

## Talk to Joseph Rowntree Foundation Summer School: July 2000

### The Disabling Society: Fighting Back

I want to use the title of this session *The Disabling Society: Fighting Back* as an opportunity for placing some of the JRF-funded research on disabled children and adults in a framework which reflects the aims of the disability movement. This framework is based on four principles: rights and entitlements; the social model of disability; needs-led approaches; and promoting choice and control.

#### Rights and entitlements

One of the clearest messages to come from the disabled people's movement is that we don't want care: we want rights. We are trying to change the nature of our relationship with the state, and with society; we are trying to bring about a shift from social welfare to social justice.

In the furtherance of this aim it is important to make a distinction between rights and entitlements. Rights – human and civil rights – are about what we all have in common, by virtue of the fact that we are human beings and citizens. Human and civil rights are about being treated the same. Entitlements on the other hand are about the things we need because of our difference. Disabled people insist that we are human beings and that we should therefore be accorded our human rights; we also insist that we are citizens, like everyone else, and that we should have access to everything that all other citizens of this country have access to. But in order to access our human and civil rights, in order to be able to do the same things as non-disabled people, we also need entitlements to the additional things we require to have equal access to human and civil rights.

For example, people with learning difficulties require support of various kinds in order to access the same opportunities to a home of their own and to paid employment, as any other citizen. Ken Simons' Foundations on *Supported living and supported employment: opening up opportunities to people with learning difficulties* highlighted the failure of the existing systems of supported housing and supported employment to deliver assistance in a flexible and empowering manner. JRF funded research shows very clearly the need for a national policy framework, based on entitlements, to make it possible for people with learning difficulties to live in ordinary housing and access paid employment (see Simons, 1998).

A more recent piece of research (Dearden and Becker, 2000) highlighted how failing to deliver disabled parents' entitlements under existing community care legislation, means that their human rights to be a parent and to a family life, and the human rights of their children, are also threatened. Under the Chronically Sick and Disabled Persons Act 1970 disabled people are entitled to practical assistance in the home, if they are assessed as needing this. They are also entitled to a full assessment of their needs, under both the Community Care Act 1990 and the Disabled Persons Act 1986. Nevertheless, the research found that disabled parents are not getting these entitlements and consequently their human rights, and those of their children, are being contravened.

### **Social model of disability**

The second principle is the social model of disability. This makes a distinction between impairment and disability. Impairment is the functional limitations that someone experiences (having learning difficulties, sensory or mobility impairments); disability is the disabling barriers of unequal access and prejudicial attitudes.

Christine Oldman and Bryony Beresford's research on the housing circumstances of families with disabled children found that disabled children were restricted in their ability to be part of their family, their health and physical potential was threatened, they were denied opportunities for play and leisure, and they were often living in unsafe environments (Oldman and Beresford, 1998). These situations were the result, not of their impairment but of the disabling barriers of:

- Physically unsuitable housing
- Local housing allocation policies which did not recognise the housing needs of disabled children and their families: for example where there is a child with significant learning difficulties it may be really important that siblings do not have to share a bedroom
- A Disabled Facilities Grants system which applies a means test which does not take account of the additional costs faced by families with disabled children
- Professional advice which is resource-led rather than needs-led and which does not take account of the specific needs of individual children and their families, and of the complex relationship between parents' caring role and children's need for developing independence.

This leads us to the third principle: a needs-led approach

### **Needs-led approaches**

Needs-led assessments were an important part of the community care reforms and, where they are carried out, service provision has become more flexible and based on the needs of individuals. Needs-led assessment is an entirely new and radical way of working with people. It is an attempt to move away from the situation where a social worker or other professional has a 'menu' of services in which to fit, and eligibility criteria against which to measure, the person who needs support. Now, the focus is on the actual needs of the person concerned, in other words:

- what is it that they want to achieve/change in their lives
- what is getting in the way of doing this
- what would help?

Needs-led assessments are essentially based on a social model of disability. They are about identifying the disabling barriers which are getting in the way of a better quality of life. Moreover, you can't do a needs led assessment unless there is effective communication with the person whose needs are being assessed.

Unfortunately, in the relationship between social services departments and disabled children, in practice neither of these things happen, as my own research has shown (Morris, 1998). Parents ask for, and are offered, existing services and there is little evidence of children's needs being assessed. Moreover, there was little evidence of disabled children's 'wishes and feelings' being 'ascertained' (as required by the Children Act). For example, the decision-making process of one social services department was analysed over a six month period. In only 12 out of a total of 66 cases presented to the Resources Panel had the social worker attempted to find out the child's views. In at least 5 cases, the social worker had not even seen the child. Typically, the section of the form headed 'Child's view' was left blank or the social worker made comments such as, 'She is unable to verbally communicate and therefore her view is not available'; 'It is not possible to know what his views are owing to his level of disability. In the case of another authority, of 24 cases analysed, in 11 instances the social worker wrote 'Not applicable' in the section headed 'Child's perception of need' and in another 9 cases the section was left blank.

A recent survey of 21 local education and social services authorities policies and practices concerning the placement of disabled children in residential schools found a similar failure to find out children's wishes and feelings, again often based on the assumption that children were unable to communicate (Abbott and Morris, 2000).

This is a denial of a human right and also means that the fourth principle – the promotion of choice and control – will inevitably be curtailed.

### **Promoting choice and control.**

If disabled children and adults can access their rights and entitlements, if the disabling barriers are addressed and their needs met, then they will have choice and control in their lives.

The disabled people's movement has challenged what is generally meant by the words 'dependent' and 'independent'. When physical impairment means that there are things that someone can't do for themselves, daily living tasks with which they need help, the assumption is often that this person is 'dependent'. And in Western culture to be dependent is to be subordinate, to be subject to the control of others. Those who cannot do things for themselves are assumed to be unable to exert choice or to have any control in their lives.

In contrast, the Independent Living Movement uses the word 'independent':

in a practical and commonsense way to mean simply being able to achieve our goals. The point is that independent people have control over their lives, not that they perform every task themselves. Independence is not linked to the physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it.

Brisenden, 1989, p.9.

The key policy change which the disabled people's movement has campaigned for, as a means of achieving independence and avoiding institutionalisation, has been direct payments – in other words cash payments which enable someone to purchase the assistance they require. Research funded by the Joseph Rowntree Foundation has played an important role in examining the case for direct payments, exploring what independent living means and, since the passing of the Community Care (Direct Payments) Act, highlighting continuing barriers to independent living.

Research by Values into Action, for example, has highlighted the reluctance of local authorities to introduce direct payments for people

with learning difficulties, and produced recommendations for addressing this (Holman and Collins, 1997). Ann Kestenbaum's research on independent living and people with high levels of support needs found:

- Wide discrepancies across the country in terms of support packages available
  - Relying on health and social services can significantly restrict the quality of people's lives when services are delivered according to rules and timetables which fit the disabled person into the service, rather than the other way round
  - Means testing of the cash payments available to pay for personal assistance (direct payments from social services departments and Independent Living Fund payments) creates a poverty trap, making it difficult to take up paid employment.
- (Kestenbaum, 1999)

The current benefits system and the way that community care is delivered creates sometimes insuperable barriers to employment and increases disabled people's vulnerability to poverty and social exclusion. Disabled people are seeking a level playing field – through entitlement to the assistance we require because of impairment, and civil rights legislation which tackles discrimination.

## **Conclusion**

This leads me to the final point I want to make, about the inadequacy of the current government's social exclusion agenda. The Human Rights Act, to be implemented this October, has enormous implications for disabled people. Like the European Convention on Human Rights it sets out everyone's right to be free from 'inhuman or degrading treatment'; the right to 'liberty'; to 'respect for private and family life'; to 'freedom of thought' and 'freedom of expression'.

In the work I've been doing recently (about young disabled people who have high levels of support needs), I have met people who are subject to 'inhuman and degrading treatment' - people whose 'incontinence' is caused by having to wait for help to go to the toilet, people who are helped to eat in the most insulting and disrespectful manner, who are talked about in front of them as if they are not there, who have decisions made for them, who are treated as if they are not full human beings.

I have met people whose 'right to liberty' is curtailed by a lack of transport, drivers and escorts, who cannot choose to meet friends, go to

the cinema, go for a walk round the block. I have met people who experience no 'respect for their private and family life', whose mail is opened, who are denied the opportunity to have sexual relationships, who are separated from their families.

I have met people who are denied 'freedom of thought' and 'freedom of expression' because they do not have access to the support they need to communicate. This is perhaps the most fundamental denial of human rights because if someone is denied communication they are denied the opportunity to make choices, denied the most essential human interactions.

Nothing in the current policy agenda on social exclusion addresses these contraventions of human rights. This is because the current policy agenda is more concerned with social cohesion than with human rights – policies contrast social exclusion not with social inclusion but with integration, by which is meant integration into the labour market.

A human rights agenda for young people with high levels of support needs would not measure social exclusion in terms of educational achievement and paid employment (or teenage pregnancies and youth crime rates). Instead, it would look at the extent to which policies deliver human rights, for example:

- Are young people able to actively participate in their community?
- Do they experience prejudice and harassment?
- Do young people have freedom of expression and a say in what happens in their lives?
- Are young people subject to degrading treatment and a denial of dignity, respect and choice?

These are, of course, questions which are of relevance to all young people but for those with high levels of support needs they lead to a series of other questions which have implications for social policy. The main question is:

- How can the disabling barriers of unequal access and prejudicial attitudes be tackled?

The setting up of the Disability Rights Commission, the implementation of the Disability Discrimination Act and its extension to education, all start to address this question. At the same time, however, government policies on education and employment, social security and community

care, assume that people with high levels of support needs will remain socially excluded. This means that issues which have major implications for the human rights of people with high levels of support needs fail to get onto the policy agenda, for example:

- Do young people with communication impairments have an entitlement to the equipment and/or support they need in order to communicate with others? What is being done to raise awareness generally about the different ways in which people communicate?
- Do young people with high levels of support needs receive personal assistance in a way which gives them choice and control in their lives?

A 'disabling society' means a society which denies human and civil rights, and fighting back means insisting that we do have human and civil rights and we need entitlements to the assistance required to access our human and civil rights

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