Response to

No decision about us without us – patients and the public as partners in health improvement

NHSCB guidance for CCGs about the collective duty to involve, section 14Z2, Health and Social Care Act 2012

Sent to Vince.Roose@dh.gsi.gov.uk on 15 October 2012

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We welcome the guidance on collective involvement for clinical commissioning groups (CCGs), including a brief outline of CCGs’ equality duties under the Equality Act 2010. We also find the case examples of involvement and of the benefits gained helpful to make a start. However, we think these case examples are not comprehensive enough for CCGs to be convinced of engaging in genuine co-production. The guidance does refer to ‘why’ involvement is necessary but it lacks a clearly illustrated business case and some kind of manual on how to go about embedding involvement throughout the commissioning cycle. This would help both commissioners and user-led projects to approach involvement hands-on.

For illustration of a more comprehensive example of an empowerment approach to involvement we will circulate as soon as possible our report on ‘user-driven commissioning’. For the time being we enclose at the end of this document a range of case studies illustrating the benefits of user-led organisations in support of commissioning.

We would like to make a few general points before turning to the guidance.

The capacity to make informed and supported choices is the highest level of involvement

We do not share the recent criticism against DH that ‘choices’ would have been conflated with and should be separated from ‘involvement’ and ‘shared decision-making’. Instead, involvement is one domain which can
reach different levels – there should be a continuum from a one-off session for an individual to share a decision for a treatment option for example to informing commissioning plans and whole systems change.

It is true that “people (can be) inclined to be more radical in their thinking about options than managers and professionals” (page 12 in the guidance). However, this requires that people are beforehand put in the position to bounce back and forth their insights between themselves and thereby familiarise themselves with and build up some kind of collective understanding of the options for service re-configuration at stake.

Therefore, much greater efforts should be taken to empower patients and the public to be involved with each other AND the emerging structures and ultimately grow into the position to make informed and supported choices for themselves – just as many Direct Payment holders make them, which can inform and should be replicated with Personal Health Budgets from April 2014. There is no reason why the types of care generated by more independent personal budget holders should not be incorporated into the portfolio of services available to everyone under NHS-managed care.

**Strategic approach to individual and collective involvement**

As long as involvement is not seen as integral to commissioning and providing services and factored into each commissioning plan (as opposed to operating a discreet overarching involvement budget), its full benefits cannot be reaped. Some of the potential outcomes that are directly associated with collective and individual involvement are: '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 pathway redesign –, is also an important outcome. Pathway protocols combined with ‘quality of life’ indicators would potentially be very important measures for integration.

Involvement should not be broken down into one-off sessions but allow user-led projects to build up and strengthen their capacity to inform strategic agendas in the longer term, in particular on commissioning
outcomes via peer support. From the commissioners’ point of view, this would create a ‘patient and public pull’ which would be of enormous assistance in the transition from commissioning services to commissioning outcomes. Individual and collective involvement should be both based on and geared towards enhancing lived experience.

**Peer support as a means to identify and improve lived experience**

Peer support is an important means to identify and improve lived experience. Peer support can help the person contextualise a condition or support solution within their 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 of peer support is to facilitate choice between different support options – hearing from someone first-hand who has travelled a similar path before. 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’. Needless to say that there are also considerable productivity gains to be made for commissioners.

Our programme on user-driven commissioning builds organically on lived experience. It follows three complementary stepping stones: 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 de-commissioning (from block to spot) and finally deliver peer support as an integrated element of new cross-sector care and support pathways which have been co-produced.

To this end, demand (and meeting demand by peer support) needs to be hardwired into service delivery – it should not be the capacity of a service that defines how a service would be delivered. This requires room for manoeuvre for independent peer supporters and their mutual organisations to set the agenda – and for commissioners to fund but otherwise at least initially let go of such pioneering activities.
A case example of peer supporters improving access and discharge pathways

For instance, in mental health on one of our sites, peer supporters have gone out to crucial locations such as A&E departments and psychiatric units to identify gaps in support and co-produce improved access and discharge solutions with their peers. 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 a well-being hub. There is no reason why such co-produced cross-sector integrated pathways with a range of providers to choose from should not be replicated in other care areas beyond mental health.

Co-producing integrated pathways with bundled, proportionate tariffs

Across these integrated pathways there could be bundled, proportionate tariffs attached to every single agency involved. Particular pathway stages (associated with specific outcomes) could then be costed and allocated between a range of those 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. To offer people real perspectives, such peer support should be paid and ideally (co-) commissioned or subcontracted to independent user-led mutuals.

Limiting involvement?

The above points refer to a strategic approach to involvement – and hopefully include a number of suggestions on how to go about a constructive process.

It may then not be helpful to enhance commissioners’ understanding of the benefits of such co-production if they are pointed at some premature limits of involvement. The guidance stipulates that the involvement duty would not be triggered in the case of:

- decisions about remuneration or procurement strategies unless there is a resulting impact on health services (page 10)
- a decision to change provider if this has no impact on the range of services or manner in which they are delivered (page 10)

We believe such caveats are counter-productive to and undermine mature relationships between local commissioners and user projects of the sort we have successfully formed in our programme. Open access to information on commissioning budgets and any perceived determinants (pros and cons) of decisions should be a matter of course.

Furthermore, we cannot think of a situation where either remuneration or procurement strategies or change of provider would not have an impact on service use. In fact, it is very hard to evidence the impact or absence of an impact of any of such crucial decisions. At the very least, we would hope that the onus for such supporting evidence be put on the commissioners – in the form of regular and contestable impact assessments.

Finally, we would propose the following additions:

- on the table showing the range of activities to constitute ‘involvement’: co-production (across the commissioning cycle)

- on the ‘engagement habits of successful CCGs’ (page 14): Involvement budgets are not treated as discreet spend but woven into new care and support pathways (which should also include a defined and accounted for peer support element)

- on ‘links to good practice and supporting resources’ (page 14) and ‘Commissioning Zone (page 15): link to our report on user-driven commissioning and associated case studies

We would welcome any opportunity to further inform the two sets of guidance on individual and collective involvement.

The Annexe contains a range of case studies illustrating the benefits of user-led organisations in support of commissioning.
Appendix

Commissioning support in practice

Three case studies on the role 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. Yet 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 (Barnes and Mercer, 2006). 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.

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 authority health and well-being boards and joint strategic needs assessments as proposed in the Health and Social Care Bill.
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 and 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, 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’ 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 act on from 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. 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, 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 might impact on their lives, helped them navigate the system and achieve good 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 run 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 demonstrates 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.

References
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.