

Developing social care: service users driving culture change



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Background

SCIE commissioned the National Centre for Independent Living (NCIL), Shaping Our Lives and the University of Leeds to look at service user-driven culture change. The objective was to research current literature and practice around service user involvement, the extent to which service user involvement had brought improvements to social work and social care and where the change had become established practice.

Scope

The research was split into two areas: the research review that was conducted by the University of Leeds Centre for Disability Studies and the practice research that was jointly conducted by Shaping Our Lives and NCIL.

The research review concentrated on a wide range of service users, including:

- children and families in need
- fostering and adoption service users
- older people
- people with learning difficulties

- mental health service users/survivors
- people with a sensory impairment
- people with a physical impairment
- service users from black and minority ethnic (BME) communities
- drug and alcohol service users
- homeless people
- carers.

A questionnaire was developed in respect of the practice research and user-led organisations were targeted and were asked a range of questions regarding service user involvement and cultural change. From the analysis of the returned questionnaires a range of focus groups were selected on the basis of their responses, including:

- older people
- people with learning difficulties
- disabled people
- parents and children
- mental health service users/survivors.

From these groups a further questionnaire was developed to find out information from professionals about service user involvement and where cultural change had occurred.

Key themes and findings

User involvement as a continuing priority

The theme of user involvement as a continuing policy priority for service providers and for service user organisations is one that comes through strongly in both the research review and the questionnaire and interviews carried out for the project. However, the review noted that current practices limit the effectiveness of user involvement and mean that the pace of change is slow.

Barriers to participation across the different types of services

Differing priorities and unequal power relationships between service users and professionals were a key barrier identified in the research review. Relationships between organisations and individuals were found to be a key issue in the focus group interviews, particularly where equity was an issue.

Differences in experience across different types of service users

There appeared to be a wide variation in levels of involvement between types of service users with some of the more seldom heard groups often absent from involvement. This may warrant further investigation. Experiences by service users ranged from tokenism to true partnerships.

Cultural change and resource issues

The research review identified funding and resources as a key issue, and the focus group interviews and questionnaires raised this as a crucial issue. In one area performance indicators were suggested as a tool to measure the continuation and development of service user involvement.

Cultural change as a long-term issue

The research review identified user involvement and participation as a key to change and the questionnaires and interviews carried out for the project offer a wealth of examples of ways in which this has happened. Examples include new schemes and services set up as a result of what service users identified as what was needed and appropriate.

The key message for practice from the project is that cultural change and service user involvement are inherently linked. Improving the practice around user involvement at all levels – which is cultural change in itself – is the key to improving change in all other aspects of service provision.

Definitions

Service user

This definition was developed by a diverse group of service users working on different projects with Shaping Our Lives.

What we mean when we say 'service user':

Shaping Our Lives National User Network sees 'service user' as an active and positive term that means more than one thing. It is important that 'service user' should always be based on self-identification. Here are some of the things we think it means:

- It means that we are in an unequal and oppressive relationship with the state and society.
- It is about entitlement to receive welfare services. This includes the past when we might have received them and the present. Some people still need to receive services but are no longer entitled to for many different reasons.
- It may mean having to use services for a long time that separate us from other people and that make people think we are inferior and that there is something wrong with us.
- Being a service user means that we can identify and recognise that we share a lot of experiences with a wide range of other people who use services. This might include, for example, young people with experience of being looked after in care, people with learning

difficulties, mental health service users, older people, physically and/or sensory impaired people, people using palliative care services and people with drug and alcohol problems.

This last point about recognising our shared experiences of using services, whoever we are, makes us powerful and gives us a strong voice to improve the services we are given and to give us more control and say over what kind of services we want.

What people sometimes mean by the term 'service user': The term 'service user' can be used to restrict your identity as if all you are is a passive recipient of health and welfare services. That is to say, that a service user can be seen to be someone who has things 'done to them' or who quietly accepts and receives a service. This makes it seem that the most important thing about you is that you use or have used services.

It ignores all the other things you do and that make up who you are as a person. This is not what Shaping Our Lives National User Network means when we talk of 'service users' (Shaping Our Lives, 2005).

Professional

For the purpose of this work, the term 'professional' has been used to identify people who are in paid employment. This is regardless

of whether or not they have a recognised qualification or whether indeed they self-identify as service users.

User-led organisations

For the purpose of this work, the term 'user-led organisations' are that the majority of the management group and/or people controlling the organisation are defined/self-define as disabled people/service users.

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