

Action for Advocacy's Response to Equity and Excellence: Liberating the NHS

Action for Advocacy can see much to celebrate and support in “Equity and Excellence: Liberating the NHS”. Coming at a time of severe financial constraint it is understandable that there is much concern amongst people about how they may be affected by any forthcoming changes to the NHS. In this context, the stated commitment to equity and equality is a hopeful indicator of the aims of the reforms and something that must not be lost in the journey from policy to implementation.

Many of the aspirations and principles of the paper echo the fundamental ethos of advocacy; that people are the experts on their life, that people should have a choice on the fundamental nature of care - not merely a choice of provider, that services should be designed around the person and not vice versa, that discrimination is unacceptable, that substandard treatment will be identified and that is not tolerated. Most strikingly of all, to see a government publication adopting the self-advocacy rallying cry of “nothing about us without us” shows a continued move towards a society where all members can take responsibility for their own lives and choices.

Action for Advocacy welcomes this tone in the paper. We support the commitments to putting patients first, making sure that care is personalised to individual need, to ensuring that need and background do not present barriers to accessing the benefits of service redesign and to strengthening patient voice.

The paper highlights that in some cases the NHS is poor at being responsive to the patients it serves – a statement that reflects the reason that many people come to independent advocacy providers. Individuals often feel the need to be supported to challenge health professionals; sometimes to ensure that the care is designed to meet their needs rather than those of the service, at other times to tackle discrimination and inequitable access to care. This need for support tends to be more pronounced amongst those with longstanding or complex conditions, particularly those which are associated with stigma. In these cases, independent advocacy has been one of the engines of transformation in the way that services are delivered to individuals, providing support and confidence to individuals to participate in designing their own care and challenging those who would deny patients fundamental choice and control. Shared decision making must be the way forward for all NHS services.

The aspiration to give people support and freedom to live the life they choose with dignity is unarguably positive. However, for many people dignity can be compromised by service centred delivery. Services in which where people are too afraid to challenge inappropriate or substandard care do not provide good health outcomes. Empowering individuals to speak up and to make decisions is a necessary requirement for this aspiration to be realised in the medium to long term. Increasing patient voice in this regard may enable people to become empowered regulators of their own care.

We are heartened to read that choice is not seen in relation merely to the time and place of appointments but is defined in the paper as, “a more fundamental control of the circumstances of the treatment and care you receive”. Access to information will define people’s ability to gain autonomy in care decisions. We therefore welcome the provision to provide assistance to those who are less able to access online health information. However, whilst access to information is necessary it is not sufficient to ensure that people can take control of their own lives. For this to happen people must be able to speak up and confident that others will listen. If these decisions are to allow people to look beyond the scope of existing service provision it will require the support of people from outside the “pure” health sector. This is the area in which independent advocacy services have developed expertise over the last 30 years. We urge the government to make use of these hard won resources to ensure that the NHS is responsive to the differing needs of a wide range of empowered individuals.

We welcome the recommendation that patients are to hold their own notes as an important step forward in empowering people and making available the information which defines which choices they may be able to make. Whilst noting that this will start with GP records and extend to health records held by all providers we would urge that there is explicit guidance that people with mental health problems are not unfairly excluded from this provision.

We will respond in more detail to the arrangements around Health Watch in the consultation specific to Local Democratic Legitimacy in Health, and our response will focus on how to ensure commissioning of health advocacy makes best use of all available resources for independent advocacy. However it is important to note that the provision of complaints advocacy will not be sufficient to realise the vision of a transformed NHS.

The Equalities Impact Assessment notes that there is unequal access to and take-up of healthcare, stating further that, “Addressing these inequalities will lead to greater efficiencies in the healthcare system as well as promoting and supporting a fairer society”. Simply put, people are more likely to access services that reflect their need, more likely to stick to plans that they have designed and such plans are more likely to work. Ensuring patients are able to co-design their care will be a fundamental challenge to meet if we are to realise the vision of empowered and independent patients. Finding a means to access the voices and experiences of previously excluded groups of people will be essential if long standing inequalities are addressed in future commissioning arrangements. Both challenges must be met if resources are to be best used.

The Equalities Impact Assessment rightly cautions that “A high quality, safe service is no good to someone who needs it but cannot access it, or who does not want to use it because it is insensitive to their needs”. This is a salutary warning when put in the context of the experience of advocacy service users. Numerous advocacy organisations tell us of the difficulties they have in getting access to GP care for some of their clients. Methods of delivery of many services have been inappropriate to the needs of individuals wishing to

access them. Exaggerated focus on one aspect of a person's life has often led to services which ignore the rest of their needs. These are all instances of people being disbarred from access to high quality healthcare which is appropriate to them. In times of tough decisions it is likely that those less able to challenge will suffer disproportionately in access to care and in the commissioning and design of services. We welcome the onus which the Equalities Impact Assessment places on GP commissioning consortia to promote equalities and ensure equality of access. We suggest that engagement with voluntary sector organisations may help consortia to meet this obligation.

To ensure that the transformation of the NHS is one that fundamentally gives power back to individuals is an immensely positive aspiration. We believe that patient centred planning and decision making will lead not only to greater satisfaction but also to more appropriate services and better health outcomes. Implementation of the programme will need to carefully consider how it will address imbalances of power, information and ability to control the decisions affecting our own lives. We believe that independent advocacy could have an important role in facilitating this change.

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