

Appendix A

Terms of reference

The review will focus on identifying the practical barriers to people exercising choice in specific areas where choice is already available to users, including for example: GPs; hospitals; community services; adult social care; schools; Further Education; Higher Education, and early years.

- Where choice is enshrined in policy or legislation, there should be genuine options for users to choose from, including for users of services in rural areas, subject to reasonable cost concerns.
- Where needed and helpful, individuals should be actively prompted to consider the choices available to them.
- High quality information, including on service outcomes and user satisfaction, should be available to individuals in an accessible form that enables them to make good choices about publicly-funded services.
- Vulnerable and disadvantaged groups should have the same choices available to them as the wider population.
- The review will predominantly focus on services in England.

The review will assess how the current system operates against these principles and make practical recommendations which take account of value for money and the limitations of capacity and public resources. In identifying the barriers that exist which prevent people from exercising choice in publicly-funded services, the review will explore the following issues:

- The factors necessary to ensure that all individuals, with an emphasis on the most disadvantaged and vulnerable, are able to choose publicly-funded services where choice is available;
- The current evidence base on choice in publicly-funded services;
- In which service areas and circumstances choice policy has been particularly effective in ensuring that people receive the right services to meet their needs, including where choice policy has demonstrated value for money;
- The extent to which lessons learnt from the implementation of current choice policy could be applied to other areas of public services;
- The extent to which different users of publicly-funded services have access to information, advice and support that meets their needs in order to determine the service that best suits their circumstances and requirements; and
- Examination of the practical options for breaking down the barriers which prevent users of publicly-funded services exercising choice in public services.

A final report setting out the Review's findings is expected to be submitted to the Chief Secretary to the Treasury and the Minister for Government Policy in early 2013 and will be published thereafter.

Appendix B

Text of call to evidence

I have been asked to take an independent look at what prevents people from being allowed to choose for themselves in services that are publicly-funded.

There has been a whole range of measures in recent years to give people more choice – over the schools for their children or their hospital or their social care package, for example – but remarkably little research so far about whether people use it.

And most important, whether people get to choose when they are disadvantaged in other ways – or whether choice is so far only the preserve of articulate, sharp-elbowed, wealthier people. The question isn't about the theory of choice, or even really about the ideological purpose of choice. It is to find out what people do with it in practice.

If you are a service user with a personal experience of choice in public services, either successful or unsuccessful, I would be extremely grateful to hear from you. In fact, I am particularly keen to hear positive stories because I have a sense that it is the variety of ways that choice actually *works* that may give us the clues we need to suggest solutions when it doesn't. Key questions include:

- Where choices in public services are available, are people-especially disadvantaged people, actually choosing?
- Do they have access to the information, advice, intermediary support they need to choose?
- If not, why not? What are the barriers they face?
- What lessons can we draw from where choice works successfully?
- What can be done to improve access to real choices for everybody?

We will be travelling around the country as much as we can, but we can't meet everyone. So drop us a line, choice.review@cabinet-office.gsi.gov.uk or by post at the address Independent Review – barriers to choice, Cabinet Office, 1 Horse Guards Rd (second floor room 2.29), London SW1A 2HQ because your experience may provide us with a clue we can get nowhere else.

Appendix C

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Appendix D

Review round tables and events

Pramacare – Poole

Centre for Innovation in Health Management – Leeds

Barca Leeds – Leeds

Holmes Christian Community – Bradford

Local Area Coordination – Middlesbrough

Connected Care – Hartlepool

Turning Point – London

Revolving Doors – London

Management Consultancies Association – London

Care at Home, Wiltshire & Swindon Users' Network – Trowbridge

Careplus Group – Grimsby

Community Catalysts/Nottinghamshire County Council – Nottingham

NHS Direct – London

NHS Alliance - London

Family Lives parent group – Hatfield

Respublica (conference event) – Brighton

Peterborough city hospital – Peterborough

Hitchingbrooke hospital – Huntingdon

Corporate Parenting User Involvement group – Norfolk County Council

Doctors' forum (organised by CIHM) – Leeds

Appendix E

Costs and benefits of navigation support pilot

Costs: The costs of the pilot on ten sites over two years will be between £355,000 and £645,000. This is based on the per person cost of training Yorkshire's Health Champions, which is £2,100 (including six months of support) or £5,000 (including a year's support). The review's calculation is based on ten trained peer support advisors trained in ten sites over two years (£210,000 or £500,000 plus evaluation (£45,000) and payments to sites to cover extra costs (£100,000).

Savings from peer support: Evidence of other peer support programmes in the UK and abroad suggest that they give rise to savings in public costs of around £1 to £3 per pound invested, and more for the Health Champions programme which is closest to what is being proposed here, where there are savings in improved health and also in improvements in the lives and employment prospects of the champions themselves.¹ The purpose of the pilots is to embed navigation support in projects that are themselves cost effective:

- The results of modelling the benefits of time banks by Martin Knapp et al suggest that, in general, the cost per time bank member averages less than £450 per year, but that the value of these economic consequences could exceed £1,300 per member. As the team pointed out, however: "This is a conservative estimate of the net economic benefit, since time banks can achieve a wider range of impacts than those we have been able to quantify and value."²
- "Despite numerous start-up expenses, peer programmes represent long-term cost effectiveness. This is largely because peer educators operate without any monetary gain 24 hours a day, seven days a week. Such a service would not be financially viable for most organizations, if conducted by professional staff... Evidence-based literature highlighting the efficacy of prison-based, peer-led programmes, research published to date suggests that such programs are well tolerated, effective, and possibly more cost effective than professionally led programs."³
- "Peer Support services [in mental health] are also proven to be extremely cost-efficient. The cost per day for one acute mental health hospital inpatient has been calculated to be £259 (Healthcare Commission 2008). By comparison, the Leeds Survivor-Led Crisis Service (see www.lslcs.org.uk) successfully supports people at £180 per day."⁴

¹ N. Hex and S. Tatlock (2011), *Altogether Better Social Return on Investment Case Studies*. York Health Economics Consortium.

² Martin Knapp et al (2010) *Building community capacity: making an economic case*. Personal Social Services Research Unit (PSSRU). See: <http://www.pssru.ac.uk/pdf/dp2772.pdf>.

³ Devilly et al (2005) 'Prison-based peer-education schemes' in *Aggression and Violent Behaviour* Vol 10, pp.219-240.

⁴ Basset et al (2010) *Lived Experience Leading the Way: Peer Support in Mental Health*. Together UK. See: http://www.nsun.org.uk/modules/downloadable_files/assets/livedexpericereport.pdf.

- Connected Care in Basildon has claimed impacts of over £1,000 per client, and a total of over £500,000 across the town.⁵
- The evaluation of the Health Champions project concluded that: “Becoming a community health champion has health benefits such as increased self-esteem and confidence and improved well-being. For some champions, this was the start of a journey to other opportunities such as education or paid employment. There were many examples of the influence of champions extending to the wider community of family, friends and neighbours, including helping to support people to take part in community life. Champions recognised the value of connecting people through social networks, group activities, and linking people into services and the impact that that had on health and well-being. Project staff and partners also recognised that champions were promoting social cohesiveness and helping to integrate people into their community... The recent public health White Paper suggested that the Altogether Better programme is improving individual and community health as well as increasing social capital, voluntary activity and wider civic participation. This evaluation supports this statement and suggests that the community health champion role can be a catalyst for change for both individuals and communities.”⁶

Cost savings from navigation support: It is hard to estimate precise cost savings, but we can expect them to fall into three categories:

- Savings from reducing wasteful and inappropriate services. When services are better suited to the specific needs of individuals, there is less waste and a greater chance that they will be effective.
- Savings from using informal or local solutions rather than unnecessary high-cost services. The best comparison here is the savings in the cost of social care achieved by Local Area Co-ordination in Western Australia by doing precisely this. Savings in the Local Area Co-ordination project in Middlesbrough have been estimated at between £1.80 and £3 per £1 invested.⁷
- Savings from resolving the complexity of services for people. At the extreme end of the spectrum are some of the savings achieved by organisations like Resolving Chaos by providing a face-to-face case worker to help people tackle chaotic lives.⁸ These costs, and therefore, these savings, will not be possible for more than a few people, but the same pattern – helping to reduce the extra costs caused when there is no face to face support – applies in smaller ways to many service users who could benefit from navigation support.

⁵ Annette Bauer et al (2011), *Economic Evaluation of an "Experts by Experience" Model in Basildon District*, LSE Health and Social Care, London.

⁶ James Woodall (2012), ‘Improving health and well-being through community health champions: a thematic evaluation of a programme in Yorkshire and Humber’, *Perspectives in Public Health*, Aug 13.

⁷ Peter Fletcher Associates Ltd (2011), *Evaluation of Local Area Co-ordination in Middlesbrough*, PFA Ltd.

⁸ See for example www.resolving-chaos.org

Appendix F

Case studies

Connected Care (Section 5)

Connected Care is Turning Point's methodology for bringing about changes in the design and delivery of health, housing and social care services by finding efficiencies in the system.⁹ The idea is to employ local service users to survey how services are used and to rethink the way services work together to support a combination of needs, and look for ways to form an equal partnership with communities in the design and delivery of public services. Connected Care is designed as a bespoke service. The community researchers work with local commissioners to help define the problem, and provide tailor-made solutions. There are four stages:

1. A community-led needs assessment is conducted by trained community representatives. These community researchers drive engagement in every section of the local community through rigorous research.
2. This research leads to recommendations based on a strict cost benefit analysis. These are reviewed by a local steering group made up of local authority, NHS, third sector and community representatives.
3. Service redesign or reconfiguration delivers new levels of efficiency – focusing on service integration and meeting the needs of service users and commissioners alike.
4. Set-up of new services co-produced by the community.

In Warrington, researchers focused on neighbourhoods with high levels of health inequalities, helping to inform the council's planning and improving engagement with the town's most vulnerable residents. In

the Gorleston area of Great Yarmouth, they found solutions that helped to reduce emergency in-patient admissions. In Hammersmith and Fulham, they launched a Community Champions scheme, providing community-based support across a wide range of services. The first Connected Care project, in Hartlepool, produced a series of professional navigators. In all these cases, the solution provides a more flexible face for disadvantaged service users, which gives them genuine choice.

Co-production (Section 5)

Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours.¹⁰ The co-production critique of conventional public services, developed in the USA by Edgar Cahn, suggests that services are less effective when they fail to engage the ultimate beneficiaries

⁹ www.turning-point.co.uk

¹⁰ David Boyle and Michael Harris (2009), *The Challenge of Co-production*, NESTA, London.

as partners in the delivery of services.¹¹ It suggests that the maintenance of service users as passive recipients is not just a waste of their skills and time; it is also the reason why systemic change doesn't happen, that – when people are never asked to give anything back, and when the assets they represent are ignored or deliberately side-lined, they atrophy. The central idea in co-production is that people who use services are hidden resources, not drains on the system, and that no service that ignores this resource can be efficient. The people who are currently defined as users, clients or patients provide the vital ingredients which allow public service professionals to be effective. Co-production goes well beyond the idea of 'citizen engagement' or 'service user', and has been developed in a range of ways in health, school, justice and housing settings, and in social care, on both sides of the Atlantic, including in time banks and youth or citizen juries, often linking different services together to be more effective.

Employment support services (Section 2)

There are a range of services now available to help people with personal budgets to employ their own personal assistants. These include:

- People 4 People. This is a specialist employment service commissioned in partnership between four London boroughs (Barking and Dagenham, Havering, Redbridge and Waltham Forest). This service provides support to employers of personal assistants. It also offers a service called 'Individual Support Service' which 'takes on the employment responsibilities for personal assistants on behalf of the customer'.¹² See
- Bexley's Holistic Community Support Services (launched May 2012).¹³
- Notts Independent Living Consultancy – supports people with responsibilities of being an employer.¹⁴

See also a recent report on the personal assistant workforce.¹⁵

Friends and Family (Section 3)

A standard Friends and Family test question is being introduced in acute in-patient wards and A&E departments from April 2013. It is intended as an easy-to-understand question that will be asked of patients about the care they received – whether they would recommend the care to friends and family – and it is being introduced because the government wants NHS organisations to get regular and timely feedback from patients about the care provided in the NHS, take ownership of the results and act on the feedback. The purpose of the information collected is to share it with the public in a totally open, transparent way, and to put

¹¹ Edgar Cahn (2001), *No More Throwaway People: The co-production imperative*, Essential Books, Washington, second edtn.

¹² www.people4people.org.uk

¹³ www.bexley.gov.uk/index.aspx?articleid=13896

¹⁴ <http://nilc.co.uk/>

¹⁵ Lynda Jones (2012), *Personal Assistants: Developing the workforce in London*, London Joint Improvement Taskforce, London.

continuous pressure on all organisations, highlighting excellence while shining the light of transparency onto sub-standard performance. The test puts into effect the link between transparent user feedback and improved service quality. For instance, efforts over many years to reduce food infection in New York restaurants finally had an impact when restaurant rating assessments were displayed on the window of every restaurant in full view of staff and diners.

Health champions (Section 5)

Community health champions are engaged, trained and supported to volunteer and use their life experience, understanding and position of influence to help their friends, families, neighbours, communities and work colleagues lead healthier lives. They are able to inspire and support others to make positive lifestyle changes and they also work with local service commissioners and providers to improve the quality of local health and social care services by contributing local intelligence, experience and knowledge of community skills and resources.¹⁶ They have been developed, among other organisations, by Yorkshire-based Altogether Better, which has been working with a number of partners, including the Department of Health, to share learning about the community health champion model and increase the voice of patients and communities in shaping health and social care services. Working in partnership with the NHS Confederation, Altogether Better is working to develop a network of health champions across England and has done so for four years, recruiting, training and supporting more than 17,000 volunteer community health champions in Yorkshire. The approach is said to provide a positive return on investment for every £1 invested.¹⁷

Local Area Co-ordination (Section 2 and 5)

Local Area Co-ordination (LAC) started in Western Australia in 1988. It is now used to support social care in most Australian states and has been successfully adopted in Scotland, Ireland, New Zealand, Canada and now England, starting in Middlesbrough and Derby, as an approach to early intervention and prevention.¹⁸ Local area co-ordinators are generalists who support practical, creative and informal ways of meeting people's aspirations and needs, increasing the control and range of choices for individuals, their carers and families whilst contributing to systems and structure reform. LAC activities focus on supporting vulnerable people including those with a disability, mental health need, sensory impairment and older people, their carers and families to build a vision for a good life that is individual to them, and to build family, relationship and community networks. LAC operates at individual, family and community levels and can help individuals, their carers and families to plan, select and receive a range of support and services to achieve their vision for a good life,

¹⁶ www.altogetherbetter.org.uk

¹⁷ N. Hex and S. Tatlock (2011), *Altogether Better Social Return on Investment Case Studies*. York Health Economics Consortium.

¹⁸ Ralph Broad (2012), *Local Area Co-ordination*, Centre for Welfare Reform, Sheffield.

enormously increasing the flexibility of services and providing users with much broader choices.

Micro-provider support (Nottinghamshire County Council) (Section 2)

The micro-provider market in Nottinghamshire has been stimulated by two things: the appointment of a dedicated micro-provider support function, and the growth of personalisation within the county, including the many people who are being offered personal budgets and direct payments.¹⁹ Micro-providers usually have between two and five staff, and offer highly personalised and flexible support, often based around developing low level preventative support, helping people stay independent, promoting active citizenship, and social inclusion. The Nottinghamshire programme increases the amount of choice people have over how and where to spend their budget, and is being used by hundreds of people across the county, including people who receive direct payments and those who are self-funders. The programme has been hugely successful and, over the past two years, the local authority has had over 180 enquiries from potential micro-providers. As a result, 45 new micro providers are now up and running. Micro-providers offer over 15 different local services and work with well over 600 people who need support to live their life. Local people support other local people, creating jobs and volunteering opportunities and enabling public money to stay circulating in the local economy.²⁰ The enterprises have expanded the variety of support on offer, and include a Friday social club, numerous personal support services that help with things like shopping, house jobs or gardening, and direct payments support and sole traders. The micro-provider support programme was organised by an effective support officer, employed by the charity Community Catalysts, but based at the council. Thirty similar projects, in the local authority areas which most need micro-providers, would cost about £4.3m over two years and might be expected to generate 900-1,350 new micro-care providers nationally.

MySupportBroker (Section 2)

My Support Broker is one of the best-known peer-to-peer brokerages, and providing training and services for independent living.²¹ They train and accredit disabled and older people to be professional peer brokers to help others like themselves to plan, find and manage their healthcare and support services funded, either through state or personal finances. They do this through a social franchise model to achieve national scale and sound financial returns. Their impact is measured by the numbers of disabled people who move from welfare to work and the number of disabled and older people who move from organisations managing their lives to be self managing. So far, a quarter of people they train become self employed brokers.

¹⁹ www.communitycatalysts.co.uk/case-studies/nottinghamshire-county-council/

²⁰ Mike Harris et al (2012), *Doing Services Differently*, New Economics Foundation, London.

²¹ See www.MySupportBroker.com

Navigators (Section 5)

Connected Care (see above) began as a national pilot scheme in the Owton Manor ward, an area of Hartlepool where deprivation has a detrimental effect on residents' health and well-being. What emerged was a service that acknowledges and addresses the multiple and often complex needs of individuals.²² The local workforce of Navigators focus on people's whole needs, support them to find their way through the complicated systems to access integrated, personalised information and services. The work of the Navigators was launched after the findings from the community audit which was carried out by residents from Owton who had been trained to carry out this work. People wanted joined up services so that they did not have to keep telling their story to different access points in the system. People also wanted a local workforce who knew what resources were available in the community and understood the local issues and they wanted to be able to say what outcomes would make a difference for them. The Navigators are able to address the individual's whole needs, encompassing social care, health, employment, housing and education. They work with people to make sure that they have the right advice, information and support to make informed decisions about what is best for them. The service is complemented by a range of preventative and support services.

Online marketplaces (Shop4support) (Section 3)

shop4support is an online marketplace where people can shop for services or equipment using their personal budget or their own money to meet their social care needs.²³ They can search and shop for support products and services, manage their personal budget, receive and share help and advice, and find local groups and activities. People using shop4support make it clear how being in control of their personal budgets through the service can have a profound impact on their confidence and independence, enabling them to participate in social activities, including finding and remaining in employment. shop4support was created when In Control, the national charity and pioneer of self-directed support, came up with the idea of using the internet to help people needing support find and buy care products and services more easily. Its 'Citizen Portal' can be tailored to an individual local authority's needs. shop4support has been appointed as the provider for a regional social care 'e-Marketplace' for the Yorkshire and Humber region.²⁴

Online self-assessment tools (Section 3)

A number of these are now available, including:

- Mysupportbroker.com has developed 'iAssess', which is 'an online tool that helps to model your care and support needs. The tool also identifies the cost of the care and support and if you might be entitled to any state funded support'.²⁵

²² www.thinklocalactpersonal.org.uk

²³ www.shop4support.com

²⁴ Mike Harris et al (2012), *Doing Services Differently*, New Economics Foundation, London.

²⁵ www.mysupportbroker.com/aboutus#contentDiv0

- Kent County Council has an online self-assessment tool.²⁶
- Equip Yourself York (online self-assessment tool, information and advice) has been developed by City of York Council.²⁷
- Wigan Borough Council has been developing an online marketplace linked to the parallel credit system, Wigan Plus.²⁸
- Shropshire council's self-assessment form assesses needs and financial circumstances at the same time, although there is a case to be made that the two should be kept separate.²⁹

Patients Know Best (Section 5)

Patients Know Best is a UK based social enterprise with a software developed to put patients in control of their own medical records.³⁰ It is used in various parts of the UK, including Great Ormond Street, and also now integrates into the NHS Connecting for Health to provide patients with tools to work with clinicians. Founded by Mohammad Al-Ubaydli in 2008, the software allows patients and professionals to exchange information in real time, securely. All medical records on the site are controlled by patients. Others, such as family members or insurance companies, can access them only if the owner gives permission. PKB is experimenting now with extending the idea to other public services, to avoid the complications of sharing data between multiple agencies.

Pooling budgets (Section 3)

Finding ways that people with direct payments can pool budgets so that they go further, and allowing them to do so, are key to extending genuine choice. One project which allows this is RUILs (Richmond Users Independent Living Scheme), an independent user-led organisation based in Richmond Upon Thames which supports social care users to take control over their care.³¹ It includes a service to help people recruit a personal assistant, a direct payment support service, the Richmond Independent Brokerage Service which provides independent advice, information and support brokerage, and a 'buddy scheme' peer support service. RUILS has also set up a guide called 'Pooling Direct Payments - Your ideas, Your Way' and a set of seminars for recipients of direct payments to learn more about pooling their budgets.

²⁶ www.sa.kent.gov.uk/ufs/ufsmain?esessionid=1&formid=SAP&RG=GR1112&esessionid=1

²⁷ www.equip-yourself-york.org.uk/smartassist/york

²⁸ www.wiganplus.com

²⁹ <https://forms.shropshire.gov.uk/cus/servlet/ep.app?type=567155&auth=304&ut=X&web.url.Value=http://shropshire.gov.uk/adultcarer.nsf/open/783A73C56656318C802574E80054DF1F>

³⁰ www.patientsknowbest.com

³¹ www.ruils.co.uk

Pramacare (Section 1 and 2)

Pramacare was founded in Poole to provide help and care for people in their own homes, enabling them to live independently.³² In the 1980s, Dr Chris Moran, a consultant at Christchurch Hospital, witnessed a growing need as he saw patients discharged from hospital care, even though there was no support for them at home. His vision was to provide Pain Relief and Management, from where the name PRAMA originated. Since Pramacare's foundation in 1982, the vision has broadened to include personal care. The organisation has grown from a handful of dedicated volunteers to more than 250 trained care attendants who provide care to around 600 people in Dorset each week. Another 1,300 people regularly use their toenail cutting service. Pramacare is faith-based and non-denominational and also co-ordinates a working group of related organisations across their area.

Preferred supplier lists (ending) (Section 3)

The London Borough of Bexley has 'removed all block contract provision for community based services and [has] concentrated on negotiating terms with providers which people can purchase directly using their personal budget. [...] Bexley report[s] seeing significant improvements both in the market and in people's satisfaction levels. Providers are adjusting to an environment without block-contracts where all support is purchased via a person's personal budget'.³³

Prepaid direct payment cards (Section 3)

Depending on the motives of the local authority, providing direct payments via prepaid cards can increase the freedom, flexibility and choice of those involved. Prepaid cards reduce bureaucracy as individual spending decisions do not need to be authorised in advance, but can be retrospectively monitored, providing accountability and allowing money to be tracked. They also increase access for service users, who do not need to have their own bank account to receive payments. Local authorities that currently offer prepaid cards for direct payments include: Barnet³⁴, Nottinghamshire³⁵, Kent and Enfield³⁶, Plymouth City Council.³⁷ Research by Ticon UK Limited estimates that adopting prepaid cards achieves average administrative savings for Local Authority Adult Social Care departments of 36 per cent.³⁸ A

³² www.pramacare.co.uk

³³ Sam Bennett and Simon Stockton (2011), 'London Joint Improvement Partnership (JIP): Best practice in Direct Payments Support – a guide for commissioners', Joint Improvement Partnership, London Councils, London, 25.

³⁴

http://www.barnet.gov.uk/news/article/128/prepaid_cards_to_give_residents_more_control_over_their_social_care

³⁵ Interview with Nottinghamshire Adult Social Care team

³⁶ Department of Health, 'Putting People First: Personal budgets for older people – making it happen' January 2010

³⁷ http://search3.openobjects.com/mediamanager/plymouth/pod/files/factsheet_prepaid_card.pdf

³⁸ Ticon UK Limited (2010) 'Budgets by Card: How prepaid can transform the delivery of Individual Budgets' http://ticon.uk.com/wp-content/uploads/2011/07/Budgets_by_Card-How-prepaid-can-transform-the-delivery-of-individual-budgets1.pdf

consultancy called OCS365 worked with East Cheshire Council to set up their pre pay card scheme.³⁹

A business case published by the London Borough of Bromley in November 2010 estimated that the net costs to the local authority of administering 800 prepaid cards to recipients of direct payments would be approximately £20,000 for a full year. These costs are almost entirely attributable to the cost of employing an administrator. It was estimated that a further £20,000 of charges would be paid by service users, including a one-off set-up cost (£15 per person) and an annual card-holder charge of £25. These charges would be deducted from the individual's direct payment.⁴⁰

A November 2011 report by the London Joint Improvement Partnership for London Councils observes that, in some cases, councils have used pre-payment cards in a restrictive way to limit the use of direct payments (for example 'restrict[ing] the user to purchasing services from a discreet [*sic*] set of providers'⁴¹). Such practices are wholly inappropriate and undermine the spirit and purpose of direct payments: to increase choice and control for the end-user.

Social enterprise providers (Care Plus) (Section 2 and 3)

Care Plus is a social business, based in Grimsby and working in communities across Northern Lincolnshire, providing adult health and social care services to people.⁴² Formed in 2011, Care Plus employs over 750 members of staff providing a wide range of community services. Any profit they make is invested back into the development and delivery of health and care services to make sure they can evolve and develop the services they offer. Services include community nursing, transport, employability services, palliative and end of life care services, community learning disability services, sexual health services, specialist nursing (including continence, diabetes, infection control, tissue viability etc.), intermediate care at home, substance misuse services, falls and chronic obstructive pulmonary disease (COPD), collaborative and community psychology service.

Time banks (Section 5)

Time banking is a pattern of reciprocal service exchange that uses units of time as a kind of credit system.⁴³ The credit unit is always valued at an hour's worth of any person's efforts to provide incentives and rewards for work such as mentoring children, caring for the elderly,

³⁹ Bennett and Stockton (2011), 20.

⁴⁰ London Borough of Bromley, Adult and Community Portfolio Holder for pre-decision scrutiny by Adult & Community Policy Development & Scrutiny Committee (2010), 'Pre-paid cards for direct payment recipients', Nov.

<http://cds.bromley.gov.uk/documents/s5170/ACS%20PDS%20021110%20Pre%20Paid%20Cards%20for%20Direct.pdf>

⁴¹ Bennett and Stockton (2011), 20.

⁴² www.careplusgroup.org

⁴³ See www.timebanking.org.uk and www.justaddspice.org.

being neighbourly—work usually done on a volunteer basis—which a pure market system finds hard to value. There are now more than 250 time banks in the UK, many of them embedded in public services, allowing them to broaden the kind of services they can offer, with a proven record of involving those hard to reach who do not usually get involved in formal volunteering. As well as earning credits, participants – particularly those more used to being recipients in other parts of their lives – can potentially gain confidence, social contact and skills through giving to others. The time banks at Rushey Green and Paxton Green group practices have demonstrated how time banking might work in health settings.⁴⁴

⁴⁴ www.rgtb.org.uk

Appendix G

Evidence review and literature search

PURPOSE AND METHODS

This paper presents a summary of available recent evidence on people's experiences of choice, and in particular the practical barriers to the exercise of choice in schools, healthcare, and social care. Excluded from this synthesis is the expansive evidence on the impact of choice on competition, management, service quality, access, and wider welfare effects – although these are clearly important and well researched questions.

The published evidence informing this paper was identified by a mix of a systematic review, review team identification, and informal consultation with analysts across government and academia. It also considered some unpublished evidence synopses from the Department for Education and Skills (DfES) and the Department of Health (DH).

The evidence comprised a variety of methodologies, from the randomised trial evaluation data of the Individual Budget pilots, through service user surveys, to theoretical and discursive analyses of participation and co-production. The most relevant evidence in terms of practical barriers tends to come from user and practitioner surveys.

This paper is structured to try to reflect the more salient issues in the different public service areas.

The theory of choice

There are many different theories in the social sciences and neuroscience about how decisions are made. As noted above, the majority of the evidence considered here investigates users' perceived and recollected experiences of choice, and is often agnostic on the underlying theory. This evidence review therefore doesn't take a stance on the different theories of choice.

It is however important to recognise the drawbacks of self-reported survey data – namely partial or total recall loss, misinterpretation, and the conscious or sub-conscious giving of a false impression. The brevity of this summary precludes this kind of assessment for all the literature referred to here.

CHOICE IN HEALTHCARE

Introduction

There are two key sources of evidence for understanding the practical barriers to choice of hospital; the 'Patient Choice' report by the Kings Fund (2010)⁴⁵, and a systematic literature review for DH by Jones and Mays (2009)⁴⁶. The section below highlights the key findings of these and other studies that are most relevant to this review.

The extent, value and equity of choice

In Patient Choice, as of September 2009, 45% of patients said they knew before visiting their GP that they had the right to choose a hospital. This is broadly consistent with the more recent (February 2010) figure of 54% from the NHS monitoring survey, the National Patient Choice Survey (NPCS)⁴⁷.

In both surveys, just under half of patients recall being offered a choice (and just 8% of these patients remember being offered non-NHS provider options). NPCS suggests that this proportion was up from 47% in March 2009, and 30% in May/June 2006.

Patient Choice found that age, level of education, ethnicity and employment status were *not* found to be significant predictors of whether or not the patient recalled being offered a choice.

75% of respondents said choice was either 'very important' or 'important' to them (in the British Attitudes Survey 2009⁴⁸ a corresponding figure was even higher at 95%). Older respondents, those with no qualifications, and those from a mixed and non-white background were more likely to value choice. According to the Patient Choice authors, 'the results show there is some intrinsic value in offering patients a choice of provider, and that GPs' perceptions that it is younger, more educated patients who want choice are misguided'.

Jones and Mays (2009) draw conclusions from the evaluations of the London Patient Choice Project 2002-2004. They find that the majority of patients (57-67%) when given a choice took the offer of quicker treatment at an alternative hospital. The offer of choice did not appear to be influenced by socio-economic status or ethnicity.

Evidence on how people choose, and what factors constrain choice

Choice Criteria and Influences

In terms of how people choose, Patient Choice finds that patients make little use of available information, and rely on personal experience and their GP. Quality is important to patients when choosing (cleanliness, quality of care and standard of facilities being rated as

⁴⁵ Dixon et al (2010) – 'Patient Choice: How Patients Choose and How Providers Respond'

⁴⁶ Jones and Mays (2009) – 'The impact of patient choice of provider in the English NHS'

⁴⁷ Department of Health (Feb 2010) – 'Report on the National Patient Choice Survey, England'

⁴⁸ British Social Attitudes 25th Report (2009), Natcen, <http://www.natcen.ac.uk/study/british-social-attitudes-25th-report/>

the three highest reported factors). However, the NPCS offers a contrasting finding⁴⁹ that for those who were offered a choice, a hospital close to home or work was selected most often as the single most important factor (by 38% of patients offered choice) when choosing their hospital, whilst quality of care was only rated the most important factor by 5% of respondents.

According to Patient Choice, of those offered a choice, 69% chose their local provider, and providers and GPs described their patients as loyal to their local trust and reluctant to consider travelling further for treatment. They suggest that between 5 and 14% more patients travel beyond their local or nearest hospital when choice is offered. This implies there may be a significant difference between the factors people report as important, and the factors that in fact dominate their decision.

Previous surveys also found that location and accessibility were most frequently mentioned. Research by the National Consumer Council (2003)⁵⁰ suggests that users' preference is for quality local services in the first instance, followed by choice to move elsewhere if that service is inadequate.

Multivariate analysis in Patient Choice suggested that patients with previous bad experience of a local hospital are more likely to travel to a non-local hospital, as are those with higher levels of education, those who live outside of cities and large towns (contrary to the perceptions of GPs), and older people. Those who normally do not travel by car were more likely to select their local trust irrespective of performance or other attributes under hypothetical conditions. Gender and ethnicity had no impact (though the study could not assess whether difficulties speaking English was a significant determinant).

The Role of GPs

Jones and Mays (2009) identify the role of GPs as important in aiding choice. For example, data from the National Patient Choice Survey 2008⁵¹ revealed that 49% of people who were offered choice of hospital used their GP as source of information to choose and in the Coulter et al. study (2005) 67% of patients preferred to receive information about choice from their GP.

In a qualitative study of GPs' views and experiences of patient choice, Rosen et al. (2007)⁵² found that GPs varied in the extent to which they actively supported patient choice. Some GPs in inner cities had always offered their patients a choice of hospital. However, in towns with a single local hospital, there was a strong feeling that the difficulties of travelling to distant providers would limit the extent to which patients would choose any hospital other than the local one, and that maintaining a good local hospital was seen as essential for patients who could not or did not want to travel.

Similarly, qualitative interviews with GPs and providers in Patient Choice offered some insights into how choice is perceived and facilitated by professionals. Whilst most GPs

⁴⁹ Although direct comparisons are not possible because of different methodologies. Patient Choice allowed respondents to score different factors, whereas NPCS only asked respondents to nominate the most important.

⁵⁰ National Consumer Council (2003) – 'Expectations of public services: consumer concerns'

⁵¹ Department of Health (September 2008) 'Report on the National Patient Choice Survey, England'

⁵² Rosen, R., Florin, D. and Hutt, R. (2007) – 'An Anatomy of GP Referral Decisions'. London: Kings Fund

supported choice in principle, there was a perception that relatively few patients want to make a choice beyond their local hospital. GPs expressed concerns about access to reliable information on hospital quality, and also felt they only had limited time to support choice. Many GPs expressed more specific concerns about Choose and Book; the amount of additional time it takes to offer choice and the difficulty of getting certain services through this system.

In light of the above evidence, the Department of Health conclude (in the Impact Assessment ‘Liberating the NHS: No decision about me, without me’⁵³) that attitudes appear to be ‘broadly positive, or ambivalent at worst, but that patients will have to be demanding and look to hold providers to account. Healthcare professionals will need to facilitate patients’ involvement in decisions about their healthcare and support patients seeking reassurance about those decisions.’

A review⁵⁴ of the operation of ‘Any Willing Provider’ went further than above. They highlight many examples of PCTs excessively constraining patients’ ability to choose, and providers’ ability to offer routine elective care services. PCTs that constrain patients’ ability to choose their routine elective care provider most frequently do so through influencing GP referral decisions, and in some cases, directing GPs to refer patients or (or away from) certain providers. The Panel’s view is that there is a serious risk that unless practices that appear endemic among certain commissioners are addressed, the expected results from the policy of Any Willing Provider, including higher quality services and better value for money, are not going to be realised to their full potential.

The Constraints on Choice

According to the NPCS, 88% of patients offered choice were able to go to the hospital they wanted, with a further 5% having no preference. This compares with 47% of patients who weren’t offered choice being able to go where they wanted, suggesting that patients’ making a choice generally translated into going to a preferred hospital.

Fotaki et al. (2005)⁵⁵ highlight 5 key messages that emerged from their review of papers on information, communication, and relationships. These were:

- patients are not fully informed;
- patients want information more than responsibility for decision-making about their treatment or care;
- patients’ and health care professionals’ perceptions of decision-making and information of professionals vary from the reality;
- what patients and health care professionals want from their relationships differs;
- there is a need to improve efforts of information gathering and communication.

⁵³ http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_134221

⁵⁴ Cooperation and Competition Panel (2011) – ‘Review of the operation of “Any Willing Provider” for the provision of routine elective care’. Final report (2011)

⁵⁵ Fotaki, M., Boyd, A., McDonald, R., Smith, L., Roland, M, Edwards, A, Elwyn, G, Sheaff, R. 2005. Patient Choice and the Organisation and Delivery of Health Services: Scoping Review. NCCSDO, Manchester Business School.

All GPs were concerned about the constraints of geography and transport. GPs also felt that language and ability to understand complex information were potential barriers to choice. Ferlie et al. (2005)⁵⁶ found that poor information flow and weak IT systems were identified as key barriers to organisational change in the London Choice pilots. Coulter et al. study (2005) found many of the patients who declined the option to move to an alternative provider said they had not been given enough information to decide. This raises the issue of equity of access to information; however there was no evidence available for the review to consider this.

The support received from patient care advisors was highly regarded by patients. Their involvement in supporting patients through the process, helping them to make a decision, and coordinating arrangements between the hospitals was especially valued by those who opted to go to an alternative hospital.

⁵⁶ Ferlie, E., Freeman, G., McDonnell, J., Pestoulas, C. and Rundle-Smith, S. (2005) – ‘NHS London Patient Choice Project Evaluation’

SCHOOL CHOICE

The extent and equity of choice

Allen (2007)⁵⁷ claims that approximately half of pupils do not attend their nearest school, although much of this can be attributed to the shape of catchment areas and the presence of grammar and Voluntary Aided schools. The mobility between non-faith comprehensives is likely to involve about 1 in 5 pupils. This proportion rises to 34% for London pupils.

According to Coldron et al. (2008)⁵⁸ parents who chose not to apply to their nearest school were more likely to live in areas with high population density or where admissions appeals were relatively high; they were more likely to actively practice religion; to have taken account of secondary school catchment areas when they last moved and more likely to have taken special actions e.g. coaching, extra tuition to maximise their chances of success.

Evidence on how people choose, and what factors constrain choice

Choice Criteria and Influences

The most recent and most nationally representative data on parents' and carers' perspectives on school choice come from a survey of secondary school admissions by Coldron et al. (2008). This was based on admissions to secondary schools in 2006 and compared findings to an earlier study in 2000. The factors which parents reported to be most influential were the school's reputation/Ofsted reports, the school's exam results, child's preference, and having a sibling already attending the school (table 1).

Table1: Reasons for parents wanting a place at their preferred school

Reasons	%
School has good reputation in the community/ good Ofsted report	40
School has good exam results	33
Child wanted to go there	31
Sibling goes there	28
Facilities are good	22
Friends are going there	20
It's the local school	20
School has good discipline/ behaviour	19
Other characteristics of school particularly liked e.g. mixed, size...	13
Pupil social characteristics	10
Religious reasons	6
Subject specialisms	5
Convenient to get to / distance from home	5
Had previous positive experience of the school	5
General – best school for the child	4

⁵⁷ Allen et al (2010) – 'Choosing secondary school by moving house: school quality and the formation of neighbourhoods'

⁵⁸ Coldron, J., Tanner, E., Finch, S., Shipton, L., Wolstenholme, C., Willis, B., Demack, S. and Stiehl, B. (2008) Secondary School Admissions. DCSF Research Report 020

Other child-related reasons e.g. SEN	3
Other	3
Unweighted N	1487

Source: Coldron et al. (2008) Base: respondents who applied to more than one school. Multiple responses were allowed.

One quarter of parents did not apply to their nearest maintained school. The main reasons cited were poor reputation, poor exam results and problems with behaviour/ discipline, child's preference, and siblings attending other schools.

Previous quantitative research by Flatley et al. (2001)⁵⁹ similarly found that academic outcomes, sibling attendance, distance, child preference, discipline and religious status were important considerations for parents and carers. They found differences between different groups of parents; academic outcomes were more likely to be cited as important influences on choice by owner occupiers, mothers from minority ethnic groups, mothers from higher social classes, and parents resident in London boroughs.

Also in terms of *stated* preferences, Burgess et al. (2009)⁶⁰ suggests that parents who are more educated and of higher socio-economic status are more likely to say that they value academic standards above other factors; and parents who are less educated and of lower socio-economic status are more likely to cite the school's proximity to their home as the key factor. They also consider *revealed* preferences i.e. their actual choice of school, relative to those available to them. Differences in location drive differential access to higher performing schools across socio-economic groups (e.g. poorer parents are likely to live much closer to schools with higher proportions of children eligible for free school meals). Taking account of this restricted choice, the study finds that richer and poorer parents actually have similar preferences across school characteristics. Therefore the authors suggest that it is differences in location rather than preferences that drive differential assignment across schools.

In a large-scale survey of 3000 parents and carers living in London, Wiseman and Dent (2005)⁶¹ reported that the factors rated as most important when choosing a secondary school were their child's happiness, the quality of teaching, school security and child safety, and the behaviour of other children in the school. Coldron et al. note that London has particular characteristics, such as a dense and ethnically diverse population, larger numbers of schools within travel distance, and public transport which makes travelling to a more distant school easier. This means that the London-based findings are not generalisable to the rest of the country.

⁵⁹ Flatley, J., Connolly, H. and Higgins, V. (2001) – 'Parents' experiences of the process of choosing a secondary school'. DfES Research Report 278

⁶⁰ Burgess et al (2009) 'What parents want: school preferences and school choice'. CMPO Working Paper No.09/222

⁶¹ Wiseman, J. and Dent, R. (2005) London Challenge: Third Survey of Parents and Carers 2005. DfES Research Report 698

Information Sources

The national survey by Coldron et al. (2008) gathered data on the sources of information which parents and carers reported using when selecting a secondary school. Parents and carers used both formal sources of information (table 5) and informal sources of information (table 6).

Table 2: Formal sources of information used by parents

Formal sources of information	Proportion of parents and carers reporting using this source	Proportion of parents and carers who rated this source as very useful
School prospectuses or	59%	43%
Local authority booklets	44%	37%
School achievement and	44%	35%
Ofsted inspection reports	29%	41%
School websites	25%	25%
None of the above	18%	n/a

Source: Coldron et al. (2008)

Table 3: Informal sources of information used by parents

Informal sources of information	Proportion of parents and carers reporting using this source	Proportion of parents and carers who rated this source as very useful
School visits	71%	77%
Talking to other parents,	57%	51%
Talking to primary school	41%	57%
Newspaper articles	17%	33%
Talks to other professionals	9%	76%
Other	2%	n/a
None of the above	13%	n/a

Source: Coldron et al. (2008)

Less affluent and less educated parents accessed fewer sources of information. Multivariate analysis suggested that mothers with degree level qualifications and those in employment were more likely to use formal information sources. Similarly, mothers with degree level qualifications and owner occupier parents were more likely to make use of informal information sources (not purely as a substitute).

The survey of London parents and carers by Wiseman and Dent (2005) similarly asked respondents about the sources of information which influenced or were likely to influence their choice of school. The most influential factors for London parents and carers were open days, and information from schools and teachers, whilst the least influential were reports in the local media, and information (written or online) from the government.

Preference Satisfaction

Burgess et al. (2006)⁶² estimate the proportion of students who have at least 3 schools within 2km, 5km and 8km of their home. They conclude that most pupils do have considerable choice of schools (so defined).

According to Coldron et al. (2008), satisfaction with the process was generally high – over 90% were satisfied with the overall provision of information; 43% were very satisfied and 38% were fairly satisfied with the choice of schools locally (with satisfaction lower in London).

In terms of the outcome of admissions, the same study finds that 97% of respondents received an offer for their child in early March. In 2006, about 85% of parents gained their first expressed preference and 93% gained either their first or second preference. Fewer parents in London gained their first preference – 70% gaining their first and about 82% gaining their first or second. They reported that four factors were associated with parents being offered their preferred school: applying for only one school; applying in a LA where first preference was the dominant preference system⁶³; having already got an older sibling in the school; and being white. They found no association between the chances of gaining first choice of school and the socio-economic status of parents. This suggests that different groups of parents seek different things from their secondary school or that parents are responding realistically to their chances of gaining entry to certain schools, or both.

Two studies looked specifically at choice amongst different groups. Bagley et al. (2001)⁶⁴ provide empirically-based insights into the preferences, perceptions and responses of parents of children with special educational needs, finding a range and depth of difficulties in exercising choice. Byrne et al. (2012)⁶⁵, based on qualitative research in Greater Manchester, examines the experience of migrants in choosing a secondary school and find that migrants often face particular barriers in negotiating the school system.

Burgess and Briggs (2006)⁶⁶ estimate the chances of poor and non-poor pupils (proxied by free school meals) getting places in schools in the top-third of performance tables. They find that children from poor families are significantly less likely to go to good schools, but much of this due to where they live in the Local Education Authority. Following on from this study, Burgess et al. (2011)⁶⁷ argue that the large differences in the range of schools genuinely available to different families, coupled with the use of proximity as a tie-break device, continues to be a significant barrier to reducing inequality of access in the English school system.

⁶² Burgess, S., Briggs, A., McConnell, B. and Slater, H. (2006), 'School Choice in England: Background Facts'. CMPO Working Paper 159

⁶³ This method of allocation does not exist anymore

⁶⁴ Bagley, C., Woods, P.A. and Woods, G. - 'Implementation of School Choice Policy: Interpretation and Response by Parents of Students with Special Educational Needs', *British Educational Research Journal* 27(3): 287-311. 2001

⁶⁵ Bridget Byrne and Carla De Tona. – 'Trying to Find the Extra Choices': Migrant Parents and Secondary School Choice in Greater Manchester. *British Journal of Sociology of Education*; v33 n1 p21-39 2012:-39 2012

⁶⁶ Burgess, S. and Briggs, A. (2006) – 'School Assignment, School Choice and Social Mobility'. CMPO Working Paper 157.

⁶⁷ Simon Burgess, Ellen Greaves, Anna Vignoles, and Deborah Wilson – 'Parental choice of primary school in England: what types of school do different types of family really have available to them'. *Policy Studies* no. 5 (pp. 531-547), /3.2011

SOCIAL CARE

Introduction

There has been a huge drive towards the personalisation of social care in recent years, with the advent of support planning, direct payments, and individualised budgets. Evidence on choice in social care therefore largely comes from process and impact evaluations of these policy initiatives.

The extent and equity of personalisation

The ADASS Personal Budgets Survey⁶⁸ suggested that in March 2012, the percentage of eligible people in receipt of a personal budget was 52.8%.

The National Personal Budget Survey (POET survey)⁶⁹ found that 87% of personal budget holders felt that their views were very much or mostly included in the support plan. There was little variation in this proportion between different social care need groups (younger adults with a physical disability, younger adults with mental health conditions, younger adults with learning disabilities, and older adults). The corresponding proportion for carers was a little lower at 75%.

Similarly, the Community Care 2012 Survey⁷⁰ found that 76% of social care workers surveyed either agreed or strongly agreed that direct payments offer service users greater choice than traditionally commissioned care packages. 54% agreed or strongly agreed that managed personal budgets offer greater choice than traditional packages.

According to POET, 72% of budget holders felt that personal budgets had a positive impact on their being able to control their support. This varied a little between groups, with younger people with a learning disability being most positive and older people being the least. A multivariate analysis of the results found that information and awareness, personal rather than council management, council support facilitating the process, and non-council help in planning appeared to be associated with greater reported empowerment through personal budgets. This analysis again suggested that older people felt less empowered by personal budgets.

These findings appear to echo the findings of the earlier Individual Budgets (IB) pilots⁷¹, where randomised trial data suggested that the IB group were significantly more likely to report feeling in control of their daily lives, the support they accessed and how it was delivered. When controlling for individual characteristics as well as for whether a support plan had yet been agreed, they found that holding an IB was associated with better overall social care outcomes and higher perceived levels of control, but not with overall psychological well-being.

⁶⁸ Association of Directors of Adult Social Services (2012) – Personal Budgets Survey

⁶⁹ Hatton, C. and Waters, J. (2011) – The National Personal Budget Survey

⁷⁰ Community Care – The State of Personalisation 2012 <http://www.communitycare.co.uk/the-state-of-personalisation-2012/>

⁷¹ Individual Budgets Evaluation Network (2008) – The National Evaluation of the Individual Budgets Pilot Programme

Challenges to personalisation

Appetite for Choice and Take up

From the IB pilot evaluation, qualitative interviews with service users indicated that many older people supported by adult services did not appear to want what many of them described as ‘the additional burden’ of planning and managing their own support. This was corroborated by interviews with providers, care co-ordinators and others.

Qualitative research by Ipsos MORI⁷² for the National Audit Office, suggested that aspirations for choice varied significantly among budget holders. Some had no desire for choice - they were satisfied with the care they (or the family member they cared for) were getting or just wanted to get good care rather than choice. Other participants welcome having some choice over their care arrangements, but many did not want the responsibility of organising and coordinating their own care. Finally, some personal budget holders wanted to be in complete control of all aspects of their care, usually in an attempt to get better care and support.

They also found that participants’ awareness of personal budgets varied greatly, between local authorities as well as within local authorities. In particular, participants living in local authorities who were more advanced with personalisation tended to be more aware of what personal budgets were about than participants from other local authorities.

The lack of awareness extends to switching care providers, according to Ipsos MORI (2012). Further, they found that some budget holders were not completely satisfied with their care but were reluctant to switch because they either didn’t want to ‘cause a fuss’ or because they feared they could end up with a worse provider.

Council Support

The POET study found that only between 50-59% of respondents felt that councils made it easy or very easy to get information and advice, assess the person’s needs, understand what a personal budget could be spent on, be in control of what the personal budget was spent on, and plan and manage the person’s support.

Overall, fewer respondents (between 37% and 46%) felt that the council had made it easy or very easy for people to change their support, choose the best option from a range of services, or voice their opinions or complain. Overall, substantial numbers of people (between 13% and 24%) reported that councils had made it difficult or very difficult in each aspect of the personal budgets process.

The Community Care Survey suggested that, ‘in terms of whether respondents felt councils were doing enough to support service users, there was a large amount of divergence between different service user groups’. For example, 44% thought that the council was doing enough to support older people, compared with 9% for problem drug/alcohol users and 5% for homeless people. Excluding ‘don’t knows’, the proportions of positive responses were 54%, 23% and 14% respectively.

⁷² Ipsos MORI (2011) – Users of Social Care Personal Budgets

Other Support

The process of making significant choices was shared between young people and parents, something which was welcomed by both parties, according to SPRU (2011)⁷³.

In a narrative review of the international literature on 'cash-for-care' schemes, SPRU (2008a)⁷⁴ argues that family carers and networks of friends and contacts have been shown to be important in assisting with the recruitment and employment of Personal Assistants (PAs); similarly, carers and relatives can assist recipients to organise and manage viable care packages (Dawson, 2000⁷⁵; Yoshida et al., 2004⁷⁶). For people with significant impairments, cash-for-care schemes require the involvement of other people, such as family carers or advocacy workers, to manage the budget and their PA (Doty et al., 1996⁷⁷). However, carers and other family members themselves need information about cash-for-care schemes and related support services in order for them to exercise this role (Freedman and Boyer, 1999⁷⁸).

Bureaucracy and the costs of choice

The Community Care Survey (2012) found that two thirds of care workers thought that the paperwork for assessments is too complicated for service users to complete themselves. Only 5% strongly agree (and 18% agree) that they feel they have enough time with service users to effectively support self-assessment.

SPRU (2011) found that the process of making choices creates some positive but mainly negative emotions. Negative emotions can lead to delays in making choices, thus also delaying any resulting benefits.

The additional bureaucracy associated with employing a personal assistant was highlighted as a barrier to uptake in SPRU (2008a).

The Role of Care Workers

The Community Care Survey found that 'there is still a significant skills and knowledge gap between what professionals perceive they need to deal with personalisation and what they possess'. 88% of respondents thought that knowledge of locally available care and support services was needed, whereas only 66% felt they possessed that knowledge. The skills gap

⁷³ SPRU (2011) – Choice and Change Series

⁷⁴ Arksey, H. and Kemp, P. (2008) – 'Dimensions of Choice: A Narrative Review of Cash-for-Care Schemes'

⁷⁵ Dawson, C. (2000) – 'Independent Successes: Implementing direct payments'. York: Joseph Rowntree Foundation.

⁷⁶ Yoshida, K., Willi, V., Parker, I. and Locker, D. (2004)- 'The emergence of self-managed attendant services in Ontario: an independent living model for Canadians requiring attendant services'. *Research in the Sociology of Health Care*, 22, 177-204.

⁷⁷ Doty, P., Kasper, J. and Litvak, S. (1996) – 'Consumer-directed models of personal care: lessons from Medicaid'. *The Milbank Quarterly*, 74, 3, 377-409

⁷⁸ Freedman, R.I. and Boyer, N.C. (1999) – 'The power to choose: supports for families caring for individuals with developmental disabilities'. *Health and Social Work*, 25, 1, 59-68.

appeared most severe for brokerage skills, where 65% thought they were required, but only 37% possessed the skills.

According to SPRU (2008a), social care professionals play a pivotal role in determining whether or not potential cash payments recipients are provided with accessible, up-to-date information. However, there is considerable research indicating that key front-line staff themselves have limited understanding, knowledge and awareness of cash payments (Clark et al., 2004⁷⁹; Priestley et al., 2006⁸⁰; Fernandez et al., 2007⁸¹). As a result, social care practitioners may lack knowledge, expertise and confidence in offering cash-for-care payments.

According to the Social Care Institute for Excellence⁸², 'A number of authors on co-production warn that professionals may be resistant, unless co-production is associated with an increase of resources rather than a threat to status'. They suggest there's a strong argument for that frontline staff are central to the delivery of co-produced services and also should be empowered, citing Boyle (2006)⁸³ – 'staff morale is as important as client morale – in practice, the participation that they are asked to extend to clients is often not extended to them.'

Information

The Social Policy Research Unit (2008b)⁸⁴ drew on a previous scoping review to highlight the importance of accessible and high-quality information as a pre-condition for informed choice in social care. However, anecdotal and informal sources of information such as friends' and families' experiences often weigh more heavily in people's decision-making than official, non-biased information based on more wide-ranging surveys (Schwartz 2004⁸⁵, Rosen et al. 2005⁸⁶).

A more nuanced point from the report is that the need for information may actually exacerbate existing inequalities in choice as 'those people who have the most cognitive and material resources use these assets to find relevant information to support choice and thus

⁷⁹ Clark, H., Hough, H. and Macfarlane, A. (2004) 'It Pays Dividends!': Direct Payments and Older People, Bristol: Policy Press.

⁸⁰ Priestley, M., Jolly, D., Pearson, C., Riddell, S., Barnes, C. and Mercer, G. (2006) Direct payments and disabled people in the UK: supply, demand and devolution, *British Journal of Social Work*, advance access, published 19 July 2006.

⁸¹ Fernandez, J-L., Kendall, J., Davey, V. and Knapp, M. (2007) Direct payments in England: factors linked to variations in local provision, *Journal of Social Policy*, 36, 1, 97-121.

⁸² Needham, Dr C., and Carr, S. (2009) - Co-production: an emerging evidence base for adult social care transformation

⁸³ Boyle, D. et al. (2006a) Hidden work: co-production by people outside paid employment, York: Joseph Rowntree Foundation

⁸⁴ Baxter, K., Glendinning, C., Clarke, S. (2008) - Making informed choices in social care: the importance of accessible information

⁸⁵ Schwartz B. (2004) – 'The Paradox of Choice. Why More is Less'. Harper Collins, New York

⁸⁶ Rosen R., Curry N. & Florin D. (2005) – 'Public Views on Choices in Health and Health Care. A Qualitative Study'. King's Fund, London.

increase their inherent advantage' (Corrigan 2005⁸⁷, Rogers & Mead 2004⁸⁸, Lent & Arend 2004⁸⁹).

The main themes identified from the project summaries in SPRU (2008b) were that information should be in an appropriate format; targeted at particular people at particular times; easy to locate; personalised; and of high quality. This finding is reinforced by a later SPRU qualitative longitudinal study⁹⁰ focused on disabled adults and older people, and disabled young people with degenerative conditions and their parents.

The Ipsos MORI (2012) research found that the quality of information available to help budget holders make an informed decision about providers varied. Importantly, participants were largely unaware of the providers available locally, and their main source of information was word of mouth - getting recommendations from friends or family, from a social worker or from the council. Many did not have access to the internet, relied on someone else to look up on the internet for information, or were too busy caring to have time to look for information on the web. Beyond contact details of providers and the services on offer, participants wanted to be able to see information on the quality of services provided, and ideally feedback from other users.

Local Availability

Ipsos MORI (2012) also highlighted some issues in terms of the ability to choose from local alternatives. Whilst there were no reported shortages of care agencies to choose from, some concerns were raised about the quality of the service provided. Professionals highlighted a number of concerns regarding the availability of providers in their area. In particular there was an issue with the availability of services that allowed budget holders to be creative with their personal budgets, or to receive overnight or out-of-hour personal care. Finding accessible facilities for independent activities was also problematic in rural areas.

Similarly, SPRU (2008a) found that there can be problems in recruiting personal assistants with the right skills, characteristics or qualities to 'match' the disabled or older person (Glendinning et al., 2000⁹¹; Witcher et al., 2000⁹²; Kremer, 2006⁹³; Poole, 2006⁹⁴).

⁸⁷ Corrigan P. (2005) Registering Choice: How Primary Care Should Change to Meet Patient Needs. The Social Market Foundation, London.

⁸⁸ Rogers A. & Mead N. (2004) More than technology and access: primary care patients' views on the use and non-use of health information in the Internet age. *Health and Social Care in the Community* 12, 102-110

⁸⁹ Lent A. & Arend N. (2004) Making Choices. How Can Choice Improve Local Public Services? New Local Government Network, London

⁹⁰ SPRU (2011) – Choice and Change Series

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Appendix H

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