients
Gained in confidence	1

SAFEGUARDING – SUPPORTING WITH 1 ISSUE

Example of issue:

- Support in going through safeguarding investigation

Outcomes achieved for clients:	Number of outcomes achieved for clients	One off payment received	Annual amount received
Views heard	1		

OTHER – SUPPORTED WITH 1 ISSUE

Example of issue:

- Support to secure passport.

Outcomes achieved for clients:	Number of outcomes achieved for clients	One off payment received	Annual amount received
More informed	1		

APPENDIX G - 6 key steps for all PHBs[23]

1. **Make contact and get clear information**
   - People receive accessible, timely information on PHBs, including management options (Notional Budget, Direct Payment, third-party budget).
   - Support options include advocacy services and opportunities for peer discussions.
   - NHS teams help people to explore the best PHB management approach.
   - Quality standards ensure comprehensive public information, advocacy support, and a clear point of contact.

2. **Understand health and wellbeing needs**
   - A personalised needs assessment is conducted, ensuring individuals feel listened to and involved.
   - Support is available to prepare for and engage in the assessment process.
   - Quality standards focus on a consistent, transparent, and person-centred approach across Integrated Care Systems (ICS).

[23] https://www.england.nhs.uk/long-read/personal-health-budget-phb-quality-framework/#principles-and-enablers-for-phbs

3. **Determine budget allocation**
    - Individuals are informed about how much funding is available and how it is calculated.
    - Contingency funds may be included for unforeseen circumstances.
    - Transparent, timely, and sufficient budget setting ensures all agreed health and wellbeing needs are met.
    - Quality standards emphasise financial sustainability, equity, and proper governance.

4. **Develop a personalised care and support plan**
    - Individuals work with healthcare teams to create a plan based on their goals and needs.
    - Choice, flexibility, and control are key elements.
    - The plan outlines budget, ensuring clinical and financial governance. Staff receive training on personalised care approaches.

5. **Organise care and support**
    - Individuals understand how to implement their support plan.
    - Various assistance options are available, such as help managing budgets and employing personal assistants.
    - Quality standards ensure a system-wide approach to service availability, commissioning, and workforce training.

6. **Monitor and review**
    - Individuals receive clear information on review processes and can request earlier reviews if needed.
    - Reviews assess whether needs and agreed outcomes are met and adjust budgets accordingly.
    - Financial audits and governance measures ensure responsible budget use.
    - Quality standards support evaluation, continuous improvement, and alignment with statutory reviews.

This structured process ensures that PHBs are personalised, transparent, and effectively managed to enhance individual health and wellbeing.