

Talk to Conference organised by London Borough of Newham on social exclusion and young people: May 2001

Social exclusion and young disabled people with high levels of support needs

We have our breakfast done by the staff, we have our lunch done by the staff, we have our main meal at half past five, and then we're done for the day.

This comment, by a 20 year old disabled young man who I talked to recently, is indicative of the restricted kind of life that some young people, who have high levels of support needs, are leading.

I am here to talk a research project I carried out in partnership with Scope, funded by the National Lottery Charities Board. The first stage of the research asked young disabled people what social exclusion and social inclusion meant to them; the second stage explored the experiences of 44 young people who have high levels of support needs.

Since 1997, the government has introduced over 100 policies to tackle social exclusion. The main aim has been to get people into paid employment. Welfare reforms are about making work pay and getting people into work: education and training policies are about ensuring people acquire the skills and qualifications to compete in the labour market.

However, when young disabled people were asked about what social exclusion meant to them, they talked about:

- Not being listened to
- Having no friends

- Finding it difficult to do the kinds of things that non-disabled young people their age did, such as shopping, going to the cinema, clubbing, etc
- Being made to feel they have no contribution to make, that they are a burden
- Feeling unsafe, being harrassed and bullied
- Not having control over spending money, not having enough money.

Being consulted and listened to

All young people want to be consulted and listened to when decisions are made which affect them and young disabled people are no different. The general message was that if adults did not listen to disabled children and young people about their preferences and their needs then they would be excluded from the things which were important to them – whether it was at school, college, or in leisure activities.

We know that, in the context of services provided by social services departments, disabled children and young people are rarely consulted about their preferences or opinions (Social Services Inspectorate, 1998, Morris 1998a,b) and that they are rarely involved in decisions about placements at residential schools (Abbott and Morris, 2000). We know very little, however, about whether disabled children are listened to in the context of, for example, the assessment of special educational need and subsequent school placements, or to what extent disabled teenagers are involved in transition planning.

In recent years there has been greater recognition of the importance of consulting with young people in the context of developing policies and services which are intended to address their needs. There have certainly been a lot of developments in terms of consulting with and involving children and young people in local government policy making and service delivery. However, few of these initiatives have involved young disabled people. For example, 87 percent of respondents to a survey of young disabled people in Bristol said that they had never been asked their opinions by local youth clubs and services (Casling and Scrase, 1999, p.8).

There is now a general recognition of the need to involve people who use services in the development of those services: the Department for Education and Employment, for example, is committed to involving young people in the design and delivery of Connexions, the new youth support service (DfEE Press Release, 3 February 2000). However, if young people with high levels of support needs are to be involved, methods of involvement must be developed which do not rely solely on holding meetings and verbal or written communication.

Moreover, consultation with young disabled people is not just a question of ensuring their communication needs are met. It may also be necessary to recognise that their limited opportunities act as a barrier to their involvement. When a focus group of young disabled people were consulted about youth provision they 'found it difficult to say what they would like to do'. The researchers commented, 'This may be a result of lack of information. They

don't get told what is available, because nobody expects them to take up activities, or the support is not available. It might equally be, that because of their experience as disabled young people, they have low expectations of what they might be able to do' (Casling and Scrase, 1999, p.12).

The disabled people's movement has learnt a lot in recent years about how to involve young disabled people (see for example Greene, 1998). Perhaps it is time for both central and local government to consult with these organisations about how to ensure young disabled people do not continue to be excluded from the decision-making processes which affect their lives.

Friends

Friends can be one of the most important parts of any child or young person's life. This is no different for disabled children and young people. According to the British Household Panel Survey, disabled children (aged 11-15) are more likely to find it difficult to make new friends and there is plenty of other evidence of social isolation experienced by disabled young people.

There is no current policy initiative which really tackles friendship as a dimension of social inclusion. Indeed, little in education policy recognises that, from children's point of view, friendship is the main motivation for going to school and that difficulties with making and maintaining friendships are a key barrier to getting the most out of education. While education policy – both in terms of school-age children and further and higher education – is now more motivated by a philosophy of inclusion, there is very little

recognition of the steps necessary to enable disabled children and young people to genuinely mix with their peer group.

There has long been resistance to even recognising prejudice against disabled people: for many years the most common argument used against civil rights legislation was that employers did not discriminate against disabled people, rather they felt sorry for them. There is a similar resistance to 'naming' the prejudice experienced by disabled children.

The Department for Education and Employment's proposals for 'citizenship education' are intended to help 'create a culture of tolerance, understanding and respect for all' (DfEE Press Release, 16 June 1999). This could be an opportunity to challenge negative attitudes towards disabled children. However, there is currently little in the government's proposals which would bring this about.

Making a contribution or being a burden?

The young disabled people consulted for the Scope research project said that being made to feel a burden, being made to feel that they had no contribution to make, was a key part of feeling 'shut out from society'. At the same time they challenged the idea that having high levels of support needs meant that a person had no contribution to friends and family or society generally. These comments go to the heart of the way the current policy agenda on social exclusion does not adequately address the experiences of these young people.

A key issue is what is meant by the terms 'independent' and 'dependent'. When David Blunkett talks about his 'vision' of 'empowered and self-reliant individuals' (Blunkett, 1999) it is clear that 'empowerment' is seen in terms of gaining work-relevant qualifications and 'self-reliance' is about supporting yourself through paid employment. Current policies to combat social exclusion are predicated on the assumption that 'independent people' are those in paid employment who can do things for themselves and 'dependent people' are those living on benefit who rely on others to do things for them.

These assumptions get in the way of developing education, employment and welfare policies which would promote social inclusion for those with high levels of support needs. I want to look at each of these policies areas in the light of what the young people consulted said about social exclusion.

Education

An education policy which is dominated by the aim of increasing employment opportunities is in danger of failing to address the needs of young disabled people with high levels of support needs.

There are a number of points to be made here:

As the Disability Consortium for Post-16 Education and Training pointed out in its response to the Learning and Skills Bill which was presented to parliament in the 1999/2000 session, 'Many people, particularly those with learning difficulties, need access to non-vocational courses' (Disability Consortium for Post-16 Education and Training, 1999). In the current climate there is little

recognition of education for its own sake or as a direct contributor to the quality of someone's life (unless it is through increasing their likelihood of getting a job).

Another problem is that the Learning and Skills Bill, together with most other policy initiatives concerning young people, is based on a pre-19 and post-19 division. There is an assumption that those who do not move on to university at 19 will no longer be in full-time or part-time education. Yet, as the Disability Consortium points out, 'A proportion of young people with learning difficulties and/or disabilities are likely to stay at school until they are 19 and then still require full-time further education provision' (Disability Consortium for Post-16 Education and Learning, 1999). This is particularly the case for those young people with high levels of support needs. Echoing an earlier campaign, the Consortium recommended that the government should introduce a statutory right to post compulsory education and training for disabled young people up to the age of 25.

Currently, further education provision for people with high levels of support needs varies considerably from area to area and many initiatives are short-term, relying on insecure sources of funding. In some areas, there is no provision at all post-19 for people with high levels of support needs (House of Commons Select Committee on Education and Employment, 1999a, para 70). The emphasis in the past on vocational education has already resulted in a narrowing of the curriculum range for adults with learning difficulties: music, art and drama classes have been lost as a result of a diminished recognition of learning as an end in itself (NIACE,

1996). There is nothing in the current policy developments which addresses these issues.

Young disabled people themselves often have a broader concept of the value of education than is apparent in the government's policy agenda. While some of those consulted for the Scope research said that they wanted to do college courses so that they could increase their chances of employment, others said that they valued learning for its own sake, for its contribution to their personal development and for the opportunities it gave them to socialise with other young people.

Employment

This tendency to exclude young disabled people with high levels of support needs from education policies aimed at tackling social exclusion is also found in the context of employment policies. One of the difficulties is that policies aimed at increasing employment opportunities for disabled people focus on the characteristics of individuals rather than the barriers that might exist within the workplace (such as lack of appropriate support). The New Deal, for example, focuses on whether individuals are 'job ready': there is little consideration of whether employers, co-workers and the workplace are 'ready' to accept a disabled employee. In the context of the Disability Discrimination Act, much has been made of the fact that the majority of adjustments made by employers are very small, emphasising that most disabled employees require very little 'accommodation' (House of Commons Select Committee on Education and Employment, 1999a). This may be true but

does little to promote employment opportunities for those who do need a lot of 'accommodation' in order to work.

For young people the research project is concerned with, employment opportunities will be tied to high, and often continuing, levels of support and adjustment within the workplace. The current situation with sheltered employment and supported employment schemes is a hotchpotch of expensive segregated jobs provided through Remploy, and inadequate and insecure funding of local projects which seek to support people in ordinary workplaces (House of Commons Select Committee on Education and Employment, 1999a). There has been little recognition in this country of the need to change the very concept of 'supported employment' in order to create employment opportunities for people who have traditionally been seen as unemployable.

If policies directed at combating social exclusion are to encompass people with high levels of support needs, then initiatives directed at increasing employment opportunities will have to broaden the type of support provided. However, opening up employment opportunities for people with high levels of support needs does not just require a conceptual shift in terms of type of support provided. It also means questioning the means-testing of direct payments, Independent Living Fund grants and services under the community care system.

The government's New Deal and other programmes aim to increase the number of disabled people in employment and also to reduce the financial disincentives to work which have sometimes

been created by the benefits system. However, recent policy initiatives have neglected to tackle a significant barrier to employment experienced by many disabled people, that which has been called the 'personal assistance trap'.

'Welfare and dependency'

It is also important to challenge the inevitability of the link between non-participation in the labour market and social exclusion. Of course, not being in paid employment does create a vulnerability to poverty and social isolation and policies which create employment opportunities will help many disabled people. Nevertheless, the young disabled people consulted challenged the idea that being without paid work inevitably meant being 'dependent', shut out from society, with no contribution to make. They also felt that being 'dependent' and unable to make a contribution is not an inevitable consequence of impairment, even a very high level of impairment. Rather the circumstances in which people experience their impairment are the determining factor. The young man whose words I quoted at the beginning is experiencing dependency, in the sense of having no choices or control over his life. He is also 'shut out from society'. However, this is because of the circumstances in which the support he requires is delivered, rather than the level of impairment itself.

As one young woman who took part in a group discussion said, 'Being excluded is having no choices, to be included you have to have help when you need it, how you need it.' Another pointed out that 'You don't have to have a job to make a contribution. You can

do that by being yourself, by being a good friend, by being good fun to be with’.

A number of young people with high levels of support needs also put the view that these needs themselves meant that they made a contribution in that they created jobs for others: ‘We’re job-creators – because we need personal assistance, equipment, assessment, health care, etc. This should be recognised in the economic value placed on people with high levels of support needs’.

The current government’s commitment to extending civil rights legislation for disabled people will undoubtedly encourage greater recognition of disabled people as citizens. However, at the same time the dominant message is that acceptance is conditional: this is certainly the message of the poster and newspaper advertising campaign run by the Department for Education and Employment ‘See the person not the disability’ – inclusion in society is only to be achieved by ignoring that which makes people different.

People who do not have paid work are not necessarily socially excluded. However, they will remain at risk of social exclusion as long as the policy agenda fails to tackle the more fundamental factors which create dependency and social isolation.

Conclusion

The young people who took part in the group discussions are challenging the very basis of the current social exclusion agenda: to them ‘being shut out of society’ is about being denied their human rights. In contrast, the current policy agenda is more

concerned with social cohesion than with human rights - the policy agenda contrasts social exclusion not with social inclusion but with integration, by which is meant integration into the labour market. One of the consequences of this is the invisibility of young disabled people with high levels of support needs in terms of the social exclusion agenda. Their irrelevance to policymakers is not surprising as their social exclusion poses little threat to social cohesion: the consequences of exclusion for this group do not include high crime rates or teenage pregnancies. Neither is the cost they pose to the state of great significance: while they do depend on state benefits they make up a small proportion of the total disability benefits bill (the bigger and more important group being those people who used to be in employment but are now claiming incapacity benefit).

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 the community?
- Do young people experience prejudice and harassment?
- Do young people have freedom of expression and have 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?

Currently, a failure to properly meet the needs of young people with high levels of support needs means that their human rights are contravened.

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