

**Better
Regulation
Task Force**

**Bridging the Gap -
Participation in
Social Care Regulation**

September 2004

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1. Foreword

This report is about promoting a greater degree of participation by people who use social care in the regulation of their care. Certainly, there are many other issues in social care that are also important, such as funding levels, improving access to services and the recruitment and retention of staff. Within the confines of this short study, we have retained our focus on our primary agenda - better regulation. However, better regulation is not an end in itself but is an important means of assuring good quality social care, which in turn enables people to make choices and live more independent lives.

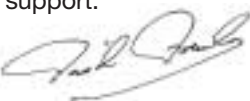
At a conference we held in February 2003 to follow up our previous reports on social care, one of the key themes to emerge was that people who use social care services should be the ultimate arbiters of what is right for them. Our aim in this study is to make recommendations that will encourage and facilitate effective participation in regulation.

When we spoke to people who live in residential homes or who live in their own home with support, we observed a number of common themes. Their experience is that the focus of regulation has been on paperwork rather than people, and on processes rather than outcomes. This has resulted in what's measured becoming important, rather than what's important being measured. Some people told us that they feel a gap has emerged between those who use and those who regulate social care. In addition, inflexible implementation of regulation threatens the survival of small-scale, often voluntary services, which are a vital part of helping people to continue to live in their own homes, where most prefer to be.

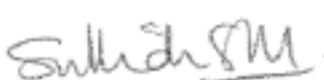
But regulation should be something you do with people, not to them.

Happily, things are changing. Both the Commission for Social Care Inspection (CSCI), which regulates social care services, and the General Social Care Council (GSCC), which regulates the social care workforce, have stated their aim to put people who use social care services at the heart of regulation. Both are developing strategies to do this. We are also encouraged by CSCI's plans to take a proportionate and targeted approach to regulation and we will monitor their progress with interest.

We are publishing this report at a time when a new vision for social care is being developed. A Green Paper on adult social care is expected in the course of the next parliamentary session. We want to see regulators of social care working in partnership with the people who use care services. We also want to help prevent the loss of diversity in social care provision and to enable people to exert more influence in ensuring that their needs are met in ways that they understand and support.



David Arculus, Chair,
Better Regulation Task Force



Sukhvinder Stubbs
Sub-group chair

2. Introduction

Social care is the generic term for all the different types of support that people may need to live an independent life. It includes residential care, drop-in day centres, meals on wheels and domiciliary (home-based) care. Social care is provided by the private, public and voluntary sectors. Approximately 4% of the working population are employed in the social care sector¹ and voluntary sector care staff account for approximately 30% of the entire social care workforce.² A lot of social care is provided informally by family and friends.

The sector is characterised by a diverse supply market. In 2000, Laing and Buisson's survey of domiciliary care estimated that there were some 3,100 suppliers of domiciliary care in the UK. 41% were owned by sole traders and partnerships (some of which may be not for profit), 41% by limited companies or PLCs and 18% by voluntary or charitable organisations. In addition, we know that informal volunteering plays a significant role. The 2003 Home Office Citizenship Survey showed that, of those people reporting involvement in informal volunteering at least once a month during the 12 months prior to interview, 7% said that they had sat with or provided personal care for another person.³

Regulators of social care operate in the public interest. But some members of the public will inevitably be more interested in social care than others. They are likely to include:

- people who use social care services, and their families and friends
- commissioners and providers of services

However, these two groups are not mutually exclusive. Through the direct payments system, people who use services receive the money that social services would have spent on their behalf and commission their own care.

Economists say that we regulate social care because of market failure. The people receiving care do not always have access to adequate information regarding what is available and its quality, or the purchasing power to exercise choice.⁴ But social care is also regulated because of concerns about risk - risk

¹ *Social Care Factsheet*, Commission for Social Care Inspection, (April 2004).

² *Social Care: The Growing Crisis - A report on recruitment and retention issues in the voluntary sector* Social Care Employers Consortium (June 2004) www.scec.uk.net/

³ Munton and Zurawan (2003) *Active Communities*; Headline Findings from the 2003 Home Office Citizenship survey.

⁴ In response to a super-complaint by the Consumers Association, the Office of Fair Trading has announced it will carry out a market study of care homes for older people, which will focus on consumer behaviour, price transparency, and contracts in relation to current or future fees. www.offt.gov.uk/Business/Market+studies/care+homes2.htm

of poor quality care, risk of neglect and risk of abuse - which the market is perceived as failing to address. Abuse is the extreme end of the spectrum of poor quality care and can take many forms, including physical, sexual and financial abuse, abuse of medication, neglect and behaviour designed to degrade and humiliate. We acknowledge that appropriate regulation has an important role to play in reducing the risks of all types of abuse. We note, however, that the recent House of Commons Health Committee report on Elder Abuse⁵ recommended further measures to increase user participation as one way of reducing and preventing abuse.

The tendency in social care has been to take an extremely risk-averse approach to regulation and to regard people who use social care as necessarily vulnerable or in need of protection. However, as we pointed out in our report '*Protecting Vulnerable People*' (2000), we should not make assumptions about vulnerability. The nature of vulnerability is personal and, as such, cannot easily be addressed by blanket regulation. Risk cannot be entirely eliminated and, wherever possible, we believe it is preferable for people with appropriate support, to make their own judgements on how "risky" a life they wish to lead.

We note that it is the people who use social care who have been leading moves away from a paternalistic, 'presumed dependency' model of care and who have set up groups and networks to lobby and share ideas and experiences on routes to more independent living. This kind of participation needs to be strongly encouraged.

Government policy on social care provision is to maintain and promote independence wherever possible, through rehabilitation and community support.⁶ In support of this, the 2004 Spending Review included the provision of a new preventative technology grant of £80 million over two years to fund local councils to provide alarm technology to 16 000 older people, making it easier for them to remain in their own homes safely.⁷

A conference organised by the Barrow Cadbury Trust⁸ in December 2003 highlighted the challenges that people who use social care face in their transition from childhood to adulthood and the challenge of maintaining independence while growing older. Delegates wanted to see greater recognition of agencies and individuals that can provide more personalised approaches to care needs. This is one area where voluntary agencies and informal volunteering can be especially useful.

⁵ House of Commons Health Committee report: *Elder Abuse*. (April 2004).

⁶ *Care Homes for Older People - National Minimum Standards* Department of Health, Third Edition (2003).

⁷ 2004 Spending Review, HM Treasury, Press Notice A2, (12 July 2004).

⁸ Getting a life and keeping it - Conference at Church House, Westminster, (8 December 2003).

It is clearly important to secure a diversity of provision to meet individual requirements, allowing people who receive care, perhaps with the support of carers, family members or advocates, to exercise choice in the services that they use.

A New Vision for Adult Social Care

The Department of Health and the Social Care Institute for Excellence have recently published “A New Vision for Adult Social Care”.⁹ It sets out the responses received to a series of seven questions posed by Stephen Ladyman, Minister at the Department of Health as part of a “national debate about the future vision for adult social care” launched in May 2004. These were:

1. Has adult social care got the balance right between positive intervention and unnecessary interference in people’s lives?
2. What more can be done in adult social care to build the capacity of families and communities to provide care and support?
3. What more can adult social care do to help people get better access to universal services and opportunities and reduce their need to depend on segregated, specialist services?
4. In setting out his ideas about a new vision for adult social care, the Minister has put the emphasis on services that are:
 - Person-centred - tailored to the individual’s circumstances and enabling people to fulfil their potential
 - Proactive - intervening in time to prevent problems and help people maintain their independence
 - Seamless - working with partner agencies and professionals to remove gaps and improve co-ordination and accessibility.Do you agree? Are there other key issues you would add?
5. It has been suggested that some models of social care can lead to increased dependency instead of giving people more independence and control over their lives. Do you agree? How can this problem be tackled?
6. In your job, how could you work differently to enable people to have more control over their own lives?
7. What kinds of support would enable you to work in these ways?

This survey is a good example of how government can promote the active participation of stakeholders in the development of policy and regulation. However, the survey “captured very few views of those using services and their

⁹ *The New Vision for Adult Social Care* - Responses to a survey conducted by the Social Care Institute for Excellence, Department of Health, (August 2004).

carers”¹⁰. Our study would support the view expressed by one respondent that “securing a stronger user voice in the process of reform would require the removal of the barriers created by the often inaccessible language and cultures which surround adult social care”.

The results of the survey are particularly relevant to our study. An analysis of the 178 responses to all the questions shows that the most frequent suggestion of how to improve adult social services was to “**develop more person-centred approaches**”. In relation to three of the questions, this suggestion was seen as the most likely way to:

- Achieve a better balance between positive intervention and unnecessary interference in people’s lives (Q1) - 24% of responses
- Giving people more independence and control over their lives (Q5) - 25% of responses
- Work differently to enable people to have more control over their lives (Q6) - 20% of responses

We hope that our recommendations will make a significant contribution to the increased participation that lies at the heart of developing a more person-centred approach to the provision of social care.

Scope of the Study

This study is focused on adult social care and looks at how people receiving care could participate more effectively in the regulation of their care. It concentrates on participation and involvement by people once they have entered the care “system”. However, we note that there may also be barriers which prevent new entrants (and people making transition from using children's services to adult services) from having full knowledge of the services that are available which may mean that people are not able to make fully informed choices. Therefore:

RECOMMENDATION 1

The Task Force recommends that, by April 2005, the Department of Health should commission research on people’s experiences of the availability and accessibility of information on the range of social care services available to them (including voluntary and informal services). The aim should be to establish a single, accessible point of information.

¹⁰ The New Vision for Adult Social Care - Responses to a survey conducted by the Social Care Institute for Excellence, Department of Health, (August 2004) - paragraph 2.1

As part of our future work programme, the Task Force intends to explore the effectiveness of the regulatory framework in allowing the voluntary and community sector to participate in the delivery of public services.

In preparing this report, we met with people who use and who provide social care, people who commission their own care, and people who work in regulatory bodies. A full list of all those who contributed can be found at Annex A. We are extremely grateful for their help. We are particularly grateful to the General Social Care Council for their help in arranging stakeholder meetings.

As with all Task Force reports, the Government is obliged to respond within 60 days of publication. Dr Stephen Ladyman MP, Parliamentary Under Secretary of State for Community Care, has kindly agreed to sponsor this report and to respond on behalf of the Government.

Language

This report focuses on the people who use social care. They may be older people; they may have a physical or sensory impairment; they may have a mental health impairment; they may have learning difficulties. In the context of social care, people are often referred to as “service users.” But many people told us that they are not comfortable with this term. Some people prefer the term “client”, “resident” or “consumer”, because they believe that “service user” has negative connotations, as it defines people by the services that they use, and is thus disempowering.

A recent speech¹¹ by Stephen Ladyman seems to acknowledge the implications of the term:

“If you are a man of 65 retiring today you can expect to live until you are 82; 84 if you are a woman. That’s wonderful and we should be celebrating it not worrying in case the loss of mental faculties or physical abilities should mean your wishes should be disregarded and you will be transformed from a citizen to a “service user”.

In this report, we have tried to use the term sparingly.

¹¹ Speech to Laing and Buisson Annual Long Term Care for Older People Conference, (17 March 2004)

3. List of Recommendations

RECOMMENDATION 1

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RECOMMENDATION 2

The Task Force recommends that, by April 2005, the Department of Health should carry out a user-centred post-hoc review of the two sets of National Minimum Standards on care homes for adults. The Standards should be rationalised, simplified and focused on personalised outcomes for individuals rather than on processes.

RECOMMENDATION 3

The Task Force recommends that the Department of Health work with the Commission for Social Care Inspection to achieve a flexible, risk-based approach to the interpretation of the National Minimum Standards.

The Commission for Social Care Inspection should consider adopting a policy of "comply or explain," particularly in relation to voluntary sector organisations which provide informal, small-scale services.

RECOMMENDATION 4

The Task Force recommends that, by April 2005, the Department of Health and the Department for Work and Pensions should work together to produce joint guidance on payment for participation. This guidance should clarify issues for those involved (participants, regulators and Job Centre Plus staff) and also help to encourage greater participation.

RECOMMENDATION 5

The Task Force recommends that, by December 2004, the Department of Health should ask the General Social Care Council and the Commission for Social Care Inspection (and all Department of Health Arm's Length Bodies which seek to involve people) to formally adopt the principles for participation which have been developed by the Joint Participation Steering Group (See Annex B).

4. Regulatory Framework

The Task Force has a long-term interest in the regulation of the social care sector. Our 1998 report *'Long-Term Care'* examined the regulatory framework as it stood at that time. **The Registered Homes Act 1984** had made local authorities responsible for registering independent homes and inspecting them twice a year. Local Health Authorities regulated nursing homes, and domiciliary care was not regulated.

The **Care Standards Act 2000** reformed the regulatory system for care services in England and Wales.

- It created the independent regulator; the National Care Standards Commission (NCSC), to regulate services previously regulated by local councils and health authorities.
- It extended the scope of regulation to services such as domiciliary care agencies, fostering agencies and residential family centres.
- It gave powers to the Secretary of State to publish National Minimum Standards, which the regulator takes into account when carrying out inspections.
- It created the General Social Care Council (GSCC) to regulate the social care workforce. Prior to this the workforce was not regulated. The GSCC issues codes of practice for social care workers and employers. In April 2003, it launched the social care register and began registering all social care workers in England, beginning with social workers.
- The Social Care Institute for Excellence was established in 2001 as an independent registered charity to develop and promote knowledge about good practice in social care.

The **Health and Social Care Act 2003** abolished the National Care Standards Commission (NCSC) and created the Commission for Social Care Inspection (CSCI). This came into being in April 2004 and covers adult and children's services throughout the public, private and voluntary sectors, with the aim of promoting improvement in social care. CSCI took over the social care regulation and inspection functions of the Social Services Inspectorate and the Audit Commission.

The most recent regulatory developments have been:

- The **Carers (Equal Opportunities) Act 2004**, which aims to ensure that all carers know that they are entitled to an assessment of their needs. Councils will have a duty to consider carers' outside interests (work, leisure or study) when carrying out an assessment.
- The phased introduction of the **Protection of Vulnerable Adults (POVA)** scheme, where care providers have a statutory duty to check that potential care workers are not listed on the POVA register.

5. Why is participation in regulation important?

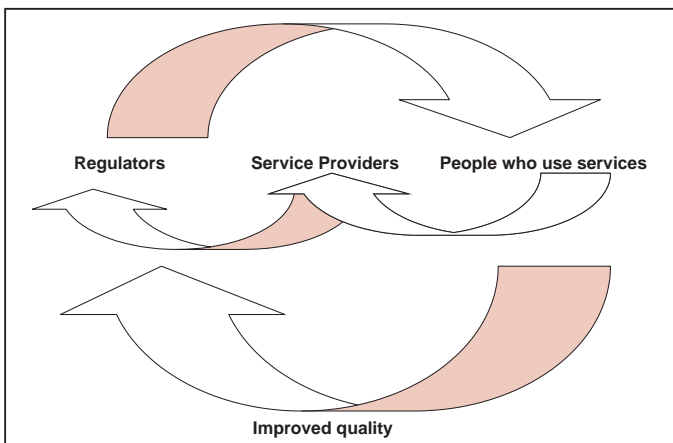
As we said in our 2003 report *'Independent Regulators'*, all regulators need to operate in a more open and transparent way in order to become more answerable to their stakeholders and to earn their respect. We described this concept as earning a “licence to operate”.

Without input from those on whose behalf regulation is carried out, regulation lacks legitimacy and a gap opens up between the regulator and the regulated, starving the process of vital information and the feedback on which good regulatory decisions depend.

Participation in regulation adds value to the information gathered by regulators and helps inform the process, as shown in the model below.

- Regulators provide information to existing users on the availability and quality of services and on the registration status of people in the social care workforce.
- People who use services, sometimes with support from their carers or advocates, use this information to make informed decisions about their social care, including the appropriate level of risk.
- People who use services contribute to the information that regulators gather and make available to other users. This increases the quality of information and helps incentivise providers to improve the quality of care provided.
- Better information is therefore available to potential recipients of social care to improve their awareness and understanding of what services are available to them and the choices they have.

Figure 1 - Model of information flow in a fully participative social care regulatory framework



It is important that people in receipt of social care can engage directly with regulators, as this enables them to voice concerns and complaints, influence the quality of information gathered and ultimately feed into policy development. But it is also important that regulators do not seek to “second-guess” the relationship between providers and users of services. As an inspection can only ever be a snapshot, inspectors of social care provision should seek to ensure that providers have robust internal mechanisms in place for regular consultation and taking people’s views into account, for example through quality groups, including relatives or advocates.

National Consumer Council (NCC) research shows that consumers are most likely to want to participate directly in issues that have an immediate and local impact on their lives. The NCC also found that consumers are poorly informed about the role of regulators.¹² We would suggest that both these findings hold true equally for consumers of social care and our experience in researching this report has shown that people who use social care services have valuable ideas to share and want to be heard. For example, we were asked,

“Why aren’t people who use services trained to become inspectors? We’ve got vast knowledge and expertise to offer.”

On the other hand, of course, some people are not interested in regulation and do not see participation in the work of regulators as relevant to their lives.

Participation in social care regulation enables people to have a voice and to exercise choice. This is now vital in a sector where traditionally there has been little opportunity for the client’s voice to be heard. This is in line with the Policy Commission on Public Services’ recommendation that regulators should develop a wider role and help channel user feedback into future policy development.¹³

We believe that there are two contexts in which participation in social care regulation is valuable and necessary:

1. Participation in the ongoing development of the regulatory framework
2. Participation in the process of regulation.

¹² *Putting up with second best: Summary of research into consumer attitudes towards involvement and representation.* National Consumer Council (2002)

¹³ *Making Public Services Personal: A new compact for public services.* Policy Commission on Public Services report to the National Consumer Council. (2004) p73

6. Participation in the ongoing development of the regulatory framework

As regulations can be difficult and time consuming to change and update, the Better Regulation Task Force has pressed for the use of alternatives to “classic” regulation¹⁴ and encouraged the use of sunset clauses in legislation where appropriate. The Task Force recommends post-hoc reviews of the working and impact of regulation within 3 years of implementation.

The Care Standards Act 2000 allowed the Department of Health to issue National Minimum Standards. Of the 12 sets of National Minimum Standards, five focus on adult social care services. These are:

- Care Homes for Older People (38 standards) 2001
- Care Homes for Adults 18 - 65 (43 standards) 2001
- Domiciliary Care (27 standards) 2003
- Nurses Agencies (18 standards) 2003
- Adult Placement Schemes (10 standards) August 2004 (which replace the National Minimum Standards for Adult Placement Carers)

There has been one major amendment to care homes standards in 2003, relating to environmental standards such as room size. There was also an amendment on Criminal Records Bureau checks for new employees in 2004. The National Minimum Standards do not have a legal status and are not enforceable in law. An explanatory paragraph in the Care Homes for Older People Standards tells us:

“Compliance with national minimum standards is not itself enforceable, but compliance with regulations is enforceable subject to national standards being taken into account. The Commission may conclude that a care home has been in breach of the regulations even though the home largely meets the standards. The Commission also has discretion to conclude that the regulations have been complied with by means other than those set out in the national minimum standards.”¹⁵

¹⁴ *Imaginative Thinking for Better Regulation*, Better Regulation Task Force, (September 2003).

¹⁵ Care Homes for Older People - National Minimum Standards Department of Health, Third Edition (2003).

Given this somewhat ambiguous legal status for the National Minimum Standards, a form of regulatory creep seems to have emerged, with care providers devoting a great deal of time and energy to proving that standards are being met. While the principle of National Minimum Standards may be sound, in practice their introduction has led to a bureaucratic paper chase. Providers concentrate on getting the paperwork right in order to demonstrate compliance with the standards which ironically can leave them with less time to spend on understanding and meeting individual needs.

In July 2004, the Department of Health reduced the number of national targets that providers of NHS care will be expected to meet.¹⁶ There are now 24 core standards and 13 developmental standards. Performance against these standards will be assessed by the Healthcare Commission. The Department of Health has stated that:

“The development of the new high level standards represents the first step towards simplifying and rationalising the expectations on the (National Health) Service. It also provides an excellent opportunity to reduce the burden of current requirements.”¹⁷

This is a welcome development and we believe that this recognition by government and regulators of the advantages of a smaller number of high level standards should apply to social care as well as health. To date there has been no evaluation of the extent to which people who use social care feel that the introduction of National Minimum Standards has led to better outcomes for them.

However, the Department of Health is funding a 3-year research project into the regulation of adult social care in England, based at the University of Portsmouth.¹⁸ The project seeks to make recommendations aimed at improving the effectiveness of regulation. The evaluative stage of their research runs from September 2004 until October 2005 and publication is due in 2006. **The Task Force suggests that this research should include an examination of whether the experiences of users, carers, commissioners and providers of care demonstrate that National Minimum Standards have led to improved outcomes and quality of care without increasing unnecessary paperwork and bureaucracy.**

The changes that have been made to the National Minimum Standards so far have been driven more by the needs of providers, although they may have indirectly benefited the users of care. We came across several examples of the application of National Minimum Standards in ways that apparently

¹⁶ *National Standards, Local Action: Health and Social Care Standards and Planning Framework 2005/6 -2007/8.*

¹⁷ *National Standards, Local Action: Health and Social Care Standards and Planning Framework 2005/6 - 2007/8.* Department of Health (2004) p21

¹⁸ <http://www.port.ac.uk/research/rasc/>

disempower people. For example,

- A man had asked the manager of his residential home if he could have a hot bath, but his request had to be refused because the National Minimum Standards specify a maximum temperature of 43 degrees. Obviously, this Standard is designed to prevent scalding, but for some people it takes away what should be a very simple personal choice.

RECOMMENDATION 2

The Task Force recommends that, by April 2005, the Department of Health should carry out a user-centred post-hoc review of the two sets of National Minimum Standards on care homes for adults. The Standards should be rationalised, simplified and focused on personalised outcomes for individuals rather than on processes.

By “user-centred” we mean that people whose lives are affected by these Standards should be invited to participate in the planning and delivery of the review, in addition to being consulted as part of the review.

Applying the Principles of Good Regulation

The Commission for Social Care Inspection has identified the areas upon which it will focus during its first year of operation. These include:

- Adopting a more proportionate and targeted approach to regulation
- Reducing paperwork
- Changing the format of their inspection reports so that they better communicate the experience of living in a particular home.

We welcome this approach but will keep a watching brief on progress to ensure that these changes reach the front-line and include domiciliary care.

Government policy is to support people to live in their own homes for as long as possible. However, we found examples of the inflexible enforcement of regulations leading to the loss of small-scale services and informal volunteering which do so much to enable independent living.

In one case, a small charity was providing a respite service for carers of older people. But because tasks like helping someone out of a chair or to go to the bathroom are classified as ‘personal care’, this charity has been obliged to register as a ‘provider of personal care’ and therefore finds itself within the scope of all the Domiciliary Care National Minimum Standards. As a result, the

charity has reluctantly decided to withdraw their personal care assistance and now provides a lower level of service, a change which benefits no one. We are aware of other instances where small-scale services (such as toenail cutting) provided by the voluntary sector have been lost because the Commission for Social Care Inspection and its predecessor the National Care Standards Commission have not been flexible in their interpretation of the National Minimum Standards.

It seems that this “one size fits all approach” is indirectly causing the loss of those small yet vital care services, reducing diversity and making it less likely that people are able to live at home, in apparent conflict with government policy on the issue.

Government policy on inspection¹⁹ is that inspection should be proportionate to risk, have a focus on outcomes and take a user perspective. In line with this policy and with the Better Regulation Task Force’s 5 Principles of Good Regulation (Proportionality, Accountability, Consistency, Transparency and Targeting);

RECOMMENDATION 3

The Task Force recommends that the Department of Health work with the Commission for Social Care Inspection to achieve a flexible, risk-based approach to the interpretation of the National Minimum Standards.

The Commission for Social Care Inspection should consider adopting a policy of “comply or explain,” particularly in relation to voluntary sector organisations which provide informal, small-scale services.

¹⁹ *The Government's Policy on Inspection of Public Services*. Office of Public Sector Reform, Cabinet Office. (2003)

7. Participation in the process of regulation

Through existing research on participation and our own work, we have identified a number of barriers to participation in regulation faced both by regulators and potential participants. These barriers are not exclusive to participation in social care regulation but may also apply to participation more generally, for example in the planning, delivery and evaluation of a range of public services.

A significant problem relates to payment for participation. Most organisations which invite participation have a policy on making payments, which may include;

- reimbursement of travelling expenses;
- meeting personal assistant costs; or
- payment for time and expertise.

However, people in receipt of benefits such as Incapacity Benefit and Income Support have limits on what they can earn and some people have experienced problems when they have been invited to participate and have received payment or expenses for doing so. The service-user led group Shaping Our Lives: National User Network produced a report “*Contributing on Equal Terms*” which highlights these experiences.²⁰ For example, they found that the fear of losing benefits can act as a deterrent to participation.

Lack of joined up thinking on this issue presents a problem for regulators and other organisations when designing their payments policy and trying to encourage greater participation. It also acts as a major disincentive for people to get involved.

In 2003, officials from the Department for Work and Pensions, Cabinet Office, the Department of Health and the NHS Appointments Commission conducted a review because of concerns that benefit rules were a barrier to increasing the proportion of public appointments held by disabled people. The issues raised by disabled people and disability organisations about the benefit system being a barrier to their taking up public appointments were very similar to those raised in ‘*Contributing on Equal Terms*’. It was agreed that, to address the problem of lack of knowledge and understanding of the benefit system, more and better information

²⁰ *Contributing on Equal Terms; Getting Involved and the Benefits System*, Shaping Our Lives: National User Network (2004)

should be provided to potential applicants for public appointments, making clear the possible impact on benefits. Officials from DWP, Cabinet Office and the NHS Appointments Commission are taking forward work on this recommendation and are considering whether there may be a need for improved guidance to staff in the field.

We think that such guidance would be helpful not only to those people considering applying for public appointments but also in the wider context of participation, and therefore;

RECOMMENDATION 4

The Task Force recommends that, by April 2005, the Department of Health and the Department for Work and Pensions should work together to produce joint guidance on payment for participation. This guidance should clarify issues for those involved (participants, regulators and Job Centre Plus staff) and also help to encourage greater participation.

Additional barriers to participation

Barriers for those inviting participation (for example regulators)

1. It is difficult to know who to involve and how to reach them.

As we found when organising discussion sessions as part of the evidence gathering process for this report, it is not easy to identify people to invite as participants.

The Social Care Institute for Excellence is supporting Shaping Our Lives: National User Network in the development of their user-controlled network database. Similarly, the British Council of Disabled People's Sustainable User Project now has 104 Older and/or Disabled People's user-led groups registered as members, with a combined membership of just under 35,000 people nationwide.

We hope that this information will be made available to regulators and others but would caution that it should be used proportionately so as not to overburden people and organisations. We are aware that many user-led groups may have limited resources to respond to invitations to participate and that there is a recognised need to build their capacity for wider participation.

2. Encouraging people to get involved - Relationships and trust.

By inviting participation, regulators are entering into a relationship with people and need to outline their expectations and what participants can expect. The main challenge for regulators is to find ways to help people to make informed decisions about how they will contribute, so that they "own" their participation and trust the process.

Where people have been involved in participation previously, they may have had negative experiences, such as consultation fatigue from continuously being asked the same questions or feeling that their involvement is a token gesture. People told us very strongly that, if they participate, they want to see how their involvement makes a difference and to receive feedback.

Barriers to participation for those invited to participate

1. Assumptions and attitudes that users of services need above all else to be protected.

Such attitudes can mean that policymakers and regulators may not take steps to include disabled people or people with learning difficulties in consultation and decision-making. Training may help to change these attitudes. For example, in the course of preparing this study, we received Disability Equality training and learnt about the social model of disability. This model views disability not as an inevitable consequence of impairment but as the loss or limitation of opportunities to take part in society on an equal basis with others due to physical, environmental, organisational or attitudinal barriers. This approach helps identify and challenge assumptions and attitudes that may limit participation.

2. Information, language and communication.

It is not enough to make information available to potential participants on websites. Information should be accessible in various formats such as Braille, Makaton (a communication system which uses symbols) and audio tape. An example of good practice in this area is the General Social Care Council's production of accessible codes of practice in different formats (Makaton, Braille, pictorial, audio tape) and 29 languages.

3. Methods of consultation

Organisations often use traditional and rather unimaginative methods when trying to reach people through consultation. Greater success may be achieved by trying to reach people in shopping centres, libraries, cinemas, doctors' surgeries and by using local radio and talking magazines.

4. Planning of consultation events

It is necessary to follow good practice when planning events such as focus groups and seminars. For example, it is important to ensure that the building and meeting room are accessible and to allow enough time and rest breaks so that participants will feel welcomed and comfortable and therefore participate effectively and get the most out of the events. It is also important to manage consultation events sensitively. Some people who are asked to participate may lack confidence in airing their views or be worried about the consequences of saying something that others may disagree with. These people could be empowered, for example by providing preparatory information, including, where appropriate, peer support and advocacy services.

All of these barriers are issues for the Commission for Social Care Inspection and the General Social Care Council to consider as they develop their strategies to put users at the heart of their regulatory processes. In line with the Better Regulation Task Force's 5 Principles of Good Regulation, it is important that these regulators prepare and follow strategies for participation which are:

Proportionate - ensuring that people who use social care are invited to participate in ways that respect their time and circumstances and maximise their opportunities for contributing.

Accountable - helping people who use social care to own their participation, make informed suggestions and decisions and to shape the nature of their involvement.

Consistent - ensuring that initiatives to increase participation in different areas of social care are consistent with one another.

Transparent - making information available in a variety of formats and ensuring that participants understand what is expected and what their participation can achieve.

Targeted - minimising burdens on participants and avoiding duplication and omission of opportunities to participate.

Emerging good practice on participation in the regulatory process includes:

- The Commission for Social Care Inspection is providing its inspectors with a range of tools that will help them to focus on people's experience.
- The General Social Care Council is facilitating a Joint Participation Steering Group. This group has developed principles for participation although these principles have yet to be formally adopted by the regulatory bodies. (See Annex B.)
- The Social Care Institute for Excellence has commissioned a project to develop a practice guide on adult service users' participation in changing and improving social care.

In order to ensure that this momentum is not lost,

RECOMMENDATION 5

The Task Force recommends that, by December 2004, the Department of Health should ask the General Social Care Council and the Commission for Social Care Inspection (and all Department of Health Arm's Length Bodies which seek to involve people) to formally adopt the principles for participation which have been developed by the Joint Participation Steering Group (See Annex B).

Annex A

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Annex B

Principles for service user and carer participation (developed by the Joint Participation Steering Group)

Introduction

A group of regulators and other key stakeholders, including service users have been meeting over many months to agree a core set of principles that underpin effective service user and carer participation. A list of these organisations can be found at the end of this document. These principles are intended to stimulate discussion and help in developing an organisation's own participation strategy. The principles were developed from existing good practice, research and knowledge from a wide range of sources. The principles are not intended to replace or duplicate existing good practice but to provide a working framework. It is anticipated that these principles will be incorporated into the individual strategies of social care regulators and other key organisations. It is recognised that this is a "work in progress" document and that language, definitions and approach to participation raise contentious and complex issues that need further debate. The paper reflects the building blocks of a much larger picture that is emerging and needs to be considered in the context of considerable policy changes in social care.

Terminology

It is recognised that the term service user is not a sufficient term as it will mean different things to different people. Not everyone identifies themselves as a service user, but it is a recognised term. Also the carer agenda is not fully inclusive in this document. These issues need to be considered when reading this document.

Vision and values

(Name of organisation) is striving to be an organisation where users and carers of health and social care services are at the heart of our work. This vision permeates throughout our work and in the actions of all our staff.

Staff in our organisation will seek to work with service users and carers in ways that:

- are relevant to people's needs and provide choice;
- value diversity;
- support people to achieve their ambitions in the work they do with us;
- enable participants to control and set the agenda in the work that they do with us;
- ensure that participants know the outcome of their involvement; and
- help them to participate as equal partners and citizens.

Principles of participation

(name of organisation):

1. is committed to changing and improving attitudes, services and practice in partnership with users of social care and health services;
2. will work with people who use social care and health services to identify the priorities for improvement and agree practical arrangements for their participation;
3. is clear about the reason for inviting people to participate so that users and carers of social care and health services can make informed decisions about their participation;
4. will give choices to service users and carers about the way they participate, in particular, whether this is done individually or with another;
5. will ensure that participation is able to make a difference through its impact on the planning, delivery and management of the organisation's services;
6. communicates in appropriate ways and gives and receives feedback about the impact of participation to users and carers of social care and health services;
7. acknowledges the difference in power in the partnership with people who use services;
8. recognises the value and benefit to the organisation of participation by people who use services, and will identify and implement equitable policies, procedures, payment arrangements and resources to support it;
9. aims to ensure equality of opportunity to participate, recognising the diversity of service user interests and perspectives, and the need for support to overcome discrimination and exclusion;
10. will support networks of service users and carers so that they can identify for themselves who should participate;
11. will ensure that participation offers benefits to both parties;
12. will seek to increase training opportunities to enhance active participation by service users and carers; and
13. will use its learning from working with service users and carers to inform changes in its ways of working, to achieve better outcomes.

Agreed by the Joint Participation Steering Group meeting 5 March 2004

The Joint Participation Steering Group is made up of representatives from a number of key organisations:

General Social Care Council
Social Care Institute for Excellence
Topss England
Social Services Inspectorate (until April 04)
National Care Standards Commission (until April 04)
Commission for Social Care Inspection (from April 04)
Shaping our Lives: National User Network
Department for Health (social care)
Department of Health, Patient and Public Experience Unit

with a monitoring brief from the following organisations

Better Regulation Task Force
Commission for Health Improvement (until April 04)
Healthcare Commission (from April 04)
Children and Families Directorate, Department for Education and Skills

Annex C

Better Regulation Task Force

Better Regulation Task Force and its approach

The Better Regulation Task Force is an independent advisory group established in 1997. Members, appointed in the first instance for two years, are unpaid. They come from a variety of backgrounds - from large and small businesses, citizen and consumer groups, unions and those responsible for enforcing regulation - and all have experience of regulatory issues. The Chair, appointed initially for three years in April 2002, is David Arculus. Officials from the Regulatory Impact Unit in the Cabinet Office provide support for the Task Force.

Terms of reference

The Task Force's terms of reference are:

“To advise the Government on action to ensure that regulation and its enforcement are proportionate, accountable, consistent, transparent and targeted.”

Reports

All Better Regulation Task Force Reports are available free on request by:

- Writing to: Better Regulation Task Force Team,
5th floor, 22 Whitehall, London SW1A 2WH
- Telephoning: 020 7276 2142
- Emailing: taskforce@cabinet-office.x.gsi.gov.uk
- Visiting the website at: www.brtf.gov.uk

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