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Executive Summary
December 2012

This set of briefings outlines the findings of the Budgets and Beyond project, which has been exploring people's experiences of social care, and in particular, of two approaches known as personalisation, and co-production. The briefings document people's experiences of social care, actions that can be taken to develop co-production in social care, and further areas for research and practical work.

Introduction

Social care is a sector in transition, and the stakes are high forall those who use social care services across England. The sector is being re-shaped by a new austerity, and has to adapt to cuts of £6 billion. The cuts are falling on local authorities, who already face rising demand for social care services due to the increasing age of the UK population, the lack of a secure funding settlement and the impact of the Welfare Reform Bill which is expected to increase people's need for support.

Our findings show how people are experiencing the transition to personalisation, the growing climate of austerity, and the challenge of social care services that often treat people as passive recipients of services, trying to 'do to', rather than work with people. Too often, people who use social care feel they have no power over what support they get, or who supports them. Many people who are proposing creative ways of getting the outcomes that are important to them are finding their suggestions rejected by a system that – in general – still has a conventional view about what 'care' should look like. These are challenges which must be urgently addressed if we are to support people to improve their well-being with diminishing financial resources. There is

a great risk that the cuts in funding will otherwise result in fewer and fewer of the same services, unable to meet the growing demand for support.

We have included a set of action points to show what can be done to introduce co-production into social care. Doing so would unleash another set of resources – the time, skill, experience, care and support that is used every day to provide informal care and support everywhere in our communities. Though co-production is not a substitute for professional support, it can be used to significantly expand the capacity of services and can create more effective services that draw on people's own expertise about what support will work best for them. Briefing 2, *Recommendations for developing co-production in Social Care* outlines some of the practical steps that can be taken to develop the approach in practice.

These findings come at a time of transition for local authorities, and we hope they can provide a practical way for commissioners and providers to develop support where power is shared equally between people and professionals, relationships are valued and nurtured, and helping people to get the outcomes they want is the central focus.

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At the inception of the project, we agreed definitions for the key terms we were going to be using: personalisation and co-production. These are laid out in box 1.

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Box 1: Key terms defined

We agreed on and discussed these definitions at the beginning of each workshop

Personalisation means that the person who needs support should have real choice and control to get the support that works for them. It can involve people having personal budgets or direct payments to directly purchase support, but it also includes a focus on person-centred thinking, and the principles of independent living.

Co-production is a way of working where people and professionals work together in an equal and reciprocal way to get things done. This definition is underpinned by six common features of co-production:

- Recognising people as assets: transforming the perception of people from passive recipients of services and burdens on the system into one where they are equal partners in designing and delivering services.
- Building on people's existing capabilities: altering the delivery model of public services from a deficit approach to one that provides opportunities to recognise and grow people's capabilities and actively support them to put these to use individually and in groups.
- Mutuality and reciprocity: offering people a range of incentives to engage in reciprocal relationships with professionals and with each other, where there are mutual responsibilities and expectations.
- Peer support networks: engaging peer and personal networks alongside professionals as the best way of transferring knowledge and supporting change.
- Breaking down barriers: dissolving the distinctions between professionals and recipients, and between producers and consumers of services, by reconfiguring the way services are developed and delivered.
- Facilitating rather than delivering: enabling public service agencies to become catalysts and facilitators of change rather than central providers of services themselves.

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About this project

The project was designed to explore the experiences of people who provide and use support and care, against a backdrop of a shift in social care towards greater personalisation of services. We explored people's current experiences of **personalisation** and considered what benefits **co-production** might bring to staff and people getting support. We also wanted to know what risks there might be if funding for care were reduced or withdrawn.

The project had three phases of work.

1 A literature review of the theory, policy and impact of personalisation in Social Care. This phase was completed in November 2011, and a final report from that phase can be downloaded here.

2 A phase of qualitative research with service 'users', carers, practitioners and commissioners to pool and exchange knowledge and ideas about:

a their experiences of providing and receiving care and support;

b the strengths and weaknesses of co-production as well as barriers and opportunities for applying it more widely;

c the costs of different types of support that people are paying for, and what kind of support people access which is not purchased.

3 Making practical recommendations for further research and practical work to test out the questions and ideas developed through this project.

A full methodology for each of the phases is provided at the end of this Executive Summary.

Context

This research took place against a backdrop of change and uncertainty for people who use and provide services. The welfare state is beset by change, and is adapting to cuts of more than £6 billion in social care, as well as cuts of £18 billion in welfare spending. Further welfare cuts are being suggested by the Coalition as the time of writing which will affect many people who use social care. Local authorities have been forced to make reductions to their budgets that average 27 per cent, and face few choices in how they might raise any additional revenue for services. As a result of the cuts, many local authorities are restricting eligibility criteria, reducing the size of people's budgets, and cutting preventative support. Many people who use services are uncertain whether their support will continue, or how far it will be reduced.

At a policy level, the national debate has been driven by the concept of personalisation, and by the findings of the Dilnot Commission on Funding of Care and Support, which are still under consideration by the Government. The implementation of personalisation was our particular focus. This policy has gone hand in hand with a more market-based approach to services in social care and in other sectors, as the Government implements policies to open up public services to different types of providers. This market-based view of support tends to convey the idea of citizens as consumers, of care and support as a commodity, and of individuals' choice to spend their own personal budget as the key mechanism for allocating care and support. It is based on an implicit assumption that consumer demand will guide the market so that it is more responsive to individual preferences.

The original vision for personalisation was set out under the last Government through the Putting People First programme, which outlined four domains for transformation: choice and control, universal services, social capital, and early intervention and prevention. This combination of policies was seen to be essential to the success of personalisation. But most aspects of the four domains have proved difficult to implement in practice, and have often been marginalised at the local level in favour of a narrower focus on personal budgets.

The policy of personalisation pre-dates the substantial cuts to public spending that have come into force since the October 2010 Comprehensive Spending Review. This new landscape of austerity, uncertainty and change is reflected in our findings. We have found that it is beginning to change how people experience personalised services on the ground. The lack of a secure funding settlement for social care, combined with biting austerity measures, is being felt on the front line. Our research showed a sector that is struggling to make a positive cultural shift towards genuinely personalised support, while it anticipates further cuts in spending and further shrinkage in the voluntary and community sector, including many user-led support and advocacy groups.

We found that austerity was at the forefront of many participants' minds when they described their experiences of social care, and their fears for what might happen in the near future. Overwhelmingly, the picture painted was of an under-resourced care system which is in transition, meaning many people were experiencing the overlap of old and new cultures and processes. Despite this sense of transition, many of the findings that emerged were features of what is perceived as a 'traditional' social care system. There are clear tensions emerging between this traditional system of social care, 'new' processes and ways of working driven by personalisation, and the new biting austerity of public services. As might be expected from a system in transition, there were a huge range of experiences from positively life changing to un-dignifying and disempowering. It is likely that the cuts in public funding will further intensify these tensions, and in some areas has led to a ''moratorium'' for Local Authorities who are battling increasing demand for services with substantially reduced budgets.

How to read this selection of briefings

This final set of briefings includes an Executive Summary and three short briefings on:

- Briefing 1: the learning from the second phase of qualitative research;
- Briefing 2: recommendations for taking forward co-production in social care;
- Briefing 3: recommendations for further research and practical work.

We also used many of the quotes and examples from phase 2 to commission an illustrated short film, exploring some of the key ideas and issues. This film can be downloaded from here.

We'd recommend you read all three briefings, which are summaries of the research. For a brief overview, continue reading the Executive Summary, and take a look at the short film.

Briefing 1: Experiences of Social Care: Summary of findings

These findings summarise how people described their experiences of social care and support in England, and particularly their experiences of personalisation and co-production. We have highlighted the key themes and insights, although there is much more detail, including quotes, personal testimonies and examples, in the main briefing.

- People's experience of social care and support vary enormously, and depend upon a range of factors from location and 'condition', to the type of provider and quality of relationship with support staff. Getting support from the local authority is seen as a battle.

- There are significant inequalities between different 'groups' of people who access social care, with particular challenges and institutional stigma experienced by people who get support for mental health conditions.

- Almost everyone who took part in the research was familiar with the term 'personalisation', although they had varying degrees of experience of it. There is a strong distinction emerging in the way personalisation is being implemented, between personal budgets, and the broader principles of personalisation, and connected concepts, such as self-directed support. Many Local Authorities are focussing on the personal budget as the key component of personalisation, as it is the only national indicator used to assess the implementation of the policy.

- Despite the greater variety of support that some people are starting to access, it seems the social care system is still tilting towards 'business as usual'. There were examples of personalisation being used in name, but people having no choice but to use their personal budget to access block funded contracts, and many people struggling to get agreement to spend their personal budget on creative forms of support that they feel would improve their well-being. A minority are being supported in ways which are genuinely personalised, giving them access to creative and outcomes focussed support, peer advocates, and the opportunity to self-direct their own support.

- Many people are told that their support is restricted, and can only cover personal care, and they are struggling to get more creative forms of support that would enhance their well-being, address social isolation, or provide support that is not related to personal care.

- Personalisation cannot improve people's outcomes and quality of support if it is not co-produced. If people aren't active participants in shaping their support plan and able to draw on a wide range of resources for support, then the service is still being determined by the provider or commissioner.

- Process is taking priority over people in the implementation of personalisation. The systemic barriers to getting meaningfully personalised support were consistently highlighted. The most common challenge was in the delays experienced by people going through the assessment and support planning process, which for some individuals had taken over a year.

- The language used in social care is a key area of contention. Many people who use services feel the way they are described puts them in a passive, consumerist role, yet they had a strong sense of citizenship, and wanted to be active participants in an explicitly recognised social contract. The use of terms such as 'service user', 'client' and 'customer' were often seen as words which re-enforced people's role as consumers of services, rather than active citizens who can contribute to and work alongside professionals in shaping support.

- Asking people to reflect on the term co-production, there was broad consensus that it meant being treated as equals, having an active role in planning and delivering support, and being able to access peers for support and advocacy. Co-producing support with professionals meant using existing community services such as leisure centres or libraries, and looking for opportunities for people to build up their skills and share their expertise.

- People who have personal budgets are buying a range of support – although many made it clear that the 'system' works against creative solutions. The most common support people are buying comes through hiring personal assistants, but other examples include services and activities based in local centres, professional skills and qualifications, art classes, gardening equipment and employment support.

- There is a huge deficit of knowledge and insight into what services cost, and what types of non-market support can be utilised. Both staff and people using support were aware of how little they knew about different types of support, and different levels of cost.

- When questioned about costs of support, many people were quick to point out that there is lots of support which does not have to be 'bought'. We asked people to describe what kind of support they got which they didn't pay for. Some of these 'non market' goods included peer support and services such as local parks, libraries and leisure centres.

- The quality of the relationship people have with their support worker, friends and family is at the heart of getting good support. People value support which gives them opportunities to participate, to socialise, and to develop consistent relationships with others, including staff as well as their peers, and to be active members of the community.

Briefing 2: action points for taking forward co-production in adult social care

Here, we set out a number of action points on how those working in social care can develop co-production within the commissioning, planning and delivery of services.

- Ensure that strategic bodies and decision making forums have strong involvement from people with lived experience of the service, and that they have genuine influence over the decision-making process. This could be done in partnership with a user-led organisation and/or local community-led groups.

- Make co-production a quality standard for all decisions and activities. Adopt this approach: 'if a decision does not have co-production at the heart of it, we will not make it'.

- Engage the people you support in new conversations about what outcomes are important to them, what types of support they need, and what local networks and resources could be used to strengthen the impact of services. Make this a consistent feature of developing support across the organisation.

- Work with staff and people who use services to identify processes that are 'getting in the way' of co-production. Examples often mentioned include: risk and safety protocols that make it difficult to engage with the community, or stop peer support networks developing; professionally led assessments of need (including assessment and approval panels); contracts that are over-specified with detail of what the activities to be delivered, and how.

- Ask people what their interests are, what is important to them, and how they might be able to use their skills and time to support others. This applies to people who use services, but also their friends, family members and others within the community.

- Think about the specific qualities and skills that staff will need if they are to work in a more equal and reciprocal way and actively recruit for this. Recruit and train staff with input from people who get support.

- Link services into local resources, such as peer support and community based networks that can help support people away from services. It is important from the outset to tackle the discrimination that keeps many people away from community resources in the first place.

Briefing 3: areas for further research and gaps in knowledge

Throughout the research we captured the gaps in knowledge and practice that exist across the social care system, and sought people's insights on what practical projects are needed to test out best practice in personalisation and coproduction:

1 Lines of enquiry for research and evaluation;

2 practical pilot projects to develop and test out particular aspects of care and support.

Lines of enquiry for research and evaluation

- How the current austerity measures and changing welfare legislation are affecting people who use social care, their carers and families.

- The research threw up a number of questions about local markets of social care and support failing to provide good quality and affordable support. Specific areas for further research include:

  • the different dynamics of local and national markets of care services;

  • the distinctive features of local markets that are seen to be working particularly well, or failing;

  • the role of the commissioner and local authority in shaping local care provision;

  • how personalisation might change the provider market as commissioning is driven down to an increasingly individual level.

- Personal budgets and, specifically, long assessment processes associated with awarding them, make it more difficult to provide support for people with rapidly changing conditions or circumstances (for example, those with fluctuating metal health or people whose condition is episodic). More insight is needed into what process and type of support works best for people in crisis situations or who have rapidly fluctuating conditions.

- User-led organisations across England are being hit hard by the cuts in public spending, and many will be forced to close. Specific questions within this line of enquiry include:

  • How is the existing infrastructure for peer/user led support being affected by the cuts in public spending, and what are the possible implications of this for people who use services, their family members, and carers?

  • ULOs, to deliver services, as in Norfolk and Essex.

  • What is the potential value to people who get support, and to public bodies, of investing in capacity building peer and user support networks?

- A majority of people involved in this research had examples of specific rules and controls which were getting in the way of good support, and were actively restricting the choice and control of people who use services – specifically those people with personal budgets. Greater knowledge about where and how local authorities are setting 'boundaries' around the permissible use of budgets is needed, and insight into what is driving these boundaries.

- Many people have indicated that the new language of personalisation is being used without real changes to existing practice and process. Practical work is needed to identify where progress towards personalisation is being blocked and where changes to systems, process and culture have actually occurred, how this change has been driven, and what impact has it had.

- Greater clarity and transparency of the different costs of support is needed, in particular, insight into inequalities that exist in the price of support for groups of people with different conditions, and other factors such as the local environment (rural, urban), the level of deprivation within the area, or the existence of monopolies within the care sector.

- Much more knowledge and practice is needed to explore how carers are being affected by the convergence of austerity, welfare reform, changing eligibility criteria, personalisation, and greater use of personal budgets.

- Developing a 'bank' of practical examples of co-production to illustrate how the principles of co-production have been applied in many different scenarios. This would help illustrate a relatively theoretical concept, and encourage practitioners to think about how the principles could be adopted in their own work.

Practical pilot projects are recommended to develop and test:

- An assessment of the skills and training required to create the cultural change needed to shift social care into taking a more asset based, personalised approach. Particular areas where participants in our research identified training needs were: understanding outcomes; how to support well-being and social inclusion; addressing inequalities and discrimination within the community; and adopting the principles of co-production into people's own work.

- How to develop ways in which people who use services can have real influence and power over the decisions that shape the provision of local care and support.

- How co-production could be applied to improve people's experience of social care. In particular, how local authorities and providers might use co-production to provide support based within the community to enable people to live independently and to prevent the need for more acute care services.

- Testing out new ways of providing people with information on care and support, particularly looking at whether this can be achieved more effectively in partnership with user-led organisations, peer support groups and community organisations and institutions.

Methodology

We described our full methodology for Phase One of the project here. This series of briefings is focused on the findings from Phase Two, for which there were several stages.

Our aim in Phase Two of the project was to engage a wide range of people in dialogue about their experiences of care and support. We chose to conduct four half day workshops with mixed groups of people who provide and use services, as well as family members, carers, commissioners and social work students. Participants included people who received funding from local authorities and people who were self-funders. The workshops took place between September and December 2011 across four sites: Kent, Leeds, Birmingham and London.

We wanted to hold the workshops in partnerships with people who provide and use services, and so we worked with four organisations to develop, plan and facilitate the workshops with us: Skillnet Group CIC, Tricia Nicoll, The Coalition for Independent Living and Community Catalysts. We also worked with these organisations, as well as with our own networks, to invite participants to the workshops. We talked to more than 85 people who had experience of social care from a range of perspectives, including those with physical and learning disabilities, mental health conditions and long term health conditions. Older people were a group who were under-represented among participants, as were young people under the age of 16, although some parents attended who had children who were using social care services. The gender balance was fairly evenly split in Leeds and Birmingham, with slightly more women than men attending in London and Kent.

We also wanted to include the perspectives of people who might not be able to attend the workshops in person. We commissioned the Coalition for Independent Living to conduct a short phase of peer research to highlight key themes and experiences. The research comprised of:

- Three interviews with: an older person with dementia receiving managed budget and his wife; two young people with learning difficulties in transition from children's to adults' services who have been assessed for adult social care and are waiting for their personal budgets; the mothers of the two young people.

- One focus group of four working age disabled people all in receipt of personal budgets.
- Ten short 'vox pop' interviews at the 2011 Disability Capital conference.

The peer research was conducted in advance of the workshops, and helped us refine specific lines of enquiry to pursue in the workshops.

The four workshops were structured around three key questions;

- How does people's experience of support differ across traditional, personalised and co-produced support?
- How could things be done differently to introduce co-production as a more common approach to supporting people?
- What do we know about the costs of different types of support or activities?

During the workshops, each group had materials available to write or draw their ideas and insights, and the conversation was captured by someone writing detailed notes. The accumulated notes were written up (some were also photographed where post -it notes had been used to capture content), and the write up was circulated to project partners for review and comment.

From this qualitative research, we developed recommendations for taking forward co-production in social care, and addressing some of the gaps and challenges that remain. All those who participated in the workshops, or as a critical advisor to the project, were invited to share their suggestions and all of these have been incorporated into our recommendations.

The project was advised by an expert reference group, which included people who are carers, receive support themselves, academics, policy leads and user led organisations.

If you have any questions on this research, please contact Julia.slay@neweconomics.org or visit: www.neweconomics.org/budgetsandbeyond