

Sampling strategy

We did not set out to obtain a 'representative' sample (as larger scale, quantitative studies often do). Detailed qualitative work does not lend itself to this kind of analysis. Rather, we were concerned to develop a purposive, or theoretical, sample that would provide a way of combining depth of analysis in our case study material with breadth of coverage across a number of important variables.

In our original project proposal we set out certain basic targets for direct work with young disabled people leaving care. We said that we would work directly with 30 young people, aged between 14 and 25, and that we wanted to include young people with a range of impairments. We also hoped to include a balance of young men and women, at least a third of whom would come from black and ethnic minority communities.

The population

Our initial task was to carry out a mapping exercise, to determine the number of children and young people who might be eligible to take part in our study. This proved to be a more complicated task than we had first imagined, highlighting a number of administrative issues. We learned a great deal from this, about the implications of defining young people as 'disabled' and as 'care leavers', and about the way that this labeling affects the services young people receive. We also found that certain groups that we had expected to find were considerably under-represented in the looked after population.

Local estimates of impairment suggested that 3.3% of children and young people, aged 0-16, and about 2.5% of those aged 17-25 might be disabled in some way (this would suggest a total population of about 4,500 disabled young people in the area concerned). Within this population, the authority's Management Action Plan identified 615 'children and young people with disabilities and complex health needs' who were receiving social services (i.e. 13.7% of all disabled children based on the above estimate). Of these, 197 were identified as 'looked after' young people (i.e. 32% of those receiving services and 4.4% of the total disabled population). The 'children and young people' referred to in these figures are those under 18 years of age.

Using these figures we estimated that there would be around 11 local disabled young people leaving care services each year, and that the total population of young disabled people in our age range (14-25) with experience of looked after services before their sixteenth birthday would be

in the region of 132. In our mapping exercise, we were eventually able to identify 131 young disabled people in this age group who had used relevant services (although a number of these would not be considered looked after as they had not used overnight accommodation). The following sections provide more detail about this population and our sampling in relation to age, gender, ethnicity and care context.

Sampling for Age

Both the leaving care literature and the government's policy agenda focus on young people over the age of 16. However, in consultation with the local authority, we decided to include young people in the age range 14-25 (although we recognised that our main focus would be on those in the middle of this age range, and therefore closest to significant points of transition). For many disabled children, transitional planning, in conjunction with the education authority, begins at 14 and we did not wish to exclude these experiences from our study. The upper age of 25 was determined by the policy framework for leaving care services, and by our recognition that disabled young people are more likely to leave care at an older age than their non-disabled peers.

In line with our initial ideas about base data coding, it was helpful to view our sampling frame in terms of relevant age groups rather than just chronological years. The relevant age groups in leaving care policy are Under 16s (covering two years), 16 and 17 year olds (covering two years), 18-21 year olds (covering four years), and Over 21s (covering 4 years). Bearing this in mind, together with our focus on those closest to transition, we set ourselves some initial sampling targets to include:

- 4 people under 16
- 7 people aged 16 or 17
- 8 people aged 18 or 19
- 7 people aged 20 or 21
- 4 people over 21

These targets were to serve as a baseline for monitoring our sample, rather than an absolute guide to including or excluding any individual. We used the start date of the project (1 October 1999) to standardize the age of our participants (rather than the date when we first met them). We calculated age in years from birth dates, where these were available, or from other available information. Most of the young disabled people we identified as having used relevant services were 16-19 year-olds (the mean average age was 17.87 years). Given the focus of our project, it was easiest to identify young people closest to transition from children's services. In addition, the identity and whereabouts of those over 19 were less likely to

be known by service providers and the authority. Our population data was therefore weighted towards the middle of our age range (we have assumed that our mapping data is broadly representative across the whole age range).

At the beginning of the project, our contact was primarily with young people using children's services. Inevitably, this meant that the first young people we came into contact with were at the lower end of our age range (our first eight contacts were all between 14-18 years old). In order to meet those in the older groups we needed to extend our sampling to those using adult services, and to those who had ceased contact with services. We also invested much effort in tracing those who had recently left children's services. These strategies were time consuming but in the end productive. We were able to identify and contact young disabled people in all of our target age groups, although our eventual sample was even more weighted towards those closest to significant points of transition than we had originally anticipated (almost half our eventual sample were aged between 18 and 21).

So far, we have worked individually with:

- 3 people aged Under 16
- 4 people aged 16-17
- 11 people aged 18-19
- 3 people aged 20-21
- 3 people aged Over 21

Sampling for Gender

The general population of young disabled people includes significantly more young men than women (about 60% to 40% respectively). On the local authority's Register of Children with Special Needs, the male-female differential was as high as 63% to 37%. We were also aware that this gender weighting towards men might be magnified within the 'looked after' population (more boys than girls are 'looked after' as children). For this reason, we expected to encounter more young men than young women in our sample of disabled care leavers. We were also aware that gender issues could be a significant factor in our research, and that disabled women's experiences could easily be marginalised by an ungendered analysis. With this in mind, we aimed initially for a 50-50 gender split in our sample. Consequently, we hoped to work individually with 15 young women and 15 young men.

As we had expected, our initial contacts (in respite centres) were mostly with young men. In fact, of the first eight people to be identified, only two

were young women. This reinforced our concerns about the potential for gender bias. However, as we developed our mapping and sampling strategies, we discovered a surprising gender balance within the population of young disabled people who had experience of being looked after. Of those that we identified (aged 14-25), 48.5% were female and 51.5% male. There are a number of possible explanations for this finding: we may have failed to identify some young men who had been looked after; more disabled young women than men may have experience of using looked after services; more young boys than girls may have died before they reached our age group.

When we looked at the use of overnight services amongst this population, we found that the proportions of young men and women remained very similar, and that the proportion of women to men actually increased with the number of nights accommodation they had experienced. Indeed, amongst 36 young people who had experience of full-time accommodation as children, 20 were women (56%). This was a surprising finding and merits further investigation beyond the scope of this project.

Bearing this in mind, it is relevant to note that our eventual sample of 30 young people included more men than women (17 and 13 respectively). This was closer to the ratio in the general population of young disabled people than to the specific population we had identified in our mapping exercise. Our concern to include young women and men with a range of ages, impairments and ethnic origins, meant that we had to make choices about who to spend time with. There appeared to be a greater range of variation in terms of ethnicity and impairment amongst the male group, and our over-sampling of young men is partly a consequence of this. In addition, three young women who we wished to include declined to be interviewed.

The observation of gendered diversity raises some additional issues. In particular, our encounters suggested that the population data might be skewed by the presence of a small, but potentially significant, number of young white women with the label of learning difficulties (but without any specifically identified impairment). It is possible that this group might account for the larger than expected number of young disabled women we identified as having experience of being looked after. If this is true, then more questions need to be asked about the way in which these young women have acquired the disability label.

Turning to the qualitative data (from the interviews and discussions) it is relevant to note that we met more young men with complex and multiple impairments, and that it was easier for many of the young women we met to participate actively in the research (particularly as the research worker

was also a woman). As the research progressed, we found that more young women than men became actively involved in shaping the research process (for example, all of the six young people who attended our initial reference group were female). Women also tended to engage in longer interviews with the researcher than men. Consequently, we felt fairly confident that their views were well represented (despite the numerical imbalance).

Sampling for Ethnicity

In designing our study, we were conscious that young disabled people of black and minority ethnic origin have often been marginalised from mainstream research (and from the provision of services). Our choice of location for the study was, in part, driven by a desire to address this issue. In our initial project proposal, we set ourselves the target of recruiting a minimum of 10 out of 30 participants for the study from black and ethnic minority backgrounds. This proved to be a considerable challenge.

Local authority statistics suggested that the proportion of young people from ethnic minority backgrounds in the District was approximately 30% and rising. Amongst young disabled people, the proportion was even higher (in the region of 38% on the Authority's Register of Children with Special Needs). The vast majority of these young people were identified with South Asian communities (predominantly Pakistani Muslim). The proportions of young people of African-Caribbean and 'other' communities were very low by comparison (1% and 2% respectively) but we were keen to recruit in these groups too if we could. In addition, the Authority's Children's Services Plan indicated that some 15% of 'looked after' young people were of 'mixed parentage', and we hoped to reflect this group in our sample. With this in mind, we revised our target upwards, with a view to recruiting at least 12 young people from minority communities or with mixed parentage.

Our monitoring baseline for the sample was as follows:

15 white
10 Asian
5 African Caribbean, 'mixed parentage' or 'Other'

Given the difficulties encountered by other researchers, and the specificity of our project, this was an ambitious target. Our experiences, in attempting to meet this challenge, raised some important questions about the significance of ethnicity and racism within children's services.

Asian young people are over-represented in the local disabled population, and we envisaged that they might also be over-represented amongst those

using services. Yet, only one of our first eight contacts was with a young person of South Asian origin (the others were all white). Since we relied on local authority staff to identify potential participants in the early stages of the project, it was interesting to monitor these initial introductions in terms of ethnicity. Our early experience seemed to validate the need for more purposive sampling, and helped us to refocus our strategy.

In discussions with senior staff, we noted that young people from South Asian communities were under-represented amongst users of the services that we were interested in. They were often users of after-school and daytime respite provision (e.g. at weekends or school holidays) but were less likely to use 'looked after' services. Specifically, young people from South Asian communities were much less likely to use overnight stays, away from home, than their peers from other ethnic backgrounds.

This tendency seemed to become more marked as children grew older. Thus, the proportion of South Asian children using overnight accommodation away from their families seemed to reduce with age. Amongst those over 14 (the age group in which we were interested) there were very few South Asian young people who might be considered as 'looked after'. Indeed, 17 out of the 21 young Asian people that we identified used overnight services less than once a week (either once a month or only occasionally). Amongst our identified population, the mean average stay for young Asian people was 1.43 nights per week, compared to 3.94 for young white people, and 6.5 nights per week for those with African, Caribbean or mixed parentage (although the numbers in the latter group were very small).

Our project was concerned with care leavers, rather than with the use of looked after services, yet our sampling raised some important questions about ethnicity and service usage. Why should there be such a low take up of looked after services by teenagers from South Asian communities, when they were over-represented in the local population of disabled young people? We discussed these issues with our advisory group, with managers, and with other researchers. Possible explanations might include: institutional racism within service provision or needs assessment (for example, an absence of Asian staff, or an assumption that extended Asian families will care at home); a lack of knowledge about, or willingness to use, overnight services on the part of South Asian families; a lower incidence of family breakdown and demand for external support within South Asian communities; a greater readiness on the part of families within such communities to use services perceived as 'health' care rather than 'social' care. Our research does not provide answers to these questions, and more work would be needed to examine the use of children's services by different ethnic communities.

It is hard to make comparisons with the representation of those with African, Caribbean or mixed parentage, due to the smaller numbers involved. However, we were able to include four young people from these groups, and their specific experiences raised a number of issues for analysis.

Overall, in our project, it was difficult to meet the sampling targets that we had set for ethnicity (despite targeted sampling and the fact that the researcher was herself a black disabled woman). In the end, our efforts paid off and we were able to include a substantial proportion of young people from black and ethnic minority backgrounds. However, the representation of South Asian young people was heavily weighted towards those with the most complex and multiple impairments (predominantly those without speech). As a consequence, we had to work hard to make sure that their voices were included in the analysis.

Sampling for impairment

Quite a lot of information was available about the impairment status of disabled children and young people locally. For example, a breakdown of the 'most frequently recorded diagnoses' was included in the authority's voluntary Register of Children with Special Needs (see Children's Services Plan, p. 17). This information suggested that the majority of young people had some form of perceived learning difficulty (mostly undefined); 34% were regarded as Deaf or having a hearing impairment and 25% were considered to have a visual impairment. At least 25% appeared to have some form of physical impairment (including various diagnoses). It is worth noting that many disabled children have more than one impairment diagnosis.

The local authority's statistical information (see Disability Bulletin, October 1999) also recorded information about 'children with special needs', and distinguished 625, who were using social services. For the purposes of our research project, this offered a better indication of our target population. The largest groups were again those defined as having 'learning disabilities', 'developmental delay' or 'communication problems' (each totaling more than 300 children, or more than 50%). 257 (41%) were recorded as having a physical impairment, 206 (33%) as having a serious illness, 120 (19%) had a visual impairment and 82 (13%) a hearing impairment. Of these children, most had more than one impairment label (especially those labeled with learning difficulties, who often had additional illness, communication, physical or sensory impairments).

It is important to note that we were much less interested in impairments than in what happens to young people when they acquire particular

impairment labels. For example, it was not within our scope to determine whether a particular person had a particular cognitive ability or impairment but we were very concerned to determine what happened to them if they became labeled as having 'learning difficulties'. Having said this, we wanted to include young people with a wide range of impairments in our study, and we were conscious that those labeled as having learning difficulties, communication impairments and/or complex health needs are often left out in research projects. We did not initially seek a representative sample, preferring to try and identify young people within each of the major administrative impairment categories. We wanted to include at least some young people with the label of learning difficulties, hearing impairments, visual impairments, physical impairments and complex health needs. We hoped to include at least four young people in each of these broad categories (allowing for the fact that many young people have multiple impairments and that some labels are more prevalent than others). We set ourselves an additional target to include at least four young people who did not use speech as their primary method of communication.

Our baseline for monitoring the sample was as follows:

- 8 people with learning difficulties
- 4 people with hearing impairments
- 4 people with visual impairments
- 8 people with physical impairments
- 4 people with complex health needs
- 4 people who did not generally use speech

Despite our initial concerns, our contacts were predominantly with young people labeled as having learning difficulties or complex health needs (including those who did not generally use speech to communicate). By comparison with previous studies, it was much harder to identify contacts with looked after young people who did not have the learning difficulties label. We pursued exhaustive mapping and sampling strategies in order to address this, and discussed our difficulties with local managers and voluntary sector staff.

Our mapping and consultation exercises led us to some important conclusions about the local leaving care population. It became apparent that children labeled as having learning difficulties (and we would question some of this labeling) were considerably more likely to use 'looked after' services than disabled young people without that label. Those with learning difficulties dominated the use of respite care, shared care and fostering services by disabled young people. Indeed, we located only 8 young people in our target age group (6.2%) who did not have the label of

learning difficulties; four of these had used less than one overnight stay per week as children.

This finding is surprising and suggests a significant shift in the local leaving care population. We had expected to find more looked after young people with physical and sensory impairment labels. A number of explanations are possible: in the rationing of scarce resources, those with learning difficulties are perceived as having the greatest need; children with physical and sensory impairments are being more readily accommodated within the mainstream, thus reducing their demand for looked after services; an increasing number of children in need or at risk are being labeled as having 'learning difficulties'; local information systems are failing to identify a hidden population of looked after disabled children with physical or sensory impairments.

Care context

In the light of previous relevant research, we wanted to include young people with a range of looked after experiences. We hoped to include those with experience of regular respite care, shared care, longer term fostering, adoption, residential care, boarding school, living in hospitals and hospices. A key part of our sampling strategy was to map the variety of placements that local young disabled people used, and to include as much variety as possible in our sample.

Mapping this data and identifying eligible young disabled people was a time-consuming but worthwhile exercise. We were successful in meeting young people with a wide range of looked after experiences. These ranged from weekend use of respite care centres and overnight stays with shared carers, to full-time accommodation in various institutional settings or with foster parents. We met care leavers who had lived away from home in respite units, children's homes, foster homes, hospital, prison and educational establishments.

Local statistical information (Disability Bulletin, October 1999) indicated that, out of 625 'children with special needs' who used social services, 318 were using some kind of respite care (139 using hostels and 238 using shared care). The database recorded 30 as fostered and 26 making use of a Family Centre. The local Management Action Plan identified 197 young disabled people who were considered to be looked after, all of whom were said to be accommodated through 'a series of planned short-term placements'. This information suggested that all social services resources were targeted at this option.

Using this information, we targeted our initial sampling at young people using respite care centres. The staff at these centres also helped us meet up with some of their users in other places (for example, at school). This was helpful, because it allowed us to expand the context of our encounters beyond the immediate site of service provision. We were able to map information about all the young people who used these respite units and to identify all those who had recently ceased to use them. We were able to map the use of shared care services in a similar way.

We were informed that it was 'very unlikely' that any disabled young people would be accommodated in the authority's mainstream Community Homes for looked after children. However, it was important for us to check this. We located a number of disabled young people who had spent time in mainstream children's homes, although we did not identify any current users of such services. We also identified disabled children with care orders who were in unusual full-time placements (for example, living alone in a staff flat above a respite care unit).

Just over 34% of children in the Authority with a Statement of Special Educational Need attend a special school. However, we were initially informed that none of these placements were in residential boarding schools outside the Authority, and that there were no residential schools within the authority. Subsequently, we were able to identify young people who had spent time living in educational establishments.

In particular, we found it very difficult to establish a clear picture of those young disabled people who had been fostered. There seemed to be a lack of information and some communication gaps between departments. Local authority statistics suggested that there were 32 children on the register of children with special needs using fostering services. However, staff in fostering and adoption found it very difficult to identify who these children might be. By working intensively with managers and social workers, we were eventually able to identify a number of disabled young people who had been fostered (although our difficulty in completing this task raised many questions about tracking and management information).