Collaborative Healthcare

Supporting CCGs and HWBs to support integrated personal commissioning and collaborative care
This short guide sets out real examples which illustrate how CCGs and HWBs can - and in some places already do – commission and support interventions which embody the principles of collaborative care, individual choice and control and patient and public participation.

It illustrates for commissioners some approaches which are less well known in health circles, but which in some cases are very well-established in the fields of social care or community development. These approaches have been selected for their potential to drive radical change in the NHS, unlocking contributions from people who use health services and their families and communities and making patient and public participation a reality.

This guide has been produced by the Inclusive Change partnership of Shared Lives Plus, Community Catalysts, In Control, Inclusion North and Inclusive Neighbourhoods, working with user-led organisation Change and national partners including Think Local, Act Personal and the Coalition for Collaborative Care. We are grateful for the support of NHSE and PHE.
Introduction

At the Local Government Association conference in July 2014, NHSE CEO Simon Stevens set out plans for a new Integrated Personal Commissioning (IPC) programme, which will for the first time enable individuals to use a blend of health and social care funding to lead the design of their support.

The first groups of people involved in the new system include people with long term conditions such as older people at risk of care home admission; children with complex needs; people with learning disabilities, and people with significant mental health problems.

The lessons from the related ‘personalisation’ reforms in social care over the last two decades are clear: individual choice and control over resources can be a powerful lever for cultural change, but only when this is part of a wider programme of reform. Here are some key lessons:

• Personal Budgets alone do not create new choices. There must be an equal focus on building new kinds of intervention, workforces, services and enterprises.
• Many of the people who could gain most from tailored support need the most support to make choices. Support to make real choices needs building into every interaction with services. Advocacy and brokerage are vital.
• People struggle to co-design creative solutions in a system which focuses primarily on need and money. Individuals, families, communities and professionals need to learn together how to recognise and build upon their collective assets, capabilities and potential.
• Choice and control at an individual level needs to be matched by shared responsibility for decision-making at the community and whole-area level. This is not achieved through traditional approaches to consultation or including a patient on a committee, but only through co-production: collaborative conversations right from the start.
• Services are vital, but they are often only one part of a much wider eco-system of support which includes the contributions of family carers and communities. Almost every intervention can be delivered in a way which results in individuals and their families being better informed, more connected to those around them and more resilient.

The IPC announcement should also be seen in the context of a number of changes and new duties which aim to create collaboration between individuals and health, care and other services:

• Health and Wellbeing Boards have been given duties and shared responsibility for significant NHS funds, in relation to Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWSs).
• The Care Bill sets out a vision for social care in which the sector’s primary purpose is to promote well-being, which is defined holistically, including the achievement of active citizenship, being able to contribute to family life and being able to pursue leisure, education, employment and volunteering.
• CCGs have a duty to promote the involvement of patients and carers in decisions about their care or treatment, which requires collaboration between patients, carers and professionals across the full spectrum of prevention or diagnosis, care planning, treatment and care management.
• The Five Year Forward View sets out a vision for the NHS. In Chapter Two, it puts forward ideas for how new relationships with patients and communities can be developed. NHS England has also set up the Realising the Value Programme which will help strengthen the case for change, identify a set of evidence-based approaches and develop tools to support their wider implementation across the NHS and local communities and has announced a number of Vanguard sites which will test new models of care.

CCGs, HWBs and local providers and partners will need to develop their capacity for collaboration with individuals, families and whole communities:

• Personalised care planning, including ‘patient choice’ and the option of a personal health budget when a person is eligible for one.
• Shared decision making during individual episodes of care and longer term care planning.
• Self-care and self-management support to better manage health and prevent illness.
• Involving citizens in every stage of the commissioning cycle: gathering their insights, building partnerships with community and voluntary organisations and sharing resources.

To implement these changes meaningfully will require significant cultural changes. CCGs and their partners may have limited local experience of commissioning in a way which builds a citizen-led health and care system. The Coalition for Collaborative Care, an alliance of organisations and individuals committed to collaborative working, encourages and supports new thinking amongst health and care practitioners about the best ways to locally implement personalised care and support planning.
About this guide

This guide illustrates some key concepts which are new to the NHS in many areas:

1. Experts by experience and self-advocacy.
2. Self-Directed Support and personal (health) budgets.
3. Capabilities (asset-based) approaches to health and care.
5. Community development and building social capital.

These approaches are deeply connected with each other. They can put citizens and communities in the driving seat and challenge deeply ingrained assumptions about the roles and capabilities of ‘professional’ and ‘patient’. We have an opportunity – and an urgent need – to change those relationships. Doing so will not only lead to better outcomes and better use of scarce resources, but to more fulfilling and enjoyable roles for the whole health workforce. Whereas many examples in this guide have been seen as add-ons to the system, or hard to embed and replicate, the message of this guide is that we can and must learn from them, create the conditions we know can lead to their success and see them as core healthcare business.

1. Experts by experience and self-advocacy

As the NHS moves from being seen as an illness-treatment service, towards becoming genuinely a health creation and maintenance collaboration with people with long term conditions, it will become ever more vital for professionals and commissioners to develop interventions which build people’s own expertise in self-management. This can seem counter-intuitive to professionals who have spent years in training to build the specialist expertise which differentiates them from the ‘lay person’. However, we know that simply being told what to do, even by people with exactly the right information, is a poor way of helping any of us to adopt the practices and lifestyles which improve health and well-being. And no amount of training makes a professional an expert in what a good life feels like to another individual. The interventions in this section recognise that people are experts in their own lives and that responsibility for better health must always be shared. People don’t create healthier or more sustainable lives in NHS buildings, but at home and at work, through their relationships with those around them. These interventions show how professionals can deploy their expertise differently, forming new kinds of partnerships in which shared knowledge becomes genuinely empowering.

Case Study: Hidden Voices of Mums with Learning Disabilities

CHANGE is a user-led organisation campaigning for the equal rights of people with learning disabilities. CHANGE supports people with learning disabilities and/or autism and uses the co-working model (in which a disabled and non-disabled person work alongside each other as equals) in all its areas of work, enabling people with learning disabilities and/or autism to be employed in meaningful jobs, earning a living wage.

The Hidden Voices project is run in partnership with the Patient Experience Network (PEN) to improve maternity services for parents with a learning disability. Catherine from CHANGE, who is an experienced employee with learning disabilities, led a series of focus groups with a member of staff from PEN with parents with learning disabilities, who described and explored their own experiences. The goal was to determine what people thought about the maternity experiences of parents with learning disabilities and the views of midwifery departments and their experiences of working with parents with learning disabilities.

The findings of the group will guide the development of two surveys, one for parents and one for midwifery services, and the report will be presented at the annual conference of the Royal College of Midwifery.

Case Study: Inclusion North and the Improving Lives Team

Inclusion North promotes the inclusion of people with learning disabilities, their families and carers. They support different ways of working that help people to get the lives they want. Inclusion North has worked with NHS England (NHSE) since 2013, supporting the Improving Lives Team in a variety of ways. It has taken a lead role in helping to share knowledge/experience and bring about lasting change across the care system for people with learning disabilities. In particular, Inclusion North has helped the Improving Lives team to:

- Develop and implement their Working Together plan in partnership with people with learning disabilities and family members
- Develop their model of working with Experts by Experience, and review the learning and impact of that model and the macro themes from the reviews of people who lived at WV
- Develop easier to understand information about the team and their work
- Increase understanding of their work and create connections through sharing information and news through national networks of people and families. They have also responded to questions / ideas that came from those networks

http://inclusionnorth.org/
2. Self-Directed Support and personal (health) budgets

The concept of Self-Directed Support (SDS) has been developed over decades in social care. It was born out of the service user and disability rights movements and is the idea that people should be in control of services which enter their lives and that where this happens, that support will often be more effective and a better ‘fit’. This is particularly true for social care interventions, which are often intimate and whose goal is to help a person to define and move towards whatever a good life looks like to them. The Care Bill says the goal of social care is to help people achieve ‘well-being’. This is defined holistically, placing its achievement well beyond the reach of traditional services, particularly if they act on their own.

Health services need to learn from the lessons of SDS in social care, both from the gains in well-being made by people who have had positive experiences of managing their own resources allocations and support, and also from the ways in which the state and services have sometimes struggled to let go of their traditional control. Implicit in the right to SDS, is a commensurate sharing of risk and responsibility. Professionals have at times under-estimated the capacity of people to take and share risks and responsibility, which can be a positive experience even for people labelled ‘vulnerable’, if they have access to the right support. Professionals have also over-estimated the desire of people to manage budgets, when doing so leads to no new choices of approach or provider. The lessons from SDS in social care include that it is vital to build a diverse marketplace of different kinds (and scales) of provider. True SDS is always about more than just the money: it is control over all of the formal and informal sources of support at an individual’s disposal.

Case Study: Ishtiaq and Shaheena

Ishtiaq Hussain, aged 59, from Manchester, suffered cerebral damage from a subarachnoid brain haemorrhage, nine years ago. A personal health budget was used to employ a rota of seven personal assistants and buy essential equipment. As a result Ishtiaq’s health and wellbeing has improved significantly.

Before the personal health budget, if Ishtiaq had increased seizures he would become more aggressive but his PAs are better trained to look out for such changes, and so medication can be altered accordingly. They will give Ishtiaq pain relief for his jaw pain as soon as he requests it whereas previously, because agency staff did not know Ishtiaq sufficiently well, they missed him becoming more aggressive but his PAs are better trained to look out for such changes, and so medication can be altered accordingly. They will give Ishtiaq pain relief for his jaw pain as soon as he requests it whereas previously, because agency staff did not know Ishtiaq sufficiently well, they missed him communicating his pain. At one point it was suggested Ishtiaq be admitted into a psychiatric hospital to monitor his medication but there is no question of that now.


Case Study: Suzanne

Suzanne has limb-girdle muscular dystrophy. She needs assistance with most physical tasks. She uses a wheelchair and has needed assisted ventilation for the past 18 years. Initially, Social Services organised the support she needed and employed people using an agency. However, this became more difficult as the agency struggled to get staff and the settings on Suzanne’s ventilator needed to be changed at night and in the morning. This need presented a logistical problem as the agency staff were not allowed to change ventilator settings.

All options for support were considered but the best one was for Suzanne to use a direct payment to employ her own staff in her own home funded 70% by healthcare and 30% by social care. The help she needs to maintain her independence, to pursue her priorities and exercise her preferences is provided by a team of Personal Assistants, whom she employs. This is a more cost-effective way of providing the care she needs than a nursing home would be, and more importantly, Suzanne is independent and lives as she chooses.

[http://www.in-control.org.uk/what-we-do/health-programme.aspx](http://www.in-control.org.uk/what-we-do/health-programme.aspx)

Case Study: Meeting the challenges of personal health budgets

In Control is a national charity working for an inclusive society where everyone has the support they need to live a good life and make a valued contribution. Now in its third year, In Control’s health programme provides the support and expertise needed to implement NHS personal health budgets and self-directed support for children and adults.

This health programme further builds on and enhances the national support offered through NHS England and is for those sites wanting to drive implementation further forward. Practical support is offered on a local level. For example, it could provide modular training, facilitate collaborative workshops geared towards each stage of implementation, help to set out a new pathway, or provide on-site dedicated support from expert advisers who attend meetings and events or act as ‘critical friends’.


Case Study: The Coalition for Collaborative Care and Think Local, Act Personal

The Coalition for Collaborative Care and NHS England have launched a new handbook focusing on new ways of working to provide the best care for people with long term conditions. The ‘Personalised Care and Support Planning Handbook’ is designed to spark new thinking amongst health and care practitioners about the best ways to locally implement personalised care and support planning. The handbook provides practical support for local health systems hoping to introduce and sustain care and support planning at a local level and give people with long term conditions more control over their lives.


The handbook complements a guide published by Think Local Act Personal (TLAP) and a short film published by the Royal College of General Practitioners (RCGP).


[https://www.youtube.com/watch?v=ZRV2lek-jXQ&feature=youtu.be&list=UUhe__4bCnImlCOuZc7F9IPxsA](https://www.youtube.com/watch?v=ZRV2lek-jXQ&feature=youtu.be&list=UUhe__4bCnImlCOuZc7F9IPxsA)
3. Capabilities approaches to health and care

If all we look for are a person’s needs, it is likely that that is all we will find, leading us inevitably to conclude that only an outside agency or expert can help. A strengths or capabilities-based approach (‘asset-based’ in the US) involves considering a person’s needs, but looking also for their current and potential strengths, skills and capabilities, including the capabilities of their family and social networks. An imaginative approach to recognising current and potential strengths can help people who have previously been seen as only recipients of care and support, to contribute and to develop their confidence and resilience, with positive consequences for their health and well-being.

Professionals who take this view of the people they work with may see themselves as facilitators and enablers, rather than experts and providers. As the sections below show, capabilities-based thinking can be the basis not just for a more creative and empowering approach to planning individual support, but also to a more collaborative approach to commissioning, which draws on all of a community’s resources (not just its public money) and ultimately to models of care which are “networked” into the complex web of family and community relationships upon which we all rely.

**Case Study: Community Catalysts**

Community entrepreneurs run very small local enterprises that provide a range of social care, housing, leisure and health services or informal supports. These include support helping people to gain a new skill or to lead a healthy life. They are offered by a wide range of people and organisations in the community, including disabled and older people and family carers. Over the last five years Community Catalysts has worked with 37 local authority areas keen to improve market diversity in order to provide more choice for local people. They have supported the development of 740 community micro care and support enterprises in 28 areas, who between them support 10,000 people. These community entrepreneurs provide 1720 jobs and 860 volunteering opportunities. They are essential to the success of personalisation and integration, forming a vital part of a diverse local market.

[http://www.communitycatalysts.co.uk/](http://www.communitycatalysts.co.uk/)

**Case Study: Telford After Care Team (TACT)**

TACT CIC was founded by Robert Eyers, who himself endured 20 years of addiction. Becoming aware of the lack of support available for people who had recovered from their addiction Rob set up TACT, a recovery group and a gardening group. TACT is now a public health commissioned service for people in recovery or people struggling to come to terms with their addiction. TACT has two paid staff and 13 trained volunteers all of whom have recovered from addiction. The service now supports between 30-50 people every day. In 2015 TACT won the NICE National Local Government Chronicle award for public health.

[http://www.solosupportservices.co.uk/home/](http://www.solosupportservices.co.uk/home/)

**Case Study: Solo Support Services**

In 2010 Nicola Darby and her partner Stephen started to explore alternatives to the traditional domiciliary care agency commissioned to provide his care using NHS Continuing Health Care funding. Stephen was deeply unhappy with the service, which was inflexible and unable to facilitate the care and support he needed to ‘live’ a purposeful and meaningful life. Nicola and Stephen took advantage of a new initiative piloting personal health budgets to explore a different way of doing things and used their expertise to set up their own care and support company.

[http://www.solosupportservices.co.uk/home/](http://www.solosupportservices.co.uk/home/)
4. Co-production and citizen-led commissioning

Co-production occurs where people who use public services, front line workers and planners all work together as equals, from the beginning of decision-making and throughout. This is different to traditional ‘consultation’, which usually begins after the initial stages of decision-making, allowing professionals to continue to set the terms of reference and goals of any consultation exercise. CCGs and NHSE must promote the involvement of patients and carers in decisions about their care or treatment. This requires collaboration between patients, carers and professionals, recognising the expertise and contribution made by all.

To be genuine and inclusive, co-production may require an organisation to change its decision-making approach. Committees and formal meetings may be poor environments in which to hear everyone’s voices on an equal basis with those of highly educated and confident professionals.

Organisations will need to consider and address all of the ways in which decision-making has been inaccessible in the past, including physical inaccessibility, the timing of meetings, the language (or jargon) used and whether people are paid to be involved. Citizens will need to be involved in setting the terms for debate, rather than asked to contribute to a service-led agenda. Productive conversations are likely to begin with questions such as “What does a good life look like?” and “What sort of community do we want to live in?” rather than, “What should happen to this service?” For instance, whereas service planners may view the future of a day centre as consultation about whether it should remain or close, the people who use the centre and their families may wish to discuss a range of options which consider the possible uses of the building as a community asset, the shape of the services currently delivered within it and the future of longstanding friendships formed at the centre and the relationships built around its use.

Case Study: Sheffield Cycling 4 All

Sheffield Cycling 4 All started from Caroline’s goal to cycle to primary school with her children following a brain injury which left her physically impaired. Caroline used a direct payment to swap her mobility scooter for a tricycle, with the aim of building up her stamina. This had many health benefits and Caroline’s GP visits went from once a month, to once every three years.

Now, a weekly Open Session gets 20-25 cyclists on adapted cycles with a specialist trainer, for a small charge. The project is aimed at people who are marginalised due to ill health, and would benefit from cycling. It draws on the support of local cycling, sports and disability groups.

http://www.thinklocalactpersonal.org.uk/Browse/Co-production/National_Co-production_Advisory_Group/

Case Study: Co-production in social care: what it is and how to do it

This at a glance briefing summarises SCIE’s guide Co-production in Social Care and has been developed in partnership with Think Local Act Personal. As well as practice examples it offers information on further reading. A useful resource for any organisation involved with implementing co-production.

http://www.thinklocalactpersonal.org.uk/Latest/Resource/?cid=10012

Partners in Health Leadership programme

Partners in Health is a leadership programme run by In Control that brings people and family carers together with professionals and frontline staff to work together to effect positive change in their local area. This includes enabling peer-to-peer support, influencing local services and policy, and keeping people central to decisions about their own health care and wellbeing.

Partners in Health is a course consisting of five, two-day sessions. It is aimed at people with disabilities or long term health needs, family carers, and professionals, including commissioners, providers and clinicians.

“We are almost at the end of the Partners in Health course in Hull and I can honestly say that it has had a profound impact on all participants” Stuart Lane, Personal Health Budgets Project Manager, City Health Care Partnership, Hull

http://www.in-control.org.uk/what-we-do/health-programme/personal-stories.asp
5. Community development and building social capital.

‘Community’ is not a place but a set of relationships. All communities contain people who do or could offer support to others. Most service providers and planners would like to be able to tap into those resources, but many see a community’s strength or inclusivity as being hard for them to influence.

In fact, community development work has been practised and studied for decades, and there is huge potential to bring lessons from its evidence base into the health sector. ‘Asset-based community development’ (ABCD) starts from the premise that all communities have assets, which are often hidden from the view of statutory services, and that people within communities themselves are always better placed than outside ‘experts’ to develop their own solutions. Services have a role to play in developing a deep knowledge of their community, valuing a wide range of forms of expertise and offering ‘right touch’ interventions, with the wisdom to step back and give people space when needed.

A health provider boss passing by a pub noticed it sounded unusually busy for a Tuesday lunchtime. Inside he found a large group of older people, enjoying a discounted lunch and entertainment. He recognised an opportunity to offer unobtrusive community health services with the potential for wider engagement than those offered at a GP’s surgery and probably at lower cost.

Building ‘community capital’ is not just about finding ways for people to help services or ‘vulnerable people’. It is also about recognising that people with support needs achieve better health and wellbeing when they can contribute to their communities themselves. We need to listen to the older person with limited mobility who says ‘I hate feeling useless’ and think creatively about the support they need to make new connections and contribute their unique gifts and skills to those around them again.

Case Study: Connecting communities and the HELP project

Connecting Communities (C2) was commissioned by Thanet CCG to work in Newington in Ramsgate, a predominantly social housing estate with a population of 6,000, which featured in the top 5% of the Indices of Multiple Deprivation.

Street-level work helped build a resident-led partnership within 6 months, which now leads on using the Big Lottery funding which had been awarded to the community. Residents have decided what to focus on: visually transforming green spaces and tackling rubbish management, whilst also improving the uptake of smoking and weight loss interventions, with a 75% success rate within the group of local participants.

The initial cost was some £75,000 over two years, with an estimated NHS saving of £550,000 across three neighbourhoods over three years, based on cautious evidence-based estimates of small improvements in health factors as a result of increased community activity and social networks.

http://www.youtube.com/watch?v=iFiF3iFat08
6 Networked models of care.

Professionals who view the people they work with as partners with their own strengths and expertise, may start to see themselves as facilitators and enablers and the services they provide as only one part of a person’s support eco-system. Whereas the drive towards the ‘personalisation’ of care services has tended to view the goal of service design as being to tailor interventions to individual need, the most cost-effective interventions are likely to be those which are arranged around and in support of an individual’s most important relationships. Achieving this shift demands from professionals a new mix of confidence and humility.

Professionals with a ‘networked’ view of their work are likely to be aware of the potential for even well-intentioned interventions to undermine a person’s confidence or isolate them from support networks and will take steps to guard against that risk, recognising that even good services are a poor substitute for forms of support which can only be achieved by family and community networks, such as the friendship needed to tackle isolation and loneliness in old age, or the peer support needed to change unhealthy behaviour.

Case Study: Shared Lives

Shared Lives is a regulated form of social care delivered by 8,000 Shared Lives carers, each approved by a CQC-registered Shared Lives scheme. Individuals who need support are matched with compatible Shared Lives carers and families, who share their family and community life. In many cases the individual moves in with their chosen Shared Lives carer, to become a long term part of a supportive household, although Shared Lives is also used as day support and as regular short breaks.

The State of Shared Lives in England 2015 shows the number of adults supported in Shared Lives has grown by 1,300 (14%) to over 10,500. There is a Shared Lives scheme in almost every local authority area in England, and the approach saves an average of £26,000 per person per year for people with learning disabilities and £8,000 per year for people with mental health issues compared with traditional forms of institutional or residential care.

‘Alan’, 23, who has Asperger syndrome, had moved between several expensive ‘out of area’ services, after his family and then a local residential service had found his behaviour and excessive drinking too challenging to manage. When he met the South Tyneside Shared Lives scheme, Alan said, “I hate it here and want to get out”. Alan was carefully matched with approved Shared Lives carers and lived with them successfully for 12 months, accessing community education and rebuilding relationships within his community. Alan’s move to a Shared Lives household saved £49,000 before his successful move to his own tenancy, with occasional support, reduced the cost of his support still further.

Khalid is a younger man who has had his third stroke, and was unable to return to live in his flat on his own. The social worker was keen that he didn’t have to go to a nursing home, where he would be so much younger than everyone else. Shared Lives were able to match him with a Shared Lives family originally from the same city in Pakistan as his own family. This has been really helpful for his family, as this has been a difficult situation for them to come to terms with. Being able to talk to the Shared Lives carers in their own language, and feel that he is receiving support similar to that he would get if his family were able to support him, is invaluable.

Living with his Shared Lives family has also meant that he is able to maintain his previous social circle, with his friends visiting. He is keen to return home and live on his own again, and this is being worked towards as a long-term goal.

http://www.sharedlivesplus.org.uk/

Developing the Power of Strong, Inclusive Communities

Think Local, Act Personal (TLAP) is supporting Health and Wellbeing Boards to ‘build community capacity’. The TLAP model is one in which local leaders, agencies and citizens collaborate in:

• Building mutual support and self-help – developing networks and user led organisations that enable peer support and offer practical advice and support outside of formal services (e.g. experts by experience)
• Facilitating connections between individuals and resources – devising local approaches for target populations, building knowledge, confidence and skills (e.g. community connectors, local area coordination, Village Agents etc)
• Enabling inclusion in community activities – so that leisure, sports, social and other organisations are open to all and reach out to excluded communities to invite and encourage participation (e.g. time banking)
• Strengthening community ownership – promoting and supporting activities that bring people together to focus on particular issues (e.g. building dementia friendly communities), and;
• Reshaping services – both universal and targeted health and social care services to explicitly recognise coproduction and build people’s confidence and skills to improve service outcomes (from redesigning streets and transport to social prescribing).
Acknowledgements

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http://www.in-control.org.uk/

Coalition for Collaborative Care, 80 Skipton House, London Road, London SE1 6L
http://coalitionforcollaborativecare.org.uk/

Inclusive Neighbourhoods, http://inclusiveneighbourhoods.co.uk/

Inclusion North, 197 Woodhouse Street, Leeds LS6 2NY
http://inclusionnorth.org/

Personal Health Budgets Delivery Team, NHS England, Skipton House, 80 London Road, London, SE1 6LH
http://www.personalhealthbudgets.england.nhs.uk/

Inclusive Neighbourhoods, http://inclusiveneighbourhoods.co.uk/

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