

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

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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.

20 year old disabled young man, living in a sheltered housing scheme.

The purpose of this article is twofold: firstly, to look at what is generally meant by social exclusion and to compare this with what the concept means to young disabled people; secondly, to look at whether current government policies address young disabled people's experiences of social exclusion, with a particular focus on those young people who have high levels of support needs. In examining these issues I want to question the rather narrow interpretation of social exclusion which underpins current policy, and highlight the relevance of a perspective which takes human rights as its starting point.

The article draws on the experiences of young disabled people in their teens and early twenties through discussions with four groups of young disabled people (29 people in all)¹ and interviews with 14

¹ These discussions were held as part of the first part of a research project (being carried out in partnership with Scope and funded by the National Lottery Charities Board) concerning social exclusion and young disabled people with high levels of support needs.

young disabled people who have high levels of support needs². It also draws on analysis of the British Household Panel Survey in terms of what it tells us about social exclusion and young disabled people³. The opportunities that are open to young people once they reach their teens are very much determined by their experiences when younger. The article therefore draws on both evidence and policies concerning disabled children, as well as that specifically concerning young people in their transition to adulthood.

While tackling social exclusion is fundamental to this current government's aims there is no one clear definition to be found in the many speeches and documents associated with policy initiatives. The government's Social Exclusion Unit's working definition focuses on the causes of social exclusion rather than being clear about what social exclusion actually is. 'Social exclusion is a shorthand term for what can happen when people or areas suffer from a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health, poverty and family breakdown' (Social Exclusion Unit, n.d.).

At the launch of the Social Exclusion Unit in 1997, the Prime Minister described social exclusion as being 'shut out from society' and stated that government policy was directed at creating a society 'in which every citizen is valued and has a chance; in which

² The 14 interviews were part of any earlier piece of work, commissioned by the Joseph Rowntree Foundation (Morris, 1999a).

³ The analysis was carried out by Tania Burchardt, of the Centre for Analysis of Social Exclusion, for the research project referred to under footnote 1 above.

no one is excluded from opportunity and the chance to develop their potential....'. While this type of rhetoric potentially opens the way for quite a broad approach to social exclusion, in practice, the main focus of government policy to combat social exclusion has been paid employment. Both material and emotional well-being have been linked to work:

Work is fundamental to modern notions of social inclusion. It is, for better or worse, a key means of self-definition and establishing the respect of one's peers, and it is the main source of a level of income that underpins a sense of inclusion. Being in paid work has become the badge of 'social inclusion' *par excellence* in the world-view and welfare policies of the New Labour government.

(Christie, 1999, pp.28-29)

As David Blunkett, Secretary of State for Education and Employment, said 'In the end, it will be work that protects people from poverty' (Blunkett, 1999).

A broader approach to social exclusion and the policy agenda to tackle it is that suggested by Burchardt, Le Grand and Piachaud: 'An individual is socially excluded if (a) he or she is geographically resident in a society and (b) he or she does not participate in the normal activities of citizens in that society' (Burchardt, Le Grand and Piachaud, 1999, p.230). Normal activities are defined thus:

there are five dimensions that we consider to represent the activities in which it is most important that individuals participate: to have a reasonable living standard, to possess

a degree of security, to be engaged in an activity which is valued by others, to have some decision-making power, and to be able to draw support from immediate family, friends and a wider community’.

(Ibid, p.231)

Drawing on this analysis of social exclusion and adults, Burchardt proposes four dimensions of social exclusion for children and young people:

- Standard of living: growing up in a household with an adequate level of material well-being
- Education, work and play: having the opportunity to develop skills and knowledge to enable them to play a socially useful role later in life
- Nurturing and socialisation: receiving love and attention in a secure environment, and having opportunities to socialise with other children
- Participation in decision-making: developing the capacity to make informed decisions through increasing involvement in decisions which affect their lives.

(Burchardt, 1999a).

As we will see, the dimensions of social exclusion identified by young disabled people themselves were in some respects similar to that proposed above but also included broader aspects of their experiences.

Social exclusion and young disabled people

The linking of poverty and unemployment with social exclusion is certainly of relevance to disabled children and young adults. Analysis of the BHPS found that disabled children and young people (aged 11-24) live in households with lower average incomes than households with non-disabled children and young people. Amongst the age groups 16-19 and 20-24, disabled young people are more likely to be living in households where no-one is in paid work (Burchardt, 1999b).

However, when young disabled people were asked about what social exclusion meant, 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 do, 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.

As with many oppressed groups it was easier for the young people to identify their experiences of exclusion and the causes than it was to identify what *inclusion* might be like. I want to take three of the dimensions of social exclusion identified by the young people and explore them in more detail, in terms of what we know and don't know about these experiences, what the policy context is and

the implications for policy. These dimensions are: the experience of not being consulted or listened to; having no friends or finding it difficult to make friends; and being made to feel a burden and that you have no contribution to make. All of these dimensions are of relevance to the major government policy areas of education, employment and welfare reform.

Not being consulted or 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. As one young woman said when asked what made her feel included, 'I think it's being able to say what you want to happen'. 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. As one young man with learning difficulties, who took part in a group discussion for the Scope research, said, 'I wanted to tell them that I wanted to do that course. And that I would need help. But they didn't listen.'

Some of the young disabled people who were interviewed identified that a failure to listen means that needs relating to impairment or illness may not be addressed and this can impact significantly on other aspects of life chances. A young woman who was eventually diagnosed with ME said, 'The doctors didn't believe me when I tried to tell them how ill I felt'. A failure to recognise her needs associated with her condition has led to her exclusion from school from the age of 14 (Morris, 1999a, p.62). Another young

woman who took part in one of the group discussions described how a failure to listen to what she had to say about her needs meant that she encountered unnecessary difficulties at school. She argued that, while it was important for teachers and others to understand what individuals needed in order to be included,

People wouldn't necessarily have to understand all the different needs relating to all the different impairments – they would just have to listen to what we say our needs are. They wouldn't have to know themselves, they'd just have to be ready to listen to us.

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 and college placements, or to what extent disabled teenagers are involved in transition planning.

None of the initiatives under the Department for Education and Employment's (DfEE) Programme of Action, which followed the green paper on special educational needs, concern listening to or consulting with children. On the other hand, government policy aimed at improving the life chances of children in the care system, the three year Quality Protects initiative, has encouraged social services departments to pay more attention to listening to children.

A few local authorities have taken steps to seek the views of disabled children using their services (see for example, Triangle, 1999, Morris, 1999b). However, it is common for both social services and education departments to assume that communication impairment precludes the possibility of giving an opinion (Abbott and Morris, 2000).

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. Only two of the 50 examples included in Carolyne Willow's resource for promoting the participation of children and young people included disabled children and young people (Willow, 1997) while none of the examples of consultation and involvement included in Cohen and Emanuel's resource on involving young people in health-related work included young disabled people (Cohen and Emanuel, 1998). Eighty-seven 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).

Existing sources of national data tell us little about the extent to which young disabled people are involved in either decisions about their own lives or in those which affect their local community. We do know that, according to the British Household Panel Survey, disabled young people aged 11-15 are more interested in politics than their non-disabled peers but that amongst the age group 16-19 they are less likely to be involved in a political or campaigning organisation (Burchardt, 1999b). 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.

The Children Act 1989 was the British government's response to signing up to the United Nations Convention on the Rights of the Child and 'ascertaining the wishes and feelings' of children was justifiably given an important place in the legislation and guidance. The general failure to 'ascertain the wishes and feelings' of children who have communication impairments is a denial of a fundamental human right and at odds with the Children Act's intention of recognising children and young people to have full human rights.

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:

I think that when you don't have friends you can't experience real life because real life is how you get on with other people. I can't do anything on my own so I am completely dependent on people helping me, so if I am not going to be surrounded by only personal assistants, I have got to find a way of making friends.

Maresa MacKeith, Presentation at Parents for Inclusive Education Conference, Lambeth, 6.11.1999.

According to the British Household Panel Survey, disabled children (aged 11-15) are more likely to find it difficult to make new friends: 26% said it was quite or very difficult, compared to 14% of non-disabled children and disabled children have fewer close friends than non-disabled children. Nearly one in five disabled young people aged 20-24 (compared to one in ten of non-disabled young people) say they lack someone to offer them support in at least one of five respects (someone who will listen, someone who will help in a crisis, someone you can relax with, someone who really appreciates you, someone you can count on to offer comfort) (Burchardt, 1999b).

We don't know enough about what causes this greater vulnerability to social isolation. Negative attitudes held by non-disabled children and young people may be an important factor and a key context to the interaction between disabled and non-disabled young people is the extent to which the latter grow up with the idea that the former are to be pitied and made the objects of charity.

For young people with high levels of support needs, there may also be practical barriers. As one young woman said, 'It's difficult because I've got my mum or my sister or a carer with me all the time'. A young man who has a communication impairment and no facilitator or equipment to enable him to use telecommunications said, 'I had a really good friend at school but I haven't seen her since I left. It's difficult. I can't talk to her on the phone'. His mobility impairment also means that he is excluded from public transport. Jane Noyes' research (Noyes, 1999) concerning the experiences of children and young people who use assisted

ventilation illustrated the barriers to social interaction but also the ways in which good practice in service delivery can enable such young people to be less socially isolated (National Health Service, 1999).

Young people with high levels of support needs, particularly those with communication impairments, may find that most of their interaction is with adults rather than their peer group. As one worker in an establishment catering for children with multiple impairments said 'The biggest thing that's missing for them is peer group pressure to do things differently. They don't communicate with each other but with us – their whole life experience is of communicating with non-disabled adults' (Morris, 1998a, p.21). Some young disabled people who were interviewed, when asked about a best friend, named a careworker.

Attending segregated school or college may also mean school and college friends are far away from the young person's home which makes socialising out of school and college difficult (Morris 1998a). Institutionalised care in childhood can particularly increase the likelihood of social isolation in adulthood. As one recent piece of research concluded, 'disabled children in residential schools are in grave danger of growing up without the opportunity to develop "ordinary" relationships with family, school friends, neighbours, or other young people in the wider community. Instead, these relationships are replaced with paid staff who teach or look after them leading almost inevitably to an institutionalised adult life' (Wilson and Jade, 1999, p.22).

Limitations on disabled children's interaction with their peers are not confined to those with high levels of support needs. Recent research on disabled children's experiences in both special and 'mainstream' schools found 'high levels of surveillance of disabled children by adults...Disabled children spent a disproportionately large amount of their time in the company of adults and in social spaces where adults were actively present (Corker, Davis and Priestley, 2000, p.11).

Disabled children and young people want to be included amongst their peer group of non-disabled children and young people but they also often get a lot from having friends who share similar experiences of impairment and disabling barriers. One young woman with cystic fibrosis talked of the importance to her of friends who have similar experiences: 'When I'm admitted to hospital we sit around in a cubicle, not very big, talking about things...it's nice to have a peer group – to have a good chat with' (Morris, 1999a, p.39).

Article 23 of the United Nations Convention on the Rights of the Child refers to governments' responsibilities to 'facilitate [disabled children's] active participation in the community.' However, there has been little thought given to what 'active participation in the community' is or of the barriers to achieving it. 'Being part of the community means having meaningful relations with community members' write Robert Bogdan and Steven Taylor in their exploration of what 'community participation' means for adults with learning difficulties (Bogdan and Taylor, 1999, p.2). For children and young people, social interaction with their disabled and non-

disabled peers at school or college is a key dimension of 'community participation' and therefore of inclusion (or exclusion). However, there is no current policy initiative which tackles friendship as a dimension of social inclusion. Indeed, little in current 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.

These steps would have to address barriers to interaction with both disabled and non-disabled peers and, in particular, would need to recognise and tackle negative attitudes about impairment. Racism is more commonly a focus of anti-bullying policies in schools, but prejudice against disabled children is not. 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 has been identified as an opportunity to 'expose all children of school age to disability issues, disabled people and the positive concept of difference. We need to ensure that disabled people are able to take up their place as fully active participants in society and are not just recipients of other people's community involvement' (Knight and Brent, 1999, p.28). However, there is currently little in the government's proposals which will bring about such changes in attitudes.

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. This is particularly the case when the criteria used to measure educational success is 5 Grades A-C at GCSE for this automatically excludes large numbers of young disabled people.

Disabled young people are more likely to have no educational qualifications than non-disabled young people. They are also more likely to have qualifications at less than GCSE grade A-C or equivalent and much less likely to attend a polytechnic or university (Burchardt, 1999b). For many disabled young people lower educational achievements measured in these traditional ways are the result of discrimination and/or a failure to provide the support required to enable them to access the national curriculum on the same basis as their non-disabled peers. However, for some young disabled people, these ways of measuring educational achievements are inappropriate and can result in the

marginalisation and under-valuing of their educational needs and achievements.

For example, the emphasis on education for employment in current policy initiatives in the field of further and adult education, excludes people with significant learning difficulties. 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. 'Going to college means that I meet people my own age and who are interested in the things I'm interested in. It means I'm finding out who I am and what I'm good at' said one young woman who spent most of her childhood at a residential school for those with 'severe learning disabilities'. In contrast, a number of young people interviewed had left school at

19 and were denied further access to education (Morris, 1999a, p.66).

- **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 the group of young people with whom we are concerned, 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. Innovators in supported employment in the United States have made two important conceptual shifts in order to expand opportunities of employment to people who have high levels of support needs, as explained by John O'Brien:

The first shift expands the focus from the person alone to the person plus a skilled coach. Instead of simply assessing the job ability of the person alone....supported employment practitioners consider what the person can do with the assistance of a job coach(O'Brien, n.d. p.1).'

As he points out, 'When [we] consider only the skills of the person with a disability, the number and variety of jobs developed depends on the number of individuals ready to go to work with minimal help' In contrast, when assistance from a job coach is provided the number and variety of jobs depends on the skills and experience of the job coach and the level of support provided.

The second conceptual shift concerns a broader identification of the resources which can make it possible for someone with a high level of support needs to take and maintain employment. O'Brien refers to 'the organised capacities of all the available social resources, including:

- What family, friends and staff from [services] involved with the person can do to contribute to on the job success
- What the employer makes available to all employees in order to ensure successful performance (e.g. training, flexible scheduling, and more person specific supervision).
- Adaptations employers and supervisors are willing to make to accommodate a person's disability, including: workplace modification, job redesign, and more person specific supervision.
- What co-workers are willing to do, including: acting as the person's mentor, modifying the ways they perform their jobs, and joining in efforts to plan and revise adaptations.'

(O'Brien, n.d. p.2)

The key to this second conceptual shift is an emphasis on the importance of social relationships, both those outside the workplace that are vital to any employee's (disabled or non-disabled) capacity to work, and those within the workplace. As O'Brien says,

Those who see the focus on organising available social resources as unrealistically idealistic should stop and think about three things. Despite a common myth of individual performance, everyone's job success depends on the continuing co-operation of others. People who belong to high performing work teams get more done with greater satisfaction than people whose co-workers feud. People with strong support from family and friends can more confidently set and pursue goals than isolated people can(O'Brien, p.2).

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'.

People who need personal assistance to go about their daily lives can look to three sources of help with this assistance:

- The care component of the Disability Living Allowance – this is not means tested so does not create any financial disincentive to work but the level of payment is not sufficient to pay for anything but the very minimal level of assistance
- Cash payments to enable the disabled person to employ their own personal assistants, thus giving them the ability to go about their lives in the same way as a non-disabled person. These cash payments come from the local authority social services department and from the Independent Living Fund. ILF

payments are means-tested and, increasingly, so are direct payments from local authorities. Local authorities commonly use Income Support levels as the 'cut-off' point and, while the ILF has recently increased the amount of money people can keep before the grant is reduced, the rules applied mean that disabled people pay a 55% tax on income up to £200 pw above IS levels and above this lose their ILF grant completely.

- Services provided by local health and social service authorities, such as home carers and district nurses. Unfortunately, the way these services are delivered assume that the person using the service is not in work: so for example someone needing a home carer to help them get up in the morning, or a district nurse, cannot rely on the service being provided at a time which enables them to get to work. Moreover, most local authorities now charge for these services and apply a means-test.

Research commissioned by the Joseph Rowntree Foundation has highlighted the unfairness of the way the benefit system and local authority charging systems penalise people who need personal assistance (Kestenbaum, 1998). The Select Committee on Education and Employment's inquiry into Opportunities for Disabled People, published in 1999, concluded that 'disabled people with high support needs who wish to work face considerable financial disincentives' and recommended that the Government establish a cross-departmental working party to examine a range of options within the tax and benefits system that might ease the 'personal assistance trap'. Unfortunately, the government failed to respond positively to this suggestion.

There is an inherent tension between the government's aims, set out most recently in the Guidance on Joint Investment Plans for Welfare to Work for Disabled People (Department of Health 2000), of 'making work pay', and its more general policy objective of 'targeting' resources on those most in need. The latter leads inexorably to more and more means-testing and an erosion of the universalist principle. There is a failure to recognise the need to establish a 'level playing field' for disabled people – in other words to make support available on the basis of people's *need* for practical assistance and/or equipment, rather than their ability to pay for it. Unless there is a level playing field approach to the additional support disabled people require, they will always remain at an economic disadvantage and therefore at greater risk of social exclusion.

Opening up employment opportunities for people with high levels of support needs also requires a shift of emphasis in terms of what motivates public policy in this area. While there is some evidence from the United States (Wehman and West, 1996) that supporting people with high levels of support needs yields benefits in terms of improving the workplace culture and decreasing the amount of public expenditure required to support an individual, the evidence of this kind of benefit (certainly in the short-term) may not be robust enough to fuel the motivation required. A potentially stronger motivation is a recognition of the human rights of people with high levels of support needs and of the action required to promote their human rights. Unfortunately, the current social exclusion policy agenda does not generally make links with the human rights agenda.

- **‘Welfare and dependency’**

The discussion about the funding and delivery of personal assistance above raises the question of whether the ‘welfare system’ makes inevitable the exclusion from the labour market of people with high levels of support needs. However, 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 are quoted at the beginning of this article 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’.

Such a perspective challenges the social perception of disabled people as objects of pity and charity. Disabled young people in the age groups 16-19 and 20-24 are less satisfied with their lives and have lower subjective well-being than non-disabled young people (Burchardt, 1999b). While there are undoubtedly a range of factors associated with this, of underlying importance is the lack of respect accorded to disabled people generally. Whenever disabled children or adults are asked about their experiences, the attitudes of others is identified as an important issue. For example, when members of two focus groups of disabled people were asked about their interaction with non-disabled people, they said that ‘they had felt:

- patronised
- avoided
- ignored
- abandoned
- mocked by strangers
- assumed to be stupid

- treated as an inconvenience
- regarded as unfit for public view’.

‘In essence’ the study concluded, ‘they do not feel that they are treated as members of the community, let alone equal members’ (Knight and Brent, 1998, p.6).

Any policy aimed at combating social exclusion has to also address these kinds of experiences. ‘By limiting social exclusion to the effects of extreme poverty, the Government ignores a whole area, which disabled people – not to mention a whole lot of other groups – know only too well – that of being excluded from society because of the attitudes of others’ (Knight and Brent, 1998, p.2).

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, one of the most important factors being the general social prejudices held about people who need help to go about their daily lives.

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 – their rights to be part of their community, to be free from prejudice, to communicate with others, to have choices in their lives. In contrast, the current policy agenda is more concerned with social cohesion than with human rights, more concerned with the threat posed to social stability by unemployment and poverty. As Ruth Levitas has argued, the policy agenda contrasts social exclusion not with social inclusion but with integration, by which is meant integration into the labour market (Levitas, 1996, p.5). 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 harrassment?
- 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. It will be interesting to see whether the implementation of the Human Rights Act has any influence on the political debate and policy developments concerning social exclusion. If Jack Straw, Home Secretary, is correct that 'Over time, the [Human Rights Act] will bring about the creation of a human rights culture in Britain' (Local Government Association, 2000) it may be within the human rights framework that the social exclusion of young people with high levels of support needs is more effectively tackled.

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