Personalisation in the reform of social care: key messages
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Background

1. This key messages paper summarises recent Equality and Human Rights Commission (Commission) research reports concerning ‘personalisation’. Personalisation refers to those services like direct payments, personal budgets and self-directed or funded support that do not rely on traditional service-led support or institutions, and which will increasingly be used to deliver care in the future.

This document draws on evidence from England but shares issues and themes with our colleagues in Scotland and Wales. In England, the Government’s Vision for Social Care reform was launched on November 16 2010 with the aim of substantially increasing the use of personalised modes of care. This approach is also envisaged in the ‘Liberating the NHS’ reform proposals, in relation to many conditions that require both social care and health support. Scotland and Wales are also increasing self-directed support and direct payments to enable greater independence for those requiring care services.

2. In 2009, the Commission published a policy paper, From Safety Net to Springboard, which set out its vision of an approach to social care and support based on equality and human rights (Equality and Human Rights Commission, 2009). It was the Commission’s view that care and support should act as a springboard by promoting people’s abilities, being based on users’ views of what they need, and by seeking to benefit society as a whole. Fundamental to the Commission’s vision was the belief that all groups should be able to access support of their choice, to enhance and maximise their life chances and quality of life across the life course. This report has been widely referenced and used since its launch. In particular, its themes relate closely to the proposals of both previous and current Governments who have recognised the need for radical reform based on such principles.

3. Since 2009, the external environment has changed substantially, but the Commission’s approach to the reform of social care remains constant. The current reductions in public sector spending now suggest, however, that protecting the perceived ‘Safety Net’ is just as pressing an issue for affected groups as the original aspiration to make reform the springboard to their greater social and economic participation. The pace of change is now accelerating, with both health and social care in England to be significantly reformed, restructured and more closely linked with each other.
4. The Commission is still of the view that greater ‘personalisation’ of areas of social care and health holds significant potential to maximise choice, autonomy, control and independence for service users, their partners, carers or families. The findings of our Triennial Review echo this theme in one of the key challenges that the report poses: ‘to reduce the rise of the need for and cost of informal care and to increase autonomy, choice and control for both carers and those who receive care’.

5. Our work since early 2009 has focused on how diverse groups of people are able to use personalised services. The Commission has undertaken and commissioned field work and research to track how far personalisation reaches diverse groups within the community. In particular, it has looked at how well groups facing particular barriers, because of the level of their impairment or their circumstances, are supported by services such as ‘independent advocacy’. These projects set out to improve our understanding of how far such groups can be ‘competent consumers’ of an increasingly mixed and personalised market of care and health provision.

6. It has become clear that this was a difficult research task. Many services and the assumptions that drive their commissioning and delivery appeared to be predicated on narrow perceptions of key characteristics of age, disability or of long-term conditions. It was not easy to test how some services reach those whose other characteristics such as their sexual orientation, their youth, faith or ethnicity might be invisible.

7. The two resulting reports suggest that there will need to be improved effort and action to make personalisation successful. Personalised services do not yet adequately reach diverse communities, despite the fact that those groups are the ones that could arguably benefit most from them. There needs to be a major effort to make independent advocacy more available and accessible. This will be essential for many citizens to become competent consumers of increasingly personalised modes of care.

**Access to personalisation**

8. During 2009-10, the Commission’s English Regional team undertook work to explore how personalisation was working in practice for four specific groups of people who use social care services. These were:
• lesbian, gay, bisexual and transgender (LGBT) people in the North West
• young adult mental health service users in the North East
• disabled Gypsies and Travellers in the East Midlands
• older people in the South West.

9. The work was mainly qualitative and was carried out in partnership, typically with regionally-based user led groups. It sought to establish good practice as well as to ascertain gaps or barriers to service provision.

10. The work of the four projects revealed that there is a real gap in the ability of information, advice, advocacy and other types of support services to meet the needs of marginalised groups. Evidence of what is missing from these services came for the most part from direct engagement with service users. Participants highlighted the following issues:

• Young men in the North East complained that any information they had been given did not seem relevant to them and was not age-appropriate.

• Participants in the focus groups for older people in the South West described the language used as ‘jargon’ and ‘difficult to understand’. In particular, older people said they preferred to have things explained to them face-to-face. Many did not have access to the Internet and found online information of no use.

• There were poor literacy rates among the young men with mental health conditions who were surveyed, and this was also the case amongst the Gypsy and Traveller community who participated. This made some written information difficult to understand.

• LGBT people in the North West mentioned that images of service users appearing in leaflets and other information rarely included LGBT people and that the language used was sometimes – and perhaps unwittingly – heterosexist

11. It had been already argued in From Safety Net to Springboard that suitably tailored information, advice, brokerage and advocacy were vital to help such new potential consumers reach and use new modes of care.
12. The projects illustrated that service commissioning and provision either tended not to identify or act upon characteristics other than the most immediate, or they still largely managed the local market by such methods as block contracts which mitigated against more personalised or diverse provision. For potential users of personalised services, this tended to create barriers, for example around the understandability or practicality of direct payments. It was clear, however, that all the groups could see real benefits in such services, not least to reduce some real risks to their health and wellbeing.

13. For some people as service users, the impact of these barriers appeared to be particularly negative. For example, Gypsies and Travellers and young men at risk of suicide identified significant difficulties in relation to securing any level of service provision at all, let alone a service that might be tailored to their personal needs. This included services that could reduce the likelihood of crisis interventions.

14. There were also substantial reported cultural and physical barriers to the actual use of personalised services:

- There was general lack of awareness of the relevance or concept of personalised services.
- Even in the areas where this understanding was better, there were barriers such as a lack of local transport, a lack of specific data on the allocated budgets, and a lack of support such as brokerage to assist consumers.
- The administration of personal budgets and other payments or support was a burden for either recipients or their carers.
- Staff delivering information on personalisation often cited its complexity, and some older participants felt that staff were generally demoralised by the prospect rather than inspired by their potential to deliver more choice.
- Amongst the groups there were some cultural barriers to full disclosure or sharing needs, even for those services that could prevent a later crisis intervention. For example, for LGBT disabled people in the survey, there was a particular issue about ‘dual identity’. Participants said that it was often hard enough to have their needs as disabled people recognised, without introducing sexuality and gender identity into the equation.
15. It appeared that most barriers were either driven by systemic lack of understanding about groups, or by stereotypical attitudes towards them, leading to services that were insufficiently flexible to reach or be used by them, even those that could prevent crisis, or improve participation in employment or social activities.

16. We concluded from the pilot projects that current practice in equality impact assessments (EIAs) was not working effectively as a means for public bodies to consider fully the needs of all groups. Often these are done without seeking the views of service users and, when consultation is carried out, the format of the consultation is not age or culturally appropriate. The research report also concluded that EIAs should include an assessment of human rights implications for different groups. A recommendation arising from this project is that public bodies should be directed to engage with and involve service users in equality impact assessment, to a far greater extent, and that more detailed guidance should be given on effective methods of involvement.

17. Other work by the Commission during this time also examined related issues for the new protected strands of equality. For example the report ‘Beyond Tolerance’ illustrated that the lesbian, gay and bisexual communities still experience persistent barriers and discrimination within some traditional services like health and social care. For such groups, access to personalised services could help to avoid and tackle this, whilst also helping any mixed economy of health and social care to function better.

18. The well documented issues of an ageing population also make it essential that notions of age, disability and caring get away from stereotypical assumptions if modes of care are to fully reach our increasingly diverse older communities. The Department of Health has already committed itself to tackling age discrimination in Health and Social Care from 2009 onwards.

19. The impact of the ageing population is also one of several strategic issues identified in the Commission’s Triennial Review.

**Access to independent advocacy**

20. As a further follow up to *From Safety Net to Springboard*, in 2009-10 the Commission commissioned research into the availability of advocacy for people in groups protected by equality legislation and requiring social care. The research also aimed to identify what advocacy providers and commissioners are doing to make advocacy services more accessible.
403 advocacy providers took part in telephone interviews, representing over a quarter of all those listed on a database of advocacy services in England, Scotland and Wales. 200 commissioners of advocacy services also participated in telephone interviews.

21. These interviews were then used to select 13 localities for case studies of good equalities practice in advocacy provision. The case studies involved in-depth interviews with advocacy providers and commissioners to draw out information about the measures they were taking to increase access to advocacy in their localities.

22. The research highlighted the frequent invisibility of some groups to both advocacy providers and commissioners. This was particularly true of groups which shared characteristics relating to religion or belief, sexual orientation or transgender status.

23. Around one in four of the advocacy providers who took part in the survey provided advocacy to anyone who needed it, regardless of personal characteristics or identity. The remainder had the objective of providing advocacy to people from one or more user groups or with one or more protected characteristics.

24. Thirty-seven per cent of providers estimated that half or more of their users had mental health conditions, 27 per cent estimated that at least half their users had learning disabilities, and 27 per cent said that half or more were older people. Amongst providers, 87 per cent said they supported people with issues involving access to health services, 79 per cent with access to social care, and 57 per cent with access to personalised services.

25. The majority of commissioners (88 per cent) made it a condition of all their contracts or agreements with advocacy providers that they should record equality information. Ninety per cent of all commissioners required providers to monitor their service users’ gender in all or some cases, 89 per cent their age and 88 per cent their race/ethnicity. The figure for disability status was 78 per cent, religion or faith 44 per cent, sexual orientation 30 per cent, and transgender status 22 per cent.

26. The proportions of providers who said they regularly recorded service users' gender, age, ethnicity, sensory or physical impairments, mental health conditions or learning disabilities varied between 80 and 96 per cent. The proportions of those who said they recorded religion or belief, sexual orientation or transgender status were much lower, at between 28 and 37 per cent. The reasons for not monitoring the latter
characteristics included views that such information was personal, not relevant or that the questions would be too intrusive.

27. Providers mentioned a range of means they had adopted to improve the accessibility of their services to people with protected characteristics. The most common were outreach (mentioned by 32 per cent of providers) and promotional materials (20 per cent).

28. Examples of good practice that were cited included organisations in Liverpool and in Devon working together to provide single points of entry for local service users. Other benefits of collaboration were: reduced duplication; sharing resources; more systematic assessment of need and referral procedures; and a shared approach to quality and standards.

29. Our overall view now is that there appears to be a postcode lottery of availability of advocacy, and that if this continues it will result in many people not being able to access and use self-directed care such as personal budgets. We believe there is a strong case for guidance to be produced by the Department of Health or the envisaged NHS commissioning board on developing local advocacy frameworks that ensure that non-statutory advocacy provision, such as that to support people to use personal budgets, is commissioned. This would be in addition to statutory provision such as Independent Mental Health and Mental Capacity Advocacy. Department of Health-funded research by Advocacy Consortium UK exploring the desirability and feasibility of such a framework for advocacy has already demonstrated indicative support for this amongst a selection of advocacy providers.

30. The Commission recognises that for most people good quality information, advice and signposting services will be adequate for them to access and utilise personal budgets. The commission strongly believes that independent advocacy needs to be available for those people, however, who are at greatest risk of not benefiting from self-directed care. These include people who have limited mental capacity and/or who face sudden vulnerable circumstances, such as onset of severe impairment.

**What now?**

31. By early 2011, a strong picture has emerged that personalisation as now envisaged may fail large sections of the community unless steps are taken to reach and support these consumers.
32. Our overall aspiration is to secure greater reliability of tailored information, advice and guidance, and access to independent advocacy in order to help people to be competent consumers of personalised services.

33. A key factor in delivering this in England will be rigorous Equality Impact Assessment by those introducing changes, commencing with the Health and Social Care Bill (January 2011) and through to the envisaged White Paper and subsequent Bill on social care reform at the end of this year.

34. We will take forward these issues in our formal relationships with the Care Quality Commission (CQC), the Department of Health and other regulators and inspectorates. For example, we will continue to stress the need for access to advocacy in our joint guidance to service assessors and inspectors with the CQC, and the need for improved equality data, impact assessment and appropriate commissioning with the Department of Health.

35. We will examine the themes of personalisation and advocacy in hearings for our disability harassment inquiry and in our inquiry into the human rights of older people receiving care in their own homes and communities.

36. We believe that From Safety Net to Spring Board and follow-up work will have contributed to key aspects of social care reform, helping to embed the principles of equality, human rights and good relations.
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