








Social service users' own definitions of quality outcomes

The Shaping Our Lives project, working in partnership with Black User Group (London), Service User Action Group (Wakefield), Ethnic Disabled Group Emerged (Manchester) and an alliance of user groups in Waltham Forest (London), looked at the application in practice of on-going work about what service users meant by 'user-defined outcomes'. Both the research and the development projects covered a range of experiences – including those of older people, mental health users, minority ethnic communities and disabled people and involving 66 users in all. The study found:

-  It was impossible to separate ideas of user-defined outcomes from action to define and achieve them.
-  Involvement to support user-defined outcomes takes more time and resources than usually envisaged.
-  Users felt that services continued to show a lack of respect. The value of their own outcomes was not acknowledged nor valued.
-  Users valued the ordinary things in life - cleaning, shopping, support at home. They found it very difficult to get services to prioritise support in these areas.
-  Other services were very important to people beyond ideas of social care, in particular, housing and information.
-  Although the initial research had highlighted the value of direct payments, the development projects showed that users were still not aware of this option.
-  It was important for users to meet together to strengthen their own voice in achieving the outcomes they valued.

Introduction and background

There has been an increasing focus on modernising of social care in general and 'outcomes' in particular. However, much of the early debate in these areas has been led by professionals; users have felt excluded from having a voice in an area of work that is central to their lives. Although there have been gains for disabled people and others in the growth of ideas of involvement (and in particular in the development of direct payments) most users still do not have choice and control over mainstream services.

The Shaping Our Lives project was established in 1996 to draw together lessons from users and to develop user views on ideas of user-led outcomes. Work between 1996 and 1998 started to develop these. The present project (which took place between 1999 and 2002, working in partnership with 4 development projects and involving 66 users in all) took ideas of user-defined outcomes into practice.

The framework for the development projects

Value of outcomes

Users recognised the value of evaluating services in terms of their outcomes, but saw it as essential that users' views are primary in this process and that it should include the subjective perspectives of individual users. They recognised that such evaluation can be supported by an element of objective measurement. For example, a mental health service user suggested that effective services could be measured in relation to spending on drugs, and that effective support would lead to less spending on drugs.

Difficulty identifying outcomes

Some users had some initial difficulty with the idea of looking at services in terms of outcomes or results. This appeared to be because they found it very difficult to determine the outcome of the service where their own experience of services had been poor.

Outcomes for users of direct payments

In contrast with other users, people in receipt of direct payments had very clear ideas about the outcomes that they had from the support that they

arranged. This clearly showed the effectiveness and importance of direct payments in this regard – and pointed to possible lessons for other services to provide a similar level of choice and empowerment.

Negative outcomes

There were some clear examples of negative outcomes. These tended to be associated with services that did not meet the wishes of the user and which users felt disempowered them or added to their sense of disempowerment.

Outcomes and process

The process of getting a service and the way in which it is delivered can have a major impact of user's experience of a service. These problems included poor access to services, delays in service provision, poor treatment from service providers, lack of consultation or consultation which was ignored or not acted upon. Such experiences have an impact on the outcome of the service and users did not perceive process as detached from outcome. This view is contrary to the prevailing view amongst academics and professionals, who have focused primarily on outcomes in terms of the end result of a service.

A holistic approach

Many service users have needs which fall beyond the current limits of social care services. Some of these may or may not be recorded as unmet in the current system, but there are also broader issues. Users viewed outcomes from a holistic perspective, covering – for instance - housing, transport, employment, income and benefits, and broader issues around discrimination and equality.

The need to consider such issues illustrates how service users want to look at their lives and their needs as a whole. However, this is difficult with current way that most social care services are organised.

The development projects

The ideas of user-defined outcomes in theory were tested out in practice with 4 development projects – Black User Group, West London; Ethnic Disabled Group Emerged in Manchester; Footprints & Waltham Forest Black Mental Health Service User

Group; and Service Users Action Group, Wakefield. The groups were diverse (disabled people, mental health users and older people) and had strong representation of the lives of people from black and minority ethnic communities. Although the groups were very different, common hopes and frustrations with the outcomes (or lack of outcomes) of services emerged. The key issues were:

Ideas and action

The project showed that it was impossible to separate the *ideas* of user-defined outcomes from action to define and achieve them. Users were not content simply to monitor and evaluate service delivery. They needed to be involved in defining the outcomes and then work to achieve them.

The need for time and support

This need to marry together ideas and action meant that the development projects had to meet more frequently and needed more time and resources than was originally envisaged when the project was first planned. Any future work on user-defined outcomes needs to take this into account.

Respect for service users

The development projects reported that users felt a lack of respect from services remained a common experience. This lack of respect was both at the level of the individual and of the groups. One user involved in a development project observed:

"People felt that the attitude of staff at the local social services was patronising and condescending. People thought that they were not treated with enough respect."

Services at home

Many of the outcomes that users wanted to achieve were about the ordinary things in life, and about having a home that was comfortable and not a 'prison'. They confirmed the now familiar message that it is very difficult to get support in this area. Service providers did not see the ordinary things in life – cleaning, shopping, household maintenance – as important. In addition, there was a lack of culturally appropriate services.

Transport and access

Issues of mobility and access were raised by different groups. Users stressed the importance of available, accessible transport and of the problems of access in terms of poor pavements and of clutter from shops. However, there could also be good outcomes. One group reported:

"Members praised the [local door-to-door transport service]. The nature of the service – picking people up from their own homes – was highly valued. They also praised the staff who run the service for the assistance they give to passengers."

Information

A lack of useful, useable information was a problem: service users could not achieve the outcomes they wanted if they were not aware of the services available to support them. A lack of information often led to low expectations of the outcomes that could be achieved.

Direct payments

Although earlier work had identified that user-defined outcomes were most evident where people use direct payments, among the development projects there was very little knowledge and awareness about the possibilities from direct payments. (This aspect may be followed up in a later project.)

Users meeting together

All four development projects highlighted the importance of people meeting together. But achieving this gave rise to a need for a centre or facilities for meetings, and also for the appropriate time and resources.

However, meeting together led to users growing in confidence, both individually and collectively, by being able to work together and feeling supported by others to shape the outcomes that *they* would want. Comments included:

"This group has really helped me to speak out. I asked to see my records and noticed that some of the information was wrong. He finally agreed that the information lacked any evidence, but initially resisted

my demands for correction. In the end he agreed, but I will make sure I see the corrections."

"As a result of group complaints about pavement access, the Highways Manager has said that the local authority is to appoint a dedicated Highways Enforcement Officer".

About the project

The project was carried out by Shaping Our Lives, which is now based at Shaping Our Lives, Unit 57, Eurolink Centre, 44 Effra Road, London, SW2 1BZ, working in partnership with Black User Group, West London, Ethnic Disabled Group Emerged in Manchester, Footprints and Waltham Forest Black Mental Health Service User Group, and Service Users Action Group, Wakefield.

The project involved 3 key stages:-

- drawing together ideas of user-defined outcomes;
- working with and supporting user groups in the four development project areas;
- sharing common themes and learning across the four development projects.

In all, 66 users were involved in the project.

SOL received three-year funding from the Department of Health in 2002 to establish a national network of service users' organisations. It has also been given project funding by the Joseph Rowntree Foundation to carry out a national survey of service users' organisations. Funding is also being sought to continue the work of the development projects.

How to get further information

The full report, **Shaping our lives – What people think of the social care services they use** by Shaping Our Lives National User Network, Black User Group (West London), Ethnic Disabled Group Emerged (Manchester), Footprints and Waltham Forest Black Mental Health Service User Group (North London), and Service Users' Action Forum (Wakefield), is published by the Joseph Rowntree Foundation (ISBN 1 85935 113 1, price £13.95).