Hidden Impairment - Public Disability:
The Pressures of Public Parenting
of Children with Learning Disabilities

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Impairment and disability

Children with learning disabilities have been marginalised and excluded in Western society for centuries (Middleton, 1992, 1998; Oliver, 1996). This has been reflected in criticism of the prevailing individual, medical model of disability in favour of the radical social model which claims that society discriminates against people with physical and mental impairments, erecting barriers to their participation (Oliver, 1996). However, Hughes and Patterson (1997) assert that impairment (i.e., medically based limitations of function) and disability (i.e., socially based limitations on performance of activities) should be distinguished prompting the need for a realignment between the body, self and society. This theory suggests that the existing social model denies the body an identity of its own and fails to acknowledge the child's body as an experiencing agent.

The Medical Gaze

Hughes (1999) cites work by Sartre and Foucault when asserting that impairment is constructed, not discovered, in the non-disabled gaze. The invalidation and disfigurement of impaired bodies is not simply an economic and cultural response to them, but arises in the mode of perception which visualises and articulates them as strangers. Medical observations pathologise and objectify impairment and the impaired body is rendered disorderly by the 'positive' observational practices that produce it (Hughes, 1999). This medicalisation of the impaired body was coined 'le regard' (the gaze) by Sartre (1958) and reinforced by Foucault (1973). The social model attempts to deflect this gaze from impaired bodies to the social body, and this has marked the beginning of an assault on the 'tyrannies of perfection' (Glaussner, 1992) which play a central role in informing intercorporeal encounters. However, overemphasis of 'the aesthetic' (Eagleton, 1990:13) when constructing impairment serves to divorce the social model from developments in the sociology of the body (e.g. issues of carnality, intercoporeality, perception).

The Body as Agency

Traditionally, the impaired body has been depicted as the passive recipient of social forces, yet this acts to deny the body as agency and activity (Paterson and Hughes, 1999). It is through the body that we as humans gain access to the world (Lyon and Barbalet, 1994). Indeed, Bendelow and Williams (1995) posit the 'lived body'; a body which simultaneously experiences and creates the world.

Dys-appearance. Paterson and Hughes (1999) maintain that when the impaired body encounters prejudice in behaviour or attitude, it 'dys-appears'. In other words, the body appears as the thematic focus of attention, but in a dys-state (Leder, 1990). In terms of intercoporeality;

> ...the essentially hidden, absorbed structure of the vocal body, in compa-
> ny with the vocal bodies of others, initiates, maintains and closes every
> kind of social setting. (Paterson and Hughes, 1999: 604)

The norms of communication and intercoporeal interaction are a product and reflection of the

carnal needs of non-disabled actors (Robillard, 1996). The impaired body dys-appears functionally and aesthetically when faced with (socially-produced) embodied norms of communication. Indeed, the scripts for communication, timing and proprioception are predisposed to exclude impaired people. This leads to impaired individuals being ostracized from opportunities to participate in everyday, mundane and sensate activities.

The everyday reality of such condescension is the perception of impaired individuals as eternal children. They are denied the label of 'socially-competent' based upon knee-jerk, aesthetic judgements (Paterson and Hughes, 1999). These instantaneous, infantilising and discriminatory judgements are reactions to body, movement and speech, and demonstrate the aestheticisation of contemporary culture (Maffesoli, 1996). Relentless marginalisation in social encounters can prompt impaired individuals to strive to restore their performance to normality, thus embracing the principles of 'normalisation'. Normalisation is seen as the price of integration, where impaired individuals reject their own bodies and adjust to the carnal norms of the non-disabled. Therefore, normalisation assists in contextualising the objectification ('dys-appearance') of impaired bodies, whilst simultaneously being experienced as impairment (Paterson and Hughes, 1999).

Bodily Perfection and Invisible Disability

The myth of bodily perfection permeated the dominant culture of the late twentieth century. The medically-inspired 'healthy body' ideal promotes social norms and values for behaviour, feelings, physical functions, thoughts and aesthetics (Turner, 1992). Individuals who do not conform (e.g., disabled children) are labelled as deviant (Goffman, 1963). This aligns with the perspective of disability as socially constructed (e.g., Social Model).

The assumption that all impairments are negative and disabling simply reinforces and sustains society's obsession with bodily perfection. Distorted and negative images of disability discourage people from acknowledging and accepting their own disability, promotes disability as a condition to be avoided, and caricatures disabled people as helpless and dependent (Stone, 1995). Stone regards this as the logical outcome of the hegemonic view of disability as personal tragedy, which is grounded in 'a paradigm of humanity as young and healthy' (Wendell, 1989:108). Therefore, the denial of disability is socially sanctioned (c.f. Hillyer, 1993).

However, differences in social explanations of disability exist, depending upon whether it is visible or invisible. Individuals in society tend to attend to what they can most readily observe and this has induced a focus upon visible disability to the extent that the prevalence of invisible disability has been ignored (Stone, 1995). This is reflected in World Health Organisation definitions of impairment and disability which fail to allow for recognition of disability as socially constructed and also fails to distinguish between people with visible and invisible disabilities (WHO, 1980).

The denial of the prevalence of disability is made easier because the majority of the (UK) population have disabilities that can be concealed. According to Stone (1995:417):

> Most people have disabilities that are invisible, meaning that the disability is not readily apparent through casual observation.

Thus, the existence of invisible disability in the population tends to be forgotten or dismissed as inconsequential even though invisible disabilities limit individuals every bit as much as visible disabilities. Despite this, many people have difficulty imagining that someone appearing able-bodied may have a disability. Indeed, some people in society think that invisible disabilities are not real disabilities (Decima, 1992).

As well as being ignored and wrongly perceived due to the invisible nature of their disability, children also possess ambiguities that have the power to cloud cherished bound-

aries. The child represents an innocence and purity of action and aesthetic character (in Western society) and children's aesthetic appeal is cherished for its very ambiguity (Ennew, 1986). This ambiguity leads to tensions in the understanding of childhood as a social and experiential phenomenon.

CATCH Questionnaire

Whilst undertaking research (1989-1995) for the Kerland Foundation in Somerset, England (a child development centre that designs home-based therapies for brain-injured children based on the Doman-Delacato method), Dr. Steve Brown had the opportunity to discuss with many parents, often at length, the issues with which they were most concerned. Consequently, the questions asked as part of the initial CATCH questionnaire (Case, 2000) evolved from dialogue and discussion with parents over the years. The questionnaire design was not arbitrary, but specific to those concerns and issues that families had outlined as pertinent (see also Middleton, 1992, 1998). Parents set the research agenda themselves, rather than having their views regulated and remoulded by professionals/researchers in order to fit neatly into preordained categories of importance (see also Rodgers, 1999). The present questionnaire elaborates upon the parental issues and concerns elucidated by the Brown (1998) and Case (2000) studies, including the areas of the child's aesthetics and bodily agency. Thus, parents set the research agenda and serve as co-researchers (Kiernan, 1999), increasing the validity of the research as a true reflection of the views of parents of children with learning disabilities.

The Parental Perspective

A focus upon the parental perspective can ignore the child's viewpoint serving to objectify and pathologise children with learning disabilities. However, learning disabilities may be accompanied by severe limitations in receptive and expressive communication rendering the child unable to participate meaningfully in research (Kiernan, 1999). In situations where inarticulateness and unresponsiveness are insurmountable obstacles, parents can hold the key to accessing the child's personal experiences and background (Spiegle and van den Pol, 1993). This enables researchers to circumvent the ethical problems of obtaining the child's 'informed consent' for study (Stalker, 1998) as well as raising awareness of the child's perspective which is 'perennially missing from these kind of debates' (Middleton, 1997: 223). Consequently, the present study will elicit the parental perspective focusing upon relationships with health professionals.

Methodology and Procedure

A 19-item questionnaire was administered by post (1998-1999) to the parents of 84 children with learning disabilities from throughout the UK (56 males, 28 females, mean age = 8.57 years). Each parent had previously contacted CATCH! for information regarding treatment and/or research and had subsequently agreed to complete a questionnaire. Children within the family sample possessed a wide variety of learning disabilities (including physical disabilities) with more than one child having been diagnosed with Cerebral Palsy (37), Autism (13), Down's Syndrome (4) and Epilepsy (2). Eleven children had not received a diagnosis. However, the inclusion of specific diagnostic details was optional (except that each parent had to confirm a diagnosis of learning disability), so complete diagnostic information for the sample is unavailable. No questions were compulsory, producing differences in response frequencies for each item (mean response rate = 82.9%). Subjects were given no time limit for completion and returned the questionnaires by post. The questionnaire was split into 2 sections: questions relating to the child's aesthetics and body.

Results

Single responses (i.e., 'yes' or 'no') and multiple responses (e.g., were the effects positive/negative/uncertain?) were analysed using the non-parametric Chi-square 'goodness of fit' test (one variable-two categories, therefore one tailed). Questions with one variable in more than two categories were analysed as two tailed. A detailed results table can be found in the appendix.

Summary

Parents confirmed that their impaired child attracts attention in public. However, public attention is not gained deliberately and is not perceived as negative, even though most attention is due to lack of public knowledge. Significantly, there is no difference between the frequency of attention attracted before or after public members have met the child.

Parents are likely to employ public coping strategies such as dressing their child in fashionable clothes even though neither parent nor child feels uncomfortable in public. However, parents cite several positive factors relating to their 'publicly' impaired child. For example, parents rate their child's appearance as positive rather than embarrassing and their behaviour as positive rather than anti-social, maintaining that neither their behaviour nor their child's behaviour changes significantly in public.

Discussion

Visibility. The nature of the parental responses elicited indicates that the definition of disability can fluctuate between the extremes of visibility and invisibility (Stone, 1995). This can depend upon the degree of disability (e.g., disability may go into remission), circumstances (e.g., the child may be sitting or standing when addressed) and environment (e.g., children perceived in different locations). Consequently, the notion of 'visibility' of disability may be too misleading and could be more appropriately conceived as 'perceptibility' or 'evidentness' (Goffman, 1963), particularly when assessing why children attract attention before or after meeting people.

Goffman distinguishes between 'known-about-ness' (i.e. the audience's prior knowledge of the disability), 'obtrusiveness' (i.e. how much the disability interferes with interaction) and 'perceived focus' (i.e. the sphere of life activity for which disability disqualifies the person, according to the audience). The public at large is engaged in this viewing so the impact and extent of any disability is dependent upon the decoding capacity of the audience. As is evident from the results, the social climate imposes powerful social rules which subjects parents to embarrassment, ridicule, ignorance and limited opportunity for discussion of their child's condition. This negative effect is compounded by the invisibility of the condition and pressures to conform to bodily perfection (Cavet, 1998). Invisible disability is not readily identifiable if there are no obvious, recognisable visual indications of impairment (reflected in the results). Children with invisible impairments are generally seen as non-disabled and often treated as such. Families work hard to maintain this 'normality' (e.g. dressing the child in fashionable clothing), adding extra complexity to their interactions with others.

Public Perception - Aesthetics

The lack of knowledge and understanding displayed by the general public means that parents no longer expect an informed or receptive response to their impaired child which functions as a disincentive to talking about the situation. Lack of public awareness compounds the need for discretion (e.g. coping strategies) in public or semi-public places (Cavet, 1998). Such public perceptions of disability act as a starting point for a consideration of what is a fundamental feature of the interactions that exist between families of children with learning disabilities and the community in which they live. It highlights that perception, both personal and public, is the favoured tool used to discern what 'appears' to be the nature of the problem with those perceptually ambiguous individuals, children with learning disabilities.

More precisely, that they are anomalous. At the same time as they deviate from the norm of 'idealised' children they also, paradoxically, confirm it.

For example, children with learning disabilities made conspicuous by problems affecting motor control and muscle tone highlight a deviance of form, but the incapacity that results from such physical disorder paradoxically strengthens the helplessness and innocence that serve to typify childhood. They are therefore simultaneously consonant with childlike meekness whilst establishing an opposition to childhood aesthetics. To be one thing and yet another at the same time does not so much depend upon the child, but depends instead upon the interpretation of the child and, of course, the categories employed by those who interpret them (Brown, 1998).

Public Perception - Body

The body must be controlled during our encounters with social actors. Disruptions to the social order are often represented by failures of the body to control its expression during social interaction with others (Ennew, 1986). For example, the management of embarrassment requires considerable control over the body (Turner, 1992) and this may be a specific problem for families of children with learning disabilities, although not in the present study. Learning disabled children possess a 'spoiled identity' (Goffman, 1963) because their inability to manage their self (presentation) compromises another social actor's space which can provoke parental feelings of guilt and responsibility (Ennew, 1986).

Public Performances

Disabled children can attract attention in public due to physically conspicuous aesthetic symptoms (e.g., spasticity, positional deformities) or 'abominations of the body' (Goffman, 1963). However, most parents do not feel uncomfortable in the child's presence, possibly because the child's disability can often only be detected in personal interactions (Brown, 1998). Also, children represent a purity and innocence of action and aesthetic character that can result in tensions in understanding the disabled child (Ennew, 1986). It is through these interactions and tensions that the politics of disability can be discerned and established (Oliver, 1996). However, parental descriptions of their child's appearance display no such tensions with children's appearance and behaviour viewed as positive. This conforms to the encouraging findings of Case (2000) where parents rated their children as attractive, happy, friendly, and interested and bright. Consequently, the positive side of parenting is recognised (see also Seligman and Darling, 1989). This supports the assertion that 'pathologising' parental experience (e.g. MacKeith, 1973) is discriminatory. Parents with disabled children must be given equal rights in society and have their positive experiences highlighted, elaborated and celebrated.

The findings illustrates that parenting has a public arena (Goodnow and Collins, 1990) which impacts upon the parents' self-concept and sense of satisfaction. As the most sensitive situations are likely to arise in public (e.g., doctor's surgery, supermarket) and may attract attention, they involve a display of coping. The public typically cannot recognise or understand the child's symptoms so the parent is in a state of continual coping in order to minimise public discomfort and manage public contacts (e.g., the 'caregiver's burden' - Montgomery, 1989). For instance, parents are more likely to inform others and start up conversations in public (Case, 2000). Thus, the 'public gaze' and the child's ambiguous body fuse in a performance of uninformed and uncontrolled 'theatre' as parents attempt to salvage a threatened script of normality from a critical audience (Brown, 1998).

However, it is not just the injured child's behaviour in public that draws audience attention. Perceptible also are the contours of bodily ambiguity that serve to identify and even spoil the aesthetic nature that underlies the 'ideals' of childhood. When families go about their daily routines, particularly in public places, their performances take on Goffman's

(1963) 'visibility'. Indeed, even though the disruption to bodily character is slight, encounters with others makes some form of detection likely. As Goffman himself states

> The consequence of a presentation that is perforce made to the public at
> large may be small in particular contacts, but in every contact there will
> be some consequence, which taken together can be immense. (1963:65)

The management of such contacts plays an important part in familial coping and although one might imagine that it increases the 'caregiver's burden' (Montgomery, 1989), it can nonetheless function to elicit a positive reaction from those whom a family encounters.

Moreover, such activities also act to reintroduce a family, and usually more frequently the mother, back into the mainstream of society so that a greater amount of contact between the parents and the larger community is realised. As a consequence of increased social engagement and other routines, like shopping and recreation activities in the outside world, parents and their disabled children establish contact with the broader aspects of society. It is often the case that these pioneering engagements a family makes with the larger society are orchestrated to minimise any overt disability that their child might possess. A significant number of parents felt equally comfortable within and outside their own community. This increased social engagement (e.g., shopping, recreation) aims to minimise the overt disability of the child (Brown, 1998).

Clothing

A popular method of 'levelling-off' (i.e., normalising) imagined differences between disabled children and others is to dress the child in fashionable clothes. This serves as a constructive opportunity to reconsider the child's possible potentials, to displace anxieties of an uncertain future, and to publicly affirm that the child is loved and cherished (Brown, 1998). However, clothing possesses connotations of maturity, desirability and conformity to group norms so dressing the impaired child in fashionable clothes could be viewed as parental capitulation to pressures to conform to narrow, stereotyped and valued ideal body shapes (Cavet, 1998). Thus, clothes are important indicators, not just to make the children with learning disabilities more or less perceptible, but also as a social statement that relates in some way to the child's parents. In this way, etiquette is being maintained.

Although it may often fail in its attempt to disguise the child's disability it nevertheless acts to elicit a mutual acknowledgement that the rules of social interaction are in play and the observance of a recognised social etiquette are being met. Thus the public performance requires that the family acknowledge the norms of social engagement through their attempts to minimise the conspicuous behaviours that signify some level of familial trauma. If clothes can act to camouflage the overt contours of disability, the child's 'cover' is given away the moment the body becomes active and moves out into the wider field of view (Goffman, 1963). In this way, even the smallest movements of body become detectable and signal to the observers that some rule of motoric etiquette is being compromised.

Conclusion

The present study supports the impairment/disability distinction (Hughes and Paterson, 1997) suggesting that 'impairment', hidden by parental coping strategies (e.g., normalisation, fashionable clothing) or the child's aesthetic ambiguity, only becomes a 'disability' following the child's interaction within the public, social arena (Cavet, 1998). However, the existing social model denies the body an identity of its own and fails to acknowledge the child's body as an experiencing agent. Therefore, an all-encompassing model of disability should avoid the individual/social binary which has emerged within UK disability theorising (Marks, 1999).

According to Marks, disability should not be theorised as residing within a particular body or environment, but in an embodied relationship. Failure to address embodiment allows the contemporary social model to contribute to the maintenance of individual model by excluding personal experiences thus leaving a theoretical vacuum which is filled by individualistic and decontextualised perspectives. Therefore, the critical study of disability needs to examine how disability is subjectively experienced using an interdisciplinary approach (e.g., incorporating biological, social relational and psychological levels of analysis) in order to understand and perceive bodily, emotional and social differences as mutually constitutive.

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Appendix

Aesthetics and Body Questionnaire:
Summary of the Main Findings

Question	Yes	No	Chi Square	Probability
AESTHETICS				
Child attracts attention?	67	12	38.30	P < O.001
Child deliberately attracts attention?	4	69	57.88	P < 0.001
Negative attention?	21	56	15.91	P < 0.001
Before or after meeting people?	35	39	0.22	NS
Coping strategies in public?	47	28	4.81	P < 0.05
Uncomfortable in public?	23	49	9.39	P < 0.01
Child uncomfortable in public?	16	57	23.03	P < 0.001
Prejudice or fear/ignorance or lack knowledge?	5	73	59.28	P < 0.001
Positive effects?	66	10	41.26	P < 0.001
Fashionable clothes?	41	24	4.45	P < 0.05
Positive appearance?	75	4	63.81	NS
Positive behaviour?	51	26	8.12	P < 0.01
Behaviour change - you?	31	50	4.46	P < 0.05
Behaviour change - child?	32	39	0.69	NS
BODY				
Child's body embarrassing?	13	60	30.26	P < 0.001
Positive expression?	45	26	5.08	P < 0.001
Seeks attention through misbehaviour?	14	54	23.53	P < 0.001
Behaviour antisocial?	28	44	3.56	P < 0.05
Lack of understanding?	32	4	21.78	P < 0.001