Evaluation of the National User Involvement Project

The National User Involvement Project was a four-site development project carried out by national user consultants working in co-operation with joint commissioners, local organisations of disabled people and users of community services. It aimed to extend the range of service users involved in commissioning decisions to include members of ethnic minorities, older service users and people receiving services following hospital discharge. People with learning difficulties and mental health service users were included in the project. The evaluation found:

- Many commissioners were still unaware of key aspects of facilitating user involvement, such as ensuring wheelchair access and providing information in appropriate formats.

- Many commissioners still had little awareness of how cultural and religious needs might affect the involvement of people from minority ethnic communities.

- It was difficult to include service users in making commissioning decisions. Even after the project, service users were typically involved at the general planning level rather than at the points of decision-making in commissioning, although some advances had been made. Despite these difficulties, most service users and commissioners wanted to form partnerships in decision-making.

- Dedicating resources to outreach work was an effective way of contacting service users from more marginalised groups, such as older people or people from minority ethnic groups. Personal contact and preparation to take part in consultation exercises were much more effective than letters and leaflets.

- Service users needed a range of support and training in order to be fully involved in decision-making.

- Disabled people often believed that commissioners needed training in order to involve service users effectively, although commissioners did not always share this view.

- The researcher concludes that employing experienced user consultants can be an effective method of assisting local groups to involve a wider range of service users if the work is well planned in advance, is undertaken in full partnership with local organisations of disabled people and if systems are in place to continue the work afterwards.
The success of the project
The project failed on one site, a Midlands town. The commissioners felt that the consultants were acting slowly and not addressing the main task expected of them. The consultants felt that commissioners did not realise how long user involvement work takes. Commissioners felt that sufficient detailed discussions should have taken place about objectives and methods of work to ensure a coincidence of expectations, and a timetable and work plan drawn up.

Detailed letters of agreement signed by chief executives and other key players greatly assisted work in the three successful sites. Involving local groups of disabled people in early discussions would have prevented the few misunderstandings that arose. Varied local backup giving access to service users and resources to address practicalities such as transport and room booking made the work easier in some places than others.

The commitment of top-ranking commissioners greatly assisted the positive outcomes that were achieved. The project changed at least one commissioner’s perception of user involvement from a “politically correct waste of time” to a relevant, essential part of her work.

Facilitating user involvement
The evaluation found that well-known fundamentals to facilitating user involvement - such as full access for wheelchair users, British Sign Language interpreting and accessible documents - were still not always in place when commissioners sought to involve service users. Payment for local user representatives as experts who are being consulted was also not routinely available: “I feel that my expertise has been milked and milked” (an active user committee member).

Commissioners accepted workers in voluntary sector services acting as proxies to speak for service users from some groups, such as people from ethnic minorities and older service users, as they did not know how to reach actual service users. However, the evaluation found that dedicating resources to outreach work was an effective way of contacting service users from more marginalised groups who were willing to become involved in various methods of consultation, including taking part in commissioning. Personal contact and preparation to take part in consultation exercises were much more effective than letters and leaflets.

There were particular considerations for deciding methods of consulting minority ethnic service users. They often had long experience of discrimination and marginalisation in services - and in wider society - which took time and hard work to allay. Even if language needs were catered for, other considerations needed to be taken into account. These ranged from knowledge that Asian women from some communities cannot travel unescorted, to provision of food acceptable to various religions and not holding meetings in premises where alcohol is served. In addition, staff in day centres and colleges often underestimated the potential of young Black and Asian people with learning difficulties. (Some young adults in the pilot areas were not aware of their ethnic background, yet these issues were not being addressed in colleges and day centres.) Workers in minority ethnic community mental health services also acted to ‘protect’ minority ethnic service users from becoming involved.

One suggested way forward was to include requirements for user involvement in specifications of voluntary sector services aimed at particular communities. Community projects would require extra funding for training and ongoing support with user involvement to achieve this. Local self-advocacy groups might be able to undertake training of community staff to encourage them to help members of these groups to realise their potential but extra resources would be needed to assist them.

Older service users also gave many ideas about how less mobile people might be consulted. For example, religious centres and other informal networks were often mentioned as one route to consultation; another suggestion was a talking newspaper.

All the service user groups said that appropriate feedback about any changes that have been made as a result of consultation was essential if they were not to feel exploited.

The role of local self-advocacy organisations
Local organisations of disabled people, people with learning difficulties and mental health service users were usually keen to offer support to people acting as user representatives. Commissioners confirmed this; for example, a local self-advocacy group for people with learning difficulties was described as showing great concern for people who do not communicate with language.

The evaluation found that self-advocacy organisations tried to ensure representatives were accountable by helping with reporting back and consulting local disabled people. They also supported representatives with training and preparation, for example at pre-meetings to discuss commissioners’ agendas.

Although existing local organisations wanted to reach out to marginalised groups of service users, this was much more problematic where single-impairment groups (such as of blind people,
people with particular conditions etc.) had
developed. This was partly because multiple
resources had to be provided for each group rather
than for one coalition or consortium of disabled
people.

**Making commissioning decisions**

Even after the National User Involvement Project,
service users were typically involved at the general
planning level rather than at the points of
decision-making in commissioning, although some
advances had been made.

Commissioners felt the following hindered full
user involvement:

The complexity of factors that can impinge on
decision-making, including budget-setting and
opposing hospital consultants in other
disciplines: “They would have to be prepared to
jump into the muddy water and get their hands
dirty”.

Reluctance to give advantage to any one interest
group over another, even though their lobbying
position is weaker.

The existing pressures of the commissioners’
work programme, and the changes and
priorities being demanded from the centre,
making it difficult to take the extra time needed
to involve service users.

The feeling that those who had to bear the legal
responsibility for making decisions should do
this alone.

For their part, service users felt they faced the
following problems:

Commissioners being unclear about the points
where decisions are made.

A lack of appreciation of the expertise of
disabled people, people with learning difficulties
and mental health service users among some
commissioners, often arising from lack of
experience of working as equals with members
of these groups.

Status differences that made joining in the
semi-social dealings before and after meetings
and making phone calls problematic. This
included the difficulties created by insufficient
care about the access needs of service users,
such as using ordinary language and meeting in
fully accessible buildings.

In addition, user participation could vary between
areas depending on the attitude of local
councillors; in a rural county, for instance, two
members of the social services committee had little
awareness of user involvement compared with a
London borough where councillors were keen to
involve service users.

Despite these difficulties, most service users
and commissioners wanted to form partnerships in
decision-making. Among advantages noted by
commissioners was an improvement in “joint
thinking” and ensuring that decisions “have been
made in an open way”.

**Training needs identified**

For service users

The project identified areas of training needed by
service users wanting to take part in user
involvement:

- Assertiveness and ‘speaking up’ courses.
- Disability equality training and other courses
  run by service user-trainers to raise people’s
  confidence.
- Guidance on purchasers’ and providers’
  decision-making structures.
- Training in committee procedures and
  negotiating skills.
- Information about what has and hasn’t worked
  in other areas.
- Equal opportunities training.
- Legal issues and rights under community care
  and other legislation.

For commissioners

Disabled people interviewed often felt that
commissioners needed training in order to involve
service users fully, but commissioners did not
always share this view. Disabled people felt that
some commissioners lacked a basic understanding
of what was needed for effective user involvement.
Some commissioners did not understand the
difference between groups ‘of’ service users
(composed of users themselves) and the groups
‘for’ service users (the traditional voluntary sector
projects). Some were not aware of the ‘social
model’ of disability adopted by most groups of
disabled people and many community service
workers. This led to lack of a shared view of
disabled people’s rights.

On one site, commissioners did agree to take
part in some training to assist them in user
participation. One year later this had not taken
place despite overtures from their local disabled
people’s organisation. One recommendation
arising from the evaluation is that management
training contains sufficient input from service user
trainers to cover not only basic essentials of user
involvement but details about including people
from more marginalised groups.
Maintaining the momentum
Commissioners in all sites, including the discontinued one, were impressed by the impact of the project on local service users in terms of their improved confidence and willingness to be involved. However, some of the local people contacted and trained by user consultants were lost because insufficient follow-up arrangements were made. In one place, yet another reorganisation compounded mistakes in not setting follow-up meetings. Nonetheless, they did have disabled people attending decision-making meetings one year later, though this attendance was described as vulnerable.

In another site, an ethnic minorities sub-group is taking forward the stated needs of minority ethnic mental health service users. This is being serviced by a predominately white self-advocacy group that some of the project’s contacts find intimidating. Service users have also been involved in making detailed specifications for some new community services, but again the involvement of users from minority ethnic groups was small. However, local commissioners see the national consultant’s work as a resounding success in changing their practices in working with Black and Asian mental health service users.

On the third site, the coincidental start of a Black self-advocacy group for people with learning difficulties means that the project’s work is being taken forward.

Conclusion
The researcher concludes that one of the major achievements of the project was a further move in the perception of disabled people less as ‘service users’ and more as experts to be consulted. Outside consultants did assist members of local organisations to reach out to older disabled people, and to ethnic minority mental health service users and younger Black and Asian people with learning difficulties to become involved in commissioning. Local service users consistently praised the training provided for assisting people to re-value themselves and to become more confident in involvement. However, the researcher concludes that detailed agreements and timetables are essential, as well as procedures to ensure that the advances made are not lost when the project ends.

“I really want things to change peacefully and happily.” (An Asian mental health service user)
documentation such as steering group minutes and project reports. Seventy-nine service users and fourteen commissioners from health and social services were interviewed. Some of these were re-interviewed one year after the project ended to assess whether the work had an enduring effect. Eight outside consultants were interviewed individually and in a group, and other relevant people such as a CVS director and two local councillors were interviewed. The evaluation took place from 1994 to 1997.