



Valuing Involvement

**Strengthening Service User and
Carer Involvement in NIMHE**

Commissioning guidelines:

**Supporting involvement at a local level by
investing in service user and carer led
groups.**

**A product of the Making a Real Difference Project (see
overview for details)**

Overview

The Making a Real Difference Project was undertaken in direct response to the HASCAS review of service user and carer involvement in NIMHE. This resulted in the Making a Real Difference report.

The following commissioning guidelines are designed to address some of the recommendations made within the report. They are intended provide NIMHE and its staff with some tools to begin to influence the commissioning process, and how it can support involvement at a local level.

Who are the Commissioning Guidelines for?

These guidelines are to be used by anyone who has contact with commissioners in any of the work they do for NIMHE or on behalf of NIMHE;

- NIMHE staff
- NIMHE volunteers
- NIMHE board members
- People with experience of mental ill health involved with NIMHE and the development and delivery of its work programmes.
- Friends and family of people with experience of mental ill health who are involved with NIMHE and the development and delivery of its work programmes.
- Strategic commissioners of mental health services
- Local service user and carer groups.

These guidelines should be used to develop relationships with commissioners to help and support the involvement of people at a local level.

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More than 340 service user and carer groups and individuals were invited to participate. We also invited 101 people in commissioning roles across PCTs, Local Authorities and Mental Health Trusts to participate in the research. We received responses from 29 service user and carer groups and 12 commissioners.

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Executive Summary

Guidelines for Commissioners

1) Consider your definition of what a service user and/or carer group is:

- a) It is important to have a clear working definition of what is meant by a service user or carer group. This will help enable robust commissioning of local groups which fit with strategic objectives, such as:
 - i) capacity building for local groups
 - ii) service user and carer support
 - iii) reflecting the diversity of the service user and carer populations
 - iv) service improvement
 - v) service monitoring
 - vi) service user and carer feedback
 - vii) service user and carer led services
- b) Here is a model definition developed from Wallcraft (2003A) and built upon from the responses from commissioners in this survey:

- A **service user or carer run group** is a group where service users or carers make all the decisions.
A **service user or carer led group** is a group where service users or carers comprise the majority of the management committee or other decision making body but are not the only decision-makers.
- A **service user** is someone who is receiving or using (or has received or used) primary or secondary mental health care services.
- A **carer** is a family member or friend helping someone with mental health support needs.

2) Clarify your strategic objectives in commissioning service user and carer groups, to take account of the following:

- a) local population and diversity factors
- b) consultation with local service users and carers
- c) Specific and changing requirements for monitoring, support and capacity building
- d) Sufficient flexibility to respond to emerging needs

Take into account the views of service user and carer groups

We found that service user and carer groups want to do much more than involvement (for example, provide services and support for their members).

This should be taken into account when developing a strategy for commissioning local groups.

3) Clearly define the key aspects of your commissioning strategy in relation to service user and carer groups. This might include the following:

- a) Reflecting the diversity of the community in the commissioned groups (using the best available information, and/or consulting local community groups)
- b) Making information about the strategy and how to apply for funding widely accessible
- c) Offering information on where to find alternative funding or where to find the information (for example, local CVS)
- d) Considering the need for continuity and sustainability of funding
- e) Enabling service user and carer groups to lead on promoting social inclusion and positive attitudes to mental health
- f) Developing performance targets that effectively measure and evaluate the commissioned groups in terms of diversity in partnership with those groups

4) Contracts and service level agreements (SLA) or memoranda of agreements:

It is useful to have a contract, SLA or memorandum of agreement, setting out mutual expectations in ways which avoid unnecessary bureaucracy.

- a) Groups should be encouraged not to be over-ambitious when seeking charitable or other independent legal status until all concerned are confident that the people involved have the requisite skills and knowledge to fulfil their legal duties
- b) In the early stages of development, hosting arrangements with local voluntary sector agencies, for instance, Mind or Rethink, could be considered, providing that skills training is available to enable groups to evolve towards greater independence
- c) The process of monitoring and evaluating service user and carer groups should be done in equal partnership with those groups
- d) Commissioners should consider:
 - i) Developing effective outcome measures in partnership with commissioned groups
 - ii) Support and training to service user and carer groups concerning
 - (1) organisational management and development
 - (2) self evaluation and monitoring

5) Involvement in the commissioning process:

- a) Service users and carers should be directly represented on Local Implementation Teams (LITs), Mental Health Partnership Boards and other similar bodies with responsibility for the strategic oversight of commissioning (rather than represented by paid workers who are not service users or carers)
- b) User and carer involvement in the commissioning process should begin at the earliest possible stage (for example, building a commissioning strategy)
- c) Money and support to groups to enable involvement :-
 - Commissioners should consider providing an infrastructure to support the involvement of groups that do not have access to photocopiers, telephones, computers and premises.

Introduction

This document was written in conjunction with the recommendations for leadership training Making a Real Difference Resource Pack.

The two documents were developed to address recommendations 5 & 11 of the Making a Real Difference report;

Recommendations 5 and 11

Recommendation 5: A key focus for NIMHE should be enabling and supporting service users and carers to be involved in local groups. NIMHE needs to work with commissioners to support investment in the development of local mental health service user and carer groups.

Recommendation 11: NIMHE needs to strengthen the support that is available to service users and carers who become involved. This needs to include a clear process of induction and training as well as ongoing support. Attention needs to be paid to the development needs which arise when there is a change in role, for example moving to being involved at a regional level to being involved at a national level.

The overall aim of our task – commissioning and capacity building

We interpreted our task as being about improving the capacity of service users, carers and families to take part in local, regional or national involvement, service improvement work, self-help support and service provision.

The following commissioning guidelines specifically focus on addressing the issues raised in recommendation 5. It is designed to inform commissioners about how they can effectively support service user and carer involvement, both within their own commissioning practice and by investing in local groups which will build the capacity of people to get involved in the future.

Chapter 1 -Method

We designed two questionnaires (one for commissioners and one for local service user and carer groups) and piloted them with one service user group, one carer group and one commissioner interview. We then recruited and trained 28 service user and carer interviewers, some of whom were graduates from the London Development Centre's (LDC's) service user leadership programmes.

The survey was done in two months from start to finish, including designing and piloting the questionnaires, recruiting and training the 28 service user and carer interviewers, and carrying out 41 interviews.

We also sought help from all the other CSIP Regional Development Centres and their contributions are included in the findings and guidelines of this report.

More than 340 service user and carer groups and individuals were invited to participate. We also invited 101 people in commissioning roles across PCTs, Local Authorities and Mental Health Trusts to participate in the research.

Due to resource and time limitations (short timescale for the research) this report covers mainly adults of working age only. Despite a wide outreach to service user and carer groups there were few black and minority ethnic (BME) responses and no time to follow this up. Young Minds were invited to participate but due to time pressures on both sides we were unable to meet in person.

We received positive responses from 29 service user and carer groups and 12 commissioners. All the commissioners were from the London Development Centre (LDC) area.

Of the service user and carer groups who participated, 1 joint service user and carer group was from North East and Humber Regional Development Centre (RDC), 4 service user groups and 1 carer group were from South West RDC.

Approaches were made to all CSIP RDCs, and all their responses have been included in this report.

We set up a working group, the membership of which was drawn from LDC staff and associates. See Appendix 2 for the working group list. The working group met 6 times and monthly reports were submitted to the 'Making a Real Difference' National Steering Group.

1.1 Participants

Commissioners

11 commissioners took part in the research programme;

- 5 Joint Primary Care Trust/Local Authority
- 3 Primary Care Trust
- 2 Local Authority
- 1 Joint Commissioning Board

Service user and carer groups

29 service user and carer groups took part in the research programme;

- 16 service user groups
- 12 carer groups
- 1 service user and carer forum

Of these:

- 1 group was for homeless people who use services
- 1 was for service users with substance misuse issues
- None were specifically for BME, young or older people

As the research was done in London the majority were London-based, however thanks to the efforts of other CSIP regional development centres we did receive responses from other areas, including about 17% from rural districts.

Chapter 2 - Findings

2.1 Independence

We asked about the level of independence and management of the groups

- 14 groups are run by service users or carers
- 12 said they are service user or carer led
- 3 are neither, usually being hosted by another organisation.

- 18 are constituted groups with a management committee

- 19 groups said they have control over their money, personnel and policy decisions
- 5 have control of their own money
- 1 group has control over its personnel and policy but not money
- 1 group has control of personnel and policy decisions but not its money
- 1 has control only over its policy decisions.
- 2 did not answer

2.2 Defining service user and carer groups

We asked Commissioners if they had a written or working definition of what is a service user and carer group:

- 7 commissioners had a definition
- 5 commissioners had no definition

Those who had no working or written definition were happy to accept the definition from On Our Own Terms – see below:

Definition of a service user or carer group (based on Wallcraft 2003)

SERVICE USER RUN GROUP - user group as a group where service users make **all** the decisions.

SERVICE USER LED GROUP -a group where service users are on the majority on the management committee or other decision making body but are not the only decision-makers.

A group run or led by non-service users, for example, a therapy group or a day-centre drop-in does not count as a user group for the purposes of this survey.

The same definition would apply to carer groups, that is, carer groups are groups where carers make all the key decisions.

Of those who did have a definition, we found the following:

- A service user or carer group is a sub-group of the Local Implementation Team (LIT), with a facilitator
- An understanding that a service user or carer group would act as advocates for service improvement
- A service user-representative service, not necessarily run by a service user, though the Commissioners would encourage this
- 'a group of people who have mental health problems who are accessing our services or may wish to access our services'
- 'Although we have no working definition, it could be said that an accepted definition is any group of people with a shared interest in a service or range of services because they are either using services or look after someone who does. Although the definition can be broader'

Summary – defining service user and carer groups

These definitions seem to indicate that Commissioners are mainly seeing service user and carer groups in terms of providing representation for service improvement. It is not a clear enough definition to enable commissioning of specific types of groups for the purpose of capacity building. There was wide support for a definition along the lines of the On Our Own Terms report definition (Wallcraft 2003).

It is important to have a clear working definition in order for robust commissioning of service user and carer groups which fit with strategic objectives, such as capacity building or reflecting the diversity of the service user and carer population.

A clear definition would support clarity in terms of which groups to commission and enable commissioners to see where there are gaps and a need to commission basic capacity building to enable such groups to emerge.

2.3 Current levels of commissioning of service user and carer groups

- 11 are commissioning service user and carer groups
- 1 is not currently commissioning service user and carer groups

Several commissioners mentioned indirectly funding service user and carer groups via an NHS Trust, or organisations such as Mind, which then supported service user and carer groups. This indirect form of commissioning may be effective but may on the other hand mean that the Commissioners have less say in what types of group are set up and for what purpose, so less strategic input to local capacity building.

One Commissioner was currently not commissioning any at present, but said that something new was being set up.

The majority were commissioning 1 user group and 1 carer group, and sometimes also a general consultation forum for service users and carers.

However two of the Commissioners were commissioning a wide range of different service user and carer groups.

One was funding 4 service user and 4 carer groups, another was funding 9 service user groups (including a "Black Service User Forum", and a "User Focussed Monitoring Group", and 7 carer groups.)

Some commissioners say that in addition to funding local groups, they are funding specific activities that service users and carers want, for example,

- Pampering sessions for carers
- A boxing group for service users

The size of a group could vary from 4 members to up to 150 or more.

Summary - Level of commissioning

The most common finding is for commissioners to fund 1 or 2 service user or carer groups plus a service user and carer forum per Commissioner.

The main purpose of groups commissioned emerges thus:

- To provide advocacy
- Representing diversity ("Black Service User Forum")
- Patients' council
- To provide representatives to the LIT and other committees
- Borough-wide forums for discussion and representation
- Carers support
- Providing a voice for service users and carers
- Other functions that service users and carers lobby for: that is, specific activities
- Monitoring services (service user focussed monitoring)

Those who are commissioning a wider range of groups may be doing better than those funding fewer though the groups are likely to be smaller. The increased numbers of groups may allow for more diversity of membership and function, for example, groups meeting particular needs of the population, such as BME, or carrying out specific functions, like service user focussed monitoring (UFM).

Some local Mind groups are included because they are service user-run or service user-led, though it would not be correct to assume the same of all Mind groups. Some carer groups are part of the Rethink network. Their level of independence is likely to vary. This may be an issue for commissioning if carer and service user led groups are sought.

Questions for discussion

- Does funding of specific activities for service users and carers count?
- Does it matter if there are only 1 service user and 1 carer group commissioned if each group is comprehensive enough to cater for everyone who wants to join?
- Does it matter if commissioning is indirect such as, commissioning the Mental Health Trust to set up a user group? Is the Trust then expected to ring-fence this money and use it in a specific way, or is it left up to that body to decide how to use the money? If so it may not meet commissioners' strategic objectives.

The commissioning guidelines should help commissioners to think about what type of group to commission and having a local strategy for commissioning that

- a) takes population and diversity into account
- b) takes account of consultation with local service users and carers
- c) meets strategic objectives about specific and changing needs regarding consultation, monitoring, support and capacity building
- d) has sufficient flexibility to respond to emerging needs
- e) has clear criteria

2.4 Service user and carer groups: membership and recruitment

Service user and carer groups were asked how people could find out about their group. The answers are summarised below:

- Leaflets and posters (GP, clinics, libraries, community centres etc)
- Outreach – (visiting detox wards, drop-ins and psychiatric units)
- Networking (links with voluntary sector)
- Websites and directories
- Advertisements
- Media coverage
- Arts and cultural events run by the group
- Self referral
- PALS
- Referral by service providers and voluntary organisations
- Word of mouth

But one group said: 'Social Services and PCT are poor at giving information about carer support'.

We asked, what are the means by which people join or get involved with the groups? The answers are summarised below:

- Being on a mailing list
- Open groups (open to any service users or carers or both)
 - This in some cases is a first step before becoming a member of the organisation or of a closed group
- Closed groups
 - Fixed term
 - Diagnosis based
 - Gender-specific
- Formal group membership (necessary for formally constituted groups, especially those registered as charities, Industrial & Provident Societies)
 - Application or interview process
 - One group has a joining policy which includes issues of diversity; prospective members fill in a form identifying their areas of interest, invitation to a meeting, then meet with a panel of group members.
- Associate group membership (not full membership – possibly allies rather than direct service users or carers)
- Trustees or management committee members (service users and carers are recruited to these roles in groups)
- Induction processes, for example a 5 day course for people who want to get involved
- Courses, such as training and education for service user or carers
- SpeakOuts: ¹ (involvement and discussion meetings led by homeless people)

¹ A SpeakOut is a space where those responsible for providing statutory and voluntary services can meet with and hear from the people who use their services. As participants and as facilitators at SpeakOuts, homeless people themselves set the agenda and work together with decision-makers to find ways forward see <http://www.groundswell.org.uk/>.

2.5 What roles do service user and carer groups take?

According to Wallcraft (2003A) self help and mutual support is the most common activity of service user groups, with 79% of groups saying they provided this. Involvement comes second, with 72% of groups doing involvement work. Other activities were: education and training, creative activities, campaigning, and service provision including advocacy, befriending and therapy.

The results of this study were similar. Here are some types and specific examples of activities from the interviews with service user and carer groups

- Involvement with services and statutory agencies
 - Acting as the voice of service users or carers
 - Providing people to sit on committees
 - Supporting representatives on committees
 - Service improvement
 - Staff recruitment
 - Training professionals
 - Monitoring services
 - Consulting local service users and carers
 - Research (e.g. researching BME access to services)
- Service provision to service users and carers
 - Support and recovery
 - Drop-ins for service users or carers
 - Café for service users or carers
 - Group for carers and cared-for (parents and 14-25 yr olds)
 - Befriending services
 - Community interpreters service
 - Women's group
 - Group for gay, lesbian and trans-gender people
 - Respite for carers
 - Crisis house for service users
 - Advocacy
 - Bi-lingual advocacy
 - Advocacy specifically for African and African-Caribbean people
 - Patients Councils
 - Providing or facilitating employment for service users and carers
 - Act as employers
 - Providing and supporting service users or carers as trainers and consultants
 - A pre-employment service to help homeless people back to work
- Outreach to local service users and carers
- Capacity building for service users and carers
 - Running conferences for service users and carers

- Training and mentoring service users or carers (for example bringing in speakers on diversity and other issues or running courses for carers and family members)
- Providing information and advice for service users or carers (including regular newsletters and websites).
- Campaigning
 - Anti-stigma work
 - Empty Homes campaign
 - Developing a Charter of Rights for homeless service users (which has now been adopted by 13 service providers)
 - Promoting use of Direct Payments
- Cultural work
 - Entertainment and performance
 - Art
 - Poetry
 - Drama
 - Festivals (for example, Bonkersfest and Mad Poetry competition – supported by Poet Laureate, Andrew Motion)

One service user group would like to act as brokers for Direct Payments to service users.

Many of the service user and carer groups interviewed employ service users or carers in running the group. This is a source of employment for service users and carers, though generally not recognised as such by the groups or the commissioners.

2.6 Types of local groups commissioned

Commissioners were asked what types of groups they currently commission. These are summarised below:

- Service user involvement groups including a service user committee
- Advocacy, including bi-lingual mental health advocacy and advocacy and support for carers (this is sometimes as part of a generic carer project)
- Patients Councils
- Mental health forums (some service user forums, some carer forums, some for other people in the voluntary sector)
- A service user led day care service
- Service user or carer led groups within Mind or Rethink
- Employment projects
- A service user pressure group based in a hospital

It would seem from the results of this question and the results of asking service users and carers what their groups do, that there is a mismatch in so far as the diversity of roles taken by service user and carer groups is not currently matched by the diversity of roles commissioners commission them to do.

2.7 Commissioning strategy

We asked service user and carer groups if they were aware of whether or not the local commissioners had a strategy for commissioning service user and carer groups, and we asked commissioners whether they had a strategy.

- 16 service user and carer groups said they were aware of whether or not the commissioners had a strategy for commissioning local groups
- 13 service user and carer groups did not know.
- 9 commissioners say they currently have a commissioning strategy that covers commissioning service user and carer groups (1 said it is embedded in other documents)
- 2 commissioners say they do not. 1 of these said it is in development.

We asked commissioners who had a strategy what it contained:

Most are clearly focussed on involvement roles though other roles do appear in some strategies. Strategies indicate that commissioners consider some of these to be their main commissioning objectives in regard to service users and carers:

- Involvement of service users in the development and planning of services, the day-to-day running and operation of individual services with which they are involved, and in the design of their individual care plans.
- Increasing service user involvement and service user-led activity is a key objective in the current plan for modernising day services.
- Supporting service users to do this involvement work.
- Supporting families, friends and neighbours of service users, including the needs of children.
- Involving carers in the design of services.
- Offering carers individual plans that support them in their caring role.
- With the agreement of service users, carers should be involved in the design of individual care plans
- Promotion of mental health for all working with individuals and communities, combatting stigma and discrimination against individuals and groups with mental health problems and promoting their social inclusion

How does strategy translate into the commissioning of service user and carer groups?

Some examples of points directly relating to commissioning groups include:

- Develop groups for sharing knowledge of treatments, coping strategies and self management.
- Promote internet access for services users
- User involvement will be assured through membership of the LIT

- Fund and support the service user committee, which will have representation from BME groups
- A review of existing arrangements for service user consultation, advocacy and involvement to consider borough specific and BME specific services

Some ways in which the strategy might be implemented:

- Employing a Mental Health User Involvement Manager to ensure that effective structures are in place to involve service users
- Service user views to inform and influence mental health policy and practice
- Ongoing user-led research to assess the views of service users
- A funded user support worker to maintain links with local service user groups
- A Mental Health User Involvement Policy developed by local service user groups.
- Commissioning of User Focused Monitoring (UFM)
- A service user housing panel to implement the housing strategy and provide a forum for other service user issues

Comment from a service user group regarding problems with commissioning strategy:

“What has not been helpful is the constant changing of goalposts, changing of criteria half way through, lack of long term thought to funding services and the view that we are tacked onto mainstream services rather than being a core service in our own right”

Commissioners also mentioned problems with implementing their strategy:

- ‘Unfortunately, there is no additional money, so we have to decommission existing services in order to commission new projects.’
- ‘Carers are not sufficiently identified by clinical staff, who are unclear about definitions. Additionally, people often do not class themselves as carers. As a result carers are not receiving the support they deserve.’

Plans to implement the strategy included:

1. Work in partnership with local service users on their idea for a service user led website
2. Support the development of quarterly service user involvement forums and a biennial service user led conference
3. Broaden the scope of UFM to research the views of users of other services.
4. Maintain and develop the level of membership of local service user groups and support joint working of the various groups and agencies that represent service users

5. For the carers' network to focus more on promotion and increased capacity for group work, representation and providing information
6. The carers' network will be providing face-to-face information and advice sessions directly in key community languages

Summary - commissioning strategies

Most commissioners said that they have a strategy for commissioning service user and carer groups. It was not clear overall how many commissioners had a strategy that included clear messages on ensuring the diversity of service user and carer groups to match the population diversity, how to build capacity to enable groups to develop and grow, or on the roles that service user and carer groups might want to take outside of direct involvement.

Comments and questions arising

We didn't see many written examples of a strategy. It seems that some at least make reference to the need for service user and carer groups to be set up, but that in many cases, these groups are seen as instrumental as a means to meet Government requirements to carry out involvement, rather than being seen as a benefit in themselves in the help they might give to service users and carers in the area.

2.8 Funding of service user and carer groups

Some groups choose not to accept funding, for example,

“Our group is self-funded and most of our monies come from car boot and yard sales. This pays for our expenses and mailing costs. The group will not be applying for funding for the foreseeable future, as there is a great advantage of being totally independent. Which is how we can retain our freedom of speech by not depending on funding. The Borough Executive of [the Mental Health Trust]and its Borough Director, work closely with us and hear what we have to say, as do the officers of the Borough but feel that we do not have the same co-operation from those responsible for mental health in [the PCT].”

“The only funding we receive is from 2 carers who contribute earnings from performances as musicians (one of which will shortly be relocating and will be unable to contribute). This funding helps to pay for the weekly project we run which provides a drop-in where service users can have teas, coffees, filled rolls and jacket potatoes at cost price, e.g. bacon roll 60p, coffee 20p.”

One group said they had put in considerable effort to prepare and submit a bid to the PCT only to have the offer of funding withdrawn due to financial deficit of the PCT.

Groups were asked what sources of funding they currently received money from.

- 23 groups received funding from a mix of funding sources. The predominant combination was PCT and local authority.
- 3 received funding from one source only (PCT or LA)
- 1 received funds from the voluntary sector
- 2 chose not to accept funding other than from self-generated sources.

2.9 Commissioning budgets for service user and carer groups

- 7 Commissioners were able to identify their budget for service user and carer group commissioning.
- 1 said they could not
- 1 said it was difficult.

The budgets that were specified ranged from £38k per annum to £130k per annum.

These amounts are combined spending on service user and carer groups in the commissioning area.

The range of spending:

- User groups £16k per annum to £80k per annum.
- Carers groups £9k -£30K
- User focussed monitoring £50k

2.10 Encouragement, support and information to service user and carer groups to apply to Commissioners for funding

Groups were asked if they had been encouraged to apply to commissioners for statutory sector funding.

- 22 service user and carer groups said they had
- 5 said they had not
- 2 said this was not applicable (did not seek funding)

Groups were asked if they were given support and information to help them apply

- 14 said they were given support
- 7 said no
- 1 did not answer

Commissioners were asked if they encouraged applications

- 6 Commissioners said they do encourage applications,
- 5 said they do not

Reasons for not encouraging applications – this was a typical response:

“No, given the current state of sector funding. Funding is identified as part of strategy but all allocated. If there are funds over at the end of the financial year they are shared out between local voluntary organisations.”

Support and information to service user and carer groups to support funding applications

Service user and carer groups were asked what support and information they received:

- Written information
 - 'Social services sent guidelines. PCT were also supportive'.
 - 'I was given information in written form, documenting how to apply for funding, this included the criteria needed to secure funding and the time-scale to which my application should be made'
- Verbal
 - Encouragement and help in applying for funding from the Mental Health Trust. One member of the Partnership Board especially wanted this training for carers and actively encouraged a bid for funding. He was the joint commissioner.
 - 'Lots of support when needed in respect of the crisis house'; 'Information was given verbally (nothing in writing) as to the required format of the bid, as a result of which a 20-page bid document was prepared by the Project'
- Training
 - 'Council gives training workshops'
- Partnership working:
 - 'We find out [informally] through networks and relationships, e.g. the partnership board'; 'By working in partnership with both commissioners and providers we were given the information we needed when we needed it and in a way that was clear and helpful'.
- Website information
- Minimal information or support
 - 'Lacking in written info – nothing presented by commissioners of their requirements/guidelines'
 - No practical support given
 - Non-statutory organisations help ('they help us more than the statutory services in a range of ways including capacity building, funding applications, accounting etc')
 - 'What has not been helpful is the constant changing of goalposts, changing of criteria half way through, lack of long-term thought to funding services and the view that we are tacked onto mainstream services rather than being a core service in our own right'

What help did groups say they would want or need in the future?

- Practical advice and support
 - Help to navigate the system.
 - Support and help to smaller organisations in completing funding applications
 - Shorter application forms
 - Free courses in fundraising
 - Designated fundraiser specialist
 - One-to-one support
 - Understanding of funding jargon (like 'ring-fencing')
 - Explanation about the process of applying for funding
 - Guidelines about sources, forms or types of funding available.
 - Training for service user consultants in funding skills
 - More information about commissioners' priorities
 - Criteria for successful application to be more transparent
 - More notice of whether funding is going to be given or not
- Help in planning for longer-term
 - Longer funding periods - 3 years not just one year
 - Help in developing a plan for longer-term sustainability

Commissioners were asked what information, encouragement and support they give:

- Of those commissioners who were willing to encourage applications, several say they do this via the local Council for Voluntary Service or other voluntary sector organisation, which they commission to do this work. Others are considering moving to this system.
- Some give informal phone support.
- One prioritises reaching out to carer groups
- One said their groups were well structured and supported and didn't need extra help in seeking funding.
- One said they advertise widely.
- One said that they had a close relationship with the local groups and did not need to make any particular efforts as the groups were already sharing all the information had about funding.
- Two had specially funded posts within the Trust to provide support to service user and carer groups

General

- About half of the commissioners give direct information and support on applying to them for funds, or commission others to provide this.
- Of those who say they don't, about half do provide informal help if asked. Others do not, either because they don't need to – they consider the service user and carer groups sufficiently well informed and supported not to need this help – or in two cases because there is no spare cash. In fact one is currently in recovery.

Comments and questions

Should Commissioners offer information and support, or is it better to go via VSC?

Should there be more outreach to groups who are less well networked? Not enough to say that the groups know. There may be others who don't receive funding because they don't know where to go or what might be available. It may privilege existing established groups.

2.11 Advice on finding funding elsewhere

Service user and carer groups were asked whether the commissioners had ever encouraged them to seek partial funding from non-statutory sources.

- 11 said yes
- 17 said no
- 1 didn't answer

Sources suggested:

- | | |
|---------------------------------------|------------------------|
| • National Lottery | • Esmée Fairbairn |
| • Tudor Trust | • Comic Relief |
| • <i>Futurebuilders</i> England | • Bridge House Trust |
| • Off The Streets and Into Work (OSW) | • Capital Volunteering |
| • Awards for All | • The Kings Fund |
| • English Churches | • The Camphill Trust |
| | • UnLtd |

Commissioners were asked whether they give advice to service user and carer groups on other places they might find funding.

8 Commissioners said they did, and 2 said they do not.

Sources of funding they recommend:

- Lottery – 3
- European funding – 3
- Dept of Health – 2
- Local Authority – 2
- Grant giving trusts – 2
- Websites – 1
- Raise own funds as a charity – 1
- Carers Grant – 1
- Work with local voluntary sector – 1

What support were groups offered to find funding elsewhere?

- ‘None. They did not advise us where to apply. Basically we were left to get on with it’
- “What does VSC stand for? VSC or other voluntary sector organisation”
- “We had the expertise in the group”
- ‘We received an information pack and booklet with all the considerations and limitations, including an invitation to a pre-meeting before the bid. I could also make contact with them directly if I needed to’
- ‘Other advocacy projects helped with bids. Networking between projects is useful and helpful’

We asked commissioners the same question:

Several commissioners said they would refer to VSC or Local Authority for help

Others would give supportive references or other help if asked.

General

There is no consistent policy on supporting service user and carer groups to look elsewhere for funding. Perhaps again the local VSC would be the best place to help rather than the commissioners, but it might be helpful if commissioners had some good and up-to-date information and advice to give to groups who are turned down for funding or do not get all the funds they need from the commissioners.

Comments and questions

It was encouraging to note the wide variety of alternative sources of funding which service user and carer groups told us they had been referred to by commissioners.

2.12 Length of funding

Service user and carer groups were asked how long they were funded for.

- 1 project was funded for 6 months
- 9 projects were annually renewable or 1 year only
- 1 project was for 18 months
- 3 projects were for 2 years
- 13 projects were for 3 years

Commissioners were asked the same question:

- 7 commissioners said they usually funded groups for one year at a time
- 4 said they funded for three years at a time.

Some say funding is relatively secure even though it may be annually renewable.

2.13 Diversity

Quotes from service user and carer groups

Some quotes showed a lack of awareness of diversity:

- 'Our groups are open to everyone irrespective of race or gender and we encourage BMEs to attend. However, our experience has shown that Asian women in particular do not want to come out in the evening.'
- 'Have had no problems, there is a very active Asian group – doing their own thing!'
- 'The group is open to anybody. There is no explicit policy for targeting any particular group'
- '... is completely egalitarian'
- 'We have an equal ops policy. Our constitution states we are inclusive of everyone'
- 'In respect of paid staff we have mainly women, there is one man, but we have male volunteers. We do not ask about gender preference'

Others showed awareness of the need to do more:

- 'Not a lot of time to actively reach out to marginalised communities. Just in the business of survival'
- 'Need to do further work in this area'
- 'Do not monitor sexuality'
- 'I think that the issue of the hidden carer, is more than a lesbian or gay or ethnic minority problem, it is wider than that. I feel that it is general. We should be pressing GPs to identify carers, especially young carers, regardless of their sex or age or race and ensure that they are treated equally The group has not had to deal with these issues as yet but [Trust staff] are dealing with that'

- 'It underpins all our work and we are conscious that there is more diversity work to be done'

Quotes from Commissioners

There were a number of statements that demonstrated lack of awareness of diversity issues or an attempt to pass the responsibility of diversity awareness on:

'Diversity is the thing which we are quite good at'

- 'We have deliberately NOT set up a separate service user committee for BME users but have rather sought to incorporate the BME view into the main User Committee'
- 'In terms of the high proportion of black people in the mental health system with possible diagnosis of some psychotic illness, it is not yet proven that there is evidence of discrimination or if this group for whatever reason is more susceptible.'
- 'we adhere to legislative requirements'
- 'BME carers' worker is responsible for picking up diversity issues'
- 'Mind specifically given SLA objective of increasing membership and involvement of people from BME communities'

There was also some hesitance and waiting for results to come in:

- One commissioner was observing the ability of the local service user and carer groups to access BME communities and if this did not work they would look again at how to fill the gap.
- Another thought they ought to do a Diversity Impact Assessment to 'help forecast the impact of service change and ensure access and service provision to disadvantaged groups' – but seemed not to have concrete plans to do one.

It could be that some commissioners are relying solely on the Delivering Race Equality programme to take on the role:

- 'We intend that the Community Development Worker will be undertaking working with BME user groups'.

However, there were some examples of service user and carer commissioning that looked promising:

- Mental Health Guides is a commissioned programme to develop a service user group in one area, and these Guides (some of whom will be BME service users) will be trained to work with a range of diverse community groups.

Another area has a range of service user and carer groups which have ethnically diverse memberships and include people with physical disabilities. Their carers' network employs speakers of some local minority languages. One area has a BME Health Forum that reports directly to the commissioners.

General findings

Service user and carer groups

Whilst diversity awareness of most groups interviewed is poor, there is a general recognition amongst groups that they need to do further work in this area. Many appear to be struggling to find effective ways of making progress. However, we did find pockets of good practice, such as,

- Asian befriending project
- Multi-cultural women's group
- Undertaking research into BME access to services
- A specialist Lesbian Gay Bisexual group
- Local (user-led) Mind Association providing housing for people from BME communities

Commissioners

The results on diversity were disappointing.

Attitudes included:

- We adhere to the legislation (but nothing more)
- We are good at diversity
- We will wait and see whether there is a problem
- We won't fund BME groups because that would ghettoise them: we expect them to join existing groups
- We will rely on small under-funded groups or individual workers to deal with the problem
- It will all be sorted by the Delivering Race Equality (DRE) programme and the Community Development Workers (CDWs)
- We don't have a problem
- We are doing plenty already

Commissioners don't have unlimited funding but a clear strategy (and perhaps some good sources of community-based or national advice) might help.

Commissioners need to take a very much more proactive approach in addressing how local groups embed diversity awareness into their organisations.

2.14 What do commissioners expect from the service user and carer groups they commission?

Answers from service user and carer groups (examples of work they have been commissioned to do)

- Providing a service
 - Support group
 - Information and advice
 - Advocacy
 - Outreach
 - Crisis or safe house
- Identify trends
 - Highlight the top 5 advocacy problems
- Capacity building
 - Providing training, for example, on service user involvement
 - Supply public speakers

Answers from commissioners

- Service improvement and feedback on service quality
- service user and carer satisfaction
- Identifying gaps
- Help with performance management monitoring and evaluation of all service providers
- Partnership with commissioners
- Being the local voice for service users and carers
- Providing advocacy
- Representation on committees, such as, LITS, and partnership groups
- Representing BME service users and carers
- service users and carers are potential providers
- Training of staff in service user and carer perspectives

Quotes from Commissioners on what they expect

- Representativeness (“are we hearing representative voices?”)
- Robustness (expect groups to have good internal processes)
- ‘We don’t want conflict!’
- ‘The tensions between the Dept of Health’s expectations that users should sit on committees means that the PCT is often caught in the middle of the local MH Trust which needs user representation and the user groups’ reluctance to participate in this way.’
- One local service user support worker has written to the Dept of Health to raise the concern that ‘mental health user involvement is often too prescriptive and tokenistic’
- Commissioners say they will expect statutory providers to respond to issues raised by service user and carer groups.

Summary

- Direct consultation
- service user and carer involvement
- Identifying service user and carer representatives
- Voicing service user and carer perspectives generally
- Staff training
- Developing service user and carer services – including advocacy and support services

Comments and questions

There is a predominance of commissioners expecting service user and carer groups to provide involvement. This often conflicts with what service user and carer groups say they want to do.

A few commissioners do mention service user and carer groups providing services such as advocacy and/or potentially providing support services. A service user-run crisis house was recently set up in one area, with some statutory funding, though most of the money was raised by the service user group from grant-giving bodies and the National Lottery.

2.15 Contracts (for example, a Service Level Agreement) – do groups have them, what do they typically contain, and what are typical evaluation criteria?

We asked service user and carer groups whether or not they have a contract or Service Level Agreement (SLA) with the commissioners.

- 22 said yes
- 6 said no
- 1 said N/A

We asked those who had no contract how they knew what the commissioners expected of them.

- Through our grant application that has to be presented on a yearly basis
- Informal verbal communication: 'We negotiated outputs with them'
- Email communication

All the commissioners said they did provide some form of contract or SLA and evaluated or planned to evaluate the groups.

One commissioner said that the service user group needed to improve its reporting such as doing questionnaires about members' experiences.

Summary

Service user and carer groups were asked what requirements were in the contracts or SLAs they were given and how they were evaluated and their involvement in this.

- Compliance with legislation and other specific requirements
 - A crisis house must meet Supporting People Grant regulations
 - Data protection
 - Health & safety
 - Equal opportunities
 - Matching of services to the core values of the NSF
- Compliance with contract requirements
 - Targets - meeting projected outputs
 - Increasing membership (for example, BME or younger people)
 - Developing and promoting group (such as producing newsletters)
 - Holding a certain number of meetings
 - Attending and participating in certain meeting (for example, LITs)
 - Number of hours a month (for example, advocacy work or consultation)
 - Supplying a certain amount of training
 - Widening the numbers of service users or carers involved (for example, in advocacy or support)
 - Facilitating a support group (type, numbers of sessions)
 - Recording and reporting progress
 - Keeping monitoring records
 - such as membership lists
 - Periodic progress reports
 - Monthly narrative reports
 - Evaluation methods
 - Based on monitoring records and statistics
 - Periodic visits to the premises (some unannounced)
 - Evaluation forms
 - Annual monitoring report
 - Annual monitoring meeting

How are service user and carer groups involved in the evaluation of their own groups?

We asked service user and carer groups whether or not they were involved in the monitoring and evaluation of their groups:

- 22 said yes
- 3 said no
- 4 said N/A

'Essentially, commissioners need to know they are getting value for money'

One service user group plans to commission external evaluation of its crisis house service 'to prove we are delivering what we say we do'.

'Visits, progress reports and regular reviews are initiated by us and look at the issues that are important to service users. We design the reviews and identify how best to monitor and evaluate based on what service users feel is the best way of doing it'

EXAMPLE OF LACK OF COMMUNICATION CONCERNING CONTRACTUAL EXPECTATIONS AND OUTCOMES

The service user group says:

'Internal methods devised by [the service user group]. We have never been told what targets to achieve. We do report to them if a project is delayed. I send quantity and quality data to the commissioners every month. Our advocates produce their own statistics. When outcome evaluation forms are returned if users have issues with an advocate I would feed them back through supervision. We are not rationed as to hours though – it is however long it takes, it is the outcome that is monitored'.

The Commissioner says:

'Service user feedback is taken into consideration. But there is no actual involvement of the users in the reviews'.

Commissioners said that contracts typically specified:

- General aim of commissioned group (for example, to run a service user involvement forum, or a carer support group)
- Detailed specification of service (if the group is providing a particular service)
- Key performance indicators or outputs expected:
 - Numbers of service users or carers involved in individual activities, and with group overall
 - New service users or carers joining, and returning
 - Increase BME members
 - Breakdown by equalities categories (age, gender, ethnicity)
 - Produce certain number of newsletters a year
 - Provision of training to members for capacity building
 - Provision of training to mental health workers
 - Patients' Council meetings (specified number)
 - Identifying carers
 - Helping carers to self-identify
 - Raising the levels of carers' assessments
 - Providing support and advice to carers
 - Establishing structures for consultation with carers

- Provide general feedback to commissioners about service user and carer views of local services
- Provide specific help to commissioners with monitoring other local services
- Supply representatives to a range of committees
- Run weekly drop-in sessions
- Provide outreach and support services to local service users and carers
- Provide advocacy and information
- Outcomes
 - What was achieved?
 - Were the aims met?
 - levels of satisfaction of group's members measured against what they are commissioned to provide.
- Performance monitoring for group
 - How the group will keep records
 - How it will report back to the commissioner
- Quality and Governance
 - Group procedures - management of group, officers, decision-making structures
 - Equal opportunities
 - Complaints procedures
 - Finance
 - Insurance if needed
 - Conflict resolution
- Evaluation by commissioners is based on:
 - Regular reports being received
 - Key performance indicators being met
 - Agreed aims and specifications being met
 - Satisfactory outcomes
 - Service user and carer satisfaction

Comments and questions

Service user groups seem to be commissioned as mental health user groups. But carer groups are often commissioned as generic services, such as, the local Carer Centre.

BME groups also seem to be commissioned as generic community services, which are often not mental health specific. BME service user groups being commissioned still seems to be exceptional.

2.16 Are business plans expected from groups, and are groups helped with producing one?

We asked service user and carer groups if they were expected to produce a business plan.

- 11 said yes
- 11 said no
- 5 said N/A
- 2 didn't answer

Of those groups who answered 'yes', 3 said they were offered information or support with this task, while 8 said they were not given any help.

Commissioners were asked the same questions

- 3 commissioners said yes they do expect a business plan
- 6 commissioners said no they don't
- 2 said they sometimes expect a plan

Only 2 commissioners said that they help groups to develop a business plan, though they could provide help if called upon. 3 commissioners said that the voluntary sector or local authority can provide this support if needed.

2.17 Ongoing help and support in meeting targets

Service user and carer groups were asked what help they received in meeting their targets:

- 5 said they received adequate help
- 5 said they received some help
- 12 said they received no help
- 4 N/A
- 3 no answer

Service user and carer group quotes:

- 'We get very little support from the Joint Commissioner of PCT and Social Services. The joint commissioner is really very rude and makes no effort to engage with us. Decisions are taken entirely unilaterally. We have complained to the Joint Commissioner's boss but to no avail'
- 'we are basically left to get on with it'
- 'Not a lot of help. All contact to commissioners comes directly from [me] the project manager'.

- ‘they give advice, listening ear, attending events, and more’
- ‘None – but I feel they would if it was needed, but they have never had to – they get far more than they commission!’
- ‘None and I wouldn’t expect it. When the money’s given out you’re expected to be self-running. I get support and supervision at [local] Carer’s Centre.’

Commissioners were asked the same question:

- 7 commissioners said they did provide ongoing support to service user and carer groups on this.
- 1 said they did not.

One commissioner said that they commission training to service user and carer groups which is provided by a local independent sector body. This training includes understanding of:

- NHS systems
- available services and how to access them
- building skills as service user representatives
- running groups
- public-speaking and presentation skills
- negotiation
- self-management.

The same commissioner made the point that support is sometimes misinterpreted as interference.

Another commissioner provides support via a service user involvement manager and a carer development worker employed by the commissioner.

Some say that they are available on email or phone to give support informally.

One commissioner regularly attends service user forums and monitoring meetings and is encouraging the service user group to develop their own forms of self-monitoring.

One says they provide training based on an annual training needs analysis.

In one area, an annual event to share and celebrate achievements is held.

2.18 Involvement in the commissioning process

We asked service user and carer groups whether they know if there is routine service user and carer involvement with the commissioning process.

- 13 said there is involvement
- 6 said there is limited involvement
- 8 said they were not aware of involvement
- 2 didn't answer

Quotes from those who said there was limited involvement

- 'Only token'
- 'There is but it does not feel like it'
- 'LIT only'
- 'Just beginning'
- 'Carers are not directly involved in commissioning as such. They influence the services that are provided but do not get involved in commissioning'
- 'Technically through our own group who feed into the LIT, but in practice it does not feel that we are really involved – rather we can tinker with commissioning decisions that have been taken elsewhere'
- 'There are a few carers (and service users) on different committees, but in general they have little time to get involved. Carers have recently been encouraged to take part; it seems this is an embryonic stage of using carers'
- 'Financial decisions [are] made outside meetings – feel not truly influencing the decision making [e.g.] LIT'.

The areas of involvement mentioned by the service user and carer groups were:

- Mental Health Partnership Board
- LIT
- 'Will be involved in [developing] the new Strategy for Mental Health'
- Locality Groups

Commissioners were asked the same question:

- 8 commissioners said there was service user and carer involvement in commissioning,
- 2 said there was none.

The involvement was listed as the following:

- LITS 6

- Mental Health Partnership Boards 3
- Executive committees (sub-groups of LITs)
- User committee
- Mental Health Forum
- service user and carer satisfaction surveys
- service user and carer workers in Local Authority
- Participation in tendering process
- Service users represented by support worker and user involvement manager
- Carers represented by carer support or development workers

2.19 Other non-monetary support offered

We asked service user and carer groups whether or not commissioners offered their groups any non-monetary support:

- 16 said yes
- said no
- 2 N/A
- 1 no answer

Quotes from service user and carer groups:

- 'There is a moral support in terms of what we do.... The borough have also agreed to be the host regarding Criminal Records Bureau checks so that it will not cost us as much'
- 'The Joint Commissioning Manager meets with us and provides guidance and practical support on a partnership basis'
- 'Available to talk to for information and training, going to give staff time e.g. ICT work'
- 'In theory [they] have in-house training but it has proved not to materialise. The forums are hindered by red tape'
- 'The commissioner...has acted as a referee for other funding bids'
- 9 commissioners said they did provide other forms of support
- 2 said they didn't

Five commissioners said they provided staff time. Others provided support such as use of facilities, help with recruitment, and information on available training.

Additional support needed by service user/carer group

We asked service user and carer groups whether they have support needs that are not being met by the commissioners

- 19 said yes
- 6 said no
- 2 N/A
- 2 no answer

They said they needed support with the following areas:

- Capacity building
- Fundraising
- Emotional support, for example, mental health of members, and impact on ones self
- Organisational support
 - Budgeting, book keeping and finance management
 - Time management
 - Personnel management
 - Staff training
 - Help with finding premises
 - Help with travel arrangements
- Legal advice including
 - Getting insurance
 - Charitable or company status
 - Equal opportunities
- ICT advice
 - Provision of computers and phones
 - Building of databases

'Our support needs are not met by the commissioners, but by [local] Voluntary Service Council. They provide a lot of training and support to the voluntary sector in [borough]. They receive part of their funding from statutory services to do this. We get external emotional support/ supervision to carry out our work which the commissioners have no objections to funding'

'It would be nice if they discussed commissioning intentions in advance, instead of making unilateral decisions with no forward planning'

'We would like to set up various groups, i.e. art groups, book groups in the library, gardening, but are unable to because we haven't got the funds'

'Currently there is a need for language interpreters/translators and BSL signers and equipment to make our literature available for Braille users'

² Full Cost Recovery

Historically, third sector organisations have struggled to secure funding for their overhead costs, leading to underinvestment in management and leadership, internal and external infrastructure, strategic development and governance. This difficulty has been exacerbated by a trend on the part of the sector's funders towards funding the direct costs of projects rather than overheads or "core funding". Failure to secure funding for overhead costs makes important services, including public services, and the organisations that deliver them, unsustainable. Both government and the sector's representatives have agreed on a solution: Full Cost Recovery (FCR).

Under FCR, organisations and their funders ensure that the price of contracts and grants reflects the full costs of delivery, including the legitimate portion of overhead costs. This commitment poses challenges for both organisations and their funders.

- Third sector organisations must cost their projects and services on an accurate, defensible and sustainable basis.
- Government must ensure that all public bodies fund services sustainably, by permitting the inclusion in prices of the relevant portion of overheads, and ensure that prices are determined on a realistic basis.

HM Treasury first endorsed the principle of Full Cost Recovery in its 2002 cross cutting review, "The role of the voluntary sector in service delivery". The review stated that "Funders should recognise that it is legitimate for providers to include the relevant element of overheads in their cost estimates for providing a given service under service agreement or contract." The review stated that the deadline for statutory funders to implement Full Cost Recovery was April 2006.

2.20 Barriers to commissioning

'Difficulty in commissioning a meaningful process that is consistent and deliverable.'

- Finance and budget cuts (not enough money to fund all groups equally)
- Groups depend on having someone with relevant skills and experience
- People need training or lack skills, such as, confidence or computer use
- Hard to find groups to commission 'We can only commission what is there'.
- Consultation fatigue
- Insufficient volunteers
- Anxiety from service users about becoming genuinely independent groups
- Large and complex commissioning agenda
- Capacity of groups to develop
- BME groups are not established providers
- Difficult for groups to incorporate diversity

Comments

This raises issues about how commissioners might deal with these identified barriers, mainly about lack of capacity or lack of sufficiently developed groups. Perhaps they need to look more closely at what service user and carer groups might need, such as mutual support instead of more committee work.

2.21 Drivers to commissioning service user and carer groups

Service improvement (7)

- Being responsive to service users and carers

Organisational and personal values (6)

- It would dull our sensitivity not to involve people
- Statutory sector wants to have meaningful involvement of service users and carers; it isn't just driven by Government policy.
- Trust wants service users involved in commissioning
- Fitness for purpose – 'our work is about meeting the needs of people using services'
- Our aim is to provide responsive services

Government policy (4)

- 'The DOH is the strongest driver'
- NSF (2)
- Autumn assessment setting targets through LIT
- NICE
- CSCI
- Our Health, Our Care, Our Say White Paper
- Lobbying from service user and carer groups (2)
- The Delivering Race Equality programme.

Comments

It was heartening to see how many commissioners were driven by 'values' and the need for service improvement.

On the other hand, it was disheartening to note how many were driven mainly by Government policy. There appeared to be a low level of awareness of organisations duties under the Health and Social Care Act 2001 –Section 11. We find this worrying if this is so.

2.22 What is working well

We asked service user and carer groups what is working well in their relationship with commissioners:

- 8 said good personal relationships and regular communication
- 4 said they have confidence in us
- 2 said involvement of service users and carers in commissioning structures including LIT
- 2 mutually agreed priorities and direction
- 1 said funding of valuable services

'The group is very successful with 100% attendance. The funding and monitoring has recognised the group as an innovative and useful project'

We asked commissioners the same question:

- User group well established and well run – 4
- Carers group well established and well run – 3
- Good relationship between service user/carers groups and commissioners – 3
- Service user and carer groups fully contributing to commissioning process and review of mental health services – 3
- User focussed monitoring – provides valuable feedback – 2
- Good local advocacy including bilingual advocacy
- Improvement of the service user voice on LIT
- Mental Health Guides programme
- User led website
- Success in commissioning new groups (user group, carer group, mental health forum)
- Good relationships with voluntary sector – 2
- Robust carer involvement due to investment
- Service user involvement in recruitment is well established
- Crisis cards
- Police liaison training

Comments

It is clear from the above list that there is much positive work being done, which can form a strong platform on which to build.

2.23 What is not working well

We asked service user and carer groups what is not working well?

- Difficulties with funding
 - Bureaucracy and red tape
 - Inflexibility and difficulty in accessing the funding process
 - Lack of support in identifying alternative funding sources
 - Lack of secure or long-term funding
- Difficulties with SLAs and contracts
- Incompatibility between health and social service monitoring systems
- Not enough consultation and involvement of service user and carer groups
 - Inaccessible meetings
 - Jargon
 - Tokenism
- Poor relationships with commissioners
 - Lack of support, contact and communication
 - Awareness of power imbalance between service user and carer groups and commissioners re decision-making
 - Lack of understanding about what groups do, or would like to do
 - Unrealistic expectations of groups
 - Staff changes in commissioning agency leads to constant 'reinventing the wheel' – going over old ground.
- Shifting goalposts – changes in the commissioning process
 - Cost pressures due to budget cuts
 - Lack of regard for NSF Standard 6 (Carers' assessments)

Quotes

- 'Some of the information they would like us to provide does not fit in with the way we work'
- 'Pressure to increase BME outreach but no support in achieving it'
- 'When they muck us about, change goalposts, or withdraw funding when it has been awarded'
- 'We are beginning to feel a little excluded. We're not sure whether it's to do with the speed of changes and they cannot afford to be held up by us, or that they are unable to hear what may be said as changes are needing to be quickly implemented with some being financially driven. We haven't been involved, for example, in the development of the Acute Care Service team and Primary Mental Health team which we feel is quite remiss'.
- 'They just tell us what they have decided. Social Services are like a closed book we would like to have the power to scrutinise them in their decision making policies and services'
- 'We want to be funded for things that we find useful such as a day when we invite carers to have complementary therapies, stress reduction, psychology tools to cope with the difficult task of mental health caring, home sitters, risk assessments of our duties' .

We asked commissioners the same question:

- Capacity – limited number of service users and carers involved – 3
- Carer voice on LIT needs to be strengthened – 2
- Difficult for service users to understand Trust issues and the bigger picture – 2
- Carers hard to engage in current service issues
- Service user group is ineffective and poorly structured, so couldn't fund it
- 'No BME reps on the Mental Health Partnership Group'
- 'No BME carer on BME Steering Group'
- Not enough Asian women involved in planning.
- LA and PCT are not working together
- Service user groups can't engage enough with wider service user population and engage them
- Tension between national drivers and local service user views on how to consult and involve

2.24 Suggestions for improvement

We asked service user and carer groups for their suggestions

- An overall strategy for commissioning service user and carer groups
- Recognition of people's vulnerabilities
- Central source of information
- Jointly developed long-term business plans
- Group infrastructure funded appropriately
- A network of service user and carer groups
- Help and guidance for groups just starting out
 - Sharing information and good practices
 - Help with costing the group's services
 - 'A mentoring scheme for new or smaller groups by the more experienced groups would be helpful'
- Service users and carers should be on commissioning groups as equal members
- Encourage more partnership working
 - for example a jointly developed local delivery plan
- Need to feel involvement is valued and appreciated
- Simplify process of payment for involvement (remuneration and expenses)

'They should be honest and straightforward. There is a lot the sector can do for themselves. But overall commissioners need to act in a fair, open honest consistent way'

'Making a Real Difference' type interviews between commissioners and service user groups leaders explaining what the process involves and means, jargon, expectations and what is needed to make it really happen'

'I would like to see a system of financial bench marking. I don't know if the price we charge is correct. I produced a model of a system for a manager, and he wrote back and said it was "too cheap". What do they mean by cheap? It is difficult to look at other people's funding. We just charge what it costs us and then add something on top'.

'That somewhere, there should be some written recognition that they are dealing with people who have mental health issues be that in the service level agreement or not. Whilst commissioners do have to work from a basis of paying for services to deliver, there should be some recognition that if people become ill all at the same time, the organisations service figures may drop. So there could be some acknowledgement that there may be times when not all the money is spent for example, or why we have not reached our outputs. Certain things can affect the organisation in a way that takes time to recover from. It's not about getting money for doing nothing. It's about recognising just how much more work is going on behind the scenes needing a structure behind it to support it and that when people are not well these structures get affected'.

Commissioners were asked the same question

- More resources better used to support representation
- More representation at higher strategic levels such as at board level or with Ministers.
- Prioritise existing resources better
- More services designed and developed by service users and carers
- Service users to commission their own services
- Reach out more to BME groups
- More work on gender issues
- If something has had a positive input on service user and carer input then we should replicate it
- Find ways to measure what difference involvement makes
- Commissioning strategies or templates should build on examples of good practice
- Set up support networks for service user and carer groups
- Training and leadership opportunities for service users and carers and improved marketing of existing programmes
- More central initiatives on training and monitoring and mentoring
- Training service users and carers on what it means to be involved in a local group
- Employment of service users as professional advisors
- Training in understanding the 'bigger picture'
- Training in involvement
- Flexibility for commissioners to commission groups, for example a 5 year SLA

References

HASCAS (2005) Making A Real Difference

Health and Social Care Act 2001 Section 11

Wallcraft J. (2003a) On Our Own Terms: Sainsbury Centre for Mental Health
<http://www.scmh.org.uk/80256FBD004F6342/vWeb/pcPCHN6FTF34>

Wallcraft J. (2003b) Training and Empowerment Literature Review, unpublished paper for the Sainsbury Centre for Mental Health.

Viv Lindow's Rowntree report on commissioning self help
Course documents

Carers Help Carers <http://www.bath.ac.uk/carershelpcarers/>

Groundswell <http://www.groundswell.org.uk/index.php>

YoungMinds (2006). A Call to Action: commissioning mental health services for 16–25 year-olds.

http://www.youngminds.org.uk/sos/SOS_YM_Commissioning.pdf

Hear Our Voice (for young people with mental distress in Cornwall)

<http://www.eefo.net/index.cfm?section=home>

Off the Streets and Into Work - <http://www.osw.org.uk/>

OSW is a registered charity that tackles homelessness by supporting individuals to access education, training, volunteering and employment.

ODPM (2004) Mental Health and Social Exclusion

<http://www.socialexclusion.gov.uk/downloaddoc.asp?id=134>

The National Social Inclusion Programme (NSIP) at NIMHE has brought together the work of government departments and other organisations in a concerted effort to challenge attitudes, to enable people to fulfil their aspirations and to significantly improve opportunities and outcomes for people with mental health problems.

Awards for All - <http://www.awardsforall.org.uk/>

Awards for All is a Lottery grants scheme for local communities.

Esmée Fairbairn Foundation is one of the largest independent grantmaking foundations in the UK, making grants to organisations which aim to improve the quality of life for people and communities in the UK, both now and in the future.

http://www.esmeefairbairn.org.uk/about_us.html

Futurebuilders; a £125m fund that plans to deliver an increase in the scale and scope of the public services delivered by the voluntary and community sector (VCS). [www.hm-](http://www.hm-treasury.gov.uk/media/D31/43/futurebuilders(309kb).pdf)

[treasury.gov.uk/media/D31/43/futurebuilders\(309kb\).pdf](http://www.hm-treasury.gov.uk/media/D31/43/futurebuilders(309kb).pdf)

Comic Relief supports long-term projects, helping people to help themselves.
<http://www.comicrelief.com/>

Tudor Trust ; an independent grant-making trust which supports organisations working across the UK. They aim to support work which addresses the social, emotional and financial needs of people at the margins of society.
<http://www.tudortrust.org.uk/>

Bridge House Trust makes grants in excess of £17 million a year to charitable projects benefiting the inhabitants of Greater London
<http://www.bridgehousegrants.org.uk/BridgeHouseTrust/>

Capital Volunteering a pan London programme which aims to tackle issues of mental health and social inclusion, through volunteering.
<http://www.capitalvolunteering.org.uk/>

The King's Fund is an independent charitable foundation working for better health, especially in London. They carry out research, policy analysis and development activities, working on our own, in partnerships, and through funding.
<http://www.kingsfund.org.uk/>

Camphill Communities build intentional communities with people of all ages who live with disabilities. <http://www.camphill.org.uk/>

UnLtd supports social entrepreneurs - people with vision, drive, commitment and passion who want to change the world for the better, by providing a complete package of funding and support to help individuals make their ideas a reality. <http://www.unltd.org.uk/>

Full Cost Recovery
<http://www.fullcostrecovery.org.uk/main/index.php?content=home>

Glossary of terms used

NIMHE	National Institute of Mental Health Partnership programme within the
CSIP	Care Services Improvement Partnership
Diversity	The term 'diversity' can be understood as referring to the diversity of people's experience, support needs and mental health issues, as well as ethnicity, culture, spiritual beliefs, gender, sexual orientation, social class, age and disability.
LDC	London Development Centre
MARD	Making a Real Difference Project
RDC	Regional Development Centre
Social exclusion/inclusion	<p>'Social inclusion is about helping to ensure that everyone feels able to contribute and be involved in his or her local community. This is aimed especially at people who often have to overcome additional barriers to enable them to become involved in their community, such as gypsy and travellers and young people. Or to put it another way, it is about tackling 'social exclusion'. The Social Exclusion Unit, a government department defines social exclusion as: " the shorthand term for what can happen when people or areas suffer from a combination of linked problems such as unemployment, poor skills, low income poor housing, high crime environments, bad health and family breakdown".'</p> <p>http://www.devonrcc.org.uk/page/social_inclusion_programme.php)</p>
Products	The policies, procedures, guidelines and systems developed during the Making a Real Difference project.

RATIFYING BODY

DATE RATIFIED

NEXT REVIEW DATE

TO BE APPROVED BY.....

Appendices

Appendix 1 - Working group list

Mark Leveson – Project Lead and Working Group Chair

Ali Davies – Programme Director and Project Sponsor

Gemma Hughes – Programme Director

Emma Raver – Project Support Manager

Dorin Varza – Project Support Manager

Margo Fallon – Service Improvement Lead

Clive Stevenson – Service Improvement Lead

Lesley Carter – Service Improvement Lead

Jan Wallcraft – Consultant

Christine Lewis – LDC Carers Associate

Fiona Hill – LDC Service User Associate

Appendix 2 – List of interviewers

Keith Halsall – Pilot interviews

Leah Ankrah

Patrick Broaders

Suzanne Collins

Pauline Edwards

Catherine El-Houdaigui

Jai Forde

Sandra Graham

Lee Gunn

Hilary Hawking

Julia King

Barbara Lopko

Rachel Lubbock

Irene May

Daniel McKenzie

Kath Lovell

Gillian (Gill)Mitra

Louise Morgan

Alan Moss

Nick Nalladorai

Susannah O'Connell

Susannah Oliver

Ayo Oyebadle

Teresa Priest

Rachel Richardson

Kay Smith

Roger Warren

Mary Wheatley

Appendix 3 – Feedback from interviewers

1. I found the preparation and information day hosted by the London Development Centre to be of great value and it was well thought out and delivered efficiently. The materials supplied for the interviews were extensive and easy to use and understand.

My difficulty in completing the work lay in a slight ambivalence from the interviewee who was difficult to pin down, and gave a more enthusiastic response to the leader of the project than myself, when it came to arranging the interview. I felt I spent a lot of time chasing the service user group and this added to the anxiety of completing the work. However when the interview was actually conducted I felt supported by the materials supplied and felt more confident in completing the work to the required standard.

Overall I thought it was a good experience and felt supported throughout by staff at the LDC.

2. I found the Making a Real Difference project very interesting. It was very well organised and all the information I needed to set up the initial interview was clear and easy to access. The drop-ins were also useful. In terms of the interview itself, the commissioner I interviewed was very co-operative, gave me plenty of time to conduct the interview and treated it very seriously, giving me immediate feedback and clarification of my first draft. I was shocked, however, at how little service user and carer involvement there had hitherto been in such an important health area until a relatively new initiative which is just being piloted.

Appendix 4 – questionnaires

Commissioners

- Question
- 1 Do you have a working definition of what a service user or carer group is?
 - 1a If YES, what is your definition?
 - 2 Are you currently commissioning any mental health user and/or carer groups in your borough?
 - 2a Roughly, how many and groups do you commission?

What is the usual type and size of group you commission?
 - 2b Can you provide us with a list of the service user and carer groups you currently commission?
 - 3 Do you have a policy or strategy for commissioning user and /or carer groups?
 - 3a Can you summarise your commissioning strategy for mental health service user and carer groups?
 - 3b Do you have a written copy you can send us?
 - 4 What type of commissioning body are you?
 - 5 Do you encourage service user and carer groups to apply to you for funding?
 - 5a If yes, what if any support or information do you give them?
 - 6 Do you encourage groups to seek partial funding from non-statutory sources?
 - 6a If so, what sources are they encouraged to go to?
 - 6b What if any support and information are they given to apply to these other sources?
 - 7 Can you comment on how you take account of diversity issues in commissioning user and carer groups?
 - 8 What do commissioners want and expect from service user and carer groups?
 - 9 Do you usually provide a form of contract to the service user/carers groups you commission?
 - 9a What is normally in such a contract/ agreement?

- Question
- 10 What is the typical funding period offered to service user and carer groups?
 - 11 Are groups required to submit a business plan in order to receive funding?
 - 11a If so do groups get help with this?
 - 11b If so, what sort of help do they get?
 - 12 Do you monitor and evaluate the work of service user and carer groups you commission?
 - 12a If so, what are the key indicators you are looking for?
 - 12b Are service users & carers routinely involved in the monitoring & evaluation of their own groups?
 - 12c If service users and carers are routinely involved how is this done?
 - 13 Do you offer any ongoing help and support to service user and carer groups to meet their targets?
 - 14 Are service users and carers routinely involved with the commissioning process?
 - 14a If so, how are they involved?
 - 15 Is it possible to identify the overall budget for commissioning user and carer groups?
 - 15a If so please state approx levels of direct funding of groups
 - 16 Do you provide other forms of support and resources for service user and carer groups?
 - 16a If so briefly say what you provide
 - 17 What are the barriers to commissioning service user and carer groups
 - 18 What are the drivers to commissioning of service user and carer groups ?
 - 19 What is working well?
 - 20 What is not working well?
 - 21 Any suggestions you have for improving commissioning for service user and carer groups?

Service user and carer group questionnaire

- Question
- 1 Is your group
 - A) Service user or carer run?
 - B) Service user or carer led?
 - C) Neither?
 - 2 Do you have a Management Committee?
 - 3 Does your group receive any funding from
 - A) The PCT
 - B) Mental Health Trust
 - C) Local Authority
 - D) Non-statutory sources
 - E) A combination
 - F) None of the above
 - 3a If none – have you
 - A) Applied and been turned down?
 - B) Decided that your group does not wish to receive funding
 - C) Are you hoping to apply for funding in the future?
 - 3b If you do not receive funding, can you say more about this?
 - 4 Does your group have control over its own:
 - A) Money
 - B) Personnel (workers, staff)
 - C) Policy decisions
 - 5 What role does your group take locally?
 - 6 How do people join your group?

 - 7 How do other service users/carers find out about your group?
 - 8 How does your group approach issues of diversity?
 - 9 Do you know if the local commissioning body (or bodies) has a policy or strategy for commissioning user and /or carer groups?
 - 10 Have you ever been encouraged to apply for funding to a statutory body
 - 10a If so, were you given adequate information and support

- Question
to apply?
- 10b If yes, what information and support did you get?
 - 10c If 'no' what information and support did you want, or would you need in the future?
 - 11 Has your group been encouraged to seek partial funding from non-statutory sources by the commissioners?
 - 11a What sources?
 - 11b What, if any, help/info were you given to apply to these other sources?
 - 12 If you have applied for statutory funding were you required to submit a business plan?
 - 12a If yes, were you offered any information or support to do this?
 - 13 Do you have a contract or a service-level agreement with the commissioners?
 - 13a If no contract or service-level agreement, do you know what the commissioners want and expect from your group?
 - 13b If yes how did you find out?
 - 13c If yes, what are the main things the commissioners expect from you?
 - 14 How do the commissioners who fund you monitor and evaluate your group's performance?
 - 14a Are you involved in this monitoring and evaluation?
 - 14b If so, how are you involved?
 - 15 What, if any, help and support is given to your group by the commissioners to enable you to meet targets (aims & objectives) and deal with any problems?
 - 16 Do the commissioners offer your group any support other than funding?
 - 16a If so, what?
 - 17 Does your group have support needs that are not being met by the commissioners?
 - 17a If so, what?
 - 18 Do you know whether service users/carers are routinely involved with the commissioning process?

- Question
- 18a If so, how?
- 19 With reference to your current funding, how long is the funding period?
- 20 What is working well in your relationship with commissioners?
- 21 What is not working well?
- 22 Any suggestions you have for improvement of commissioning of service user and carer groups?