

Chapter 11 (In 'Implementing the Social Model of Disability: Theory and Research' edited by Colin Barnes and Geof Mercer (2004); Leeds: The Disability Press, pp. 172-190).

CHAPTER 11

Research with Children: ethnography, participation,
disability, self-empowerment

John Davis and John Hogan

Introduction

This chapter discusses the use of participatory and emancipatory methods with children and young people. Initially, it discusses the theoretical basis of such work before critically reflecting on the practical benefits and limitations of such approaches. It specifically reports on the experiences of a participatory project carried out in Liverpool in 2001/2002 (Davis and Hogan 2002).

Children/young people and participation

A number of authors have argued that children in the UK are positioned within a welfare discourse that does not respect their abilities (De Winter 1997; Roche 1997; Cockburn 1998; Hogan 2002). That welfare policy focuses on making children into 'better' future adults rather than making children's lives better in the present (Cockburn 1998; Prout 2000). In schools, an elitist culture is reinforced by rigid control of the curriculum, inflexible processes of assessment and regular HMI (Her Majesty's Inspectors) evaluation (Hargreaves 1989). The focus on schools as a place where future workers are produced

leads to exaggerated adult control of school and free time and results in children's own wishes becoming 'invisible' (Prout 2000).

The philosophical basis of the welfarist agenda is found in the idea of socialisation. This concept haunts both sociological writing on social capital and constructivist perspectives in psychology (Davis and Watson 2001; Davis 2002). In sociology, Parsonian perspectives on socialisation have resulted in the child being represented as a danger to society unless properly taught, trained and controlled by parents and professionals (Corsaro 1997).

In psychology, notions of development from Piaget and Vygotskia underpin the perception that adults must intervene in children's lives to ensure 'normal' development. Such intervention is required at the earliest age possible:

Modern social policy starts from the perspective that children are weak, meek, poor, dependent, and needy. They require redemption by way of a technical rational child care that is privatised, universalised, has specific goals/outcomes and that can be scrutinised to establish its usefulness. (Moss and Petrie 2002: 84).

Welfare discourses have been challenged by a children's rights perspective, that aims to pave the way for childhood citizenship that is both empowering and inclusive (Hogan 2002). Examples ranging from the UN Convention On the Rights Of the Child, The Children Act 1989, to Quality Protects have helped to promote the idea that children are agents that can influence the policy agenda around them. This is particularly evident in the *Reggio Emilia* experience in Italy:

Fascism taught them that people who conformed and obeyed were dangerous and therefore they

wanted to encourage children to think and act for themselves. This requires the local policies to be discussed and scrutinised by children parents and practitioners. It also requires us to view the child (not as an isolated human being) as always in relationships with other children and adults, with the past, with society/cultures, etc. (Moss and Petrie 2002: 103).

Moss and Petrie (2002) believe that participatory approaches can shift us from viewing parents as the protectors of children to viewing them as the protectors of children's rights who ensure that they enable children to put forward their own views as 'social participants'. A similar separation occurs in disability studies where non-disabled people are encouraged to contribute to those processes that enable disabled people to achieve self-emancipation (Barnes 1992).

The children's rights perspective has led a number of writers to promote the idea that adults should develop partnerships with children as fellow citizens and equal members of communities (De Winter 1997; Hart 1997; Roche 1999; Tisdall and Davis 2003). They suggest that citizenship is not simply a formal legal status but is enacted through social processes (Davis and Watson 2001; Hogan 2002). The children's rights agenda has created a clamour to carry out participatory projects. These projects invariably aim to 'enable' children to exercise their rights, to make choices about things that influence their lives and/or to be consulted by policy makers.

Participation projects also have their own problems. On a practical note it is worth recognising that many participatory projects fail to achieve tangible outcomes because they:

- take the form of consultation without action;
- are selective in the types of children they allow to participate;
- do not include children as organisers or in decision-making positions;
- do not create ongoing and sustained dialogue between policy makers and children (Davis 2002).

There is little evidence that children and young people have had an impact on policymaking (Kirby and Bryson 2002). Indeed, there is little practical evidence in childhood studies within the UK to support claims that participatory projects are a path to emancipation (Bailey 2004). On the contrary, in childhood studies participatory approaches have been labelled as tokenistic because the children and young people who take part very often receive no feedback on what happened to their ideas and do not discover if their views have stimulated policy change (Morrow 2000; Hill 2003; Tisdall and Davis 2003).

A classic example of token consultation occurs in relation to children's rights in schools. A number of children and young people have complained about the processes by which specific children are chosen to participate in school based forums and projects (Alderson 1999; Morrow 2000; Hill 2003). The suggestion is that some schools may create mechanisms for 'listening' but rather than contributing to the process of developing 'democratic communities', these mechanisms often act to reinforce traditional divisions (Alderson 2002). This means that though schools may inform children about 'rights' within their curriculum, they very often fail to demonstrate how children can exercise rights by example.

This criticism can also be found in the field of health promotion, where it is suggested that though schools teach children about healthy life styles they very often fail

to set an example of what healthy living might be. For example, they have been criticised in relation to the standard of food provided in canteens and levels of hygiene particularly with regard to toilet facilities (Mayall 1994). In practice, young people's roles within participation projects are variable due to lack of time, confidence, interest and skills. Problems can arise: if young people are expected to be 'professional researchers'; if project organisers fail to identify young people's own skills; and if organisers fail to ask young people how they want to work in a participatory team (Kirby with Bryson 2002).

However, there are some participatory projects that overcome these hurdles. For example, a few have enabled children to be involved in processes of change. This has been achieved by developing policy in partnership with service providers and creating processes of dialogue that lead to agreed change rather than consultation that leads to nothing (Cairns 2001; Mitchell 2001). These examples suggest that the creation of useful participation projects is very much dependant on the types of organisations that control the development processes (Kirby with Bryson 2002). Indeed, there is very little evidence that university based research projects that claim to be participatory actually lead to tangible changes in the life experiences of those who participate (Morrow 2000; Tisdall and Davis 2003). This raises the question; what are participation projects that include children and young people really for?

Emancipatory research

In the interest of avoiding overlap with other chapters in this volume, we merely note that emancipatory projects are promoted by a number of key works in disability studies (Barnes 1992, 1996; Oliver 1992, 1996, 1999; Zarb 1992; Shakespeare 1996, 1997; Stone and Priestley 1996; Corker 1999). These works are underpinned by a

number of key ideas:

- disabled people should take an active role in the projects that involve them;
- disabled people should lead projects themselves or work in equal partnership with those who lead projects;
- disabled people should be consulted about the planning of projects and that they should be able to alter the course of such projects;
- projects should not be done simply to improve the careers of non-disabled academics; disabled people should not be treated as guinea pigs in experiments; and projects should lead to real changes in the life conditions of disabled people;
- it is not possible to carry out value free projects and those that organise projects should state their emancipatory aims (e.g. their relationship to the social model) from the outset.

There is an underlying assumption in the early literature on emancipatory research that it is mostly carried out by academics in universities. This assumption can also be found in literature concerning research with children (Grieg and Taylor 1999). Traditionally the university bias meant that the lust for original research findings was put before any recognition of the importance of the educational processes available during research. That is, the participatory and emancipatory potential of research projects went unrecognised.

However, in recent years the division between the academy and disabled people has changed. Many academic projects have been designed and carried out by disabled people who are also academics. Their outputs include a variety of forms of writing, for example: writing that contributes to our knowledge of the structural barriers that disabled people encounter, for example, a lack of

support for transition to adult services (Morris 1999); projects that illustrate the cultural processes that create disability, for example, values held by educational professionals that lead to discrimination in schools (Adams et al. 2000); writing that breaks down stereotypes about different disabled people, for example, by explaining the diversity of experiences of disabled People (Corker and Davis 2001); and texts that examine the potential for collaboration between service users and providers that challenge traditional power relations (Beresford 2004).

Many disabled academics aspire to carry out projects that are participatory and emancipatory. Often they collaborate with academics that are not disabled. We do not know the exact extent to which disabled academics have contributed to the long-term self-emancipation of disabled people. Some of their projects may have had immediate impacts, while others have contributed less dramatically to the overall raising of awareness of the barriers to inclusion that disabled people experience. Occasionally there is a clear link between a research project and social change. For example, the ESRC 'Life as a Disabled Child' project that was designed and managed by a team of academics (3 with impairments, one without) contributed to local processes of dialogue between disabled young people and policy makers in both Edinburgh and Leeds (Davis 2000). This type of contribution by university-based projects is rare because the Research Assessment Exercise judges researchers by their production of academic publications and because academic researchers tend to look at the 'meaning' of phenomena (e.g. what is a disabled child?) rather than the practical aspects of people's lives.

This means that though many academics aspire to carry out emancipatory projects, the ideal may not always come to practical fruition. If we relate this problem to the earlier criticism of participatory projects in childhood studies, we

can raise a number of questions:

- what criteria are used to chose/invite disabled people to take part in emancipatory projects?
- does participation in emancipatory projects actually involve sharing or gaining control of the project from the organisers?
- does choosing which side we are on (e.g. that of the social model) guarantee that projects contribute to the self-emancipation of disabled people?
- are researchers/academics/project organisers who have impairments just as careerist as the non-impaired academics who traditionally have used disabled people as a stepping stone on their career path?
- do emancipatory projects in the field of disability studies actually achieve changes in disabled people's lives, or are they an ideological utopia?

In looking for a vehicle by which to consider some of these questions we will discuss a participatory project carried out in Liverpool by John Davis (previously a university-based researcher who had become an independent research consultant and has since rejoined the ranks of academia), in collaboration with John Hogan (a senior project worker from a voluntary organisation with experience of working in community education/ with young people). The intention was to build on our complementary and contrasting skills and experience of developing participatory approaches. It was supported by a group of interested parties, including the assistant director of children's services, two senior managers in children's services, a number of disabled people employed in health and social services, the leader of a disabled people's arts forum, a group of disabled young adults, and a number of groups of disabled children/young people.

Diversity and difference: a case study from Liverpool

This project was first raised by Mike Jones, Director of the Liverpool Bureau for Children and Young People, in conversation with John Davis. He pointed out the lack of participatory work with disabled children in Liverpool. On returning to Liverpool, Mike Jones and John Hogan worked with Jackie O'Carroll and Peter Duxberry (Liverpool children's/social services) to identify funding for such a project. The aim was to improve on the current position whereby managers within children's and social services rarely consulted with disabled children and young people. The aim was to develop a process where children and young people were enabled to participate in ongoing and substantive service planning. We hoped to be able to support (on a long-term basis) disabled children and young people to influence decisions affecting their lives.

With this aim in mind we established the Diversity and Difference Group to oversee the project. Its aims and objectives were to:

- develop a range of mechanisms to enable children and young people who experienced a variety of social and attitudinal barriers to express their views and influence decision-making including forums, newsletters, website, IT, a variety of communication systems, and advocacy;
- develop agreed standards of practice across agencies for promoting the involvement and participation of disabled children and children with complex needs;
- develop a culture in which the participation of all children in the decision making process is promoted and valued;
- enable children to identify their own issues and agendas;
- consult with children on issues which affect them from a service agenda

- including integrated services, transition, advocacy services, review processes;
- enable children to develop their own mechanisms of communicating their views collectively and individually;
- support children in developing ongoing mechanisms for participation;
- highlight models of good practice.

The aims and objectives of the 'Diversity and Difference Group' complemented a number of other initiatives that aimed to influence service delivery for children and young people in Liverpool. One example was Quality Protects Objectives 6 and 8 (which are used to audit the outcome of services delivered by local authorities in England and Wales) and the Liverpool Children's Fund Plan 'Realising Dreams and Ambitions' (June 2001).

Quality Protects objectives

Objective 6 To ensure that children with specific social needs arising out of disability or a health condition are living in families or other appropriate settings in the community where their assessed needs are adequately met and reviewed.

Objective 8 To actively involve users and carers in planning services and in tailoring individual packages of care and to ensure effective mechanisms are in place to handle complaints.

Liverpool Children's Fund Plan

This sets a number of aims with regards to disabled children:

- engage with disabled children to improve participation, inclusion and access to services;
- empower children as users of services and to

- increase their participation in service planning;
- support improved co-ordination of services and access to information;
- achieve a shift in the culture of play, youth and leisure services towards greater inclusion.

These policy initiatives provided us with a sound platform from which to encourage disabled people to support the Diversity and Difference Group. Principally, support was sought on the basis that the projects would lead to policy change that took account of children and young people's views.

Project details/methods

Approximately 40 children and young people aged 9-21 years took part in the consultation exercise. Focus groups and informal discussions were carried out with 16-21 year olds working as volunteers of a local voluntary organisation, 11-16 year olds who attended a mainstream school and 9-18 year olds who attended a Deaf youth club. The consultation process covered 2 stages. The first comprised an open discussion to enable the children and young people to raise their own issues. The second stage involved asking the children and young people to comment on the objectives of Quality Protects.

Many of the stage one comments involved descriptions of very negative experiences. These reflected the depth of discrimination that disabled children and young people experience on a daily basis. However, in an effort to move beyond a culture of complaint we asked the children and young people to tell us about the positive as well as the negative situations they had experienced. Where they complained about services we asked them how they would change the service if they were put in charge. Their responses enabled us to create a list of recommendations on what and how services should be improved. We also asked the children and young people to suggest specific

projects (outlined later in the chapter) that they wanted to participate in to enable 'ongoing and sustained consultation and dialogue' with service providers.

What follows is not an exhaustive illustration of disabled children's lives in Liverpool. For example, very few children with learning difficulties took part in the project. However, this did act as a starting point from which to gather a broader range of views and experiences. The findings are separated into a number of sections that the children and young people developed in their discussions (Davis and Hogan 2002).

Social Services

The children and young people did not feel that social service staff fully consulted them about the services they received. Indeed, many of the older children had been involved in legal processes aimed at improving their service provision:

Some staff treat you as stupid.

The system creates an atmosphere of constant crisis in the family.

There are inequalities in service provision. I'm not being funny but some people get loads of support because their parents have got big gobs and those that need it don't get any. There has got to be a fairer way. Social Services are fighting in court not to give me a support worker and my mum says she is not going to do all the things she used to cause she is getting older. It's not just the kids that need help it's the parents too. My Mum's doing a placement with her work and she just can't look after me too. She needs her independence too. She has to be out to work at 8 am and social services don't care about that because they haven't got a budget to provide what we need.

Respite care

Most children who had experienced respite care were positive about this service.

However issues of concern were raised with regards to ownership of the service: Respite is designed more for parents, I mean I got on well at respite but it wasn't really like that I was consulted. It might have been better if I got a say in what the respite was. I'm a lot older now but my parents still make the choice of when I go to respite. It should be designed more for young people.

Education

The children and young people suggested that they experienced restriction of choice of which schools they attended; a lack of opportunities to be included structurally and culturally in mainstream schools; and a lack of disability equality awareness, mediation and advocacy. I wasn't allowed to go to a mainstream school – just cos I can't do it physically it doesn't mean I can't do it mentally. A lot of teachers are arrogant. At my first school three teachers sat down to discuss who was teaching me next year and the new teacher said I don't want her in my class. She doesn't have the qualities I like. So I was going to have to move classes but my Mum moved me school. There is no one to complain to in the schools, even if we did have someone to complain to they would have to know how to communicate properly. Like you've brought a level 5 signer with you that's good we can understand them but in school there are not enough staff who can sign (to level 5). The stage 1-2 teachers are just crap, and there are just not enough BSL communicators.

Health care

Disabled children did not present themselves as people in need of continuous health care. It is worth noting that a

number of university studies have indicated that children associate good health with good relationships rather than issues of health and illness (Backett-Milburn et al. 2000). Illness tends to be an event that gets in the way of everyday life (Christensen 1999). Most of the children who participated in the review had impairments that did not involve continuous ill health, though many made regular visits to hospitals. Those who did discuss issues relating to health services discussed issues such as the behaviour of staff, rather than whether they were receiving appropriate medical care.

At hospital they tell your parents instead of you and you don't know what's going on. We should know what happens, it should be explained in a way we can understand. I think the Doctor should come and talk to the staff in schools. Here a nurse did come and speak to the teachers but not at my old school.

Clubs and leisure/play services

All of the children and young people felt that play and leisure services could be substantially improved. Blind kids need balls with bells and play schemes don't have them. At my church there is a boy who is autistic. They sang songs in maketon, taught people to sign and all kinds of ways of communicating. When he was aged three to six they used to take him in and he wasn't any different. When he got older they left him out and wouldn't include him.

Transition

The disabled young people who had experienced careers advice were scathing about the attitudes of staff. They felt:

- they were not offered the same opportunities as other young people;

- staff were prejudiced about their potential to gain full-time employment;
- staff attempted to coerce them into dead end jobs or benefits;

I phoned the Disabled Advice Line at the job centre, it was an answering machine – useless – I hung up. I was on work placement and they went to health and safety and wouldn't let me, I wasn't allowed to type or be a receptionist even though I have level 3 and this was a major health authority. They didn't want me there at reception because I was disabled. I just gave up the placement I wasn't putting up with that.

Role models

Many children and young people were aware that job opportunities were limited for disabled people:

When I leave school I want to be a builder so that I can train other deaf people to be builders so that they get jobs.

Why aren't there any deaf teachers?

Where are the disabled social workers?

Why are none of the support workers in schools disabled?

Unfortunately these observations are not that surprising but are in keeping with the findings of other studies (Middleton 1999; Morris 1999). What was different with this project was the steps taken after we had carried out the consultation.

Recommendations

There is a list of recommendations that the young people suggested in the full report (Davis and Hogan 2002). For example, the development of key workers, disability equality training for all local authority staff, and an

increase in peer education, mediation and advocacy. However in this chapter we want to concentrate on how the young people wanted to influence service planning and delivery.

All the young people expressed a wish to be able to put their views across to service providers and participate in projects that might challenge their experiences of exclusion and discrimination. Their specific proposals were for:

- an Art and Drama project to highlight the issues that disabled children have identified as key to their everyday lives (e.g. inclusive education, play and leisure opportunities, school and home transition, transport);
- a peer education/counselling and disability equality training project to be run in schools to counteract stereotypes and bullying by staff and pupils;
- an independent advocacy project to provide support across different sites e.g. schools, hospitals, multi-agency meetings;
- a project to check local buildings compliance on accessibility and to evaluate the availability of support to aid access to cultural activities within buildings;
- an event to enable disabled children to meet service providers face-to-face to put forward their views on the development of services

These projects are under development. The Disability and Diversity Group are in negotiation with a number of organisations who are well placed to organise and/or fund the projects (e.g. local art groups, disability equality training providers, local planners, local advocacy projects, the children's fund). An action plan has been developed and many of the children and young people's recommendations have already been addressed. For

example:

- the Diversity and Difference Group collaborated with North West Disability Arts Forum to submit a funding proposal to the Liverpool Children's Fund (and received a £150,000 grant to enable disabled artists to develop a number of creative projects involving both disabled and non-disabled children);
- some disabled young people now sit as equals on the Diversity and Difference Group and contribute to developing policies;
- disabled young people were involved in accessibility audits of summer play schemes and are working with support workers to develop an apprenticeship scheme for disabled young people to become access auditors;
- the Liverpool Children's Fund has funded two advocacy support workers posts to develop support across a range of services;
- the Liverpool Bureau for Children and Young People has run a number of conferences and day seminars to establish agreed standards of good practice for increasing children and young people's participation in decision making processes across services and within voluntary organisations in Liverpool.

Though we both worked from a social model perspective and were keen that the project should be emancipatory, it has thrown up problems:

- though we achieved our major aims, it remains to be seen, in the long term, if the Diversity and Difference Group will sustain itself;
- though our project was participatory and disabled young people moved into partnership roles, we wrote the final report, and the participants chose the style of cover and received copy of the report;

- had there been more time and money (we failed to receive funding from the Joseph Rowntree Foundation for a fuller evaluation), it may have been more participatory during the writing up stage, and we would have carried out a more rigorous evaluation. Indeed, this field is underdeveloped, there being very few cases of full scale research to assess children and young people's views of research projects and methods (Hill 2003);
- our evaluation took the form of checking the children and young people's views once we gave them the report. We assumed that participation was a good thing. Subsequently, we realised that further dialogue is required to investigate participant's views over the longer term and to consider the effectiveness of the new projects.

This suggests that that even after deciding 'whose side are you on' (that of the social model/emancipatory practice), the researcher cannot guarantee that the emancipatory objectives will be met in full. Moreover, there is a danger that researchers and project organisers might impose their own view of the social model on participants, and so dis-empower them. Finkelstein (1999) has suggested that a new type of expert might emerge just as disablist as those associated with the medical model. It has been argued that many social model studies of childhood (disabled and non-disabled) are just as restricting as medical model perspectives because they reduce disabled children and young people to the status of passive social victims (Davis et al. 2003). Our feeling is that any dogma (social or medical) is dangerous because it encourages people to scrutinise, comment on and regulate each other's behaviour in ways that can suppress self-expression. In short, you cannot encourage self-empowerment at the same time as telling people how to think. This means that emancipatory projects should in a post-structural way recognise people's varied life

experiences and opinions at the same time as asking people what material changes they require. If and when disabled people offer conflicting opinions we should not see this as a starting point for collective crisis, rather as an agenda for consultation, dialogue, negotiation and agreed action. We should also not deride participatory projects because they fail to challenge immediately the influence of national policy networks. We believe that emancipatory research can be judged successful where it supports disabled children and young people in challenging their local life conditions or where it enables children and young people to develop skills that will support them in later life.

An associated argument is that those running participatory projects need to use a mixture of methods to evaluate participant's (both service users and providers) experiences and the short/ long term benefits to participants/ service providers/ communities (Davis 2002). It is arrogant to assume that simply because a researcher chooses a specific philosophical stance that he/she has legitimacy. More efforts should be made in both disability and childhood studies to carry out long term post-project evaluation of participant's views on the extent to which participatory/ emancipatory projects actually meet participant's objectives.

A further concern is to represent the diversity of disabled people. Though the arts projects in Liverpool will mean that a greater range of disabled young people will have the opportunity to put forward their views, the original focus groups were not representative of a wide range of disabled children and young people. A great deal of money is required if participatory projects are to achieve this representative target.

Discussion

What is emancipation and participation? We had an idea that we would build a process in Liverpool that began to

reconstitute power relationships between adults and children. The children and young people in our study engaged with this perspective and they suggested that they wanted:

- to work with policy makers on a face to face basis;
- to access resources to plan and carryout their own projects;
- to work in partnership with adults;
- to have time to meaningfully develop their ideas.

These findings challenge the stereotypical representation of disabled childhood as static, vulnerable and dependent, and disabled children as lacking agency, imagination and creativity (Shakespeare and Watson 1998). It requires that adults who provide services stop treating disabled children as objects of service delivery and start engaging with disabled children as subjects who can work together with adults to plan and deliver services (Davis et al. 2003).

The Diversity and Difference Group were able to initiate a participatory process that required policy makers and service providers to listen to disabled children and young people and act on their ideas. We were also able to begin to develop self-emancipatory processes where disabled young people developed their own services (e.g. the access audit apprenticeship). The power relations between adult professionals and disabled children and young people were not totally changed but the processes of negotiation and partnership were beginning to develop.

This project provides evidence to support Bailey's (2004) view that participatory projects can enable emancipatory agendas. It suggests that there are benefits from joining the two approaches. However, in Liverpool we were lucky to have strong links with senior managers in local authorities who had the power to act on the wishes of

participants and to bring together a multi-agency group. This experience appears to reinforce Kirkby with Bryson's (2001) view that the success of participatory projects is dependent on the way they are supported and organised. John Hogan's local contacts and knowledge meant that the participants treated us like insiders. Unlike many university-based projects, we did not parachute into the community. This meant that we received little resistance from children and young people. Indeed, the Deaf children who participated commented that they only chose to speak to us because we were accompanied by an experienced BSL interpreter already well known to them. This recognition of the local social/cultural context is a very important aspect in planning participatory projects.

This means that, like other writers, we believe that there is no one way to do participatory or emancipatory projects (Davis 1998; Hill 2003). Many of the texts that promote emancipatory research show little awareness of the need to take account of local circumstances and cultures (Davis 2000). A variety of approaches might have value. For example, sometimes disabled children and young people want to take full control of projects, policy developments, or service planning/delivery; on other occasions they ask for support from adults or expect adults to provide various services. Therefore, it is important to provide opportunities for disabled children and young people to say what they think about emancipatory and participatory projects and ensure that the processes of project evaluation are better scrutinised by funding providers.

We also have to recognise the dangers of using participatory and emancipatory approaches with children and young people. Firstly, it would be unwise to assume that children and young people are only able to gain control of their lives through 'projects'. Indeed, the children's rights perspective appears to assume that most

children don't already carry out citizenship/responsible roles despite contrary evidence from, for example, many studies of families. Very often children successfully combine responsible roles, including supporting parents in health settings and acting as interpreters during negotiations between adult service providers and their parents, with the everyday processes of childhood, such as leisure time and playing with friends (Backett et al. 2000; Candappa and Egharevba 2001). Indeed, in terms of childhood theory, there is a danger that writers on children's rights reproduce the 'passive' discourse they try so hard to refute (Davis et al. 2003). For if we truly believe that children and young people are active/creative social agents then we must also accept they can achieve self-emancipation without the intervention of over-bearing adults. This argument can be linked to the development of post-structural theory in disability studies (Corker and Shakespeare 2002). It is claimed that we should move beyond modernist preoccupations with categorising groups of people to recognise that children and young people (disabled or not) have multiple identities and abilities, and that these cannot be reduced to simple notions of class, 'race', impairment, or age (Davis 2000; Corker and Davis 2001; Davis 2003). On a daily basis these abilities enable them to challenge, resist and overcome the barriers they encounter in their lives.

Secondly, we should recognise that the 'projects' based approach can be too rigid and not what all children and young people want. Some writers argue that most of the pressure for children and young people to attend participatory projects comes from adults (Hill 2003). We are aware that some participatory projects have led to the creation of a 'professional child' who is constantly involved in pseudo-consultation (Hogan 2002). It is important that participatory projects balance the serious topic of socio-political change with creativity and fun. Otherwise, we run

the danger of organising projects that corral, discipline, examine and over regulate the everyday experiences of childhood. Indeed, participatory projects may enable professional and service provider agendas to take precedence over the agendas of disabled people (Finkelstein 1999; Mercer 2004).

Finally, we should not assume that the outputs of successful participatory and emancipatory projects can always be fully controlled by the participants or the organisers. As Tom Shakespeare (1996) has pointed out, the idea of independent living was very usefully adopted by Thatcherites hell bent on cutting public expenditure. Yet, when this happens we should not be overly critical if the benefits of experiencing the participation process outweigh the failure to achieve specific outcomes and/or goals. For, in keeping with Friere (1972), Bailey (2004) and Mercer (2004), we consider the educational and social processes of participatory and emancipatory projects to be as important as any of the project's findings and outcomes.

Bibliography

- Adams, J., Swain, J. and Clark, J. 2000: What's So Special? Teachers' Models and Their Realisation in Practice in Segregated Schools. *Disability and Society*, 15 (2), 233-246.
- Alderson, P. 2002: Student Rights in British Schools: trust, autonomy, connection and regulation. In R Edwards (ed.), *Children, Home and School: Autonomy, Connection or Regulation*. London: Falmer Press.
- Alderson, P. 1999: Civic rights in schools. *Youth and Policy*, 56-73.
- Backett-Milburn, K., Davis, J. M. and Cunningham-Burley, S. 2000: Discussion of the social and cultural context of children's lifestyles and the production of health variations relevant to adult risk of CVD. NHF 'Young at

- Heart' Summit Meeting.
- Bailey, K. 2004: Learning More from the Social Model: linking experience, participation and knowledge production. In C.Barnes and G. Mercer (eds), ***Implementing the Social Model of Disability: Theory and Research***. Leeds: The Disability Press.
- Barnes, C. 1992: Qualitative Research: Valuable or irrelevant? ***Disability, Handicap and Society***, 7 (2), 115-124.
- Barnes, C. 1996: Disability and the Myth of the Independent Researcher, ***Disability and Society***, 11 (1), 107-110.
- Barnes, C. 2003: What a Difference a Decade Makes: Reflections on Doing 'Emancipatory' Disability Research. ***Disability and Society***, 18 (1), 3 17.
- Beresford, P. 2004: Madness, Distress, Research and the Social Model. In C.Barnes and G. Mercer (eds), ***Implementing the Social Model of Disability: Theory and Research***. Leeds: The Disability Press.
- Candappa, M. and Egharevba, I. 2001: Negotiating Boundaries: Tensions within home and school life for refugee children. In R Edwards (ed.), ***Children, Home and School: Regulation, Autonomy or Connection***. London: Routledge.
- Cairns, L. 2001: Investing in Children: Learning how to promote the rights of all children. ***Children and Society***, 15 (5), 347-360.
- Cockburn, T. 1998: Children and Citizenship in Britain. ***Childhood***, 5 (1), 99-118.
- Christensen, P. 1999: It Hurts: Children's cultural Learning about everyday illness. ***ETNOFOOR***. XII (1), 39-52.
- Corker, M. and Davis, J. M. 2001: Portrait of Callum: the disabling of a childhood. In R Edwards (ed.), ***Children, Home and School: Regulation, Autonomy or Connection***. London: Routledge.
- Corker, M. 1999: Differences, Conflations and

- Foundations: The limits to 'accurate' theoretical representation of disabled people's experiences. *Disability and Society*, 14 (5), 627-642.
- Corker, M. and Shakespeare, T. (eds.) 2002: *Disability and Postmodernity*. London: Continuum
- Corsaro, W. 1997: *The Sociology of Childhood*. London: Pine Forge.
- Davis, J. M. 1998: Understanding The Meanings of Children: A Reflexive Process. *Children and Society*, 12 (5), 325-335.
- Davis, J. M. 2000: Disability studies as ethnographic research and text: Research strategies and roles for promoting social change? *Disability and Society*, 15 (2), 191-206.
- Davis, J. M. 2002: Reconstructing 'Health Promotion' with children and young people. Presented at European Conference: Reducing Social Inequalities in Health Among Children and Young People. December, Copenhagen.
- Davis, J. M. 2003: Engaging Children and Disability Through Ethnography: Negotiating Everyday Identities With Adults And Children. In D. Kasnitz and R. Shuttleworth (eds), *Engaging Anthropology in Disability Studies*.
- Davis, J.M. and Hogan, J. 2002: Diversity and Difference: Consultation and Involvement of Disabled Children and Young People in Policy Planning and Development in Liverpool Quality Protects/Children's Fund/Liverpool Bureau for Children and Young People. Unpublished paper.
- Davis, J.M. and Watson, N. 2001: Theories Of Social Exclusion In Childhood. 5th European Sociological Association Conference Visions And Divisions. Helsinki, Finland. Aug. 28-Sept. 1, 2001.
- Davis, J.M., Watson, N., Corker, M., and Shakespeare, T. 2003: Reconstructing Disabled Childhoods and Social Policy in the UK. In A. Prout and C. Hallet (eds),

- Hearing the Voices of Children.*** London: Falmer Press.
- De Winter, M. 1997: Children as Fellow Citizens: participation and commitment. Oxford: Radcliff Medical Press.
- Friere, P. 1972: ***Pedagogy of the Oppressed.*** Harmondsworth: Penguin.
- Finkelstein, V. 1999: Doing disability research. *Disability and Society*, 14 (6), 859-67.
- Grieg, A. and Taylor, J. 1999: Doing research With Children. London: Sage.
- Hargreaves, A. 1989: ***Curriculum and Assessment Reform.*** Oxford: Oxford University Press.
- Hart, R. 1997: ***Children's Participation.*** London: Earthscan, in association with UNICEF.
- Hill, M. 2003: Children's Voices On Ways Of Having A Voice. ESRC Seminar Series: Challenging 'Social Inclusion' Perspectives For and From Young People. April: Glasgow.
- Hogan, J. 2002: Rhetoric or Reality. Unpublished MA Thesis. University of Liverpool.
- Kirby, P. with Bryson, S. 2002: ***Measuring the Magic? Evaluating and researching young people's participation in public decision making.*** London: Carnegie Young People Initiative.
- Kirby, P. 2001: Involving Young People in Research. In B. Franklin (ed.), ***The New Handbook of Children's Rights: Contemporary Policy and Practice.*** London: Routledge.
- Mayall, B. 1994: ***Negotiating health: Primary School Children at Home and School.*** London: Cassell.
- Mercer, G. 2004: From Critique to Practice: emancipatory disability research. In C. Barnes and G. Mercer (eds), ***Implementing the Social Model of Disability: Theory and Research.*** Leeds: The Disability Press.
- Middleton, S. 1999: ***Disabled Children: Challenging***

- Social Exclusion***. Oxford: Blackwell.
- Mitchell, R.C. 2001: Implementing Children's Rights in British Columbia: Using The Population Health Framework. ***International Journal of Children's Rights***, 8, 333-349.
- Moss, P. and Petrie, P. 2002: ***From Children's Services to Children's Spaces: Public Policy, Children and Childhood***. London: Routledge.
- Morris, J. 1999: ***Hurting Into A Void. Transition to Adulthood for Young Disabled People***. York: Joseph Rowntree Foundation.
- Morrow, G. 2000: 'It's cool...cos' you can't give us detentions and things, can you?': Reflections on research with children. In P. Milner and B. Carolin (eds), ***Time to Listen to Children***. London: Routledge.
- Oliver, M. 1992: Changing the Social Relations of Research Production. ***Disability, Handicap and Society***, 7 (2), 101-114.
- Oliver, M. 1996: ***Understanding Disability: From theory to practice***. Basingstoke: Macmillan.
- Oliver, M. 1999: Final accounts and The Parasite People. In M. Corker and S. French (eds), ***Disability Discourse***. Buckingham: Open University Press.
- Prout, A. 2000: Children's Participation: Control and Self-Realisation in British Late Modernity. ***Children and Society***, 14 (4), 304-15.
- Roche, J. 1997: Children's Rights: Participation and Dialogue. In J. Roche and S. Tucker (eds), ***Youth in Society***. London: Sage
- Roche, J. 1999: Childhood: rights, participation and citizenship. ***Childhood***, 6 (4), 475-94.
- Shakespeare, T. 1996: Rules of Engagement: Doing disability research. ***Disability and Society***. 11 (1), 115-119.
- Shakespeare, T. 1997: Researching Disabled Sexuality. In C. Barnes and G. Mercer (eds), ***Doing Disability Research***. Leeds:

The Disability Press.

Shakespeare, T. and Watson, N. 1998: Theoretical Perspectives on Disabled Childhood. In C. Robinson and K. Stalker (eds), ***Growing Up With Disability***. London: Jessica Kingsley.

Stone, E. and Priestley, M. 1996: Parasites, pawns and partners: disability research and the role of non-disabled researchers. *British Journal of Sociology*, 47 (4), 699-716.

Tisdall, K. and Davis, J. M. 2003: Making A Difference, Bringing Children And Young People's Views Into Policy Making. ESRC Seminar: Challenging 'Social Inclusion'. April: Glasgow.

Zarb, G. 1992: On The Road to Damascus: First steps towards changing the relations of disability research production. ***Disability, Handicap and Society***, 7 (2), 125-138.