

# A stronger local voice



## Introduction

SCIE welcomes the opportunity to comment on the Department of Health's plans for creating a stronger local voice in the development of health and social care services. SCIE also welcomes the role assigned to us in promoting and supporting public and patient involvement by providing resources for commissioners, providers and regulators.

SCIE's extensive work into stakeholder participation shows the importance of involving users and carers in the design and the delivery of the services they receive. We support the Government's focus on involving service users in all levels of the health and social care system, including in commissioning and regulating services.

Social care has an established record of user involvement and has many good practice examples of how local and national organisations can adopt a culture of participation to benefit service delivery. However, our work has also shown there to be potential obstacles to full and meaningful involvement.

In this document we make a general response to Department of Health (DH) proposals with specific reference to the best ways of encouraging people to participate through, for example, becoming members of LINKs. We also set out our advice for overcoming potential problems associated with achieving local involvement and highlight some existing barriers against service user and carer participation. We also outline some of the issues that the Patient and Public Involvement (PPI) team at the DH will have to consider in order to ensure that patients and the public who are seldom heard are also included in this vision.

## Potential problems

Efforts to promote a user focus in planning and development of social care are already taking place across the UK and there are lessons that the PPI team can learn.

SCIE's work on user participation in social care services highlighted some potential obstacles associated with efforts to promote a user focus in planning and developing services. SCIE's position paper 3<sup>i</sup>, 'Has service user participation made a difference to social care services?' offers suggestions for overcoming these obstacles thus maximising service user influence.

Some of the potential problems and advice for dealing with them are outlined below:

- Service users say they need to receive feedback as an integral part of the participation process, but up to now, this does not appear to have been happening. Agencies should see monitoring of impact and meaningful feedback as a vital constituent of process, as it is related to engagement and commitment. When little or nothing is communicated back to participants, this can have a negative effect on their motivation, trust and confidence.

- In some cases there is a risk of user participation initiatives being conducted as externalised consultation exercises to approve of professional service planning and policy proposals, rather than enabling service users to be integral partners for their formulation. Embedded, continuous but varied participation approaches which engage service users as partners in decision making seem to have most potential for influencing change. Service users want to choose how they are represented. Health and social care agencies are recommended to re-examine their notion of service users who are thought to be 'hard to reach'<sup>1</sup>. Some service users may lack structures of representation or the knowledge and support to empower them to participate.
- Limited funds and service remits can restrain the degree to which service users may be able to influence changes in services. Organisations should be clear from the outset about what can and cannot be done as a result of participation and the true extent of user influence in the given circumstances.

SCIE is also concerned that user groups should be better supported and funded to maintain their independence and critical function. More thought and resources need to be directed at local service user groups to build their capacity to respond effectively to requests for engagement or involvement. When budgeting for programmes there is a need to create a clear budget line for user involvement and also for the evaluation and monitoring of the outcomes of this involvement.

## Participation and the benefits system

The plans set out in *A stronger local voice* clearly reiterate that this government recognises the crucial contribution service users and carers can make. Sometimes with a lifetime of experience of health and social care services, users and carers are expertly placed to contribute to all aspects of service planning and delivery. However, people whose quality of life and independence depends on health and social care services are often also in receipt of incapacity and means tested benefits. SCIE's work on service user participation has shown how the benefits system as it currently stands, actually functions to prevent service user participation of the kind proposed in *A Stronger Local Voice*. When we responded to the DWP's recent proposals for welfare reform, we pointed out that the benefits system seems completely at odds with the climate of user involvement.

Indeed as it currently stands, the existing benefits system actually puts people off engaging in activities such as those associated with becoming members of LINKs. The main point is that the current rules on paying people who are receiving benefits are making payments for participation difficult and in some cases, impossible. This must be addressed. Although the rules allow those receiving benefits to be paid a little for their involvement, some people think they should be changed so that they could be paid more. However, there is also need for greater transparency. The rules are not terribly

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<sup>1</sup> SCIE does not refer to people as 'hard to reach' but rather as 'seldom heard'.

clear. It is of particular concern, that the current rules seem just as confusing for Job Centre Plus advisors as they are for recipients. As a result recipients have described experiences dealing with Jobcentre Plus as ‘difficult and demoralising’ and in some instances, ‘threatening’. Advisors seem to have been wrongly informed and do not understand that users are invited to become involved in service planning or evaluations and so on *because* of their on going experiences of health and social care. We are concerned that user participation is misunderstood to represent capacity for work.

We would be delighted to discuss with DH colleagues, the barriers to patient participation that the benefits system has caused up till now. We have already made a commitment with a number of other national social care organisations, to work with DWP ministers to help remove the barriers to involvement that some people on incapacity benefit currently face. We are optimistic about the progress being made but the issues do highlight that plans to give a stronger local voice face broad challenges.

## A stronger voice for *everyone*

The issues outlined above constitute some general problems that must be overcome in order to achieve the vision set out in *A Stronger Local Voice*. However, further stakeholder participation work at SCIE has shown that certain groups using health and social care services traditionally have an even weaker voice than others. Recently published, ‘Doing it for themselves: participation and black and minority ethnic service users’<sup>ii</sup> and ‘Working together: carer participation in England, Wales and Northern Ireland’<sup>iii</sup> explore how specific attention should be given to engaging these two groups.

## A stronger voice for carers

A SCIE practice survey on carer participation in service delivery and planning was carried out across the UK covering the statutory and voluntary sector in social care, NHS and primary care trusts, joint trusts, learning disability partnership boards and carers’ organisations. Although there are already wide ranging examples of how carers are participating in service planning and delivery decisions, the survey also revealed some barriers to their participation which the PPI team at the DH should consider in trying to achieve their vision:

- There is as yet no shared standard practice or definition of carer participation. This can mean that carers are consulted about decisions rather than being directly involved in making them.
- Respite care is central to carers being enabled to participate, to develop greater autonomy, and to have a break from the strain of caring. However, the literature strongly indicates a shortfall of provision against carer expectations.

- More could be done to identify and increase the participation of historically 'hidden' or marginalised carers. Not surprisingly, some of the most innovative work is being undertaken in localities with significant ethnic and cultural diversity.
- Funding and professional and organisational cultures are seen as obstructing consistent partnership working. Some organisations, especially health trusts, are felt not to perceive carer participation as 'core business'.
- Lack of resources was commonly cited by carers, carers' centre staff and statutory professionals as one of the main reasons for lack of involvement at individual carer level. The most common points from carers related to difficulty getting hold of social work staff except in emergencies or only after prolonged efforts.
- Tight budgetary allocations determine the practice of social care professionals at the same time as they are being encouraged to engage carers more fully. This may limit the extent to which carers' views are being formulated into service metrics that equate to firm service outcomes.

The survey and accompanying literature review also highlighted some examples of *what works* in carer participation. These should also be considered in relation to attracting carer members of LINKs, for example and ensuring carers' voices are heard:

- Most well-established carer participation schemes involve carers at both strategic and grass-roots level, and include feedback mechanisms that ensure carer input makes a difference to service delivery.
- Funding individual carer's time was the prevalent form of resource support. This was paid either directly or through carers' organisations. Carers Grant monies were the main source of revenue.
- Some in the statutory sector feel that more guidance networks would be useful in cementing best practice ideas into service standards and delivery.
- Some of the most creative inputs to carer centred work are being undertaken by primary care trusts supporting substantial staffing input. However, primary care and health trusts are also more likely to state that carers are not seen as 'core business' and, so, often receive non-recurrent funding.
- In some local authorities, 'modernisation and reform groups' are being used to embed their carer participation work in a successful way. This has helped to promote more seamless cross-departmental working.
- Some statutory organisations express the view that where targets have been set (such as, Valuing People or the National Service Framework for Mental Health) there is more carer participation. However, the practice survey also found that there is a risk that carer issues outside statutory targets may not be addressed.

- There are some examples in the literature and in practice that point to creative joint commissioning and provision of carer participation support. Some of the most innovative activity is being funded and provided by social services departments, primary care trusts and health trusts, for example in the mental health and learning disability areas.
- Power sharing should lie at the heart of a progressive shift to the fullest carer participation.

## A stronger voice for BME service users

We are reassured that the plans in a stronger local voice aim to achieve involvement that is real and constructive. In order to ensure that this extends to black and minority ethnic (BME) patients and members of the public, those striving to implement stronger local voice should reflect on the myths and realities around participation of BME communities:

- Policy-makers and practitioners often seek the participation of professionals and leaders within black and minority ethnic communities. They rarely attempt to engage black and minority ethnic service users themselves. There is ample evidence documenting the difficulties black and minority ethnic service users face in accessing and using services. It is also imperative for black and minority ethnic service users to be involved in the design, delivery and evaluation of services. Only then will they want to participate in the process.
- Another myth states that participation is not a priority or as relevant to black and minority ethnic service users. Indeed, having difficulty accessing services may cause participation to be less of a priority unless it is at an individual level. Fear, lack of trust, and a feeling that one ought to appear forever grateful may also inhibit participation for some groups. But there is no evidence to suggest that black and minority ethnic service users do not want to participate at some level. Policymakers need to keep an open mind and sometimes think laterally to facilitate the involvement of black and minority ethnic service users. They may need to be flexible and creative to do things differently to enable service users to participate in a way that is relevant and appropriate to them. They also need to reassure the service user that their involvement is more than merely consultative and can genuinely affect and shape policy.
- Often when agencies want black and minority ethnic service users to participate, the first port of call is community 'leaders', voluntary sector workers and black and minority ethnic professionals. Indeed, they have been a loud voice in the struggle to put the needs of black and minority ethnic service users on the social care agenda. But a large proportion of these 'representatives' do not have direct experience of being social care service users. Possible solutions could include recruitment and appropriate training of black and minority ethnic staff. It is

important though that they aren't forced into having to address race equality issues simply on the basis of their ethnic background.

- Leading on from this, it must be acknowledged that the mainstream service user movement cannot represent black and minority ethnic service users until race equality and anti-discriminatory practice becomes integral to everyone's work. The service user movement is as likely to be as racist as any other part of society and for black and minority ethnic service users to feel less marginalised and to encourage greater participation, this must be addressed.
- Social care professionals have an important role to play. They need to support the participation of service users to develop social care that promotes social inclusion, recognises service users as citizens and allocates services based on what service users define as important. The assumption that empowerment and participation requires social care professionals to take a back seat is short-sighted and naïve. They can be strong allies although the parameters of such partnerships must be agreed at the outset to ensure only the most appropriate pre-existing professional systems and structures are used.

Black and minority ethnic communities have a long history of self-help and direct experience. There are no reasons to suggest that participation cannot work for black and minority ethnic service users. If policy-makers and practitioners are to make a genuine commitment to developing social care services that are relevant, appropriate and based on the notions of choice, then it is imperative that black and minority ethnic service users are actively engaged. They need to be actively supported and their involvement must be real and constructive and not purely consultative.

## Conclusion

SCIE strongly endorses the Department of Health's proposed framework for achieving a stronger local voice in the development of health and social care services. Indeed we maintain that all service users and carers should be able to influence service planning, delivery and regulation and inspection. Service users should be actively involved in determining desired outcomes in terms of value and priority to them, and measures to assess whether and how far they have been achieved. SCIE maintains that service users need a stronger voice in defining what is the most appropriate and effective service to meet their needs, and how it can be shaped and delivered to their specification. Service users should be far more involved in planning and performance arrangements, and particularly in identifying good *outcomes* at a local level as opposed to *outputs*. They should also work alongside CSCI and other inspectorates in undertaking inspections.

We are reassured to see that *A Stronger Local Voice* recognises many of the problems we have identified as traditionally limiting the strength of service user influence. In particular, we welcome plans to promote equal access for less well funded groups, especially those that are user led. Limited funds and service remits can restrain the

degree to which service users may be able to influence changes in services. We also welcome plans to develop involvement systems that ensure the participation of *all* service user groups, including those who are seldom heard.

Finally, it is important to reiterate that achieving the vision of true and meaningful public and patient participation requires the co operation of departments and agencies beyond the remit of health and social care. The barriers to involvement that have existed until now in the benefits system are an example of the need to address wider structures.

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## References

<sup>i</sup> Carr, S. (2004) *Has service user participation made a difference to social care services?* SCIE position paper no 3, London: Social Care Institute for Excellence

<sup>ii</sup> Begum, N. (2006) *Doing it for themselves: participation and black and minority ethnic service users* London: Social Care Institute for Excellence and the Race Equality Unit

<sup>iii</sup> Roulstone, R., Hudson, V., Kearney, J., Martin, A. and Warren, J. (2006) *Working together: Carer participation in England, Wales and Northern Ireland*, London: Social Care Institute for Excellence