

## **DRAFT COPY**

### **“I’m sorry, she’s special needs”: Explaining learning disabilities in public encounters**

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This paper is based upon part of my PhD research which is drawing upon three areas of study; the sociology of public spaces, disability studies and mothering, to explore the experiences of mothers of learning disabled children in public encounters. For mothers of learning disabled children, public encounters may offer unusual and sometime problematic challenges because their children may display unconventional, or even socially unacceptable, behaviour and yet their learning impairment may not be immediately apparent. My research is examining how mothers mediate and negotiate such encounters, the impact that any social disapproval has upon themselves and their children and what strategies they use to facilitate social encounters. This paper will focus upon one particular element of the study, the use of explanations in explaining learning disabilities.

The significance of the study of public spaces, defined by Lofland as “those non private sectors or areas of urban settlements in which individuals in co-presence tend to be personally unknown or only categorically known to each other” (Lofland 1973) has been well documented within social science literature (Birenbaum and Sagarin 1973; Lofland 1978; Lofland 1989; Cooper 1998). Goffman, in particular, has drawn attention to the significance of the study of everyday encounters highlighting the importance attached to socially acceptable behaviour in public places (Goffman 1961; 1963; 1967; 1967; 1969; 1971; 1983) suggesting how:

Participants in interactions are expected to suppress immediate heartfelt feelings, convey a view of a situation which is at least temporarily acceptable and reach a working consensus. (Goffman, 1969:21)

The management of public interactions by disabled people has also been well documented (W.Schneider and Conrad 1980; Gardner 1991; Morris 1991; Keith 1996; Morris 1996; Farrell and Corrin 2001; Lenny and Sercombe 2002) and this literature demonstrates the problematic experiences disabled people may have in public encounters. For Morris:

It is not only physical limitations that restrict us to our homes and those whom we know. It is the knowledge that each entry into the public world will be dominated by stares, by condescension, by pity and by hostility. (Morris, 1991:25)

Whilst there is not the space within this paper to explore why disabled people are subjected to public negativity and hostile, it is clear that repeatedly experiencing negative interactions can have considerable consequences for disabled people, and those close to them, and may lead to social isolation, low self esteem, depression and social exclusion. (Morris 1991; Keith 1996) Furthermore, the exclusion of disabled people from mainstream life prevents non-disabled people from getting to know disabled people and, moreover, ignores the life experiences of disabled people which are sources of knowledge not directly accessible to non-disabled people (Wendell 1996). For Lenny, the solution is simple:

If a person's difference is to be understood, then it seems plausible that people need to start communicating with each other in an open fashion and not to fear people because of their difference. (Lenny and Sercombe, 2002:13)

However, despite the efforts of the disability movement over the past few decades to promote an acceptance and celebration of diversity, the limited impact of this campaign, particularly for people with learning disabilities is clearly illustrated by recent research (Todd 2000). For Todd, "relatively little is known about the nature and structure of everyday encounters in the public domain and how people with intellectual disability deal with the potential difficulties and opportunities which face them there." (Todd, 2000:601). This gap in research is significant because there is considerable evidence that people with learning disabilities are socially excluded from their communities and, even where they are ostensibly included, their social presence is a tenuous one (Brown 1994).

This study will focus upon the explanations mothers choose to give (or not give) during public encounters involving their learning disabled children. One of the main issues emerging from the data in the study is the discrepancy between the anticipated and actual behaviour of learning disabled children due to the non-visibility of the impairment. Goffman makes the distinction between discredited (i.e. apparent) and discreditable (i.e. non-apparent) stigmas and suggests that whilst the emphasis for people with discredited stigmas is on tension management, for those with discreditable stigmas the emphasis is on information control (Goffman 1963). The issue of information control is a consistent

theme for mothers going out with their learning disabled children as they, and their children, may experience social disapproval at what is perceived by others to be inappropriate or unacceptable behaviour.

Cahill suggests that it is more important for the person in charge of the child to show that he or she is aware that the child has transgressed some social rule or rules of behaviour than the actual behaviour of the child. Whilst this may be a recognisable experience to most parents, if the child has a learning impairment then what may be construed as misbehaviour by others may not be by the parents or carer of the child. One way of dealing with this tension is to provide an account or explanation of the child's learning impairment thereby redefining the situation. This may have the effect of restoring maternal competence in the eyes of others but it may also involve transferring the responsibility for the disruption to the encounter from the mother to the child's impairment and, at the same time, ascribing a particular identity to the child. Whilst some research argues that drawing attention away from the acknowledgement of difference merely compounds the person's powerlessness and instead people should accentuate their differences (Brown, 1994: 156), this argument arguably has less mileage when applied to learning disabled people who occupy an ambiguous position within the disability movement, let alone within the community (Walmsley 2001; Chappell 2002).

Before going on to look in some details to how mothers deal with this dilemma, I will briefly outline some of the key themes emerging from the data in order to provide a context for the findings.

### **Listening to mothers' experiences**

The data for the study is being collected through a combination of focus groups and semi-structured interviews with mothers of learning disabled children living in Oxfordshire. The sample has been drawn from mothers of school age (5-16 year olds) children attending two special schools. So far twenty mothers have taken part in the study.

One of the key themes, as already indicated, is the visibility or non-visibility of the children's learning impairments and this appears to be clearly related to the age of the child. The younger the child, the less apparent the learning impairment. Participants with younger children describe how much easier they would find going out in public if their children had some visible sign of impairment. For example

A friend of mine, her son had a problem with his hearing for a while and wore a hearing aid. She was mortified when it improved and it had to go. She said that with that hearing aid people could see and make some sort of allowance. (Jill, focus group)

Other participants describe how they use major buggies as a means of alerting people in public encounters. As one participant commented; “we get a lot of smiles when she’s in her major buggy” (Lisa, interview). Another participant has a physically disabled daughter and a learning disabled son and she clearly illustrates the different treatment afforded to her children when she is out with them:

There is an extra allowance made immediately when people see that wheelchair and people are often extra nice in a way to Beth. They are really quite kind to her. I mean in some ways there’s a danger that they’ll patronise her but on the other hand, on the whole people are kinder and there’s a bit more understanding. Whereas I find with Peter there’s considerable intolerance of him impairment because he looks normal. (June, focus group)

There appears to be a point as the children grow older that participants realise that their impairment has become more apparent to others. For example:

That was the turning point for me because I put him up on the check out in order to keep him in one place while I was packing and this guy was talking to me, and I said “he’s got special needs” and he said “I know”. I thought from that minute on I don’t have to say it anymore, it’s pretty obvious. (Sue, focus group)

Another theme emerging from the data is experiencing social disapproval. All participants describe experiencing social disapproval when out with their children and this can take the form of comments, tuts, stares or glares. For participants with younger children this appears to be linked to the perception of their children’s behaviour as naughty. For example:

She kicked this lady. Well, she didn’t really kick her, she touched her leg with her toe. I tried to get her away but the lady kept standing closer and anyway, Charlotte poked her with her toe and this lady came over and said “If that was my child I’d give her a good hiding.” (Lisa, interview)

However, mothers of older (i.e. discredited children) also experience social disapproval and this appears to be linked to issues of fear, unpredictability and control. Participants describe how people seem to be genuinely alarmed by their children:

If I take him to Millets Farm I take him at a time when it's really quiet because you know he can't wait to get near the animals and he charges off down there and can quite sort of loud. Everybody turns round and looks and moves away as if, you know, something abhorrent is approaching and some days you're not actually strong enough to want to actually face that look from everybody and you know that they're actually physically moving their child as if something awful is coming. (Susan, focus group).

I try to be very bright and chatty when people react like this and sort of normalise it in a way. I mainly try and allay peoples fear that he is going to do something that will threaten them. (June, focus group)

So what do participants do to ameliorate this disapproval? The data suggests that participants use a number of strategies to facilitate public encounters, including timing trips out carefully or restricting outings to tried and tested places, but this paper will focus upon one particular area, the use (or non-use) of explanations.

### **Explaining learning disabilities**

Overall explanations when used are brief, accessible and understandable: "I tell it in a way that Joe Public will understand" (June, focus group). The explanations are not static but vary according to a number of factors including the particular context of the interaction, the intention of the outing, the perceived reaction from the public, who is present with the mother and child and so on. As one participant says "I assess the person whose had a go at me and think now what might you understand." (Lisa, interview)

The simplest and most common way of explaining that a child has a learning impairment is to use a label or medical diagnosis. Participants describe using a variety of labels as explanatory tools in public interactions and these include specific medical diagnoses such as autism and more general terms such as 'special needs', 'learning disability' and 'learning difficulty'. Most commonly were 'he or she has got special needs' and 'he/she's autistic'.

Some research has criticised parents for reifying the medical profession and over medicalising their children (Avery 1999). However, this is not apparent within the study and, in fact, the majority of participants appear to be fairly nonchalant about their children's diagnoses, viewing them more as a means of accessing resources and as useful explanatory tools, than significant in themselves. Not all the children in the study have specific diagnoses although that does not stop their mothers from using them. For example:

Sometimes I tell people she's got autistic tendencies because people know what autism is, rather than saying she's got ADHD. She's got ADHD so they tell me though I'm not convinced. She's also got autistic tendencies though she's not autistic. I mean she's just Charlotte but I can't go round saying to people "she's just Charlotte." (Lucy, interview)

Because she hasn't got a label it's very difficult for me to actually say 'sorry, she's autistic' or whatever. Sometimes, it sounds really silly, but I do say 'sorry but she's a bit autistic'. (Gail, focus group)

While research underlines the effectiveness of bringing "beyond my control medical interpretation to potentially discrediting events" (Schneider and Conrad, 1980:41), using a medical disclaimer will only be effective if it is mutually accepted by those providing it and those for whom it is provided. Some participants describe instances in which the explanation they provided was not accepted by others. For example:

We were queuing up for something to eat and Julie saw something she wanted. She'd been quite good and she went to the front of the queue and took what she wanted and then she came back to us. I said 'excuse me, she's autistic and she doesn't understand how to queue' and this woman said 'well I've got an autistic grand daughter and she does know how to queue.' (Jane, interview)

Recent research suggests that mothers strongly challenge the dominant narrative, challenge medical knowledge and assert their own knowledge about their children. This process involves them redefining their own values and priorities and revising their opinions of what is normal (Landsman 1998) For Landsman, "advocacy for one's disabled child becomes part of the identity of the mother, but is born of the recognition of the child's humanity and of one's fear that the full value of the child is missed by

others.” (Landsman, 1998: ) Whilst for some participants this involves speaking out about their children’s impairment, for others it means the opposite. For example;

And I actually think it helps people become more aware. I don’t think it helps with the general awareness of whatever disability if you hide behind it. If you say this child is autistic and is behaving in an autistic manner then actually people do learn. (Caroline, interview)

I’m trying very hard for Hannah to grow up and have an identity that is not entirely wrapped up with epilepsy. That’s she’s my little girl first. I think that if the first thing you say is like “this is my daughter and she’s epileptic..” I’m trying to get away from that because it’s easy to become so focused on the problems. (Mary, interview)

Read suggests that, for many women, finding out they are the mother of a disabled child can be a distressing and dislocating process (Read 2000) and further research describes the “therapeutic function for the self of sharing or diffusing the burden of such information” (Schneider and Conrad, 1980:40).. These feelings are apparent within the data although this appears to be a short lived approach as mothers readapt, readjust and make sense of their new status. For example:

It took about a year and a half then all of a sudden I said to my husband “Do you realise we’ve just done a whole shopping trip in Sainsbury’s without saying “he’s autistic”? It was like, wow, we can do it and now we only really say something if he’s really in one. (Karen, focus group)

A further reason for providing explanations is to facilitate inclusion within different groups. For example:

I find as long as I explain to older children that Paul and James are different and they don’t always understand but they want you to play with them, then that child will make an effort to include my boys. (Karen, focus group)

I tell the kids in the park, the older ones, in a way that they can understand. Like I say he can’t speak like they can and he’s not quite as clever as they are and they’ve always been fine with him. It’s the same with Mary and Matthew (siblings) (Dawn, interview)

## **Saying ‘sorry’**

Within the focus groups the use of the word 'sorry' was a consistent theme and these discussions provide some interesting insights into the complexity of the relationship participants perceive between their children as individuals, their children's impairment, the way they feel others perceive their children and their awareness of what is acceptable behaviour in public. One participant regularly apologises for her daughter's behaviour in public encounters:

Sometimes you get people looking at you because obviously they've got different mannerisms don't they? Like if Rebecca is sitting in the pushchair they're thinking why is this child in a pushchair. Some people are funny but I tend to say something like, if she's having one of her funny moods, I say 'sorry, she's a child with special needs and she can't help it'. (Gail, focus group)

For the majority of participants, however, there is a clear distinction between apologising for a specific incident and apologising for their child's impairment. They view the difficulties they may experience during a public encounter as external to their child and as long as their child is not behaving in a manner which **the mother** judges to be inappropriate then they refrain from apologising:

I do say sorry to people if he hits them or bumps into them but I never feel I have to apologise for him being disabled. (Dawn, interview)

If it's bothering other people then I'll say 'look Martina, come on, back in the pushchair'. I won't apologise, I'll just say 'come away' because she's got to learn (Christine, interview).

It is clear there is a very fine line between saying to people "look, you are judging my child by rules which are not appropriate to him or her" and saying "it's not her fault – she has learning disabilities." The data suggests that participants are aware that their children's behaviour is not problematic in itself but that it is not acceptable and there are a number of references to there being no space within society for their children.

### **Resisting explanation**

Within the sample a number of participants do not provide explanations for their children's behaviour in public encounters. This is largely because they feel that their children's learning disability is obvious and does not need explaining. The data suggests that participants with older children view public



encounters as often hostile environments in which they and their children are subject to inappropriate intrusions. For example:

You feel why should you need to explain yourself? People should be more understanding. I mean if you went out with, perhaps, an elderly person you wouldn't expect people to come up and start questioning you about them. You know I wouldn't dream of going up to somebody who was out with someone quite old and start saying 'What's the matter with them?'. I mean why you have to justify yourself and why should I have to explain to people? I don't know. (Susan, focus group)

Some participants also feel strongly that there is no point in explaining because people rarely understand and the process of explaining can create greater distance between the mother and others and expose her and her child to the risk of rejection (Bury 1982; Read 2000). For example:

I'm so sick of it I don't like to make eye contact. I don't want to explain to anyone. I've spent so many years having to explain his behaviour and I've always found people very unsympathetic anyway. They just look like they haven't a clue what you're on about or why you can't control this child. Also if you get a bad reaction back it just upsets you even more so it's best not to put yourself in a position to be open to .. because you won't get any 90% of the time or even understanding. Yeah, I used to try to but I only used to get a blank expression. Maybe I wasn't good at explaining. But I've lost heart to keep explaining because I've never found it was really worth it. (Ruth, interview)

## **Conclusion**

There does appear to be a link between the age of a child and the visibility of his or her learning impairment. For participants with younger children, the learning impairment is often not apparent and the emphasis in public encounters, therefore, is upon information control. The use of explanations is fluid, context based and may involve the use of a (sometimes borrowed) medical disclaimer/label. Participants use explanations to raise awareness about learning impairments, to advocate on behalf of their children, because it has therapeutic function or to facilitate social inclusion. Overall, participants will apologise for their children's behaviour but only when they judge the behaviour to be inappropriate or unacceptable. For participants with older children the need for explanations is reduced by the visibility of their children's learning impairment and, for them, the emphasis shifts to tension management.

When the child is younger it appears that social disapproval can be ameliorated by providing a medical disclaimer. This approach is largely successful as the data suggests that people tend to respond positively to the explanations provided and the children are still young enough not to pose a threat. Cahill argues that the social tolerance of any child decreases as the child grows older and that public environments become more hostile to older children who are given less leeway to misbehave (Cahill 1990). This could again be linked to issues of control because non-disabled older children are perhaps more likely to be in public spaces without an adult caretaker.

Marion Barnes suggests that families with learning disabled children become isolated by a lack of understanding which itself comes from the invisibility of learning disabilities. I think that what this paper is showing is that it is not necessarily the invisibility of the learning impairment that people do not understand. There are certainly misunderstandings that arise over the behaviour of young, learning disabled children in public that appear to be ameliorated by the provision of an explanation of the learning impairment. This ambiguity can lead to mothers choosing to 'bring to the surface' their children's learning impairment though the use of signifiers such as major buggies. However, such explanations or signifiers are not necessary when the child grows older and the learning impairment becomes more apparent. Whilst participants with younger children attribute the social disapproval they and their children experience to the non-visibility of the learning impairment (like Barnes), in reality the social acceptance of the learning disabled child decreases as the child grows older. This would suggest that it is the fear and negativity surrounding learning impairments which is the problem and, in the context of public encounters, this is linked to issues of control and predictability.

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