

Access to social care – Service users' perspectives

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Shaping Our Lives

This contribution is offered from a service user's perspective. I speak as a long term user of mental health services and Chair of Shaping Our Lives, an independent national user controlled organization and network. We are made up of and work across a wide range of service users. This includes people with physical and sensory impairments, mental health service users/survivors, people living with HIV/AIDS, people with learning difficulties, older people, people with alcohol and drug problems and people with life limiting illnesses and conditions who may use palliative care services.

One of the things we have learned over the 10 years that we have been in existence is that different groups of service users may have very different issues and experiences, but frequently share common issues of discrimination and the restriction of their human and civil rights. I want to draw on some of the work which we have done in Shaping Our Lives to address issues of human rights in relation to social care.

Improving quality

For some time there has been an emphasis in public policy, including health and social care, on 'quality', the need to improve quality and the development of quality standards and outcome measures. This 'quality agenda' has become one of the explicit drivers of policy and practice from the top down. Shaping Our Lives was concerned that these quality measures tended to be conceived, developed and calculated on the basis of professional and managerial understandings, priorities and concerns. It does not take much to realize that what is important to service providers and purchasers may not be important to service users and vice versa. Shaping Our Lives, has over the last ten years done both research and development work to explore *user-defined* outcome measures, based on what service users want from services and support.

Quality and human rights

We found that while everyone has their own individual personal preferences – their own idiosyncratic priorities – there also seem to be a core of concerns that people have as health and social care service users generally. These also seem to relate closely to the achievement and safeguarding of their civil and human rights. They are concerned with them having the support that they need to live on equal term with non-disabled people; to enable them to have freedom of movement, equal access to relationships, education

and training, an adequate income, employment opportunities, access to leisure opportunities, to privacy, political participation and so on – and to be treated with equality and respect.

Involving service users

We also found that for service users, process and outcomes of social care and other policies and services were indivisible. A poor process of service and support would result in poor outcomes. If you got support in ways which were disrespectful and discriminatory and unpleasant – even if it ‘did the job’ (for example, getting you up, transporting you, washing and dressing you, and so on), its outcomes were fundamentally qualified and undermined. So what we have come to realize is that the nature of support – how it is provided – is inseparable from what it can and cannot do.

The shortcomings of existing social care

Next I want to turn to what service users say about the support they receive now from social care policy and provision. Over the last year, Shaping Our Lives has undertaken two major national consultations of social care service users in the build up to the production of first the social care green paper (2005) and then the health and social care white paper, Our Health, Our Care, Our Say (2006). The second consultation was undertaken jointly with the National Centre for Independent Living. In these two consultations we spoke to a large number and diverse range of social care service users. There was a strong consistency in what different service users said and in what emerged from the two consultations.

Generally they said that social care now was:

- Inadequate
- Unreliable – from day to day and over longer periods
- Often inaccessible because of charging, narrow eligibility criteria and bureaucratic obstacles and complexities
- Unpleasant – particularly as provided by ever changing, poor quality and uncommitted agency domiciliary staff
- Inappropriate – based on models that didn’t necessarily fit their rights, wants and needs
- Inflexible
- Unresponsive and not open to influence or improvement – people were generally reluctant to complain, often frightened of retaliation or loss of service
- Often offering no more than personal rather than social support – providing bodily maintenance at best, keeping people within their own four walls, rather than offering social support to enable them to be part of the wider world

And perhaps most important and overshadowing everything:

- Grossly and chronically under funded.

People with learning difficulties talked about the bullying that they experienced in the service system. They and some other service users also talked about the discrimination they faced, particularly along lines of racism.

There are two additional issues to raise at this point. First, the key system that the government has adopted to maintain 'quality' in social care is one of formal regulation, including inspection. The Commission for Social Care Inspection (CSCI) is working hard to refine and make its approaches to regulation sensitive and participatory. But it is still important to raise the question of whether a regulation based model is workable in the context of social care to safeguard the support that service users receive, to ensure its quality and safeguard and enhance their human and social rights. The repeated indications from both Shaping Our Lives' work and other research, including that of CSCI itself, is that this may be difficult to achieve.

Improving outcomes

Second, in Shaping Our Lives' research and development work on user defined outcomes, we have learned that many service users receiving conventional service based social care support, find it difficult to understand what 'outcomes' actually mean in relation to their experience. They have not been used to thinking in that way. With engagement and support, we have found that they are able to understand and connect with the idea of outcomes. Then we have found that they are particularly likely to talk about the *negative* outcomes that they experience from such social care.

In contrast, though, we have found repeatedly in our work – and this is borne out by much other research and evaluation, at both local and national levels, that service users are much more able to relate to ideas of outcomes and to identify *positive* outcomes from their support, when they are receiving direct payments. Direct payments quite clearly can come much closer, more regularly, to meeting people's self-defined rights and needs.

Human rights and independent living: an inclusive approach

This however raises a further issue. How far will direct payments and the new personalized budgets (an extension of direct payments which bring together a range of funding streams under the control of the individual service user) continue to do this if the government develops them adopting a consumerist/market driven based model for their operation, rather than retaining the principles that originally underpinned them as they were pioneered by the disabled people's movement? The original principles of direct payments were of them being user led and based on the philosophy of independent living. This means ensuring the service user the level of support that they need to live on as equal terms as possible to non-disabled people.

To ensure that people have the support that they require to manage direct payments, direct payments need to be linked with the provision of a proper infrastructure of information, advice, advocacy, expertise and support. This historically has been best provided by a network of local user controlled organizations. The government seems to

see direct payments as the social care equivalent of buying a car, a holiday or any conventional commercial service. But without the infrastructure of support that service users argue for, how inclusive and effective are direct payment schemes likely to be?

Taking forward the human rights agenda in social care: issues and approaches

In *Shaping Our Lives*, we have learned that the key issue for service users is how to have in place good quality, reliable, appropriate and adequate support, consistent with their definitions of their rights and needs. This means:

- How to ensure entitlement to such support
- How to ensure that both individual and collective rights are met
- How human rights and disability anti-discrimination legislation can back this up to make it possible.

There are big questions here for us to address. There are such questions relating to Lord Ashley's crucial new Bill. How can it help make such entitlements to adequate, appropriate and good quality social care support real for the wide range of social care service users?

There are also additional issues in those heavily contested area where the 'capacity' of service users is unduly questioned, for example, in relation to people with learning difficulties. How can they be ensured a real say to ensure they have equal rights? Also, how is this to be achieved for mental health service users/survivors, where compulsory 'treatment', the restriction of people's rights and 'treatment' which people associate with damaging and distressing 'side' effects, has been separated from ordinary understandings of protection under Human Rights legislation, so that its protection is not ensured?

Finally, how can we ensure that a diverse range of service users and user controlled organizations can be fully involved in taking forward discussion, campaigning and action for an effective rights-based approach to social care? These are key issues for future agenda building if we are to see human rights transforming social care services.

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