Unfinished Business:
Disabled Children and Disability Identity
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This short paper arises from work in progress on a two year research project called "Life as a Disabled Child," funded by the UK Economic and Social Research Council's Childhood 5-16 Programme (award number L129251047). The research was carried out in two locations, one in England and one in Scotland.

We were able to spend time with many children in different social settings (both in and out of school). All the children we met were aged between 11 and 16 years old and would be considered as disabled within the terms of children's legislation in the two countries concerned. During the course of our research,
we accumulated a large amount of ethnographic field notes, group discussions, interviews and creative writing from children themselves. This paper gives a flavour of the richness and diversity of this data in relation to one particular topic - disability and identity. In so doing, it also builds on previously published work by members of the research team (Barnes, 1990; Shakespeare, 1996; Shakespeare et al., 1996; Corker, 1996; 1998; 1999; Priestley, 1996; 1998; 1999; Shakespeare and Watson, 1998; Davis, Priestley and Watson, 1999; Davis, 1999; Davis, Watson and Cunningham-Burley, in press).

Disability and Identity

A great deal has been written about disability and identity formation in the past. For example, Goffman's (1963) analysis of "spoiled identity" and Scott's (1969) *The Making of Blind Men* (sic!) brought issues of impairment and identity into the sociological mainstream, and medical sociologists have shown a great interest in these issues over the years (e.g. Kelly, 1992; Pinder, 1995). However, few of these accounts come from what we now think of as a disability perspective. Thus, Barnes' (1990) research with young disabled people made important steps towards a more social model account of socialisation and identity formation.

Shakespeare (1996) argues that issues of disability identity are particularly important because they help us to understand the complex relationships between individuals, biology and society. In particular, Shakespeare identifies a tension between the concerns of social science and those of the disabled peoples' movement. For contemporary social scientists, identity has become a complex and nuanced concept, reflecting the diversity and richness of human experience in an uncertain and changing world (Giddens, 1991), and this is reflected in the range of identities which exist amongst disabled people (Oliver 1996; Corker 1999). However, the mobilisation of the disabled peoples' movement has drawn on the idea that disability identity can be something more stable - a shared experience, based on common interests (Finkelstein, 1993; Campbell and Oliver, 1996). Indeed, disability studies itself has arisen, in part, from an attempt to be clear about what disability identity really means in a social world (Linton, 1998). However, given that most writing about "identity" tends to place emphasis on self-definition and/or social definition in terms of language, it is interesting that in both accounts it is assumed that disability identity exists prior to language, and is simply "marked" or "reflected" in how disabled people come to use language (Corker 1999a).

Writing from a politicised disability perspective, Oliver (1996, p. 5) chooses to define disabled people according to three elements - as those who have an impairment, who experience externally imposed restrictions and who self-identify as a disabled people. For Oliver then, becoming "disabled" was part of a particular political identity, completely different from being someone "with impairments." Shakespeare et al. (1996) adopt a more fluid approach, drawing on Plummer's (1995)

description of identity as "telling stories." Plummer attributes particular significance to the process of "coming out" and Shakespeare (1996) suggests that "similar processes in self-understanding are going on in the field of disability identity." However, it is important to recognise that the ability to tell believable stories about one's identity depends to a large extent on the power and resources available to the story teller (Corker 1998, 1999a). As children, and disabled children in particular, invent their own stories about who they are, they often come up against more influential versions told by adults.

Partly for these reasons, we were interested to discover something about the stories that older disabled children told about themselves - how they identified themselves in relation to disability and how others identified them. We were interested to observe how children revealed themselves in different situations and the kinds of language they used to do this. We met some children who were working hard to maintain a positive disability identity, similar to the versions popular within the disabled peoples' movement. We also met children who wanted nothing to do with any kind of disability identity. Unsurprisingly, most of the children we met had a more fluid approach. They thought about disability in different ways, and this aspect of their identity was more important to them in some situations than in others (see also Jahoda et al., 1988; Allan, 1996; Norwich, 1997).

Two Poems

Davis, Priestley and Watson (1999) highlight two poems, collected during our research, which illustrate how children may choose to present 'disability' either as a shared experience of social exclusion or as a feature of their own bodily difference. Both were written by teenage girls attending a special school for children with physical impairments.

'Disability'

To some people disabled can mean,
Being abnormal and different,
Why can't they see,
That we are quite normal and similar to them,
We're just normal women and men.
They see our chairs,
They see our sticks,
These help us move,
They don't do tricks,
Some people think it will make us sad,
But we like being different,
We're happy and glad.
Most people we meet just treat us as normal,
Not being so reserved and formal,
They should see us as people and not as chairs,
We're the same as them,
Going to parks and fairs,
Whether you are disabled or not,
Be content with your life,
And happy with what you've got.

'Disabled'

When I was little I had lots of operations,
I remember lots of tubes about me,
I looked at my legs,

I realised I wasn't like everyone else,
I was different,
I wish I could have my feet in the centre,
And walk in a straight line,
I've coped better now as I've got older,
My mum said 'Walk away from nasty comments',
And I've learnt to stand up for myself,
One day I'd like to paint.

In the first poem, the author describes how the trappings of impairment are less important than the way other people react. The second author prioritises her individual experience of impairment. The first poem talks of disabled people as "we"; the second uses "I". The first is called "Disability"; the second is called "Disabled". When we met disabled children we found many different ways of thinking about these things. The following discussion uses data from our research to illustrate some of the ways that children identified themselves to us and to others. All the names have been changed.

My body, our bodies

When Robbie says he is "disabled," he talks about physical impairment. He attends a special school and says there are "quite a lot" of disabled children there. When Mark asked him what it was like being the only disabled person in his family, Robbie said it was 'not very good...'cos my arm gets stiff sometimes.' He identified common experiences with children who had similar impairments, like his friend Josh - "he's got a poorly arm and another arm like me." Although Robbie has learning difficulties himself, he didn't think that children without physical impairments could be "disabled." There were other examples like this, especially from children with physical impairments in special schools. They seemed to have accepted a sense of disability identity linked to a particular category of perceived impairment, which ruled out many other children who we might also think of as "disabled."

However, some children with impairments, who identify themselves as disabled, want to include children with different kinds of impairment. When Mark asked Martin about disability language, he came up with a very general definition. For Martin, "Disabled is more like a general word for people with physical difficulties and learning and mental difficulties." Another good example came from a conversation between Mairian and Stewart. Mairian showed him a newsletter about our research project.

Stewart: Does that word (points to 'disability') include us?

Mairian: What do you think?

Stewart: Well...that's a "wheelchair" sign (points to picture)...I think people who have problems walking, people with cerebral palsy...and people in wheelchairs and blind people and people who can't speak properly or have got something wrong with their brain and can't learn. I think it includes them...

[All of this is signed very graphically, often with the use of mime, so he's absolutely clear about what he is referring to - but he's describing impairment.]

Mairian: What about deaf people?

Stewart: (with emphasis) OF COURSE! Deaf people can't hear that means we're disabled...
[again, this is impairment]

Mairian: You know some Deaf adults say they're not disabled...

Stewart: That's rubbish! ...if we can't hear we're different from everyone else...can't do the same things, we get bullied... [impairment and disability]

Mairian: So you mean you're like blind people and people with learning difficulties?

Stewart: Of course...we're disabled, we can't communicate. [impairment]

Mairian: But you communicate really well with me.

Stewart: You're deaf. That's different.

There are many complex things going on here, about disability (in the social model sense) and about impairment. Although Stewart is clear that people with any kind of perceived functional impairment are disabled, he is less clear that things like bullying can be called "disability," in the social model sense. When Steve saw the international disability access symbol in a computer clip art file, he told Mairian "...it means that people who can't walk and need to use a wheelchair to help 'em around...they can get into the place...." He didn't see himself as disabled, although he wore a hearing aid.

Your body

Some children focused on other children's impairments to boost their own sense of identity. Often they wanted to separate themselves from those they thought of as "disabled." When Mark asked John about disability identities he was very unsure. In the end he said, "I think Down Syndrome are disabled" (there are a number of children with Down Syndrome in his school). As someone with a visual impairment, he wanted to emphasise that these children were more disabled than he was. Kirsty, who is also registered blind, reacted similarly. For her, disabled people were - "Down's [sic] Syndrome kids, people deaf, deaf and blind I suppose in a way, because you can't hear or see...I don't know about people with cerebral palsy. I don't s'pose. Well, I suppose they are disabled in a way. I've got a friend who's got cerebral palsy, she comes on the minibus with me." It was hard for Kirsty to think of herself or her friend as "disabled."

Foregrounding disability in our research conversations often raised issues for children about who they saw as "like" or "not like" themselves. This revealed a great deal to us about the process of identification. Gilly and Alison talked to Mairian about disabled friends who, whilst part of their social circle, were "not the same":

Mairian: OK... so you have disabled friends? They experience similar things?

Alison: (nods)...disabled (frowns/nods) have...I think wonderful, how cope...my friend...disabled...umm [name], [name]...umm...have, brain problem and leg problem, have strange walk its not...communication...can sign...anyway, her name Gilly ...(looks at Gilly) same name as you...she from the [local] area, umm [name of place]. She BIN told me, some behaviour problem like laughing at her which makes her frustrated because she talk different, have different sign, but when with us she sign VEE, no problem.

Gilly: Yes, I have friend who's deaf called Simon, have problem arms and sometime difficult to understand, but good person, good relations and funny.

Mairian: So different school?

Gilly: Yes (names school in different LEA).

Mairian: You think yourself disabled?

Gilly: No....

Alison: (frowns, shakes head) well, not really...not disabled because born hearing...but become deaf when very young...and so I feel not disabled because don't miss it.

Gilly: I agree...and I born profoundly deaf... not become deaf ...don't understand really because me use hearing aids and my mum sometime argue about whether out or in, but that's all.

Mairian: But you think disabled people are OK...

Gilly: Yes.

Ben and Kevin didn't think their dyslexia had anything to do with disability. As Kevin put it, "it doesn't refer to us...'Cos we're dyslexic, its like another thing". For Ben, disability was, "Wheelchair, blind with stick or...somet' like that...Physical disabled...And maybe mentally, like Down's [sic] Syndrome or somet'." Clare did see herself as disabled but was keen to tell Mark that "there's a lot more things that could be a lot worse than dyslexia, now I could have been disabled in a wheelchair. I couldn't be able to cope with that I don't think...It's just really really sad to see these people." Children on the receiving end of such hierarchies reacted in different ways. For example, Lucy was very aware of a hierarchy between "walkers" and "wheelchair users" in her special school. She thought

this was reflected in the way that they were treated - "If they can walk they treat them a bit better than us." However, she had a very positive view about her own disability identity as a wheelchair user.

Us lot

In some schools, especially resourced mainstream schools, there was a tendency for disabled children to feel a sense of collective identity. This was most obvious when children with particular kinds of impairment were grouped together so that curriculum support could be provided. More than once we heard the phrase "us lot" used to describe an impairment specific group of children drawing on the same special unit for support in school. Emma talked this way about children with visual impairments in her school (to distinguish them from children with learning difficulties in the same school). Furzana used the same phrase to refer to a group of girls with learning difficulties using the support service in another school. The common experience here was not necessarily impairment so much as administrative segregation.

Various authors have highlighted the significance of disability as an administrative category in modern industrial societies (e.g. Stone, 1984; Finkelstein, 1991; Albrecht, 1992). On a smaller scale, the administrative division of disabled children into groups is often clearly visible to their friends and marks them out as different. Allan (1996) argues that the organisation and administration of "special needs" education in Britain plays a big part in making disabled children known to others in this way. Priestley (1999) uses data from our research to provide more examples of how this happens in mainstream high schools.

The social context is clearly important here. For example, being with other disabled people in an enabling environment could make a big difference. Becky told Mark, "It's quite different when I'm round them...it's different from being with able-bodied...I think it's better." When Mark asked Becky about the word "disabled" she said it was "a good word" but she added that "in some situations...we're not always disabled" - "At the wheelchair basketball it's quite interesting 'cos you're not really disabled...Because we're all in much the same position and although we have varying degrees of disability, we all have a common objective there." Brendan added that he had enjoyed going on a disability protest with his mum. He enjoyed the atmosphere and told Mark, "I like the idea of having power as a disabled person. I mean, instead of being fobbed off."

Nobody's disabled, everybody's disabled

Kirsty did not want to make a big deal out of her own situation - "I suppose in some cases it is, you are disabled, but in other, you know, like having eyesight problems, I suppose it's not really a disability. I suppose it's just a minor problem." Kelly, who is terminally ill, said "I don't really think anybody's disabled, I just think everybody's got something that's wrong with them, just like people who aren't disabled can have a cough or cold, you're not going to class them as disabled, are you?" She went on, "I don't class myself as disabled. I just class myself as having a little problem, but when I go up me friends' I forget about it and then when I come home, and I've got to have me medicine, it's there for five minutes and then it's gone again. I just comes and goes for me."

Dionne doesn't like the word "disabled" much (although she does use it herself). She doesn't see being disabled, or being black, as having any necessary impact on her life and prefers to think of people as individuals. "Nobody's disabled 'cos, like everyone has problems doing something don't they? So you could say that we all are in some way or another." As Claire put it - "Everybody has some sort of disability, some sort in size, shape or whatever, 'cos they can't walk or they find difficulties or whatever." We heard these views often, echoing Zola's (1989) view that impairment is a universal human attribute - "everyone has got one and they will likely have them a lot longer than anyone realises" (Zola, 1993). However, many of the deaf children Mairian worked with made it clear that they wanted to distance themselves from the word "disability." "We're deaf .. that's all," said Andy. They saw disability as "illness" or impairment and resistant to the suggestion that disability might be defined differently.

Some children, like Aquila, didn't talk about "disability" at all. Although she has learning difficulties, Aquila does not seem to face the same barriers that some of her friends do, and she is well integrated into family life at home. This was true for most of the children from ethnic minority families, as it was for most children with learning difficulties. This may reflect the fact that ideas about disability identity in the UK have been dominated by white accounts of living with physical impairment, or that some children face difficult decisions about which aspects of their visible identity are more important to them at any particular time (see, Stuart, 1992, or Ahmad, 1999, for a discussion of the relationship between disability identities and black identities in Britain). As we have argued elsewhere, gender, age, class, ethnicity and sexuality are often more important than disability for children with impairments when they are in enabling situations (Priestley, 1998).

Researching these issues is complex because it is apparent from children's everyday talk that social issues like disability are often "backgrounded," "presupposed" or "absent," unless they are raised in the school curriculum (Fairclough, 1995). Within youth cultures, "who's going out with who," "who likes or doesn't like who," clothes, sport and music are very much to the fore in everyday talk. Adults are, for the most part, not included in these cultures and the questions adults ask about social issues can seem out of place, unless these cultural reference points are used as a way into children's worlds (Corker, 1999). We have many examples of this in our research data.

Disabling Environments

When Kevin talks about disability, he focuses on physical access issues for wheelchair users and on public attitudes. He tends not to talk about impairment issues at all (his own or other people's). In an interview with Mark, he described how difficult it was to get into badly designed buildings. He was particularly annoyed about the new McDonald's restaurant near his school. Recently, the local youth worker has been encouraging Kevin to get involved in disability issues. He has now written a letter to MacDonald's about wheelchair access and volunteered to join a local advisory group of young disabled people.

Brendan also talked about access issues for wheelchair users and other people's attitudes, rather than his own impairments. He talked about disabled people in a collective way - as "us" or "we." When he first heard about our research project he said, "We're not liked are we in this country?" Brendan feels comfortable with his identity as a disabled person in a mainstream school, although he does not mix much with other disabled students. By contrast, Alex did not pick up any on physical access issues in his interview, unlike other wheelchair users in his special school. All the examples Alex used were concerned with communication barriers, such as noisy playgrounds where people found it difficult to understand his speech (something he finds very frustrating) - "If someone's not deaf, it really makes me wanna hit 'em'."

Low (1996) emphasises the importance of disabling environments and the organisation of social space in identity formation amongst young disabled people. She describes how Canadian college students sought to reject the (negative) disabled identities imposed on them by staff and students. However, in order to negotiate disabling barriers in a mainstream college campus, they often had to revert to a "disabled" identity in order to get support: "In order to achieve a non-disabled identity, students with disabilities must successfully negotiate a physical environment which in its inaccessibility isolates them from interaction with others, emphasising their disabled identities." (Low, 1996, p. 246)

Conclusions

For some children, being disabled is defined by having an impairment or an assistive device (e.g. having Down Syndrome or using a wheelchair). Different children include different kinds of impairment, depending whether they want to adopt or reject a disability identity themselves. Other children want to acknowledge their disability identity, while placing themselves as superior to chil-

dren with "worse" kinds of impairment. Some children saw all those with impairments as disabled and were happy to include themselves. Children who identified with impairment in these various ways often saw disability identity as a fairly negative thing.

Some children identify with common experiences of discrimination, shared by children with a variety of different impairments. For example, a number of children identified their experiences of being teased, bullied, stared at or denied access to buildings as a common bond. These children seemed less likely to talk about changing themselves and more likely to talk about changing environments and other people's attitudes. Other children want to acknowledge their disability identity while emphasising the ordinariness of it. We met children who felt that everybody is disabled and that nobody is disabled. Sometimes they showed us how they could be disabled in one situation and not in another.

In this short paper we have highlighted only a few of the stories that children told us about themselves. However, the examples do illustrate some themes for further investigation. Much disability writing has focused on the body as a key factor in identity formation. For example, Bleeker and Mulderij (1992) and Mulderij (1996) emphasise the experience of the impaired body in their account of the "lifeworld of physically disabled children" in the Netherlands. In England, Anderson and Clarke's (1982) study also quoted children talking about their impairments at length. However, we found far fewer children who seemed to talk about themselves in this way. They were more likely to talk about other children's supposed limitations than their own. Where children revealed personal experiences, these seemed to have more to do with discrimination, disabling environments or acceptance by others than with impairment.

It is important to note that these observations may well reflect the fact that we came to the research from a broadly social model perspective and that we did not restrict our sampling to children with particular categories of perceived impairment (Priestley, 1998). It may also be a product of our attempts to balance ethnographic research - recording, and involving ourselves in, the naturally occurring events of disabled children's lives - with more focused interviews about these events (Corker 1999). These are issues that we will continue to explore in our analysis of the lives of disabled children.

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