

3. Income Maintenance for People with Disabilities

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Personal

As those of my colleagues who have been active in relation to social security and disability over the past thirty years or so already know, my starting point is very different from theirs. At various periods over those thirty years, and especially at key periods in the development of invalidity pension and non-contributory invalidity pension, invalidity addition, the therapeutic earnings limit, invalid care allowance, attendance allowance and mobility allowance, and ideas running beyond those benefits and research on which to build a developing policy, they were dealing with me as ‘the man from the Ministry’.

That does not mean that I can claim pride (or otherwise) of ownership. At most, civil servants propose and Ministers and Parliament dispose; and at most I can say that things might have been different in relation to the contingencies covered by invalid care allowance, invalidity addition, and the therapeutic earnings limit, and a little different in relation to those covered by attendance allowance and mobility allowance, if some other combination of civil servants had been there putting proposals together for Ministers. One of the ‘perks’ of being a civil servant in or near the focal point of particular policy developments over a longish period is the chance to be heard when not directly involved – as long as you do not expect to convert privileged inputs into guaranteed outcomes!

Is there a policy or isn’t there?

One of the most consistent attacks on disability benefit changes under successive governments over the past thirty years has been based on

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the view that there is no policy. For civil servants whose successive reviews have all begun with carefully constructed frameworks of analysis within which the politically acceptable and financially feasible can be cradled, this 'no policy' criticism rings hollow. Seen from the inside looking out, it is all of a piece with the political naïveté of bids which wave airily at the menu and say 'we'll have it all, and keep the bill'. In fact there has been a fairly clear policy thread running through changes over the years, though economic necessities/conveniences (according to one's standpoint) and the conflicting principles within social security generally have obscured that policy thread.

It runs something like this: disability is in socio-economic terms a rather fragile prop for policy, since every generalisation about the effects of disability is largely untrue in relation to large numbers of people with disabilities. This applies to the effects of disability on ability to work, level of earnings, extra costs, and even more immediate things such as mobility and self-care. On the other hand, in the constant tussle between the general public's/electorate's broad sympathy for those who are worse-off and its reluctance to make itself worse-off in order to do something about comparative poverty, disability (and old age) come off rather better than being unemployed or having large numbers of children – choice being felt to play some part in the latter contingencies. These are *not* party political judgments, as anyone who has done any canvassing will testify.

Since disability is respectable and deserving but rather hard to define at the margins, it is sensible to focus on those areas of interplay between clinical impairment and social handicap where things are least in dispute: long-term incapacity, attendance needs and major mobility problems. What can be done for people with problems in these areas is constrained in procedural terms by the inevitable problems of disability means-testing (the harder you try and the quieter you keep, the less you get), and in presentational terms by what happens elsewhere in the system and by what the neighbours might think. As one example, the logic of support for long-term incapacity for work is a citizen's invalidity benefit at a standard rate irrespective of work/contribution record; but how can this be explained to the disabled person who made it to pension age with a reduced contribution record and who gets less pension for a substantial working life than his next-door neighbour who never made it to the

factory gate? Similarly, the general level of provision for basic costs has some bearing on what can be paid to people with 'extra' costs.

One other strand in the policy logic relates to special scheme preference. People do tend to sympathise with the person who is a battle casualty or who has been disabled in a pit accident, and to expect 'compensation' to be awarded without the hassle of taking the Ministry of Defence or the employer to court. The same people would not be so favourably disposed towards the soldier whose injuries were incurred when he fell off the back of the lorry on the way to the VD clinic, or towards the person whose milk dermatitis might or might not be due to doing a lot of washing up in the factory canteen. So there are dividing lines to be drawn here too. I may add that I spent five years on war pensions work, and I personally share the acceptance of war pensions preference.

The final strand in policy that I want to underline is one that might sound a little improbable, given the way the rules actually operate, but it has been a fairly consistent aim to encourage people with disabilities to work. This is reflected in the transformation of the therapeutic earnings limit from a static thing allowing long-term hospital patients to while away the weary hours and get a little something in cash, to a very much larger allowance which has more than kept pace with earnings. It is reflected too in the design of mobility and attendance allowances to enable people who are working to get them. It surfaces again in the determination, despite procedural hassles and some arguments of principle, to let people qualify for invalidity benefit through linked periods of incapacity, rather than requiring a straight run of incapacity. (Let me add in passing that, setting aside arguments about level of benefit, our simple-entry no-prognosis-test benefit makes more sense than all the complicated overseas variants.) The encouragement of work even surfaces, a little uneasily, in the income support rules.

The radical approach

If successive governments have been criticised unfairly for not having a policy, the critics have failed to present a coherent policy of their own. The Disablement Income Group has come nearest to consistency and credibility, and has done least harm by pleas for simplification and bids for a single benefit which was nothing of the sort. There is a real difficulty here, because if the government's policy is based largely on

acceptability to a public which does not actually want to put its money behind its questionnaire response, the radical critics also have to live with the public.

There is a wholly logical case for a national minimum 'wage' whether one is working or not, and whether one is not working because of unemployment, incapacity, old age, care responsibilities or whatever. The same logic would sweep away state wage-related discrimination, since on one political theory this is the sort of thing people should be doing for themselves, and on another political theory most wage differences are unfair and should not be passported into non-working periods by the state. While logic is having its day in the sun, we would abandon special scheme preference which compensates as heroes of war or industry those who suffer misfortune on their first day in the services or the factory, but does nothing for the man or woman who serves for forty years and becomes disabled the day after. We would scrap the inane tort system, which does most for lawyers, a little for a modest number of randomly selected victims, and nothing for the majority of people with disabilities; and we would ban disaster appeals – appeals which mean that if you are going to have an accident, you really must find twenty other people to share it with, because otherwise nobody will notice. We would certainly not extend the scope of compensation schemes to cover more 'injuries'; and fines for negligence would go into the service not into the pockets of 'victims'.

The radical approach is the one favoured by exponents of minimum income guarantees (or basic income guarantees) (MIG/BIG) – for whom the complications of the existing tax and benefit system are only a little less irritating than the complications of real life and the irrationality of human attitudes which between them keep their ideas in the debate but off the agenda. The nearer one gets to a system which allocates to every individual, disabled or not, a sum of money adequate to maintain him or her at an acceptable minimum standard, while allowing a clear gain from earning, the less one needs to resort to conventional means-testing or to picking some people out, for good or ill, as being disabled. Sadly for the radical agenda, it seems to be now widely accepted, except among the most ardent exponents of the victory of theory over reality, that full-blown MIG/BIG is not on. The more partial the provision for all needs through a universal scheme, the more necessary additional cover through a selective

scheme – for those recognised as having special needs or simply enjoying special sympathy.

The OPCS reports

The test of good research is how well it answers the questions that are inherently unanswerable, or that did not quite make it to the researcher's brief. The OPCS reports are a good piece of research. They broadly confirm some generalisations about the link between disability and relative poverty, and between severity of disability and extent of financial effect of disability. They also say that disability is very often multiple disability with multiple effects, and that the community's response needs to be multipartite too. Those whose priority is social security need to share agendas with those whose priority is housing or respite care or chiropody or speech therapy, because the core finding of the OPCS survey is not poverty, but a mismatch between need and provision and service delivery and information. In a sense the key is assessment, to remedy our shortcomings in recognising people's needs and wishes; but sometimes, like the Athenians, we know what is needed but fail to do much about it.

That leaves us with the age-old balancing act between general and specific: more even distribution of wealth or enhancing the range and value of special benefits; greater investment in homes for all or a drive on special-needs housing; transformation of the public transport system or increased mobility allowance to enable people with disabilities to buy solutions outside the mainstream; small classes and good supported teaching for all children or special classes. Those with the clearest answers on selectivity generally, and on selectivity between people with disabilities, often make the least sense to anyone who does not start where they start. I suspect that not the least attraction about the way that policies have actually developed is that a gently incremental system with recognised inconsistencies mirrors very well the way most of us feel – and ought to feel, since neither macro nor micro research provides definitive answers to tentative questions. It also mirrors very well the reality of which both people in government and those facing them are at heart aware, that there are more priorities than there are resources. If we can keep the manifold needs of people with disabilities among the priorities, we can keep gaining a little and losing less than we gain; and that is probably much

better than 'getting it right' – which is altogether too much either to define or achieve in this life.

What we have and what we can expect

I like the sort of politics and planning that starts with people rather than theories. So I start with a young lady of eleven who is severely mentally handicapped, has no speech, is encased to prevent further spinal deformity, can walk but very unsteadily and not very far, who can manage a drinking cup but not yet to feed herself. With some perseverance and a lot of love you can get a giggle of pleasure; more often you get a quizzical look which also in a way bridges the gap between two worlds.

For investment in her future, I want a service system staffed by people, across a range of disciplines, who are well enough trained to recognise her potential and to know how to help her achieve it, well enough equipped to do what they believe can be done, and well enough paid to be able to stay with a job they value while not undervaluing themselves and their own families. I want adequate funding between systems and for joint activity by adjacent systems to secure consistency in current support and over time; and research so that what we don't know today we may know tomorrow. I want her to have a comfortable home which offers opportunity and support, and access within that home and beyond it to shared and special activities in which she can, according to her tastes, enjoy what others enjoy. Since she is an attractive girl, and dribbles and sometimes has had problems of a more personal nature, I want her to be attractively dressed, and with enough changes of clothing to stay attractively dressed.

Against that background, I want her parents, insofar as they are able to look after her at home, to receive through her benefits and theirs the cash to enable them to meet her needs without penalties for the rest of the family: basic costs, special costs, opportunity costs. What they receive to enable them to care for their own child ought not to be less than what they would receive as foster parents caring for someone else's child with special needs. To the extent that they are not able to meet her needs in the family home, I want the costs of respite care, and when necessary of alternative residential or family care, covered; and, as necessary, costs of maintaining family contact. I doubt that she will ever handle money with much understanding, but when she grows up I want the financing of her personal living expenses, her

accommodation costs, and her mobility costs, to be seen as her money – whoever handles it on her behalf and gives account of their stewardship.

So, I believe that with attendance and mobility allowances (and maybe it is still not too late to give them back their proper names), the Independent Living Fund (and, *pace* local authorities, we need that too), income support, and housing benefit, we are not too far from what we ought to have. But if by community care we mean more than uncertainty about survival, we have to build in better guarantees about tomorrow; and we have to see my friend's support needs as ranking in terms of priority (and probably in this case in terms of cost) with the earning requirements of a high-paid civil servant. That asks for some adjustment in attitudes, but not unrealistically so ... for those who know us both!