

# USER and CARER INVOLVEMENT IN SOCIAL CARE AND RELATED SERVICES IN DEVON

## Guidance and Information for Service Providers

Paul Grimsey and Geoff King - 8.6.07

This guidance and information is aimed at helping staff within statutory services to comply with their duties and good practice in involving service users and carers in service provision, development and planning.

It may also be used to help service users and carers to be involved in service provision, development and planning.

### Contents

**1. Where When and How to involve service users and carers**

An outline of some of the main ways in which service users and carers involvement can be enabled

**2. Current representation and involved in planning**

Information on Organisations, Groups and Boards etc, in Devon that currently enable service user and carer involvement.

**3. More on why and how to involve service users and carers**

The best summary we could find of why service users should be involved and how they should be involved, from Asking the Experts – Community Care Needs Assessment Project

## 1. Where When and How to involve service users and carers

### **When and where to involve users and carers**

All health and social care activity/processes impacting directly on the public should include user and carer involvement. Where national policy and guidance requirements are being implemented user and carer views may already have been taken into account. But further user and care involvement may be needed in planning implementation and monitoring.

- Planning
- Provision of Public Information
- Service Commissioning
- Quality Assurance/Service Improvement
- Recruitment of Staff
- Training of Staff
- Other project work

In relation to any of the above areas of activity, the following elements must be considered;

### **Ways of involving service users and carers**

More than one of these methods will often be necessary to ensure adequate involvement. Sources of more information on these methods and other issues are provided at the end of this section

- surveys
- discussion/listening groups
- time limited task group
- on-going representation
- open meetings
- use of existing groups/processes

### **Issues to consider in user and care involvement**

#### **1) Identifying the Users/Carers to involved**

e.g. existing user/carer representatives on planning groups etc  
voluntary sector support organisations  
groups at risk of exclusion of discrimination (sometimes referred to as hard to reach groups)  
local media?

#### **2) Scope of Involvement**

e.g. information only  
consultation only  
shared decision making

#### **4) Training/Support needs of Users/Carers Involved**

e.g. one-off briefing material for specific task  
previously delivered training

#### **5) Reimbursement/Payment of Users/Carers involved**

e.g. reimbursement only  
payment rates  
budget commitment

## 6) **Explaining the process or plan for Decision-Making**

e.g. where/when are relevant proposals and decisions to be made?  
how will user/carer “voice” influence those decisions?

## 7) **Feedback on how user and carer views are reflected in proposals and decisions**

e.g. to individual users/carers involved  
to wider user/carer group  
to staff groups

## 8) **Confidentiality**

### **Information on managing these issues**

The following sources of information may be helpful in planning for and addressing the issues listed above.

- also see the last section - **More on why and how to involve service users and carers**

- Project Prompt List for Devon Adult and Community Services– available from Paul Grimsey – (link to follow)
- Corporate Consultation and Consultation Finder  
<http://www.devon.gov.uk/consultation.htm>
- Equalities groups and contacts  
[http://www.devon.gov.uk/equality\\_diversity/contacts\\_eq.htm](http://www.devon.gov.uk/equality_diversity/contacts_eq.htm)
- Carers  
<http://www.devon.gov.uk/carers.htm>
- Research Governance  
<http://www.devon.gov.uk/research-governance.htm>

## **2. Current representation and involved in planning**

Organisations, Groups and Boards etc in Devon that currently enable service user and carer involvement.

Some of the information in Section 2 may become out of date. Please send any information updates that you are aware of to:  
Paul Grimsey, Policy Manager, DCC Adult and Community Services, Room A117, County Hall, Topsham Road, Exeter, EX2 4QR .  
email [paul.grimsey@devon.gov.uk](mailto:paul.grimsey@devon.gov.uk)

**N.B.** From 1<sup>st</sup> April 2008 Local Involvement Networks or LINKs will be developed to enable public involvement in Health and social care services

	<b>ALL ADULTS</b>	<b>ALL CARERS</b>	<b>MENTAL HEALTH</b>	<b>LEARNING DISABILITY</b>	<b>OLDER PEOPLE</b>	<b>OPMH</b>	<b>PHYSICAL/SENSORY DISABILITY</b>
<b>COUNTY</b>	<ul style="list-style-type: none"> <li>i) Devon Voice/ Citizen's Panel</li> <li>ii) Local Area Agreement</li> <li>iii) PPI Forum</li> <li>iv) Devon Strategic Partnership</li> </ul>	<ul style="list-style-type: none"> <li>County Carers Forum</li> <li>County Carers Steering Group</li> </ul>	<ul style="list-style-type: none"> <li>Local Implementation Team (LIT)</li> </ul>	<ul style="list-style-type: none"> <li>i) SURF Group</li> <li>ii) LD County Carers Forum</li> <li>iii) LD Partnership Board</li> </ul>	<ul style="list-style-type: none"> <li>i) Senior Council</li> <li>ii) Older People's Strategic Partnership</li> </ul>	<ul style="list-style-type: none"> <li>Joint Implementation Group (JIG)</li> </ul>	<ul style="list-style-type: none"> <li>i) Living Options Devon</li> <li>ii) PD/SD Strategic Partnership</li> </ul>
<b>EXETER</b>	<ul style="list-style-type: none"> <li>i) Local Strategic Partnership</li> <li>ii) Council of Voluntary Service</li> </ul>	<ul style="list-style-type: none"> <li>Local Carers Forum</li> </ul>	<ul style="list-style-type: none"> <li>i) User Involvement Project</li> <li>ii) Locality Implementation Group (LIG)</li> </ul>	<ul style="list-style-type: none"> <li>i) LD Locality Planning Group</li> <li>ii) Local Carers Groups</li> </ul>	<ul style="list-style-type: none"> <li>i) Senior Voice</li> <li>ii) Locality Planning Group</li> </ul>	<ul style="list-style-type: none"> <li>Exeter &amp; East Devon Local Implementation Group (LIG)</li> </ul>	<ul style="list-style-type: none"> <li>i) Living Options Devon</li> <li>ii) Locality Planning Group</li> </ul>
<b>EAST DEVON</b>	<ul style="list-style-type: none"> <li>i) Local Strategic Partnership</li> <li>ii) CVS</li> </ul>	<ul style="list-style-type: none"> <li>Local Carers Forum</li> </ul>	<ul style="list-style-type: none"> <li>i) User Involvement Project</li> <li>ii) Locality Implementation Group (LIG)</li> </ul>		<ul style="list-style-type: none"> <li>OP Locality Planning Group</li> </ul>	<ul style="list-style-type: none"> <li>Exeter &amp; East Devon Local Implementation Group (LIG)</li> </ul>	<ul style="list-style-type: none"> <li>i) Living Options Devon</li> <li>ii) Locality Planning Group</li> </ul>

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<b>MID DEVON</b>	i) Local Strategic Partnership ii) CVS	Local Carers Forum	i) User Involvement Project ii) Locality Implementation Group (LIG)		OP Locality Planning Group	North & Mid Devon LIG	i) Living Options Devon ii) Locality Planning Group
<b>NORTH DEVON</b>	i) Local Strategic Partnership ii) CVS	Local Carers Forum	i) User Involvement Project ii) Locality Implementation Group (LIG)		OP Locality Planning Group	North & Mid Devon LIG	i) Living Options Devon ii) Locality Planning Group
<b>TEIGNBRIDGE</b>	i) Local Strategic Partnership ii) CVS	Local Carers Forum	i) User Involvement Project ii) Locality Implementation Group (LIG)		OP Locality Planning Group	No planning group currently	i) Living Options Devon ii) Locality Planning Group
<b>SOUTH HAMS / WEST DEVON</b>	i) Local Strategic Partnership ii) CVS	Local Carers Forum	i) User Involvement Project ii) Locality Implementation Group (LIG)		OP Locality Planning Group	No planning group currently	i) Living Options Devon ii) Locality Planning Group

**ADULT AND COMMUNITY SERVICES**  
**VEHICLES FOR USER/CARER INVOLVEMENT**

i) Ongoing – ii) Contact Details

**ALL ADULTS**

	<b>NAME</b>	<b>DESCRIPTION</b>	<b>LEAD PERSON</b>	<b>TELEPHONE</b>	<b>E-MAIL</b>
<b>COUNTY</b>	i) Devon Voice / Citizens Panel		Malcolm MacDonald	01392 382002	
	ii) Local Area Agreement		Sara Cretney	01392 382913	
	iii) Patient & Public Involvement (PPI) Forum (to be replaced by LINKs)				
	iv) Devon Strategic Partnership		Caroline Rea	01392 38	
<b>EXETER</b>	Local Strategic Partnership CVS		John Bunting	01392 202055	
<b>EAST DEVON</b>	Local Strategic Partnership CVS		Marilyn Fearon	01404 549045	
<b>MID DEVON</b>	Local Strategic Partnership CVS		Duncan Wood	01884 355734	
<b>NORTH DEVON</b>	Local Strategic Partnership CVS		Penny Archer	01237 425554	

	<b>NAME</b>	<b>DESCRIPTION</b>	<b>LEAD PERSON</b>	<b>TELEPHONE</b>	<b>E-MAIL</b>
<b>TEIGNBRIDGE</b>	Local Strategic Partnership CVS		Sue Wroe	01626 203050	
<b>SOUTH HAMS / WEST DEVON</b>	Local Strategic Partnership South Hams CVS West Devon CVS		Laura Whitehead Karen Nolan	01803 862266	

## Key Points - A Summary from Asking The Experts

from the Community Care Needs Assessment Project

full report available from - [ccnap.org.uk](http://ccnap.org.uk)

*"...the organisation, driven...by national requirements, requires instant action and clearly identifiable outcomes. This tends to skew their work towards the superficial and short-term, so missing opportunities for the development of more substantial and ongoing forms of public involvement."*<sup>1</sup>

- Being involved in decisions about health or social care is a right, not a privilege.
- A 'consultation culture' starts within the organisation or work setting. Are staff consulted and involved?
- Top level commitment is needed to provide leadership, to express the importance the organisation places on 'user involvement', to maintain momentum and to make things happen. Identified 'champions' at every level within an organisation can act as a network to pass on information and ideas.
- Involving people in shaping health and social care services is a long-term, ongoing, developmental process, not a one-off project or exercise. It is a way of working that is integrated into practice.
- Be realistic about the time it will take for attitudes to change, for skills, knowledge and trust to develop and infrastructures to be built. The groundwork that you are doing now will bear fruit in the future.
- There is often disillusion about involving people. Agencies interpret low levels of participation as lack of interest rather than inappropriate choice of approach. Users feel that their views are not taken seriously, as they don't see them acted upon. It takes time to overcome cynicism borne of previous poor experiences, establish trust and mutual respect, and for people unused to participating to develop confidence and skills.
- Agencies, staff, service users and others with a key interest should work together to develop a clear and easily understood statement of values and a long-term plan. Be clear about why you want to involve users, and what you wish to achieve. Make this transparent to staff and service users.
- There is benefit in working across agencies to pool resources and avoid duplication. The public does not understand agency boundaries.
- To avoid duplication one partner agency might hold a database of initiatives. This would also help in identifying gaps and deciding on priorities.
- Resources are needed. Allocate a budget. Development and link-workers have been found to be of benefit. Recognise dedicated time for other staff.
- Build user involvement into contract specifications and job descriptions, and involve service users in monitoring to ensure that engagement is real and meaningful rather than token.

- Be clear about the consequences of involving users. Is the organisation or staff group prepared to make changes? Have people been able to work through their response to criticism? Provide training and opportunities for reflection.
- Agencies often consult too lightly, to meet their own needs without intention of change, or recognition of the cost to participants. If you are only interested in 'ticking the box', do as little as possible. Ill-conceived one-off initiatives can damage relationships for others.
- If resources are limited it is better to do something on a small scale well than to be over-ambitious.
- Do you really need to undertake a particular exercise? Is the information already available? Has someone else, either nationally or locally, done a similar piece of work that will meet your needs? People all over the country make remarkably similar points. Resources are too scarce to duplicate work unnecessarily.
- Gather and make effective use of existing information.
- Do you need to do this yourself? Other people may be better at engaging with people than you. Provide resources and support to those who have the skills and contacts (user groups, community groups, voluntary organisations, staff, for example).
- Effectiveness in involving people comes from approach rather than technique. Successful user involvement derives from a genuine and positive approach that respects and values the expertise users contribute.
- There is no one method of involving service users that 'works'. You will need to use a variety of approaches. This allows a wider range of people to be involved and provides richer information and ideas.
- Be clear about purpose. The approaches chosen will follow from what you wish to achieve, and the characteristics of the group.
- Be open and honest about your intent and about any limitations on what is possible.
- Topics and methods are often defined by professionals. People are committed to what is important to them. They are more likely to become engaged when they own the ideas. Service users have their own agenda, and it may not match that of the agency or work setting. Negotiation will be needed to establish common ground.
- Involve users from the beginning of the process. The user perspective in defining priorities, setting and monitoring standards, devising surveys, staff training etc. will make the process more appropriate, accessible and effective.
- Approach people individually to ask for their help. The most common motivation for getting involved is 'to make a difference for others'. *"Personal contact and preparation to take part in consultation exercises were much more effective than letters and leaflets."*
- In order to become involved people need information or awareness, a perception of benefit or relevance, and confidence about their own role. People need a clear explanation about what is involved, what is expected of them and the time commitment required. They need to know that any particular needs they have will be met, and what support will be available to them. Provide the opportunity to try something out before making a commitment.
- An 'agreement' with participants can ensure informed involvement, reflect the value placed on their contribution, and promote ongoing engagement.

- Users need to be sure that their input can have influence and be translated into practice. Feedback is extremely important to them. People need to see a result that has an immediate link to their participation, as well as to believe that things can be improved for others in the future. Small successes create confidence.
- Establish the level of involvement participants want initially, but be prepared for people to want to take on more as their skills and confidence develop.
- *“Service users need a range of support and training in order to be fully involved in decision-making.”*<sup>3</sup> Support or link-workers have been found to be of benefit. Similarly, community and user groups need resources and support to develop their skills in working with agencies.
- Don't expect service users to be representatives. Their own experience and perception is what is of value, and others are likely to relate to it.
- Users and carers will have a different experience of services. Carers should contribute in their own right, not as representatives of those they support.
- Good equal opportunities practice (expenses, childcare/ carer substitution, transport, accessible, comfortable venues, production of materials in other than written form, use of advocates, signers etc.) demonstrates to people the value placed on their contribution and allows a wider range of people to participate.
- Have a clear policy on payment. Pay people whose expertise you use.