

Access to social care – Gerry Zarb, Disability Rights Commission

1. White paper

Claims to have user and patient choice at its heart but it's a very middle class/consumerist conception of choice (e.g. evening and Saturday opening hours) and doesn't begin to address issue like imbalance of power and knowledge between people who depend on public services and professionals. So, most important issue is how to make choice really mean something for ALL, rather than just those who are able to flex their muscles as consumers?

For example, there is potential mileage in looking at what makes social care, health and other public services universally accessible and equitable. For example, a right to communication support or independent advocacy could cover any situation where people are faced with different forms of compulsion about treatment they should/should not receive, or where they need support to make decisions, discuss their treatment options etc. (An issue for CEHR to develop perhaps as it could apply equally to say asylum seekers as it does to disabled people?)

2. Using the DED

Existing framework of support is geared towards 'life and limb' view of independence, not citizenship and participation

Ultimately, it's possible that only enforceable rights to Independent Living support can guarantee the changes needed, but much greater use could also be made of new Disability Equality Duty which comes into force in December this year.

At the local level, DRC proposes that local authorities should draw up 'independent living strategies', either as part of, or to complement, their Disability Equality Schemes.

Action Plans should also specify what outcomes they intend to produce to demonstrate that opportunities for participation are actually improving. These can then be used for monitoring progress and, where, necessary as leverage to ensure compliance.

There will also be a duty to involve local disabled people in drawing up the Action Plans so that can add further leverage. However, this has to be meaningful involvement. This means LAs should be required to demonstrate:

a) That they have properly involved all sections of the local community and especially those who are most often left out or underrepresented (e.g. disabled people from BME communities, people living in institutions and children);

and,

b) What actions they have taken, or propose to take, based on what local people have identified as their own priorities.

3. Outcomes

Paul has suggested that there are no statutory rights to receive care of any particular standard.

This is not completely true but existing measures of quality are mainly process based so do not offer very much by way of entitlement to any particular outcome that you may believe is essential for you to be properly supported.

Again, ultimately, this can only be properly fixed by legally defined entitlements to support. But, we also need to have far more outcome-based indicators built into the Performance Assessment Framework.

In health there is additional leverage in that performance can be linked to payments (e.g. in enhanced GP contracts).

Also very important that any assessment of quality and/or outcomes takes self-assessment as it's starting point. This also needs to go beyond assessment of problems with functional independence to include explicit plans based on what goals people define for themselves. People do not use support services as an end in themselves but as a means to an end - to have a life basically. That's what should define success or failure.

Tower Hamlets counseling service - evaluated outcomes based on whether or not people using the service were able to achieve the things they wanted to achieve in their lives. It doesn't usually happen that way, but it can be done - given the will and the imagination.

4. FACS (Fair Access to Care Services)

The FACS assessment framework for community care is regularly abused or distorted by inaccurate application of the guidance and the imposition of cost ceilings.

The guidance quite clearly states that all risks to a person's independence should be considered in a holistic way. However, local authorities routinely

impose thresholds that have the effect of making all but the most critical or life threatening needs ineligible. Most councils state quite clearly in their local policies that people who do not have what they define as 'critical' or 'substantial' risks to independence are most unlikely to receive any support other than, perhaps, being given details of local voluntary agencies who might be able to help.

Even then the application of these critical and substantial bands of risk can be quite arbitrary. For example, I took part in my mothers community care review just last week. We were told that she could have help with cooking and cleaning but not shopping because shopping is considered a low priority. How does that make sense as a blanket proposition? It might be true for some people but if getting to the shops happens to be the main difficulty you have (e.g. because you don't have transport) it most certainly would be a priority. In any case, if you don't get to the shops what is it exactly that the worker they sent round to do your cooking is going to use to make a meal? Surely, some mistake here Dr Spock....

More seriously perhaps, the way that FACS is applied in practice is often heavily biased towards physical or functional needs and against consideration of psychological or emotional needs - which for many people can be just as crucial to maintaining any kind of quality of life let alone independence.

At the risk of sounding like the record has got stuck, establishing rights to Independent Living would go along way to solving these problems. But in the meantime we urgently need to put in place some proper monitoring of the way that FACS is being used or abused. We have numerous anecdotal examples but someone needs to pull this together in a systematic way so that the weight of evidence will hopefully prompt some corrective action. The Commission for Social Care is really the only body who are in a position to do this at the moment.

5. Costs

Cost ceilings are a tax on disability!!

Solutions include comparing like for like when making cost comparisons. If residential care often seems cheaper than supporting people in the community that is only possible because of the difference in the range and/or quality of support provided. If everyone in institutions were supported to participate to same extent as people living in the community, with the same degree of choice and freedom, the cost comparisons would soon be turned on their head.

Cost-effectiveness is (or should be) about producing good outcomes, not just lowest cost. But, due to the severe strain on their finances, this is all too often ignored or glossed over by many local authorities.

There also needs to be much greater scrutiny of 'specialist services' which quite apart from keeping disabled people apart from mainstream activities are

often hugely expensive. Health Trusts commissioning places for people 'complex needs' are often the biggest culprits with places in specialist learning disability units for example often costing upwards of 180k per place.

Finally - and I've saved the most controversial point until last - how about changing procurement rules to place a cap on the profit margins Independent Sector providers can take out of local authority contracts. These are regularly in double digits and in one case I have seen recently (again for specialist learning disability services) as much as 35%. Such a measure - perhaps combined with a more pro-active approach to developing the capacity of the not-for-profit sector would not necessarily solve all the problems of social care financing, but it would certainly help to make our scarce resources go much further than they do now.