



# USER-DRIVEN COMMISSIONING

## Building on the 'lived experience' of disabled and older people – the most under-used resource in social care

Report on an informal programme to establish, support and strengthen user-driven commissioning in six local sites by focusing on three complementary stepping stones

Bernd Sass, Disability Rights UK; Peter Beresford, Shaping Our Lives (full report at [www.disabilityrightsuk.org/userdrivencommissioning.htm](http://www.disabilityrightsuk.org/userdrivencommissioning.htm) )

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## Summary

An informal programme was set up by a consortium of Strategic Partners to the Department of Health in March 2011 (led by Disability Rights UK and Shaping Our Lives) in order to initiate, take stock of and further develop local work on 'user-driven commissioning'. The programme focuses on three complementary stepping stones co-produced by local pairs of (joint) commissioners and user projects: Starting by pooling their personal budgets (eg to achieve greater economies of scale), disabled and older people use their insights gained as micro-commissioners to inform and push for re-commissioning (from block to spot) and finally deliver peer support as integrated element of cross-sector care and support pathways.

This on the ground initiative has begun to bring about more positive health and quality of life outcomes– with potential for whole systems improvement, integration and productivity gains. It has built on local people and mature relationships and thereby paved the way for using the emerging structures under the Health and Social Care Act 2012. Further development relies on sustainable funding for user-led organisations and open access to budget information so that commissioners and user projects can co-produce better evidence on cost-benefits and a sound business case for mainstreaming.

Contact: [Bernd.Sass@DisabilityRightsUK.org](mailto:Bernd.Sass@DisabilityRightsUK.org) London, 0044-7906-521536

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## Introduction

This report sets out the background to and learning from an informal national programme on user-driven commissioning which culminated in a roundtable event in London in December 2011 and has been further developed since. The aim of this event was to bring together the key stakeholders involved in six pioneering local initiatives that have been taking forward this approach since at least March 2011. This publication reports the background and findings as a resource to help roll out this approach in social care and health, which can turn the rhetoric about user-centred and user-driven support into reality with numerous positive by-products. The report draws on the development paths taken on the six sites as well as on the discussion between a wide range of co-productive service users, disabled people, commissioners and friends and supporters.

Richard Jones, past President of the Association of Directors of Social Services and Lancashire Director for Adult Services, set the context for this development. He highlighted that the overall context for care and support and for commissioning in particular is 'extremely challenging'. The 2011 Autumn statement from the Chancellor suggests that the national financial situation is unlikely to improve before 2016 or 2017 – now, a year later we know further welfare cuts are still to come. The challenge is whether what will be offered locally is reform or retrenchment. Some of the discussion about taking forward health and social care integration could result in fragmenting people's lives. There is a risk of an inadequate approach to the integration. Richard identified three shifts that he is concerned to create:

- Think Local Act Personal: to shift from thinking about people as 'service users' to thinking about people as 'citizens';
- A shift from a clinical to a community perspective;
- Co-production to develop a set of outcomes that can be used positively by people and communities.

A recent DEMOS report<sup>1</sup> came to similar conclusions. When comparing 152 local councils, the following interventions proved most effective in mitigating the impacts of cuts to social care budgets:

- Coproduction – involving service users in designing and planning their services, and in some cases delivering them.

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<sup>1</sup> <http://www.demos.co.uk/publications/copingwiththecuts>

- A move towards more integrated services, bringing in care, health and often housing and leisure.
- A commitment to personalisation, not as a short-term cost-cutting measure, but as a foundation on which these other strategies can be built.

At present, developments are often pushing in the opposite direction, to partial solutions rather than joined-up thinking. Current interventions often contribute to people's isolation rather than tackle it. The vast majority of care and support takes place in communities, by families, friends, neighbours. So how can commissioners link in with and support these assets by freeing up commissioning resources? We need to co-produce outcomes which can be owned by people and communities. Accountability to local people is a key issue, particularly because as yet there is no true mechanism to monitor the social care outcomes framework. High profile cases such as the abuse at Winterbourne View illustrate that we are still a long way away from a reform agenda that enables co-production around a shared set of outcomes.

User-driven commissioning may well help prevent such abuse in future. Disabled people are experts in improving their life chances and other outcomes. Every condition is both a crisis and an opportunity to re-assess life, set new priorities and – most importantly – make use of care and support in ways that are personal, effective and efficient. Disabled people have the passion and empathy to support others and have learned to come up with creative solutions to a crisis and the challenges of everyday life. Disabled people make sense of a condition and contextualise this within every aspect of their life. They see both what and how things could improve.

These qualities are highly applicable and in great demand in social care and the NHS. But the care sector as a whole is still very much a closed system geared towards 'treating' people as passive recipients who merely fill out questionnaires and take up beds until they can be discharged. Professional status is often not achieved together with disabled people but rather against them or at least outside of direct encounters with them. Yet, there is a whole life to be lived and managed – with often far greater consequences than any single clinical encounter or social care appointment can ever address positively.

Involving people in decisions about their care and support early on can make the key difference to more positive health and quality of life outcomes

– as stated in the NHS White Paper<sup>2</sup>, Health and Social Care Act 2012 and highlighted throughout the more recent Care and Support White Paper and corresponding bill. We hope that the corresponding duties<sup>3</sup> will be taken seriously not just ‘after the event’ but throughout the commissioning cycle.

Little things such as commissioning extended time to be spent on support planning can reduce the demand on more costly care, just because people have been involved at an early stage and feel good about that. ‘Peer navigators’ sometimes support disabled people through an ever complex landscape of services. Others pool their personal budgets so that they become micro-commissioners and achieve greater economies of scale. There is no reason why social care departments and (forthcoming) clinical commissioning groups should not give a parity of voice to disabled people when it comes to de-commission large block contracts and re-commission more innovative types of support instead – peer support could be co-commissioned or subcontracted as defined parts of integrated ‘whole life domains’ pathways.

However, by too many such co-production in all its facets is seen as an add-on to core provision (with a separate overarching involvement budget) when genuine co-production should be recognised as a direct contributor to positive health and quality of life outcomes and hence factored in and threaded through commissioning pathways.

So how do we develop a moral imperative – hold up a mirror for decision-makers to guide them to make informed judgements about how to improve present arrangements for care and support? Engaging with people as active citizens over the lifecourse is the challenge for the future – even more so in a context of resource demands and fragmented policies.

We need to ask and respond to what the reforms mean to people. ‘Making it real’ – the Think Local, Act Personal document, has set out 26 statements and ‘makers of progress’ to guide us through what people want and need from social care, at a high level.

User-driven commissioning is about applying user-led agendas in practice. It is at the heart of the reform agenda and can deliver these high level goals on the ground – foremost through people and relationships but alongside and supported by the emerging legal structures that have been put in place.

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<sup>2</sup> Equity and excellence: Liberating the NHS

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_117353](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353)

<sup>3</sup> Involvement duties in the Health and Social Care Act 2012: Duty to promote involvement of each patient (13H) and Public involvement and consultation by clinical commissioning groups (14Z2)

## The Programme

There are six different local sites in the programme working on distinct aspects of this agenda none of which follows a linear protocol but all of which aim to strengthen direct user input into commissioning. The sites are:

- Richmond User Independent Living Service and Richmond Council
- Incontrol-able Hartlepool and Hartlepool Council
- Essex Council of Disabled People and Essex County Council
- Lancashire County Council
- Sight Service Gateshead and Gateshead Council
- All Together Positive Stockport, Stockport Mind and Stockport Council

Together we wanted to explore how to create the leadership to deliver user-driven commissioning as commissioners, service users, survivors and disabled people and with our own and infrastructure support organisations.

Commissioning has been defined as “the process of specifying, securing and monitoring services to meet people’s needs at a strategic level” (Audit Commission, 2003<sup>4</sup>) and “making the best use of all available resources to produce the best outcomes for our locality” (DCLG, 2011<sup>5</sup>). What probably supports this programme most is the current shift from commissioning services to outcomes-based commissioning which puts users of services at the centre – possibly more so than the personalisation agenda so far. For us this means people are seen and empowered to pursue their own pathways and necessary support (rather than set services) – which commissioning systems have to pick up on to the benefit of all of us.

## Background: What we did

This programme on user-driven commissioning focuses on local people and relationships rather than structures and systems. It began more than 1 ½ years ago in March 2011 by making contact with, talking to and identifying innovative user-led projects and commissioners up and down the country. We did this with a view to create or build on direct relationships between service users and commissioners as strong local ‘pairs’ or pillars. This aim for an exclusive focus on the key players and decision-makers – service users and commissioners – appears to be distinct from similar pilot-

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<sup>4</sup> Audit Commission (2003). Making Ends Meet, London, Audit Commission

<sup>5</sup> DCLG (2011). Strategic Commissioning for place-shaping. Volume 1: A report written by practitioners for practitioners, London, DCLG

based schemes such as People Powered Health<sup>6</sup>, UpToUs<sup>7</sup> and Building health partnerships<sup>8</sup> (between voluntary community and social enterprise organisations and forthcoming Clinical Commissioning Groups in the NHS).

We wanted to engage these two key stakeholder groups as catalysts for sustainable change which could be rolled out more widely. It turned out that the programme provided a valuable opportunity to start or refresh local dialogues about how to put users of social services in the driving seat across the commissioning cycle including in the delivery of some defined parts of new care and support pathways for commissioning. We have supported these initiatives, asked powerful questions, coached and advised on positive ways forward and win-win solutions. This co-produced programme therefore goes beyond related schemes such as the course-based Expert Patients Programme<sup>9</sup> which goes further in reach but is limited to the delivery of courses by expert patients. Our aim was to create a model of coproduction in the sense of continuous user involvement towards shared outcomes across the whole commissioning cycle. Rather than just setting out better services (no matter how great the demand for them is) we wish to strengthen the commissioning capacity from within user projects themselves as this is where the crucial lived experience is located.

Providers, social care staff, clinicians, carers and *potential* service users were deliberately not involved at this initial stage – with two exceptions, one in Lancashire where the council engaged wider communities in ‘Working Together for Change’ and the other in Gateshead where we felt a provider consortium had taken an unusual step towards ‘seed commissioning’. This focus was for practical reasons of what could be managed within a limited small-scale programme but also borne out of strategic considerations.

We all look to peers to support us in making sense of and contextualising a crisis, condition or treatment within our whole life, just as with any everyday life problem. Peer support is the most organic source of support and has huge potential, but is often undermined by professional styles and behaviours, provider interests and commissioning preferences and simply unquestioned routines in social care and health. We knew that there were plenty of gaps in provision of care and support in some places but rather than looking to providers straight away we wanted to first explore how we could identify and perhaps plug some of these gaps ourselves.

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<sup>6</sup> [http://www.nesta.org.uk/areas\\_of\\_work/public\\_services\\_lab/people\\_powered\\_health](http://www.nesta.org.uk/areas_of_work/public_services_lab/people_powered_health)

<sup>7</sup> <http://discuss.bis.gov.uk/buying/the-guide/case-studies/up2us/>

<sup>8</sup> <http://www.commissioningboard.nhs.uk/2012/11/27/health-partners/>

<sup>9</sup> <http://www.expertpatients.co.uk/>



In several meetings with each local pair of commissioners and service user projects, we jointly considered the terms “nothing about me without me” and “outcome-based commissioning” and analysed what we saw behind these terms. Then we found our own take on it and set out ways in which service users themselves could determine and contribute to the identification, delivery and monitoring of shared outcomes.

At this stage it was essential to map out the challenges ahead and identify potential win-win solutions. The challenges were quickly apparent. Commissioners faced cuts to central Government formula grants and new expectations under the prevention agenda. Meanwhile local budgets were no longer ring-fenced (to protect local minorities) and resources were tied up in commitments to large contracts and salaries which made it difficult to shift from a capacity-driven system to a customer insight or demand-led model which would be much more personal, effective and efficient.

Service user projects in turn faced significant cuts to grants and contracts from local authorities and primary care trusts (or at an earlier stage, knew that there was no prospect of start-up funding). At the outset, virtually none of the six local sites had managed to engage with their local clinical commissioning groups in shadow form. This was despite the strong emphasis on strengthening the choice agenda in social care and health as well as in other public service areas. At the same time, service user projects had to come to terms with playing an increasingly strategic role in formulating needs of disabled and older people and responsive ways to meet them by peers. Furthermore, often with limited resources and capacity, they had to catch up with business development compared to their more advanced counterparts in the wider voluntary community sector (VCS), for example, in the transition from costing their support services to pricing them accordingly for a competitive market.

As to win-win solutions, across the six local sites we came up with a preliminary model of three stepping stones for taking forward user-driven commissioning. They represent different yet complementary ways of moving towards the same goal of user-driven commissioning. These are:

**First stepping stone** – setting out and supporting initiatives for people to pool their personal budgets to maximise (previously inaccessible) outcomes on people’s terms and achieve greater economies of scale, while also building up and sharing collective experiences and identities as teams.

**Second stepping stone** – evolving into mature conversations about de-commissioning and re-commissioning to free up resources for more

innovative ideas and personalised approaches while ensuring a fair, viable and comprehensive transition away from large block contracts such as those for day services ('chicken and egg' dilemma). This could evolve into new co-produced 'whole life' and cross-sector care and support pathways with bundled, proportionate tariffs for particular stages (based on specific outcomes) – to be allocated to different providers working in partnership.

**Third stepping stone** – creating foundations for user-led or hybrid mutual organisations (the latter to be jointly led by disabled people and staff). This would enable the delivery of peer support as an integrated element of those pathways and to promote and facilitate choice and thereby support others to navigate those new pathways and create their own solutions.

This is what we envisaged the three stepping stones to look like:

<p><b>1. Pooling Personal Budgets to maximise outcomes on people’s terms, meet uptake targets (eg 50.000 Personal Health Budgets) and make costs transparent:</b> <i>Match</i></p>	<p><b>2. De-commissioning in-house care and block contracts to free up resources and innovate - yet master ‘chicken and egg’ dilemma:</b> <i>Drive</i></p>	<p><b>3. Form and build on small providers and user-led mutuals to strengthen peer support and foster integration</b> <i>Deliver</i></p>
<p>Bring people together, eg to share a PA, access / fund new activities and ventures and build up collective insights along the way</p>	<p>Build on insights and identify unit costs with the aim to shift resources into more time for support planning and more innovative types of care and support</p>	<p>Paid peer navigators and mutuals to support peers to contextualise a treatment/condition within life domains and make choices</p>

While the three stepping stones evolved freely over time in co-production with the six sites, we knew from the outset that for the programme to be effective we needed to create the necessary momentum. Pooling personal budgets was the crucial trigger. Once disabled people have come together to form collective views and identities, they may then go on to inform de-commissioning and even provide paid peer support eventually.

These are some of the drivers and outcomes we had in mind:

### ***Save and Share***

Improvement drivers: mature relationships; transparent budgets; focus on partnerships, projects, 'co-produced' delivery, IT, staff / user buy-in

#### Potential outcomes

- better preventing / managing soars, medicines, equipment, etc
- improved independent living, continuity / integration, quality of care
- extended personal budgets across other public service areas
- reduced waste, eg in assessments, hospital / A&E admissions, lengths of stay, referrals into residential care

Then share efficiency savings between users of services, commissioners and wider local community.

The three stepping stones build on each other and reflect the formula 'Match, Drive, Deliver, Save and Share'. This formula was intended to take everyone on board and foster budgetary fairness between users of services, commissioners and the wider local community – in the context of fierce cuts faced by disabled people yet frozen council tax benefiting the wider local community for example. Currently, the few (limited) mechanisms to bring about this fairness are through the Public Sector Equality Duty, impact assessments and judicial reviews 'after the event'. We hoped to foster the understanding of productivity gains and set out innovative ways forward to inform, empower and benefit all of the above three stakeholders.

Sometimes it pays to look back to a time where there had been more of such mutual empowerment. When Direct Payments had first been introduced disabled people had been encouraged to achieve greater productivity by spending their money in more efficient ways than councils had previously achieved under traditional 'in-house care'. Such savings – eg from better suited equipment or mutual arrangements with neighbours for cooking – could be identified, kept and spent by the Direct Payment holder on unforeseen expenditure such as overheads for employing a personal assistant, care from an agency to plug a gap or respite care.

This power to make independent decisions and build up some 'slack' has now been largely abolished. Direct Payment holders can only pay their personal assistants much less than what councils would otherwise pay traditional care providers – one of the reasons why Direct Payments have become a barrier in recent years. Otherwise, even the smallest savings will

be clawed back immediately – without professionals or commissioning systems necessarily taking note of the learning behind these savings.

If disabled people are not supported and incentivised to find their own creative solutions but have their support cut instead, their needs deteriorate much faster. Their quality of life can diminish and the NHS (paid for by every taxpayer) eventually has to step in earlier and more frequently at greater cost. In effect, the valuable lived experience of people with support needs has largely ceased to play a role throughout the commissioning cycle. Coming up with the formula of ‘Match, Drive, Deliver, Save and Share’, we wanted to initiate a dialogue on how to reinstate the valuable impact of lived experience on the care and support system.

The term ‘user-driven’ - rather than user-led - commissioning reflects and recognises the fact that further stakeholders need to come on board to drive and deliver this agenda in co-production with disabled people.

## **Learning from the local sites**

In reality, the six sites had very different starting points but all were engaged in activities which related to at least one of the stepping stones set out above, though not necessarily in the linear order envisaged.

We met for the first time together with all but one of the six local sites at the roundtable in London in December 2011. This was to exchange ideas and experiences made so far and further co-produce the leadership around user-driven commissioning. This report brings together what we had been tackling in previous planning meetings from March 2011 onwards and sets out how far we have got by then, including updates up until October 2012.

A great deal of the model – and associated formula of ‘Match, Drive, Deliver, Save and Share’ – has still to be delivered. Given the complexity of the objectives and challenges faced in all sites, we have realised that we can create some of the narrative for change through people and relationships but in future will have to complement this with sound evidence.

While we are aware that there is still a long way to go for us, we hope that the learning from this initiative will be spread further and our start-up work replicated in local areas up and down the country – all of which will identify further pitfalls, enhance access to relevant budget information and help build up the evidence base for user-driven commissioning. We now look at the forms which the three stepping stones have taken so far.

## **I. First stepping stone – what are the opportunities and barriers to supporting personal budget holders to pool their budgets?**

Personal budgets have become the norm of how social care is delivered in England – although the 100% take-up target has just been reduced to 70%, the majority of users of social care services are now in receipt of personal budgets. It is important to note that personal budgets can be taken out or deployed in different forms offering the personal budget holder different levels of choice & control: A personal budget can continue to be managed by the local council (but its value must be made transparent to the person), it can be managed by a charity or an independent user trust on behalf of the person or it can be paid out directly as a Direct Payment with the greatest level of choice & control – or any mixture of these options. In reality, certain groups – in particular older people and people with mental health issues – are not routinely offered Direct Payments due to sometimes questionable assumptions about their readiness to manage them<sup>10</sup>.

Pooling direct payments refers to a number of personal budget holders coming together to tie up all or parts of their personal budgets. For the purposes of ‘pooling’, the above deployment options do not really matter as even someone with a personal budget managed by the council should be supported to pool (some or all of) it with peers if this corresponds with his or her expressed wishes and feelings and the agreed outcomes in the support plan.

We expected this approach to go beyond managing the technicalities and reaping the immediate benefits of pooling direct payments or personal budgets – for instance sharing responsibilities and hence the burden as employer of personal assistants (PAs). It turned out that pooling helps disabled people to develop and share a vision, skills, joint interests and identify and draw on additional community resources. Some of the things that can be achieved further down the line are about sharing personal assistants (PAs), improving social life with friendship groups, and other arrangements for support and also setting up micro-enterprises. However, for pooling initiatives to achieve true impact on the current care and support system and much greater economies of scale, a more forthcoming and strategic approach is required from commissioners.

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<sup>10</sup> ‘Keeping personal budgets personal’ – report from Social Care Institute of Excellence  
<http://www.scie.org.uk/publications/reports/report40/files/report40.pdf>

The Richmond Users Independent Living Scheme (RUILS) – as one of two sites engaged in this approach – presented the following initiatives:

- “Stepping on Out”: a group of people with learning disabilities formed a non-profit micro-enterprise to design, make and sell cards<sup>11</sup>
- “Out and about consortium”: young people set up a friendship group and shared personal assistants to support them to access diverse leisure activities in the community. This has given the group a sense of being on their own and feeling more like adults.
- “Mereway Friends”: mutual friends hired a regular place to get together, socialise and offer peer support to each other. A couple of the members have been nominated to take on certain responsibilities to make sure the group runs properly.
- “Buddy Travel Solutions” – setting up a tailored transport service

Further examples of creative spending relate to buying group training or tickets for the cinema, concerts, theme parks, football or organise a group holiday. By sharing provider costs, better terms and conditions can be negotiated and proper economies of scale achieved; these can potentially lead to the replacement of traditional day care if sufficient personal budget holders get together to set up their own innovative support instead.

It is absolutely essential that the approach is at all stages driven by disabled people and other players do not take over. This applies to both setting out the required support and determining the purpose and pace of the initiative. Any project must be allowed to fail if people do not see a way forward to actually improve their care and support and lives on the basis of pooled personal budgets. It is important that commissioners develop and have support packages in place for those approaching them with pooling initiatives. In fact, the noticeable absence of most commissioners from this agenda leads to some personal budget holders fearing that pooling could be used to cut spending and reduce rather than improve their support and independence. A planned, strategic approach would be open and upfront with people about the budget and support available and give clear assurances that any savings would not be clawed back but could be re-invested into the enterprise at least for a defined period – all of which should be supported by sound evidence in the interest of both stakeholders.

There might be a temptation to aim for a consistent model but in fact people and circumstances will be so diverse that it will be impossible to not only tease out but also generalise 'key elements'. Every journey will be different,

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<sup>11</sup> [www.steppingonout.org.uk](http://www.steppingonout.org.uk)

and a lot will depend on how the pooling teams have come together and set out the purpose of their initiative.

Costs for facilitation – at least for the set-up stage – need to be factored in. RUILS has not had start-up funding (apart from perhaps some small allocations for pooling in the support plans of some personal budget holders) but seeks to recoup its investment from supporting other initiatives. The RUILS guide on ‘Pooling Direct Payments’ details these and further success stories and provides an excellent start-up framework. It is structured in seven steps to getting ready to start pooling: ‘Pooling Direct Payments – Your ideas, Your Way’ is currently available for £6.95 from [info@ruils.co.uk](mailto:info@ruils.co.uk) .

### Strengths of pooling personal budgets

One of the criticisms of personal budgets has been that people end up in isolation (taken out of day centres, etc.) without having sufficient options available to spend their money on. Pooling can address this concern. If facilitated carefully on disabled people’s terms, pooling personal budgets creates an environment for inventive, varied and streamlined funding options and planning ideas. The approach has enabled growth in the market place and increased the range of available support, co-production and learning new skills for all local partners involved. Outcomes stated in the support plan can be more easily defined and measured than with individual provision of care and support. The support for those who pool their direct payments can then be more creatively tailored to the outcomes.

Pooling personal budgets helps multiply the benefits of personal budgets in that care and support become more personal, effective and efficient. The approach builds multiple circles of mutual support by tapping into wider community resources far beyond those for people with (similar) support needs. It also reduces the need for support. Satisfaction and independent living are greater, and in the longer term costs are reduced.

One pooling project we came across at a later point was initiated by carers to help their learning disabled relatives out of institutional care and be supported in the community instead. This case mirrors the story about how Direct Payments had come about – through a group of disabled people breaking out of institutional care to make their own more empowering and more cost-effective arrangements. Despite a sound business case (and the expressed wishes and feeling of the relatives) for a cooperative domiciliary care support agency, it took this project considerable efforts for more than a year to convince the adult social care department of the win-win solution at stake. This is an example of how far user-driven innovation can and

sadly often has to go in order to be picked up by traditional mindsets within in-house adult social care. In this case, even the commissioners themselves had to fight quite a few battles to achieve that success for all. There seems to be scope for better coordination in-house between the different council departments – let alone between different councils pioneering new pooling initiatives. Again, the lesson from this is that we need evidence and upfront investment in support set up by strategic commissioning. Only then can we systematically approach how similar pooling projects could evolve elsewhere and share the learning.

### Further steps in pooling personal budgets

A number of areas for improvement in relation to pooling personal budgets emerged which can be broken down into four broad categories:

- 1) Setting up and providing ongoing facilitation support
- 2) Evaluation, governance, liability and further practicalities to address
- 3) Finances (commissioners' interests in investing and reaping benefits)
- 4) Building bridges (across social care and health and between users and providers)

We will now go through these areas one by one.

#### 1) Setting up and providing ongoing facilitation support

Pooling personal budgets requires co-producing solutions with disabled people and maintaining a shared vision. Sometimes people are first having to find like-minded peers with whom they could begin to share such a vision if they are not already engaged in shared activities or arrangements. This can be facilitated by 'time banks' which may already run in the local area [www.timebanking.org](http://www.timebanking.org). An important role in building up such timebanks for personal budget holders and other citizens may not only fall to user-led organisations<sup>12</sup> but also to forthcoming local HealthWatch<sup>13</sup> (replacing former Local Involvement Networks LINks) – a new citizen-led process (established under the Health and Social Care Act 2012) to strengthen engagement with and representation of whole sections of the community including seldom heard groups.

Such engagement is initially to gather insights about local needs, assets and aspirations to feed into Joint Strategic Needs Assessments but often HealthWatch may at the same time help put in place innovative types of care and support, eg by linking up schemes such as crafts-based

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<sup>12</sup> NHS Choices list a range of independent living support agencies including user-led organisations <http://www.nhs.uk/servicedirectories/pages/serviceadditional.aspx?ServiceType=SocialCare>

<sup>13</sup> [www.healthwatch.co.uk](http://www.healthwatch.co.uk)



workshops in the community with pooling teams across a range of years of age. Local authorities may want to think about the extent to which they want to reflect such (additional) work in the commissioning brief for their local HealthWatch or user-led organisation.

Furthermore, the pooling of personal budgets could already be promoted at the assessment or support planning stages – either by voluntary community sector and user-led organisations involved with Direct Payment support or the in-house social services team at the local council. Subject to the consent of the people involved, completed support plans and reviews may be scrutinised to identify groups of people with shared interests which they may just not be able to pursue on their own. In all this, it is crucial to break out of defined *care areas* to ensure that pooling teams actually form on the basis of shared interests rather than needs. Such breaking out can also be an important driver for the team activity such as in the example of “Stepping on Out” described above who produce cards and thereby engage with the wider (local) public. The wider the initiative the greater the potential for tapping into further networks and resources.

Once people have got together, they need to agree on a purpose for pooling, and a framework to deliver it and also the criteria which they consider essential for some or all team members to achieve that purpose. If the purpose is about a micro-enterprise, then a business plan and a suite of essential policies are also required. Members also need to reach consensus on the type and level of support they require. If the initiative is funded, there may be a need for monitoring outcomes such as quality of life to satisfy the funder and inform further mainstreaming of similar initiatives. So what outcomes does the team find most appropriate to have progress measured against (this will be continued in the next section under evaluation)?

Throughout, it is important to shape and keep alive the shared vision. There will be times of dwindling interest, and it is important for the team to identify one or two champions or involve an external facilitator if possible. Personal assistants (PAs) do not become redundant as a result of pooling. Instead, PAs are essential in the transition and hence need to meet new personal requirements and be creative and committed to the approach. Although there have been several initiatives to support PAs (eg the Department of Health’s PA framework<sup>14</sup>), the

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<sup>14</sup>[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_128733](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128733)

specific environment of pooled budgets and the active role PAs need to play in this context do not seem to have been addressed so far.

2) Evaluation, governance, liability and further practicalities to address

In the spirit of shared learning, pooling projects should early on identify some outcomes which they hope they can most readily impact on with their initiative. This will help to keep the focus on real, hands-on improvements (and also help commissioners to justify any investment in related pooling projects elsewhere).

To this end, an evaluation at baseline and follow-up time points is key. Members of the pooling teams could assess themselves on fairly straightforward indicators such as 'quality of life', 'activation measures for self care', 'amount of GP visits per quarter' and any health outcomes. There will be further productivity gains which can be measured such as the number of referrals into A&E by the members of the pooling team. Finally, integration, i.e. the extent to which services and support have been joined up and centred around the individual across social care and health and community and primary care levels – both at the start and midway through the project –, is also an important outcome measure. An academic partner may advise on the evaluation part. Or this can be delivered by the commissioner's team directly.

Pretty soon some more formal and questions of the law will inevitably come up. For instance, what legal status will the pooling team have? What will the governance arrangements be, in particular when it comes to trading with third parties? How and by what methods will consensus be reached? When it comes to employing PAs, contracts and public liability issues arise which concern every employer of PAs. Forming a Community Interest Company (CIC)<sup>15</sup> is a fairly straightforward process, and this enables liability to be limited to a limited company, whereas in a consortium all members would still be liable individually.

Additional challenges may arise when it comes to tie up individual insurances and in relation to employment. At the time of writing this report, the two main insurance schemes had different arrangements in place: Peninsula<sup>16</sup> required an additional joint policy held by nominated consortium partners of the pooling team, whereas Fish Insurance<sup>17</sup> proposed adding a term on pooling to the existing individual policies. Employment contracts must always set out clearly who the employer(s) and the employee are, and liability cannot switch. It is recommended to

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<sup>15</sup> [www.cicregulator.gov.uk](http://www.cicregulator.gov.uk)

<sup>16</sup> [www.peninsula-uk.com](http://www.peninsula-uk.com)

<sup>17</sup> See for example <https://www.fishinsurance.co.uk/carer-and-personal-assistant-insurance.php>

set out a fixed-term contract for any temporary arrangement – for instance if a PA should be shared during the holidays only. Some PAs may wish to work under a self-employed status for which HMRC has set out rigorous tests – otherwise tax and national insurance are to be paid at source by the employer, i.e. the pooling project.

Most of the answers to these questions will evolve naturally in the process, and there should be a range of local infrastructure support organisations (such as user-led organisations<sup>18</sup>, local members of the National Association of Voluntary Community Action NAVCA<sup>19</sup> and Community Catalysts<sup>20</sup>) who can help. It is important to take care that such challenges do not take over the initiative and lead to its ethos being lost in bureaucracy. Often, it is better to slow down and obtain the necessary advice first.

- 3) Finances (commissioners' interests in investing and reaping benefits)  
The success and scale of pooling projects depend on the full commitment of the local authority and/or the forthcoming clinical commissioning groups, and significant interests have been created for them – in particular under the new Health and Social Care Act 2012. The Act has created duties<sup>21</sup> to ensure individual and collective involvement in social care and health provision which pooling initiatives can count towards alongside more system-based and hence limited drivers for involvement such as Shared Decision-Making (between different treatment options) for example.

As a matter of fact, direct payment holders already act as micro commissioners, although this role has been constrained in recent years. With pooling this role in shaping the local social care and NHS market can be much more readily recognised and scaled up. Commissioners need to be pointed at – by means of evidence from comparable projects if possible – what they may get out of investing in new pooling projects in order to put in that investment. For personal budget holders this means they need to provide information on the outcomes they aim to achieve and the likely resources required to get their pooling projects off the ground.

Currently, the lack of real investment in spending time with people on the support plan and providing support with managing personal budgets means that, in practice, many disabled people do not feel in control of

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<sup>18</sup> NHS Choices list a range of independent living support agencies including user-led organisations <http://www.nhs.uk/servicedirectorios/pages/servicesearchadditional.aspx?ServiceType=SocialCare>

<sup>19</sup> [www.navca.org.uk](http://www.navca.org.uk)

<sup>20</sup> [www.communitycatalysts.co.uk](http://www.communitycatalysts.co.uk)

<sup>21</sup> Involvement duties in the Health and Social Care Act 2012: Duty to promote involvement of each patient (13H) and Public involvement and consultation by clinical commissioning groups (14Z2)

them right at the outset. As a result, the benefits and productivity gains of more person-centred care and support can neither be imagined nor identified let alone reaped. If supported, pooling teams can mitigate some of this loss. However, the reality is that there is currently a culture of cuts which leads to two adversarial consequences.

Either control is taken back in-house. Or responsibility is being placed more and more on service users to meet their own needs with fewer resources or on carers. Often, these two consequences go hand in hand. As a result, disabled people are denied their right to participate in the community, their needs deteriorate much faster than with support, quality of life can diminish and the NHS (paid for by every taxpayer) eventually has to step in earlier and more frequently at greater cost.

All this cannot be turned around with just a small allocation (say 5%) for pooling in the support plan of the individual. It is pivotal that care and support is much better joined up with free community support, but any progress in simply replacing the former with the latter will inevitably make things much worse. There needs to be far greater and more strategic and system-wide investment (including for peers to promote pooling in the first place to support people to make informed choices from the outset) given the great benefits that commissioners (and also providers if incentivised accordingly) can reap: ultimately happier and healthier communities.

The Stockport story (see chapter on third stepping stone) demonstrates an example of how a user project (peers setting out improved access and discharge pathways in mental health) can be initiated by a commissioning team. There is no reason why this or a similar initiative could not be taken on by a pooling team elsewhere on their own terms.

#### 4. Building bridges (across social care and health and between users and providers):

User-driven commissioning deliberately builds on local pairs of commissioners and innovative user projects in the first instance. These pairs can act as strong local pillars ensuring the clarity and coherence of the approach. However, further down the line other stakeholders need to come on board. For pooling projects to come to fruition, a much wider infrastructure of like-minded support is required.

Providers need to prepare for personal budget holders (acting as micro commissioners), and statutory commissioners need to put in place real incentives for providers to get ready for marketing improved services to pooling teams (demanding more flexible and personal solutions).

For individuals the option of individual (provider-held) service funds (ISF) has been created. When someone wants to use their personal budget to buy support from a chosen provider, that provider can use the person's budget (or part of it) on their behalf in the way that the person specifies. There are two ways that providers can develop ISFs<sup>22</sup>. One is to respond to individual commissions from people or their families acting on their behalf, or from care managers through the commissioning process. The other is to proactively transform the block contract monies that providers receive and commit to using that money in an individualised way – in partnership with the commissioner. Time will show whether pooling can be arranged between different individual service funds in the same way as between personal budget holders.

At any rate, there are practicalities described throughout the report which need to be addressed by a wider pool of agencies in terms of support and specialist advice that is tailored, flexible and entrepreneurial, i.e. promoting self-initiative. The policy shift from commissioning services to commissioning outcomes should help with putting user projects at the centre of delivery. However, the major barrier with getting providers on board is that often their contracts do not incentivise true personalisation let alone defined outcomes or pooling. Moving from block contracts to framework agreements (where a council can request a service from a selection of providers without committing to a fixed provision) or even spot contracts (where terms, conditions and price would be negotiated separately for each transaction) would certainly pave the way for pooling. Providers fear the 'extra work' for a much more empowered citizen approach as this may challenge established short-term business models. So this again requires a discussion with both commissioners and providers on outcomes-based rather than service-based contracts which allow for and build in individual choice.

Some providers are already proactive in responding to needs and aspirations from service users. The Gateshead story (see chapter on third stepping stone) demonstrates how a provider-led consortium can kick off a fully fledged user-led Community Interest Company (disabled people supporting peers across whole life domains) and thereby act in its own interest. There is no reason why the learning from this initiative could not be applied to help pooling projects but then great care needs to be taken to build in the necessary 'user drive' from the outset.

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<sup>22</sup> <http://www.groundswellpartnership.co.uk/choice-and-control-for-all>

## Conclusions on pooling personal budgets

Perhaps the most exciting prospect of personal budgets is about pooling them in order to multiply their benefits – bringing together the strengths and assets of the personal budget holders but also those of their networks and whole sections of local communities. It should not matter in what form the personal budget is deployed or taken out, i.e. managed by another agency or as a Direct Payment. Commissioners need to be prepared for, foster and invest in pooling projects to build up greater evidence for what works.

As this is still a very new initiative, time will show what further benefits can be reached, as to whether pooling teams will actively exert influence on relevant commissioning decisions or even themselves deliver peer support as a defined and costed element of new care pathways. Could pooling even transform the care and support sector through economies of scale?

It is essential for pooling teams to build on their own initiative. Sometimes, enormous cultural resistance has to be overcome within a council despite a sound business case already having been made, as in the example of a cooperative domiciliary care support agency which could finally be set up. At any rate, there should be a 'get out' clause in place at any point in time, especially during difficult negotiations on pooling budgets with the council.

A lot of (facilitated) time and energy needs to be put in at the beginning in order to get a project off the ground and enhance the building of positive relationships and trust. A dedicated person or rather a set of champions with the right skill set is needed to ensure that the approach is inclusive at all stages, can gain momentum, overcome dwindling interest and achieve sustainability. This requires business and entrepreneurial skills as well as experiential knowledge of disability based on the social model of disability.

This investment certainly goes beyond that required for related timebanks – bringing together local people so that they can exchange their distinct skills. How can timebanks open up to accommodate the support needs of disabled people who may not always have something to give in return – except their personal budget? Pooled personal budgets may just be that distinct element lacking timebanks which can be far in reach but are often less sustainable as they do not usually form around significant support needs of the individuals engaged in them. How can we get better at

identifying and evaluating this increased social value locally? Relevant work would certainly be supported by and contribute to the implementation of the Social Value Act<sup>23</sup> from January 2013.

## **Second stepping stone – How can collective user insights inform de/re-commissioning and what levers enhance a move towards more demand-led provision with and for service users?**

We started with the expectation that involving disabled and older people and other service users in (joint) commissioning would increase the range of available support and hence make it more personalised, effective and efficient. A key vehicle for this would be that outcomes for contract monitoring and service reviews could be directly informed and set by the users of services. In effect, disabled people and other service users could exercise greater levels of choice and control, and this would also lead to more joined up services and support. This ‘push for choice’ would be facilitated by new cross-sector care and support pathways with ‘bundled, proportionate tariffs’ for particular stages associated with specific outcomes.

We found that having established and strong relationships between commissioners and service user projects and organisations was critical to achieving certain milestones towards this fundamental change.

So far three of the six pilots have directly focused on user insights informing de- and re-commissioning – two with a one-off approach applied to specific care areas and the other pursuing co-production across the different stages of the commissioning cycle, breaking out of the constraints of defined care areas and departments.

### Co-production – gathering and using individual data to inform strategic commissioning in representative involvement sessions

The Lancashire and Hartlepool pilots produced abridged versions of the Department of Health paper on using person-centred data for commissioning: “Working Together for Change<sup>24</sup>” (WTFC). This uses a series of ‘coat-hangers’ to explore what is working and what is not working. People vote for what they want to change.

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<sup>23</sup> <http://www.legislation.gov.uk/ukpga/2012/3/enacted>

<sup>24</sup> <http://www.lancashire.gov.uk/acs/sites/commissioning/toolkit/display.asp?siteid=5081&pageid=32699&e%E2%80%93>

It works by putting people at the centre of the commissioning cycle. The cycle includes four elements over eight stages: to analyse, plan, do and review. It involves citizen engagement to improve commissioning across the local community. The aim is to understand what makes sense to people, enabling them to be involved effectively in the design of services and support. The approach includes events with service users, commissioners, carers and a range of professionals to evaluate services – for example, professionals involved in dementia day services, safeguarding and reablement. Stakeholders should participate in equal ratios. Throughout, it draws on the experience of people using self-directed support.

#### Snapshot from the roundtable

Q The shift from a needs based approach to meeting aspirations is being undermined by the cuts – how can we meet this challenge?

A Inevitably there are resource constraints. Many local authorities are trying to protect the front line. We have to move to a citizen-based approach, where the person is the expert on their own life. Local authorities are shrinking in size and their staff will never have time to be the expert in people's lives. The expertise in communities and individuals needs to be recognised and supported. This is where the assets are. But there needs to be start-up funding to support these and to achieve real improvements in people's quality of life.

#### Strengths of the 'Working Together for Change' approach

In Lancashire, action plans have been developed and examples include:

- Personalisation in relation to the 'stroke pathway'
- Bringing all stakeholders together to identify themes to kick-start the Health and Wellbeing Board being set up under the Health and Social Care Act 2012

The scheme works on the principle of "You told us this, so together we have done this". It offers a process for aggregating individual views to influence strategic commissioning, sometimes gathered from a great number of individual working sessions. A lot of practical improvements have been made that do not cost additional money.

WTFC has raised many issues which have been taken forward under these arrangements, for example over balancing safeguarding against choice and control. Progress is tracked, and milestones are incorporated into



strategies (for example, a dementia strategy). Issues are also incorporated into service specifications and regularly monitored. For example, the approach has been used to track service development with people who had recently experienced a stroke. Action plans have been cross-referenced with the quality markers that are part of the local stroke strategy. The process provides evidence to drive improvements and help make 'universal' services more responsive. In turn, disabled and older people who have been involved are now telling a different, more positive story about their services, and this has positive knock-on effects on their networks, neighbours and friends as potential service users as well.

Hartlepool has applied the WTFC approach to its day opportunities provided in-house. This has likewise led to an action plan based on what is working, not working and needs to change. The WTFC process has also been used to provide people with Autism the opportunity to develop a commissioning strategy (currently being drafted by a user-led organisation). Taken together, the outcomes from both reviews have enabled two of the in-house services to offer supported employment and also opened day services to people with Autism. Furthermore, the reviews have informed initiatives to align the council's services and to provide greater flexibility and extend the use of personal budgets from other funding streams in health (Personal Health Budgets) and education (Education Funding Agency).

Further steps in 'Working Together for Change'

The approach helps gather a lot of data on user experience for quick implementation across whole systems, but it does not necessarily shift these systems more fundamentally towards user-driving commissioning. The drive towards improvements still largely rests with professionals and their networks which reinforces the current divisions of care areas and social care departments. To an extent, these limitations can be overcome. Hartlepool has handed over a significant part of the approach to a local user-led organisation, and the approach created momentum reaching far beyond social care where it had been initiated. Lancashire has used the approach to ensure that 'potential' and not just current service users can be integrated from the start to ensure a much wider community focus.

Snapshot from the roundtable

Q	How could building stronger and more sustainable user groups of disabled and older people strengthen this approach?
A	Stronger groups can have more influence. But it's important to gather all views – those of potential service users and families as well as existing service users. It's about bringing these different perspectives together.

## De-commissioning in-house care and block contracts to free up resources and innovate: a chicken and egg dilemma?

The Essex site focused on how best practice in user-driven commissioning can evolve in the longer term. There is a long established, positive but challenging relationship between the Essex Coalition of Disabled People<sup>25</sup> (ECDP) and Essex County Council. The user-led organisation ECDP has focussed on the ‘lived experience’ of disabled people, developing collaborative services that are designed and delivered by disabled people. They create a disability voice through collaborative approaches. In a commercial context, this would be called ‘market intelligence’ or ‘customer insight’ – hardwiring demand into the ways care and support is being provided to ensure that care and support is personal, effective and efficient.

### Snapshot from the roundtable

Q Can you explain more about what you mean by “lived experience”?

A “Lived experience” is about capturing what day to day life is like for disabled people and other service users. This data should feed into Healthwatch and inform commissioning, through service user champions. It is also about tapping into resources, aspirations and enabling disabled people to be part of the solution – that means, for example, disabled people delivering better services for peers. Coming together and using lived experience can be very powerful.

Essex started discussing and introducing personalisation very early. The personalisation strategy was taken forward rapidly. A formal strategic partnership was established to do so, based on the goal of co-production and involving a secondment to the ULO from the local authority of a key worker to support it. This would not have been possible at the time if it had been competitively tendered. It needed a strategic partnership approach.

Personalisation has shifted the primary relationship. Formerly, this was between the local authority and care and support providers. Now instead the relationship is between the service user and the provider, with the user-led organisation acting as a go-between in a supporting and facilitating role.

## Strengths of continuous user input in de- and re-commissioning

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<sup>25</sup>[www.ecdp.org.uk](http://www.ecdp.org.uk)

On the back of this clear and mature long-term relationship, the strategic partnership in Essex has made a number of achievements.

There has been an 8% increase in the number of service users receiving Direct 'cash' Payments as opposed to care and support managed by the council 'in-house'. Interestingly, there was also a 10% increase in the actual value of those cash payments (when many other councils have been reported to cut spending in the transition from council-managed care to a Direct Payment). ECDP has also been instrumental in proposing improved regulations for the Right to Control<sup>26</sup>, and Essex has become one of seven Right to Control Trailblazer sites. As a result, user-led organisations are now able to carry out non-complex reviews in social care for example.

Snapshot from the roundtable

Q	Have local authority staff felt undermined by ECDP doing non-complex reviews?
A	There were concerns among social workers at first that this undermined their role, but they are now on side. There is likely to be a shift towards more self-assessment, but there will still be a role for social workers. A good communication strategy is needed to win hearts and minds. Local authorities are increasingly becoming commissioning organisations, not providers. As staff leave, Essex County Council considers whether their salaries could be better used to commission more support from ECDP and others.

In the meantime a real shift towards user-driven commissioning has taken place. This is reflected in a number of further significant improvements:

Essex County Council has moved away from large block contracts to framework agreements in 2011. A framework agreement does not commit the council to purchasing any volume of work from any one provider, but it allows the council (and potentially personal budget holders and pooling teams) to select an appropriate service for a shorter period of time from a wider selected range of providers.

It is now not just the case that services are being procured but performance is measured on the basis of outcomes achieved for and with the individual.

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<sup>26</sup> The Right to Control is a new legal right for disabled people. It gives disabled people more choice and control over the support they need to go about their daily lives. Disabled adults living in seven test areas will be able to combine the support they receive from six different sources and decide how best to spend that funding to meet their needs. See <http://odi.dwp.gov.uk/odi-projects/right-to-control-trailblazers.php>

There is also a more balanced weighting of criteria, with less emphasis on price, approximately 60% weight on cost and 40% weight on quality.

ECDP won a tendered service for support planning, and peer support was put in place to deliver non-complex reviews. All forms were overhauled to ensure a simple, user-friendly presentation that does not need guidance.

### Further steps in continuous user input in de- and re-commissioning

A number of challenges are also still apparent all of which emphasise the coherence of the path the strategic partnership in Essex has taken so far.

- 1) De-commissioning needs to lead to greater resources for peer information, advice, advocacy (strengthened customer insight role)  
Quick wins should not overshadow the need for the delivery of sustainable long-term solutions. If the default position for service users is to take cash payments as Direct Payments, then there is a need for the provision of high quality information, advice, advocacy and guidance to empower people to take on that role. This is a particular difficulty in a time of heavy cuts. Yet, peer information and advice are critical to manage and make the most of Direct Payments – both for the council and the people who hold them. Therefore, proper information, advice, advocacy services and guidance need to be commissioned alongside core services in social care and health, and a business case for those supporting services has to be made.

More support planning means there must be resources freed up by de-commissioning large block contracts by local authorities to avoid double running. There is a risk that local authorities will still use in-house staff and that this will create barriers to real transformation. Conversations are needed about further innovation such as pooling personal budgets – in the absence of funding ECDP has had to set up its own pilot selling peer support units to self-funders for a trial period. There are also many other conversations to be had – this is only one of a number of priorities.

In turn, ECDP needs to compete to provide services for disabled people. There are risks and challenges around the transition. ECDP knows its unit costs, but must move on to think about costing and pricing its services, based on a contribution towards outcomes which ECDP can reasonably claim and which have been co-produced with disabled and older people beforehand.

2) Joint commissioning must be reflected in integrated care and support pathways with a range of providers

While delivering its part of the transformation in commissioning, ECDP's primary relationship must continue to be with disabled people to gather and voice needs, experiences and aspirations. At the same time, ECDP needs to engage with the emerging structures under the Health and Social Care Act 2012, eg HealthWatch, Joint Strategic Needs Assessments and the Health and Well-Being Board.

Furthermore, ECDP is having to learn to work with commercial organisations, that is to operate in a commercial environment and in partnership with commercial organisations. Like some larger providers ECDP itself has had to shift from tendering for block grants to hourly rates for services. The lesson for ECDP (and for other providers) is that new types of support have to be co-produced with and then marketed to disabled people. As a result, ECDP are anticipating and preparing themselves for new joint venture models and governance arrangements involving commercial organisations to deliver pathways together. This requires new skills and understanding on both sides. This uncharted territory carries risks, but ECDP does not feel there is any going back to traditional arrangements. IF ECDP is to maintain its commitment to a social model of disability based approach, there will be new and additional tensions coming up.

Snapshot from the roundtable

Q How will you deal with these pulls in different directions – between functioning in an increasingly commercial context, alongside and in partnership with commercial organisations and retaining the values of a user-led organisation?

A Our values and the primacy of “lived experience” need to inform the strategic direction. In terms of governance, ECDP would retain at least 51% of the business to ensure it is led by disabled people.

Conclusions on the prospects of collective user insights to inform de/re-commissioning?

The Lancashire and Hartlepool sites have shown how quick wins can be achieved by adopting the ‘Working Together for Change’ approach on an *as and when* basis. This process can act as a significant push for and align ‘internal’ improvements between different care areas and even spark new

day and employment opportunities. Thereby, disabled and older people are not directly acting as the driving force, and control is largely retained in-house. The approach does not seem to be easily adoptable for a Pan-Disability perspective across impairments. That is, once the findings have been gathered, it is usually for the professionals to act on them for each single care area. On the other hand, a council-managed impairment-specific approach may well engage wider sections of the community and also reach potential rather than just existing service users. It is then for the council to bring the different perspectives together and achieve consensus.

By contrast, ECDP and Essex County Council have engaged in a long-term strategic partnership and both have built on high visibility and reputation in the local area. They have demonstrated some of the multiple benefits that can be reached on the back of strong and lasting co-production between innovative user initiatives and commissioners. They have also found that – once they have taken that path – they need to continue in transforming the ways care and support are commissioned or risk losing everything.

This also means engaging with the emerging local democratic structures such as HealthWatch (replacing former Local Involvement Networks LINKs) with a seat on statutory Health & Wellbeing Boards, which can all helpfully pave the way for greater investment into user-driven commissioning as a whole. By building on existing and far-reaching user involvement, Joint Strategic Needs Assessments (JSNAs) can truly evolve from and be directly informed by the expressed needs of people with support needs themselves. Mapping services and community assets and resources that reflect those expressed needs comes next, and this would be fed back to the Health & Wellbeing Boards via the new Health & Wellbeing Strategies.

This approach requires a certain power shift from local authority, clinical commissioning groups and contracted providers to innovative user groups of disabled and older people and patients. We have yet to see what works to change the culture and approach of providers and more traditional commissioners. Empowering user-led organisations to carry out non-complex reviews is certainly an essential step in that direction.

A strong local market firstly consists of a large number of providers and a great range of innovative types of support available for disabled and older people to choose from. Secondly, there is free entry into and exit from any market-customer relationship – moving from block to spot contracts (eg providers offering those who have pooled their personal budgets maximum flexibility for unplanned homecare arrangements). Thirdly, there is a comprehensive information strategy to gather insights from disabled and

older people and patients and inform them continuously about how commissioners have acted upon those insights – by setting up new support.

Commissioners need to define – by means of evidence from comparable projects – what they may get out of investing in continuous user input in de- and re-commissioning in order to put in that investment. We have found commissioners much more ready to be engaged with co-production where the emphasis is on ‘reconfiguration of services’ – shifting and freeing up existing resources to do new things – rather than requesting new resources.

To this end, user projects need to push commissioners for information on existing budgets spent on traditional care and support. Only from such open access to budget information and contract monitoring can meaningful debates, relationships of trust and sustainable win-win solutions evolve.

As a matter of fact, direct payment holders already act as micro commissioners but this role in shaping the local social care and NHS market needs to be much more readily recognised. There is plenty of evidence of positive outcomes as a result of the independent choices taken by individuals who have been supported and empowered to make them by user-led organisations, including potential productivity gains<sup>27</sup>. One of the questions arising from this is how these innovative individual choices can be built into the support portfolio available to everyone with support needs – with or without a Direct Payment in social care or the NHS.

Finally, local stakeholders need to be incentivised to collaborate in providing care and support – with individuals exercising informed choices between the diverse support options. Any transition from institutional care (eg day centres) to more innovative types of support should be co-produced, comprehensive, viable, clear and transparent. With their work on de-commissioning block contracts Essex has paved the way for user-driven commissioning and increased use of peer support at all junctions of care and support pathways. Other local areas may take this up by setting out integrated cross-sector pathways with bundled, proportionate tariffs for every agency involved. Particular pathway stages (associated with specific outcomes) could then be costed and allocated between a range of (‘any qualified’) providers. Peer support – and communicating the benefits of hearing from someone who has walked a similar path before – should be a defined element of these new pathways.

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<sup>27</sup> <http://odi.dwp.gov.uk/docs/ils/support-planning-and-brokerage-project-report.pdf>

## **Third stepping stone – how can peer support from service user/staff-led mutual organisations achieve better quality and value for money?**

We expected to gather insights leading to some kind of route map on how disabled and older people could be supported and funded to both access and deliver peer support. Peer support can help contextualise a condition or support solution within the person's whole life domains – for instance, 'how best to go about preventing soars?' or 'how will this equipment or new medication affect my work and social activities?' Another role is to facilitate choice between different support options. After all, peer support is often experienced as the greatest contributor to positive health and quality of life outcomes by those few who have come to know about and access it. Most peer support is non-tangible, that is people subconsciously pick up on what peer supporters do and wish to prove to themselves 'I can do this or get it done by myself'. Peer support also offers considerable productivity gains to be made for commissioners, if there is sufficient backing behind it.

However, in many local areas the commissioning process already feels fragile. Creating paid opportunities for and building peer support into care and support pathways is often the least commissioners have in mind. More than once we have faced reservations like 'I've got to fill a day care gap in learning difficulties by next Tuesday so better don't come up with that now'. Innovation of the kind we were focusing on demands taking risks and a strategic approach, but the current environment is not an easy one to support that. On the other hand, which climate would support tapping into user expertise more consistently if not the current austerity measures?

There are a great number of initiatives to put in place volunteer 'peer supporters' to support service users to get the support they want. However, this risks that neither the volunteers nor the commissioners (or providers) commit to fully delving into peer support. It has become clear that there is a long way to go to create fully fledged mutuals and social enterprises that are either user-led or at least jointly led by peers and social care staff – which have clout locally and can pay everyone involved.

Three sites in our programme focused on peer support with the aim to make it a more or less independent and costed element of care and support provision in the longer term. The first two of the sites acted on their own initiative without any funding from commissioning budgets (solely relying on fundraising and a small allocation from a development grant held by Disability Rights UK). The 'user-driven commissioning' programme has enabled both these sites to start making a business case to commissioners



so that innovation can first be tested out and then mainstreamed locally. The third site has embarked on a journey to set up peer support ‘in-house’ from within the adult social care department of the local council, and over time a critical mass was achieved to win over staff and change the culture.

Peer Mentors established by a voluntary community sector (VCS) consortium – Gateshead “Seed Commissioning”

A consortium of voluntary community sector (VCS) agencies in Gateshead was formed (led by Sight Service<sup>28</sup> together with Age UK; Alzheimer’s Society; Your Voice Counts; Mental Health Matters), and a programme board was established. Their key aim from the outset was to develop a social enterprise that would create employment for disabled people to support peers in navigating the health and social care system. Peer mentors were then recruited as volunteers to support disabled and older people in accessing personal budgets – directly building on their own experience in managing personal budgets.

Snapshot from the roundtable

Q	How is the project managed with all the different partner agencies involved? What holds them together?
A	Different partner organisations have recruited different peer mentors. There is a co-ordinator and they have developed good relationships across the organisational boundaries of the partners.

The project provides a user-led one stop shop for people taking up personal budgets, along with training and employment opportunities for disabled people. It has now been running for almost three years and has 20 peer mentors reaching 350 people with a wide range of support needs every month. These encounters provide disabled and older people with first-hand insights on what differences personal budgets can make to independent living and choice & control. Later on, peer mentors would support their peers across the whole personal budgets process from (self-) assessment, resource allocation, support planning through to review stages.

Snapshot from the roundtable

Q	Do you aim for an inter-generational approach?
A	This can happen. Older peer mentors may not necessarily support other older people, so there is an opportunity to match people in different ways, maximising what works best for them.

In an attempt to pick up on the 'real' whole life domains of disabled and older people, there are plans to go beyond social care and health and extend peer support around welfare reform and benefits such as Employment & Support Allowance and (forthcoming) Personal Independence Payment (PIP). Some consortium partners also support disabled people into employment, a role which may likewise be increasingly passed over to peer mentors.

A further line of work is about engaging with care providers (beyond those directly represented in the VCS consortium) to establish an independent and direct 'quality checking' role for peer mentors. Furthermore, some peer mentors contribute their insights at strategic levels, eg the council's Personalisation Board. In the process some peer mentors have gained an NVQ3 in advocacy, and there is now increasing recognition at the council that (peer) advocacy not only enhances positive health and service quality outcomes but also improves efficiency (as bottlenecks in the system are more easily spotted and more readily rectified).

The programme board has founded a Community Interest Company (CIC). Several successful funding bids have – independently of the council – enabled the programme board to work with and strengthen the voice of disabled and older people and also to prepare a business plan to ensure sustainability. The key aim now is to find a mechanism to pay the (as yet voluntary) peer mentors, offer annualised hours and enable them to obtain stakes in the CIC. As yet, two of the three directors are disabled, and the programme board is writing up a strategy for the CIC to become fully user-led in everything it does.

### Strengths of peer mentoring established by voluntary community sector (VCS)

With its plans to extend peer support beyond social care and health to welfare benefits, this VCS consortium shows remarkable capacity to join up support around the 'real' whole life domains of disabled and older people. This rationale is also reflected in the engagement with a wider network of local care providers to establish an independent and direct 'quality checking' role for peer mentors.

Both approaches to expand the role of peer mentors help make peer support rooted in a better joined-up universal system while increasing its accountability to the users of its services. Taking on such a far-reaching initiative is certainly a great advantage of working through a consortium of established local voluntary community sector (VCS) partners.

## Further steps in peer mentoring established by voluntary community sector (VCS)

### 1) Building user voice as key asset into the governance of the CIC

The downside is that with such great momentum direct user voice may not have had the attention required to form a fully-fledged user-led mutual. Important questions need to be asked and resolved. For instance, how and by what methods will a mission statement be set out and consensus be reached between peer mentors? How can the peer mentors be empowered in identifying and using their very personal assets and sometimes very fresh and frustrating experiences with social care, health, welfare reform and employment? For peer support to reach its greatest effect, the peer mentors need to be empowered to find their own diverse ways of supporting others – without replicating what professionals do but acting truly independently of them.

This may be the time for the three CIC directors to allow for space to strengthen the company's user-led asset and adjust its pace if necessary.

### 2) Contracts and legal matters

Business planning, contracts, and legal matters need to be further addressed on the terms of the peer mentors themselves. What is the *cutting edge* peer mentors feel they can bring to the care and support system as a whole? How can their added value be established and marketed? In all this there should of course still be infrastructure and facilitation support from the programme board and other agencies to the CIC, but a pathway to increasing independence should be set out.

When it comes to formal trading, contracts and public liability issues will arise as concern every social enterprise – some of these challenges we have addressed in the chapter on the first stepping stone, i.e. pooling personal budgets. For most of these questions there should be a range of local infrastructure support organisations (such as user-led organisations<sup>29</sup>, local members of the National Association of Voluntary Community Action NAVCA<sup>30</sup> and Community Catalysts<sup>31</sup>) who can help.

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<sup>29</sup> NHS Choices list a range of independent living support agencies including user-led organisations <http://www.nhs.uk/servicedirectories/pages/servicesearchadditional.aspx?ServiceType=SocialCare>

<sup>30</sup> [www.navca.org.uk](http://www.navca.org.uk)

<sup>31</sup> [www.communitycatalysts.co.uk](http://www.communitycatalysts.co.uk)

### 3) Aligning service development with (joint) commissioning from council NHS and further statutory providers

With the fast pace and largely independent journey taken by the VCS partnership there is a risk that plans are not sufficiently joined up with support commissioned by the council, NHS and Jobcentre Plus. There could be duplication of efforts and spending with disabled and older people missing out on the sustainability of the good outcomes which may otherwise be achievable. Therefore, it is crucial to build up an evidence base for statutory services to draw on and increasingly bring in and align their commissioning budgets with the support that has been set up.

In the spirit of shared learning, the CIC should early on identify some outcomes which they hope they can most readily impact on with their service of peer mentoring. This will help to keep the focus on real, hands-on improvements (and also help commissioners to justify any investment in this and related peer mentoring projects elsewhere).

To this end, an evaluation at baseline and follow-up time points is key. Just as outlined for pooling projects (in the chapter on the first stepping stone), those benefiting from peer mentors could assess themselves on fairly straightforward indicators such as 'quality of life', 'activation measures for self care and peer support', 'amount of GP visits per quarter' and any health and employment outcomes (insofar as applicable). There will be further productivity gains which can be measured and compared over time such as the number of referrals into A&E and any other routine data on service use. Finally, integration, i.e. the extent to which services and support have been joined up and centred around the individual across social care and health and community and primary and secondary care levels – both at the start and midway through the project –, is also an important outcome. Pathway protocols combined with 'quality of life' indicators would potentially be very important measures. An academic partner may be available to support the evaluation part. Or this can be delivered by the commissioner's team directly.

### Peer support piloted with self-funders

Building on their high visibility as a local user-led organisation, the Essex Coalition of Disabled People (ECDP) has put in place a pilot to test a peer support service. This relates to peer support across the personal budget process from assessment through to review stages. The service is marketed to self-funders in the first instance. The approximate cost for the

service charged to self-funders is £200 for support from a peer over a defined period. Peer support can be accessed on an as and when basis but – depending on the pilot findings – there may be a time limit or an account of hours put in place to access peer support.

This pilot rather than a fully-fledged service has been established due to the lack of funding. The findings will help build up the much needed evidence base for Essex County Council so that peer support can be delivered to older and disabled people who (start to) manage council-funded personal budgets.

### Establishing peer support from within a commissioning team

Ten years ago Stockport<sup>32</sup> ran a traditional mental health service. Mental health commissioners saw their role in ensuring statutory and acute provision. There was little preventive work or support. User voices were not strong or developed let alone taken on board.

Over time, a partnership with Stockport MIND<sup>33</sup> and the user-led organisation 'All Together Positive'<sup>34</sup>, developed a number of initiatives. This included value-based awareness training. It sought to shift the focus from rehabilitation and 'curing' towards 'recovery'. A value-based approach was introduced, which placed the emphasis on 'seeing the person, not the patient'. There was a clear commitment to positive risk taking. People were seen as assets, who were able to contribute. This approach is consistent with person-centred support and personalisation.

Stockport council then ran a pilot scheme using Direct Payments to enable people with mental health difficulties to do very different things. Support planning was aimed at supporting people to take up and follow their aspirations and dreams.

Nevertheless, it turned out that clinical support planning was still very different from what was by then envisaged as 'peer-led support planning'. The council recognised that professionals tend to professionalise support planning without necessarily passing on choice & control and seeking

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<sup>32</sup> [www.stockport.gov.uk](http://www.stockport.gov.uk)

<sup>33</sup> [www.stockportmind.org.uk](http://www.stockportmind.org.uk)

<sup>34</sup> <http://www.alltogetherpositive.org/>

solutions rooted in the person's strengths. While at the surface this can look like proper support planning, it may in fact still be very similar to traditional care planning. By contrast, peer-led support planning has made it possible to co-produce more creative support plans at people's own pace in their own styles. Key to this is that peers are supporting each other with support planning and training. This has begun to change the culture in-house including for those mainly supported by council-managed care and support.

#### Snapshot from the roundtable

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|---|--|
| Q | For peer to peer support to work, we need to change the traditional dynamic with professionals. How do we break this down?   |
| A | It's a journey. For Stockport, this journey started ten years ago. There have been a number of watershed moments - recognition of the importance of user voice and the need for leadership to drive forward a recovery approach. Narratives of success stories win the argument. You need to build a critical mass of support. |

This move towards the recovery approach was heavily driven by the engagement of external agencies. The user-led organisation All Together Positive and Stockport MIND have jointly developed 'wellbeing pathway planners'. This is a peer review service to help people review their plans which they own themselves. Other resources that have been developed include a one-stop shop, a peer brokerage service to provide advice and support about what support is available and the 'My care, my choice' website which offers information, support and guidance. This is neatly summed up by All Together Positive's strap line: *Inform, involve, inspire*.

At the same time, commissioners managed to set out more holistic support pathways and along the way reaped financial benefits as well. Mental health services in Stockport scrutinised and aimed to avoid unnecessary admissions to the acute trust where this previously would have been accepted as a matter of routine. Instead of waiting for people to reach crisis, mental health services improved the ways people can get support in the community at much earlier stages (improved access pathways). If people do have to be admitted, much greater efforts are now being taken to support them to get out of the mental health system earlier or at least be referred to lower intensity support (improved discharge processes).

To being with, peer volunteers and social networks were established to spot and focus on particular 'early warning signs' of:

- people on the care programme approach (CPA) who had specific barriers to discharge
- outpatients of psychiatrists who were only being seen once a year

This has led to a number of schemes and initiatives to focus on specific barriers. These initiatives included:

- a peer prevention service (where the support from peers right at the outset establishes self-help and thereby helps prevent a crisis)
- stepped support (where the person does not face an *all or nothing* choice but can engage flexibly in support and then step up or down)
- a community-based well-being hub (which brings together a diverse range of support all available in a one-stop drop-in setting)

All these initiatives and schemes involved rethinking relationships and power as people with mental health issues were co-producing them.

### Strengths of establishing peer support from within a council

Stockport council has acted in line with the national policy context by introducing stepped support, revamping the 'Care Programme Approach' and generally enhancing pathways to recovery. This has certainly happened in many places over the last few years. However, in doing so, Stockport has over time managed to *let go* bit by bit in favour of the partnership with the user-led organisation All Together Positive and Stockport MIND.

Together they have gathered and shared a lot of evidence as to why commissioning peer support (to hear first-hand about positive recovery pathways) is beneficial for people with mental health problems, the peer supporters themselves and crucially the mental health system as a whole.

As a result of the productive partnership, there are now a range of beneficial flexible and personalised pathways (including peer support as a defined element) which have been made accessible to people with mental health problems across social care and the NHS. At the same time, adversarial pathways have been reduced or abolished. A great deal of this agenda will be taken further by linking GP practices and outpatient clinics to the well-being hub. There is no reason why such cross-sector integrated pathways with a range of providers to choose from should not be replicated in other care areas beyond mental health.

## Further steps in establishing peer support from within a council

The journey to offer more community-based solutions that are designed and jointly delivered by service users and carers continues very effectively.

There have been plans for peer volunteers and social networks to spot and focus on particular 'early warning signs' of people attending accident and emergency services (A&E) with mental health or alcohol problems. This could further improve access and discharge pathways. However, political sensitivities (between foundation trusts and Primary Care Trust) required Stockport Council to put these plans on hold for the time being.

Stockport Council have set up a co-produced Mental Health Collaborative Co-Design Forum to inform commissioning decisions with provider, user and carer representatives alongside clinicians and commissioners – to receive data, analyse, interpret and inform changes. A business case is being developed supplemented by a data warehouse. As part of this they have begun to gather several measures at baseline and follow-up time points over the next two to three years:

- Reduction of referrals to Pennine Care NHS Trust Access Point from GPs
- Reduction in returns to Pennine Care Access Point for the presenting problem or similar
- Reduction in returns to GP for the presenting problem or similar
- Reduction of the average length of stay within Pennine Care community MH services
- Reduction in returns to Pennine Care community MH services for people discharged
- Self Directed Support savings achieved by attaining outcomes
- The sustainable outcomes achieved, as measured within the newly developed Social Inclusion Outcomes Framework

In all this there is however a danger that the partnership relies too heavily on agenda-setting by the council and on commissioning imperatives per se. For peer support to reach its greatest effect, the peer mentors need to find their own ways of supporting others – without replicating what professionals do but acting truly independently of them. As for the VCS-led peer mentoring project in Gateshead, this may be the time for the partnership to allow for greater space to further strengthen its user-led asset and focus and adjust its pace if necessary.



## Conclusions on peer support from service user/staff-led mutual organisations to achieve better quality and value for money?

Traditional mainstream cultures remain the biggest barrier for user-led mutuals to be recognised and accepted, so that they can serve as a catalyst to real and long-lasting whole systems improvement and more positive health and quality of life outcomes. Fundamental change in service, organisational and commissioning cultures is still needed.

The three sites have revealed interesting and distinct points of departure in proactively establishing peer support. Unfortunately, - unlike the project examples for pooling in the corresponding chapter - for peer support there was no initiative departing solely from a small group of disabled and/or older people without back-up from an established organisation at the outset. It would have been interesting to explore their journey to providing (paid) peer support – if this had been possible at all. On the other hand, across the country there is certainly a lot of diverse activity in setting up peer support but the question is how independent, comprehensive, influential and sustainable such schemes (mostly provided by volunteers) truly are.

For peer support to reach its greatest effects, people with support needs and their organisations should not be trapped in service delivery. One certainly needs to be involved in delivery to make a change. But of equal importance is the capacity to step back from the system and reflect on what peer support is and how it can be further developed in its own right. It can be difficult to strike that balance as for any new user-led organisation.

New innovative and cost-effective care and support pathways are often informed or even sparked by peer supporters (eg in mental health). There is a stark contrast between the compelling evidence for the positive outcomes delivered through peer support<sup>35</sup> and also the softer evidence for user-led organisations<sup>36</sup> (which we hope to replicate in this programme) and the modest financial commitment to those mainly achieving those outcomes, peer supporters themselves: employment or stakes in fully-fledged user-led mutuals are often out of reach. The findings from the diverse imminent evaluations may demonstrate the win-win solutions from hardwiring paid peer support into the ways care and support is provided across the board.

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<sup>35</sup> See for instance report from former National Centre for Independent Living (now Disability Rights UK) [www.thinklocalactpersonal.org.uk/Browse/SDSAndpersonalbudgets/Supportplanning/?parent=2673&child=5962](http://www.thinklocalactpersonal.org.uk/Browse/SDSAndpersonalbudgets/Supportplanning/?parent=2673&child=5962)

<sup>36</sup> <http://odi.dwp.gov.uk/docs/ils/support-planning-and-brokerage-project-report.pdf>

Effective commissioning systems should pick up on the insights gained from peers and systematically build the learning into commissioning cross-sector pathways (such as those advanced in Stockport for mental health) with bundled, proportionate tariffs – including for peer support as a defined and integrated element. Particular stages (associated with specific outcomes) could then be costed and allocated to a range of providers.

Through their informed choices along these pathways, disabled and older people themselves would then validate what makes valuable contributions to their positive health and quality of life outcomes. The VCS partnership in Gateshead has paved the way for such pathways to go even further and include peer support across whole life domains such as welfare benefits and employment support. This way, holistic care and support would not only be led by actual demand – rather than capacity set by providers – but also joined up around people’s needs and aspirations. As a result, providers would be strongly incentivised to establish personalisation more akin to the levels enjoyed by those who hold and manage Direct Payments.

In conjunction with peers and VCS providers, this would certainly be one way for councils to implement one of the latest programmes put in place by the Department of Health to develop care markets for quality and choice<sup>37</sup>.

Finally, there is still a range of more practical challenges to be tackled. Commissioners (and those subcontracting peer support at their own initiative or by way of a contractual term) need to consider longer and hence more sustainable contract periods confined to mutuals covering smaller geographical areas, improved regulations for permitted work and test-trading (for those on benefits) in addition to safe profit margins. There are also still difficulties with Criminal Records Bureau checks as they cannot be obtained for oneself. What may help for tendering is that mutuals and user-led organisations more widely (irrespective of the business purpose at stake) can be exempted from the EU procurement rules if at least 50% staff are disabled.

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<sup>37</sup> The Developing Care Markets for Quality and Choice (DCMQC) programme runs from September 2012 to January 2014 and is available to all local councils, fulfilling the Government’s commitment in the Caring for our Future White Paper to provide support to help develop their market facilitation capacity. See <http://ipc.brookes.ac.uk/>

## **Break-out Session: Stakeholder-based discussions at roundtable**

A key aim for the roundtable was to bring together for the first time all stakeholders involved in developing user-driven commissioning across the sites. This enabled us to share and synthesise views, ideas and experience. But an opportunity was also provided for commissioners, user-led organisations and people with support needs to have their own discussions and then feed back to each other. The aim was for each to work on some kind of 'offer' to make to the other.

This final chapter therefore illustrates the direct contributions from all stakeholders as 'declarations of intent', further building on the concrete projects of the local sites.

### 1) Commissioners' discussion – strategic dialogue and open access to budget information

The starting point for this discussion was that joint commissioning of outcomes, alongside co-production, is vital for getting people's support right for the future and this requires dialogue. Existing procurement rules, or their interpretation, can act as a barrier. This is a systems issue – commissioners need to be creative. But it can be challenging for councils with their corporate procurement procedures, traditions and functions.

There needs to be an open, transparent conversation about budgets. This requires a maturity in the relationship between commissioners and service users and their organisation to enable up-front discussions about costs and budgets. For example, local authorities need to be clear and open about their unit costs to help user-led organisations develop meaningful business models. It still happens that a single service user can manage a great allocation of money attached to their support plan but in order to do so must choose from a limited, pre-set list of options; this means considerable user expertise and insight is being wasted while the individual is denied real empowerment. If one does not look at individuals but at pooling teams seeking to pursue shared interests, this waste from ignoring combined expertise and insight is multiplied.

There is a need to balance an 'evidence-based' approach with a values-based approach in order to secure senior management and elected members' buy-in for user-driven commissioning. This involves getting

better at evidencing well-being and social value, using social return on investment (SROI) or other models to help. The added value derived from support schemes to empower active and contributing citizens, paid peer supporters and whole sections of local communities needs to be taken into consideration in commissioning processes.

Some overarching issues:

- Local authorities are increasingly moving towards becoming slimmed-down commissioning only bodies, which requires a strategic enabling rather than 'doer' role.
- Local authorities need to get better at joining up commissioning – not just commissioning for social care in isolation, but taking a much broader perspective – a place-shaping approach. Leadership is needed in order to create and sustain this role for commissioning.
- There is still a lack of confidence about user involvement amongst many commissioners. This needs to change if we are to strengthen relationships with user-led organisations. A roundtable like this one can bring a lot of input for further whole systems improvement.
- Commissioners need to be proactive in nurturing new models and supporting user-led organisations to enter the market place. The policy environment needs to support this at a local and national level.

## 2) User led organisations' discussion – building up the evidence

The pooling guide produced by Richmond User Independent Living Service (RUILS) is seen as a good start. We need to know how we could approach a commissioner and engage in a more strategic dialogue to create win-win solutions. We need to package up our offers as viable business plans.

Pilots of at least three years duration are needed to see if projects will work and to create a product or establish a marketable offer.

In Richmond and elsewhere relationships are starting to develop with other London boroughs and across regions. This has the potential to develop into a cross-borough or regional model.

There is also a need to understand the commissioning language and framework to be able to negotiate it. User-led organisations need support to develop a more commercial approach. In all this, user-led organisations must continue to focus on the experience of and outcomes for the service

user. It is crucial not to lose sight of this. Finally, points of departure differ greatly between ULOs across the country, as is reflected by the diversity of the applications to the Office for Disability Issues' (ODI's) Facilitation Fund<sup>38</sup>. Hartlepool has been funded to provide disabled people with the skills and knowledge to understand personalisation and build up local voice while developing its ULO Incontrol-able. By comparison, the South East Network of Disabled People's Organisations (SENDPO) has been funded to build up further evidence and toolkits for commissioning (greater volumes to) established user-led organisations.

### 3) Service users' discussion – start-up funding for off-springs from user-led organisations

The current context for most service users is unfortunately one of fear and anxiety rather than opportunity. We face a double whammy, encouraged by policy rhetoric. First there is a lack of work opportunities and second, there are difficulties with accessing and maintaining welfare benefits where necessary.

Procurement and sourcing policies need to change. We feel that more strategic and comprehensive action is needed for more user-led projects to evolve and become providers. The same is true for local community organisations and black and minority ethnic (BME)-led organisations.

- There is a need for cultural change and leadership at councils.
- There is a need for positive risk taking, but also a need to minimise negative risk (which results in cases like Winterbourne View in Bristol where people with learning difficulties were appallingly abused).
- Local authorities could offer low-cost loans to user-led organisations / community interest companies, along with free access to their resources, including training, buildings, infrastructure and other in-kind support – some of this may be realised under the community 'right to challenge'<sup>39</sup> to get hold of unused community assets but further guidance is needed to inform such initiatives.
- An example was given of "care farms", an initiative where farmers offer disabled people live and work opportunities.

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<sup>38</sup> [www.odi.dwp.gov.uk/odi-projects/user-led-organisations.php](http://www.odi.dwp.gov.uk/odi-projects/user-led-organisations.php)

<sup>39</sup> [www.communities.gov.uk/publications/communities/righttochallengestatguide](http://www.communities.gov.uk/publications/communities/righttochallengestatguide)

## **Final conclusions – moving from positive experiences with user-driven commissioning to mainstreaming them**

A concluding session to the roundtable gave us the opportunity both to take stock of the learning on the sites and also to consider next steps. A major concern is how we can further develop and translate the existing initiatives and ideas for user-driven commissioning into workable win-win solutions across systems and sectors, involving all key stakeholders, most crucially disabled and older people, service users and their organisations.

### Taking stock

First we reminded ourselves of the context and some of the key issues facing us. These are difficult times and what the programme has so far highlighted is the crucial importance of bottom-up change, alongside top-down reform. Many councils find themselves at the crossroads between taking back control in-house versus reaching out towards whole systems improvement. User-driven commissioning is concerned with the latter and with improving lives – at all levels. Revamping commissioning systems creates win-win solutions for everyone.

We have grown used to large systems, bulk purchase and one-size fits all approaches to meeting rights and needs. In reality, these are waning – despite councils' often resistant corporate procurement procedures, traditions and functions. At the same time, further promising steps have been made. A few councils such as Essex County Council have increased their credibility and commitment to personalisation by actually increasing the cash value of Direct Payments as an overall percentage of spending rather than just increasing the numbers of Direct Payments. At the same time more resource has gone into support planning. By contrast, many other councils have used the transition from council-managed care to personal budgets to cut spending – and thereby undermined transformation.

We need to rethink what micro and macro means – which is which? It is actually a macro issue to transform the lives of each and every individual service user. So why do we not systematically capture and replicate the choices for support being made by empowered Direct Payment holders (or pooling teams) so that a far greater number of service users can access a similar level of choice & control in both social care and the NHS to start with?

There was strong agreement that all three stepping stones of user-driven commissioning are valuable to advance where we could already see meaningful gains and progress:

- Pooling personal budgets
- Collective user insights to inform de- and re-commissioning
- Peer support to achieve better quality and value for money

There was a strong sense that all three of these ‘stepping stones’ to user-driven commissioning need to be based on as well as geared towards enhancing lived experience. There can be a striking discrepancy between what commissioners set out as care and support pathways and how disabled and older people and service users themselves go about finding or missing out on support. People pursue their own pathways, and their lived experience needs to be far better understood and factored in. New care and support pathways have been informed and often sparked by peer supporters (eg in mental health), going way beyond set provisions under Shared Decision-Making and current Choice Frameworks<sup>40</sup> for example.

There are clear benefits of hardwiring paid peer support into the ways care and support is provided. The presented innovation should not be mistaken as some fringe experiments – our sites and those in many other areas (which we could not all identify and present within the constraints of this programme) may well act as early adopters for much wider efforts to increase choice & control and reduce health inequalities across the country<sup>41</sup>.

The social model of disability and the philosophy of independent living are seen as key underpinnings for these developments. The Essex Coalition of Disabled People raised new issues. If user-led organisations are to survive then they need to develop new relationships, notably with the commercial sector. They may enter into new partnerships and consortia – potentially to co-produce integrated cross-sector pathways with bundled, proportionate tariffs for every agency involved and with peer support established at all junctions. This is likely to pose risks as well as opportunities. The message from Essex is that this is a development that must be explored. It is also one we need to make sure to monitor and evaluate properly.

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<sup>40</sup> <http://consultations.dh.gov.uk/choice/choice-future-proposals>

<sup>41</sup> Incontrol-able Hartlepool carries out the project CHERISH (‘Creating Health Equalities, Rights, Inclusion in Stockton and Hartlepool’) to assist the NHS Tees in the uptake of Health Action Plans, Annual Health Checks and Screening by people with learning disabilities. Further down the line, this ULO will have potential to link in their grassroots work with more dedicated work on user-driven commissioning.

## Setting and achieving co-produced ‘universal’ outcomes

To take the goals and approaches within our programme forward, we need to create models and blueprints which carry force and conviction and will gain significant support. We need to develop an evidence base which reflects the complexity and subtlety of user-driven commissioning, for instance knock-on effects from improved quality of life, independent living and joined-up support on healthier communities and productivity gains. Evidence needs to centrally include lived experience as both input and outcome measure – no matter how soft this may be considered by some.

Outside of this programme, some general exemplary summary business cases have been produced, highlighting key costs, benefits and return on investment, albeit without a co-production angle and for defined care areas only such as the termination of pregnancies – produced by In-Health.<sup>42</sup>

We believe that user insights should inform commissioning across public service areas to make support more personal, effective and efficient. The Right to Control trailblazers have been found to be more advanced where co-production has been invested in from the outset (qualitative evaluation wave 1<sup>43</sup>). We hope to see from further evaluations what improvements could be made by asking users (eg of Access to Work) for their support preferences and then systematically capturing, costing and comparing those support preferences against actual support provisions people have been allocated. The *value* of lived experience could then be established.

Commissioners – for the time being – act in an environment of corporate procurement procedures, traditions and functions. This means they need to have a clear understanding of the outcomes to be achieved – the ‘what’; only then can they move on to the ‘how’ to go about commissioning those outcomes. Richmond, Essex and Stockport have begun to co-produce and evaluate outcomes that are much closer to the lived experience of people than more traditional measures. The forthcoming ‘Long-term Conditions Outcomes Strategy’<sup>44</sup> by the Department of Health with its emphasis on the lifecourse and whole life domains (rather than impairments or care areas) may further inform and support this process. Only by co-producing ‘universal’ outcomes at a much greater scale will we be able to support disabled and older people to co-deliver these outcomes through peer support and user-led mutuals or mutuals that are jointly led by disabled

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<sup>42</sup><http://www.inhealthassociates.co.uk/uploads/documents/An%20economic%20case%20for%20involvement%20v4.pdf>

<sup>43</sup><http://odi.dwp.gov.uk/docs/wor/rtc/rtc-process-evaluation.pdf>

<sup>44</sup><http://www.longtermconditions.dh.gov.uk>



people and other staff. Then we can also aim for, define and share any productivity gains between users of services, commissioners and the wider community – perhaps the last stepping stone which could not yet be explored further and still needs to be addressed.

## Next steps

Our strong aim is to keep this discussion and work programme with commissioners and people with support needs alive – to encourage a snowballing approach, spreading insights locally, in neighbouring local authorities, amongst other user-led organisations (ULO) and service users and through our national organisations.

The conversation ranged from the reality of how things are on the ground to big issues arising from the wider policy environment and strategic vision for the future.

We have begun with a virtual network – sharing our ideas and building our confidence. We have heard about the good cutting edge of user-driven commissioning (perhaps the furthest personalisation can go), and we need to spread this innovation as widely as possible.

Contact:

Bernd Sass, Disability Rights UK  
[Bernd.Sass@disabilityrightsuk.org](mailto:Bernd.Sass@disabilityrightsuk.org), mobile 07906 521536  
12 City Forum,  
250 City Road,  
London EC1V 8AF

## Appendix

### Commissioning support in practice

#### Three case studies on current and future roles of peer support and disabled people's user-led organisations (DPULOs)

##### Introduction

Present moves and policy commitments to mainstream 'personalisation', person-centred support, self-directed support, personal budgets and direct payments have fundamental implications for the future of health and social care commissioning. The policy direction is away from top-down, centralised commissioning and block contracts, towards more user-led, customised approaches, which recognise the role and contribution of disabled people and other service users as both commissioners and micro-providers.

Local disabled people's user-led organisations (DPULOs) have been in the business of providing services and supporting people to run their own self-directed support schemes since at least the 1990s. Despite the value attached to such 'user-led services' by disabled people and service users, they are still relatively marginal in the overall pattern of service provision<sup>45</sup>. However the evidence suggests that DPULOs have a number of gains to offer as both commissioners and providers of services and support. This requires that they are better supported and funded and given equal recognition with other providers in the social care and health market.

DPULOs can substantially improve choice and control by disabled people and the integration of health, social care and other services by enhancing access to new types of support. DPULOs have been and are instrumental in acting as a hub to support disabled people to come together and develop shared insights and support networks freely on their own terms. In this way they can build skills and capacity, through increasing disabled people's self-confidence and self-esteem. None of this could be achieved on an individual basis without supporting DPULOs.

DPULOs have an important role to play in gathering and voicing disabled people's needs and aspirations locally. They can do this, for example by linking and engaging with the new structures of HealthWatch, local

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<sup>45</sup> Barnes, C. and Mercer, G. 2006: *Independent Futures. Creating user-led disability services in a disabling society*. Bristol: The Policy Press.

authority health and well-being boards and joint strategic needs assessments under the Health and Social Care Act 2012.

Moreover, DPULOs can directly and more effectively than through the use of 'in-house' social workers intervene and advocate in difficulties and disputes on behalf of individual or groups of service users. They can help identify and implement more cost-effective alternatives to meeting a need than the system would normally make possible. There are also multiple roles for DPULOs in facilitating disabled people's choice & control in a social care and health system which we can expect to be increasingly fragmented due to the advent of arrangements for 'any qualified provider' for example. In addition to experiences of improved quality and continuity of care, the involvement of DPULOs can lead to a reduction in unplanned care and further productivity gains in the shift from an industrial model to one that is personalised, effective and efficient.

DPULOs can also help different key players understand and apply:

- what information and advice people will need to help them take greater control of their health and care and make choices;
- how people can be further engaged in their own care and treatment;
- what shared decision-making and choice actually mean for people;
- what roles patients, service users, clinicians, providers and commissioners need to play in making it all happen – from service mapping, outreach (help-seeking behaviour; case-finding) through to new cross-sector or 'whole life' care and support pathways.

## **Case study examples**

To illustrate the benefits that DPULOs can bring to commissioning, we are now offering a series of illustrative case studies. These highlight the kind of issues to be faced in the new environment of health and social care commissioning and personalised support and the contributions that DPULOs can offer. All draw on real life experience and examples as a starting point and some also reflect emerging structures, although none is intended to portray an actual individual.

### **I. Unlocking 'Lived experience' and peer support - the most under-used assets in social care and health - with the support of a disabled people's user-led organisation**

Sarah has a progressive neurological condition. She recently had a visit from the wheelchair service and was also prescribed painkiller medication. This triggered mixed feelings in her. On the one hand, these provisions

meant that her primary health and well-being needs were finally being recognised. On the other hand, she very much felt that she was being forced onto a pre-determined pathway and had to give up what she had put in place as support funded by her direct payment and Disability Living Allowance. The announced change to Personal Independence Payment could also mean that with a wheelchair, she would no longer be seen as in need of support for independent living. It was also unclear whether her direct payment could be transferred to NHS Continuing Care.

In addition she felt depressed in facing the prospects of having a wheelchair in her life. She felt as if the whole system was set up to promote technical solutions and pay for them, rather than building on people's confidence and look out for more imaginative means of support. She was afraid of losing control and being restricted to her new wheelchair for most of the time. This undermined her own sense of independence and created concerns that she would become more dependent more quickly. Sarah's own approach to meeting her needs has always been very much about motivating herself to manage and do without aids and adaptations as long as she possibly can. A significant part of her 'programme' is about going out and spending two hours a day in fresh air in addition to a range of community activities (for example, cooking), but the system struggles to assess such personal needs and pay for 'lower intensity' support.

Sarah is also a member of her local DPULO, who run a user-led one stop shop which had been established as a separate community of interest company (CIC). There she met Janet, a wheelchair user for some years and paid peer mentor, with whom she was able to have very personal exchanges on her feelings about the progression of the condition. These encounters with a peer empowered her to contextualise the condition within her personal life and to take action. Sarah asked the local DPULO to intervene on her behalf directly with the local commissioners at the council and the PCT / CCG. The DPULO did this, deliberately by-passing the care manager who had not been able to make the case for Sarah 'in-house' with her team manager.

The commissioners finally agreed that Sarah could keep her direct payment (the PCT / CCG paying out the major NHS part through adult social care funding), and that it will be for her to decide when more technical support would be required. Engagement and co-production have been recognised as core values and embedded in strategic commissioning. The commissioners have asked clinicians to build and act on the peer mentor's work and consider the various ways in which even a progressive condition can be controlled to an extent by the individual. In turn, de-

commissioning some large block contracts has freed up resources which are being re-invested in more time for support planning. Many clinicians have started to value working together and more flexibly with disabled people. Sarah now works herself as a 'peer mentor' for the CIC to demonstrate to both peers and professionals the value of independent living, self-assessment and support outside of tight traditional service and referral criteria.

## **II. Supporting peers to develop and multiply insights as experts of social care and health**

A local authority has funded a pilot to set up several initiatives for personal budget holders to pool their budgets on their own terms. To ensure independence, the pilot is being run by the local DPULO, who already have several activity-based groups of disabled people up and running. The groups had been formed on the basis of shared interests – rather than externally defined 'needs'. Members of the group looked for ways to achieve better outcomes and greater choice and control in their lives than they could have done solely with their 'individual' personal budgets. This could be by sharing a personal assistant (PA), arranging joint weekly activities or pursuing ventures unrelated to social care and health provision, such as running crafts-based workshops open for the public. The DPULO facilitated the groups' regular meetings on members' own terms, set the scene and stepped in when interest started to dwindle. Crucially, discussions on sharing arrangements were not disclosed to the local authority, so that nobody could be pushed in any subtle way to pool their personal budget if they did not want to.

Over time members got to know each other better and started to voice and engage on their experiences of the social care and health systems. This was when the commissioners came into play and funded the DPULO to work with interested members to inform the content of a website aimed at comparing local social care support and NHS care. The DPULO shared the work and the funding with interested members of the groups. Again, the acceptance of this website depended hugely on the members' capacity to make it relevant to the diverse walks of lives of disabled people, by using their own words and criteria for what mattered to them. Soon the ball got rolling, and there were plenty of entries from other people who had used local services and rated their experiences. Website hits increased day by day, and this started to have a measurable effect on people's informed choices between services. In turn, commissioners, HealthWatch and Health & Well-Being Boards started to build some of their work on the regular

reports which could be easily pulled together from this user-driven care and support ratings system. Some user-reported experience measures were directly built into contract monitoring reviews of providers. The website – with its roots in pooled personal budgets – became a key tool in helping people make sense of disability, and of how specific treatments or support schemes might impact on their lives, helped them navigate the system and achieve better health outcomes. Commissioners benefitted from productivity gains, for example a decrease in the need for unplanned care.

### **III. Engaging seldom heard groups**

Gill and Janek have never met. Gill is 35 and experiences anxiety, and she self-harms. Despite her apparent difficulties, she has never found a way to access benefits. At times, Gill has to ‘couch-surf’ when her father feels overburdened by her behaviour and ‘demands’. Janek is 22 and moved from Poland to England in 2008. He is homeless and has had several encounters with the criminal justice system, mainly for burglaries. It seems that Janek mainly burgles gay men who he comes to know in bars and clubs while working in them short-term. He was recently sectioned under the Mental Health Act and diagnosed with ‘personality disorder’.

Gill tries to cope as well as she can on the surface. But having achieved her A levels in maths, she could only hold down the few jobs she had in data-inputting for a month at the most. Both Gill and Janek have difficulties with adjusting to sudden changes in the sensory environment, and they sometimes and to varying degrees show repetitive behaviour which can seem obsessive to the outsider.

A local DPULO of peers had decided to become proactive and systematically reach out to ‘find’ peers with similar signs among homeless people, in the criminal justice system, the Jobcentre, in mental health recovery and acute settings and in the wider community. The DPULO met Gill, and Janek was signposted to the DPULO by an HIV clinic. It was only through the DPULO’s continuous lobbying over a year that the local council’s team for learning difficulties assessed Gill’s and Janek’s needs. But they were both seen to be far too ‘articulate’ for what was considered an expected level of needs by that team. This required a further referral and the involvement of the mental health team. Only contacting the council’s adult social care and housing overview and scrutiny panel finally led to a diagnosis being secured for both Gill and Janek. This was for ‘high functioning autism’. Every single struggle they both had experienced from

an early age with social interaction, communication and imagination – and Janek also with his sexuality – started to make sense and fall into places.

With the support of the DPULO both of them learned to identify and build on their own assets, which proved to be attention to detail, logic and a profound sense of fairness. The DPULO runs a fortnightly drop-in service for peers and offers a range of activities in the community. They offer hands-on support to 300 people, 50 of whom are in crisis at any one time. The support includes guidance and advice to access housing, benefits, volunteering and employment opportunities. In all what they do, they break down information and provide structure and so help people work out and voice their concerns and aspirations. Many people diagnosed with high functioning autism, however, had to realise that even a diagnosis does not always lead to support or sufficient level of provision to be able to participate fully in the community.

Therefore, the DPULO has strengthened its lobbying work with the council's newly formed Asperger Stakeholder Group and with other local decision-makers. As a result, they have managed to influence the environment affecting them, for example working with local employers to set out job descriptions that hint at other skills than just communication when this is not needed to a great extent. They have also put their outreach work on a more systematic footing and ran a service mapping exercise to capture if and how the needs of people diagnosed with high functioning autism are being met in the local area. This involved training frontline council and provider staff.

The DPULO has also supported the local HealthWatch in its diverse roles, i.e. to act as a conduit for many different service user, patient and community groups, coordinate local consultations and contribute to some targeted work to join up services and support. In turn, it is useful to the DPULO and other community organisations that HealthWatch collates all evidence to demonstrate that and how involvement leads to improvement in the quality of life of disabled people.

Together with HealthWatch the DPULO has been instrumental in setting out new care and support pathways that are geared towards the whole life of people diagnosed with high functioning autism. These pathways go beyond departments and sectors (for example, housing, the NHS, social care, police) and include proportionate, bundled tariffs associated with specific (intermediate) outcomes. Thus, each provider can contribute its specific strengths towards set outcomes that have been identified by the DPULO and its members.

**Disability Rights UK** has been formed – as a new robust, resilient and sustainable user-led charity partnership, to represent and serve all disabled people in the UK – out of Disability Alliance (DA), National Centre for Independent Living (NCIL) and The Royal Association of Disability Rights (RADAR). In the DH Strategic Partner consortium (together with Shaping Our Lives) Disability Rights UK has taken the place of NCIL and RADAR. Disability Rights UK will be launched formally in the autumn of 2012. Disability Rights UK contributes a national network of disability organisations, local disabled people’s user-led organisations (DPULOs) and disabled people, representing its members by fast-tracking their opinions and concerns to policy-makers and legislators, and by launching their own campaigns to promote equality for all disabled people, to have control over how their assistance needs are met and to break the link between disability and poverty. It strives to bridge the gap between national policy and local delivery – of which the user-driven commissioning programme is one example.

**Shaping Our Lives** is a national disabled people’s and user-controlled organisation and network that is made up of and works with a wide range of long-term health and social care service users, including older people, people with learning difficulties, with mental health problems, physical and sensory impairments, with chronic and life-limiting conditions, living with HIV/AIDS and who have drug and alcohol problems. Its network includes more than 400 user led organisations. It works to increase the say and involvement of disabled people and service users over their lives and the support they need.

Disability Rights UK and Shaping Our Lives share a fundamental belief in equality of opportunity regardless of impairment and disabling barriers; and we share a commitment to disabled people controlling their own organisations. We want to see a society that is equal and fair where all people have the same choices, rights and responsibilities, a society where people have choice and control over the way they live and the support services they use. The sharing of these core values is the basis for our partnership working.