

Issues raised by users on the future of welfare, rights and support

The Shaping Our Lives project, working in partnership with the Shropshire Disability Consortium and with a coalition of user organisations in Sheffield, looked at the issues that had emerged from discussions with users about the future of rights and welfare, and the ways that users were being involved in shaping the support they received. The project worked at a national and a local level, with Shaping Our Lives carrying out country-wide work through booklets and a questionnaire on key issues, which produced a qualitative sample of 26. The local work in Shropshire involved a series of focus group meetings and a one-day conference was held in Sheffield:



Responses to the questionnaire showed that:

- Most respondents believed that rights and welfare went beyond the needs of any individual and that there was a need to recognise shared rights, citizenship and entitlements.
- However, most felt that present systems were "paternalistic" and unequal in the way they viewed people's rights.
- Many saw benefit levels as being too low for recipients to maintain a reasonable standard of living.
- Almost every respondent criticised charges for social care services. People saw charging for such services as compounding the exclusion and discrimination experienced by service users.
- Respondents were very sceptical about current practices around 'user involvement' and their own experiences of it. They regarded the implementation as patchy and tokenistic.
- Mental health was an area where all respondents felt issues around rights, practice, benefits and involvement were particularly problematic.



Work with the local projects raised the following issues:

- Group members reported bad experiences of service delivery, including not being listened to by workers, and unreliable or inadequate provision. Good experiences related to being treated as an individual and to supportive staff.
- Group members felt that strategies for "working together" across different services were very important, and that these should be developed with meaningful involvement of service users.
- Group members were strongly motivated to get involved if that was going to lead to real improvements but they expressed a great deal of "involvement fatigue" where consultation had seemed "tokenistic". They felt there was a need to invest time, resources and money into making involvement meaningful.

Background

The Shaping Our Lives project (SOL) was commissioned by the Joseph Rowntree Foundation to look at the issues of rights and welfare from the points of view of service users - disabled people, older people, people with learning difficulties and users/survivors of mental health services.

This work was taken forward at a national level through three booklets on the key topics of benefits, support services and mental health. The booklets included a questionnaire for readers to give their feedback. Between 300 and 550 of each booklet were distributed using the Shaping Our Lives database and other routes. There were 26 responses to the questionnaire.

The project was designed to focus on two particular areas, one rural and one urban, and to work with organisations run by service users in those areas. Shropshire Disability Consortium put together a project based on focus groups that brought together different types of service users. In Sheffield a steering group with representatives of different user organisations arranged a one-day conference.

Initial consultations

The project was designed through consultations with representatives from a range of service users' organisations. Twelve people took part in a seminar which provided the basis for the proposal that was submitted to the Joseph Rowntree Foundation. Further input was provided by the Shaping Our Lives National User Group.

Issues raised by the questionnaire

Value of the welfare state

Most respondents believed that the value of the welfare state went beyond the specific value to any given individual. The formulation of the welfare state was that it should give an equal right to people in terms of their basic human rights, and should therefore embrace housing, education, employment and transport as well as health, social care and benefits. However, respondents felt that their experiences of the welfare state were that it was

"paternalistic". There was a feeling that it should move from being a 'safety net' to being a 'bridge' to enable people to be equal members of society.

Benefits

Most respondents felt that benefit levels were too low. Some also said that benefits needed to move away from being seen as 'compensating income' to being viewed as 'enabling income', with the same status as 'earned income'. There was clear support for benefit fraud to be tackled, but almost all respondents said that this issue is over-played. They felt that emphasis on fraud was a deliberate attempt to distract attention from the low levels of many benefits.

Social care services

Respondents generally opposed charging on social care services, often seeing charges as discriminatory and undermining the human rights of disabled people. They felt, if charges had to be in place, there should at least be a reciprocal power for users to determine the types and quality of services they received.

User involvement

Respondents were very sceptical about current practices around user involvement – "patchy", "a lot on paper but very little in practice" were some of the comments made. Some criticised a lack of user involvement at a national level. It was felt that there should be more compulsion on the part of public bodies – including the NHS – to incorporate user involvement. Respondents felt there was a need for national standards on involvement; they felt that consultation was often meaningless, which drained the energies of users and user groups but with little result.

Mental health

The project took place at the same time as changes proposed in mental health legislation. Respondents who addressed mental health issues felt that medical perspectives still dominated the agenda and that

perceptions of survivors and mental health users were stereotyped and negative. Respondents suggested that the need for public safety would be addressed by having the types of support that users were asking for, in particular integrated support which fully involved the user. Mental health users also mentioned employment as a central issue.

The local projects

The next phase of the project worked with two local groups in Sheffield and Shropshire over a more extended period. There were issues in setting up the project locally and supporting the two local groups. The project identified the need for dedicated resources, a fatigue about consultation on the part of users which has resulted from the lack of purposeful outcomes from their involvement and for support for local structures for user involvement in the form of user-controlled organisations.

There was a wider lesson that working in this way takes time. The experience here suggests that future projects that follow this model would benefit from a lengthier preparatory period and giving local organisations more scope to input into the main project.

In terms of other wider findings from the two local groups, there were several common issues:

Experiences of services

Service users expressed some negative views. These included workers ignoring or not listening to the views of users, home care workers with inadequate time, social services transport being unreliable or forcing people to leave events before they had finished. One service user commented:

"It feels like workers in the social and health care fields simply have no respect for service users as equal citizens."

There were some positive views too. These related to supportive staff and services which treated users as individuals.

The need for a holistic approach to services

Another theme running through much of the work was that service users look at their lives as a whole, whereas services do not. Services separate themselves into different disciplines with different budgets and different values. Users see issues such as housing, hospital waiting lists and public transport as being interlinked. Group members felt that strategies for "working together" across different services were very important, and that these strategies should be developed with meaningful involvement of service users. A questionnaire or a token user on a strategy group was not sufficient.

User involvement

Group members expressed a great deal of "involvement fatigue" due to services having many initiatives but low standards on involvement. Group members often equated this with tokenistic consultation. One example given was having to respond to a 10-page pre-set questionnaire based on a 60-page consultation document in a very short timescale. Despite this, it was clear that group members were strongly motivated to get involved if that was going to lead to real changes and improvements. However, group members expressed the view that users will increasingly choose not to be involved if they judge that involvement is not meaningful. Users felt that services need to develop and agree standards on involvement – for example, making sure that users are involved in the early negotiations about the aims of a new initiative and the likely resources required to make it workable.

A common approach to user involvement

Both development projects worked in a similar way to Shaping Our Lives – working across different user groups, investing time in processes of involvement, proactively reaching out to different groups and communities (for example, with disabled Somali refugees in Sheffield). Group members felt there was a need to build on these approaches and to invest time, resources and money into making involvement meaningful.

About the project

The findings from this phase of the work are being taken forward, nationally and in local development projects, through the foundation of a National User Network (Shaping Our Lives National User Network or SOLNUN). This work is funded by Department of Health and by the Joseph Rowntree Foundation.

The project was based at Shaping Our Lives, Unit 57, Eurolink Centre, 44 Effra Road, London, SW2 1BZ, working with Shropshire Disability Consortium, a steering group of user organisations in Sheffield and a national advisory group to develop Our Voice In Our Future.

The project was in 3 stages

- An initial consultation to look at the issues of importance to different groups of people with experience of social exclusion due to issues relating to disability, age, cognitive impairment or survival of mental health services (including those also experiencing racism).
- The production of 3 booklets on services, benefits and mental health that were widely distributed and formed the basis of responses from users in a qualitative sample of 26 people.
- More long-term work in partnership with user/disability groups in Sheffield and Shropshire, including a conference 'Influencing Our Future' in Sheffield.

How to get further information

The full report, **Our voice in our future: Service users debate the future of the welfare state** by Michael Turner, Phil Brough and R B Williams-Findlay, is published by the Joseph Rowntree Foundation (ISBN 1 85935 117 4, price £9.95).