

**Personalisation and equalities:
Understanding, developing & making
personalisation work for all communities**

**Findings from a learning event held by
Disability Rights UK, the Race Equality Foundation and the
LGB&T Partnership, in conjunction with the Department of
Health, Public Health England and NHS England**

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Introduction

This one-day learning event, run jointly by the Race Equality Foundation, Disability Rights UK and the National LGB&T Partnership, brought together practitioners from across the voluntary, community and statutory sectors to explore the relationship between the personalisation and equalities agendas, exploring if and how the two agendas can complement each other.

The learning event was funded by the Department of Health as part of their Health and Voluntary Sector Strategic Partnership Programme, and was also supported by Public Health England and NHS England. The learning event built upon an earlier session held in March 2013.

Speakers and facilitators at the learning event included:

Jabeer Butt Race Equality Foundation	Bernd Sass Disability Rights UK
Paul Roberts National LGB&T Partnership	Katherine Carter CHANGE
Kevin Kitching Department of Health	Patricia Muramatsu NHS England

Personalisation and equalities are both prominent agendas in the ongoing health and social care reforms. Personalisation focuses on strengthening individuals' choice and control, through mechanisms such as Direct Payments, patient-led services and person-centred care plans. Equalities focuses on the protected characteristics as covered in the Equality Act, and on the reduction of health inequalities, often through strategic policies designed to respond to the needs of particular groups or communities. This event explored how the two distinct agendas can complement each other.

What is Personalisation?

Personalisation takes the view that "It's all about you" as an individual, rather than as a member of a group of people whose needs are assumed to be similar: it is about giving service users maximum choice and control. It recognises that often the people receiving services will have a better knowledge and understanding of their needs, and also of the services needed to cater for those needs. It also recognises that service users may have particular skills that will allow them to develop or commission services which better suit them. In this sense, it sees a shift in the role of service users as passive recipients of care services to active participants in shaping the services they use. Through strategies such as direct payments, self-directed support and co-production, service users and staff are empowered to shape better services, transforming the allocation of resources and the balance of power.

Although personalisation is a relatively new term, key issues include:

Self-directed support

The ultimate goal of personalisation is person-centred care, directed by the service user. It involves finding out what is important to the individual, and making decisions based on the best use of the budget available. Individuals should be able to pick from a range of services from government, private and third sector organisations. These decisions should be led by the individual and should not be constrained by what is currently available- service users are encouraged to think about user-led services, and ways that they can shape the care agenda: by creating a market for services they

may trigger their creation (by putting people in the driving seat 'patient pull' can lead professionals and others along).

Co-production/user-led organisations

Although individuals may choose to spend their direct payments on their own care, they can also choose to “club together” with other service users to push for or commission a particular service, or to use the money for other purposes to support their independent living. Bernd Sass gave the example of a group of people who combined their personal budgets to start a smoothie business as this gave them the freedom to be flexible in balancing work and independence, and their health needs.

Co-production may also refer to collaborative ways of working, with local partnerships co-producing services for people to choose from.

Support

Although personalisation is ultimately about “choice” and “control”, it does not mean service users having to do everything for themselves. Rather it means that service users can make decisions about their care needs, whilst at the same receiving sufficient support to take control.

Personal budgets

All people eligible for social care should receive a personal budget, which will be theirs to spend as they wish, in line with a support plan agreed by the individual and Local Authority. These payments are sometimes very small but can go up to around £10k per annum.

Direct payments

Personalisation is most commonly associated with direct payments, means-tested cash payments which are received in place of social service provision. Individuals are then entitled to arrange their own support from a provider of their choice, for example, from social services, the private sector, from voluntary or user-led organisations or (as may be more popular for black and minority ethnic people) paid family carers.

Managed payments

Not all service users are comfortable with receiving payments. A managed budget presents an alternative model, in which the Local Authority holds the budget or places it with third party and then arranges payments on behalf of the service user. Although the service user does not directly control the budget, their care agenda should still be personalised to their needs.

Case study: CHANGE

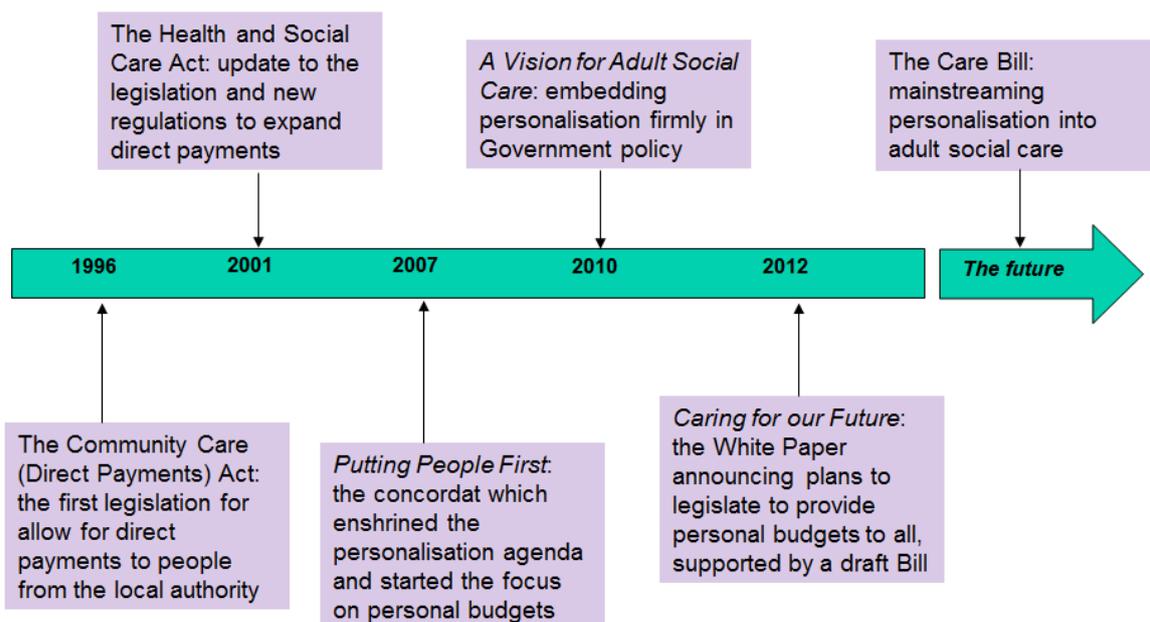
CHANGE is a user-led organisation, which supports, engages and employs people with learning disabilities. Katherine Carter, a learning disabled employee and representative from CHANGE, spoke about what the organisation does, and how it has promoted the personalisation agenda for people with learning disabilities.

- Change is led and controlled by disabled people- at least 75% of its board have learning disabilities and it shows an active commitment to increasing participation by employing learning disabled people.

- The organisation also works *for* people with learning disabilities by making information accessible, for example, through easy words and pictures books on health issues, government policy etc.
- They believe that by making information easier to understand, they are increasing the opportunities for people to get people involved and gain ownership over issues/consultations etc.
- The organisation works using a peer-to-peer model, which means that one person with learning disability leads and teaches another person with learning disabilities, or a co-working model, in which one person who has learning disabilities works with another person who does not.
- The organisation works on a number of issues including parenting, hate crime, the institutionalisation of children with learning disabilities.

Personalisation and government policy

Participants at the conference also heard from Kevin Kitching, the Department of Health Personalisation Policy Manager, and Patricia Muramatsu, Senior Strategy Advisor from the Patient Participation team at NHS England. Their presentations provided information on how the personalisation agenda fits with the reforms currently underway in health and social care.



The NHS Mandate, 2012: “to ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment”

The vision outlined in the *Care and Support White Paper* is:

- To promote people’s independence and wellbeing by enabling them to prevent and postpone the need for care and support.
- To transform people’s experience of care and support, putting them in control and ensuring that services respond to what they want.

The Care Bill updates the current raft of social care legislation into one consolidated piece of law and outlines responsibilities relating to prevention, responsibility, markets, continuity of care, safeguarding frameworks.

- Notably it places carers on an equal footing to service users
- There are a number of [factsheets](#) which provide more detail.

Personalisation summit- Norman Lamb

- The Personalisation Summit, chaired by Norman Lamb, Minister for Care and Support, brought together central and local government with representatives of key social care sector organisations to review progress with personalisation.
- The summit covered two specific areas of personalisation: personal budgets, and commissioning and market development.
- While significant progress has been made, particularly in increasing the numbers of people accessing personal budgets, much still remained to be done to ensure:
 - progress is made in different areas and with different groups of people;
 - personal budgets are delivering the best possible outcomes for people, carers and families
- An action plan will be published in early 2014.

Action plan 2014

- A continued focus on the personalisation agenda, increasing opportunities for greater choice and control
- Placing personal budgets into law for the first time, ensuring they will be provided to everyone as part of the care and support plan.
- Improving the range of services on offer for people with a direct payment or personal budget by focusing on the local authority market shaping role.
- Creating better information, advice and support for users of adult social care to inform their choices.
- Testing direct payments in residential care.
- Integrating with Personal Health Budgets - integration pioneers and the BCF (Better Care Fund).

Patricia spoke in particular about the transformation of the relationship between patients and clinicians. Rather than patients being passive recipients of care provided “for” or “to” them, care services will be a “collaborative endeavour with active patient involvement and effective self-management support”.

This is attributed to several factors:

- Gaps between what patients want and what doctors *think* patients want- studies show that patients choose different treatments after they become better informed.
- Problem of the silent misdiagnosis- dramatic geographic variations in care
- Need for honest debate about costs- NHS cannot go on functioning as it has been, particularly with the aging population and the rising number of complex health problems relating to multiple long term conditions

- Need to draw on the asset value of individuals and communities – transform health care from a largely reactive system to one that is proactive, preventative and patient-centred - supporting patients to self-manage.

Passive model	Participative model
Acute – Poorly informed patients and paternalistic treatment	Acute – Informed patients & shared decision making
Primary care - Single disease treated reactively. 10 minute consultation	Primary Care - Personalised proactive care planned for multiple LTCs. Greater self management.
Mental Health – treat and manage symptoms of disease. Dependency	Mental Health – holistic support focused on wider personal goals. Greater self and peer support.
Information one size fits all. Not a commissioned service	Information and support services built into commissioning
The consultation – single patient meets professional face to face	Consultation in groups, peer support, expert patients, Skype
Disjointed services for people with multiple morbidity. No care planning.	Integrated services and personalised care planning

Where are we now?

- Where is the NHS now in terms of patient participation?
- What is the evidence base in terms of shared decision making, support for self-management, personalised care planning (and personal health budgets)?
- What are the future trends (including technology and personalised medicine) and public health/life course perspectives?
- What are patient/public enablers/barriers towards participation (attitudes/ability)?
- What are workforce enablers/barriers to participation (attitudes/ability)?
- Analysis of metrics, incentives and commissioning
- Analysis of existing work programmes

Personalisation as a means to achieve independence

One of the major discussions of the day was the role that personalisation, and more specifically personal budgets, can play in allowing people to live independent lives. Bernd Sass felt that the existing model took a functional view of care and support, i.e. helping people to get washed and dressed, rather than supporting them in their “right to life” i.e. having a family (a lack of sufficient support will often mean that people with learning disabilities are denied the right to be a parent, and their children are taken away rather than supported to stay with them), participating in society (working, political participation), socialising, taking risks. In particular, he felt that the ability to take risks was a key part of independent living, with the need for individuals to balance between surviving, being able to do what everybody else does and realising their dreams. He argued that direct payments could be used for many “non-care” purposes, to give individuals the flexibility to shape their lives and develop their work or social lives.

A participant talked about the difficulties of facilitating this independence in a culture which focuses on health and safety i.e. when organising football games for people with disabilities he found that they were not allowed to use a real football, they couldn't have a mixed gender or mixed disabled/non-disabled team which meant that staff members couldn't play. He felt that attempts to safeguard actually restricted the whole process.

Another participant from a homelessness charity talked about challenges in practical applications- he had hoped that personalisation would present an opportunity for his organisation to empower homeless people and show them their capabilities. However, the Local Authority felt that giving direct payments to homeless people was too risky, as many individuals had addiction problems. The threat of people spending the money on drugs/overdosing was felt to outweigh the potential benefits of choice and independence.

Another participant recounted the story of a patient who used his direct payments to pay for prostitutes. The story was picked up by the media who criticised the use of public money for sex. Whilst some participants agreed that this was not appropriate, others felt that the government has no control over how people spend their other benefits (i.e. cigarettes, alcohol and therefore, Direct Payments should be viewed in the same light. It was felt that there was a lack of clarity in financial reporting to show how free people actually are making choices about their spending.

This example also led to some discussion around whether the media actually understand what is meant by personalisation, and whether it could play a greater role in acceptance and understanding of the agenda.

Personalisation and the voluntary and community sector

There is a strong tendency to associate personalisation with direct payments, and direct payments only. However, personalisation is also about ways of working and thinking about how systems and processes can be altered to increase patients' choice and control.

Personalisation presents a number of opportunities for the voluntary and community sector, as not only does it present the opportunity to work outside conventional commissioning structures, but also because voluntary organisations may also be more flexible than the public or private sector, both in developing organisational systems that allow staff to work in person-centred ways, and when pursuing opportunities for partnership working. Voluntary organisations may also possess greater expertise and understanding of patient needs. Personalisation has also been seen as fitting with a Localism Agenda as it involves communities making decisions for themselves, rather than being told what to do by "higher authorities".

However, participants also outlined the risk that voluntary organisations and small care providers may be excluded from commissioning processes by risk averse Local Authorities who prefer larger providers.

Personalisation and equalities

It could be argued that there are tensions between the personalisation agenda and the equalities agenda due to the different areas of focus. Whilst the equalities agenda looks at issues such as communities and social determinants of health, often from the perspective of strategic decision-making (i.e. the use of JSNAs), personalisation looks more at individuals and issues such as choice and control. However, the two are not mutually exclusive. Increasingly, there is the recognition that not all people who share a protected characteristic are the same- the same racial background does not mean the same religious belief; shared age or gender does not lead to the same opinions on care. A more personalised approach could therefore respond to these individual preferences, rather than treating service users as if they are the same.

There were also concerns that personalisation could actually increase inequalities, as service users who were articulate, time-rich or familiar with the system could enjoy better outcomes, whilst others were left behind (and effectively blamed for bad outcomes). In addition, without positive discrimination/“proportionate universalism” (more support for those who need more) gaps may emerge. It was suggested that mainstreaming choices/good practice made by articulate/innovative personal budget holders might help those who were struggling.

Participants also emphasised the need for better monitoring to check whether the personalisation agenda was meeting the needs of all communities. Distinct gaps in experience between individuals with different protected characteristics were identified- while disabled people were often seen as “being up to speed with personalisation”, LGBT and black and minority ethnic groups were not (i.e. health and social care satisfaction is lower amongst black and minority ethnic groups; LGBT people seen as being “forced back into the closet” when accessing care homes). Without an evidence base to prove demand, specialist services are unlikely to be commissioned, but participants said that it was usually only once a service was set up that the need emerges, and that when small pilot projects were funded, they had experienced high demand. At present, a lack of investment in specialist services means that diverse communities in rural communities “take what they can get”.

Raising awareness of personalisation: Information and engagement

Several attendees argued that gaining acceptance by service users was a major challenge for personalisation, and that there was a need for a shift in mind set, particularly amongst older people or some minority ethnic communities.

- The development of personalisation out of campaigns for independent living has meant that in some sectors, personalisation is seen as a “disabled thing”, rather than as a system which can support people with a variety of different needs and from a variety of different backgrounds. People do not engage with health and social care until they need to: as one participant put it “social care is a foreign land until people get ill themselves”.
- One participant described a fear of criticising service provision amongst service users in case services were withdrawn or worsened (“I’ll have what’s given to me and I won’t argue”).
- Another participant said that a lot of the older people she worked with would not want to receive benefits, as they would be ashamed (“we’ve never had a hand out”) or because they wouldn’t want a stranger coming in/seeing their house in a mess/seeing that they weren’t coping.

- Others talked about attitudes towards health professionals and a sense that “practitioners know best”.
- Others stated that some service users might view responsibility for their own care as a burden for them or their carers, and that not only would they have to think about what they wanted/didn’t want, but that they would also ultimately be responsible for any negative results.
- This burden might be compounded by other existing barriers i.e. Gypsy-Travellers may have busy, difficult lives focused on things other than social care/health; the stigma of disability and discrimination may act as a barrier to accessing and using services; people may experience discrimination based on different levels of disability (mental health being invisible for example); stigma on HIV and misconception of treatments leading to reduced funding may affect LGB&T people
- Although it is the duty of Local Authorities to inform people about their options in relation to personalisation, there is massive variation in awareness of personalisation, whether deliberately, due to opposition to the personalisation agenda, or simply because of a lack of understanding/time amongst professionals themselves ('that's how we do things here').
- Participants also highlighted a need for a change in the mindset of workers- many social workers are still going through a checklist, rather than responding to the individual needs of patients.

Increasing engagement: Taking ownership of personalisation

There were several suggestions to increase engagement with the personalisation agenda:

- Create a climate in which personalisation is on the agenda early on, rather than just when just when people are actually using services- seeing personalisation as a preventative measure or as building on people’s assets.
- Talk about personalisation with service users of all ages, for example, in schools rather than service users – they are the service users of the future/can influence family members
- Make sure that the right information is available for all audiences (professionals, patients, Local Authorities, those with learning disabilities etc) and that information from Think Local - Act Personal (TLAP) Markers of Progress, Making it real! and others is better disseminated.
- Make sure that information is available in the right formats- not just on the internet. In particular there is a need for good case studies/stories of personalisation working in practice.
- There is a need for clearer, simpler, more consistent language- even the term “personalisation” itself may be regarded as jargon, and practitioners need to be comfortable with the language and its implications for their own practice.
- Service users may need help to learn “how” to make decisions and to cope with the wealth of information that might be available.
- Provide information/case studies on co-production so that professionals actually know where to start.
- Follow good practice examples, for example, organisations in Leeds were seen as being “good at personalisation” with cross-sector working between networks in the community and integrated health and social care hubs.
- Recognise that implementing personalisation is not always about money-the role of professionals/role models in inspiring individuals/providing information is key, for example, a project in rural North Yorkshire, which works to connect communities, by looking at available services and what businesses are doing, and then connecting people together with guidance, information, support and existing networks

- Exploit existing networks/community services to connect people: GPs, vets, local chipshop, libraries, places with free internet, football, businesses which pursue corporate social responsibility
- See the benefits that “social” activities can bring to people i.e. dancing may improve balance and reduce falls; singing may improve breathing; socialising reduces isolation/increases wellbeing.
- Commissioning needs to tie in better with what people are already doing to improve their health, and the system needs to support local councils and CCGs with the transition to more innovation, e.g. on double running costs
- Have a “go-to person” within each local area who can steer people through the system and help them make sense of personalisation locally i.e. “peer support navigators”.
- BUT commissioners need to understand that the voluntary and community sector cannot work for free.

Need for evidence that personalisation leads to better outcomes

Several delegates felt that more case studies and evidence around personalisation were needed in order for them to make the case to Local Authorities and service providers that such an approach was in their best interest. They wanted evidence that services would be:

- more efficient
- more cost effective
- lead to better outcomes for service users

Paul Roberts of the National LGB&T Partnership said that the National Audit Office had produced research showing that personalisation could deliver better outcomes from the same money (not cost savings), but that this was only when personalisation was implemented properly and standards were met.

Other suggestions:

- SCIE, user-led organisations, universities, ASCOF, Google scholar, FOI requests, HealthWatch/LINKs

It was suggested that it might be difficult to find “Personalisation stories” as it means different things to different people. It was also seen as important to find examples of cross-equality case studies (e.g. LGBT disabled people from black and minority ethnic origins) which would not only show multiplied problems but also highlight the potential to find multiplied solutions by tapping into greater and more diverse support networks.

The possibility of using collective contracting was also raised as a way of ensuring that providers are held to account for achieving better health and independent living outcomes: providers would need to build alliances for contracting and would then be held to account collectively. Likewise, linking payment for services to positive patient feedback could see improvements.

Other challenges relating to personalisation

- Several participants questioned whether there was the risk of raising expectations, but not actually being able to follow through. They said that in a time of funding cuts, shortages of staff and resources were common, and that it was often not possible to recruit suitable candidates to fulfil care needs. This could have a knock on effect whether in giving access to the type of services that individuals wanted, sufficiently supporting patients to manage their personal budgets or providing infrastructure support to organisations.
- Some participants believed that there was a risk of patients who don't have a personal budget falling into a hole/Local Authorities failing to deliver/ personalisation used by councils as a smokescreen for cuts
- Participants talked about the difficulty of balancing finances when there are conflicting agendas "one day you can have a cut to your housing benefits, the next day you can have free driving lessons for your wellbeing"
- Personalisation is considered "fluffy", as an issue for money that is left, rather than a way of working (especially with current focus on austerity/welfare): we need for personalisation to be "just done" rather than thought about.
- Control is not being passed on-some Local Authorities seem to be actively shifting away from the personalisation agenda and taking back control.
- In some areas "personalisation reference groups" have been established, but criticised as "talking shops" with no real control, or as making no progress.
- No incentives in current spending rounds – services are usually only commissioned for 1 year, no business case for longer term investments/improvements
- Personalisation may present a challenge to partnership work if two organisations offer the same services- experience of it leading to competition rather than collaboration.

NEXT STEPS

- Offer from NHS England to continue conversation- attend future sessions, support alliance, stakeholder participant groups, consultations
- Facilitation by organisations who delivered event
- Forum for individuals to share expertise/brief description of work they actually do- learning from others, campaigning, fostering dialogue with commissioners
- CSV supporting volunteers to bring about changes
- Case to engage more with national delivery partners i.e. SCIE, TLAP