



# **LONDON SELF DIRECTED SUPPORT FORUM**

*CARE ACTions speak louder than words*

Conference 5 June 2015

**Report by Alison Giraud-Saunders**

# CONFERENCE SPEAKERS

**Pat Stack**, Chair of the London Self Directed Support Forum

**Tim Gollins**, lead on self directed support and personal budget work streams, Think Local Act Personal

**Robin Murray-Neill**, independent adviser

**Smriti Singh**, London personal health budgets lead, NHS England

**Luke Clements**, Cerebra Professor of Law at Cardiff University

**Sharon Allen**, Chief Executive, Skills for Care

**Tracy Jannaway**, Director, Independent Living Alternatives

**Belinda Schwehr**, Care and Health Law

**Toby Williamson**, Head of Development & Later Life, Mental Health Foundation

**Peter Gay**, freelance adviser and London Self Directed Support Forum board member

**Peter Beresford OBE**, Professor of Social Policy at Brunel University and Chair, Shaping Our Lives

## Acknowledgements

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# CHAIR'S FOREWORD

On the 5th of June 2015 The London Self Directed Support Forum held a conference to discuss the impact of the Care Act on the Personalisation Agenda in both social and health care.

We decided to call the conference because the impact of the new Care Act on all aspects of Social Care will be profound. Given personal budgets, and within them Direct Payments continue to be the favoured choice for delivering care by the Government and local authorities it is important to judge the Act's impact on the process.

There is always a danger when new developments come along that they are enthusiastically championed by their supporters, and savaged by their critics, and most conferences are organised either by the champions or the critics. We felt that being comprised of practitioners working in the closest proximity to the field of Self Directed Support the Forum was well placed to deliver a balanced event.

As practitioners the reality experienced is often more nuanced than either view, new developments often bring both new opportunities, but also new difficulties. Often things that seem problematic are successfully ironed out in practice, whereas proposals that look great on paper end up having unforeseen consequences.

The practitioner needs to hear honest assessments, the improvements and the problems. Pollyanna type enthusiasm that neglects the difficulties can frustrate the practitioner, and indeed make them feel that any shortcomings are theirs rather than systematic. Total negativity often leads the practitioner to feelings of inertia; if it's all rubbish what's the point, what can we do.

We therefore sought to highlight the opportunities and the difficulties arising from the Care Act so that enthusiasts, doubters, sceptics, champions and critics could come together to raise questions, concerns, hopes and fears, and make suggestions and contributions to the process.



Pat Stack

The conference enjoyed the participation of a wide spectrum of speakers, panelists and participants. The debate was often lively and frank, and the input of the speakers hugely informative.

Although made up of practitioners, the ethos of the Forum has always been that what concerns us most is the impact of change not on our work, but on the lives of service users. In these harsh economic times when both health care and social care in particular are desperately short of funds, change will always be met with caution, and change for the good is often harder to implement than talk about.

The Forum remains committed to being a champion for everything that promotes the choice, independence and control of all older and disabled people and mental health service users.

As an organisation organised entirely on a voluntary basis we are very proud of the day we put on, but it goes without saying that we could not have done so without the help of others.

Firstly a big thank you to all our speakers. Also to Scope for the use of their excellent facilities. And grateful thanks to our sponsors Premier Care and PayPacket.

Lastly I would like to thank Lloyd Wylde who gave coherence and structure to the many, ever altering decisions the Forum committee made.

I hope you find this report, skilfully put together by Alison Giraud-Saunders, a useful tool in the days ahead as we continue to strive to ensure that social and health care is nothing without independent living, and independent living is often only possible with the input of a social care system that constantly strives to provide service users with not just dignity and compassion, but also with choice and control.

## About the Forum

Active for nearly 20 years, since direct payments began, the London Self-Directed Support Forum is a network for workers who deal with frontline issues in social and health care. We represent the value of practical experience.

### Our aims are:

- To spread and share best practice among England's and primarily London's direct payment support services, support planners, brokers

and self-directed support staff in local authorities and clinical commissioning groups as well as in the voluntary and independent sectors.

- To support the take-up of self-directed support throughout London and nationally by encouraging and developing professional excellence in its members.
- To support the development of genuine routes to independence for all recipients of self-directed support in London and nationally, through open and honest cooperation of its members.
- To strive to be an independent voice in the field nationally, accurately reflecting the reality of the provision of self-directed support in London and nationally by means of conferences, training events, surveys and reports.

**Pat Stack**  
*Chair LSDSF*

## EXECUTIVE SUMMARY

The London Self-Directed Support Forum's conference on 5 June 2015 focused on the opportunities and challenges of making self directed support a reality for more people in the current policy and economic environment.

The Care Act 2014 includes some provisions that have the potential to be very helpful, such as those relating to:

- **wellbeing**
- **co-production**
- **the full range of personal budget options**
- **carers**
- **transition from childhood to adult life.**

Concepts such as 'wellbeing' may be more difficult to define and enforce in practice, but on balance speakers thought that the Act conferred some stronger rights. People need good information about these rights and support to challenge poor practice.

Some elements of the Care Act have parallels in health care, such as the roll out of personal health budgets and improved integration of health and social care. Speakers expressed differing views about the risks and benefits: some argued that health and social care outcomes cannot be disentangled from the individual's perspective and that personal health budgets help to shift the balance of power towards the individual. Others noted the differing legal frameworks and cultures of health and social care and were concerned that the principle of universal entitlement to health care free at the point of delivery should not be compromised.

Examples were given of good practice in self directed support and co-production. Experience is mixed, however, and the rhetoric of personalisation and co-production can be misused to disguise less acceptable realities. It is more important than ever for individuals and support organisations to be well informed and



**Belinda Schwehr**

equipped to assert rights, and to ensure that their collective voice is strong.

The growth in personal budgets and employment of personal assistants (PAs) over the last five years has highlighted the need for good information, training and support for individual employers and PAs. There is a growing range of resources and support, but not all of it is well tailored to the PA role and information about what is available and possible is not always reaching those who need it. Local authorities vary in their funding and support for training, as well as in the pay rates they will agree.

Self directed support will have a better chance of success if it is set within a wider supportive social policy context, with attention to all the elements of personalisation. This needs to include collective grassroots action as well as investment by commissioners in infrastructure such as workforce development, community capacity development, peer and advocacy support and market development.

Making self directed support work for everyone also requires good understanding of the Mental Capacity Act 2005 and availability of the full range of options for personal budgets and personal health budgets. Advocacy and brokerage are both needed to ensure that individual employers and PAs are well informed and supported, but the availability and quality of both are currently variable and there is often confusion about terminology and roles. All this adds to the importance of having well informed, adequately funded and well run support services.

Discussions throughout the day affirmed the importance of debating the issues raised by personalisation, sharing ideas and good practice, and highlighting areas of concern. The London Self Directed Support Forum is well placed to support members and the wider London community by collating evidence about what is helping or hindering progress and by raising the collective voice.

## INTRODUCTION

The London Self-Directed Support Forum's conference on 5 June 2015 took place against a backdrop of significant developments in law and policy<sup>1</sup>, combined with the recent election of a new government that promises further substantial reductions in public sector spending. This affects social care and health services directly; it is of course necessary to consider the wider picture of welfare rights, housing, education, employment and justice to understand the full impact on disabled people and their families<sup>2</sup>.

Speakers at the event presented a range of perspectives on the current opportunities, risks and challenges related to self-directed support. The speakers' details are shown inside the front cover. Copies of their presentations are available at:

[www.londonsdsforum.org.uk/news/conference-success](http://www.londonsdsforum.org.uk/news/conference-success)

A number of themes recurred throughout the day:

- **reality versus rhetoric in hard times**
- **the power of knowledge and allies**
- **keeping the 'personal' in assistance**
- **collective action and infrastructure**
- **making all this work for everyone.**



Tim Gollins

<sup>1</sup> For example, the Children and Families Act 2014, the Care Act 2014, continued substantial reductions in welfare benefits, the revised Code of Practice for the Mental Health Act, roll-out of personal health budgets, the 'Transforming Care' programme related to people with learning disabilities at risk of inpatient admission, and increased reliance by Government on digital communications.

<sup>2</sup> See Peter Beresford's column in The Guardian, 28.5.15: <http://www.theguardian.com/social-care-network/2015/may/28/service-users-rely-benefits-queens-speech-no-relief-social-care-nhs>



Tracey Jannaway

## REALITY VERSUS RHETORIC IN HARD TIMES

Tim Gollins (Think Local Act Personal) provided an introduction to some of the key duties in the Care Act 2014, which he described as 'game-changers':

- promoting wellbeing, rather than 'just' assessing people for eligibility for social care, and preventing the onset of needs for social care
- providing information and advice to:
  - enable people to take action themselves
  - direct people to other relevant services, amenities and resources
  - support access to a range of social care for people with eligible needs
- co-producing support and care with the people who need this, and co-operating with a range of partner agencies to improve both the range of options and the join-up of responses to people's needs
- rolling out personal budgets (in all their forms) to become the default option
- shaping, developing and overseeing the market for social care and support.

All this would require close collaboration between social care, public health and health services and a strategic shift to different ways of working. Constantly shaving costs would not deliver either the new priorities or the reductions in spending that will be required. A different relationship would be needed between commissioners (at both strategic and individual levels) and service providers: strategic commissioners would need to create the conditions within which social workers could give up the 'professional gift' model and have sufficient time to work with disabled people, their families and trusted providers to co-produce agreed outcomes.

Strong corporate and collaborative leadership would be

required to look beyond the next financial year, guiding cultural change and combining the challenges of devolution with personalisation and integration.

Luke Clements (Cardiff University) presented a critical review of the key features of the Care Act. While highly sceptical about the Government's commitment to the rhetoric of independence, personalisation, prevention and integration, he argued that the rights enshrined in the Act were strong enough to 'trump' austerity. Resources would thus be compelled to flow back into social care. Much of the Act was concerned with consolidation and tidying up of previous policy and legislation; however, rights for carers and provisions for transition to adult life represented real gains. The principle that the individual is best placed to judge their own wellbeing was welcome; prevention sounded promising (though it did not have a robust evidence base), but it was unclear how councils would afford it.

He felt that two features of the Act were less positive: the sections on quality could be characterised as "putting the fox in charge of the chicken coop" (i.e. local authorities wish to drive down costs whilst supposedly demanding improved quality) and the drive towards integration between health and social care was of even greater concern, given the fundamental differences between them in both law and culture.

The latter theme was picked up by some other speakers. Smriti Singh (NHS England) summarised the challenges posed to the NHS by the declared priority<sup>3</sup> of rolling out personal health budgets. Some of the challenges were to do with capacity and new processes; others were cultural. For example, considering 'wellbeing' as a need was still novel and the concept of costing support plans was alien to many NHS staff. Other challenges to NHS culture included: shaping the market and sharing a 'local offer'; collaborative working and shifts in power between professionals and people needing support, and positive approaches to risk



Luke Clements

assessment and enablement. Smriti Singh thought that the independent living movement had made a considerable difference to NHS ways of thinking about support for people with long term conditions and she cited a quote from a family carer to illustrate the change that a conversation about personal health budgets can bring about:

*"No-one ever asked me before – what do you want for your son?"*

It is expected that demand will grow; clinical commissioning groups have a duty to consider requests for personal health budgets and must give reasons for refusal. NHS England can offer support, with examples and help to develop local approaches in addition to the wealth of material available on the website<sup>4</sup>. (See Smriti Singh's presentation for a summary of the key features of personal health budgets.)

Robin Murray-Neill (independent adviser) argued that health and social care outcomes cannot be disentangled in mental health. The core principles of personalisation, reflected in the Care Act, need to be put into practice whichever statutory authority is responsible for funding. It is important to remember the purpose of tools such as personal budgets and personal health budgets, in whatever form they are taken, and to reinforce co-productive ways of working even when this is not explicitly mandated. There is a risk of co-production being reduced to 'involvement', whereas it should entail bringing two or more perspectives and sets of expertise together (for example, in relation to support planning). Much can be achieved with imagination and creativity, when those involved are able to step outside traditional system thinking and focus on what the person really wants. This should include supporting decision-making and personalising support for people who may lack capacity to make some or all of the relevant decisions (in accordance with the Mental Capacity Act). Robin's presentation had strong echoes of a quote from George Bernard Shaw's 'Man and Superman':

*"The reasonable man adapts himself to the world: the unreasonable*

<sup>3</sup> <http://www.england.nhs.uk/ourwork/futurenhs/>

<sup>4</sup> <http://www.england.nhs.uk/healthbudgets/>

*one persists in trying to adapt the world to himself. Therefore all progress depends on the unreasonable man."*

Questions from the floor stimulated further discussion about whether personalisation would deliver cost savings, as some claimed, or better value. Speakers agreed that the concept can be corrupted: some of the early thinking had led to bureaucratic systems (for example, rigid resource allocation systems) and some tokenistic personal budgets had changed nothing. Belinda Schwehr (Care and Health Law) reminded participants that legal precedent had established that resource allocation systems must provide a rational link between needs and funding. It is essential, as Robin Murray-Neill had noted, to focus on the principles of personalisation, wellbeing and independent living. User-led organisations have a vital role in supporting people to assert their rights and in challenging councils, clinical commissioning groups and NHS trusts.

## **Summary**

- the Care Act directs councils to improve information and advice, promote wellbeing, shape the market and roll out personal budgets
- councils are expected to co-produce all this with local people and partner agencies, creating the conditions for personalisation to succeed
- many of the Act's provisions represent consolidation, but rights for carers and arrangements for transition to adult life are real gains
- there is a declared intention for the NHS to roll out similar approaches through personal health budgets, though this poses challenges to established culture
- many commentators are sceptical about whether reality will match the rhetoric and question whether councils will be able to invest in prevention, wellbeing and quality, however, confident assertion of legal rights conferred by the Care Act may force money to follow
- from an individual perspective it can make little sense to try to disentangle health and social care outcomes

- but fundamental differences in law and culture between health and social care mean that some people are very concerned that forced 'integration' will not benefit the end user
- the principles of personalisation can be corrupted; user led organisations and individual practitioners need to hold fast and continue to assert the principles and associated rights conferred by the law
- there is an important role for the Forum in peer support and sharing good practice (members helping each other to sustain principled approaches) and ensuring that members are well informed about rights, precedents and examples of solutions.



Peter Gay



## THE POWER OF KNOWLEDGE AND ALLIES

The theme of knowing and asserting rights was picked up again by Belinda Schwehr, who pointed out that many frontline practitioners in social care do not get training on the legal framework. She noted the importance of people knowing their own rights. Independent advocacy, as described in the Care Act, had the potential to be a ‘game-changer’ alongside the other points Tim Gollins had picked out – but only if advocates were well equipped. The rights described in the Care Act were also confusing in places (e.g. in relation to Ordinary Residence) and limited in some respects. For example, ‘wellbeing’ was a concept so open to debate that it was effectively unenforceable (though she hoped that someone would use it to challenge failure to continue funding for people who had received Independent Living Fund money). The provisions for person-centred assessment and care planning were rights to a process rather than to specific types or levels of support. Nevertheless, it was vital to get information about the Act out to its potential beneficiaries, including carers. Belinda Schwehr plans to use her blog to invite stories upon which she could offer comments. Citing the shared interests of local authority leaders and national government, she said,

*“The time has come for people not to be embarrassed to assert their rights.”*

Peter Gay (freelance adviser and London SDS Forum) noted there had been some positive changes since the Forum’s 2008 conference, “If we’re going to do it, let’s do it right”, with evidence of some very good practice and many more examples of people who use services being at the heart of support provision. However, it was more important than ever for basic systems to work well and for people to be well informed in order to make real choices. In a recent peer group discussion in a London borough 19 out of 20 people receiving a direct payment said they were unaware of having a care and support plan. Apart from being the rock upon which good self-directed social care is based, current work such as market development would be ineffective without demanding

'customers' informed by their robust plans. Further trust in the local system was being eroded by local authorities focusing on finance and risk (as opposed to life outcomes) while denying that real cuts were taking place. There were also real concerns about the succession of new or increasing demands on individuals employing personal assistants (such as pension provisions, statutory sick pay, working time directive interpretations) and expectations that more and more would be done on-line, specifically auto-enrolment to provide employees with pensions. Yet nearly 50 percent of older and disabled people are not on-line and risk being disadvantaged as a result. Frontline workers who support people using self-directed social and health care were good at making things work and well placed to give an honest appraisal about process and systems; their voices need to be heard more clearly.

Peter Beresford (Brunel University and Shaping our Lives) commented, however, that the social care workforce was marginalised and had a weak voice. The low status of social care remained problematic. Organisations such as the Care and Support Alliance and Skills for Care's network for social care managers had been involved in discussions about the Care Act at the drafting stage, but they did not represent practitioners' voices. Sharon Allen (Skills for Care) suggested that continued commentary from the practitioner perspective was essential.

A question about how co-production can work if the parties' aims differ prompted more discussion about the consequences of inequalities in power, particularly when resources are very limited. While the reality (in Smriti Singh's phrase) was sometimes 'consultation plus', Peter Beresford was able to cite examples of true co-production, such as collaborative research. In the past there had been great antagonism between support services and carers, but there are now good examples of working together (not speaking for each other) in trusting relationships. More of such win/win alliances would be helpful: co-production was not a zero sum game. Belinda Schwehr noted that two of the pilot sites for personal budgets had invested in skilled assessment and support planning; overall spending was shown to be less than in the sites

that allocated a budget upfront. Toby Williamson (Mental Health Foundation) added that professionals can recognise inequalities in power and give some up: for example, trying the 'hearing voices' approach with people with dementia. Robin Murray-Neill echoed this, reinforcing the value of engaging with people's own realities and really listening to them in order to work out how to improve things, particularly as austerity bites deeper.

## Summary

- some rights in the Care Act are confusing or may be promising but hard to enforce
- there are growing examples of good practice, but also concerns that these are not sufficiently widespread and there are increasing pressures on individual employers
- councils are not always open about the real local picture
- front line workers are well placed to give honest views about progress and barriers, but their voices are not always heard
- there are mixed experiences of co-production, with some strong examples of real collaboration, listening and trust, but other instances of consultation or involvement being presented as if they were co-production
- all this means it is really important to ensure that individuals and their families, advocates, user led organisations and other kinds of supporters are well informed and equipped with examples and resources
- the Forum has an important role in providing a channel for the collective voice.



Peter Beresford



## KEEPING THE 'PERSONAL' IN ASSISTANCE

Sharon Allen, CEO of Skills For Care, described some significant changes over the last five years: with around 120,000 people working as personal assistants (employed through personal budgets taken as direct payments, not including self-funders) there is now much improved emphasis on supporting PAs as part of the recognised workforce and individual employers as part of the employer 'landscape'. Skills for Care encourages individual employers to submit data (which is used to inform policy) and includes them in its Accolades.

Noting the rapidity with which employment law changes, Sharon Allen highlighted the resources available on the Skills for Care website. These were produced with people with lived experience. Recruitment and retention is a big issue when there can be 60,000 vacancies on any given day; Skills for Care is talking to JobcentrePlus about encouraging jobseekers to consider PA roles. The workforce development fund includes an element ringfenced for individual employers and local authorities are also encouraged to include PAs, individual employers and user led organisations in the training and development they organise. This is further supported by Think Local Act Personal's 'leadership for local communities' programme, which covers self directed support.

Tracey Jannaway (Independent Living Alternatives) drew a clear distinction between support workers employed through organisations and true personal assistance: the latter entails complete control by the person receiving the assistance. As she pointed out, not everyone wants this. Some people prefer more traditional residential or domiciliary care, and some people want a mix of types of support. For example, the way an individual wants to organise their support to go to work might be different from the model of support they want at home; their preferences might also change over time. Individual employers do not have a human

### **Example from Skills for Care**

*Richard employed his brother Kevin as a PA. Kevin was supported to achieve Level 5 qualifications via the apprenticeship route. It was challenging to adapt to the workplace being a person's home and to find ways of evidencing achievement, but it was managed.*

resources department to advise them on employment practice, pensions, and so on. It is therefore vital for people to have good information about the variety of options and to think through what they want. Advisers need to understand the advantages and disadvantages of different options; support from user led organisations and peers is highly valued. The reality is that well informed, independent advocacy is often not available and people who need information and support to make and assert their choices are often isolated.

Both Sharon Allen and Tracey Jannaway highlighted some of the dilemmas about balancing personalisation with change on a large scale and stimulated questions and discussion about training, regulation and development, and pay of the PA workforce.

## Training

Several participants commented on the frequent lack of attention to and funding for training in support planning (relating to both local authorities and the NHS). Sharon Allen noted that investment in training and development was an issue across the social care workforce; cutting this was a false economy, though always a temptation for hard-pressed local authorities. Skills for Care has produced a lot of materials, such as pocket guides and toolkits, as well as offering a training and development fund (not matched by the NHS) and working with the ADASS<sup>5</sup> workforce group to encourage the inclusion of PAs in local training. There is a persistent issue about dissemination of information; people are not always aware of what is available and may need support to challenge local authorities about their legal obligations. User led organisations and direct payment support organisations are well placed to help with dissemination and to advise Skills for Care about ways of reaching the thousands of individual employers and support organisations who could benefit. Tracey Jannaway commented that Skills for Care produces some good materials, although these are not always accurately oriented towards individual employers and PAs. Guidance and practice development based on traditional residential or domiciliary care (e.g. relating to safeguarding) needs to be rewritten from scratch to be suitable for PAs

<sup>5</sup> Association of Directors of Adult Social Services

## Regulation

On a similar point, concern was expressed about the possibility that regulation and the application of care certification to PAs could crush person-centred practice. Sharon Allen pointed out that individual employers (unlike regulated organisations) have a choice about whether to use certification based on the common induction standards or not. She saw no appetite for regulation to be extended to individual employers. Tracey Jannaway commented on dilemmas for organisations such as hers: developing to act as an agency (for people who want to manage their PAs day to day but do not want to be the employer) means they have to offer 'care' qualifications. This can jar with their values. There is also a risk of conflict with their role in providing independent advice



## Pay

Local authority practice on pay rates for PAs varies from one area to another; in some authorities no increase in rate has been agreed for four years. Some seem prepared to pay more to agencies than they will for PAs, and in some cases clinical commissioning groups are simply replicating what the local authority offers. Where the same rates are agreed for PAs as for agencies, this can allow money to be earmarked for training. In relation to the downward pressure on pay rates for staff employed through organisations, Belinda Schwehr suggested that employers should bear in mind that councils have a duty to provide services themselves (entailing local authority terms and conditions) if they are unable to buy from others. At present too many service providers are prepared to undercut each other to win a contract. While recognising the financial pressure on funders, Sharon Allen emphasised the importance of a collective voice speaking up about the need for a well-trained and well-led workforce to deliver person-centred care.

## Summary

- there has been a huge growth over the last five years in

individual employers and in PAs; it is challenging to work out how to support thousands of individuals while being true to the principles of personalised support

- a lot of help is available from Skills for Care and others, including workforce development funding, but information about what is available does not always reach the people who need it
- personal assistance is fundamentally different from more traditional types of care and support; this means that training and development needs to be tailored to the PA role. More needs to be done on this front
- it is really important for individuals to have information about the different options and support to think through and implement what will suit them; some people do not get this help at present
- training and development is often not covered or funded adequately through support plans or as part of the local infrastructure. Local authorities and the NHS could do more to offer individualised training themselves and open up existing training to individuals, families and PAs
- there are dilemmas for independent advice organisations about whether to become agencies: this might increase the options for people who do not want to be employers, but compromise the organisations' values
- there are widespread concerns about pay rates agreed in personal budgets, though also some examples of agency rates being offered (allowing greater flexibility)
- once again this underlined the importance of shared information about the duties of local authorities and examples of good practice, together with a collective voice to push for improvements
- all this adds to the evidence that an adequately funded and well run support service is often crucial to the success of personal assistance, both for the employer and the PA.

## COLLECTIVE ACTION AND INFRASTRUCTURE

Several presenters noted that there were risks in seeing self directed support as a purely individual matter (with undertones of Victorian belief about personal responsibility and self help). Toby Williamson discussed this, arguing that the individual approach is essential but not sufficient: collective responsibility is also required to ensure that everyone can benefit and this must include the infrastructure to sustain self directed support.

Peter Beresford made a strong case for taking a broader view to encompass not only social care and health, but also benefits and welfare rights, employment, education and training, housing, and other services and amenities that everyone uses. The system was based on lots of inequities including, for example, the variable approaches being taken locally to the ending of the Independent Living Fund, the expectation that universities would pick up funding for support for disabled students, and the inaccurate information given to some people about benefits such as Access to Work. Noting the cumulative impact of Government policy across all these areas, he said,

*"We mustn't sit here talking about the usual things; it isn't business as usual."*

Personal budgets and personal health budgets could not be viewed in isolation from this bigger picture. Peter Beresford accepted that personal budgets could be liberating, but was concerned that in practice they would be used to control and cut costs. The social care 'world' should stop agreeing that more could be done for less. He was particularly opposed to the allocation of fixed personal health budgets as an alternative to the universal entitlement to health care free at the point of need. Smriti Singh suggested that health care was typically prescribed as a finite quantum of service in response to assessed need and that personal health budgets could help to shift the balance of power between the NHS and its users, but



Robin Muarray-Neill

Peter Beresford held to the view that NHS failings should be tackled directly, rather than being sidestepped.

The theme of collective action and support was developed further through questions and discussion.

There was a reminder from participants that personalisation is a broader concept than personal budgets and personal health budgets. As described elsewhere<sup>6</sup>, personalisation includes concepts of:

*“understanding what families and communities do, and could do, to achieve outcomes, and remodelling universal and targeted services and community activities to support them.”*

This view of personalisation requires commissioners to support and invest in:

- **peer support and networks**
- **advocacy**
- **collating intelligence and evidence to shape local strategy, linking the experience of individuals (whether self directing support or not) to strategic plans**
- **community capacity development, workforce development, market development and flexible contractual and procurement practice.**
- **Commissioning can thus help to create the conditions for success in personalisation<sup>7</sup>.**

Toby Williamson was encouraged by examples cited earlier of people coming together to offer peer support, pool resources and influence local services. This kind of grassroots community activism offered hope. He said,

*“Interdependence has power.”*

<sup>6</sup> Lazarus et al 2014 'Making it Personal: 2' commissioning guide available at: <http://www.kids.org.uk/mip2>

<sup>7</sup> See guides available at: <http://www.preparingforadulthood.org.uk/what-we-do/joint-commissioning>

## Summary

- **the individual approach to self directed support is essential, but not sufficient: collective action and infrastructure are also needed**
- **self directed support also needs to be set within the wider social policy context, as well as variable local provision of universal and targeted services**
- **there are differing perspectives on personal budgets as liberating versus the risk that they become a tool for local authority control**
- **views about personal health budgets are even more divergent, with some seeing them as a valuable tool for shifting the balance of power away from health professionals and others opposing on principle anything that could be construed as a move away from universal entitlement to health care free at the point of delivery**
- **the wider view of personalisation 'in the round' requires a broad range of commissioning activities to create the conditions for success**
- **commissioning investment in such infrastructure needs to sit alongside grassroots community activism.**



Toby Williamson



## MAKING ALL THIS WORK FOR EVERYONE

Toby Williamson's presentation included examples about how to make the core principles of self directed support work for people who:

- might lack capacity to make some or all of the relevant decisions
- did not want a direct payment.

Evaluation of both personal budgets and personal health budgets had shown that some people benefited from having more choice and control, but did not want or did not have capacity to have a direct payment. They should not be excluded from opportunities for personal budgeting. For example, Toby Williamson was undertaking work on the rights of people with dementia under the Care Act and the Mental Health Foundation had recently published research<sup>8</sup> on direct payments made to a 'suitable' other person on behalf of a person lacking capacity. Applying the principles of the Mental Capacity Act 2005, these 'suitable persons' manage the direct payment account with the best interests of the service user at the centre of all decisions.

Sharon Allen had already mentioned the importance of the Mental Capacity Act and the range of resources available from both Skills for Care<sup>9</sup> and the Social Care Institute for Excellence<sup>10</sup>. Think Local Act Personal has also published resources on different ways of achieving flexible support, such as Individual Service Funds<sup>11</sup>, and guidance on rolling out personal health budgets to more people with learning disabilities<sup>12</sup>.

Questions led to further discussion about advocacy, brokerage and 'third parties'. The speaker panel agreed that the terms were sometimes used interchangeably, but there were important distinctions:

- under the Care Act advocacy means support for an individual

8 <http://www.mentalhealth.org.uk/our-work/research/indirect-payments/>

9 <http://www.skillsforcare.org.uk/Skills/Mental-Capacity-Act/Mental-Capacity-Act-%282005%29.aspx>

10 <http://www.scie.org.uk/mca-directory/>

11 <http://www.thinklocalactpersonal.org.uk/Latest/Resource/?cid=10714>

12 <http://www.thinklocalactpersonal.org.uk/Latest/Resource/?cid=10079>

to be involved in the key processes leading up to the arrangement of support. Toby Williamson noted that the test for 'substantial difficulty' in understanding the processes was confusingly similar to the test for mental capacity. Advocacy is about helping to ensure that the person's views are asserted. Peter Beresford said that even well informed people need advocacy alongside them on occasion. Information about demand for advocacy will need to be collected to influence spending; there is no spare capacity in existing advocacy contracts. The Mental Health Foundation is helping to re-establish an umbrella group for advocacy organisations and hopes this will collect and analyse information from across the country

- brokerage is the type of assistance that can help a person to explore and organise options for support. It may be offered directly by the local authority, or it could be funded through grants or contracts to local organisations or by including an amount in a personal budget. Practice varies significantly between different local authorities and some are not funding brokerage properly at all. Belinda Schwehr pointed out some other confusing use of language: in some circumstances 'third party' is used to mean an organisation receiving a personal budget to manage on a person's behalf whereas in others it means an individual supporting the person. Smriti Singh suggested that the Forum could be very useful in clarifying terminology for use London-wide. Robust advocacy and brokerage are very important parts of the infrastructure of support needed to ensure that personal budgets and personal health budgets can work for everyone.



Smriti Singh

## Summary

- **some people do not have capacity to make some or all of the relevant decisions about direct payments and some people do not want direct payments**
- **a full range of options is therefore needed to ensure that everyone can benefit equally from personal budgets and personal health budgets**
- **there are a number of resources available to support the offer of all the options**
- **advocacy and brokerage are both needed to ensure that individuals are well informed about the options, that their views are elicited and asserted and that their preferences then shape their support**
- **the availability and quality of advocacy and brokerage are variable, as is local funding, and there is often confusion about terminology**
- **the Forum could fulfil a useful role in identifying provision and clarifying terminology for use London-wide.**



## CONCLUSION

It was clear from the discussions throughout the day that there is an important role for the London Self Directed Support Forum in debating the issues raised by personalisation, sharing ideas and good practice, and highlighting areas of concern. While there has been considerable growth in numbers of people with personal budgets (and now some personal health budgets) employing personal assistants, this brings challenges in ensuring that such scale does not dilute the principles of personalisation. There are encouraging examples of changes that have been achieved, and committed individuals and organisations that are determined to sustain and extend this progress despite the threats posed by austerity. The Forum is well placed to support such activism, to collate evidence about what is helping or hindering progress, and to be heard as a collective voice for London.



## APPENDIX 1: USEFUL RESOURCES

Links to a number of resources have been given in the preceding text. Here is a selection of further useful resources:

### Care Act

Think Local Act Personal have published Care Act resources, including:

- care and support planning practice guide
- minimum process framework
- individual service fund practice guide
- information, advice and brokerage guide

<http://www.thinklocalactpersonal.org.uk/Browse/careact2014/>

### The Social Care Institute for Excellence

<http://www.scie.org.uk/care-act-2014/>

### Independent living

**Report from the Independent Living Fund on 27 years of providing independent living support**

<http://disabilityrightsuk.org/news/2015/june/ilf-celebrates-27-years-independent-living-support-provision>

### Disability Rights UK

<http://www.disabilityrightsuk.org/how-we-can-help/independent-living>

**'Rough Guide to managing Personal Assistants' edited by Sian Vasey**

<http://www.independentliving.org/docs6/vasey2000.html>

### Personalisation for young people

**Preparing for Adulthood resources, including those on joint commissioning (across age groups as well as across agencies)**

<http://www.kids.org.uk/mip2>

## Websites of the speakers or their organisations

**London Self Directed Support Forum**

<http://www.londonsdsforum.org.uk>

**Think Local Act Personal**

<http://www.thinklocalactpersonal.org.uk>

**Robin Murray-Neill**

<http://robinmurray-neill.co.uk/>

**Personal health budgets**

<http://www.england.nhs.uk/healthbudgets/>

**Luke Clement**

<http://www.lukeclements.co.uk/>

**Skills for Care**

<http://www.skillsforcare.org.uk>

**Independent Living Alternative**

<http://www.ilanet.co.uk/>

**Care and Health Law**

<http://www.careandhealthlaw.com/>  
and <http://www.schwehroncare.co.uk/>

**Mental Health Foundation**

<http://www.mentalhealth.org.uk>

**Peter Beresford**

<http://www.brunel.ac.uk/people/peter-beresford>

**Peter Gay**

<http://www.personalisationpartnership.co.uk>

