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GETTING SERIOUS ABOUT PERSONALISATION IN THE NHS

September 2014

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About this report

This report has been developed jointly by Think Local Act Personal (TLAP), the Association of Directors of Adult Social Services (ADASS) and the Local Government Association (LGA), with the support of NHS England to accompany the publication of the Prospectus for the Integrated Personal Commissioning Programme. It has been written for those who are working in health and care organisations that will need to change systems and practices to deliver personalised, integrated care and support.

An easy read version has also been produced and can be accessed at www.thinklocalactpersonal.org.uk/coordinatedcare

Information on personal health budgets can be found at www.personalhealthbudgets.england.nhs.uk

Information on personal budgets for people who use services, families and carers can also be found at www.peoplehub.org.uk or by checking local council websites.

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1 Introduction

On the 9th July 2014, NHS England Chief Executive Simon Stevens announced a new form of radical, people-powered commissioning of health and social care, including the extended use of personal health budgets and integrated personal budgets across health and social care. The Integrated Personal Commissioning (IPC) programme, starting from April 2015, will bring together health and social care funding around individuals, enabling them to direct how it is used for the first time.¹ This represents a step change in ambition for actively involving people, carers and families as partners in their care. This is underpinned by the support and leadership of the NHS, local government and the voluntary sector.

Personal budgets are part of a wider approach to personalisation, a mechanism for shifting the culture and practice of care to be better coordinated and person-centred. Alongside the reshaping of services, supporting self-management and personal care and support planning, personal budgets help meet the challenge of changing expectations of care while promoting better quality of life and value for money. The objective is that in future people should expect the same focus on their independence, the same regard for their wishes and the same opportunities to make choices and take control, whether they have a long term condition or a social care need, a mental health problem or a learning disability. This means getting serious about personalisation in the NHS.

For the NHS, this is the opportunity to realise the huge potential for activating patient's knowledge, skills, and confidence to take a greater role in improving health outcomes.² For local government, it is the opportunity to build on many years of leading the way with personalisation, to create a shared approach to early intervention and prevention and a joined up offer for personalised care and support. For people with health and care needs, it is an opportunity to build on their collective lived experience, including through user-led organisations. For all, there is a compelling case for change and an urgent need to act now.

This document complements the prospectus for the IPC programme. It explains the context for these reforms and the story so far, sharing learning about what personal budgets are, including their proven and anticipated benefits. It also describes the broader implications of personalisation for the health and social care system, drawing on evidence of what works.

The Integrated Personal Commissioning (IPC) Programme

'We stand on the cusp of a revolution in the role that patients – and also communities – will play in their own health and care. Harnessing...this renewable energy is potentially the make it or break-it difference between the NHS being sustainable or not.' Simon Stevens

Objectives:

- People with complex needs and their carers have better quality of life and can achieve the outcomes that are important to them and their families through greater involvement in their care, and being able to design support around their needs and circumstances.
- Prevention of crises in people's lives that lead to unplanned hospital and institutional care, by keeping them well, and supporting effective self-management - using measures such as 'patient activation' – so ensuring better value for money.
- Better integration and quality of care, including better user and family experience of care.

Groups that may be included in the first wave of work:

- Children and young people with complex needs, including those eligible for education, health and care plans.
- People with multiple long-term conditions, particularly older people with frailty.
- People with learning disabilities with high support needs, including those who are in institutional settings (or at risk of being placed in these settings).
- People with significant mental health needs, such as those eligible for the Care Programme Approach or those who use high levels of unplanned care.

The benefits of personal budgets*

- Help people feel in control of their condition and remain independent.
- Improvements in quality of life and psychological wellbeing.
- No adverse impact on clinical outcomes.
- Reductions in unplanned admissions and overall use of formal services.
- Improvements in people's ability to manage fluctuating needs and plan for a crisis.
- Most effective for people with the very complex needs.
- Increased satisfaction with services.

**For a fuller exploration of the benefits of personal budgets, see 3. The story so far*

The implications for services and commissioning**

- Co-production with people, carers and families must be at the heart of the way services are designed and delivered.
- Resources must be freed up for people to use differently.
- More flexible and outcome focused commissioning will be needed.
- More flexible and responsive services designed around people's needs and preferences.
- A broader range of service options are required, alongside more conventional provision.
- New types of provider, including social enterprises and user led organisations.
- An expanded role for the voluntary and community sector, supporting people to plan and self-manage.
- Part of a coordinated approach to early intervention and prevention, keeping people away from acute services.

Policy and legislation

Policy and legislation are now aligned to enable coordinated working across health and social care and put more power in the hands of people with health and social care needs and their carers. The Health and Social Care Act 2012 gave commissioners a duty to promote the involvement of individual patients in decisions relating to their care and the NHS Mandate includes an objective to radically increase people's control of their care and to extend the use of personal budgets.

The Care Act, which comes into force in April 2015, represents the biggest reform of care and support since 1948, reshaping the system around prevention and promoting individual wellbeing. Personalisation is at the heart of the Act, which:

- Enshrines in law the duty to prevent, reduce and delay people's need for formal services, including considering the role of communities and local networks and resources in helping people stay independent for longer.
- Requires there to be universal information and advice available locally to help people understand how to access care.
- Describes how local authorities should work with providers of care and support to develop services to meet people's needs and preferences.
- Modernises the right to assessments, ensuring a focus on the person's needs and outcomes and their involvement in the process, whilst providing flexibility to align and integrate assessments to fit around the person.
- Provides new entitlements to personalised care and support plans, which can be integrated with other plans, setting out how needs will be met.
- Enables people and carers to expect similar levels of care and support when moving areas.
- Confirms personal budgets in law for people with eligible assessed needs and carers, including the right to direct payment.

** For more details on the implications, see 4. What works

STORIES OF PEOPLE WITH PERSONAL BUDGETS...

Louise, 90, has a personal health budget to pay for personal assistants to care for her at home with her family rather than living in a nursing home. Louise is totally dependent on others for her personal care and day-to-day needs as she has chronic physical health problems, trouble communicating and Alzheimer's disease. A local user-led organisation provided support to Louise's family with the recruitment of staff and with payroll. The budget includes money for osteopathy and has paid for a laptop for the personal assistants to input information systematically about Louise's food and fluid intake, blood pressure and temperature. The budget also covers respite for Louise's daughter and husband. Louise has not had any emergency admissions to a nursing home or hospital since taking up the personal health budget.³

Airdrina was one of the first Lambeth recipients of an integrated personal budget. She used to live in residential care, entirely dependent on services costing £62,000 each year. Now, living in her own flat and supported at the times of her choice by the people she's chosen, Airdrina is starting to live the life she wants rather than the life services said she could have, freeing up £45,000. "Creating my own support plan was very exciting. It gave me a chance to say what I wanted in life...I chose to spend my budget on a PA to have a bit of company...Angel and I just hit it off. She's amazing. We go out places... She makes me happy. We've got the same weird sense of humour! My life is very settled and I thank God for that. I can do what I want when I want. And I'm not bullied or patronised anymore."⁴

STORIES OF PEOPLE WITH PERSONAL BUDGETS...

Sarah had a lifetime of severe mental distress, rejection and addiction problems before she was supported to live independently, funded through a personal budget. Despite having a diagnosis of schizophrenia, Sarah had often been unable to access local inpatient mental health services because of bed shortages and had spent time in prison and residential care. In May 2010, Sarah took on a supported tenancy for a two bedroom flat provided by the Amber Trust. She had very little self-esteem and confidence so she was offered the opportunity to become involved in the Trust's allotment project. Initially very anxious, Sarah's confidence grew so she could make her own way to the allotment with the friends she had made there, and after two years, become a volunteer "buddy" to support newcomers to the project. Her confidence and independence have grown so much that she is moving on from supported accommodation to a home where she will have her own tenancy.⁵

Jason lived in a long stay in-patient unit for 22 years. When he first moved out, some of the staff transferred to a support agency to provide his care but it didn't work well. Jason's sister used a personal health budget to recruit a new staff team with help from an independent support agency. She gave the team leader more autonomy in developing a personal care plan that allowed for flexibility and creativity, involving Jason throughout the process. Jason moved from his original rented home to a self-contained bungalow on a farm where he is surrounded by animals, a similar environment to where he grew up. His sister has purchased a car on his behalf and staff now take him out regularly. Since the move, Jason has had no incidents of self-harm and significant reductions in the frequency and duration of his seizures. Jason's challenging behaviour has ceased, with no ongoing need for 2:1 or 3:1 staffing. He's now part of the local community and a frequent visitor to the local pub and social events in the village, supported by one of his team of workers.⁶

2 The context

Health and social care is facing unprecedented challenges. There is widespread acceptance that the current system is too fragmented and will be incapable of meeting projected growth and rising expectations. Demographic pressures, technological advances and changing attitudes are all resulting in the need to re-think the way health and social care will work in future. These are challenges that cannot be addressed by conventional methods alone or by focusing on services in silos. The only sustainable path requires a more proactive, holistic and preventative approach, involving far greater engagement with patients, carers and communities to collectively meet the challenges ahead.

Rising demand

One of the greatest challenges for health and social care in the 21st century is responding to the increasing and different needs of an ageing population:

- The population of the UK is growing at an average 0.5% each year, its fastest rate since the 1960s and is set to reach 65 million by 2017.⁷
- In 2012 there were an estimated nine million people aged over 65 in England. This number is expected to rise by almost 43% to close to 13 million by 2030. The number of people aged over 85 will rise by one million people (84%) to reach 3.1 million by 2032.⁸
- The proportion of the population of working age is projected to fall from 65% to 60% during the same period as the “baby boom” generation reaches retirement age.
- Life expectancy is also growing. In 1948, a 65-year-old woman could on average expect to live around 15 years beyond retirement age, a man 12 years. Today this is more than 24 and almost 22 years.

Against this backdrop, increased morbidity is impacting on the demand for health and social care with significant implications for costs.⁹

- Current estimates show there are 15 million people with a long term condition living in the UK. The total number of people living with multiple long term conditions is set to rise from 1.9 million in 2008 to 2.9 million by 2018.¹⁰
- This picture is not restricted to older people with 15% of all school pupils aged 11-15 also reporting diagnoses of long-term illness, disability or medical conditions.¹¹
- A substantial proportion of those living with co-morbidities experience mental health problems. As a result, the prognosis for their long-term conditions and quality of life can both deteriorate markedly.¹²
- There is a projected rise of over 67% in the number of people living with a disability over the next 20 years,¹³ with 1.7 million more people needing care and support by 2040,¹⁴ including significant increases in older people with learning disabilities and younger people with complex needs.¹⁵
- The numbers of people living with a dementia are set to double to 1.4 million within the same period.¹⁶

Financial pressure

Alongside this, health and social care is facing one of the longest and deepest periods of financial austerity since the creation of the NHS. Between 2010 and 2015 alone, the NHS is on course to deliver £20 billion of efficiency savings through the Quality, Innovation, Productivity and Prevention (QIPP) programme.¹⁷ At the same time, social care and community services have experienced budget pressures unprecedented in the history of these services.¹⁸

- Since 2010, real terms spending on adult social care has fallen by 12% as councils have delivered savings of £3.53 billion to adult social care budgets at a time when demand has increased by 14%.^{19,20} Analysis of budget strategies by the Local Government Association suggests that two thirds of councils believe that the scope for delivering further efficiencies will be running out by 2015/16 with a projected funding gap of £12.4 billion by the end of the decade.²¹ The Association of Directors of Adult Social Services (ADASS) expects 13% of current planned savings (£104 million) to come from direct reductions in services,²² leading to fewer people receiving support.²³ Many councils expect not to be able to meet all their statutory responsibilities in the near future.²⁴
- A recent report from the Commons Health Select Committee concluded that what was now needed was transformation of services, which was now urgent.²⁵ Think Local Act Personal's (TLAP) work on the use of resources in adult social care reached similar conclusions.²⁶

Integration

Better integration between health and social care has recently emerged as a firm priority. The Health and Social Care Act 2012 placed duties on NHS commissioners, Monitor, and various other arm's length bodies to promote integration and the forthcoming Care Act also sets out clear obligations for cooperation across the system. The profile of integration grew further in 2013, with 13 system leading organisations announcing their shared commitment to driving forward integration at pace and scale, the subsequent announcement of 14 integrated care pioneers and expectations that all areas make significant progress over the next five years.²⁷

Integration is not a new idea, with concerns that people could “fall through the gaps” in care dating back to before the foundation of the NHS,²⁸ but the need to ramp up ambition has intensified as growing numbers of people live longer with co-morbidities. People with mental health problems, complex needs and long-term conditions frequently need to access different health, social care, housing and other services, often simultaneously. With £7 out of every £10 spent on health and care in England already directed towards this population and significant increases in demand projected, minds are now fixed on integration like never before.²⁹

The outcomes of integration

Some early indications of the positive impact of integration on quality and outcomes from the QIPP Long Term Conditions workstream include:³⁰

- People feeling more confident to manage their condition.
- Fewer GP consultations.
- Improved shared decision making with patients about their care.
- Improved team working across the system.
- Improved partnerships and relationships.
- Better sharing of information, with the patient and among different services.
- Faster referral processes between organisations.
- Better identification of patients using risk stratification.
- Embedding tele-health within the care model.

While the evidence base is formative for integration as the answer to current funding challenges,³¹ there is wide consensus that it is part of the solution to addressing fragmentation between services and improving patient experience. The more concerted focus on integration facilitated through the Better Care Fund³² and Pioneers Programme³³ presents the opportunity to take a joined up approach to previously intractable problems across health, public health, primary, community and social care so that care and support helps people to become active, empowered participants in society, as well as meeting their needs as early as possible, rather than intervening at the point of crisis.

To date, most efforts to integrate care and support have focused at the system, organisational or functional level, on joint financing arrangements and commissioning, better coordination between professional groups, clinical teams or providers.³⁴ But integration at these levels does not guarantee a more joined up experience of care³⁵ and has rarely recognised the opportunity for people themselves to shape and coordinate the care and support they need. Unleashing this potential will require a personalised approach to delivering integration at the level of the individual.

Integration at individual level

The *Shared Commitment* began to make the shift towards a broader view of integrated care which extends, “beyond traditional perceptions of ‘healthcare’ and ‘social care’ and into areas involving early intervention, prevention, self-care and promoting and supporting independent living.”³⁶ This is encapsulated in the Narrative for person-centred, coordinated care, developed by National Voices and Think Local Act Personal, which sets out what good integrated care and support looks and feels like for individuals, to be adopted by all parts of the health and care system. The headline definition describes the intended outcomes of integration in the form of an “I” statement:

*“I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.”*³⁷

The Narrative makes the case for starting from what people themselves identify as important when delivering integration and involving them actively throughout the process. Further versions of the narrative which reflect the particular experiences of people with enduring mental health problems, older people with multiple long term conditions and children with complex needs (cohorts of people identified as the focus of the IPC Programme), similarly demonstrate that:

- Older people identify independence, social interactions and the ability to keep active as the most important factors when thinking about managing their lives and conditions.³⁸
- People with mental health problems particularly value flexible and responsive support earlier in the development of illness, including from peers or user led groups,³⁹ and
- Children with complex lives want to access the things other young people enjoy, such as friends, a social life, and meaningful community activities as well as wanting services that work better for them.⁴⁰

This suggests that integration and personalisation need to be seen as two sides of the same coin. Defined by government as, “the process by which services are tailored to the needs and preferences of citizens...empowering (them) to shape their own lives and the services they receive,”⁴¹ personalisation has begun to take hold in the NHS, is central to the ongoing reforms underway in social care^{42, 43} and is integral to the future of special educational needs and disability services.⁴⁴ Bringing this ethos together with current efforts to integrate care and support offers an approach to integration at the individual level, including through the use of integrated personal care and support planning and personal budgets.

3 The story so far

The focus of the IPC programme and the cultural changes it seeks to accelerate are grounded in many years of learning and experimentation for what works in empowering patients and people with care and support needs to be active partners in their own care. This reflects a growing recognition that people are perhaps the greatest untapped resource in the health and social care system, already managing their needs on their own or with support, the vast majority of the time.⁴⁵

The evidence suggests people want to be more actively engaged as partners, that services frequently underestimate their willingness and that the potential impact of harnessing this contribution could have huge economic value and lead to better outcomes.^{46,47} Approaches that personalise support to people's level of activation, that build skills and confidence and use peer-support have been shown to have a positive impact. Additionally, people who start at the lowest "activation levels" have been shown to improve the most, indicating the opportunity for a personalised approach to support the least engaged and challenge health inequalities.⁴⁸

Realising this opportunity will mean creating fundamentally different relationships between patients, the NHS and other services they need, building on the considerable progress made with personalisation in social care. The Royal College of Nursing describes the aspiration as people being seen as "equal partners" in their health care, with significant implications for how the system operates, including shared decision making becoming commonplace, actively supporting self-management and extending the use of personal care and support planning.⁴⁹

Personal health budgets are another important catalyst for placing people at the centre of decisions about their care and enabling them to take more control, working alongside health and other professionals. Lord Darzi described the intention behind the initiative as being, "to support the cultural change that is needed to create a more personalised NHS."⁵⁰ Originally piloted in social care, personal budgets were extended to health and were recently described by the Kings Fund as "an idea whose time has come."⁵¹

Personalisation in social care

The story of personalisation in social care has deep roots, characterised by a deliberate shift away from care delivered in long-stay institutions towards more tailored support in the community and underpinned by the demands of disabled people and their families for independent living and full involvement in society.⁵² The Community Care reforms which followed the Griffiths Report, led eventually to the closure of nearly all long-stay institutions for disabled people and a significant shift of care for people with long-term conditions, including mental health problems, into community-based settings. The right to take cash in lieu of services as a direct payment was enshrined in law in 1996.

While a lot of attention has focused on personal budgets, personalisation has always been a far wider agenda encompassing universally accessible information and advice, prevention and early intervention, community capacity building, making greater and more creative use of universal services and tailoring the formal support people need. This transformation was initially signaled in the social care Green Paper, *Independence, Well-being and Choice* (2005), then reinforced in the White Paper, *Our health, our care, our say* in 2006 and confirmed in *Putting People First* in December 2007. The *Putting People First* concordat described a shared vision and commitment to transform adult social care through a programme of reforms “co-produced, co-developed, co-evaluated” with the sector.⁵³

In 2011, TLAP took on the mantle of responsibility for continuing to shape and drive this transformation, though a partnership spanning central and local government, health and social care, the voluntary and community sectors and people with care and support needs, carers and family members themselves.⁵⁴

WHAT TLAP MEANS BY PERSONALISATION ⁵⁵



There is consensus that this is an ongoing journey and that moving from a system where professionals know best to one that is acutely personal will take a full generation, but there has also been significant progress, not least with personal budgets.

Personal budgets in social care

In adult social care, personal budgets are the intended delivery mechanism for everyone with an eligible need, regardless of age, disability or mental capacity. They are intended to enable people to exercise greater choice and control over how their care and support is managed. This means:

- Knowing, before care and support planning begins, how much money is available (to meet eligible, assessed needs).
- Being able to choose from a range of options for how the money is managed, including direct payments, the local authority managing the budget and a provider or third party managing the budget on the individual's behalf (an individual service fund), or a combination of these approaches.
- Having a choice of over who is involved in developing the care and support plan for how the personal budget will be spent, including from family or friends.
- Having greater choice and control over how the personal budget is used.

A word on terminology

Personal budgets are the allocation of funding available to people with eligible social care needs after an assessment which must be sufficient to meet their assessed needs. The budget can be taken as a direct payment, or as services commissioned on the person's behalf by the council, or by an organisation contracted by the council (see ISFs below). In some cases, part of the budget is taken as a Direct Payment and the other part managed by the council.

Individual service funds (ISFs) are one way of taking a council-managed personal budget and mean that the budget is held by a care provider under a contract with the council, but the person chooses how it is spent to meet their needs.

Direct payments are cash payments and are intended to enable greater choice and control. The payments can be made directly to the person, to a trusted third party or to an organisation that manages the direct payment on the person's behalf. Direct payments are available to all groups, including carers, disabled children and people who lack mental capacity. However, they cannot currently be used to purchase residential care.

The piloting of personal budgets was first proposed in the Prime Minister's Strategy Unit report *Improving the Life Chances of Disabled People* in 2005 and repeated in the Adult Social Care Green Paper in the same year.⁵⁶ Individual budgets were piloted by 13 councils in England between 2005 and 2007, the original model intending to combine the various funding streams people with care and support needs draw upon in their lives into one pot, including social care but also a range of other funding. The evaluation of the individual budgets pilots concluded that they were cost-effective in relation to social care outcomes and were welcomed by budget holders because they offered greater opportunities for choice and control.⁵⁷ Personal budgets, including only social care funding, were subsequently rolled out from 2007 and have had the support of successive governments from all sides of the political spectrum.⁵⁸

Further independent research has shown that when implemented well, personal budgets can improve outcomes for people and deliver greater value for money.^{59, 60, 61} The Care Act 2014 mandates that all people with an eligible care and support need and carers should have their support managed in this way in future.⁶² The current picture of progress shows that:

THE NUMBERS

- At the end of March 2014, 648,000 people, or 62% of all those eligible for community based services, were accessing care and support through a personal budget across England, this represents a continued increase year-on-year, from 29.2% in 2010-11 to 43% in 2011-12, to 56.2% in 2012-13.⁶³
- Of these numbers, 23.6% of people have their personal budget managed through a direct payment.⁶⁴ Other personal budgets are either managed accounts where the council continues to arrange services for the person, or Individual Service Funds.⁶⁵
- The number of carers with personal budgets was 111,000 (an increase of 7 per cent from 2012-13). Of these, 80,000 received a direct payment.⁶⁶
- There remain significant variances from one area to another, with 28 councils currently reporting less than 50% of people with personal budgets and several councils at or under 25%; 21 councils reporting over 80% of people with personal budgets, with seven over 90%.⁶⁷
- Similarly there remain significant variances in take up between different groups of people, with more than 80% of people with a learning disability having personal budgets as opposed to less than 30% of people with a mental health problem. This is despite evidence that suggests people with mental health problems can be amongst the groups most likely to benefit.^{68, 69}
- People who take their personal budget as a direct payment are more likely to have positive outcomes than those who budget is managed in different ways.⁷⁰
- Pilots are currently now underway to extend the use of direct payments for people in residential settings, currently excluded under Care Act regulations.⁷¹

THE PROCESS

- Work is still needed to refine the process of accessing and using personal budgets, which can too often mean delays, restrictions, disproportionate bureaucracy and confusion for people on the receiving end.^{72, 73}
- A significant minority of people still find key elements of the process such as making changes to their support, choosing different services and feeding back about their experience either difficult or extremely difficult.⁷⁴
- There are particularly strong associations between certain aspects of the process and positive outcomes for people, most notably people feeling that their views have been fully taken into account in the planning process.⁷⁵

THE FINANCES

- Expenditure through personal budgets in 2012-13 was £3.3 billion, up 27% percent on 2011-12.⁷⁶
- There is little evidence of increased fraud, abuse or inappropriate use of personal budgets.⁷⁷
- Initial evaluations suggested that personal budgets were unlikely to result in significant cost savings for councils, though they could lead to savings in forcing the redesign of poorly commissioned high cost packages.⁷⁸
- Though there have been real terms reductions in adult social care expenditure in each of the last five years, there is no evidence that personal budgets have added to the cost pressures facing services.⁷⁹

THE OUTCOMES

- The majority of people with care and support needs and carers report increasing levels of satisfaction with services during the timeframe that personal budgets have been implemented.⁸⁰
- Choice is considered important by most personal budgets recipients, though secondary to their health, quality of life and sense of “personal dignity and respect,”⁸¹ objectives that personal budgets are also designed to help achieve.⁸²
- The most recent national personal budgets survey⁸³ which included more than 2000 personal budget holders and almost 1500 carers found that:
 - Over 70% of personal budget holders reported a positive impact on being as independent as they wanted to be, getting the support they need and want and being supported with dignity.
 - Over 60% of personal budget holders reported a positive impact on their physical health, mental wellbeing, having control over important things in life and control over their support.

- Over 50% of personal budget holders reported a positive impact on feeling safe in and outside your home and their relationships with paid supporters.
- Overall, over 80% of personal budget holders reported their budget making no difference in getting and keeping a paid job or volunteering.
- More than half of the carers surveyed reported that having a personal budget for the person they cared for made their life better in four of the nine areas of life considered – finances (52%), having the support they needed to continue caring and remain well (69%) and their own quality of life (60%).
- Fewer than 10% of carers reported things getting worse as a result of having a personal budget in all but two of the nine areas of carers lives considered – physical and mental well-being (11%) and carers social lives (11%).

The wider impact of personalisation

Beyond personal budgets, there have been a range of changes in how adult social care services are commissioned and provided and a gradual shift towards preventing and delaying people's need for formal care and support and promoting individual wellbeing, duties now enshrined in the Care Act:

- The evidence regarding the shift towards early intervention and prevention is relatively limited, but encouraging. The evaluation of Partnerships for Older People projects in 2010 reported improvements in quality of life, particularly in health-related domains, from a range of preventative interventions, suggesting that for every £1 spent, an average of £0.73 could be saved on the per month cost of emergency hospital bed-days.⁸⁴ Subsequent work by the London School of Economics found that several preventative interventions "were not only cost effective but 'generated net economic benefits in quite a short time period.'"^{85, 86}
- Despite this and many positive individual examples, it appears that currently very few areas have developed a strategic approach to community capacity building and that disinvestment in these services is the more likely scenario in the current climate.^{87, 88}

- Personal budgets have resulted in changes in commissioning and procurement, most notably a shift away from the use of block contracts by councils to help manage the double funding risk inherent in budget holders making different choices.⁸⁹ “In house” service provision has also continued to retract as a proportion of services overall. The last several years has also seen a continued reconfiguration of day services, away from buildings-based provision towards individual purchasing and activities that make greater use of community-based and universally available services.
- As personal budget numbers increase and purchasing decisions are increasingly devolved to individuals, so the budgets available for aggregate commissioning have decreased. This is reflected in the new role councils are assuming as shapers of local supply in co-production with people with care and support needs, rather than simply purchasers.^{90, 91}
- There has been growth in the use of “virtual market places” which enable people with personal budgets and self-funders to navigate and purchase care and support and other services.⁹² These are usually web portals that provide information about care services alongside signposting to voluntary and community sector provision and other sources of information and advice.
- There is some evidence to suggest that personal budgets and direct payments have had an impact on the range of care and support services people choose and those available locally, most notably a significant rise in the numbers of people employing personal assistants, estimated by Skills for Care as now making up 23% of the 1.6 million strong social care workforce.⁹³
- There has been an increase in the number of non-traditional service options and providers, particularly those offered by micro enterprises, small businesses and people with care and support needs themselves.⁹⁴
- Provider organisations have increasingly led the way in developing new and innovative service models that enable people to exercise greater choice and control.⁹⁵ Some organisations have also occupied a new space, offering services to individuals around personal budget management, such as budgeting, employment support and facilitating reviews.⁹⁶

Personal health budgets

A personal health budget is an allocation of money by the NHS to someone with an identified health need, made so they can buy what they need to improve their health and wellbeing. They are intended to give the person more control over the care they receive. Guidance from NHS England identifies five essential features, meaning that personal health budget holders (or their representatives) should:

- Be able to choose the health and wellbeing outcomes they want to achieve, in agreement with a health care professional.
- Know how much money they have for their health care and support.
- Be enabled to create their own care plan, with support if they want it.
- Be able to choose how their budget is held and managed, including the right to ask for a direct payment.
- Be able to spend the money in ways and at times that make sense to them, as agreed in their care plan.⁹⁷

Launched in 2009 following the Next Stage Review, the pilot programme for personal health budgets involved 64 sites. Twenty of these were the subject of an in-depth evaluation aimed at identifying whether personal health budgets led to better health and care outcomes, the best way for them to be implemented and for whom. The pilot sites focused their work on a wide range of different health conditions, including people in receipt of NHS Continuing Health Care (people with complex care needs and severely disabling conditions), people with mental health problems, chronic obstructive pulmonary disease (COPD), diabetes and long-term neurological conditions.

An early evaluation^{98, 99} suggested that:

- Personal health budgets were cost-effective relative to conventional service delivery – though cost neutral overall, there were some savings for people with the most complex needs.
- People with higher levels of need benefited most regardless of diagnosis, similarly high-value personal health budgets (over £1,000 a year) were found to be more cost-effective than low-value budgets.
- Personal health budgets were found to be effective for both mental and physical health conditions and the net benefits of personal health budgets for Continuing Health Care and mental health were tentatively found to be greater than for other patient groups.

The study showed that most people appreciated the increased choice, control and flexibility that personal health budgets afforded and that many chose to use their budget on treatments and services outside NHS provision, including through employing personal assistants.¹⁰⁰

A subsequent survey of personal health budget holders showed that:¹⁰¹

- Over 70% of personal health budget holders reported their budget having a positive impact on their independence (72.6%).
- Over 60% of personal health budget holders reported their budget having a positive impact on their physical health (68.8%), getting the support they wanted (68.3%), being supported with dignity and respect (67.9%), being in control of their support (67.7%), being in control over the important things in life (67.2%), and on their mental wellbeing (63.9%).
- Over 50% of personal health budget holders reported their budget having a positive impact on the long-term condition for which they held the budget (59.4%), feeling safe in and outside the home (58.2%), their relationships with people paid to support them (53.1%), and their relationships with members of their family (50.8%).
- Fewer personal health budget holders reported a positive impact of their budget on their relationships with friends (41.6%) or choosing where and with whom they lived (34.3%). Very few people reported a positive impact on volunteering (17.3%) or getting and keeping a paid job (12.3%).
- Small numbers of people (between 1.7% and 4.9%) reported their personal health budget having a negative impact on any of these 15 aspects of people's lives.
- A large majority of personal health budget holders (82.6%) felt confident or very confident that their needs would be met with their personal health budget, with the remainder (17.4%) undecided; no one reported feeling unconfident or very unconfident that their needs would be met.

Following the conclusion of the pilot, the government announced the rollout of personal health budgets, identified in the NHS Mandate as a route to better involve and empower people to make decisions about their care. The policy has since been strengthened to ensure everyone with NHS Continuing Healthcare and young people and families eligible for continuing care have the "right to have" a personal budget from October 2014, including a direct payment and anyone else that might benefit has the option by April 2015.¹⁰²

10 lessons for personalisation in the NHS



KEEP THE PERSON AT THE CENTRE – engaging people meaningfully in the design, delivery and evaluation of care and support is intuitively right to ensure it works in the best way possible. But services are often bad at this and genuine coproduction with people as active partners in their care is challenging in practice. This is an ongoing journey in social care, but there is growing evidence of the benefits.



CULTURE OVER PROCESS – personalisation is primarily an ethos requiring profound cultural change and different ways of thinking and working, but getting bogged down by process is easy to do. Much of the early story of personalisation in social care revolved around protracted efforts to devise the perfect method of resource allocation, with very mixed results. Getting the process right is important – but shifting the culture of care should be the primary goal.



EVOLUTION NOT REVOLUTION – it is impossible to shift culture overnight and immediate change risks destabilizing things that are working well. There have been benefits to urgency and a place for targets in the social care story, but the transformation envisaged was always going to take a generation to deliver and the same will be the case in health.



CREATE A COMMON LANGUAGE – the proliferation of different terminology surrounding personalisation in social care has caused confusion. Agreeing a common, jargon free language will help convey the benefits to people, staff and the public. New ways of thinking may need new language, but being person-centred shouldn't require a thesaurus!



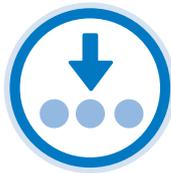
BUILD AWARENESS – People with health and care needs should understand their rights, know what to expect and be able to explore the potential benefits of personal care and support planning and personal budgets. Insufficient attention was paid to these aspects of personal budgets in social care, but there can be no stronger lever for change.



INFORMATION IS THE KEY – a lack of clear and accessible information and advice is always part of the problem when things don't go well, yet is rarely top of the list of priorities. Universal information and advice is an essential building block for personalisation and the Care Act presents the opportunity to build on the learning from social care and take a more strategic, joined up approach.



SOCIAL CAPITAL IS NOT A SIDELINE – personalisation has always involved a broader range of paradigm shifts than individualising funding, but some of these have had less attention than others in social care. The importance of focusing on building community capacity and recognising and strengthening people's social capital is integral to the model and should be built in from the outset.



CHOICE DOESN'T JUST HAPPEN – for personal budgets to deliver greater choice and control there need to be a greater range of options available. While providers do adapt over time to different purchasing decisions, commissioners have an important role to play in shaping what is available locally and working with providers to redesign services. This requires a different and more facilitative sort of commissioning – social care is only just starting to make this shift.



GET PROVIDERS ON BOARD EARLY – personalisation is not just about commissioning differently, it has significant implications for providers and how services operate. This means it is important that providers are part of how the change is planned and delivered. In social care this focus was not sufficiently clear at an early stage leading to unnecessary anxiety and services delivering more of the same.



MEASURE WHAT MATTERS – across the breadth of the agenda and starting from what is important to people with health and care needs rather than just measuring the things that are easiest to quantify. The social care experience has been instructive about the limitations of measuring culture change through the blunt instrument of personal budgets numbers. The Narrative provides a useful starting point.

4 What works?

There is no fixed blueprint for personalisation in the NHS, but there are many examples that can point the way to what will be required of a system where personal health budgets and personal budgets across health and care are part of the mainstream. By drawing on experience to date for personal budgets for health and social care and on wider examples of personalised care, a picture emerges about what works that should inform future developments through the IPC Programme.

This falls into three areas:

- **Focusing on wellbeing** including the role of the voluntary sector, connecting people to informal resources, peer support and universal services that contribute to wider determinants of health and wellbeing and improve patient experience.
- **Transforming commissioning** with people, families and carers to enable a shift in resources, reshape the range of care and support options available and create the infrastructure needed for people to access what they need.
- **Supporting self-management** through a person-centred approach across health and care, so that people have holistic personal care and support plans and can access personal budgets with minimum fuss and maximum flexibility where appropriate.

Focusing on wellbeing

People with long term physical health or enduring mental health problems commonly need a range of support beyond the purely medical. This might include access to information and advice or support from a peer or carer to better manage symptoms or maintain the social interactions and day-to-day tasks critical to maintaining good health and wellbeing. Supporting people to access this broader range of options and engaging the community in strengthening them will be key factors in the success of personalisation in the NHS.

This focus builds on the growing evidence base for asset based community development and the importance of supporting self-management for producing better outcomes for people.¹⁰³ It also recognises the potential for a greatly expanded role for the voluntary and community sector and for “Non Traditional Providers,” brokering access to community resources, alongside or instead of formal services.¹⁰⁴

Underpinning these ideas is the concept that health and wellbeing outcomes are not produced by services or health interventions alone. Rather, the outcomes result from what people and communities do or do not do in co-production with services. So, recognising these “assets,” further developing them and rethinking how services make best use of them makes good sense.

While there are numerous ways of conceptualising the related but different initiatives that can loosely be described as “community development,” Think Local Act Personal’s work suggests the benefits of a strategic approach combining a range of linked activities, including:

- **Building mutual support and self-help** – developing networks and user led organisations that enable peer support and offer practical advice and support outside of formal services.
- **Facilitating connections between individuals and resources** – devising local approaches for target populations, building knowledge, confidence and skills (e.g. community connectors, local area coordination, Village Agents etc).
- **Enabling inclusion in community activities** – so that leisure, sports, social and other organisations are open to all and reach out to excluded communities to invite and encourage participation.
- **Strengthening community ownership** – promoting and supporting activities that bring people together to focus on particular issues (e.g. building dementia friendly communities), and
- **Reshaping services** – both universal and targeted health and social care services to explicitly recognise coproduction and build people’s confidence and skills to improve service outcomes.¹⁰⁵

The IPC Programme envisages the chance for the voluntary sector and communities to be at the forefront of driving a radical change in how care is designed and delivered with a key role in supporting people to access personalised care. Several models from around the country are already tapping into this potential with impressive results.

Examples

Rotherham Social Prescribing Service helps people with long-term health conditions access a wide variety of services and activities provided by local voluntary organisations and community groups. Health, care and voluntary sector professionals coordinate their work together to plan care with people. Early results are showing reductions in three types of hospital episodes compared to the six months prior to referral, including Accident and Emergency attendances reducing by 21%, hospital admissions reducing by 9% and outpatient appointments reducing by 29%. Patients report they are becoming better at managing their long-term condition themselves and reduced social isolation.¹⁰⁶

Community navigator services help people, carers and families to access and use local community services. Navigators can be local volunteers or paid staff. In Cambridgeshire, it includes helping older people to access local clubs and activity groups, information on and mobility aids, financial health checks, transport to get to activities and appointments and voluntary sector services. In Birmingham, the range of activities includes one-to-one community outreach, practical support to solve housing and employment issues, mentoring and befriending and support to manage health conditions. Evaluation of the model has found that the costs average out at £300 per person per year, with savings of at least £900 per person in the first year alone through reduced reliance on formal services.^{107, 108}

Local Area Coordination (LAC) involves people from within their own local community, providing information, advice and support to help other local people of all ages who may be vulnerable due to age, disability or mental illness. Instead of focusing on deficits, the Local Area Coordinator helps people focus on their own vision for a good life, building on their own assets and relationships. They act as a bridge to community and transform local systems to help people make good use of necessary services and helps to transform the impact of services on local communities. First developed in Western Australia is now in use in Scotland, England and Wales. Evaluations in Australia have repeatedly concluded that LAC both improves wellbeing and reduces demand for formal services.¹⁰⁹

Integrated Community Brokerage in Lancashire involves local user-led organisations (ULOs) working to support up to 4,000 local people to manage their personal budgets. The ULOs, supported and coordinated through a lead provider, facilitate care and support planning, arrange support and perform key behind the scenes activity. This model is currently being used with local Clinical Commissioning Groups (CCGs) to support people with Continuing Health Care Funding to take a direct payment and will be jointly commissioned in the future by the council and CCGs to meet the needs of a broader range of personal health budget holders.

The council has also worked with three CCGs to develop Integrated Neighbourhood Teams. This involves working with 66 GP surgeries to hold regular meetings between multi-disciplinary teams of clinicians and care professionals resulting in a 'Connect4Life' service. People are connected to local assets and universal services, alongside 'medical' solutions. Once a GP makes a referral to Connect4Life, care and support planning principles are followed, regardless of the person's eligibility for social care services and there is a strong focus on linking and connecting people within their neighbourhood to a range of offers that keep them safe and well. There were over 200 referrals within the first eight months, with a reported reduction in Primary Care service usage, A&E attendance and acute admissions.

For a wealth of other examples and materials on community capacity building see: www.thinklocalactpersonal.org.uk/BCC

Transforming commissioning

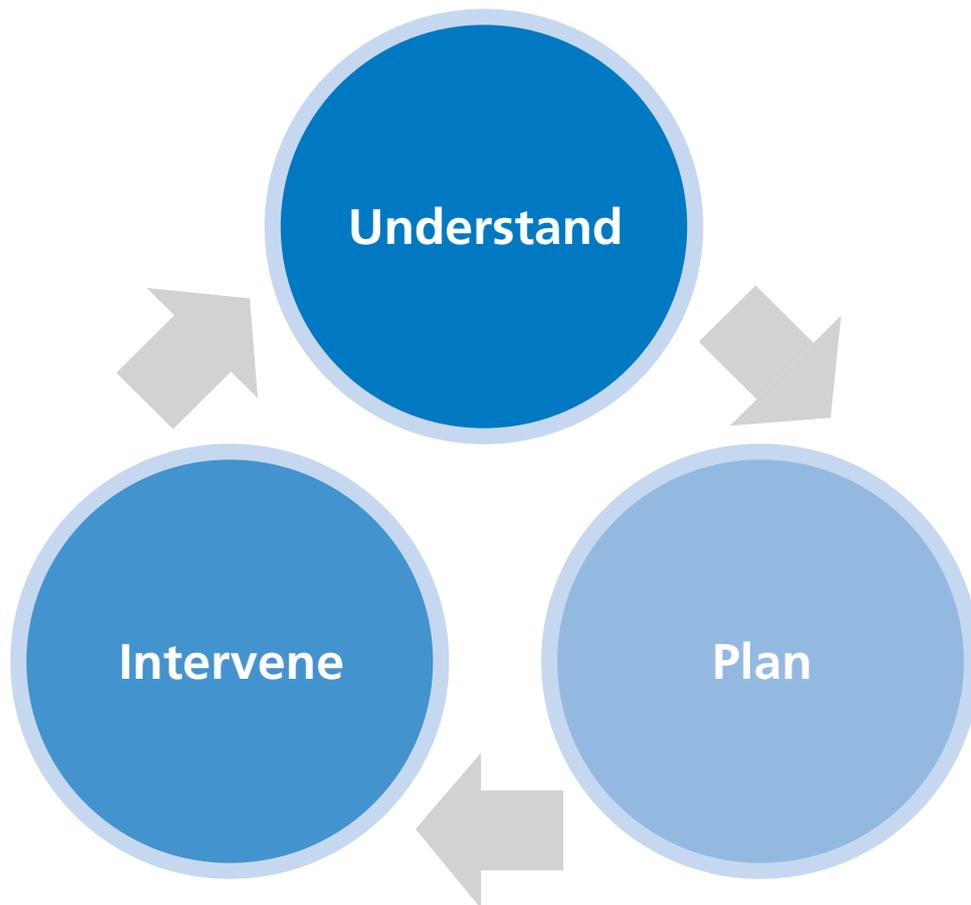
Personalisation comes hand-in-hand with the need for a different and wider range of options for people to choose as well as a focus on tailoring the more conventional services people may need. At a population level, commissioners will need to work across health, social care and other services, to implement a model of person-centred care where funding is pooled for key populations and payment systems shift away from incentivising service activity towards supporting an outcomes focused approach. Commissioners will also need to reconfigure services around what people want and need, looking at their funding in the round and enabling them to direct how it is used. Naturally, what this means will be different from one area to the next given local needs and preferences, but commissioners of health and care will play an important role in shaping what is available in every area.^{110, 111}

Commissioning should be understood as a cycle of coordinated action, beginning with the identification of need and intended outcome and an analysis of the options and resources available and progressing through the specification of a model, its procurement and review. This means that commissioning is essentially transformational rather than just transactional, extending beyond procurement to working collaboratively across organisational boundaries to reshape services and develop community resources. Meeting this challenge will require action at all stages of the commissioning cycle, building partnerships with other commissioners and providers, and maintaining strong engagement with patients and communities throughout:

- **Understanding what is available** – where the scope of services under consideration is far wider than those currently dealt with, reflecting the focus on supporting self-management, prevention and community capacity building.
- **Planning what needs to change** – where the mechanisms for influencing supply reflect the shift in power towards patients, connecting individuals and communities to services, mapping assets and resources and sharing information about what people want and need.
- **Intervening where needed** – where the approaches to securing supply and encouraging innovation may differ from block contracts, where providers are supported through a transition to different contractual models and where individuals increasingly purchase care and support for themselves, with the support they need to navigate their options.

COMMISSIONING: A CYCLE OF COORDINATED ACTION ¹¹²

Develop a shared understanding
of what is available.



Intervene where needed to shape what is available, incentivise innovation and improve quality

Work collaboratively with providers and people with care and support needs to plan what needs to change.

The extended use of personal health budgets will also require a coordinated approach between councils and CCGs, to develop the infrastructure needed for effective “micro commissioning” by budget holders themselves, either individually or in groups. This may involve ensuring the availability of information and advice, commissioning brokerage and direct payments support services and investing in web-based tools to support people to easily understand and navigate their options. It will also require a joint approach with provider organisations to ensure that notional budget options (known as managed budgets in social care) enable people to take control of their care and support day-to-day – for example, by extending the use of Independent User Trusts and Individual Service Funds.

10 key messages for NHS commissioners

- A significant increase in personal health budgets will require commissioners to develop a more rounded understanding of the local system and the diversity of different health, care and support services available.
- This will mean focusing on what people want with leadership for risk enablement and an ability to think beyond conventional services and tariffs.
- This requires a different approach to engagement to ensure that commissioning decisions are coproduced with people and communities.
- Personal health budgets can enable services to be integrated around the person with health and care needs.
- Over time, NHS commissioners may cease to be the primary purchasers of services in parts of the system opened up to personal health budgets.
- Commissioners need to address the current use of NHS resources proactively, to free up money for personal health budgets and avoid double funding.
- Commissioners will need to work with providers to ensure a safe and sustainable transition to new funding models, supporting and nurturing the development of a diverse range of personalised services.
- There will need to be changes in contracting practice to enable more flexible arrangements (including independent user trusts and individual service funds, lead provider models and outcomes based approaches) that free providers up to respond directly to customers and enable budget holders to buy bespoke support.
- This will enable the growth of new types of provider, including micro-providers and social enterprise, well placed to focus on personal needs.
- An increase in direct payments will mean more personal assistants and a need to develop local direct payment support services.

A NUMBER OF PROMISING DEVELOPMENTS THAT ARE TRANSFORMING COMMISSIONING

MARKET POSITION STATEMENTS

Market Position Statements (MPS) are part of an approach to engaging differently with providers and people with care and support needs which has gathered momentum in recent years in adult social care. An MPS is a short, evidence based and analytical document that brings together information in one place for the benefit of current and prospective suppliers, of all shapes, sizes and sectors. This includes information about future anticipated demand and funding, the sorts of things people say they want to buy and how commissioners expect to be working with providers in the future, including the sorts of contracts and incentives likely. An MPS can cover a particular segment of the market (e.g. learning disability), or a specific geographical area.

The development of an MPS is intended to stimulate an ongoing dialogue between commissioners, providers and people with care needs. It should not be a repetition of other key documents, like the JSNA or the Health and Wellbeing Strategy, but a practical document focused on helping providers make good decisions about service and business development and setting out the commissioners anticipated approach for engaging with providers in the future.

All councils have engaged with the Developing Care Markets for Quality and Choice Programme, funded by the Department of Health and delivered through the Institute of Public Care, to develop their skills and competencies in using MPS to facilitate local care markets. The following is an extract from an MPS for day opportunities setting out the future “direction” and “opportunities” this presents.

Example

DIRECTION AND POSSIBLE BUSINESS OPPORTUNITIES¹³

Older people will increasingly require more choice and control regarding the way they access support, which includes self-directed assessment

Warwickshire wants providers to make self-directed support options such as direct payments and Individual Service Funds become an attractive alternative. There is a gap in the market for alternative day opportunities options in North Warwickshire, Nuneaton & Bedworth and Stratford Upon-Avon. Commissioners are looking to engage with providers to address gaps in these localities.

We are seeking to redesign our community support services for people with dementia. This includes lower level, community and peer support. Over time the amount of people with dementia is increasing substantially and diagnosis rates are

likely to improve. We therefore need to increase the range and type of community support options available to people to help them live well with dementia within their local communities and remain independent for longer.

We encourage a diverse market of providers to offer outcomes focused services. Providers are encouraged to promote their services on the Warwick Directory.

There is a need for social and community enterprises across the county and Warwickshire are able to facilitate business development and planning if required

Through our “New Sparks” initiative we want to facilitate change by investing in community engagement and supporting those most vulnerable in local communities. We will encourage micro projects that focus on care and support to increase independence and reduce isolation.

CAPITATED BUDGETS AND THE LEAD PROVIDER MODEL

NHS commissioning has tended to focus on outputs, such as the number of procedures completed or appointments made. The use of capitated budgets and a lead provider model shifts this towards a commissioning approach where the budget is based on the needs of an identified population, including financial incentives for achieving specified outcomes. The budget generally covers all care for a group of people, for example, people with mental health problems, based on a weighted per person cost over a specified timeframe. The outcome-based incentives, reward groups of providers that together deliver high quality care.

An accountable lead provider takes the model further, so that the commissioner does not need to separate out discrete services and manage the multiple providers for them. Instead, by procuring outcomes, the commissioner transfers the responsibility for integrating the care pathway to the accountable lead provider who develops a network to deliver the services required within the pathway, and it is responsible for navigating all of its patients through the care pathway efficiently and effectively. This sort of model could potentially work well for designing more personalised care for the cohorts of people identified for the IPC programme.

Example

The Kent Long Term Conditions Year of Care Early Implementer site is currently working with health and social care organisations in developing a capitated funding model for people with complex care needs. Key to the programme’s success is the design and development of whole population person level linked data sets across all care settings. The Kent Long Term Conditions Year of Care Dashboard currently links information from acute services, community, mental health, hospice care and social care. There is an intention to link others such as ambulance services, Out of Hours services, Primary Care and NHS Continuing Healthcare.¹¹⁴

COMMISSIONING FOR OUTCOMES

Even without capitated budgets, some areas have made considerable strides with the development of outcomes based approaches to commissioning, including framing service specifications around the individual or population outcomes required (using ASCOF or the “I” statements in Making it Real / the Narrative) and shifting towards payment mechanisms that reflect outcomes for people rather than units of provision.

Example

The New Economics Foundation have worked alongside several councils to implement a new approach to commissioning for outcomes. This started in Camden with the re-commissioning of a Mental Health Day Service, and has involved a greater focus on wellbeing and prevention and a stronger role for people intended to benefit from the service in the commissioning process itself. The commissioning approach radically changed the tendering and procurement process, including:

- Developing an outcomes framework that included social, environmental and economic outcomes for people who used the service and the wider community. These outcomes included, for example, increased access to skills and employment, supporting people to lead healthier lives and creating a sustainable social infrastructure.
- Specifying that co-production should be a key feature of the service and that providers should show how they would work with people using the service, and with the wider community.
- Tendering by using the outcomes framework and a set of quality characteristics to help refine the offer, and asking prospective providers to design the activities and support that would achieve the required outcomes.
- Monitoring and evaluating outcomes, rather than outputs, throughout the duration of the contract.

The winning tender was a consortium of Camden-based third sector organisations: MIND in Camden, Holy Cross Centre Trust (HCCT) and Camden Volunteer Bureau, a mainstream volunteering organisation. Their vision of how co-production could transform the local offer has resulted in one of the most innovative service models in the UK. Camden is now using the outcome model to commission a range of services across different directorates and building it into the new council-wide procurement operating model.¹¹⁵

NAVIGATING CARE AND SUPPORT OPTIONS ONLINE

Many areas are exploring the potential of web-based solutions to enable people to navigate the range of care and support options available, in some cases also buying them online. The most promising examples involve looking at ways of making websites much more interactive, so that people can not only find information but also share their feedback about services.

Example

Stockport council was an early innovator. In 2009/10, the council partnered with a specialist website design company to build a new site, working together with people using adult social care services. Their approach involved using an ethnographic methodology to understand how people wanted to see information, what sort of language was important to them, their perception of social care and the sorts of navigation tools they might value. A very early evaluation concluded that the site had contributed to a 29% drop in enquiries and a 38% drop in calls to the council contact centre, equating to a saving of 74 hours of telephone calls every day.

The council has since built on this platform to develop an online market place where local providers can advertise their services, with improved functionality and search options. Disability Stockport, the local Centre for Independent Living is developing a facility for people to leave “trip advisor” style reviews of services they have used and will be responsible for monitoring comments. A key aspect of the council’s vision now is to enable people to build up private personal records. The idea is that more people will be able to self-assess and develop their own support plans at an earlier stage, even before they need to access more formal services.¹¹⁶

For a wealth of other examples and materials on market development see: www.thinklocalactpersonal.org.uk/marketdevelopment

Supporting self-management

Supporting self-management through a person-centred approach means putting patients and people with care and support needs at the centre of all decisions made and seeing them as equal partners in assessing, planning and developing care to meet their needs and aspirations. A person-centred approach should promote independence and autonomy, enable choice and control and recognise people’s skills, gifts and talents, as well as their needs. Providers have a critical role to play in this day to day, both conventional NHS services, social care providers and voluntary and community sector organisations offering a wider range of options.

This should entail improved access to clear and accessible information, advice, advocacy and peer support, alongside:

- **Personal care and support planning:** Access to support to develop a person-centred plan which covers all aspects of life, not just tightly defined health and care needs.
- **An integrated personal budgets offer:** Available to all those who might benefit across health and social care, combining funding where necessary and including the option of direct payments.

PERSONAL CARE AND SUPPORT PLANNING

At the heart of a person-centred approach is personal care and support planning. This should reflect people's whole life needs, preferences and self-determined outcomes, alongside any clinical and professional expertise required. The Year of Care pilots demonstrated that where personal care and support planning is embedded in practice it is highly valued by healthcare professionals, leads to improvements in clinical outcomes and is cost effective.¹¹⁷

Personal care and support planning involves the person or carer being able to talk about what matters to them and what they want to achieve, identifying objectives that are personal to them as well as meeting health needs. This can include working out the best treatment, or care and support option as well as things the person can do themselves to manage their needs better.¹¹⁸ Personal care and support planning is mandated in the Care Act for everyone with an eligible social care need, including the provision for combining plans across health and care. The draft Care Act guidance describes the guiding principle in the development of a plan being that the process, " should be person-centred and person-led, in order to meet the needs and outcomes...built holistically around people's wishes and feelings, their needs, values and aspirations."¹¹⁹

Personal care and support planning should:

- Be supported by good prior information for people and professionals about what is involved and the intended benefits.
- Involve the right people, which could mean a carer, family member, peer or advocate, a health professional, social worker, voluntary sector planner, or independent broker.
- Focus on outcomes and leave room for creativity in how they are met, not beginning from assumptions about the services people need.
- Cover everything the person needs to live a good life, not just the treatments or services they draw upon.
- Take an enabling approach to risk and how it is managed, making clear contingencies where necessary.
- Where developed as part of a personal budget process, start with an indicative allocation already identified.
- Produce a plan that is owned by the person, reflecting them as an individual.

Example

Imagine is a voluntary organisation that provides support planning and brokerage services for personal health budget holders with mental health problems. They have worked in partnership with Mersey Care NHS Trust on “recovery budgets,” involving around 200 people with mental health problems being given one-off budgets of between £400 and £1,000 to spend on something they thought would help them with their mental health.

An advisor from Imagine spends time with each person and their family, to help them think through what they want to achieve and how they might go about doing it. The support plan is then discussed and agreed with a health professional, for example the person’s community psychiatric nurse, social worker or occupational therapist. The CCG pays the personal health budget directly to Imagine, who then helps the person to arrange and manage the support day to day. This makes it possible to buy items that the NHS would not normally be able to arrange and means that people do not have to take on the additional responsibilities associated with managing a direct payment.¹²⁰

Seven key messages for NHS funded providers

- Focus on the person and on building support around them – delivering services that people really want and value, not what is most convenient for the service or the commissioner.
- Plan for a change in the way services are funded, as some block purchasing by commissioning agencies may be replaced by smaller-scale purchasing and people buying their own care.
- Ensure resources, including staff and money, can be used flexibly to meet people’s changing needs and aspirations over time.
- Find new and better ways to listen, so that services can adapt and respond to what people say they want and need.
- Take a more positive approach to risk, so that people can make decisions about their support that make sense to them and the lives they want to lead.
- Focus on outcomes, so that people’s self-reported health and wellbeing outcomes drive service development and business planning.
- Review back-office systems and processes to ensure they don’t get in the way of people making different choices and taking control (finance, management, human resources).

AN INTEGRATED PERSONAL BUDGETS OFFER

Following the conclusion of the personal health budget pilot phase, a number of areas worked with NHS England to further refine and extend their approach to personal health budgets through the *Going Further Faster* programme. A number of these sites did work to design and test an approach bringing together personal health budgets with personal budgets for social care. While numbers have so far remained small and systems are still evolving, some conclusions were reached about the factors most closely associated with a successful model:

- Pooled funding arrangements were found to be helpful, though not critical.
- A willingness to think laterally about budget setting has helped avoid unnecessary complication and inertia.
- Learning from the approach in social care has helped avoid reinventing the wheel where processes are already established and may just need tweaking.
- Joint approaches to giving information and advice have helped to present a coherent picture to potential budget holders and the public.
- Joint assessment has been complex to date and has often meant alignment rather than integration of processes.
- Joint approaches to care and support planning are valuable, enabling people to create single, holistic plans while encouraging professionals to build mutual understanding across disciplines.
- There are quick wins available by piggybacking existing local authority contracts for direct payment support and budget management services.¹²¹

A further piece of valuable learning from *Going Further Faster* was that there are commonly held misconceptions about what it is currently possible to do to bring personal budgets together, ranging from the legal basis for such arrangements, through to perceived restrictions in data sharing and misalignment of financial accounting. In reality, while undoubtedly challenging, there is little to stand in the way of progressing with an integrated approach to personal budgets. The full findings are pulled together in a “myth buster” that covers all of these areas and incorporates examples of how sites were making progress.¹²²

GETTING THE PROCESS RIGHT

All the available evidence suggests there is a significant correlation between people's experience of the personal budgets process and the likelihood of achieving a good outcome. In other words, the more difficult and cumbersome the process of accessing and using a personal budget feels, the less effective it is likely to be for the person, carer or family member. The factors most robustly associated with positive outcomes for personal health budget holders during the pilot phase included knowing the amount of the personal health budget early, having help to plan from family, friends or peers, people feeling that their views were fully included in their personal care and support plan and having the option of holding the personal health budget as a direct payment.

Several areas are now working to bring together the referral, assessment, budget setting and care and support planning processes needed to deliver integrated personal budgets, alongside wider integration between organisations and teams:

- **Stockport** have targeted personal health budgets use for people who have frequently attended the emergency department (over three attendances in a month).
- **South Coastal Kent** is targeting personal health budgets for people with medically unexplained physical symptoms.
- **Dorset** are using personal health budgets for people on mental health Community Treatment Orders.
- **Islington** are having success with personal health budgets for young people using mental health services transitioning to adult services.
- **Northamptonshire** are working with individuals with mental health needs across clusters, except cluster 1 and 2.
- **Brighton and Sussex Care** are using personal health budgets with people who would otherwise be supported in low secure or highly structure care home settings.

Integrating personal budgets presents major cultural, technical and structural challenges, and there are a number of genuine barriers to overcome to make them a success.¹²³ But it is already clear that significant progress can be made with the right approach and that when fully aligned with a broader strategy for delivering integration, personal budgets can play a big part in shaping a more responsive and person-centred future for social care and the NHS.

A good integrated personal budgets process should be...



INCLUSIVE – people with long-term conditions and disabilities should have the opportunity to live good lives by making the decisions about their health and wellbeing that matter most to them. To ensure this is possible, the process needs to be built around people and to engage them fully at all stages.



INFORMATIVE – information about what to expect from the process needs to be clear and well communicated. The process should build up a picture of how resources can be used to best effect in a way that suits each person.



RIGHT FIRST TIME – health and social care professionals need to work together to ensure things are done right the first time and that there is no unnecessary duplication of work.



PERSON CENTRED – professionals should be skilled in using person-centred thinking and practice in all their work with people.



FLEXIBLE AND PROPORTIONATE – processes should not be one size fits all, but should work flexibly and proportionately in a way that reflects each person's needs and circumstances.



CREATIVE – people need permission to be creative in order to use resources to best effect. Professionals should encourage and support all those involved to think differently.



PORTABLE – personal budgets should enable care and support to follow the person, rather than prescribing where support should happen.



IMPARTIAL – the process of allocating budgets and the rules surrounding how they can be used need to be fair and rational, and clearly communicated.



OUTCOMES FOCUSED – a good process should be built around identifying the best health and wellbeing outcomes for the person, and making sure care and support can be arranged to offer the best chance of achieving them.



UNIVERSAL – much of the support and advice people need to achieve good outcomes can work just as well for people with lower level needs or with the means to arrange support for themselves. Good advice, information and planning tools should be widely available for everyone who could benefit from them.¹²⁴

For a wealth of other examples and materials on personal budgets and coordinated care see: www.thinklocalactpersonal.org.uk/selfdirectedsupport
www.thinklocalactpersonal.org.uk/coordinatedcare

5 What next?

The IPC Programme confirms the next stage of personalisation will be its most ambitious – a person-centred, coordinated approach to meeting whole life needs, strengthening communities, transforming commissioning and supporting self-management. The challenge of delivering this at scale, across system boundaries and for people with some of the most complex needs will be significant. To be successful, the programme will need to build on the wealth of learning from the experience in social care and harness the leadership of people and communities as well as clinicians, professionals and their organisations.

The time is now right – the pressures on the system demand that we think differently and embrace the transformations necessary to drive forward a new model of care and a truly person-centred NHS. This means people with health and social care needs themselves, with the support they need, leading the change as the most effective integrators of their own care and support.

The IPC prospectus makes a triple offer to people with health and care needs, to local commissioners and to the voluntary sector. People with health and care needs will be offered real power and improved support to shape care that is meaningful to them in their lives. NHS and social care commissioners will be offered dedicated support and flexibilities to address systemic barriers to change. And the voluntary sector will be invited to be a key partner in designing effective approaches, supporting individuals and driving cultural change.

Think Local Act Personal will support the IPC programme as a key delivery partner, bringing together years of learning and experience, the leadership of the wider health and care sector around a shared commitment to make the next stage of personalisation a success. TLAP will:

- Work across the national partnership to identify and address national barriers to progress through the TLAP work programme.
- Develop guidance and resources to support implementation, including for personal care and support planning and integrated personal budgets.
- Enable access for IPC sites to networks, including the National Market Development Forum and Building Community Capacity Network.
- Deliver bespoke, onsite support to IPC areas through our Coordinated Care work stream.
- Share examples of what works through a dedicated area of the TLAP website.

To read the IPC programme prospectus, please visit:
www.personalhealthbudgets.england.nhs.uk

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THINK LOCAL ACT PERSONAL PARTNERSHIP ORGANISATIONS



Think Local Act Personal

Think Local Act Personal (TLAP) is a national strategic partnership of more than 50 organisations committed to supporting the continued implementation of personalisation and community-based health, care and support.

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