Improving the Life Chances of Disabled People: A Response

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The philosophy of the Strategy Unit Paper

1. It has been an important strand in the disability debate that disablement is what society does to people with physical or mental impairments. The logic of this social or rather society "model" of disability is that the emphasis of the response to disability should be on a whole-hearted and determined programme to remove physical, structural and attitudinal barriers that convert people's impairments into disabilities. Such an approach goes beyond merely removing barriers to include extra help where this is needed to create a more equal society – people with a range of disabilities, in a range of situation, need support from someone else to live their daily lives.

2. The Strategy Unit paper respects and advances this approach, and in particular makes the point that catering for groups or categories of disabled people needs to be taken a stage further – recognising and catering for the individual needs of disabled people, to provide them with individual life opportunities and an enhanced personal quality of life.

3. There are risks, and indeed inherent weaknesses, in this approach, for all its great advantages as a strategic approach to tackling disability as a social issue across the age range. For example:

    - It tends to focus on mainstream outcomes, such as "ordinary" schools, open employment, integrated leisure opportunities, generic health services, age-specific rather than disability-specific residential and other social care provision, supported living rather than residential care. This is a problem if it blocks off the question whether in an individual case something different is appropriate.
    - It tends to award respect, inclusion, citizenship, on the basis of achievement and of doing what everyone else does. The person whose disabilities mean that, despite everybody's best efforts, paid employment, use of public transport, educational achievement in any conventionally measurable

sense, active citizenship as we normally judge it, remain out of reach, is seen as in some sense a failure.

- The emphasis is on progression, and the person with a progressive or indeed terminal condition, whose "achievements" diminish year on year, and for whom doors are closing rather than opening, does not comfortably fit the model.
- Those disabled people who are heard (as indeed they have every right to be heard) are predominantly those who most obviously fit the barriers to opportunities model. Someone with profound and multiple disability from birth, with increasing support needs as they move into (a probably fairly short) adulthood; someone with severe learning disability whose acquired skills are diminishing with early onset dementia; someone whose learning disability is now clouded with inoperable brain cancer; is in danger of falling off the valued list.
- (Re)habilitiation in its various forms is seen as having both a social and economic edge on intensive health and other support and decent incapacity benefit levels designed to keep people comfortably alive.
- There is a strong temptation to concentrate effort on those requiring least effort, in order to meet targets.

The implications of a person-centred approach

3. Person-centred planning challenges all service models and policy priorities with the over-riding question of what is right for this person in these circumstances at this time. Just as a network of systems apparently primarily based on separate provision and low expectations could disadvantage people who might have achieved more with greater inclusion and greater challenge, so – as the report indeed recognises – a network of systems very differently based could leave some people suffering in the corner, or with nothing.

4. For children and young people, and in many cases for adults too, person-centred planning demands that we address the needs of the family in which the disabled person is living. Staff in and managers of services are often not very good at respecting the identity of families. They tend to see the family as part of the problem rather than as part of the solution. They inter-pose hang-ups about their own families. They fail to recognise that where

there is going to be continuing dependence rather than full independence, dependence on staff working a shift system, with other priorities, and who will have moved on within twelve months, is a poor sort of substitute for a family with a life-long personal commitment. (Maybe professional training puts too much emphasis on family dysfunction and too little on family solidarity – confirming staff nervousness about their own credibility with families.)

5. Someone has to hold the person-centred plan for those who are not effectively in charge themselves and who do not have supportive families – often, though not exclusively, older people.

6. Person-centred planning has too often been seen as inseparable from "direct payments" – including direct payments that are really third party payments made in the interests of but with little or no participation from the disabled person. The report does something to correct the balance by recognising that direct payments are only a means to an end, and not an end in themselves. The end is a comprehensive and regularly revisited person-centred plan, with direct payments simply one – and often not the best – means of achieving that end. Hard-pressed families and isolated individuals should not have to take on responsibility for planning and managing services because full-time professionals are not up to the job. Individualised budgets recognise necessary cost without abandoning responsibility.

The economics of disability

7. A policy of invest in order to save is perfectly valid, but only as one element in a broader policy. There are some starkly stupid fault lines in current policies, such as a £20 income support earnings disregard/lower permitted earnings limit which is frozen for years on end and will not allow even four hours work on the minimum wage as from next October. That particular stupidity certainly discourages working, and makes it far harder to move on through the higher permitted earnings limit to earnings plus tax credits. However, even here the gain for most people affected by the earnings disregard may be that in the longer as well as the shorter term they can combine a very modest amount of work with income support/incapacity benefit. There are other people with severe disabilities who would like to do paid work, but for whom

the costs of subsidy and support will exceed benefit savings and tax returns. Are we willing to pay that price? In principle, we should be.

8. The reality is that benefit levels are very modest, and not commensurate either with earnings “lost” or with disability-related costs. More disabled people working would mean more disabled people with higher incomes. But employment will not of itself break the link between disability and poverty. A further reality is that many disabled people do not get services they need or get services that fall below their needs in terms of both extent and quality. Here we need an invest to improve policy rather than an invest to save policy.

9. Funding issues even more than principle have encouraged the shift towards mainstream education, supported living rather than residential care, the closure of large day centres, and a preference for accessible rather than specialist transport. All these issues ought to be tackled first on the basis of what is best for individuals, then on the basis of inclusion as a preferred option where it does not conflict with the interests or wishes of individual disabled people, and only finally on the basis of costs. We have a wholly artificial debate about accommodation and support because the basic accommodation and support and choice of companions and living styles issues have been over-laid with budgetary and personal income and independent monitoring issues.

Conclusion

10. “Improving the Life Chances” is an excellent document, reflecting a lot of hard work and a lot of listening. As its accepted policies are rolled out, they need to be checked against the daily realities of more severely disabled people and their needs. “Success” will mean that these more severely disabled people also experience welfare gain, and are also valued as equal citizens.

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