

“Personalisation must  
work for those who  
need it most...”

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## TAILOR MADE

Claudia Wood



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Any omissions or errors remain my own.

Claudia Wood  
October 2011



# Foreword

My generation is very different to that of my parents. When they went on holiday, they were happy to stay in a B&B sharing a bathroom with other couples and families. My expectations, and that of the generation after mine, are different to this. We want our own en suite.

The same is true of care.

Reading through the minutes of residents' meetings for our neurological centres, I am always struck by the amount of time spent thanking staff for doing their jobs. And the small amount spent asking for things to be done differently.

That isn't because Sue Ryder gets it right every time – in the current climate, our service users and their families reach us after they have spent time, often years, fighting the system. They are so grateful to receive any support that they don't want to risk rocking the boat by asking for more. The next generation will not be so accommodating.

Personalisation, choice and control are overused words in the sector and society at the moment. They seem to be the solution to all problems and the answer to all questions. Yes, they are important because they articulate what we feel about care – that people deserve better than the standard service. But we mustn't get complacent before we've begun to deliver a better service.

As a provider, our role is to help people to fulfil their goals and aspirations in life. Entering a care home or supported living service shouldn't be about moving into a home to die in, it should be about moving into a home you can have a fulfilled life in. The hospice model works with this approach and, throughout this pamphlet, you will read examples of how hospices were established with personalisation at their heart years before the term was introduced.

There is a tremendous force behind personalisation; providers, service users and all of the political parties support it. Moving the system on from personalisation being achieved by having good relationships to a system where personalisation is delivered by different funding mechanisms, co-design, co-production and changing the way organisations operate is the next step. But we must never lose sight of the individual, which is the danger of letting systems take over. Personal budgets are a way forward, but they aren't the only way. We need a more inclusive personalisation that supports the most vulnerable in society to make their own choices and take control of their lives.

For those with complex needs it can be more challenging but, as the report shows, there are solutions. The sector talks a lot about resources or our lack of resources. This can't be the reason for not making personalisation happen regardless of how much strain services are under. Talking to service users about their aspirations and helping them to fulfil them is paramount; it's not an option.

Steve Jenkin  
Director of Health and Social Care, Sue Ryder  
October 2011

## Executive summary

This report considers the future of personalisation in health and social care in an era of considerable social, economic and policy change.

Personalisation as a distinct policy aim in health and social care is not new – while the term is now five years old, the concepts of self-directed support and choice and control have been inherent in the disability movement for two decades. And yet we are now at a crossroads in its development. Medical advances mean we are fortunate enough to be living longer, and seeing increasing numbers of disabled people with multiple and complex needs surviving into adulthood. This is placing greater burdens on our health and care system, and also challenging our perceptions about the level of choice, control and independence that people can have, even when their needs require significant levels of care and support. Alongside this, the Coalition Government has taken two game-changing steps: a range of budgetary cuts to central government departments and local authorities, leading to unprecedented pressures on the funding of health and social care services and cuts to third sector grants; and a series of radical reforms to local health structures and social care funding, which look set to change the way care and health will be delivered in the future. Part of this includes an increased focus on the personalisation agenda, and particularly the promotion of personal budgets in health, care and eventually a range of other service areas.

But the increasing interrelation of the personalisation agenda and the roll-out of personal budgets is causing concern in some quarters. Practitioners, encouraged by policy makers, sometimes see the two as interchangeable terms, creating a belief that once the 2013 target of achieving 100 per cent take-up of personal budgets among social care users and carers has been

met – as set out in the Government’s report *A Vision for Adult Social Care*<sup>1</sup> – we will have ‘achieved’ personalisation. It is likely that a similar target will be set for personal health budgets, while Scotland is poised to create a default opt-in for all care users to have a direct payment. However, *personal budgets do not guarantee personalisation* – just as an absence of personal budgets does not guarantee an absence of personalisation.

By confusing the two, we risk complacency – once a personal budget has been given to an individual, his or her support may automatically be seen as ‘personalised’, and no further work needs to be done to ensure this is the case. Moreover, we risk excluding those less able or willing to engage with the personal budget process from the personalisation agenda.

This second issue is of particular relevance to commissioners and providers dealing with groups of care users in residential or other collective settings, using services that cross health and social care, and those with complex needs, for whom personal budgets can be more challenging to deliver.

Of course, we cannot deny that personal budgets have been hugely important in making life-changing differences to people using care services, and driving a shift from a service-centred, paternalistic care system to one where the individual is in control. But even the greatest proponents of personal budgets recognise that they are necessary but not sufficient for personalisation. Several other factors have to be in place. While we would never suggest denying people the chance of using a personal budget, we must recognise that for some people, and in some situations, personal budgets may not be the most effective method of personalising services.

Now is the time to look again at personalisation and ensure that the way in which we are implementing it is fit for purpose for an era of budgetary cuts, a new emphasis on community and collective empowerment, and increases in those with complex needs.

This report argues for a more inclusive personalisation agenda – one that enables everyone to enjoy the benefits of personalisation, regardless of their preferences, care needs, personal capacity or care setting. To achieve this, we must have a

‘personalised approach to personalisation’ – one where everyone can choose the method of personalisation that suits them.

## Chapter 1 The limits of personal budgets

This report begins by exploring some of the limitations of personal budgets, including considering whether personal budgets can always deliver what people actually want. For example, the care users we spoke to during our research told us that the most important things in their lives were:

- retaining their independence
- having a job or volunteering
- maintaining links with their family
- being with people they know

It is striking that none of these rely specifically on having a personal budget. Although some of these points entail a person having greater control and autonomy, which personal budgets can certainly help deliver, there is nothing in this list that a person cannot achieve without a personal budget. However, it may be necessary for multiple services to work in unison with a person if they are to achieve the goal of being independent, having a job or volunteering. So another important question to address is whether personal budgets are powerful enough to achieve multi-service integration, and in turn deliver the outcomes people want. We would suggest this is unlikely to be the case, and the health, care, housing and other systems, which have yet to be integrated, even after considerable political focus and resources being spent to achieve it, are unlikely to come together in a seamless package through the force of an individual’s purchasing power alone. Additional steps will need to be taken.

We consider some of the complexities around personal health budgets, and the difficulties of using personal budgets in settings on the fault line of health and care systems – in particular, palliative care settings. We also look at the importance of the ‘personal touch’ and the ‘small things’ when it

comes to care and support services, which risk falling below the radar of personal budget planning.

Overall, we identify those with complex and multiple support needs, including those with communication difficulties and less capacity, those in residential and collective care settings, and those in palliative care as the groups for whom personal budgets could prove the most challenging to implement and who may not prove an effective vehicle for personalisation.

## Chapter 2 The barriers to personalisation

The limitations of personal budgets do not mean personalisation is doomed to fail. While they have been hugely beneficial and nothing short of life changing for some groups, and have also helped galvanise policies around person-centred support, personalisation can be achieved without personal budgets. Specialist palliative care is a good example of this. Therefore, although we should try to overcome the barriers to the effectiveness of personal budgets, we should be far more concerned about the challenges that personalisation – in its widest sense – faces in the coming months of budgetary constraints and significant reform to local health and care services. In chapter 2 we consider some of the challenges to personalisation, with a particular focus on those groups and care contexts identified above as being difficult for personal budgets. This is because we recognise that where personal budgets may be less effective, other methods of personalisation will need to step in. Looking at the barriers to personalisation more broadly (and distinct from personal budgets) for these groups and care settings is therefore particularly important. The barriers to personalisation we identify include:

- a lack of funding
- poor integration of health and social care
- the limitations of the health, care and wider service markets
- the lack of integration of health and care with housing
- the constraints of communal living for those in residential care
- the challenges for palliative care (eg the low take-up of advance care plans)

- service user resistance to personalisation
- staff cultures and leadership

### Chapter 3 How to overcome these barriers

In chapter 3 we consider how one might overcome some of the barriers to personalisation for those with complex needs and in care settings where personal budgets may not be effective. Looking at some examples of good practice already under way, we explore in particular how personalisation might be improved.

#### A more inclusive approach to personal budgets

The emphasis placed on direct payments as the primary form of personal budget is too restrictive and risks excluding large numbers of people who do not have the capacity or desire to use a direct payment. No one should be excluded from having a personal budget if they so wish, but to make personal budgets as accessible as possible for all groups and in all care contexts, we need to think beyond direct payments as the only, or even the preferred, form of personal budget.

There are several alternative forms of personal budget, but because of the emphasis on direct payments these have been relatively under-developed and seen as ‘second best’ options. More effort needs to be made to develop these direct payment alternatives so they become credible and effective methods of achieving choice and control. We also describe examples of personal budget pooling and mix and match personal budgets, where users have different types of budget for different aspects of their care – showing that greater flexibility around personal budgets can make them accessible to everyone.

#### Innovative personalisation methods in residential settings, including co-production

We look at how personal budgets in residential care might be used to good effect, but also consider alternatives – such as co-production and co-design, backed up by robust democratic

structures to enable care users to gain ‘ownership’ of their care as an empowered group. Personalisation in collective care settings *is* possible, but we must remember that personalisation is not the same as individualisation. Personalisation does not always mean the achievement of one’s preferences in every aspect of life, irrespective of practical limitations or others’ wants and needs. Compromise is sometimes necessary – as it is for everyone in everyday life.

The key in residential care is to make this compromise legitimate and transparent, and based on negotiation and discussion, rather than the ‘say-so’ of authority figures. Democratic structures in communal settings should enable residents to negotiate with each other, and with the staff and management. Treating residential settings as micro-communities, run for *and by* the residents, is a powerful model to aspire to in residential care. This does not mean that care providers should not strive to ensure that each individual in a collective care setting can pursue their own interests and spend time doing things separately from the group.

We explore several strategies which can help deliver personalisation in a financially sustainable way in residential settings, including the concept of providing ‘just enough support’ and developing social networks and peer support, and using volunteers and ‘enablers’ to bring the community into the home and residents out into their communities.

### Changes in staff culture and encouraging the ‘personal touch’

Supporting those with complex needs and in residential and palliative care settings often requires more formal support, and the presence of more support staff, than other groups. It is therefore vital to remember that personalisation does not just involve giving a person choice and control – it is also necessary to provide support in a personalised way. Something we might call ‘the personal touch’.

One of the things people told us they valued in life was the maintenance of relationships, and being around people they knew and who knew them. Their comments referred as often to

their peers and friends as to the care staff and volunteers who supported them.

This personal touch is only possible if staff providing that support get to know their clients well. This, in turn, can only be achieved if there is not a high turnover of staff or multiple staff members providing care. Consistency in relationships are particularly important for those with complex needs and in settings where personal budgets may not be suitable or be a long way off in their implementation – for example in palliative care settings. It is also particularly important for those with fluctuating or degenerative conditions, where the ability to communicate or the capacity to make choices and express preferences may come and go, or be lost permanently. If support is provided by someone who knows their client well, wishes and preferences can still be acted on based on that personal knowledge – this can help deliver personalisation even when the ability to communicate or actively choose declines.

Having a positive staff culture is also vital. Being prepared to enable clients to take risks and become more independent, treating people's needs holistically and giving their preferences priority even in the face of professional reservations can be a cultural challenge to those with a vocation of 'looking after' people or those with specialist areas of medical knowledge. There are some positive cases where staff cultures are being changed through the appropriate training around personalisation and enablement, as well as recruitment which looks for the right skills *and* the right attitude.

### Personalisation strategies in palliative care settings

End of life care poses distinct challenges to personalisation, which need tackling:

- lack of staff training in being able to talk about end of life planning with people and their families, coupled with individuals' reticence to do the same
- low take-up of advanced care plans

- practical difficulties around personal budgets and the flexibility required for rapid changes to be made in the last weeks and days of life
- friction between the health and care systems, as end of life care sits on the fault line between these two systems

There are some good examples of how health and care staff have been trained in end of life care to great effect, leading to greater confidence in talking about planning for death and an increased take-up of advanced care plans, which in turn improved personalisation. Moreover, and in spite of these challenges, specialist palliative care remains the gold standard of personalised care – looking at people’s needs holistically, and adopting a balanced approach to risk and enablement.

#### The integration of health and social care

Those groups for whom personal budgets are not always practicable or desirable – such as those with multiple and complex needs, those in residential or collective settings (often due to their complex needs) and those needing end of life care are the same groups for whom the integration of health and personal care is critically important. Hospices and residential and nursing homes for those with complex needs sit on the fault line between health and social care and the lack of integration acts as a significant barrier to delivering joined-up and personalised support. However, there are some examples of bottom-up initiatives which have driven greater integration between health and social care, even where top down policies from central government have been less successful. These include Herefordshire Council, the first local authority to integrate its health and care teams and which was given approval to become an integrated care organisation in 2010, and North East Lincolnshire, the first local authority to establish integrated care through the Care Trust Plus model. These examples show the importance of staff culture, relationships and trust, using staff insight to resolve problems, buy-in from leadership, and a vision for change, which everyone can work towards.

### Bringing housing into integrated support

The integration of housing with health and care is a fundamental step towards personalisation – in particular for those with complex needs, whose transition to greater independence and move from residential settings into more personalised environments is fundamentally dependent on housing being available, suitable and fully integrated with their care and support packages. In many areas looking at service integration, however, integration has primarily begun with health and care, with other areas – housing, education, leisure and so on – sometimes being ‘pulled in’ once initial processes and joint teams were established. It is rare for housing alongside care and health to be the key integration partners from the beginning.

We consider the experience of South Essex’s Commission of Enquiry into Co-operation between Housing, Health and Adult Social Care and the experiences of Sutton local authority in this section to consider how housing can be given a greater role alongside health and care. In South Essex, housing is being brought into the health and care plans as part of a reablement and prevention strategy, aimed first at older people who are at risk of moving into residential care. In Sutton, the local authority has put in place an innovative strategy to move those with learning disabilities out of residential settings. In this instance, the difficulties of overcoming staff’s, care users’ and their families’ perceptions around the ‘safety’ of living in the community with greater independence is a key challenge. In both cases, the commitment of the local authority housing teams and housing providers has proved crucial to progress.

### Chapter 4 Policy and practice recommendations

Personal budgets must be seen as one of many tools for personalisation, and equal effort and policy focus must be expended on the other tools outlined in this report if we are to create a truly universal and accessible personalisation agenda. With this broad principle in mind, we present a series of more specific recommendations for policy and practice.

### There needs to be a more inclusive personal budget agenda

The focus on direct payments and individual purchasing risks excluding some groups who might find other forms of managed budgets as a more effective means of personalisation, and may inhibit the collective purchasing power of groups of care users. We recommend that the alternatives to direct payments are developed to become credible alternatives, which can deliver equivalent levels of choice and control. This includes supporting providers in transforming their internal financial structures to ensure effective delivery of individual service funds, while care staff and families need to be trained and given advice on how to make the most of managed and indirect budgets. Local authority commissioners and in the future clinical commissioners in health must also scrutinise their ‘managed personal budget’ processes, to ensure they deliver choice and control and are not part of a tick box exercise.

An inclusive personal budget strategy is also one where more innovative uses of personal budgets are developed – including collective purchasing and mix and match approaches. The latter would mean people could use two or more forms of personal budget at the same time – for example, use a managed budget for the basic ‘care core’ of a support package, combined with direct payments or indirect payments to purchase other elements of support.

### A strategy for progression

Considerable political support and funding has been given to rehabilitation to prevent people from moving into residential care. Equal emphasis needs to be placed on strategies to move those in residential care into their communities with supported living. This includes ensuring adequate funding is available to support care providers in establishing links with housing providers and promoting rehabilitation and progression in staff training, local commissioning strategies and national policy narrative.

We recognise that not everyone will be able to move from residential care to supported living, but this does not mean that they would not benefit from a focus on progression and

rehabilitation. Inspired by the examples we witnessed during the course of this research, we recommend providers consider how to create progression opportunities within their facilities. Some may look to purchase semi-supported units nearby the main residential home, and share staff between the two settings, but those who cannot purchase additional property may be able to look to innovate – creating, for example, semi-independent or ‘lower support’ rooms within the home to encourage greater independence in the spirit of progression. Enabling people to move out of residential care, and also to become more independent and self-supporting in residential care, will reap significant cost savings in the longer term.

#### Recognising the importance of housing

We recommend that housing is recognised as a fundamental component of the rehabilitation and progression strategies we outline above, which requires additional political focus and funding with a clear recognition of cost savings being made in the longer term. A rehabilitation strategy must include active engagement with the housing sector (both private and social housing) to become partners in local authority care commissioning plans. There also needs to be brokerage carried out by local authorities between housing and health and care providers, to develop progression routes for those who may be ready to move on from residential settings.

#### Co-production and democracy in residential settings

While personalisation may for many in residential care involve progression towards independent living, some groups – those with the most complex needs, dementia and so on – may need to remain in registered residential and nursing settings. We strongly recommend that, in order to bring personalisation to those in residential settings, an active co-design and co-production strategy is applied as standard good practice across the sector, supported by strong democratic processes and structures. Health and care commissioners, personal budget care planners and

social care regulators should all look for the presence of co-production and democratic structures as a mark of quality in residential settings.

Providers must move beyond resident consultation and discussion of the ‘small things’, and actually give residents the opportunity to fundamentally design and influence aspects of their home and their care. This includes the design of job specifications for new staff and resident representatives sitting on the recruitment and interview panel, as well as the design of daily routines and activities, the purchasing and placement of furniture and equipment, and so on. The ethos in care homes should be one of ownership, where a powerful residents’ association is tasked with sharing the running of the home, as active members of a community might do in housing associations. Residential care should not be seen as ‘hotel living’.

#### Develop social networks and a concept of ‘just enough’ support

For many years the standard approach towards those with complex needs has been to provide all-encompassing care and support. We recommend that providers and commissioners provide the *appropriate* amount of formal support, recognising that there is such a thing as ‘too much’ support. Independence, autonomy, dignity and privacy all have to be weighed against the need for support and supervision, but the development of community alternatives to formal support provide an excellent method of balancing the two in a way that is better for the individual. Assistive technology, Homeshare, good neighbour schemes, community living networks, time banks and peer support networks are all ways to supplement (and for some people ultimately reduce) the need for providing full formal support to all of those with care needs.

In residential settings, care is by its nature all encompassing (provided on site, round the clock, hand in hand with people’s accommodation). Achieving ‘just enough support’ will be particularly challenging in this scenario but is only likely to be achieved by facilitating residents to go out into their

community and build links, with the aid of community groups, faith groups, volunteers and peer support schemes, as well as bringing the community into the home itself. Not only are these activities likely to improve outcomes for individuals through greater independence and opportunities to build social networks, they are also likely to reduce costs – reliance on expensive formal support can be reduced and replaced by less costly community and peer support.

### Staffing

Personalisation does not just mean giving a person choice and control over the services they receive. It also entails *providing those services in a personalised way* – having a ‘personal touch’. Care users told us that being around people they knew and who knew them was an important part of life. We recommend, therefore, that providers of residential care and palliative care settings and domiciliary care look carefully at how they maintain the ‘personal touch’. We believe the personal touch is only possible if staff providing support get to know their clients well. This, in turn, can only be achieved if there is not a high turnover of staff or multiple staff members providing care. Providers must look at their recruitment and staffing strategies to ensure staff are paired with those they care for. A single key worker, or named nurse, is vital, as is contingency planning, so when a key worker is absent, a single alternative worker or nurse who is familiar to the person being cared for can step in.

Throughout this report we have seen excellent examples of people who do not have personal budgets enjoying personalised services. This has been aided by democratic decision-making structures, innovative designs of facilities, and the support of the wider community, but the critical factor has been a staff culture that enables personalisation. We recommend that training and guidance materials on how to deliver personalisation become standard practice across the care sector, but that particular attention is paid to personalisation for those with multiple and complex needs, in end of life care and residential health and care settings. It is in these contexts that personalisation can be most

challenging and staff working in these fields need to think more creatively about how to achieve it.

There must also be clear leadership which supports this approach. Local authorities and NHS commissioning consortia, as well as the Care Quality Commission, must be clear about their vision for ‘quality’ in care. The vision must not just look at the level of personalisation or personal budget structures in place, but also place equal emphasis on enablement and empowerment of individuals with complex needs. Commissioning strategies must support this by looking for providers who place emphasis on empowerment and self-care and incentivise this through contractual outcomes.

As well as training and leadership for existing staff, recruitment of new staff must also support personalisation. Providers and local authorities should ensure that those involved in recruitment policies at every level of care staff and social work emphasise that staff need *the right enabling and empowering attitude*, in addition to the appropriate skill set. Moreover, recruitment of staff without care backgrounds will be increasingly important in delivering personalisation.

### Personalisation at the end of life

End of life care is a uniquely challenging context for personal budgets, but we have seen that many specialist palliative centres are excellent examples of personalisation. We recommend that the good work being done by hospices and palliative care teams in teaching social care and NHS staff about end of life care should also include training about personalisation and holistic support. This should include advice on how to communicate about planning for the end of life and enabling people to articulate their wishes. Training in palliative care needs to be much more widespread among doctors, nurses and care home staff if those approaching the end of life are to enjoy personalisation regardless of where they die – be that at their home, in a hospital or a nursing home. Of course, there are still barriers to personalisation in end of life care – such as a lack of communication about end of life planning and the low take-up

of advance care plans – which need to be tackled. NHS reforms should be seen as an opportunity to embed good end of life planning as part of a community’s health and wellbeing strategy.

### The integration of health and care

Improving the integration of health and care is a vast topic, which would require a considerable amount of time to explore fully. There are many suggestions about how to improve integration in academic research and policy papers, and there is little value in reiterating them here. Nonetheless, in our research we identified two issues which are relevant to this debate:

- people tend to articulate their needs broadly, crossing over several service silos – when we asked what was important in life, people we spoke to often replied that maintaining their independence and family and friendships were most important to them, which can only be achieved when several services work together
- examples of successful integration thus far have been bottom-up, relationship based and local context-specific, and therefore highly variable

As we are now faced with significant structural reform to local health services, we therefore recommend that joint health and social care outcomes should be set under the auspices of new health and wellbeing boards, which clinical consortia and the local authority would be jointly responsible for delivering. This will not only resonate with people’s actual lives, but also give discretion to health and care professionals at the front line to develop their own integration solutions which are most appropriate to the local context.

Providers should also not underestimate the role they can play in reaching out to their NHS or social care counterparts to ensure their clients receive more integrated care – for example in co-locating health provision within residential care sites, and developing professional relationships between care providers and GPs and community health services as part of informal

integrative relationships. In the wake of potentially more complex local health structures, providers of care to those with complex needs and multi-agency support requirements will play an increasingly important role in helping to bring together services around their clients and navigate those systems on their behalf.

## Final thoughts

Through the course of this project we met many care users who enjoy independent and active lives, with care staff committed to giving them as much choice over their lives as possible. We have also seen care users dissatisfied with their opportunities in life, but displaying grim acceptance that rules and regulations had to come to bear and that these limitations were inevitable. Staff felt equally frustrated with such limitations, but could not see a financially sustainable solution to offering more personalised care. Neither group of care users was using personal budgets – and yet differences in care setting, staff approach, the use of co-design and wider community engagement all played a part in creating significant differences between them.

It is for this reason that we must move away from the narrow focus on personal budgets and the mindset which assumes that without personal budgets personalisation cannot be achieved. Personal budgets are just one of several tools to achieve personalisation, and they are less effective for some people than others. Personal budgets do not guarantee personalisation – just as an absence of personal budgets does not guarantee an absence of personalisation.

We must, therefore, invest more resources in exploring how personalisation can be achieved by other means, not just to enable everyone to enjoy the benefits of more person-centred support, but also to strengthen the personal budget agenda and make it more effective by applying additional tools alongside personal budgets.

The future success of the personalisation strategy relies on it becoming more inclusive. Everyone in need of care and support, regardless of their preferences, care needs, personal

capacity or care setting, should be able to enjoy the benefits of personalisation. But to achieve this, we must have a 'personalised approach to personalisation' – one where everyone can choose the method of personalisation that suits them.



# Introduction

This report explores the future of personalisation in the light of a shifting policy context. We are at a unique point in health and social care reform. Over the next two years we will see the publication and beginning of the implementation of the social care white paper, with a radical new care funding model and integrated social care statute. We will also see new local health infrastructure, with an end to primary care trusts (PCTs) and new health and wellbeing boards, a number of clinical commissioning consortia and a new palliative care funding strategy.

At the same time, the personalisation agenda is also gaining momentum. Most notably, local authorities will have to move from 30 per cent of care users with personal budgets to 100 per cent in this same two-year period. But as the roll-out continues, so harder-to-reach groups will be brought into the scheme – including those with multiple and complex needs and mental health needs, those in residential settings, older people, and those needing end of life care. As this happens, so the challenges and limitations of personal budgets will begin to appear.

In light of these developments, this report considers how the personalisation agenda will look in the future and how, most importantly, it can reach every care user group – regardless of their care need, the form of care they receive, and how it is funded.

We believe the future of personalisation must be more inclusive: personalisation must become more flexible and accessible to all care users. This will inevitably lead to broadening the current policy and political focus on personal budgets as the only vehicle for personalisation, and recognising that alternatives do exist, and may prove more suitable for some care users where personal budgets are currently encountering difficulties. In short, we need a personalised approach to personalisation.

The report will first, therefore, look at some of the limitations and difficulties of personal budgets, and in particular the current government preference for direct payments. In chapter 2 we identify the more fundamental obstacles to personalisation in its wider sense. We focus particularly on the barrier to personalisation for those groups for whom personal budgets may not be a viable solution. Obstacles we consider include a lack of integration between health, care and housing; the collective nature of residential care; and a lack of staff training in talking about end of life care. In chapter 3 we discuss how some of these obstacles are being overcome, drawing on the good practice we saw through the course of this research. Finally, in chapter 4 we look to the future of personalisation, presenting a series of policy recommendations, which seek to create a more inclusive personalisation agenda – by overcoming the obstacles to personalisation identified in chapter 2 and ensuring that the benefits of personalisation can be enjoyed by every care user – with or without a personal budget.

## The evolution of personalisation and personal budgets

*Personalisation...in social care...means there has to be a change of emphasis – from welfare to wellbeing; from passive clients to active citizens; from services which potentially create dependence to services that support independence; from a state which donates services to a state where people are in control of their own services; to a system where pluralism of providers creates choice for individuals.*

Dame Denise Platt, Chair, Commission for Social Care Inspection, June 2006

Personalisation is a relatively new term, but other phraseology driving at the same idea, such as person-centred care or person-centred support, has been part of the disability movement for many years. The development of direct payments was a key aspect of this.<sup>2</sup> At the same time, the concept of self-directed support was developed by In Control from 2003, which in turn was inspired by the Independent Living movement and

pioneered the use of individual budgets to achieve this aim.<sup>3</sup> These two parallel and connected narratives – self-directed support and individual budgets – heavily influenced the development of the Labour Government’s 2005 green paper,<sup>4</sup> which first coined the phrase ‘personalisation’. The subsequent 2007 strategy document *Putting People First*<sup>5</sup> placed personalisation at the forefront of the Labour Government’s social care agenda.

Within a few short years personalisation has become the lynchpin of social care reform and has gained cross-party support – surviving the election of a new government and becoming the first of the seven principles of the Coalition Government’s 2010 vision for adult social care.<sup>6</sup> With the Dilnot review of care funding and the Law Commission’s proposal for a new social care statute, this vision will form the basis of the social care white paper due in spring 2012.<sup>7</sup>

The vision document defines personalisation as:

*individuals not institutions take control of their care. Personal budgets, preferably as direct payments, are provided to all eligible people. Information about care and support is available for all local people, regardless of whether or not they fund their own care.*<sup>8</sup>

From this description, it is clear that personal budgets are central to the concept of personalisation. Personal budgets, whereby an individual is given their care funding as a cash sum or virtual budget to be spent as they see fit, have increasingly become the primary tool through which personalisation is delivered in adult social care. Again, the association first became clear in the Labour Government’s strategy *Putting People First*, which set out a series of milestones for local authorities, one of which was to achieve a 30 per cent take-up of personal budgets among council-funded care users by April 2011.

However the Coalition Government has shown even greater enthusiasm for personal budgets as a central platform of its personalisation policy, as can be seen from the description of personalisation above. In October 2010, in the spending review George Osborne announced that the Government was intending

to significantly extend the use of personal budgets across a range of service areas, including special education needs, support for children with disabilities, long-term health conditions and adult social care. This was reiterated in the Open Public Services White Paper.<sup>9</sup> *A Vision for Adult Social Care* also listed as its first priority to ‘extend the roll-out of personal budgets’ and announced a new milestone – that by 2013 all local authorities should have 100 per cent take-up of personal budgets, effectively ending local authority commissioned and delivered care services. It also stated that the preferred format of personal budgets should be a direct payment, wherever possible. This means individuals would be given funds to spend directly, rather than being passed to an intermediary as a managed budget or individual service fund.<sup>10</sup>

Personal budgets in health have progressed at a slower rate than personal budgets in social care, although the Coalition Government has added impetus to this agenda by investing £4 million to pilot personal health budgets in half of all PCTs in July 2010, giving people a monetary equivalent of their NHS treatment to spend on a wider range of health services.<sup>11</sup> A year on from this announcement, in July 2011, the NHS Future Forum, a group of clinicians, patient representatives, voluntary sector representatives and frontline staff convened to oversee the listening exercise for the government’s NHS reform proposals, stated in the report *Choice and Competition*:

*Personal budgets are very powerful tools in driving choice and greater control and could be particularly effective where people are receiving both health and social care services.*

*The current pilots of personal health budgets are welcome but do not go far enough and have not received enough support. We believe it is important for the government now to set out a clear ambition for the role that personal health budgets will play in the future. This ambition will need to recognise that healthcare is complex and personal budgets are not right for everyone. Some people will not want one; they may prefer to leave the decisions in the hands of their GP. But where it is appropriate, it is important that commissioners and providers are geared up to support people in using their budgets.*

*So to drive more progress, this report recommends that within five years all those who are eligible for a personal health budget should be offered one. This mirrors the entitlement in social care and will help ensure that all consortia see this as a core part of their role. Taking into account the evaluation of current pilots, delivery should particularly focus on the overlaps between health and social care and on integrated packages of care for long term conditions.<sup>12</sup>*

Therefore, over the course of this parliament, we may see everyone who is entitled to health and social care budgets being offered or using one, and for many it may take the form of an integrated budget.

However, this is still a long way off. As we explain further in chapter 2, converting the value of a service that is broadly free at the point of use into a cash equivalent, to give to people to purchase services, is not without its complexities. As the Department of Health explains:

*As personal budgets in health are new to the NHS, there are a lot of things we don't know about how they will work. For example we don't know if they will be right for everyone and we are using the pilot programme to look at this. We also do not know yet how they should be implemented in the NHS.*

*There are some practical issues which we are looking at during the pilot programme like how to set a budget, how to support people through the whole process, and how to develop the market of products and services you can choose from, so people have real choice.<sup>13</sup>*

So currently, personal health budgets cannot be used to purchase the type of NHS services the majority of people use most frequently – GP and hospital services – but rather those health services needed to support long-term health conditions (such as diabetes, chronic obstructive pulmonary disease, multiple sclerosis) as well as continuing healthcare (those with complex needs, in need of intensive nursing) or end of life care.<sup>14</sup> Long-term conditions often also imply ongoing social or personal care needs and it is likely that this is where the first integrated care and health budgets will be used in practice – particularly for the increasing number of people with social care

budgets, who may move to continuing and end of life care and ‘transition’ to a personal health budget. Indeed, investigating the integration of these two budgets is a specific aim of the personal health budget pilot evaluation, not due to complete until 2012:

*As part of the personal health budgets pilot programme we are looking at how to join personal budgets in health and social care together, to make them more efficient and easier for people to manage.<sup>15</sup>*

The personalisation agenda in Scotland and Wales differs from that in England – Wales’ ten-year vision for social care, released in February 2011 does not use the term ‘personal budget’ once.<sup>16</sup> Although Wales has a system of direct payments, and the strategy includes offering direct payments to all who want them, it focuses more on citizen-centred services and giving service users a role in running their own services. Some Welsh directors of social services admit they are still unsure what personalisation will mean in Wales.<sup>17</sup>

In Scotland, the agenda has progressed further, with a clearer vision – the Self Directed Support Strategy was released in November 2010, followed by the Self Directed Support Bill. Self-directed support is another term often used interchangeably with personalisation, though the emphasis is on people being in control of their own care – personal budgets are inherent to the concept of self-directed support in England.<sup>18</sup> The proposals in the bill, put out for consultation in spring 2011, included a system of ‘opt out’ instead of ‘opt in’ for self-directed support – in other words, self-directed support would be the default system for social care in Scotland. The Bill also proposes that self-directed support is defined in statute, along with a provision which will: ‘make it clear that direct payments are one mechanism within the options for self-directed support alongside the more traditional forms of support’.<sup>19</sup>

It is interesting that Scotland plans to recognise formally that direct payments (like Wales, it does not use the term personal budgets) are *one* form of self-directed support, but nonetheless, it seeks to increase the use of direct payments, as take-up is lower in Scotland than in England and Wales:

*The benefits of self-directed support, and particularly direct payments, are clear: it increases the autonomy of those who choose how their support should be delivered and enables packages to be tailored more closely to people's needs. At the same time, self-directed support will not be the best solution for everyone. Indeed some people may not welcome nor benefit from the increased control and the responsibility that comes with a direct payment or individual budget.*

*Despite a steady increase over the last ten years, the use of direct payments for social care remains low. On average, Scottish local authorities make less use of direct payments per head of population than England and Wales. The Government wants to build on the achievements made to date, remove any unnecessary barriers put in place by existing legislation and provide a clear and consistent framework to allow for development in the future.<sup>20</sup>*

It seems, therefore, that while England has progressed furthest in the personal budgets agenda, Scotland at least is not far behind in encouraging the use of direct payments.

It is unsurprising, then, that although the NHS Future Forum proposed choice in health through a 'right to challenge' and the 'right to provide', and Think Local, Act Personal (the successor of Putting People First, made up of a broad range of care providers, charities and other stakeholders<sup>21</sup>) is developing a wider personalisation work stream in social care to include collective action, personal budget pooling, social capital and family carers, many experts agree that the personalisation narrative in care, and increasingly in health, predominantly focuses on personal budgets.<sup>22</sup> For example, the Department of Health's *A Vision for Adult Social Care* states:

*A personal budget alone does not in itself mean that services are automatically personalised.*

*This requires a wholesale change – a change of attitude by councils and staff; reform of financial and management and information systems, and reduction of inflexible block contracts. People should get personal choice and control over their services – from supported housing through to personal care. Even those with the most complex needs can benefit from personalised services.<sup>23</sup>*

However, on closer inspection of this statement, it is clear the elements identified are not (with the exception of a change of staff attitude) barriers to personalisation per se, but rather barriers to personal budgets – the change of financial systems. Moreover, the text makes no mention of those living in collective settings (only those in supported housing to personal care). Even the final statement – ‘even those with the most complex needs can benefit from personalised services’ – references a Department of Health report, *Raising our Sights*, which examines how families of disabled young people had been able to personalise services primarily *through personal budgets*.<sup>24</sup>

Some are concerned that the Coalition Government’s thinking around personalisation in health and care has become narrow, relying considerably on the use of personal budgets to achieve it. As Beresford et al point out:

*Both self-directed support and personalisation can be seen as goals to be achieved, rather than methods to achieve them. Yet, so far, in discussions about the reforms intended for social care, the focus has tended to be much more on the detail and processes of the techniques identified to advance these objectives, than the objectives themselves.*<sup>25</sup>

The fact that the Government has set a target for English local authorities to ensure 100 per cent take-up of personal budgets in social care by 2013, and the NHS Forum has recommended a similar target for personal health budgets, rather than a target to achieve personalised services, adds credence to the theory that the process (personal budgets) is being confused with the outcome (personalised services).<sup>26</sup> There is so much faith that personal budgets will guarantee personalisation that delivering personal budgets is viewed as an outcome in and of itself. This gives a clear message to providers and commissioners – that rolling out personal budgets equals success in the achievement of personalisation.<sup>27</sup>

This is understandable. Personal budgets are the most visible, quantifiable and measurable aspect of personalisation – a concept that is itself highly subjective and hard to measure, based as it is on individual experience. While new attempts at

defining and measuring outcomes in social care are a potentially promising avenue, as they will enable practitioners and policy makers to evaluate to what extent service users' outcomes have been met,<sup>28</sup> these have yet to be incorporated into mainstream personalisation strategies and have not yet formed part of a wider measure of achieving personalisation (as distinct from achieving take-up of personal budgets).

There are a number of competing opinions on the interrelation of personal budgets and the personalisation agenda. At one end of the spectrum are those who believe personal budgets have been a distraction to the real spirit of personalisation – that the roll-out of personal budgets has in some cases been a tick box exercise without actually delivering greater personalisation. This group agrees that personal budgets work for some people, but that many people do not want a consumer choice as much as good quality services that listen to their needs (the Welsh government falls into this category<sup>29</sup>). Those at the other end of the spectrum believe personal budgets are a vital instrument to personalisation, though they recognise that personal budgets alone may not deliver it: personal budgets are 'necessary but not sufficient'. Those in the group between these two poles believe personal budgets are one of many tools that can deliver personalisation – they work extremely well for some people in some situations, but are not wholly necessary to personalisation for others.

In spite of these differences in opinion, it is clear that no one believes that personal budgets are a magic bullet for personalisation, and that other elements need to be in place to achieve it. If we use a robust definition of person-centred support (often used interchangeably with personalisation, though the latter is now the most commonly used phrase by English policy makers at least), we can see it requires a number of aspects to be in place:

- putting the person at the centre
- treating service users as individuals
- choice and control for service users
- setting goals

- the importance of the relationship between service users and practitioners
- listening to service users
- up to date, accessible information about appropriate services
- flexibility
- a positive approach<sup>30</sup>

Clearly, a personal budget alone cannot guarantee all of these elements – indeed, a personal budget is not necessarily required to achieve these at all. This report will therefore be written based on the assumption of the moderate view outlined above – that personal budgets are one of many tools to achieve personalisation. Pamela Mackenzie, a regional manager at Sue Ryder, articulated this very succinctly:

*Personal budgets simply won't always be feasible, perhaps due to the capacity of the individual or a problematic setting – I think there is something there around using alternative methods to achieve the same sorts of outcomes in terms of personalization.*

We should also bear in mind that the definition above of person-centred support is made from the individual's perspective – but to achieve some of these elements, the correct external conditions also have to be in place. These include:

- a range of health services to choose from – the Health and Social Care Bill first proposed radical duties to promote competition in health services to give people choice of 'any willing provider' and the extension of 'choose and book' services, though the NHS Future Forum has recommended these competition plans be scaled back
- a broad range of affordable support services for people to choose from; in the current care context, this is seen to be most effectively delivered through an established care and support market, and a market for universal services (eg leisure), which is accessible and does not discriminate against those with care and support needs
- accessible public services, such as transport and housing, and an accessible job market

- adequate resources so that support is not rationed (or indeed personal budgets are not set at an insufficiently low level to make purchasing sufficient support impossible)
- improved integration between key services – in particular, health, care and housing
- the availability of information, advice, guidance and brokerage so people know what services are available, what they are entitled to and – if they have a personal budget – how to best spend their resources

There is a real risk, however, that faced with a target for personal budget roll-out, the dominant narrative coming from the Government, and a time of tough finances, health and care commissioners and providers may forget that these additional internal and external elements are necessary for successful personalisation and focus on achieving just one thing – the 100 per cent take-up of personal budgets in health and care services.

Indeed if ‘personalisation’ is increasingly viewed as ‘personal budgets’, a number of negative side-effects may result. The first is a risk of complacency – once a personal budget has been given to an individual, his or her support may automatically be seen as ‘personalised’, and no further work needs to be done to ensure this is the case through the other elements outlined above. The second is that those less able or willing to engage with the personal budget process may find themselves overlooked and somewhat excluded from the personalisation agenda.

This second issue is of particular relevance to commissioners and providers dealing with groups of care users in residential or other collective settings, using services that cross health and social care, and those with complex needs, for whom personal budgets can be more challenging to deliver.

We cannot deny that personal budgets have been hugely important in making life-changing differences to people using care services and also to the system as a whole, in being a driver in the shift from a service-centred, paternalistic care system to one where self-assessment, co-production and the achievement of outcomes are increasingly the norm. Personal budgets can

coordinate services at the point of use, they can improve quality of life and delivery around outcomes, and they are almost universally appreciated by those who use them. Becoming one's own care commissioner also gives a sense of control and empowerment to groups who have been passive and silent service recipients for decades.

But it is clear, as outlined above, that even the greatest proponents of personal budgets recognise that they are necessary but not sufficient for personalisation. Several other factors have to be in place. While we would never suggest denying people the chance of using a personal budget, we must recognise that for some people and in some situations personal budgets may not be the most effective method of personalising services – something the Government recognises in healthcare, but less so in social care.

Now is the time to ensure personalisation is available to all. Both the health and social care systems are undergoing a period of radical reform. The social care white paper, due in spring 2012, could usher in an entirely new funding system, based on the individual contributing towards the initial costs of care up to £35,000 followed by the state then stepping in.<sup>31</sup> It could also see a new definition of community care and a legal framework based on outcomes, rather than services.<sup>32</sup> Both of these developments may generate new opportunities for personalisation – not least the inclusion of universal services within its scope. At the same time, reorganisation of health commissioning and delivery at local level could potentially create a wider choice of providers and opportunities for 'choose and book' and personal budgets in more health settings, but equally, it could create a more fragmented and complex system for those people whose needs cross health and care services. In July 2011 the Palliative Care Funding Review recommended among other things a palliative care tariff so that levels of funding are standardised for different levels of need and 'follow the patient' across different palliative care settings – allowing greater flexibility and choice of care package and potentially paving the way for a greater use of personal budgets.<sup>33</sup> The ten-year social care strategy for Wales and the Self Directed Support Bill in Scotland have also been

published this year – both presenting slightly different interpretations of the personalisation agenda (indeed, neither even adopts this term) but nonetheless a commitment to its person-centred principles.

Therefore, while the concept remains unchanged, the implementation of personalisation is now very much on shifting sands. How it will look in the future – with a new care and health regime, and set in the context of other highly influential public service reform agendas such as on localism and the Big Society – has once again become an open question. Rather than narrowing the debate to focus on personal budgets, there is now an opportunity to open it up and bring in concepts which are beginning to thrive under the new public service regime – such as collective decision making, co-production, community development, reciprocity and social entrepreneurialism.

It is critical that if we are to achieve universal personalisation (though not necessarily 100 per cent take-up of personal budgets) we have to make sure these alternative routes to personalisation, and those elements that supplement personal budgets in being an effective personalisation tool are nurtured with equivalent force as personal budgets themselves. The work of Think Local, Act Personal on community development is a positive step in the right direction, but we need to go further, and ensure this is as well recognised by practitioners and commissioners as the personal budget target itself. A wider, more inclusive model of personalisation, which works for every care user and in every care setting, must be integral to the NHS and social care reform plans ushered in over the course of this parliament.

## Methodology

In exploring the future of personalisation, we drew on four sources of evidence. The first involved a review of existing research and policy development around personalisation in England, Scotland and Wales, as well as a review of the recent data on the use of personal budgets in health and social care in England, where the personal budget agenda has progressed the

most. This was enriched by new qualitative research with care users themselves: we carried out three focus groups with care users, two with adults with learning disabilities and mental health problems in semi-supported and residential-nursing care, respectively, and one with adults with neurological conditions, some of whom were living in a residential home, and some of whom were using a day centre in the home, but living in the community. We also interviewed day patients and staff at a day therapy unit for those needing end of life care, and a residential facility in Scotland for those with neurological conditions. We asked about the services they used and the integration between those services, the level of personalisation they currently enjoyed and what they would like to have, and what aspects of their lives they felt were most important.

We also interviewed a number of care staff, delivering services on the front line, as well as care centre managers and senior staff within Sue Ryder to gain a wider perspective of the challenges of personalisation across Sue Ryder's client groups, including those needing end of life care.

Finally, we drew together evidence of good practice, through desk-based research and by interviewing care commissioners and directors of adult social services, in areas leading the way on integration of health, social care and housing. These areas are North East Lincolnshire Care Trust Plus, Herefordshire, Sutton, Essex and the South Essex Coalition.

# 1 The limitations of personal budgets as a tool for personalisation

## Can personal budgets achieve what people want?

At its heart, personalisation is about supporting people meet the outcomes they themselves value and want to achieve. The Social Care Institute for Excellence uses the following working definition:

*Personalisation means thinking about care and support services in an entirely different way. This means starting with the person as an individual with strengths, preferences and aspirations and putting them at the centre of the process of identifying their needs and making choices. It requires a significant transformation of adult social care and jointly provided services so that all systems, processes, staff and services are geared up to put people first.<sup>34</sup>*

However, there is a substantial body of evidence which shows that people articulate their needs, preferences and aspirations not in neat service silos, but rather in broad outcomes which, by their nature, require multiple services if they are to be achieved.

The Joseph Rowntree Foundation, for example, has carried out extensive studies including the programmes A Better Life and Shaping our Lives,<sup>35</sup> looking at what really matters to older people with high support needs and working age adults with learning disabilities, mental health needs and physical impairments. Such studies have concluded that people's wants and needs are almost always expressed in the form of outcomes rather than types of services. People participating in these studies did not express their needs and wants in terms of health or care, but rather in a series of broad aspirations related to quality of life, which touched on health, care, housing, transport, employment, income and benefits, and broader issues around discrimination

and equality.<sup>36</sup> While every person's desired outcomes are inevitably different, the Joseph Rowntree Foundation identified some common themes that are important to most people, for example: personal identity and self-esteem, a desire for an 'ordinary life' and independence, social and intimate relationships, and a sense of belonging to and participating in communities and wider society.<sup>37</sup>

Our own research with service users supports this finding. We asked each person we spoke to what was the most important thing in their life – the most common answers were:

- retaining my independence
- having a job or volunteering
- maintaining links with my family
- being with people I know

It is striking that none of these points relies specifically on having a personal budget. While they imply greater control and autonomy, which personal budgets can certainly help deliver, there is nothing in this list that cannot be achieved *without* a personal budget. The question we must ask is whether personal budgets are the most effective way of achieving these outcomes for every person in need of health and social care support.

### Personal budgets stimulating markets and integrating services

The most important things in people's lives, listed above, do not specify a type of care, or a specific service. However, such goals may often require multiple services to work in unison to achieve them. As we explained in the introduction, one of the key 'external conditions' of successful personalisation is greater integration of services, with the integration of health, care and housing being especially important.<sup>38</sup>

So another important question is whether personal budgets are powerful enough to enable people to achieve multi-service integration, and in turn deliver the outcomes they want. Paul Burstow MP, the minister for social care, suggests this is

possible: in a speech given at the launch of personal health budgets in December 2010, he announced:

*[Personal budgets] can also help us bring health, social care and the voluntary sector together in ways we've not seen before. I want a much stronger focus on integration between organisations than in recent years. And through personal budgets, we've now got the chance to put the tools of integration in the hands of individuals themselves.<sup>39</sup>*

This would suggest the power to integrate services lies in the 'care consumer' who, through the sheer force of their purchasing power, will be able to lever the care, health, housing, transport and other systems to work around them as an individual commissioner. This is clearly conceptually related to another belief – that the care consumer, armed with a personal budget, will stimulate the health and care markets so that supply is created to meet new demand.

In reality, neither of these outcomes are assured. 'Care consumers' will not be operating in a perfect market, and it is highly unlikely that a health and care market will spring into life and be responsive to the individual purchasing decisions of individual personal budget holders – particularly if providers do not have the wherewithal to identify and respond to market signals, as they are accustomed to primary care trust (PCT) commissioning or local authority block contracts. The National Market Development Forum, hosted by Think Local, Act Personal to help local commissioners stimulate their social care markets, clearly indicates that an underdeveloped market has been recognised as a potential barrier to personalisation, which requires more than consumer spending to resolve.<sup>40</sup> A similar concept called 'market making' has been proposed by the NHS Future Forum for inclusion in the 'choice mandate' of the Health and Social Care Bill, which includes reducing barriers to market entry for new health providers.<sup>41</sup>

'Care consumers' are also unlikely to be able to lever the NHS, local authorities and housing providers, not to mention other services, into joint coherent working, without some additional 'supply side' or 'top down' reform to how these

systems work together on the ground. However, and unlike moves towards market development in health and social care, improving the integration between these markets has been much slower and less successful, despite several years and different attempts to achieve this. It is also possible that current NHS reform may make this process more challenging by increasing the number of actors in the health sphere (with clinical commissioning consortia and health and wellbeing boards vying for leadership), making navigation and integration more complex, and undermining some of the good practice that has been nurtured of joint working between local authorities and PCTs.

In addition, the third key component of integrated support for those with health and care needs – housing – is very often overlooked in attempts to improve integration. Funding for Supporting People (housing related funding to support vulnerable people to live as independently as possible in the community) has been cut by up to 60 per cent in some areas,<sup>42</sup> while one of the key measures of its quality, the Supporting People Quality Assessment Framework, had been terminated.<sup>43</sup> The Association of Directors of Adult Social Services has reported that some housing providers are leaving the Supporting People market, because they lack confidence in local commissioning intentions and have lost funding when block contracts were being replaced with personal budgets.<sup>44</sup>

Taking all this into account, it is possible that the integration of housing, care and health may be taking a step backwards in its very tentative progress under the combined weight of budgetary cuts and structural reform. It is clear that personal budgets will not be powerful enough on their own to stimulate a vibrant market of care and support services, nor integrate monolithic systems of health, care, housing and other services into a seamless package. A holistic, multi-agency package of support coordinated around the individual is the mark of truly successful personalisation, but it is clear personal budgets alone cannot achieve this.

## Personal budgets and bureaucracy

While these first questions – whether personal budgets can actually achieve the outcomes people want and can integrate services – point to potential limitations of personal budgets at a conceptual level, there are also more pragmatic challenges to how personal budgets are being used on the ground.

For example, the recent personal budget survey by the Association of Directors of Adult Social Services found that most councils in England hit their Putting People First target of ensuring a 30 per cent take-up of personal budgets among care users and carers by April 2011, but that two-thirds of personal budgets were managed by local authorities, as opposed to given to service users as a direct payment. This led to concerns that personal budgets are offering little more than a traditional service. Julie Stansfield, chief executive of In Control, the organisation that pioneered self-directed support, said: ‘It is critical that local authorities remember that personal budgets will only deliver good outcomes for people if they truly offer choice and control and do not simply become a “box ticking” exercise.’<sup>45</sup> Further analysis of a survey by Think Local, Act Personal and In Control found that those managing their own budgets, with direct payments, reported much better outcomes than those with council managed budgets – making local authorities’ extensive use of managed budgets problematic.<sup>46</sup>

The same survey also uncovered problems with the personal budget process – that it was too complex at present, with respondents reporting a lack of information on what their budget could be spent on, and difficulty in getting their needs assessed and taking control of the planning process and spending of the budget. Between 13 per cent and 24 per cent of respondents reported that their local authority had made it difficult or very difficult to secure and manage a personal budget.<sup>47</sup>

These findings are supported by the 2011 personal budget survey of social care professionals by Community Care, which found that a quarter of respondents said service users faced a ‘high level of restrictions’ in using their budgets for holidays; 13 per cent said this was the case for computer equipment or attending sporting or entertainment events, and 10 per cent for participating in sport.<sup>48</sup> According to government guidance,

personal budgets can be used for all of these sorts of items, to achieve the outcomes a care user specifies in his or her care plan. Indeed, Paul Burstow MP, the minister for social care, said in September 2010 about personal health budgets:

*What we're going to be saying is that it's not about spending more money. It's about focusing on what matters. If [people] want to spend £350 [of a personal budget] on a laptop and that allows them to reconnect with their friends if they have a disability and have not been able to leave the house – we recognise it's the small things which make a huge difference.<sup>49</sup>*

Three-quarters of the professionals responding to this survey also said they had to deal with more bureaucracy as a result of personal budgets. Jeff Jerome, lead for personalisation at the Association of Directors of Adult Social Services, responded to the results by stating that the level of bureaucracy was one of his 'biggest worries' in the implementation of personalisation,<sup>50</sup> while Simon Duffy, one of the architects of the personal budget system, spoke of 'managerial nonsense' in determining the value of personal budgets through assessment.<sup>51</sup>

## Personal budgets and 'free' services

Services that fall within the remit of social care (including personal and community care) are means tested in England and Wales. A person must be on a low income and have sufficient need for care and support in order to receive social care funding from their local authority. Many people, therefore, have to pay for part or all of their care. As this system has been in place for a number of years, social care commissioners and providers have become accustomed to pricing care packages (domiciliary care hourly rates, residential bed fees and so on). For commissioners, this has been important to calculate how much funding the local authority will provide, relative to the individual who may have to provide partial funding for their care package. For independent providers, this is important as their services have hitherto been (and some still are) commissioned from the local authority – knowing how much each service costs is vital when it comes to

winning contracts. Also, self-funders – people purchasing their own social care – are a significant (and growing) proportion of the population and this group obviously needs to know the price of services.

However, this is not the case when it comes to NHS services, most of which have been free at the point of use since the system's inception over 60 years ago. While individual health services, operations, inpatient and outpatient procedures, drugs, and so on are all costed by the PCT, hospital trust and so on for procurement purposes, these have not been priced at an individual purchaser level. Pricing a package of health care for an individual to then 'commission' from individual health providers, who have hitherto delivered 'free' services to their patients, requires some detailed thinking and reworking of financial structures to allow funding to be disaggregated in this way and 'follow the patient', so to speak. As the Department of Health states,

*Setting a budget is one of a number of key practical and operational challenges being explored within the personal health budgets pilot programme. We currently do not have enough information on the cost of NHS services at the level of individual patients to say how this should be done.<sup>52</sup>*

As currently piloted, personal health budgets are often being used to purchase easier-to-cost *care and support services*, by those people who happen to be entitled to NHS funding (eg those with continuing care needs or mental health needs), rather than to buy what many might think of as health services. The Government has already stipulated that personal health budgets cannot be spent on emergency health services (A&E) or on the services you might receive after an emergency (eg x-rays, plaster cast). It also cannot be spent on GP services or prescriptions. Also, people are not able to add their own money to their personal health budget, as – and unlike in social care – 'You cannot spend your own money on your NHS care.'<sup>53</sup>

We could create a situation, therefore, where people with care and support needs are given more freedom to use a personal budget combined with their own resources when they use a

personal (social care) budget, but are more restricted in this regard when they become eligible for NHS-funded care and receive a personal (health) budget.

These and other complexities related to the costing of a 'free' service (eg creating a large enough market for health services to offer choice, but one that can be coordinated readily with NHS primary and acute care) may make personal health budgets more restrictive than first envisaged.

### Personal budgets and harder to reach groups

It is widely recognised that the take-up of personal budgets not only varies significantly between groups, but also that enthusiasm to use them and to depart from traditional care models also varies. For example, the personal budget survey of English local authorities by Community Care, mentioned above, also found that older people and those with complex or mental health needs continued to be overlooked in the roll-out of personal budgets, with 10 per cent of older people having a personal budget in 2010, along with 5 per cent of mental health service users, compared with 23 per cent of adults with learning disabilities.<sup>54</sup> Further work by Mind, the mental health charity, identified a range of barriers to personal budgets being used by those with mental health needs, including paternalism and risk aversion by mental health teams leading to service users not being told about or offered personal budgets, plus a lack of specialist advocacy and support to enable those with mental health needs to manage their budget.

Nonetheless, those who had managed to access a personal budget had higher levels of independence, accessed more mainstream communities, and were more likely to have an individual programme of support in the community.<sup>55</sup> Demos' own research found that younger care users and those with learning difficulties were more enthusiastic about personal budgets to facilitate changes in their care packages, while older people, those with mental health needs and some black and minority ethnic groups were less enthusiastic, concerned about the administrative burden, and less willing to consider changing

their care even when they were unhappy with it.<sup>56</sup> As a result, the personal budget agenda is potentially passing some groups by – either by their own choosing or perhaps because of assumptions made about their desire or ability to use a personal budget. And this is not an English problem – in Scotland, just 2 per cent of those with direct payments have mental health needs.<sup>57</sup> Overall, Scotland’s low take-up of direct payments (there are 30 times fewer people with direct payments in Scotland than England)<sup>58</sup> is one of the reasons why Scotland’s Self Direct Support Bill proposes making self-directed support (and primarily direct payments) the default option for care users.<sup>59</sup>

There are also many care contexts where personal budgets are proving challenging – for example in residential or communal living settings, and in palliative care. At the moment direct payments are not available in residential care, although other budgets are (in theory at least), whereas, as we explained above, personal health budgets have their own particular difficulties, and are not sufficiently widely available to make inroads into palliative care settings.<sup>60</sup>

Beyond these technical barriers is a more fundamental question – addressed in more detail in the next chapter: are personal budgets fundamentally incompatible with collective care settings? Personal budgets are, after all, a tool for an individual to exercise consumer-style rights regarding their support package, but if that person lives with a group of people, who each might want to spend their budgets on different services and potentially change their accommodation in different ways, an impasse may be inevitable.

It is possible, therefore, that personal budgets may not be the most effective way of achieving personalisation for residents of care homes, nursing homes, hospices and even smaller rehabilitative units, as they are a vehicle more suited to those receiving care and support in their own homes.

### Personal budgets and cost cutting

As the personal budget roll-out is coinciding with unprecedented levels of cuts to local authority funding, there are concerns that

personal budgets will be used to systematically reduce local authority spending. Recent work by Demos has found a growing minority of local authorities are placing a ‘deflator’ on their personal budgets – giving a personal budget value of up to 25 per cent lower than the monetary equivalent of the care a person needs, based on their assessment.<sup>61</sup> One local authority explicitly stated that the value of their personal budgets were 20 per cent lower than the value of the care they had previously provided, because evidence had suggested personal budgets were 20 per cent cheaper.<sup>62</sup>

In fact, there is limited evidence to suggest the value of services bought by individuals with personal budgets will be cheaper than when local authorities deliver it themselves. Studies tend to be based on small samples and findings are not always statistically significant.<sup>63</sup> As a research briefing by the Social Care Institute for Excellence explains:

*There is virtually no reliable evidence on the long-term social care cost implications for individual budget schemes for the UK. Equally there is no firm evidence on the actual cost effectiveness of individual budget schemes apart from indications that they appear to cost less when compared with the monetary value of traditional packages. Policy is based on the assumption that individual budgets should be at least cost-neutral and some authors have speculated that the long-term effect could mean savings for public services in general, especially health.*<sup>64</sup>

This is certainly a tenuous evidence base on which to implement a universal reduction and it is very possible that some care users will spend less with a personal budget than the value of the care they were receiving directly from their local authority. But this is not guaranteed for every group. Moreover, individual budget holders will not enjoy the economies of scale that comes from being a dominant purchaser in the market, a position local authorities have been able to use in the past to push down prices by buying in ‘bulk’ (eg thousands of care hours, hundreds of residential places).

Think Local, Act Personal’s Common Resource Allocation Framework<sup>65</sup> also provides a guide for local authorities to set the

monetary value of a personal budget according to a person's need. Most local authorities now use this model or a variation of it. One aspect of accepted good practice in the framework is to set a 'contingency' level – a proportion of a person's personal budget is set aside so that, should they have fluctuating needs or for some reason need to spend more than their allocation, a contingency fund is available for them to do that without a drawn-out process of reassessment. The Framework leaves it to the discretion of local authorities to set their own level but suggests within the region of 15–25 per cent of the budget total is a reasonable contingency, with an expectation that this will be reduced as personal budgets are embedded in the system and assessments become more expert in allocating the correct amount to each individual.

However, it is difficult to see how a contingency may not be used to disguise a universal decrease in personal budget values as an efficiency saving. For example, if a care user requires care worth £100, local authorities will not set a 20 per cent contingency *on top of* that amount (and give a person £100 and £20 reserve). They will instead give a person £80 (£100 minus 20 per cent) and leave the remainder as a contingency.

Demos has found around a fifth of local authorities are now applying some sort of deflator to their personal budgets in social care.<sup>66</sup> This lends credence to anecdotal evidence from front-line practitioners, expressed in forums like Community Care Space and by Unison,<sup>67</sup> that personal budgets are being systematically set at a lower level than the actual value of care needed. It is also easy to imagine a similar operating model being applied to personal health budgets, where a nascent market and the costing of hitherto uncosted health packages could see an 'efficiency' automatically built in to the cost calculation. Certainly, most personal health budget pilot sites anticipate cost savings as a result of rolling out health budgets,<sup>68</sup> but there is a difference between anticipating savings and manufacturing them.

## The importance of small (and big) things

Another potential limitation of personal budgets is that some seemingly trivial things – which may fall beneath the radar of a personalised care plan and allocation of funds – are centrally important to a person's quality of life. The project *Small is Beautiful* by the National Council for Palliative Care, for example, emphasised the importance of small details in improving the quality of palliative care. Examples provided from the people they surveyed included having food cut up into very small pieces and giving relatives a cup of tea. These are dependent on the quality of staff and an attitude of personalised care – not something that can be levered by a financial mechanism. Indeed, if we consider those aspects of life the care users we spoke to told us about:

- retaining my independence
- having a job or volunteering
- maintaining links with my family
- being with people I know

It is clear that the last two at least – maintaining links with family and being with people you know – are not particularly radical, nor are significant resources required to achieve them. It is not necessary to have a personal budget to achieve any of them, and realising some of these may fall outside the remit of a personal budget care plan.

Certainly some of the 'small things' that were raised frequently by these care users, including redecoration of rooms, timing of activities, food and so on, may not be captured on a care plan, particularly a care plan for someone with complex needs in a residential setting who may have significant social care and health input. The methods they cited for having made these small changes ranged from formal residents' meetings through to informal one-off requests. One care user told us: 'When I first came here, the vegetables were all tinned or frozen, and we had this big push for fresh vegetables, and we have actually got them now, so it did work.'

Therefore, while a personal budget may be effective in personalising the 'big things' (eg the type of care provided, the

time a carer visits), they should not replace or be an excuse not to engage in other channels of communication or other personalisation mechanisms, to ensure the ‘small things’ are also taken care of informally (rather than at a formal care plan review). These channels will differ for different groups, but it is not guaranteed that the ‘small things’ will be taken care of simply through an informal chat with a carer. This is particularly the case for those in residential or palliative care settings, or for those with complex needs, mental health conditions or older people where communication may be a problem. As Fiona Fettes, care service manager of Dee View Court (a Sue Ryder residential care setting for those with neurological conditions), told us:

*Some people we can work out what they’re saying by gestures, and that works, but when people can no longer communicate it can be hard, but if we’ve known them for say eight years, and we know their families, we know what they like... so we keep going with that.*

This comment emphasises the value of personal relationships between carers and those using care services – something the care users we spoke to often told us about. When they described the importance of ‘being with people I know’, care users were referring as often to peers as to care staff. Personal relationships are particularly important for those with deteriorating conditions or those where the ability to communicate or actively choose declines, so that wishes and preferences can still be acted on based on that personal knowledge – something we discuss further in chapter 3. While it is possible that a personal budget could help foster such stable personal relationships, for example by using a personal budget to hire a personal assistant (who may already be a friend or a relative), rather than relying on home carers, we must remember that the *quality of relationships* and people ‘knowing what you like’ are nothing really to do with the way in which a person receives their care funding.

By placing too much emphasis on the importance of small details, there is a risk that practitioners will overlook the bigger picture and neglect people’s wider aspirations for their quality of

life. This had certainly occurred to those setting policy at Sue Ryder – one said ‘personalisation is not all about shampoos and food. You [have to] think about where someone has come from, where they want to get to, and I think all we had dealt with, at that time, was the present.’

A Sue Ryder residential home manager recognised the potential difficulties in looking at the bigger picture of aspirations and not being able to deliver on the promise:

*If we start talking to them about what's important, their hopes and dreams and things, we have to be able to deliver. And that is what worries me. Because we've got to be clear what our limitations are.*

In this particular instance, limitations that were concerning this manager included a lack of resources to personalise (shortage of available staff to undertake individual activities and outings), but more fundamentally, the constraints of the collective setting in which the residents lived. It was recognised that achieving the ‘big things’ – hopes and aspirations for a better life – would almost inevitably entail a move to supported or independent living from residential care, which was not a straightforward process. We discuss this further below.

Yet even taking these caveats into account, we should still not underestimate the value of the ‘little things’ and the risk that personal budgets in care and health cannot deliver on them. Not just because small touches are important in and of themselves in improving quality of life, but also because they have an important psychological impact, particularly in residential or small unit settings. This is because being able to control or affect the things around us contributes to *environmental mastery* – being able to manage the demands of everyday life and feeling in control of our surroundings – which is one of the building blocks of psychological wellbeing. A study by Knight et al found there was a clear link between level of environmental mastery and depression among older people living in residential homes, emphasising the need for opportunities for decision making and taking control as an important element in improving mental health for those living in settings where they may be dependent

on others.<sup>69</sup> Another study by Haslam and colleagues cited evidence showing that these opportunities for control need not be ‘big things’ to have a positive psychological impact – the process of engagement and ownership of decisions was the crucial factor:

*If residents are to have a sense of freedom and choicefulness, they need to be trusted to make at least some of their own important welfare decisions, eg choosing bedtimes, leisure activities, meal choices and seating arrangements. Enabling such choices helps ensure that those who reside in care homes feel in charge of their living space and are not controlled by it. Evidence also suggests that engagement with, and a sense of ownership of, a home’s physical space contributes to a sense of social belonging. Further, the devolvement of responsibility amongst older adults feeds mutual respect, strengthens social ties and may improve physical wellbeing.<sup>70</sup>*

The study went on to test this theory by carrying out an experiment in a new care home, where residents on one floor were involved in decisions about its decor, and residents on another floor were not. Their findings showed that the former group identified more with staff and fellow residents, displayed more considerate ‘citizenship behaviour’ towards those sharing the communal space, and made more use of the communal space. The former group also reported higher levels of wellbeing than the latter group who had not been involved in deciding the decor. These effects were still found four months after the initial observation.<sup>71</sup>

Such evidence raises important questions about the most effective form of personalisation in collective settings. The people in this study were empowered and enjoyed the psychological benefits of choice and control without the use of a personal budget – so, are residential homes doing enough to ensure their residents can ‘own’ their environments and exercise collective decision making, either alongside personal budgets, or where personal budgets are not used? This form of personalisation is rooted much more in the concept of co-production<sup>72</sup> than the consumerism of personal budgets – an issue we explore in the following chapter.



## 2 The barriers to broader personalisation

The limitations of personal budgets do not mean personalisation is doomed to fail. As we have explained above, personal budgets are but one vehicle for personalisation. While they have been hugely beneficial and nothing short of life changing for some groups, and have also helped galvanise policies around person-centred support, personalisation can be achieved in their absence. As we discuss below, specialist palliative care is a good example of how highly personalised support can be delivered without personal budgets, but the ideas around choice and control in health services, as proposed by the NHS Future Forum, also describe credible alternatives to personal budgets in the achievement of personalisation.<sup>73</sup>

Therefore, we should try to overcome the barriers to the effectiveness of personal budgets presented above, but *we should be far more concerned* about the challenges that personalisation – in its widest sense – faces in the coming months of budgetary constraints and significant reform to local health and care services.

In this section, we consider these challenges. In particular, we focus on the potential obstacles to personalisation for the groups of care users and care settings identified above as being potentially beyond the reach or less compatible with personal budgets (eg those with complex needs, in residential settings and needing end of life of NHS continuing care). What is stopping them from achieving those outcomes they told us were most important to them? Things like:

- retaining my independence
- having a job or volunteering
- maintaining links with my family
- being with people I know

We focus on these groups of care users because they are likely to be more affected by the obstacles to personalisation in its broader sense, as they are less likely to be able to rely on personal budgets. Many of these issues will also be highly relevant to self-funders of social care – another group excluded from the personal budget agenda.

We draw on new evidence from interviews and focus groups with care users themselves – those with mental health needs, learning disabilities, neurological conditions, life limiting conditions and communication difficulties, as well as a range of care and management staff, in settings ranging from semi-supported shared houses through to residential and nursing homes, a hospice and a psychiatric unit. We also spoke to a number of Sue Ryder regional and senior managers about the challenges they face as a provider offering primarily residential care to a client group with complex or end of life support needs.

## Funding

Many of the practitioners and professionals we spoke to were concerned about the current economic situation and tightened budgets across a range of social and other services. It cannot be denied that inadequate funding in social care has led to increasingly tightened eligibility criteria, so that around 80 per cent of local authorities only provide care to those in the top two categories of need – substantial and critical. Not having any financial support from the state to meet one's care needs can make questions around personalisation academic. Inadequate funding can also lead to poor quality care, which again fundamentally limits the impact personalisation can have in improving people's quality of life.<sup>74</sup> A recent survey by Community Care of social workers and practitioners found that 83 per cent said cuts to adult care budgets in their areas would impede personalisation and 33 per cent said resources had been the greatest barrier in making progress in implementing personalisation.<sup>75</sup>

However, we should treat these figures with caution. We must remember that reduced eligibility for state funding means *fewer people will have personal budgets*. If many people conflate

personal budgets with personalisation, then restricted access to personal budgets will instantly reduce personalisation. However this suggests that the growing numbers of people not eligible for state support and therefore not entitled to a personal budget – the self-funders – are automatically cut off from the personalisation agenda. It is difficult to interpret from these statistics whether the respondents to the survey were thinking about reduced numbers of personal budgets, and reduced values of personal budgets, when they said funding was a major barrier to personalisation, or if they were thinking about personalisation more broadly, and the need for adequate funding to deliver it.

In reality, resource constraints are likely to limit personalisation in two ways: by reducing people's eligibility for personal budgets, which are a vehicle for personalisation; and, more importantly, by making personalisation in its widest sense more difficult because of lack of resources. The professionals and care users we spoke to during the course of this project raised issues including lack of staff and resourcing for 'extra-curricular' and 'low level' activities, which are so vital to meeting people's desired outcomes, as well as pressures from commissioners to reduce costs. We describe them in more detail below.

Personalisation requires a broader, holistic view of a person's desired outcomes and preferences. As our own research about what people find important in life demonstrated, these very rarely fall into the neat categories of health or care, and will in particular bring in concepts such as independence and maintaining friendships and meaningful relationships – the keys to a 'normal life'. To achieve these, people must be supported to pursue hobbies and interests, and have opportunities to socialise and engage in leisure pursuits in the community. But in a tightly resourced environment, these activities may be seen as luxuries that people cannot afford. These are commonly thought to be 'lower level' or 'preventative' activities, which are excluded from state-delivered care packages in areas where funding is only provided for those with substantial or critical needs. This also holds true for personal budget holders. While, arguably, they have more freedom about how to spend their budget, so someone with substantial needs could spend it on anything they

want, including activities or support deemed ‘low level’, in practice someone with substantial needs is likely to require a considerable amount of care and may therefore find the amount they are given in their budget only just about covers their basic care costs. This leaves no additional income to meet their broader aspirations through ‘non essential’ activities.<sup>76</sup>

### ‘Extra-curricular’ activities

Staff at The Chantry, a Sue Ryder home in Suffolk, actively sought to provide ‘lower level’ support to people with its ten-week ‘5Rs’ programme for those with multiple sclerosis. This programme includes taster sessions of therapeutic activities, such as yoga, reflexology, acupuncture and music therapy, along with specialist health information delivered by a specialist nurse, educational and IT classes, and sessions on benefits eligibility. At the end of the ten weeks, people are encouraged to pursue a college course, hobby or therapy they have enjoyed. In spite of being recognised by the Department of Health as a case of good practice and aimed at prevention when it was established in 2008, the service has no statutory funding, delivered as it is to many people who fall below the eligibility criteria for state funded care.<sup>77</sup> The course is currently lottery funded, but those running the scheme are now hopeful that people will choose to pay for it if they are entitled to a personal budget (subject to the potential funding restraints above – after the local authority cuts, the value of personal budgets may be set too low to enable people to buy such ‘non essential’ support).

Some of the residential care staff we spoke to felt they were limited in what they were able to provide above and beyond the ‘core care package’, other than a limited menu of social activities. They explained that ‘total’ personalisation for those in residential care would require a one on one relationship with a personal carer, who would be able to take their client into the community and accompany them in anything they wanted to do.

This is the position of some care users with personal budgets employing their own personal assistants – the numbers of personal assistants has grown by 35 per cent over the last year,

as a result of more people having a personal budget.<sup>78</sup> But this may not be financially viable for those with more complex needs, who require more intensive one to one support or indeed two to one support, as well as those living in residential or nursing homes. Staff costs may simply outstrip the available care funding – or the value of a personal budget – if round the clock one to one support were purchased (indeed, this is the case now where councils place some people with the most complex needs outside their personal budget resource allocation system, recognising their needs do not fall into the established point scale used to allocate budgets). Some of the residential settings we visited recognised this staff-related constraint. Pamela Mackenzie, a regional manager at Sue Ryder based at Dee View Court, explained:

*Some people say, can I go out this afternoon, can I go into town, and we can't make that happen because of our limitations, we don't have the staff and support.*

*We used to have programmed activities, but we're using a more personal approach now. It's about the individuals and what they want; it's not just a calendar of activities now, it's a personal approach to it... It is much more labour intensive, you then have to spread yourself a bit thinner and say 'we can do this every two weeks and not every week'.*

In chapter 3 we describe how some residential providers are overcoming this by using volunteers and community groups more effectively.

One group of residents we spoke to felt there were enough group activities to keep them busy during the week (though clearly, this may not be fully personalised as the activities may not be to their taste), but they described weekends as 'like a morgue'. They explained that this was because physiotherapy and the day centre were not available on weekends, leaving residents without anything to do. It is perhaps telling of the limitations of the activities available that physiotherapy was viewed as an activity in itself, to stave off boredom, rather than part of their care on top of which other activities were added. They suggested additional part-time staff would be useful to

provide more activities on weekends – this would involve an additional cost to the home, and illustrates how personalisation can be resource (staff) intensive.

In The Chantry, non-care staff are employed specifically to organise and provide leisure and other activities for and with the residents. This was seen as financially sustainable because these staff could be employed at a lower cost than qualified nursing staff.

### Creating smaller living units

The experience of residents of The Chantry is markedly different from that of care users we visited in semi-supported communal living (five residents in a shared house with one full-time carer), who engaged in a range of leisure and sporting activities, group holidays, training, voluntary work and employment. One resident told us:

*I go to work, college, yoga class and keep fit. I go to town. Everything I want to do. I'm going to a new college in September... I like my flat. We do food shopping and buy stuff for the house. We saved up for a holiday. The cottage we stayed in was lovely, we had ducks. I'm going to a new college in September.*

The residents of the care home and the supported unit we visited have different levels of need, but they were not so markedly different to explain the widely different experiences of their residents. Neither group was using personal budgets, but the environments in which they were living clearly varied: residents in the supported unit had more opportunities for independence and personalisation than those in the larger scale home. One unit manager explained that the size of the unit mattered:

*When [the supported unit] was set up it was very much let's run with it – let's see. They can have more choices in this environment; next door [in the residential home] is difficult because there are double the numbers and more staff.*

As we explain below, the communal aspect of residential care can be a constraint on personalisation, and larger units are often harder to personalise for practical reasons (there are more residents whose competing individual preferences need to be weighed up against one another). However, while smaller units may be more conducive to personalisation, they are likely to be more expensive. The small bed units we saw, and others we were told about, were only financially sustainable because they were attached to larger residential or nursing homes. Attaching such units to homes meant staff in the units could be less well qualified, or there could be fewer of them, as a full complement of nursing staff was nearby and on call to visit the unit should they be needed. As one care manager told us:

*[Local authority] commissioners were clear when the supported living unit was first being set up that the cost of care would need to be less than in the main care home. Because of the smaller number of residents and high staff ratio, we could only achieve this by employing non-nursing staff.*

### Reductions of out of authority placements

Another funding related issue was the clamp down on out of authority placements. These are usually to be avoided – as they place people away from their local communities and are more expensive than in-borough placements. Nonetheless, for those with multiple or complex needs requiring specialist forms of support, out of authority placements can sometimes be necessary as appropriate local provision may simply not exist. The centre manager of one care home – whose residents were mostly from other parts of the country – said he had seen a noticeable push from local authorities to find ways to bring their clients back to their home areas as a result of reduced resources. This could prove problematic if equivalent levels of support are not available in the area they are being sent back to (one would assume this was what necessitated an out of authority placement in the first place). More importantly, many of this care manager’s clients had been out of their home authority for so many years that they had started new lives and built new relationships for themselves

in their new areas. This is particularly difficult for those people who need stability of surroundings and relationships:

*I've known [the care user] for twenty years and I know that if she moves, within six weeks she will end up detained under the Mental Health Act.*

Care manager

*They have to keep things the same for me; if I had to chop and change my anxiety would go flying out the window.*

Care user being referred to

Clearly, achieving an adequate funding settlement so that enough good quality care and support can be provided is the first step in any personalisation strategy. The Dilnot Commission on Funding of Social Care looks set to provide such a framework, proposing as it does to bring in an additional £1.7 million into the care system annually.<sup>79</sup> The Palliative Care Funding Review's proposals for a set palliative funding tariff may also resolve the variability in local resourcing of palliative care beds.<sup>80</sup> However, we must remember that the reform process needed to implement Dilnot and the Palliative Care Funding Review's proposals will not be ushered in until around 2015. Moreover, the wider context of cuts – affecting everything from welfare benefits to libraries, leisure services and third sector grants – means these two strategies alone will not fully resolve the problem. If personalisation requires the use of a wider range of services than just health and care, in order to support someone to achieve their aspirations, then clearly these wider cuts will have a detrimental effect on personalisation.

In chapter 3 we show how some local authorities and organisations are pioneering personalisation strategies that cost less to deliver than traditional services, so we should not underestimate how much can be achieved in personalisation, even with relatively limited resources. But at the same time, we should not expect personalisation to deliver improved outcomes irrespective of the size of budgetary cuts in place. Beresford et al's recent overview of user-centred practice and policy concluded:

*The inadequate funding of social care and negative aspects of its culture underlie these barriers [to personalisation]. These encourage institutionalisation, poor quality provision, inequity and late intervention. As a result people's basic rights are often not being met. Achieving person-centred support emerges as inseparable from fundamental cultural and funding change.<sup>81</sup>*

## Integration of health and care

An obstacle to personalisation that is particularly acute for those with complex needs, and which emerged throughout the course of our research, was the lack of integration between health and social care. As outlined in chapter 1, joined-up support – particularly across health and social care – is a critical component of personalised services. It is simply not possible to meet an individual's needs and aspirations (like those described by the care users we spoke to, such as being as independent as possible and maintaining family relationships) by delivering health and care in artificially separate packages.<sup>82</sup>

In 2011 the personal budget agendas in social care and health are running along parallel paths, with social care budgets progressing at a faster pace than the counterparts in health. This is in part the result of the complexities of using personal health budgets for NHS services, as explained in chapter 2, but the health budget pilots have ambitions to better integrate health and care services into a single personal budget structure. However, this remains a long way off, and in the meantime, those with multiple needs occupy an uneasy position balanced between two very different systems – financially, operationally and culturally.

Moreover, many of the professionals we spoke to raised three further issues. The first was the imminent reform of NHS structures at local level. Responses were mixed among practitioners and experts, with some cautiously optimistic that health and wellbeing boards would improve place-based integration of services, while others foresaw greater fragmentation, confusion over leadership and the undoing of progress made to build relationships between primary care trusts (PCTs) and local authorities. This could potentially make local health

structures harder to navigate by those with multiple and complex needs. Dr John Hughes, Group Medical Director at Sue Ryder, also raised the possibility that the new reform proposals as set out by the NHS Future Forum<sup>83</sup> could lead to a fragmentation of leadership and financial control, making joint working more difficult. Even if these reforms do create greater opportunities for joint working – particularly through new health and wellbeing boards – there will inevitably be a bedding-in period. In the meantime, some of the bottom-up, relationship-driven initiatives to integrate health and care, between PCTs and authorities, may be threatened as personnel are replaced.

A second issue was the fact that although some of the specialist health disciplines – such as palliative care and cancer care – were identified as being of very high quality and highly personalised (we discuss palliative care at length below), the practitioners we spoke to felt mainstream NHS services were less personalised than those in social care; health and social care staff differed in their approach towards personalisation; and the culture of personalisation also varied between health disciplines. This made integration more problematic, but also threatened personalisation where greater joint working *had* been achieved – a lose–lose situation.

A third pressing concern for many practitioners relating to the integration of health and care was that society is changing. Not only are we ageing as a population, but as a result of advances in medicine disabled people are living into old age and more people are surviving with multiple conditions, and physical and mental health needs. The high frequency of instances of dementia among those with learning disabilities who reach middle age, and physical illnesses such as cancer and diabetes among those with mental health conditions or learning disabilities, are examples of areas where integrated, multi-agency care is vital – not just across health and social care, but also between different health teams within the NHS. The need to integrate multiple specialisms in this way to create personalised support for these groups is a relatively new phenomenon – a by-product of medical advances – and one that has yet to be achieved with any great success.

Although these specific challenges are recent developments, the need for improved integration between health and care has been a live debate in policy making and academic circles for many years. It is now firmly back on the agenda as one of the key areas likely to be included in the social care white paper in spring 2012 and the subject of a select committee inquiry.<sup>84</sup> Nonetheless, limited progress has been made thus far. One area of breakthrough has been in mental health services, where integrated community mental health teams are recognised as providing good practice in joint working between NHS and community care services around shared outcomes. Apart from this service area, however, it has often been left to individual local authorities and PCTs to find bottom-up solutions in the face of a lack of incentives, and structural or policy levers from national government to create joint working. Some of these bottom-up initiatives are described in chapter 3.

Whatever the future holds for the integration of health and care, the current state of affairs was a source of frustration for both the practitioners and care users we spoke to. As we describe below, palliative care sits on the fault line between health and social care, and hospices trying to create integrated and holistic packages of support across these two divergent services areas face a constant challenge. A regional manager at Sue Ryder who has hospice experience gave one example of disjointed services she saw in her region (Yorkshire and Humber): delayed discharge penalties apply to hospitals, but not hospices – hospice patients who are not ill enough to qualify for NHS continuing care may be pushed back in the queue for discharge if a patient needs discharging from hospital. As hospice patients straddle social care and NHS continuing care services, the two groups may receive unequal treatment. Samantha Cheverton, a regional manager at Sue Ryder with hospice experience, told us:

*They are often not ill enough to be fast tracked, so they cannot go home with a continuing healthcare package. They're trapped in an awkward position; they're not going to die imminently, they shouldn't be in the hospice and they want to go home. Sometimes they deteriorate rapidly and die in the hospice against their wishes. This is not an outcome that anybody wants. It's difficult*

*trying to quickly pull in all the different types of funding to get the residents the correct care packages to go home.*

Sue Ryder, along with the National Council for Palliative Care and Help the Hospices, has welcomed recommendations for NHS reform, as an opportunity to improve the integration of health and social care. Nonetheless, a lack of experience of end of life care among commissioning consortia could prove a challenge,<sup>85</sup> as could a lack of representation on health and wellbeing board and consortia. Samantha Cheverton explained:

*If we have a good lead in those consortiums and good communication, working well as partners, it could be a really good experience. But anything other than that and it could be terrible; we could end up with poor referrals and lack of income. Longer term, if we end up with a bad partnership, it could be a challenge and a threat to our reputation. We'd like to think that it could be a positive thing for our patients, but it's too soon to tell.*

### Tensions between health and care services

Support delivered within nursing and residential homes can also highlight the tensions between health and care – The Chantry, like many other long-running homes around the country, is now trying to provide care for people with more complex needs, but some of the residents – who would not necessarily be referred to a care home now – had been there for a long time. This resulted in a mixture of residents across the need spectrum, and confusion from commissioners about what services the home was offering. Jo Marshall, the business development manager at Sue Ryder, explained: ‘This is where the debate is between what nursing care is and what is social care. It’s a difficult one to get your head around.’

To help remedy this, Sue Ryder worked in partnership with a local housing provider, and residents from The Chantry were able to move out and become tenants of a housing association – while Sue Ryder delivered care and support. Dee View Court, another Sue Ryder home, is about to take a similar step by registering one of its units as a supported living unit. As we

discuss below, a lack of appropriate housing can prove a barrier to such moves.

Interestingly, those in residential settings and supported units we spoke to felt they benefited from their situation, as some health services (such as physiotherapy and psychotherapy) were delivered in-house, while other clinicians would visit regularly, leading to long-standing relationships between care users and health professionals: ‘To be fair to this place, if you wanted to pay for a neurological physio to visit your home, it would cost a hundred pounds an hour. In here, we get three hours a week.’

This is not the case everywhere: a recent report by the British Geriatrics Society found that access to primary and secondary health services for older people in care homes was limited, of poor quality, and locally variable.<sup>86</sup> Nevertheless, we found that of the care users we spoke to, accessing NHS support in their community proved to be more challenging than accessing it ‘in house’. We spoke to two day-centre visitors to The Chantry, for example, who reported considerable difficulties in securing health and personal care in a coherent way in their own homes. Problems included having to repeat their case details to two different teams, having multiple and duplicated visits, and a lack of communication between staff in health and care. One described how she had been visited and assessed by a health occupational therapist, then a social care occupational therapist, ending up with two sets of equipment:

*My husband and I are stuck in the middle, trying to communicate between the two. It would be so much easier if there was one OT [occupational therapist] who did everything, or at least two OTs who spoke to each other.*

Another commented:

*I don't think [the hospital staff] were interested in what happens here. If you mentioned the Chantry, all you got were rolling eyes.*

A day patient we spoke to at Wheatfields, a Sue Ryder hospice, told us how she had fallen foul of the disjointedness of the different arms of the NHS – in this case, between

orthopaedics and oncology. Having had a hip and knee replacement, she returned to her consultant with hip pain, and was scheduled for surgery immediately. On enquiring why it was to be done urgently, she was told she had been diagnosed with bone cancer, but her consultant was not aware she had not been told as her notes had not been passed to her oncologist. While this is an extreme case, it does illustrate how joined-up care *even within the NHS* – as such a large and multi-disciplinary organisation – can be a challenge for those with multiple health needs.

The managers of some of the homes we visited painted a similar picture. They described a variable relationship between different elements of the NHS, for example, good relationships with dietitians, speech therapists and the hospices were common, but some received less support from mental health teams. There had been examples where patients' conditions had deteriorated because of the lack of access to support, as often mental health treatment was viewed as a low priority for care home residents because they were seen as being in a place of safety.

Jo Marshall, business development manager at Sue Ryder who had formerly been care manager at The Chantry, explained how the management had tried hard to raise the profile of the centre with GPs and hospital staff, but progress had been slow:

*We always have a problem with awareness of who we are and what we do. Despite the amount of work we do locally raising our profile, we still come across health professionals who don't have a clear understanding, or people who see The Chantry as an elderly care home. And I am thinking GPs who have perhaps not come into contact with us for whatever reason; they won't have an awareness of what we do. So that is a worry, I think a big worry, for the whole organisation.*

*We haven't had good information, good communication, back from the acute hospital. Sometimes when a resident is discharged back to us we don't even know what treatment has taken place.*

The manager of a supported living unit in another part of the country reported similar difficulties, this time with the GP service:

*We struggle with our GPs. Yes [the residents] see them, and they do provide a service, but there are some problems. If someone drops medication on the floor, we then have to acquire a replacement prescription. We have difficulty getting that medication just as a one-off. It comes in instead on the next cycle [as a whole new prescription] and consequently, we get criticised for possession of excessive medication from CQC [the Care Quality Commission] ... there has been criticism of some of the [NHS] services. There's one of the bigger practices in Hartlepool where [the residents] don't always get the same GP.*

The manager explained that the unit used to have an understanding with their local surgery so that if one of their residents needed to see a GP, they could ring up and request that they were seen straightaway on arrival, since some residents would not be able to cope with waiting. However, that arrangement had been based on personal relationships built between the surgery and unit, which had disappeared with the replacement of GPs and surgery staff.

### **The state of the (health and care) market**

At its heart, personalisation requires service users to have a credible choice of the types of services they use to support them daily. The Government's vision for adult social care recognises this:

*Councils have a role in stimulating, managing and shaping this market, supporting communities, voluntary organisations, social enterprises and mutuals to flourish and develop innovative and creative ways of addressing care needs.<sup>87</sup>*

and the NHS Future Forum states that there needs to be a role for Monitor in NHS 'market making':

*A diverse range of providers is a good way of stimulating innovation – whether this is from within the NHS, from the third sector or independent organisations. People with new ideas need to be able to offer their services, as long as they meet all necessary quality standards... The NHS Commissioning*

*Board and Monitor should work together to ensure there is a level playing field that enables people with new ideas to enter the market.<sup>88</sup>*

The concept of ‘market shaping’ (or ‘market making’) has been around as long as personalisation – perhaps even before, if we consider that the foundations of personalisation existed in the direct payments of the disability movement of the late 1990s. Direct payments – cash in lieu of services – necessitated a range of providers for direct payment holders to purchase from. While councils are increasingly being directed away from delivering or commissioning services on behalf of care users, their role to shape, stimulate or facilitate local markets of care providers has become one of their key functions, alongside the NHS Commissioning Board and Monitor, the independent regulator of NHS Foundation Trusts, which through the forthcoming Health and Social Care Bill will be given greater powers to tackle anti-competitive practices in the NHS.

The Think Local, Act Personal coalition has furthered this agenda for social care, providing sophisticated guidance for local authorities to work with providers to ensure they are able to respond to market intelligence on the local population’s needs and preferences.<sup>89</sup> Healthcare is no doubt more challenging; as explained in chapter 1, the monetarisation of a ‘free’ service is a complex business, as is the creation of a market of providers where the forces of supply and demand had never really existed on an individual level. The concepts of ‘any willing provider’ and ‘the right to provide’ are promising first steps towards creating a more diverse mix of health provision at local level, to include social enterprises and user led organisations.

Nonetheless, the health and care markets are just one piece of the picture. Personalisation requires us to look beyond people’s care and health needs and to consider their wider aspirations. The care users we spoke to identified, for example, the importance of maintaining family links and having a job or volunteering, as well as maintaining independence. These cannot be achieved within the constraints of health and care services. Therefore, successful personalisation will require looking to the

job market and universal services, such as leisure and cultural services, transport and housing.

It is clear local authorities have limited ability to ‘shape’ these markets – unlike markets in health and social care, which remain relatively underdeveloped, with several providers still operating on block contracts with their local authority and PCTs. This puts the commissioners in a position to intervene directly and provide transitional support to providers, and market intelligence about care users’ needs, to stimulate the health and care markets in a way that supports care users’ outcomes. But the same cannot be said for wholly private, mature markets, which have had little or no exposure to disabled people, or those with support needs. For example, a local authority or a health and wellbeing board may have limited influence over the private gyms in the area, or the theatres. In London boroughs, transport operated by Transport for London is another service beyond ‘shaping’. But it is gyms, theatres, educational institutions, transport, training and employment opportunities that are critical to people’s quality of life, and are likely to be the sorts of things people will want to access in designing their own personalised support.

Sue Ryder’s Dee View Court in Aberdeen is located in the heart of the local community and residents are able to use the local shops, the library and community centre, but the care manager Fiona Fettes described the difficulties with transport and accessibility for residents getting to some services ‘With the local hairdresser there is a problem getting wheelchairs through the front door, and a lot of opticians are upstairs.’

Moreover, following local budgetary cuts, Aberdeen council had scrapped the taxi-card scheme and dial-a-bus. As local (public) buses only take one wheelchair user at a time, residents (most of whom use wheelchairs) are now unable to travel together on public transport. Residents therefore often resort to taxis, which, without the taxi-card, ‘cost a fortune’, but are often a necessity if the services residents need to access are not available locally.

If care and support services are to help people achieve their goals in life, not simply to meet their health and personal care

needs, local authorities and health commissioners will need to look to a multitude of local markets and consider their availability, accessibility and affordability. This is not just to enable people with personal care and health budgets to select and purchase services in the local area for themselves; it will also allow local authorities and clinical commissioners, and providers of residential, palliative, nursing care and supporting housing providers, to help their clients pursue their ambitions and interests outside the walls, so to speak, of the residential setting.

Several of the care staff we spoke to in residential and supported units spoke of their frustration at trying to find appropriate services in the mainstream market for their residents – everything from accessible cinemas, to training opportunities and voluntary jobs. Sue Ryder's scheme Stepping Out is designed specifically to overcome the barriers to accessing mainstream services for disabled people (described in more detail in chapter 4), but this is a fairly resource-intensive initiative. Free or low-cost leisure activities which are accessible (such as festivals and outdoors activities in parks) are also vital given tight resources. Managers in some residential homes we spoke to were also thinking more laterally when faced with access difficulties, and bringing free activities into the home. The Chantry, for example, had arranged for art and dance students to perform in the gardens, and Wheatfields hospice had arranged for the local museum to bring artefacts into a day therapy unit to spark reminiscence and discussion among the patients. Identifying such local opportunities and then pursuing them could in itself be resource intensive.

It is clear, therefore, that personalisation will only be as successful as the quality and variety of services and local facilities in an area. In spite of the transport difficulties, Dee View Court's residents and staff all spoke positively about its central location to the community centre, library and local transport links. They felt lucky such amenities were close by, and they generated many low cost opportunities for activities and outings.

## Housing

The housing market has an even more fundamental impact on personalisation. As outlined above, the development of personalisation as a concept was heavily influenced by the Independent Living Movement and personal budgets, in their earliest forms, were a driver for many younger people (primarily with learning disabilities) to move out of residential and hospital settings and into a home of their own. The personalisation movement has therefore often been associated with a move to supported living. Also, many of the outcomes people told us they value – having a family life, being independent, forming meaningful relationships, and being active in the community – will often be easier (or indeed require) people to have a home of their choosing.

The availability of appropriate housing is, therefore, a critical element to ensure personalisation is successful for the thousands of people in accommodation not of their choosing – whether a residential home (33 per cent of adults with learning disabilities live in residential care),<sup>90</sup> their family home or indeed independent supported accommodation, which has been allocated to them, which they do not like or which is unsuitable for their needs.

And yet, as we outline above, the integration between health, care and housing remains seriously under-developed. While policy focus has been set on the greater integration between health and care (with admittedly limited success) for years, housing remains the poor relation, with few incentives to encourage joint working. Indeed, as funding for Supporting People (housing related funding to support vulnerable people to live as independently as possible in the community) is under threat, and in some areas cut by up to 60 per cent,<sup>91</sup> the availability of suitable housing may well decline<sup>92</sup> and the limited linkages between care and housing that do exist could be undermined.

For example, although the Coalition Government has committed £150 million to reablement services and given hospitals a 30-day duty of care post-discharge to ensure readmission is avoided through community care,<sup>93</sup> housing providers have been more or less excluded from the reablement conversation, despite having much to offer in the way of home-

based support. The recent report of the All Party Parliamentary Group on Housing and Care for Older People, *Living Well at Home*, cites substantive evidence of the importance of integrated health, housing and care in improving wellbeing and a range of health-related outcomes, as well as preventing the need for a move to residential care.<sup>94</sup> It also noted that the NHS spends £600 million treating people every year because of poor housing, and that 1.4 million people have a medical condition or disability that requires specifically adapted accommodation.<sup>95</sup>

Access to supported accommodation was certainly a key issue for the providers of the care homes we spoke to, including Sue Ryder. Some Sue Ryder residential settings had large proportions of residents ready and able to live more independently – estimates for some sites suggested about half of the residents could make a move to a supported living environment, a quarter would need to stay in a registered nursing or registered residential care environment, while the remainder would need some form of extra care housing. But a barrier to this move was a lack of appropriate facilities, which could only be resolved by engaging with the respective local authority commissioners to work towards that goal. This might include looking for potential sites for providers like Sue Ryder to build new independent living units on, providing additional investment for the re-provision, creating more supported living units within the community as part of the wider local housing strategy, and creating a transition strategy for commissioners and providers to work in parallel.

For Sue Ryder, creating new supported living provision was not just a question of creating personalised care pathways – it is also the right thing for business development, to respond to demand. Steve Jenkin, Director of Health and Social Care at Sue Ryder explained:

*It [not providing supported living options] seems wrong morally for the people we have supported for many years, who like Sue Ryder and would choose Sue Ryder every time. It also feels morally wrong for the staff we are supporting, that we are not actually trying to find a creative solution that keeps jobs.*

However, many of the residential care managers we spoke to, from different providers, expressed frustration over the difficulties in finding suitable housing locally. For example, the managers of Dee View Court explained how they had heard of two houses for sale in the local area, which were suitable for disabled people, but on viewing them they found they would need considerable renovation, taking them above budget. They were in the process of re-registering as supported living one of their self-contained units to create a pathway to greater independence within the site itself. Pamela Mackenzie, a regional manager for Sue Ryder based at Dee View Court, told us, ‘The real issue for people who are severely and physically disabled is that they are limited by the lack of availability of accessible and appropriate properties.’

We saw this in other places – one residential home manager we met who was providing support to those in need of psychiatric care had already opened a smaller, supported unit next door for those residents able to live semi-independently in a shared house. But he expressed frustration at having no provision locally for those taking the ‘next step’:

*A couple [from the supported unit] are ready to move into supported living, but then look into the future with care pathways and we realise it stops with us [in the semi-supported house]. It sort of stagnates with us here... I'd like to see more movement – we've got people ready to move on to the next step but no facilities for it.*

This had a knock-on effect on the entire care pathway – as those in the supported unit had nowhere to move on to, so those in the larger unit ready to make a move into the smaller unit were unable to do so as the beds were all full:

*There's people ready now to move [from the residential unit]; we've got a number of people who have technically retired, they could move in here tomorrow.*

*There's hardly any movement... it does get frustrating because we can do so much more for people if we had the beds... Ideally I'd want to tag on to this another two-bedded house as a tester for supported living, and if it does break down we can start the process again.*

This manager was primarily working with people who could be rehabilitated to become more independent, but Fiona Fettes, Care service manager at Dee View Court, whose clients include those who can be rehabilitated and those with degenerative neurological conditions, also raised the idea of a two-way pathway:

*We have a waiting list of 11 at the moment, but we could do it the other way. People could have supported living until they deteriorate and then they could come here. We could work both ways.*

Another practitioner also recognised that a lack of progression was not entirely down to a lack of facilities, and that there was a greater need for residential providers to engage with external housing providers to create care pathways into the community, and that progress may be held back because his staff felt protective of their clients and were therefore cautious to work with external and non-care agencies (housing providers). We discuss staff culture as a barrier to personalisation further below.

## Residential care and the constraints of communal living

We must bear in mind that personalisation will not lead to a move from residential care into supported living, or from supported living into independent living, for everyone. For younger people with multiple and complex needs, older people with dementia, and for end of life or NHS continuing care, often residential, nursing, palliative or other communal settings can be both appropriate and desired. These groups may not move on from residential care, but are equally entitled to personalised services.

An obvious difficulty in such settings is that people are not permitted to use a direct payment to purchase residential care, so by default no one in residential care has a direct payment.<sup>96</sup> The fact that the Government is strongly encouraging direct payments as the default form of personal budget potentially excludes people in residential settings from this way of exercising

choice. Nonetheless, other forms of personal budget – such as an individual service fund<sup>97</sup> – can be used in residential settings, and we discuss these in chapter 4.

The greater barrier to personalisation in residential settings is not the availability (or not) of particular funding vehicles, but rather the fundamental premise on which residential and other supported units are based – *communal* living. Pamela Mackenzie, a regional manager at Sue Ryder, told us:

*When you're in a communal setting, you're restricted to how many staff you're able to put on, what needs are at that time. There are going to be restrictions because of the communal setting. We do work very hard to have it as deinstitutionalised as possible.*

The debate as to whether group settings can ever deliver individualised services or self-directed support is still hotly debated, with many, such as Beresford et al, believing the institutionalisation of homes inevitably leads to ‘collective disempowerment’.<sup>98</sup> Knight et al similarly cite a range of academic literature on the negative psychological effects of communal care environments:

*Indeed, it has been argued that caring as an activity can so encompass the needs of residents that they are prevented from engaging in decision making and from interacting with their surroundings. Thus whilst it is recognised that compassion and caring are well represented among the care staff's skills, researchers have argued that caring alone is insufficient. If a resident cannot engage with the environment and its people, then she or he is effectively disempowered, even in the most benign surroundings. Disempowerment has been shown to be associated with lower levels of motivation, reduced self-esteem and a lack of psychological comfort.<sup>99</sup>*

However, the authors go on to cite a wealth of evidence on the positive impacts of social engagement and peer support:

*In almost every walk of life, people who are socially active live longer than the more isolated (Marmot, Siegrist and Theorell 2005; Maugeri et al. 2001). Those engaged in society also tend to be happier (Haslam et al. 2008,*

2010) and less prone to physical illness and cognitive decline (Barnes et al. 2004; Mendes de Leon, Glass and Berkman 2003; Ertel, Glymour and Berkman 2008).

Accordingly, there is growing evidence of the positive effects of social interaction in residential care homes (eg Barkay and Tabak 2002; Cheng 2009; Dixon 1991; Hjaltadottir and Gustafsdottir 2007; Klinefelter 1984; Short 1992). For example, Dixon observed that residents who had high levels of social interaction in a care facility felt 'at home' in their living space, as opposed to no more than living in 'a homelike environment' (1991: 160). Such work highlights the importance of friendship and interaction as determinants of residents' happiness and wellbeing (Regev 1997), but also recognises that the quality of social interactions can be compromised by standardised practices that, over time, reduce individuals' quality of life (see also Lidz, Fischer and Arnold 1992).<sup>100</sup>

Residential settings have the potential, therefore, to improve people's wellbeing by creating opportunities for peer support and social interaction. An important part of this is collective decision-making as a tool for 'collective empowerment'.

Supporters of this concept believe personal budgets, as a fundamentally individualistic, consumerist tool, could actually undermine collective decision making and empowerment, and are incompatible with the reality of people's 'collective' lives – based as they are on communities, families and relationships. For example the Welsh Government, in its new social care strategy, stated it wanted to create 'citizen-centred services', with service users more involved in running services and providing access to direct payments for all who want them. It distanced itself from the term 'personalisation' because it had become 'too closely associated with a market-led model of consumer choice'.<sup>101</sup>

From this point of view, personal budgets in care homes could 'individualise' residents and break down community spirit, but the Think Local, Act Personal coalition is making great progress in finding alternatives, by considering new, collective ways to deliver choice and control within the personal budget framework (for example through personal budget pooling). Nonetheless, many professionals are still concerned by the

dominant thread in political narrative, which equates personalisation with individualism, and suggests that every ‘care consumer’ is entitled to a package of support, unlimited by the consideration of other’s preferences.<sup>102</sup> As Scotland’s self-directed support strategy states:

*There is a view that one way to shift power to the consumer and to remove the structural bias in favour of service provision, is to adopt a default position of opt out rather than opt in [of direct payments].<sup>103</sup>*

Such an approach is not readily compatible with group living environments. Alternatives to ‘individualistic’ personalisation are therefore important, if those in residential homes are to be included in the personalisation agenda. When considering ‘collective’ personalisation, one care manager we spoke to identified a basic problem – the smaller the group, the easier it was to personalise. The practical difficulties of balancing large numbers of people’s individual preferences were such that it was much easier for this care manager to provide personalised support to residents in the five-bed unit he oversaw than to those in the eleven-bed home next door, as there were fewer competing demands to manage.

Although the care home market is moving to provide a larger number of small-bedded units, this is clearly not always financially sustainable. The current instability in the market that we have seen with the collapse of Southern Cross,<sup>104</sup> for example, as a result of reduced per-bed payments, makes questions of economies of scale all the more pertinent, but this is not a hard and fast rule. Larger groups can still be personalised. Dee View Court, a Sue Ryder facility offering long-term residential care for people living with neurological conditions, is built in a different way. With 22 beds, it is a large home, but residents live in small, self-contained units in groups of four or two, with their own kitchen and living space, located off a large internal ‘street’, where communal facilities are located. As a result of this unique design staff have been able to achieve some of the benefits of ‘small scale’ living and improved personalisation within a large-scale facility.

Moreover, by assuming that small groups are easier to personalise, and that personalisation means balancing the needs of several competing individuals, we are still trapped in a mindset that ‘personalisation is individualisation’. If personalisation is ever to be meaningful in collective care settings, we must start recognising people’s group identities and interpreting personalisation collectively as well as individually, and look for opportunities for collective empowerment, democracy and co-production. These issues, and how Dee View Court balances large facilities with small-group living, will be discussed further in chapter 3 when we consider how to overcome barriers to personalisation.

### Palliative care

End of life care is perhaps one of the most challenging scenarios for personalisation. In this section, we consider several obstacles that palliative care faces, including its uneasy position on the fault line between health and social care services, and the difficulties in discussing wishes and preferences at the end of life, which fundamentally inhibit personalisation.

### Communication

As Demos’ research found in 2010, two-thirds of people want to die at home, and yet only 18 per cent currently do so.<sup>105</sup> The majority of people die in hospital (60 per cent), followed by those dying in residential care (17 per cent), but both options have significant limitations when it comes to delivering personalised support. Hospitals, for example, can be very impersonal because of the large number of specialists on wards when a person is dying from a complex condition; several nurses working in shifts, who have little time to develop relationships with patients and their families; and a large, often public space, which may not afford much privacy or dignity.<sup>106</sup> Moreover, staff in hospitals are primarily focused on medical aspects of care – rather than social, personal or spiritual matters, which are so important at the end of life. Some of the experts we spoke to

during the course of this project who worked in social care and the health services admitted that the latter, embodied in the NHS, was in some cases ‘further behind’ when it came to personalisation, with many staff still focusing on clinical outcomes and operating in an unequal expert–patient relationship.

Moreover, a hospital’s primary function is to cure, or protect and prolong life, and research suggests this makes it challenging for hospital staff to talk to patients and their families about death where nothing can be done to prevent it.<sup>107</sup> Not being able to talk honestly about the process makes personalisation much harder, as the wishes of the patients and families cannot be discussed constructively. Yet the National Audit Office estimates that 40 per cent of people who die in hospital do not need to be there for the treatment of a medical condition.<sup>108</sup>

Care homes face similar challenges to personalisation for end of life care. There is a similar lack of staff training and experience when it comes to communicating about death with residents and their families, again making it difficult to personalise the experience as wishes and concerns are not discussed openly.<sup>109</sup> Care homes often have a high staff turnover; this can undermine the continuity of relationships, which are so important during end of life care.

The authors of the 2010 Demos report *Dying for Change* concluded that a fundamental limitation to personalised end of life care is lack of communication. And importantly, this lack of communication about death is not just driven by inexperienced staff – people themselves are often reluctant to talk, making the need for well-trained staff even more important:

*Efforts to personalise services depend on professionals talking to consumers to understand what they want. Expectant mothers are happy to talk at length about their birth plans. In contrast many people do not like talking about dying. Indeed for some people, a good death depends on not talking about it.*

*Not everyone will want to talk about how they want to die. But everyone should be offered the opportunity to do so. Those conversations should not be one off events, reduced to a simple checklist. Most people do not want grand planning sessions. They should be friendly and low key,*

*teasing out what people feel and most of all what they value most. The more people are encouraged to talk about what matters to them about life the more likely they are to get it even while they are dying.*<sup>110</sup>

### Challenges for hospices

In the midst of these limited options, hospices are an exception to the rule. They were set up in the UK in 1967 as a direct response to the medicalised and impersonal palliative care available at the time, and specialise in holistic end of life support that combines medical services with social activities, spiritual and psychological care. Staff in hospices are trained to talk about death and dying, to help patients and families through the process, and hospices usually include inpatient and outpatient support as well as home visitors to provide end of life care in the community.

Comments made at the workshops carried out for *Dying for Change* last year capture the value of hospices:

*It's saved my life. It's got me out of the house, made me more independent, given me people to see and lots to do. It's comforting and helpful. It's more for life than death.*

*I really look forward to coming to the hospice. You need a feeling that life is good even if it is coming to an end.*<sup>111</sup>

Similar opinions were expressed by day patients of Sue Ryder's Wheatfields hospice in Leeds, who attend the day therapy unit attached to the in-patient hospice in order to have their medication and treatment stabilised and receive complementary therapies for a 12-week period. Two of the patients we spoke to compared the support they received at the hospice with other care services they used:

*Well there's more personalised staff here. Where my wife goes [a respite home] they're overworked and understaffed, but you make allowances because of the cuts. But I mean, once they lost her coat. They sent her home with someone else's coat and we never got ours back. But they weren't to know it wasn't hers. They're more personalised here in the hospice.*

*I like coming here on Thursdays... it's always the same volunteers and I see the same people. With my home carers I get an assortment of people.*

A Sue Ryder manager with hospice experience summed up hospice care thus:

*Across the country, not just Sue Ryder, hospice care is very good. It's very special care. It matches the ethos of personalisation and holistic care; we look at what's important to the individual psychologically, socially and spiritually, as well as looking at individuals' families. If a patient is admitted into an acute medical ward the ratio of staff to patients will probably be very low. They might have very disturbed sleep and would probably have to get up earlier in the morning because the beds need to be made. This is very different to hospice care; the ratio of staff to patients in hospices is much higher, patients have their own room, there's a better quality of food, there's more continuity with the staff that care for patients, it works at a pace that is led by patients – for example some patients do not have their breakfast until two o'clock in the afternoon. There are people that can actually come and talk or listen to patients for an hour or so. There's no rush to get such things finished before the night staff come in. In the nicest possible way, when patients have had a taste for that, they wouldn't choose any other type of care.*

We saw this first hand in Wheatfields, where individuals were each asked, once they had settled in, what sorts of activities they liked. The activities coordinator then saw to it that options were available which suited each person – but at the same time recognised that many patients who arrived simply wanted company and a chat, so spend a considerable amount of time befriending the patients during their day visits. Other personal touches (allowing patients to eat where they wanted, rather than in the dining area, having a grid with details of how each patient liked their tea or coffee so that volunteers did not have to ask patients every time, and so on) were indicative of the 'small things' that the National Council for Palliative Care identified as being so crucial to a sense of wellbeing in end of life care.

In short, hospices are perhaps the best formal setting through which personalised end of life care can be achieved.

Yet, only around 5 per cent of people die in a hospice each year, and a recent Demos poll found only 7 per cent of people wanted to die in a hospice.<sup>112</sup> This is because many people with no experience of hospices regard them as depressing places, where people ‘go to die’, and therefore entering a hospice is seen as giving in to, and somehow hastening, death. This is very far from the reality of hospices, which are warmer and friendlier than hospitals, with far greater opportunities for holistic and personalised support. Studies also show that those people entering hospices live as long (and for some conditions, longer) than those entering hospitals for palliative care.<sup>113</sup>

One of the barriers to personalisation in end of life care may be, therefore, the common misconceptions about hospices, which mean fewer people choose them as a positive option – and therefore do not experience the personalised support they offer.

### The fault line

Palliative care can also be challenging to personalise as it sits on the fault line between health and social care systems. In this section we talk about the lack of integration between health and social care as a fundamental barrier to personalisation for all care users, and particularly those with complex needs. However, in palliative care, this lack of integration has special relevance, as it is in direct opposition to the holistic and joined-up support offered by specialist palliative care services.

#### **Specialist palliative care services**

*Specialist palliative care services are defined by the Palliative Care Funding Review as ‘care delivered by specialist providers such as specialist in-patient facilities’,<sup>114</sup> but the National Council for Palliative Care provides a more detailed description:*

*Specialist palliative services are provided by specialist multidisciplinary palliative care teams and include:*

- *Assessment, advice and care for patients and families in all care settings, including hospitals and care homes.*
- *Specialist in-patient facilities (in hospices or hospitals) for patients who benefit from the continuous support and care of specialist palliative care teams.*
- *Intensive coordinated home support for patients with complex needs who wish to stay at home.*
  - *This may involve the specialist palliative care service providing specialist advice alongside the patient's own doctor and district nurse to enable someone to stay in their own home.*
  - *Many teams also now provide extended specialist palliative nursing, medical, social and emotional support and care in the patient's home, often known as 'hospice at home'.*
- *Day care facilities that offer a range of opportunities for assessment and review of patients' needs and enable the provision of physical, psychological and social interventions within a context of social interaction, support and friendship. Many also offer creative and complementary therapies.*
- *Advice and support to all the people involved in a patient's care.*
- *Bereavement support services which provide support for the people involved in a patient's care following the patient's death.*
- *Education and training in palliative care.*

*The specialist teams should include palliative medicine consultants and palliative care nurse specialists together with a range of expertise provided by physiotherapists, occupational therapists, dieticians, pharmacists, social workers and those able to give spiritual and psychological support.<sup>115</sup>*

The unique character of specialist palliative care, therefore, as opposed to what the Palliative Care Funding Review calls 'core' palliative services and 'universal' palliative services, is the

multi-disciplinary, holistic support for both the patient and their family. This spans emotional, practical and spiritual aspects, as well as several disciplines in social care and the medical professions. Thus specialist palliative care sits in an uneasy position across health and social care – worse still, across multiple disciplines within these two large systems. To deliver this in a seamless package when time is often of the essence is an enormous challenge for specialist palliative providers, yet clearly the holistic and multi-disciplinary nature of specialist palliative care is the gold standard of truly personalised support.

There is a weakness in specialist palliative care provision, which undermines its highly personalised status – as Sue Ryder, a specialist palliative provider has found, offering specialist services means having an admissions criteria which can exclude those with less complex needs. Samantha Cheverton explained:

*One of the main challenges to personalisation is going to be how we draw the line on our service delivery and how our current service criteria will fit in with patient choice. For example: if I had a personal budget and I knew I had got a terminal illness, I might decide that I would like to go to a day hospice once a week, or come in for two weeks and have my medication regulated for me. Currently our hospice does not have that capacity, unless the patient has a specialist need. We aren't able to manage those types of patients any more as current service delivery is for complex needs. If someone with a personal budget were to say 'I haven't got complex needs but I've decided that my preferred place of care would be in the hospice' then with our current criteria, we may find ourselves turning them away, since we are without the capacity to care for them. That will be a real challenge for us; people will have their own personal budgets and will perhaps be choosing services that we do not have the capacity to provide.*

Not to be able to provide specialist palliative care – and the personalised, multidisciplinary support this entails – to those with less complex needs is in itself contrary to personalisation, but symptomatic of funding constraints and commissioning structures which currently allocate the most intensive support to those with the greatest needs. Personal health budgets could end this system, however, requiring greater flexibility from

providers to cater to all need levels. In the meantime, specialist palliative care inevitably leaves some people under-served. Samantha added:

*Due to the focus on specialist needs, there's a gap in the middle; we are unable to provide basic and respite care. There are people who perhaps aren't acutely ill, but who want that palliative support, or who want to die peacefully but not at home.*

### Advanced care plans

Of course, hospices are not for everyone. Nearly one in five people dies at home. A further two-thirds would like to, associating death at home with greater control, dignity and the presence of family and wider support, but this is not guaranteed – the very nature of end of life care can militate against personalisation. We already know, for example, that many people do not feel comfortable discussing their wishes about care at death and the process of dying. This can make it very difficult to personalise support and express a wish for a death at home. Additional barriers include the fact that choices can be difficult to make in the last days or hours of life, particularly for the individual dying who may not have capacity, but also for their families, so personalisation can be undermined. One important tool to overcome this is advanced care planning, where a person can set out their wishes for care and treatment, refusal of treatment and so on for their end of life if and when they no longer have the capacity to make such decisions. This can ensure people dying at home receive the appropriate support, and if people draft advanced care plans before admission to a hospital or hospice, it can be much easier to deliver personalised support.

Despite this it is an exception rather than the rule for those dying to have written advance care plans. A NatCen survey for Dying Matters in 2009 found that while 29 per cent of people had talked about their wishes around dying, only 4 per cent had written an advance care plan<sup>116</sup> – perhaps as a result (as outlined above) of the difficulties staff and individuals and their families encountered in broaching such a sensitive subject.

Moreover, even if an advance care plan is in place, there are still risks to personalisation – advance care plans have been criticised for being too inflexible, as they capture a person’s preferences at a moment in time and are then followed regardless of whether a person’s circumstances or opinion changes. However, advance care plans are not inevitably inflexible. Samantha Cheverton told us that training and confidence in revisiting those plans were key:

*An advance care plan is a living document; it’s not set in stone. There’s an issue surrounding training staff to be comfortable with that. Clinical nurse specialists work at high levels and have to be very comfortable with having those difficult conversations. It’s all about education and training. It’s definitely a living document; it could change backwards and forwards several times in a week.*

Moreover, if someone changes their mind in the last days or hours of care, and departs from the care plan through verbal communication, end of life staff must be flexible enough to adapt accordingly: ‘If a patient changes their mind and wishes to die either at home or at the hospice, we will get them there. There would be no debate, it would just happen naturally.’

Therefore, the value of advance care plans may be undermined by a lack of staff training and reticence to talk about dying – this is no doubt one reason (along with individual and family reticence to discuss dying) for the low take-up of advance care plans, and one reason why advance care plans might become set in stone (because staff uncomfortable with such conversations are likely to be unwilling to revisit the advance care plan and repeat the conversation.)

Personalisation in end of life care could be strengthened by giving people (and perhaps more often their families) budgetary control (through a personal budget) to ensure their plans are put into place. Last year, Demos polling found that two-thirds of people said they would opt for a personal budget if they had three months to live, even if that personal budget were worth 15 per cent less than state funding over that

period. This suggests there is an appetite for greater personalisation in end of life care, and financial control as a means of achieving it.

### Personal budgets in palliative care

Another barrier to personalisation in palliative care is the limitations of personal budgets in these settings. As we mention in chapter 2, palliative care is one area where it may be challenging to implement personal budgets. As palliative care falls under NHS Continuing Care, personal social care budgets are not available in this context, but personal health budgets (which, as outlined above, are being piloted in around half of all PCTS) would be. Many of the pilot sites are specifically trialling personal health budgets in end of life care and are making it possible for those care users who already have a personal (social care) budget to transition to a personal health budget when they become eligible for continuing care.<sup>117</sup> A new standard palliative care tariff, as proposed by the Palliative Care Funding Review of July 2011,<sup>118</sup> will also potentially make the process of taking charge of one's own funding for end of life care more straightforward.

Nonetheless, given the need for flexibility and last minute decisions being made in the last hours of life, there may be limited potential for personal budgets to act as vehicles for personalisation in palliative care. Chapman and Fuller, writing for the National Council for Palliative Care, have expressed concerns that as needs change often and rapidly, personal budgets may not be able to change quickly enough to adapt to fluctuations in condition or capacity – citing instances of where equipment arrives too late to be useful or even after someone has died. They also point out that there is little guidance as yet on what end of life services could be bought.<sup>119</sup> We must also bear in mind that the Demos poll posed a hypothetical question about a personal budget in the *last three months* of life – the last days of life, in real life, could be a very different matter, and Chapman and Fuller question whether people who have never had a personal budget would be overwhelmed by the extra choice and

responsibility a personal budget might bring when they have a matter of weeks to live. They conclude:

*We are optimistic that budgets, carefully designed and delivered, could present substantial benefits to many people approaching the end of life and their carers. We hope that the final evaluation of the programme will provide solutions to the challenges laid out above. At the same time, it is important to acknowledge that there will also inevitably be some people unable [to do this], due to a lack of capacity, or [because they are] simply unwilling to make complex choices about the services they want as is required by SDS [self-directed support] models such as budgets. It is critical that we avoid building a two tier system in which people who don't take up the offer of having a budget receive below par services as a result.<sup>120</sup>*

It is important, therefore, to consider a range of tools that could be used to personalise end of life care, should personal budgets prove too inflexible a vehicle, impractical given the time constraints, or not wanted by those with a short time to live.

### Service user push-back – ‘a home for life’ and ‘getting what you’re given’

It would be a mistake to believe that personalisation and taking control of one’s care and support is universally popular. While it began as a bottom-up movement, driven by disabled people and their families seeking greater empowerment and choice, many disabled and older people remain reluctant, or simply unaware, of the possibilities of personalisation. This can manifest in a number of ways. During this research, we saw care users display:

- passive acceptance of the status quo, even if they were not happy with the situation
- anxiety or fear of the unknown and reliance on the security that came with familiar care and support packages
- positive appreciation of their current care and unwillingness to make changes (which may, or may not, have been a result of being unaware of the alternatives)

Service user resistance to challenging the status quo can be particularly acute in health settings, where the prevailing culture towards ‘free’ NHS services is to accept what you are given – a culture no doubt compounded by deference towards the medical professions, particularly among older people. When one day patient at Sue Ryder’s Wheatfields Hospice in Leeds was asked about whether she would like to take control of her health services, she reasoned: ‘Well, I’ve nothing to control have I? There’s nothing for me to organise, it’s all organised for me. You’re given a letter telling you when your appointment is and you go.’

This woman’s acceptance of the inflexible hospital booking system contrasted with the control she exercised over her domiciliary care services, where her expectations to have her needs met were higher:

*I stopped having [home carers] in the evenings because they could only come for 15 minutes and do me a ready meal. It was no good for me. They sometimes came at 4 then at 6, and you’re not always ready for your dinner... I’ll stop using them in the morning as soon as I can as well, when I get on my feet again.*

This difference in perceptions of different services may mean some providers (perhaps those supplying services which are perceived to be ‘medical’, such as in-patient palliative care) may encounter higher levels of passiveness and resistance to taking greater control than other providers.

The reluctance of those with complex needs in residential settings to change the status quo and be more active in their care (for whatever reason) can be problematic, as it can act as a barrier to progression to greater independence.

A problem that Sue Ryder reported to be struggling with as an organisation trying to deliver greater personalisation is that many long-term care home residents, while ready for supported living, are reluctant to move out of their home, or are unaware of the alternatives. Other residential providers we spoke to – particularly those who had been providing services for many years – echoed these concerns, recalling the policy of ‘a home for

life' in residential care 20 years ago at a time when there were no alternative accommodation options (such as supported living or extra care). Sutton Council's difficulties in tackling residents' and their families' objections to the prospect of moving from residential care to supported living is an illustrative example of this issue, which we describe in detail in chapter 4.

As long-term residents of care homes were offered 'a home for life', and many reject the idea of being moved on to smaller units or supported living, this raises the question of how far practitioners should push residents to become more ambitious and seek greater independence under the auspices of personalisation. A care manager we spoke to from another care provider told us:

*We promised people at the time that it would be a home for life, because at the time it was; there was no progression for the people who we cared for. We developed services on top of services, and now it is stagnant, there's no next step.*

Resistance to change in residential settings is not always a positive experience, but rather a result of people accepting the limitations of their living environments and a 'self-limiting' belief that their condition or impairment makes greater independence or control out of the question. Residents of care homes told us:

*You get what you are given a bit.*

*I've got no area that I feel like I would change. It is a home, and rules and regs within that have to come to bear.*

*You have to make the most of what you have, and adapting to your circumstances is important in achieving happiness.*

This may be interpreted as the symptom of what Beresford et al call 'collective disempowerment' and institutionalisation,<sup>121</sup> though as we discuss in chapter 3, there is a difference between social negotiation associated with all group settings and institutionalisation. In the smaller living units we visited,

residents were less accepting of the status quo and more positively appreciative of the support on offer. It was clear that the residents were happy, and therefore did not want to move:

*I've been here 20 years... I'm just part of the furniture now.*

*I go to work, college, yoga class and keep fit. I go to town. Everything I want to do. I like my flat. I'm not moving.*

*I like being round people. I wouldn't want to live alone.*

*The most important thing for me is support and care from staff, someone who knows me. I've been here 11 years and they know me – if people want to know what I like or know about me they can just ask [a member of staff] and she'll tell them what I'm like.*

However, others expressed anxiety at the prospect of a move and reluctance to leave the security of their current care arrangements:

*Eventually I'd like to be more independent – supported living – but the move would be difficult.*

*[You have to] keep things the same for me; if I had to chop and change my anxiety would go flying out the window.*

In Dee View Court, a large Sue Ryder facility for people with neurological conditions, which enables residents to live in small groups as there are a number of self-contained flats, one resident was physically ready to leave the unit, but when the subject was raised of leaving she would emphasise her support needs. The centre manager explained: 'She doesn't want to leave. It's not that she doesn't want to be with her family, but she feels secure here.'

In the next chapter we describe how one Sue Ryder home, Hickleton Hall, is using the Planning Live system of workshops with care users and their relatives to help overcome resistance to changing their support packages and, for some, the possibility of

moving to more independent settings. But it is clear that practitioners supporting people who insist they are happy and ‘do not want to change anything’ or – worse – actively resist and seem anxious at the prospect of greater choice and control (whether that implies a move to greater independence or not) are up against a powerful obstacle to personalisation. However, in many cases, care users and care staff are complicit, so to speak, in their reluctance to change the status quo – just as care users may be unwilling to leave their comfort zone, so those providing that care may be equally unwilling to challenge them to do so.

### Staff culture

Personalisation can be extremely testing for some health and care staff, in a number of ways. Personalisation may require a shift in working practices, and a departure from established processes and tried and tested methods. This may require staff to take a step back and think strategically in an environment that does not often afford the time for reflective thinking.

First and foremost, personalisation involves placing services users at the centre of decision making, enabling them to set their own outcomes and make service choices. This can be a challenge for staff who often, through years of experience and training, believe they know what is best for their client.<sup>122</sup>

Medical and specialist care staff in particular may find this difficult as it challenges the premise of professional expertise and the infallibility of professional judgement. A manager of a Sue Ryder day therapy unit told us,

*Nurses will often want to always be doing something for the patients when they come in. I think sometimes it's a bit overwhelming with assessments then all their therapies – I say ‘they don't all need to be assessed every week’. Sometimes people don't want to be involved in anything while they're here. They should be able to do that – that's personalisation.*

It is professional paternalism, which the forerunners of personalisation – independent living, direct payments and so on – were originally designed to challenge. The phrase ‘nothing

about me without me' was coined by the disability movement to reflect this objection to professionals making unilateral decisions on behalf of their clients and disempowering them as a result.

Second, personalisation requires professionals to think about an individual holistically – looking not just at the area of need that falls within that professional's area of expertise, but also at their wider needs. Considering people's needs in the round (eg medical, personal, social, spiritual), can be a challenge for staff with specialist fields of knowledge – perhaps with the exception of those in specialist palliative care, which is actually based on the premise of providing holistic support. Some of the practitioners of palliative care felt that some medical professionals found it more of a challenge to consider non-medical aspects of care.

Third, personalisation requires more of an 'enabling' approach – doing things with people, not for people, and encouraging more independence and self-care. Staff must challenge people's passive acceptance of services and reliance on a safety net – which, as explained above, is so common a phenomenon among those with complex needs used to 'all encompassing' care or residential care. It is only by challenging people's passivity that they will be able to make active choices and take control of their lives. This, in turn, requires 'risk enablement', rather than 'risk aversion'.<sup>123</sup> This remains one of the greatest challenges for health and care professionals. Those who joined the caring professions as a vocation, seeking to 'care for' and 'look after' people, may have supported the same people for ten, or even 20 years, creating strong emotional bonds. These staff understandably want to protect their clients, in the same way the client's families do. This includes not putting people outside their comfort zone or challenging them to be more ambitious in their aspirations for greater control over their lives. As a report for the Social Care Institute for Excellence states:

*Risk enablement should become an integral part of the transformation of adult social care into a system which puts the person in control. It cannot be a 'bolt-on' solution to existing systems which do not have the person at the centre.*<sup>124</sup>

In this case, too, those in palliative care may be better prepared professionally for personalisation – Samantha Cheverton described how there was often a more balanced approach to risk in palliative settings:

*If someone in a residential home or acute medical ward kept falling every time they had been mobilized, there might be a restriction condemning the patient to a wheelchair... In the hospice – this is where the personalisation comes in – within reason, we take a guarded risk. We think it's part of this person's independence to have mobility if that is what they have chosen. It is possible that they may fall a couple of times in a day, but if it's safe and manageable and that's what they want to continue doing, we will give people that extra freedom. It may require a high level of staff, but we want patients to remain as independent as they possibly can. It's about calculating the risk.*

*A hospital may insist that a patient be washed every day even though they may not, in other circumstances, choose to. [In a hospice] we would aim to follow the patient's wishes, if they chose not to be washed; we would ensure that we check their pressure areas and ensure that they are comfortable, change their sheets, wash their hands and feet etc. But the main thing is what the patient really wants. It's what we all went into nursing to do, to be able to care for people properly and thoroughly and have the time to explore their feelings and psychological needs.*

This need not be the preserve of palliative care, however. A manager in Sue Ryder's Aberdeen-based neurological residential home Dee View Court also demonstrated a similar empowering and measured approach to risk and allowing people to do things for themselves:

*We have springy floors and soft walls so if anyone does fall they won't hurt themselves. We don't make anyone have a chair... but we also often fit wheelchairs in advance before people really need them so when people do need them, they don't have to wait. A lot of people will use their wheelchair as a zimmer frame and take it around with them, and then they sit in it when they are tired.*

*One of our residents is writing to our MP at the moment to get a crossing put in front here, to make it safer to cross the road. Before you never*

*would have had people crossing the road to go over to the shop on their own but now we do.*

The fact that a resident is writing to their MP themselves (rather than the manager of the home making the request) is as important a point as the fact that residents are going out unaccompanied.

Given the multiple challenges personalisation can pose for health and social care staff, aligning social care and NHS training to the skills required for personalisation is clearly important. Practitioners must understand both the concept and practice of personalisation – eg how to work in partnership with care users to set outcomes, how to manage risk, how to help people think ‘outside the box’ and become more ambitious in their choices, and how to act as a broker for choosing the right care package and other key competencies.<sup>125</sup> However, the recent annual personalisation survey by Community Care found many front-line social workers felt they did not possess the right skills for personalisation.<sup>126</sup>

It is important to remember that training alone is not sufficient – personalisation also requires a change of attitudes and professional cultures around health and care. Indeed, personalisation could be a challenge to the entire public service ethos as professionals move from a position of ‘looking after’ someone to empowering them to make choices about their own care. One chief executive officer of a not for profit company providing supported living for young adults with learning difficulties and autism told us that when hiring staff, he looked for the right *attitude* – an attitude that sought to empower people, to take charge of their own lives and in some cases challenge their comfort zone. He commented this was not always held by the applicants with the most experience of working in social care, and he had sometimes recruited staff who came from other disciplines because their attitude was conducive to personalisation.<sup>127</sup> This supports a comment made by Neil Wright, activities coordinator at Wheatfields Hospice, who explained he was ‘not burdened by a clinical background’ – but had had lots of customer support experience in his previous job.

This made him the ideal candidate to take an enabling and capabilities led approach – where he could befriend patients and didn't feel compelled to 'do things' to or for patients if they simply wanted to sit and relax.

### 3 Meeting the challenges of personalisation for those with complex needs

In this chapter we consider how some of the barriers to personalisation for those with complex needs – outlined in chapter 2 – might be overcome, and present some examples of good practice already under way. We explore in particular how personalisation might be improved through:

- a more inclusive approach to personal budgets
- innovative personalisation methods in residential settings, including co-production
- changes in staff culture and encouraging the ‘personal touch’
- personalisation strategies in palliative care settings
- the integration of health and social care
- bringing housing into integrated support

#### Inclusive personal budgets

We have been clear throughout this report that personal budgets are *one of many* tools that can be used to personalise care and support, but for some groups and in some care contexts, they are not the most effective method to achieve person-centred support. However, no one should be excluded from having a personal budget if they so wish. In order to make personal budgets as accessible as possible for all groups and in all care contexts, we need to think beyond direct payments as the only, or even the preferred, form of personal budget.

There are six forms of personal budget used in social care in England:

- a direct payment (held by individual)
- an indirect payment (held by trusted other – eg a friend or family)

- a trust fund (held by a trust of people)
- a brokered fund (held by a professional broker)
- an individual service fund (held by a provider)
- a care managed fund (held by local commissioner)<sup>128</sup>

and three types of personal health budget:

- a notional budget (held by the NHS)
- a third party arrangement (held by an independent user trust or a voluntary organisation)
- a direct payment (held by the individual)<sup>129</sup>

In Scotland, the Self-directed Support Bill outlines a similar range of options for social care:

*Self directed support allows individuals to choose from taking a direct payment, having a direct payment managed by a third party, or to direct the available individual budget to arrange support from the local authority or commission it from a provider. Some people may choose a combination of these options.*<sup>130</sup>

Interestingly, and in stark contrast to social care services in England and Scotland, where direct payments are strongly encouraged, a direct payment personal health budget can only be offered by approved primary care trusts (PCTs) in the pilot programme.<sup>131</sup>

For those with complex needs, older people with dementia, those receiving end of life care and so on, some of these options will be more appropriate than others. Not everyone is able or wants to use a direct payment (and at the moment, an anomaly in social care legislation means people living in residential care cannot have a direct payment). There is a danger, however, that as the Scottish and English governments focus on direct payments as the default and preferred modus operandi for personal budgets (in social care at least), people may assume these other forms of personal budget are not capable of ‘real’ personalisation.

This can become a self-fulfilling prophecy, with providers spending less time developing their systems for these other forms

of personal budget and them becoming tokenistic forms of personal budget, which do not deliver real control. This is already being demonstrated in the results of a recent Community Care survey, which found that local authorities were ‘failing to offer choice and control’ by primarily offering their service users ‘care managed funds’ and providing little more than a traditional service.<sup>132</sup> The InControl POET (Personal Budgets Outcome Evaluation) survey 2011 also found that the satisfaction scores among those with direct payments were higher than those with other types of personal budgets.<sup>133</sup> This may be because direct payments are inherently better at delivering improved outcomes and a greater sense of control and satisfaction, but it is also possible that these other methods have been under-developed to deliver that same sense of direct control. There is no reason why an individual service fund, brokered fund and so on cannot achieve the same sense of financial independence and empowerment as a direct financial payment, if it is administered properly – for example, if the service user is told exactly how much funding they have and is given the primary role in planning how to spend it (see the section ‘Co-production and co-design’, below).

Staff at the Mental Health Foundation recently piloted Dementia Choices, a scheme to bring self-directed support to older people with dementia and their families, and demonstrated how effective other forms of personal budget could be when used properly.<sup>134</sup> They pointed out that a personal budget can be managed in several ways simultaneously, so a person could choose a direct payment to pay for their transport, for example, while giving responsibility to their family for the rest of the budget to arrange care to their family. The idea of using more than one type of personal budget at one time has been proposed in the Scottish Self-Directed Support Bill. Indirect or brokered funds, *or ISFs combined with direct payments*, could be extremely valuable for those with complex needs, perhaps in residential homes, in delivering a virtual (and real) sense of purchasing power.

Look Ahead, a housing and care organisation supporting people with learning disabilities and mental health needs, has piloted a project with Tower Hamlets where individuals with

complex mental health and high support needs receive core support (around 70 per cent) provided by Look Ahead staff and covering the risk-related elements; flexible support (20 per cent), where tenants are able to purchase support worker hours from Look Ahead, to be delivered at a time and in a way to suit them; and a cash fund (10 per cent) to be used to purchase support services or goods.<sup>135</sup> This mix and match approach could enable even those with the highest support needs to have greater control over their support.

It is vital, therefore, that in order to ensure the benefits of self-directed support are available to all – regardless of their capacity or appetite to manage a direct payment – other forms of personal budget are invested in so they are as effective at delivering choice and control as direct payments, and not seen as a ‘second best’ option. They can only be developed and improved through training care staff and providers about ISFs, stimulating the personal budget brokerage market, providing information to families about managing an indirect budget for relatives, and ensuring local authorities use care managed funds not as a disguise for a traditional care package but rather as a distinct new offer where they act as a facilitator in giving their clients active choice and decision-making power in how the budget is used.

## Personalisation in residential care

As outlined above, providing personalisation in residential care can be challenging – though why is often a question up for debate. Some believe residential care is inherently disempowering,<sup>136</sup> making personalisation – which requires individuals to take charge of their lives and choose their support – impossible to achieve. Others are more pragmatic, suggesting it is less about the characteristics of residential care per se, and more about the inherent limitations posed by communal living.

Whichever side of the argument we might choose, the fact remains that some people with multiple and complex needs and requiring intensive support do need to be in residential settings. This may not – indeed almost certainly will not – be the same

number of people who are in residential settings at the moment and, over the coming years, we are inevitably going to see a reduction in the residential population in this country. This is continuing a trend that began as long ago as the mid-1990s,<sup>137</sup> as the concept of supported living, extra care, shared lives and other housing alternatives have become more popular and achievable – particularly for adults with learning disabilities and mental health needs, and older people without significant needs (such as dementia). But we will never do away with residential care altogether. Indeed, as dementia rates are increasing rapidly,<sup>138</sup> along with the numbers of very old, the demand for nursing and residential support options may turn around from its long period of decline.

With this in mind, residential providers are now asking what their service offer should look like. Does residential care in the future need to be provided in a traditional multiple-bed care home? Is it financially sustainable to operate in another way? With the collapse of Southern Cross, one of the largest residential providers in the country, the sustainability of the residential market has become of greater political interest in recent months.<sup>139</sup>

But putting aside these broader questions about the future shape of residential care, the fundamental question of how to achieve personalisation in collective settings – whatever they may look like – when considering the future of personalisation for those with the most complex needs is extremely pertinent to this report. Those groups who will need residential or collective care in the future – those with multiple and complex needs (often physical and cognitive impairment), advanced dementia and so on are still entitled to personalised services and choice and control about their support, and the opportunity to make decisions about their day to day lives. As the evidence outlined above shows, this can have a dramatic impact on residents' mental health and sense of wellbeing in their care setting. Yet as the personalisation agenda develops, focusing on personal budgets, so too does the risk that those in residential settings may be overlooked because they are in a setting in which personal budgets do not find an easy fit.

## How do we personalise residential care?

### *Personal budgets*

Those with complex needs, who may live in residential or extra care, or in small groups in supported living units, will always have a challenge of using an individual pot of money to secure different support services. However, it is easy to see how the mix and match approach mentioned above – where individuals use different forms of personal budget for different aspects of their care – could apply in communal residential settings, where a resident's individual service fund or care managed fund could cover core residential care, while a direct or indirect budget could cover the additional costs associated with activities in the residential home or community. While this would require providers to have a clearer sense of the unit costs of what they provide in order to separate 'core' and 'non-core' costs, such as financial management, this is now becoming more widespread and guidance is available for providers on how to go about such an organisational transformation (figure 1).<sup>140</sup>

### **Planning Live!**

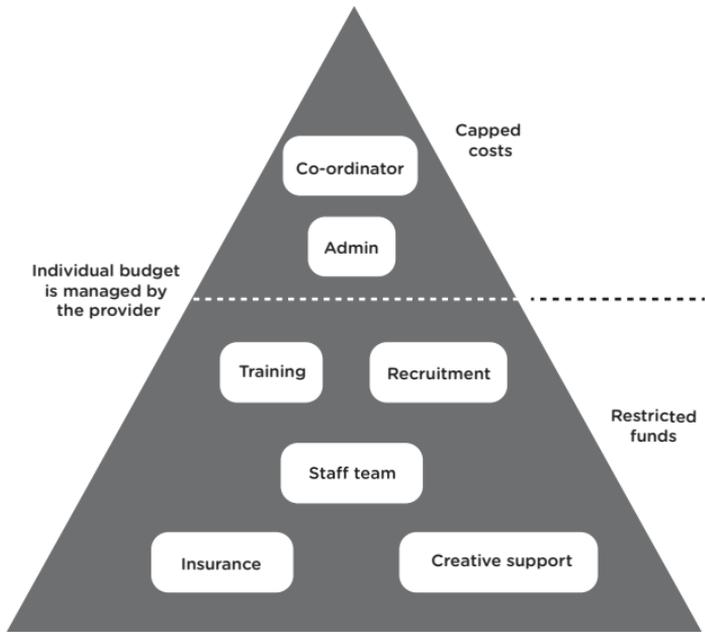
*Sue Ryder is running the Helen Anderson Associates Planning Live workshops in a number of its centres, including Hickleton Hall, a large residential and nursing home for those with neurological conditions and older people. Planning Live! is a three-day course for service users (with their families, friends and carers) to develop their support plan. Each service user starts the course with an indicative allocation (the amount they are likely to receive as a personal budget, based on their assessed needs) and by the end of the course will have developed a support plan that can be signed off by the budget holder (the local authority).*

### **Day 1**

*The first day is designed to help people think about:*

- *who they are and what is important to them*
- *how they want to live, what they want to keep doing and what needs to change*

Figure 1 **An individual service fund - provider breaks down costs so a budget holder can understand what they are spending money on**



Source: In Control

- *what support they may need to keep doing the things they want to do, and how to make these changes and stay healthy and safe*

### **Day 2**

*The second day of the workshop is focused on supporting people to design the support they will need in order to make the changes they have identified. It includes creative service design and providing information about what is possible locally.*

### **Day 3**

*The third day is an opportunity to develop and check the first draft of the plan based on the information that has been collected so far.*

*Planning Live! is particularly valuable for people with complex needs or living in residential care. They are likely to need help in developing support plans, encouragement to think outside the box when it comes to planning their care, and also require the input of their family and friends, who may share in the support with formal carers.*

If we imagine a mix and match form of personal budget in a residential setting, it is likely that the ‘care core’ (which includes core costs, such as staffing, insurance, facilities maintenance) might be subject to an individual service fund or managed budget while a resident or their family may hold the rest of the budget to spend on all non-core costs – such as activities, optional therapies, meals and so on. How these remaining funds are spent may require negotiation with fellow residents and it may prove challenging to ensure that everyone’s needs and interests are met. We discuss collective negotiation in such settings in the next section.

Such challenges could also present opportunities – for example, if a small group of residents in a care home decided they wanted to go to a football match, while the majority of residents did not, the small group could pool their resources and pay for a personal assistant to accompany them, specialist transport to get them to and from their home, and so on. The economies of scale they would achieve would mean their budgets went further in securing a variety of different activities.

This concept of collective purchasing with personal budgets is a new frontier in personal budget thinking and in its early stages. Nonetheless, some believe it is an inevitable evolution of the personalisation agenda and are investing a significant amount of effort into developing it.<sup>141</sup>

This could have powerful implications for residential settings, which present the perfect budget pooling opportunity. In the future, different groups of residents in extra care,

supported living and residential units could form at different times to pool budgets for outings, visits of specialists, perhaps even meals – the opportunities for such personalisation is only limited by the residential provider's ability to break down operating costs into these base components. Indeed, the first experiments of collective purchasing are in extra care and social housing. The housing action charity HACT's project up2us (<http://hact.org.uk/up2us>), for example, has been piloting collective purchasing with personal budget holders in social housing providers in six pilot areas.

The evaluation of the pilots found the biggest challenges to the scheme were a lack of organisational structures to facilitate collective decision making and purchasing, and the staff and organisational culture to facilitate personalisation. The study concluded:

*Understanding what people value and want in their lives is critical to making personalisation successful and will inform how services must change. Many providers involved in the up2us pilots have found it useful to begin a series of 'conversations', or facilitated sessions with people who use their services, to try and understand what type of life people want, and how services and support might best realise this.*

*Providers should widen their focus beyond the disaggregation of services: personalisation is far more than allocating budgets. It is also not necessarily synonymous with individualisation. The potential of collective and collaborative purchasing may not be fulfilled if this remains the lens through which you see personalisation.<sup>142</sup>*

The Housing Learning and Improvement Network is also exploring collective purchasing, in this case with extra care residents. It has identified four different models, which it believes could work for extra care residents. The first is perhaps the most radical, where it envisages the group of tenants collectively purchasing their entire support provision themselves by commissioning a housing and care provider:

*Services would include round the clock provision of personal care – both planned and unplanned – and housing related support. They might also*

*include the organisation of activities in the scheme, management of Individual Service Funds on behalf of service users, and/or brokerage or signposting to other organisations and services.*<sup>143</sup>

The commissioning group would be a user-led organisation, with a management board, whose members would be responsible for renewing the contract each period. If the company commissioned was for profit, the users could become shareholders of the company for additional democratic control.

This may or may not work in every residential setting, but the Housing Learning and Improvement Network also proposed three variations of the mix and match model outlined above, including one where the core service is commissioned by the council, and one where an extra care provider takes 70 per cent of each client's personal budget for housing and care support, leaving 30 per cent to be spent on additional services:

*They could also purchase any other services needed (in addition to personal care) from providers of their choice. For example, tenants would have the option to pay the provider direct for other services supplied to them such as meals, hairdressing, activities etc – or they can choose to purchase these services off-site.*<sup>144</sup>

While these models clearly need further development to catch up with the individual purchasing processes in place around the personal budget agenda, they have the potential to marry collective living with purchasing power – and could therefore be revolutionary for those living in residential or supported settings (with more complex needs).

There is, therefore, definitely scope for personal budgets to be used in residential settings, as long as we think outside the direct payment box and develop alternatives which can deliver the same levels of control that direct payments have been set up to achieve. In particular, there is a significant opportunity to apply a mix and match approach to enable collective purchasing alongside individual freedoms to purchase add-ons to a care core.

We know that residential care settings do not provide care alone. All provide additional activities as well as elements that

have always fallen under ‘hotel costs’. What if a residential home were able to break down its costs in such a way to enable personal budget holders to spend a portion of their budgets more freely around social costs, activities, even meals? Might we see budget holders hire their own assistants to come in to the home and engage in activities of their choosing?

Such a revolution in residential provision is some way off, and only financially sustainable if many more residents have personal budgets to incentivise residential providers to operate in this wholly new way. The next section considers more immediate measures that might be employed as alternatives to personal budgets, or as ways of enhancing the impact of personal budgets, to deliver greater personalisation in residential settings.

#### *Co-production and co-design*

The co-design and co-production of residential care are potentially powerful and important ways of personalising residential services, which can work independently of personal budgets or alongside them to improve them where they cannot be fully implemented. The term co-production was first coined in the USA in the 1970s by Elinor Ostrom, the 2009 Nobel prize winner for economics, in her studies of the Chicago police.<sup>145</sup> She defined it as a ‘process through which inputs used to produce a good or service are contributed by individuals who are not “in” the same organisation’.<sup>146</sup>

Since then, co-production has been refined and developed, and a related concept – co-design – has been used to describe a situation where users of a service help design it at the outset, to ensure it meets their needs. Co-production implies that users both design and help the delivery of a service.<sup>147</sup> Put simply, if personal budgets achieve personalisation through *choice*, co-design and co-production creates personalisation through *voice*.

Co-production has been particularly important and influential in health and social care. Initially, it was recognised by government that people with impairments or long-term conditions were likely to be the most expert in managing their

care and therefore they could dramatically improve services if that knowledge and experience were harnessed to be used to plan, develop and even sometimes deliver health and care services. One successful outshoot of this was the NHS Expert Patients Programme, which began in 2005/6 and is still going strong today.<sup>148</sup> Patient involvement in health services is now embedded in the NHS Constitution (section 2a), which states:

*You have the right to be involved, directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services.*<sup>149</sup>

However, the concept of involvement can be open to interpretation, and may not lead to meaningful co-production. The NHS Future Forum's 2011 report, *Patient Involvement and Public Accountability*, suggests that the NHS needs a stronger definition of 'involvement' and that 'to involve' and 'to promote patient involvement' should mean embracing the principle of shared decision making.<sup>150</sup>

Co-production in social care, on the other hand, has proved to be more robust – resonating as it does with the principles of empowerment, independent living and the mantra 'nothing about me without me' of the disability movement. Co-production enabled these long held beliefs to be put into practice, and in a way facilitated their translation into policy-making structures. In a report for the Social Care Institute for Excellence Needham and Carr explain why co-production is so well suited to social care:

*The nature of adult social care makes co-production particularly apt... Co-production is especially relevant for areas in which services are individualised, site-specific and of sustained importance to people's lives, requiring ongoing dialogue between many people and agencies and frequent review. Adult social care services meet all of those criteria. People who use services are by necessity strongly involved in the production of their care and notions that they are passive consumers of services produced for them by others are particularly inappropriate.*<sup>151</sup>

Needham and Carr define co-production specifically in a social care context thus:

*[Co-production] refers to active input by the people who use services, as well as – or instead of – those who have traditionally provided them. So it contrasts with approaches that treat people as passive recipients of services designed and delivered by someone else. It emphasises that the people who use services have assets which can help to improve those services, rather than simply needs which must be met. These assets are not usually financial, but rather are the skills, expertise and mutual support that service users can contribute to effective public services.<sup>152</sup>*

Co-production has, as a result, also become integral to the concept of personalisation. As outlined in chapter 1, personalisation requires individuals to help establish the outcomes they want to achieve, and develop their support plan to achieve that. This, in its strictest sense, is co-design. However the frequent result of personalisation – where service users are more independent, through personal budgets choosing and buying their own care, often using personal assistants and developing their own resources to support their own outcomes – is co-production. The concept of personal budgets is based on the idea that individuals become partners in their care, not passive recipients – co-production is inherent in this.

The interrelationship between co-production and personalisation was first made clear in the 2007 strategy *Putting People First*, where the Labour Government stated that the transformation of adult social care programmes ‘seeks to be the first public service reform programme which is co-produced, co-developed, co-evaluated and recognises that real change will only be achieved through the participation of users and carers at every stage.’<sup>153</sup> Phil Hope, the last Labour care minister before the new government, said of co-production in 2009:

*It makes the system more efficient, more effective and more responsive to community needs. More importantly, it makes social care altogether more humane, more trustworthy, more valued – and altogether more transforming for those who use it.<sup>154</sup>*

### *Co-production instead of personal budgets?*

While the concept of co-production has become integral to personalisation, experts we spoke to during the course of this project suggested that co-production should not just be seen as an underpinning of personal budgets, but that it could rival the consumerist approach of personal budgets and deliver personalisation in a wholly different way. In short – personalisation by voice, *rather than* choice.<sup>155</sup> This seems to be the underlying principle of the 2011 Welsh social care strategy, which looks to create citizen-centred services and is less explicit about ‘consumer choice’ than its English and Scottish counterparts.<sup>156</sup>

This has powerful implications for residential social and health care. By exploring opportunities for co-design and co-production in residential and communal settings, providers have an opportunity to involve and empower their residents in the design and delivery not just of their care, but of their day to day lives and living environment. This, in turn, could be an effective pathway to greater personalisation – and one which is compatible with, but does not rely on, personal budgets being present.

### *Some examples of co-production*

We must remember – as the NHS Future Forum recognises – that meaningful co-production is not the same as consultation or even ‘involvement’. Co-production requires care homes to go beyond residents’ forums or feedback mechanisms and consider how their residents can actively design aspects of care and accommodation. For example, residents would need to be not just consulted on redecoration, but actually work together with care staff and managers to decide the design and layout of their rooms and communal spaces, feeding in their expertise on their physical or mental limitations and how their environment needs to be adjusted accordingly. Co-design should also be applied to the timing and structure of activities, meal planning and so on, and co-production could be used in some cases – for example, with residents helping to arrange and deliver some of their activities both on site and in the community (see below).

Care users should be given an opportunity also to design guidance materials and training packs for staff on their

preferences and needs related to their support and daily lives and, where possible, actively train new staff who arrive on their own and their peers' needs. Going further than this, some providers enable their clients to help recruit staff. Residents could be asked to develop job specifications with the care management, to ensure the right balance of skills and attitude are reflected in job advertising. Individuals with personal budgets have the freedom to do this when hiring a personal assistant – there is no reason why a similar process could not be undertaken collectively among care residents. Indeed, where staff are hired as key workers or dedicated carers for one or a small group of residents, those people should have an active role in deciding what it is they are looking for in a support worker. The relevant residents, or representatives of the residents, could also sit on interview panels.

For example, in Dee View Court, Sue Ryder's neurological residential centre in Aberdeen, candidates for staff positions are assessed on how they will pair with residents, as well as on their skills and experience. Residents are included in the interview process and compile questions for candidates. They also show candidates around the centre, and residents are asked for advice and feedback on what they think of the selected candidates.

Although some residents may not want to co-produce to such an extent, group discussions can provide valuable material to enable staff, trained in the concept of co-design, to develop a range of elements of residential life and care. The most important principle of this approach is for those facilitating group discussions to recognise that experiential knowledge (from residents based on experience) is as important, or even more important, than professional knowledge (from care staff or management).<sup>157</sup>

Research also shows that often very low-tech, non-specialist measures can be employed to enable those with dementia and communication difficulties to make themselves heard and make choices about their day to day lives – for example, the Talking Mat has proved highly effective in giving older people with dementia in care homes a way to make choices and has significantly improved their quality of life.<sup>158</sup> Even those with

multiple and complex needs can play a role in collective participatory decision making.

### *Democratic structures*

To co-produce, co-design or make decisions in residential and collective settings, structures need to be in place to enable groups of people to have their collective and individual voices heard. It is important at this stage to point out that there is a difference between personalisation and individualisation. In the wider health and care context, these concepts have considerable overlap, but in residential settings, it is vital that the two are seen as more distinct and we think more creatively about personalisation. It is not an inevitable outcome of personalisation that a person will be 'individualised' in their choices of care or decision-making processes. As we have seen above, Think Local, Act Personal and others are leading the thinking in the collective spending of personal budgets where people's collective preferences coincide.

But what about cases where individual preferences do not neatly coincide? There need to be processes which enable individuals living together to have their voice heard, and negotiate their preferences and concerns with the collective. There then has to be a way of fairly balancing the preferences of individuals with those of the majority, where no compromise or consensus can be achieved.

Many health and care residential homes, supported living communities, extra care homes and so on have residents' forums, which have varying degrees of power and influence – from acting as a consultative body or communication channel for the wider resident population, through to being more actively engaged in influencing policies and practice in partnership with staff and management. These should be introduced as standard practice, and used as a form of collective empowerment<sup>159</sup> and a forum of collective negotiation, to ensure the views of individuals are aired and weighed against others. These could be supplemented by plenary sessions with the entire residential group, small group discussion and one-to-one conversations, to enable residents with varying levels of capability to contribute. While we should never

underestimate the power of an informal chat with a carer to generate change, it is also vital that there is a proper process behind this communication channel, so staff can record, escalate and deliver on these conversations or feed them into the collective decision-making process. Groups of care users living together are likely to have varying levers of capacity and ability to communicate, and care will need to be taken to ensure all voices are heard. Having multiple communication channels will increase the likelihood of this, but tools like the Talking Mat, mentioned above, and other techniques will need to be in place.

There is a clear difference between this form of collective negotiation – something many of us do every day in our workplaces or with flatmates – and disempowerment or lack of personalisation. The negotiations flatmates might have over buying items for their home, or groups of friends or a family might have regarding social activities, are natural social phenomena based on the fact that people live collective lives – spending time in social or family groups. This is distinct from institutionalisation, where an individual is expected to compromise their individual needs or preferences based on organisational routine or diktat from home staff or management, in an unequal power relationship.

On the other hand, residents' forums – where individuals can negotiate as a group of equal peers about choices for their surroundings, the activities they undertake and so on, and then have that collective voice influence decisions and make visible change to their environment – can be an extremely powerful tool in creating collective empowerment, as well as social capital among residents as the processes of negotiation and decision making can also help form stronger relationships between residents, creating bonds of peer support.

Bowers et al found in 2009 that older people in different settings (including residential and extra care) consistently identified the following points were key to a good quality of life:

- people knowing and caring about you
- the importance of belonging, relationships and links with your local or chosen communities

- being able to contribute (to family, social, community and communal life) and being valued for what you do
- being treated as an equal and as an adult
- having respect for your routines and commitments
- being able to choose how to spend your time – pursuing interests, dreams and goals – and who you spend your time with
- having and retaining your own sense of self and personal identity – including being able to express your views and feelings<sup>160</sup>

Collective decision-making forums and opportunities to co-produce – collectively and individually – can be important vehicles for achieving many of these outcomes. A residential setting ought to be seen as a micro-community in itself, with its own opportunities for decision making, participation and contribution.

Dee View Court, a Sue Ryder home for those with neurological conditions, is an excellent example of this concept working in practice.

#### **Dee View Court – creating a natural community life within a residential setting**

*The centre has six self-contained apartments running off the central concourse, with 22 permanent beds. It is designed on a village layout with a street running down the centre – people's apartments are on one side of the 'street', the care services and facilities (activities room, therapy rooms) are on the other side of the street. The whole unit is housed under a glass roof so residents have the feeling of being outside. One of the self-contained apartments has two bedrooms, the other five have four bedrooms, all with en-suite, shower, lounge and kitchenette. Residents are encouraged to maintain their independence and continue their everyday lives by cooking for themselves, inviting other residents into their units to socialise, and so on.*

*In the main atrium is a café where residents can socialise – meals are not delivered in a formal dining room at a set time, but rather residents can sit in the café and eat when it*

*suits them, have their meals in their apartments, or cook for themselves or with help in their own kitchenettes.*

*As Dee View Court is run as a small community, so the residents participate in a number of user groups in order to take control of their environment, deciding on the decoration of their units, the use of the communal space, the meals and activities provided, the scheduling of therapy for the group, and input into staff recruitment. The residents work collectively to ensure everyone's needs and preferences are met when making decisions on behalf of their peers.*

*The combination of a communal space and activities with smaller self-contained living units means individual residents have different levels of group identity and decision making. They are part of the larger collective of 22 residents, who come together to decide collective aspects of life such as the scheduling of therapies. But they are also part of a group of four 'flatmates', so to speak, who make decisions about their shared self-contained living space. Residents then also have opportunities as individuals to make decisions about what they do and when – there are no set times for getting up or going to bed, nor meals, so residents order their days as they wish. This approach emulates a very natural environment, where people are recognised both as independent individuals and as part of their communities.*

Of course, it will not always be possible to collectively agree on every matter. Care home residents are a heterogeneous group of individuals, after all, with different preferences and interests and will not always speak with one voice. The care staff we spoke to were often concerned that personalisation would mean total individualisation – that each individual resident would need to have a wholly separate set of needs catered for, perhaps with an individual member of staff to facilitate each one. In reality, it is unlikely that groups living in collective settings would fall to this extreme position. While they may not always talk with one voice, in many cases, there may well be small groups of individuals with common interests and concerns whose wishes can be accommodated alongside other small groups. But

more importantly, the *process* of negotiation and decision making, weighing up pros and cons and making tradeoffs, is an empowering experience in and of itself, even if an individual finds themselves giving way to the majority view. Individuals are more satisfied with a decision they were involved in making, even when the outcome of that decision was not their preference.

We must remember – and make it clear to those on the front line – that personalisation does not always mean the achievement of one's preferences in every aspect of life irrespective of practical limitations or others' wants and needs, and compromise is sometimes necessary – as it is for everyone in everyday life. The key is to make this compromise legitimate and transparent, and based on negotiation and discussion, rather than the 'say-so' of authority figures. Democratic structures in communal settings enable residents to negotiate with each other *and* with the staff and management of the residential setting. It is important, therefore, that feedback is acted on and actions followed through, and where action cannot be taken, it is explained why this was the case.

Below are two comments, the first from a staff member, the second from a resident in the same residential unit. The difference in perceptions between the two is important as, while it may very well be that residents *are* listened to and actions *are* taken, the *quality of the democratic process* makes a great deal of difference to how this is perceived and the level of satisfaction with it. What is important is not simply the outcome but how that outcome is reached:

*I have worked in a lot of care homes over the years, and this is the first one I have come across that has anything where the residents have a say, and they are actually listened to.*

Carer

*The way this place is set up, the management are behind a firewall. They never ever talk face-to-face with the residents. We have a meeting, and they pass on what we said in that meeting to another woman, and then that woman has a meeting with the management.*

Resident

### Delivering on personalisation

The previous section explains the potential of co-production, co-design and collective decision making in the personalisation of residential care. Underpinning this is a recognition that personalisation is not the same as individualisation, in that often people make collective choices and negotiate within a collective of equal peers as part of human society. We also pointed out that personalisation does not imply that a person has limitless choice and can disregard the preferences of others.

However, this does *not* mean that care providers should not strive to ensure that each individual in collective care settings can pursue their own interests and spend time doing things separately from the group. Moreover, it is vital that once processes are in place for co-production and decision making, care providers can deliver change based on the feedback from residents. While some requests – for example having resident input over recruitment processes – may be culturally challenging but more or less cost neutral, there will be resource implications for other actions arising from personalisation. Care staff frequently expressed this concern during the course of our research. A lack of resources – both to provide additional activities, equipment and decoration, as well as simply a lack of staff to provide the additional support residents might need to enable them to pursue their own hobbies, go into the community and so on – made staff cautious about discussing people’s aspirations and pursuits for fear that they would simply be unable to deliver these things and did not want to ‘get people’s hopes up’.<sup>161</sup>

We explain below how volunteers can be used to improve this situation, but given the potential cost implications, it is understandable that personalisation in residential care is often polarised. At one extreme, residents are enabled to move on from residential care or NHS campuses and access supported living, with the greater personalisation and independence that entails. At the other extreme, those who are not able or ready to progress to supported living may only see micro-changes – such as changes in their lunch menu. There is an obvious gap in the middle – for those who are not able to move out of residential settings, but who still have aspirations and clear ideas about how to improve their quality of life and control over what they do.

As mentioned above, the care users we met during this research told us that independence, maintaining relationships with friends and family, being surrounded by people you know, and jobs and volunteering were all important to them. These go beyond the ‘small things’ – which although they are important for quality of life do not address people’s deep-seated needs and aspirations – and are at the heart of meaningful personalisation. Steve Jenkin, Director of Health and Social Care at Sue Ryder, explained:

*Personalisation is not all about shampoos and food. You [have to] think about where someone has come from, where they want to get to, and I think all we had dealt with, at that time, was the present.*

Therefore, once processes are in place to enable care users to communicate, negotiate and make joint and individual decisions, considerable work needs to be done to *deliver* personalisation at a more fundamental and meaningful level for people in residential homes, in a financially sustainable way. Some of the opportunities that need to be explored by the sector include:

- developing the concept of ‘just enough support’ – an approach which recognises that too much support is as bad as not enough, and that developing community-based alternatives, including a greater use of volunteers, peer support and social networks, to formal support is both more financially sustainable and better for the individual
- related to the first point, embedding residential homes within the wider community – enabling a two-way flow between the ‘micro-community’ of the residential home and the wider community in which it belongs; this includes having residents go out into the community regularly as individuals and as a group, but also facilitating and encouraging the community to come into the home
- employing non-care staff to act as ‘enablers’ or ‘facilitators’ – a role that goes beyond coordinating activities to enabling individuals to pursue their own interests and build their own networks – while care staff can focus on their specialist roles

- assigning a key worker to each resident; this can be an existing member of the care staff and each key worker can have more than one resident, but the key worker acts as a gateway for the resident – leading on the implementation of the care plan and acting as a broker or communication channel so the resident has an individual point of access for their concerns or to express their preferences

### *Just enough support and community development*

An evolution in thinking around personalisation is under way – led by the Think Local, Act Personal coalition. There is increasing recognition that personalised support is more effectively delivered in conjunction with building community capacity. The principle behind this is asset-based community development (ABCD), which looks at what community and informal support networks can be developed and harnessed to supplement formal support sources. The idea is to look at what can be done without support, rather than beginning with a deficit model of what cannot be achieved without support. Many local authorities are realising personal budgets can be a catalyst in this – as people are given a sum of money, so they are bringing in other resources – financial and non financial – to boost their care package.<sup>162</sup> Some local authorities are actively encouraging this agenda – Southwark Circle ([www.southwarkcircle.org.uk](http://www.southwarkcircle.org.uk)) is a well-known time banking and peer support network for people with support needs living in the local community, but other local authorities such as Hartlepool and Darlington are engaging their voluntary and community sectors to create ‘connected care’ and ‘citizen-centred commissioning’ respectively. Both are based on the idea that informal and community supports can be used to enrich and expand the formal support offered by the local authority or traditional care providers.

Paradigm UK has developed a closely related concept of providing ‘just enough support’. This is based on the idea that over-support can be as harmful as not enough support for those with care needs. Too much support – for example the idea that someone needs to be looked after by a qualified carer all of the time – can be a barrier to community participation, intrusive,

even oppressive. On the other hand, the provision of just the right amount of formal support can be combined with a range of informal support arrangements from family, friends, neighbours, social clubs and so on. Paradigm UK points out that over-support often discourages this:

*Paid staff are both a necessity for many people and a potential barrier to true community inclusion. There is a danger that community members see no or little need to become involved in the lives of disabled people because 'staff are there to do that'. Using alternatives to paid staff, for many people as part of an overall package of support, may provide opportunities for both more efficient use of resources and increased involvement from community members.*<sup>163</sup>

There are clear lessons to be learnt here for residential and collective care settings. Living in a residential home can be all-encompassing and isolating from the wider community, as the community sees no need to become involved – as Paradigm UK describes it – because ‘staff are there to do that’. Some of the residential care managers we spoke to certainly felt as if the community did not know they were there, or what they did.<sup>164</sup> If residential providers operated on the model of providing ‘just enough support’ and drew on the external community capacity to provide additional elements, there would be a number of benefits: residents would have a wider choice of pursuits and opportunities to socialise with peers and people, other than care staff, who share similar interests; they would have greater opportunities to participate and contribute to the community outside the care home; and care staff would have more time to focus on core caring roles. This model would, in short, achieve improved outcomes at lower cost. Steve Jenkin, Director of Health and Social Care at Sue Ryder, described this in a different way:

*So it is not all about what we should provide, it is about creating opportunities for people to have very active lives, and supporting them to have fulfilled lives, which bring other people into that equation as well.*

He told us about a resident in Bixley Road, a Sue Ryder supported living facility, who had moved from residential care and accessed greater levels of community support:

*He said... 'I used to live in a home, now I live at home.' I thought that was a very strong comment about him realising what the difference was. What he has got now is the life that he chooses, how he wants to spend his time. Having created that life for him, he now has other friends, a circle of friends that he never had before. He goes to the local church, but those people from the church also take him to the pub now, because they are his friends.*

Two other residents were building links with the local Women's Institute, going to local meetings together in their electric wheelchairs. Another said:

*It's brilliant having the chance to socialise again. I am a churchgoer and able to go once a week. I have been welcomed by my new church with open arms and I now feel like part of the community again. Every Friday I now go into my friend's house in Dee View and the four of us hang out. I like being social and it's good to have a social life. My hometown of Dyce isn't far away. My local friends can come and visit any time they want and get a tea and coffee. There are kettles in the sitting room so I can make my own tea and coffee if I want to.*

Pamela Mackenzie, regional manager at Sue Ryder, based at Dee View Court, also told us about one of their clients:

*We had a young lady, a 23 year old who had a brain haemorrhage. She was sitting in an older people's, long-term ward when we assessed her – totally depressed, wasn't eating, doing nothing for herself. She's now walking to the shop to get her morning paper – the possibility is real independence and getting her back living in her own house. We aren't recognised as a rehabilitation service but boy have we rehabilitated this lady and she is ready to move on. There needs to be recognition from commissioners about the breadth of work we do.*

While Dee View Court has – through its unique accommodation design and approach to encouraging resident independence

– created opportunities for people to build their own social networks with the wider community, not every residential setting is conducive to this. Paradigm UK has advice on how to create such an environment, which includes some valuable lessons for residential providers:

- *Employ local people, with local knowledge and local connections. Advertise very locally.*
- *Free staff up to have dedicated time to make contact with people who are ‘active’, who are the connectors and the ‘welcomers’ in the neighbourhood.*
- *Create a post to initiate community connections and to coordinate all the small scale efforts.*
- *Phased withdrawal of support to give a person some unsupported time, and opportunity for connection without the ‘guard’.*
- *Work with staff and develop their role in this. Focus down on the micro level i.e. street/neighbourhood; get to know neighbours and other local people. Develop ways of making connections and people becoming included.<sup>165</sup>*

### *Embedding residential homes in their communities*

To develop community links, which are so vital in the delivery of ‘just enough’ formal support, residential homes must become more involved in and central to the communities in which they are set. This can be achieved in many ways, by bringing the community into residential settings, and by enabling residents to go out into their community.

Many residential homes, hospices and extra care campuses have facilities and grounds which could be of use to community groups who need room to meet, rehearse, hold fayres and so on. As many third sector grants are being cut by local authorities in the face of budgetary constraints, and day centres and luncheon clubs are closing, there is likely to be more demand for such facilities. Partnering with third sector organisations would be relatively cost neutral (or indeed, could generate income if meeting space was rented out) but hugely effective in bringing the community into the home.

Not every residential setting is fortunate enough to have grounds and meetings rooms to spare to allow managers to invite

community groups, schools and so on into their premises, but resourceful staff in homes might encourage one-off events, staging of school plays, still life classes, trainee hairdressers and a variety of other activities to take place in their premises to enable residents to mix with the wider community.

On the other side of this coin is the opportunity for residents to go out into the community. As well as formally arranged group visits and day trips, which offer limited flexibility and personalisation to individual preferences, residential providers must consider how to create opportunities for small groups and individual residents to engage in activities of their choosing or connect with local groups (eg faith, sports and so on). Some staff we spoke to during this project explained how such opportunities were limited because of lack of staff to accompany residents out – but in some residential settings staff are already looking at how volunteers might change this. Rather than having volunteers coming into residential settings, volunteers could be used to accompany residents out into the community, either to supplement or in some cases replace care staff. This increases the capacity of staff without significantly increasing cost:

*We need to think of other non-paid staff who we can work with, and work with [the residents], in developing new friends and developing new connections, and that will decrease our costs.*

There are several other ways of building community links. Just within Sue Ryder's provision, there are a number of innovative approaches under way. For example, Sue Ryder's Manorlands Hospice is running an apprenticeship scheme for people from black and minority ethnic (BME) groups. Recruiting locally from the BME population has helped build ties with the diverse communities of Bradford which it serves, leading to more palliative support being provided to BME groups in their homes, raising awareness of the service among this under-serviced group, and also enabling Manorlands to develop more culturally-appropriate palliative care.

At Hickleton Hall, the neurological residential centre, the Stepping Out scheme was developed to remove the barriers that

stop disabled people participating in their community and accessing universal services. As a result, transport, access, equipment and personal care issues are all dealt with by members of a single support team, who work with an individual to access the full range of care, social and leisure services in the area, including swimming and sports, cultural and arts activities.<sup>166</sup>

The managers and recreational therapists at Dee View Court told us how fortunate they were in being located in the heart of their community, with shops, the community centre, library and church nearby. Residents were encouraged to make full use of these, and to use the local bus services to venture further afield. While some transport did exist (as described in chapter 2 – as a direct result of Aberdeen Council scrapping the dial-a-bus and taxi-card schemes), the experience for residents was broadly positive: ‘And all the shops around here know her [a resident] now. If she doesn’t come in they’ll ask, “Oh [resident] wasn’t in yesterday, is everything ok?”’

Peer support networks also provide a significantly under-explored opportunity to build community links with residential settings. There is no reason, for example, why residents of care homes and supported units could not join peer support networks, such as KeyRing, Never Watch Alone and so on. While these have been originally targeted at joining people up who live in the community, staff help seek out these opportunities and facilitate them.

### *KeyRing*

KeyRing living support networks provide services to people with learning disabilities and other vulnerable adults, enabling them to live independently in the community in ordinary tenancies. They work in partnership with local authorities and housing associations to support a group of nine individuals who live in the same area, usually within walking distance of each other. These individuals (members) live in ordinary one-person properties, and a tenth flat is provided to a volunteer who supports the network of members.

Individuals are members of a network, which aims to support them in living in the community and maintaining their tenancy, through pooling their resources and skills. These may include practical skills such as gardening or changing light bulbs, as well as social skills to include individuals in activities that are already happening in the community.

KeyRing recruits a community living volunteer, whose role is not like that of a key worker or social worker, but one of a skilled good neighbour who can give direct support and offer access to networks of support in the local community.

The community living volunteer gives information, advice and support in practical matters relating to the tenancy. Support can be offered, for example, in reminding members to pay rent and service bills, ensuring they understand that they must comply with tenancy conditions, and helping them with benefits. There can also be a demand from members for reassurance and emotional support. While KeyRing does not expect community living volunteers to offer counselling, it expects them to respond sympathetically to these needs.

To encourage members to help and support each other in problem solving relating to day-to-day matters and through meetings with the members' own group, community living volunteers help members to set up and maintain this group.<sup>167</sup>

### *Never Watch Alone*

The Never Watch Alone Initiative was launched in January 2009 in partnership with the Wigan Council, Wigan Learning Disability Partnership Board, Embrace Wigan and Leigh, the National Association of Disabled Supporters, Wigan Warriors Rugby League Club and Wigan Athletic Football Club. It enables football and rugby supporters with a learning disability to attend matches alongside their fellow supporters.

Through a network of buddies, the Never Watch Alone Initiative enables those supporters with a learning disability to go to games with a friend – a like-minded fan who shares their passion as well as the camaraderie and socialising before and after the game – rather than with a professional carer.

Fans of the Warriors are welcome to sign up as buddies to the Never Watch Alone Initiative. Buddies don't need experience; ongoing guidance, support and responsibility are handled by the professionals overseeing the Initiative.<sup>168</sup>

## Staff matter

### Consistency and the personal touch

One of the things people told us they valued in life was the maintenance of relationships, and being around people they knew and who knew them. Their comments referred as often to their peers and friends, as to the care staff and volunteers who supported them. As one day-patient of a day therapy unit for end of life care explained, she liked attending on the same day each week as: 'All the staff and volunteers are the same. They get to know what you like.' She compared this to the domiciliary care she received, where she had 'an assortment of people' and was looking to dispense with the service as soon as she could.

The importance of consistency in staffing and having someone who 'knows what you like' in achieving personalisation is demonstrated by the fact that as personal budgets are being rolled out, so the number of personal assistants has increased rapidly – up 35 per cent in 2011.<sup>169</sup> Personal budget holders are moving away from traditional home care services – where they may be visited by a different carer every day – to hiring a single personal assistant to provide them with truly personalised support.

It is important to remember that personalisation does not just mean giving a person choice and control; it also involves providing support in a personalised way – what we might call 'the personal touch'. One inpatient at Sue Ryder's Leckhampton hospice described it as a 'human approach':

*My care was one in a million, I haven't experienced nursing quite like it; everyone is treated as an individual. All of the staff treat you with dignity, something you don't get everywhere... The nursing care stands out by far. It's a human approach, everyone means what they say and if you ask for something it will turn up. They treat everyone as a human being, not an item in a bed.*

This personal touch is only possible if staff providing that support get to know their clients well. This, in turn, can only be achieved if there is not a high turnover of staff or multiple staff members providing care. Some of the Sue Ryder sites we visited recognised the importance of this consistency. At Dee View Court, for example, each resident has a key worker, and an ‘associate’ key worker who also knows the resident well. If the key worker is on leave, or ill, the associate key worker can step in and the resident is still supported by someone who is familiar with their needs and preferences and has an established relationship with them. At Wheatfields day hospice, something as simple as a grid outlining each patient’s tea and coffee preferences was seen as an important step in ensuring patients got a ‘personal touch’, as volunteers and staff would not need to ask patients every time how they took their tea.

Consistency in relationships is particularly important for those with complex needs and in settings where personal budgets may not be suitable or may be a long way off in their implementation – for example in palliative care settings. It is also particularly important for those with fluctuating or degenerative conditions, where the ability to communicate or the capacity to make choices and express preferences may come and go, or be lost permanently. If support is provided by someone who knows their client well, wishes and preferences can still be acted on based on that personal knowledge – this can help deliver personalisation even when the ability to communicate or actively choose declines.

### Staff culture

A significant barrier to personalisation can be the cultural shift required of staff to deliver personalisation. As outlined in chapter 3, being prepared to enable clients to take risks and become more independent, treat people’s needs holistically and give their preferences priority even in the face of professional reservations can be a cultural challenge to those with a vocation of ‘looking after’ people or those with specialist areas of medical knowledge. Dee View Court’s approach to the provision of physiotherapy –

there are no set times, leaving residents to access it when they want – is a radical departure from established views on the validity of professional judgement. But the facility's stated position is:

*Often in a nursing home whether a patient receives physiotherapy is decided by the staff, according to what they think the patient needs and benefits from, often conflicting with the wishes of the patient. At Dee View it is believed that if you benefit from having physio and you want it, then you should be entitled to receive it when you want it.<sup>170</sup>*

This is a highly exceptional case of placing control in the hands of the individual needing care. In reality, staff resistance is likely to be a considerable barrier to approaches that seek to free people from professional constraints, and roll back formal support and facilitate a commensurate increase in informal and community alternatives. Health and care cultures have developed, over many years, to provide comprehensive support for people. Nowhere is this more pronounced than in residential settings, where individuals receive round-the-clock and on-site support and supervision.

Those with complex needs are seen to require all-encompassing care and protection. Based on a long history of medical opinion about the limitations of particular conditions, this remains the accepted approach among providers and commissioners, families and indeed care users themselves. This can make it extremely difficult for people to challenge this accepted wisdom, with most associating the withdrawal of formal support with negative outcomes and increased risk. Yet some have begun to drive change – both Essex and Sutton local authorities recognise the oppressive nature of a person receiving intensive support and seek to reduce it where possible.

Sutton, for example, has a pro-active strategy to move those with learning disabilities from residential care and day centres into communities. As outlined in the following section, which looks at the provision of housing with care, Sutton's commissioners encountered considerable resistance from providers and care users' families. But through persistence and clear

evidence of improved outcomes, Sutton has significantly increased the number of people with learning disabilities living in their own accommodation in the community, with jobs and using universal services. Sutton's executive head of adults and safeguarding told us that local NHS staff had been encouraged to see themselves as the social 'aunties' and 'uncles' of the people they served and some still had this title in the job descriptions in 2006, when Sutton began their strategy to move those with learning disabilities into the community. This led to family members, supported by care home staff, feeling that their sons or daughters would only be safe in 'family type' residential settings – a view which needed to be challenged:

*Independent living challenges models of care that nurture dependency, giving people access to an expression of human rights, and challenges the deeply entrenched sense that people with LD [learning difficulties] are not 'full' citizens and where many are 'infantilised' through the care planning process and institutional models of care. What other group of people would we be discussing as to whether they had a right to live in the community?*

Shaun O'Leary, Executive Head of Adults and Safeguarding,  
Sutton Council

### **Progression**

*Essex County Council's social care strategy for learning disabled groups has the concept of progression at its heart. This involves the gradual reduction of support, in line with increased independence and ensuring people are able to participate in a normal life. The 'normalisation agenda' looks at employment and independence, and not just traditional community access issues. Resource plans do not just look at levels of activity, but the direction of travel – where the person is going to be three years from now, and whether resources are focused on achieving the right outcomes over the longer term, not simply inputs or outputs. Nick Presmeg, senior operational manager of adult social care at Essex County Council, explained:*

*Providers tell us they are focusing on progression but then people still require the same level of support every year.*

*Essex Council realised they had to have a better command of the relevant information for discussions with providers – looking not just at what is being ‘done’ by the provider, but at what progress an individual has made against the outcomes he or she has set for themselves:*

*Contracts and plans are often focused on ‘here’s a level of support’ – especially the ones we inherit from health services... they were quite paternalist in a way.*

*While Nick recognised there are always some people in the community who will require intensive and continued support, he feels there is still a great way to go among learning disabled groups in Essex who are only limited by their aspirations in the move to greater independence:*

*Very focused enablement for people with LD [learning difficulties] is very different to a six-week input you get for older people – with LD you might need a six-year input, because it can happen in very small steps.*

*The ideal outcome for Essex Council is that each individual requires less support as they become more independent – this is a win-win situation for both the individual and the council:*

*Someone getting two to one care is an oppressive situation for somebody. If you can find a way of reducing that hopefully they’ll get more choice control and freedom and economically it’s much more efficient.*

Such approaches will remain exceptions to the rule, as long as risk aversion and a deficit approach – doing things *for* people out of a misplaced sense of kindness – remain at the forefront of health and care provision.

To achieve such a shift in cultures, those in senior strategic positions must take the lead – beginning with Department of Health guidance, through to directors of adult social services in local authorities and the director level of care providers. Training and guidance around personalisation and choice is vital.

Sue Ryder has commissioned Helen Sanderson Associates to lead the organisation's transition to personalised services, training staff and rolling out self-assessments, care plans and so on. Over the next 12 months, the organisation's managers will be trained in personalisation and prepared to lead the change; every Sue Ryder service user will have a personalised support plan, self-assessment and resource allocation where appropriate to prepare them for a move to personal budgets; and a common user-friendly set of personalised paperwork will be rolled out. Introductory training for all centre staff teams is now under way and a 'change leader' is being designated in each region. Personalisation training sessions encourage people to think about their daily routine and the personal choices that they make within that routine, such as what time to wake up, what to have for breakfast, what brand of toothpaste to use, and so on.

Going through this helps staff recognise the lack of personalisation and choice that exists for people living in care. Steve Jenkin told us:

*I think at the time it was a case of 'that's the way we've always done it'. You talk to managers about, for example, choice of food, and you begin to see people beginning to realise that we should be offering much greater choice.*

In addition to staff training, providers must also start with the right recruitment strategy – one that looks not just for the right set of skills, but also the right attitude and approach to giving people independence. Dee View Court's approach to having residents on interview panels, seeking feedback from its residents on staff candidates, and having the residents themselves show potential recruits around the facility is likely to be an effective way of identifying the right skills, the right attitude and personal compatibility with those being supported.

As mentioned in chapter 2, one care provider we spoke to who supported people with challenging behaviour to live independently placed significant weight on his new staff having the right empowering attitude. He often recruited from outside the sector because experienced carers did not always have the right mindset to provide the enabling support he was looking for. Indeed, the activities coordinator at Wheatfields explained how he did not have ‘the burden of a medical background’, but rather experience in customer services, as a positive advantage in his work. He described how some patients in the day hospice would be reticent to talk to medical staff, but through informal conversations over a game of cards or dominos he was able to gain a far greater insight into people’s needs and concerns, which he could feed into the care assessments and help improve the support being offered.

Local authorities must look for social workers and commissioners who have the attitude and willingness to facilitate and empower – even challenge – people to do things for themselves, rather than encourage passivity and paternalistic models of care. Shaun O’Leary, Executive Head of Adults and Safeguarding at Sutton Council, whose progression strategy for those with learning disabilities we describe in more detail below, told us:

*I advertised and recruited frequently to find social workers with the appropriate skills and value base to deliver statutory assessments of needs that identified strengths as well as deficits, as well as work with some traumatised staff and relatives to secure a positive outcome.*

## Personalisation at the end of life

End of life care poses distinct challenges to personalisation, which need tackling. They include:

- as we outlined above, lack of staff training in being able to talk about end of life planning with people and their families, coupled with individuals’ reticence to do the same

- low take-up of advanced care plans and practical difficulties around personal budgets and the flexibility required for rapid changes to be made in the last weeks and days of life
- frictions between the health and care systems, as end of life care sits on the fault line between these two systems

This last point – frictions between health and care systems – will be tackled in more detail in the next section as this problem goes beyond palliative care, being one of the most significant barriers to personalisation for those with complex needs. This section considers how some of the challenges specific to end of life care are currently being tackled.

### Talking about death

*There's an issue surrounding training staff to be comfortable with that. Clinical nurse specialists work at high levels and have to be very comfortable with having those difficult conversations.*

Samantha Cheverton, regional manager at Sue Ryder

As outlined in chapter 2, the discomfort clinical staff – GPs, hospital staff, health visitors – and social care staff have with talking to people about their wishes and preferences at the end of life is a distinct barrier to personalisation, as we identified in the conversations we had with staff with palliative experience and with organisations such as the National Council for Palliative Care and Dying Matters. This lack of communication fundamentally inhibits people's opportunities to think about and proactively plan and choose around the end of life, and thus undermines personalisation.

Work is being done to improve this. For example, the Dying Matters Coalition recently piloted a scheme which gave GPs communication training around end of life choices through workshops, and developed a range of communication materials with them to give to their patients. The pilot was initiated by the Coalition Government, which recognised that GPs are often people's first port of call for health advice, and 59 GPs

participated. They had 155 separate conversations with their patients (across a variety of terminal illnesses as well as old age and frailty). The pilots showed that GP confidence increased significantly in talking about end of life choices, from 60 per cent who said they were not confident about having such conversations to just 17 per cent not being confident. They also found only 13 of the 155 patients they spoke to did not want to continue the conversation about end of life care.<sup>171</sup> Overall, the study showed that even with limited intervention (a short workshop and the provision of leaflets and posters), communication with people facing the end of life could be drastically improved and their wishes and preferences recorded as a result.

Individual hospices also play their part – many offer training to other NHS staff and residential care workers to enable them to better communicate with the people they care for.<sup>172</sup> Examples include the St Christopher's Gold Standard communication training and Macmillan nurses training. Samantha Cheverton, a regional manager at Sue Ryder who has hospice experience, described a scheme in Sue Ryder hospices where there are staff rotations with staff from the local hospital – junior doctors for example are given a two-week placement in the hospice to provide support, but also to gain hands-on experience of end of life care and how to communicate with patients and their families:

*We have registrars on rotation in most of our hospices who work alongside the permanent hospice staff. Some of the junior doctors come through on rotation as well. The registrars who come through from their specialist training will come and work at the hospices for six months at a time. Those links are really important to keep those relationships going.*

*Hospice managers have to work hard to build up that kind of relationship. But it's really important. If you've got people coming in from different practices, they help us in keeping our care updated, and inform us when there are changes in their practice. It sends knowledge and skills into the wider community and means we work as a bigger team.*

Another successful initiative is the Liverpool Care Pathway for the Dying Patient tool.

### The Liverpool Care Pathway for the Dying Patient

*The Liverpool Care Pathway for the Dying Patient (LCP) is a tool designed to improve communication and coordination of care for people who are predicted to die within 48 hours. It consists of assessment leading to a plan that all healthcare professionals can contribute to and a system for recording and sharing the information in this plan. It covers the following aspects of care:*

- *symptom control*
- *anticipatory prescribing of certain drugs to prevent symptoms before they start*
- *when to discontinue some treatments or aspects of care*
- *psychological and spiritual support*
- *support for the family*

*The LCP began as an attempt to export and formalise good practice in the hospice sector to improve care for the dying in other settings. Developed in the late 1990s, it is now in its twelfth iteration.*

*Significant media attention has focused on the LCP, often reporting that it is dangerous and hastens death in some cases. Yet on several occasions the Department of Health has recognised the LCP as a model of good practice. Studies have shown that use of the LCP lessens the symptom burden on patients and improves the way staff deal with documentation.*

*One study found that 84 per cent of 25 bereaved carers surveyed at one hospital were highly satisfied with the use of the LCP for their loved one.<sup>173</sup>*

In addition to these efforts by hospices are training schemes provided by individual hospitals for their staff. Indeed, a study by Marie Curie in 2008 found 160 separate courses training around end of life care in South East London alone,<sup>174</sup> yet awareness of end of life and comfort with communication remains poor. This may be exacerbated by the high staff turnover in social care and with front-line care staff, as well as the

progression of front-line medical staff to positions of seniority, necessitating ongoing awareness raising and training for new staff.

In light of this patchy progress, the National Council for Palliative Care has recommended that end of life care should become a core part of the curriculum for all health and care professionals, both pre-registration and as part of continuing development.<sup>175</sup>

### Improving the take-up of advance care planning

An important tool in personalising end of life care is through the use of an advance care plan. This enables people to think ahead and make choices for when they are perhaps not capable of communicating their wishes. This includes where they want to die, the nature of the medical care they receive (eg resuscitation) and so on, and is based on a holistic assessment of end of life care needs, as recommended by the government's National End of Life Care strategy.<sup>176</sup> This should include the person's physical, psychological, social, cultural, environmental, spiritual and financial needs in the last phase of their life.

Samantha Cheverton told us:

*When patients are very ill, it's hard to see how true personalisation could take place unless there has been an advance care plan. For example if somebody comes in with 48 or even 4 hours to live, there's no opportunity to ask the patient how they would like their care to proceed. However if nurses were to work on their advance care planning, and discuss their future care at the outset of their terminal illness – for example whether they would want to be resuscitated or have a blood transfusion at certain stages – then decisions would have been made by the individual and personalisation would work in these cases.*

When West Essex PCT audited the first 100 patients who died with a preferred priorities for care plan, 88 per cent of the group died in their preferred place of care, including 67 per cent at home. Research suggests that advanced care planning can increase patients' hope for the future, improve

patients' quality of life and reduce the risk of depression in bereaved carers.<sup>177</sup>

As these plans are developed in partnership between a professional (GP, carer and so on) and an individual, this is an important chance for co-design – enabling a person to have an active role in planning how things will look for their care. Yet only a minority of people use advance care plans. A NatCen survey for Dying Matters in 2009 found that while 29 per cent of people had talked about their wishes around dying, only 4 per cent had written advance care plans.<sup>178</sup> This is perhaps as a result of professionals' unwillingness to broach the subject combined with people's own reticence to plan for such an event. As we outline above, Demos' own research found people felt planning for death or moving to a hospice somehow hastened the event.<sup>179</sup>

An important step in promoting personalisation in end of life care is, therefore, to encourage the wider use of advance care plans. This has to be provided with the appropriate training so that advance care plans are not written once and then set in stone. Professionals who find the co-design of an advance care plan an uncomfortable process may be tempted to minimise the opportunities for revisiting that conversation, however, the palliative experts we spoke to at Sue Ryder and National Council for Palliative Care both spoke about advance care plans being a living document, one that needs to be changed as a person's condition and preferences change. Even then, care staff must be prepared to depart from the plan should a person express a change of heart in the final days and hours of life – it is this flexibility, found in hospice staff but less so in other medical or social care staff, that comes from confidence to speak about dying, and is an important element of end of care training.

### Personal budgets in palliative care

Personal budgets are an important tool in personalisation, but further work is needed to consider how they will be of use in end of life care. The bureaucracy around personal budgets has been described as problematic,<sup>180</sup> suggesting they may not be flexible enough or able to be arranged and changed swiftly enough to be

of use in the last weeks and days of life should preferences change. Personal budgets are perhaps more suited to long-term conditions where care plans need to be reviewed less frequently.

Nonetheless, with the advent of personal health budgets and the continued roll-out of personal social care budgets, it is increasingly likely that people will reach the end of life having a personal budget, or will be offered one when they are eligible for NHS continuing care. It is too early to tell how well these will function at the end of life – but apart from the potential lack of flexibility, a number of other concerns have arisen:

- How will hospices develop their financial arrangements with people buying their services with a personal budget, when hitherto they had relied on a combination of NHS funding and a considerable proportion of charitable donations?
- Will these donations perhaps subsidise people's personal budget spending in the future?
- Will the transfer of budget management be a smooth process if a person begins with a direct payment, then, through deterioration of condition, transfer budget management to a relative or provider?

These and other tricky procedural issues will need to be ironed out before budgets become a viable option for end of life care, and are one of the objectives of the personal health budget pilot programme, as described in chapter 2.

#### Person centred planning - with or without a personal budget

Helen Sanderson Associates has carried out research looking at how personal health budgets might work in end of life care. They identify the following factors as critical for a health budget for those approaching end of life:

- timely and relevant information available beforehand
- knowing who is involved
- clear goals and outcomes

- identification of services to be bought or commissioned that can meet the need
- contingency and change planning and risk management
- how and when the plan will be reviewed
- planning after death

In addition, for personal health budgets the care plan should record:

- how the budget is going to be spent
- how the budget is going to be managed<sup>181</sup>

Clearly, many of these elements – such as contingency planning, planning when to review the plan, planning for after death and budget management – are more important for a budget used at the end of life than regular health or care budgets. But it is also clear from the research that person-centred planning would be extremely valuable even if it did not result in a personal budget. The Living Well tool, for example, developed by Helen Sanderson Associates and Lancashire County Council,<sup>182</sup> enables individuals facing the end of life to think about their life now and also to then plan for their death.

Sue Ryder is also implementing this tool as part of its work with Helen Sanderson Associates to embed personalisation across the organisation. It includes the following elements:

- the relationship circle – who is important to me
- describing a good and a bad day
- what's important to me
- what is working and what is not working
- what I want in the future – hopes and fears
- action planning

The tool is strongly person centred, and could be used in conjunction with an advance care plan or form the basis of an advance care plan and guide for carers and relatives to improve outcomes even if a personal budget were not used. It will be important that such tools to facilitate person-centred planning

are used even if personal budgets are slower to progress in this field.

### The integration of health and care

Throughout this report we have considered the future of personalisation for those groups for whom personalisation might be most challenging. These are often the same groups for whom personal budgets are not always practicable or desirable – such as those with multiple and complex needs, those in residential or collective settings (often because of their complex needs) and those needing end of life care. But it is *also* these groups for whom the integration of health and personal care is critically important. Hospices and residential and nursing homes for those with complex needs sit on the fault line between health and social care, and the lack of integration acts as a significant barrier to delivering joined-up and personalised support.

The current slow progress in integrating health and care is perhaps the biggest obstacle to personalisation for those with complex and multi-agency needs. Dr John Hughes, group medical director at Sue Ryder, reflected on this lack of progress in integrating health and care systems with ‘top down’ incentives and policy levers, and felt bottom-up initiatives might promise greater progress. This resonates with the findings of Professor Jon Glasby and a team at the University of Birmingham, who concluded that structural change had had limited impact on integration and that bottom-up initiatives, which led to health and care teams working towards joint outcomes, was a potential solution.<sup>183</sup> The current NHS reform agenda, however, brings a degree of uncertainty over local structures – some of the practitioners we spoke to were concerned that with an increased number of organisations – health and wellbeing boards, clinical commissioning consortia, the NHS Commissioning Board – could make it harder for those with multiple needs to achieve an integrated package of care, and increase the risk that some individuals may fall through the cracks of different organisations’ responsibilities. It is too early to tell if such changes could also undermine the good progress already

achieved in some parts of the country in constructing integrated and personalised packages of care, or reinforce progress.

With these shifting policy structures as a backdrop, we should first make note of the legal framework in which integration is made possible.

### **Section 75 powers**

*New powers to enable health and local authority partners to work together more effectively came into force on 1 April 2000. These were outlined in Section 31 of the 1999 Health Act, which facilitated partnership arrangements for health bodies, such as strategic health authorities and PCTs, together with any health-related local authority services such as social services, housing, transport, leisure and library services, community and acute services.*

*Section 31 of the Health Act 1999 was repealed and replaced for England by Section 75 of the National Health Service Act 2006, though the new provision remains identical.*

*These are some of the Section 75 powers:*

- *pooled funds – the ability for partners each to contribute agreed funds to a single pot, to be spent on agreed projects for designated services*
- *lead commissioning – the partners can agree to delegate commissioning of a service to one lead organisation*
- *integrated provision – the partners can join together their staff, resources and management structures to integrate the provision of a service from managerial level to the front line<sup>184</sup>*

It is interesting to note the permissiveness of this legislation both in the areas of operation that can be integrated, as well as the range of partners who can be involved: social services, housing, transport, leisure and library services, community and many acute services. In reality, most attempts at integration have begun with integrating health only services – for example the acute and community health sectors. Others have begun

to bring in social care. A very few have also begun to consider, under the auspices of public health, wider services such as education and housing. The cases outlined below are some of the most progressive attempts at integration, but clearly there is potential – even within existing legislation – to go much further.

The Department of Health launched an integrated care pilot in 16 areas in April 2009. The results of this pilot are due at the end of 2011, but these are not the only attempts at integration currently under way. Several others are pursuing their own models, though most are looking at the integration of primary medical care and community health services run by PCTs, rather than bringing in social care services.<sup>185</sup>

In June 2010, an interim evaluation of the pilot sites was carried out. This was before the NHS reform proposals were fully developed and therefore did not take into account the impact of these structural changes. Nonetheless, the evaluation team's initial impressions, based on interviews with staff, were that there were a variety of facilitators and barriers to integration – ranging from lack of good communication and co-location, ineffective use of IT and leadership, to external shocks and financial pressures, fear of patient risk, lack of trust and inertia – putting pilots off course.<sup>186</sup>

Perhaps most interestingly, the pilot evaluation team found that no clear integration models were emerging:

*Although there are undoubtedly dimensions of systemic integration (for example in information systems, assessment, access, standardised communication and finance), each Pilot is also embedded in its local areas in different ways, making such integration very context-dependent. Rather than a discrete set of models, broadly comparable across the Pilots, what is apparent... is a more fluid process of change and evolution.*

*Integration is a process and not a model. Furthermore it is a process that is to a degree self-limiting (that is, there will never be complete integration). Information-sharing, pooled budgets, shared communications protocols and so forth all have practical limits to scale and scope beyond which they become suboptimal. These limits will manifest themselves differently in different contexts.*

*We found that, rather than identifying a discrete set of models of integration, [participants] described a wide range of skills and resources used to conduct a variety of integrating activities in pursuit of many different outcomes. Each particular combination of resources, activities and intended outcomes appears to depend upon local leadership and context at least as much as upon the adoption of models... A more accurate term than 'model' might be a 'cluster' of activities that evolves over time as learning takes place, relationships mature and the environment changes... It is also apparent that each locality has developed its own distinct cluster.<sup>187</sup>*

It seems, therefore, there is no 'magic bullet' when it comes to the integration of health and care. Although the integration of services (not just of health and care but also of housing, transport and others) is the holy grail of personalisation, the evaluation's early impressions seem to chime with Professor Glasby and those we spoke to during this project: solutions are not wholly structural and replicable as a model, but rather rely on local contexts and relationships. With this in mind, we consider two local models below: Herefordshire Council, not a pilot site but the first local authority to integrate its health and care teams and which was recently given approval to become an integrated care organisation in 2010, and North East Lincolnshire, again not a pilot site but the first local authority to establish integrated care through the Care Trust Plus model.

### Herefordshire Council

Although Herefordshire's population live longer and are healthier than other parts of the country, they have a disproportionately larger older population and a rapidly ageing demographic, leading to a growing demand for health and care services. With this in mind, in early 2008, Herefordshire Council and NHS Herefordshire became the first local authority and PCT to combine their operations under a single chief executive and joint management team.

They work as one organisation in planning, purchasing, designing and delivering care, and providing a set of agreed values and a single corporate plan with shared targets. They

began in 2008 with a strategy of agreeing joint policies wherever possible, including a new joint environment policy, and a joint disability equality scheme. They moved to a single corporate headquarters, so the 1,600 council and PCT staff shared a single working environment. This was seen as a way of reducing administrative costs but also as a means of enabling closer joint working and information sharing.

Between 2008 and 2010 Herefordshire Council worked on what they described as the ‘deep partnership’ between NHS Herefordshire and Herefordshire Council, and in May 2010 applied to become an integrated care organisation. The integrated care organisation would build on the progress already made and combine community, acute and adult social care as far as was practicable, under a single mission: ‘We will provide integrated, high quality and safe care to support personal health, well being and independence within a sustainable Herefordshire health and social care community.’<sup>188</sup>

In 2011, the creation of the integrated care organisation was approved by the NHS Competition Commission. This paved the way for a third partner – the Hereford Hospitals NHS Trust – to join NHS Herefordshire and Herefordshire Council, and share its back office functions to save a predicted £33 million by 2020.<sup>189</sup>

### The importance of a vision of change

Effective change management relies on strong underlying principles, or a shared vision, to drive coherent structural and organisational change. Herefordshire Council has taken this route and has outlined a series of principles and objectives for integration: staff are not experiencing change for change’s sake, but rather to work towards improved outcomes which are *facilitated* by the change – the organisational integration is not the end in itself, but a tool for improvement. The underpinning principles of the new integrated care organisation are:

- risk stratification – identifying the most vulnerable clients and shifting from a diagnose and treat service to one that predicts and prevents

- recognising the critical importance of GPs and locality health and social care teams
- shifting the focus of care towards the home setting and away from institutional provision
- creating care pathways to underpin service delivery<sup>190</sup>

The first five pathways being created are for people most likely to benefit from integrated care: frail older people, stroke patients, and those with diabetes, chronic obstructive pulmonary disease and lower back pain.<sup>191</sup>

With these objectives in mind, the process of integration has focused on creating not just a combined health and care organisation, but also one that builds links with a range of other services. Herefordshire Council now has integrated information technology, systems and support across the local authority, and a PCT, a hospital trust, schools, mental health services, GP practices and voluntary sector organisations, which streamline communication channels for local residents using these services. The authority has been able to produce a guide for residents that presents information about multiple services linked to important events – such as starting a family, moving into the area, becoming a carer or bereavement.

The authority has also been able to shift from providing a piecemeal and reactive service to more coordinated and preventative packages, for example bringing in several different agencies, which promote healthy lifestyles in a package for older people and children. These packages look at tackling early the causes of ill health – including poverty, education, housing, upbringing and the choices people make about smoking, alcohol, diet, sexual behaviour and exercise. This ambitious approach has only been made possible by the integration of health and several council services (not just social care).<sup>192</sup>

### *Staffing*

Staff in Herefordshire were reorganised into multi-agency operational teams, organised around group needs (eg children and families), which work across health and care, rather than traditional groupings (eg district nursing). The workforce has

also been reshaped to provide care closer to the home, with staff redeployed from the acute sector and investment in devolved community services. They are also pursuing foundation trust status for 2013 and in the interim following that model where responsibility is devolved to front-line practitioners and staff feel they 'own' the organisation.

#### *Herefordshire's older people pathway*<sup>193</sup>

Figure 2 shows Herefordshire Council's older people pathway, which identifies older people at risk of hospital admission and puts multi-agency packages together to support them and prevent this from happening. This includes a joint health and care assessment, which is delivered by the multi-agency teams within the integrated care organisation as well as the other organisations (eg fire service, third sector organisations) with which the integrated care organisation is establishing links. Note also the provision of GP commissioner sign off – making Herefordshire Council's plans compatible with the forthcoming NHS reform to clinical commissioning.

#### **North East Lincolnshire Care Trust Plus**

The PCT of North East Lincolnshire (NE Lincs) Council received ministerial approval to become the country's first Care Trust Plus in 2007. This new organisation assumed the same responsibilities at the NE Lincs's PCT, as well as commissioning and delivering responsibilities for adult social care from the local authority. This means the local authority essentially outsourced its care to the PCT.

The Care Trust Plus has a strong focus on joint commissioning around health and care, with four key themes to describe the overall goals of the organisation and its partners:

- creating a healthier community
- accessible, responsive and quality care
- people in control of their own care
- a social and financially sustainable care system<sup>194</sup>

Figure 2 Herefordshire Council's older people pathway

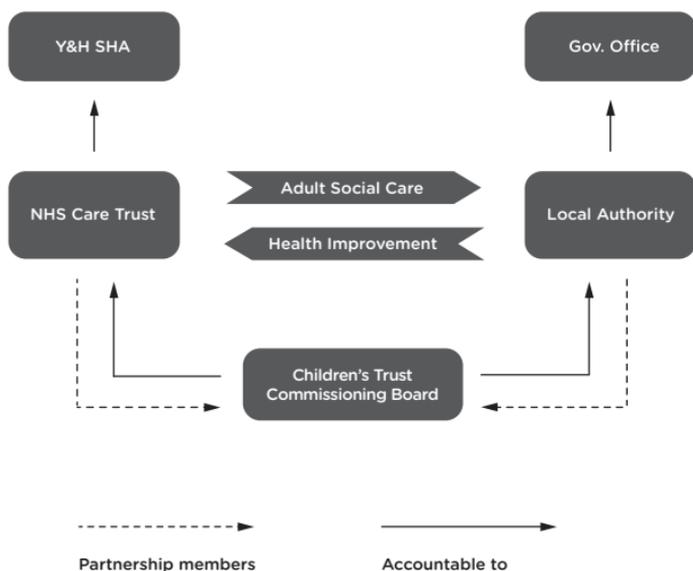


Source: Cunningham and Budd, 'Care pathways'.

Each theme has three component areas, linked to the Care Trust Plus's internal performance framework and a number of actions.

Geoff Lake, Adult Social Care Strategic Advisor at NE Lincs Care Trust Plus, told Demos that there were three dimensions to the Care Trust Plus: adult social care commissioning and

Figure 3 **Characteristics of North-East Lincolnshire Care Trust Plus**



Source: NE Lincs Care Trust Plus strategic plan 2010–15

delivery, public health, and children's commissioning and delivery in the larger polity. The Trust is underpinned by a legal agreement – a three-year strategic plan and annual business plan approach. The legal agreement incorporates transfers of money and the distribution of risk.

#### *The process of integration*

Geoff explained that producing the legal agreement was a relatively straightforward process that took around 18 months – most of the negotiation was concerned with dealing with the external environment, which had been hostile to radical change. Internally, there had been great willingness to compromise as there was a shared understanding of the need to become financially sustainable in the longer term. The complexity was in

dealing with an environment that could not accommodate territorial and constitutional dominances.

### *The current climate*

One of the ways in which the Care Trust Plus has been very successful over the past three years has been through rebranding for the external world:

*We were quite assertive about the idea that though we had an NHS constitution we were actually a different kind of organisation. We managed to deal with the external aspect by rebranding ourselves locally and by being quite assertive with the NHS and the regulators.*

He expressed concern, however, that the ongoing changes might make their continued integration more challenging, because of a move to more one size fits all local structures. He felt that there was a risk that his colleagues from NHS backgrounds would be forced back into NHS positions:

*Many of us would argue that the NHS is centralizing and is introducing new layers of bureaucracy whilst it is paying no regard to localization... Some of what has been put into this agenda will be put under threat unless the localism issue becomes dominant.*

### *The Trust's 'magic ingredient'*

Geoff maintains that a strong drive for horizontal integration – creating ‘total place’ type services – is central to the Trust’s success and in delivering personalisation. He recognised this was not a comfortable fit with traditional NHS structures and this was the basis for his concerns about the NHS reform process: ‘The NHS arrangements are very vertical. But the kind of relationships you want for localism are horizontal. You can’t introduce personalisation without integration.’

He explained there were three clear goals of the Trust:

- to use integrated commissioning under Section 75 as a means to an end – to take a whole system, a whole economy view of how you commission to meet the full range of need

- to integrate budgets at a personal level
- to commission for improved delivery and community and market shaping, rather than simply distribute funds: ‘that is quality personalization, not just giving out money’

The Trust has developed a model for combining health and social care personal budgets, particularly around dementia and continuing NHS healthcare. This means they can deliver personal and social care to someone with dementia in one pot. However, there still remain challenges between the Trust’s role as a commissioner and facilitator of individual purchasers:

*In the kind of market economy the Government is trying to set up, what they have not quite grasped is that if you go down this agenda for health and social care you effectively have to rewrite contracts that are in existence.*

*You cannot give [providers] money and give the citizen money – you give the citizen money and they decide where they want to go. The provider side has got to become responsive to citizens. You cannot, for instance, contract a provider for a number of hours, even if they are very good, because you have to give the money to the citizen who will then decide where to go. There are so many paradoxes in it that nobody has really thought through.*

The Trust is therefore trying to develop a system where providers can be very flexible with their customers, so that radical new market shaping is not required but rather existing providers are capable of changing on demand: ‘If you invest well in a provider, what you’re trying to do is to move what they are doing around a bit so that they can respond to what people are telling commissioners they need.’ For example, the Trust is developing a system whereby people are made aware of the services they could have used had it been there, to create awareness of and intelligence needed to stimulate changes.

### *Housing*

According to Geoff Lake, the council had been less successful in developing a housing strategy that accommodates people with disabilities. To remedy this, the Trust is scaling back residential

provision and has appointed three special housing providers, all of which are bringing capital to the table. The Trust is working with them and different care providers and is reassessing 143 people – many of whom are in traditional models of care, which are costing on average £130,000–140,000 a year – and moving them to supported living models where the support is flexible. This has reduced the average care cost to roughly £80,000 a year.

The Trust is now in the last stages of planning applications to create a housing development in North East Lincolnshire, of which the Trust has commissioned some of the adaptations to the housing in order to make the housing suitable to bring people from residential settings back into the community.

#### *How savings will be made*

The Trust is now delivering £10 million worth of savings, £8 million of which will come through market reshaping; this takes account of working to create, with the local authority, an integrated approach to community development. Part of this is substituting traditional and often expensive ways of meeting people's needs. For example, Geoff spent over £2 million a year on shopping and domestic services for people – this is done through the independent home care sector. He explained how he had shopped around and had found that he could subsidise a personal shopper service, which instead of delivering shopping for people takes people shopping, for 70 per cent less cost than the previous service.

It has also begun very close work with leisure and culture services on the wellbeing agenda so that both services are using local facilities to full effect. In one area, for example, they are using the primary care centre as the point of entry for the local authority and for adult social care and health. They are also considering making cultural and leisure services a social enterprise, which opens up new opportunities to do more work around the wellbeing agenda. The Trust has just signed off an integrated community development strategy, to take an integrated approach to every service in a horizontal rather than vertical way. The Trust has also started to introduce place-based budgets.

While NE Lincs Council has created integrated funding and commissioning processes, Geoff felt it was the integration of people and cultures which proved most effective:

*To get the benefits from integration, as we've discovered in our intermediate tier work, you have to pool all the money, you have to pool all the staff and you have to talk about single management and a single workforce approach, and these are huge steps.*

*You don't need a structural solution to integration, you just need a collegiate way of working – you can provide health and social care for a single person without structural or workforce solutions.*

### Bringing housing into integrated support

In many areas looking at service integration, integration has primarily begun with health and care, with other areas – housing, education, leisure and so on sometimes being drawn in once initial processes and joint teams were established. This gradual service by service approach may be inevitable and indeed wise, given the disruptive nature of such transformations. Nonetheless, it is clear that housing remains a secondary consideration in integration plans, with few beginning with housing alongside care and health as the key integration partners.

However, it is clear that the integration of housing with health and care is a fundamental step towards personalisation, in particular for those with complex needs, whose transition to greater independence and move from a residential setting into a more personalised environment is fundamentally dependent on housing being available, suitable and fully integrated with their care and support packages. Without this being in place, it is likely groups of care users may find themselves unable to move from residential settings, even though they are ready to move on to less intensive support environments and the greater freedom, independence and personalisation this can bring. Table 1 shows how the National Development Team for Inclusion summarises the benefits of supported living.

Clearly, therefore, an effective and seamless housing and care strategy is vital to personalisation – at least for those groups

Table 1 **A comparison between supported living and residential living**

Supported living	Residential care
Own home or tenancy. Security of tenure	Licence agreement with no security of tenure
As a tenant or homeowner the person has a right to choose who provides their support and can change support arrangements without moving home or move home without changing support arrangements	Support is provided as part of a package with housing and either element cannot be changed without impacting on the other
As a tenant or homeowner the person has a right to choose who they live with if anyone	Good practice in residential care dictates that housemates should be well matched as much as possible but in practice many people live with people they do not choose to live with
Tenants and homeowners have rights to full welfare benefits including housing benefit, income support and disability living allowance	People in residential care have rights to limited amounts of welfare benefits and most people access a residential care allowance of approximately £20 per week to purchase personal belongings, clothes and holidays
Can access Direct Payments, Personal Budget, Supporting People Grant, Independent Living Fund for support	Cannot access most additional funding for support

Source: Wood and Greig, *Supported Living*.

for whom personalisation may involve a move from residential settings into supported living environments.

With this in mind, the experiences of the South Essex Commission and Sutton Council may prove informative. We start with the South Essex Commission, which is somewhat unique in that it is an ambitious integration plan which *begins* with housing, rather than just health and care on its own.

### The South Essex Commission

The Commission of Enquiry into Co-operation between Housing, Health and Adult Social Care was set up in summer 2010 to look at how housing (across all tenures) can contribute to health and wellbeing in South Essex. Members include all of the councils and local NHS organisations operating within the Thames Gateway South Essex sub-region: Essex County Council, Basildon District Council, Castle Point Borough Council, Rochford District Council, Southend-on-Sea Borough Council and Thurrock Council, and NHS South West Essex and NHS South East Essex. The Commission has been gathering evidence over the past year and in March 2011 produced its interim report. The recommendations from the Commission will benefit all ages and the final report will address the specific needs of all those who use housing, health and adult social care services – including older people and people with disabilities and sensory impairments.

#### **South Essex Commission's findings on the integration of services<sup>195</sup>**

*South Essex, like everywhere else, has a mismatch of services, not always working together to address current and future needs. Services are mostly reactive, and very rarely proactive – this can often mean spending more and achieving less. Outlined here are some examples of poor coordination between services and organisations highlighted by staff and service users in South Essex:*

- *The flat that has been brought up to Decent Homes standards, but is now more difficult to live in for the elderly disabled occupant*
- *The new housing scheme that fails to plan for people growing older – leading to expensive adaptations further down the line*
- *The new road that does not provide adequate dropped kerbs or suitable crossings for older people and people with a disability*
- *Distressing stand-offs between care and health services over end of life care funding arrangements*

- *Unacceptable and expensive use of acute beds when people should be supported to die in their home setting if that is their wish*
- *Under-resourcing of low cost, preventative services and over-reliance on high cost care home placements*
- *Different bureaucratic systems that cause needless complexity for service users and the health providers working with different councils*
- *Slow and cumbersome arrangements for home adaptations*
- *Lack of clear, consistent information about local services and activities that people can use to help themselves*
- *A cradle to grave mentality that relies too heavily on the assumption that the public sector will be there to assist*

Les Billingham, head of transformation and independence at Thurrock Council, told us the Commission was now focusing on four streams of work. The first is to develop housing alternatives, primarily for older people but also for people with disabilities and long-term conditions. Les explained that there are over 100 schemes of sheltered housing in South Essex, but the vast majority of them were built in the 1960s and are not particularly fit for purpose. He explained:

*Because of a lack of quality housing for older people, people are reluctant to go into it; they tend to stay in their own homes which are often not the ideal place or situation for them. They tend to go from their own homes straight into residential care. So we're looking to try and build some really high quality housing for older people that will give them a range of different options and will enable them much earlier on in the cycle of their ageing to start making choices about moving.*

The Commission's interim report found that 20 per cent of discharges from hospital involving people over 65 were delayed because there was inadequate provision for their return home, such as a home care package, home adaptations, admission to an intermediate care facility for reablement or provision of a suitable residential care home place. The Commission also

explored the potential cost savings of appropriate housing compared with residential care spending:

*For example, home adaptations can help prevent or defer people having to go into residential care; one year's delay can save £26,000 per person – the average cost of adaptations is £6,000; if a shower is fitted enabling independent bathing, this can reduce home care costs even if there is still a need for some support for frailer service users – an hour's home care per day costs an average £5,000 each year and preventing accidents brings down costs to health and social care.<sup>196</sup>*

The transformation of local suitable housing is an ambitious project, bringing together the public and private sectors, large-scale development and regeneration, and buying from the local health and social care partners. It also involves looking at changing planning processes and policy.

The second piece of work is to bring together health and social care, particularly encouraging a more early intervention and preventative model, linking to ongoing work around admissions avoidance in hospitals, and reabling people. Les explained that this did not automatically mean everyone in the coalition would pool their social care teams:

*There would be no reason why ours and the district adult social care couldn't be integrated into a cohesive single model. But it won't always be the best way. It's about doing that only where it makes sense to do so.*

The third work stream is to bring in an integrated information and advice system across the whole sub-region, potentially with TripAdvisor-type service reviews:

*That would mean that when people start to think about the long-term care needs of their parents or their children there is a lot more richness and variety of information for them out there.*

The fourth piece of work is trying to bring together private sector investment and third sector services within communities to build community resilience, and improve community

involvement in the planning and provision of care in individual communities. Les explains:

*So even though we are looking at a big area we are looking to bring that down to a much more community focus. Different communities have different issues and problems, and solutions to those problems need to be generated by those local communities themselves. We're looking to really strengthen third sector involvement in that; to give that community voice and have that involvement.*

#### *Political support*

Les explained that those politically involved in the scheme, across the different political parties of the sub-region, had been very supportive. They had expected they might meet some kind of resistance given the different governance arrangements, but everyone had been enthusiastic about the idea of bringing some of their services much more close together. Les told us:

*Because of the financial pressure all local authorities are now under, the increased demands of adult social care, and the pressure of personalisation, there is a growing realisation that significant transformation has to take place. This looks to be a credible way of doing some of the things that we need to do. We must make sure that we manage demand in the most cost-effective way, by improving independence through that early intervention and improving conditions to avoid that long term dependency.*

#### *The importance of housing*

The housing teams from every area in the Commission were very involved from the outset. Les told us:

*That 'us and them' about housing and social care is increasingly becoming a thing of the past because housing realised their growth and demand is fuelled, in the majority of cases, by that vulnerable group of people who are the people you find in social housing nowadays.*

He also referred to the financial situation, which had helped spur broad political support for the work:

*And the other thing is that everyone is under such intense financial pressure, there is a much clearer understanding of the need to work collegially both within local authorities and across local authorities. Something like this may have been quite challenging a few years ago and may have met quite a bit of resistance. We have now found we are knocking on open doors.*

#### *Where do personal budgets fit in with this?*

Les felt that personal budgets had been less of a driver for personalisation in Thurrock than the work they were doing to integrate health, care and housing, as personal budgets had not increased people's choice as much as they had liked, as work was still needed to improve the choice of local services that personal budget holders could spend their money on. He also said that budgetary constraints – whereby eligibility in Thurrock was reserved for those with substantial and critical needs only – meant it was hard to invest in preventative work and to give people support who fell slightly outside the criteria but who would benefit from the choice of a personal budget. This is why radical change as proposed by the Commission was the only solution to financial sustainability:

*There's a real tension at the moment between delivering choice and being able to stay within a reducing budget. In an ideal world we would be able to truly give people a service which reflects their choices and aspirations entirely. We endeavour to do so, but there are times where there simply isn't the resource to make it as creative as we would like it to be.*

*Unless we do something really radical about how we reduce some of this demand – systemically rather than in one-off packages – then it is difficult to see how we are ever going to deliver real choice with far less resources to invest in that.*

#### **Sutton Council**

While the South Essex Commission will soon expand its strategy to consider the needs of those with learning disabilities and mental health needs, its initial focus has been on older people and the way in which integrated health, care and housing can improve older people's wellbeing. This is often about *preventing a*

*move to residential care.* We now look at Sutton Council, whose housing and care strategy has focused on learning disabilities and some older people *to facilitate a move from residential care*, for those already there.

The council has a clear strategic priority (rather than a wholly economic one) of moving vulnerable adults out of residential care and into supported living – something it has been doing since 2006 for people with learning disabilities. The authority has closed all its learning disabilities day centres and is focused on improving community support opportunities within universal provision and the wider community. It has taken many people out of residential care, considering this approach to be both cost-effective and capable of improving life outcomes.

In closing Orchard Hill Hospital, its last long-stay NHS hospital for people with learning disabilities, the authority invested NHS capital receipts into new ‘state of the art’ flats for those with multiple learning disabilities to facilitate the move into NHS institutional settings. These flats are purpose-built, located in popular parts of the borough with good amenities and have Telecare wiring integrated into the buildings, as staff on the council believe that people have the right to privacy and dignity without 24-hour surveillance, but that there should always be paid staff on hand to be supportive and give guidance if things go wrong.

A recent study of the resettlement of residents of Orchard Hill Hospital into supported living has provided Sutton Council with clear evaluative data demonstrating the positive impact of such a strategy.<sup>197</sup> The study surveyed all 39 former Sutton Council residents of Orchard Hill on leaving the hospital and then at six-month intervals for a further 18 months. The research measured quality of life outcomes in the following seven areas:

- quality and location of housing
- care planning and governance
- physical wellbeing
- social interaction and leisure activities
- autonomy and choice

- relationships
- psychological wellbeing

The study found significant improvements in all these areas of wellbeing, particularly in care planning and governance, autonomy and choice, and quality and location of housing.

These improved outcomes were also less expensive: the average annual cost of care at Orchard Hill was estimated to be £133,531, compared with £101,000 for care in a community-supported living environment, although the savings were spread across care costs, housing benefit costs and income-related benefits.

Sutton Council does offer residential care to some people – recognising that there needs to be residential support for people with dementia or other acute needs who require intensive round-the-clock support. People with learning disabilities do not fall into this category, and even the number of elderly people in residential care has declined considerably.

### *Challenging perceptions*

Closing residential services in a move towards greater personalisation and more independence for people in supported living can be problematic. Residential homes are highly visible and often become representative of council-provided care in local communities. Their closure is often met with local protest and seen as symptomatic of funding cuts. Moreover, care home residents and their families can be reluctant to make such a radical move.

Shaun O’Leary, executive head of adults and safeguarding at Sutton Council, described how there was considerable anxiety and resistance from many care staff and some families, with some relatives finding it difficult to accept the concept of their family members moving out of residential settings and into more independent living:

*They couldn’t visualise it. This was a world not open to them before. Family members thought it would be a push too far. For people with learning disabilities in particular, it is akin to a civil rights movement, a*

*fundamental, whole-system challenge for change. When you say that these people can live normal lives without having to compromise their basic rights as citizens – for example not having to live in shared accommodation – you really sense you are up against a huge belief system of resistance from many relatives, advocates, some national charities and many health and social care professionals.*

The council helped overcome this by ensuring social workers (working with people with complex cases such as dementia and learning disabilities) and community care assessors (unqualified social care assessors, working with people with less complex needs) were tasked with addressing issues such as maintaining relationships and empowering families and individuals to take responsibility for their lives. This required two changes to staff culture. The first was to move from a deficit model (an assessment of people's limitations) to a model that identified and assessed people's strengths and capabilities. The second was to adopt a social, rather than medical, model of care, identifying external factors and obstacles that can be changed or removed to enable independent living, instead of focusing on 'internal' obstacles that are related to a person's disability. This social work model also supports people who have been in institutional care for decades, enabling them to regard living in their own flat as a viable option.

When social workers spend more time looking at positive capabilities this often results in less conflict with family members when it comes to planning care: 'The research shows that as people are living more meaningful lives they need less and less support.'

Shaun explained that the personalisation agenda empowers vulnerable adults to have more control over their budgets and their world. This means that many carers and family members also need to develop a different view of the world. Carers who have been caring throughout their life (who have adult sons and daughters with learning or physical disabilities) have to rediscover a belief that their sons and daughters can live more meaningful lives in the community rather than needing to be protected from it. This is not a quick process but rather a slow,

long and often painful journey. However, once achieved, it can deliver improved wellbeing and quality of life for both the individual and their family: ‘You cannot start today and hope to fix things by tomorrow. You have to build that trust over a period of time.’

### *Community links*

Sutton Council has also been working to improve community links to enable people to supplement their support with less formal care, along similar lines to the progression strategy of South Essex Commission we describe above. Shaun told us:

*We’ve been working hard to develop people’s informal networks through personal assistants – highly motivated care staff commissioned to help develop and strengthen informal networks. Previously this budget had been spent on running day centres but [it] is now being spent on people with learning disabilities to have wider social experiences and develop networks outside of paid support.*

In this way, Sutton Council is tackling loneliness and isolation, and avoiding the use of more expensive formal supports.

### *Housing*

Sutton Council has been successful in moving learning disabled groups and others back into the community in part because of their capabilities approach to social care, but also as a result of the strong commitment from Sutton Council’s housing services to drive forward this agenda.

Simon Latham, Sutton Council’s executive head of community living, explained how he is expanding the stock of purpose-built flats within wider community developments. For example, whenever there is a development which includes one-bedroom flats being built in the authority, Simon’s team tries to get a portion designated for letting to people with a disability, and fits the flat with the right technology so people with learning and physical disabilities can live independently. The team also works closely with Sutton Housing Partnership and registered

social landlords to make best use of existing housing stock so it is as accessible as possible to people with learning disabilities. They then have the same opportunity as anyone else to live a normal life in the community, with people integrating into some of the more affluent parts of the borough. People with learning disabilities are not confined to the outskirts of town, the edge of greenbelt land or trapped on an isolated campus. The community wellbeing teams are also using library and leisure centres as natural community hubs, and are developing neighbourhood centres.



## 4 Policy and practice recommendations

This report thus far has identified the barriers to personalisation for care users with complex needs, or living in care settings, which may prove challenging to personalisation. This may include residential and other collective health and social care settings, as well as those receiving end of life care, which often sits on the fault line between health and care systems. In chapter 3 we also looked at some examples of good practice in overcoming some of these obstacles. Drawing on the range of evidence we gathered during the course of this research – including hearing about what is most important to care users themselves, we have developed the following recommendations for national policy makers, local commissioners and care providers in health and care.

### An overarching policy approach

In much of the national policy narrative and among practitioners, personal budgets and personalisation remain interchangeable terms. This needs to change if we hope to bring personalisation to every care user – including social care self-funders, those with complex needs, in health and care residential settings, in hospices, and so on. We must set our sights wider than personal budgets. There is no doubt that they can be life changing, but they may not be the most effective method of achieving personalisation for every care user. They must be seen as one of many tools for personalisation, and equal effort and policy focus must be expended on the other tools outlined in this report if we are to create a truly universal and accessible personalisation agenda. With this broad principle in mind, we now present some more specific recommendations.

### A more inclusive personal budget offer

The current policy focus on direct payments and individual purchasing risks excluding some groups who might find other forms of managed budgets a more effective means of personalisation, and may inhibit the collective purchasing power of groups of care users.

National government, the Think Local, Act Personal coalition (for social care) and local health and care commissioners therefore need to work towards implementing a more inclusive personal budget agenda for health and care budgets. This includes one where alternatives to direct payments are not seen as second best options, but are developed with equal vigour and given equal political support to ensure they deliver equivalent levels of choice and control as credible alternatives. Providers will need to be supported in transforming their internal financial structures to ensure effective delivery of individual service funds, while care staff and families need to be trained and given advice on how to make the most of managed and indirect budgets. Local authority commissioners and in the future clinical commissioners in health must also scrutinise their managed personal budget processes, to ensure they deliver choice and control and are not part of a tick box exercise. The Scottish Government would do well to learn from the English experience and must ensure that its new self-directed support model offers credible alternatives to direct payments, so that the terms 'self-directed support' and 'direct payments' do not become interchangeable and exclude those who cannot or do not want to use a direct payment. We must ensure that everyone, including those for whom a direct payment may not be viable, is able to reap the benefits of personal budgets.

An inclusive personal budget strategy is also one where more innovative uses of personal budgets are developed – including collective purchasing and mix and match approaches. The latter would mean people could use two or more forms of personal budget at the same time – for example, use a managed budget for the basic care core of a support package, combined with direct payments or indirect payments to purchase other elements of support. Collective and mix and match approaches need to be developed to become viable alternatives

to the single consumer or single budget model currently in operation.

Such changes would not require a significant investment in resources, as the structures for alternative forms of budgets already exist, and the Think Local, Act Personal coalition among others, including local third sector organisations, is already pioneering collective budget purchasing and mix and match budgets. To bring these to the fore would require a change in focus and emphasis by national government, and some investment in developing and distributing more guidance to local authorities, providers and care users and their families about how to make the most of alternatives to direct payments. The forthcoming social care white paper and the guidance produced following the results of the personal health budget pilots are both excellent opportunities to reflect this more inclusive approach to personal budgets in the national policy narrative.

#### A strategy for progression and rehabilitation

The strategies of progression and rehabilitation strategies must be given greater emphasis in the forthcoming social care white paper and the guidance issued following the Health and Social Care Bill, and must be reflected in local authority and clinical commissioning strategies and provider service offers.

The government has put £150 million of funding into reablement strategies for people leaving hospital to live back at home.<sup>198</sup> But this strategy focuses very much on older people, as a means of preventing a move to residential care. We need equal emphasis on strategies to enable people already in residential care to move on to supported living, and to gradually reduce their dependency on formal care. This has received far less political backing and funding to develop good practice.

Yet this is fundamental to improving personalisation for the 50 per cent of the population with learning disabilities who live at home with their parents, and the 33 per cent in residential care,<sup>199</sup> as well as those with mental health needs – who can move from hospitalisation to supported independent living, with the

right rehabilitative interventions. We therefore recommend that the Government gives equal weight to progression and rehabilitation as good practice strategies for working age adults as it does for reablement for older people.

Part of this strategy will be challenging the concept – embedded in providers, medical and care professionals, commissioners, families and care users themselves – that residential care is a ‘home for life’. The prospect of progress, moving on, enablement, rehabilitation and readiness for independence must become standard when commissioning residential care for working age adults and in individuals’ care planning, with outcomes and targets set accordingly. Residential staff must similarly be trained to consider progression from residential care as a viable option for every resident until proven otherwise. This will include learning how to use tools such as the National Development Team for Inclusion’s Inclusion Web to identify people ready to move on,<sup>200</sup> which ought to become standard in the residential sector, as well as a capabilities and enablement approach, with the encouragement of life skills, self-care and readiness for independent living. For example, this could include using occupational therapists in residential settings to help residents develop such skills and having carers teach residents how to do their own paperwork rather than doing it for them.

We recognise that not everyone will be able to move from residential care to supported living, but this does not mean that they would not benefit from a focus on progression and rehabilitation. Inspired by the examples we witnessed during the course of this research, we recommend providers consider how to create progression opportunities within their facilities. Some may consider purchasing semi-supported units nearby the main residential home, and share staff between the two settings, but those who cannot purchase additional property may be able to innovate – creating, for example, semi-independent or ‘lower support’ rooms within the home to encourage greater independence in the spirit of progression. Dee View Court is an excellent example of how small-group living, encouraging independence and social networks, even among

those with very complex needs, can be created within a large residential facility.

As with the investment in reablement and the prevention of residential care, an investment in rehabilitation to return residential care users back to their communities will reap considerable financial savings in the long run. The business case for both strategies is equally robust. Progression for those who cannot leave residential settings can be aided by investment in new facilities – but it is actually more about staff cultures. And the benefits to staff of having more independent and self-caring individuals, and peer support groups within residential settings, are clear.

### Recognising the importance of housing

A stronger national rehabilitation and progression strategy is only possible with housing becoming a key partner and integrated with health and social care. Many groups have called for such a step,<sup>201</sup> and yet progress remains stubbornly slow. The Department of Health's integrated care pilot programme does not seem to have provided any further insight into how housing can be brought into the policy space currently dominated by health and care. We add our voice to those who have called for the integration of housing in care planning, and stimulation of the housing sector as part of the wider care and support market.

We recommend that housing is recognised as a fundamental component of the rehabilitation and progression strategies we outline above, which requires additional political focus and funding with a clear recognition of cost savings being made in the longer term. A rehabilitation strategy must include active engagement with the housing sector (both private and social housing) to become partners in local authority care commissioning plans. There also needs to be brokerage carried out by local authorities between housing and health and care providers, to develop progression routes for those who may be ready to move on from residential settings. For example, residential care staff should be encouraged to come to supported housing settings, and vice versa, to overcome professional

reticence to joint working and improve awareness among residential providers of what can be achieved in supported living environments. Regular case meetings between residential and supported housing providers in a local area ought to be encouraged as part of a place-based progression strategy. This would encourage residential care providers to keep progression front and centre of their approach to caring for their residents, and would also help supported housing providers understand their local markets.

We also recommend that the Government carefully considers the impact of its budgetary cuts to non-ring-fenced budgets, which are likely to see a considerable reduction in funding for supported living,<sup>202</sup> and the closure of the Independent Living Fund. In the light of the review of residential care for learning disabled groups sparked by the Winterbourne View case, part of the Government's social care market growth strategy<sup>203</sup> must surely include plans for expanding suitable housing options so the supported living sector grows. This is unlikely to be achieved without dedicated funding streams.

### Co-production and democracy in residential settings

While for many in residential care personalisation may involve progression towards independent living, some groups – those with the most complex needs, with dementia and so on – may need to remain in residential settings. As mentioned above, we recommend these groups should also be included in progression strategies. We also strongly recommend that, in order to bring personalisation to those in residential settings, an active co-design and co-production strategy is applied as standard good practice across the sector, supported by strong democratic processes and structures. Health and care commissioners, personal budget care planners and the Care Quality Commission should all look for the presence of co-production and democratic structures as a mark of quality in residential settings.

Providers must move beyond resident consultation and discussion of the 'small things', and give residents the

opportunity to fundamentally design and influence aspects of their home and their care. This includes designing job specifications for new staff, resident representatives sitting on the recruitment and interview panel, designing daily routines and activities, the purchasing and placement of furniture and equipment, and so on. The ethos in care homes should be one of ownership, where a powerful residents' association is tasked with sharing the running of the home, as active members of a community might do in housing associations. Residential care should not be seen as 'hotel living'.

This is an issue of culture, not cash. It would cost very little to introduce decision-making opportunities and empower residents to 'own' their home, but it requires a fundamental rethinking of how homes are managed and how staff discharge their duties. Examples such as Dee View Court – where residents form groups to decide their therapy schedule for the month – demonstrate that the only real limitation to resident empowerment is the level of staff ambition and willingness to achieve this.

#### Develop social networks and a concept of 'just enough' support

For those with complex needs, all-encompassing care and support has been the standard approach for many years. Yet personalisation could change this by developing a more measured approach to the provision of formal care. We recommend that greater emphasis is placed on the approaches currently pioneered by Think Local, Act Personal and Paradigm UK. These aim to provide the *appropriate* amount of formal support, recognising that there is such a thing as 'too much' support. Independence, autonomy, dignity and privacy all have to be weighed against the need for support and supervision, but the development of community alternatives to formal support provides an excellent method of balancing the two in a way that is better for the individual.

We recommend health and care commissioners and providers should also follow this lead, and look to assistive technology, Homeshare, good neighbour schemes, community

living networks, time banks and peer support networks as ways to supplement (and for some people ultimately reduce) the need for full formal support for all of those with care needs. Where formal care is rolled back, so informal community support can fill the gaps, giving people greater flexibility over who supports them and how, as well as greater privacy, independence and dignity. This is a challenging step, and open to resistance from providers, social workers and families who are concerned about safeguarding and risk. It is also not appropriate for everyone. Nonetheless, a risk management (rather than risk aversion) and capabilities (rather than deficit) approach is central to the spirit of personalisation, and this must be pursued if personalisation is to become a reality for those with complex needs. These concepts need to be reinforced at all levels – through national guidance and training, local commissioning and provider management – to transform front-line practice.

In residential settings care is by its nature all-encompassing (provided on site, round the clock, hand in hand with people's accommodation). Achieving 'just enough support' will be particularly challenging in this scenario but is only likely to be achieved by facilitating residents to go out into their community and build links, with the aid of community groups, faith groups, volunteers and schemes like KeyRing, as well as bringing the community into the home itself.

Not only are these activities likely to improve outcomes for individuals through greater independence and opportunities to build social networks, they are also likely to reduce costs – reliance on expensive formal support can be reduced and replaced by less costly community and peer support.

## Staffing

### *The personal touch*

Personalisation does not just mean giving a person choice and control over the services they receive. It also means *providing those services in a personalised way* – having a 'personal touch'.

Personal budgets do not guarantee this form of personalisation – they cannot guarantee the personal touch. What they

can do is be used as a tool to achieve it. It is no coincidence that as personal budgets are being rolled out, so the number of personal assistants, individuals who can be hired to provide one to one support consistently rather than using a range of home carers from an agency, has increased significantly.<sup>204</sup>

But the personal touch, and consistent and personal relationships with carers, should not be the preserve of personal budget holders. We recommend, therefore, that providers of residential care and palliative care settings and domiciliary care look carefully at how they maintain the personal touch. We believe the personal touch is only possible if staff providing support get to know their clients well. This, in turn, can only be achieved if there is not a high turnover of staff or multiple staff members providing care. Providers must look at their recruitment and staffing strategies to ensure staff are paired with those they care for. A single key worker, or named nurse, is vital, as is contingency planning – so that when a key worker is absent, a single alternative person who is familiar to the person being cared for can step in.

It is often the ‘little things’ and attention to detail that create a personal touch – like simply knowing a person’s food and drink preferences, without having to ask. Care has to be taken not to overlook these things in the wider picture of personalisation, which often focuses on meeting people’s larger, longer-term aspirations and outcomes for a better life.

### *Staff culture*

Throughout our research for this report we have seen excellent examples of people who do not have personal budgets enjoying personalised services. This has been aided by democratic decision-making structures, innovative designs of facilities, and the support of the wider community, but the critical factor has been a staff culture that enables personalisation.

We recommend that training and guidance materials on how to deliver personalisation become standard practice across the care sector, but that particular attention is paid to personalisation for those with multiple and complex needs, in end of life care and residential health and care settings. It is in

these contexts that personalisation can be most challenging and staff working in these fields need to think more creatively about how to achieve it. This requires bespoke training, which looks at facilitation and empowerment in residential settings, how to overcome communication difficulties and personalisation for different levels of capability, and the importance of a 'risk enablement' approach. Training must also help challenge cultures that have grown up around caring for those with complex needs, in which people often believe all-encompassing support is the only 'safe' method of working. Sutton Council internally supports and 'trains' its social workers to assess needs in a positive way, to look at people's natural gifts and aptitudes rather than their deficiencies: what can they do themselves? what sort of life do they want? The goal is to enable people, and avoid being risk averse. Such training – which is not just about improving skills but changing attitudes – needs to be widely available, and rolled out across health and care provision by local commissioners and providers alike.

In addition, there must be clear leadership, which supports this approach. Local authorities, NHS commissioning consortia and the Care Quality Commission must be clear about their vision for 'quality' in care. The vision must not just look at the level of personalisation or personal budget structures in place, but also place equal emphasis on enablement and empowerment of individuals with complex needs. Commissioning strategies must support this by looking for providers who place emphasis on empowerment and self-care and incentivise this through contractual outcomes.

In turn, this must be communicated to care users and their families, and local authorities must be prepared for the inevitable initial resistance. Working with user-led organisations and disability forums to develop this agenda is likely to be the most effective way of creating an empowerment strategy that resonates with local concerns and has approval from the community. Those in senior strategic positions in local authorities and health commissioning teams, and health and care providers, must challenge the accepted wisdom among care staff, families and indeed care users themselves that care must inevitably involve

looking after and doing things for people, rather than encouraging them to do things for themselves. As Scotland's strategy for self-directed support states: 'The shift to co-production, outcomes monitoring and risk enablement will require training for staff across the social care and health sectors, and leadership from all levels of management.'<sup>205</sup>

As well as providing training and leadership for existing staff, those recruiting new staff must also support personalisation. Providers and local authorities should ensure that recruitment policies at every level of care staff and social work place emphasis on new staff having the right enabling and empowering attitude, in addition to the appropriate skill set. Moreover, recruitment of staff without care backgrounds will be increasingly important in delivering personalisation. It is unnecessary (and inefficient) for professionally trained health and care staff to engage in tasks that vocationally trained, experienced non-care staff or indeed volunteers can carry out. As personalisation progresses, so we will see a reduction in directly provided support and an increase in services that facilitate individuals choosing their own care and achieving their goals independently or with support from their peers.

In many residential and palliative care settings, activities coordinators and volunteers play an important role in providing support outside the basic care package – this role usually goes beyond organising activities, to befriending and encouraging residents and patients to participate in community life. We recommend that health and care providers look to these current positions in their organisations and think how they can be formally recognised as something more in keeping with the personalisation agenda – they should be tasked specifically with helping residents pursue their independence and also have a greater say in how the home was run. These on-site 'enablers' could – should – come from non-care backgrounds; a strong customer service ethos, a sensible approach to risk and an empowering attitude are the most important qualities required. Providers and commissioners should also look to the third sector, including peer support and user-led organisations, and the existing volunteer workforce for candidates for such roles.

Providers must consider whether every function their care staff carry out is appropriate to their level of training – or whether some navigation, enablement and social functions might not be better discharged by someone with the right know-how, rather than a nursing qualification. Employing such staff is likely to prove cost-effective – not only because it is likely that such roles can in some cases be carried out by volunteers, with appropriate training, but also because employing navigators or enablers will free up care workers and social workers to fulfil their more specialist duties. Improved advice and encouragement in building community links is likely to lead to improved use of resources and better outcomes for care users.

Changing staff cultures and leadership can be extremely difficult, but not particularly resource intensive. While some additional training might be necessary, health and care staff are already trained in a number of areas – so in many cases change in culture could be driven by reviewing existing training materials to ensure adequate emphasis is placed on creative ways to personalise services for those with complex needs, as well as tackling the issues of risk, co-production, empowerment and progression. National guidance, commissioning strategies and providers' organisational visions and mission statements would need to be reviewed to ensure a language of empowerment and personalisation prevails, but would not imply significant new investment. The imminent social care white paper and Health and Social Care Bill would be good opportunities to ensure national policy narratives supported these themes at little extra cost.

### Personalisation at the end of life

End of life care is a uniquely challenging context for personal budgets, but we have seen that many specialist palliative centres are excellent examples of personalisation. An inclusive personal budget strategy, as described above, will be important in bringing personal health and care budgets into end of life settings, but we believe the standard of personalisation already being delivered in this field should be something that is more widely spread.

We recommend that the good work being carried out by hospices and palliative care teams in teaching social care and NHS staff about end of life care should also include training about personalisation and holistic support, and advice on how to communicate about planning for the end of life and enabling people to articulate their wishes. Training in palliative care needs to be much more widespread among doctors, nurses and care home staff if those approaching the end of life are to enjoy personalisation regardless of where they die – be that at their home, in a hospital or a nursing home. Palliative care should not become another specialism, rather the skills of palliative care need to be spread broadly through the nursing and care workforce. We should consider, for example, how hospices and groups of care homes could be linked, so that hospices' skills and values can migrate into care homes.

Of course, there are still barriers to personalisation in end of life care – such as a lack of communication on end of life planning and the low take-up of advance care plans – which need to be tackled. NHS reforms should be seen as an opportunity to embed good end of life planning as part of a community's health and wellbeing strategy. We recommend that palliative care experts must be members of clinical commissioning consortia and the Dying Matters resources to promote the communication, and planning for the end of life should be integrated in health and wellbeing board strategies. Care plans for those with terminal illnesses or for older people should include end of life care planning, including contingency planning, timing for reviewing the plan, and transfer of personal budget management. People with terminal illnesses and older people, and their families, should be made aware of what advance care plans are, even though they may not complete one. Advance care plans should be destigmatised and promoted strongly by health and wellbeing boards among older people as part of sensible forward planning, not unlike financial planning, for example. GP surgeries should hold all the required information on them, and be encouraged to include literature in their communications with patients (eg on the variety of health checks offered to the over-65s). The take-up of advance care

plans in each local area should be monitored to establish whether take-up is increasing, and if it is not, further promotional activities ought to be considered.

As local reorganisation of health services is under way in 2011, now would be the time to embed palliative care at a local level without the additional cost of structural or procedural reorganisation later.

### Integrating health and care

Improving the integration of health and care is a vast topic, and one that would require a considerable amount of time to explore fully. There are many suggestions about how to improve integration in academic research and policy papers, and there is little value in reiterating them here. Nonetheless, in our research we identified two issues relevant to this debate:

- People tend to articulate their needs as broad outcomes, which cross over several service silos. When we asked what was important in life, people often told us they placed most value on having independence and maintaining family and friendships, which can only be achieved when several services work together.
- Examples of successful integration thus far have been bottom-up, relationship based, and local context-specific, and are therefore highly variable.

We therefore recommend, as we are now faced with significant structural reform to local health services, the setting of joint health and social care outcomes under the auspices of new health and wellbeing boards, which clinical consortia and the local authority will be jointly responsible for delivering. This will not only resonate with people's actual lives, it will also give discretion to health and care professionals at the front line to develop integration solutions that are most appropriate to the local context, and most efficient in meeting these outcomes. Health and wellbeing boards should emphasise the what, not the how.

These outcomes should be part of a wider vision to improve people's lives, so as to demonstrate to staff involved that integration is not an end in itself, but a vehicle to improve care and support and quality of life for the local population. We also recommend that these outcomes are ambitious with a clear emphasis on prevention, so that wider integration of services – including housing, transport and leisure – also become necessary to achieve these outcomes.

This will no doubt lead to considerable local variability in how care and health (and other) services are integrated. But in the light of decades of stalled progress in providing integrated health and care, it is clear that centrally dictated structural reforms, targets and incentive systems have had limited impact on the features that really make a difference to integration – relationships, trust and shared approaches and goals between staff from the front line through to middle management and up to a joint leadership. Perhaps more than ever before, in the wake of the Localism Bill and open public services strategy, we now have an opportunity to grasp these bottom-up approaches to integration.

Within this context, providers could have a highly influential role in setting the course and driving progress in integration. Joint commissioning structures will need to be reflected in joint service offers, so that providers (either through dual provision, or through brokering partnerships between coalitions of providers or providers and third sector organisations) can help commissioners achieve seamless packages of care and care pathways. Providers should also not underestimate the role they can play in reaching out to their NHS or social care counterparts to ensure their clients receive more integrated care – for example in co-locating health provision within residential care sites, and developing professional relationships between care providers and GPs and community health services as part of informal integrative relationships. In the wake of potentially more complex local health structures, providers of care to those with complex needs and multi-agency support requirements will play an increasingly important role in helping to bring together services around their client and navigate those systems on their behalf.

While there are some resource implications for the setting of joint outcomes and the encouragement of bottom-up approaches to service integration, the overall cost savings of a more integrated health, care and housing system are very significant indeed. Considerable resources have already been expended on encouraging service integration through top-down strategies – a bottom-up approach, with increased front-line discretion, may be both more effective and less costly.

## Final thoughts

Through the course of this project we have met many care users who enjoy independent and active lives, with care staff committed to giving them as much choice over their lives as possible. Enablement has been the order of the day. But we have also seen care users dissatisfied with their opportunities in life, but displaying grim acceptance that rules and regs had to come to bear and that these limitations were inevitable. Staff felt equally frustrated with such limitations, but could not see a financially sustainable solution to more personalised care. Neither group of care users was using personal budgets, yet the former group's support was inherently more personalised. Differences in care setting, staff approach, the use of co-design and wider community engagement all played a part in making this so.

It is for this reason that we must move away from the narrow focus on personal budgets and the mindset which assumes that without personal budgets personalisation cannot be achieved. It clearly can. This narrow focus risks excluding many groups from the personalisation agenda, and also leads to complacency – policy makers are in danger of assuming that when we have 100 per cent personal budget take-up in social care in 2013, we will have a personalised system. The fact remains that personal budgets are just one of several tools to achieve personalisation, and they are more effective for some people than others. Personal budgets do not guarantee personalisation – just as an *absence* of personal budgets does not guarantee an *absence* of personalisation.

We must, therefore, invest more resources into exploring how personalisation can be achieved by other means. Not just so that everyone can enjoy the benefits of more person-centred support, but also so that the personal budget agenda can be

strengthened and made more effective by applying additional tools alongside personal budgets.

The future success of the personalisation strategy relies on it becoming more inclusive. Everyone in need of care and support – regardless of their preferences, care needs, personal capacity, or care setting – should be able to enjoy the benefits of personalisation. But to achieve this, we must have a ‘personalised approach to personalisation’ – one where everyone can choose the method of personalisation that suits them.

Moving beyond a one size fits all approach to a personalisation approach is going to be increasingly important in the years to come – as the population of self-funders, those with complex and multiple needs, and older people with dementia grow in size, so too will the challenges to the effectiveness of personal budgets. As a result, in 2013, when 100 per cent of care users should be using a personal budget, we may still fall short of providing truly person-centred care. We are at risk of a situation where local authorities follow the letter of personalisation, but not the spirit. The additional suggestions presented in this report on co-production, group decision making, staff cultures, progression and empowerment, collective purchasing, advance care plans and so on are not simply viable alternatives to personal budgets – they are also important additional tools which must be used alongside personal budgets to achieve meaningful personalisation.

With ongoing reforms to social care, health and local government, now is the time to make this shift in policy focus and narrative around personalisation. Personalisation has undergone many phases of development in its long history from the early days of direct payments. An expansion of the personalisation agenda, from a narrow approach of individual consumer purchasing to a more flexible, accessible approach, which includes consumer elements as well as collective empowerment and community development, should be seen as the next phase in its evolution.

## Notes

- 1 DH, *A Vision for Adult Social Care: Capable communities and active citizens*, London: Department of Health, 2010, [www.cpa.org.uk/cpa\\_documents/vision\\_for\\_social\\_care2010.pdf](http://www.cpa.org.uk/cpa_documents/vision_for_social_care2010.pdf) (accessed 19 Sep 2011).
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Social care in the UK is facing a two-part revolution. First, local authority social care budgets are subject to substantial cuts, driven by cuts in grants from central government. Second, the health and social care structures which exist are undergoing radical reform, which will fundamentally change how services are delivered in future. In this context, the Government has announced a target of 100 per cent take-up of personal budgets, in order to fully achieve 'personalisation'.

But this pamphlet shows that whilst personal budgets may be one very effective way of achieving personalisation, they do not guarantee it. By focusing solely on personal budgets as the only way to achieve personalisation, we risk excluding some groups from the personalisation agenda altogether. Through in-depth interviews and focus groups with care users and staff, this pamphlet explores how person-centred services can be achieved for those who need it most – those with multiple and complex needs, and in settings where personalisation is most challenging such as residential care homes and palliative care centres. It considers the importance of co-production and democratic structures to collectively empower residents of care homes, staff cultures and risk, and the integration of health, care and housing.

*Tailor Made* finds that the future success of personalisation relies on it becoming more inclusive. Everyone in need of care and support should be able to enjoy the benefits of personalisation in a way that suits them, with or without a personal budget.

Claudia Wood is Head of the Public Services and Welfare programme at Demos.

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