

FINAL REPORT

LIFE AS A DISABLED CHILD: A Qualitative Study of Young People's Experiences and Perspectives

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LIFE AS A DISABLED CHILD: A QUALITATIVE STUDY OF YOUNG PEOPLE'S EXPERIENCES AND PERSPECTIVES

Summary

Much research into disabled childhood has been preoccupied with impairment, vulnerability and service use; this has compounded a view of disabled children as passive and dependent. The voices of disabled children themselves have frequently been excluded as research has focused on the perspectives of parents, professionals and other adults. This project aimed to explore the perspectives of disabled children themselves, their own roles in negotiating their daily lives, and to investigate the relationships, environments and structures which shaped their experiences.

The project involved young, disabled people aged between 11 and 16 years, with a wide range of physical, sensory and cognitive impairments, living in two locations in England and Scotland. Our research methods involved both participant observation and in-depth interviewing. Fourteen schools were visited by the research team, often for a sustained period of fieldwork. These included both mainstream and segregated schools in both locations. The researchers adopted non-adult teaching roles, and involved themselves in a range of observational and participatory activities with the children. This enabled a range of contexts to be observed, and the perspectives of a range of children incorporated. Importantly, the study developed from the children's own involvement and experiences. The different styles of research relationships and activities were often mediated by the children themselves. In addition to the participant observation work, involving more than 300 children, 165 were included in further in-depth work, using a range of qualitative interviewing styles (individual, paired or group interviews). During this component of the study, we were able to generate a rich picture of individual children's lives, focus on their families and non-school settings, and follow up some of the issues emerging from the participant observation.

A striking feature of the study was the high degree of surveillance by adults which disabled children experience. As well as having an effect on the young people's lives,

this also influenced the research process itself. The young people in the study described their need for privacy, and the way in which the presence of adult assistants especially influenced their relationships with their non-disabled peers. Social interaction within the school, and social contact outside was thus often limited in nature and scope. However, the study also found disabled children resisting such surveillance at times, and witnessed their attempts to reassert their own values and autonomy.

The categorisation of children as disabled also formed part of the adult world which bounded children's experiences. Such labelling often involved disability as a dominant status, where other differences or similarities remained muted or unattended to, and everything related to a children being explained by their impairment. Normality and difference were daily and institutionally reinforced by the use of social and physical space, and through both mainstream and segregated schooling. The children themselves were more ambivalent about the use of the category of 'disabled' both in relation to themselves and to others, suggesting their perspectives were based on experience and context.

Relationships with peers were often limited for many of the children in the study. Physical, attitudinal and communication barriers existed. Children described their experiences of bullying for example. The nature of their schooling often meant that they did not attend schools in their home neighbourhood and the transition from primary to secondary school often involved severing friendships. While for some children associating with their own impairment group was an active choice, for example for communication reasons, for others the wider environment supported separation even within mainstream schools. Where peer relationships with non-disabled children developed, they were sometimes dominated by the assumption of need and care. Most children also highlighted a common experience of being picked on, even if they were sometimes able to resist the process.

The young people in the study identified with disability in many different ways. Sometimes they saw themselves as the same as others with their impairment, or indeed the wider group of disabled children. Sometimes they saw disability as something which marked their difference from other children. They saw disability as a term with different

meanings, and contested boundaries; some children disavowed the label for themselves, whilst ascribing it to others. Children displayed fluidity in claiming disability as an identity: they described how they were not always disabled in every situation. They also resisted adult discourses which gave primacy to disability when dealing with disabled children.

The data from the study challenge a universal concept of 'a disabled child' and instead identified the range of ways in which meanings and values were contested or reinforced in daily interactions and institutional practices. The fluidity of categories and dynamics of experience all suggest that listening to children's voices leads to a more nuanced understanding of their lives. If this process, which demands that adults too reflect on their practices, were part of policy and practice, then the structures which promote a disabling environment could begin to be dismantled. We recommend that future research on childhood always incorporates disability, and that useful comparisons could be made of the experiences of disabled and non-disabled children. Periods of transition, particularly from primary to secondary school, and towards independent adulthood also require to be researched in depth.

LIFE AS A DISABLED CHILD: A QUALITATIVE STUDY OF YOUNG PEOPLE'S EXPERIENCES AND PERSPECTIVES

FULL REPORT OF RESEARCH ACTIVITIES AND RESULTS

Background

Approximately one in twenty children are considered disabled and increasing numbers of children with serious medical conditions now survive into adulthood. Social policy research has revealed that families with disabled children experience a range of social and economic difficulties. However, most research into disabled childhood has been preoccupied with impairment, vulnerability and service usage, and has compounded a view of disabled children as passive and dependent. Moreover, the voices of disabled children themselves have frequently been excluded, as research has focused on the perspectives of parents, professionals and other adults. This has often had the effect of objectifying and silencing disabled children. As a consequence, research has often concealed the roles of disabled children as social actors, negotiating complex identities and social relationships within a disabling environment, and as agents of change who can adapt to, challenge and inform the individuals, cultures and institutions which they encounter during their childhoods.

The *Life as a Disabled Child* project was founded on the principle that in order to understand the lives of disabled children, it was necessary to engage simultaneously with new approaches to the study of disability and with new approaches to the study of childhood. In the UK, disability studies grew out of the increasing political consciousness of disabled people engaged in collective struggles for emancipation from a disabling society. Above all, disability studies promoted new ways of thinking about disability - what we now refer to as social models of disability, that re-define disability as a social relation, rather than as an individual 'impairment'. The disability studies perspective incorporates particular ideas about how we 'do' disability research that reflects the 'emancipatory' traditions of, for example, feminism, anthropology and the new sociology of childhood. We hoped this approach would enable us to approach disabled children's lives in a way

that was relevant to them, within the broader discourses of rights, inclusion and citizenship.

The project focused on disabled young people aged 11-16, with a wide range of physical, sensory and cognitive impairments, and living in two locations in England and Scotland. The main aims were to explore the perspectives of disabled children themselves, and to investigate the relationships, environments and structures which shaped their lives.

We hoped that we would gain a sense of disabled young people's *collective* experience as impacted on by social and environmental barriers, cultural processes and policy frameworks and definitions. However, we also came to the research with a desire to reflect the rich contextual nature of these young people's *individual lived experiences*. We were concerned to understand their own experiences and perspectives, and to provide opportunities for their voices to be heard. We considered disabled young people to be the 'experts' on their lives and we aspired to learn from them. In so doing, we hoped to challenge some of the traditional hierarchies in research production – for example, those of researcher and researched, and of adult and child, and to assess the relevance of social theory to understanding daily practices.

The research team consisted of seven people with diverse biographies (four of us disabled, six of us parents, none of us children). We came from academic backgrounds that spanned teaching, youth work, rehabilitation, social policy, social anthropology, sociolinguistics, feminism, deaf studies, disability studies, sociology and medical sociology. The breadth of the team was helpful in developing a rich and nuanced understanding of the lives of disabled children, as we worked together to generate and interpret the ethnographic data.

Objectives

The overall aim of the project was to explore young disabled children's experiences, and their perceptions of impairment; of services; and of their social relationships with family, peers and professionals. We also aimed to examine the role of structural and cultural factors in shaping children's experiences; to make recommendations relevant to policy

and practice; and to develop appropriate methodological approaches and methods for researching the experiences of young people with a range of impairments.

The breadth and depth of our data meant that we were successful in meeting our overall aim, and in the results section we highlight key themes from our analyses: adult surveillance; the creation of the disability category; peer relationships and identity. Importantly, we could develop an understanding of the children's lives across different contexts, and involving interactions with different peers and adults. This led to an understanding which embraced variety and difference as well as similarities between children and settings. The project has already led to a number of publications around different substantive themes.

Importantly, we were able to work with and develop a range of methods and we were guided by how children wished to contribute to the project. For example, whether and where they wished to be interviewed, what written material they wished to supply, as well as what they wanted to talk or write about. We aimed to be as inclusive as possible. For example, one member of the research team, as a BSL fluent deaf researcher, enabled effective communication with deaf and hard of hearing children. This also sensitised other team members to the importance of body language and non-oral communication in other children. Reflexivity and sensitivity were vital in gaining an understanding of the views of children with profound learning difficulties who could not communicate in speech. We have a number of publications directly addressing methodological issues.

Our analysis of the importance of structural factors highlighted the variations in the treatment of children, as well as the contingency of professional responses, particularly the differences between schools which were committed to an inclusive philosophy, and those which were segregated, either in practice or in ethos. We succeeded in gaining insight into the ways in which disabled children's lives are dominated by adults, as we discuss in our results below. By working in two different locations and many different schools, we were able to consider the broader contexts of legislation, policy, educational and social service provision as they impinged on children's own lives and experience. However, because the research focussed on a range of children across many contexts, we were unable to provide systematic comparison of the differential impact of different

policies, except perhaps in education. Nonetheless, we did generate understanding of the range of factors contribute to the shaping of children's environments and how they negotiate their lives.

Our understanding of the importance of variables such as gender, ethnicity, impairment, social class, and locality on these young people's capacity to be independent social actors was again drawn from detailed analyses of their experiences and cultures. While all these variables shaped social interaction in different ways, and influenced our research relationships, we were again unable to make systematic comparisons across such a diverse sample. We suggest that this diversity enabled us to provide rich documentation of experience and we avoided reifying variables which operated in complex and context specific ways. Interestingly, we were able to highlight the way gender and ethnicity were ignored in most services for disabled children, as impairment operated as a dominant status. For example, in one area a service for children with Downs syndrome was part of a school on an estate with a history of racial violence, which meant that black and Asian families were reluctant to send their children there. In some special school classes, boys significantly outnumbered girls. We also noted the way that hierarchies of impairment were generated from particular forms of educational or social provision, and reproduced in the discourse of children themselves. However, gender, ethnicity and impairment were all important in understanding social interaction, styles of talk and peer groups, especially amongst groups of children with the same impairment.

The process of developing recommendations for better support and provision is ongoing. As we discuss below, we are feeding back our findings to schools, voluntary organisations and disabled people's groups. By taking the voices of disabled children seriously, we have impacted on the rest of the Child 5-16 project, and supported simultaneous developments in the field of childcare, as our list of activities demonstrates.

Methods

The study used a range of methods broadly subsumed within a qualitative methodology. We aimed to mix breadth with depth, and combined participant observation with

interviewing. However, these two methods embrace a range of actual fieldwork roles and techniques, and we paid particular attention to developing good research relationships, on the young people's own terms. Such flexibility and sensitivity necessarily challenged our assumptions and frameworks, but led to the exploration of young disabled people's diverse views and experiences.

Participant Observation: Settings

The research was carried out in two different locations in Scotland and England. In Scotland, three special schools (including a range of impairments) and three mainstream schools (including a specialist unit) participated. In England, four special schools and four main stream schools were included.

The time the researchers spent in the schools varied for several reasons. The numbers of disabled children within a school varied with type of school; the relationships developed with the young people varied; the relationships between the researcher and staff within the schools varied and other factors such as school holidays, inspection visits also influenced the length of time the researchers spent in different settings.

The researchers adopted different roles within the setting, depending both on personal fieldwork styles, and the negotiations and relationships between staff, young people and the research team. The researchers adopted roles of non-teaching adults, in order to be able to spend time with the children in different contexts. School structures, classroom practices and the content of the curriculum were utilised to create moments where the researcher could discuss issues with young people. In this way, local cultures and cultural artefacts were employed as the foundation from which to understand different young people's experiences. This included, for example, drama groups, reading groups, symbols and signs classes, music therapy, physical education classes, outdoor activities, school trips, playground time and, in residential schools, out of hours leisure time. The aim, at all times, was for the researcher to contribute to and interpret naturally occurring interactions. Despite, or indeed because of this diversity of practice, we were able to examine the ways in which disabled young people interact with their peers and adults in

different contexts, and the meanings which they bring to such interactions. There were some draw backs, from time to time, especially where the nature of the research method challenged staff assumptions about the research process, and their control over the interactions between the researcher and the young people within the school.

During this part of the study, we were able to build up relationships with a range of children in order to develop the more focussed component of the project, which involved generating a more detailed picture of individual young people's lives.

Interviewing: study participants

From observing more than 300 children in their schools, we then continued to work with 165, involving them in more in-depth techniques. This included informal individual, paired or group interviews, as well as the compilation of written and visual accounts. These study participants reflected diversity in terms of gender, ethnicity, social class, type of school, locality as well as impairment. Although most of this study group came from the participating schools, a few joined the study through other routes. Our flexibility here supports the aim of including children on their own terms and of making their voices heard. Eighty-five young people invited the researchers to their own home, after school residential setting, summer playgroups and after school clubs/leisure activities. The rest preferred to participate during school hours in focus groups or paired and individual interviews.

The number of contacts with these study participants varied, as a strong separation between the participant observation and interviewing components was not sustainable in practice. Depending on the relationship with each child, and the picture that was being generated of their lives, more focussed research interactions with the study group ranged from one to eight contacts. The benefits of building up a relationship with children in the school setting were that the children themselves often insisted that we attended specific clubs or events that they were involved in, e.g. sports days, football games, swimming clubs, drama clubs, Boys' Brigade, school plays. Again, children's local cultural artefacts (e.g. games, books, favourite music, tv programmes, diary's, pictures, photographs,

paintings, ways of speaking (oral and sign)) acted as a basis from which to explore their everyday experiences. Issues that had arisen in the school setting could be re-examined at home and this allowed for a very detailed exploration of how disabled children perceive themselves and their interactions with others. Also, we were able to explore children's experiences within the family and other settings, often while participating in a shared activity or interest. Interestingly, the process of gaining access to the home setting by child invitation contrasted to that of obtaining consent to enter schools where local authorities, head teachers, parents and classroom teachers all acted as gate keepers.

Flexibility and Reflexivity

The quality of qualitative research is contingent on the quality of research relationships, and the reflexivity of the researchers. This project involved three researchers and four grant-holders, and was conducted in two different locations. The diversity of disciplinary and biographical experience made collaboration exciting and required us all to reflexively learn about each other's cultural and academic practices. There was a great deal of discussion in team meetings, during supervisions and through email about our individual research practices and interpretive procedures. We think this enhances both the quality of field relations and analytical work (Davis et al 1999).

Results

We highlight below four key themes from our analyses: adult surveillance; the creation of the disability category; peer relationships; and identity. Some of these are considered in more detail in our publications, where detailed analyses from fieldnotes and transcripts can be included.

Adult surveillance

A striking feature of the study was the high levels of surveillance of disabled children by adults which we observed. Disabled children spent a disproportionately large amount of their time in the company of adults and in social spaces where adults were actively present. As well as teachers and a range of assistants including Special Needs

Assistants (SNAs), disabled children also came into contact with other adults, such as the drivers of taxis and other transport, therapists, volunteers, which meant that almost the entire day was in the presence of adults.

For some children, social contacts and outings were restricted to the company of parents or guardians. Going out with parents often meant being in places and spaces geared towards adult needs, with few (if any) other children present. This was also true for many disability specific activities, which were often undifferentiated by age or generation. Many of the children had few social contacts outside the family, and these often comprised specific adults, such as volunteers, respite carers or professionals with an interest in disabled children, rather than other young people.

Both in segregated and inclusive schools, there was a high adult to child ratio. Disabled children in schools were under closer surveillance than non-disabled children. The most prominent issue in children's accounts of school concerned their relationships with specific adult support staff. For example, many of the children in mainstream schools had regular help from an SNA. This support had the effect of increasing surveillance and control, and some children felt that it excluded them from their peer group. The SNA added another level of control, which both prevented the individual child from acting up, but also meant that even when the teacher left the room, the whole class still had an adult present. Some children suggested that this created resentment against them from non-disabled peers, and could affect peer relationships. Another consequence of the presence of SNAs in a mainstream classroom was that the class teacher could ignore the disabled child. A situation prevailed where the non-disabled children were taught by a qualified teacher, while the disabled children received most of their educational input from an unqualified SNA.

Class sizes in segregated schools varied from three to ten children per adult. In some schools, the adult to child ratio was one to one. Play and interaction between children were mediated through adults. Indeed, in one school, an adult commented to us that she felt that if it was not for her presence the children would not communicate at all. This statement was undermined by our own observations of child-child interaction on the rare occasions when staff were absent. For children with mild to moderate learning

difficulties, however, there was much more autonomy in a segregated setting than in a mainstream setting. In the latter, they would have had an SNA, whereas in the special schools they were much more free to associate with others in child-defined spaces, albeit within the usual parameters of the school environment.

For many children, the school environment was adult orientated: indeed, some of the special needs units were more like offices than classrooms. There was little or no privacy for the children to talk. Teachers also commonly talked about the children as if they were not there, openly discussing the children's medical conditions or what they understood about their home life in front of other children. As one child told us; "It may be hard to believe, but even I have things that I want to keep private." However, not all adults treated disabled children in the same way, and each setting contained some contrasting practices within this overall picture. Similarly, the young people themselves could resist adult surveillance by reasserting peer group values through interaction, and sometimes enlisting the assistant or even the researcher in such activity.

Creation of the disability category

Social settings and adult behaviour were instrumental in the creation of disability as a distinct category. This process operated through the way in which adults discussed disabled children, the way in which social space was organised, and the way in which other differences were minimised. Concepts of normality and difference were reinforced for disabled children. Our research suggests that disabled children are involved in what Bourdieu (1992) would term a 'rite of institution', either through their identification as different in the mainstream, or through their segregation from the mainstream. This process transforms the child, changing the way that others represent him or her. The children themselves were more ambivalent about and varied in their use of the category 'disabled' both in relation to themselves and others, so that even children with the same impairment do not agree on whether or not they are disabled. Children's use of such categorisation and their lived experience may contrast with the approach within the many of the schools we visited.

On entering many of the research settings, adults often began to label the children for us, promoting the idea that disabled children were distinct both from ourselves and from

other children. We were regularly told how different these children were from other children, how they did not understand things in the way other children could, how they were dependent on adults, and how it was only through adults that they were able to interact. These comments legitimised the institutionalisation of difference and the establishment of rhetoric which could be used by adults within schools and other settings to justify a variety of practices and policies, as well as the existence of the institutions themselves. These processes operated within both segregated and mainstream schools.

In many cases, teachers deployed subjective judgements about the intellect or ability of children, which they presented as objective measures. Especially in segregated schools, children were further subdivided and streamed in terms of their distance from a perceived norm. Unlike in mainstream schools, progress did not depend on age, but on attainment of targets for independence. Autonomy increased only when staff judged that the child was capable of moving on to a different stage.

When children misbehaved, teachers attributed this to the effects of their impairment. Any resistance displayed by children was thus neutralised or diagnosed as indicative of abnormality. For example, a boy displaying age-appropriate 'naughtiness' was labelled as ADHD. Further, if the behaviour could not be explained away by the existing impairment, some teachers sought a diagnosis of ADHD. Again, disabled children were exempt from many normal requirements within mainstream settings; for example, their lateness, or failure to complete work assignments, were ignored. Other children were very aware of this privilege, and it tended to cause resentment and reinforce perception of difference.

The way in which space was organised often tended to separate out and define the disabled children as a group. Many of the children in mainstream schools tended to be separated from the other children for much of the day. They were labelled and put together in the class, told which table they should sit at for lunch, and they were supervised as a group. Often this reinforced their sense of difference. One care worker told us: "They find it very difficult to make up their own minds. We have to tell them what to do, help them decide." There was a tendency to homogenise impairment, both in discourse and in social organisation: all children with a particular impairment were put

together, through speech and through practice. However, we also found that there was an element of choice amongst children who stayed with their own impairment group, for example for reasons of communication.

It seemed that disability was a dominant status in which other differences were submerged. We found it difficult to trace the impact of gender and race, for example, partly because these features were largely ignored in the way that disabled children were treated. It was common to find special school classes which comprised one girl and nine or ten boys. On the other hand, while the majority of disabled children were male, most workers in special education were female: this suggests that there is a lack of role models for boys to emulate. There were few disabled adult role models either. Disability provision also conflicted with gender norms, when an SNA was shared between two or more pupils: this could result in boys and girls being forced together, which went against the peer group culture, and was disliked by the children. Again, in one setting a special unit for a particular impairment group was located in a neighbourhood notorious for racial abuse; consequently black and Asian families were reluctant to send their children to this facility.

At the core of the disability dilemma was a tension between the ways in which difference was constructed and reinforced, alongside an imperative to assimilate. On the one hand, children were constantly reminded that they were essentially different from their non-disabled peers, whilst on the other they were compelled to adopt the behaviour, the ways of speaking, the ways of walking which most closely approximated that of non-disabled children. Impairment-specific traits – such as ‘blindisms’ were suppressed, at the same time as difference was being reinforced through the procedures discussed above, as well as the very structure of segregation. The special school is designed to promote normality, but by identifying difference as abnormality. This introduces an inherent contradiction in institutional approaches to disabled children.

There were some adults working with disabled children who recognised and tried to undermine the processes of labelling and differentiation. For example, after one child had been diagnosed by an educational psychologist, the teachers worked intensively with the child to produce evidence which undermined the label. Some teachers appeared to

develop strong bonds with their children, partly because they were perceived to be on the side of the children. Even children with complex and multiple impairments were able to recognise such distinctions, and worked differently for such staff. These individual cases seemed to be working against the prevailing currents of educational practice. Some teachers faced opposition from other staff for 'just wanting to be friends with the kids' or not following accepted practice.

Very few adults in the schools questioned the processes and social contexts in which they impose these distinctions. However, our data also shows that some disabled children are aware of the ways that adults structure their lives. We have seen moments when children resist adult discourses of dependency, where they resist adult attempts to control their lives and where they enter into negotiations with adults. Children told us how they felt more capable and independent than they were given credit for. Their responses revealed their opposition and refusal of the discourse and priorities of adults.

Moreover, we have identified disabled children's ability to differentiate between the adults they encounter in schools and to state why they prefer one adult over another. Disabled children are capable of identifying good practice. Our data suggests that where children encounter disablist practices in schools, they should be encouraged to put forward their own solutions to their problems. If given space, they are capable of empowering themselves where they encounter teachers and other adult helpers, provided these adults reflexively question their own practices.

Peer relationships

Although disabled children wanted to locate themselves within the world of children, there were various barriers to their full participation. As well as the adult surveillance discussed above, these included physical barriers such as access to playgrounds and facilities and attitudinal barriers on the part of other children. Many children talked to us about their experience or perception of bullying, although they also shared happy experiences and lively exchanges with us.

Many children often did not attend their local school, either because they went to segregated schools some distance from their homes, or because the only accessible mainstream school also involved travelling. They therefore had few friends at home. In these cases, friendships outside the school day tended to be confined to family members. This problem was particularly acute for children in the transition from primary to secondary: they were sometimes separated from their peer group, and sent to an alternative mainstream school. Isolation at the new school caused them difficulties, which might then be used as a justification for transferring them to a segregated school. Bullying was also sometimes a reason for transferring schools.

The way provision was delivered shaped the peer groups of disabled children: for example, some schools had a 'base' for children with particular impairments; in other schools disabled children were placed at a specific table in the dining hall; often children associated with others as a result of shared transport facilities. This outcome was sometimes used by staff to reinforce their belief that disabled children preferred to associate with other disabled children.

Some of the children complained to us that it was difficult to maintain friendships with non-disabled children when they were unable to access areas like some fast food outlets and other child-centred spaces. They did not feel that they could ask their friends to push their wheelchairs around all the time. Often, non-disabled children were unwilling to associate with disabled children, or would only do so in certain contexts. Sometimes, this was associated with gender differences: disabled girls reported that non-disabled girls were less likely to be discriminatory than non-disabled boys. Personal likes and dislikes interweave with these categories (disabled/non-disabled), often further restricting peer relations. As one girl said: "I can't choose 'cos maybe 18 disabled and 16 are not nice people, and so many non-disabled are awful which mean maybe only 3 or 4 people that I like".

Where peer relationships with non-disabled children developed, sometimes they were dominated by the assumption of need and care; the non-disabled children behaved not as equals, but as guides or helpers. For example, we observed a special needs playground for disabled children, where non-disabled children were brought into the

space specifically to assist disabled children. On another occasion, non-disabled children who were involved in the Duke of Edinburgh Award Scheme were given credits for volunteering in the special school.

Disabled children, according to many of our respondents, all have one thing in common: as one of the children told us, when asked what disability meant, “we all get picked on”. Children told us about experiences of physical, emotional and verbal bullying, for example being called names such as ‘spastic’, being excluded from peer groups, or being kicked and hit, and we observed all these processes. Even those who had not actually experienced bullying personally, were aware of the possibility, and it therefore shaped their sense of self and their social relationships.

Many of the children in special schools explained that bullying was the reason for them leaving mainstream provision. However, we also observed bullying in segregated settings. For example, informal impairment hierarchies operated in special schools, and disabled children themselves were quite capable of bullying other disabled children. For that matter, these children were not always passive victims of bullying from non-disabled people; one child described how he “gave the left hook and booted them” after he had been insulted. However, in general, special schools were felt to be safer than either mainstream schools or the outside world. In fact, as children got older, they expressed fears about their future, when they would rejoin mainstream society on leaving school.

Of course, we also encountered children who were well integrated with their peer groups, had many friends, and experienced positive social relationships. However, arguably, this was as a result of their having minimised their perceived impairment status, or having ‘passed’ as normal. Of course, this was not an option open to many disabled children.

Identity

Children identified with disability in many different ways. Sometimes they saw themselves as the same as others with their impairment, or indeed the wider group of disabled children. Sometimes they saw disability as something which marked their difference from other children. They saw ‘disability’ as a term with different meanings,

and contested boundaries; some children disavowed the label for themselves, whilst ascribing it to others. Many children spoke about everyone being different, or alternatively, everyone being disabled to a certain extent.

When we asked the children what 'disability' meant to them, we received a variety of answers, including how being disabled meant that they encountered disabling barriers in the social world (mainly access and attitudes). For other children, being 'disabled' meant having a visible physical, sensory or cognitive impairment. This definition of disability meant that some children with a hidden impairment could exclude themselves from the category. Some children gave very specific and practical explanations of disability, in terms of the way impairment impinged on their lives – for example, not being able to eat everything they wanted. As we have indicated, for other children, disability was associated most closely with being picked on.

Children displayed fluidity in claiming disability as an identity. They described how they were not always disabled. One girl talked about how wheelchair basketball equalised social relationships and, as she put it, "in some situations I'm not, we're not, always disabled". However, another child described how the hearing children keep the ball to themselves, leaving this deaf child waiting "for the ball to take goal". For some of the children in special schools, disability was normalised, and hence disappeared as an identity in that setting. Even when children refused to occupy the disability category, there could be a strategic claim of privilege and exemption in certain school situations ("can we go early, Miss, 'cos we're disabled".) In these examples, the difference could become a benefit.

The children's own sense of identity also became apparent through their resistance to dominant discourses about them. The data showed us how the children adopted strategies through which they attempted to assert their own agency (Corker forthcoming, Davis and Watson 1999, Priestley 1999). In some cases this agency was read by adults as bad behaviour, and the children were labelled as having difficulty coming to terms with their impairment.

We have demonstrated a link between adult discourses and children's hierarchies (Davis and Watson 1998). This suggests that disabled children employ similar criteria to adults to differentiate between themselves, and to construct distinctions. They sometimes deployed similar distinctions on the basis of capability or behaviour that we had witnessed teachers using. In a school for children with visual impairments, the children ranked each other in terms of sight, and possession of other impairments. However, as noted above, adult discourses were also resisted.

Identity, and notions of difference, are not the product of impairment, structure or culture, but are the result of the interplay of these and other factors as children negotiate their life-worlds. The data challenge a universalised concept of 'the disabled child'. Indeed, it could be argued that the diversity of the children's definitions and descriptions of disability subvert the very notion of 'a disabled child'. Previous writings on disabled childhood have tended to homogenise these different lives, creating a composite and singular disabled child. This tendency was also recognised by the children: as one said to us, "Yeah, like people sort of label people. Aw, that guy's in a wheelchair. He's disabled. Or like, that's guy's got a white stick. [...] They tend to label disabled people in one big group."

For the most part, children suggested that difference leads to difficulties. However, the children themselves illustrate occasions when they bracket impairment, or universalise it. As well as describing problems they have experienced, they also outline possible solutions. A key strategy they identify is for teachers and others to be flexible in their response to children for whom disability is only one aspect of their lives. The children themselves recognise that they are different, but, as they make clear, this difference only becomes relevant at certain times and in particular contexts.

Overall, the study clearly demonstrated the interactive effects of culture and structure on these young disabled people's lives, yet was able to explore the ways in which they negotiated, challenged or reinforced different values and practices. The range of children (with different, physical, sensory and cognitive impairments) involved in the study, the different schools and the diverse contexts, enabled us to produce a rich picture of disabled children's lives. This identified positive and negative elements, and reflected

the fluidity and variation within what are often viewed and robust and defining categories. This demands a reflective and reflexive approach amongst those adults involved in these children's lives, and a need to bring young disabled people themselves into debates about their lives on an everyday as well as policy level.

Activities and outputs

Published papers

Corker, M (forthcoming) New Labour, new language? - disabled people, language planning and social policy, *Disability & Society*

Corker M and Davis J M (forthcoming) Portrait of Callum: the disabling of a childhood. In R Edwards (ed) *Children, Home and School: Autonomy, Connection or Regulation*, London: Falmer Press.

Davis J M (1998) Understanding the meanings of children: a reflexive process, *Children and Society* 12 (5): 325-335

Davis J M (forthcoming) Disability Studies as Ethnographic Research & Text: Can we Represent cultural diversity whilst promoting social change?, *Disability and Society*.

Davis J M and Corker M (forthcoming) Disability Studies and Anthropology: Difference Troubles in Academic Paradigms. *Anthropology in Action*.

Davis, J M, Watson N, Cunningham-Burley S (forthcoming), Learning the lives of disabled children: developing a reflexive approach, in Christensen P and James A eds, *Conducting Research With Children*, Falmer.

Priestley, M. (1998) Childhood Disability and Disabled Childhoods: agendas for research *Childhood*, Vol. 5(2), pp. 207-223

Priestley, M. (1998) Discourse and identity: disabled children in mainstream high schools in, M.Corker and S. French (eds) *Disability Discourse*, Buckingham, Open University Press

Priestley, M., Corker, M. and Watson, N. (1999) Unfinished business: disabled children and disability identities, *Disability Studies Quarterly*, Vol. 19(2) (Spring 1999)

Priestley, M., Davis, J. and Watson, N. (forthcoming) Play away: disabled children and anti-social spaces, *Urban Geography*, 20:

Priestley M, Davis J M, Watson N, Cunningham-Burley S (in preparation) 'Disabled children doing families' chapter for an edited collection arising from cross-project collaboration within the programme.

Shakespeare, T & Watson N (1998) Theoretical perspectives on research with disabled children, Robinson, C & Stalker K (eds) *Growing Up with Disability*, London: Jessica Kingsley

Shakespeare, T & Watson N (1998) Perspectives théoriques sur l'enfance handicapée, *Handicaps et Inadaptions* (les cahiers du CTNERHI), number 78, pp 71-83

Shakespeare T & Watson (forthcoming) Five ages of impairment, Jamieson L, Cunningham-Burley S (eds) *Families and the State: Changing Relationships.*, Basingstoke: Macmillan.

Book Reviews

Davis, J M (1999) Disabled Children: challenging social exclusion', by Laura Middleton, *Health and Social Care in the Community*:

Priestley, M. (1998) Critical Commentary: Listening to disabled children, *British Journal of Social Work*, 28: 969-973

Priestley, M. (1999) 'Still Missing? (Volumes 1 and 2)' by Jenny Morris, *Disability & Society*, 14(3)

Priestley, M. (1999) Disabled Children: challenging social exclusion', by Laura Middleton, *Disability & Society*, 14(4):

Presentations

Corker, M (1998) Project report, CRPC Conference, Institute of Education, London.

Corker, M (1998) New Labour, new language? - disabled people, language planning and social policy, Disability Studies Seminar, Edinburgh.

Corker, M & Davis J M (1998) Shifting selves, shifting meanings, learning culture - deaf and hearing researchers working with disabled children, Deaf Education Seminar, University of Birmingham.

Corker, M & Priestley M (1999) Project report, Cross-project meeting, SSRU, Institute of Education, London.

Corker, M (1999) The performance of disability in children's and adults' talk, Centre for Applied Linguistics Research, Thames Valley University.

Corker, M (1999) Data analysis workshop, Centre for Applied Linguistics Research, Thames Valley University.

Corker, M (1999) Young, gay, lesbian - and disabled: the social construction of multiple and simultaneous others, Inaugural European conference on Gay and Lesbian Identities: Working with Young people, their Families and Schools, University College London.

Corker, M (1999) "They don't know what they don't know" – disability research as an 'emancipatory' site of learning. 'Sites of Learning' Conference, University of Hull (paper forthcoming in James et al (eds)).

Corker, M, Davis J M, Priestley, M (1999) Data analysis paper, Cross projects meeting 2,

University of Leeds.

Corker, M, Davis J M, Priestley, M (1999) Cross Projects Meeting 3, University of Leeds, (leading to chapter for cross-project publication, volume will be co-edited by M Corker, with Allison James, Pia Christensen).

Corker, M (1999) Data workshop for trainee postgraduate educational psychologists. University College London,

Corker, M (1999) The ties that bind - disability research as an 'emancipatory' site of learning, Sites of Learning Conference, University of Hull.

Corker, M (1999) Discriminatory language, talking disability and the quiet revolution in language change, British Association of Applied Linguistics annual meeting, Edinburgh..

Davis J M (1998) Social exclusion in physical education: whose game is it anyway?, Children and Social Exclusion Conference, University of Hull.

Davis J M (1999) The politics of the qualitative research role: changing the power relations of research production, Researching for Health - Challenges and Controversies Conference, Edinburgh Research Unit For Health and Behavioural Change.

Davis J M, Watson N & Cunningham-Burley S (1998), Obstacles to listening to disabled children, Moray House Institute of Education, Edinburgh.

Davis J M, Watson N & Cunningham-Burley S (1998), Researching disabled childhoods, BSA Conference, Edinburgh.

Davis JM & Cunningham-Burley S (1998), Involving the views of children and young people' Children In Scotland Special Citizens? Conference, Glasgow.

Davis J M & Watson N (1998), The lives of disabled children: emerging issues, Child, Health and Welfare Seminar, University of Hull.

Davis J M & Watson N (1999), Challenging the stereotypes: disabled children and resistance, Sites of Learning Conference, Centre for the Social Study of Childhood, University of Hull.

Davis, J., Watson, N. and Priestley, M. (1999) Dilemmas of the field: What can the study of disabled childhoods tell us about contemporary sociology? paper presented at the 1999 BSA conference 'For Sociology' University of Glasgow, 6-9 April 1999.

Priestley, M. (1997) Childhood disability or disabled childhood? paper presented to the Cambridge Social Stratification Research Seminar, Clare College, Cambridge.

Priestley, M. and Davis, J M (1999) In and out of childhood: disabled children in adult worlds
paper to be presented at the 'Mind the Gap' conference University of Leicester, September 1999

Shakespeare, T (1998) No voice, no choice, Centre for Research on Family, Kinship and Childhood Seminar, University of Leeds.

Shakespeare, T (1998) A constant burden: constructing disability and childhood in social policy, Child, Health and Welfare Seminar, University of Hull.

Watson N (1998) The lives of disabled children, keynote address to Children In Scotland Special Citizens? Conference, Glasgow.

Watson N (1999) The everyday worlds of disabled children, Department of Nursing Studies Seminar, University of Edinburgh.

Watson, N & Davis, J.M. (1998) Working With Disabled Children: The Reflexive Imperative, Disability Studies Seminar, Edinburgh.

Other Dissemination

- The project has produced three newsletters to date, which have been distributed widely to academic, voluntary and statutory organisations. A fourth publication, reporting on the project as a whole, is planned for distribution through the same channels. Two editions of a newsletter reporting on the Leeds research were also circulated on a more local basis.
- At a local level, there have been extensive and ongoing contacts with voluntary and statutory sectors in Leeds and Edinburgh. There have been numerous requests for information about the project from academic researchers (in a number of countries) and disabled people's organisations in the UK - including the Alliance for Inclusive Education and Disability Equality in Education.

Non-academic presentations

Priestley, M. (1998) Preparing children with disabilities for family placement: direct work and communication workshop for NCH Action for Children Family Placement Seminar, Bodington Hall, Leeds.

Shakespeare, T (1998) Keynote speech, NCH Action for Children Family Placement Seminar, Bodington Hall, Leeds.

Shakespeare, T (1997) Keynote speech, British Association of Dentistry for the Handicapped, London.

Shakespeare, T (1998) Keynote speech, National Association of Paediatric Occupational Therapists, Cambridge.

Shakespeare, T (1999) Presentation of key findings, ESRC Child 5-16 Programme User Dissemination Conference, London.

Shakespeare, T (1999) Meeting the challenge of the challenging child, 17th Congress of the International Association of Paediatric Dentistry, London.

Project events and activities

The project advisory team, comprising academics and representatives of voluntary and statutory organisations, has met twice.

Mairian Corker, Mark Priestley and Tom Shakespeare gave a presentation for the Hearing Impaired Service of Leeds City Council, May 1999, reporting on the project, particularly the work with deaf and hearing impaired children.

Mark Priestley organised a one-day seminar for local service planners and providers in the Leeds/Bradford area on 'Disability and Childhood' in May 1999, with presentations by project members and other researchers in the field.. More than 20 representatives attended from social services, health authority, education authority, voluntary sector and disabled people's organisations. The momentum from this event will be used to generate interest in a further collaborative event with Leeds Centre for Integrated Living (Leeds CIL)

The Edinburgh sub-team will be organising a conference in 2000, in association with Accessibility Lothian and Children in Scotland, to feed results from our research back to children, parents and professionals.

Mark Priestley is working with Leeds City Council, Leeds CIL and the Children's Rights Office towards a local conference in February 2000

John M Davis sits on the Children and Young People's sub-committee of Accessibility Lothian which has LA officials, head teachers, disabled teachers and parents and a young people's advisory group guiding the support of children in mainstream and special education. A National Lottery Charities Board grant is funding this work.

John M Davis has worked with Sophie Pilgrim of Children in Scotland and contributed to their training days for local authorities and other people who work with disabled children specifically attending a training work shop called 'Onwards and Upwards: Involving disabled children and young people in decision-making' 27 of April 1999, where he was able to put some of our findings to statutory and voluntary sector workers from health, education and social services.

Mark Priestley has been involved in direct liaison with the Leeds Local Education Authority, Leeds Social Services, Leeds City Councillors, and local voluntary organisations including Mencap, Barnardo's, NCH Action for Children, PHAB club etc. He has supported the statutory young disabled persons advisory group for Leeds City Council.

Mark Priestley has held specific dissemination meetings with the local authority development officer for children's services and the disability sports development officer. These meetings were to examine how research findings might inform future practice. There were also specific feedback sessions for staff in three local high schools and key workers at the Leeds CIL

Mairian Corker has been invited to return to one of the schools for hearing impaired children to give feedback to children and staff.

Tom Shakespeare has served on the Family Fund Trust Research Advisory Group.

Nick Watson has served on the Riddell Committee on Education for Children with Severe Low Incidence Disability, The Scottish Office, and project data has been used in this Committee's final report.

Nick Watson has also been involved in disseminating findings to Accessibility Lothian, where project data was used as a basis for two successful grant applications to the NLCB and the European Social Fund, and to the Lothian Coalition of Disabled People.

Impacts

Our research has contributed to Leeds City Council's ongoing efforts to listen to the voices of disabled children through their advisory group, and to the work of Accessibility Lothian and Children in Scotland. Data has been made available to the Save the Children Alliance Task Group on Disability & Discrimination project documenting examples of violations and good practice in to the Convention on the Rights of the Child and disabled children, as well as other childcare organisations. Other researchers nationally and internationally have expressed interest in our methodology and findings for their own research with specific groups of disabled children. There has been no commercial exploitation of the research.

Future Research Priorities

The emphasis on young people's experiences and perceptions, the open methodological approach, and the absence of previous child-centred research in this area, provided an ideal opportunity for disabled children involved with the project to discuss their lives and for themes and issues relevant to their lives to be identified. Further questions and priorities for future research were also generated from within the project team, arising from fieldwork observations, methodological debates and discussions with significant adults (including local policy makers). Thus, the project findings suggest a number of important and potentially fruitful directions for future research with disabled children and young people.

The project focused on the perceptions and experiences of disabled young people themselves. This allowed for a great deal of specificity and helped to address the absence of disabled voices within childhood research. As a next step, it would be beneficial to compare some of the findings with the experiences and perceptions of non-disabled children. This could be done in three ways:

- there is some scope to develop specific comparative studies of disabled and non-disabled children's experiences and perceptions, focusing on particular themes and issues raised by the research.
- comparative work could be developed through the secondary analysis of qualitative data sets in which disability status was not originally considered as a variable (other projects within the ESRC programme provide ample scope for such work).
- childhood researchers and funders should be encouraged to consider disability in future studies of childhood, in order to ensure that their experiences are not excluded from such work and the understandings it generates (in the way that gender and race/ethnicity have already been incorporated).

There are many possibilities for such research. For example, many disabled children perceived their experiences of peer friendships and bullying as very different to those of non-disabled children. Some comparison with the perceptions of non-disabled children on these issues would help to clarify this perception. Other fruitful areas for comparison might include career aspirations, perceptions of future selves, use of public services and the built environment. Such research would also assist policy makers in monitoring the impact of equal opportunities and in targeting appropriate support to young people. More specifically, implementation of the 1995 Disability Discrimination Act and current government concerns with bullying, parenting, educational standards, youth unemployment and citizenship suggest numerous ways in which such research could be targeted.

The rich research data from the project illustrates graphically the diverse ways in which children encounter and negotiate disability labels and identities. It therefore offers a window on the many processes of disablement in 1990s Britain, as they impact on individual children. In developing this analysis it would be useful to link data from disabled children and young people to qualitative data on the life experiences of disabled adults and elders. For example:

- it would be useful to ask how generation interacts with disability and how disability has influenced the life course pathways of different generational cohorts.
- there is also a need to develop more sophisticated analyses of the ways in which gender, race, class and sexuality influence these experiences.
- in particular, there is considerable scope to develop a better understanding of the significance of disability in generational transitions (e.g. from childhood to adulthood and from adulthood to old age). For example, considerable rhetoric, energy and resources are targeted at supporting transitions for young disabled people yet many encounter significant disabling barriers in seeking to achieve an independent adulthood.

The project did not seek to make explicit evaluations of educational provision. However, extensive ethnographic work in schools highlighted a number of issues of concern to young disabled people. A considerable amount of work has been done, and continues to be done, on the relative merits of segregated and integrated schooling. This is clearly a fruitful area for further research and the project findings emphasise the importance of gaining children's own accounts in this context. The age range for the study targeted children in compulsory secondary education. However, children's accounts repeatedly emphasised the transition from primary to secondary school as a significant point in their experience of disability. It would be fruitful to develop research with disabled children around this period of transition.

Another recurrent feature in children's accounts of school was their relationship with adult staff, and specifically with classroom assistants (special needs assistants and non-teaching assistants). Children labelled as disabled are required to negotiate more intensive, interdependent and long-lasting relationships with such adults than their non-disabled peers. Moreover, the quality of these relationships, and the support provided, have a significant impact on children's experience and attainment in school. Yet, the dynamics and impact of these relationships are poorly monitored and under-researched. There is then considerable scope for child-centred research on the provision of

classroom support by non-teaching staff (including the role, status and training of such staff in schools). In general, the disabling discourses in which adults were engaged, and the tendency to label children, are important areas for research. One particular concern was with the application of the ADHD label, and the prescription of Ritalin, to control 'difficult' children.

Specific further research developments include Mark Priestley's ESRC Fellowship, which involves work on disability and the life course. Nick Watson and John M Davis have been awarded a small projects grant by The Interdisciplinary Research Group (IDG) in Social Processes, Society and Health, Medical School, University of Edinburgh to carry out a 'Specialist Literature Review of Attention Deficit Hyperactivity Disorder and the Prescribing of Ritalin Amongst Children and Adolescents'. The aim is to use this review to write a paper for publication and to act as a base from which to apply for funding to look into the issue of ADHD. Mairian Corker is developing socio-linguistic work drawing on the data from this project, offering a unique opportunity for collaborative interdisciplinary work in this field. John Davis and Sarah Cunningham-Burley are also involved in a project exploring children's everyday experiences of health variations funded under the ESRC Health Variations Programme.