'That kind of life?' Social exclusion and young disabled people with high levels of support needs

Jenny Morris.

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Introduction

This report is concerned with the experiences of a group of children and young people who are at a high risk of social exclusion. It is based the experiences of forty-four young people, aged between 15 and 20, all of whom have high levels of support needs. Although the policy context and policy implications of the research are discussed in this introduction and in the conclusion to the report, the main purpose of the report is to highlight the experiences of the children and young people themselves.

In the not-too-distant past 'severely disabled' children were likely to be shut away in long-stay hospitals and other institutions. Today, their right to 'active participation in the community' is recognised in the United Nations Convention on the Rights of the Child and in the Children Act of 1989. Government policy generally over the last 20 years or so has been underpinned by a commitment to enabling disabled children and adults to be included in society.

We know very little, however, about the impact of these policies from children and young people's points of view[1]. Hardly any of the information contained in the wealth of research about disabled children and young people comes directly from young people themselves. In particular, there is very little about the experiences of those with high levels of needs associated with physical,

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[1] A review of some of the relevant research and policies is contained in Morris, 2000.

sensory, communication and/or cognitive impairment. This research project sought to begin to fill this gap in our knowledge and understanding.

What do we mean by 'social exclusion'

An important motivation behind this research was the recognition that current debates on, and policies to tackle, social exclusion do not generally address the experiences of young disabled people with high levels of support needs[2]. There is a need to explore what social exclusion means to this group of young people and what kind of policies would tackle their experiences.

Although addressing social exclusion is fundamental to the 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 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 said, when he was Secretary of State for Education and Employment, '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)

Burchardt drew on this analysis of social exclusion and adults to propose four dimensions of social exclusion for children and young people, in a paper written for this research project:

- 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

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[2] A discussion of the concept of social exclusion and its application to disability policies is contained in Morris, 2001.

- 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).

Our research project also sought the views of young disabled people themselves on what social exclusion meant. Before embarking on the research interviews, discussions were held with four groups of young disabled people (29 in all). When 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.

We looked at what nationally available data might tell us about these dimensions of social exclusion as they affect disabled children and young people. The British Household Panel Survey (BHPS) is the only national data set which identifies disabled young people, includes both under- and over-16 age ranges and provides relevant information. Even then, there is limited information about the experiences of young disabled people and how they contrast with young non-disabled people.

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, and disabled young people in the age groups 16-19 and 20-24 are more likely than their non-disabled peers to

be living in households where no-one is in paid work (Burchardt, 1999b). We already know from research that parents of disabled children face three times the costs of parents of non-disabled children and that disability benefit levels would have to be increased by between £30 and £90 per week, at 1998 prices, (depending on age and level of impairment) in order to meet the additional costs (Dobson and Middleton, 1998). We also know that Black and minority ethnic families with disabled children are less likely than the equivalent white families to receive the benefits they are entitled to (Chamba et al, 1999). Parents of disabled children, particularly mothers, find it difficult to combine paid work with looking after a disabled child because employers fail to take account of parents' caring responsibilities, local support services are inadequate, and schools and hospitals assume parents do not work (Kagan, Lewis and Heaton, 1998).

The four groups of young disabled people consulted at the beginning of this research project identified having friends as an important aspect of social inclusion. However, there is little research about this aspect of disabled children's lives. 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. There appear to be increasing differences in levels of self-esteem between disabled and non-disabled teenagers as they get older and 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).

There is little national data on disabled young people's leisure activities in comparision with their non-disabled peers. Previous research indicates that they have fewer opportunities for leisure activities and that the more significant the impairment, the more limited their involvement in leisure activities (Hirst and Baldwin, 1994, Flynn and Hirst, 1992). Recent research

confirmed that young disabled people participate in leisure activities less frequently than non-disabled young people and also found that parents were much more heavily involved in facilitating leisure activities for young disabled people (Aitchison, 2000). The BHPS found that fewer disabled teenagers (67%) live in households which have access to a car than non-disabled teenagers (80%). This must have an important, limiting impact on leisure opportunities, given the importance of transport for many disabled young people and the general inaccessibility of public transport.

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). Qualitative research has found that disabled children are rarely consulted or involved in decisions about their care (see for example, Morris, 1998, Noyes, 1999) and young disabled people themselves have highlighted the lack of choice and control they have in their lives (see for example, Jawaan Aur Azaad, 1994; Greene, 1998; Bignell and Butt, 2000).

Finally, it is important to note that analysis of the BHPS indicates that 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).

The research participants and research methodology
Forty-four young people, between the ages of 15 and 20, participated in the research. All of them had high levels of support needs – which means they needed a lot of support from other people in order to go about their daily lives. For most, this involved assistance with personal care but for a minority their need for assistance related to their behaviour. The majority of them also had some form of communication and/or cognitive impairment, and a significant

minority also had needs considered to require nursing care (associated with, for example, a tracheotomy, gastrostomy, epilepsy).

We made contact with the young people by approaching schools and social work teams in four parts of the country. The criteria for inclusion in the research project was (a) that they had high levels of support needs and (b) were between the ages of 16 and 19 (although in the event the age range of the sample was between 15 and 20). Of the 44, 18 were female and 26 male; two were African-Caribbean and four were Asian. Twenty-six of the young people were living at home with their parents and of these, 19 were attending a special school, two a mainstream school, five had left school and two of these attended a day centre while three did not use any day services. The remainder of the sample (18) were living in some form of residential provision: seven were in 52-week residential school placements; two were at residential further education colleges; three were living in children's homes (two attending special school, one receiving home tuition) and six were living in adult residential settings (three using a day service).

Twenty-eight out of the 44 young people were not able to participate in a traditional interview so we used other methods to gather information about their experiences (interviewing those who knew them well; observation and 'being with' the young person)[3]. We tried very hard to gather information which indicated how *they* experienced things. While their experiences might be represented by what other people said, or what an interviewer observed, we were careful to get as close as we could to what it seemed the young person was experiencing rather than those around them. There are of course difficulties and limitations with this. A number of those who we could ask questions of used methods of communication which did not use speech, but instead used body language and/or augmented communication (such as Makaton, a communication book or a piece of equipment).

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[3] See Morris (1999) for a discussion of research methods when gathering information about the experiences of young people with communication and/or cognitive impairments.

The structure of the report

This research concerns young people who are generally missing from current debates on social exclusion and whose experiences have also not been fully represented in disability research. This report focuses therefore on what life is like for a group of young people whose 'voices' have hitherto not been heard.

The report is structured according to the issues which were highlighted in our interviews and visits with young people. There are four main sections: relationships; having a say; being 'out in the community'; and the future. From our contact with the young people, it was immediately apparent that relationships were both the most important aspect of their lives, and also a key to whether their support needs were met and their human rights promoted. Also central to the quality of life was whether their wishes were recognised and acted upon, and, for the majority of our sample, communication needs were a major issue here. If they participated in the life of their local community (a key aspect of social inclusion), this could take a number of different forms and we therefore explored both opportunities and barriers to this participation. Finally, we asked questions about the young people's future and this is therefore the last section of the report.

1. Relationships

For the majority of the young people, being with other people was obviously very important to them and they got the most pleasure from interacting with people they knew and who cared about them. This was particularly evident for those with the highest levels of communication impairment. When first observed at a day centre, 19-year-old Mark seemed almost totally 'absent' and – to someone who didn't know him – it would have seemed that he had little consciousness at all. Yet immediately his keyworker came into the room, he came alive, his smile took up his whole face and, as she put her face close to his and spoke to him, his interaction with her was very apparent.

Family

For most young people with high levels of support needs, as for most non-disabled young people, their families are central to their lives. This was clearly observable, not just for those who lived with their families and attended local schools or colleges, but also for those who had gone away to school, college or a residential unit. Sixteen-year-old Philip, for example, went away to a residential school at the age of five. His mother says she knows from his behaviour that he would rather be at home than at school: when he sees his mum and dad at school he 'nearly jumps out of his wheelchair with joy'.

Family celebrations may be an important part of a young person's life. Thomas had been at a residential school from the age of eight and was now in a residential unit about 80 miles away from his parents' home but he was involved in all the family celebrations and smiled a lot when his mother referred to the last wedding they went to. Kamal also went to family weddings, including one which had been held in India. Tahiba was included in all her family's celebrations and enjoyed getting dressed up for Eid.

Siblings are very important to many of the young people in the sample: Joseph, who uses body language to communicate, was observed as being 'very excited when he sees his older brother who he clearly adores'. Fifteen-

year-old Danny watches his younger siblings playing together with delight. Michael, who at the age of 19 moved into a residential unit 80 miles away from his home, is visited every fortnight by his older brother who takes him out to the cinema, to restaurants, and bowling. He communicated that his favourite activity was seeing his brother.

Even when they spend most of their lives elsewhere, some young people are very much part of their families and sometimes create closer family relationships for all members of the family. Katherine's sister described Katherine as 'the centre of the family, the glue that binds them together'. She said that her sister's needs bring the family together in a practical way, because Katherine always needs someone around to look after her but 'also because of the sort of person she is, she's a very loving sort of a person, she likes cuddles, she likes physical contact and she likes being around everyone…I think because she is a very loving sort of a person, she keeps us all together'.

Yet there are barriers to Katherine being part of her family, the most significant being that she went away to residential school at the age of four and a half because her parents wanted her to have access to conductive education. She comes home every six weeks for a fortnight but her home itself is not very physically suitable for her, and her parents are not able to get equipment or support services easily. When Philip is at home during school holidays he has to go to a respite care unit while his parents are at work, which does not seem to meet his needs very well – but his family put up with this because this is the only way he can be at home. We could not assess what the experience was like for Philip.

Ron, who is 19 and moved from a residential school to an adult residential unit, rarely goes home to his parents' house now: there is no downstairs bathroom and his mother finds looking after him very tiring and worrying – because his state of health can deteriorate so quickly. 'But he knows when he's home and he enjoys it,' says his mother. We observed how positively

Ron responded when his parents walked through the door at the residential unit on their fortnightly visit to see him.

Most non-disabled young people leave home when they can afford to and when they feel ready. For these young people, who have high levels of support needs, the decision will almost always be made by parents and be determined by the availability of funding and services.   Parents told us of making decisions which they felt were in the best interests of their child but also revealed how a variety of factors constrained their choices: concern about what would happen when they themselves got older and were unable to provide the level of personal assistance required; concern that their other children should not take on a caring role. They were also constrained by a need for adaptations to their own home which could prove hard to get; a lack of support services which would enable their child to stay living at home. These factors and constraints often seemed to mean that the young people themselves had little say in decisions which have a big impact on their relationships with their families.

Lois' mother hopes that, like other young people, her sixteen-year-old daughter will eventually leave home and share a house with other people her own age. 'Not too far away, so that she can still bring her dirty washing home, like anyone else!' In reality, Lois' mother may well be faced with the same lack of options faced by nineteen-year-old Keith's parents, resulting in his placement in a nursing home, 120 miles away from his parents' home and where the majority of the other residents are over the age of 40. Keith communicated that his favourite activity was being taken out by his parents when they came on their monthly visit.

Possibly the most important aspect of family relationships for this group of young people was that their parents, and sometimes their siblings, were the people who knew the subtleties of how they communicated. Ron's mother felt that staff at the residential unit where he lives did not always pick up his fairly subtle methods of communication. When she comes to visit him, he will

sometimes start to communicate that he is in pain or discomfort but has not communicated this to staff. His parents visit him about every fortnight.

Friends

Very few of the young people taking part in this research had friends of their own age who they socialised with. Most had contact with young disabled peers at school or college but rarely saw them in their leisure time. Only one had friendships with non-disabled peers: this was Joe who was at a mainstream school.

Most young people in this age group would be spending time with people of their own age, doing the things they enjoy doing, or just 'hanging out'. This, however, was not a feature of the lives of many of the young people involved in this research. Kamal, for example, enjoys playing chess but only plays with her brother and mother. She named one girl she was friends with at college but they did not see each other outside college. The barriers to friendships were both simple and complex. Joe expressed his frustration that he couldn't get into his friends' houses, that he had no independent access to transport (which was particularly inhibiting as he lived on a farm), and that some of his friends had developed interests which he could not share – such as playing football. Joe, however, was unusual in that he had a group of friends, disabled and non-disabled, with whom he had been at school for some years. A more common experience was that of Lois, who attended a special school. She had no contact with her classmates outside school and no contact with non-disabled peers. Her mother said, 'Friends is the biggest gap. Because I know what Lois is like when we're in a shop and a group of girls come in. I can see her attitude changing, she's interested and that makes me very sad. But I don't know how to change people's perceptions really.' She talked of how she felt that teenage girls of Lois' age (16) are not interested in having someone like Lois as a friend – 'I understand it's tricky because you know they won't know what it's like to be like Lois and might not be able to find a way of being with her.'

Gwen's mother described how her daughter does not go anywhere else other than school and home. Gwen used to spend time with the children of her mother's friends when she was younger, but this stopped as they became adolescents – 'It's difficult now, they're leading completely different lives, they've got boyfriends, they're doing A levels and going to university.' Sharon's mother similarly explained that she had hoped that the sons and daughters of her friends would have taken an interest in Sharon. However, 'they will be nice to her but they know she's got special needs and that's as far as it goes.' Even if someone of her own age did offer to take Sharon out, her mother said she would find it difficult to trust them 'because she has fits or she might be stubborn and just sit on the floor and not move'.

Jane's mother described how, when Jane was younger, she used to play out with the non-disabled children in the neighbourhood: 'A lot of the children round here used to take her out and play with her. They would push her fast, they all knew how to communicate with her. She has no speech but she speaks with her body and they could understand that. She was in the brownies and in the guides.' However, at the age of 12 Jane went to boarding school and, as her mother said, 'all that stopped'.

Nicky, who lives in a residential home, enjoys going down the pub with his father when he goes home for the weekend. However, his father feels that he would enjoy it much more if he was with young people his own age: 'The most important message I would have for services is that they should make it possible for young people like Nicky to have friends.'

Some young people taking part in this research project named those who work with them as their friends when asked about friendships and who they liked being with. Tony, who is 17 and lives in a children's home, was asked:

> *Who do you like spending your time with?* Clare [keyworker] *Who else?* Mike [another keyworker] And Rosemary [who also works there].

What about the other young people that you live with, do you like being with them? I like being with Clare. I like being with Mike.

Do you have friends at school? Yes. *Who are your friends?* I don't know. *Do you see them out of school or do you just see them at school?* See them at school. *Do you hang around with them after school or see them out of school?* No. I don't have time. Got to come home.

Both Roy and Jane were very close to their keyworker and saw him as their friend. Unfortunately, service providers do not always recognise young people's needs for friends from their own peer group and sometimes see nothing inappropriate in them naming members of staff as their friends. Joseph spends time at a residential respite unit where the manager described his friendship with a staff member and did not seem to think it problematic that the other children there were younger than Joseph.

Young people with high levels of support needs rely on others to enable them to maintain their friendships. For example, when Tahiba left school no-one made any attempt to enable her to continue to see her schoolfriends and effectively they have disappeared from her life. This was a common experience amongst the young people taking part in this research.

Sexual relationships

For non-disabled young people, adolescence and early adulthood is a time of developing sexuality and sexual relationships. It would be hard to imagine talking to non-disabled young people in this age group for very long without the question of girlfriends and boyfriends coming up. In contrast, this happened in only two interviews amongst this group of young people and, even in these two circumstances, it was clear that – given the level of personal assistance the young people concerned required and the failure of those around them to recognise their sexuality – it is unlikely that they had the opportunity to experiment with a physical relationship in the way their non-disabled peers would have been doing. Adrian indicated, for example, that he

had a girlfriend at school but that they very rarely had any opportunity to spend time on their own together. He asked the interviewer if she knew any other disabled people who had got married or lived together: he wanted information about how a sexual relationship might be possible for him.

In spite of the lack of positive adult role models, Adrian was at least lucky in that he had received sex education at school. Tony, aged 17, and Kevin, 15, both live in the same children's home and have received no sex education. Tony's keyworker expressed her concern that he seemed to be scared and confused by what was happening to his body. His special school had a policy of only covering sex education during the final year at school (when they are 18 and 19) and no-one within the children's home had so far felt able to tell Tony 'the facts of life'.   Tony developed an obsession which was perceived to be sexual and inappropriate, and Tony's social worker subsequently organised for him to have access to a 'sexual awareness programme for adolescents with learning disabilities'. However, she didn't think it was necessary to arrange this for 15-year-old Kevin. 'There's not been any particular issues with Kevin with sexuality,' she said. 'You tend to think well if there isn't a problem there then, you know, you don't look for it.' *Do you know if Kevin has been told the facts of life?* 'I doubt it. I don't think that's come up as something we need to do at this point in time.'

Adults often assumed that sexuality was irrelevant because of the young people's level of cognitive and communication impairments. However, some of the young people themselves indicated in various ways that this was not necessarily so.   Mark made it very clear that he did not want women workers in the day centre he attends to assist him in the toilet and Thomas showed both his interest in attractive young women (by following them with his eyes) and his wish to model himself on his stepfather (by insisting on drinking beer with him in the pub – even though Thomas has a gastrostomy). Katherine, who has no clear method of communication, was present when her sister was interviewed about her. The interviewer noted that the only point when Katherine showed any interest in the conversation was when 'we started to talk about boys and sex. At this point Katherine really came to life and clearly

enjoyed the conversation.' Jane's mother described how Jane flirts with young men when she goes down the pub and had communicated to her mother that she wanted to marry and have children when she was older: 'She sees herself as having that kind of life, she wants a good quality of life.'

Adam has two 'enablers', both young men. He has been able to ask them about things that he did not want to discuss with his parents – and neither did he wish to share these concerns with the interviewer.

Affection and physical contact

Physical affection is important to most people. Physical contact is particularly important for a number of the young people in our study because their level of cognitive and communication impairment means that touch is an important method of communication. Yet some of these young people spend long periods of time in situations where there is no-one with whom they have a close personal relationship. For example, Katherine was observed both at home and at the residential school where she spends most of her life. The interviewer noted: 'The difference in the amount of physical contact Katherine has at home and at school is striking. At school, when Katherine is not in her wheelchair, I have only ever seen her lying on the floor (I was told about one evening when she was not well that she was cuddled by the staff). At home she lies on the sofa with someone beside her or is sat on someone's knee.'

For many young people the only physical contact they have with others is when they are being assisted in personal care and other tasks. Tracey was observed at school and the interviewer noted, 'There was little interaction coming from Tracey during the whole session (about two hours long). Several times she did smile when she was touched around the shoulders (this was especially when she was lying on the floor having exercises done to her).' Sometimes, a paid worker providing personal assistance can be a source of positive physical contact. Lois, who experienced very little interaction in a classroom setting, received help from a support worker at lunchtime who was observed greeting her with affection and taking great care and time to feed her. The interviewer noted, 'Progress was slow but not fraught. [The support

worker] often stroked parts of Lois' face and jaw line, both with affection and with the intention of stimulating her.'

Support workers

For some young people a close relationship with a paid worker was key to the quality of their lives. This could be because the worker was someone who they felt they could confide in (for example Rosalie said she could talk to her support worker about things that made her unhappy at school); the worker enabled them to have access to the activities they enjoyed (Darren's support worker took him out to look at construction sites); or the worker could pick up when they were unhappy or unwell because they were so familiar with their method of communication (Danny's respite carer realised that his behaviour meant he was in pain and eventually it was discovered that he had toothache). In contrast, Ron's keyworker worked nights and it is difficult, as his mother pointed out, to know how she could build up a relationship with him – as he was asleep when she was on duty.

We sometimes observed a carelessness amongst support workers in terms of whether they thought about things from the point of view of the young person. For example, after observing a school trip out with a group of young people, the interviewer commented that the support workers 'appeared to care for the young people, but did not focus a lot of attention on them…there was a marked absence of explaining of what was happening, a lack of reassurance and of praise'. We also observed support workers talking about young people in front of them, laughing at them, pushing them suddenly very fast in their wheelchair, placing them on platform lifts or other equipment with no explanation, shoving food or drink into their mouths with no warning, and so on. Some support workers seem to have no respect for the young people they look after. One interviewer accompanied a group of four young people being taken out to a local beauty spot one afternoon from school. Most of the time the staff conversation was with each other, with the occasional comment and banter directed at the young people. Sometimes the staff joked to each other about the young people: the interviewer noted, for example,

Whilst going down to the viewing area, the two staff I was with talked about the night shift staff and how they would have to clean the wheelchair wheels that night, and how they wouldn't like it. When we arrived at the viewing point, they had a bit of a laugh about the necessity to put the wheelchair wheels up against the grass verge and put on the breaks on so that the young people did not end up rolling down the hill. The classroom teacher said to the staff that they'd 'have to run down after them if they did' and 'think of all the paper work I'd have to complete if that happened'. Staff talked about the young people to each other and when someone reacted to their name being mentioned, a member of staff would say 'Yes we're talking about you'.

On the other hand, Kevin's two keyworkers at the children's home where he lived, obviously cared deeply about him and talked in great detail about his needs and their concerns for his future. And Darren's support worker said, 'He's a lovely, lovely little lad, he is, I love him and I've got loads of time for him.'

Most of the young people taking part in this research rely on others to make interaction possible and, if support workers or teachers do not do this, it is easy for the young person to be denied interaction with others. The young people in this study experienced a number of barriers to making friends and maintaining friendships and they often got little support in this important area. Family members were usually both central to the young person's life and also the people who knew best how they communicated. Yet young people and their families seemed to have received little support to maintain these relationships.

2. Having a say

For most non-disabled young people, adolescence is a time when they are able to make more and more decisions for themselves – about what they wear, what they do, who their friends are, what music they listen to, and what values they hold. This was not the experience of most of the young people involved in this research project. There were a number of barriers to having a say in their lives, the most important being other people's reactions to their communication needs.

Recognition of communication

In the case of those who have high levels of communication needs, we found it was very common for the people who knew them well (parents, teachers and support workers) to be unable to provide concrete examples of how they communicated. 'I just know when he's not happy because I know him so well' was a common response. This may be a positive aspect of a close relationship but it means that young people may not have a way of communicating with those who do not know them well. It may also mean that they have limited interaction even with those who *do* know them well. This vulnerability is not necessarily created by impairment but by a failure to establish a means of communicating, and by a failure to share information about or even recognise ways of communicating.

The following dialogue with Gwen's mother illustrates a number of issues common to the situation of many of the young people we visited.

> *When was the last time Gwen had an assessment of her communication needs?* I would imagine at school, I have a speech therapy report – it says Gwen's communication difficulties are profound, that's all it says. *Does she have a way of communicating yes or no?* Yes.   *Are they profound then?* Well they're not. Gwen I think has 95% understanding, so if she has that understanding, if there was a way through… For years I've fought this, for years I've said it's

not 'profound', but I'm just tired of that now, if that's what they say…
you can't go on battling. *How does she communicate yes and no.* Yes
is a positive look at you and if it's no then she looks away from you. It's
eye contact. It's the only thing she has which is really accurate. Her
movement isn't accurate. *Do they work with that at school?* Yes but
they've been trying to go forward with a more universally acceptable
form of communication because not everyone on first meeting Gwen
will understand her. So they want her to be tactile [ie they want her to
touch switches or pictures as a means of communicating], which is
very difficult for Gwen because she's very athetoid, her movement's
aren't controlled. *So why do they think being tactile might be
appropriate?* Well I think they think it's what society would expect. *So
how does she communicate with them at school?* I think they just
know her now. She really indicates with body language. She really
has quite explicit body language. If she wants the loo she does this
shuffling, if she's thirsty she tongues, she looks a lot at what she wants,
until you get the message. If you don't get the message quickly she'll
get agitated and you'll have to ask her and she'll try and eye point,
gesture. *What about responding to questions? If I asked her a
question, like do you like music?* Yes, she'd smile. *And if I went
through a list of different kinds of music?* You mean would she choose,
probably, but she likes a lot of music, from classical, to pop to rap. *But
if I closed the question, if I said do you like classical music?* Yes, she'd
say yes. *If I asked her something more complicated, like do you feel
you have a say?* I wonder what her response would be. I think she'd
understand but I must say I don't think she has a say, not in what she's
going to do in the future. *Why's that do you think?* Because there's so
little on offer for her, so what would it matter what she wants to do?

Possibly the most shocking fact here is that Gwen is 19 and was about to
leave school. During all her years of education she had not apparently had
access to effective assessment of, and response to, her communication
needs. Instead, she was labelled as having 'profound communication
difficulties' and this undoubtedly contributed to her mother's limited

expectations of Gwen's communication abilities. Rather than working with the methods of communication which suited Gwen, the school tried to get her to communicate in a way which was particularly unsuited to her – as someone with athetoid cerebral palsy she has great difficulty controlling her arm and hand movements. However, as Gwen's mother indicates from her last point, even if Gwen's methods of communicating were fully recognised and maximised she would still have few options because our society does not offer much to young people with high levels of support needs like Gwen.

From our observations of her at school and at home, it would seem that Gwen is probably quite similar to Adam, in terms of how cerebral palsy affects her body and cognitive ability. However, their experiences around communication and having a say in their lives could not be more different.   We were told that Gwen would not be able to participate in an interview, although it would seem that she does not have significant cognitive impairment, while we were told that Adam would 'speak' for himself, using clear methods of indicating 'yes' and 'no'. Adam's methods of communicating 'yes' and 'no' had been recognised from an early age by his parents, who had high expectations of his potential for communication. His school did not try to get him to communicate using switches or other methods which would not have suited him. And possibly most importantly he had, as discussed in the next section, been given many experiences of making choices and having a say in his life. When asked *Do you feel you have a say in what happens in your life?* he responded, Yes.

It seems to be quite common for young people to be encouraged to use methods of communication which are seen as socially acceptable, or which a professional has knowledge of, but which may not be best suited to their needs, while those methods which do suit them are ignored or belittled. Katherine, for example, was set an objective by her teachers of using two switches to indicate 'yes' and 'no' although she seemed much more able to communicate by facial expression.

We observed a number of young people at school and it was clear that some of them experienced situations where no-one understood how they communicated. Sometimes their inclusion in lessons – and their opportunities for learning – was tokenistic. One interviewer observed 16-year-old Lois and described how the teacher, using photographs in an exercise about different types of jobs:

> showed her two possibilities, taking care to try to get the photos into her eyeline by placing them vertically on the edge of her tray. Lois did scan these, but no methodology was employed to get her to make her choice – no eye pointing or other method. I had asked [the teacher] at lunch break about this. "How does Lois make choices, what is her 'yes' and 'no'?" and she replied that she really had no idea.

Even when a young person is able to use a communication system such as Makaton, there often seem to be barriers. Philip, who uses Makaton signs as his primary means of communication, was visited one day when he had just moved from one bungalow to another at his residential school. The interviewer noted:

> As the morning went on it became apparent that no-one in the staff group was proficient at Makaton (the teacher who seemed to have the most knowledge was unsure of many signs and was also unaware of any 'peculiarities' Philip had). There did not appear to have been any transition time between staff who knew Philip well from the last bungalow and present staff. There was also disagreement between the staff as to what the signs for certain words were.

There often seemed to be a distressing carelessness about maximising a young person's communication abilities. Sharon was observed to use Makaton at home. When the interviewer asked her teacher about her own use of Makaton she replied that she had just got BSL Stage One and tried to teach staff the 'odd word'. 'However' she went on, 'because we have so many supply teachers, we cannot use Makaton and in any case, they don't use it further down the school so there's no point using it in my class.'

So many times we were told by teachers or other workers that they had plans to do work around communication – when it seemed this should have been done years before (all the young people in the research project were between the ages of 15 and 20). For example, we were told, by his teacher, that 15-year-old Joseph is very effective in communicating with eye pointing and can recognise symbols for everyday objects. However the teacher also admitted that the school had not really 'done much with this' and they 'hoped to build on it next year'.

Sometimes, equipment was inadequate or had fallen into disrepair. Anjum is bilingual in Urdu and English but only has a blissboard in English.   Her blissboard had not been updated and this forced her to use unnecessarily simplified language. Annette had a Liberator Talker which had been supplied to her five years ago and was now broken. Two of the young people interviewed had recently been assessed as needing a piece of communication equipment which was very expensive (£7,000 and £12,000) and which neither education, health nor social services were willing to pay for. Their parents were therefore trying to raise the money through charities.

It seemed to be quite common – particularly amongst those young people with the highest levels of communication and cognitive impairments – for passivity to be treated as a good thing. Philippa's support worker said, 'She's very pleasant, she'll go along with anything.' In contrast, young people's attempts to communicate are sometimes seen as troublesome – particularly in school. Philip was observed during a day at school and many times his attempts at communication were either ignored or suppressed.   The interviewer wrote: 'Philip was often told off during the day for making a noise, going on about things. He seems to have a series of signs which he uses over and over again and this was described to me as being attention seeking.' In contrast, Philip's mother describes him as 'a great communicator'. Danny is someone who uses noises and body language to communicate. He readily establishes eye contact and is often 'reaching out' with his eyes to initiate communication. However, in class his attempts to establish contact with fellow students,

support workers and with the teacher were usually seen as inappropriate and disruptive.

We interviewed or visited with a number of young people who had recently moved from school to a residential home. In some cases, the home had received useful and comprehensive information about how the young person communicated but in others they had either not received any information or the information turned out to be of little use. We were sometimes shown information, for example, which seemed to have been based on communication assessments made many years ago, and instructions which did not make much sense. Michael's keyworker, for example, said 'The school gave us information about communication – but it wasn't always accurate and some of it's quite old. It listed "key gestures to use when speaking to Michael" which didn't mean anything to us. Also it didn't tell us that he has clear ways of communicating yes and no.'

It was clear that, for many of these young people, a failure to maximise their communication potential meant that, once they moved out of a situation where someone knew them well, they were very vulnerable. They had no way of telling anyone if they had toothache, or were feeling unwell, or uncomfortable, or were being abused. This must be very frightening and at times could be life-threatening.

In only a few instances did we encounter a situation where a move from one service to another increased someone's potential for communication. This was Mark's experience. We had been told by his school and by his mother that Mark was not able to express preferences and had no method of communication. Indeed, observation at school and at home seemed to confirm this. In contrast, when he was visited at the day service he moved onto when he left school, the manager described him as 'one of our more able clients'. She went on to recount how he had received an assessment from a speech therapist over a six-week period, and described the work that had then been done with support workers on Mark's communication needs, and

how each day his support workers were expected to fill in a form showing what choices Mark had made and how he had communicated his preferences.

Making choices

Perhaps one of the biggest barriers to making choices is when it is assumed that impairment means that it is not possible for the young person to make choices. Her sister and mother said that 19-year-old Tahiba was not able to make choices – 'It makes it very difficult, we have to think for her. To be honest with you, there's no communication there at all. It's difficult.' However, Tahiba was present during the interview and was communicating using body language and facial expressions – particularly when the interviewer asked about friends and what she liked doing. Indeed, her sister described situations where Tahiba communicated her needs and preferences very clearly: 'For example, if she wants a cuddle, she'll crawl up to you and sort of put her face near you and she'll initiate that she wants a cuddle.'

It is not always cognitive or communication impairment which gets in the way of exerting choice. Anjum's family allow her very little choice in her life. She told us that her mother keeps her benefits and her parents buy her clothes (without taking Anjum with them to the shops). She does not go out much. 'It's too hard' she said. 'The wheelchair and me are too heavy. If I had a specialist vehicle or chair, I might perhaps go out more but I don't have this opportunity.' Two care workers come into her home each morning and evening to help her but she has no influence or choice over the selection of carers who are sent by an agency. She would like to be able to choose. She told us that sometimes the care workers do things which she doesn't like and she tells her mother about this, as she wouldn't be comfortable complaining directly herself – 'they seem to be in such a hurry all the time'.

Sometimes a lot of attention is given to choices over day-to-day things like eating and drinking and little or no attention to the bigger things – like going out, or where the young person will move on to following school. When Katherine was visited at her residential school, it seemed that a lot of attention

was given to going through almost a ritual of choice of whether to drink tea or coffee, but she was given no opportunity of choosing what to do after school or at weekends. She was also not able to choose to have a calendar of the Chippendales on the wall in her bedroom but had to keep it under the bed, to be brought out on 'special occasions'.

Ron's ability to make choices is very much determined by the ability of others around him to recognise the way he communicates preferences. This was illustrated in the disagreement between his parents and staff at the residential home as to whether he should go on holiday. His father said, 'We felt that the benefits were more in the mind of the staff. It would involve Ron spending long periods of time in his wheelchair which he finds very uncomfortable and being in an unfamiliar place which he doesn't like. But because he can't say what he is feeling they might think it's OK.' Ron's way of saying 'no' is that he just puts his head down and 'shuts out' the rest of the world: his parents feel this is easy to ignore.

Most of the young people involved in this research project spent time away from their homes, at boarding school, residential homes and/or in respite care settings. These were choices that others made for them. In some cases it was seen to be in their best interests (to attend a specialist school or college for example); in others it was for the benefit of others (primarily in order to give their parents a break for example); while in other cases this was seen to be the only way their needs could be met (for example young people who are considered to have nursing care needs). It was only rarely possible to discern what the young person themselves felt about these placements. Nicky's father reported that Nicky associated the theme tune to the television series *Heartbeat* with the time, on a Sunday evening, when his parents took him back to boarding school and told of how 'every-time he heard the music for *Heartbeat* he used to cry his eyes out'.

When young people do not have a say within a setting in which they spend time, this is reflected in the institutional 'feel' of, for example, the residential respite unit where 15-year-old Joseph goes on a Friday night. His bedroom,

the interviewer noted, was 'very, very bare…no posters or anything bright and no toys'. Another interviewer, who visited 19-year-old Lawrence at the residential unit where he lives, commented: 'There was little evidence of an effort being made to make the place homely. It certainly does not feel like someone's home. There is a lack of art/pictures and colour. I remember seeing one vase of daffodils, but they were lost in such a large (sitting) room. There was a lot of clutter that made the place look unkempt, for example rubbish outside by the barbeque, equipment left in hallways. The exterior of the building also made me think of a hospital or doctor's surgery. The physical space therefore was enough, I thought, to make one feel down.'

Music is often very important to young people and even those with very little other choice in their lives make their preferences known when it comes to music. Gwen has little choice over the clothes she wears or over food, which are both chosen by her mother. However, when it comes to music she expresses her preferences very clearly and her choice of music is very different from her mother's. Anjum is able to express her preferences in terms of the music she likes – the radio station India 1 – and, like many teenagers, experiences her mother's disapproval of her taste in music.

Rosalie was the only person who said that she had control over who gave her personal assistance. She also had clear ideas about having a home of her own, where she wanted to live and go to college. While she has a high level of personal assistance needs and uses augmented communication, she was one of the very few young people who came across as confident, and able to express her opinions and individuality freely. Physical dependency and communication impairment does not necessarily create passivity and a lack of independence.

Communication of needs
If young people are not able to say what their needs are, this can have a major impact on the quality of their lives unless those around them are able to understand whether they are in pain or are unhappy. We found that, for those

with the higher levels of communication and cognitive impairments, it was common for those around them to feel that they cannot know what is going on for them. Philippa's headteacher reported that she had been through a period of 'crying and touching her eyes a lot'. She said that the staff had called a meeting to discuss this and 'felt it might be epilepsy and decided to monitor her'. After a while Philippa seemed better and they decided that it must have been that she was 'unwell or had some internal trauma'. Anna's acute appendicitis was misdiagnosed as 'pain associated with ovulation' because the doctor did not recognise Anna's communication of her symptoms – or did not pay much attention to the information her mother gave him.

Both Thomas and Ron had recently been diagnosed as needing glasses as a result of eye tests which were done at the residential unit they moved into when leaving school. Their visual impairment had not been recognised at the residential schools they attended.

Ron had recently started biting his lip which, according to his mother, is a sign that he is in pain but no-one has managed so far to find out what is going on for him. We also picked up instances when those around them did not recognise that some experiences may be distressing. Philip, for example, had become distressed while on a visit to a museum when his group were being shown human bones on display. Philip has on occasion been extremely ill and had nearly died two years ago. The interviewer noted that she felt 'There's an awful lot to Philip that is just getting ignored.'

Sometimes, even when young people are able to communicate their feelings this seems not to be picked up by those around them. Jane boards weekly at her school and when she was interviewed, communicated that she does not like the boarding house. She indicated that she has no choice over things such as what she ate or what activities she does after school, that she did not like the people who assisted her there, and that the housemother shouts at her and tells her off. This information, which Jane communicated by a combination of indicating 'Yes' and 'No' and using Bliss Symbolics, came as a surprise to her support worker who was present at the interview.

For some young people, a failure to maximise their communication abilities can make them very vulnerable to abuse. Paul's mother found out that the driver who picked her son up from school had been hitting him but it was only when a teacher saw this happen that anyone knew. Anna's mother also found out that another child had been hitting her daughter in the children's home they both lived in. 'I only knew about it because it happened one day I was there. Anna didn't react… I was just amazed that she didn't flinch.'

Some young people may use speech to communicate, yet other aspects of their impairment or experience make them vulnerable to not being able to communicate their needs. Darren's mother said that while Darren expresses his frustration and dissatisfaction with things at home, 'He tends to be very compliant at school. He's very vulnerable. He asks questions but he will never answer questions. You would have to know him very, very well before you knew whether he was unhappy with something.' Kamal said she was bullied at school, but didn't tell anyone about it – 'I didn't have a chance,' she said, although she has recently been able to tell her social worker about being bullied at college.

Sometimes, it is necessary to have access to specialist advice in order to understand someone's behaviour but this is not always available. Darren's autism was undiagnosed for some years and this meant his family had difficulty understanding why he behaved as he did. Having information about the nature and impact of someone's impairment can make a big difference to whether needs are recognised. Anna's mother found her habit of eating anything she could get her hands on very, very difficult to deal with. 'I really didn't know why she was doing it. I knew it wasn't hunger, I thought it was attention, and I thought, "Well I give you all the attention I can why are you doing it?" I know it sounds ridiculous but it really did get me so annoyed. I thought, "Why are you doing this to yourself? It must be dangerous."' After some years of this, a community mental health nurse became involved who – by monitoring Anna's behaviour – found that it manifested itself during the 72 hours leading up to an epileptic fit. Having received a diagnosis and a reason

for her daughter's behaviour, her mother found that she was able to respond to Anna's needs more effectively: 'Once he told me it was just like a weight had been lifted.'

Unless channels of communication are opened up between these young people and those around them, it is difficult to see how they can experience ordinary human relationships. A denial of communication means a denial of so much of what it is to be human. It means being denied a say in what happens to you and creates a risk that needs will not be recognised. At best this results in a very poor quality of life; at worst it results in a threat to life itself.

3. Being 'out in the community'

An important part of an experience of social inclusion is of being part of the local community. We therefore sought out information about young people's experiences which brought them into contact with their local communities.

School and college

Schools and colleges are not only (potentially) part of the community but also communities themselves. Thirty-two young people who participated in this research were attending school or college. Only two of these went to a local 'mainstream' school.

In order to participate within a community such as a school or college, it is necessary to interact with others and to have one's individuality recognised. This can be inhibited within any education setting because there is a curriculum to be got through and teachers have to exert a level of control over behaviour in order to create a productive learning experience. So in some senses, the lack of choice and control experienced by young people with high levels of support needs, when they are in a school classroom, is no different from that experienced by their non-disabled peers. However, the greater powerlessness experienced by these young people – because of their high level of support needs – has particular implications.

For example, it is quite common for teachers to use ridicule as a method of controlling naughty non-disabled children and we observed a teacher using ridicule in a class of seven disabled young people, all of whom had significant communication and cognitive impairments. As the interviewer noted, 'These remarks can seem intimate and affectionate, but underneath there is often a sense of insult, and a reminder of who has the power.' The fine line between control and a lack of respect is easily crossed.

Darren's mother felt that, because his school did not have the resources to cater for his particular needs, 'School has always been something that Darren

has endured rather than participated in.' We observed some classroom situations where the lesson and the interaction between class and teacher seemed to have no relevance for the young person concerned. Lois, for example, has no speech and neither her mother nor her teacher was able to tell us how she communicated. She was observed at school and the interviewer noted:

> In the first lesson, which was about prepositions (students being asked to stand [sic] behind, in front, beside someone else) Lois was simply pushed into place and spent that time with her back to the rest of the group, having been pushed in that direction [in her wheelchair]. She looked impassive, occasionally moving her head slightly as if scanning for the light or some movement… After that exercise, Lois was returned to her place with the others and they had a sort of game round the table where objects (such as cutlery) were placed under a cloth and they had to say which one had been taken away. As Lois was next to [the teacher] on her left and the circle went the other way, it seemed an endless time (actually 20 minutes) before Lois was in anyway involved. She could not see what was on the table, nor did anyone explain to her what was going on. There was quite a bit of laughter, praise, joshing from [the teacher and support workers], with [one of the other children] making a sustained angry outburst... Lois frowned and moved her head from side to side, or sat with her eyes almost shut. She occasionally moved her arms. She looked absent. I felt that, if it were not for the noise and sense of activity, she might go to sleep but she did not. Finally it came to her turn. Basically [the teacher] did it all for her, putting the objects on her tray and quickly going through the process in a way which Lois could not possibly access, because it was too fast, out of her eyeline and anyway incomprehensible.'

Later on in the day there was a session which the teacher called yoga, but which, for Lois, involved being lifted out of her wheelchair onto a foam wedge

> 'tummy down and head over the end, hanging down. Her hair hung down over her face. She moved her head from side to side trying, I imagine, to get some bearing and maybe to see the others, as she

could not easily do that, being sort of sideways onto the group and slightly into one corner… she lay there, her head dangling, for [about half an hour and then the teacher] took Lois off the wedge and rocked her holding onto her from behind, facing into the corner…This lasted for about six minutes. She was then lifted into her chair and taken out to the toilet.

Lois' mother had said that the school gave her a lot of choices but the interviewer noted 'I never saw her being given one option.' Moreover, 'Throughout the day I never saw any act of praise towards Lois.'

Breaks in the school day, when children play outside, are the times when friendships are made and relationships develop. In contrast, for some children and young people with high levels of support needs, these times can be experienced as being placed in their wheelchairs in a corner of the playground, where the play equipment is not accessible to them and where no-one facilitates or recognises their communication.

School can also be a place where young people experience bullying by their peers and this is no different for young people with high levels of support needs. While Rosalie was in control of most parts of her life, she had not felt able to tell anyone about a boy at school who called her names and taunted her about her electric wheelchair.

A number of the young people involved in this research, while attending a special school, also went with their class to a local further education college. Their school teachers obviously hoped that this would provide some experience of social inclusion for them, although we were told of many barriers – such as lack of physical access, lack of preparation or relevant skills on the part of staff, and sometimes hostile reactions from other students. Our observations also highlighted difficulties created by teachers and support staff from the special schools. Some indication of what it all might be like for the young people involved is gained from one interviewer's account when she

accompanied three young people when they went to a further education college with their class group from a residential special school:

When we arrived at the appointed door, there was no suitable parking space. The students were taken off the mini-bus which then had to be re-parked nearby. The teacher taking the class came out to greet the students and promised to sort parking out for the following week. We went into the building and up to the art department in the lifts. The class the students were taking was being put on especially for them – there were no other students there, although students in the next door classroom would occasionally pop in for equipment/materials.

There were four students from the school, one teacher, three support workers and the teacher from the college. It emerged that the college teacher had no knowledge of the students, what they might enjoy doing or their communication methods and needs. At one point the teacher from the school said that he had not sent information about the students, in spite of the fact that they did have a form outlining numeracy, literacy and communication skills, as it might have put her (college teacher) off to such an extent that she would not have been willing to have them. This was said within the hearing of the students.

The college teacher had laid out some materials on the table – Tracey and Philip immediately grabbed at them and tried to pull them off – Tracey looked very mischievous and cheeky as she did this – indeed it was only during these 'naughty' moments that she seemed to come alive.

The first activity was papermaking. This involved putting different materials into a shallow tray of water, mixing them up, stirring, pulling them out in strainers and placing them on j-cloths. They were then taken to a nearby table to dry. Initially the college teacher had said that it was her plan they should all make a little book which they could put things in (photos etc.). Once they had started, however, she said that

she didn't think this would be possible and they could just make one or two sheets of paper each.

At no point did the college teacher say hello and/or introduce herself to the students although as the lesson went on she did interact with Philip and Katherine. Each student had a teacher or support worker supporting them. None of the students seemed particularly interested in the activity going on, nor did they appear distressed by it – indeed the staff mentioned on several occasions how relaxed they all were and how much they seemed to be enjoying it. It appeared to me that the activity was done by the supporting adult who would occasionally take the student's hand/arm, put something in it and stir the mixture. Philip wanted to communicate with sign and showed little interest in mixing etc although he went along with it when his hand was taken. Philip pointed to his head and then at the school teacher – this was because the teacher had arrived at work with a hat on and Philip wanted him to put it on again. From time to time this would happen and then Philip would be told to 'get back to his work'. The college teacher picked up on this interest in hats and said that they would have a hat making session one week.

Tracey did not participate at all in the mixing, nor did her support worker make any big attempts to involve her – it was just as if he was doing all the stuff for himself. She responded noticeably and very positively when she was touched – even touched by mistake – and took a couple of opportunities to hug her support worker when he was in the right position to do so.

Katherine also did not seem to be engaged in the task, but was quite happy to sit alongside [Katherine has quite a significant visual impairment and it is unclear whether any accommodation was made for this in the activities that were being carried on]. The collages were very like the kind of thing young children make at playgroup…

At the end of the session the school teacher gave each support worker an evaluation sheet to fill in – 'what I liked best', 'what I didn't like', etc. No one communicated what they were doing to the students at this point, nor did they ask them what they thought.

When it was time to go, in spite of the fact that some of the staff put jackets on to go outside they made a joint decision not to put jumpers back on the students as it was 'too difficult' when they were tired.

Perhaps the most distressing part of this description concerns the lost opportunities for communication. This was a situation which was potentially 'resource-rich' – there was one teacher and four support workers shared between four young people. Yet these human resources were used to focus on a 'product' which had been set by the teacher with no knowledge of the needs, interests or abilities of the young people. The sheets of paper were in fact produced by the support workers, with little input by the young people, who had to endure a session where they were effectively excluded from interaction and learning.

It is difficult to imagine the cumulative effect of a daily experience of being treated with little respect and a careless disregard for individuality. These young people are certainly not participating in their school or college community when they are treated like this. Moreover, for most of them, their school was not part of the wider community and going there meant that they were set apart from their non-disabled peers.

Going out

Most non-disabled adolescents have more freedom to go out and about in their locality as they get older. Their use of public transport is an important part of this increasing independence but for young disabled people, public transport rarely offers such freedom. Nineteen-year-old Nicky has left school and recently moved into a residential home. Nicky's father said, 'Nicky enjoys company, he's a very social lad, he loves being out and about, doesn't matter where it is.' The biggest barriers to Nicky being 'out and about', according to

his father, are difficulties with transport. Public transport is difficult because Nicky uses a wheelchair: 'It's a problem firstly to find a station without stairs, which is horrendous, and then to find one with lifts, with lifts that are working. We often go to plan a route and go somewhere and then find the lifts aren't working. The authorities aren't helpful at all despite phoning through and making arrangements for someone to help you, you get to the station and they say, "I'm on me own, I can't help you".'

Some wheelchairs are too heavy for going out and about if the young person is likely to encounter steps or kerbs. Young people and parents can find it difficult to get professionals to recognise this need. Mark's mother said: 'I've been moaning about the wheelchair for a year now, to the physio, but she thinks she's right and everyone else is wrong. I said, "You come down to London and try pushing it along the pavements, where people park their cars over the pavements, where you can't get up and down." I said, "You try it." It's all right here [at school] because you're all on one level. She said, "He can't possibly have another wheelchair because it would cost too much money."' Young people can find it very difficult to get mobility equipment which not just meets their needs but which also looks good. As Joe said, 'I mean you want something with a bit of class. I *am* 17.'

For some young people who are at residential school, there are not enough staff around to enable them to go out. At one residential school we were told that sometimes when staff take the young people out in a group, one staff member has to push two wheelchairs. We were also told that the new lifting regulations meant that staff had been instructed that hoists should always be used when transferring a young person in and out of their wheelchair. This could inhibit the possibility of going out and about.

Some young people with high levels of personal assistance needs, and particularly those with so-called nursing care needs, are denied access to activities which other disabled young people have access to. For example, Lois couldn't go on a summer camp organised for young disabled people –

her mother told us, 'She couldn't go last year because they couldn't get someone to take care of her personal care needs.'

On the other hand, Joe, who is one of only two in our sample to go to a mainstream school and who has non-disabled friends, is quite happy to instruct his friends in the assistance he requires. He has a tracheotomy and described how he has instructed some of his friends on how to do suction: 'If people say I don't want to do that I can understand that. But those that are pretty willing… You can't really go wrong and at least I can shout back at them if they do something terribly wrong.' However, like most of those in our study, Joe does not have independent access to transport and has to rely on his mother to drive him.

The attitudes of the general public can make being 'out in the community' an unpleasant experience. Gwen's mother recounted how sometimes Gwen was 'not very happy to be out, particularly in shopping malls and places where there's people, and children tend to be inquisitive, and she doesn't like that, you can see, her head hangs very low'. Gwen also doesn't like to eat and drink in front of others: 'Gwen has eating problems and drinking problems and she will not drink when she's out. She won't drink from a bottle when you're out, not in front of people… she won't eat in a place where there's other people, her food has to be mashed.' *Do you think that's because she's aware of people staring?* 'Yes. Well, people don't just stare they make comments – "Oh it's so difficult for you, how do you cope?" I mean, they do say things like that, people are so stupid and thoughtless.'

The manager of the day centre that Mark attends described how 'We've been banned from certain cafes and shops, because of the way certain service users eat, we were told it puts people off'. Philippa's mother talked about the difficulties they experienced on a family trip to a leisure park: 'You feel you shouldn't be there, as if it's not for you.' Philippa's father explained that it was difficult to get Philippa on the rides and there weren't any 'allowances' made for Philippa to enable her to go on the rides.

Ron's parents are Christians and when their son moved into a residential home on leaving school at the age of 19 they made contact with the local church to see whether he could attend services. Initially, it was suggested that his mother took him to a service for children: 'It was a mother and toddler Christmas service and they thought it would be a more suitable service but it was almost a disaster because we went into a side room, which was very small room, and of course we almost filled it [Ron's wheelchair is quite large] and then these mothers with young children came in and they didn't know what to expect with Ron and the children were frightened. It was a very negative experience.' Subsequently, however, Ron started going to the regular Sunday service and has been welcomed as part of the church community, who are, however, all older than him. Ron enjoys the conversation of young people his own age, says his mother, but rarely comes into contact with them except through his sister and brothers.

Ron's mother thinks that negative attitudes of the general public got worse when he started tube feeding – she thinks people are frightened by the tube which has been inserted into his nose. On the other hand, she has recently been pleasantly surprised by the reactions of people working at the leisure centre near to where Ron now lives. 'Staff hold the doors open and don't look negatively at us as we approach the kiosk or whatever, and don't assume that we would be a problem.' In the same complex there is an ice rink and his mother took him ice skating which he enjoyed. 'I rang up the leisure centre and again they were very positive. They didn't seem to think there would be any problem. They said there'll be someone there to meet you and sure enough there was. They got the mobile ramp out and helped us onto the ice with his wheelchair… As a community generally I think we've had very positive experiences here, very different from where we live.'

Particular needs related to impairment can make being 'out in the community' difficult. The standard wheelchair-accessible toilet is not suitable for someone who needs to lie down to have an incontinence pad changed and this was a major physical barrier to going out for any length of time for a number of the young people in this study. There can also be attitudinal barriers associated

with impairment. Philippa's mother explained that she didn't like changing Philippa's incontinence pad in the communal changing room at the local swimming pool as she felt people stared at an adult (ie Philippa) having to lie down and be changed. The consequences of someone's impairment for their behaviour can also make being 'out in the community' difficult. Anna's mother described how:

> If Anna likes your face she'll go up to you, kiss you, cuddle you and some people don't like that. It was an awful problem, we couldn't go anywhere, it really was very very bad… Elderly people didn't mind so much, although she could knock them flying if you weren't careful, but it was the younger ones that were frightened of her, either her age or a bit younger. They would be very put off by her. They just couldn't understand why she was in their faces. Some people were absolutely horrified that she was doing this to them.

Both Philippa and John's parents talked about how some members of the public don't realise that their child is disabled and then react badly to their behaviour. 'He doesn't look any different from any other 16-year-old and when he's having tantrums you get comments, "He wants his backside slapped, a lad that size shouldn't be allowed to behave like that…"' reported John's mother. Philippa's father said, 'From a distance, when she's sat there, she looks like a normal 12 year old, although she's 18, and they think she's having a tantrum… We got her on the beach and she started screaming, shouting, everyone else around was looking…'

John's mother explained that she doesn't let her son go into the men's toilet when they are out because he would have to go in on his own and she thinks he is too vulnerable. 'I've had one or two comments, when I've taken him to a disabled toilet, while he's in the toilet, he should be going into a normal toilet… One member of staff turned round and said, "Do you know that's a disabled toilet?" and I said, "He *is* disabled" and she said, "he's not in a wheelchair…"'

In some instances, a young disabled person appears not to notice public attitudes towards them, but the person accompanying them is more affected by such attitudes – and this of course can then impact on the young person's opportunities for going out. Thomas' mother describes what happens when they go on their regular holiday to a caravan park on the South coast. 'We take him into the clubhouse… and we're by the bar and everyone coming in stares at us all the time and it really gets to me. He doesn't give a damn, he's laughing at the competition or whatever's going on.' She also talked about how she finds the pitying looks of other adults out on the street so difficult to deal with:

> You've got people with strange views… who'll come up to him and say "Oh bless him" and I remember one lady coming up to me and saying "Have you got any children who are normal?"… Sometimes, when I'm having an off day, I just don't want to walk down the road with him – when you're walking along they just stare and it can feel continuous.

Impairment in itself can get in the way of going out: 17-year-old Roy gets tired for example and this limits his activities. Ron's parents felt that the residential home he moved into didn't understand that Ron finds it very uncomfortable being in his wheelchair for longer than a couple of hours. 'It's all very well saying that he should be going out shopping, going on trips, but he'll be in real pain after a couple of hours.' On the other hand, the residential home where Lawrence lives recognised that he gets very tired and that, while some of his co-residents might want to be out and about every day, Lawrence wouldn't want to do this.

Some young people in this study rarely went out of their homes. Nineteen-year-old Tahiba, having left school, was at home all day – her sister said, 'When we do take her out to the park she's just oooh, you know, she's like a little kid, she goes mental, she's so excited, she wants to look at everything…'

Holidays

Holidays can be an important part of a young person and their family's life, particularly when – as for Gwen – life otherwise revolves entirely around

school and being at home. Gwen's mother said: 'Holidays are a really important part of Gwen's life… We try to have a really good holiday every two years. I suppose it's the only time we take her to discos, that we actually, you know, the whole holiday is time for her.' A number of barriers have to be tackled, however, to make this possible. Gwen's mother has to make sure that the airline can provide blended meals and that there is a bath rather than the shower which is more usual in wheelchair-accessible hotels or self-catering accommodation. As Gwen can be 'quite vocal' they also look for the type of holiday which will keep them away from people who might object. One holiday which worked well was where a hotel had separate bungalows in the grounds but at the same time had 'in-house entertainment, two pools, the beach a walk away without steep slopes'.

John, however, has never been on holiday. He is one of two disabled children and his mother is parenting on her own. When we asked young people about their hopes for the future, a number of them talked about holidays that they wanted to go on – particularly trips abroad.

An independent social life?

Having a social life independent of family is part of growing up. For these young people this can be very difficult. Roy was unusual in that he said that he has a social life independent of his family and that he has a good deal of choice in his life. He also has a girlfriend. His independent participation in the community is inhibited, however, by the fact that he has been waiting three years for an electric wheelchair that he can use out of school. His parents have generally found it very difficult to find information about sources of assistance. They had had no contact with social services for a year and found other parents the most useful source of information and advice.

Nicky's father felt that the biggest gap in his son's life was a friend with whom he could go out to the pub. The lack of a friend his own age meant that Nicky had to rely on his father for this kind of social life. Indeed, many of these young people rely on their families for access to all the activities that take them 'out into the community', particularly because, apart from Joe and

Richard, none of them had a group of non-disabled friends and, apart from Adam and Darren, none of them had access to the support they needed to go 'out and about'.

Adam is 18 and goes to boarding school. During the school holidays at home he has an 'enabler' for a certain number of hours per week (provided by his local social services department). Adam, who uses body language to communicate 'yes' and 'no', told of how they go shopping together and have waged a campaign against a large clothing store in London's Oxford Street because the changing rooms were not accessible. When asked what else he did, Adam told his enabler to describe this and he said:

> We go shopping, we do cooking, we do lots of things around transport – for the last couple of years since more buses have started to be accessible sometimes we just literally go out and get on any bus we see that has disabled access and see where we end up, so we've visited a lot of places. Using buses, trains, boats, hot air balloons, anything else we can get on.'

Adam has a video camera and films a lot of what he is doing and where he is going. He hoped to spend his summer holidays doing digital arts.

Some young people, if supported to, have their own way of being in the community. Darren, for example, is solely interested in building construction. 'He knows all the different building sites in the North East' said his mother. 'If someone is having double glazing put in he just wants to stand and watch, talk to the workmen… This construction stuff has sort of taken over his life but he's so happy and gets such a lot out of it and he's 15 now and he's decided what he wants.' However, this particular form of participation in the community is only possible because Darren has a 'befriender' provided by social services who spends three-hour sessions with him twice a week after school during term time and 15 hours a week during the school holidays. This means that Darren can go around the building sites that fascinate him, spending time watching and talking to workmen.

Sharon has just been allocated a support worker who will take her to activities she enjoys doing. Her mother was delighted that Sharon would now get the opportunity to go places and do things that would be inappropriate for her mother to support her in – such as clubs and concerts. She hoped this would also give her the opportunity to make friends.

One important factor which gets in the way of making friends is that casual interaction with people is difficult when a young person has to rely on others to take the time and trouble to understand how they communicate. Gwen's mother said that she felt Gwen would very seldom even have eye contact with anyone she didn't know – 'I always feel she doesn't trust them. But I blame the public at large because they ask such stupid questions. "Does she understand? Can she hear?" You know, when she's sitting there. I think if someone talked about me in the third person, I'd also tend to ignore them.'

Institutionalisation within the community

Many of the young people in our study were living very limited lives. Angela had left a residential school at 19 and lived with her parents and brother. She rarely went out and had no friends of her own. Her mother said that they could rarely go out together as a family as Angela's wheelchair was too heavy and large to get into their car and her care needs meant that being away from home for more than a few hours was difficult.

Lawrence lives in a residential home which, according to the manager, is part of the local community. However, it was not possible to identify any activities or occasions where Lawrence came into contact with the community – other than visiting his local GP or when the local community was invited into the home for fundraising events. For a number of the young people in this study, contact with non-disabled people (other than their families) was limited to paid workers and to situations where they were the recipients of other people's philanthropic activities.

Most of the young people in residential homes did not have access to any form of public and personal transport: in other words their only means of going

out and about is the transport belonging to the home which is usually a large bus, often with a logo of the organisation or of a charity which had donated it emblazoned on the side. One residential home, however, had sold their two large buses and bought people carriers instead.

Few of the young people involved in this research had a peer group with whom they 'hung out' or pursued activities they enjoyed doing.   Their contact with their local community was often difficult; they were stared at and had to endure negative comments when they went out. Many of them also experienced physical barriers to going out and about, such as lack of adequate mobility equipment, or inaccessible public transport and venues. Most of them lacked the one-to-one support which they needed in order to really be included in their local community.

4. The future

Amongst those in our sample who had not yet left school, plans were being made by parents and professionals for their future. Parents sometimes find the meetings to discuss these plans very unsatisfactory. Darren's mother, for example, had just been to a transition review meeting when she was interviewed. She said 'I'm still quite emotional about it… That transition review meeting to me was very important but I didn't feel it was as important to anybody else.' Katherine's parents were shocked to find that a total of 22 professionals – some of whom they had never seen before yet all of whom had their own ideas about on what should happen to their daughter – turned up at a social services meeting to discuss their daughter's future. Ron's parents felt that the transition planning which had started when their son was 14 had been a waste of time: 'Once he hit 18 they handed him over to adult services and they started from scratch – they did their own assessment and the social worker then contacted health about funding a residential placement.'

For most of the young people involved in this research, meetings – which rely on speech and writing for communication – are an inappropriate method of involvement. Only a few of them participated in these plans for their future. One was Roy who felt that he was fully involved in the transition planning process. He said at the review meeting, held during his last year at school, that he did not want to go away to college but wanted to go to the adult centre attached to his school.

Joe is also involved in discussing plans for his future when he leaves school but he faces a dilemma. He currently attends a mainstream school which has a 'special needs' unit and is studying for GCSEs. However, none of the further education provision locally can cater for his personal assistance needs and, so far, none of the specialist colleges that he has looked at are able to meet both his academic and his care needs. Joe explained, 'My head is virtually all I've got and it's important I use my brain.' *So you need*

somewhere that's good academically? 'Yes but that's also got the care, and that can deal with blocked catheters and trachy changes and things'.

Most of those who had turned 19 in our sample had left school in the term of their 19th birthday and had not moved on to any other educational provision. The general opinion about the needs of these young people seemed to be that there was no benefit to be gained by further education and/or no provision within further education for them. As Lois' mother put it: 'I think they think you're a day centre case, Lois.'

Ron's parents said that lack of information about where their son could move onto when he left residential school at 19 was a major problem. The only information provided by their social services department was 'a list of old people's homes'. Ron has needs that are considered to require nursing care and, as was the case with many of the young people in our study, his parents did not feel able to look after him at home. Gwen is 19 and should be leaving school this term. At her last annual review of her Statement of special educational needs, no-one from the social services or the education department turned up. As her mother said, 'It was just school, her teacher, her physio, the headteacher and myself. I don't know what transition plans we can make.' Ten months ago, for the first time, a social worker carried out an assessment of Gwen's needs. However, this just covered what she couldn't do for herself and what her mother had to do for her. It did not cover her communication needs, nor her needs for continuing education or for leisure or friends. Gwen's mother recounted how, as a result of the assessment 'They graded her at level three in terms of care which means 597 care hours a year… and we haven't had one hour of that yet.' Gwen's mother had a letter from social services, following the assessment, which stated that 11 hours care per week would be provided 'when services are available'.

Unfortunately, there were few instances of assessments being used as a way of exploring what someone might like to do with their life and what help was required to make it possible. Jane, aged 18, who uses body language to

communicate, had been helped by her mother to aspire to a home of her own but both of them lacked information about how this might be possible.

Has anyone ever talked to you about one day you maybe having your own home? Yes. *Who was it? Was it your family?* Yes. *Would you like to have your own house one day?* Yes [smiles a lot] *Has anyone ever given you information about different ways you could live on your own, what kind of support you might get?* No.

Joe too was dreaming about having a home of his own. 'To be honest' he said, 'I don't want to live with my parents all my life… In a perfect world I'd have someone to live in all the time, just to look after me. I'd love to live in a house of my own and there's no reason why I shouldn't.' Kamal, aged 18, has told her mother that she wants to get married and that she wants to go to India to meet someone. According to her mother, however, this aspiration had been a source of conflict between them.

For non-disabled young people, their transition to independent adulthood is very much influenced by their own actions and aspirations. For most of the young people in this study, however, whether they leave their parents' home and what they do with their lives is much more determined by their parents' actions and aspirations than their own.

Some parents feel that they want to be able to look after their child for as long as possible. Anna's mother had put her into a children's home when she was 12, partly because she found it very difficult to deal with her behaviour and look after two other children, partly because she thought Anna would thereby get the specialist help she needed. By the time Anna was 16, however, her mother wanted her back home. The other children were now older and – having been given more information about the nature and impact of Anna's impairment – her mother felt she could cope better. 'The family,' she said, 'has always been the best place for her and it shouldn't really have happened that she had to go away… I would like her to be at home until we can't look after her… I know that eventually she'll have to go back into a residential

home but hopefully we've got lots of more years of her maturing and maturing and being at home.'

Transition to adulthood can also be very much influenced by professionals' ideas about what would be best for young people. Darren is only 15 and already his mother feels that she has experienced pressure from professionals that she should be thinking about him leaving home:

> I remember reading an article about how more young men are staying at home until they're 30, having the best of both worlds, and I'm not saying I want that to happen but I feel there's been pressure put on me as the parent of a disabled child to constantly move towards independence, like it doesn't happen with other children. And it wasn't until I read that article that I thought, "Well I feel OK about the idea of Darren staying at home when he's older." It's got to be what he wants. If I really felt that Darren wanted to move away from home I would support him to do that however hard it was for me but… it's not me thinking I'm not going to let him go, it's whether it's right for him.'

Roy's parents said that the pressure from professionals that their 18 year old son should leave home 'is an old fashioned attitude – somebody that's disabled you put them somewhere and you forget about them.' They felt that the group homes that many of the young people like Roy moved into, when they left school, could not be called 'living in the community'.

Like many parents, Darren's mother is worried about the quality of the support available to her son as he grows up. 'In terms of independent living, the provision has to be right but I haven't seen anything so far that's good enough for my son… I need to be 200 percent sure that he's OK.' The headteacher at Philippa's school spoke of the difficulties that parents experience in finding an adult residential placement for their children. Some parents, she said, look for something that's 'perfect' for their children, while others are 'more sensible' and will settle for somewhere that is 'good enough' and they tend to find places more quickly.

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Katherine's parents have decided that, when their daughter leaves her current residential school at the age of 19, they want her to move into an adult residential unit because they are worried about what would happen to her when they die and they do not want their other children to take on responsibility for her. Having set this as the goal they are fully involving Katherine in the decision as to which residential home she should move to. They do this by taking her on a visit to any that seem suitable and closely watching her reaction. However, the interviewer commented, from her observation of Katherine, 'I would guess that Katherine would choose to stay at home with her mum and dad.'

Anjum is caught between two sets of adults who feel they each know what is best for her. Her parents do not want her to leave home to go away to college while her support workers think it would be good for her to become more independent from her family. Anjum herself would not like to move away from home but definitely does not want to be confined there. She doesn't know what will happen to her next and worries about it. She found being asked questions about her future very upsetting.

Conclusion

These young people's lives are characterised by absence. They are absent from the communities in which they live – generally they don't go to local schools and colleges, hang out on the streets, go to the local cinemas, clubs, or other places where non-disabled young people of their age are to be found. They often spend large parts of their childhood away from their families, and for many, transition to adulthood is transition to a residential setting which continues this separation. Those who have significant communication impairments are often treated as if they have no individuality, no personality, as if they are essentially absent. When these young people do come into contact with the wider community they are often treated as if they *shouldn't* be there and, particularly if their behaviour is different and difficult, the wider community would rather they *weren't* there.

Many of the young people included in this research are denied close personal relationships, denied a means of communicating with others, and shut away from their local communities. For them, social exclusion is about being denied basic human rights. Yet Britain now has a Human Rights Act, which protects its citizens against 'degrading and inhumane treatment', and guarantees a right to privacy, to family life and to freedom of expression. The United Kingdom is a signatory to the United Nations Convention on the Rights of the Child, which promotes the right of disabled children and young people to 'active participation in the community'. The experiences of this group of young people are an illustration of the failure of existing policies and practices to protect and promote these human rights.

While there have been important policy initiatives in recent years which address some of the issues raised in this research, there has yet not been sufficient focus on those children and young people with the highest levels of support needs. The government has acknowledged that there is not enough known about either the numbers or the circumstances of disabled children with high levels of support needs (Department of Health, 2001, p. 37, p.40).

The Children in Need census, carried out by the Department of Health, did not provide better information, although there is an intention to gather more information about disabled children in residential placements (Department of Health, 2001, p.37). The Quality Protects initiative has not, so far, directed particular resources or targets at the needs of children with high levels of support needs. This group of children should benefit from the targeting of resources to, for example, increase generally the number of disabled children involved in play and leisure activities (through both the Quality Protects programme and the Children's Fund). However, children who have support needs which are considered to require nursing care and those who need one-to-one support continue to experience significant barriers to accessing play and leisure activities (as discussed below). There is a need for both Quality Protects and the Children's Fund to specifically target these barriers to such 'active participation in the community'. It is also disappointing that neither initiative has, so far, focussed on the communication needs of some children. It is not enough to leave the assessment and provision of communication needs to schools and education services. Children need to communicate in all aspects of their lives.

Indeed, for many of the young people included in this research the most significant way in which our society has failed them is in the area of their communication needs. A child who has a communication and/or cognitive impairment has an entitlement, under existing legislation covering both education and the delivery of social services, to an assessment of their needs and for those needs to be met. All the young people participating in this research had had a Statement of Special Educational Needs and this should have described their difficulties and set out all the provision that was required to meet those needs. The Statement should also have covered the arrangements for reviewing progress. Yet many of the young people reached the end of their schooling with very little evidence of there having been a proper and on-going assessment of their communication difficulties or concerted attempts to meet their communication needs. The most stark example of this was when the teacher of 16-year-old Lois was asked: 'How does Lois make choices, what is her yes and no?' and the teacher replied, 'I

really have no idea'. Unfortunately, such lack of attention to how a child or young person communicated was not unusual. Even when a young person had received a proper assessment this did not always lead to communication needs being met, as in the case of Jason, whose parents were told that his school could not afford to pay for the equipment he required.

Recent government initiatives have recognised the shortcomings of current systems for assessing and meeting communication needs. The Joint Working Party set up by the Department of Health and the Department for Education and Employment, recommended a number of improvements, some of which have been acted upon (Department of Health/Department for Education and Employment, 2000). The DfEE announced in March 2001 that £10 million would be made available over a period of two years from April 2002 for assessment of communication needs, provision of equipment (hardware and software), training for children, parents and school staff, and review arrangements (Department for Education and Employment, 2001). It was particularly welcome that the government announced its intention that young people should be able to keep a piece of communication equipment that they had been supplied with while at school when they left school. Funding has also been made available through the DfEE's Standards Fund to promote good practice in speech and language therapy services.

The government also announced a total of £100 million to be made available for 'community equipment' for adults and children over the next three years. This initiative is tied to joint planning by health and local authorities and the setting up of pooled funding under the Health Act 1999. 'Community equipment' includes communication aids (Department of Health, 2001) and the funding should also make possible the delivery of entitlements under both the NHS and Community Care Act 1990 and the Chronically Sick and Disabled Persons Act 1970.

There is a danger, however, that the low expectations of people with significant communication impairments – particularly of those who do not use speech to communicate – will continue to impede proper assessment of their

communication needs and provision of whatever support and/or equipment they require. This is particularly the case for those who, having suffered a failure to meet their needs during childhood, have now passed into adulthood. Only one of our research participants moved from school into a service which had high expectations of his ability to communicate and sought to address his needs. Within current initiatives there continues, also, to be an assumption that the 'proper' way to communicate is through using speech. One illustration of this is that the government's own Working Party recommended a National Speaking Strategy for schools, arguing that such a strategy would 'reinforce the importance of oral language'. (Department of Health/Department for Education and Employment, 2000, p.13.)

Generally, current policy initiatives have paid little attention 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). Twenty-year old Nicky's father confirmed this when he told us: 'The most important message I would have for services is that they should make it possible for young people like Nicky to have friends'. Yet such a goal is rarely recorded as an assessed need or as an aim for a service provider.

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). The experiences of the young people involved in this research project demonstrate the importance of, and the barriers to, friendship. Previous qualitative research highlighted the way in which 'being picked on' was a common experience for disabled children and how, when relationships did develop with non-disabled peers, they were often dominated by assumptions that disabled children needed 'care' (Shakespeare, Priestley and Barnes, 2000). 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 genuinely to 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. We need to listen to disabled children's experiences. Our society is not very good at listening to children generally, and non-disabled children's experiences of bullying and racism have only been put on the policy agenda following tragedies where children have been killed, sustained serious injuries or taken their own lives. 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 and this increases the urgency of listening to disabled children's own point of view.

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). However, there is currently little in the government's proposals which will bring about such changes in attitudes towards disabled people.

There is also a danger that, although the current government is committed to an inclusive education policy, those children and young people with the highest levels of support needs will continue to be excluded from local mainstream schools. Recent research on the processes of decision-making concerning residential school placements indicates that parents continue to

find that local schools do not adequately meet the needs of children who require a high level of support in their daily lives (Abbott, Morris and Ward, 2001). Moreover, those children who have continuing health needs which require medication or who, for example, use ventilators or need tube feeding, are at risk of being denied any education at all (Mencap, 2001).

The new SEN and Disability in Education legislation allows the exclusion of a disabled child from his/her local school if inclusion 'is incompatible with the wishes of his or her parents'. This glosses over the many reasons that parents may be forced into such 'wishes'. If a child is not assured of an entitlement to their needs being met in a mainstream environment then it is not surprising that some parents will opt for segregated schooling where they may feel that specialist knowledge and equipment is more readily available. If a school does not have an effective anti-bullying policy which protects and promotes the human rights of disabled children, then it is not surprising that some parents will opt to protect their child from harassment and bullying. If a parent is not given the support they need to cope with a child's care needs or difficult behaviour at home, it is not surprising that a residential special school feels like a lifeline. Children should be entitled to be educated in their local school and to receive the support required to make this possible. There is also a need for new guidance which places clear responsibilities on health and education authorities in respect of enabling children with continuing health needs to attend their local school (Mencap, 2001).

Many of the young people in our study needed good quality mobility and other equipment, adaptations to their homes, and personal assistance with the activities of daily living, in order to go about their lives and, in particular, to assist in the transition to independent living in adulthood. Over 30 years ago, the Chronically Sick and Disabled Persons Act 1970 gave an entitlement to aids, adaptations and equipment, and to practical assistance, if someone was assessed as needing any of these things. The Disabled Persons Act 1986 gave a right to an assessment for the things covered under Section 2 of the 1970 Act, and the Children Act 1989 extended the 1970 Act to children. The NHS and Community Care Act 1990 not only confirmed the right to

assessment but policy guidance required social services authorities to involve disabled people fully in the assessment and care planning process, whatever their level of communication and/or cognitive impairment. However, there was little evidence, amongst our research participants, of their involvement in assessments and care plans.   Assessments seemed generally to have been about whether a child or young person qualified for a service rather than what their needs actually were. All too often, for those with the highest level of needs, residential or nursing homes are seen as the only way of meeting their needs as they make the transition to adulthood.

Those whose support needs are related to cognitive impairment seem to be at particular risk of being denied the opportunity of their own home as they move into adulthood. According to Mencap, 'as high a proportion of (now more severely disabled) people with a learning disability are living with their families, by necessity rather than choice, as were living with their families thirty years ago.' (Mencap, 2000, p.1) A survey of services for people with learning difficulties in 24 local authority areas found that, although local health and social services agencies subscribed to 'principles of social inclusion, citizenship and ordinary community living….congregate [residential] forms of care still predominated, with two thirds of people accommodated in some form of congregate living arrangement, and two thirds still using block day services such as Adult Training Centres or Social Education Centres.' (Department of Health 1999, p.3) People with high levels of needs were particularly unlikely to be catered for by local services. Although most of the authorities surveyed expected to increase the number of people in individual supported accommodation, half of the authorities also expected to increase the number of placements in residential homes. This research finding reflects the institutional future faced by many of the young people in this current research. It is worrying that the White Paper, *Valuing People*, envisages that the capital element of the Learning Disability Development Fund will be used to develop 'integrated health and social services facilities for children and young people with severe disabilities and complex needs' , which sounds like yet more buildings-based rather than community- or family-based provision.

The development of direct payments and the growth of the Independent Living Fund have increased disabled people's choice and control over how personal assistance is delivered. Unfortunately, people with the highest levels of support needs have not benefited from this. The government's strategy for learning disability intends to promote a wider take-up of direct payments amongst people with learning disabilities (Department of Health, 2001, p.48). However, if this is to include young people who have high levels of support needs there will need to be more resources put into Personal Assistance Support Schemes (which assist disabled people to use direct payments). The pioneering work to promote independent living for disabled people was led by, and mainly covered, people with physical impairments. If those who have high levels of support needs associated with communication and/or cognitive impairments are to have access to independent living, a lot of work will be required to provide the support necessary to enable them to recruit their own personal assistants and direct the way personal assistance is provided (see Edge, 2001, for a fuller discussion of this issue). There is also a need to focus attention on the barriers to independence for young Black and minority ethnic disabled young people, who are particularly unlikely to benefit from independent living schemes (Bignell and Butt, 2000).

It is important that disabled people who need personal assistance learn, at as early an age as possible, how to exert choice and control over the way assistance is provided. The extension of direct payments to 16- and 17-year-olds, provided by the Carers and Disabled Children Act, is a start. However, there is also a lot of potential for involving disabled children and young people in the recruitment and managing of support workers in schools (see Alliance for Inclusive Education, 2001) and in the provision of short-break services. Direct payments, or services which deliver flexible support, have an important role to play in enabling children and young people with high levels of support needs to be in, rather than absent from, their local communities. The two young people amongst our research participants who were able to go out and about and do activities of their own choosing were able to do this because they had one-to-one support. Other young people were limited in what they

could do because they were expected to slot into existing services, rather than services being designed to meet their particular needs.

A number of the young people were specifically excluded from services which might have promoted their 'active participation in the community' because their particular needs were not catered for. This included Joe, whose local authority was in dispute with the health authority about who provides training and insurance for 'carers' working with someone who has a tracheotomy. In contrast, Joe himself was quite happy to show his non-disabled friends what to do. The workers at Katherine's residential school were no longer able to take Katherine and her peers out on day trips as they had been told that new 'manual handling' regulations meant they had to use a hoist when transferring a young person out of a wheelchair.

There is growing evidence of the discrimination experienced by children and young people who require lifting and/or have continuing health care needs (Jones and Lenehan, 2000, Noyes, 1999). Currently, manual handling regulations are too often being interpreted as a 'no lifting' policy, and practices developed for use in hospitals are being applied to community services (Lenehan, 2000, Cunningham 2000). A failure to sort out responsibilities for equipment, training and insurance amongst education, health and social services authorities means that children and young people who need lifting and/or who have continuing health needs are all too often excluded from services. There is an urgent need for government action to ensure that services tackle barriers to 'active participation in the community' for these young people rather than, as is currently the case, create barriers to their inclusion within their local community.

Perhaps the most important message for policy and practice is that the direct experiences of young people with high levels of support needs are often missing when policies are discussed and practice developed. Qualitative research which attempts to create a space for these 'voices' which hitherto have been absent challenges the very basis of the current social exclusion agenda. For these young people 'being shut out of society' (as the Prime

Minister described social exclusion) 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 on social exclusion is more concerned with social cohesion than with human rights, more concerned with the threat posed to social stability by unemployment and poverty. 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 largest group being those people who used to be in employment but are now claiming incapacity benefit).

A social exclusion policy agenda which included young disabled 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. The White Paper, *Valuing People*, also contains some important proposals. However, while social policy is generally dominated by the assumption that paid employment is the route to social inclusion, issues which have major implications for the human rights of people with high levels of support needs will remain, at the best, on the margins of the policy agenda. It is not clear, for example, how the particular experiences and needs of children and adults with high levels of support needs will be represented on the National Forum for People with Learning Disabilities, to be set up following the White Paper, *Valuing People.*

If policies are to address our research participants' experiences of 'being left out of society', they would need to ask, for example:

• Do young people with communication impairments have entitlements 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. The title of this report comes from a comment by the mother of one teenager, who told us that Jane, in expressing her wish to marry and have children, had made clear that 'She sees herself as having that kind of life, she wants a good quality of life.' Jane's aspirations are similar to those of her non-disabled peers – she wants to love and be loved, to be part of a family and a community. Yet unless Jane is accorded the basic human right of 'freedom of expression' by having her communication needs recognised and respected, she will be barred from 'that kind of life'. Unless Jane has access to the housing and support she needs to live independently, within her local

community, she will be barred from 'that kind of life'. Unless Jane is accepted and respected as a full human being, she will be barred from 'that kind of life'. And that is the key to the experiences of these young people. So many times and by so many people, they are treated as somehow less than fully human. So their need to communicate is not recognised and it is considered acceptable that their lives are so narrow that they have few if any opportunities for friendships, for relationships, for doing anything which makes their lives meaningful. While the practical needs associated with their impairments may be considerable, the biggest barrier to 'that kind of life' is the prejudice they experience, a prejudice which is so deep that it is unrecognised, considered almost natural. We may have moved away from the days when children with high levels of support needs were confined within long stay hospitals, but we still, as a society, have not accorded these children and young people entitlements to the support necessary to enable them to be fully a part of our community.

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