

A Family Affair?

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"This edition of "Coalition" focuses' on Disability and the Family. This opening article, looks at how government legislation can dictate the roles of both family members and the "extended family" represented by the community.

Ken Davis warns that disabled people's organisations in danger of being lured into becoming compliant accomplices in a massive cost-cutting exercise?

Despite the fact that most of us seem to have one, Family is usually special in one way or another; but, for disabled people, it can be very special indeed. To start with, at a personal level, we bring with us into our families a very singular bit of baggage - a socially imposed burden of disability caused by widespread discrimination that affects every disabled person in some area of their lives. For many of us, these unnecessary barriers and restrictions reflect back into our families, dramatically changing the lives of those involved.

Another special feature of the family is revealed by the impunity with which Government has been able to ignore, block and weaken the call for full civil rights for disabled people over most of the last thirteen years. This reluctance to put disabled people on a par with everyone else once led the late Jean Keller, a former member of UPIAS (Union of the Physically Impaired Against Segregation) and the Derbyshire Coalition, to remark that if all our families went on strike, the government would be forced very quickly to get off their butts and do something about our demands.

Jean was making the point that Family is special, because the way it is used politically makes our continued discrimination possible. This was very much on show during the right-wing political rampage of the Thatcher years. So fervent was the crusade to roll back the boundaries of socialism that Society itself was deemed no longer to exist, except in the mind's-eye of a supposed left-wing distortion of the world. Accordingly, Family was promoted to take its place and protect people like us from falling into the costly embrace of the State. Family values and tax-cuts were in, social solidarity was out.

The right-wing point was to reinforce the idea of Family as being the source of unpaid support for those of us who fail the self-sufficiency test. Family was a vital link in a policy chain designed to keep the lid on public spending, and its effect on the lives of disabled people is now being sharply felt as local authorities cut services to stay within budgets. Another important link in the same policy chain is, of course, Charity, which introduces another sense in which Family is special for disabled people. When we and our families are no longer able to cope, we now increasingly turn to Charity, the role of which has been enhanced for the purpose.

Here then, is a political vision of the Disability Family in all its fullness: an extended conglomerate, comprising not just our kin and other "informal carers", but also the disability charities in their role of diminishing the charge on public funds. Now, as we scratch around in the social rubble the political vandals have left behind, the right wing tide of ideas is beginning to ebb. Nevertheless, across the political spectrum, Family is still seen as the vital social institution it always has been, but the extent to which either the new Tories or new Labour will harness the power of the State in the task of removing the barriers that have, in the past, been shored up by Family and the disability charities in the Voluntary Sector, has yet to be fully revealed.

The choice our movement has offered the Government over the last decade has, in essence, been between civil rights and care. We've been saying, instead of using the taxes we give you to look after and "care" for us, use the money to get rid of the barriers that create the need for care. For years, until we were forced to resort to direct action, we tried education and persuasion to get policy makers to see it was a better use of public money to get rid of the things that made us dependent, than to carry on footing the bill for it. Like the Government's own education and persuasion policy, it failed. Their reaction to all our reasoned arguments has been to promote Community Care and demote civil rights. Family is an important feature of Community Care. In the daily round, it doesn't come easy to visualise our partners, wives, husbands, mums, dads and distant aunts that smell of mothballs, as pliable instruments of public policy. But in the Community Care League, these same people are rounded up and fielded in the shape of an homogeneous heap labelled "Carers", in the "Informal" sub-division. These are the New Carers, a late twentieth century addition to the Voluntary Sector, with an important part to play.

There, this most recent manifestation of Caring joins with earlier denizens of the charity-voluntary nexus. There, for example, the newer Carers National Association jostles for funds alongside the remnants of some of the older philanthropic Victorian charities like John Grooms Crippleage, their successors, like the Central Council for the Care of Cripples (now RADAR), and more recent, parent-inspired groups like the Spastics Society (now SCOPE) or the Muscular Dystrophy Group.

The political part that has been scripted for this Extended Family in Community Care comes down to two main features: involvement and incorporation. Get involved in our policy, the Government has said, and play your part in shaping its future. By participating you will find you not just have a role in our vision of a "mixed economy of care", but also a future in a market place of providers that will offer disabled people more diversity and choice. Quite a juicy little carrot!

What wasn't explained was that once the great big Family had been roped in, it would also become part of the overall policy of forcing down some people's wages, and controlling public spending. Once there, the Family would help break down the "monopoly of the State" and help to control the influence of others with a vested interest in maintaining our socially engineered need for "care". Once there, the Family would be forced to weigh its future in the business of "care" against any solidarity with us in our struggle for full civil rights.

As for the role for statutory "carers" in all this, their position is reminiscent of that of their fellow agents of the state following the right-wing purge that led to the New Poor Law over a century and a half ago. The invidious task they were given at that time was to deter people from using the very services they provided on behalf of the State. Then, they used the most

draconian controls in pursuit of their policy of reducing public expenditure. They failed, not just because it was not in their interest to succeed, but also because the Government of the day was attempting to suppress the effects rather than remove the causes of poverty.

Now the government has avoided putting today's successors to the Overseers of the Poor in quite the same direct conflict of interest, by charging them with the task of merely displacing their various "caring" roles into a mixed market-place of providers, where they hope a combination of market forces and cash-limited budgets will fund its next round of tax bribes. Though the task is still an invidious one, there nevertheless remains a prospective role for "caring professionals" because current policy hinges on the idea that we are people in need of care. Thus present policy remains one of dealing with the effects rather than the social causes of disability. Clearly, the Government is persuaded that this is a cheaper and less troublesome approach and, in turn, this tells us that, for all the advances we have made, our movement's power to influence still remains relatively weak. We demand full civil rights, they dig their heels in for thirteen years before yielding their own toothless version of partial concessions: we call for independence, they inflict "care"; we call for direct payments, they assess us, purchase for us and consume on our behalf; we say "in the community" means living in the social mainstream, they let it mean anything from roughing it out under railway bridges to dumping us in segregated institutions.

Nevertheless, as we know, the Government has yielded under pressure, and the extent of its weakening grip on its own policy line can be judged by the way it is throwing the crumb of partial rights to our movement, and dangling the carrot of "care" before the Extended Family of "carers". Naturally enough, they are quite happy to apply the tactics of incorporation in the development of Community Care policy to ourselves. From their point of view, "user involvement" is fine, providing it doesn't cost anything.

It all looks mightily liberal, pluralistic and progressive, but when it comes down to it, the central and most pressing issue is not Community Care, but the removal of discriminatory barriers that cause our disability. There is little in the Government's Disability Discrimination Bill that applies itself properly to that task. That should be the focus of attention for all our genuine supporters. We will have to wait and see whether the Government's tactics have been enough to break down the consensus that has held the Extended Family together through the Rights Now Campaign. But whatever happens, at the end of the day, it will be the strength of the disabled people's movement that will see us through. Disabled people everywhere need to respond to the call.

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