

Creating sustainable communities: Supporting independence



Supporting people in its strategic context

How could we ensure appropriate provision and useful outcome measures?

Setting outcome measures in the support and care fields is not easy, but progress is being made in some areas. The important thing is to recognise that outcomes are about the experience of users, and they should be closely involved in defining acceptable outcomes and the measures or indicators to assess if they are being met. SCIE's work on user involvement indicates that very simple outcomes, like the amount of contact an isolated person has with family and neighbours in a week, may be more appropriate to assess than sophisticated 'level of independence' or 'functioning' measures.

Both central and local government need to look at outcomes across the range of support and care that people receive, and not try too hard to link a single outcome to a specific service-related input. The present fragmented approach can be counterproductive, pushing services apart to claim their separate outcomes rather than bringing them together to achieve outcomes jointly. Good practice demonstrates that people experience outcomes holistically (e.g. a sense of security and well-being) and don't ascribe parts to different services.

Although government policy, most recently presented in the white paper, *Our health, our care, our say* (2006)ⁱ, is moving toward an outcome focus this approach has been very slow to manifest itself in practice. SCIE's recent practice survey on outcome-focused services for older people found that very few local authorities are using an outcomes-focused approach. Although the results of the survey have yet to be analysed, anecdotal feedback suggests that current commissioning and delivery systems are so rigid they do not allow for this approach to be taken. Talking to service users and finding out what outcomes they desire is very resource intensive. However, the issue would appear to be about more than the cost implications of putting this approach into practice – a fundamental shift in the culture of commissioning and provision is also required.

What more might central and local government do to build upon, and transfer more widely, the steps already taken to create a user focus within Supporting People?

In brief, SCIE's studies of whether user participation makes a difference show that user responsiveness requires them to be involved not just in service design, but also in quality assurance arrangements and identifying the need and scope for change and improvement. It should be a continuing dialogue, not a one-off consultation. Efforts to promote a user focus in the planning and development of social care are taking place across the UK and there are lessons that Supporting People can learn. SCIE's work on user participation in social care services, referred to above, highlighted some potential obstacles associated with efforts to promote a user focus in planning and developing services. SCIE's *Position paper 3: Has service user participation made a difference to*

*social care services?*ⁱⁱ offers suggestions for overcoming these obstacles and 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 this does not appear to be 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. Agencies are recommended to re-examine their notion of service users who are thought to be ‘hard to reach’¹. 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. SCIE is currently advertising a commission for the development of measures for effective service user and carer participation and would be delighted to share project findings with Supporting People later this year.

¹ SCIE does not refer to people as ‘hard to reach’ but rather as ‘seldom heard’.

Focusing and integrating support

What more can Government, authorities and providers do to focus services more effectively on individuals to create better choice and control?

SCIE's work on commissioning shows there is an urgent need for an integrated approach to commissioning care and support services, and mechanisms for linking them together at the level of the individual and family. The care manager for the user should be well-placed to do this, and extended use of direct payments and the introduction of individual budgets should enable the user to pull together funds from several public service sources. There is too large a gap at present between macro-level commissioning (often through inflexible block contracts) and individuals' needs as identified by them and their front-line workers. The job of the Director of Adult Social Services should include finding ways to increase user influence over commissioning decisions, as well as involving them in quality assurance across statutory, voluntary and private sector provision.

Two particular areas of SCIE's work provide further insight into the means of securing increased choice and control in planning and commissioning support services.

Direct payments offer greater flexibility in support arrangements and allow users control over planning the services they require to support their independence. However, take up of direct payments has been patchy and worse among some groups than others. SCIE's work on direct payments highlighted a number of ways of increasing user control through encouraging the uptake of direct payments. It should be noted that our response to the question, 'What more can be done to ensure authorities make proper provision for socially excluded groups?' below, provides suggestions for improving the uptake of direct payments specifically among black and minority ethnic groups. The suggestions listed here apply generally:

- **Reduce bureaucracy.** Direct payments are still taking months to reach people and this is discouraging people from applying.
- **Ensure direct payments are adequate** to enable people to pay workers a decent hourly rate. Failure to do this will ensure failure.
- **Provide better accessibility to information.** Many people in social care are still unaware of direct payments, as are many service users. The DH should play a leading role in ensuring publicity and accessible information is available.
- **Train and inform your workforce.** The DH has under-estimated the impact direct payments have on social care staff. Using them requires a massive culture change and an element of re-training.
- **Increase funding to independent advocacy services and independent living centres.** This is essential if the bureaucracy and finances are to be managed well.
- **Re-structure existing services.** Services are not prepared for such a major change in how social care is delivered.

- **Include healthcare provision.** Much of social care is entwined with the health service, and mental health and some learning disability services are supposedly joined-up teams.
- **Joint governance of budgets,** that is, health, social care and housing.

Ensuring a user focus also demands that service users have choice over the way their needs are met (although in this context, choice and control are of course inextricably linked). SCIE's work, including its practice survey on person-centred planning in adult placements, explored the success with which the principle has been introduced. In the related Practice guide 4ⁱⁱⁱ, SCIE also provided examples of approaches to ensuring person-centred planning is embedded into the commissioning and provision of support.

The concept of person-centred planning was introduced in the white paper *Valuing people* (2001)^{iv}, in which it is defined as 'the process for continual listening and learning, focusing on what is important to someone now and in the future, and acting upon this in alliance with their family and friends'. SCIE believes this principle should be rooted in care planning and provision for all users of social care and support services. However, SCIE's practice survey on adult placement schemes found that although adult placement carers were working in a person-centred way, good practice was not being achieved through schemes' use of formal person-centred planning systems.

SCIE's Practice guide 4 provided the following examples of models for achieving truly person-centred planning in the provision of support and SCIE suggests that lessons could be transferred for the provision of support via Supporting People:

- **Essential lifestyle planning (ELP)** is a tool that lets you know how someone wants to live and shows you how they would like it to happen through an extremely detailed action plan. ELP lets you discover what is important to service users and what support they need (from their perspective) to remain healthy and safe. A good plan reflects the perceptions of the service user and those who love and care for that person. Essential lifestyle plans look at:
 - > what people like and admire about service users
 - > what is important to service users
 - > communication
 - > how to provide support
 - > identification of successful methods
 - > how to solve problems.

ELP is a good way of starting to get to know someone, and work out what is needed on a day-to-day basis. It does not focus on 'dreams' unlike some of the other methods.

- **Personal futures planning** is similar to essential lifestyle planning and includes access to community resources. It is a way of describing life now and looking at what the person wants in the future. It provides more of an overview than the detail of some of the other approaches.

- **MAPS** is similar to PATH, below, in that it focuses on desirable futures or dreams, and how service users might try to achieve these. It covers people's history and identifies their gifts.
- **PATH** stands for Planning Alternate Tomorrows with Hope. This is a fast-moving tool that can be quite graphic and powerful. It pays most attention to the process of change, and helps a group of people who are committed to the service user to understand the plan and how it will progress. This is not so much about gathering information, but planning action. It focuses on the 'dream' and works its way back from there, mapping actions required along the way.
- **Individual service design** aims to gain a greater understanding of service users by seeing the past through their eyes. From this it is possible to identify how services need to be designed.
- **Circles of support** is a support network of people who meet to help someone along the path to their hopes and dreams. The focus person asks the support group to help them to leap over barriers that they might come across. The support group also helps the person by opening new doors to opportunities and experiences.

Are there any obstacles specific to integrating care and support services? How might they be overcome?

Obstacles to integrating services come from inflexible professional and agency boundaries, line and financial management systems that are too tight, and even 'neutral' factors like incompatible IT and communications systems in organisations trying to collaborate. Similar risks are there for the workings of individual budget systems, if financial accountability requirements are too stringent. Already in direct payments schemes, the requirement on users to maintain a separate bank account (so that the local authority can see how the money is being spent) has for instance put some people with learning disabilities at a disadvantage because banks discriminate against them and refuse them accounts they can manage themselves.

A further concern with an integrated system would be that, under the philosophy of 'concentrating services on those in greatest need', strict eligibility criteria tend to exclude many people who need services and squeeze budgets for early intervention, support and preventive services such as those Supporting People provides.

What more can be done to ensure authorities make proper provision for socially excluded groups?

Socially excluded groups are almost all high risk groups in health and social care terms and integrated strategies for housing, support, health and social care for these groups

are particularly important. Government and local authorities need to create incentives for outreach and coverage of services to encourage greater take-up, although this may be difficult in a context of gross resource shortfalls for some excluded groups.

Outcomes assessment needs to recognise the prevalence of poverty and debt among a number of the excluded groups. It must also recognise the consequences of multiple financial, social, psychological and health factors in the chaotic lifestyles of some marginalised people and the extreme discrimination and exclusion suffered by others.

SCIE has direct experience of consulting and involving people from excluded groups and those whose voices are not often heard. Some of the challenges and related suggestions for good practice are outlined below in relation to particular groups often marginalised by traditional social care and support.

Refugees and asylum seekers

People with social care needs are some of the most vulnerable within refugee communities and their needs are frequently overlooked. SCIE's work on stakeholder participation recently explored the barriers faced by refugee and asylum seekers with social care needs and ultimately made recommendations for overcoming those barriers^v. Barriers to access were found to include: frequent and high profile changes to legislation generating much confusion about entitlement; language and communication problems particularly for women; and agencies' lack of information about the numbers, characteristics and needs of local refugees.

Good practice in ensuring proper provision for asylum seekers and refugees included: partnerships between the statutory and voluntary sectors; and a holistic view of individual social situations taking into consideration practical and legal issues, as well as social care needs. Good practice is also based on partnership with refugee communities. In particular, refugee community organisations can play a valuable role in the planning, design and provision of social care services, yet their potential is largely untapped.

SCIE makes the following recommendations for the proper provision of social care and support for asylum seekers and refugees:

- As part of planning and designing services, authorities should carry out local mapping and consultation exercises to collect data and information about refugees and asylum seekers. As those with social care needs are likely to be the hardest to reach, innovative methods should be used.
- The social care needs of refugees and asylum seekers cannot and should not be met by generic 'asylum teams'. Instead, specialist teams and services should plan and deliver services that meet the needs of service users who are refugees or asylum seekers. Consultation and feedback with refugees and asylum seekers would be a good basis for doing this.
- The refugee community and voluntary sectors should play a far bigger role in the planning, design and delivery of social care services.

Black and minority ethnic service users

One way of ensuring the proper provision of services for black and minority ethnic (BME) social care service users is by encouraging the take up of direct payments. SCIE endorses the use of direct payments because they offer greater independence and flexibility in support arrangements and, for people from BME communities, this can mean improved access to culturally sensitive support. However, despite the hopes of the Department of Health, BME service users and carers are faced with considerable barriers in accessing direct payments. SCIE's work on stakeholder participation found that these are:

- confusion over the meaning of 'independent living'
- assessment processes not taking account of the background and requirements of black and minority ethnic BME service users and carers
- lack of awareness of direct payments
- difficulties in recruiting personal assistants able to meet the cultural, linguistic and religious requirements of service users
- a failure to consider using direct payments in more innovative and creative ways, than the usual direct employment of carers
- a shortage of appropriate advocacy and support services
- a lack of resources for local schemes
- varied levels of commitment to direct payments among local authorities
- the possibility for confusion over the 'relatives' rules'
- lack of support for people to use the available information.

Together, these barriers present a considerable challenge to authorities. SCIE recommends the use of imaginative and original methods to promote the take up of direct payments among seldom-heard groups, as a means of ensuring proper provision of support. Furthermore, the training of care managers needs to reflect the inclusive goal of direct payments and should encourage them to look carefully at the kinds of advocacy and support and services that they have. Work is also needed to recruit people from minority ethnic backgrounds who are able to provide culturally sensitive services to their local communities.

SCIE's work on direct payments highlighted the following specific examples that authorities should consider as means of promoting direct payments. Although they relate specifically to BME groups, some of the principles can usefully be applied to the promotion of direct payments among other marginalised groups:

- target people to attend specific events where information is being provided, such as community events
- recruit service users to schemes/local authorities and using their knowledge and expertise in informing others
- conduct outreach work in the community
- encourage service users to share their experiences
- use educational material in accessible formats, such as Braille, video, easy read (see www.valuingpeople.gov.uk and www.nimhe.org.uk)

- employ specialist workers from specific community groups.

People with mental health difficulties who are 18+ years of age

More attention needs to be given to ensuring appropriate support for people who are 18 and over and who have mental health difficulties. They include people suffering with depression and anxiety and people who self harm. Additionally, they may have other needs such as housing, employment and drug or alcohol problems, but they are not a priority for the mental health and other statutory support services. SCIE recognises that Supporting People has helped with floating support schemes, but there are a significant number of people who are hidden from services, living in inadequate or unsuitable accommodation and without skills to access employment. Additionally, floating support workers do not necessarily have the training or skills to adequately support people who have multiple and complex needs.

Children living with severely disabled parents

SCIE is concerned about inadequate home-based support for disabled parents. Children and young people in families where a parent is severely disabled or suffering from severe mental illness are often carrying excessive caring responsibilities to the detriment of their education and well-being as they grow up. SCIE believes current policies for so called 'young carers' may be misguided. What is needed is much better home support to assist disabled parents in managing their physical disabilities or mental health problems and their responsibilities as parents.

How might this be incentivised, including through outcomes and through performance arrangements?

Improvements in quality of life can be extremely difficult to measure. For some people, engaging with support services and sustaining that relationship is a huge achievement. Service users should be actively involved in determining desired outcomes in terms of value and priority to them, and in developing 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, particularly in identifying good outcomes at a local level as opposed to outputs. They should also work alongside the Commission for Social Care Inspection (CSCI) and other inspectorates in undertaking inspections.

References

- ⁱ Department of Health (2006) *Our health, our care, our say: a new direction for community service*, London: TSO
- ⁱⁱ Carr S (2004) *Position paper 3: Has service user participation made a difference to social care services?*, London: SCIE
- ⁱⁱⁱ Social Care Institute for Excellence (2005) *Practice guide 4: Adult placements and person-centred approaches*, London: SCIE
- ^{iv} Department of Health (2001) *Valuing People: a new strategy for learning disability for the 21st century*, London: Department of Health
- ^v Butt J, Patel B and Stuart O (2005) *Race equality discussion papers*, London: SCIE