RSA
Action and Research Centre

PEOPLE POWERED NHS

A POWER TO CREATE DISCUSSION PAPER

BY ALEX FOX | OCTOBER 2014

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About the author

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Foreword

Alex Fox takes stock of almost two decades of personal budgets and quickly identifies the nature of the opportunity:

> 'With greater individual empowerment and responsibility comes the possibility of greater creativity.'

This chimes very neatly with a blog that we recently published to invite thoughts and research contributions to a policy project we have undertaken to examine the relationship between the citizen and the state. We wrote:

> 'The public sector and wider government has yet to feel part of these creative times or to unleash the power to create in pursuit of public service ends. Our contention is that this is because the fundamental relationship between citizen and state is not being addressed.'

Our instinct is that the manner in which state resources are disbursed misses an enormous creative opportunity. Once we view citizens as creative agents in their own right rather than as passive recipients that challenges us to fundamentally reassess the manner in which power and resource flows through the system.

This discussion paper - an excellent contribution to our thinking and wider dialogue around these issues - advocates the widening of the system of direct payments. This would be precisely the type of shift that interests us in the context of what will become an RSA 'Power to Create' paper early in 2015.

However, Alex Fox adopts a cautionary note also. The promise of direct payments as a creative resource will not be realised unless systems, cultures and leadership are fully committed to change. There is much to be done.

We hope that others will join the discussion, encouraged by the bold and persuasive argument of this paper. If you are interested in further involvement in the discussion then please read our blog 'Let citizens spend tax revenues rather than the technocrats at the top' which presents our broader arguments and provides contact details. We would also encourage you to explore the wealth of resources on the 'Power to Create', including the RSA Chief Executive's annual lecture, available on www.thersa.org.uk.

We would like to thank Alex Fox for his generous effort and also Paul Buddery, Rowan Conway, Amanda Kanojia and Luke Robinson for their help also.

Anthony Painter

Director of Institutional Reform, the RSA

Introduction

People who necessarily make long-term use of social care have repeatedly demonstrated over the past two decades that they are often better than bureaucracies at making effective use of public resources. Tens of thousands of people now manage their allocation of resources prudently and many have proved better than professionals at integrating those resources with their own capabilities and with the support of their families and friends. For many, the freedom to construct support which fits the life they want to live, rather than having to eke out a life around distantly-managed services and systems, has been transformative, from the Direct Payment holder managing a team of support staff which enable her to hold down a valued job, to the social entrepreneur who hasn't let Down's Syndrome stand in the way of becoming the director of a small business.

Every public service sector could learn from those reforms and benefit from the potential to collaborate with individuals, families and communities on the design and delivery of the interventions needed to live well by the quarter of the population now living with a long-term condition.

But seven years after the Department of Health definitively put its weight behind the vision for 'personalisation' set out in *Putting People First*,[1] and 18 years after the right to individual control over state social care budgets was enshrined in law,[2] the term 'personalisation' remains deeply contested and only partially understood, even by many practitioners working in the social care sector.

Personalisation envisages a power-shift, from bureaucracies and organisations towards individuals and their families. But entrenched systems always place barriers in the way of transfers of their power, either deliberately or inadvertently. Some of that power-shift rests on shifts in control over the money being spent in an individual's name, but money does not directly equate to power within public service delivery.

For any power-shift to be real, there must be a commensurate change in how responsibility is taken and shared. Many service

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[1] *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*, HM Government, 2007.
[2] The Community Care (Direct Payments) Act (1996) came into force in 1997.

planners dream of their 'service users' taking more responsibility for their own wellbeing, or communities 'stepping up', but few bureaucracies have built their trust and investment in individuals, families and communities, or been willing to reshape their work in support of people's own contributions.

With greater individual empowerment and responsibility comes the possibility of greater creativity. But creativity is difficult to engender and sustain within public service systems which are focused primarily upon a person's needs and deficits, not their capabilities and potential, and which are selectively risk averse, particularly when it comes to the risks faced by bureaucracies and organisations, and those who work within them.

Citizens are teaching the social care sector both the power and also the limitations of reforms involving individual control over public service budgets. Many in social care still resist or misunderstand the radicalism at the heart of personalisation as it was envisaged by the disability rights activists and self-advocates who first developed self-directed support as part of the broader movement towards independent living, equality and inclusion. As the healthcare, welfare, housing, criminal justice and other sectors begin to think radically in the face of the extreme challenges they all face, there is an opportunity to build upon the life-changing gains which personalisation has achieved for significant numbers of people using social care services.

If more sectors can embrace not only the systems of personalisation, but also its values, we could even see integrated, cross-sector personal budgets, which proved a challenge too far during the original 'Individual Budget' pilot sites[3] in 2005, but are now seen by NHS England's new CEO as necessary to support the rapidly growing number of people with several long-term conditions.

There is, though, also the risk of taking a simplistic approach to reforms, based mainly or solely upon introducing personal budgets, without the commensurate culture change, power transfers and community development work needed for real transformation. This would tie up increasingly scarce resources in addressing pointless process design challenges. And it would squander the effort and energy of many thousands of citizens, professionals and planners, who have learned the hard way about what works and what does not.

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[3] The Department of Health (DH) funded 13 'Individual Budget' pilot areas in 2005-7, which attempted to give people control not only of social care allocations, but also to pool those allocations with other sources of funding. The budget pooling aspect of these pilots was not successful, due to incompatible cultures and systems.

What is personalisation and why was it needed?

A key goal for social care in the 1990s was to close the large, long-stay institutions for disabled adults and people with mental health problems, which had proliferated during the earlier part of the century and which were widely recognised as failing to offer people the opportunity of pursuing ordinary life goals, as well as having been exposed as harbouring high levels of abuse and poor practice by the Griffiths Report[4] and others. In place of warehousing people out of sight of their communities in undifferentiated hospital settings, initiatives such as Person Centred Care focused on developing an individual picture of a person, particularly with a focus upon their support needs, and developing an individually-tailored care plan. Large numbers of people moved out of large institutions and into much smaller care homes, often based in ordinary family-sized homes. Whilst the worst excesses of institutionalisation were largely eradicated, there was no strong evidence that people were consistently achieving the independent living and inclusion goals in their person-centred plans, nor that radically different models of support were being developed at scale. Once plans were drawn up, resources were still being allocated to individuals by professionals in processes which excluded individuals and their families and based upon the costs of a narrow range of interventions.

Self-Directed Support was developed from US thinking by In Control (an organisation set up by a small group of families in 2003) and others and was based upon the idea that individuals and their natural support networks were best placed to be the experts in their own lives and support needs, had more potential to think creatively and take positive risks than professionals and needed to be the key decision-makers about their own support and lives if they were to become and be seen as full citizens.

Direct Payments – the right to take the cash equivalent of a social care service offered to you – were made available to all in 1997, but take-up remained very low, due to barriers including the failure of existing power structures to embrace and promote them and the challenges inherent in becoming legally responsible for spending money on support, which can include taking on the responsibilities of an employer.

The idea of personal budgets was intended to address these difficulties and to make the goal of personal control over state budgets based system more widely achievable. People who have

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[4] *Community Care: Agenda for Action*, Griffiths, Roy, Health Service management board, 1988.

been assessed (or in some cases, have self-assessed) as eligible for a service are told how much money is available to fund their service and are given the option of taking control of that money, either through taking a cash Direct Payment, or through co-designing an individual spending plan with the council (a 'managed personal budget'), an independent brokerage organisation, or a service provider which is contracted by the council to coordinate care as well as to provide some or all of it (an 'Individual Service Fund'). From 2010, family carers and other 'Suitable Persons' could take on the legal responsibilities of managing and spending a Direct Payment on behalf of an individual who lacks capacity to do so.

The work of In Control and others influenced the development of the government's *Putting People First* concordat in 2007, which recognised that even radical changes to the control of public money would not on their own ensure that people with support needs could lead fulfilled and independent lives. Choice and control was only one of four 'quadrants' set out in *Putting People First*. The others were a universally available offer of advice and information to help people make informed choices, the development of preventative interventions to reduce the risk of people reaching crisis before they could access support and the building of inclusive and supportive communities ('social capital'). However, the commissioning of information, advice and preventative services remained locally determined and variable, particularly in the case of prevention which lacks a clear definition, an evidence base and a set of outcomes and outcomes measures. Similarly, there is no widely-shared approach to building social capital, although learning from the Asset Based Community Development movement is starting to gain ground within the sector whilst support approaches which attempt to help individuals build relationships and informal support networks, such as Shared Lives, are growing in scale and interest.[5]

The Care Act 2014 attempts to reset social care's aims away from solely reacting to medically-defined support needs and towards the achievement of wellbeing, which is defined holistically in the Act's first section, to include healthy family relationships, connections to others and active citizenship, which will only be achievable through viewing services as one part of a complex set of supportive relationships and societal factors. It is not enough for services to be 'community-based' in order for them to help people build and participate in their community, which is not a location but a set of relationships.[6]

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[5] *The State of Shared Lives in England*, Shared Lives Plus, 2014.
[6] For instance, the Centre for Social Justice's *Completing the Revolution* critiques the lack of community development work to accompany moves towards 'community based' mental health services. *Completing the revolution Transforming mental health and tackling poverty*, Callan, S., Centre for Social Justice, 2011.

Liberating individuals; gatekeeping resources

The mechanisms of personal budgets and Direct Payments, with their implications of trust and empowerment, were introduced into a sector whose culture remained focused exclusively on a person's 'deficits'. This culture is one of 'gatekeeping' scarce resources, through needs assessments, eligibility tests and means tests which can be characterised as requiring individuals to prove they are sufficiently vulnerable and poor, before they can engage with planning processes intended to promote independence and creativity.[7] The Care Act of 2014 attempts to bring at least some consideration of a person's capabilities, informal and family support networks and community resources into planning processes, along with an expectation of councils acting preventatively rather than reactively, and building a diverse local marketplace of providers.

In order to help people plan realistically, most areas have developed a Resource Allocation System (RAS),[8] an algorithm designed to translate assessed eligible needs into a proportionate, 'fair' share of limited state budgets. The figure generated by a RAS is intended to be an indicative 'ball park' figure to aid planning, with the final figure arrived at through user-led, 'co-produced' individual planning. Much has been written about the concept of a RAS, and it is an area of the reforms which has been most criticised, with many commentators agreeing that councils have a tendency to create RASs which are overly complex, opaque and bureaucratic. For instance, in some areas, a RAS is used to set what is ostensibly a guide amount for the personal budget to aid planning, but in reality can only be changed by an appeals process. Other forms of bureaucracy are well-documented.[9]

Some have argued that a system for arriving at an 'upfront allocation' is not even necessary. However, an individual can only plan the purchased portion of their support package meaningfully, if s/he is aware of how much money s/he is likely to be able to spend. The alternative is the more traditional care 'management system', in which a plan is produced but then resources are

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[7] *Redesigning the front end of social care,* In Control, Community Catalysts, Shared Lives Plus and Inclusive Neighbourhoods, 2013. http://www.in-control.org.uk/news/in-control-news/new-paper-redesigning-the-front-end-of-social-care.aspx
[8] See the tools developed by pioneer user-led organisation, In Control: www.in-control.org.uk.
[9] *Leaner approaches to council operating systems* and *Adult Social Care Minimum Process Framework,* Think Local, Act Personal, 2011; Use of Social Care Budgets, National Audit Office and Ipsos Mori, 2011.

allocated by a professional, from the budget they are responsible for managing – and balancing.

The necessity for a RAS indicates a 'chicken and egg' challenge at the heart of personal budget control: an individual doesn't know how much money they need to plan until they have developed an idea of the support package they want; but they do not know what kind of support package to work towards without some idea of how much money they are likely to be entitled to. This paradox is rooted in the continuing separation in the social care system, despite the ostensible transfer of budget control, between the people upon whom public money is spent and the people ultimately responsible for managing an area's care budgets.

That any brief description of personalisation must necessarily engage with the philosophically and technically complex challenges outlined above, is a good example of how the universal but deeply personal goal of living a good life in a good place quickly runs up against systems designed to manage the needs of large numbers of people. We all share the desire to live a good life in a good place, but pursue it in a way which is unique to each of us; service systems on the other hand tend to be both complex in their goals and reductionist in their view of what makes for a good life, as they attempt to organise service offers and staffing around the needs of diverse populations.

It is tempting to reject these technical challenges and hope that it is enough to articulate a clear vision and direction towards individual empowerment, which professionals can interpret on behalf of the people they support. However, the social care experience is one in which only a minority of practitioners both fully understand and consistently feel able to prioritise individual empowerment above the demands of burgeoning case loads and shrinking budgets, with those who do often feeling that they are putting their career at some risk, within a system which remains focused on its own resources, goals and risks. To change system and professional behaviour at pace and scale, we must address the challenges directly, building systems which are aligned with the resources, capabilities and responsibilities of the individual, and which allow and encourage professionals to use their empathy and creativity.

To date, the strongest evidence for the creative potential of individual control of state resources can be seen in the achievements of those who have been able to achieve the greatest independence from state bureaucracies in their individual spending decisions: people who hold cash Direct Payments. It is this group who have created an entirely new social care workforce: the Personal Assistant (PA), estimated to make up 23 percent of the 1.6 million

strong social care workforce.[10] The outcomes and wellbeing of Direct Payment holders are, on average, significantly better than for other groups,[11] with some disabled people able to become fully active citizens for the first time: "Employing a PA doesn't just mean I can get better support, it gave me the confidence to start my own business and I take more part in my family and my community".[12]

At 150,000,[13] the number of people using Direct Payments is significant and the changes to some lives dramatic. There is also likely to be a significant gain to the overall public purse when people who might previously have relied upon state benefits and services for every area of their life, are now able to organise their own care, to pursue a more active and included lifestyle and in some cases to gain employment.

But there remain limitations to the transformative impact of individual control over budgets, particularly where people still need or want state involvement in organising or delivering their support. Those whose personal budgets are managed for them by their council typically experience better outcomes and wellbeing than they had before, but their gains are not as large as those of Direct Payment holders.[14] This could be partly influenced by the fact that people with large, stable resource entitlements are more likely to take their personal budget as a Direct Payment, and that the potential gains from shaping and controlling a large budget for complex and usually intimate care are greater than those of taking control of a smaller amount. However, there is also some evidence that when the council continues to manage their budget for them, people experience more bureaucracy[15] and less tangible change. There are accounts of people who have been counted as taking a personal budget who, when asked, do not know that this is the case, suggesting that no real support with making choices has been offered. As one personal budget user put it,

> "This morning we had the review of the Personal Budget …It was the usual stuff of extraordinary controlling behaviour and total lack of understanding of the life of the person receiving the budget or of the person they're expecting to manage the budget."[16]

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[10] *The State of the Adult Social Care Sector and Workforce in England 2012*, Skills for Care.
[11] *National Personal Budgets Survey 2013*, Think Local Act Personal.
[12] Direct Payment holder in conversation with the author in 2013.
[13] ASCOF, Health and Social Care Information Centre, July 2014 http://ascof.hscic.gov.uk/outcome
[14] *National Personal Budgets Survey 2013*, Think Local Act Personal.
[15] *Self-directed support: Reducing process, increasing choice and control*, Think Local Act Personal, 2013; *Do personal budgets lead to personalisation?*, Guy Daly and John Woolham for UK Social Policy Association, 2010; *Choice Review*, David Boyle, Cabinet Office, 2013.
[16] From Mark Neary's blog: http://markneary1dotcom1.wordpress.com/2014/05/27/the-personal-budget-review/

The organisation, Community Catalysts, supports a network of over 600 very small 'micro-enterprises' which offer a very wide range of support and inclusion opportunities. Micro-enterprises are typically highly personalised to the needs of a small group of people who contribute to their design and in some cases run or work in them. For instance, some practitioners have started to offer a small group of older people home care directly, in competition with large agencies, often allowing workers to earn the same income whilst offering more time and additional forms of support such as trips to see friends or to visit shops. Some people with learning disabilities have become directors or employees of micro-enterprises in which they offer services such as dance activities or smoothies at events, giving them learning, inclusion and employment opportunities which benefit them and the local community.[17]

These micro-enterprises are usually purchased by Direct Payments rather than managed personal budgets. The most creative and niche social enterprises often struggle to engage with conventional commissioning processes or are specifically excluded by local application of procurement rules[18] which specify, for instance, that council-managed budgets can only be spent on organisations within framework agreements, on preferred provider lists or with a history of contracting with the council.[19]

This is an example of how councils have struggled to redesign whole service systems to support individual choice-making. The user-driven creativity of the more autonomous Direct Payment holders has remained concentrated in certain parts of the system and on certain groups of people. Commentators debating personalisation often put the arguments in the form of either/or choices for the sector: towards Direct Payments (autonomy, independence, but also greater responsibility and less back-up when things go wrong), or retaining traditional care management (less responsibility and more security, but less choice). People will always require varying levels of support to make choices and be willing and able to take on varying levels of responsibility, but regardless of this, interventions across the entire sector should seek to minimise intrusion and dependence whilst maximising empowerment, autonomy and independence. Embedding the values of personalisation throughout the whole sector will be particularly important and challenging for the NHS as it attempts to personalise its approach, because there will be periods during which most people with long-term conditions will be seeking greater levels of support and able to take on less responsibility for choice-making

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[17] See examples at www.communitycatalysts.co.uk which has a network of around 600 'micro-enterprises'.
[18] *Commissioning for Provider Diversity*, Shared Lives Plus and Community Catalysts, 2013.
[19] *Ten ways to stop bashing - and start boosting - micro-enterprise*, Community Catalysts and Shared Lives Plus, 2012.

(during acute episodes, for instance). If some parts of the health system remain medically-focused and lack an ethos of collaboration, those interventions are likely to undermine the effectiveness of the more personalised parts of the sector in building independence and collaboration.

Personalisation; far-reaching, but far from universal

The unevenness of the personalisation vision in social care is evident in many ways. Whilst the majority of social care users report slowly increasing choice and control, in 2011, 26 percent of disabled people reported that they did not "frequently" have choice and control in their lives, a slight increase on 2008.[20] The BBC Panorama exposé of abuse of people with learning disabilities at the Winterbourne View Assessment and Treatment Centre in 2011 brought to light the existence of over 3,000 people with learning disabilities who were living, in some cases for many years, in hospital-style medical facilities, which were found to have high levels of failure to comply with even basic standards[21] and little evidence of progress towards independence. Despite a high profile government and NHS England backed Joint Improvement Programme charged with reducing this number, it grew in subsequent years. This is particularly relevant to the NHS 'Integrated Personal Commissioning' (IPC) programme, as this area of low-outcome care is NHS-commissioned or jointly commissioned, but there are also 35,000 people with a learning disability who live in local authority-commissioned residential care.[22]

The variable uptake of personal budgets by some groups is well-noted. Only 29 percent of eligible people with mental health problems have taken up a personal budget, compared to 83 percent of people with learning disabilities. Uptake for older people, people with physical impairments and family carers all stand at 64 percent.[23]

What can be derived from these fluctuating variations between sub-sectors is that there are likely to be a number of factors interacting in complex ways, including:

- the typical size and stability of resource allocations;
- the range of available service options which could be purchased with personal budgets;
- the availability of advocacy and support brokerage systems;

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[20] *Disability Equality Indicators*, Office for Disability Issues. http://odi.dwp.gov.uk/disability-statistics-and-research/disability-equality-indicators.php. Data taken from ONS Opinions and Lifestyle Survey.
[21] Care Quality Commission's 2012 report on learning disability service inspections.
[22] *Independent Living Strategy: A review of progress*, Jenny Morris, In Control and Disability Rights UK, July 2014.
[23] ASCOF, Health and Social Care Information Centre, July 2014. http://ascof.hscic.gov.uk/Outcome

- the prevailing culture and assumptions of the relevant professions;
- the expectations of the individuals and their families;
- the translation to other groups of systems and processes which have often been driven by the learning disability sector.

Consideration of these factors as they apply to two of the lower-uptake groups – older people and people with mental health problems - gives a sense of the challenge of creating the conditions in which people can meaningfully take up the opportunity of greater control and new support choices.

It has been argued in the past that the concepts of choice and control over care are not important or attractive to older people, whose levels of personal budget uptake remained for some time behind that of other groups. This is belied by the recent increases in their personal budget uptake to levels commensurate with other groups, but it remains inescapable that support for older people is dominated by institutional and low-aspiration care of the kind rejected by other sectors. In 2011/12 there were 13,134 residential care homes with 247,824 beds and 4,672 nursing homes with 215,463 beds provided by councils in England, the majority for older people.[24] The number of people supported within this kind of care is increasing and the average size of facility is increasing.[25] Numerous reports into both care homes and home care have found high levels of failure, neglect and abuse.[26] This market is dominated by independent providers and is one in which there are large numbers of people purchasing their own care, often at great expense, both of which should be factors which would suggest that people have a high degree of choice and control, but which are fatally weakened by a culture of low expectations for older people in the sector and society more generally, by the commensurate low status and low pay of the workforce, and the high entrance costs to the market. Care home and home care providers have both argued

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[24] *Towards excellence in adult social care: Progress with adult social care priorities England 2011/12*, Local Government Association, October 2012; *State of Health and Care* 2011/12, CQC, 2013.

[25] See http://www.communitycare.co.uk/2010/11/08/cqc-report-reveals-care-home-size-is-increasing/ which notes an increase from 23 beds in 2004 to 25 beds in 2010. The Care Quality Commission's *State of Health and Care 2013* suggests this rose again to 26.

[26] For instance, the final report of the Equality and Human Rights Commission inquiry, *Close to home: older people and human rights in home care* found "evidence that the poor treatment of many older people is breaching their human rights and too many are struggling to voice their concerns about their care or be listened to about what kind of support they want". The Care Quality Commission's annual *State of Health and Care* reports consistently note a significant minority of care services as inadequate. Chief Inspector of Adult Social Care, Andrea Sutcliffe told the BBC in October 2014 that there remains too much "awful" care for older people.

that councils are attempting to purchase older people's care at rates which make even paying the minimum wage challenging.[27]

Lowest uptake is by people with mental health problems, although they are a group who are less frequently offered choices and tailored responses and therefore could arguably benefit most.[28] Here, factors which could play a role include a medicalised culture and concerns about the real and perceived risks of people controlling their own support.

It is important to recognise that even within these low-uptake groups there are nevertheless pockets of highly personalised approaches. For instance, hundreds of older people with dementia access Shared Lives day support and short breaks in place of day centres and respite in care homes. In Shared Lives, the older person is matched with a trained and approved Shared Lives carer and then visits them regularly, being treated much like one of the family. Dementia Adventure is a social enterprise offering older people and their partners or families supported outdoor activities. Some micro-enterprises are developed with or by both older people and people with mental health problems, including a number of 'men's shed' projects in which older men use and share skills such as wood-working and the Jam Club, a music group for people with mental health problems founded and run by a man who uses mental health services.[29]

Even within sectors associated with a 'traditional' or medicalised approach, there are examples of personalised and 'asset-based' thinking. Medically-based mental health services are supporting patients to become their trainers.[30] Some care homes for older people are building links with their local community through, for instance, inviting community members to use gardens previously given over to lawn as allotments, whilst others invite residents to take on roles such as meeting and greeting visitors, in response to residents saying they wanted to contribute, despite their high support needs or low mobility.

Conversely, within those groups whose uptake of personal budgets is high, there remain individuals who could benefit from highly-tailored or non-traditional support approaches, who do not or cannot take up a personal budget and use it to change or control

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[27] *An evaluation of National Minimum Wage enforcement in the social care sector over the period 1st April 2011 to 31st March 2013*, HMRC 2013. See also *National Minimum Wage, Low Pay Commission Report 2014*, paragraph 4.61, page 141, Low Pay Commission, 2014.
[28] *No Assumptions: A narrative for personalised, coordinated care and support in mental health,* Think Local Act Personal, NHS England, National Voices, 2014.
[29] Examples from Community Catalysts www.communitycatalysts.co.uk.
[30] NHS Excellence in Participation Awards 2014: https://www.youtube.com/watch?v=GudYEABcH8w&index=18&list=P L6IQwMACXkj3MMcQKY0XFrwjd5QmaDBvx

their support package. Those who may have most to gain from greater autonomy and collaboration with professionals are often those with the fewest natural resources to support them in communicating, asserting and organising new choices. Support to make choices and purchase care ('brokerage') has never been resourced through a national funding stream nor consistently resourced by local councils. It was assumed when personal budgets were introduced that brokerage could be funded by top-slicing personal budgets, whilst still leaving enough money to meet support needs. Equalities expert, Neil Crowther, proposes that the apparent stalling of gains in autonomy for disabled people can only be addressed by introducing a right to unified personal budget across all service sectors and local and national Access to Living Centres resourced to help people achieve the rights detailed in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities.[31]

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[31] http://www.slideshare.net/neilmcrowther/proposal-for-an-access-to-living-scheme-for-englanf

Developing people power in health and other sectors

I have tried to demonstrate that there is enough compelling evidence for the transformative impacts of personalisation and Self-Directed Support for other sectors to attempt to use them to disrupt current service models, particularly where practice is widely regarded as underachieving due to its inability to fit with individuals' needs and to support the contributions that they and those close to them could make to achieving good outcomes. Whilst noting that personalised approaches can be found in areas of practice least commonly associated with the term, I have also attempted to be realistic about the huge variation in understanding and implementation of personalisation and the risks of poor or partial implementation.

So, given this hugely variable picture of how the vision and practices of personalisation have been embedded within the social care sector, how do other sectors maximise their chances of successfully developing personalised approaches? There are clearly more factors at play than simply control over the money. It is these factors which social care is beginning to understand and which other sectors must rapidly get to grips with, if they are to embed changes which improve services and lives.

NHS England CEO, Simon Stevens', first high profile announcement was for a programme for 'people-power' in the NHS, based around personal health and care budgets, or 'Integrated Personal Commissioning' (IPC). Personal Health Budgets have been trialled with promising results, including better quality of life and fewer unplanned admissions, in 64 NHS areas.[32] So it is timely to consider how the NHS could learn from the implementation of personalisation in the social care sector.

The variable understanding and implementation of personalisation in social care illustrates the need to remain focused on the problems which personalisation was intended to address and the goals it was hoped it would help to achieve. The problems which personalising support could be expected to address include:

- monopolistic, one-size-fits-all services which struggle to respond to individual or fluctuating needs;
- a service culture of 'doing to' rather than of collaboration with people with long-term conditions, and the commensurate culture of dependency and disempowerment amongst people using services;

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[32] *Personal Health Budgets Pilot Evaluation*, 2012
https://www.phbe.org.uk/

- a lack of innovation, particularly where small-scale and niche organisations could play a bigger role in innovation;
- a poor fit between service interventions and the lives and relationships of people who need to have ongoing contact with those services;
- a lack of investment in families and communities.

It has also been argued by some that personalisation is a way of addressing the problem of rising service costs. Others have argued that personal budget control will lead to greater demands, costs or even to waste and fraud. There is evidence that personalised care packages are more cost-effective, but not that overall support costs per person are consistently lower.[33] Neither is there evidence of increased waste nor fraud.[34] Attempts to implement changes under the banner of personalisation, with the intention of cutting costs, are highly likely to be counter-productive, because they are likely to focus upon cutting service costs in the short term, rather than investing in people, families and communities in the long-term. Where personalisation has been associated with service cuts, this has been a significant barrier to participation and uptake. So whilst addressing the problems above could be expected to lead to greater cost-effectiveness, and in some cases to reduced dependency upon state services, it seems likely, if paradoxical, that these goals are more likely to be achieved if they are not treated as the priorities of the reforms.

A personalised public service system which successfully addresses the problems above could be expected to be characterised by:

- a wide variety of different service types, sizes and governance models, including small providers and examples of mutual ownership;
- individuals with personal budgets and the advocacy and brokerage needed to make informed and creative choices; people confident in sharing responsibility for creating their own wellbeing with responsive support available when they need it;
- thriving peer support and people with lived experience in employed roles;
- people who use services and their families networked with each other and able to participate in planning at neighbourhood and area level;

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[33] *Personal Health Budgets Pilot Evaluation*, 2012 https://www.phbe.org.uk/
[34] *Personalisation, productivity and efficiency*, Carr, S., Senior Research Analyst, Social Care Institute for Excellence, 2010; *Protecting the Public Purse*, Audit Commission, 2011 notes that £2.2m of personal budget fraud was reported in 2011, against social care spend of £16bn (compared to public procurement fraud of £855m).

- new kinds of intervention available, with opportunities for people who use services and family carers to co-design and support innovations, including through pooling resources;
- services and professionals which routinely design their interventions to support (and avoid undermining) people's natural support networks and who measure their impact upon family support and community connections.

Some poor or partial implementations of personalisation have simply replaced one set of challenges with another:

- monopolies transferred from unaccountable public service bureaucracies to even less accountable, predominantly large, private sector monopolies, with further reduced investment in quality, safety and staff;
- clientism maintained by providers which are procured primarily on price and which are poorly incentivised to achieve wellbeing outcomes;
- narrow restrictions on individual choices and continued bulk procurement of low-outcome services;
- procurement and service planning poorly informed by the views of citizens and carried out in isolation from any investment in families and communities;
- unrealistic expectations of communities and volunteers; citizens blamed for service failures.

Three ways to personalise the NHS

Learning from personalisation in social care suggests that creating such a system requires some deep changes in culture and expectations within the sector and in the expectations of people coming into contact with it. Three changes are particularly important:

    a. A collaborative approach to reforming supply as well as demand.

    b. Build trust in the capabilities and potential of individuals.

    c. Service systems reshaped to fit within support eco-systems.

a. A collaborative approach to reforming supply as well as demand.

As outlined below, demand-side reforms (personal budgets and Direct Payments) without the commensurate development of new forms of supply is likely to result in people's ability to make new choices being frustrated, leaving individuals with new and sometimes more complex resource allocation and planning processes to contend with, without the commensurate gains which would make the extra effort worthwhile.

Whilst personal budgets have in some areas been ostensibly offered to almost every user of social care, commissioners have continued to procure significant amounts of care, sometimes with little sense of the relationship between the two approaches to spending public money. Sceptics of personal budgets, including the Shadow Health Secretary, Andy Burnham, have talked of the risk that they 'fragment' previously centrally-organised services.[35] There is little documented evidence of this effect (and some Direct Payment holders have created impressively unified and successful care packages to meet complex challenges), but concerns about this risk are based upon a false opposition between centralised planning and individual choice. With the exception of Direct Payment holders with large budgets, individuals who purchase services are rarely able to act as commissioners, who plan and design services. Many

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[35] The Shadow Health Secretary in various speeches including to SOLACE in 2013.

find themselves isolated consumers of offers from large and distant organisations.

The role of the commissioner in such a system becomes arguably more difficult, because they wield less buying power, but just as important. Commissioners gain from being able to draw upon new sources of information and to involve people in powerful new ways. In *Commissioning for Provider Diversity* (2013), Shared Lives Plus and Community Catalysts set out a model which commissioning and service planning activity changes rather than stops. Each of the stages of a typical commissioning cycle remains important, but each can involve citizens in developing a picture of what is needed, wanted and available and in responding to that data. Citizens, including individuals spending public resources and 'self-funders' spending their own can be involved in:

- gathering information about what people want and need;
- feeding that information into service design;
- getting feedback on the outcomes and quality of those services;
- redesigning services and innovating.

For instance, Hertfordshire County Council has built a virtual marketplace for personal budget holders in which information can be gathered from personal budget holders and self-funders about the fit between available services and their needs and goals, and that information shared with current and potential local providers of all scales. Personal budget holders are likely to need support in order to link up with others with similar needs and goals, and with local social entrepreneurs who might be able to respond effectively. This support has been lacking in most 'personalised' local systems, contributing to the impression that personalisation is to blame for services failing financially.

To build a new range of interventions, the NHS must collaborate with citizens to:

Recommendation 1: build advocacy and brokerage into all Personal Health Budget development;

Recommendation 2: develop a new model of commissioning in which citizens and communities are involved as well as clinicians and managers;

Recommendation 3: work with councils to include Personal Health Budget holders and health providers in local marketplaces created for social care personal budget holders, with promotion of collective purchasing;

Recommendation 4: identify and commission new models of provision which have the most potential to deliver wellbeing and resilience outcomes.

b. Build trust in the capabilities and potential of individuals.

Implicit in a drive towards collaboration is a belief in the potential for individuals to contribute something of value, or even to lead the work of professionals. As one professional described the impact of introducing self-directed support approaches in substance misuse treatment: "It's created an equalisation of power, as they are doing their own self-assessment. They're telling you things that they wouldn't have told you before. You're spending more time with them. There is a lot more care that goes into this care plan. It has opened our minds, so rather than just banging them into rehab we're looking at the full picture."[36]

An asset-based or capabilities-based approach is one which looks first for what people can or could achieve, alongside considering their needs, conditions and challenges. It is based on the observation by John McKnight[37] and others, that if all a professional looks for is need, it is often all they will find and they will generally conclude that a professional or service is needed from outside, without considering how to help an individual, family or community to build their own resources and resilience. Taking an asset-based approach requires more investment in knowing an individual than is allowed for in brief clinical appointments, but this investment may be repaid by less misdirection of resources at a later stage. This willingness to work alongside an individual and their family or community can be particularly important in work with groups, such as people with learning disabilities, dementia or mental health problems, who are often seen primarily in terms of their dysfunction or lack of capacity.

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

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[36] *Implementing personal health budgets within substance misuse services Final Report*, Welch, E., et al, PSSRU, November 2013.
[37] *The Careless Society*, McKnight, J, see www.abcdinstitute.org.

supported accommodation to a home where she will have her own tenancy.[38]

Most people with long-term support needs take some degree of responsibility for their own wellbeing and care, but health systems are not designed to enable and maximise these contributions sustainably. The language of healthcare is of 'compliance', not collaboration and the recent vision for NHS commissioning has been based on a power shift from professional managers towards clinicians, not towards citizens.

To build trust in individuals and their families will require professionals and systems to value different forms of expertise alongside (not instead of) clinical expertise. This will change the expectations which citizens and professionals have of each other. The expectation of being 'fixed' regardless of lifestyle and self-care may reduce, but the expectation of information sharing and being fully included in decisions should increase.

To begin this culture change, the NHS needs to:

Recommendation 5: train all health professionals to build their listening skills and planning support skills;

Recommendation 6: routinely involve citizens and the representatives of people with long-term conditions in planning and commissioning, including through peer support and trained, paid roles;

Recommendation 7: start a debate with the public about the responsibility we all need to take for our own wellbeing and the expectations citizens should be able to have of their health professionals.

c. Service systems reshaped to fit within support eco-systems.

With over a quarter of us living with a long-term condition[39] and 2.9 million living with three or more conditions by 2018,[40] the key challenge is not to treat the symptoms of long-term conditions such as diabetes, mental health problems or obesity, but to help individuals to live well and manage their conditions. A service may be essential in order to live well, but it never creates a good life on its own. A good life comes from our relationships with others,

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[38] From *No Assumptions: A narrative for personalised, coordinated care and support in mental health*, Think Local Act Personal, NHS England, National Voices. 2014.
[39] *Outcomes Framework* NHS England 2013.
[40] *Outcomes Framework* NHS England 2013.

particularly close family members, friends and our community, however we define it.

Many care packages are led by the UK's 6.5 million unpaid and largely untrained family carers, who contribute well over £100bn to the health economy,[41] but they are rarely regarded as partners, experts or leaders by professionals and services. Carers, particularly the 1.4 million contributing more than 50 hours per week,[42] should be confident of recognition, information sharing and responsive help in emergencies. The NHS has trialled initiatives such as peer-support, expert patient programmes and 'partners in care' approaches to working with family carers, with promising results, but has not embedded the culture change across the system.

Helping people to build their social networks will not only help those networks remain effective and sustainable, it is also likely directly to improve people's health. One large scale international study concludes that: "The quality and quantity of individuals' social relationships has been linked not only to mental health but also to both morbidity and mortality [and] it is comparable with well-established risk factors for mortality," such as smoking.[43] Hazel Stuteley was struggling to achieve public health gains as a Health Visitor on a deprived estate in Cornwall. Stepping outside of their roles, Hazel and her colleague convened a community group, which began with five residents, each confronting significant health issues. In Hazel's words, "They didn't look like a group that was going to change the world." That group became the Beacon Project which went on to transform life for hundreds of people, managing a £2.2m budget, with outcomes as diverse as postnatal depression rates down by 77 percent, and crime down by 50 percent.[44]

There is an urgent need to build 'networked' models of support in which services are designed to complement and support people's informal networks. Services will only be designed with this level of sophistication if individuals, families and communities are involved in that design process. This is not a case of 'dumping' greater responsibility upon individuals or families, nor of asking volunteers to take on inappropriate roles. That would be to transfer the workload and the risk to families and communities, without offering the respect, investment and back-up which should be commensurate with the increased responsibility. Families and communities cannot be coerced into contributing more; simply

[41] *Facts about carers 2014*, Carers UK.
[42] *Facts about carers 2014*, Carers UK.
[43] Holt-Lunstad et al 2010, quoted in *Building Community Capacity Evidence, efficiency and cost-effectiveness*, Wilton, C., Think Local, Act Personal 2012.
[44] *Empowering Communities for Health Business Case and Practice Framework*, Fisher, B., Stutely, H., et al NHS Alliance and H.E.L.P., 2011.

withdrawing or reducing formal services results in widening health inequalities, with the most vulnerable and isolated put at most risk.

An example of reframing the role of support interventions, without withdrawing services or increasing risk, is the Shared Lives model, used by 12,000 people across the UK. One hundred and fifty-two local schemes recruit, train and approve people from many different backgrounds to become Shared Lives carers, who are then matched with up to three adults with substantial support needs, including 8,000 people with learning disabilities, nearly 1,000 with mental health problems and several hundred with dementia. Once matches are found, the participants share family and community life, either through the adult moving in with the Shared Lives carer and living as part of their family, or regularly visiting them for day support or overnight breaks. Shared Lives carers are trained as part of a CQC-regulated service and they are paid and work within a professional contract. But they are not paid by the hour, and typically they and their family and friends choose to contribute much which is unpaid, because they come to value the adult as 'one of the family'. Shared Lives is considerably lower cost than paid-per-hour alternatives,[45] but also has the strongest care inspection record and evidence of achieving outcomes such as increased friendship circles which are usually considered out of reach of service aims.[46] Hertfordshire Partnership Foundation Trust has used the model to develop its Family Hosts scheme, providing acute mental health care.

For the NHS to move beyond its 1948 roots as a hospital-centred illness treatment service and become a world-leader in creating health and wellbeing, it must:

Recommendation 8: formally recognise unpaid family carers as partners in care, with a guaranteed offer of information sharing (once consent has been established), involvement in planning, training, advice and emergency back-up;

Recommendation 9: commission for a new expectation for all health providers that they measure their impact upon people's wellbeing and resilience, alongside clinical outcomes, using a framework shared with other sectors including social care and housing;

Recommendation 10: become funding partners in a programme of asset-based community development which is measured upon the creation of wellbeing and resilience.

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[45] *Investing in Shared Lives*, Social Finance, 2013.
[46] *The State of Shared Lives in England*, Shared Lives Plus, 2014.

Appendix: RSA in action

The RSA has been undertaking practical work with communities and services to put into action many of the ideas and aspirations in this paper. Our work is demonstrating ways in which people in communities can find creative solutions – people-powered solutions - to the challenges they face. Public services have a key role in supporting this, but they need to become much better at understanding how people connect, and want to connect, with each other and the institutions around them.

The RSA Connected Communities team explores how focusing on social connections and assets can help shift power to people and their communities to help them meet their social and economic needs and aspirations. Reduced public finances are forcing a revaluation of what the state can provide for communities and how communities can become more resilient. Social network approaches can inform new policy and practice to address this challenge. Drawing on research in New Cross Gate and Knowle West, Connected Communities has explored how to overcome some of the limitations of traditional, place-based redevelopment through understanding social networks. The team is currently completing action research on collaborative approaches to supply and demand management in health, exploring what 'not coping' means to residents in a deprived neighbourhood in west London. In spring 2015 it will publish a report on its five year longitudinal study into social exclusion and mental wellbeing.

For further information:

Marcus et al, 2014, Social mirror, 2014, RSA: London. Forthcoming

Parsfield et al, 2014, Not coping, RSA: London. Forthcoming

Rowson, Broome and Jones, Connected Communities: how social networks power and sustain the Big Society, 2010, RSA: London; http://www.thersa.org/__data/assets/pdf_file/0006/333483/Connect edCommunities_report_150910.pdf

The RSA Whole Person Recovery Team in West Kent is testing, at scale, a service delivery model that fosters community networks in order to support sustainable, long-term recovery from drug and alcohol abuse. The service develops 'recovery capital', defined by Granfield and Cloud as "the breadth and depth of internal and external resources that can be drawn upon to initiate and sustain recovery from AOD (alcohol and other drug) problems" (quoted in Best and Laudet, 2010). The approach transcends the boundaries of commissioned services and allows for the development of a support

'ecosystem' from initial engagement. Co-production is at its heart. Treatment systems can only work effectively to support the development of recovery capital in collaboration with individuals, families and communities.

For further information:

The team will be publishing a further report on its work in Winter 2014.

Best and Laudet, The potential of recovery capital, 2010, RSA: London
http://www.thersa.org/__data/assets/pdf_file/0006/328623/A4-recovery-capital-230710-v5.pdf

Daddow and Broome, Whole person recovery: a user-centred systems approach to problem drug use, 2010, RSA: London
http://www.thersa.org/__data/assets/pdf_file/0011/362099/RSA-Whole-Person-Recovery-report.pdf