

The Orchestrated Body:

An Anthropology of Embodiment and Experience
in Brain Injured Children

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Declaration

Except when specific reference is made to other sources cited in this work, the work in this thesis is the original work of the author. It has not been submitted in whole or in part for any other degree.



Stephen Brown.

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Abstract

This thesis explores issues of embodiment and experiences that serve to orchestrate the lives of brain injured children and their families. In discerning the myriad ramifications that affect childhood disability the body is treated as both a semiological system that presents disability in a conspicuous manner and the 'object' on which therapeutics (orthodox and alternative) are enacted. It is with reference to the brain injured child's body that explanations concerning personal disability, familial trauma and the hope for future amelioration are discussed.

An anthropology, examining embodiment and experience, is initially developed through an analysis of the social construction that led to the development of childhood as an ideological state. The thesis argues that this category of childhood was, in part, constituted by the institutional powers that Foucault (1973) et al saw as the monitoring and control (primarily through the objectifying of the body) of individuals within society. 'The Orchestrated Body' discusses brain injured children's embodiment as an assimilation of divergent social states which describe the child's body with a series of competing notions. For example, the bio-medical approach gives primacy to an organic pathology that resists habilitation, while the consequence of this 'failure to cure' lends support to the notion that brain injury represents Goffmans' (1963) deviance model.

The alternative therapy centre is yet another 'orchestration' of the child's body. However, here the ideology which underpins treatment is in contrast to that advocated by medical professionals. That cultural perceptions are involved in interpreting the behaviours that manifest an altered physical state for brain injured children is analysed with reference to their similarities with possession cults where the body, once again, comes into sharp focus as an aetiological feature of personal chaos. As disrupted motor function acts as a social emblem of disability, this thesis asks can such manifestations be reinterpreted to the benefit of the child and his or her family? Finally, brain injured children are posited as self performers being personally responsible for 'orchestrating' themselves in an attempt to experientially extend an incapacitated body with detail and accounts of living from which they are typically excluded. The main arguments of the thesis are developed from a collection of narratives provided by parents of brain injured children who attend an alternative therapy centre.

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Discerning the Body

Introduction

This thesis attempts to explore those experiences that are situated in the physical motor expressions which function to characterise a specific group of children as brain injured. Such a focus on embodiment is not only intended to illuminate the medical agendas that control and manage a symptomological approach for disability, but more importantly provides a referral point in the attempt to encounter the personal phenomenology of brain injured children. In this sense the body of the brain injured child is not only valuable because it permits a narrative of disability to be semantically located in its pathological and mechanical operations, but also because the body is that very genesis where intent and potential are fused with experience. The result of this, as I intend to show, is that the brain injured child's body is indeed 'orchestrated' by professional practice, but embedded in this 'management score' are the hidden motifs of self expression if one can but discern the experiential child from the labelling condition.

The notions which are developed here were kindled when I was appointed as research and development officer for a national charity that devised family habilitation programmes for brain injured children. My main responsibilities were to research into new therapeutic techniques and rationales which could expand those already in practice. However, during my stay with the Kerland Foundation I became increasingly aware of the trauma that shaped the lives of many families who were attending the centre in the hope that something might be done to help their children realise a better independence

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than that offered through traditional medical practice. The fact that many families had felt their consultations with medical personnel to be less than satisfactory played a large role in the development of this thesis.

However the focus on clinical practitioners, alternative therapists and the families themselves kept, in an almost subliminal way, returning me to a singular preoccupation with that physical entity which makes the child a unique embodied individual. It seemed that the child's body was being orchestrated by professionals, the family and even the community in ways that made their dealings with the child more meaningful in terms of therapy and its underlying social constructions.

Although these children are described as brain injured, the abstract and technical implications of linking specific problems to brain function are often too theoretically challenging to be valid for any meaningful insight into the ontology and nature of the underlying condition. Instead, the focus on aspects of physical form and function seem to provide much greater currency to the understanding of the problems of brain injury (see Chapter 3). In this way, the brain injured child is constructed not only in medical diagnosis but also in terms of social discourses which act to fix the largely 'hidden' neurological impairment to the more readily perceived somatic manifestations of disablement. It was, then, the body and its performances that appeared to me and, if my analysis of the family material presented here is a sympathetic one for the parents also, which served as the defining feature of brain injured children. Brain injury may well be the cause of their child's difference but it is the body that makes impairment conspicuous and causes disability to have an

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experiential reality for both parent and child. Thus, it is the body as that one tangible artefact of trauma which will be utilised in diverse ways in this thesis to explore the embodied reality of these children and the ameliorative possibilities offered by both therapist and doctor.

It is in this sense that I refer, throughout this study, to the brain injured child's body as 'orchestrated'. As an orchestra is composed of different instruments, each with its particular voice, so too is the body. The limbs and senses inform one another in a concerted effort to make motility a harmony of intent and action. However, this is but a part of the orchestrations that I shall explore in this study. The musical analogies that pepper this work are not merely metaphors of motor function but are also intended to demonstrate the collective influences that arrange the particular 'scores' for the disabled bodies of children in our society. The variations and themes that I will elucidate, therefore, are not intended to obliterate the unique and essential melody on which these orchestrations are developed (the phenomenological body) so that the tune is no longer recognised, but are instead an exploration of all those 'soloists' involved with the orchestrations of disability. In my account I intend understanding the composers as conductors, doctors, alternative therapists, parents and families - the performers as children - and the performance as that quintessential stage on which all the soloists compete for primacy of expression in a world that has already been defined by the politics of the adult (see Chapter 2). In this sense the body of the brain injured child carries the tune, a tune that has been composed by personal phenomenology, and it is

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within this tune that the eventual embodiment and experience of the disabled child is to be heard expressed.

The fact that others, both professionals and lay observers, have implicitly constructed meaning from the somatic, and sometimes chaotic, manifestations these children present seemed to require exploring in greater detail. This, in turn, gave rise to the idea that somatic manipulations, themselves a form of orchestration, might be practised by the individual as a method of extending personal phenomenology. This led to the question of whether it was possible that the injured child, too, could be manipulating his or her body in diverse ways that enhanced their experience of the physical and social world so as to develop greater self understanding and, from this, the ability to construct their own personal realities (see Chapter 8). Before being able to answer these more complex questions, however, I realised that I would have to examine the social constructions which were imposed upon these children by those who held differing responsibilities for their future. To this end my sources for this investigation required a multi-disciplinary approach, as literature from medical anthropology alone would not have allowed an exploration of the injured child and his or her embodied possibilities to be unfolded. In this way, although the ethnographic 'visions' in my thesis are conducted by an anthropology of brain injury they are not limited to one. It has been argued that

ethnography is an emergent interdisciplinary phenomena. Its authority and rhetoric have spread to many fields where "culture" is a newly problematic object of description and critique (Clifford 1986: 3).

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The point Clifford makes about culture, then, has relevance also to those children who are the subject of this work. They can no better be understood by any one discipline, be it anthropology or neurology, than can society by economics alone. Therefore, in this thesis explanations and understandings of children with brain injury are sought from a variety of disciplines in the attempt to make their experience and embodiment more explicit. Moreover, the methodology of this thesis has been devised is an attempt to locate an experiential disability through discursive ethnography. Familial 'texts' are, therefore, used to structure the arguments and accounts that provide the research narrative. However, it is unlikely that these 'texts' are solely the product of those who express them, since the accounts contained here concern those families who may be referred to as therapeutically articulate. That is, they have *'first hand'* experience of the rhetoric and practice of alternative therapy, something with which I myself am more than familiar, and which, methodologically, needs to be accounted for.

For example, a number of questions were raised with regard to the reflexivity that naturally occurs within the relationships between clinician\therapist and child. It appeared to me, from my work in the Kerland, that the alternative therapists were more inclined to be affected by their encounters with a particular child than orthodox clinicians. This would often involve them modifying their therapy programmes to accommodate those observations that resulted directly from their interactions with the children. On the other hand, doctors appeared, particularly to the parents, less tolerant of their child's unique capacities, preferring instead to be constrained by the

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inevitable assumption of diagnostics and pharmacological applications. Moreover, my own position was also embroiled within this reflexive paradigm. After all, I was a researcher employed by the Kerland to investigate both the possibility of extending therapeutic procedures and to explore new methods of understanding the children with whom we worked. That is, I was already involved with many of the parents who were to help with this research and I wondered how this familiarity could affect the interpretation of the data I was to collect. Would this prior experience, for example, affect my objectivity so as to confound my study or could it be used to more sharply discern the experiences of disability that were a target of this research? Could I, and my encounters with brain injured children, ever be productive in helping to make more explicit the embodied reality of disability? If the assumptions of the philosopher Peter Winch (1958) are correct, then my interpretations of another's consciousness (embodied potential) inevitably arise from my own. Tony Cohen (1994) has argued that this is a oversimplification of the problem in anthropological account.

It is plainly unacceptable to assume that the anthropologist and the anthropologised are alike; indeed, it could be perverse, for it might risk rendering anthropology redundant. But equally, the assumption that they are *not* alike is unacceptable for it seems to lead inexorably to the construction of their difference. It is also perverse, for it denies the pertinence of the most potent investigative and interpretive weapons in the anthropologists armoury; his own experience and consciousness (Cohen 1994: 4)

I, too, soon realised that it was my own experiences of an encountered disability that made possible the connection between myself and my subject, and it was the reflexivity of this encounter that would act to reform my experience from the relatively naive to a more informed position. In this

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sense all the ideas presented here are the product of that inevitable ethnographic process which contained both myself and those with whom I worked.

Issues in Accessing Children's Experiences: Embodiment

Traditionally, general anthropological research involving what might be referred to as 'issues of childhood' has reflected those agendas proposed by adults, and has tended to relate to social change in urban culture (Turner 1987) or the emphasis and value placed upon the socialisation of children (Grylls 1978). Furthermore, Mayall (1994) has noted that studies involving children may often conceptualise them as if they were characters from some other or 'separate' world. However, there is a rapidly increasing corpus of more sensitive literature concerning the child and the social processes in which childhood is framed (James & Prout 1990, Jenks 1996.1982, Voysey 1975 and Aries 1962). Studies reflecting death in childhood (Bluebond-Langner 1978) and the effect of handicap on the family (Blacher 1984) for example, have demonstrated that childhood and all its presentations are occupying an increasing interest for the social scientist. There is, however, little material that specifically looks at children with brain injury from an anthropological perspective, and which considers these disabled children as a disempowered community under the regulatory influences of professionals, be they orthodox or alternative in their persuasion¹. Moreover, such issues which reference the body and its actions are likely to be coloured by the cultural variants at play in

¹ Cf Disability literature on the empowerment of adults (Oliver 1996, Barton 1996 and Barnes 1996).

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their given situation. That is, anomalous patterns of motor behaviour produce, to different degrees, different rationales to the understanding of the somatic meanings that bodies convey. Indeed, this is particularly relevant for the interpretation of brain injured children's bodies in both our own and other societies. However, there is a substrate on which even these cultural dynamics (see Chapter 7) must rely for their expression because at their most fundamental level they require that corporeal enterprise, embodiment. Thomas Csordas expresses this notion well when he states

The approach I will develop from the perspective of psychological anthropology leans strongly in the direction of phenomenology. This approach to embodiment begins from the methodological postulate that the body is not an *object* to be studied in relation to culture, but is to be considered as the *subject* of culture, or in other words the existential ground of culture. (Csordas 1989: 32)

The problem I faced was how would I discern this existential cultural bedrock so that an unfolding of a phenomenology of brain injury would be realised? I had reasoned that although brain injury was the term for an aetiological taxonomy, professionals, parents and lay observers scrutinised the surface and behaviours of the body and showed surprisingly little interest in precise neural detail. Indeed, even if a therapeutic procedure resulted from some neurological theory its pragmatic focus nevertheless remained on the body (i.e. doing this or that to the body, physically or pharmacologically, should affect the associated neurological problem). Having being convinced by an exhaustive analysis of my family material that embodiment held the key to understanding the phenomenology of brain injury, something that had been largely overlooked by the professionals, I sought a way to gain detailed

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awareness of the brain injured child's embodied reality. In my attempt to address this I saw the family as the methodological key.

Not only do the families' biographies and narratives presented here offer a rich source of material to help piece together the mesh of detail needed to explore the social issues of brain injury at the personal, or phenomenological, level but they also show, I was soon to realise, that families' expertise would be needed if I was ever to experience, even in a vague way, the world in which brain injured children live. Narratives, of course, provide a broad context for discussing disability (see Monks and Frankenberg 1995) whilst the creation of opportunities for autobiographical accounts has been argued, in phenomenological theory, to be 'one of the essential dimensions of the articulation of the streams of consciousness' (Schutz and Luckman, 1974, cited in Kholi 1981). Indeed, it was through such streams of consciousness that it became clear to me that brain injury was not about the brain but about the body, not about physical dysfunction but social embodiment, and finally, not about neurological theory but personal experience. The problem now would be how might I begin to access the relevant data that could provide an answer to these speculations?

A few of those children with whom I did my fieldwork could articulate quite well but, due to their physical and/or mental incapacity, and the result of this on their experiences, even their words and actions meant very little unless I could access the 'dialect' in which these statements became meaningful. Furthermore, with those children whose accounts were not available, due to gross impairment, families might, I hoped, provide a context in which

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meanings could be attached to my observations. The 'dialect', then, which engendered our discussion was not that which influenced the ways these children's, and even their parent's, statements sounded, as one might expect to find in some phonetic shift that occurs in a regional accent, but was, instead, that total phenomenology which enveloped their lives and perhaps my own in ways which could engage a common emotive union of interpersonal expression.

Although inarticulateness and unresponsiveness present problems these, in themselves, are not insurmountable (see Booth & Booth 1996 and Booth 1996 for a good account of such difficulties in narrative research). However, the total communicative inability of many of the children with whom I worked proved somewhat more challenging. Families, as I suspected, held the resources I needed to access the essential personal background that would make translation between myself and these children's accounts possible. Their narratives made possible a phenomenology of encounter, action, purpose, environment and disability that was to underscore every aspect of my research.

The families with whom I worked were eager to help, not perhaps because their information would make explicit the problems of embodiment and experience that were becoming central to this research, but rather because my study gave them the opportunity to explore, through conversation, internal ideas and statements that they had thought but had not, for a variety of reasons, articulated. I also noted that sometimes the role of interviewer / interviewee was reversed, I became the respondent and would be systematically questioned

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by the families about my ideas and particular statements that came to light during the interview. Sometimes this would involve asking me how I felt about the minor modifications that the parents had made to their child's therapy programme and, occasionally, how did I see the future, in terms of development, for their particular child. This usually served to make our discussion a two way exchange of ideas, although at times I was aware that my comments affected their statements and, unintentionally, provided them with a structure for interpreting their material in ways which would have not been solely their own. However, parents do have a unique insight into their child's corporeal management and, potentially, their experience of embodiment due to both the all consuming time they spend with their children and their fundamental need to make sense of, and understand, the expressions of a child orchestrated by physical and mental disability.

There are, of course, methodological problems to any study that attempts to access personal embodiment through a 'third party' but I, myself, have spent considerable time with brain injured children and could also draw on the wealth of the encountered experience of my colleagues when it came to analysing parental observations of their child's behaviour. Although I could not assume that the words that formed the parental statements, which related to their notions of the child, had implicitly the same meaning for the child or myself, they nevertheless functioned to enrich my own observations and in doing so frequently convinced me as to the naivety of my own initial observational assumptions.

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For example, I imagined that those brain injured children who were aware of a particular circumstance or event would necessarily have an opinion about it, even if it were an entirely egocentric one. This proved to be a mistake. One mother told me that her son Timothy was about to start at mainstream school. 'Is he looking forward to that?' I asked. His mother simply replied, 'he is not looking forward to it neither is he dreading it, but rather he just knows he's going'. Such statements show that it is not always possible to fix explanations to 'either / or' options and that the alternatives expressed are no less valid to research even if, as in the above comment, they prove somewhat problematic for analysis. Thus, whether the accounts presented here do highlight the experiences of the children involved or simply represent parental rhetoric must be, in the final analysis, up to the reader to decide. I hope, however, that the presented ethnography, if not convincing the reader of the possibility that parents' statements actually can inform us about the brain injured child's experiences, may demonstrate that something tangible and pertinent to issues of disability can be learnt from such an investigation.

Ambiguities: The Developmentalist & Researcher

Ambiguities as to my role in the clinic acted added a further dimension to the problematic nature of my family research. What I was getting from these discourses was clear. I was collecting data by which to formulate my ideas, but I soon realised this was, in fact, also what some of the families were achieving. They too had formulated ideas about their child and were seeking confirmation that, in terms of his or her future developmental capacity, their

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child was a suitable candidate for their prolonged commitment and subscription to a particular variety of therapeutic ideas. Furthermore, being employed by the Kerland Foundation, a therapeutic community to which they were committed by the fact of being part of this research programme, I became a 'testing ground' on which they could explore the rationale of particular methods of treatment. This, I initially reasoned, required me to be specifically careful in selecting which data was rhetorical, and intended to show support for the therapeutics they saw me as representing, and which, on the other hand, was heart felt or unbiased by a particular ideology. Although this is not necessarily to imply that these are mutually exclusive, some parental accounts did occasionally sound as if they had been lifted from a brochure for the Kerland. I recall one mother telling me that the therapy makes sense because it involves an *'increase in frequency, intensity and duration'*, sentiments which appeared in much of the Kerland literature. The main reason for this was that in the years preceding this research all of the families had seen me as a member of the clinic's staff and not as a researcher. Although my role was not that of a 'developmentalist'² but rather was concerned with the Foundation's research and development programme, my close working relationship with the 'developmentalists' in the clinic did not help to clarify my true role to the families.

During my initial research contact, for example, the ambiguities of my real 'role' were often so uncertain that parents would open our discussions with comments relating purely to those of administering therapy. This was

² A 'developmentalist' is the name given to the person who has been trained in the particular therapeutics of the Kerland and who design therapy programmes for the children.

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intended, no doubt, for the 'developmentalist' who had designed their child's therapy programme. At first I felt that this was not the information that I required, as my concern was for the 'deeper meanings' that lay beneath the surface therapeutics with which they were engaged. I did not need to know whether they were having difficulty with their programme or, for that matter, getting volunteers (patterners) to help or, indeed, having problems obtaining their child's compliance to the routines of therapy. But as I later realised, all of this was, in fact, important. But in my naivety, and researchers are, initially at least, more naive than those under their investigation, I was after the 'true meanings of disability', that reality of experience, that very phenomena which made brain injury exactly that what it is, encountering a world in such a way as to make our access mere speculation. I understood, from the years I had worked with brain injured children, the rationale of therapeutics. However, I did not know the personal embodied implications of brain injury, and how these manifest in both the individual's and the collective consciousness that I assumed were being affected. I was, after all, based in the clinic, a member of staff and had but little previous opportunity to encounter the children in their homes with their families. This was soon to be remedied by the extensive travel and frequent homes visits over the following two years.

During and after my field visits I soon realised that my concern for the 'true meanings' was misguided as none of the material I was gathering and which is presented here represented an ultimate truth in an objective sense. Rather the personal descriptions of, and encounters with, disability - a disability that exists in real terms for the family - are, nevertheless, also

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communicated as a collection of narratives and discourses. Through this, disability becomes socially constructed into a somatic manifestation of unique personhoods. Thus, the information given on those first interviews was as relevant to my research as that collected in subsequent visits, but I needed those latter visits in order to recognise this fact.

The meanings that would eventually arise from this research were constructed from a plethora of arbitrary symbols concerning disability, and therefore specifically used for their plasticity to be shaped and moulded by personal experience. This brings me to another point with regard to narrative research and its validity. It has been argued by Baron (1991), for example, that those whose stories most need telling are not necessarily the most competent to tell them. Of course, with such a diverse group of participating families, representing difference in socio-economic class and educational attainment, the level of narrative expression and literary imagery will vary considerably. However, provided that the families' narratives can be anchored into a more readable text a parental 'loss of word' need not make their accounts ineffective. In this one important sense I was not only a researcher collecting and interpreting data, but I was also an amanuensis writing down the traumatic, angry and hopeful stories of a brain injured child's parent. These familial and child related accounts provide an 'inner view of the person' (Birren and Deutchman 1991) or, in this study, a closer view of the child and make the scenarios of disability 'more tangible by grounding them in concrete lived experience' (Booth 1996: 239)

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As my research focused on the tangible, the observable and its accompanying narrative, my own embodiment was brought into sharp focus. It had become a catalyst. I represented the Kerland Foundation and the suspicion was, for a few families at least, that I was a spy, checking-up on them and making sure that they were following the therapy programmes that they had received from the clinic. As I became more aware of my role as an embodied Kerland representative it became increasingly clear that the politics which engendered my role were also going to influence the ways in which the family and child were about to be presented to me in this research. On several occasions I felt that a few of the mothers who were being interviewed had prepared for my visit. Some of my general questions yielded such precise and well thought out answers that they led me to suspect that certain notions had been previously rehearsed.

At other times, however, the parent would take a moment or two then reply 'I don't know, I will have to think about that'. The mother who made this statement appeared a little uncertain about the interview and had postponed my visit twice before she finally phoned the clinic to ask what exactly did I want to know. When we eventually met she actually made the comment that she had bet that she was the last family for me to visit, and I confirmed this. This made me realise that I was not a neutral but interested bystander to whom the families were going to articulate their personal understanding and experiences of the trauma that accompanies brain injury. Rather I was, after all, a member of the Kerland's staff, a person with an agenda, and they would need to know that agenda before any real trust and

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co-operation could be developed. As the interviews progressed I attempted to make it explicit that my concern was not to discover how well they were achieving therapeutic targets³ but rather that I wanted to learn how they made sense of their brain injured children's consciousness and the experiences of embodiment that possibly acted to underscore it.

The embodiment of brain injured children had possibly a divergent reality from those not mentally and physically impaired. This may well function to make our understanding of the personal phenomenology with which these children experience the world almost inaccessible. If I could convince the families that I wanted only to account for their children as children, not as a therapist discerning disability, but more as a parent perceiving the subtler cues of some corporeal enactment, I reasoned that this would allow me to reveal new insights into their personal phenomenology. Disengaging the clinical associations that parents felt I represented, then, would permit a new perspective on brain injury. This role would not only allow a more holistic view of the child with disabilities to inform therapeutics, but might also help challenge the negative professional rhetoric that had, for so long, orchestrated disability. If families would entrust their accounts, their fears, hopes and unique insights to me I may gain a deeper understanding of what disability means. That is, I could establish a conceivable consciousness for their injured child in the face of often contrary somatic 'evidence'. This is the challenge of the present study.

³ My role as researcher visiting their homes had been, to a degree, compromised by the fact that it had been traditional practice for developmentalists, particularly when training, to make home calls to see how the family was coping with the therapy.

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Over the course of this research a new relationship therefore developed between me, the families and some of the children⁴, and so did personal confidences. The initial ambiguities of my role in the clinic dissipated, they stopped viewing me as a developmentalist and started to see how someone in my position (a researcher) could be utilised to convey their opinions and sentiments to the Kerland and thereby give some form of personal expression to their child's therapy⁵. Although, as already mentioned, this particular research project was but one of several, since my other responsibilities involved finding new ways to enhance therapeutic goals, particularly in vision and cognition, I soon realised that insight into these and other problems was not solely to be discovered in the literature and through experiments that were so typical to my working routines. There was a mass of detail that had been overlooked. In subscribing to the notion that only the professionals know what they are doing, and that therefore any solutions that exist are to be found solely in the archives, journals and academic papers, we had lost sight of the intrinsic nature of our subject, the child. I felt that if credibility was given to the families' statements concerning their children it may help disclose other issues pertinent to brain injury that had, perhaps for political reason (see Chapter 2), been largely neglected by the professionals. By looking at the embodiment of these children in the family setting I might call into question those speculations that regarded the brain injured child as a non-participater in

⁴ I say some of the children because the severity of impairment made it at times impossible to ascertain whether the children knew that I was there let alone understand what I was doing. However, the family and I always acted as if the child understood my presence by introducing me, directing rhetorical comments at the child and at the end of the interview saying goodbye.

⁵ I often wondered if this was, in fact, one of the reasons families had for assisting in this research.

the social world. Surely, simply qualifying these children with the term 'brain injured' did not make their comments or expressions of an experienced embodiment any less valid.

Participating Families: The Nature of the Sample

My fieldwork was carried out between October 1991 and March 1993. At this time the Kerland Foundation had some 189 families on programme (receiving an alternative therapy based loosely on the Doman-Delacato method involving neurological organisation). The initial stage involved sending out some 40 preliminary statements asking if the family would be interested in participating in a research project that would attempt to explore a possible anthropology of brain injured children. The 40 families contacted were from all over the country and were selected to represent the range of age, sex, level of disability and economic class typical of that larger group of families who attended the clinic. Some 36 families responded, 23 of them favourably⁶. The interviews took place at the families' homes. The initial visits involved unstructured interviews where discussion on a variety of topics took place, usually initiated by the parents. These were taped for subsequent analysis. The first stage involved, on average, three visits to each household where the family would talk about their concerns, occasionally prompted by some of my own, relating to general statements about professionals, their child's problems and their understanding of these problems. Before commencement of the second stage I transferred the taped interviews into note form, which were then

⁶ See Appendix 1.

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analysed for common themes or variations that seemed specific to their particular experiences of having a disabled child. This material tended to reflect general dissatisfaction with professionals, their ability to cope, understanding their child, alternatives in therapy and education, the effects of time and concern for the future.

The second phase consisted of interviews that were to be more structured, with reference to exploring, in greater detail, those articulated concerns that seemed common to most families taking part in this research. This required, on average, another two visits to the homes of each of my participating families. Although each family is unique in terms of their child's specific problems there is, nevertheless, a great commonality of experience. This is primarily expressed in their hope that something positive might be done for their child and their seemingly universal dissatisfaction with orthodox medicine. It was, in fact, this latter loss of faith in conventional medical practice that had brought them to the Kerland in the first place. Margaret Voysey (1975), in her classic study of families coping with a disabled child, had also noted this apparent professional neglect of families when she states that:

Actually, I rather think that I doubted whether people concerned with the parents, notably doctors, were 'reasonable men' - they were either misguided or wilfully putting their own interests first (Voysey 1975: 61)

It is probably true that the families who responded favourably to my request for volunteers to assist with my research were those most willing to discuss their problems with doctors. Almost without exception, the families

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whose material is both presented and represented here initiated our interviews with their own critical accounts and experiences of orthodox medical practice. Over time, however, I realised that they did not just want to express the injustice they felt had been delivered to them during their consultations with doctors, but that they also needed to understand it. Indeed, that is the defining common feature of all those families who had assisted this research. Through exploring the issues that surrounded their trauma they had the opportunity to 'air' those particular uncertainties which would now challenge their lives and future. In this sense the families that would be my sample were also researchers, they were trying new therapies, developing propositions and voicing their results.

Selecting Family Material

Once sensitised to the issues and concerns that my research families identified I found that many others, who attended the centre but were not directly part of this study, were only too willing to express their views. In this sense the material presented in this thesis is inspired by those 23 families that assisted me but is not, by any means, restricted to those families. As already mentioned, there was a great deal of common ground expressed by the families and much replication as to the parents' views concerning the central themes of this study - professional attitudes, coping, future concerns, and their child's chances of some level of amelioration. In order to clarify the impressions and agendas of all of those families with whom I worked I decided that the visions

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presented here would be clarified by focusing on a smaller sample of 11 families.

This is not to confirm that these families were more articulate than the others, or had sharper insight into the issues explored, but they certainly did have a gift for expressing the collective concerns that my research began to reveal. I also felt that adopting a more restrictive, in terms of number only, ethnographic account would make clearer methodological sense. In reading through my field notes obtained from all 23 families even I, who had known and worked with them, found it difficult to retain which particular family had said what. The data obtained from all of those families with whom I worked demonstrated that families' concerns were certainly being expressed, but with so many differing accounts on the common perspectives identified there was little continuity to help the reader trace a single parent's view through the engaged issues. I therefore decided to present the accounts of the 11 families who best encapsulated the familial themes here portrayed, and which are as typical as possible of all those accounts of parents who attended the Kerland Clinic. But our discussions were often informed, to varying degrees, by the comments of other the families with whom I had worked.

The ethnographic accounts presented here act to situate my thesis of embodied brain injured children in the biomedical and political world in which they are corporeally retained. Given the physical limitations of these children, and the exhaustive routines of parents coping with these limitations, their corporeal situation has greater attachment to the home sphere than those without such disabilities.

Presentation of Family Material

The families' accounts are to be found in the discourses that weave through this study. Of course the language is my own, but this is not entirely true of the ideas. When starting this research I envisaged its presentation to be like that encountered in the case studies of the final chapter. However, working with the families forced me to reconsider this approach. In working with families I was not just collecting facts or accounts of personal phenomenology, I was being invited to participate in the discovery of meaning. This, I eventually learnt, was my common ground with the families. One cannot just collect material, unbiased and unmoved by the situations you observe, as one's presence there makes you a participant. Participant observation is a key feature in much anthropological research, but what I became aware of is how large a part of this process depends not on observations but on participation, and participate I did. I was being invited by the parents to look for meaning in the trauma which had engulfed their lives. In this way we sought understanding together, not just of what it must be like to experience brain injury, but more basically to be a child with brain injury. It was, then, this need to locate children first, and only after this brain injury, that gradually transformed the intended structure of this work.

As I hope to demonstrate in the following chapters, irrespective of personal meanings and views there is a childhood world view to be accounted for. In Western societies childhood is a bio-political reality as much as it is a familial one. In accounting for their injured children and their medical

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treatment parents had attempted to understand their problems without reference to these agendas (and sometimes hidden ones at that) in the professional procedures that attempted to manage them. During fieldwork I found a function for my participation, I could consider the families' accounts in terms of the control that is exercised over their lives when their child presents a problem that is considered to be within medical jurisprudence. In this way my thesis explores control, the body and, most importantly, our understanding of these and its affect on the personal embodiment of brain injured children.

To understand these dynamics my argument must firstly locate children, their childhood and the politics, inspired from adulthood, which contains them. The second issue is to attempt to understand the singular prestige with which medicine controls the body in both illness and health. Thirdly, only when we have accounted for the dynamics of childhood and control can we be sure that the family ethnography given here connects with the reality of experience that orchestrates the lives of the families and children with brain injury.

In order to protect the confidences of the families I have given a fictitious name to each child. The child's name will precede each family quote so that the reader may be better placed to track and cross reference each particular family though the thesis's argument. Occasionally, when it is felt necessary to contextualise the quote, I will include a brief description of the child's condition and the situation surrounding the family so as to make their accounts more relevant to the argument⁷. In this way I hope to show that the

⁷ See Appendix 1 for a breakdown of the diagnoses given to the children with whom this research was conducted.

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personal statements and expressions given here inform and enrich our understanding of that experiential reality which brain injured children possess but have few means to articulate. It is probably true that much of the familial ethnography voiced within these pages occupies a subjective position, but that is necessary if I am to explore the phenomenology of *'The Orchestrated Body'*

Objectivity and Subjectivity

This leads to an important point: the view that research in the social sciences, like those in the other sciences, is objective, merely describing the world as it is without imposing personal values, cannot be sustained. Research is not value-free (Smith 1981, Bell & Roberts 1884) and neither can the account presented here be completely neutral (Hammersley & Atkinson 1983: 9-23). However, I hope my ethics in the collection, interpretation and presentation of the data here have been guided by my concern for the families and the children who have helped me realise that disability is as much a concept for control and embodiment as it is an expression of limited physical and mental action.

As mentioned above, it is not entirely relevant to refer to the material provided here as being essentially the 'truth', but it is necessary to establish that the data is valid for the analyses I attempt to make. With this in mind I will briefly consider the problems of validity in biographical and narrative research as it relates to my fieldwork.

Autobiographical narratives rely upon what has been suggested to be their 'reconstructive character' (Kohli 1981). Evaluation is thus dependent

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upon narratives being presented in their temporal order, but they are also required to relate to the present so as to make clear their intentions to the participants and situations in which they occur. In this way narratives are reconstructed to convey relative meaning. We are inclined, when involved in this process, to believe that the accounts presented are sincere and valid, after all 'nobody knows his own history better than he himself' (Kohli 1981: 69). However, conscious distortions may act to reduce the validity of these accounts. Therefore, the process of subjectivity may compromise the sincerity and accuracy of the statements, making narrative research somewhat problematic.

However, in the research presented here the problems of subjectivity are largely dissipated as it is the family's subjectivity in relation to their encounters with, and narratives of, their brain injured children that may provide the most suitable insight into the child who cannot otherwise facilitate communication. It is, of course, possible that the child's phenomenology is exchanged for that of the parents, but as a participant in the biographical enterprise I am at least allowed the opportunity to question, speculate and, in a passive way, contribute to the explorations of a given narrative context. It is through such discourses with a variety of families, and with my observations of their children, that a picture of the personal trauma of childhood disablement has been made not only possible but perhaps also valid.

Finally, when dealing with such topics that involve personal disability and its affect on other close family members one must be aware that certain sensitive statements are offered to provide the researcher with a better

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understanding of the events being narrated. Therefore, some accounts of a highly personal or confidential nature are not intended for publication, but are the way in which the respondent develops or extends an empathy with the interviewer in order to facilitate a clearer understanding of particular events, and the concerns to which they relate. It was by providing such discursive opportunities for families to explore their relationships, both intellectually and emotionally, with their brain injured children that the general research questions gradually emerged.

Brannen (1988) has suggested that this two-way process provides a theoretical and methodological strategy that has implications for the 'meaning and conceptualisation of the research questions' (1988: 523) as well as acting as a technique for data collection. It also highlights the patterns of disclosure of information, insomuch that the great amount of confidentiality I was exposed to seemed to affirm my trust. Once this was established families tended to make me a confidant to ideas and notions that were generally privy to only a very close few. The material presented in this work does not, however, include those most intimate statements given in confidence, but they have helped me colour my analyses so that their experiences are better expressed.

Structuring the Orchestrated Body

Although sociology has been anxious to identify structural social processes and minimise the role of the individual in life histories (Thompson 1981), the account presented in this study will champion the embodied

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experience of brain injured children and their families so as to make explicit the role of the body in both therapeutics and social theory. This is not to suggest that the body is 'fixed' to any particular theoretical argument, but rather that it has the capacity to change its role to meet the demands of both biological and sociological input over the individual's life span. In Shilling's (1993) terms the body is indeed best 'conceptualised as an unfinished biological and social phenomenon which is transformed, within certain limits, as a result of its entry into, and participation in, society' (1993: 12). In fact, it is this belief in the transmutable nature of the body that encourages families to seek therapeutic options, so as to assure that future scenarios will not be determined by present disabilities.

My intention in Chapter 2, 'Orchestrating Childhood'; is to demonstrate that bodies, and especially brain injured bodies, not only express in a culturally specific way the perceived nature of the person but are also the fundamental units in enabling this perception. I will attempt to show how bodies are manipulated in both social and clinical space by the professional language and procedures invested in both medicine and education. After exploring these issues, Chapter 3 will consider brain injury as a problem of embodiment, aligning the actions and behaviours of the physical body to an expressionism that may permit an insight into the personal experiences of disability itself. Chapter 4, 'Scoring Professional Parts', will review the complex and often ambiguous feelings that result from family consultations with the medical orthodoxy, and locate the role of alternative practitioners and their orthodox counterparts with the family in a network of interdependencies. The ways in

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which brain injury is dealt with occupies Chapter 5, 'The Irreverent Method', wherein the considerations of a particular therapy are outlined, as are the many motivations that structure therapeutics and their implication for both the brain injured child and his or her family. The reality of brain injury is then encountered through an analysis of the 'Coping Strategies', Chapter 6, that permeate the living rituals of the individuals involved. That these coping strategies are not passive, but are often active devices that may help to change perceptions and alter goals, ties them in to a deep substructure out of which the experiences of disability may be illuminated.

Chapter 7 reviews the perceptions that are induced from bodies that, for a variety of reasons (possession or injury), appear different, and the significant ways in which an 'audience' observing these phenomena might well affect its presentation and subsequent meaning. Throughout this chapter, and the final one, I return once again to the body, only here the issues not only relate to the socially constructed aestheticism of children, but also identify the anomalies of physical character, due to injury, that impinge upon the appeal that children are typically regarded as possessing. Here I explore children's own construction of reality. I argue that notions derived from clinical science, familial relationships and the larger community make appeals for their validity to different criteria which reflect personal competencies that are largely incommensurate with one another. The results of these competing theories and rationales leave children themselves little room for developing, let alone demonstrating, their own agendas to a largely unsympathetic adult centred audience.

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Finally Chapter 8, 'The Orchestrated Body', concludes by postulating that an understanding of the brain injured child's body not only acts as a valuable semiotic schema helping us to relate to disability, but demonstrates also that both the social and individual phenomena that orchestrate the body permit an acknowledgement of the part we may personally play in structuring disability. The experience of brain injury may well be a personal and isolating trauma, but its amelioration involves us all because the issue is not so much an abstract notion of neurological impairment as one of social construction. The part we play critically affects the child's performance and may even dictate the tempo of possible habilitation programmes.

Notes on the 'Patterning' Method.

Before concluding this chapter I would like to briefly describe the method of therapy that the Kerland was practising when I was employed as research officer. The Kerland Foundation's 'patterning' method was devised from those procedures advanced primarily by Doman-Delacato (1960, 1961, 1964), Doman, Spitz, Zucman, Delacato and Doman (1960) and Doman, Le Winn and Wilkinson (1977). I intend only to outline the theory and method of this therapy so that the reader will have a better understanding of the basic therapeutic accounts that I present. Before beginning, however, I should also point out that although those techniques practised by the Kerland had their genesis in the Doman-Delacato method, they had, nevertheless, evolved independently over the years, so that some practices are more uniquely those

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of the Kerland. Although this method has attracted a great deal of criticism (see appendage 2 and Chapter 4) the emphases of such critiques relate to its supposed scientific validity. For brevity, however, the present account will simply outline the method and theory of this therapeutic regimen.

At its most basic level the therapy entails passive manipulations of the brain injured child's body so that sensory-motor input, believed vital for neurological organisation, is accommodated by the brain. In this way the child is taught patterns of movement that follow the developmental stages that the child would have naturally experienced if not for the brain injury. However, before the child's body can be patterned to establish such movements the effects of hypertonic and hypotonic muscle conditions must be challenged. This is achieved by a series of exercises designed to release the contractures of stiff muscles and improve the tension in floppy ones. Such exercises act as a 'warm up' before the 'input' and 'output' techniques are practised.

Input is regarded by the practitioners of this technique as those manipulations of the body that, via proprioceptive information, provide the brain with the co-ordinated movements that facilitate purposeful motility. In this way the child experiences his or her limbs being extended in space in a manner that provides experience of specific functional motor behaviour. For example, the 'cross-pattern' involves placing the child either supine or prone on a table with the parents or helpers (patterners) standing either side and at the child's head. The procedure involves turning the head to face the extending right arm while pushing the left leg to a knee bend position, while at the same time the left arm is placed down the child's body and the right leg is

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kept straight. The second movement requires the same procedure to be administered in the opposite direction. This alternating patterning is repeated for perhaps three minutes. The procedure attempts to mimic the movements of a crawling action. Indeed, the 'output' form of this exercise would involve providing the child with the opportunity to practice these movements on the floor with a procedure called the 'assisted crawl'. In this technique the child is placed prone on the floor and encouraged to move his or her limbs in the fashion shown in the cross-pattern above. Helpers assist the child by extending one arm and/or placing the leg in its correct position for the required movement. It is intended that through an extensive range of such input and output techniques the child's body develops the motor skills necessary for independent mobility.

Other practices concern sensory and cognitive development. For example, vision, language and hearing are often disrupted in children with brain injuries. These problems, as are those of motor function, are addressed by a similar method of treatment that increases the intensity, duration and frequency of a particular stimuli in the attempt to breach the child's incapacity. Thus a 'Black Room' is utilised to promote visual development, wherein the darkness masks all other visual detail save that of a simple high definition object. Luminescent patterns presented in ultraviolet light are also employed so that familiar items and objects are contrasted against a masked background. In this way it is believed that the child can be encouraged to develop a visual capacity and learn to see the world in which she or he lives. The child is also

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assisted to use tactile information to help explore 3D visual objects and in this way hand eye co-ordination may be aided.

As with all the techniques, their rationale depends upon increasing stimuli intensity, frequency and duration so that the child with sensory-motor impairments is given an extended opportunity to attend to a variety of movements, sounds, patterns and experiences. In this structured way the child is helped to develop the capacities of sensory-motor integration. The techniques are quite demanding on the family so helpers, i.e. volunteers who come into the home to assist with the therapy programmes (patterners), play an important role in administering therapy and enriching the child's social contact with others.

These procedures have attracted a great deal of criticism, some of which will be discussed in later chapters. However, it is important to state that many families who have committed to the programme have believed that it has directly improved their child's condition. It is in this light that the present study reviews families' encounters with therapy. However, this thesis does not intend to validate or reject the techniques of therapy. Rather it explores the phenomenology that results from a procedural approach that engages the child's body, and the ramifications of such an engagement for an enterprise which attempts to address issues of embodiment and experience in brain injured children.

Finally, one remaining point concerning the therapy presented here involves the undirected or unintentional processes that are likely to arise from a families' commitment to therapy. These tend to accompany therapy, but are

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primarily involved with the social more than the therapeutic situation. For example, the process of therapy may yield advantages in terms of coping with the demands of a brain injured child. Having goals that are believed attainable gives purpose to action and can help to structure the daily routines of care giving. Patterners or helpers often develop strong bonds with both families and their children, and can provide both moral support and attentive listeners. In such ways therapy can enrich the social sphere and, as such, may play a valuable role in helping to lessen some of the trauma that is encountered when a family realise their child is brain injured. Irrespective of therapeutic efficacy, the fact that families commit to the disciplines of a particular therapy needs to be understood as a social process, rooted in both trauma management and habilitation, and not merely concerned with providing scientific validity. In this light it is unlikely that speculations concerning parental naivety or 'magical thinking' (Cummins 1988, see appendage 2) will be helpful in understanding the familial considerations that support a particular therapy.

Orchestrating Childhood

Let us consider it (objective thought) then at work in the constitution of our body as object, since this is a crucial moment in the genesis of the objective world. It will be seen that one's body invades, even within science itself, the treatment to which it is intended to subject it. And since the genesis of the objective body is only a moment in the constitution of the object, the body, by withdrawing from the objective world, will carry with it the intentional threads linking it to its surroundings and finally reveal to us the perceiving subject as the perceived world (Merleau-Ponty 1962: 72).

Introduction

In Merleau-Ponty's phenomenological discourse the body is not only regarded as a means of expressing the world in which we live, it is also our way of experiencing it. Although seeming distant from a study that concerns itself with the anthropology of brain injured children and their embodied experience of disablement, Merleau-Ponty's observations illuminate a remarkable insight. They highlight the importance of the body, not only as a baseline for a semiological system, a popular anthropological construction and one which has inspired scholars such as Mary Douglas (1966), Mauss (1937) and Hertz (1909) but rather as a living, tangible entity with the power to perceive as well as being the very object of perception. Indeed, it is this notion of the body as an object in the world, as well as it being our way of conceiving the world, that concerns us here.

The crucial point, then, that I wish to develop in this thesis is that the body of the brain injured child plays both a passive and an active role in the construction of the individual child. It is passive in the sense that because almost every aspect of the disabled child's body and behaviour is medically structured in a language of dysfunction and pathology (Armstrong 1983), such

terms bring with them overtones of negativity. That this might help to legitimise the subsequent medical procedures as some form of 'positive' intervention strategy is likely not to be a coincidence. However, I shall argue that the use of professional language might even act to restrict individual expression since it often dictates a course of medical supervision that manages the symptomology of brain injury without affecting the underlying condition. That is, it treats the symptoms without reference to the patient's underlying needs, concerns and problems. Unfortunately, in adopting such a posture the child's agency with respect to his or her own behaviour is inevitably terminated. It is replaced by professional control which manages trauma as a purely clinical expression and disrupts the child's 'normalising' routines within a nurturing environment of familial care. This can be regarded, as indeed disabled writers on disability have already argued, to be a form of 'social oppression' (see Oliver 1996).

Whilst undertaking research for the Kerland Foundation¹ I had the opportunity to discuss with many parents, often at length, the issues with which they were most concerned. Inevitably, after only a short time parents would talk about doctors, their relationship with them and the treatment of their child's condition. Most comments centred on their belief that medical professionals often failed to understand that they and their children had needs other than those singularly prescribed for by medical practice which, historically, had disciplined and regulated the body through the bio-politics of control (Foucault 1973, Turner 1992). Furthermore, they would often feel

¹ The Kerland Foundation operate a child development centre that designs home based therapies for brain injured children based on the Doman-Delacato method.

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dehumanised by the experiences that had resulted from their encounters with medicine. For example, Sarah is a 5 year old cerebral palsied girl who suffered a brain injury during birth. Mum had experienced poor health throughout pregnancy when Sarah was born weighing 8lbs 1oz after a 10 hour labour with a comfortable forceps delivery. Her parents' main concern relates to developing effective communication. Sarah's father's comment can be seen to illustrate an uneasy parental tension with medical professionals.

(Sarah)

One of the things which were a consequence of all the drugs they gave her was, of course, a muscle relaxant so she couldn't breathe as well and she was lying on her back so the fluids built up in her lungs..... Plus they put her on steroids so she was so fat not only were her muscles relaxed with the drugs but she couldn't move them anyway because she was so damn fat.

It was statements such as this that first kindled my interest in the medical management of brain injured children. In order to understand why this child's body should be treated in such a fashion, I felt that I needed to understand more about the ways in which medicine dealt with the body and how these models of practice had come to involve, to differing degrees, an orchestration of the body for the brain injured children with whom I worked. As I explored the copious notes generated from my family fieldwork interviews I realised that, for all the medical skills of the clinicians, they too were compelled to operate within the larger societal framework of social policy, politics and economics that had already created a social construction of the body (Foucault 1973, 1979, Armstrong 1983 and Turner 1992). Reconsider, then, the father's statement above concerning his child's treatment.

Does this represent 'sound' medical thinking or does it serve some other interest? And if so, might this other interest involve control, not only over the physical body but of the human expression that embodiment permits? Another question one might wish to ask is one that challenges the very wisdom on which medicine is based - do such clinical practices (e.g., drug regimens) really reflect a thorough understanding of the child's condition? Some families, of course, know that doctors can't offer very much. Karen is 8 years old and suffers from a genetic disorder, her mother is a health visitor who has had both personal and professional experience of a parent's plight.

(Karen)

I know they can't do anything for my child, I know that but I think some people who don't know about doctors and nurses quite the same think that they are going to get a cure, or this doctor is magic and he can do something. Perhaps they go into hospital and their anxieties become less because they are dealing with people who think they know better. Well I'm sorry I know they don't because I've worked and trained with them, so I know they are just human, like me.

It was problems like this that prompted David Armstrong to doubt the assumptions of clinical practice when he was a medical student. How, he asks, 'had the body become so evident in the first place' (1983: xi). After all, the pre-enlightenment generations that practised medicine before the late eighteenth century had failed to understand the most rudimentary procedures that now operate in modern medicine. Was it not possible that modern medicine did much more than simply describe the body? Had it, as Armstrong suggests, begun to construct it 'as an invariable biological reality' (1983: xi)? For Armstrong, medicine developed a reality for the body as a physical and

biological entity and, in doing so, it constructed embodiment, the very experiences and potentials of an individual, as a clinical expression of their medically controlled organic material, the body. Stimulated by his own observations, Armstrong sought an explanation in the writings of Michel Foucault who argued that 'the concept of the body which emerged at the end of the eighteenth century - discrete, objective, passive, analysable - was the effect as well as the object of medical enquiry' (1983: xi).

The body now emerged from the discourse of a new language, a language constructed by what Foucault refers to as a 'political anatomy' (Armstrong 1983: 2). This new anatomy of the body selected certain aspects or structures from that amorphous mass of the body which could allow physicians, with their new clinical skill, to confer a power over the body and, with it, control.

However, my concern with the body is not with the somatic detail at both the cellular and functional level, nor indeed with that undifferentiated space between bodies that was quickly forging the political sphere of a new anatomy - the social relationship between bodies (Armstrong 1983, Foucault 1973). Although both perspectives inform an objective analysis of the body my interest here is mainly concerned with the experience of embodiment as both a discursive paradigm (Csordas 1989 and James, forthcoming) and as a lived phenomenological entity in its own right. Bodies are not just objects manipulated, controlled and understood by the objective analysis of a given society or people within it; they are themselves lived expressions of their own actively interpreting consciousness. The body is an object in the material

sense, but it is more than this; it is the subject of the individual's intentionality, an intentionality which permits the individual to be a proactive agent in a social, political and physical world of potentialities and communities. Anthony Cohen (1994) has shown how the physical transformations, sometimes even mutilations, which occur in the rituals that confer gender and other changes in status on children affect their consciousness. The interest for Cohen is whether or not such rituals impress on the bodies and minds of children a conformity to replicate society, acting and being like others, or does it provide its initiates with a relevant 'text' to enhance personal experience (1994: 58)? Either way it does suggest that practices which specifically target children, be they ritual initiations conferring a new status or medical procedures that manage symptoms, are likely to be reflected in the child's consciousness. The question for this thesis is, what are the implications of such procedures on the brain injured child? Can these treatment protocols, which administer the drugs or physiotherapy of bio-medicine, confer social and motoric norms to the injured child or might they further displace his or her experience of those typical encounters that initiate children into their childhood? These considerations, as I hope to demonstrate, are rarely explored when referring to the brain injured child. Sarah's father recalls his concern about medical provision when his developmentally delayed daughter was just a few months old.

(Sarah)

You sat (in hospital waiting rooms) not knowing what's happening and you don't know if she is going to be dead in three months, and that half her

life time. So we just gave up on the NHS and the belief that they were doing any good.

What this thesis explores, then, is how the child impaired by brain injury might be more completely understood if we interpret the manifest orchestrations of the body (therapy, the consequences of non therapeutic approaches and the child's own orchestrative attempts) as being both the experiences of personal embodiment and the result of a social construction that encompasses brain injured children and their bodies. An initial problem is deciphering these bodily orchestrations into their primary interpretative classes. Do, for example, the hypertonic (abnormally tensed muscle) contractions and extensions of a child's limbs only confirm a medical diagnosis of cerebral palsy as the bio-medical model would suggest? Or, might such a motor pattern sometimes be used by the same child to express some personal intention, statement or frustration? In the contemporary semantics of medicine, can the disabled child's very behaviour ever be considered to reflect a conscious attempt at self expressionism, as might be considered in some traditional societies² or are they just the manifestations of pathology?

David Armstrong (1983) is cautious of the solely 'clinical gaze' (Foucault 1973) that medicine uses in both observing and constructing the body and its pathology. That medicine has agendas, political and social, which affect its scrutiny of the body, only suggests that children disabled by brain injury may have little means left to them by which to express themselves

²For example, shamanism, trance and possession are often typified by overt changes to the body's usual character and expression.

without these orchestrations of body being possibly misrepresented as the sole features of clinical pathology. Such effective orchestrations of the body will be considered later in more detail (see chapter 7). Here I shall first examine the role of medicine in constructing the body as object and the influence such a clinical gaze has upon our own perceptions of the body, especially that body which has come to typify the brain injured child.

Medical Power and the Body

Medicine has a selective eye when considering the body, though with the influence of sociology and anthropology, and their observations on clinical practice and treatment, it may be beginning to apply a less reductionist model to its investigations³. The anatomical atlas, which focused exclusively on cellular mechanisms as the only causal factors of illness, is becoming complemented by environmental considerations of the modern lifestyle. With such notions a change in emphasis is evolving which considers a much wider set of causal factors than those which were to be found illuminated in the anatomical atlases of enlightened medicine and in which the aetiologies of tissue disease were located. If, as Turner (1987) points out, changes in the nature of disease are to some extent a reflection of an alliance between medicine and sociology, it seems appropriate that social factors, economics, demography and lifestyle have affected the causal assumptions that underlie disease. Indeed, Brian Turner has been moved to suggest that 'to some extent

³ See Oliver (1996) for a critical account of a sociology of disability.

stress has replaced the germ as a major explanation of modern illness' (1987: 8).

In considering stress as a possible component in disease development (a notion that will be further developed in Chapter 5), the social setting in which bodies are located becomes subject to medical scrutiny and, in doing so, the social interstices that demarcate embodiment become reconstructed as legitimate clinical space. As a result of this widening of the field of medical enquiry, not only are the operations of the body medically located but the very social fabric in which embodiment is experienced and expressed is also brought into sharp clinical focus.

There are obvious benefits from such a procedure. Medicine is now forced to adopt a more holistic view of the individual, but there are concessions to be accounted for with such an expansionist mode of clinical operations. It may be true that what Mangen (1982) sees as a new sociological perspective, encouraging 'medical professionals' to consider the person and not the patient as the focus of an enquiry into illness, is a procedural improvement. However, this also legitimises the application of clinical metaphors to social behaviour. For example, while medicine conceptualises the body as a biochemical machine, wherein illness is causally linked to dysfunction, within this mechanism (the body) social problems too can now be articulated within a medical rhetoric, established and validated by scientific empiricism. This authoritative contemporary voice of medicine thus not only claims the body as its specific area of interest, but is also beginning to claim the social space in which people live. As I shall show this can be seen, clearly, in the influences

exerted on the brain injured child and his or her family to conform to their appropriate 'illness' roles (Parsons 1951). As one mother mentioned when she told the doctor that she had considered alternative therapy for her five year old daughter.

(Jayne)

I mean Jayne's paediatrician, I nearly 'bopped' her last year she was so arrogant. 'Oh no, that sort of thing (alternative therapy) doesn't work for a child like Jayne'. And I say why? 'Because she has got global problems and it tends to work for specific things but it won't work for Jayne'.

How had such a finality concerning alternative practice been achieved by the medical profession? In order to address this I shall now attempt to locate the disparity between orthodoxy and alternative regimes by briefly reviewing the historical lineages of both traditions.

In the *Westminster Review* of 1852 the literary critic Samuel Brown had noted the increase in 'physiological reformers' who accounted for health care in terms of 'physical puritanism' (Smith 1987: 174)

nobody can deny that this is pre-eminently the age of the physiological reformers. A new sort of puritanism has arisen in our times, and its influence is as extensive as its origin is various. and in all not inexpressive of certain of the wants and aspirations of society. It is the puritanism of the body; but the common purpose of all its manifestations is the healing, cleansing, and restoration of the animal man (cited in Smith 1987: 174)

Virginia Smith has shown that much of the historical understanding concerning health was established through a 'popular physiology between 1650 and 1840, in relation to certain 'core' beliefs connected with the philosophy of hygiene' (Smith 1987: 174). This popular physiology was also extended by

vegetarianism, hydropathy, mesmerism and phrenology, to name but a few of the trends of the day⁴, the important point being that much of these new and all encompassing disciplines were invested in both folk healers and the professionals who held clinical skills. During the eighteenth and nineteenth centuries professional practitioners encompassed a diverse group of individuals with barber-surgeons, apothecaries, educated householders and commercial 'quacks' offering traditional remedies and moral self-help therapies that could not be ignored by the other professionals (doctors) (Smith 1987: 181) This, Smith tells us, divided the medical profession not only on therapeutic, but also on pious grounds.

By the 1840s significant changes in the medical world, which also took account of the nation's social and political reform, had propelled medicine into a constitutionally much 'tighter' group. As Sharma (1992) has argued:

The orthodox medical profession was a very powerful group in the nineteenth century, an alliance of physicians, surgeons and apothecaries. This alliance was not without its internal tensions, but the consolidation of medical education and the state recognition of orthodox medicine through the 1858 Medical Registration Act promoted the amalgamated power of qualified practitioners of this kind of medicine, ... (Sharma 1992: 116).

Indeed, by this time many authors of popular books on general health 'were careful to indicate that they were qualified professionals' (Smith 1987: 182). Public hygiene had now become a major political issue but its amelioration, in the practical sense, caused great debate. The problem, then, was not one of simply educating the public and the politicians but one of

⁴ Many of these trends have become incorporated into modern mainstream medical practice with the appropriate 'clinical' (legitimising) modifications. '... mesmerism - which was once a desperate heresy - later became acceptable to medicine on a more empirical basis and under the guise of hypnotism' (Brown 1987: 228)

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standards in training and hygiene. At this time a great deal of confidence had been lost in the medical profession, so much so that Sir Anthony Carlisle, president of the Royal College of Surgeons, commented on the deleterious effect of the 'heroic' drugging practices of an inexperienced younger generation of practitioners of the profession (Smith 1987: 190). However, even with a 'tightening up' of professional standards there still remained then, and even today, (Sharma 1992) an alternative position on therapeutics.

Why, then, are the alternativists still advocating different procedures to those offered by the orthodoxy? A possible explanation has perhaps less to do with clinical wisdom and technological advancement than it has with common belief. That this belief concerns the empirical accounts of parents more than the clinical observations of medicine is a line of enquiry that will be explored later (see chapter 5). However, as Smith (1987) convincingly argues

If we accept that the terms 'fringe' (alternative) and 'orthodoxy' (like 'regular' and 'irregular') are primarily related to a defensive professional strategy that is intended to deny the common ownership of medical knowledge, there remains a question yet to be resolved. Just how successful was this defence after the medical state had been publicly reinstated? (Smith 1987: 191)

As I intend to show, it appears that orthodox medicine has had but a little, if any, deleterious effect on alternative practices (see Sharma 1992). What it has done, then, is to exert its primacy over mainstream conditions, such as those which are successfully remedied by surgery and drugs. However, its lack of clinical efficacy in treating brain injury has kept the door open for alternative intervention. Indeed, it can be seen that the boundaries

between the orthodoxy and alternative or fringe practitioners has a long tradition of demarcation problems. Brown (1987) has suggested that one possible blurring of the boundaries between the orthodoxy and the fringe may have resulted from the fact that many proprietary or 'patent' medications were constitutionally similar to those medications dispensed at public hospitals (1987: 217). The difference was not that one medication was efficacious and the other not, but that one was supplied through the orthodox outlets (i.e. hospitals etc) and the other offered through advertisements in the popular press (Brown 1987: 217). This persists today as many medications are serviced over the counter, but few would argue that these medications are 'fringe' treatments (Sharma 1992).

It was, then, this historical development of institutional power, and the knowledge base which permitted it, that intrigued the French philosopher, Foucault. However, for medicine to make authoritative statements and influence the social processes which regulate personal behaviour in society it needed to gain access to, and mastery over, the organic units from which society is constructed. Medicine had, since the formal tightening of a new professionalism in the 1790's (Smith 1987), been responsible for providing knowledge of the body which was both expressed and described through a technical language. However, Foucault saw that language did much more than describe the processes of organic pathology; it had the power to invest these descriptive metaphors of medicine with a new 'reality' that helped establish a mastery over the body. As Turner states, when referring to Foucault's contribution to medical sociology,

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we can no longer regard 'diseases' as natural events in the world which occur outside the language with which they are described. A disease entity is the product of medical discourses which in turn reflect the dominant mode of thinking (the episteme in Foucault's terminology) within a society (1987: 11).

By the end of the nineteenth century medical professionals had accessed scientific knowledge, a knowledge which as already mentioned was selectively acquired by paying attention to certain features of anatomy whilst ignoring others. As Foucault points out this gaze acted to include a totality of understanding.

What now constituted the unity of the medical gaze was not the circle of knowledge in which it was achieved but the open, infinite, moving totality, ceaselessly displaced and enriched by time, whose course it began but would never be able to stop - by this time a clinical recording of the infinite, variable series of events. But its support was not the perception of the patient in his singularity, but a collective consciousness, with all the information that intersects in it, growing in a complex, ever-proliferating way until it finally achieves the dimensions of a history, a geography, a state. (Foucault, 1973: 29)

Such endeavours conferred many advantages, not least the fact that access to this scientific knowledge enabled its advocates (doctors) to gain considerable social prestige and influence (Turner 1987). So much was their influence that they were not only able to define reality but also to establish the range of norms which could act as a measure for social disorder and deviance (Turner 1987: 11). For Foucault, medicine was another agency, along with the prison and the school, that sought to morally regulate the population through surveillance (panopticism⁵). Within medicine, the human body had become the target of medical enquiry, language would describe it and medical

⁵The Panopticon represented a creative arrangement of power which fabricated an individual body - that very body which was to be the point on which repression could be exercised and into which ideologies could be inscribed, but, nonetheless, a body which had no existence prior to its crystallisation in the space delineated by a monitoring gaze'. (Armstrong 1983: 5).

practice could now exercise unprecedented control over it. Through such procedures the body would be disciplined by a new and overwhelming medical etiquette into operating in a morally correct fashion. Indeed, Foucault informs us that the major contrast between 18th and 19th century medicine was the fact that during the former medicine related more to the notions of good health. However,

nineteenth century medicine, on the other hand, was regulated more in accord with normality than with health (Foucault 1973: 35)

But what about those bodies that could not conform? Through observing, describing⁶ and regulating bodies, medicine had developed 'scientific' criteria for appropriateness and conformity within which the ill were contrasted with the healthy, the mad with the sane, and the abnormal with the normal.

Armstrong (1983) refers to these dichotomies as 'binary separations' which result from the increasing sophistication of the panoptic mechanism employed by medicine. Not only was medicine involved with surveillance, but the introduction of compulsory education created the opportunity for medical practitioners to develop their observational skills of the child's body through the development, in 1908, of the school medical service⁷. The consequences of this double pronged approach was an increasing medical

⁶ I use the term 'describing' to reflect the power a language, expressing anatomical considerations, has to control the body by placing its functioning and behaviour under the authority of those who practice medicine.

⁷ Interdepartmental Committee on Physical Deterioration 1904: The School Health Service 1908-74.

interest in children's pathologies and the creation of a further distinction within the category 'child'

in which the child could be manipulated and transformed within the new field of observation established by the large halls of the new schools and the open wards of the new children's hospitals (Armstrong 1983: 14).

The need now was to establish both a normality and commonality for children. Post war medicine shifted its focus from an ontological perspective, addressing the 'child as a solitary figure in the Panopticon' (Armstrong 1983: 57), to one which considered a phylogenetic interest (Foucault 1973: 29) with children and their bodies. Longitudinal studies that employed charts to measure children's development indexed periods of change over time, thereby allowing comparisons to be made. As Armstrong notes

The sick body of the child was no longer to be constructed by a clinical gaze which sought to analyse in the context of nosological referents, but by a gaze over the normal child against whom, by juxtaposition, the sick child was created (1983: 57).

The result of this was that children were becoming categorised, and the developing observation of childhood was not to stop at the inspection of the child's body. During routine medical examinations at school and at the clinic medical practitioners also sought to map the social space in which children's relationships with others were enacted. Children's homes were visited by health visitors, and by 1910 it was made compulsory 'that only qualified midwives and doctors could supervise the actual birth' (Armstrong 1983: 15). Thus the child's body, from conception to maturity and throughout adulthood, became the object of medical enquiry. The consequence of this surveillance

regimen would not, as perhaps it was hoped, clarify the roles of biology and society as independent variables, functioning and being responsible for the body's development and ultimate clinical understanding. Instead, it acted to obscure the interdependency of the social and the physical which united and determined embodiment. As Shilling has pointed out

Medical and other technical interventions into the body also highlight the biological and social character of the body and have made it even more difficult to grasp exactly what the body is (1993: 12).

This discourse which concerns the nature/nurture argument has yet to be settled. However, biological reductionism has had the effect of controlling the body, even if it has not understood the social substrate that transfigures embodiment with experiential capacity. The authority medical practitioners had conferred upon them was significant enough to allow them to make decisions as to whether or not a child should live. Doctors and midwives, when faced with the birth of a *deformed* (my italics) baby, sometimes conspired to kill the child without the parents' knowledge (Humphries and Gordon 1992: 13). The following gives a tragically descriptive account of one such birth when in 1929 Marjorie Collins was born with cerebral palsy.

Apparently I was not a pretty sight from being rather bruised, with one eye pushed up into my head, which quickly righted itself. The doctor took me downstairs, put me to one side and left me for dead. But my grandma was there. She told me that she noticed that I was not breathing very well so she washed me and put something around me and put me next to the fire. The doctor came down after seeing to my mother. He said, 'Shall I take it away, the dead baby? You don't want it left there do you?' My grandma was horrified and she said that I had to live. The doctor left without saying another word (In Humphries and Gordon 1992: 14).

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This is but one expression of the power that has been historically conferred on those who practice medicine. Indeed, doctors yield supreme authority in medical matters which is a reflection of the high status given to the profession generally (Morgan 1986). This status is as much derived from doctors' ability to operate an efficient surveillance mechanism as it is a reflection of their competence to guard our medical welfare (Foucault 1973, 1974). Such surveillance starts at birth and continues through school because the state of childhood, once identified and observed, has come to reflect yet another concern for the authorities. The increasing sophistication of childhood surveillance techniques in the school, clinic and at home acted to highlight the hidden agendas of the panoptic mechanism. These agendas concerned themselves with the apparent danger of an 'inadequately supervised' childhood, because after all, 'some of these children might eventually rise to a high career in public affairs'⁸ and thereby pose a threat to the very fabric of state. Childhood, it could now be reasoned, was not merely a state of developing biological maturity but was seen to also involve the acquisition of social traits that could pollute as well as benefit the society into which they would eventually emerge.

Childhood as a Historical Invention

It has been suggested that childhood has rarely been so highly profiled as in the twentieth century (James and Prout 1990). Children had historically become an interest to society, not simply because they represented the

⁸ Board of Education, Annual report for 1920 of the Chief Medical Officer, London. (reference in Armstrong (1983: 14)

reproductive growth of adults and therefore organic continuity, but also because they might, in adulthood, influence public affairs (Armstrong 1983: 14). As already noted, under the auspices of moral regulation children in the United Kingdom were subjected to surveillance⁹. Their bodies were examined and their education and upbringing were more increasingly being supervised by state institutions. In order to accommodate this new interest, the various doctrines of medicine, education and social work sought to identify a scientific rationale for the emergent phenomena of childhood. Through the observations of children in hospital, schools and the home new methods were being evolved that were to have several implications for the 'nature' of children. Some earlier understandings of the child had been brought to bear on these reconstructed ideologies of childhood. For example, the early and influential notion of 'preformation'¹⁰, which denied human development and proposed that peoples' 'tendencies and characteristics exist preformed and prestructured at birth' (McNeil 1966) was disregarded, and so too was the 'homunculus' (that notion that a perfect little man or woman was inside and operated the outward self) thrown out with the bath water. So if children could not be considered as little adults, what were they?

For Rousseau [1762](1895) children were born pure and innocent, struggling to adulthood through the corruptions and evils of organised society. This view proposed that children were natural and innocent, and that institutions, like education, should not distract from the natural unfolding

⁹ By the 1830s extensive investigations were carried out on morbidity, deformities and life expectancy among children working in factories and mills (Smith 1979: 170)

¹⁰ This view probably descended from a religious and theological explanation of development which although dominant in the early 16th century still courted some favour with 19th and 20th century theorists such as Rousseau and Jung.

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talents of the child. In some ways, such a notion re-enacted the preformationist's beliefs since both views subscribed to the idea that the essence of man, or indeed childhood, is to some degree predetermined and natural. For these doctrines the environment, physically or socially, represented chaos, uncertainty and perhaps even evil. This notion however was challenged by John Locke who, earlier in the 18th century, saw children as possessing a clean slate or *tabula rasa*, inheriting ideas via the germ plasm and chromosome. In this instance 'the neonate becomes, then, living material to be moulded, for better or worse, by the people and things that surround him' (McNeil 1966: 2). However, even Locke assumed that there must be, to some degree, a predisposition in children towards unruliness. He argued, in a treatise on education, that regulation or restraint of children would be necessary to control their 'natural impulses' before they could be considered as full members of civilised society. Such 'humanistic' assumptions considered the environment in which the child lives as playing a crucial part in his or her development.

The behaviourism of John Watson (1919)¹¹ aligned itself closely to the principles of environmental influence that had been a key feature of those who adopted a *humanist* position. For Watson, the infants were such '*blank slates*' that even thinking was beyond their immature capabilities. Children's thought processes were considered to be nothing more than "subliminal vocalisation" that had little or nothing to do with abstract thought. This view replaced the homunculus with a mechanism, albeit a biological one, controlled through a

¹¹ John Broadus Watson (1878-1958) founded the American school of 'Behaviourist Psychology' which regarded only that which could be observed objectively as the true concern of psychology.

system of innate reflexes that responded to stimuli. With such a notion, children moved from being traditionally considered as little people to being thought of as simple mechanisms acquiring, via selective input, adult maturation. But children are not merely simple biological machines, and therefore childhood cannot only be understood as a chronological event.

Although Western science intellectualised children with discourses sympathetic to their newly established and professional doctrines, it is only relatively recently that children's own realities have begun to be of interest (Richards 1974, James 1979, Jenks 1982 and James & Prout et al 1990). That children's development takes place over time makes it likely that with maturation comes differing issues of interest and concern for children able to perceive and construct for themselves alternatives to that world presented by adults. For example, Hendrick (1990: 36) has argued that

the numerous perceptions of childhood, which have been produced over the last two hundred years or so, can only be fully comprehended within the context of how different generations (and, no less significant, social classes) responded to the social, economic, religious and political challenges of their respective eras.

Hendrick identifies a number of socially constructed states of childhood which reflected the prominent doctrines of their day. In Britain *'The Romantic Child'*, for example, resulted from the humanist's concerns with the ideals of innocence. But Rousseau's inspirations for childhood were to become short lived as new issues became pertinent to society and so, too, moved the ideals under which children were considered. The need for a 'settled society' (Hendrick 1990: 39) in the face of social, political and economic unrest desired children to be obedient and respectful of authority.

This notion, Hendrick points out, courted much favour with the Evangelicals and the upper classes. Subjected to order and moral regulation, children's economic worth was soon exploited and the factory child was a rediscovery of historically earlier routines of child labour. With the establishment of social welfare agencies, and an increasing interest in children's medical conditions, issues of childhood became highlighted and constructed by the professionals who represented official and legitimate authority, an authority that was, in its very nature, adult centred. Out of this a 'desirable state of childhood' (Hendrick 1990: 55) required manufacturing which in some way attempted to understand the various trends that had been enacted over the last three hundred years or so. Such an archaeology of childhood has generally been more concerned with the illumination of adult recognition of childhood states and their socio-chronological changes (Aries 1962) than children's own construction of an experiential childhood. Parents, too, are occasionally reminded that their assumptions need remodelling in the light of observation and experience. For example, Jayne is a five year old girl with developmental delay. Her mother recalls Jayne watching a little boy playing with his truck on the other side of the road.

(Jayne)

I was talking to somebody not taking a lot of notice of Jayne when she went in doors and found a truck, which had something in it, emptied it out came outside and got my attention. She was standing by the side of the road nodding her head and because she wanted to attract my attention going ugh, ugh to show she wanted to cross the road. I thought that was a really complex situation. She knew what the other little boy had, she had found a similar, not the same but a similar item, and came and asked me if she could cross the road. I was amazed for her to do all that.

What is important in this thesis, however, is that childhood is seen as being a construction of the personal statements and experiences of a child's embodied reality which might, and perhaps often does, contrast radically with that proposed by adults. Indeed, it is only when we identify the lives and dialogues of real children in the discourse of social theory that we can be certain that our propositions of childhood are commensurate with those experiences of childhood themselves. Such an approach can be found in the 'new paradigms' which are emerging (see James and Prout 1990) as more researchers are concerned with identifying those issues which suggest that children are responsible for constructing their own realities. But notwithstanding this need, these new child-inspired constructions of childhood must be also accounted for in the adult conceptual and socially structured framework within which children have been historically placed.

Unfortunately, because the bodies of brain injured children are often contorted by spasticity or other deforming conditions, which incidentally are the diagnostic features that indicate neurological impairment, they are conspicuous when compared with the bodies of other children. As one mother with two congenitally disabled children points out.

(Fiona & Tony)

Yes, I think unfortunately that handicapped children do have several sort of characteristic problems, a lot of them dribble, don't speak very well and because of this make noises. They often have strange jerky movements, are slow and can't sit up right. A lot of them have visual problems. On the whole, you know I can say it because I'm a mother of two handicapped children, they don't look very nice.

Doctors, armed with their clinical skills and assessment procedures, are not only empowered by their diagnostic abilities to identify normality but enforce also the social parameters which determine it. This normality is engineered with many social consequences but singularly constructed by clinical medicine. Little or no consultation takes place with its recipients, brain injured children themselves and their bodies (cf., Alderson 1993, on consent to surgery) .

As I have already mentioned, children's own experiences are recently beginning to be considered by adults. Although significant changes are being made to the conceptualisation of children, guided in the main by agencies which claim to be sensitive to children's own experiences and expressions, such interest has also brought into sharp relief issues which are incommensurate with many modern views on the nature of childhood. For example childhood criminality, although not a recent phenomena, is one which has caused great public outrage and condemnation, particularly when it involves children being murdered by children. James and Jenks (1994), highlighting the public perceptions of childhood criminality that resulted, in the main, from the 'Bulger' case, have attempted to locate the ambiguous public feelings towards childhood in a sociological context. They argue that although there is a plurality of childhoods, stratified and fragmented by class, gender, ethnicity and disablement, children's experiences are nonetheless supposed to conform to some statutory normalising routines that dictate an ideological commonality for children. These have worked to create a vision of

childhood that depends upon morality and capability (Hockey & James 1993)¹². That some children should transgress their imposed boundaries of moral innocence, and prove capable of acting out violence that takes another child's life, is irreconcilably problematic to a cherished state of childhood.

What James and Jenks suggest is that childhood criminality has come to be a metaphor for social decay, an index of the moral slippage to which society has moved. If society cannot maintain the ideological incorruptibility of childhood then its adults, which are the very future of childhood states, cannot maintain a caring and compassionate society. Thus childhood is much more than a state in which the experiences and expressions of children are articulated with adult sentiment. Childhood expresses a pastoral purity within which the worth of society is nurtured. It is of little surprise, then, that childhood criminality incites so much public anger and dismay.

What this example demonstrates is that it is not only the professional bodies that attribute a particular condition to childhood. It seems, then, that before children have any chance of being encouraged to negotiate, develop and articulate their unique realities, the present adult ideologies which regulate our perception of childhood must firstly be deconstructed. That is, any analysis of childhood must, as its starting point, discover how adults structure childhood. Benno Glauser (1990) had experienced similar problems with his research when he wished to understand the implicit concepts that operated with regard to Street Children in Asunción, Paraguay. He suggests that the discourses in which concern for these children of the street are expressed relate more to the

¹²In James and Jenks (1994)

external observations of the adult community than to the internal experiences and lived situations of the children in question. In order to unravel such dichotomies he proposes that the assumptions under which such children are perceived need deconstructing.

Thus the importance of 'deconstructing' lies in trying to find out what lies behind and at the origin of the concepts currently dominant. It means trying to answer questions such as: to what do the terms used refer; how were they generated; in response to what problems and issues did they arise; and whose interests and needs do they serve? (Glaser 1990: 144).

Childhood as Multiple Realities

The approach postulated above by Glaser is useful to help deconstruct our perceptions of brain injured children which have for too long governed the way in which this group of children are considered. Much of this perception focuses on the negative as the only expression of these children capacities. However, one father has a different vision of his children and although this family enjoy a more luxuriant life than many, in my experience it is not an entirely uncommon perception at all.

(Fiona and Tony)

One thing that we recently spoke about is that everyone thinks our children are desperately unlucky,.... our children have had a very happy childhood so far. You know, I think if they had a perception of how they live they would say they have been very happy. Are they more unlucky than a child who has had no health problems but as lived a miserable life?

As we have briefly seen then, childhood has been an adult-centred state - even the parent statement above confirms this - in which children, their needs, expressions and obligations have been, to a large degree, manufactured

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by determinate societies at differing periods of time. Within this category, brain injured children have only been loosely placed since physical and or mental disability has often acted to exclude such individuals from membership of that already ambiguous group that composes childhood. Historically, the practice of infanticide in Western Society is well documented. Hocart, writing back in the thirties, remarked that 'the newly-born child is not reckoned a person, except under Christian influence: to kill it is not murder. It is still (or was) only homicide in some European codes' (1933: 230). This does serve to highlight the relatively recent uncertainties concerning the status of children. Moreover, though children are undoubtedly important to all societies, ambiguities as to what exactly constitutes a child in any particular culture remain. Ethnography is rich in such detail the Inuit of Greenland, for example, have no moral regulation whatsoever against the termination of the foetus 'a woman who is pregnant, depending on her personal circumstances, will make her own decision as to whether she will keep the child' (Nuttall 1992: 62). It appears that every birth itself does not ensure, for that child, the status of a person; the child must be firstly named in order to prevent infanticide being an option (Balikci 1970).

However, it is not only in traditional societies that children are excluded from many important rituals that confer advantage until they are formally initiated usually at puberty. Interestingly enough, they were also not considered 'fit for full membership' in the Christian church (Hocart 1933: 141). This may suggest that children represented, at one level at least, a potential for corruptibility, or perhaps a contagion of the adult boundaries that regulate and

maintain the continuity of the moral and social systems, for if the argument centred on the fact that they were simply not yet adults; and that being a child was just an immature form of being, there would be no need to exercise such controls over the child's access to adult social institutions and behaviours. It is more likely that children do have a power, a potential to pollute an etiquette of social order, which can be exercised even in their marginal state of childhood because it ultimately provides accent to adulthood. Freud, in attempting to understand the possible influence that is exerted upon the rules of exogamy by the practice of totem and taboo, cites the behaviour of children as an illuminating psychoanalytic example.

There is a great deal of resemblance between the relations of children and of primitive men towards animals. Children show no trace of the arrogance which urges adult civilised men to draw a hard-and-fast line between their own nature and that of other animals. Children have no scruples over allowing animals to rank as their full equals. Uninhibited as they are in the avowal of their bodily needs, they no doubt feel themselves more akin to animals than to their elders (1983: 126-7).

The point I am attempting to make is not to support a Freudian notion, which is of little concern here, but to show that it does highlight the uncomfortable and potentially dangerous contamination that children and their childhood realities may impose on our systems of classification. The question we must ask is, if children have the potential to disrupt our rules of homogeneity and threaten social order how much more disruptive to social categories could brain injured children be?

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Jenks (1996) has argued that childhood has been traditionally understood in social theory to be an expression of those trends that relate more to adult society, its cultural reproduction and capital. He suggests that

the child is always revealing of the grounds of social control. Thus in one sense (with historical changes and a contemporary weakening of authority in social and education patterns) we get the children we deserve or, to put it more formally, our historical perspectives on normality in childhood reflect the changes in the organisation of our social structure (Jenks 1996: 80).

Presumably childhood disability has, however, had its perspectives embedded in a society's social structure. For example, Henri-Jacques Stiker (1982) attempted to understand society through an analysis of the way it dealt with difference in terms of discourse on bodily abnormality. For Stiker, Western society's focus on difference gave rise to disability as a specific category, and its responses to this difference invoke a variety of procedures that involve 'charity, medical analysis, special education and rehabilitation' (Reynolds Whyte 1995: 269) all of which, no doubt, are stratified in social structure. However, these perspectives on disability are those originated by wider society and tend not to be informed by the experiences of the disabled themselves (Eayrs & Ellis 1990 & Shakespeare 1994)

The potential for brain injured children's bodies to disrupt society is made apparent by their inability to perform the appropriate behaviours (normal) that help categorise children as a special group. Furthermore, their disabilities are not only conspicuously ambiguous and emotionally challenging but often threatening, too. As Fiona and Tony's mother commented:

(Tony)

My mother came over just to check that Tony had not grown into an ogre.

Mary Douglas (1984: 39) has argued that anomalies cannot be ignored but must be dealt with. In this sense fear, shame, repulsion and suspicion are common avoiding strategies used to negotiate the 'threat' that brain injured children may pose to the moral and experiential regulators which enforce an ideological role for childhood. In this way these children are, however, confined within a conceptual space whose boundaries are maintained by both professional and lay statements that attempt to control and regulate the expression of children's own agendas. For example, medical rhetoric and 'special' educational discourses function not to simply identify or clarify the needs of injured children, but also to exclude them from the larger category of children. A mother with a 7 year cerebral palsied son recalls the problems she experienced when trying to get Tom who has difficulty with breathing, speech and vision into mainstream school.

(Tom)

I think it just interrupts their routine, I think they think that children like Tom do not benefit from mainstream school. We were actually told that by somebody from County Hall. 'Of course, there are some children who come outside of the school and your son is probably one of them'.

The exclusion of the brain injured child is thus achieved by redefining the boundaries that may govern children, and by placing them in a sub-category that is even further removed. This, then, dictates a course of

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social action which serves more to discharge our obligations to these children than to understand their needs. Indeed, it could be argued that many of the so called special institutions within which some of these children find themselves placed fulfil this function.

A comparative anthropological example might prove useful at this point. It concerns the practice of selective infanticide amongst the Nuer of the Southern Sudan.

When a monstrous birth occurs, the defining lines between humans and animals may be threatened. If a monstrous birth can be labelled an event of a particular kind the categories can be restored. So the Nuer treat monstrous births as baby hippopotamuses, accidentally born to humans and, with this labelling, the appropriate action is clear. They gently lay them in the river where they belong (Evans-Pritchard 1956: 84, In Douglas 1983: 39).

This practice presumably not only maintains the defining categories which help the Nuer conceptualise their own unique natures, but also discharges their responsibility to one of their own who would require an inordinate amount of special care if the child was to survive. Moreover, the Nuer example is, structurally at least, similar to what the doctor wanted to do with Marjorie Collins (earlier in the present chapter)). However, in this latter case, taking away the injured baby was not to be justified by the cultural myths that combat anomalies and maintain social order, but only in the sense that it enforces a medical decision onto a social problem for which clinical practice has no solution. Removing the injured baby was not solely the attempt to maintain the boundaries of an all important classification system, as in the Nuer example, it was also a move to minimise the threat this baby posed to a clinical system that was at a loss to do anything efficacious but which must, at

all costs, maintain control. Another striking similarity between the mothers of the hippopotamus child amongst the Nuer and Marjorie Collins is that they both experienced the same disempowerment that results from the regulating influences which operate in their own societies. Order and control are paramount features of regulation and anomalies, particularly those in children, must be contrasted with those individuals who establish the norms.

Aesthetic Tensions in Childhood

What, then, shapes the concepts which define brain injured children as, by their very nature, being different from others? In Goffman's analysis of *'Stigma'* he identifies three main forms, (1) 'abominations of the body', (2) 'blemishes of physical character' and (3) 'tribal stigma of race, nation and religion' (1963: 14) It is likely to be the case that all three impinge upon the brain injured child and his or her family to some degree, but there is none more conspicuous to the closure of normality than those notions concerning the abominations of the body. Goffman argues that

an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have upon us. He possesses a stigma, an undesired differentness from what we had anticipated (1963: 15).

The brain injured child motorically disfigured, by a lesion to the central nervous system, presents further problems. There are expectations of the body at issue here and children too, even injured ones, are not to depart from these, unless we consider 'by definition, of course, (that) we believe the person with a stigma (spasticity, for example) is not quite human' (Goffman 1984: 15).

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However children, almost by default, possess ambiguities that have the power to cloud cherished boundaries. They still represent, in Western society at least, an innocence and purity not only of action (and although the Bulger case might have threatened this concept, it has not destroyed it), but also of aesthetic character. The aestheticism of children has been widely used not only because it has 'consumer appeal', and thus has become the marketing person's ace in selling campaigns, but rather children's aesthetic appeal seems most cherished for its very ambiguity (Ennew 1986). Furthermore, this ambiguity produces tensions in the understanding of childhood as a social and experiential phenomenon. In a similar way our sensitivity to the contours and expressions of physical form permeates consciousness at all levels and, as a result, is also likely to be utilised in perceiving the child as different from adult.

Donatello's 'David' provides one expression of this ambiguity. In this depiction the boy David has a naked androgynous form, an almost feminine pose and by what Gill refers to as being , '.... clad only in a saucy hat and kinky boots' (1989: 205) reflects what can be seen to be a sexual tension. This bronze is challenging in two ways. Firstly, maturity has yet to confirm David with the typical form of his gender, so that he is in one sense physically ambiguous. Secondly, his behaviour is not commensurate with that of children, since the decapitated head of Goliath lies upon the ground whereupon David has rested his left foot, thereby portraying his victory over the giant (adult). Although there seems little doubt that Donatello's David externalises his own interest in young boys, it also acts to confirm a social unease with the ideological state of childhood and the particular physical

characteristics and aesthetics that accompany it. This too, not surprisingly, relies for its validation upon the adult physical form that portrays gender in both a biological and culturally acceptable fashion. In this sense perhaps children portray an innocence because they lack definite, gender typical, bodies. Indeed, Kitzinger (1990: 160) has suggested that it may well be the association of such ambiguity of maturity and innocence that so strongly appeals to child sex abusers. She states that 'a glance at pornography leaves little doubt that innocence is a sexual commodity'.

Such considerations are I believe important to help highlight the tensions that underscore childhood and its embodiment as a transitional state. Although childhood represents a moral stasis within which children are obliged to behave in a predefined way, and wherein adult attainments are usually prohibited, this stasis is, nevertheless, punctuated by change which requires them to move along the maturing ladder to an ideal adulthood. Such transitions are rarely achieved without some personal trauma and threat to that social system which regulates the child's 'passage' to adulthood. It is in this potentially dangerous procession that innocence acts as the ensign of moral well-being and one which will permit the child to navigate his or her development under the watchful adult eye.

But childhood innocence is a construction that historically appears first in the Renaissance, when the appreciation of childhood as a special state of being replaced the earlier notions that considered them as tiny adults. Art, too, visualised children as the possessors, for the first time, of a truly childlike form. The fact that the depiction of cherubs started to reflect an anatomical

realism also illuminates possible physical ambiguities that suggest a sexual tension. Moreover, several artists demonstrated the potential for a corruptibility of children's form with artistic nuances, revealing an adult centred sexuality (see Gill 1989: 208). Before this time, children being considered as nothing more than 'little adults' presumably presented no greater problems to the enforcing moral, religious and social regulations governing sexuality than those which operated over adults. Indeed, by the eighteenth century sexuality was beginning to be conceptualised within a framework that advocated productivity, procreating children within marriage, along the lines of their present day labour theories. Before this time, Turner informs us that behaviours such as juvenile masturbation were tolerated by the religious and medical authorities (1987: 100).

However, with the developing role of childhood as a special and transitional expression of humanity, regulation was required to ensure that children conformed to the adult ideal within which childhood was to be structured. Masturbation, or for that matter any expression of the child's sexuality, was not only considered polluting and aetiologically linked with madness (Turner 1987) but also threatening to the social construction that was manufacturing a new childhood. However, childhood is a dynamic which eventually confers adulthood and as long as the individual's sexuality is expressed within the institution of marriage such contacts are permissible.

This particular illustration of the ambivalence of childhood raises another interesting problem for those persons who have some form of disability. Before the last war, contact between disabled boys and girls was

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discouraged because it was seen as dangerous due to their vulnerable age (childhood). Furthermore, 'Poor Law officials' and religious charities assumed that the disabled were potentially highly fertile and promiscuous, particularly 'women classified as "feeble-minded" (who) were seen as slaves to their animal passions and were thus supposedly a moral danger to the community' (Humphries & Gordon, 1989: 100). Sexuality has also been argued to play a part in the modern 'disabling' ideas about disabled people.

In the realm of sex and love, the generalised assumption that disability is a medical tragedy becomes dominant and inescapable. In modern western societies, sexual agency is considered the essential element of full adult personhood, replacing the role formally taken by paid work: because disabled people are infantilised, and denied the status of active subjects, consequently their sexuality is undermined. This also works the other way, in that the assumption of sexuality is a contributing factor towards the disregard of disabled people. There are clear parallels with the situation of children and older people (Shakespeare 1996: 192).

These examples demonstrate the limits society places on the full embodiment of not only disabled people but on children too. I am not advocating sexual experiences for children but rather accepting the fact that such aspects of embodiment exist in humankind and therefore, with regard to disabled people, elderly people and children are problematic where social etiquette is concerned..

The aesthetic issue is not merely important for aestheticism alone but because the 'assumption is that the person who looks very different is in some way morally inferior to those who are normal' (Lansdown 1980: 25). The potential threat of corruptibility embodied in the brain injured child, then, whose behaviour makes it difficult to conform to the appropriate stereotypes that frame childhood, challenges the very moral existence of this cherished

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category, 'childhood'. For this reason such children must be conceptually dealt with.

Lansdown points out that Shakespeare's portrayal of Richard III exemplifies the notion that a misshapen body is the outward manifestation of a distorted mind. Indeed, the 'disnated' Richard III is so much a dramatic construction that his body depicts his moral corruption so plainly that even those at the back of the theatre are in no doubt as to his character. And so, too, on the social stage, the audience who observes the brain injured child has already been familiarised by a script that gives meaning to the orchestrations of disability. It is, then, the very orchestrations which must be deconstructed.

We must explore the language of dysfunction that uses, for its own semiological system, the overt body. Not just the body, but that of the child and that which has been orchestrated by both disability and its subsequent interpretations. The body, as Douglas (1966) informs us, has the potential to put in danger those boundaries that embody the moral regulation of society. However, these boundaries are not only breached with 'matter issuing from them' (Douglas 1989: 121), spittle, blood, urine, hair clipping and sweat etc, but are transgressed also by the inability of an impaired body to conform, and control its functions in socially acceptable ways.

(Jayne)

She might decide that she doesn't want to go down a particular aisle in the supermarket and she will sit down and kick her legs in the air. I'm sure people think she is just an incredibly badly behaved child.

For this very reason the brain injured child risks being excluded from that enterprise in which other children are located, their childhood.

These overt incapacities are not the only threat to the boundaries within which the moral welfare of children is contained. Maturation and gender also present problems. The fact that many brain injured children transgress the aesthetic and behavioural requirements that constitute childhood threatens not their moral validity but our interpretation of it¹³. Physical completeness complies with the requirements of an overt morality (to be just that which we think they should be) in which all children are located. The need, then, to rethink the problems and naive transgressions of the child incapacitated by brain injury is fundamental to enclosing them within the same essential boundaries that their peers enjoy. Adjustments are indeed required, but the starting point is not so much with the injured bodies as with those injured assumptions that sustain childhood as a restricted embodiment, that expresses little more than an aesthetically pure unfolding state toward adulthood.

Conclusion

The issue of embodiment has, until recently, played but a little part in sociological theory, and has been very much an 'absent presence' in social theory (Shilling 1993) and childhood studies (Jenks 1996). Emphasis has been traditionally placed on the 'social meaning of social action at the level of values and beliefs' (Turner 1992: 37). Whilst this is still crucial to the analysis

¹³ One cannot help wondering whether the systematic sexual and physical abuse of young children recorded in the many state institutions is made possible by the perpetrators entertaining the notion that because these children are injured or delinquent they somehow have forfeited the right to be considered and cared for as the children they really are.

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of the implicit statements that express the observer's position with regard to the brain injured child, it fails to illuminate the phenomenological events of disability. Thus, not only must we attempt to discover that which is conveniently embedded in the adult centred rhetoric, which serves to confirm the reality of childhood, we must also give credibility to the lived experiences of brain injured children. This is, however, likely to be difficult for two reasons. Firstly, the agendas of brain injured children are not easily understood, primarily because the statements of children, let alone brain injured ones, tend only to be valued if they reflect the adult's perceptions (Alderson 1993, 1995). The second difficulty arises when one seeks to explore the experiential worlds of children who, due to their very disability, have often evolved expressive and communication systems that present problems for decoding. The present paradox can be expressed thus - even if the brain injured child's communicative expressions were successfully deciphered, we would still be left with the problem of getting them accepted, particularly if they had little consonance with those that adults accept. This is made even more problematic by the fact that the disabled body often presents what Goffman (1959) might call management problems. Stated simply, the body must be controlled during our encounters with other social actors. Disruptions to social order are often represented by failures of the body to control its expression during social interactions with others. The management of embarrassment requires, for example, considerable control over the body (Turner 1992) and may be a specific problem for families with a brain injured child. As one mother recalls.

(Sarah)

As soon as you get Sarah out into a big open space she squeals and she screams and if you have got her in a buggy she grabs at everybody. I've had countless people coming up to me and say, I should have kept it at home. And last year I was told, 'you shouldn't bring her out, she's mental'.

More than a notion of a '*spoiled identity*' (Goffman 1963) a child whose inability to manage his or her self (presentation), for whatever reason, compromises another social actor's space, and in this example the mother is considered to be courting her child's misconduct and thus playing a part in the offending conspiracy. That such statements sometimes give rise to feelings of guilt and personal responsibility will be considered in more detail later. The point I wish to make is that, whether brain injured or not, children are playing roles, these roles or behaviours are expected to conform to the constructions of childhood which give them social meaning. That this meaning may not represent the internal realities that children construct for themselves is something that I shall later consider (see Chapter 8).

In summary, this chapter has shown how a child's existence is confined to a conceptual space referred to as childhood, within which his or her behaviour and agency is regulated by special institutions that ensure that the child develops and conducts his or her self in the appropriate way. Brain injured children are constitutionally problematic because they represent an anomaly to the rules of conduct. Professional agencies, responsible for their social management and moral control, are brought in to regulate and control them. The result is that childhood is an orchestrated enterprise and brain

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injured children are not so much reasoned with as instructed, not considered but informed.

Brain Injury : A Problem of Embodiment

Introduction

In the previous chapter I argued that children and their childhood experiences had yet to be fully understood. Although there is no paucity of concepts that attempt to locate children in adult centred space, I have suggested that such procedures provide little opportunity for the children themselves to express their own realities. I outlined briefly also some of the issues which are particular to those children who have suffered a form of brain injury. In this chapter I will attempt to explore, in greater detail, the problems that confound our understanding of these children and their conditions - and the consequence of these misunderstandings for the injured child's experiences and personal expression. It will be seen that scientific notions concerning the brain have, historically, strong and influential links with philosophies of mind. Therefore any analysis of the brain would be incomplete without reference to the capacities of, and statements concerning, mental function.

In the following analysis I shall show that the mind itself is best understood as an attribute empowering corporeal agency. The dichotomy between mind and body that appears so prevalent in much social and philosophical theory can often be resolved by perceiving the person as the union of both mental intentions and physical capacity. It is this union that interests Shilling when he states it 'is for a view of the mind and body inextricably linked as a result of the mind's location within the body' (1993: 13). First, however, I shall outline brain injury and the current assumptions

made about this traumatic event so that the arguments I wish to develop in this thesis may be better evaluated.

Non Progressive Brain Injury

Brain injury is clinically considered to be of two types which act to dictate not only the theoretical assumptions about what this traumatic event entails, but also the responses and postures that the therapeutic communities are most likely to undertake. The first approach considers injury which is progressive in nature. That is to say, damage to the central nervous system is due to some dynamic agent that persists in compromising function until it reaches its terminal phase. Such conditions can arise from inoperable malignant tumours, genetic degenerative conditions and the so called demyelinating diseases such as motor neurone disease and multiple sclerosis. These constitute 'progressive brain injury'. In such cases medical concern is usually placed on making the person comfortable since ameliorative procedures are, at present, rarely available¹. The other group, which is my major concern throughout this thesis, constitute those forms of injury that are not progressive in nature. This form of neurological insult can typically occur at any time of life from a variety of factors, irrespective of gender, class or occupation. Stroke, accident or viral infection can all result in the individual suffering neurological impairment. However, my concern is with young victims and the special problems that this trauma entails for children and their families.

¹ Multiple sclerosis is possibly an exception here as techniques utilising hyperbaric oxygen are proving successful in alleviating much of the symptomology associated with the condition.

In recent years medical technology has had an enormous impact on monitoring the pre and postnatal development of infants. As a result many of the conditions that contribute to non-progressive brain injury in the new born can now be identified. Some of these techniques have also proved valuable in preventing the deleterious affects that exposure to radiation, drugs and alcohol may cause to the developing foetus. However, even with such procedures readily available they have generally had little impact on the 'incidence of chronic childhood disorders' (Logigian 1989: 1). What has, however, become apparent with the utilisation of modern monitoring technology in hospitals and clinics is that the survival rate for children with chronic diseases has increased considerably: that is to say, more of the infants born with or acquiring some form of neurological impairment are surviving into adulthood.

Although 'the object of neurological assessment is to recognise the nature, site and extent of pathological lesions of the central nervous system (Forfar 1984: 677), for children this presents some rather unique problems. Unlike the adult who may have acquired neurological impairment after the central nervous system has properly matured, the infant, with its immature nervous system, has yet to inhibit the stereotyped behaviours and reflexes with which it was born. Such reflexes involve hand and feet grasping and the rooting reflex (mouth and head movements to locate the nipple) etc. However, as the uninjured baby develops, these reflexes become increasingly difficult to illicit, until eventually they disappear or are inhibited and integrated into more purposeful and evolved motor behaviours (Teitelbaum 1967: 67, Logigian 1988: 25). This may not be so for the brain injured baby who may still possess

a primitive repertoire of such behaviours. Therefore, assessments which seek to diagnose deficits in functioning involving integrated sensory, motor or intellectual performances are not so easily obtained, as the infant has not developed these abilities to a recognisable state where a precise evaluation would be meaningful. There are, of course, procedures that utilise the reflexes of the infant to evaluate the integrity of the central nervous system. For example, some of these stereotyped reflexes to stimuli may illicit abnormal patterns or be absent altogether, which may indicate a potential neurological problem. In order to investigate these lesions in the cerebral cortex a level of neuronal and synaptic maturation is required which permits the development of motor, cognitive, adaptive and social behaviours in the child. Therefore some deficits in the child's behaviour are likely to not be detected until the time when one would expect such assessable functions to have developed.

The other main problem for those wishing to localise a lesion of a child's brain, only after which would a treatment regime be suggested, arises from the 'plasticity' of the central nervous system. The assumption is that, unlike the adult, children's brains are more flexible so that disruption of function caused by a lesion at a particular site may be recovered by a different area taking over that function. This notion of 'recovery' is the therapeutic ideal. However it is also a problematic one due, in the most part, to semantic differences used by researchers and clinicians to define exactly what constitutes 'recovery'. Almli & Finger (1988) suggest that the problem may be resolved if a working definition of recovery demanded 'a complete regaining of *those* identical functions that were lost or impaired after brain injury'

(1988: 12). However, this is not straightforward for children with immature and functionally adaptable nervous systems. Moreover, even applying this definition to adults may prove problematic as recovery may be misinterpreted as 'behavioural sparing' or 'compensation'. The former is 'defined as an absence of a specific performance deficit after a brain lesion' (Almli & Finger 1988: 5).

However, this in itself is not evidence of behavioural sparing, because even if behavioural dysfunction is not observed after an injury it need not imply that dysfunction may not, at some time in the future, develop. This typically occurs in '*slow-growing*' or '*staged lesions*'. For example, if a child had a tumour removed from a part of the brain responsible for language (Broca's area) and subsequently proved to be indistinguishable in language skills from others in her class, one might argue that she had not recovered her language because in fact she had not lost it in the first place, i.e. behavioural sparing. The other phenomenon which may confound neurological assessment is whether the individual has 'recovered' from or 'compensated' for an impairment. The latter implies that the injury persists, but that new behavioural strategies or goals have been developed which compensate for specific impairments.

The ability to determine whether compensation or recovery has taken place can be exceedingly difficult under some conditions. To appreciate this, one might think of a mute, brain-damaged child who may now use visual imagery to solve simple subtraction problems that previously were handled by rote memory (Almli & Finger 1988: 7).

This may account for much of the difficulty encountered in diagnosing the extent of brain injury. It also seriously affects the clinicians' ability to

provide an accurate prognosis. Such problems persist in challenging the understanding of those professionals who work with the so called non-progressive brain injured. It also, moreover, causes great concern for the parents as the initial confirmation that the child has problems is typically met by a level of parental confusion and uncertainty in the doctor's statements. The following example shows one aspect of this for a mother of a 6 year old girl with hydrocephalus and athetoid spasticity.

(Cindy)

Mother: *My husband came in and I said to him, 'they're saying she's deaf' and he said 'rubbish'. She isn't in fact its very acute. So we had lots of things told us but we didn't really believe them or have time to be shocked over the news that Cindy was disabled. We had realised for a long time that things were not right. When I went down and saw the consultant and she said this child is slightly spastic it didn't surprise me, the term did because I didn't know what it meant, but I wasn't surprised that she had problems.*

Interviewer: Do you feel that in an initial way you came to terms with it through disbelief, because of all the misinformation you had been given?

Mother: *Yes, you just thought well lets take each day as it comes. She was healthy, she was sleeping, eating, she was fine in every other way but I did all the normal things you would do with a normal baby. At 10 months we were told she was slightly spastic when I challenged that and said all right what does that mean? 'Oh her ankles are stiff' was the reply. The actual statement was made to a trainee, not to her dad and me.*

Where, then, are we to look for the rationales that inform professional judgements on the clinical features of non-progressive brain injury?

Surprisingly enough many notions concerning cerebral lesions have their genesis in a much older tradition than neurology.

'Ghosts in the Machine'

Neurological models, whether involving injury or function, tend to be both informing to, and informed by, a philosophy that locates the 'mind as a global property of the brain' (Hodgson 1991: 64) The fact that a correlation exists between neural events and mental phenomena does not directly confirm that the latter is purely the result of the former. A description of the physical events that occur in the brain is not essentially a description of specific mental actions of which minds are capable, it merely suggests some relationship between them. Likewise, as I am arguing in this thesis, the problem of understanding a brain injured child may not be one of just understanding the neural pathology of lesions, but one of understanding the whole embodied world to which the child is attempting to accommodate.

However, problems concerning the brain, mind and their dysfunctions have traditionally been related to a mechanical theory, i.e. to organic and pathological lesions in the very material substance of the physical brain, thereby locating dysfunction to particular cerebral sites. Whilst not arguing against this, I wish to demonstrate that such explorations are often so exclusively focused on cerebral models that the body, that very corporeal

expression of central nervous system (CNS) activity, is at times completely ignored.

The following will entail a reverse order chronology of the philosophical notions which have influenced the study of brain injury. The reason for this is that they have been listed not historically but in order of their importance to my argument.

One of the major reasons why such a mechanical theory of mind should arise stems, in the main, from the influential work of René Descartes who as a man both of science and of God could not accept, as indeed Hobbes did, 'that human nature differs only in degree of complexity from clockwork' (Ryle 1976: 20). Overwhelmed by the moral and ethical constraints of his religiosity, Descartes proposed that the mental could not simply be a variety of the mechanical. Ryle, although himself not a supporter of an independent mind (the possibility of conscious mental events ensuing from an immaterial mind Hodgson 1991), points out that he and other philosophers availed themselves of an escape route that postulated the following explanation.

Since mental-conduct words are not to be construed as signifying the occurrence of mechanical processes, they must be construed as signifying the occurrence of non-mechanical processes; since mechanical laws explain movement in space as the effects of other movements in space, other laws must explain some of the non-spatial workings of minds. The difference between the human behaviours we describe as intelligent and those we describe as unintelligent must be a difference in causation; so, while some movements of human tongues and limbs are the effects of mechanical causes, others must be the effects of non-mechanical causes, i.e. some issue from movements of particles of matter, others from the workings of minds (1976: 20).

Gilbert Ryle, in arguing against Descartes' dualist doctrine, proposed that the errors that postulate phantom embodiment, or in Ryle's words '*The*

Ghost in the Machine', evolved from a category mistake. Furthermore, it is one which assumed that the differences between the mental and the physical were expressed in one common framework. This encouraged the idea that both minds and bodies functioned relative to some form or expression of mechanical law. Bodies were governed by material processes, so minds were obliged to be governed by non-material processes. Thus, although minds are 'things' and bodies are 'things' they are different types of 'things'.

Most importantly, they can have different causal attributes. This 'para-mechanical hypothesis' (Ryle 1976: 21) was, however, at loss to explain the subtleties of a physical and mental unity that operated and could be perceived in human behaviour, since it could not ascertain the nature of one from the other. Aligning his discourse to mechanics, Descartes had assumed that both mind and body operated in the same category but were polarised by the fact that their behaviours were constrained by the terms of the same logical type. That is, since the body is a machine observing its mechanical principles, so too is the mind obliged to observe its non-mechanical operations. The consequence of this erroneous assumption was the proposition of the mind as a spectral machine operating within the physical or corporeal machine that constitutes the body. In Ryle's view, such notions over-sophisticate the operations of mind, leaving the body behind as nothing more than a mechanical receptacle of some spectral agent, the mind.

How many of us are able to deny the pleasures of an experienced embodiment involved with routines of eating, bathing, creating music and art? These have, at their very essence, not just some spectral monitoring of the

mechanical operation of body by mind, but serve to gratify that conscious vehicle which permits these performances. The body is not just a hollow machine, awaiting a sentience installed only by the operations of mind. The body is, in itself, a conscious entity that, with its very presence in social space, kindles a consciousness in others with whom it interacts.

Merleau-Ponty offers such an example. He studied the psychology of phantom limb experiences² and their consequence on cognitive judgements and, after noting the disruption limb loss can produce on perception, concluded that 'all 'higher' mental functions are also somatic activities' (Turner 1992: 43). Such was his commitment to the role of embodiment, Merleau-Ponty proposed that

the body is not an object for itself; it is in fact a spontaneous synthesis of powers, a bodily spatiality, a bodily unity, a bodily intentionality, which distinguish it radically from the scientific object posed by traditional schools of thought (Langer 1989: 56).

Likewise, neither are the mind or the processes which are traditionally considered to arise from it (e.g. conscious experience) objects with a single kind of property. Ryle argues that "mental' does not denote a status to talk of a person's mind is to talk of a person's abilities, liabilities and inclinations (dispositions) to do and undergo certain sorts of things..... in the ordinary world' (1976: 190).

In order to achieve such a conscious state sensations, feelings and images, either external or internal, help to constitute that 'stuff of which minds are composed' (Ryle 1976: 190). Thus, put simply, sensations require the stuff

² Phantom limbs are limbs which have been lost due to accident or disease and often reported to still provide sensation to their former host many years after their surgical removal.

of the body and its specialised organs of perception to the same extent that they require the stuff of minds. Bodies and their organs are unlikely to be passive vehicles of sensation, as iconic storage³ demonstrates that the sensory organs themselves may act as a register, with perhaps certain processing attributes built in.

An Aristotelian Psyche

In proposing that a distinction existed between mind and body, Descartes saw the body as a machine, behaving according to the mechanical principles of matter, while the mind had no such constraint upon its operations. This proposition is very problematic and to review, to a satisfactory depth, the arguments for and against would be well beyond the scope of this thesis. However, one critical issue will be addressed. This does not involve the dualist's arguments, entrenched as they are in the notion of mechanical 'entity', for the argument presented in this thesis rests not on what matter or stuff constitutes and forms the distinctions between bodies and minds, but on what are the capacities of human beings. As Smith and Jones (1986) point out in their excellent book:

an analysis of what it is to have a mind should mention *capacities* rather than *entities*. And that points the direction for progress. To give a fuller account of the nature of the mind is to give a fuller account not of some special sort of thing but of the capacities which constitute the mind (1986: 74-75).

³ Iconic sensations are those images or indeed sounds which persist in their receptive organs after its physical termination (see Gregory, R.L. 1987: 336).

Furthermore, these capacities are not only the result of institutionalised conventions of behaviour operating on the person, for the individual's self is also a contributor to the genesis of capacity:

In treating individuals either explicitly or by default as merely socially or culturally driven, ignoring the authorial or '*self-driven*' aspects of behaviour, is to render them at best partially, and perhaps more often, as fictitious ciphers of the anthropologist's theoretical invention (Cohen 1994: 7).

For Aristotle, such capacities (that derive from individual and socio-cultural authorship) are those which make us human beings and are invested in the 'soul'. However, Aristotle's soul, or in his terms 'psyche', is not to be confused with that common usage of the word which owes much to theological coloration, and which expresses strong dualistic connotations. Instead, the word mind would be a better translation. In this sense the mind (*psyche* in Aristotelian terms) is '... simply what determines' a particular creature 'to have the sort of life characteristic of creatures of that kind' (Smith & Jones 1986: 78). Aristotle was not concerned with issues that give rise to mind / body dichotomies but was rather more interested in '*substance*', '*matter*' and '*form*'. That these have a particular meaning for Aristotle should not come as any surprise. In Aristotelian terms, a 'substance' can be any particular entity - for our purposes let us say a brain injured child - but it could as easily apply to a dolphin or a bread knife. All these entities have 'matter' and 'form' but it is the unique arrangement of these features that make a particular thing what it is. 'Matter' and 'form' are not singularly concerned with questions relating to the material and shape of things or entities, but rather state the capabilities of

entities ('substances') and how they behave. For Aristotle, 'substance', 'matter' and 'form' are the very attributes which express the nature of things, not the components from which they are made. Descartes postulated that people were made up from two contrasting components, corporeal stuff (body) and non-material stuff (mind). For Aristotle, however, 'substance' is the aggregate entity, comprising 'matter' and 'form', the former providing potentiality and the latter actuality. Indeed, it is due to this unique arrangement and their interrelationship with one another that minds, expressed as capacity, perception and knowledge, are tangibly evolved within the living body. Thus the soul, mind or psyche is that which

makes a body a living creature of the kind it is - that is, the soul (or perhaps better *having* such a soul) is the 'what it is to be what it is' or form of a living creature (Smith & Jones 1986: 78).

The important point is that for Aristotle the soul, or in our terms the mind, is not a separate feature or aspect of the body but one of its defining characteristics, and one which constitutes the very nature of the body. Moreover, it is this augmentation that gives the living body potentiality and actuality, and in so doing defines the unique qualities and capabilities of a particular living creature.

The Nature of Mind.

I have mentioned two contrasting and competing theories that attempt to locate the mind. The dualist's notions, postulated by Descartes, assume that the world consisted of two things, *res extensa* and *res cogitans*. The former

referred to extending things, such as the body, whilst the latter concerned those thinking things i.e. the mind. The body, being embedded in space and time due to its corporeality, contrasted radically from the mind, which observed few if any of the laws which operated on the body. Descartes himself envisaged a problem of interaction between these two conditions and proposed that the pineal gland⁴ mediated the operations of *res extensa* and *res cogitans* (Edelman 1992: 11). According to Edelman, such dualist notions persist today and can be attributed to the behaviourists' assumptions⁵ which deny the processes of mind, believing that, since they cannot be observed, they must be beyond the scope of scientific exploration, and therefore should be disregarded. As I shall demonstrate in later chapters the influence of Descartes also remains insidiously discernible in much of modern medical practice.

In an attempt to relocate the mind within modern science a new discipline has evolved which combines psychology, computer science, artificial intelligence, biology and philosophy to address the issues of cognition. In a simplified way these new cognitive scientists have attuned themselves to those mental functions, those internal processes of mind, that were largely rejected by the behaviourist tradition. The cognitive school rely

on the concept of mental representations and on a set of assumptions collectively called the functionalist position. From this viewpoint, people behave accordingly to knowledge made up of symbolic mental representations. Cognition consists of the manipulation of these symbols. Psychological phenomena are described in terms of functional processes. The efficacy of such processes resides in the possibility of interpreting items as symbols in an abstract and well-defined way, according to a set of unequivocal rules. Such a set of rules constitutes what is known as a syntax (Edelman 1992: 13).

⁴ The precise function of the pineal body is still obscure and species dependent, however, it does play a role as a neuroendocrinological mechanism, particularly relating to the effect of light on gonad inhibiting substances. (Gardner 1975: 352)

⁵ According to Hodgson, Ryle's proposition also adopted a similar stance to that posited by the behaviourist tradition (1991: 64)

However, Edelman is cautious of such an approach that considers the mind to be analogous with that of a computer, running specified programmes to manipulate data in the brain. For the cognitivists, these mental processes are largely independent of the structure and developmental modes of the nervous system, making the underpinning biology (and perhaps the body) incidental to the operations. For Edelman such views, as influential as they are, fail to give an adequate description of the mind because they fail to provide an adequate description of the very substrate of mind, the brain as a biological unit. Indeed, as Edelman notes

one of the most curious deficiencies is that it makes only marginal reference to the biological foundations that underline the mechanisms it purports to explain (1992: 14)

However, this biological mechanism should not only encompass the brain but should also explore the issues of embodiment and the conscious experiences which result from such an interplay, and which may serve to help empower the mind.

Evolving Bodies

That bodies are important in determining behaviour is well documented. More precisely, morphological adaptations, such as an opposing fifth digit (thumb), a bipedal gait and large brain development, have probably played a major role in the evolving behaviour of our species. To what extent changes in morphology have preceded behaviour, or whether behaviour itself may have just as likely acted to induce morphological adaptation, remains,

however, unclear. What is clear though, is that flying requires wings of some description to the same extent that thinking requires a brain (Edelman 1992: 50). That genes play a crucial role in the evolution of our bodies is not surprising. The importance of genetic material is not one of gross difference, as one might initially imagine, but one which relates to the expression of specific sets of instructions. The genetic similarity between man and the other primates has been well described. For example, the difference between the DNA of man and that of the chimpanzee is less than two per cent. That is to say the genetic similarity between us is so great that more than 98 per cent of our genetic material is identical to that of the apes (Passingham 1982: 5).

However, although discerning the difference between our shared DNA is difficult we have little trouble in identifying a chimp from a man. Presumably the differences between our body types or phenotypes arise from less than two percent of our DNA. It has been postulated that the variation between our own bodies and those of the chimp results from the influence of control genes which may act to turn on and off developmental regulating processes, thereby affecting size and shape of the body and its organs (Gould 1977). This, then, accounts for the anatomical difference between man and apes even though our DNA is almost identical. It also provides some insight into the significance of the body in determining the operations of mind.

There has always been a deep rooted problem with aligning the physical to the mental. Although we have little problem identifying the existence of a conscious corporeality motivating the behaviour of man and many other species, reducing it to its constituent elements has not proven

fruitful. For Thomas Nagel (1979) the trouble with understanding the mind-body problem rests with interpreting the consciousness that results from such interactions. But answers have not been discovered by the intellectual disciplines that attempt to explain consciousness through the principles of material reductionism. It is not always wise to imagine that the incomprehensible will be explained by applying the deduction of what is familiar or well understood. Surprisingly enough, much of modern science and philosophy has been doing just that, reducing consciousness to something entirely mental and then looking for its physical expression within a material entity. Anthony Cohen (1994) has been one scholar who has attempted to insert the 'self' back into an extended consciousness which unites the social, cultural and individual into a meaningful and, most importantly, an interdependent consciousness. However, there remains one final incorporation to complete that functional system of a fully aware mental capacity, the body.

To describe the animation of the human body, not in terms of the descent into it of pure consciousness or reflection, but as a metamorphosis of life, and the body as the "body of the spirit" (Valery). The latter purpose would demand an "esthesiology," a study of the body as a perceiving animal. For there can be no question of analysing the fact of birth as if a body-instrument had received from elsewhere a thought pilot, or inversely as if an object called the body had mysteriously produced consciousness out of itself..... Thus the body proper is a sensible and it is the "sensing"; it can be seen and it can see itself, and, in this latter respect, it comprises an aspect inaccessible to others, open in principle only to itself. The body proper embraces a philosophy of the flesh as the visibility of the invisible (Merleau-Ponty 1970: 128-129).

The Conscious Body

When I talk of a person being kind, honest, tall or ugly I am likely to be addressing the issues of consciousness. It is true that the consciousness to which I refer is my own and the adjectives used more likely describe, or at

least represent, my own assumptions about the person. Nevertheless, the person about whom I speak is, in part although not exclusively, responsible for my statements. It therefore seems natural to assume that these statements I make about another ensue from the person I am. This, then, will be my starting point for a brief corporeal tour of consciousness. My consciousness is most basically *that* what it is to *be* me. As Thomas Nagel argues

but no matter how the form may vary, the fact that an organism has conscious experience *at all* means, basically, that there is something it is like to be that organism.... But fundamentally an organism has conscious mental states if and only if there is something that it is like to *be* that organism - something it is like for the organism (1979: 166).

This 'subjective character of experience' (Nagel 1979) is essential to any analysis of consciousness for without it we cannot ever really know what are its material requirements. It has been pointed out earlier that minds require the material substance of a brain, and although we do not understand the exact relationship between the physical matter of the brain and the conscious thoughts that constitute the mind, the brain seems, nevertheless, an essential feature of the processes of mind. But any account of the physical basis of mind must explain a plethora of things. Amongst these the phenomenological detail of experience is central. Nagel argues that physical reductionism would require that the 'phenomenological features must themselves be given a physical account' (1979: 167) but the impossibility of this task is evoked by their very subjective character. Indeed, as Nagel goes on to point out, any objective physical theory must abandon this because every subjective phenomenon is essentially derived from a single point of view. Furthermore, a

point of view that is only accessed from the personal character most likely incorporates all of the physical, spatial and behavioural features of that organism.

As an example of this Nagel asks '*what is it like to be a bat*'? The bat, although a mammal like ourselves with conscious experience, has a profoundly different way of relating to the world that we both share. Its sensory capacities differ, as do its bodily structure and the functions that result from those different structures. It is also likely that its nervous system is arranged in such a way as to initiate the behaviour we recognise as being that of the bat. Nagel's point is, however, what can we ever know about what it is like to be a bat? Because it uses sonar, which is just one of its describing characteristics, to orientate itself in three dimensional space it has subjective experiences which are beyond our capacity to acquire⁶. Our own experiences are of little use. Even with our imagination we will not *experience* that what it is to be like a bat. At its most basic this is because we are restricted by our own resources of both mind and body. Simply being informed about the structure and function of the bat is clearly not enough to enable us to infer the internal conscious states, and the resulting experiences, that help make the bat what it is. Bats, like other conscious organisms, have experiences embodied within a particular point of view. That points of view can be shared is not contested, but that points of view can be subjectively experienced is certainly

⁶ I think Nagel's point is generally a valid one, although sonar is not exclusive to bats, or for that matter cetaceans, humans can also develop the capacity for echo-location. (See R.P Power, et al (1981: 35) Therefore, if his argument were to rest solely on the uniqueness of sonar being a perceptual capacity of the bat, thereby excluding human comprehension of this experience his argument would be somewhat weaker but still not invalid since subjectivity must be one of the defining characters of individualism.

more problematic. We do not understand how physical events produce subjective phenomenological experiences because we have yet to account for the interface that permits such transmissions. It is likely, however, that the physical architecture, within which the mind is materially placed, has many implications for the processes that ensue from its operations. Presumably the subjective phenomenological experiences that Nagel refers to are, in part at least, the result of the physical capacities of that particular organism.

Therefore he is quite right in maintaining that there are facts and experiential details involved with being a bat that are well beyond our human capacity to express, experience or articulate. But the fact that 'we can be compelled to recognise the existence of such facts without being able to state or comprehend them' (Nagel 1979: 171) need not lead us to deny that such phenomena are indeed experienced and acted on by our friend the bat.

But it is not just the bat's experiences that lie beyond our capacity to describe. The subjective nature of those experiences that relate to individuals born blind, deaf and brain injured are equally likely to not be accessible to others. It is for this very reason that embodiment, those experiences, accounts and the influencing speculations of others, climax to significance. That a body, orchestrated by brain injury, is conscious and has experiences of the world in perhaps a subtle, but also a dramatic, way poses another problem for those attempting to understand the individualised encounters with life that brain injured children experience (see chapter 8).

An Individualised Body

Why is individual phenomenology not public experience ? Let me phrase this question another way, i.e. why does the individual have subjectively unique experiences? The initial answer seems simple - because they are unique and individual they will experience events in the world in their own particular way. But then we must ask, what makes the individual an individual? One possible explanation would arise from the genetic varieties that result from sexual recombination and mutation. In fact it has been suggested that

by mixing genes with those of another individual, (and) even one pair of human parents, at one mating, can produce 64 trillion genetically different offspring... (Ornstein 1991:116).

Although this genetic variety confers benefit to the species in evolutionary successful ways, this genetic drift does not alone account for our individuality. The psychological and biological literature is full of facts on individual differences. However, a central component in the individualism of humankind is environment. It appears that both social and physical environments influence the development of the individual (Jenkins 1997). That different worlds confront different people seems to be important here. Position in the family, diet, sex, height and personal interest all act to individualise the person (Ornstein 1991: 114). Indeed, the idea that race, socio-economic status and age also help to individualise the person is no longer a surprise. In addition to this there is phenotype, which for our

purposes will include shape and the body's functional properties, which also plays an important role in the individual's consciousness. Interest in the human body, its form and expression, and how such somatic varieties impinge, presumably, upon the mind donating different personality traits is not a new idea. Hippocrates (460-377 BC.) classified people according to their body type and the diseases to which each type were likely to be associated. Sheldon et al (1970) developed a hypothesis that distinguished three body types or somatotypes, endomorphy (fat), mesomorphy (muscular) and ectomorphy (thin). Each type had its accompanying temperament and was also seemingly inclined to develop a corresponding variety of mental illness (Sheldon, Lewis and Tenny, 1969).

Physical attractiveness is another aspect of the body which can influence the personal experiences of an individual so much, in fact, as to affect their treatment in judicial matters. Efran (1974) showed that those who were regarded as more physically attractive tended to be given the benefit of the doubt by juries as compared to those perceived as plain or unattractive. Moreover beauty, as defined by the external contours of the body (aesthetics), or in Featherstone's et al (1991) terms the surfaces of the body, has given emphasis to the growth of both consumerism and the fashion industry which play a key part in not only the medicalisation of diet and fitness but also in the development of 'the body beautiful' as the 'target of advertising and consumer luxury' (Turner 1992: 164-165). This serves to show that the body may well be a physical and biological entity but its individual management is as much one of social regulation as it is of hormonal activation.

So it appears that the specific details of human bodies, their aesthetics, capacities and incapacities, are important in influencing the conscious experiences of the individuals in the same way that the bat's body influences its experiences. We may conclude that bodies, their individual characters and their functional properties, help engage our minds with the world in which we live. Is it not possible then, that our minds which consciously operate on our experiences of self, other and the perceived world can influence the very physical nature of our bodies? For example, many brain injured children will dissociate themselves from their hemiplegic limbs, making any form of functioning with that limb seem impossible. They have developed a 'neglect' for that area of the body that does not conform, due to a lesion of the brain, to its appropriate motility. In doing so, however, they further decrease their opportunities to exercise control over it. This leads to an escalation of the problem, reinforced by a negative feedback link of dysfunction. However, developing uses such as supporting roles for the spastic or athetoid limb, where the dysfunctional hand and arm, for example, are used to simply keep some weight on a paper for writing or to push against an object so that the other limb may get a better grasp of it, helps to reintroduce a purpose for that limb and also re-establishes a sense of completeness in the mind of the injured child. In this way the neglect shown to dysfunctional limbs can be challenged and over time, with therapy, function can improve. The problem is and still remains one originated by injury to the brain, but an ameliorative solution may nevertheless be found in engaging the mind through the body.

Indeed, this is often the underlying philosophy, although rarely articulated, in many alternative therapeutic systems⁷. We know that injury to the brain often results, particularly when occurring at the time of birth, in motor and sometimes sensory and intellectual impairment. One of the most frequent causes of this has been suggested to involve a disruption of oxygen supply to vital areas which control the movement of limbs in the child's developing brain (Pape, et al 1979). In such cases the nerve cells do not develop sufficiently to establish a pathway down the spinal cord, but nevertheless continue to emit an excess of signals to the muscles resulting in 'uncontrolled contractions known as spasticity' (James 1995). What we must now explore is, how might such contractions of the body affect the individual's experiences and what are the consequences of these '*adjusted*' experiences, due to motor impairment, for the particular individual's consciousness?

Chaotic States

I have attempted to show that bodies, or perhaps more importantly an individual's experiences of embodiment, are to a large extent constructed on the personal and subjective experiences an individual encounters. Nagel's discussion (*above*) on the unique morphological adaptations of the bat frustrates our ability to imagine what it must be like to be such a creature, but does serve to provide an interesting insight into how bodies might play a

⁷ Both Doman-Delacato and Conductive Education approaches imply, sometimes on a subliminal level, that amelioration of brain injured children involves addressing the processes of mind. The Doman method refers to 'neurological organisation' whilst the rhetoric of conductive education states that one uses the brain not legs to walk. Interestingly enough although many therapeutic rationales identify the biological unit of the brain in language, in practice they are often attempting to engage the mind.

critical role in individual phenomenology. We have seen also that a more pragmatic approach to addressing the mind / body dichotomy is to refer to the capacities and potentials of individuals - and attribute these expressions to be the result of minds, or brains working through the somatic activities of the body to establish a personal actuality and potentiality. Indeed, for this reason it is also possible that the minds of brain injured children are found expressed in the limited somatic but, nevertheless, communicative functions of the body, as related by the parents in the following account. Karen was born with a chromosomal disorder and a heart defect that required surgery. Communication, feeding, balance and scoliosis and the major concern for the parents.

(Karen)

Interviewer: You were saying that Karen enjoys physical contact.

Father: *Although people tend to think that she is delicate she likes and always has liked rough play. She likes to be physically bounced around she likes movement.*

Interviewer: Has she any concepts of her body, for example, is she modest?

Mother: *No, but she does think its funny to have her clothes off. You know when she goes for a bath she scratches her bottom and laughs about it.*

Father: *She's not far enough on to have a concept of her body. Well Sally (Karen's sister) doesn't worry about running around the house without her clothes and she's 6.*

Mother: *Well she would at school.*

Father: *Yes, but at home she wouldn't.*

Mother: *But then she would know the difference because she would not do that outside. But on the other hand I think Karen would think if someone undressed her out of the house she would find that strange. So I think she does know the difference. There are times when she won't let you brush her teeth, she doesn't want you to invade her mouth.*

Interviewer: Especially considering her problems with language, is it possible that she may use her body as a communicative tool?

Mother: *Oh yes she can exclude you with her eyes.*

Father: *She puts her arms around you, that's her favourite thing now, she digs her nails into the back of you neck to pull your head down into a cuddle.*

Mother: *But she will push people away, the ones she doesn't like and at school they say if she doesn't want to do her work she will close her eyes and switch off.*

Like that of other children Karen's body has an actuality and potentiality but due to motor impairment is embedded in the deep semiotics of disability. But even here it is likely to be the reciprocal genesis of a personal phenomenology and, as such, at least one account of the processes that underlie subjective experience. However, in order for this statement to represent, although very simply, a possible solution to a confounding 'dualism' I make the assumption that the operations that ensue from both body and mind

are to some level united, co-ordinated and functionally operable together.

Consider, for a moment, the implications to self expression and experience if disruption was to occur at any vital point of this integrated system.

Luria (1973) investigated a tragic case in which an individual's brain (left parietal area) was damaged by a war wound. Although the person had difficulty with memory, vision, speech and reading he managed to reconstruct his life well enough to describe his experiences.

I'll look to the right of me and be horrified to discover half of my body is gone. I'm terrified - sometimes when I'm sitting down I suddenly feel as though my head is the size of a table, every bit as big - while my hands and feet and torso become very small.
Sometimes when I'm sitting on a chair, I suddenly become very tall, but my torso becomes terribly short and my head very, very tiny - no bigger than a chicken's head. You can't imagine what this is like even if you have tried - its just got to happen to you (Luria 1973, cited in Young 1978: 215).

This statement informs on more than just the personal tragedy of an individual, for it also supports the notion that experiences cannot be accounted for in any other way than that given by personal involvement. Indeed, it really has '*got to happen to you*'. Social anthropology is laden with rich ethnographic resources describing and theorising the pragmatic function and semiological significance of culturally and socially retained bodies. However, a specific aspect of this embodiment paradigm remains, in the large, undisclosed. Because human bodies are, in Hallowell's (1955) terms, 'objects in a world of objects' they have a social value which depends largely upon their normative expression that is, of course, normative within their particular social and cultural context. This normative account of embodiment depends,

to a large extent, on shared personal experiences or phenomenology, being the result of socially defined bodies acting in socially defined space.

Of course, the operational rules which serve to govern bodies can and do change when transformations such as possession, trance and obsession etc, are recognised (see chapter 7). Although these altered states of consciousness often have accompanying bodily manifestations (as I shall show later), in the main embodiment, as an anthropological issue, has often been concerned with either the functionally normal body or that recognised as illness behaviour. The latter, indeed, has given rise to medical sociology and medical anthropology (Good 1994, Radley 1993 and Helman 1986). Thus the fact that there are bodies that do not conform to normative expression, due to some underlying trauma, not only presents the anthropological enterprise with an interesting methodological issue, it also likely presents an individual so affected with a set of unique, and perhaps socially isolating, experiences incommensurate with those already discerned from studies of normative embodiment.

What, then, are the implications of radically different experiences of embodiment due to changes of physical expression and ability? The fixed or sometimes fluctuating muscular contractions, which can often not only distort the brain injured child's body but also reduce his or her capacity to purposefully engage with the world, must then surely effect the very consciousness therein restrained. However, that individual consciousness is thus restrained need not confirm it as a limited capacity but rather as one that presents a greater challenge to interpretation. The problem, then, of

interpretation is as equally true for the parent as it is for the anthropologist.

The following mother's statement may help to illuminate this uncertainty.

(Cindy)

Its just those little things she says (wishing she was someone else, not disabled) every now and again that gets you. She's not saying it in a way like, 'oh I wish I could walk', she's not saying it like she's making a statement and that's the end of it. She said to me a little while back, 'oh I had a nightmare last night' and I said 'did you'? 'Yes, I was being chased and I was running like mad'. I said 'were you running or were you in your wheelchair', 'no I was running' she said. She actually dreams she's running. So you know its in her subconscious, its us that get upset. I mean if there are other children here they all run off into the garden and there's Cindy crawling along the floor and by the time she gets to the door they have all come back in again so she turns around and comes back in and I think 'oh poor little thing'. I don't think she worries about it she just plods along. I mean she knows she can't walk, well she used to. We've had a long chat and I've explained to her the best as my ability will allow about the brain and that a little part had been damaged, but she doesn't really seem to be that worried about it. What is going on in her mind? I don't really know what she is thinking. She came in yesterday and had a school journal for spelling open on a blank page, but she was reading a story, I said 'what are you doing Cindy'? She said, 'shush' I'm nearly finished, so she finished her story and said 'right, you can talk to me now' and I said 'what were you doing? 'Oh I was just reading a story'.

These states of motor impairment establish an actuality for the injured child but do little to provide him or her with an easily recognisable and interpretable personal potentiality. What are the consequences for such children when their own bodies do not project into the world in such a fashion as to provide them with a construct for what Mauss (1934) and Bourdieu (1977) might term '*habitus*'? It is surely not that these children evade this concept, for even motorically and intellectually impaired children have bodies. But if '*habitus*' is the concept which refers '*...to the sum total of culturally patterned uses of the body in society*' (Csordas 1989: 11) where are we to

locate the dysfunctional patterns of bodily expression within this cultural environment? If functionally normative bodies have culturally patterned uses, which establish them as both the tool and purpose of culture in society, what part is left for the disabled body? If we continue this line of reasoning for a moment longer we can see that disabled bodies play but a little part in the cultural construction of society, and as such are neither likely to be its object. Perhaps the only exception to this is a negative role: they may help to make explicit the boundaries of normality.

Thus if one of the purposes of an abled embodiment is to be personally empowered as a functional representative of society, then disablement is likely to be the signature expression of the disempowered. Furthermore, if we consider that not only are brain injured children's bodies culturally less manipulative, but they also have the added disadvantage of being children, a category which, as we have seen, (see chapter 2) has little status in the adult affairs that largely determine society, we begin to see the depth of the isolation to which many such children must be subjected. The brain injured child's experience of embodiment must, at some deep and important level, reflect the child's conscious position in the external world, for Merleau-Ponty argues that

the body is a "setting in relation to the world," and that consciousness is the body projecting itself in the world (cited in Csordas 1989: 8).

Merleau-Ponty's observation is based on perception and its phenomenological nature, and in his account our bodies are the starting point of this process. Thus perception is, in the first instance, a style or pattern of

the body behaving that encounters (perceives) objects after reflective analysis. Encountering objects is the experience of perception permitted by the body engaging at all levels (physical and social) in the world. So, for Merleau-Ponty objects are indeterminate until determined by the conscious body. But if our experience of objects, presumably existing independently in the world, is only determined after our conscious bodies have encountered them, then there is likely to be a particular way for bodies to correctly behave in order to achieve their perceptual goal. The following account concerns Timothy (see 'case two' in chapter 8) and one consequence of his body's motility. The present account is presented as a narrative simply because Timothy's mother was not comfortable with the tape recorder being used so I took notes contemporaneously and wrote them up after returning to the clinic.

(Timothy)

Mother talked about Timothy's behaviour and in particular one element that was of some concern to them. This involved Timothy "escaping" i.e. getting out of places and making a run for it. He could be quite devious about it and seemed to carefully choose his moment when just the right circumstances existed he would make a dash for it and escape. On one occasion he was caught running up the middle of the road seemingly oblivious to the danger of the situation. On another occasion, a neighbour was looking after him for an hour when he climbed out of an open window and into the garden. Both his mother and father had spent much time considering the rationale for this behaviour and are at a loss to account for it..

We talked for some time about this and I suggested that perhaps one way to interpret this was to consider notions of confinement wherein the body and his mental disability are contrasted with some aspect of the outside, possibly unconfined space and freedom. For example, Timothy has to be closely watched so most of his time revolves around being kept indoors. The sphere of the home may now give rise to feelings of confinement and routine attached to familiar experiences. However, outside provides new possibilities, opportunities and stimulation which may not only be very attractive to an inquisitive child, but also provide an important extensions to experience. Thus, the external outside sphere, as opposed to the internalised one of the home, may provide a new experience for the body, through escape both the body and the mind are liberated. That is, inside represents confinement and emphasis on disability whereas, the outside represents in some way, perhaps even just spatially, freedom and new levels of experience and autonomy.

As Merleau-Ponty would argue movement, either imagined or real, is one of the key features of the body's discerning ability, for without it we are unable to purposely project into the world. However, unlike those patients with whom Merleau-Ponty worked and studied, many brain injured children have often not lost their body's motility but rather have failed to acquire it in the first place. Thus it is unlikely that one could even imagine purposeful movement if one had never had the opportunity to develop such a facility. So how are such children to be, in this sense at least, *'in the world'* if their bodies

fail them as culturally and socially refined phenomenological receptacles?

This problem is perhaps alluded to when Merleau-Ponty writes

It is true that even in the normal person the perception of the body and of objects in contact with the body is vague when there is no movement (1962: 108).

The so called '*normal*' body in this view does not need to rely upon real movements of the body to experience a stimulus, as these can be aroused by a kind of '*potential movement*' (1962: 109). This is due, argues Merleau-Ponty, to the fact that for the

normal person every event related to movement or sense of touch causes consciousness to put up a host of intentions which run from the body as the centre of potential action either towards the body itself or towards the object (*i.e. what is perceived*) (1962: 109).

Now the lack of purposeful and intentional movement is very likely to exclude the brain injured child from that consciousness inspired by the body's potentiality. There is little point, argues Merleau-Ponty, in attempting to 'deduce the normal from the pathological' (1962: 107) or transferring the meaningful patterns of normal movement to the injured child. In this sense the child is not in some temporary or virtual world but in a concrete one that is itself a 'complete form of existence' like that which naturally occurs in childhood, old age and illness (1962: 107). Although this world is indeed a real one it can have few, if any, of the conscious fusions between object and self that are both the purpose and result of the functional body actively engaging with the external world.

However, there are possibilities here for those brain injured children who have little motor ability. Although they might have never experienced the necessary motility of body as a facility to Merleau-Pontian perception they might, through discourses and observations with others, imagine or construct a representation of themselves as both 'subject' and 'object' and thus extend themselves into an external world (see chapter 8).

The Antisocial Body

What I have attempted to argue is not that children with a brain injury fail to be conscious of themselves and the world in which they live but that we, the abled bodied, are presented with many problems in gaining insight into their conscious states unless we investigate the fundamental roles embodiment plays in developing their consciousness. This problem might be more clearly expressed if presented in a different way. In 1950 A.M. Turing predicted that by the year 2000 computers will have a 30% chance of fooling an interrogator into thinking it was a person. There were several conditions attached to this prediction governed by a specific methodology⁸. However, one thoughtful critique of "Turin's Test" asks how could an interrogator (a given person) assume that the object he was interrogating was, for example, either (1) a concealed woman or (2) a digital computer, when he had no evidence that the object uses words as he himself might understand them. That is, 'uses its words to refer to objects in the world' (Davidson 1990: 7) which he too

⁸ For a good review of Turing's prediction see D. Davidson (1990)

recognises to be the same objects. Furthermore, the references made would need to be responses to events and aspects of a shared world with mutual access. Donald Davidson continues his evaluation and makes an observation which is equally relevant to the present discussion when he states that

It is clear, then, that the physical characteristics of the Object (computer or woman) will matter a great deal. We have already noticed that one physical characteristic was essential: the Object had to be causally responsible for the 'messages' observed by the interrogator. But now we see that the Object's 'body' matters for further reasons, since the Object must be able to respond to many of the same features of the world that can be noted by the interrogator, and it must be possible for the interrogator to see or otherwise learn that the object is responding to those features. For the Object to have a semantics, it must operate in the world a certain way, and for someone else to grasp these semantics, there must be a three-way interaction between Object, interrogator and shared world (1990: 8).

Now this argument against the so called 'Turing's Test' postulates the same problem for brain injured children. Bodies, especially those which operate in a particular way, provide a baseline for consciousness through experience. The body that is unable to interact in culturally and socially specific ways with aspects of the world that impute meaning is unlikely to have developed a commonality of experience and expression commensurate with those who do. Unless of course, they have circumvented the problem by initiating novel strategies that we have yet to explore (a possibility that will be considered later).

Furthermore, I must include into my analysis the fact that bodies, abled or disabled, have properties other than their motility and perceptual skills. They also have deep social meaning attached to them. One of the most inspiring contributions to the cultural value of bodies, and the social regulating mechanisms imposed on those that do not conform to 'normative' values, is

presented in Erving Goffman's book 'Stigma' (1963). To be physically disabled may not just limit the semantics, or the rules for interpreting experiences that result from a collective phenomenology in a shared world, but may also limit one's personal experience or contact with the social world. That is, prejudices relating to disability impose their own explanations on an individual's behaviour without reference to the individual's self-account of the presented behaviour (Shakespeare 1994 and Oliver 1996) Moreover, such 'stigmatising' will inevitably lead to a restriction of activities and experiences regarded as unsuitable or inappropriate simply because their understanding of the problems involved is based on prejudice and ignorance. Thus, we can identify another isolating dimension to be encountered by brain injured children and to be discerned by us. To be in the mainstream requires that the body, its physical, social and political functioning, must not challenge the cultural norms of operation.

Paediatricians Duff and Campbell (1979, cited in Finkelstein 1991: 51) have recognised that those children, who they refer to as 'defective', will receive little if any acceptance into mainstream society and have subsequently termed these infants 'socially dead'. The underlying rationale which often determines such statements reflects the notion that physiognomic appearance is socially defined. It has been argued that much of the modern industry of the body uses exercise, cosmetics, clothes and even surgery to fashion a portrayal of personal character by developing an 'ideal' body (Featherstone et al 1991, Finkelstein 1991 and Turner 1992). This, of course, would not be possible if there were not precedents and accessible substructures already developed to

propagate such an ideology. The body is not just a functional mechanism of personal intention or collective expression, or for that matter 'an architectural metaphor of the society at large' (Régnier-Bohler (1988) cited in Finkelstein 1991: 50). Bodies are, most fundamentally, the very material repository of society and that on which its appraisals and regulations fall. It is of little wonder, then, that the normative and aesthetic attributes of the body have evolved a prerequisite role in the maintenance of a social, as well as a personal, identity. The primacy of an aesthetic body, a socially acceptable one with no anomalous detail, is witnessed by the industry which serves it. However, it seems that enlightenment has yet to sympathise with the seemingly socially intolerable forms of disablement. Deficiencies and inadequacies are, at every opportunity, regulated and, where possible, corrected.

The increasingly detailed notation of correctable human features is a reflection of the proliferation of techniques now available with which to alter and presumably refine appearance. These mechanisms and services are available not because modern individuals are inherently more flawed, but because the belief in physical appearance as a signpost to human character has not been expunged from our culture. Indeed, if we consider the growth in the 'body industries', including the development of modern medicine, the possibility emerges that the belief in character as immanent in appearance has intensified (Finkelstein 1991: 69).

Finkelstein's observation that bodies have a social currency, providing this currency has not been defaced in any way, is particularly true of children, whose aesthetic qualities, as noted in chapter 2, are regarded as emblematic of an ideal state or innocence. Thus many brain injured children may become physically conspicuous due to the associated aesthetic symptoms which often accompany a neurological insult. Positional deformities, spasticity and facial

grimaces act to signal the child's marginal status to a motorically competent community. However, if such symptoms are not overtly present then discovery of the child's problems are often only detected during personal interaction. It is through such encounters that the politics of disability (Oliver 1996, Barnes 1996) are discerned and established.

(Karen)

Father: *To the outside person Karen's not immediately handicapped, she quite a pretty child really, isn't she?*

Mother: *Yes, but she's becoming now father interjects, 'its becoming more noticeable, that's what we are going to face'. Yes because up to now she's just been a baby and everything was well she's just a pretty little baby.*

Father: *She still goes around and is big enough to fit into an oversize McClaren buggy.*

Mother: *That is straight way a mark that she's disabled in some way but she doesn't have any abnormal behaviour.*

Comments may be made which reference the 'shame' that such an otherwise 'pretty little girl' should be mentally incapacitated, imposing once again the notion that physical attractiveness is incompatible with disability. It is, of course, both possible and likely that people feel uncomfortable when they discover that the 'pretty' little child is brain injured and thus attempt to salvage their embarrassment by making reference to the child's 'saving'

physical normality, her general aesthetic appearance. However, either reaction simply serves to highlight the notion that physically anomalous bodies, or in some cases anomalous behaviour, seem to contaminate their possessors, and that disability is regarded as an unlikely associate of the aesthetic or normative body. Indeed, it appears that the physiognomic practices of the nineteenth century which assumed that an individual's internal character, or for that matter state of mind, was pictorially represented by a misshapen body and face may still remain persuasive⁹.

Conclusion

In this chapter I have explored the relationship the body has with the clinical notion of brain injury. Bodies, to a greater or lesser degree, are the external representatives of a given person and as such they are emblazoned with both social and clinical significance. Typically, the hidden neurological trauma is outwardly manifest in the body. Bodies thus affected are conspicuously charged with disablement, an emblem in itself for social exclusion.

What I have attempted to demonstrate is that brain injury makes few substantive references, neither social nor clinical, to that complex physical organ wherein, presumably, the problems are located. This probably has less to do with our present level of understanding concerning the brain and its diverse functions than with the body as a narrative for social engagement. It is

⁹ For a good account of Physiognomy see Holcrofts' (1804) translation of the great physiognomist, Lavater.

the body, not the brain, that is continually on show, that has a public function and responsibility and which acts to make the definitive statement of the possessor's underlying character. Physical appearances are not the result of the fashion industry but the cause. Fashion, in one sense, is not the process of simply obtaining a cosmetic change of appearance, it has more to do with a particular way of behaving in a socially prescribed manner.

The value of the individual's physical appearance lies not so much in its approximation to a specific style or ideal of beauty but as an indication of his or her willingness to treat the body as malleable, and so to subject him- or herself to the array of tools and techniques that can fashion it (Finkelstein 1991: 184).

That this 'malleability' is likely to be present in the bodies of brain injured children seems obvious enough, but identifying the subtle self adaptations of form, appearance and expression that these children may engage in order to offer some statement about themselves to an external and prejudiced world remains problematic. To engage in the cultural practice of adornment, to transform the body with the prevailing tools of society, serves as a reaffirmation of the values held by that society. The body is, once again, both the purpose and tool of social unity, wherein the perceived 'non-transformers' are, for whatever reason, viewed as deviants. It is little wonder that so many parents of brain injured children seek to minimise their children's disability with active therapies that attempt to reinstate 'positional normality' and dress their children in fashionable clothes so as not to attract public gaze (see chapter 6).

Whereas brain injury as a neurological condition is only ever loosely articulated by the clinical communities its presence, as indicated by a

transformation of the body, provides much more scope for social debate. The fact that such children are often unable to benefit from the tools of a body culture industry to effect change acts to conspicuously confirm that these children are indeed on the social periphery. The fact that the consumer industry is challenged by their anomalous bodies only threatens to further distance these children from its transforming services, and as a result, their social position becomes as equally anomalous as their bodies (Turner 1984).

The body has become a fundamental feature of taste and distinction in which the management of the human form becomes part of the major aspect of cultural or physical capital (Bourdieu 1984 cited in Turner 1992: 47).

However, by 'disembodying' the significant aspects of such a trauma, i.e. the personal experiences that result from embodiment, which often occurs in the clinical setting, we risk failing to understand the interactions that give meaning to consciousness itself and which are likely to be an important aspect of brain injury. Indeed, as argued, this consciousness is not solely restricted to the individual but, by means of a socially engaging body, is paramount in the aggregate experiences that establish a societal or collective consciousness.

For Wittgenstein the body provides 'the best picture of the human soul', and portrays the essence of human character itself (cited in Finkelstein 1991: 184). Such rhetoric places great demand upon the body, a demand that cannot always be met, particularly by disabled bodies. So a thorough understanding of embodiment is essential if we are to account for the personal isolation that injured children experience, and which inevitably is partly constructed by the debilitating perceptions and demands placed upon bodies that fail to conform.

Scoring Professional Parts

Introduction

Up to this point I have developed my theme on the 'Orchestrated Body' with particular reference to the social construction of childhood and the body that gives meaning to the public performances which conspicuously present brain injury. That childhood has been explored socially, clinically and philosophically by so many scholars testifies to the enormity of interest that underscores the developmental events which chronologically locate children for particular concern. Specialist groups have evolved a variety of professional roles to educate children's intellect, doctor their bodies and sometimes their minds, regulate infringements of conduct and even, when felt necessary, remove the child from its parents. It seems, then, that the socialising of children merits much concern. It is true that, as adults, they will be charged with the responsibility of replicating society, and as such must be schooled in the commensurate ideologies and practices that are, for better or worse, its future investment¹ (Jenks 1996). However some children, almost by default, will be viewed as transgressors or deviants simply because of their inability to conform and perform to the prevailing tempos that orchestrate childhood as a part in the larger societal score. The fact that such issues arise from specific aspects of embodiment being perceived as abnormal or pathological helps to constrain the brain injured child within a medical

¹ See Armstrong (1983: 13-18).

perception. In contrast to this, alternative therapy attempts to help the parents engage with the child as an embodied person, not an entity of disability.

In this chapter I will explore, in greater depth, brain injured children who may well be construed as 'non-performers', and the interest and ultimate control that management centred systems impose on so many of them and their experience of disability. That is, I shall explain the consequences of the work done by the 'professional players' (doctors) in structuring clinical pathology as some independent aspect of the social constructions which attempt to provide meaning for those traumatically involved. In this way, brain injured children are regarded as a particular construction of an 'objective' medical gaze largely concerned with identifying paediatric pathology. This, perhaps, is what parents who seek alternative therapy are hoping to get away from, as they try to reach and realise the embodied potential that they feel by intuition is present.

The Cellular Concept

Engel (1962) suggested that often the orthodox approach is fixated with disease and dysfunction at the cellular level, and argued that such medical reductionism affects the practitioner's ability to conceptualise the problems at all levels of organisation. Indeed, this trend was noted by Armstrong (1983) as one of the historical products of medical enlightenment in the late eighteenth century.

When the "body appears to have been discrete because it was recorded in separate case notes; it was accessible because at this time medicine began to use methods of physical examination; it was analysable because pathology became localisable to a distinct point within

the body; it was passive because the patient's personal history was relegated from its primary position as the key to the diagnosis to (that of) a preliminary" (Armstrong 1983: 6).

This is particularly true with regard to brain injured children. The primary focus of clinical attention is some (often vague) area of neurological cell destruction, and the behavioural dysfunction that ensues is directly attributed to this defined pathology. The question now is to what extent are the gross observed dysfunctions solely associated with the underlying neuronal damage², and how much are they contributed to by sensory and general environmental deprivations that may, in part, be a product of some medical labelling theory and its associations? Indeed, might not some of the observed dysfunction result from the absence of an appropriate therapy? Whatever the aetiological agents responsible, it is, for example, now recognised that they are likely to associate with a myriad of external and non clinical factors that serve to further confound our perception of the aetiology of dysfunction and its subsequent amelioration. Furthermore, with increasing diagnostic techniques disease, or more specifically brain damage, is identified as a deviation from normal structure. The temptation now is to consider such findings as the explanation for the present condition rather than a manifestation of the condition's state (see note 2). The logical approach for orthodox medicine, then, is to attempt an amelioration of the condition by directly treating the damaged area concerned i.e. that which deviates from the normal. The fact

² Neubauer et al (1990) have noted that some tissue in the brain may be viable but non functioning ('idling neurons'). Research involving hyperbaric oxygen suggests that recovery of function may, in some cases, be related to oxygen uptake in this partial hypoxic area which surrounds the more densely ischemic centre of the lesion (Astrup 1981). Thus, many of the disabilities we observe in brain injured children may well be related to the inability of these idling neurons to 'come on line'. Therefore, any prognosis based on dead tissue (pathology) may not be a valuable indicator of outcome.

that often in medicine such measures prove successful, as perhaps in some form of surgical intervention, is not in itself 'evidence for the general validity of such a point of view' (Engel 1962: 241).

That all bodies are, in some way and to differing degrees, orchestrated by the professional gaze of the society in which they live seems reasonable enough, but why many will be given an active voice and others seemingly kept mute may not be so easily deciphered. My purpose in this chapter will be to attempt to show the method of 'muting' certain potential 'instrumentalists' and the consequence of this on the overall harmonic quality of society. If I maintain this musical analogy for a little longer we will see that the 'soloists' in our symphonic impressions of society are the professionals, playing the leading parts and heard over all the other members³.

Medicalising the Family

Zola (1975, in Hillier 1986: 175) and Foucault (1973) have argued that medical institutions function as agents of social control whilst Hillier points out that 'despite medicine's acknowledged contribution to public welfare it can be dangerous to life, liberty and happiness' (1986 :175, Illich 1975). This process, which Hillier (1986) refers to as the 'medicalisation of human affairs', encourages the application of medical practice and principles to the social setting. By defining the expression of normative values for behaviour, physical function, feelings, thoughts and perhaps even aesthetics⁴ (Gill 1989,

³ However, one should remember a cautionary maxim that states 'you do not create a choir with soloists alone!'

⁴ One only has to look at the anatomical charts to see classical proportions presented as ideal body types. Not only did Western medicine inherit the Greek medical system (Turner

Turner 1987 and Featherstone 1982) as the medically inspired healthy body, those individuals identified (through surveillance) as not conforming to this criteria risk being treated as deviant (Scambler 1986, Featherstone 1982, Freidson 1970 and Goffman 1963). However, it is not just those who visit the doctors' surgeries with organic and or social problems who are likely to be labelled deviant. Parents of a brain injured child may, by questioning medical provisions, be labelled deviant by the supervising doctor. Many families with whom I have personally worked recall seeing notes attached to their medical records identifying them as belligerent or troublesome, as Philip's mother recounted her experiences with doctors when attempting to secure information and treatment for her 22 month old boy following a drowning accident.

(Philip)

I know I'm down on a lot of people's lists as being that awful woman.

But it is not just that parents may be labelled troublesome. Worse, is their feeling of disempowerment, their inability to effectively negotiate on their child's behalf with the medical profession. The mother with two disabled children recalls

(Fiona & Tony)

There is a time when you sit there and they (doctors) say, you're very lucky that your child has got this far and there is not much more we can do. And there comes a time when even you, because you are going through this trauma, actually think, are we mad? Why are we still pushing? You need to go home have some rest and then start again. So it is a great body (medicine) that you are up against and fighting, and unfortunately for most people, they

1987: 20) it also adopted their aestheticism, their celebration of an ideal, healthy, body which was "a moral as well as an aesthetic experience" (Gill 1989: 27).

are stronger because you are brought up to be in awe of the medical profession. They do save lives, they can blind you with science, they can actually make you feel that it is not your child, its the condition, that the child doesn't have a personality, the family doesn't have a personality, all this is the condition.

'All this is the condition' - what condition? By ascribing both the child's disablement and the parent's trauma of coping with it as legitimate clinical dysfunction, 'the condition', medical practice sets out to supervise not only the child's treatment but also the ways in which parents attempt to deal with it (Voysey 1975). However, as I have shown in Chapter 3, brain injury presents some rather unique problems for medicine and its ameliorative processes, particularly with regard to treatment efficacy. As a result medicine offers clinical wisdom as a guide to the social consequences of disablement so as to legitimise its own medical role in the social situation of the family. Its inability to ameliorate brain injury is threatening to its professional competence, and it is therefore through the imposition of other kinds of medical control that legitimacy is re-established. The following is another account from Philip's mother.

(Philip)

And this professor came in and said. 'Well Mr and Mrs Jones we've done the scan', and my husband said. 'Well before you start I don't want no beating around the bush, you know what is wrong with him and what is happening'. He said 'OK we'll be honest. I would put him in a home, you forget about him and have another baby', he said. 'Because he will never do anything'. He said with the extent of Philip's brain damage he will be no more than a cabbage, he'll never do anything because it's (brain injury) too severe.

The result of this conversation was to encourage this family to seek an alternative approach to that offered by doctors which led them to the Kerland Foundation. Philip is now 12 years old and has made some progress and is showing interest in people and his surroundings. The family recently had another child.

Such statements are, surprisingly, not uncommon. The problems of the child's injury tend often not to be addressed directly by medicine. Instead the social sphere in which the child is dependent may become the focus of clinical concern. The following is, once again, a statement from Philip's mother which typifies this adjustment in the clinical gaze from injured child to familial distress.

(Philip)

That's right, keep him quiet, don't disrupt your life too much you've got to get on with it. Because that's what we found with everybody, they were more concerned about me and John, all they kept saying was, 'how are you and John getting on', you know? 'Are you two all right'? And I would say, yeah we're fine. But they would (always) seem more interested in us.....

In fact, doctors are often more eager to discuss the parents' well-being than those features which are likely to affect the child's development.

There are, however, few professionals eager to inform the parents that something may be wrong with their child if the problem is believed to have resulted from some trauma at birth. In such cases most appear to play the 'waiting game' which allows parents the opportunity of self discovery, to come to terms with the child's problems over an extended period of time. Unfortunately, such tactics often increase parental anxiety, since many mothers

are especially sensitive to their child's behaviour, even if it is their first child. Some mothers have experienced health visitors and other professionals calling at the home, examining their child and leaving without mentioning that something could be wrong with the baby's development. The following statement expresses well this anxiety. (For a more detailed review of Cindy's condition see the first case study in Chapter 8)

(Cindy)

Surely as a trained person he could have seen that (spasticity), and if he had seen it and thought there was a problem, he should have said (something) shouldn't he?

Another mother recalls her disappointment and puzzlement at the lack of information relating to her son's condition (cerebral palsy) when she states

(Tom)

They wouldn't actually tell us if anything was wrong with him. We had a physio coming for a couple of months before they gave us a diagnosis. She came when Tom was five months old, and she knew, she knew exactly what was wrong with him but she wasn't allowed to tell us.

What these statements identify is the resistance by doctors to inform parents about the possibility of disability. Indeed, it has been suggested that until quite recently, the mean age for diagnosis of cerebral palsy was four years. At this age positional deformity⁵ is often quite evident due to the deleterious effects of immobility (Brown & Pulford 1984: 739) The interesting point is, why should medical practitioners be so reluctant to make

⁵ This may result from the continuation of spastic muscle tension distorting, over time, the child's limbs or body, or due to the effects of unsuitable posture and the lack of mobility.

an early diagnosis, given that medicine functions, in part, as a method of surveillance, to identify deviance (illness and disease) and to regulate it? Why, then, do many medical practitioners appear to be so slow to diagnose children who have suffered brain injury?

There are several explanations for this. The first involves the possibility that doctors may be reluctant to make a diagnosis as it involves labelling the child abnormal. Whilst I am certain that many practitioners are uncomfortable with this labelling rhetoric, the data does not seem to support such a consideration. An analysis of the families' accounts identifies no such medical sensitivity to labelling an injured child abnormal, though this, of course, is not expressed directly as 'severe brain damage'. An 'inability to lead a normal life' is often the preferred statement.

The second explanation for such a discrepancy is that practitioners are reluctant to diagnose disability because they fear it may be positively correlated with their (the medical profession) inability to do something about it. As noted (see 2) doctors view the body as a type of machine, with illness and disease regarded as malfunctions of this mechanical system. The purpose of medical practice is to observe the body, identify the causal processes of dysfunction (pathology) and administer treatment. As I shall demonstrate later, brain injury tends to respond at best poorly to such clinical treatments. Indeed, it may only be able to address symptoms of brain injury, such as epilepsy and spasticity, by further reducing the child's personal functioning and experiences through inhibiting drugs or short lived surgical procedures. The latter is sometimes appropriately termed the 'birthday syndrome' (Patrick 1989)

as surgery may typically need to be carried out annually. Such techniques invariably act both to restrict the essential contact that the child 'naturally' requires with his or her family and immediate environment, and rarely confer any long term therapeutic benefit⁶. A third reason may be found in parental unwillingness to accept negative information. For example, Karen's mother is a health visitor as well as a parent of a brain injured child and when we were discussing the problem of obtaining a diagnosis she mentioned that she had personally found it very difficult to inform some parents that she suspected that their child had a developmental problem. This was due, in the main, to the difficulty of getting the parents to accept the possibility that their child might have a problem. This is particularly interesting for in my own discussion with parents I found them very eager and willing to identify any specific problems their child may be experiencing. However, the families I saw in the Kerland had made a leap to alternative therapy because they had suspected a problem, sought diagnosis and needed to do something about it. It may, therefore, be likely that those families who find it more difficult to accept a developmental problem prefer not to engage in alternative therapies. This might suggest that those families who prefer to ignore, for whatever reason, the possibility that their child may have a problem do not seek alternative treatment as doing this would confirm that which they do not wish to accept.

It can be seen, then, that medical procedures fail to cure the child and in so doing seriously undermine clinical competencies. It is little wonder that

⁶ The lack of clinical efficacy in ameliorating brain injury is attested to by the many families who attend alternative therapy centres.

passive management regimens (as noted in the family statements above) often structure the parents' encounters with doctors.

Resources are often a further factor affecting diagnosis and other medical decisions, and parents are usually more than capable of identifying when economic considerations underpin medical objectives. As Karen's mother recalled

(Karen)

Yes, if they diagnose then they have got to provide money and once the professional says "Oh there is something wrong", that's it. And it will be worse when they go into the 'Trusts' system because there will be less money to help decide what to do.

Using pharmacological agents to manage patients' symptoms not only conforms to an ideological correct way of practice which involves a reliance on science and technology⁷, but it avoids giving priority to that most expensive of resources to place, human contact⁸. There is likely to be no substitute for the labour intensive approaches which demand that considerable opportunities are given to the injured child and his or her helpers to interact in a structured way over extended periods of time. This is unlikely to find favour with the economic managers of the regional health trusts.

However, it is not solely the economics of such considerations that is problematic, but also the fact that this approach, adopted by many alternative centres, requires that the child and his or her development is considered as

⁷ See Illich, I (1975) for an excellent critique on medicine and its reliance on technology.

⁸ A discussion into the political economy of health care is beyond the scope of this thesis. However for an interesting introduction into health care politics see Patrick, D. (1986).

involving a meaningful continuum of attention and appropriate experience. 'The nervous system is responsive to what is happening all of the time and not just during short intensive stimulation called therapy' (Levitt 1982: 17). Thus contact with the child, in a stimulating environment that provides ample opportunities for the child to experiment and practice behaviours that utilise physical, perceptual, social and cognitive functions is essential, but difficult and deeply involving for parents and carers. Indeed, it is often claimed that, precisely because this treatment creates such familial pressures to care for their child, doctors advocate pharmacological control as the best prescription for the family.

The family is, of course, very important and their needs require careful consideration, but so too is the child. What rights does the child have? Indeed, are these rights inalienable to all children, irrespective of disability, or do they require that the child should firstly function in ways appropriate to the services already provided by the state? Is it not possible that many state provided services institutionalise a process which serves to discriminate against the injured body, so much so as to constitute a rationale for 'disablism' (Abberley 1987)? Because many brain injured children rarely develop in the ordered ways that state provisions typically support. This frustration is expressed by one mother outlining the educational needs of her daughter.

(Karen)

They have to provide special education, which they really need before the age of five, but they're not statutory (sic) obliged to provide it until they're five, well these children need it much sooner.

It appears, then, that not only does medicine defer a diagnosis and the subsequent entitlement to treatment but education, too, is reluctant to initiate a programme of pre-schooling to help combat some of the deleterious affects of brain injury that may act to isolate the child. This, as we shall discuss in chapter 5, is very often in contrast to the ideology of the alternative centre which assesses the child's development and subsequently designs a programme of therapy that provides staged input for the child and a daily routine of involvement for the carers. Despite doctors fear of over involvement of the parents this routine seems to play an important part in families subscribing to an alternative centre such as the Kerland. As Philip's mother explains

(Philip)

Oh he was well even now if I showed you photographs, well we've got the video when we left the hospital. His spine was curving because I was just holding him to get him comfortable in one position all the time. His feet had dropped and this hand here was in his neck like this, twisted. To pull it down, well he just wouldn't let you, it was stiff and too painful. His shoulder was sticking right out and I don't think that would have gone back all right without the exercises. And things like his personality, not just the physical side but I think the Kerland has helped him socially as well because he meets so many people.

Interviewer: *Your home is now your place of work then?*

Mother: *Yes, which is nice because you're working at home you can have a cup of tea when you like so I would rather be doing this than out nine*

to five in an office. So its my job, my job is being with Philip, doing what I'm doing.

It seems clear that economic restructuring is required to make such provisions available. However, there are few incentives. Special education teachers and other resources receive a similar treatment as do those who work with geriatrics, psychiatry and community medicine, i.e. they are given low priorities. Hillier (1986: 177) has argued that such specialities are regarded as low status by the profession generally, and subsequently often deprived of resources. This, once again, points to the social construction of brain injured children, a construction which seems dependent upon ideal types of 'natural' children decided, in the large part, by medical perception. Such a definition, concerned as it is with clinical conditions, inadvertently functions to establish the brain injured child as an imperfect construction by default. This process suspends the diversities of childhood that are being discerned through sociology and anthropology (Qvortrup et al 1994) in favour of a medical reductionism that locates clinical pathology as the main focus of expression. The child is now no more than an observational process within a clinical discipline, and, as such, the brain injured child is reconstructed by medical power to be no more than the sum of the pathologies he or she presents.

(Tom)

We had an orthopaedic consultant, and there wasn't any way to describe him. He treated Tom like a slab of meat, he manipulated his foot and hurt him and didn't talk to him, didn't treat him like a child.

The alternative approach differs radically from this in its definition of the brain injured child. Whereas medical practice discerns the overt pathology presented in the child, the alternative practitioner is more concerned to discover those behaviours that remain relatively unaffected, so that new patterns of expression can be assimilated from present abilities. The issue is not so much one of economics but of commitment which, as we shall see in chapter 5, involves an entirely different construction of the brain injured child from that inspired by medical practice. However, in order to explore, more fully, the medical metaphors that express the brain injured child, and the clinical decisions that result from such professional discourses, we need to locate disabled children in both the larger category of childhood within which they are typically expected to exist and function and within the 'gaze' of medical speculation.

Doctoring the Score

In the second chapter I showed the influence the medical profession exerts over the embodiment of brain injured children. At first sight this seems appropriate since brain injured children are by definition injured and therefore require the attention of medical practitioners. However this assumption, although prevalent, may nevertheless be an erroneous one. As noted, many children who have suffered a brain injury have a non-progressive form of lesion, and although they may present with epileptic seizures, spasticity and developmental problems their general health may be quite good. They thus warrant *little* medical intervention. Often, however, parents with a disabled

child receive a great deal of attention from doctors even though their child's condition may not require long term and continued medication. The reason for this is twofold. Firstly, parents have little recourse to detailed information concerning their child's problems other than that given by the medical profession⁹. As Tony and Fiona's father noted

(Fiona and Tony)

You know most of us don't bring our children to places like the Kerland until they are, perhaps 2, 3 or 4 years old because we don't know about them, we only find out by chance.

Secondly, because brain injury implies illness, a term which we will see is laden with moral judgements and accountability, it creates an access for medicine to develop.... 'a potential for moralising and social control' (Zola 1972: 492). Indeed, as Freidson argues in his now classic account:

The medical profession has first claim to jurisdiction over the label of illness and *anything* to which it may be attached, irrespective of its capacity to deal with it effectively (cited in Zola 1972: 492).

Medicine has not merely attached itself to the illness phenomenon but with such involvements it has also legitimised its engagement with procedures that attempt to professionally manage the very process of living (Illich 1975) by what Zola (1972: 492) has referred to as 'The Medicalising of Society'. Here Zola identifies an 'attaching' process which consists of four concrete objectives. The first involves establishing social compliance to aid good

⁹ Although this is changing with many charity based organisations offering a wide range of information such charities are, however, often viewed sceptically by doctors which acts to reduce the legitimacy of such organisations.

medical practice. Physicians change the behaviours and habits of their patients in an attempt to negate the believed aetiological factors of a given disease process. But deterring individuals from engaging in potentially harmful practices necessitates a professional scrutiny, not only of their bodies 'but also the symptoms of daily living' (1972: 493). Secondly, physicians have sole jurisdiction over certain technical procedures. When one considers the social consequences of abortion, major organ transplantation and cosmetic surgery, all of which are the exclusive practice of medicine, it becomes almost impossible to detach the individuals who yield such technical power, invested in medical procedures, from those issues that are primarily concerned with social policy, requiring a different set of competencies from those obtained in clinical practice. Thirdly, medicine has almost absolute access to the most private and intimate possessions of individuals, their bodies and minds. For Zola, these normally 'taboo' areas are the very territories in which illness is located. Once diagnosed the problem becomes, by its very nature, a medical one. Zola argues that whereas once ageing and pregnancy were considered as natural processes, they are now so enveloped in clinical supervision that specialist physicians have transformed these natural events of the life cycle into technologies of medicine (1972: 495 - see also Graham & Oakley 1986). Furthermore, in America declaring alcoholism and drug addiction as diseases serves to constitutionally affect the status of many so labelled individuals. 'Offenders' are, in such situations, far more likely to be the responsibility of institutions supervised by physicians rather than penal reformers. The power medical rhetoric exerts in social discourses can not be overstated.

Today the prestige of any proposal is immensely enhanced, if not justified, when it is expressed in the idiom of medical science, (Attributed to Wootton, cited in Zola 1972: 496).

Medicine, then, has insidiously expanded its expertise into almost every sphere of society with many social issues given over to comments from medical specialists. Furthermore, the language of the physician is continually engaging moral metaphors (Sontag 1978) to explain societal misfortune, an unhealthy economy, a diseased state or a cancer in the community. Such medicalising terms serve to identify social and economic dysfunction or pathology equally as well as their ability to label organic disease. Zola (1972) and Illich (1975) are rightly concerned that such processes that '*medicalise*' social issues remove these very issues from a wider public enquiry and debate. Social policy becomes engendered with technical considerations best suited to the expertise of the medical professional, and disempowers the individual by transferring concerns for public debate to the scientific stadium of modern medicine. This is in contrast to the alternative centre. Although practitioners here too have a specialised skill and knowledge, the language in which it is expressed and the therapies undertaken tend to be less technological and more readily understood by those who subscribe to them.

However, the fact that illness, both clinical and apparently social, is a target for the aspirations of medicine must not prevent us from questioning the validity of those assumptions that accommodate 'good' health into the same medicalising schemata. That a person's health may well be compromised through contact with medicine has been outlined by Illich (1975) who used the

term 'iatrogenesis' to describe the pathologies, once again both clinical and social, that result from the activities of physicians. This regulatory conquest of medicine over nearly all aspects of the living process could have only been made possible with the tacit approval and support of the political authorities. Since both people's illness and health have consequences for a country's economic system, clinical diagnosis does not, in Illich's view, merely attempt to objectify biological pathology it also monitors financial loss and unprofitability. In this way 'health' becomes associated with profit, whilst illness represents underproduction of the Nation's capital. This reiteration of economics, through medical metaphors, acts to further fix a scientific rationale, although a borrowed one at that, to the prevailing capital needs of the state. Indeed, Marxist writers have proposed that capitalism influences the way medicine formulates the process of disease by attaching individual culpability for illness. For example,

tuberculosis..... was regarded as a 'constitutional weakness' rather than something which resulted from poverty and poor living conditions. Today, diseases like heart disease and lung cancer are seen as problems of *individual* lifestyle (Hillier 1986: 182).

One thing however is clear, the role medicine plays in politicising the body is not solely for the person's health but also for the nation's wealth.

The History of Political Doctoring

Medicine, however, has not always enjoyed the support of the governmental authorities. Radical change in the needs of economic production had, by the early 1800s, forced a closer alliance with medicine

(Smith 1990). The early days, though, were fraught with official and legislative conflicts for all those who aspired to professionalise and unite the medical community. By 1842 Edwin Chadwick, following the political economists' tradition of Sir William Petty, calculated the economic value of man in order to coerce the political authorities to invest in an adequate health service (Smith 1990: 420). Furthermore, changes brought about by industrialisation required not only a work force but a productive and 'healthy' one at that. People were now being calculated as unit investments of capital production. Dr Farr's *'Vital Statistics'* estimated the worth of a Norfolk agricultural labourer's life to the state in the mid 1800s as being £5 at birth and £1 at seventy years, peaking at £246 at twenty five years old when most productive. Indeed, if he should survive to some eighty years old, his equity would be negative to the sum of £41 (Smith 1990: 420).

At this time, young children, especially those under two years old, had little economic value to the state, which most certainly was reflected in low health provision. Britain was slow to introduce hospitals for children and it was only in 1853 that the now famous 'Great Ormond Street Hospital' opened up for the admission of children. However, even here children under the age of two years were 'absolutely excluded' (Smith 1990: 152). Ironically, however, the setting up of children's hospitals nationwide did much to aggravate epidemics, as the outpatient rooms tended to be hotbeds of contagion. Although vaccination to combat smallpox had been available since the 1790s it was only really considered by the rich, as the poor apparently had 'an acceptance of the inescapability of death' (Smith 1990: 158)

Once the link between hospitals and epidemics was noted Parliament started to move into state medicine with its poorly drafted Vaccination Act of 1840. Indeed, by 1871 a fine of 25 shillings or imprisonment was to be faced by parents who would not comply with the government's infant vaccination programme (Beck 1960). By the late 1800s medicine could be seen to be emerging with a greater regulatory and monitoring influence on societal issues, as can be seen by the reaction of Anti-Vaccination League who regarded medical inspection as the augmentation of state power and an intrusion into the People's privacy (Smith 1990: 166). Thus, the family was being scrutinised and inspected by the medical orthodoxy which argued that the only effective way to improve children's health was to encourage 'indolent' and 'incompetent mothers' to develop 'total care' regimens (Smith 1990). Such practices, it was argued, would provide self respect. Thus parenthood had become the clinical gaze for the newly establishing medical profession. As Smith notes

inspection was only worth while if it remained under professional medical control, distinct from, but ancillary to, the state and state purposes. Only doctors could determine the defects in sight, hearing and physique that marked out the mentally deficient and thereby rendered them incapable of 'becoming.....normal citizens (1990: 186).

Even by the end of the eighteenth century doctors had begun to subject their patients to the physical examination. Pathology was now firmly fixed in the interior spaces of the body, and new methods of examination were devised to diagnose it (Armstrong 1983: 2). Regulations regarding hygiene sought not only to medicalise the spaces within the body, where dysfunction was to be

located, but space between bodies, i.e. social space, was also to be scrutinised. With the introduction of such procedures childhood had now come into sharp focus, as noted in Chapter 2, and by the end of the nineteenth century children and, more particularly, their diseases warranted a special interest for medicine. Moreover, the 'inventing' of childhood (that constructed children as a special category no longer considering them as mere little adults) and the accompanying diseases (more specifically, children's disabilities) were not singularly identified by medicine through scientific rationalism. As we have already seen other agendas of a social and symbolic nature (aesthetics, innocence and purity) were embedded in this enterprise. Furthermore the body, particularly that which presented overt disability, attracted not only a clinical concern from medicine but also a re-emerging belief in corporeal pollution. Physical completeness, or being without a blemish, was not only biblically praised¹⁰, representing a social semaphore for purity, but also acted as a procedural training in child management. That is to say, children must be schooled in managing their bodies' functions and secretions in order to be admitted into the structured society of the adult.

One problem with disease is that it threatens the moral management of our bodies by robbing us of voluntary control and organisation. As a result, we need the social support of a medical regimen and therapeutic intervention (Turner 1987: 85).

Perhaps nowhere is such a regimen regarded as being more pertinent than in the medical attempt to manage brain injured children. Indeed, paediatric medicine plays a central role in engaging management policies to

¹⁰ See Douglas (1966: 51).

address the symptomology of brain injury. Unfortunately, a great deal of what constitutes such a practice can also act to disable the parent's very coping strategies.

Parents and Physicians

Cummins writes, in his critique of the Doman-Delacato method¹¹ that medical professionals have the unfortunate tendency to conclude that

diagnoses vested upon very young children... have the air of the absolute. Such diagnoses are usually pessimistic about the child's potential for development and are frequently wrong. The reason for the pessimism is tied up with traditional and outmoded professional thought, that the most that can be done for brain injured children is to provide medical help and then to encourage both them and their caregivers to adjust to the handicaps. (Cummins 1988: 16-17).

That parental involvement is likely to be important in any structured habilitation programme (orthodox or alternative) tends not to be considered, and implies a serious loss of valuable resources- resources that would be essential to combat disability and not simply adjust to the handicaps. Furthermore, that such interventions should naturally focus on the family as a whole, more than just singling out the child (Bristol & Gallagher 1982) is an informed way to address the problem but, so far, seems to have merited little concern for many orthodox doctors.

However, before parents can act in any effective way it is crucial that they receive an 'informed' diagnosis based on professional understanding of the child's disorder, rather than the vague professional speculations born out of the ambiguities of developmental uncertainty which, as Chapter 2 notes, is a common experience. This is not to suggest that ambivalence in discerning

¹¹ See the Introduction and Appendage 2 for a fuller account.

behavioural evidence for brain injury leads the physician to 'label' the child with the nearest fitting syndrome (speculation) - this could and has, proven to be extremely upsetting to the parents - but to say that parents have the right to both be informed and to question the professional's underlying suspicions. If, for example, parents were more encouraged to present their accounts of their child's motor behaviour, cognitive function and general development in a more positive and sympathetic setting, as often is the case in many alternative settings, then much of the present misdiagnosis and pessimism to which Cummins (1988) alludes might well be avoided. Bristol & Schopler (1984: 128) recall one child who had received no less than twenty four different diagnoses, and their accompanying conflicting therapeutic programmes, before autism was identified. Such clinical misinterpretations of a child's problem and future prognosis are as equally negative to the family, as are the frequent professional silences that keep the parents guessing.

(Philip)

But nobody told us for nearly twelve weeks that he was brain damaged. We thought he was going to wake up and be normal. Nobody said anything, nobody mentioned brain damage, nobody mentioned the future, nobody mentioned anything at all until we went to Guy's Hospital. We said why hasn't he woke up? 'Well, he's been through a great trauma, you know'. But why doesn't he?He should be awake by now. 'Well, you know his brain is still very swollen, he's been through a traumatic time, you don't know the seriousness of it'. But no one actually said those words, brain injury or brain damage, there was no mention of that at all.

The parents of this little boy, who had tragically drowned, were allowed to assume that, because their son was alive, he would awaken and be that same little normal boy he was before the accident. But it is not just after

traumatic injury that doctors feel it unnecessary or unhelpful to inform the parents about their concerns or speculations. Even in cases involving birth injury the same procedures are often involved. As a mother with a cerebral palsied daughter relates

(Jayne)

It was quite late before we got a diagnosis, I kept taking her to the clinic and they kept on saying go away she's developed. Its a normal situation, I know, because I have been talking to other mothers. I knew there was something wrong and they kept telling me to go away, so it was about 22 months later before we got a diagnosis.

Chapter 2 suggested some of the motives for the professional's silence, but from my own research with families over the last six years it is clear that parents need information, not speculative prognoses. They want indicative diagnoses, communicated with sensitivity and genuine empathy for their parental situation. However, information is seldom given in the initial stages when an injury may be suspected. The consequences of this mismatch may lead to conflict between professional and parent. Professionals often fail to recognise the ways parents relate to the impending uncertainties concerning their child's development. In some cases this uncertainty can encourage parents to believe that they had, in part, been responsible. As one mother with a dystonic cerebral palsied 6 year old daughter informed me.

(Rachel)

I think feelings of guilt come and go. Was it anything to do with us we just don't know because they (doctors) won't say. We don't know if it was genetic or if it happened at birth or what it was. From time to time it does arise, were we to blame?

That external factors, such as the tangible severity of the disability, stress and the availability of social support are related to internal variables, parents' beliefs and attitudes towards disability and its suspected culpability, should also be recognised. It is within such variables that understanding of the full impact of their situation is encountered and it is this that affects the family's changing situation (Sewell Wight, Granger & Sameroff 1984: 52).

When we examine how intervention programs have dealt with parents, we find that there has been a fragmentation among programs that focus on parents' educational skills, attitudes and emotions,.... Each of these aspects has something to contribute to the intervention process, but each taken alone may reduce the parent's competence in other important domains (Sewell Wright, Granger & Sameroff) (1984: 52).

The effective communication between parent and professional is one of paramount importance but appears to have been given little professional attention.

(Fiona and Tony)

I mean we were told all sorts of conflicting information, in fact, conflicting information was written down on notes and caused a lot of problems when I wanted to have my second child. Because Fiona was born premature and she developed hydrocephalus after 19 days. But on a note from a doctor it said that she was born with hydrocephalus so any future children I might have would have the possibility of developing this.

Increasingly more research is concerning itself with the 'internal' and 'external' variables that structure the parents reactions to their brain injured child¹², but there has been relatively little material that accounts for parental stress in terms of the social relations, and tensions, that are developed with

¹² See Sewell Wright et al (1982 P 53-57)

doctors, although it has been well established in medical anthropology literature that communication between professionals and their patients is often considered unsatisfactory (Lauritzen & Saks 1994, McGhee 1961). The culpability for this dissatisfaction has been recognised in the failure of the professional to attend to the social and psychological requirement of patients (Radley 1993, and Cartwright 1964). Korsch et al (1969) have, more specifically, concentrated on the communications between hospital doctors and mothers with an ill child. Indeed, as Locker's (1986) review confirms

a fifth of the mothers reported that they had not been given a clear statement of what was wrong with the child and half had not been told what had caused their child's illness. In analysing tapes of the consultations it became clear that the doctors did little to encourage mothers to take an active role in the interview and few paid attention to what worried the mothers about her child's health (Locker 1986: 99).

It has been suggested that professional attitudes, interviewing styles, patient diffidence, differing cognitive styles and patient/doctor perspectives (Locker 1986 p 99-103) all contribute to communication failures. It is also possible that informing families in a clear and understandable way gives knowledge to parents which might well compromise the authority of doctors. In such cases speculations concerning the child's condition may be framed in technical terms suitable for a specialised audience so that the parents are excluded from the discussion. The following account from Cindy's mother exemplifies this.

(Cindy)

We were sat on the bed and a consultant came in and started talking to all his trainees, and he just chatted about Cindy to them and he didn't include me in his conversation. I stood up and said, 'excuse me, I am here do you

think I could be included'. Could you tell me what you are telling them'? He just completely ignored me.

Although there can indeed be little doubt that such neglect is involved in patient/doctor relations there are, as I have indicated in the previous chapters, also other agendas operating here. Embedded in the very centre of these medical communication problems, that all too often fail to facilitate the exchange of information between patient and doctor, are the insidious, and frequently ambiguous, prescriptions for regulation and control (Foucault 1971, 1973, Armstrong 1983 and Turner 1987, 1992). It may be due to the very fact that doctors 'control' their interactions with patients, and make their invested medical authority so conspicuous to the families, that so many fail to register their dissatisfaction with the professionals concerned.

However, Turner (1987, 1992) et al, have simply aligned theories of control, which they argue are ever present in the operations of the professional, to that socio-biological entity, the body. As we have seen in chapter 2, doctors have an invested authority over this entity. Their control is derived from the attempt to manipulate both individuals and populations through regulating practices which assert their influence directly upon the physical operations of the body. Such propositions basically align themselves to the Weberian interest in medicalisation as a method of control. Brian Turner, reiterating the *bio-politics* central to modern systems of power (Foucault 1973) also locates medicine at the heart of this endeavour (1992: 10). That such mechanisms of control should be directed upon the body, to induce both change and greater regulation, is not surprising given the increasing '*capitalistic*' motives of state

(Foucault. 1979). However, if the rationale for this endeavour is to manufacture productive, disciplined and docile bodies that benefit the state enterprise, then where are we to locate the disabled bodies of injured children? They are perhaps found in the miscellany of disciplines that have evolved to submerge the individual and collective potentials of childhood.

Muting Soloists

In their book "The European Family" Mitterauer and Sieder (1977) argue that socialising or, more importantly in this study, controlling children has undergone various historical changes. Not only are these changes represented by economic and demographic operations but also, more interestingly, by changes affecting familial responsibilities and practices. This trend has been most visible in the transition of society from organisation based around domestic production, to meet the family's needs, to the larger industrial production that better serves the state. Where once the child acquired its identity directly from the its interpersonal affiliations and immediate contact with, and regulation by, the family and their occupations, institutions have evolved to replace this traditional role.

The domestic group and its neighbourhood no longer form a relatively autonomous society in which all types of behaviour patterns and ideas are to be found. Even the so-called 'private sphere' of people is interwoven with structures of economy and administration, with politics and commerce. The primary group of the family no longer determines the socialisation of the young to the same extent as before (Mitterauer & Sieder 1977: 94).

These practices have contributed, to some degree at least, to the alienation of childhood, particularly adolescence, from the domestic group

(family) into extra-familial institutions (Mitterauer & Sieder 1977) such as nurseries, schools and clubs. As we have already seen, the establishment of hospitals for children took over the responsibility for ill children from their parents in the same way that education and other disciplinary institutions are determining, more and more, the upbringing of children in systems other than those developed by the family. The net result of these state enforced child regulatory facilities has reduced the active role parents play in helping to determine their child's mode of development, and with such practices in operation the right of parents, especially those who have disabled children, are likely to have been further eroded. Moreover, it is not just the parents who are effected by these procedures of professional control; their children too are often enveloped by these very same mechanisms of regulation. Parents may, in such cases, interpret this underlying professional's authoritative conduct as a failure to understand their experiences, i.e. clinical 'coldness'. As Philip's mother recalls

(Philip)

I mean doctors are cold, aren't they? I think they are, generally speaking. You know they enter that profession because they care about people, well, they have certainly got a funny way of showing it.

Such perceptions are not uncommon, as many parents with a disabled child have expressed a similar concern. As we saw earlier in Zola's (1972) discussion, the physician's medicalising knowledge transforms language from one of social communication to that of scientific rhetoric. In this transformation, the underlying personal expressions that naturally punctuate

social discourse are likely to be lost or misinterpreted. It is therefore possible that parents feel a coldness in their engagement with professionals or, at the very least, an unwillingness to identify and address their child's problems. As the father of two brain injured children stated

(Fiona and Tony)

one hell of a lot of medical problems, or potential medical problems, would resolve themselves if the medical profession did nothing. And that seems to be the first line of treatment, 'well, lets do nothing' and see if there is still a problem in six months time.

The point I wish to make is that although the power invested in doctors may not be perceived by parents in terms of Foucault's regulatory influence or Weber's *medicalisation*, its effects are, nevertheless, recognised. They are expressed in terms of a more personal individual level as a coldness or reluctance to relate to their trauma. As a direct result of their experience with professionals, with whom they are legally obliged to negotiate treatment and care, parents and their disabled children may become increasingly isolated. Since the family's very future seems dependent upon addressing their child's needs with regular hospital visits and other forms of medical compliance, which can only be achieved through professional contact, disempowerment will most likely prevail as the common experience. And it is within this helpless environment that the brain injured child is expected to be nurtured.

Parents are often only too aware that many doctors are simply going through the motions, that those medicalising procedures which they initially experience are not the attempts of professionals to address the condition,

sometimes not even the symptomology. They understand that they relate more to a theatrical production of medical practice:

(Fiona and Tony)

And then we went through a stage where we said, 'we're not really happy with what you're doing'. Then they made an effort to do some more tests its almost like they knew they weren't going to achieve anything but they went through the motions for our benefit so that at the end of the day if we made any complaints they would say, 'oh we've done everything we possibly can'.

When a family encounters these ambiguous sentiments that seem to run, at the very least, counter to that which they typically expect from the professionals, they may seek an explanation for this discontinuity in their own behaviour.

(Jayne)

I think Pete thinks to himself whether it is his fault that she is like she is because you don't know, and I think what did I do when I was pregnant, is it my fault? That's why its important for parents to know what's going on so that they can be assured that it's not their fault.

The conclusions they now draw upon become internalised as the helplessness of their situation becomes increasingly evident and guilt, anger and frustration, together with a lack of faith with the provided services, underscores their interactions with professionals. Rachel's mother describes the uncertainty and guilt that a family may now experience.

(Rachel)

Mother: *When you start analysing why she is as she is I think the feeling of guilt does come up. We still wonder because we don't know what cause it. You know, its not like knowing it was a lack of oxygen or something to do with the hospital. When you don't know the cause you wonder was it something to do with us.*

Interviewer: Did you receive any advice about this?

Mother: *We had genetic counselling, but because they can't pin it down to anything they wonder if it is genetic. But I wouldn't say that really helped, I mean we were just told what the risk factor was for a family who had a C.P. child having another. I didn't feel it helped in any way, I didn't feel they helped..*

The notion that disparities exist between the experience of parents and those of the professionals has been investigated by Blackard & Barsh (1982)¹³ who suggest that professionals exaggerate the impact of a disabled child on a family's functioning whilst minimising the ability of that family to manage the accompanying problems. But this can only happen once a diagnosis has been provided. The issue I am addressing here is that of the isolation parents encounter before such statements have been finalised. Indeed, it is within this suspended marginality of clinical uncertainty and familial anguish that communication first begins to break down. However, the fact that parents and professionals rarely, if ever, share a common clinical

¹³ see Kaiser & Hayden (1984) for a good review.

knowledge or personal experience may further contribute to communication failure.

Moreover, it is not just failures in communication that may prove detrimental to the child's development. Information that is not factual¹⁴, due to poor assessment and diagnosis, will equally incite conflict between parents and professionals. An example of this can be found in the work by Strauss et al (1982)¹⁵ who reassessed the visual impairments of severely disabled children.

(They), ... experimented with several new methodologies for assessing visual acuity in severely handicapped infants. Their research uncovered the startling fact that many infant previously diagnosed as blind, (using traditional methodologies) were, in fact, able to see". "... One wonders what changes in care giving patterns and intervention approaches might result from such a marked shift in assessment results and how much damage may have been done through the care givers believing that these infants were blind (Kaiser & Hayden 1984: 296).

Believing in professional statements is something that tends to come naturally to parents when a trauma has threatened their child's future potential. If the language used contains negative sentiments, which sadly is often the case, such as *'he'll never walk'*, *'you know she won't ever speak'* or *'its best that you stick him in a home and get on with your own life'*¹⁶, then these statements can and do affect the parent's interpretation of their child's behaviour. Thus opportunities may be lost to both child and parent, simply because they are

¹⁴ It is beyond the scope of this thesis to speculate about the 'scientific method' other than to say there are many critics of it. Feyerabend argues that 'non-scientific' procedures can not be pushed aside by argument. To say: the procedure you used is non-scientific, therefore we cannot trust your results assumes that science is successful because it uses uniform procedures.... (this) is not true.... there are lots of failures also (1988: 2). Science, for Feyerabend 'should be taught as one view among many and not as the one and only road to truth and reality' (1990: viii). Indeed, it is this fallibility of scientific medicine that kindles parental interest in the alternative method which, generally speaking, communicates its intentions in ways that are more understandable to the family

¹⁵ In Kaiser & Hayden (1994)

¹⁶ Statements reported from families with a brain injured child.

following professional but also, perhaps 'misguided', advice. The consequences can be far reaching, not only directly for child's development. Negative information giving by doctors concerning infants can interfere with the parent/infant bonds of attachment, which can further exacerbate development. One of the dimensions of this phenomenon has been identified as 'anticipatory grief' (Kaplan & Mason 1960), which describes the ways in which a parent might deliberately withhold feelings of attachment in anticipation of the infant's death (Kaiser & Hayden, 1984: 294). Moreover, a study by Clyman, Sniderman, Ballard & Roth (1979) reported that physicians commonly underestimate an ill infant's chances of survival, even though they may have knowledge of statistics that indicate that the contrary is in fact likely. In such cases, with the emotional ties that help ensure a positive environment broken, the infant's potential is likely to be further muted, not solely now because of the effects of an actual pathology in the child but more probably from a disorder involving the attachment that exists between child and parent.

However, in reality more brain injured children survive into adulthood than was the case in the past (Logigian 1989). Consequently, the phenomenon of "*anticipatory grief*" is, for many parents, frequently displaced by an irrepressible personal responsibility for their child's continual welfare. This is often realised through developing strategies (sometimes commitment to alternative therapies) that promote or encourage the child's development. For example, Sarah's mother works as a teacher of mentally disabled children her own account shows her adjustment to the fact that her daughter was developmentally delayed.

(Sarah)

I think, initially, when she was first born it was a bit of a trauma, realising that she is handicapped and personally it felt a bit of a burden. But once you realise and come to terms with the fact that she is never going to leave the home so that anything you can do to help you and her enjoy life to the best of her ability is a bonus.

In such ways grief can be submerged by ameliorative action that works for a better future for both child and parent.

Re-scoring the Accompaniment.

We have seen above some of the problems that arise from families' encounters with doctors. Although early diagnosis presents many difficulties for the paediatrician nevertheless for parents the amount of accurate clinical assessment they receive often remains totally unsatisfactory. The general trend, then, amongst many physicians, seems firstly to involve denial. Secondly, when the child's problems become significantly conspicuous, doctors may estimate the familial efficacy of parent's coping with their child's problem differently from those estimates the family themselves might use (Clyman et al. 1979). The phenomenal rise in alternative ameliorative therapies, then, may be related to the largely negative and pessimistic perceptions that physicians hold regarding brain injured children and their future.

(Cindy)

I have friends that I speak to who have children with disabilities and one friend was told, 'your son's a cabbage he'll never do anything' (see Philip's account earlier in this chapter where a similar point is made)

However, with parental dissatisfaction for the role of clinical medicine comes the transference of responsibility from doctor to parent to do the best for the injured child. It is usually at this point that parents begin to actively search for alternative approaches to orthodox medicine. Some parents, then, will recognise the unsatisfactory nature of this situation and attempt to redress the problems by seeking out other forms of treatment. The following outlines the events that led Cindy's mother to go to the Kerland Clinic.

(Cindy)

Interviewer: Was it that they didn't know what was wrong with Cindy or was it that they didn't want to tell you what was wrong?

Mother: *I think it was a bit of both, also we saw so many different people. Every time she was in hospital, every time I went down the shift had just changed and we saw different nurses. Doctors wouldn't talk to us they would completely ignore me so I thought right, I don't want anyone else looking at her, I'll be funny, you can go and train on somebody else.*

Interviewer: So there was no continuity and little information?

Mother: *There was no continuity, I go down every six months or whenever and I wonder why, because it seems to be a complete waste of time they ask have you got any problems I say no and that's basically it. That was another reason why we decided to do Kerland exercises, we thought we would*

do something instead of being left on a list. I mean I never really felt they were doing anything, its hard to explain really and they never actually spoke to Cindy either.

Many alternative approaches, as we will see in the next chapter, involve direct familial participation but this in itself brings with it new levels of responsibility, sometimes even guilt and fear of failure. The comment below from a mother of a 8 year old girl who was born with chromosomal disorder demonstrates this point well.

(Karen)

I wanted to spend all my time stimulating her or doing something with her. Its horrendous, you can't relax because you feel guilty all the time. You know, I said to the paediatrician, the biggest thing that a parent wants is to be doing something, if you're not doing something you feel guilty. So it relieves you of the guilt whilst doing the best for your child.

Whether or not adopting an alternative posture in therapy is, as this mother confidently states, best for the child will be explored in greater detail later. At this point it is my intention to show only the frustration and dissatisfaction that often accompanies orthodox procedures and the relief they may gain from alternative procedures.

In undertaking a programme of alternative therapy parents are empowered, or at the very least feel that the passivity they experienced during their encounters with the orthodoxy is largely dissipated. Many parents feel that alternative approaches provide new windows of opportunities that simply did not exist in orthodox medicine, for example finding the "child" within the

mal-functioning body. Thus, although participating directly in their child's therapy can place many new demands upon the family, it can also prove therapeutic for both parents and child alike, particularly in the adjustment period when parents are attempting to come to terms with the reality of their situation¹⁷.

(Sarah)

When I didn't know anything, before I went to the clinic (alternative centre), I didn't have anything to aim for, then all of a sudden you realise there is something I can do.

Moreover, from my own experience of the alternative settings of therapy, the professionals who work on the fringe of orthodox medicine are more likely to address the underlying psychological and social needs of parents as well as patients, as a mother recalls when she first visited the Kerland Clinic with her genetically disabled daughter. Sarah had been born underweight with a heart murmur that required surgery.

(Sarah)

I think that one of the positive things was, that we were so 'down' with Sarah, ... what we really got out of the clinic, (alternative child development centre) that first visit was that it boosted us so much that somebody thought that something could be done with our little girl. That was the thing, it was a tremendous boost.

The positive advantage of a low stress non-clinical setting can also help in the two way exchange of information, so parents feel more comfortable

¹⁷ For a good review of the literature concerning familial adjustment and acceptance of infant disability see, Blacher, J. (1984)

in communicating observations of their child's behaviour and concerns for his or her future potential.

(Karen)

It was also the enthusiasm of everybody down there, (alternative therapy centre) instead of wanting us to shove her up in the corner and get on with our lives, somebody actually took us seriously.

Even with such obvious benefits provided by alternative centres it is necessary to point out that unorthodox therapeutic regimes have attracted a great deal of criticism (Cohen et al 1970, Charlton 1973, Chapanis 1981 and Cummins 1988), in some cases deservedly so. Many of these criticisms argue that there is a lack of 'scientific method' in their approach while others align themselves to the level of unreasonable demands that may be placed upon families that are already traumatised by infant disability. However, one feature of many alternative procedures, irrespective of their level of clinical efficacy, is the sense of optimism they create as well as providing increased access for familial commitment to a given habilitation programme. These changes in the behaviour of parents, which promoted optimism and a willingness to get involved with their child's habilitation, were viewed positively in a governmental report for the education of handicapped children (Warnock Report 1978). This report recommended the direct involvement of parents in their child's amelioration programme.

Why, then, are doctors generally so sceptical of parental involvements? Illich (1975) and Cummins (1988) have argued that doctors' over reliance on technology has reduced their role to that of a technician. Thus the social and

psychological comfort they once had to provide, in favour of effective medication, has been replaced by pharmacological wizardry. With this shift from 'caring' to 'curing' technological procedures are seen as scientifically validated, and thus those procedures that do not rely upon technology are viewed with scepticism. Unfortunately for brain injured children, many of their disabilities are not responsive to drugs which are, after all, the main armament of modern medicine's control over the body. Thus parental 'needs' and doctor's 'ideologies' become incommensurate with one another. As it was shown earlier, drugs may manage the symptomology of brain injury but may fail to address the underlying aetiology.

This is not, however, to argue that the alternative therapies have found the key to neural dysfunction, although many alternative centres do promote motor competence and other functional attainments which directly influences the child's level of functional behaviour. This contrasts with the orthodox medical regime which, in many cases of non-progressive brain injury, acts to pharmacologically suppress behaviour. Thus a 'drugged' compliance with medical management protocols is viewed more favourably by doctors than the active routines of physical therapy that are engaged by many alternative practitioners. In this way, for the alternative therapist, the disabled child's problems are reconsidered. Within this approach, what the child cannot do seems no longer a gauge to assessment. Instead the focus falls upon what the child can or may achieve if given the right encouragement. With this, a new optimism is installed into the family's daily routines that parents feel helps nurture a more stimulating and structured environment for the child.

(Sarah)

I can't prove whether it was or wasn't what the programme (therapy) did that made Sarah as she is (improvement in motility and awareness). But what it did do, was to give us an impetus to actually do something with her and to have somebody to say, 'yes, you're doing a great job, keep going'.

The very fact that families are working, on a daily basis, with their child exacerbates the already fragile relationship that many parents have with orthodox medicine¹⁸. Furthermore, the benefit derived from a parent's involvement with their child's physical programme may affect more than the child's motor development. For example, as one mother related.

(Fiona and Tony)

What you do in those sessions is start. You know you start with just the physical exercises but the physical exercises then enable you to start doing things at home and you suddenly find your child starts to eat and you start on potty training. You start then to use 'flash cards'¹⁹ and you start to read books. Then you find that its not just physical sessions you're doing, you suddenly change your way of life and everything fits neatly into it. Suddenly, you have a system for living which you probably didn't have with a handicapped child. I'm sure most people with a mentally handicapped child find they don't have a routine, and its very frustrating.

What we see here is the child's physical therapy programme also acting to structure a wide range of social and environmental stimulation that benefits both child and parent alike²⁰. Thus families who adopt an active role, which

¹⁸ Traditionally this level of involvement with the child's therapy as been regarded as detrimental to the family. However, a recent study showed that parental involvement was now identified as being an important 'component of care' for both medical professionals and parents alike (Rosenbaum, King & Cadman, 1992). Furthermore, many families with whom I have worked informed me that continuing to attend an alternative centre had jeopardised their relationships with their GPs. In extreme cases being forced to find another doctor more sympathetic to their personal habilitation programme.

¹⁹ Cards with different pictures, images or words drawn upon them, presented rapidly to the child to stimulate visual awareness and cognition.

usually involves the counsel of an alternative therapy centre, may often be better placed to promote their injured child's development, though there are no guarantees given except those which ensure a great deal of commitment and heightened responsibilities for the parents. However, in this undertaking they will attempt to animate not only their disabled child but also the general passivity they frequently experience during their encounters with physicians. In the next Chapter I shall show how parents, empowered by active involvement in therapy, may find an alternative to the bio-politics of orthodox medicine. In this way their needs and those of their child are reconsidered so as to optimise their contribution to the ameliorative complex in which they are situated.

Conclusion

In this chapter I have attempted to show the power and control doctors possess in relation to brain injured children. As I have demonstrated, this control does not only retain the brain injured child's 'clinical' considerations within a medical enterprise but also empowers those professionals who have a licence to practice it in divergent ways. For example, the social setting in which both the child and his or her parents experience disability may be overwritten with prescriptions that attempt to organise the family's behaviour in line with those practices that lend support to medical management protocols while, at the same time, ignoring those practices that may help to ameliorate some of the accompanying problems. For many families such practices fail to

²⁰ Interestingly enough, general infant stimulation programmes have also been shown to advantage motor development (Palmer, Shapiro & Renee et al, 1988).

consider the daily dynamics and responsibilities that are involved with caring for a brain injured child, thereby reducing the child to a product of its disability rather than a person. The fact that some doctors may frequently underestimate the possible value of familial input in the various daily routines of child care and stimulation may act to encourage families to look elsewhere for guidance. The shift in focus is often now to the alternative therapy centre.

As I shall show in the next chapter, with this move from orthodox to alternative the balance of power, which is itself an emblem of medical authority, becomes transferred back to the family. The effects of this are that familial empowerment to address, in an active way, their child's needs is increased, and so too is the threat to the competencies of doctors who are, by their very profession, obliged to retain control in medical matters.

The Irreverent Method

Introduction

In the previous chapter I discussed the events that led to the surveillance and control of modern orthodox medicine and the resulting dissatisfaction that many parents with a brain injured child experience during their consultations with doctors. As was shown, this dissatisfaction with doctors' inability both to effectively communicate with lay persons and to address that which families perceive as their child's underlying problems often results in some parents looking elsewhere for help. In this chapter I shall explore in greater depth the help, method and appropriateness of an alternative procedure to address what parents determine to be their child's problems, and the consequence of these procedures on both the child and his or her family, suggesting that this might allow them to see the person embedded within the body. This may well in turn allow greater access to the child because it results in a more individual manifestation of the idea of 'disability'. Such a view will be contrasted with those notions that maintain the orthodox position with regard to the medical processes that the child and family are often encouraged to follow.

There has been an astounding corpus of knowledge generated by both researchers and professionals (alternative and orthodox) whose concerns can be broadly understood as exploring neurological dysfunction. What is most surprising, however, is that little of this information is able to unite the methodologies of both the orthodox and alternative practitioner's approach to

ameliorate brain injury. As noted in chapters 3 and 4, specific doctrines bring with them particular agendas: for orthodox medicine these respond to the scientific validity of a given objective phenomena, so its diagnosis and prognosis are therefore typically its focus. However, for the alternative practitioner the subjective experience of a phenomenon such as brain injury is paramount in framing the tangible and meaningful detail into a therapeutic regime.

(Sarah)

Interviewer: At the most basic level could you say that the Kerland programme listened to you and your experiences of Sarah?

Mother: *Yes, but it also gave us a structure, because you can spend hours and hours with your child and it can be a complete waste of time. You need somebody from outside to listen to you and actually assess your child. You need somebody to stand outside your family, but someone you know who understands Sarah and her potential.*

Father: *You're here, you do this (alternative therapy) you're now there. I mean we went from week to week and we didn't notice any difference, but the health visitor did. She would only see her every fortnight but she could see the difference. Certainly, when we went to see the 'developmentalists' they could say, 'look there it is, there's your chart, that's where she was and that's where she gone'. And we would think, well she's got somewhere, whether it was entirely due to the Kerland programme was irrelevant the fact that we got there and someone listened was a hell of a boost to us.*

How are we, then, to understand the difference in opinions that result from the conceptualisation of brain injury by these two contrasting methodological approaches?

The problem might best be considered if we firstly understand that these differing perspectives arise not from the notions relating to brain injury, but from the collection of attributed facts (symptomology and its aetiology) and, more importantly, their implication for therapy. That is to say brain injury is not the issue, but rather the techniques that attempt to ameliorate it, along with those professionals who devise them, are of greater concern to us. Thus there appears to be a problem here between the supposed facts of neurological trauma (what causes the symptoms) and their therapeutic conclusion (how best are they treated). Moreover, this problem may not only work to distort understanding of the issues involved, but may also prevent the adoption of a suitable posture to enhance a given therapeutic procedure.

The problem, then, might well once again concern the concept of mind. As we saw in chapter 3, the higher operations of mind are difficult to account for in terms of clinical studies as their logical postulates, which dictate a scientific method, rarely aid analysis. However, such speculations play only a small part for parents. They prefer, instead, to rely upon their experience from continual encounters with their child in the normalising environment that is their home.

(Karen)

We feel she has actually reached, well she has not reached her potential yet, but she has reached a level. She has reached this plateau really, if she wanted to walk she could, 'she can walk' (both parents say in unison) she's got her balance.

Such considerations are more typical of those techniques employed by many alternative rather than orthodox practitioners. I use the term alternative here because it best reflects those notions articulated by parents themselves and also because it conveys 'the idea of a parallel but independent system' (Sharma 1992: 6). This notion contrasts with that proposed by the term complementary as this latter one implies 'the possibility of co-operation with orthodox medicine' (Sharma 1992: 6), a co-operation which remains problematic¹ for many in orthodox practice as they feel alternative therapy fails to establish a credible scientific account of its methods and practice (BMJ 1980: 1-2)

However, the fact that the orthodox and alternative treatment regimes adopt differing postures highlights their contrasting methodologies, which in turn reflects the characterisation of mind and body with which both groups conceptualise the significance that neurological dysfunction has for the sufferer. That is to say, although doctor, parent, injured child and alternative therapist all have some experience of neurological dysfunction, there are no certainties that their experiences share a commonality other than that given by terminology alone. The fact that many alternative approaches rely upon

¹ From my own experience many alternative therapists would welcome the opportunity to develop some complementary role with medicine. In fact, they may often see their work as complementing those services provided by orthodox practice. This position tends not, however, to be entertained by orthodox medicine which often devalues alternative input without knowing anything about it.

familial experience to structure assessments is likely to help them empathise more with the family's therapeutic objectives. These can, however, be unrealistic in terms of clinical medicine and its expectations as Ursula Sharma notes:

A fairly common view is that modern medical science has been a victim of its own success. It has done so well in curing many acute and infectious conditions that people now expect doctors to be able to cure everything. When they find this is not the case they may become impatient and turn (unreasonably, in the BMA's view) to non orthodox medicine (Sharma 1992:115)

However, many families may simply believe their child has a greater potential for development than that given by medical prognosis. Therefore, alternative procedures that attempt to affiliate themselves with parental ambitions may well be seen as threatening (Smith 1987: 192) and unscientific (Cummins 1988)² to the orthodox medical community. In view of this we may now account for alternative therapies in terms of the way they interpret the clinical detail and apply their methods with what sometimes appears to be a singular irreverency to the principles of clinical medicine.

The purpose of this chapter, then, will be to account for the differences that exist between the alternative and orthodox treatment procedures which attempt to address brain injury in children, taking note that these differences do not arise from the discernible facts of neurological trauma. They arise instead from differences in interpretation.

² See Cummins, R. A. (1988) for a critique against the unscientific nature of the Doman-Delacato method.

Two Part Dissonance

In the last chapter I used a musical analogy to outline the way medical professionals manage children with a brain injury. I suggested that a particular score (clinical) is orchestrated to minimise the possible contribution that brain injured children might make to the larger societal symphony. Moreover, the effects of such medical management (orchestrations) may not only impoverish the harmonic quality of the total work but are equally likely to discourage the aspirations of those potential soloists (brain injured children) who have yet to find their voice. Maintaining this analogy for a moment longer, I shall show that many alternative therapies are also concerned with orchestrating disabled children but their scoring procedures differ. They attempt to highlight the brain injured child's 'instrumental' potential by allowing the body to be used as a medium for social expression.

What seems to be crucial in deciding where to draw the boundaries between the orthodox and the alternative is the collection of beliefs which underpin each doctrine. For Brown (1987) the feature that moulds a fringe or orthodox practice is its level of social cohesion, a shared set of beliefs and practices that are commonly held among a group of individuals. This group identity (alternativists) not only develops because of the 'assemblage of interrelated ideas: (1987: 229) but because this cohesion proves even more resistant to dismissal by the orthodoxy. The important point is that though demarcation between the alternative and the orthodox may well be one of medical theory, it also involves the social boundaries that maintain the cohesion of shared ideology and identity. Furthermore, in relation to the

alternative therapy for brain injured children, as I shall show, it is the very ideas that parents have concerning their child's future which draw the lines that demarcate their position from that of the orthodoxy. It is also the case that their ideas may appear to be most sympathetically voiced in the procedures of the alternativist and therefore seem to offer new levels of encouragement (see Tony and Fiona's parent's quote at the end of chapter 4).

Moreover, parental belief in the hidden capacity of their child to achieve more than that which is speculated by clinical medicine acts to catapult parents into alternative therapies which 'feel', to the family anyway, more sensitive and more aligned to their beliefs. An example of this is provided by Tom's mother. Tom was born by emergency caesarean section when at 36 weeks he showed signs of foetal distress, his weight was just 5lbs he also had a lung infection and heart murmur. He spent 6 days in an incubator and returned home; after 3 weeks tom was subsequently diagnosed as being cerebral palsied.

(Tom)

One of the reasons we went to the Kerland was because this particular physio started saying, 'oh well its far to early to tell what level of ability he will have at 15 months'. Yet he could tell her car from all the others and would start crying when he saw it because he hated her so much. We knew he was bright, even if she didn't.

As briefly mentioned, a great deal of research has been carried out relating to brain injury and its myriad manifestations to personal function. Furthermore, this enquiry has established pertinent facts which cannot be disregarded. However, such facts can also be no more than speculations. As

noted, the professional's attempt to predict the functional outcome by presented 'facts' may result in inaccurate speculations which often further act to the detriment of a family's future hopes and beliefs of habilitation. This demonstrates the tension between the 'objective' analysis of an orthodox medicine and the 'subjective' concerns of a parent with a brain injured child. In this light, the methods which I term 'irreverent', unlike those of orthodox medicine, are not fixated with the objective clinical facts but refer, instead, to the observed dysfunction and its supposed immunity from a positive course of treatment. In this sense alternative procedures rely on empirical accounts of the child's disability to structure the varied programmes of habilitation³; that is, personal observations and experiences, or perhaps phenomenology, act to advocate a particular therapeutic stance. Thus, the empirical accounts that I shall present in my argument, against the frequent clinical myopia of a singular medical methodology, relate not to the neurological facts but to their often debilitating conclusion.

Before continuing, however, I should reiterate some of the implications of neurological dysfunction and the beliefs which attempt to impart a working knowledge of brain injury so as to affect some level of amelioration. These beliefs, and beliefs they must be until a clearer notion of the brain's global manifestations are discovered, relate to both the varied aetiologies of disability and their impact on our understanding of brain injured children and their lived experience.

³ Although this in itself has become problematic, as the term 'empirical' is often used in the derogatory sense to imply a lack of 'wider scientific knowledge' (Drever 1952) or indeed quackery.

Neurological Dysfunction

The clinical characteristics of neurological dysfunction depend almost entirely, in the living child, on the cataloguing of behavioural disabilities. If such problems are overt then they may be considered symptoms of some underlying neurological pathology. However, there need be 'no correlation between the localisation of a symptom and that of the function which has been impaired'⁴. That is to say, a diplegic child (e.g. spasticity affecting both legs) will have great difficulty in walking, so we may now be tempted to assume that the problems that prevent this child from walking arise from the fact that spasticity renders movement impossible. However, this need not be the case. There may well be some deeper underlying neurological trauma of which spasticity is but one expression. Therefore, spasticity is just one manifestation of some neurological lesion while the lack of purposeful control of the legs (which in itself would render walking near impossible) may be another. These two symptoms of disability may have no other link to one another, other than that both are expressions (perhaps even diverse ones) of some underlying neurological lesion. In such a case spasticity may not be the cause but rather a confounding symptom of disability. Indeed, it has been suggested that greater understanding of neurological dysfunction might be achieved if those whose interests involved clinical pathology showed an equal concern for the living brain injured children in whom such pathology is detected (Thomas, 1969).

There can be little doubt, however, that new clinical methods, aimed primarily at maintaining life support after neurological assault, have by far

⁴This statement Luria (1966) attributes to Hughlings Jackson, cited in Thomas (1969: 32)

outstripped the management procedures which deal with the residual problems that exist after the child has been medically stabilised. This is a crucial point that has both moral and ethical implications for the medical attendants, the child, and his or her family. However, perhaps our first concern should be that of the child. It is almost impossible to conceptualise treatment without making some appeal to prognostic factors. Yet any authoritative prognosis based on early diagnosis alone may be no more reliable in predicting the outcome for a brain injured child than guesswork. Philip's mother recalls the information she was given after her son had been resuscitated following his drowning accident.

(Philip)

Well one consultant told us that he probably would not live to double figures because of the extent of his brain damage. He had to be tube fed. He said his liver, kidneys and bowels will 'pack-up' because he's only having liquids. There were all sorts of things and drugs and they said 'we can't see him surviving'. And now, four years later, they say he could live into his fifties because the way he is cared for and the way he is now.

Statements are often made which offer little hope to parents but provide instead, feelings of inevitability and impotence to do something positive to help their child. This is given expression by a mother whose daughter suffers from athetoid spasticity and hydrocephalus.

(Cindy)

And then we went for another check-up.... and I said, 'well look, you've given us three different statements, you don't know, do you?' And she said, 'no' and I said fine, I can cope with that. But don't make all these statements because I've got to go home, we've got to live with her.....

Why, when so little is understood about recovery mechanisms, do orthodox medical personnel still tend to underestimate the possible future expectations for the brain injured child?

Particularly problematic, for the parents of newly diagnosed infants, is the often negative speculations concerning 'outcome' offered by orthodox medicine.

(Cindy)

It was all sorts of little things, I don't know, they didn't treat me as human. They kept on spilling out all these words, hydrocephalus, she's got this wrong with her, she's got that wrong with her, they just don't consider that at the end of the day you've got to go home with her and worry about it.

Such statements show how the clinical formulations of orthodox medicine only offer uncertain outcomes, and yet are couched in a discourse which attempts to maintain an air of authority. It is, of course, possible that there are confounding variables that blights prognosis. For example, these may be due to the fact that improvements in childhood outcome can either reflect the true long term insignificance of the trauma itself, or some mechanism associated with the lesion and / or the recoverability and plasticity of the young brain (Bruce 1990). That is, it may be possible that some children regain function simply because the initial trauma was in the long term superficial (see chapter 3), or that the brain readjusts to the lesion through some, as yet unknown, process of repair. Or indeed, that new areas are stimulated to 'take over' the control of that 'lost' function, demonstrating a

possible plasticity. These 'internal' factors, broadly concerning tissue recovery, are themselves independent of any benefit derived from 'external' therapy aimed at habilitating the child. To add a further confounding variable to the present ameliorative complex there exists, as I have already mentioned, that which may be referred to as a 'discontinuity of perspectives' between the orthodox and alternative approaches to treatment. This seems largely based on medical 'protectionism' which 'denies the common ownership of knowledge' (Smith 1987: 192), and establishes the 'social boundaries' (Brown 1987) that retain 'professional' cohesion and identity. Is it possible, then, to identify those factors in the working medical rationales that maintain orthodox clinical distinctions and those practised by the alternativists? I believe it is, but before tackling this issue the problem must be more clearly formulated.

Differing Perspectives

That trauma to the brain can result in damage to its specialised neurons and interfere with functioning, either focally or diffusely, is unimportant for the present analysis. Instead, what is important, are the implications for the brain injured child and his or her parents. In contrast, then, to the clinical speculations of medicine many families feel that the alternative therapies offer a more positive approach to both the problems of brain injury and the general familial concerns that establish the whole trauma experience.

(Timothy)

I must admit I do think the 'child centre' was really good, I felt that they knew exactly what we had been through, what we were going through, so that it was a sigh of relief that we didn't have to explain anything.

Many alternative centres offer an approach to treatment that is often considered more controversial than the sum of its procedures. Underlying this controversy, for the orthodoxy at least, is the alternative practitioner's disbelief in the finality of brain injury. It is, of course, true that much of the criticism levelled at unorthodox approaches refer to the lack of scientific support for the theoretical tenets which underpin their method⁵. However, it is worth mentioning that although theory and technique are frequently associated with one another they can, nevertheless, be mutually exclusive. For example, that a theoretical proposition does not support the application of a particular therapeutic technique can as equally imply an unsound proposition as invalidate the technique. Many alternative therapies, particularly those that involve manipulations of posture, position and physical stimulation, use a variety of techniques that have little scientific rationale to locate them in clinical practice. They are designed, instead, in terms of parental aspirations: what they want their child to do. Similar to physiotherapy, these techniques are however usually much more intensive, which is often a source of conflict. Many families feel that the service provided by physiotherapy is too intermittent and not challenging enough. Physiotherapists, on the other hand, may be so angered by families attending alternative centres that they refuse to work with the child.

⁵ See Cummins (1988) for a critique on the alternative methods employed by Doman-Delacato.

(Tom)

We had physio but I didn't feel it was doing a lot of good but as soon as we told them we were going to the Kerland Child Development Centre she dropped us completely, refused to see Tom and we had no more physio for two years. She was coming once a week before that, she treated him up to the week we went and then stopped, she was Bobath trained and didn't believe in what we were doing at all.

This is often the very point where the ongoing controversy between orthodox and alternative procedures clash. The focus of medicine concerns the clinical and scientific management of the condition, while that of the unorthodox practitioner is typically more child/family centred and proactive in relation to the body. Once again it can be seen that the notions at the foundation of this discontinuity of perspective involve those claims, by orthodox medicine, that the child's condition should be objectively dealt with. This doctrine tends to negate the possibility that subjective inferences, generated by the family and alternative therapist, can be useful in determining a positive course of action. Thus, for the alternative therapist, concern is given to how the child's development might be encouraged with the appropriate stimulation, while that of medicine and its employment of physiotherapy is concerned more with bodily maintenance, at the biological level. The issue, then, is not neurological dysfunction but its subsequent treatment, and the differing perspectives are thus the result of the way each approach views possible treatment rationales. For doctors the brain injured child is constructed as an impersonal 'clinical case' presenting the symptomology of an objective orthodox medicine. In contrast, the alternative therapist's position is more willing to regard the child and family's phenomenology as an incentive to

habilitation. The difference is that for the alternative therapist, the child and his or her whole phenomenology is central to the ameliorative process. On the other hand, orthodox medicine's concern for pathology often occludes those person centred dimensions from consideration. In so doing the brain injured child receives no more concern than the clinical pathology that serves to label her.

The Child in Alternative Therapy

Many of the surgical procedures practised on diplegic children have proved to be of little use in improving walking (Patrick 1989). Even though this mainstream approach has generally failed there seems, however, to be an unwillingness for the profession to adopt or consider alternative procedures. This might well be related to what Foucault, (1973: 1977: 1979) Armstrong, (1983) and Turner (1987: 1992) have noted as a general inability of clinical medicine to understand that the patient or- in this case, the brain injured child - is, in essence, more than the sum of the disabilities with which he or she is labelled. Such a proposition underscores much of the alternativists' approach. They do not view clinical assessment as a separate phenomena from the social trauma that it accompanies. They tend to see the child as being far more significant than the condition he or she may present.

From my own experience of the Kerland method, initial assessment of the child required somewhat detailed histories to be recorded. This not only involved collecting information about the child's present level of ability and what concerns the parents might have with regard to physical and mental potential but was also concerned with those issues that provide the child with

an opportunity to encounter a more normal experience of the world than that often traditionally prescribed for disabled children. Reminding parents that the needs of their brain injured child were not, in nature, any different to those of his or her siblings helped to make the Kerland clinic a centre where dialogue could replace rhetoric and where discussion would have victory over dictation. In this way parents were empowered to explore those options of therapy that had been previously withheld. However, seeking out alternative procedures does not just have a long historical precedent but remains a common practice for a variety of conditions, as testified by the amount of people using self-treatments with non-prescribed medicines (Wadsworth et al. 1971) and alternative treatments (Sharma 1992). Furthermore, it has been estimated that

approximately 20000 people in Britain are practising 'medicine' without any official qualification or approval, about a quarter of them deriving a full time living from their various therapies. Moreover, it has been estimated that alternative medicine is growing five-times as rapidly as orthodox medicine (Scambler 1986: 51).

This increase in alternative services and their frequent usage, particularly the self help groups, has resulted from 'the lack of adequate understanding, care, treatment or support from the various health professionals' (Scambler 1986: 52). Such sentiments are frequently articulated by parents of a brain injured child. A perceived lack of continuity and a 'matter of fact' approach to their child's condition further aggravates the situation.

(Cindy)

We kept on seeing different doctors and we had gone down to Bristol and saw this women doctor who I had never seen before. She came in late at night and Cindy was ill and she said 'you do realise that this child is brain damaged'? And I said no and that was the first time I knew. I said, 'can you explain to me what that will entail'? Well, 'she will have mental problems' replied the doctor.

There are, of course, other contributing factors that affect orthodox treatment regimes, such as the large scale service they must provide with its attendant managerial and administrative difficulties. Many medical professionals are aware of the importance of addressing both the child's and family's social, psychological and environmental needs, but the fragmentary way in which such support is given tends to minimise its efficacy. This may leave parents dissatisfied and make them feel that their child would be better off with a more concerted approach. As one perceptive mother noted

(Tom)

Speech therapists don't get involved with respiration, the physio does it. Ridiculous, isn't? Because when you think about it you can't speak without breathing.

In order to combat the fragmentation of services, the injured child - a child within a body, not just the body as a maladapted phenomenon - needs to be conceptually restored to that of a complete individual. The restoration of a clinical subject to that of a human being is something many practitioners, both orthodox and alternative, are striving for.

Chapter 5

The patient's essential being is very relevant in the higher reaches of neurology, and in psychology; for here the patient's personhood is essentially involved, and the study of identity cannot be disjoined (Sacks 1985: X)

However, as we have already seen in chapter 2 much of the rhetoric associated with the patient's personhood is far more likely to relate to the adult than to the child. Indeed, though children may well be a legitimate object for orthodox medical enquiry they have little social status to negotiate a viable identity for themselves within it. This is possibly even more difficult for brain injured children to achieve. However, for the non medical approaches the acceptance of the child as an individual is frequently less problematic, as the reliance of therapy rests on observing the child's immediate problems in terms of physical function and behavioural aspirations. This is often the result of seeing therapy as a mediating process between the brain injured child and personal functioning. This process must accept the child as a child with his or her attendant capacities or incapacities. In this light the child is seen as not some incomplete adult, awaiting the chronology of maturation, but as a striving person in need of assistance to fulfil his or her potential.

Thus many alternative procedures work, through therapy, to integrate the child, his or her personal functioning and the family into 'meaningful' routines. Although some therapy centres localise the staff and provide space for assessments, therapy is typically done at home by family, relatives and friends on a regular basis. There is, therefore, little or no clinical space to impose a medical discipline upon the child (Davis 1982). Although a discipline is being exercised by the requirements of daily therapy, its focus is (or at least should be) in concord to those routines that attempt to establish

new levels of personal potential. They need not, then, ensure clinical compliance to a management regime.

Thus, the sterility that is the investment of medical space and the control it exerts (Zola 1972, Illich 1975) is tempered with the normalising environment that is the child's home in alternative practice. Though regarded as a contentious issue for many orthodox physicians, who argue that such therapies disrupt family life to an intolerable level, the passivity that families experience while subscribing to medical management policies is often far more intolerable than the activities they may undertake at home⁶. Karen's mother points this out to a doctor when questioned about the alternative treatment she sought to help combat some of the problems associated with her daughter's chromosomal disorder.

(Karen)

I had a long discussion with the paediatrician... about the fact that we were doing something, (alternative therapy). He was concerned that it was actually a form of cruelty and that people might be overdoing these excises. Well I disagreed, you can say that about any treatment,... after I had chatted to him he did change his attitude because I know from other professionals that he has spoken better of it since. We had a long talk about it and I told him that I thought it was actually a boost to the parents because they were doing something instead of just sitting back and expecting something.

Understanding that the requirements for a child with a brain injury are essentially the same as those of an uninjured child would be a fundamental shift in perception for orthodox medicine. It involves focusing on the method

⁶There has been some controversy over the amount of time home based therapy programmes impose on the child and family. Traditionally, with those centres that offered the Doman-Delacato approach this would involve an excessive daily commitment. However, there are hopefully but a few practitioners who would advocate such a detrimental, regime the majority preferring to involve short but frequent sessions of therapy.

of delivery and not just the appropriateness of stimulation. This highlights yet another one of the basic perceptual and conceptual conflicts that exist between orthodox medicine and the unorthodoxy of alternative practitioners. The needs and desires of a brain injured child and his or her parents differ from those of the non-traumatised family, not in their common wish for a successful future, but only in the chances their child will have of achieving one. Of course, any possible future outcome will depend almost entirely upon two essential but sometimes conflicting factors. The first of these concerns the child's encouraged propensity to develop when given optimal opportunities. The second depends on the overriding clinical considerations of a detected pathology which, owing to the special status afforded to the clinician, may receive more attention, and therefore has greater influence on 'outcome', than the child's own possibly submerged abilities. One mother recalls the misdiagnosis of her hydrocephalic daughter and the resentment this caused.

(Cindy)

Then she had a 'shunt'⁷ revision at sixteen weeks, this is when that woman doctor announced she was brain damaged. Every time I said, now look, come on something's not right they would say 'don't worry she's had the ops she's all right'. But my health visitor, she was excellent, she kept on saying 'I'm going to measure her head' and every day she said her head is getting too big. And this is from the time when things were getting blocked up, only through her that we found out her head was growing too big. Because her head control wasn't very good they kept telling me that she was deaf, I said she's not it was because she couldn't (physically) turn her head around when they made a sound.

⁷ A shunt is a procedure that involves inserting a device into the head so that the excess fluid can be drawn out from the brain in the hydrocephalic patient.

As this example shows the doctor has authority in clinical decisions even if, as this parent suspected, the diagnosis may be incorrect. If these parents had accepted that she was deaf the possible lost opportunities for normal auditory input might well have contributed further to her disability. Thus the authority and control of orthodox medicine can, and often does, provide doctors with the ability to override the parents in therapy decisions. Once again we see the clinical agendas of medicine (notions regarding organic pathology and its speculations) orchestrating the disabled body with little reference to its possessor, the child. In this way the brain injured child may remain a prisoner of his or her disabilities because clinical notions of pathology dictate therapy, or a lack of it, more so than the child's unique qualities that may lie submerged under an overt disability.

In alternative therapy, by contrast, the child is far more likely to be considered as a 'particular' child, an individual possessing unique capacities and special problems. In this way children are re-individualised in accord with their personal needs and their particular familial situations. Whereas orthodox medicine requires brain injured children to be a taxonomic class, a group defined by types of organic pathology which adopts a generalised approach to their management, the alternative practitioner's concern is for the particular. This view holds that the child is unique and though similar problems may be observed in other brain injured children they are highly particular to this child. Therefore, any general therapeutic techniques must be individually tailored, not solely in the attempt to combat the manifestations of disability, but also to acknowledge the unique individuality of the child.

Humanism as a Counterpoint to Medicine

It is not my intention to devalue the work being carried out by both clinical and experimental investigators with regards to brain pathology. Their task is as difficult as it is necessary. The point I wish to make clear, however, is simply that their subject matter is far greater in breadth and depth than merely the observation of pathologies. Indeed, if they were ever to completely lose sight of the essential human character of their enquiry, how could their work have meaning to the human condition and its continual struggle to understand disability at both the social and medical level? With this in mind, the progressive way forward may be not to follow a single path but to make several advances in all possible directions. In this way, many alternative approaches are attempting to make a valuable contribution to the problems of brain injury by positing the child as a possessor of potential. The key to alternative therapy lies in finding the processes that may help the child realise this potential.

At the centre of the alternative approach are the child, the child's injury and the child's family: behind them lies the child's clinical diagnosis, whilst ahead there is a chance of discovering that the child's prognosis is more likely to be a reflection of the orthodox clinician's negative dogma than an understanding of his or her available options if given all the necessary encouragement and therapeutic support.

(Tony)

Although I didn't agree with what I was doing initially, I had to give it a go and then, of course, it didn't take very long to realise that it was working. The very first change we saw was at the first visit because they put Tony on a ramp he had never moved and then he came down it. Not under his own volition, he slid down it but he moved, and on his face was 'I've just done something, I've just moved'. So they did something for us that very first session so we had to keep going.

This is not to suggest that the alternativists have found a panacea for the amelioration of brain injury. However, unlike orthodox medicine, they regard the child as being not at the end of her future, but possibly at the start of a new one. As I mentioned in chapter 1, my knowledge and information is particularly relevant to those procedures that in some way 'pattern'⁸ the child's body in an attempt to establish functional behaviour. Indeed, the majority of alternative and mainstream procedures for brain injury are fundamentally focused on the body as the physical, manipulatable, experiential and often the only tangible manifestations of the child with a brain injury.

This focus on the child, his or her disability and the child's family is frequently visible in the stance taken when alternative practitioners make an assessment of the child and his or her future potential. For those centres of 'good practice' this requires: (1) that the child becomes the focus of concern, as it is the child that will be the ultimate measure of any therapeutic benefit that may be achieved: (2) that disability will be regarded as the focus of a therapy which is therefore specifically designed to effect a positive change in the

⁸ "Patterning" is the term given to a sequence of passive manipulations of the body that are intended to programme the child's brain with developmental experience. These somatosensory experiences are then utilised by the child as templates for purposeful behaviours. This method was pioneered by Doman-Delacato but has been extensively modified by many alternative therapy centres..

child's functional capacities: (3) that it is the family who, when committed and permitted to contribute to their child's habilitation, are likely to be their child's therapists *par excellence*. Addressing these basic requirements helps form a tripartite operational mesh which structures the alternativists' concerns and their resultant therapeutic implications. In this sense the alternative programme does not attempt to evolve management strategies, as is the case of orthodox medicine. Neither does it restrict its perception to a fixation on the symptomology. Nevertheless it is generally believed that an appropriate therapy will offer support to both these considerations but it is not guided by them alone.

Indeed, the alternative practitioners' responsibility is to ensure that they address what Sacks (1985) refers to as 'the suffering, afflicted, fighting human subject', in this case, the brain injured child. It is certainly true that any therapy that maintains this underpinning ideology may seem unconventional. This is particularly so when one considers that its therapeutic tenet is to provide the child with the most basic experiences of normal development so that further emergent behaviours have a relevant substrate on which to build.

For example, the Doman-Delacato method is directed on the tangible body and its disrupted patterns of motor behaviour, for these are the summation of present functional output and as such play a significant role in the child's holistic capacity. By establishing incremental "patterns" for motor expression the latter hierarchical requirements of development are believed satisfied, leading to greater motor control. Procedures such as these (as outlined in chapter 1), simple though they are, may provide the disabled child

with greater personal control over his or her environment. They may promote exploratory behaviour, spatial awareness and self motivation, processes which can help establish a feedback link to further encourage more refined motor development⁹. It is also likely that any technique that helps to enhance the child's ability to purposefully engage with the environment might well act to lessen the effects of some of the accompanying cognitive deprivation that may result from severe disability.

Magician or Musician

As in the past, there remains a great controversy over the validity of alternative therapies to provide an effective recourse for brain injured children. In his paper "Magical thinking" (1989) Robert Cummins champions the orthodox medical position when he attacks the Doman-Delacato method (see appendage 2) by referring to it as "nonsense". Once again his criticisms are based on the failure of Doman-Delacato to account for their method in a scientifically acceptable fashion. The fact that much of his argument is well articulated, and with reference to the Doman-Delacato indeed at times valid, does not establish the certainties that he considers must apply to all alternative therapies. Furthermore, his comments regarding parents as 'vulnerable to the seduction of 'magical thinking', which he establishes as a derogatory cognitive process of self delusion making them susceptible to 'therapeutic predation', does much to undermine the sophistication that many parents possess with

⁹The possible beneficial effects resulting from an increase in exploratory behaviour and motivation have been postulated by Palmer & Bruce (1988) to contribute to enhanced motor development in children with spastic diplegia.

particular reference to their child's condition. The father with two disabled children stated:

(Fiona and Tony)

We're not ignoramuses you know, they don't realise (doctors) that we know more about Tony's functioning, and what he needs than they will ever know.

It is likely that many parents traumatised by their child's brain injury do look for understandable explanations and remedial techniques to reinstate that child they feel may be lost to them. In doing so they may well be, at the initial stages at least, more vulnerable to the persuasions of any practitioner who offers a brighter hope for a positive future. The point is, however, that such hope is as likely to be peddled by the legitimate orthopaedic practitioners with their often debilitating surgical procedures¹⁰ as it is by unsound and unethical alternativists. Indeed, the higher the status of the professional involved the more credible the information may appear. In this sense medical decisions are likely to have far greater negative impact upon the child and his family than those of the committed alternative therapist. Moreover, as alternative practitioners cannot prescribe drugs, surgery or hospitalisation any help they give can, under the supervision of an interested parent, be monitored to ensure that what is being done makes sense. This is rarely experienced by parents who submit to the medical regimes of the physician¹¹ even when they know their child's real needs are not being addressed.

¹⁰ See Patrick (1989)

¹¹ For a more in depth argument against Cummins' criticisms refer to appendage 2.

(Cindy)

I find him totally useless, I usually end up cancelling appointments and making them some months further on. I know there's nothing else medically wrong with her.

It is not, then, that alternative practitioners are magicians creating illusions to trick vulnerable parents. Though such charlatans exist, the role played by the many alternative therapists in relation to brain injured children can, as I have already mentioned, be likened more to that of a musician. The therapist manipulates the child's body to give expression and purpose to behaviour in the way a musician manipulates raw sound to create a melody. This, I would argue, is not magic but appears to involve a particular skill, and one that cannot be easily dismissed by 'naive rationalism' and scientific protectionism which acts to maintain a different set of beliefs (Brown 1987).

There are, and must certainly be, 'down sides' to all approaches that attempt to deal with the trauma of children with brain injury, and in this sense the alternativist is no better placed than those who operate in the mainstream. However, considering that the problem involves all aspects of the child's social, physical and psychological functioning, there is unlikely to be a single method that can address all of the manifest issues.

A Therapeutic Rational

There has been little scientific fact accrued in support of alternative therapies that address brain injury. The problem has been that for many such professionals their practice has rarely lent itself to the testable hypotheses that would substantiate their therapeutic claims. Hypotheses must, of course,

reflect a series of formulated statements which outline a testable form of action. Furthermore, the fact that some alternative practitioners¹² have, in their attempt to make credible their techniques of therapy, been over zealous in proposing many of the supposedly substantiated neurological models as evidence of their efficacy, need not devalue the good work that can be achieved. It is worth remembering that there has been, as yet, no convincing physiological model to explain the effects of placebo, but nevertheless its affects can be overt. This returns the argument back once again to those issues which support the 'objectivists' viewpoint, largely denying, as it does, the subjective phenomena of disability.

My point is simply that the lack of a convincing (i.e. in the presently acceptable scientific schema) neurological model should not in itself negate the application of a particular technique. For example, this is especially relevant when the techniques which many practitioners have evolved allow the child to experience a graduation of sensory-motor patterns (facilitators of a conscious embodied potential, Merleau-Ponty 1962: 109) which were previously unavailable to her or him, and which have no medical contra-indications. Families, and even therapists, might not always understand exactly how the therapy works but have little problem in identifying improvements. As the parents with a developmentally delayed daughter recall

¹²The Doman and Delacato method provides a good example of those therapists who postulate scientific rationales to support their therapeutic claims. Moreover, it is this method that has received a great deal of criticism from other professionals. Another example is that of the Peto Institute and their 'conductive education' programme which has attracted much medical scepticism concerning their habilitation approach.

(Jayne)

But then I thought, you yourselves (alternative therapists) had said, 'you don't always know how the programme works', but it does, and any child thrives on attention, and physical exercise does promote development.

We know, obviously better than you do, the programme (therapy) has definitely helped her to improve.

Thus those not utilising alternative therapy may be deprived of such 'common sense' stimulation due to the institutionalised inability of the attending orthodox physician to see that the child's requirements are more than the suppression of symptoms alone¹³. All therapy need not be antagonistic to orthodox medicine since, ideologically, alternative therapy should supplement that which is provided by physicians¹⁴ i.e. complementary medicine. However, this is rarely the case as the alternativists' approach pays little attention to the scientism that underscores medicine (although this is not to argue that objective scientific practices are the only ones that operate within medicine). Furthermore, we should not be seduced into believing that rational science regulates all orthodox medical conduct. Indeed, that which Thomas Kuhn (1970) saw operating in general science is also true about much that is prescribed by doctors. Procedures of both are equally likely to result from events that have more to do with the sociological factors that maintain

¹³ Physiotherapy, on the other hand, if sensitive to the child's needs, can be of some value when delivered on a regular and consistent basis (Patterson 1989: 46). However, owing to the increasing financial constraints placed on the NHS Trust systems this is unlikely to be realised in the present economic climate. The use of drugs and surgical procedures can prove particularly distressing to both child and family and have, I believe, proved themselves to align closer to management practices than to therapy (Patrick 1989, Patterson 1989 & Gans, et al 1990). The primary responsibility for the alternative therapist, then, should not attempt to manage the associated distress but work to improve it, if not to resolve it. In view of this the alternative approach will no doubt continue to be available to those parents who are dissatisfied with the orthodox system.

¹⁴ I agree with Ursula Sharma's definition here, when she suggests that 'alternative medicine' conveys the idea of a parallel but independent system whereas 'complementary medicine' 'implies as it does a co-operation with orthodox medicine (1992: 6).

cohesion in their professional community than they have with the principles of scientific logic and methodology alone¹⁵. Given that the alternative approach attempts to enhance the child's functional ability through structured programmes of physical, sensory and cognitive stimulation, why should such practices be perceived as so antagonistic to the medical profession? The data suggests that orthodox medicine may be threatened by the fact that parents, committing to such therapies, might prove the doctors wrong. Therefore, it may challenge their professional authority to supervise such matters. As one father commented.

(Sarah)

Yes, I mean it does change your life (receiving alternative therapy), but the thing is with Sarah, we have fought against what we see as the National Health system because they wouldn't do the things we wanted them to. And they thought they were right but they were wrong, they were definitely wrong.

What many therapists do is by no means remarkable but can often prove effective. The conflict of rational assessment, lies in how such procedures are to be measured. The efficacy of family based therapy is measured only by its relative success in habilitating the problems associated with brain injury. It therefore need not appeal to the objective clinical criteria that regulate medicine¹⁶. This does not imply that therapy must not make good its account to a peer group, as there does exist an authority to whom it must

¹⁵ Thomas Kuhn (1970) has shown considerable interest in the sociological dimension of the scientific community, which can strongly influence the perceived nature of science. Indeed, Kuhn's '*paradigm anomalies*', (fundamental assumptions which direct scientific endeavour but begin to lose favour because of their inability to resolve relative problems) may resist rejection due more to their ability to retain a functional level of social contract than to their capacity for pure scientific appeal.

¹⁶ That is, the underlying neural pathology may have not changed but this does not always correlate with functional change and improvement.

answer. But this authority, however, is not invested in the medical institutions. Instead it is found ultimately in the child and his or her parents. This does identify a possible problem which concerns regulation. Alternative approaches need to open discourse with other professionals, orthodox and unorthodox, to ensure that standards and good and ethical practice are being observed and monitored. However, this in itself is unlikely to evolve when medicine, which could lend a welcomed professional expertise, seem so unwilling to consider that some alternative postures could advance therapeutics in strictly non clinical ways.

This same unwillingness to address the alternative therapist's concerns is further implicated in the disparity that exists between doctor and parent. That is, unlike Cummins' (1988) critique, which sees conflict arising from parental naivety and unrealistic goal attainment (which is, I believe, not the source of the problem but its product) the most likely contributing candidate is found in professional misconceptions. The problem, then, is not what can be done for the child's brain injury but what can be done for the child. This simple but vital category mistake, which recognises the clinical but not the human condition, is fundamental to both the intellectual and emotional disparities that separate the medical from the other primary considerations of personhood.

The majority of alternative therapists do not let their senses become overpowered by the neurological complexity of the brain and its myriad processes, as this is the work of others. Their concern is to help the child with a brain injury to establish, firstly through improved motor behaviours, a better

relationship with the world of which this child is still a part. After all, the criteria with which he or she is likely to be assessed will necessarily reflect this world so, by all possible means, the child must obtain some experience of it. After all, this is the nature of the embodied enterprise, disabled or not. Therefore, against this backdrop the techniques of the alternative therapist can be seen as pragmatic attempts to mediate the suppressed, but nevertheless primary, experiences of normal development to the child from whom such vital needs have been withheld due to injury. Providing motor input (passive manipulations that imitate a desired function) helps establish both a physical potentiality for the particular behaviour and the corresponding awareness of what is required to achieve it. As one mother with a six year old cerebral palsied daughter recalls

(Sarah)

It was the crawling, I mean even right at the beginning she crawled to the pattern. It was incredible, she started crawling exactly like the 'cross pattern' (input exercise).

Such a rationale (providing children with embodied experience), then, may not require scientific detachment, but perhaps is better served by those who operate through an informed humanism. Thus, alternative therapy need not be considered as a failure to apply a scientific method but more as the champion of common sense, and in so doing it restructures the body for its intended capacities.

However, as it is the parents, their families and friends who provide this therapeutic input on a daily basis it is only natural that such a sustained

level of commitment may give rise to parental anger and frustration.

Sometimes this frustration is directed inward towards the child.

(Jayne)

I could have killed her sometimes, I was so anxious for her to do her patterning and she wouldn't. We were all doing this hard work, we were restructuring our whole life and she wouldn't do it and she has got to, because if she doesn't how is she going to get better?

Sometimes it has an external focus and the alternative therapist is blamed for the problems they may be experiencing.

(Jayne)

So there is this sort of pressure and I thought you (alternative therapist) have given us this and left us with it and she won't do it. You never told us that she wouldn't do it. And it was so demoralising and at time I thought, I wish I had never heard of it, because it was almost like I had been given a goal and then because of the situation here, we couldn't even attempt it.

The reality of the situation is that it is extremely hard work and often in the beginning the injured child fights this new discipline of therapy. Tied in to this adjustment phase is also the suspicion that they are responsible, if not for the cause of their child's injury, then for the therapies success.

(Sarah)

I think its quite natural to feel some responsibility, and even guilt perhaps. But there's nothing more you can do in many cases but ride through all the complications. So you may be a part of all these complications but you did not cause them.

I shall examine the responsibilities and guilt that families experience in the next chapter. For the moment, however, I simply wish to show that making such a contribution to the child's possible future demands a considerable fortitude from both parent and child. After these initial adjustments families and their brain injured children tend to settle down to the routines of therapy. This is, of course, made much easier if they perceive some benefit for all their hard work and see the therapy as a practical application.

(Jayne)

Its the practical things that you can do you know. How do you help a child with brain injury? Its a substantial thing, there's no technology you can apply then all of a sudden you're given something really practical to do, it's just what we need.

Therapeutic Responsibilities

Throughout this chapter I have attempted to maintain a humanist rather than a clinical posture with regards to a therapeutic rationale for the treatment of brain injured children and have argued that the therapy designed by the alternative is only alternative inasmuch as it does not adopt a pseudo medical explanation of its practice¹⁷. Instead its focus is upon the developmental requirements of the child with behavioural impairment. In this sense the alternative therapists are exclusively non-medical agents, which sometimes does not, however, preclude them from their responsibility to ensure that all

¹⁷The Doman-Delacato method has, in fact, been criticised for this and thus have soured much of the good work that the alternative therapies have achieved.

programmes of therapy are commensurate with the child's ongoing medical needs. However, considerations that align themselves to some form of therapeutic activity remain important, particularly for parents concerned with the subject of how to access their child.

(Fiona and Tony)

One of the things we would feel guilty about is if we hadn't done everything that we possibly could to overcome the problems associated with their brain injury.

Encouraging parents to work with their child is a hallmark of the many differing alternative approaches and is often the very reason that many parents subscribe to these therapies. George Storm (1983) has quite a different notion to explain the parent's selection of an alternative therapeutic centre. He suggests that parents are

often confused by diagnostic interpretations resulting from their child's evaluation because of their own emotional state, which can impair information processing, parents may pursue opinions and unproved interventions endlessly (1983: 1160).

Here yet again, as with Cummins' (1988) reappraisal, the critics of alternative practice attempt to discharge any responsibility from the medical profession by assuming that parental inadequacies (i.e. information processing failures) are now responsible for a family's shift to alternativism. Although both Storm and Cummins concur with the idea that medical professionals may at times be insensitive to the family's position, they nevertheless fail to appreciate that general medical behaviour plays a crucial part in initially

alienating families from their services and, due to their continued censure, maintain familial disparity with medically recognised objectives.

The following account from a mother and her cerebral palsied daughter's encounter with a paediatrician demonstrates how an alienation from medicine might occur.

(Cindy)

But she doesn't like him and he is a paediatric doctor and was trained to work with children and his attitude is, well, we're trying to get Cindy into mainstream school, his attitude is they should all be loaded together. He actually said it..... and he wonders why we don't go down and see him. So when you've got that sort of prejudice against you from somebody who is supposed to be on your side and your child's side, what do you do? You give up and you don't bother with them.

Such failures, on the medical side, are further aggravated by the general lack of training, experience and counselling many doctors have in these situations (Carey and Levine 1983). For many families, to participate in some therapeutic objective, even if remote, is perceived to be the better option than the helpless criticisms of a therapeutically passive orthodox medicine.

For parents this may be because alternative therapy provides a focus of the mind situated in the body. For example, ideas concerning the mind become more imaginable when the body is referenced as a key to understanding its myriad associations. Consider vision for a moment, not merely to register light, shade, colour and texture but to process all such hues into a recognisable pattern with particular meanings. Now how could one ever know that such information is capable of being processed by the brain injured

child if that child cannot speak to inform on what he sees? How might we gain some insight into the 'visualised' experiences of this child? One possible way would be to observe the child's bodily expression, or indeed changes in the character of expression, to various exposures involving differing stimuli. This is, in fact, what many parents do, almost unconsciously.

(Philip)

We've noticed a couple of things about him with people we know and strangers. We asked people he didn't know to walk up and stand in front of him without saying a word and he would look and study them. Then we got somebody else who he really knows well to do exactly the same and he would be like giggling and laughing, he recognised them!

Such experiments are unlikely to be regarded as good science. But they do help to 'fill-in' some of the uncertainties between parent and injured child and allow families to see their children as truly embodied beings. This might well play a role in the development of effective attachments that maintain a familial persistence to their child and perhaps therapy. The need then to understand what is going on 'inside' is not just of clinical or philosophical interest it is also a necessary concern for the parent.

Conclusion

I have suggested, in chapter 3 that 'dualist' notions concerning mind/body questions are still prevalent today and perhaps influence much of what parents encounter during their consultations with the medical profession. Most simply, this involves a narrow clinical focus on the child's underlying neural pathology. However, this is not so much to criticise biological

reductionism, as it is to question why concepts involved with mental existencies are so often ignored by the practitioner? Is it possible that physical and mental events have been artificially demarcated because the former have more relevance to medical exploration than the latter? Although there are likely to be close associations between mental and physical events (Hodgson 1991: 58), is the reason why the 'mental' states are largely ignored by the medical attendants of these children that they can only be understood if they represent some 'ghostly possession of the brain-injured machine'¹⁸, and are therefore beyond medical scope? Or do they, in fact, believe that simply because the brain is damaged therefore the mind, too, is beyond redemption? Gilbert Ryle (1947) may provide some insight in his suggestion that one of the agents responsible may be the idiomatic use of 'in the mind statements' which act to over-sophisticate the actions or behaviours we wish to describe.

Moreover, it

habituates its employers to the view that minds are 'queer' places, the occupants of which are special-status phantasms (Ryle 1947: 40).

Could such an assumption contribute, at least in part, to the separation of physical from mental events and the specific allocation of these former events to the confines of medical propriety? Cannot minds, which are both the genesis and result of physical functioning, be pragmatically associated with the body so as to achieve a better understanding of disablement through embodiment?

¹⁸ This expression owes much to Gilbert Ryle's (1947) thesis on the 'Concept of Mind'.

Chapter 5

Now we must think of the human body (and not of "consciousness") as that which perceives nature which it also inhabits (Merleau-Ponty 1970: 128).

In this way the category mistake that regards issues of brain injury as purely the physical manifestation of pathological neuronal tissue, without reference to the implications of physical disability on the spectrum of mental operations, does not confirm an absence of mind, but rather neglects one. The assumption that both mind and body are the association of a single entity, exchanging, sharing and producing essential input, seems not to be a consideration for the clinician. The integrity of the living system, that is the whole embodied child, must be maintained if therapeutics are to prove successful in addressing the needs of the child and parent. As I have suggested, the goal of alternative therapy is to attempt to mediate vital external stimuli, via the child's body, so that continuity between physical and mental events are reconfigured into 'purposeful' behaviour. Although the exact mechanisms which provide such continuity remain largely unknown, the multiplicity of cortical and somatic representations which affect a given event, mental or physical, suggest a variety of stimuli are necessary to achieve union between physical and mental associations as we have seen earlier.

This rationale gives meaning to those procedures that are frequently employed by alternative therapists. Since the nature of physical and mental events that ensue from an individual are not considered separate phenomena, stimulation of one is likely to be conducted to the other and vice versa. In this way it is believed that programmes of therapy directed at the body can influence mental functioning¹⁹. Thus many alternative therapies employ

¹⁹ Indeed, the sensory-motor cortex reflects this arrangement. Gardener (1975) makes

techniques that use the afferent²⁰ system to conduct input from the exterior body to their appropriate cortical centres. In a way this provides a template for organised neurological communication, partly expressed by input (motor patterns), to articulate strategies of purposeful behaviour²¹. Over the last few years some researchers have looked at family therapy systems and concluded that the popularity of this practice rests in either parental dissatisfaction with the orthodoxy (Cummins²² 1987 and Storm 1983) or the contrasting view which considers that benefit may in fact be derived from familial participation with their child's habilitation programme (Palmer and Bruce²³ et al 1988).

an interesting point about the muscular (physical) influences on cortical (mental) activity. 'Discharges from, or the result of, stimulation of the motor cortex are modified, or even determined, by the state of contraction or activity in the muscle group supplied by the stimulated region. Even passive alteration of the position of a muscle may alter its subsequent response or even abolish it. In other words, the proprioceptive impulses reaching the cerebral cortex condition the motor cortex' (Gardener 1975: 405).

This has serious implications, because if therapy does not attempt to correct the abnormal physical patterns that the child presents the absence of directive treatment rationale will likely condition them instead. Moreover, this may be one possible explanation why at birth spasticity is unrecognisable but as the child matures, particularly without therapy to correct abnormal muscle patterns, spasticity becomes more prominent.

²⁰ Refers to the conduction of sensory input inwards as opposed to efferent which would conduct impulses from central nervous function outward to the muscles.

²¹ For example if, because of an underlying pathology, such a dialogue is absent then one must be initiated externally with therapy so that the child may experience the possible benefits of this intimate conversation between physical and mental events. Continuing this linguistic analogy we could describe the single physical event (the raising of the heel) as constituting a morpheme, a sequence of which would provide the syntax, or in our case a purposeful movement (the lifting of an entire leg and placing it forward). A dialogue would now result from the complex co-ordination of both serial and parallel motor events under the guidance of deliberate mental control. This, at its most basic, is the rationale for passive manipulation which can only ever be the introduction to purposeful movement. Independent mobility, and other fine tuned behaviours, may only develop by succession from these primary events. Such a dialogue between movement and its genesis (purposeful motor behaviour) within the child is monitored, assisted and, if need be, corrected by the child's parents whose familial and therapeutic role acts as a complement for increased levels of development.

²² There is a great deal of literature concerning parental dissatisfaction with orthodox medicine. A brief summary can be found in Cummins (1987: 15-24). This source, however, is better suited to finding a useful bibliography of related material than it is at giving an objective account of relevant information which support parental shift to alternativism

²³ Not only are such possible benefits to be found in the sociological and psychological literature but the notion that positive parental involvement can influence outcome is suggested by medical agencies also. See, "The effects of physical therapy on cerebral palsy". Although this paper found little support for traditional physical therapy it does suggest that cognitive programmes and enhanced parental awareness can have a positive effect on the child's development.

Chapter 5

This controversy will no doubt continue for some time. However, the fact that many parents prescribe to alternative therapy regimes confirms that a problem persists between parental requirements and their physician's ability to address them.

Coping Strategies

(Sarah)

Interviewer: When Sarah was diagnosed as developmentally delayed did you have any coping strategies or techniques that helped you?

Mother : *No, we just kept going really. But now we tend to be well, this has happened lets get on with it. I mean I have my bad days when I think I just can't cope with it we've got to manage Sarah for the rest of her life. Its been made a lot easier with John (father) coming here (moving to be nearer mother's family home) but that has caused a lot of problems for him also.*

Father: *There's no doubt about it and with a child like Sarah it turns your life upside down completely. My philosophy in life has changed because its had to whether I wanted it to or not. I mean I was trying to run my own business, boy I was going to go places and I was going to be a millionaire,..... (but now) my aims in life are different. Certainly, Samantha (wife) is more important now than what she was, she should have been before but she wasn't or I didn't think she was. Tommy and Sarah are paramount to us and it wouldn't worry me if I didn't have any more money now as long as I can get by and we're happy, the four of us, and the dog and rabbit.*

Introduction

The above parents' statement illuminates what appears to be a common theme in the emotional and intellectual adjustments that families attempt to make when coming to terms with the knowledge that their child is brain injured. This is not merely to effect some psychological accommodation of

the problem but also, more importantly, to actually change the very meanings and behaviours that were present before the all consuming trauma was discovered. In lay understanding, coping implicitly assumes that we manage the problem whilst continuing with our lives as normally as possible. This is simply not the case. Coping, and the strategies we adopt to facilitate this process, often require fundamental and pertinent changes to all levels of personal and familial functioning (Lazarus & Folkman 1984)

In this chapter I wish to explore the coping strategies that families employ in order that those issues and feelings that underscore every aspect of their lives can be located in their wider social context. I will argue that these modifications of behaviour have their genesis in the multiplicity of human encounters. The spaces in which these take place are not, therefore, isolated within or restricted to the immediate family but are, at one level at least, an expression of a social reason that attempts to both explain and ameliorate the whole social context of their child's disability. In this way both the brain injured child's resources (to encounter greater habilitating opportunities), and social handicaps (which may act to disrupt effective social engagement) are enacted through both familial contacts and those with the larger society. If 'the level of esteem and the social standing of disabled people is derived from their position in relation to the wider social conditions and relations of a given society' (The Equality Studies Centre 1994; Finkelstein 1995, cited in Barton 1996: 13), then brain injured children are also a product of this social construction. Acknowledging this, coping strategies allow the involved

individuals to deal with or attempt to deal with their personal trauma in a manner that is both socially definable and defensible.

Throughout this chapter one of the central issues I shall attempt to demonstrate is that the process of coping can often be enhanced when it is attached to outside agencies. In some way this extends the public dimension of coping by turning the child into a member of society. This may not merely help to dissipate some of the personal trauma but can also provide a method of action that is personally beneficial through the fact that it is publicly overt. Parents may take on a new professionalism that revolves around their increased 'specialised' activities. Traditional parenting roles now become adapted with the new abilities of informed carers. As a mother confirms

(Jayne)

You have to be pretty dedicated and want to do it for your child.

The facility to externalise or present a public account of coping with a brain injured child may act to establish a link with the societal dynamics that underscore a broader meaning of this trauma, and one which is more understandable (through frequent observation) to those who have had the good fortune not to be in a similar position. By externalising (making public) the personal trauma, participating in therapy acts like a two way mirror. It provides a course of action to deal with the child's disability whilst at the same time making the family's coping routines more public. In doing so, of course, a greater number of people gain increased awareness of not only the child's

disability but also what it might mean to have such a child yourself. In this way personal trauma, through its external contacts (going out in public, doing therapy, joining support groups and special centres etc), can leach into the empathetic resources of society. Indeed, such processes may help to provide society with a broader social understanding of non-personalised trauma, whilst those directly employing these strategies may benefit from increased sensitivity or tolerance to the personal changes that might result from coping with such great trauma.

However, although encountering the public can benefit child and family in many diverse ways there is, nonetheless, a negative side to be considered. First of all, some of those public encounters attract the anonymous gaze of unsympathetic bystanders who, failing to recognise the sensitivity of the situation, may scrutinise the child with wondering stares or make 'unthinking' comments.

(Tom)

Tom has always been fairly small and before he had his wheelchair his pushchair looked quite normal, people often found it difficult to make up their minds as to whether there actually was something wrong with him

Naturally enough, some parents find it difficult not to respond to the enquiring stares of an uninformed public. As one mother recounted whilst visiting shops with her 4 year old daughter who suffers from dystonic cerebral palsy.

(Rachel)

I feel a bit tempted at times to stare back and then at other times, I think that it is more my attitude at the moment, (I feel I should) say, 'what are you looking at'? I don't know, my husband thinks I shouldn't say anything but I think I should sometimes.

Secondly, the fact that the child has greater public exposure may act to increase public prejudices, since many of the brief contacts the child and family will make with a 'by-standing' public are observational and not intimate enough to be informing. This does little to counteract seeing the child's disability as having singularly negative implications for the family. The consequences of such are likely to be further implicated in the liminality these children often experience. Murphy, Scheer, Murphy and Mack (1988) have been concerned that the deviance model of disability proposed by Goffman advocates a culpability for impairment to their possessors, the disabled. Following an anthropological methodology that uses symbolism as a referent, Murphy et al propose instead that the physically disabled might be better understood if they were considered within the framework of social liminality.

They are persons having an undefined status: they are neither ill nor well, neither socially alive and active nor socially expunged and removed (Murphy et al 1988: 235).

That which makes brain injured children socially liminal is now not just physical impairment but also that which arises from their own and their families' desires to engage in the social world. However, it is these encounters with the social world that facilitate, in the public imagination, the notion that these individuals are, in fact, different to others, deserving to be kept apart and therefore socially liminal.

Millions of disabled people lead an almost cloistered existence, detached from the mainstream of society by loss of communicative functions- as are the blind, the deeply deaf and many other kinds of physically impaired persons-- or loss of mobility, as in the case of paraplegics. The former are able to go out into a world with which they cannot fully exchange meanings, and the latter are inhibited from such exchanges by physical inability to go out into the world. This isolation is one among many reasons for the fact that many 'normal' people find them opaque and enigmatic- almost alien and rather suspect- which further compounds the problems of communication (Murphy et al 1988: 237)

For Murphy et al liminal people 'have been declassified but not yet reclassified' (1988: 237). They have not, therefore, moved from one status to another but remain between both the socially alive and dead. The point is that like other 'rites of passage' the making of status changes is public, but for the disabled there is no social confirming of a new identity. There is no mediation between disability and ability and there is no socially prescribed way for parents to gain full public recognition that their child is indeed a child and that is merely disabled.

The fact that for both child and family making 'public appearances' have negative consequences, however, does not exclude the fact that they also have positive outcomes. These might eventually challenge the public 'ignorance' that serves to displace these children from that group to which they rightly belong. However, before we consider the positive aspects of public contact I should mention the underlying stress that accompanies the coping routines for families with a brain injured child.

Stress as a Situational Component

In their article '*Managing Stress in Families*', Falloon and Fadden et al. (1993) argue that the family 'constitutes the greatest natural resource for the

management of the wide range of stresses associated with life in our communities' (1993 :1). Indeed, they argue that research indicates that the family is critically involved in the recovery mechanisms that address the many stresses that families may face. The question is now, what is stress? In what situations does it arise, and are there quantitative and perhaps qualitative differences in its presentations? Although these questions seem very general, stress affects people in a multiplicity of ways. Before an account of the unique stresses experienced by families coping with their injured children can be explored we firstly need to review the less specific ways stress affects people. There is an abundance of psychological literature referencing stress but much less in the sociological and anthropological annals. However, the following examination will concern most the sociological aspects of stress as they relate to families with brain injured children.

In order to account for the diverse responses to stress one may be inclined to imagine a plethora of differing forms of stress. However, stress is very much the individual's response to threat which may be experienced through psychological, behavioural, and or physiological reactions to a particular situation, (Falloon & Fadden et al 1993). Threats, moreover, are likely to be woven into everyday social life and to play an integral part in conditioning one's own behaviour and that of others (Milburn & Watman 1981). They also have differing aetiologies that encompass almost every situation and can be found not only in action but also in speech. In this way, stress has implications for both the way people behave and for what they might say. In such situations communication tends to be largely scripted with

consequences involving promises or threats that, in some way, are intended to influence other peoples' behaviour.

While all attempts to influence another by messages that link requests or demands conditionally to explicit, implicit or tacit indications of intention to produce outcomes of interest to us, our particular focus here is upon threats whether clear and explicit, or hinted at or implied, that persons and groups use to influence one another; the conditions under which these occur, which in part serve to influence the meanings; their consequences; and of course the correlates of these (Milburn & Watman 1981: 4).

The literature concerning threat identifies two main categories of threat perception, external (Sawyer & Guetzkow 1965) and internal (Brody, Benham and Milstein 1966). The former is the type of threat with which most will be able to identify. It involves a scenario something like the following statement - 'if you don't do this for our child, we're going to see our solicitor'. (In this case the family want a particular procedure or service from their doctor with which failure to provide will result in them commissioning a solicitor in the attempt to legally compel (threaten) him or her into compliance).

However, other forms of threat are less tangible; these may be regarded as 'internal'. As such, they are much more likely to be associated with the cognitive and emotional reactions that occur in response to a person, or in our case a parent's, perception of harm resulting from anxieties, anger and frustrations that arise from beliefs about their child's condition. The important difference is that unlike an external threat, the internal form requires only that some sensation of threat is perceived; it need not be validated, but just assessed as being threatening. With particular reference to families with brain injured children, the fact that they feel concerned about their baby's development is sufficient to illicit anxiety and anger. These are the very

components that induce stress, especially when uncertainty and the lack of information induce a helplessness.

(Jayne)

Because we saw the wrong doctor for about the first six weeks we were running around like chickens with their heads cut off because we were told there was no special schooling available for her, there was nothing. We didn't know what to do or where to go and I kept on phoning the Social Services but because we hadn't been referred to the correct doctor I couldn't get into the system and that made me very angry.

The opportunity to exercise some level of control over uncertain situations, such as the future developmental potential of an injured child, seems to be an integral component of engaging successful coping strategies. However, circumstances change, especially with age. When disability appears to be continuing to affect the child, whose physical growth now makes impairment more pronounced, this can affect familial perceptions and particularly those that involve possible future scenarios. Coping with these changes is rarely a permanent state but one of spasmodic fluctuation. Thus stresses that arise from the fear that your child may actually never walk (even if unconfirmed by the professionals) can radically impinge upon the ability of the parents to cope with the day to day routines of caring for their child.

(Karen)

I think up to a couple of years ago we thought she would be all right, we thought she was going to be a bit slow but OK..... eventually we thought she's not going to change by any stretch of the imagination. If she can achieve an independent life we will be doing well. So we fluctuate, you know, between hope and despair.

Karen's family above, like many other families with a brain injured child, experience stress as a continual changing dynamic which is, moreover, fundamentally located in specific situations or, more correctly, parent's responses to these situations. Stress, however, affects us all and although certain situations are more stressful than others (going out and socialising) the family with a brain injured child has to deal with these specific highly charged situations with differing stratagems from those employed to cope with the 'ambient stress' (Falloon et al, 1993: 2) that is likely to be experienced at home. Situations, then, play an important part in exciting or pacifying stressors. Hospitals, for example, are often regarded as more stressing to families than their home when they are required to make general visits. Consider, for a moment the following mother's struggle to visit a hospital consultant with her severely disabled son after his drowning accident.

(Philip)

We had been home for about four weeks I suppose and we had an appointment to see a hospital consultant and I struggled with Philip to get him into his pushchair and get him up there, and we sat in a waiting room for nearly an hour with Philip moaning. So we went in and sat down and she said 'how is he'? And I thought you have made me sit in that bloody waiting room for an hour to ask me 'how is he', I'm here for you to tell me what you think.

These situations, however, can be less stressful when their child presents problems that need resources or expertise not available in the home providing, of course, that the professionals they see can relate to the child and parents in a sympathetic manner then hospitals can be a source of comfort. As the next example highlights.

(Cindy)

As I said he (orthopaedic surgeon) has seven children and he talks to Cindy and says to her, 'I'm going to check your hips because as you know such and such is wrong with them' or 'this isn't right', and she doesn't mind going to see him.

Or as another mother recalled

(Rachel)

but of course we were hoping, in the long term, that it would work out favourably. I think we were living from hospital appointment to appointment.

In such cases the hospital can help reduce the parents experience of stress by providing a continuity to structure the coping process over extended periods of time. The diverse accounts above act to demonstrate that situational factors are proportionally related to an individual's experience of stress as a social event. Not only is the stress experienced by a family with a brain injured child related to the situations in which it is encountered, it is also an expression of the ways particular individuals within the family may uniquely respond to different events.

Public, as opposed to private, situations can further increase anxiety and aggravate stress. That social factors, such as being out in public, increase an individual's level of 'autonomic nervous system arousal' resulting in enhanced reactions to a given stressor (Davis 1969) further demonstrates the impact public situations have on the family. The following account shows the

impact that visiting a hospital waiting room can have on those parents and children who are confronted by other brain injured children in a public setting.

(Karen)

There was another child there who was severely brain damaged screaming incessantly, you know, and Karen got upset. She was quite disturbed, so it shows you that even in her case she found this really abnormal behaviour frightening, you know she didn't know how to take it. That was the general atmosphere in the waiting room, even the adults were uncomfortable, you know, should we look or shouldn't we.

Indeed, much of the literature on stress is peppered with accounts concerning the detrimental effects of exposure to stress which, in certain cases, can induce both mental breakdown and physical disorder (Falloon & Fadden et al, 1993), thereby exacerbating the family's general ability to cope with their injured child.

Although particular episodes in life and the general ambient features of living regularly produce stress, the continual heightened parental concerns of a family with a brain injured child require a differing analytical approach to those usually accounted for in the literature. Stressors, for the majority of us, are typically accounted for in an episodic fashion. That is, the coping strategies employed deal with the immediacy of the problem giving 'time' the opportunity to help dissipate the daily anxieties that associate with a particular stressor. The old adage 'things will be better in the morning' exemplifies this. The loss of a partner or the threat of unemployment, for example, have a temporal component to which an 'ending' or some other adjustment can be envisaged. This 'temporal component' is structurally different for a family

with the long term anxieties that are associated with the life time of a brain injured child. The following statement gives some insight into the realisation that providing care may have long term implications for coping.

(Sarah)

I just didn't look beyond today. You know I lived from day to day, I didn't go any further. I mean it was difficult for me because having Sarah, well that was my career gone as well and I suddenly thought 'I can't do this job (looking after Sarah) for twenty four hours a day....

Therefore, the coping strategies that are devised must be more open-ended than those which address the more 'temporally fixed' stresses, such as bereavement¹ or unemployment. I shall consider the temporal elements later in this chapter. For the moment, however, the question now is in what ways are such stressors dealt with, given the reality of the situation and the persistence of associative stress?

Acceptance and Maintenance

At the start of this chapter I argued that parental coping with the trauma of a brain injured child involved more than simple practical accommodation of the impact that disablement brings to the family. That there is great grief in the families concerned is an understatement, but if the child is to remain with

¹ It is certainly not my intention to minimise the profound effect grief has on individuals and though it may be true to say that one never really gets over the loss of a partner or close relative one does learn to cope. However, although this form of coping is temporally extended, as with that associated with a brain injured child, it differs in respect of tangibility. Whereas grief for a deceased person involves corporeal loss, the grief for a brain injured child's parent is continually challenged by the hope that this situation is not that final. The child's persistent corporeal presence fixes new aspects of grief to every day that ideally should be rewarded with parental pride for the child's accomplishments. In this sense the grief is cyclically persistent.

the parents at home then acceptance of the disabilities, and maintenance over time and the challenges this itself brings, must be successfully adopted².

Acceptance that a child is brain injured rarely occurs spontaneously. It develops spasmodically, as does the awareness that a family's life will never be quite the same again. Early literature concerning family counselling, for example, often advocated institutionalisation for severely disabled children (Kozier 1957). According to Blacher (1984) social class might influence the decisions that parents are likely to make.

Some parents,..... particularly those from middle class families, regarded the institutionalised child as "dead or depersoned" and maintained little contact with him or her. Lower class families, on the other hand, regarded institutionalisation as a form of living away from home, and appeared more willing or ready to reincorporate the child back into the family (Blacher 1984 :27).

However, for the families with whom I have worked, who incidentally represent a wide spectrum of the class system, the unifying factor was that their children all lived at home, though it would be fair to acknowledge that some parents do entertain ideas of institutionalising their child at some future point, particularly if amelioration proves unsuccessful. Indeed, this is yet another reason why many adopt a therapeutic activity. The acceptance, then, that their child is brain injured is not necessarily acquired by experiencing a different 'adjustment phase' to that of other parents in traumatic situations,

² Up to this point I have not mentioned those families that choose not to keep their children with them but prefer, instead, the services of an institution. I make no moral judgement about such placements or those who elect this provision, rather my thesis relates purely to those families who have sought, and sometimes with great difficulty, to keep their children at home. This does not make them, by this fact alone, morally superior, but does introduce them to considerations and experiences that would not otherwise be encountered and as such are the basis of the present work.

such as bereavement. Both traumas require the family to adjust to a 'loss' in terms of the child or how he or she was before the injury. The difference is that the brain injured child's parents must face the growing acceptance that their child will need a continuity of coping throughout life³. The literature is heavily skewed with accounts relating the negativity that a family with a brain injured child experiences, and as Hewett (1970) has suggested, there is little published material to reflect the views of those families who meet with 'resilience and common sense' those demands that disability places upon them. The fact that doctors' statements concerning the level of disability may influence the parents to regard their child in a similar manner as that posited by the clinician (Voysey 1975: 101) may further compound the problems.

In one sense the accounts presented here concern those families that are fighting to salvage something from their trauma which can help shift the situation toward a more positive experience. Because definitions of the disabled child are constructed in interaction with others, families must manage these interpersonal encounters so as to maintain normal appearances (Voysey 1975: 57). To achieve this families may adopt a levelling procedure that enables them to imagine that the situations they encounter with their disabled child differ but little from those which accompany the development of other siblings, even if the disability itself involves developmental delay as in the following example.

³For a good review of adjustment stages and the methodological problems for their interpretation, see Blacher (1984 : 3-42)

(Jayne)

Because I think of all the other aspects of being a teenager today, periods, and if she takes an interest in men. I mean I worry about things like that. But I suppose any person with a six year old can't imagine them being sixteen. You know, what I said to you about Jayne, not being very much different to (that of) an ordinary sister to Kate, in ways maybe there's not very much difference in the feelings you would have for any child growing up. I just think about everything she is going to do.

Considering the injured child as one would any other child is also structurally reflected in the ways many parents clothe their children, using fashion to help 'normalise' the child's presentation in public. This not only acts to minimise detection but also more importantly displays and structures an equity between siblings.

(Karen)

Yes,..... she has the same as George, I mean I don't think, oh it's not worth doing that because she is ill.

Focusing on those aspects which engender childhood can help to offset much of that which is diagnostic of disability. Placing disabled children in fashionable clothing and 'levelling-off' the imagined differences between them and their siblings provides parents with constructive opportunities to reconsider their child's possible potentials. Clothes can also act to displace anxieties of an uncertain future, which are often conspicuously displayed by an inappropriate (non-conforming to trends of age and gender) attire that further signals disability. As one parent recounts

(Cindy)

I have always said that I would never dress Cindy in anything I didn't like. You know, because to me it brings back memories of children who were slightly slow or something, you would always see them in short trousers when everyone else was in long trousers.

Dealing with these issues is, in itself, enriching the personal resources required to maintain effective coping strategies. However, for many parents with severely disabled children, acceptance means that more evolved adjustment mechanisms (to their child's disability) are engaged to maintain the level of familial care that their child requires. The important point here is that the child is not a passive receptacle into which the parents pour their loving acceptance, but rather that the child is expected to meet the family half way. This typically involves him or her achieving some developmental milestone, or at least the appropriate behaviours that help to accomplish them. In one sense, parental acceptance moves almost parallel to the child's 'encouraged' developmental accomplishment. I use the term encouraged, because many parents believe that you only get out what you put in. Even so, there must be some return for familial effort in terms of developmental improvement. This is demonstrated in the comments recounted by Sarah's parents when they were attempting to encourage their developmentally delayed daughter to crawl and walk.

(Sarah)

Father : *I'm not sure that we would be doing the programme (therapy) if after 2 years we got nowhere. I mean I could see the difference, at one time,*

every 2 months. In one year it was ridiculous, we were going back to the clinic every eight weeks for a reassessment, she was like a gun going off. We would do something for a week or two and she had got it. I would have to phone up (the clinic) and say, 'what can we do next'?

Mother: *It was like once she got it she would say OK I've done that what's next?*

Father: *If we would have had somebody who just didn't get anywhere, well then, that would have been it, but a lot of people kept our faith in it because they would come after a week or two and say, 'oh I can see a difference', now we couldn't see it but they could.*

Mother: *It doesn't seem possible that 2 years ago we couldn't get her to move and she just lay there, on the crawling strip, we couldn't even get her to push with one leg. And then, all of a sudden it was wham-bam, we were off, it was incredible. I shall never forget coming back and the developmentalist saying, 'we're going to have her stand against the wall, just hold her and get her to stand up with her back against the wall'. I thought to myself she will never do anything like that and in about a week she just stood up one day and they said (alternative centre) get her to walk away from the wall, one step at a time. And you would pull her toward you and she would do one step if you were lucky and then collapse. We did that for about one week and you just couldn't stop her, she was across the room. It was really amazing!*

Establishing new behaviours, whether small or major, are exceedingly encouraging to the family, and in a way fuel acceptance of the child.

Frequently, however, disabled children reach a plateau where development is temporarily arrested. The following account is provided from a father who has two young disabled children.

(Fiona and Tony)

The nice thing about going to the clinic was that there were dramatic improvements, and then you find that the improvements get slower and slower and you reach a plateau where there's no improvement. We used to despair for a while and think for three months we've been doing this and nothing has happened. Then suddenly one small breakthrough and there's another surge. What seems to happen is that the children learn some basic or small skill, upon which they can build, so you get some dramatic improvement. Then the improvement slows and they have to make another vital improvement upon which you can build again.

It appears that when the child is progressing with a repertoire of behaviours that enable accomplishment of specific skills - crawling, walking or talking etc - acknowledgement that things are happening make for optimistic acceptance of the child problems. The plateau that disabled children reach, however, often acts to frustrate this essential process. At such times, it is interestingly, the routine commitment to therapy, and the very effect this has on familial life, that offers some consolation until a new skill is acquired.

(Karen)

Suddenly you have a system for living which you probably don't (normally) have with a handicapped child. I'm sure that most people with a mentally handicapped child find they don't have a routine, and it's frustrating.

(Sarah)

And each day you find a great long tunnel in front of you and you just can't wait for the end of the day, but when you start 'patterning' (therapy) we find there is an order to our lives

It is the lack of order when living with a brain injured child that makes acceptance so difficult. Thus, routines that maintain an order help promote acceptance, since they provide a structure that permits the lives of those affected by disability to progress with similar daily cycles to those routines that define other families. In so doing, the family not only attempts to manage some of the associated stress but also to give their child an opportunity to express his or her embodiment. For example, the family who have dedicated a time for daily therapy have also created non-therapy intervals in the day. It is in these periods of discharged therapeutic responsibility that the family can engage in those 'normalising routines' that reflect typical family life. This also provides ample opportunities for their child to experience the real or imagined experiential detail of a personal phenomenology (see chapter 8). Moreover, for the present, being able to maintain some attachment to normative familial patterns releases much of the anxiety that can interfere with the process of acceptance and the ability to maintain it in the future.

It would, however, be unrealistic to imagine that acceptance of the many factors that impinge upon the family with a disabled child are solely addressed by commitment to a structured programme of therapy or, indeed, that such a commitment is the sole provider of their child's capacity to experience embodiment. Friends, relatives and the larger community, as well as the families' own responses to their input play an important role. They can,

for example, encourage a positive approach to both the child with a brain injury and his or her parents by offering support and understanding of the whole social system in which the family and child live. This is particularly important when professional advice is not forthcoming.

(Philip)

But luckily enough we had a supportive family, you know, my mum, my dad and my sister, everybody tried to support us and help us. But apart from that we had no counselling.

On the other hand, their input can also be very disabling, particularly if the family have an ambivalent view of what they should be doing. As Blacher points out, in such cases a relative's concerns can stir an uncertainty that perhaps was always there, but un-voiced.

Such conflicting views from members of one's own close personal network can create considerable conflict and stress for the parents, with the result that the severely impaired child has a more negative impact on the family than might otherwise be the case (Blacher 1984 : 32).

Acceptance of the brain injured child is a process that involves acquiring a positive attitude of the child's disability through a series of adjustments that primarily affect the family. The child is, essentially, an active agent in this process in as much as expectancies, to acquire specific levels of functioning for example, are often a requisite (see Sarah's case above). In this way the child's experience of embodiment is shaped by the ways in which brain injury is accepted and dealt with by the parents. Moreover, because of the complex social interactions with others (see Voysey 1975) the family's

ability to accept the child's disability is, to an extent, a confirmation that those outside the immediate family empathise with and support the family in some positive way. These are typically those neighbours and friends who unconditionally offer their support either directly as 'patterners' (therapy assistants) or indirectly as with offering to do the various household chores.

(Sarah)

I mean a lot of people (patterners who assist with the child's therapy) kept our faith in it, if that's right, because they would come after a week or two and say 'oh I can see a difference'.

Helpers though, can themselves be problematic. This is experienced in particular by those families who feel that their home has become a constant 'open ground' wherein little privacy is afforded the family's personal enclosure. As Sarah's mother confirms 'patterners' can be both a blessing and an aggravation.

(Sarah)

I know they're (patterners) doing something to help but you still have got all these people in and out of your home, morning, noon and night, and at times, does get on top of you.

The positive side, as I have shown above, besides helping in the physical routines of patterning, is that they do often provide a 'sounding-board' for parents to externalise their concerns.

(Philip)

Well I know that some people don't like patterners because they feel their home is being invaded. I suppose I just get on with it, it gives me someone to talk to, adult conversation.

Parental acceptance of their child's disability involves many interrelating factors concerning the immediate family's adopted coping strategies. The injured child's ability to conform to therapeutic goals and the support given by friends, neighbours and helpers all serve to position the child in the present, a day to day response to coping. However, as I shall now explore, time has more than just a passing significance to families with a brain injured child. If coping, for any length of time, is to be achieved it needs to extend its expression further than today, it must deal with the many tomorrows that each day precedes.

Temporal Considerations

'.....each moment of time calls all the others to witness' (Merleau-Ponty 1962: 69).

This statement has great relevance to the coping strategies that parents utilise to deal with the stress they daily encounter. For Merleau-Ponty the past, present and future are not discrete temporal events wherein a given occurrence remains engaged, for the present is actually the future's past. In this sense the traumatic event that precedes a brain injury did not simply start, happen or conclude itself at a specific point of time. Brain injury is not experienced, by the parents or perhaps the child itself, as originating discreetly

(in time) but develops following the same emotional, situational and cognitive processes of realisation that accompany those individuals who are inseparably tied to it, the brain injured. In this sense brain injury is not simply a case of being aware of trauma at one point of time. Rather it is the capacity (or incapacity) of growing to realise its effect on the individuals, and those who will care for them, in the years to come.

My point is not that a brain injury did not occur at a given point in time- although clinicians themselves can rarely confirm when such events took place- but that the confirmation has historical antecedents and future expectancies that possibly stir before detection. At what point injury occurred is purely academic for the families concerned, although the confirmation that their child *is* brain injured does give rise to some form of temporal location. The consequences of this process act to establish a vague impression of time that is experienced as being largely disengaged from those temporal routines that position other families with children and their ongoing development. Indeed, this notion has, by one unthinking and insensitive paediatrician, been used as a form of comfort for a family whose child was diagnosed as brain injured.

(Jayne)

Just think, most parents have children who grow up but you will have a child for the rest of its life.

Thus, the fact that time is experienced as being in a state of suspension for many families with injured children requires that their coping strategies, too, need to operate in a relative fashion.

(Karen)

I try not to think about the future because you could be torturing yourself with things like, what happens when I get too old to pick her up and lift her around?

We know we have got those decisions to come (whether to actively prolong life) but I think it is more short term, at the moment we are all going to Florida in May.

So families tend to function, that is cope, by the avoidance of situations wherein future expectancies are seen as threatening. In the future, parents fear that things will get worse, and in this sense time is considered negatively for many of these families; i.e. the future is regarded as the harbinger of increased despair. This is likely to be related to both the fact that the parents' own ageing process will be likely to impede on their ability to care for their growing child

(Philip)

I think that if someone said to me, right picture this, you're going to be sixty four years old and Philip is going to be forty or whatever and you're going to have to lift him into bed and bath him, I would do myself in now.

and that the child's own disabilities might increase, or at least become more conspicuous, with age.

(Karen)

Well I took her to their party, didn't I? And when I came home I said, never again, because that does make you look into the future because you see them all (disabled children) at different stages of development and further on. And the thing is you see a child that is not your child but you compare them and say, 'will she turn into that'? And seeing fifteen or twenty of them, all in the same place, and all these adults trying to be nice to them, I just couldn't cope with it. I just said 'I would never take her again'.

This illustrates that as well as needing to cope with the daily temporal routines of a disabled child, the future has to be distanced so that possible negative thoughts do not impinge upon the present. Indeed, the notion that future events are largely perceived as negative may itself be a result of some pragmatic fixation with the present. For it is in the present, and its historical precedents, that the future is cast in the imagination of the parents. This is clearly expressed by the mother whose son tragically drowned.

(Philip)

If I sat and thought about the future, well,..... that's not going to happen see, I won't have that or I kid myself that it won't happen. Today is today.

Today is today, and we all hope that tomorrow will be another day; there are no tomorrows, but to carry on today requires great fortitude. Myra Bluebond-Langner had noted a similar phenomena of suppressing the future in her research on children dying from leukaemia.

The children's view of time itself changed. It was no longer, as it is for most other children, endless. It became quite finite, marked by relapses and remissions. One of the consequences of this changed view was that the children no longer spoke of the future (1978 :11-12).

For terminally ill children the future locates that point in time where death is inevitable and finally reached, and as Bluebond-Langner shows, the child develops through five stages of gradual acceptance. Although some families with brain injured children occasionally entertain the hope that some time hence their child may achieve a level of independence -

(Tom)

Now whether he is then going to be able to live by himself, I don't know.

- the majority of families consulted try not to envisage their present lives in future scenarios.

(Philip)

Sometimes you really relax and have a drink and sit there, and with the alcohol and one thing and another you think, god, what are we going to do in the future ?..... I don't even imagine what he's going to be like when he's twenty one. I don't even want to know to be honest, because I don't think I would get through the next ten years or whatever.

Suppressing the future then is one temporal coping strategy that acts to tie the emotional life of the family to segmented routines. These can be dealt with and understood as recurring daily events. The only expectancies now that need to be addressed are those that arise from the limiting confines of the present day. Such coping strategies avoid the potential distress that is envisaged for the future.

Nevertheless time, and the inevitable changes this brings, often forces some consolidation of the threatening future. In such cases an alternative stratagem is required that can not only accommodate a realistic future outcome for themselves and their child, but one which can also provide a level of parental autonomy. That is, in order to imagine a future that is tolerable two sets of requirements must be satisfied. The first of these addresses their child as an adult.

(Tom)

I think our aim for him is to leave school educated to a level where he can earn his own living.

This stratagem involves considering the child as able to develop to a level of self sufficiency, thereby disengaging parental responsibility for his or her daily welfare. This certainly can happen but rarely does, due in part to the positional deformities that can accompany a growing brain injured individual. These are often further aggravated by the decreasing physical abilities of ageing caregivers to deal with the demands of a maturing disabled person. The second stratagem for dealing with the future involves some level of displacement. In this case parents may hope that, with increasingly better social services, facilities commensurate with their child's home care will become available.

(Tom)

We were kicking around with an idea and were saying, wouldn't it be nice if housing associations built flats, warden controlled, for physically disabled people. You know, you could have a couple of flats for carers. We

certainly don't envisage him living at home. He's going to be kicked out into the big wide world (mother laughs).

This suggests that the future, if not suppressed by day to day routines, will inevitably surface at some point and require attention if coping is to be successfully maintained.

But even the best coping strategies develop fatigue and in such cases the ability to address the demands of an uncertain future with some envisaged stratagem, real or not, relieves much of the stress that accompanies uncertainty. Here, I believe, is an important location for the role therapy plays in the daily routines of a family with a brain injured child.

(Karen)

We don't worry, I mean we have fleeting anxieties about the future but we certainly don't worry. I think if we had to stop 'patterning', just think of all the time we would have,..... I'm sure we would miss the therapy, (and) especially the people'.

Therapy might or might not address the child's functional problems to a level where total independence results. What it does do, as I have shown earlier in the present chapter, is structure daily routines so that notions of the future are displaced or given an air of optimism.

(Sarah)

We never used the word hope, everyone said we can't give up hope and we said what is hope ? As my wife said, once we went down there (the alternative clinic) they didn't say there's nothing (we can do) they said there maybe something but we don't know how far we can go with it. But it gave us something to work with, and if you like, work for.

Therapy, then, helps provide routines that are, if families commit to them, perceived as beneficial. This, then, acts to not only provide structure but also give reason to the daily duties which critically fix time to the present.

However, fixing time presents an analytical problem for understanding the temporality that locates childhood. Brain injured children are also inextricably involved in the same temporal paradigms that structure notions of 'ordinary' childhood, which are themselves conceptually 'tied-in' with movement in time. That is, the future is where children 'evolve' into adults and as such many researchers consider the temporal aspects - moving on in time, ageing and development - critical to understanding the social representations of childhood phenomena (see James & Prout 1990: 216-237). However, as suggested above many of the coping strategies that parents of injured children adopt suppress the future. Thus the brain injured child's own experience of time may be amorphously⁴ lengthened.

Although the continuity that children bring to the linkage between present and future is as much the investment of parents as it is of society, unfortunately for the parents of brain injured children many of their children will not be active agents in the replication of society. They are confined, by disability and general attitude, into a perpetual state of child-likeness without experiencing the social metamorphosis that results in adulthood. This is not to argue that tensions do not arise in the conceptual or pragmatic voyage the child ordinarily makes to adulthood (Jenkins 1990), and that many ideas concerning the worlds in which children are generally constructed present methodological

⁴I use the term 'amorphously' here since it gives an inclination of some movement of time without specific form or developmental change, other than that which accompanies physical maturation.

problems⁵ in terms of time span, but for brain injured children and their parents chronology is physically enacted (the ageing process, for example) with, sometimes, only slight developmental engagement. That is, time passes with all the negative attributes but with few of the associated rewards. It is for this very stasis of experience and expectation that families must devise a coping device that addresses the present. This 'fixing' the present with day to day routines is recounted in the following father's statement concerning his daughter developmental problems.

(Sarah)

I still don't think about what will happen in ten years, I think you would go berserk if you did. You know the long term problems, you've got to cross that bridge when it comes. 'You take it day by day' (mother interjects), I mean you don't think about it, there's no way, you would just go mad.

However, as I have shown, displacing the future with daily routines such as therapy does not completely suppress the temporal dimension, it rather submerges it. Many events can arise which force parents, and perhaps even their children, to address the inevitable implications of an uncertain future. In such cases acceptance of the child's present condition as having consequences for the future needs to be structured into a broader familial coping schema.

⁵ The notion that childhood is, to a fashion, idealised into a "mythical past or magic present" needs to be accounted for in the contemporary study of children's lives (James & Prout 1990). Moreover, the fact that temporal problems affect our understanding of the issues pertinent to the lives and experiences of non-injured children acts to illuminate the depth that such temporal dimensions run in the lives of brain injured children and their families.

Public Performances

Parenting, as any parent knows, involves diverse responsibilities for the nurturing and general welfare of their children. However these responsibilities are not just the private affairs of families, for they also impinge upon the interests of society. Therefore parenting has a public arena as well as its private dimensions that largely revolve around the home. This societal function has been noted by Goodnow and Collins (1990: 109) who state that parenting

.....is carried out under the eyes of children, partners, relatives, friends, "and the state", all of whom feel the right to judge, and with varying degrees of openness, to comment. The standards applied are not simply one's own. Such a feature suggests that one way to consider ideas about parenting is to ask when parents feel the need to explain or to justify family events.... . It also suggests that one way to describe a social context-for parents or children- is in terms of the people who perceive themselves as having the right or obligation to judge, praise, criticise, and perhaps over-ride a parent's decision, and who are accepted by parents as having this role.

For Goodnow & Collins this highlights dynamics pertinent to the development of a parent's self-concept and, as such, impacts on the sense of satisfaction that may be derived from parenthood. For a family with a brain injured child, however, the most sensitive situations are likely to be those which arise in public and which involve some display of coping. Whether this is manifest in the waiting room of a doctor's surgery or in the aisles of a busy supermarket, the brain injured child is often typically conspicuous, if not by active display then by an uneasy passivity. 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.

The 'public' rarely fail to recognise the presenting symptoms, even if they are at a loss to understand them. The glances, stares and staged shows of disinterest that ensue serve to simultaneously inform and request some explanation from the child's caregiver. Families with a brain injured child are often, then, publicly recognised as being in a state of continually 'coping' with their child by displays of selflessness parenting.

(Karen)

I think it's made me more caring, I don't worry about whether I need a new carpet or coat, I just think there are more important things in life now.

This is, of course, part and parcel of the typical repertoire of parenting, but with extended responsibilities and, in some situations, with obligations to account for their injured children in an attempt to minimise the discomfort it may cause others.

(Sarah)

They would walk up and say, 'hello darling, what's your name'? And of course, they get nothing and then they go 'oh', and then I say 'yes, she's mentally handicapped and she can't speak'. I don't get angry, I feel embarrassed for them a lot of the time, I feel embarrassed for other people. I mean, we go out and about and you tend to forget that Sarah is Sarah and everybody who knows her or who is in the family know that's how she is and you forget about it. Then you go out, and you're walking along and she goes, 'arhhhhh' at ninety decibels and everybody is turning around and looking and then they look and realise that you've noticed that they have looked, and they look away.

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 (see chapter 2). When families go about their daily routines, particularly in public places, their performances take on what Goffman (1963) would call '*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 what has been referred to as 'caregiver's burden'⁶ (Montgomery 1989) it can nonetheless function to illicit a positive reaction from those whom a family encounters.

(Cindy)

Well we were in the supermarket one day and a lady came along to us and she knew that there was something wrong with Cindy, she was in her buggy, just like a normal child but because she had those boots on (conspicuous orthopaedic footwear) and she was lovely. I'd rather people did that, it was nice actually, she said 'I hope you don't mind me talking to you' and then we had a lovely chat.

Initially, however, many mothers may seek activities outside the home, away from those routines that define the social and physical space that typify the caring needs of their injured child. In this way they may attempt to leave the situations that continually remind them of their trauma.

⁶ For a critical analysis of the appropriateness of this term see Montgomery's (1989) essay.

(Tom)

I found it quite important to have at least one outside interest that had nothing to do with Tom. That helped tremendously, I mean it was something very banal to start off with, a mother's club you know, just something to get me away from it.

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. In such situations items of clothing, spectacles or any other required commodity conform to the norms of the prevailing fashion. As Karen's mother recalls

(Karen)

I would go over the top to buy her normal things to make her look normal you (must) give these kids every chance to survive out there so that they look and appear as normal to the population out there as possible, (this, as the child's father remarked, is) not to deceive them but (to help them) to fit in.

Clothes that reflect the current trends not only act to make the child less conspicuous, but can also be a public affirmation that their child is loved and cherished.

(Cindy)

She was a bit over dressed, but I felt it was important in a way for me that she always looked nice. And I wanted people to realise that I did care for her even if she did have problems, I do love her, I still do.

Nevertheless adjustments, and not only with regard to aesthetics, are made so that the daily presentations of the family in public align to popular normative expressions⁷. In this way an etiquette is being maintained. Although it may often fail in its attempt to disguise the child's disability it nevertheless acts to illicit 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.

I have suggested that coping has a public dimension, and that this facility may also help to enlist greater empathy with, and support for, the family with a brain injured child. Indeed, it was as a direct result of 'going out' that one mother was able to secure the benefits of 'stair-lift' for her brain injured daughter.

(Cindy)

Another lady in a shop said, 'how do you manage to carry a big lump like that up the stairs ? You know having a giggle with Cindy, anyway she gave us a stair-lift, we couldn't get one from the social services.

Practical, as well as emotional, benefit may be the result of excursions out into the public world. However, any successful coping strategy must

⁷ See Voysey's (1975) discussion on 'normal appearance and official morality'

certainly achieve its specific personal function which, in some way, helps to manage the increased demanding routines and familial concerns that a disabled child places on the various family members. Moreover, in the family's attempts to achieve this they are, at the same time, providing an enriched experiential background in which the disabled child may merge. That the child's embodiment may be expressed in relation to these new situations may act to charge disability with new meaning, not solely in terms of the child's personal corporeal experience, but also in ways which provide the parents with greater understanding of their child as an embodied capacity. Indeed the very process of coping seems, at times, a coping strategy in itself - i.e. the process of coping, irrespective of goal success, often acts to alleviate familial tensions that arise in response to childhood disability. Therefore doing something which may be intended to address a specific problem, frustration or concern gives purpose to action, and in doing so may displace some of the stress and tensions that result from having a child with disability. Furthermore, strategies such as making a public performance help to extend the responsibility for a child's care into the wider community. This not only enriches that community, and enhances the disabled child's personal phenomenology, but helps also to dissipate some of the family's pain that ties them to the trauma. Seeing that some others do, in fact, care acts as an analgesic, whilst the long term benefits of successful coping strategies can be both devised and practised.

Conclusion

The extending out, through relatives, friends and sensitive community media coverage, of the commitment that a family is making to their disabled child establishes the substrate on which 'coping' and the associated strategies are cultivated. It is not just the genesis of coping that originates in the interstices of social space, but also, its fruition. That is, the efficacy of coping strategies to maintain a positive commitment to the child over extended periods of time is a product of the acknowledgement of an underlying social reason. For without the cultivated acceptance and support from those outside the family who make possible the family's engagement with the larger community, isolation would otherwise confound familial resources. These resources, as I have suggested, not only permit a maintaining of a coping rationale, but also shape the family's experiences of their child's embodiment. Social reason, then, in the terms applied here, is an acceptance that what the parents are attempting to do for their disabled child is not just good for the child and immediate family but good also for the larger society. Put simply, if parents did not care for these children what would be the impact on the already over-stretched resources of health and social services? This is irrespective of the cost in terms of the brain injured child's personal embodiment that might further frustrate any hopes for an positive outcome. Finally, when considering the fortitude required there are likely to be few others more willing to commit so much effort and time to a disabled child than his or her family. For parents this, in itself, is a reaffirmation that the social cohesion of the family should remain stable for the benefit of all society.

**Altered States and Audience Perception : An
Anthropology of Brain Injury.**

Introduction

The last chapter looked at the processes of coping with the trauma of having a brain injured child. I argued that such familial trauma inevitably produces stress and anxiety which requires a method of dealing with the changes that these events have on family life. Furthermore, I demonstrated that the private world in which such concerns are manifest has strong public points of access. Not only are the clinical procedures bound to engage the family and child with new external¹ responsibilities, such as those following therapy and administering medicines etc, but social input is also commonly encountered as the family attend to their changed daily routines. Having a disabled child thus puts the family on a public stage², some would even argue that, so much so that when the curtain rises the audience may treat the performers as if an interactive moral play were being performed that begs public comment. Although going out and moving around in public space is what families do, public comments are likely to be registered more painfully by parents who are accompanied by their brain injured child. Discriminating firstly the artefacts of disability, and following swiftly with judgmental

¹ I use the term 'external' here because these are procedures that originate from outside. They reflect a 'professional' knowledge and power base to which the family can often only blindly follow, and where non-compliance can result in increased isolation and despair.

² This is in reference to those ambivalent public responses that occur in supermarkets and doctor's surgeries, in such cases the brain injured child's behaviour is seen as some form of performance that enacts disability (See family comments in chapter 6).

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comments is, naturally enough, deeply upsetting to the parents of a wheelchair bound child.

(Cindy)

Because they look at the wheelchair first, then they look at Cindy and then they look at me. I've had people look me up and down and then look at Cindy like, 'what's wrong with her'? Especially, if she's got plaster or something on. The other day someone actually said 'that little girl has got broken legs'. She had an "A-Plaster" on for her hips to go back in. I said excuse me, her legs are not broke her hips are out of place, and she went beetroot.

The media in recent years, of course, has done much to publicise child abuse and neglect. Thus the often conspicuous presentation of disabled children in ambiguous therapeutic plaster may, not surprisingly, incite some concern as to the cause. This can be seen in the following grandmother's comment.

(Cindy)

If you can't look at a child and see whether she's a 'battered child' or not..... I mean you only have to look at Cindy's healthy and happy little face to see she's perfectly normal (not abused).

Such public perceptions of disability are the focus of this chapter and act as a starting point for a consideration of what I believe is a fundamental feature of the interactions that exist between families with brain injured children 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

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be the nature of the problem with those perceptually ambiguous individuals, brain injured children.

In this chapter I examine, however, the interpretation of perceptual encounters with disability. In doing so, I attempt to disclose the ambiguities in the physical character of brain injury and the subsequent interpretation of these children as the dysfunctional embodiment of pathology. This postulates a 'deficit mode' for the child which is 'rooted in a view of disability as a problem of the individual', legitimising their exclusion not only from 'narrative research', which could give them the opportunity to express their own concerns, but also from the wider society (Booth & Booth 1996: 67).

Central to this interpretation is the assumption that these children are regarded as ambiguous. More precisely, that they are anomalous; at the same time as they deviate from the norm of 'idealised' children they also, paradoxically, confirm it. Brain injured children, 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.

Anthropological research has a rich and diverse history in both demonstrating and interpreting the embedded social categories that operate

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within differing societies. One of the major contributions to this line of enquiry has been Mary Douglas (1966). She has developed a fascinating account of the conceptual anomalies that appear in the categories that some traditional societies use. For example, these anomalies may be items or creatures that should belong to one group but, due to some ambiguous detail, are perceived as inhabiting two discreet and separate categories at the one time. That is to say, they possess some feature or aspects that confirm and corrupt the arbitrary distinctions that people use to order their world:

Above all the subject of this chapter is impossible to discuss except in the light of men's common urge to make a unity of all their experience and to overcome distinctions and separations in acts of atonement. The dramatic combination of opposites is a psychologically satisfying theme full of scope for interpretation at varying levels. But at the same time any ritual which expresses the happy union of opposites is also an apt vehicle for essentially religious themes. The Lele pangolin cult is only one example of cults which invite their initiates to turn round and confront the categories on which their whole surrounding culture has been built up and to recognise them for the fictive, man-made, arbitrary creations that they are. Throughout their daily, and especially their religious life the Lele are preoccupied with form. If they consistently shunned ambiguity they would commit themselves to division between ideal and reality. But they confront ambiguity in an extreme and concentrated form. They dare to grasp the pangolin and put it to ritual use (Douglas 1984: 169-170).

Here, Douglas is describing the conceptual anomalies that the pangolin represents for the Lele. Animal categories, then, do not just concern what is edible food and what is not but such notions are reflected in a total Lele cosmology. The pangolin

contradicts all the most obvious animal categories. It is scaly like a fish, but it climbs trees. It is more like an egg laying lizard than a mammal, yet it suckles its young. And most significant of all, unlike other small mammals its young are born singly (Douglas 1984: 168)

Such a creature is conceptually anomalous to the Lele's categories which impose order on their world for it possesses features akin to both animals and

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man. In dealing with these man-made ambiguities the Lele have devised a cult that enables such oppositions to be translated into a meaningful system that has concord with their beliefs.

My purpose in mentioning the above Lele example is simply to suggest that we have yet to establish the same unity for the ambiguities that people in our society perceive in those who present brain injury. As for the Lele, form is critical and this perhaps offers a key to understanding the ambiguities that surround brain injured children. As I shall now show 'form', or more precisely the physical manifestations that usually accompany brain injury, (spasticity, athetosis and ataxia) is fundamental to the interpretations made of these children. Moreover, it is not just the brain injured child's physical adjustments to a chaotic body orchestrated by dysfunction that are important here, but the implications that such corporeal states may have for the child's self-consciousness are both likely to be involved to a corresponding level.

Altered States: Dimensions of Interpretation

For the anthropologist, altered states of consciousness are perhaps best demonstrated in the many possession cults that exist throughout the world.

This is not surprising when one considers that

Given the belief that there are non-human spirits, and that these affect living human beings the idea that men may be possessed by them is an almost inevitable corollary (Beattie 1964: 229).

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More important for our purposes are the distinctions Beattie (1964), following Firth's earlier notions, makes between the various manifestations of possession. Spirit possession contrasts with mediumship and shamanism,

.... when a person assumes a state of apparent auto-hypnosis or dissociation, and his behaviour, which is not that of his ordinary self, is understood to be due to control by some spiritual agent normally outside him (Beattie 1964 :229).

The important point is that for spirit possession to take place there must be a belief in spirits and their power of occupation. Therefore in many traditional societies illness, abnormality, mental derangement and dissociation may give rise to spirit possession. Historically, western cultures also held similar explanations for the perceived aberrations of a person's behaviour. However, with the renaissance of scientific experimentations such notions had been largely submerged and lost in the 'rational' intellect of Freudian psychopathology (Porter 1991). But the problems of recognising unusual patterns of behaviour and making sense of such aberrations remain. Psychologists may use 'attribution theory', which attempts to make sense of another's behaviour through analysis of the underlying motives, intentions, traits and situations that give rise to a person's behaviour³. However, for both the anthropologist investigating an alien society and the clinician attempting to research brain injury, understanding these often subtle and embedded causal 'agents' can prove somewhat problematic.

In such cases one's experience of another's behaviour is greatly restricted and constantly open to review. The attempt to interpret an

³ For a good general overview of attribution theory see Kelley (1973).

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individual's actions gives rise to the possibility of bias which may be due to 'actor-observer differences' (Jones & Nisbett 1972) which in turn result in the observer ascribing a different set of motives for his own behaviour than he would give to others in a similar situation. All in all, the problem of understanding the behaviour of others is essentially the problem of understanding the influences that affect perception. The causal agents, be they real or imagined, spirit possession or cerebral palsy, not only affect their host's behaviour but also the interpretation of it. I shall return to this point later. For now I must ask whether or not considering altered states of consciousness is a useful model for understanding the various expressions of brain injury.

From the biomedical point of view brain injury can result in disruption of motor, intellectual and developmental processes. In traditional societies, to a greater or lesser degree, these same functions, with the exception of development, are affected in states of possession or trance. A first major distinction between these two types of events is that in the former such behaviours tend to be persistent, whilst in the latter they are usually transient. A second distinction refers to treatment regimens. In Western society treating brain injury involves drug management or therapies which attempt to confer a lasting positive outcome on the injured person and minimise the level of dysfunction to his or her behaviour. On the other hand the induced state of possession in traditional societies is argued, in many cases, to facilitate communion with ancestors or spirits who can offer some relief or insight into the largely temporal and corporeal concerns of those involved (Lindblom 1920, Harris 1955, Obeyeskere 1981 and Stirratt 1992). As with alternative

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therapy for the child with brain injury, possession may therefore benefit one's well being. Janice Boddy's excellent ethnography of spirit possession in the Hofriyati women of the Northern Sudan goes even further to understand the unique experiences amongst those in whom possession illness occurs, as diagnosis and participation in the healing rites provide the individual with scope to 'recontextualise her experiences' and generate self identity (Boddy 1988: 4).

According to villagers, since possession trance fulfils their part of the bargain with the spirit world to restore and maintain human health, it is not pathological but therapeutic' (Boddy 1987: 12).

Boddy demonstrates that the *zar* rite (in which the possession trance is meaningfully fixed into a cultural context) is a therapy to address what Boddy believes to be the Hofriyati women's problematic selfhood. The fact that selfhood is also a problem for the brain injured child may act to register yet another piece of situated commonality to the experiences of brain injury and possession. However, it is unlikely to be the case that the therapeutic treatment of the brain injured child involves those issues of self identity that appear to be so important in structuring the Hofriyati example. On a more superficial level it can be seen that they do, in fact, share requests for appeasement through socially prescribed procedures, be they the *zar* rites or clinical therapeutics. Of course, their underlying rationales differ due to the beliefs that each society holds concerning the amelioration of the presented problem. There is a temporal component at play here and it involves the immediacy of prescribed actions (therapy) to affect that which is afflicting the

individual⁴. If possession trance permanently occupied the body, as does brain injury, and did not improve even after the correct practices were observed, might not this provoke a shift in the underlying beliefs to consider spirit possession as some expression of medical pathology? My point is that permanence of the phenomena, and its resistance to accepted treatment rationales, whether brain injury or possession, is crucial to interpreting the afflicting event. Furthermore, this permanence would need to be explicit in the visible body.

More importantly, then, both brain injury in Western ideology and possession in traditional societies involve specific manifestations of the body and its behaviour. Indeed it is, in many cases, the overt activity of such bodily action and presence that kindles our suspicion that a particular individual is affected. The interpretation of these physical manifestations is based upon culturally appropriate inferences, designed to provide understanding of such events. But if we were now to exchange not the affected individual, but merely the observer's position from traditional to Western setting and vice-versa, the explanation of cause and effect may also be modified. Presumably, might not the prescriptions of treatment aimed at recovering the individual from their present condition also be modified⁵? Here, then, is perhaps one of the primary social contrasts between the conceptual frameworks of brain injury and possession. While possession may be thought

⁴ One wonders how the Hofriyati woman's possession would be interpreted if it persisted indefinitely, would some other condition now be evoked to explain the permanence of corporeal disruption?

⁵ Cross cultural responses to mental 'illness' has been a problem for psychiatry as different taxonomies occur in different cultures which in turn specify different treatment rationales (see Littlewood & Lipsedge 1989).

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of as a transitory state to request favour, or contextualise one's identity (except of course when it is regarded as demonic possession⁶), brain injury in Western society is generally accepted by the medical orthodoxy⁷ as an incurable state with few available options. Possession is often understood, by those more traditional societies in which it occurs, as an event controlled and managed by readily available prescribed actions, usually ritual and spirit mediumship, whereas brain injury reflects a taxonomy of distress for which little action is available to modify the event. My argument is not that these two phenomena have homogenous aetiologies, but that both these different phenomena affect the body's corporeality in quite similar ways. As such, these somatic manifestations are perceived, by others, to involve some crisis in personal embodiment.

Although spirit possession need not necessarily involve healing practices it does often tend to offer a way for individuals to deal with personal and social dissatisfaction (see Gell 1980). In this light possession may, for our purposes, be analogous with Young's (1983) definition of healing as being efficacious from the point of view of those who suffer, whilst curing concerns those

practices which are efficacious from the point of view of biomedical science (Young 1983 :1210).

⁶ Demonic possession differs from that which we have considered here by the fact that it is malevolent, reflecting the destructive nature of evil spirits, a cause of much illness and turmoil. Interestingly it is considered by those involved to be best dealt with through the powers of other benevolent spirits working through a possessed individual. See P.C. Ray (1969) for an account of possession amongst the men of the Lodha.

⁷ And perhaps for many parents due to the authority orthodox medicine has to influence parental decision (see Voysey 1975).

It is from within this latter definition that we find the rational medical statements concerning the outcome for children with brain injury most often argued. In contrast to this, for many parents using alternative therapy, the acceptance that some treatment might assist their child in a positive way makes coping with the coming years (permanence of injury) more plausible and the future more positive.

(Karen)

I think, initially, when she was first born it was a bit of a trauma realising that she is handicapped, and personally on me it felt a bit of a burden because I knew that I had got someone that I would have to look after. With a normal child in twenty years your obligations, theoretically, are discharged but you know with a handicapped child you've got her forever. So I think once you realise and come to terms with the fact that she is never going to leave the home, anything you can do to help you and her enjoy life to the best of her ability is a bonus.

In this one important sense, then, the parental beliefs of brain injury, and those people who subscribe to possession, share the hope that some of the trauma will be, if not resolved, accepted by those involved. This suggests that therapeutic efficacy could be considered more constructively, from the patients view at least, if it attempted to measure its success at the same personal level that makes possession so meaningful to those societies in which it occurs i.e. not 'objective' in the strict sense.

As noted, both events are also likely to be perceived primarily by the outward bodily aspect, that is physical form. Indeed, the very issue here is that deviations of posture, dissociation and general untypical motor activity is likely to be perceived by an observer as a sign of perhaps possession in some

traditional societies and as brain injury in the Western context. Whereas other manifestations of the body i.e. anger, grief and frustration work also to modify physical activity, the person's behavioural integrity remains unaffected because such expressions of posture merely act to highlight the action. In fact they are, in a way, purposefully used to communicate the very emotional state which inspired them⁸. However, for brain injured children in our society such fine tuned expressive behaviours are submerged or lost beneath the spastic and / or athetoid muscle conditions that most typically attract public attention. The tendency is to at once perceive the abnormal postures of body, and the sometimes accompanying distortions to the face, as the deviated manipulations of a person out of control.

Ekman (1977) identifies several types of non-verbal behaviours or kinetics which can contribute to observer perception, the three main types being 'emblems', 'body manipulators' and 'illustrations'. The former and latter have the effect of conveying supporting information about what is being said. However, 'body manipulators' concern'.... movements in which one part of the body does something to another body part' (Ekman 1977: 47). It is important to contrast this activity with both 'emblems' and 'illustrations' since 'body manipulators' are more likely idiosyncratic, unconscious and non-supportive of the speaker's dialogue. That is, they do not facilitate an extra-expressive dimension to the speaker's statement as would both emblem and illustration.

However, because such actions are likely to, albeit unintentionally, inform the observer in some way or another, they are of interest here because

⁸ For a good account of the body aiding emotional expression and the various actions it performs, see Ekman (1977).

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similar kinetic expressions are often operating during contacts with brain injured children. Although such interactions are not intended to transmit a message, they do provide an observer with information. For example, it has been shown that people who demonstrate these idiosyncratic body manipulator actions are characterised by observers as tense, awkward and untrustworthy (Ekman 1977: 47). I would suggest that the spontaneous reflexes or contractions which occur extraneously to intentional activity in the cerebral palsied child are read with a similar interpretation. Such manifestations can, at times, be so conspicuous as to inform other brain injured children that an individual is, in some way, affected.

(Karen)

Because Karen got off my lap, and she is the size of a six year old with the behaviour of an eighteen month old, and I had to keep retrieving her because this child was screaming and stuff in his wheelchair and Karen stopped in her tracks and looked at the child and instantly saw that this was not normal and came shooting back to us. She was a bit upset and quite disturbed.

Of course, no real responsibility can be attached to the injured child for such actions as it is due to the underlying neurological trauma. This is likely not to be the case for other individuals who must, to some degree, assume the responsibility for their supplementary kinetic behaviours. Ekman states that

parents, of course, hold their children accountable for body manipulations, but it is for being uncouth, impolite, etc, not for having said something with this type of activity (Ekman 1977: 48).

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Although these responses are not wilfully inappropriate, they nevertheless provoke a certain level of discomfort in the observer. I would argue that the perceptions which result from such encounters are actively constructed by the observer in response to his or her own anxiety toward a particular situation they find in some way threatening.

Furthermore, these perceptions may reflect a shift in focus by the observer to explore, in greater detail, the extraneous behaviours in order to negotiate a fuller understanding of the causal agent responsible. The purpose of such perceptual responses by an observer may be to identify the elements of personal anxiety as resulting from maladaptive patterns and actions that are manifest in the behaviour of the person they are observing, and which are discontinuous with their own. As individuals tend to be culturally situated any explanations sought may now reflect the prevalent view of the society in which the observer operates. Such a view may help to confirm that these extra-expressive kinetic actions, observed in a child within our own society, are perceived as resulting from some form of brain injury, whereas similar modifications to behaviour occurring in a traditional society might well be indicative of spirit possession. Thus whether observing the behaviour of a brain injured child or a spirit possessed person the tendency is to adopt a focused account of the physical activity that orchestrates their bodies in the attempt to reposition the extraneous elements of the affected person's behaviour away from one's own typical actions.

In this way bodies, in both form and expression, occupy a space laden with meaning, a space which must be interpreted by all those who encounter it.

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For this reason even the lack of deliberate purposeful action in the brain injured child becomes understandable as the deviated expression of typical behaviour. In this way we are all likely to be critics of the corporeal manifestations of embodiment. One of the explanations for such an active interest with the body is given by Merleau-Ponty in the *'Phenomenology of Perception'* who postulates the significance of the body as being

no longer conceived as an object of the world, but as our means of communication with it, to the world no longer conceived as a collection of determinate objects, but as the horizon latent in all our experiences and itself ever-present and anterior to every dominating thought (1962: 92).

The idea that the body enables communication with the world in which it is situated may help to explain our interest with it, but does it answer how valid such introspection is to the appreciation of therapeutic procedures designed to address the disability we perceive in others? This question is especially relevant when our experience of disability results from the imaginary contrast between that external disability which affects others and the internal abilities which we regard as central to one's self. In another sense this same dilemma is likely to be faced by those who must transform their status to communicate with spirits in order to effect changes that can only be achieved when they are no longer under temporal and corporeal constraints. Thus although spirit possession, in the general terms used here, may not be directly analogous to brain injury it could be relevant to the activities of the therapist, who must transcend his or her own physical and mental accomplishments in the attempt to bring the disabilities of the injured child into the light of

personal experience. This would clearly be impossible for the therapist who intellectualises over dysfunction from the security of medical science, thereby favouring physiological knowledge over personal experience. If to perceive the injured child's problems requires such reductionism, we are perhaps no longer dealing with the child. In fact, this is the situation many parents fear during their consultations with clinical medicine.

(Cindy)

I just felt that soon as they (doctors) had given Cindy a handle (label) that was it, they felt they could slot us away.

This, then, highlights the different interpretations of brain injury that exist between those who attempt to gain experience of disability and those who intellectualise it⁹. The point I wish to stress for the moment is that 'altered states' do not just depend upon postural, cognitive and aesthetic factors for their determination. They also require a conceptual framework into which such detail can be located and socially interpreted. Interpretation, then, is not just important for the reconciliation that some problem is occurring in the individual but is also required for the appropriate directing of action. Talle's (1995) monograph concerning childhood disability and equality amongst the pastoral Maasai in Kenya provides a good example of this by noting that

disabilities that are caused by humans may not differ in kind from those inflicted by the deity, but the former may be identified and can be healed (Talle 1995: 63)

⁹See 'Chapter 5' for a discussion on the orthodox and the alternative with regard to therapy.

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Making sense of a such anomalous behaviour allows the Maasai to recognise which individuals can be effectively treated. That is to say, identification of one 'type' or 'condition' is not only exemplified by observing the physical character or aesthetics of the individual, but also by how well the condition responds to procedures that attempt to ameliorate it (see Chapter 5). This not only reinforces the notion that temporal factors (in terms of long-term resistance to treatment protocols, be it magic or medicine) are important but also confirms the notion that the physical presentations of the body (anomalous behaviours) in any given society require the 'appropriate' i.e. culturally situated schema. This is crucial if observers are to find meaning in the 'overt' displays of disability. Not finding this meaning may give rise to statements that are unsympathetic to the personal trauma of disability. This is typified in the following mother's account.

(Cindy)

People look and stare and sometimes say stupid things. Sometimes I ignore it, it really depends on ... ('its hurtful', Grandmother interjects) perhaps if I've had other problems within the family or things have gone wrong in the day then I can get really upset.

These culturally fixed schema act not only as the genesis of interpretation but are instrumental in creating and maintaining the perceptual categories or states in the first place and, as I intend to show, these schema may exist largely independently of the individuals and the behaviour that they perceptually locate.

In summary, I have suggested that when one encounters a particular behavioural pattern accompanied by atypical motor activity, an explanation is sought to understand the deviant expression as a reflection of some specific causal agent. In those societies where spirit possession or brain injury are socially recognised, the presumed responsible agent underpins the observed action and orchestrates the body in such a manner as to make abnormality evident. I shall now consider such manifestations of the body's motor activity and their direct affect upon possible cultural interpretations.

Audience Perception.

Fine tuned motor behaviour is a complex event involving a well integrated central nervous system. It requires that cortical, cerebella and ganglionic systems function in unity to express well articulated movement (Gardner 1975: 206). The precision with which we navigate our bodies is rarely appreciated unless its accomplishments are contrasted with those of a person with motor impairment. In order to make this point clear I shall now attempt a symbolic\semiotic sociological analysis of motor dysfunction to discover the level to which underlying causal agents may be implicated. However, it should be noted that the patterns of motor activity that concern us here should not be confused with the variety of '*Les techniques du corps*' that Mauss (1936) has postulated to be specific to gender and to determinate societies, although in fact these same techniques may well be implicated, at a submerged level, in the dysfunctional motor processes with which we are

concerned. I shall return to this point later. For now, however, I shall describe some of the more salient features of affected motor behaviour.

The co-ordinated actions of motility go largely unnoticed by the other 'specialists' who have also mastered the precarious ambulence of bipedal dexterity. We take for granted the unity of co-ordinated mechanical action of the musculature in response to vestibular (balance) information operating through cortical systems informing the purposeful body as it skilfully operates in space. The fact that this complex action of walking is even further enriched by individual, gender and cultural artefacts imposing their character on the person's gait, adds an apparent infinite variety to the action¹⁰. Of course, as we are specialists in this enterprise any falterings observed in the mechanical competencies of others are immediately noted and an explanation is usually sought. An accidental slip on the mythical banana skin seems hardly ever to fail to give rise to a smile, if not an outburst of contagious laughter. Indeed, the popular TV shows that transmit the unfortunate mishaps of individuals provide great comedy for the viewing public¹¹. Why should such misfortune attract so much attention? Is it because, for a moment at least, they have lost control to the prevailing influences of gravity or have succumbed to some incompetence wherein poise, posture and motor control have been momentarily superseded by chaos? Or can one interpret such misadventures of motility as evidence of interest not in cause but effect? In this way, the banana skin, spirit possession, and brain injury can all be attributed as the

¹⁰ See Mauss (1936).

¹¹ Programmes such as 'You've Been Framed' and 'It Will be All Right on the Night' attest to this.

causal agents of atypical motor function, and work to provide symptomological proof for the varied *social* constructions of such behaviour.

Only through the employment of a specialist can the true diagnosis be recorded. As the shaman must discover which spirits are involved in the possession, so too must the clinician attempt to define the problem of brain injury by identifying the underlying pathology. Lewis (1989) demonstrates convincingly that many of the accounts of spirit possession among traditional societies provide an ideological way for individuals, particularly those who are in some way marginalised, to readdress their misfortune by spiritual intervention. This may involve requests for items of clothing, food and foreign goods, from which they are normally prohibited¹². In contrast, however, although the clinical diagnosis of brain injured children may well aid medical thinking, it is not a satisfactory model on which to base educational provision (Brown 1984: 705).

Therefore the benefits derived from the clinical treatment of brain injured children may have less value to the child and his or her parents than those procedures that operate in possession cults. Indeed, within those societies where spirit possession occurs the affected individual is believed to be either

¹²Lewis provides a well developed view of spirit possession as involving 'female problems of many cultures, whose diagnosis and treatment gives women the opportunity to gain ends (material and non-material) which they cannot readily secure more directly' (1989: 77). Lindblom (1920: 237) refers to such states as, 'deceitful feminine tactics', employed to obtain or extort her desires from her husband (see also Grace 1957). Men are not immune from possession although it seems a more frequent event amongst low status men. 'Those men and women who experience these afflictions do so regularly in situations of stress and conflict with their superiors, and, in the attention and respect which they temporarily attract, influence their masters. Thus adversity is turned to advantage, and spirit possession of this type can be seen to provide an oblique strategy of attack' (Lewis 1989: 105).

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cured or favoured by a particular spirit. This is not the case in Western societies where disability is 'clinically managed' even though

the needs of the physically *handicapped* (my italics) child are to some extent independent of his medical condition (Brown 1984: 705).

As such, spirit possession is likely to result in a more sensitive appraisal of the individual's needs than that offered to children with brain injury by medical professionals.

(Cindy)

They don't listen to mums, they think mums are overreacting When I actually had her she came out of the incubator and was put in her cot this doctor came to do his rounds and I said to him 'why is Cindy's big toe stuck out? He said, 'you're being fussy mother, push them down' . Well that was her spasticity in her feet.

The contrasts between diagnosis on the one hand and therapeutic efficacy on the other are evident in the specialist's approach, be it medicine (as in the insensitive example above) or shamanism. These contrasts are not present, however, when describing the character of the physical manifestations which serve to typify a given condition. In both situations the detail of anomalous behavioural patterns, which are, incidentally, what initially inform on the occurrence of some change, 'deviation' (Goffman 1963) or 'liminality' (Murphy et al 1988) in the person reflect the various aetiological agents believed to be responsible in that particular situation i.e. spirit possession or brain injury. In this way hypertonic episodes of the arms (spasticity) may be considered to involve a cortical or pyramidal tract lesion, epileptic seizures or,

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in some traditional societies, the first stages of spirit possession. Of course, my intention is not to argue that the suspected cause of motor disruption entirely depends upon an interchangeable notion reflecting only the situation in which it occurs. It is instead to suggest that organic forms of dysfunction may not always be interpreted as being discrete from spiritual types in traditional societies. Lewis confirms this when he states that

we should note that where spirit possession is a regular explanation for disease, that fact that certain forms of insanity and epilepsy may also be regarded as manifestations of possession does not necessarily mean that the people concerned are unable to differentiate between them and other forms of possession (Lewis 1989: 165).

Indeed, although the conditions Lewis describes, namely insanity and epilepsy, are 'usually clearly distinguished from other possession states' (Lewis 1989: 165), it is not clear from his account how such distinctions are made, particularly when the overt behaviours of cerebral palsy, for example, and possession can sometimes be similar in their motor expression.

I have mentioned earlier that the fact that such events occur in space and time is likely to be of great importance: for example, the deviated extortions of body and accompanying loss of motor control that tend to typify both events would be almost undifferentiated from one another if not for the mediating feature of time. Transience and permanence of a particular incident may greatly affect its subsequent interpretation. However, another way of determining the origin of a condition might be dependent on how well change is effected when the particular specialist is called in. In the case of spirit possession, if the condition is ameliorated by the involvement of an

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appropriate person it is likely that the possessing spirit has been contacted and, to some degree, appeased. The failure of an otherwise successful shaman to negotiate success might suggest, however, that a causal agent other than that of a spirit is involved. Could now brain injury be conceived as being at least a possibility? The point I wish to clarify is that bodies and their functioning are embedded in a socio-cultural setting, and as such their actions are constantly being interpreted by other members of a given cultural set. Overt disability is often culturally represented as being a product of brain injury for mothers of impaired children in Western society, while for a child born in another society a different explanation is likely to be sought. An ethnographic example from the Punan Bah of Central Borneo confirms this, as here a child disfigured by impairment may well be classified as a 'non-human spirit' (Nicolaisen 1995: 44). As Douglas (1984) has shown with the Lele example categories that maintain boundaries between human and animals or children and non-human spirits have at their centre an interest in the form which typifies the nature of its possessor. In this way a child born to a Punan Bah family with conspicuous disability breaks the rules that govern how a human infant should be. The child's essential human spirit is now compromised and must be reclassified as non human. Somatic manifestations are therefore not aetiologic in themselves but rely more upon interpretation than mere presentation. In discussing the importance of the somatic manifestations of the body for anthropology John Blacking suggests that

somatic idiosyncrasies are the concern of an anthropology of the body only if they need to be evoked to explain a person's action in a particular situation (Blacking 1977: 13).

Thus, similarly, aspects of physical form are only relevant to an anthropology of brain injury if they can be shown to affect awareness and subsequent interpretation of some process. Deviations from typical somatic expression, as would be associated with spasticity, not only act, in Western society, as clinical indicators of central nervous system pathology but are also here laden with social and cultural meaning, a point that some clinicians seem unaware of.

For example, doctors not only believe in their clinical diagnoses but are also subscribing to current, and socially informed, lay ideas that nothing can be done to help brain injured children. As one father recalls

(Fiona and Tony)

Certainly, a lot of doctors, after we had gone away, must have said 'gosh, those poor naive parents they think there is something that could be done, and we've told them there isn't'. And that came across several times.

This may, for some parents, have a debilitating affect on the brain injured child and his or her family who are attempting to both ameliorate the condition and cope with the stress of their situation in the community. As Voysey (1975) has shown, parents may often comply with such medical speculations.

Negative audience perception, then, generated by both lay and professional perspectives, may act to de-structure their social relationship with

others. Furthermore, these perceptions do not only arise from adults since children also are sensitive to the physical expressions of the body.

(Karen)

I sometimes see other children ask our children 'what's wrong with your sister'? We had a football team come to school and some boy said 'oh, what's wrong with her?' And in fact, it wasn't my son but his friend who said 'she's handicapped that's why she doesn't move'.

It is because the ramifications of neural injury inform on a body, in both a reflective and overt fashion, that social detection of a personal traumatic event is recognisable. More importantly, it is not just recognised, it is actively interpreted to either the benefit or detriment of the child and family in question.

(Karen)

Yes, you can always pick out the 'Downs' kids who are born to old mothers as compared to those born to young mothers..... You can spot them a mile off, with the girls they have their skirts and 'twin sets' and their hair cut round here (pointing to the forehead) and their long cardies over the top and you think 'oh look at that girl'. The 'Downs' kids that are dressed normally you wouldn't notice them, its only when you come to talk to them. I mean you would notice Glyn (a young Down's syndrome boy) when he starts to run.

Clothes, as we saw earlier, are important indicators, not just to make the brain injured child more or less perceptible but also as a social statement that relates in some way to the child's parents. However, 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.

It is for this very reason that the issues of audience perception are more than theoretical. I shall now consider more closely the characteristics of these 'somatic idiosyncrasies' and attempt to analyse their social significance.

Social Meaning and Physical Form

Many researchers have emphasised the role of body actions and expressions in human communication systems (see Blacking et al 1977). In perhaps a more subtle fashion, an historical legacy given by Mauss (1937) and Hertz (1909) has demonstrated that functional techniques and preferential asymmetry, respectively, also enrich the social identity that bodies implicitly express. It is no wonder, then, that deviation of physical form and its consequent expressions also convey information. This information is, however, ambiguous because it fails to conform to the typical processes that are believed to be present. Thus there is an expectancy that the behavioural performance of individuals will conform to appropriate cultural patterns in particular situations. In the new-born infant, the mother and enlisted professionals observe carefully that infantile reflexive responses are superseded by more purposefully integrated activities as the child develops. Likewise, many of the ecstatic convulsions that possess cult initiates conform to stereotypes that confirm spirit involvement. It is such events that I shall now attempt to explore so that a deeper insight into the situational dynamics of bodily interpretation can be disclosed.

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Cerebral palsy is a generic term that covers a variety of neurological disorders of movement. More precisely, 'cerebral palsy is the motor manifestation of non-progressive brain damage sustained during infancy and childhood' (Brown 1984: 706). For children with cerebral palsy, neurological diagnosis could include such statements as hemiplegia, ataxia or dyskinesia¹³. Although these conditions are often clinically regarded as discrete it is not infrequent to find that the brain damaging event may have affected other areas of CNS functioning. Thus, the child with spastic diplegia (affecting lower limbs) may present other problems which are not neuro-motor in origin. Epilepsy, learning or behavioural problems and hyperactivity may or may not be present, but should not be solely regarded as complications of cerebral palsy. More specifically, cerebral palsy 'results in abnormal posture and movement' (Jani & Sapienza, 1989 : 41) and it has, therefore, at least a tenuous relationship with those features that characterise the physical disorder induced through dissociation and possession. The idea that processes of the vestibular complex (balance) play an important role in motor management highlights the contribution that some anthropologists have made to our understanding of the cultural specificity of bodily function. Huxley, for example, in discussing the use of drum beats in voodoo, argues that

we can trace the physical pathways by which they (dissociation and possession) have their affect without much difficulty: they centre on the inner ear whose automatisms, when thrown into disorder, affect posture, heartbeat and the use of the eyes (1977: 36).

¹³ Hemiplegia refers to neural injury that cause problems to one side of the body. Ataxia concerns those behaviours the are affected by balance and cause voluntary movements to be clumsy and uncoordinated. Dyskinesia involves involuntary movements and abnormal muscle tone to be prominent.

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This vestibular complex, as we shall see later, is often a central feature of dissociation and possession and has, not surprisingly, equally important implications for the brain injured child.

Alfred Gell's (1980) excellent monograph concerning '*Vertigo and Spirit Possession in Muria Religion*' shows not only how vertiginous activity 'becomes a means to religious awareness' (1980: 218) but also that such activities, which encourage deautomatised states, may have theoretical parallels in childhood autism. The participating Muria, a tribal people of Central India, achieve 'certain special experiential states which perhaps border on ecstasy' (Gell 1980: 225) with the use of specific techniques and items associated with the gods. Gell demonstrates that dance, swinging and possession trance (particular somatic activities) help to disembed sensori-motor integration and alter consciousness. One such item employed by the Muria is the *anga*, a quadrangular wooden framework with a forward projection likened to a horse's head. During the *Divine Games*, a religious festival wherein an assault on the equilibrium sense seems compulsory, the *anga* is supported on the shoulders of two, sometimes four, youths. The music, which establishes '.... a mood of excitement and dissociation' (Gell 1980), is provided by the *ganda* cast (weavers). As the dance continues the *anga*, imposing its gravitational influence upon its supporters, seems to be compensated by the almost autonomous somatic and kinetic energy of the youths.

Gell is careful to point out, however, that such responses are not those of the intellect reacting to the forces imposed by the presence of the divinity articulating the *anga*, but concern the *kinetic forces* generated by the dance.

These forces act to create a *gap* between the initiates' intentions, i.e. those kinetic compensatory mechanisms that attempt to maintain a degree of homeostasis, and the consequence of their own action with regard to such influences. The results of these procedures affect vestibular system function, which allows the individual to regulate his own behaviour relative to the external actions of others. Thus, a state of dissociation is achieved. The Muria employ several techniques that affect or alter consciousness during their festivals of religious awareness, but it is particularly those altered states that induce Muria possession that are of most interest to my discussion. Arguing that the psycho-physiological mechanisms, normally described in the literature, play only a small part in Muria possession, Gell suggests that

we should recognise that certain patterns of motor activity are capable, in and of themselves, of producing alterations in consciousness, as well as being signs that such an alteration has taken place. The external indicators that a particular medium has been entered by a divinity are certain motor patterns which produce changes in the medium's own internally monitored self-world relationship..... (1980: 233-234).

In a similar way patterns of motor activity, or even their absence or frustration, are indicated in non-progressive states of brain injury. The crucial point in both Gell's analysis of Muria possession and the observations of brain injury recounted here is that the physical manifestations of these two events act as a semaphore signalling to bystanders that ordinary corporeal conduct has been compromised. For example, an observer witnessing a person with rigid body, an extended neck and an increasing tremble affecting primarily the forearms and hands, while the eyes maintain a fixed stare until, with eyelid flutter, they droop, naturally seek an explanation for this behaviour.

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Moreover, the violent extensions of the limbs accompanied by repetitive yawning, staring eyes, groans and trembling body, escalating to a total and sudden rigidification whereupon he falls to the earth in a contorted position, would surely indicate that this person is in need of assistance. Indeed, assistance he receives from those around him who, having recognised a break with motoric convention, attempt to bend and massage his stiffened limbs. During this phase one notes the apparent loss of normal muscle tone, especially in the neck and arms. The head rolls loosely to and fro, and the arms limply rest at the sides while he lies prone on the earth. If we now compare the above observations with another description of anomalous motor activity we might be able to discern similar and variant features occurring in dissimilar situations. For example, in this next case an observer notes bizarre and uncontrollable movements, tremor and or writhing and jerky movements of the limbs. The face and tongue may also be affected. There is a paucity of controlled movement, affecting fine tuned behaviours and causing general weakness. Muscular tone fluctuates with hypertonia and hypotonia, they may be unable to maintain their weight, giving rise to a strange dance of alternation of the supporting leg whilst the other paws or scrapes the ground. A paralysis of gaze is noted, as is a fixed stare, and dystonia or twisting of the head, trunk or limbs may also be present.

There are, without doubt, behavioural similarities between these two events, even though they are not at all related to one another in any way other than their presenting atypical, that is from the normal, range of motor activity. As in the former case, this latter activity elicits succour from those around who

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recognise, by abnormal motor patterns, that some form of help is required. However, in order to interpret these two situationally discrete events one must first enquire into their cause or aetiology.

In the former case I have narrated the ecstatic religious event of a Muria medium who has, in the possession state, become the steer of the divinity, and as such mediates communion between the Muria and their god (Gell 1980). In the latter example I have related the observations of a physiotherapist with some considerable experience of children with athetoid cerebral palsy (see Levitt 1982: 8-9). One possible link between these two cases of abnormal motor patterns is the experiential deficit with reality that results from the motor manifestations of such activity. As mentioned, in the Muria possession example Gell shows that the Muria

represent their divinities as experiencing the world in the same modalities as the Muria employ when they seek to have access to them. The Muria, that is to say, experience their divinities through engaging in certain activities involving the body, and in particular, the equilibrium sense: when they represent their divinities through enactments (as with the swinging of the mediums) or by icon (temple images of gods on elephants, swings, horses, etc.) they do so in situations in which this same sense modality is brought into play, (Gell 1980)

The effects are transitory, for in Muria religion the medium engaging in these vertiginous activities is not emulating the gods he is the 'divinity performing the actions which render experience divine, which abstract it and set it apart from mundane experiences' (Gell 1980). In contrast to this, in the athetoid description the behaviours reported here are not separate from 'mundane' (usual) experiences, but rather, represent the continual engagement of aberrant motor patterns or develop into other forms of dysfunction. The

temporal considerations that make such experiences transitory for the Muria provide a lifelong time scale for the parents of a brain injured child. Gell argues that a possible common feature to both severe autism (brain injury) and Muria possession might involve dissociation through vestibular dysfunction or over stimulation. His suggestion is beyond the scope of my discussion here, but there certainly are pertinent points in his analysis which warrant further research¹⁴, particularly with reference to the possible implications of sustained vertiginous activity and the consequence of this on an individual over extended periods of time.

It was shown earlier that in some traditional societies errors are seldom made in perceiving possession as discrete in nature from mental illness or epilepsy (see Lewis 1989: 165). As we have mentioned above, transience of the event may be one possible diagnostic feature of possession¹⁵ but epilepsy is also a transient condition. So there must be other factors involved. Muria possession occurs during religious festivals, although many other forms of spirit possession affect those individuals who feel themselves more permanently marginalised by the dominant and powerful groups within their society (see footnote no 12). This, in one important sense, is similar to that

¹⁴ Certainly the vestibular system, with its cerebellar associations in the cortex, brainstem and spinal cord, plays a key role in affecting motor behaviour in the cerebral palsied child as well as its involvement in Muria possession. Although it is intriguing to consider the possible affinity between childhood autism and possession, our concern here is to ask how onlookers recognise and interpret these similar motor events. Furthermore, it is probable that higher cortical (cognitive) association respond to specific stimulation of the cerebellum (involved with motor behaviour) in particular ways which in turn act to induce alterations in consciousness that are recognised as the states of dissociation that are here discussed.

¹⁵ Once again we can observe that temporal phenomena underscore much of the experiences that are involved with the interpretation of disorder in physical form (see the discussion on time in Chapter 6, *Coping Strategies*).

view argued by Murphy et al (1988) who suggest that disability gives rise to an experience of 'liminality' for those individuals affected in Western society.

However brain injury, and more specifically the type with which we are here concerned, can have its onset in the uterus, birth or early infancy and unlike possession is not, generally at least, influenced by the individual's status, position or membership of a particular group¹⁶. Thus, although the distortions to physical form are similar in both their expression and in the alteration of the individual's consciousness that may be suspected to have taken place, there remains one major difference.

Possession, as we have seen, occupies the individual and manipulates his or her behaviour in a prescribed manner that acts to both contextualise the individual's experience and its subsequent interpretation by others. The resultant corporeal manifestations that are perceived in the brain injured child, however, reflect a contrasting ideology inasmuch that the child may be reduced to the state of a virtual automaton. In a way, the brain injured child may be commonly thought of as being metaphysically dispossessed of his or her human spirit¹⁷ unlike the individual who is possessed by an extra and external spiritual agent. This notion is empirically attested to by the many families who express a desire that therapeutic practice might return or reinstate

¹⁶ For an interesting account of those who are most vulnerable to demonic intentions see Stirrat (1992: 79-98). He proposes a van Gennep (1908) '*rites de passage*' notion wherein young women, between puberty and marriage, (marginalised) are more susceptible than are adult males who are typically more aggregated into the dominant aspects of society.

¹⁷ Among the Punan Bah of central Borneo a severely disabled child may be referred to as being a non-human spirit because the body is believed to be the exact copy of the spiritual ego. Deformity of the body must now image something other than the reincarnated essence of an ancestor. 'The boy looked monstrous, as do the spirits, hence he was one' (Nicolaisen 1995: 44).

their child, lost to them through brain injury. As one mother who recounted her husband's hopes stated.

(Philip)

He's fighting to get his son back, the one he had before the accident. You know, when Philip does something now, personality wise, that he did before the accident he (father) gets more excited because its still there, his personality is still there.

In cases where the injury occurred in early life, from some traumatic event, for example, it is common to find parents retaining a photograph of their child before injury, believing that the child in the photo is not the same child they brought to the clinic.

(Philip)

In a photograph its 'still life', its like you know they were there yet they are not there.....

Another researcher, working in an intensive care unit, has also noted the contradiction of the past tense being applied to their child's present state whilst a photo is retained, once again from before the event, to represent the child they believe may be now lost to them¹⁸.

The altered states that affect the brain injured child, then, are seen as the result of some very special quality, which the parents readily identify, being suppressed, obstructed or even lost due to some technical agent represented by medical terminology. In this light the role of therapy is to help

¹⁸ From a personal correspondence with Dr Allison James which refer to an observation by one of her post graduate students, Bernard Place (1997).

the family acquire a more positive resolve, and achieve a better outcome for themselves and their child. The child dispossessed of its spirit is not believed to have been occupied or taken over by another entity but to have lost his or her very own identity. The resultant anomalous patterns of behaviour that disrupt motility are not the manifestations of *divine occupation* which act to enrich the experiences of its initiates as can be seen in the Muria example but, instead, are seen as the consequence of spiritual deprivation. Indeed, it is the enormous implications of dispossession that lead many, even some professionals, to the conclusion that there is little to be done.

Finally, here is one of the most pertinent contrasts between spirit possession and the symbolic dispossession of brain injured children. It has been shown that in some traditional societies spirit possession can be a device to negotiate a positive change to the circumstances of the possessed individual via exorcism, catharsis or healing (Stirrat 1992 and Lewis 1989) or confirm self identity (Boddy 1988). Here we see the altered states and abnormal motor patterns that accompany and characterise possession helping to inform the community that an individual is affected and that he or she requires appropriate treatment. This is typically achieved with prescribed procedures that appease the affecting spirit (and often the individual), and heal or cure the possessed person. Brain injury, too, is often recognised as involving divergent or abnormal behaviour but this recognition plays but a little, if any, part in prescribing effective treatment procedures. Indeed, once brain injury is diagnosed and the child's medical condition is stabilised, the focus of attention

is, as we have seen, directed largely at management, since a cure tends to be professionally regarded as implausible.

There are, without doubt, many differences between brain damage and spirit possession. For example, the organic nature of the former constitutes precise problems for those who wish to attempt an amelioration of the condition. But as difficult as this is, organic pathology is not sufficient evidence for the notion that there is no positive course of action to be taken, although it can often provide a powerful excuse for such statements. Rather, corporeal manifestations, (brain injury or spirit possession) are best tackled by exploring the assumptions on which therapy, exorcism or management are made. The point I wish to clarify here is that, independent of the nature of the event, the important issue is how the accompanying social problems are addressed. Though there may be no final conclusion in terms of therapeutic success for those who suffer brain injury, it might be more profitable to recognise the possibility that there are likely to be other options than those which purely address a symptomology.

This, then, points to a possible explanation of why alternative therapy is so popular. As in many possession cults, alternative therapy, particularly that form with which I am presently associated, attempts to address the problems of brain injury through exploring the child's functioning potential within the social world of familial enactment. (see chapter 6). That the social constructs which underpin spirit possession in many traditional societies seem more sensitive to the embodied enterprise than those structural notions which address brain injury in orthodox medicine suggests that in the former case they

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provide a rationale for action in a prescribed, and generally accepted, cultural manner. In the latter case of brain injury the very lack of recognisable ameliorative procedures is more likely to encourage apathy or frustration with the medical conventions that exercise control. Furthermore, as we have seen, this model does little to encourage positive familial strategies, even though they may prove to be amongst the best available options (see chapter 6 *Coping Strategies*). Thus the spirit possessed person, through open and sympathetic recognition of the event and its exorcism, is 'brought back to the fold', whereas the classification of a child as brain injured tends to produce an effect to the contrary.

The fact that the temporal dimension is important as an assessment of efficacy need not negate the possibility that future changes in both therapeutic practice and social sensitivity could improve the situation dramatically for brain injured children. Unfortunately, however, at present many families attest to the fact that diagnosis of brain injury is often accompanied by social isolation, wherein the prescribed treatment offers little in the way of enabling the child and its parents to maintain their relationships with the larger community.

(Timothy)

After hearing the diagnosis that Timothy was severely brain damaged, we returned home, sat down and felt that we had nothing left. Our lives had changed and the people about us seemed to have changed, we felt alone.

In this way clinical medicine does little to encourage the techniques of positive social action that are in many ways similar to those notions advocated by Illich (1975)¹⁹ and are seen, in part, to be a function of spirit possession.

Anthropology and Brain Injury

What, then, has spirit possession to do with the brain injured child? Does it provide a convincing model to analyse and interpret the common features of motor dysfunction that are diagnostic of both conditions, or even explain them? The answer to these basic questions must be no. What I have explored in this chapter, however, is that both phenomena have common features which, although not structurally related, share interesting behavioural aspects with one another. Indeed, the issues addressed here concern the identification and interpretation of specific physical expressions of the human body, and their implication for the construction of social meaning. If my account has been clear, then we have seen that particular manifestations of physical form and behaviour share common features with one another, but are distinguished by their relevant community members, not so much by technical skill as by social reasoning. To understand the complex aetiological agents involved in both spirit possession and brain injury may well require the sophistication of the shaman or neurologist respectively, but there is yet another, more basic, reasoning at play here which is more readily available to those it concerns.

¹⁹ This statement concerns the notions postulated by Illich which he refers to as 'iatrogenesis' that 'describe the social and physical pathology that originates in medicine and in the activities of doctors' (Hillier 1982: 180). The affect of this most likely suppresses the abilities of individuals to take an active role in their own well being.

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The categories most used by those involved with these two phenomena reflect the contrasting notions of possession and dispossession. In the former these act to identify man's humanity, as the body is the target of divine occupation (Gell 1980). Not so for the brain injured child, whose body is, at the extreme, regarded as the discharged chattel of a lost spirit ousted by gross physical impairment. It may, however, be true that physical impairment plays only a small part in such a view, as it is the impact of disability upon the child's social development that is likely to cause the most concern. Blacking has noted a similar concern when he states

sense-deprivations such as congenital blindness or deafness may inhibit or change the course of development, but they do not impair the humanity of the organism as does social deprivation (1973: 3).

This is, I believe, a major distinction between spirit possession and brain injury. The behavioural effects of spirit possession are, as we have seen, not only transitory but as such have not, or do not, affect the individual's continued social functioning in time. They act rather to punctuate it. The child with severe brain injury, however, may have lost, or even failed to acquire the subtle patterns, attitudes, expressions and behaviours that are the result of continued and effective social interaction. The question I must now return to is what is the significance of these considerations for anthropology, and are they relevant to understanding children with brain injury?

My first consideration has been with the body and its experience, more specifically its social construction, itself a concern of anthropology. This interest has demonstrated that the body is not just a physical entity; rather it is

an expressive tool utilised by individuals and groups in communities and cultures to communicate and express their personal and collective identity in a myriad of social situations. In this sense the body is a social entity with private aspects. Indeed, as Ann Becker (1995) argues.

The Western cultivation of the personal body requires that personal excellence and identity can be represented (or misrepresented) by manipulation of bodily symbols indexing aptitude and discipline. Moreover, this cultivation presupposes that the self has jurisdiction over the body for the purpose of communication, and that the body represents a *personal* as opposed to a *communal* resources for expression. On the other hand, in the context of an intensified degree of embeddedness in social relations (and perhaps less in one's body) cultivation of the body is not legitimised as an exclusive personal enterprise (1995: 37).

Thus, any phenomenon that can influence the symbolism and social expression that bodies confer is of interest not just to academic anthropology but to us all. This is particularly relevant to the families of brain injured children whose physical impairment orchestrates bodily form in diverse ways likely to distort perception so that frequently only the negative is perceived. This will not only affect their social opportunities, but clinical decisions may also be influenced by such interpretation of physical form.

The second point I wish to establish in favour of an anthropology of brain injury concerns its possible applied therapeutic benefits. I have briefly shown that during many cases of spirit possession the resultant procedures often involve catharsis of some turmoil. Thus, in a very significant way, personal problems are openly displayed but the individual's responsibility for his or her actions is often minimised. Consequently, he or she is not held to account for behaviours that might normally be regarded as antisocial²⁰. That

²⁰ This is not unlike that advocated by the 'radical school of psychiatry' who implicated the family and other interpersonal relations in the individuals' psychotic episodes. Thereby the person's 'illness' was a manifestations of some familial or interpersonal pathology which could

is, personal conflicts or problems are expressed for all to see, and appeasement is negotiated through prescribed procedures and conduct that all may bear witness to. If we compare this form of action with that of clinical medicine we can observe some pertinent contrasts.

For example, medicine often prefers to isolate cases of brain injury to clinical situations for monitoring and management. Families may be encouraged to take their children home, but are often cautioned not to expect too much.

(Philip)

This one doctor said 'just take him home and try to get on with your life, he's not going to do much. Why don't you have more children'?

Doctors will usually not subscribe to and, even further, often actively discourage any attempts to secure alternative forms of treatment for the child in the community, believing that only orthodox medicine should be consulted in such circumstances, even if it has little to offer in terms of therapy or family support. The most significant contrast between spirit possession and brain injury is not that these two states reflect differing aetiologies, in fact, the difference between these two events is a distinction not of kind but of degree. The significant difference, therefore, involves the efficacy of treatment rationales to negotiate a successful conclusion.

In those traditional societies in which it occurs possession is readily identified and effectively dealt with so that a level of normality is returned to those affected. In contrast to this, many parents with a brain injured child

be seen to minimise personal responsibility (see Laing 1970, 1971 and Szasz 1994: 1995).

experience considerable trouble when attempting to elicit recognition for their child's problems from a professional.

(Fiona and Tony)

They did a chromosome analysis at the local hospital and they couldn't see anything wrong. But it was obvious there was.

In the past cerebral palsy was often not diagnosed until the child was four years old and positional deformity had been established (Brown & Fulford 1984: 734). Even after diagnosis some clinical procedures may work to the detriment of the child²¹ (Patrick 1989). Thus unlike the shaman - who is able to identify the person possessed, the responsible spirit and effect a prescribed treatment - the clinician may fail in his responsibilities on many accounts. It is of no surprise, then, that many families seek alternative therapies that may be more able to effectively relate to the family's concerns and communicate their procedures to the appropriate level of sophistication that parents demand. This may also account for the increase in 'holistic' treatments which are as sensitive to the social as they are to the clinical procedures, often working to envelop the whole of the patients' experience into a socially meaningful enterprise. The fact that there exists a common ground on which the family, community and therapeutic agents interact, be they shamans or clinicians, indicates a system of belief, independent of relevant technical knowledge, wherein trauma or possession can be located and understood. It is the process of bringing the same level of anthropological

²¹ "The lack of a reliable benefit from surgery has led to empirical or idiosyncratic treatment regimens that require surgery every year and physiotherapy afterwards for up to a year until more surgery is undertaken - the so-called *birthday syndrome* (Patrick 1989 : 1115).

discernment that explores possession as a social fact to the issues that underscore brain injury that is, to my mind, long overdue. In this sense brain injury is not only a clinical description for the orthodox medical profession; it is also a social fact in the larger society.

Conclusion

In this chapter my purpose has been to incorporate an anthropological rationale in the understanding of the differing perception of the human body characterised by processes of abnormal behaviour, be they brain injury or spirit possession. I have argued that the contrast between these two independent phenomena may implicitly be recognised as a common schema derived more from the symbolic expression of the body than scientific rationalism.

Although a possible conflict arises between the parents of a brain injured child and the medical profession, this may prove useful in analysing an underlying source of the conflict. That is, parents and doctors subscribe to contrasting notions of body and its significance to the social world in which it is cultivated. For the parents it is the shrine of possible future intentionality - the body to which their child lost to them (see above) will one day return; for the physician it exists as a mechanism of anatomical integration.

Unlike the skill of the shaman in some traditional societies, which is developed to be commensurate with the causal notion of possession held by his or her people, those of medical science may seem to arise from a doctrine that itself has great difficulty in relating to the collective experiences of those who are afflicted.

I have briefly shown that the way possession is understood and treated offers a more tangible rationale to the members of those societies in which it occurs than medicine may do for brain injured children in our communities. The difference is that the prescriptions, advocated by medicine, do not involve the traumatised child and his or her family's understanding of the procedures involved. In this sense while possession has a culture of wide acceptance, the clinically rationalised body of the brain injured child is inaccessible to many people, framed as it is by a medical rhetoric of inexplicable pathology. For an anthropology of brain injury to make a successful contribution it must start, however, by considering the contrasting roles played by medicine as 'providers' and the injured as 'subscribers', and the convergent / divergent belief systems that support these roles. That perception, as a sociological phenomenon, is both structurally and functionally entwined in our experience of those whose bodies are constructed as being in some way afflicted, offers yet another level for anthropological analysis.

Finally, I have considered the altered states that are induced through brain injury and spirit possession by exploring the influence anomalous motor patterns have on the perception of body and, most importantly, the information that is thereby communicated to others²². The two differing phenomena presented here share many common features but are interpreted in contrasting ways. As has been shown, irrespective of the nature or aetiology of such conditions, efficacy of treatment is measured not so much by cure as by

²² It may be interesting to speculate that the altered states of consciousness that are a result of motor dissociation with cognitive intention in those afflicted by particular forms of brain injury and possession are equally likely (via perception) to alter an observer's consciousness in some way.

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procedures which are understood, by those involved, to address the common experience of those affected. However, whilst shamanism achieves this criteria, medicine may all too often fail. This may suggest that there is, indeed, a need for many therapeutic regimens to consolidate much of the anthropological insight into their working rationales.

For example, both Gell (1980) and Huxley (1977) have demonstrated that the vestibular mechanism (balance and spatial awareness) is strongly associated with altered states of consciousness, which is a necessary prerequisite for certain possession states. It also influences the postural aspects of the body, which in turn influence perception, and which have been my concern in this chapter. However, although many therapeutic rationales that treat brain injury employ techniques that encourage vestibular awareness their theoretical aims seem at odds with that identified in the anthropological literature. Vestibular techniques are intended to provide the afferent system with appropriate stimuli that can be effectively utilised by the child to affect sensory-motor integration. Surprisingly, in much of the relevant anthropological literature, we see such techniques as spinning, swinging and adopting precarious postures that deliberately discourage correct equilibrium, used to negate sensory-motor homeostasis and induce the deautomatised state found in trance and possession. Is it possible, then, that some techniques of vestibular awareness are counter productive in therapy since they may further dissociate the child from intentional experience? Indeed, it is Gell's (1980) postulate that the many stereotyped repetitive behaviours observed in

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childhood autism utilise such inappropriate behaviours in an attempt to establish 'intelligible proprioceptive feedback'. He continues and suggests that

this is their way of bridging the 'gap' between themselves as the locus of efferent intention and afferent experience (Gell 1980: 244).

Another possible application of anthropology might also consider 'techniques of the body' (Mauss 1937) in establishing the finer aspects of behavioural performance which utilise the idiosyncrasies of society and gender. Of course, before the injured child's behaviour develops to this specific level of social functioning the basic templates particular to human co-ordinated and controlled movement must be achieved. For many brain injured children this level is seldom satisfactorily realised and provides instead perceptible interest and recognition of the deviated forms of body that announce dysfunction. However, no matter how severe the motor impairment, the import of certain socially acquired manners of movement may significantly improve our perception of the presented disability.

Because the ways our boys and girls are brought up we imagine that both acquire the same manners and postures and receive the same training everywhere. The idea is already erroneous about ourselves and is totally false in the so-called primitive countries (Mauss 1937).

Indeed, therapy that is cognisant of such detail, no matter how rudimentary in its application, may enhance the child's behaviour in as yet unforeseen ways that actually improve not only motor performance, but also the way in which the child is considered and perceived by its peers.

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To conclude, then, anthropology does not have the expertise to investigate the clinical detail of neurology and its application to the medical treatment of brain injury. However, it can legitimately investigate the social consequences of clinical practice on those who are forced, through necessity, to subscribe to a doctrine of which they may understand but little. Making these events more understandable to those it affects is not merely of anthropological interest, but also has the applied benefit of making therapeutic common sense.

My analysis so far has concerned the image of the body, a body in which interpretation and social meaning have a cultural currency to both the individuals and societies which retain the corporeal self as an emblem of personhood. That this interpretation requires the encultured perception of others, acts in a way to minimise personal agency in the embodied expression of brain injured children. In the next, and final chapter, I shall outline the concern that orchestrations of the body are not only the result of the operations of others but that the self too, is an indivisible part of the orchestrations that embody brain injured children.

The Orchestrated Body

Neurons, Spirit and Physical Form.

Throughout this thesis I have attempted to argue that brain injury cannot be solely reduced to clinical notions of neurological dysfunction and pathology. Indeed, such models of medically inspired rationalism serve as little more than management guidelines that plot a course for clinical dogma on the chart of human distress, without ever exploring the continents of hope that so many parents attempt to reach. I have suggested that brain injured children have had their identity shaped through professional / public discourses with little, if any, account taken of the child's own view of the world. However, as mentioned in the *Introduction*, accounting for the injured child's own experiences and embodied expression is difficult when, due to gross impairment, the child is unable to engage in discussions that might serve to 'colour-in' the detail of their personal enterprise in life. Therefore, almost the entirety of this work has had to be informed by the observations, speculations and beliefs of parents. These have, I hope, given an impression of the form to which brain injured children's constructs of the world might be homologous.

The problems, then, of interpreting the *dialogue* that gives the parents' observations meaning is essentially the problem of deconstructing the professional and lay 'myths' that negate the personal potentials of these children. This has, in fact, been the main theme throughout this work.

The process by which the experiences of the brain injured child have been reconstructed has involved, however, animating parental observations

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into pertinent accounts of individual phenomenology; in the attempt to find greater meaning in those events that punctuate the family's and child's life. However, there remains one account that has been omitted so far, and this concerns those meaningful performances that children enact to enrich their experiential embodiment and orchestrate potentiality.

In this final chapter I shall try to show that orchestrations are conducted not only on the body but also on those experiences of self which may help to reveal a wider phenomenology of disabled children. The fact that these orchestrations derive from medical practice, social reason and even self performance (as we shall discover) is as methodologically challenging to anthropology as is the construction of a specific identity (brain injured) that serves to label the child as the sole referent to a dysfunctional body. As I have shown, many of the notions which affect our understanding of these children, and their subsequent therapeutic options, originate from disparate beliefs concerning the very nature of a child and his or her organic condition. We must therefore begin this analysis with how these children are constructed, in the social sense (see James and Prout 1990), by those who are, to varying degrees, responsible for their well being. I will begin by revisiting the diverse landscapes which detail some of the components typically used to negotiate the categories that serve as the defining characters of brain injured children and their resultant experiences of embodiment.

With the recent advances in the sociology of childhood, 'new paradigms' (James & Prout 1990) have emerged that rightfully decentre children from the traditional doctrines of biology and psychology. These

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reduced childhood to no more than a maturational unfolding to adulthood. Moreover, these *'reconstructionists of childhood'* have been equally engaged with the central question of 'what is the child'? (See Chapter 1). Indeed, this is the question with which we are here concerned, but my focus is on what is the brain injured child? For purposes of analysis I hope to demonstrate that there exist intriguing conceptual extensions to those child-centred postulates already influencing the study of childhood in which children are seen as social actors. Those critical of theories that propose that children can be regarded as actively constructing their own social worlds are often professional adults who consider their own rational wisdom as superior to the believed *'naive'* or *'immature'* capacities of children. It seems, to many at least, that the diagnosed pathological dysfunction of the brain injured child lends support to this type of intellectual reductionism by adult over child. Once again, the body and its biological workings, a legitimate study for science, not only investigates its subject but also, in fact, socially constructs it (Foucault 1973 and Armstrong 1983: see Chapter 1).

I would like to argue that clinical descriptions which propose a passivity for the brain injured child, inspired by pathology, help establish a conceptual location of children. However, that this is incomplete in its tracing of the full dimensions that constitute children, particularly injured ones, identifies a conspicuous lack of detail which may serve to elucidate a 'hidden landscape' rarely explored by adults; indeed, a landscape which has only recently been perceived, let alone explored. I have already discussed much of the detail which I will now analyse, but my purpose here is to draw the threads

together so that a fuller account of the orchestrations that alter these children's experience of disability may be understood in their social sense. An important point to consider is that these orchestrations obtain their social meaning from the experiences of embodiment that not only affect brain injured children, but also those who encounter them. I wish to suggest, then, that there are three common frames of reference or templates used, typically by adults, to discern, articulate and orchestrate the embodied experiential world of the brain injured child. The three templates of analysis are identified by their central tenets of observation and refer to, in an abstract sense, 'neurons' for the medico-physiological approach, 'spirit' as the feature of parental concern, and 'physical form' as the most overt mediator between parent, clinician and the larger community of observers¹.

Neurons

It is not my intention to examine neurological principles here but to suggest that notions relating to this physical architecture and function on the child's brain influence the gaze adopted by the medical profession. This perspective views non-progressive brain injured children as dysfunctional bodies of pathology. The clinical gaze of medicine has been argued (see Chapters 1 & 3) to have not only described and constructed the human body in a medically appropriate form, but also to have established a method of control over it. This 'political anatomy' (Foucault 1979) forms the substrate on which every parent with a brain injured child is forced to make their appeals to

¹ The terms used, 'neurons', 'spirit' and 'physical form', are my own and I will endeavour to clarify the semantics in the following pages.

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medical orthodoxy. Unfortunately, as we have seen, in many cases the parent's views concerning their injured child lack credibility in such consultations, and have little or no negotiative power.

Doctors and teachers frequently gave opinions we knew to be incorrect and we would just have to sit there and express gratitude. The fact is that we knew more about her condition than any of them. But whenever we started to give information in the hope that they would be able to use it to help Jenny, they just turned off or dismissed what we said with opinions of their own which were intended to show us that only professional opinions have any worth. It was all very frustrating (Baxter 1986, cited in Cummins 1988: 18)

This frustration with doctors may encourage a parental obstinacy towards the clinical rationale.

(Cindy)

So over the years I've just gradually made up my own mind. I listen to what they have got to say to me and think, right, I've listened to the medical side of it but I know my instincts as a parent and I know Cindy better than they do, and I know what she can do 'indoors'. Just because she doesn't perform like a seal when we go down to the hospital, I know what she can actually do. So I do listen to what they say,(but) I don't take a lot of notice of it.

Why is it that parents' understanding of their child's condition is ignored? Is it that they have no contribution to make to the habilitation programme or is it because they are subordinate in a power game of health and, as such, are expected to be passively informed, not actively informing? If 'the needs of the physically disabled child', as we have indeed seen, are 'to some extent independent of his medical condition' (Brown 1984: 705), are not parents' observations valuable to medically inspired regimens? But we are forgetting the office of medicine and its control over the body as distinguished by pathology (Hillier 1986: 175-84), a body that can be truly identified as

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deviant by its failure to conform to the norms of health established through medical enquiry (Scambler 1986: 185-93) and its policing (Turner 1987: 212-26).

There is, however, yet another feature of deviance to be discerned here. This is expressed by the resistance brain injury has shown to treatment protocols. The notion that medicine is a curative discipline is seriously eroded by the dysfunctions that are present in psychiatry, geriatrics, community medicine and of course, the treatment of brain injury. Not only are such specialities often regarded as low status by the profession in general but they are also more than likely disadvantaged in terms of resources (Hillier 1986: 177). Indeed, in such cases the lack of medical efficacy highlights the shortcomings of the discipline. The fact that the professional cannot effect a cure, and in so doing maintain his or her superiority over that of the patient, is likely implicated in the dogmatic approach adopted by many of the profession during their consultation with parents (see Chapter 4).

The point I am attempting to clarify here, then, is that the theories and postulates of neurology establish the intellectual and professional tenets for understanding brain injury without reference to what Turner (1987: 219-21) describes as the 'phenomenology of sickness'. That is, brain injury is considered without the important references obtained from those who actually suffer, or those immediately related to the patient (Radley 1993). This suggests, then, that 'sickness' is negotiated between doctor and patient. Scientific medicine concerns itself more with the 'hardware' implications of neurological impairment than with the experienced consequences of such

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dysfunction to the social realities that establish the embodied world of the injured child. This 'objective'/'subjective' dichotomy which can be seen in the different positions adopted by the orthodox and alternative therapy settings plays a major role in determining options. As noted by Sharma

Orthodox medicine has become even more technological in its approach, favouring interventions based on 'objective' knowledge about the patient, or rather his/her body, which take no account of the subjective and social experience of illness (1992: 201)

A possible source of conflict between parent and doctor can now be identified as their failure to share a common conception of what the significant features of brain injury really involve.

Spirit

This brings us to the next view of the terrain on which brain injured children are mapped. Once again this is orchestrated by those professionals and individuals with whom the child has contact. The family perspective decentres from the mechanics of neurology and instead focuses on the myriad social relations that exist between child and parent. Whereas the impulses of neural activity at the micro-level constitute a human condition for neurology, parents are likely to be more concerned with the macro-level of their child's own experience of injury, and its ramifications for both the child's and the family's future. Thus I use the term 'spirit' to help with my identification of that entity that parents may feel is embedded and subdued, due to injury, somewhere in their child's body. Occasionally parents refer to their child as being 'there' but not in an apparent way. This becomes intelligible only when

the child does something, i.e., expresses a mood or action, that serves to register a glimpse of recognition that there is indeed a commonality between the present injured child and the one they wish would return. The fact that these 'visions' appear, as would a spectre to those who can remember and interpret such actions, convinces me that 'spirit' is an appropriate general term for this phenomena.

(Philip)

If a certain song comes on the radio my husband will say Philip used to like that before his accident, and I say yeah, he likes music and he does remember things from before. When John (father) sees things that remind him of how Philip was he finds that very encouraging, he thinks, you know, he did that before the accident, its still there.

Spirit, then, is that essence that many parents believe to be suspended from their child during the 'marginal state' of brain injury. As we have already seen in the previous chapter, parents may often regard the injured child as little more than a facsimile of the child it was before the tragedy. It is important to remember, however, that this child in his or her present condition is, at the same time, the only tangible link to the one now lost to them. We have also seen that there exist many interesting analogies between brain injury and spirit possession (see Chapter 6). Moreover, not only are the physical manifestations of the body, orchestrated by the specificity of both conditions, remarkably similar at times (see Gell 1980), but the very notion of spirit, as identified in this study, is also likely to be implicated. That is, since occupation by a spiritual entity is regarded by many as the aetiological feature of possession (Lewis 1989, Obeyesekere 1981) dispossession of the injured child's spirit

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may, for some, establish the notion that confirms brain damage. The anomalous behaviour of the body during ecstatic religious events of spirit possession reveals spiritual occupancy. In a comparable way, abnormality of posture and spasticity indicates a dispossessed child. Though I do not believe that those who care for the injured child would ever articulate spiritual dispossession as a feature of concern, elements in their behaviour would perhaps confirm such a notion. Through careful observation by those who socially interact with the child, anomalies can be perceived in behaviour which demonstrate a conceptual discontinuity between their child as it was before the trauma, and that impaired being which it is now. As I have shown in the previous chapter, parents often retain a photograph of their child before the injury as a reminder of that child they believe is now lost to them². However, because the child's external physical characteristics seem to attract greater attention than his or her internal potential, social interactions tend to be targeted at a level appropriate to the child's projected disability. In such circumstances it is common to find adults over simplifying their social communications, with both dialogue and mannerisms directed only at the child's gross impairments. The possible harm such behaviours can do to the child's cognitive development is likely to confirm intellectual disability and frustrate his or her emerging personality. Therefore overt disability, and not the child's capacity, becomes the stadium for social communications and contact.

²The continuity between these events (before and after injury) is maintained through a temporal displacement wherein the present loses its forward dynamism and the past is fixed (retaining photos and particular memories) until it returns almost full circle to that future commensurate only to how the child was.

Physical Form

That the child's physical impairments play such an important role in informing both professionals and other individuals' relations to the brain injured child is something that has been discussed throughout this thesis, and many scholars, not least anthropologists, have been concerned with the physical forms that contextualise embodiment and the impact these features have on interpretation of the human body as a social entity (Becker 1995; Douglas 1984; Gell 1980; Blacking et al 1977; Merleau-Ponty 1963; Mauss 1936; and Hertz 1909). However, whereas the interest of these scholars has been, largely with the functional body and its expression, my concern is for the body characterised primarily by its *dysfunctional* attitude. That all bodies confer social meaning is neither a new nor novel idea but the notion that the deviated form and behaviour of the brain injured child represents a chaotic state, wherein the aesthetics of behaviour are suspended, may well illuminate new insights. Most importantly, it may help to understand why the child in desperate need of the normalising routines of appropriate interaction does not, in fact, receive them. Can it be that the projection of overt disability in children overwhelms sensibility to the exclusion of appropriate ('normal') stimulation? Unfortunately, it appears that the injured child's physical form acts as the most conspicuous social statement requiring others to develop strategies, often inappropriately, in their attempt to effect communication.

One explanation for this may be that these strategies have another purpose and may help maintain a safe distance from a tragedy too close for

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comfort. In this sense they may be analogous to what Frazer (1912, in Douglas 1984:20) might well have identified as 'rites of hygiene' which give protection from some form of contamination, certainly not physically but perhaps conceptually. The danger perceived here is not to one's own physical being but to one's classificatory system. In Douglas's terms, the injured child may be thought of as polluting because its physical impairment is in conflict with those notions which maintain that children are most favoured for their aesthetic appeal.

In short, our pollution behaviour (in our case this might well be oversimplified or inappropriate communication skill) is the reaction which condemns any object or idea likely to confuse or contradict cherished classifications (Douglas 1984: 36).

In this sense physical form plays a key role in our interpretation of the brain injured child. But what is most significant about physical form is that, unlike those perceptions visualised with reference to neurons and spirit and largely restricted to doctors and parents, it establishes a public perspective. This is a perspective that situates the parents between the 'inside' (child's capacities) and the 'outside' (his or her physical manifestations of injury), between the medical and the public. Unlike the more private statements, where neurons and spirit reflect differing competencies of observation, the public dimension rests more on the character of physical form than on an intimate personal knowledge. As such it is likely to form that substrate which may be used to map a hidden landscape in which brain injured children's experiences are discovered.

The Hidden Landscape

Having identified three of the most overt themes which structure the conceptual landscape that locates brain injured children, I shall now explore the invisible details which lie in the interstices of such features. In one sense the material most overlooked by professionals, parents and the interacting community is those notions derived from children themselves. It seems that considering children's own internal rationales and beliefs has merited little concern until relatively recently (see James and Prout 1990). I have already made more than passing reference to the importance of adopting a more child centred position in order to better understand the realities that children themselves are responsible for creating. In fairness, more and more of those whose interest rests with the phenomena of childhood are attempting now to explore this world of the child as it is personally experienced. Indeed, Qvortrup argues for a voice to be given to children in statistical and social accounting and suggests that

there may be a reality which is common for children irrespective of their parents' background. This reality might furthermore be one which in principle differs from the reality of adults (Qvortrup 1990: 83).

Is it really possible that children might be experiencing a different world from that occupied by their parents, a world in which adult interests are projected onto children in a manner which, due to their very nature, reflect concerns and beliefs that have little substance in the internalised world of the child? Although many researchers are now beginning to identify some of the

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parameters that are likely to be involved in children's self constructions of reality, there are few studies which have addressed these issues for the brain injured child. However, until we have a more concrete understanding of those details which are at the forefront of the brain injured child's concerns, studies derived from non injured children themselves may prove valuable..

James (1993) has researched into children's notions of what may be termed embodiment, and discovered some very pertinent facts about the meanings that bodies may express to children. Indeed, she has demonstrated that what children find significant about their bodies is height, shape, gender and use (1993). However, for children such defining categories are not fixed but are dynamically expressed by a 'subtle interplay between physical appearance, morality and social skills' (James 1993). Changes in physical competencies, behaviour and appearances affect the child's social image and can be used by children to negotiate differing personal identities for themselves. Unfortunately, for the brain injured child the possession of appropriate bodily skills by which to express themselves in a stereotypical fashion, which seem so important to children's own construction of identity, is rarely acquired. Indeed, the failure of many brain injured children to develop such skills to an acceptable level of sophistication may, as I have shown, account for the marginal status they are accorded by other, more competent, children. At times this may even involve their siblings. As the mother below recalls

(Timothy)

Betty will play with him (Timothy, her mentally disabled younger brother) but only if she's on her own. She prefers the company of other (non-injured) children.

If James (1993) is correct in assuming that 'the way the body is used has more significance and power to confer identity than simply how the body appears' then therapeutic programmes need to be aware of such detail in their ameliorative attempts. This requires that function, in terms of motor capacity, is far more significant than solely providing mobility, for it gives rise also to personal identity, a feature that is, in itself, all too often embedded in, and synonymous with, the child's disability. Here we can see the significance of Marcel Mauss's (1936) notions concerning the 'techniques of bodies'. Not only are such techniques specific to the societies and individuals in which they arise, but also, for children, the subtle features of physical skill categorise its possessor in socially important ways. Is it now possible that adults, in the guise of parents and professionals, are so concerned with what they believe to be the targets of therapy (restoring the lost child, for example) that any other feature, even that which has the power to confer identity, merits but little consideration? Although it is likely to be true that many of the parents' and doctors' wishes are commensurate with those of the injured child (wishing to develop a level of independence) the question is, however, whether our expectations of those techniques (therapy) that attempt to achieve this entirely concur with those of the child in practice³.

³ Many children, particularly those new to home based therapy and those who have experienced several years of therapeutic routine, resent the sessions and rarely subscribe to them with the same enthusiasm as do their parents.

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One may ask whether or not adopting a child centred view to therapy is practicable, or indeed necessary, since, surely, the concerned and informed adult is in a much better position than the injured child to decide upon the most appropriate strategy to be taken in terms of therapy? Certainly stereotypes, in the form of behavioural competencies, are important social constructs in both the child's and adult's world realities. Therefore, the idea that the injured child should be assisted to acquire the skills of walking, dressing, washing and language, etc, seems natural enough. Indeed, these are very often the aims of therapy. Shilling's (1993) perceptive thesis on 'The Body and Social Theory' argues that the body is born as an unfinished biological entity and subsequently only completed through social action. Brain injured children offer a pertinent example of this, for injury can often reduce the child to a biological rather than a social functioning entity. In this sense, brain injured children certainly are, in Shilling's terms, 'unfinished'. However therapy, particularly that employed by the alternativists, introduces the child to a series of social actions and manipulations which attempt to restart the processes that are hoped to eventually complete the child's body.

The question is, however, in the attempt to establish these milestones of competence is it possible that a hidden landscape, vital to the acquisition of these skills, and much more in the child's own experience of reality, is being overlooked? The fact is, many children simply do not like subscribing to their therapy programmes but prefer instead to practice their own social actions of completion with behaviours that appear, on the surface at least, idiosyncratic.

(Cindy)

She likes to feel it (hair) on her back, she sits there and does this (mother imitates child rolling her head backwards so as to brush the hair over her shoulders) I ask, do you want to go to the toilet? Because she sometimes does that when she wants to use the toilet and she says, no, I'm doing my hair, I'm feeling my hair.

She also likes to feel her skirt, the material, on her legs, as if she was walking and would tap the sole's of her shoes with a pencil as if to make the sound that shoes make when walking.

Could such experiences, the movement of hair on the shoulders, the feel of a dress caressing the legs, and the sound of shoes stepping on the pavement all contribute in helping the child approximate some of the sensation that would occur if walking was possible? Is it possible that the child is constructing kinaesthetic experiences to accentuate motoric imagery, or are such practices purely the result of pathological development?

I can see that such a sociological account of personal dysfunction would produce few tenets to impress the neurologist, for whom disability is purely an organic matter. Some brain injured children have indeed recovered functioning to such a level that personal identity, as an ability of body use (James 1993), is established even though the professionals have been at a loss to explain or account for it in satisfactory medical terms. The question now so fundamental to the therapeutics that orchestrate the bodies of these children in both the clinic and the home is, then, how can the potential for 'recovery' be enhanced and optimised without our sentience of the reality within which the disabled child is embodied? What clues may there be in the child's own experience of disability that may point to novel solutions to old problems?

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The hidden landscape, then, can here be identified as that detail - reality and experience - that uniquely encapsulates the individual child within a larger and perhaps myopic⁴ social context. If we assume that this reality is internal and reflective of only the child's personal experiences, is it ever possible for us to obtain any meaningful insight into these private worlds that the suffering child constructs? I believe it is, but only if as adults we are prepared to accept, unconditionally, their statements, expressions, fears and beliefs as being truly descriptive and not merely infantile metaphors of the world in which they must really exist. Furthermore, we should attempt to understand that these 'idiosyncratic' behaviours which typically get dismissed may well be operational performances that provide a 'concrete' (somatic) expression to an active imagination.

There is, of course, no certainty. Self deception is probably as common as the more deliberate type we use against others, and there is no reason to believe that children too, even injured ones, may not practice it. More importantly, however, it may prove beneficial to assume that children's statements⁵, however expressed, contain many pertinent facts and provide a more representative view of the injured child's world, if only we can decipher them.

As I have already shown, such a sentiment is visibly encountered in the statements of many parents who wish that the medical profession could

⁴ I use the term 'myopic' with reference to the adult interpretations of a childhood reality that seem largely based on expectation rather than perceptive insight.

⁵ For brevity I use the term statements: this in fact relates to those articulations of words, vocal sounds, actions, moods and aspects of sociality that the child may employ in response to other people or events that he or she encounters. They are, of course, not always interpretable but this may be equally due to the lack of an acceptable child-sensitive schema in which to reference the observations as it is to be a total incapacity of the child to express some issue of his or her experience.

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decentre from their own esteemed position for just long enough to consider the parents' statements and feelings. To consider children, whether disabled or not, as constructors of their own reality requests no greater favour. Both child and parent have their own important contributions to make to the way others perceive and regard them.

Robert Coles (1990), a child psychoanalyst, became shrewdly aware of this fact when he recounted his experience of an eight year old girl attending a psychiatric clinic. Her religiosity was initially regarded as a smoke screen for the 'bad habits' which he presumed arose from the sexual feelings 'she had and possibly acted on' (Coles 1990 :11). Coles continues and states that

the heart of the matter for me and my psychiatric kind (*is*) our conviction that there is an ultimate bedrock psychological reality to whose depths and contours we are specifically privy. Sometimes we have good reason for our claims. But conquistadors (Freud called himself one) have a way of becoming wanton imperialists at times. I wasn't letting Connie tell me about an important part of her life (I would eventually realise) because in my mind and in my manner I was pressing her to hurry up, let me get (with her cooperation) to what was far more important, the "truth" underneath, "disguised" in the child's life by a Catholic fastidiousness that had already broken down in school and put her in our clinic (Coles 1990: 13).

But it is not just the professionals that make such mistakes and wrongly assume that intellectual reductionism is the only way to interpret the discourse of others, especially children. The process that articulates 'adults know better' is but one of the responsible agents that underscore the world in which children live. It may not be the inability of children to account for their reality that rests at the heart of the problem, then, but rather our unwillingness to really listen. If infants as young as three months have the capacity to initiate communicative channels for the mutual exchange of information (Bruner

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1975: Trevarthen 1979) with their mothers, then even severely brain injured children may plausibly have developed some communication systems. The question is, how well are these processes recognised as communicative attempts? We know that disability is a problem, but in whom is it observed? Abberley (1995) suggests that Occupational Therapy, as perhaps for the other 'service providers'

perpetuates the notion that disability is an individual problem to which professional intervention can provide a solution, and to ascribe responsibility for any perceived failure in therapy to the client rather than the practitioner (1996: 221).

Even in the most brain injured child there is likely to be some undiscovered personal world, rich in opportunities for contact and understanding which might well suggest that our inability to perceive their embedded potential is as disabling to the child as is their own impairment (see Oliver 1996).

The Orchestrated Body

However, the very fact that we have yet to identify the realities that they construct may go some way to helping us accept that the world in which they live may have little consort with the world in which we perceive our interactions with these children to take place. The notion that all bodies are to some extent orchestrated by ourselves and by others plays a critical part in the phenomenology of human existence. Brain injured children are also required to account for their actions. However, the fluid use of socially gendered and culturally determined bodies makes their attempts at personhood both

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conspicuous and suspicious. As I have shown, the 'failings' of the brain injured child are identified, located, diagnosed and labelled with specific reference to the body. This is not just because the body is the material artefact of pathology but because it is also the semiological substrate on which social dysfunction is contextualised and discussed. Bodies are, by intent, the arbitrators of social conduct. Moreover, the fact that bodies are defined in such ways extends our collective consciousness of these integral entities with regard to the 'normal and pathological' (Durkheim 1938) which further acts to both determine acceptability and define sensitivity. That is, the dysfunctional bodies of brain injured children not only kindle an interest in 'objective' medical science due to their deviation from the norm - and thereby establish the boundaries whereon the typical is replaced by the untypical - but more importantly, and in the classical anthropological sense, these bodies, 'bad' in the sense of normal, are good in the ways in which they enrich and impinge on the human imagination. Emile Durkheim well understood the importance of deviation from the norm when comparing the method of biological reduction to that of social systems to discover the *'Rules for Distinguishing Between the Normal and the Pathological'*.

Disease does not always leave us helpless or in a state of irremediable maladaptation: it only constrains us to adapt ourselves differently from most of our fellows (1964: 52).

Indeed, Durkheim continues and argues that as disease is a function of the healthy so, too, is crime part of normal society.

Let us make no mistake. To classify crime among the phenomena of normal sociology is not to say merely that it is an inevitable, although regrettable phenomenon, due to

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the incorrigible wickedness of men: it is to affirm that it is a factor in public health, an integral part of all healthy societies (1964: 67)

In a similar way the disabled body of the brain injured child is, conceptually speaking, equally a part of the same healthy collective in which all other bodies are located. As crime for Durkheim sensitises society to confirm a better moral and more enlightened consciousness on its members, so too the distorted physical forms that we may perceive in our brain injured children affirm the dimensions of possibility in embodiment. Moreover, an embodiment that is both natural and cultural is part of that essential human experience. It is little wonder, then, that these children are orchestrated by the disciplines of medicine, therapeutics, education and social work, but 'to what effect?' we must ask ourselves. Is it really to make accessible pathways into that 'normal' experienced embodied world, as such practitioners would have us believe, or is their purpose purely to define its limits, the very boundaries at which function is termed dysfunctional and consequently perceived as abnormal? As Durkheim shows with criminality, absence of crime arouses a greater sensitivity to perceive failings in the actions of others that would not have been previously regarded as criminal.

Imagine a society of saints, a perfect cloister of exemplary individuals. Crimes, properly so called, will there be unknown: but faults which appear venial to the layman will create there the same scandal that the ordinary offences does in ordinary consciousness (Durkheim 1964: 69)

So, too, if all injured bodies were to be homogenised, would not now any deviation from the accepted typical physical form, no matter how small, be regarded as violating the rules of normality? That the bodies of brain injured

children are conceived of as peripheral distracts social gaze from those others whose physical form would, if not for these children, transgress the limits of acceptability. Might these children, with their overt disability, kindle a tolerance for other less than 'perfect' bodies that create an industry of consumerism for physical appeal and pleasure (see Featherstone 1982; Featherstone et al. 1991) which might not exist but for the position brain injured children occupy in our collective consciousness? Thus in establishing the 'forms' which demarcate normality, control, in almost every conceivable way, must be exercised over them. These children are the orchestrated and disempowered bodies of 'normal' society's institutions, institutions that, by their very purpose, act more to desensitise our tolerance of disability by manipulating the bodies and minds of brain injured children at the periphery of social engagement than by reaffirming that these children are truly part of the whole and complete range of embodied enterprise and, as such, a major contributor to it.

Distinctions are the very genesis of this enterprise, and the 'special' placements these children attract in the institutions of our society affirm discontinuity from the universals that we are ready and willing to perceive in those of us who live outside their reasonability. The one inescapable conclusion, if we were to be really sentient of our own embodiment, is that no matter how we conceptualise disability there must surely be some commonality in the experiences that arise from the endeavours of all bodies, be they disabled or abled ones. Of course there will also be differences, particularly in the utility of action and perhaps purpose, but this does not in

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itself preclude the fact that there are likely to be certain universals underscoring our collective and individual embodiment.

Anthropologists, in studying other people in cultures and societies vastly different from our own, are realising that there are indeed processes of every day life that are not entirely unfamiliar. These universals do not only account for a commonality of interpretation of particular social phenomena, but also the physical conditions (embodiment) in which such phenomena will inevitably arise. Donald Brown (1991) has provided a good account of this in his book *Human Universals*.

Steadman had to learn the Hewa language in the field, but long before he was conversant in it he discovered - somewhat to his surprise, because it didn't jibe with his assumptions about the influence of differing world views - that he and the Hewa "could understand each other well enough to live together" (1971: 26-27). As time went by, and he learnt more about the ways in which the world is put together differently in Hewa than in English, he was led to observe that the differences were largely superficial: "The fact of experiencing the world in a similar way," in spite of its being carved up differently in different languages, "became increasingly obvious as I acquired greater proficiency in the language" (1971: 27, cited in Brown 1991: 3).

This essential human background, in which the anthropologist, the people he or she studies and 'the readers of ethnography share, is a vast reservoir of interpretative principles' (Brown 1991: 5) and is also likely to be shared by children. The point I am making is that disability is itself an involuntary dimension of that common ability that children's bodies possess. The difference is therefore not one of kind, which would then be more likely to make it incomprehensible, but in fact, yet again, one of degree. For there are many actions and moods that ensue from the brain injured child that are understood by the parent or carer if we accept, as we must inevitably do, that

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the injured body before them is still that inalienable body of a child even if he or she now appears different. I shall now attempt to clarify this important point by using examples taken from my fieldwork with parents and their brain injured children that will demonstrate the shared common elements of childhood that are likely to be part of all children's experiences.

Case Studies

(Cindy)

Cindy is an intelligent seven year old girl who lives in the West Country with her mother, father and younger brother. At thirty one weeks doctors suspected '*placenta previa*', mum was given a scan and Cindy was born one week later after three and a half hours in labour during which mother experienced no contractions. Cindy was 3lbs 4ozs at birth and showed signs of distress, she was given a blood transfusion and lumbar puncture which confirmed meningitis. Cindy developed hydrocephalus nineteen days later when a 'shunt' was subsequently fitted. Cindy is diagnosed as having cerebral palsy with athetoid spasticity. She attends a special school and is doing very well; her mother's main concerns are for Cindy to develop walking, toileting and independence.

Cindy's favourite games tend to involve role play in which she is often the princess or other good character whilst her mum is inevitably the witch or wicked step mother. Cindy thinks all step mothers are cruel and Cindy, being the good princess, is the one going to be saved. The family spend some time

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each day on their therapy programme⁶ which Cindy does not like and she will regularly engage the helpers in conversation to distract them from administering her exercises. She prefers younger children, particularly babies, to play with and wants to teach young children when she grows up. She will often say to her mother 'look I can walk on my own, do babies do that?' Cindy has few friends who are the same age as herself. She is very concerned about her development and likes to keep a record of her achievements, always wanting to know how far along the line she is at any particular time. The line is a type of metaphor she has constructed with what babies do at one end and adults at the other. She feels herself to be about half way along it at the present and believes (perhaps because she has been told it) that her exercises will help her move along this line. Cindy often tells her mother that she will be glad when she doesn't have to do them any more but persists for fear of the therapists finding out that she hasn't done them. Being perceived as good by everyone is very important for her.

Some of Cindy's friends in school, who are also disabled, often make comments that upset her. For example, she asked one boy if he liked her dress, he said he didn't and she came home crying that night from school. Cindy likes to be considered a good girl at all times and worries that her mother might say something negative about her⁷. Generally, she behaves better when in the company of strangers as she likes to give them the

⁶ This involves a modified regimen based on the Doman-Delacato method which entail passive manipulation of the limbs in order to teach the child the co-ordinated movements of purposeful motility.

⁷ She was very concerned that I would be seeing her mother whilst she was in school in case her mother told me that she had been 'playing up' and promised her mother that she would do her exercises.

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impression that she is good all the time. Cindy has become very interested in the recollections of her mother and grandmother, especially when they were little girls, wanting to know everything they did. She then uses these stories and recollections to construct her games, creating present scenarios from other's past events and peopled with the characters and experiences recalled by others.

Cindy has often commented to her mother that 'you don't know what it is like to be disabled'. Cindy has an imaginary husband called Kelly, a daughter Michele and a son named Graham.

This brief description is full of understandable relief; it is of course, much more meaningful for Cindy's parents than the interested reader but both are likely to be able to make sense of some of the issues that are a concern to Cindy. Being disabled (diplegic) Cindy prefers younger children, particularly babies, perhaps because they have less motor ability than herself. Older children, however are more problematic as she feels compromised when engaging in games with those children who demonstrate greater physical competence. In this case her disability is accentuated. In her role play games, the notion of good and bad are meaningfully understood as a metaphor for able and disabled. Her character, the princess, is good and therefore able to compensate for the possible bad elements that are associated with her disability. Her mother is considered the witch or wicked step mother, able to walk and command an influence over the pitiful plight of the princess who cannot escape her situation. When Cindy informs her mother that *'you don't*

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know what it's like to be disabled' she is not posing a question but is, in fact, making a statement that challenges her mother's, and perhaps her own, acceptance of this disability.

Because of the implications of her disability her own experiences of the childhood she is presently encountering are minimised, to some extent confined to the living room floor and tiled hall⁸, thus Cindy must find alternatives to improve this situation. But not just any fantasy will do; it must be as real as possible, constructed with the real events that occurred to the real people she knows and loves. These games or performances, so developed, are no longer the fancy of an imagination; they are an extension to physical actuality, an experiencing of those routines and events that created real people and which will confer on her disabled body an enriched encounter with an eventful childhood. Through utilising these actual occurrences Cindy has established a method for re-experiencing her mother's and grandmother's accounts from childhood. The events that made their childhood so typical of the able bodied can now be accessed to provide Cindy with insight and meaning of those behaviours and events from which she would normally be excluded. In this way her own childhood phenomenology is enhanced by understandable detail commensurate with the people she knows best, loves and identifies with.

⁸on which her body moves with a fluidity and speed not possible on the carpeted surfaces.

Case Two

(Timothy)

Timothy is a nine year old boy who was born after a normal birth but developed viral encephalitis at the age of twelve months. He was hospitalised and had more than one hundred fits during two weeks. A lumbar puncture was administered, which proved negative⁹, however a positive EEG was confirmed¹⁰. One week prior to this Timothy had a high temperature and fever and fell down two steps onto concrete. His mother's and father's concerns are to improve his general abilities so that he will one day attend high school.

Timothy is about to start a mainstream junior school but is not looking forward to it, neither is he dreading it but rather he just knows he going. His mother recalls when he seemed unemotional and disinterested but now he'll 'throw a paddy and that's great to see all this emotion' as his mother recounts. These tantrums arise when people attempt to take things away from him. Timothy has reasonable language skills, especially since he has started playing with other children. His sister Kate occasionally plays with him when she has none of her own friends to play with, preferring the company of her own friends. Although Timothy seems to enjoy playing with other children he rarely gets involved; even when other children are present he remains somewhat a loner, watching and only participating to spoil their games on purpose. Timothy's mother says that when he spoils their games he has a

⁹ A negative result from a lumbar puncture would confirm that the cerebrospinal fluid is not contaminated. This procedure is carried out for many reasons but in this case to illuminate the presence of meningitis and encephalitis.

¹⁰ Although paediatric EEG's are difficult to read in this case 'spike' activity was recorded that may well indicate the possibility of seizures occurring.

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malicious look in his eyes; she believes he does this because he is not getting the attention.

Timothy will often talk to himself, for example if he has done something wrong he will tell himself off, saying 'you've been a very naughty boy and I'm going to smack your bottom'. Jenny, Timothy's mother, recounted a time when she felt he had no or little self awareness but now he never stops looking at himself in the mirror, or when riding his cycle in the back yard he seems fascinated with his own reflection in the patio doors as he rides by. He enjoys being outdoors and when out shopping he's starting to choose the items he prefers. Jenny feels 'he's starting to know his own mind'. When meeting people he will now ask their names as way of an introduction but this can be very repetitive, repeating the same question until his mother stops him. At times he has a slight stutter but will happily carry on until he gets it right or gives up with pure fatigue. Interestingly he never gets frustrated by this problem. He's also become much more aware of the names and parts of his body and will tell his mother if he has a tummy ache. This is one of the great improvements for his mother because his inability to inform her when he felt ill or in pain was very distressing to her.

Timothy also seems to recognise his mother's emotional state. If Jenny is tense or a little anxious Timothy will frustrate everything she attempts to do. Mother believes that he senses when she is having trouble coping with him and if he catches her crying will ask, 'why are you crying mummy'? Timothy's mother believes that he does many things just to frustrate or aggravate ('wind her up'). His memory has lately improved, especially his recall. For example,

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he not only remembers items of interest but they also appear to act as mnemonics for particular associations and characters.

Once again the experiences that Timothy's mother encounters from being with her child are not uninterpretable in the sense of a mother caring for her son. As we have seen, Timothy's behaviour provides meanings which are relevant to the child he is. As many mothers know, particularly at his age, boys will get up to mischief and inevitably cause some level of anxiety, deliberate or not. In this sense Timothy's behaviour is little different from that of any other active nine year old. He can be disruptive, spoiling the games of the other children, perceptive, able to recognise his mother's anxiety and be naughty enough to increase it and finally, sensitive as when asking his mother why she is crying. In fact, Timothy's behaviour reflects that which is typical of other children of similar gender and age.

However, although elements of his behaviour are embedded in that common repertoire of childhood there are without doubt absences of action and sociality which make Timothy's behaviour conspicuous. In this way it is not what Timothy does that highlights this little boy's problems, but more what he doesn't do that has far more implications for our interpretation and understanding of his existence. For example, when Timothy's mother informs us that he senses when she is having trouble coping with him and will seemingly aggravate the problem this may not, in fact, be done purposely to make things worse due to Timothy's total insensitivity to the situation. On the contrary, Timothy recognises quite well changes in mood and timing of

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situations as demonstrated by his ability to interrupt games, show concern and even recognise when he has done something wrong and chastise himself with the threat of punishment such as a smack on the bottom. Thus it is far more likely that Timothy's behaviour is not the pure belligerence of a brain injured child who knows no better but is, in fact, the result of a self discernment that is advantaging his personal situation when an appropriate opportunity arises. We must remember that although Timothy has no serious motor problems, unlike Cindy's diplegia for example, his disability derives from the fact that his cognitive skills are in some way affected. The meaning behind his aggravating and frustrating actions may now be understood as (1) a possible way of extending personal opportunities that serve to enrich his embodied enterprise, i.e. his mother becoming even more distracted allows him the opportunity to get away with behaviour he would normally not be able to experience, or (2) a way of demonstrating his anger or resentment at his mother's inability to pay the level of attention he likes or needs to receive. Either way, his mother and myself are convinced that what may appear as belligerence on the surface to other less intimate observers, in fact, performs a much more meaningful role, for both himself and his family, it is a manifestation of some personal expression relating to his childhood experiences and which would otherwise have but few ways to be articulated.

Case Three

(Tom)

Because of the detail in this case I have decided to draw my description of Tom, and his experiences of the reality which he is in the process of constructing, directly from my field work notes with his parents.

Tom was born by emergency caesarean after a pregnancy of thirty six weeks. He was in distress and his birth weight was 5lbs. He was subsequently incubated for six days with a lung infection and murmur of the heart. Tom was allowed home after three weeks and later diagnosed as having cerebral palsy. He is seven years old, has one older sister, and lives with his family in the South East of England.

Interviewer : At what level do you see Tom's consciousness focused, or perhaps how does he conceive of himself?

Mother : *I don't think he sees himself as being different to anybody else, I think he knows he can't do things like everybody else but he doesn't think of himself as being any different to them.*

Interviewer : Does he ever mention his disability (walking)?

Mother : *He's quite interested in walking, what he has never been interested in is sitting. That's given us a real problem because up until about three days ago we couldn't get him to sit by himself because I think he had a fear of falling, that's all it was. He's been able to do it for two to three years and suddenly he's decided he can sit and he's got his own special chair.*

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Interviewer : What type of things or people does Tom show an interest in?

Mother : *He's certainly happier having me to handle him than anybody else and at school he's got one welfare helper that he's happy with. He knows which people are happy (comfortable) handling him, I think.*

Interviewer: How sensitive do you feel he is to non-verbal communications?

Mother : *Oh he's very tuned in.*

Interviewer : He responds to changes in people's mood and to their lack of confidence with him?

Mother : *Yes right from the start, his first reception class teacher, when he was five, didn't want him in her class. Well he knew that and he really didn't help himself at all that term because he knew that she really didn't want him. And with people like educational psychologists, he can spot them a mile off. I always have to make the point to them that he doesn't suffer fools gladly, I'm afraid. He knows when somebody comes in and doesn't expect him to achieve what he is capable of.*

Interviewer : How does he respond to this ?

Mother : *He plays them up for all he's worth, if they don't want him to do something he will do exactly the opposite or he'll play dumb, he won't do anything. You know, like I don't understand that or I can't do it. Which in certain circumstances is extremely frustrating. That's why we never had an assessment in the hospitals.*

Interviewer : What level of language does Tom at present use?

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Mother : *He's got extremely good verbal communication skills but very poor diction. So if you can tune in to the way he talks, I mean, vocabulary and everything is up to normal for his age but his diction is poor. We are working on it and it's coming.*

Interviewer : So Tom will engage conversation?

Mother : *At home you can't shut him up. He's not forthcoming out of doors, particularly if he thinks people aren't going to understand him but he's capable of rephrasing things now, so if they don't understand him the first time, words he says he can think of another way to say or put it. Invariably he gets through to them.*

Interviewer : You have, presumably, become very sensitive to his diction problems?

Mother : *Oh yes, I can understand small babies now even when their mothers can't; its really funny if there's 13 to 14 month olds just starting to talk I can invariably understand them when their mothers can't. I've tuned into his way of talking.*

Interviewer : You mentioned that he doesn't see his lack of mobility as a problem, if it isn't a problem how does he reconcile himself to the fact that other children are doing things that he can't?

Mother : *He gets them to do things for him, he's not daft. He won't, or is not motivated, to do things for himself because he knows damn well if he bucks his eye lashes one of the girls will run around and do it for him.*

Interviewer : So he's learnt that?

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Mother : *Oh yes, he learnt that very early on and he's got his entourage at school.*

Interviewer : So would you say that this is almost like learned helplessness?

Mother : *Oh yeah, but there is an awful lot he can do for himself but he won't, (a) because its quicker and easier to get somebody else to do it for him and (b) its hard work and he's not going to put himself out. He's never been a very highly motivated person lets face it, even when he was tiny and that's been his problem.*

Interviewer : Does he like adult company or does he prefer children?

Mother : *He likes adult company, he probably does prefer adults but he's got friends, they tend to be girls because they can play more on the sort of level that he can play, whereas boys tend to want to run around and do active things. You can sit a girl down with a board game, but he's got one little friend, Peter, he will get out a game he knows Tom can play he's gone past the stage of trying to get Tom to do the things he would normally do.*

Interviewer : So his games tend to be of a more static kind, verbal types for example?

Mother : *Yes, he is into verbal games, mainly 'Neighbours' everybody has to be a character from 'Neighbours'. Particularly when something is happening like a holiday, he wants to play the holiday so you have to go through all the things that you are going to do, especially if it's something you haven't done before. I think it helps him get into context what he's learnt.*

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Interviewer : Are you saying that if you are going on holiday Tom wants to rehearse the things you are going to do before they happen?

Mother : *Well, it tends to be the getting there.*

Interviewer : What type of information does he ask for when you are playing these games?

Mother : *I can't think of things that he would want, he doesn't normally want to play the journey bit, little by little he just wants to get there. Its more the getting there and once you're there actually meeting the people who are there. He always likes to know who's going to be there.*

Interviewer : For example, if you were going to a hotel would he be interested in who was the manager and other staff or characters?

Mother : *Yeah, he knows the hotel we go to and he knows all the people there, I think he likes to guess who's going to be on reception and who's going to be around when we arrive.*

Interviewer : How long as he been constructing these scenarios?

Mother : *For years, it started off when we were 'patterning' (therapy) when we used to do the respiratory pattern and we would have a half hour of really boring..... and he would get all his 'patterners' (helpers) to play these games. All sorts of weird games and he was young without a lot of verbal communication, but he used to direct what they were doing and get them to play all the different characters to entertain him.*

Interviewer : How would he do that?

Mother : *I'm not sure it was a long while ago, I must have been around because one or two of them would be able to communicate with him, not all of*

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them but I knew he had them all playing. Playing different characters from different games, either different things on the television or ... he never made up characters they were always people he knew or characters from the television.

Interviewer : Did he construct scenarios for them?

Mother : *Yes.*

Interviewer : Do you think that this could have been a way for him to expand his experiences?

Mother : *It could be, yes, and I think in his mind when playing he was not confined to his wheelchair. He's got one little friend, Jane, and he's always playing, right, tonight I'm going to take Jane out for a meal or I'm going to take Jane on holiday, you know, he's driving the car taking her away for the weekend.*

Interviewer : So in the scenarios his disability is suspended, they are not limited by his lack of mobility?

Mother : *That's right.*

Interviewer : I wonder if these games may act like dreams with an extended reality, because the people who engage in his scenarios are real people. Do you think it is possible that these games or interactive scenarios are a way of experiencing action and routines of life, that due to his disability, he may feel he is missing out on?

Mother : *I don't feel that he thinks he's been left out of things, he's always trying new things even if he can't do them. He's tried skiing, you know he sits down on his seat and the person standing at the back steers, he doesn't*

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*have to do anything, but he can if he wants to. If he's capable he could direct himself. There isn't anything we wouldn't let him try and I don't think it particularly bothers him that he can't play sport and those sorts of things*¹¹.

Interviewer : Do you feel that he does certain things in an attempt to replace those things that he finds too difficult to do?

Mother : *He does like board games but that is only because he can play a board game on a mental level.*

Mother : *When he's grown up he's going to open a restaurant, that's one of his favourite games, the restaurant. In his imagination he owns a restaurant, we have to make up menus on the computer. He's getting to the stage now where he's very interested in cooking and actually knows recipes. He watches me cooking, in fact, he was telling his welfare worker in school how to make something that I was making and got it exactly right. He also likes to know what's going to happen and he doesn't like it if things change at the last minute. Tom's very particular about time, he could tell the time very early on and watches the clock. If you say to him call me in two or five minutes he can do that, it's as if he has an in-built clock.*

Interviewer : Do you feel that he places himself into different points in time. That is, take experiences from a present situation and compare or utilise it into a past event or one in the future?

Mother : *He's not very concerned with what's gone on in the past he's more concerned with the future. He doesn't mention the past very much. I think in his mind he is grown up already.*

¹¹ I had the impression that my question might have inadvertently caused Tom's mother to take up a defensive posture.

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Interviewer : What makes you think, 'in his mind', how do you get such inferences?

Mother : *Because when we play these games he is never Tom as he is now, its always Tom driving a car and things like that.*

Interviewer : Doing things on his own, independently? Is he still living with your family when playing these games?

Mother : *Oh no, it's him going by himself.*

Interviewer : Does he make references to coming back to see you in these future games?

Mother : *Yes, we invariably end up back here at the end of the game.*

Interviewer : Is he a little boy when he's back here or still in his adult persona?

Mother : *I don't know, I think he's still an adult, certainly when we're playing the restaurant game he's in charge and asks me can I work for him in the restaurant.*

Interviewer : Does he tell you how much he intends paying you?

Mother : *He'll draw up contracts of employment, that was John (father) he got him into that.*

Interviewer : Does he tell you about Jane, his friend?

Mother : *He tells me what Jane has done, they had a big argument as to whether they are going to get married at the moment. He wants to marry her but she's not sure. A couple of months ago she was all for it and whenever she came around to play they would have a wedding and I would have to*

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produce a doll from somewhere for the baby. It was always touch and go which one would come first.

Interviewer : Does Tom throw tantrums and if so what is likely to start them?

Mother : *It tends to be if I want him to do something physically that he doesn't think he can do. When he throws a tantrum he just goes stiff then it is counter productive to try and get him to do anything.*

Interviewer : How do you interpret that?

Mother : *Well I suppose there are just some days when he just can't do it, I don't always know whether he really can't do it or whether he is just being bolshi.*

In reading the above parents could identify the games that Tom plays as being, in nature, the same imaginative constructions that they have encountered in their own children's play. Are these elements adapted extensions of those 'human universals' that Brown (1991) discerns as being largely suppressed from the mainframe anthropological enterprise?

As Sperber (1982: 179-80) notes, anthropologists routinely conduct research that can only be done because in crucial ways the differences between us and the people we study are not in fact not very great; yet because everybody likes to hear that 'they' are different from 'us' anthropologists dwell on the difference (cited in Brown 1991: 5).

In similar ways the children with brain injuries, who are the concern of this thesis, are believed to be quite different from those uninjured children who inform our interpretation of the norms we use to characterise childhood.

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However, as there are differing levels of expectation and attainment for different children in adulthood, so too are these universals (which serve to dictate inequalities of opportunity) also incorporated into the injured child's expectations. Unfortunately, the prevalent discriminations that arise from social, economic and educational factors which affect children's attainment are further aggravated by the social construction that disability unloads on our speculations about the physical frame within which the injured child lives. The bodies of these children are not just those material aspects of a dysfunctional childhood, as some would have us believe, but are, in fact, that essential dynamic that springboards the expectancies of otherwise confined children into potentiality. This potentiality with, hopefully, real alternative futures is provided by the self therapeutic practices of a performance that is aimed not at an amorphous and desensitised public, but is constructed to enrich one's own personal embodiment. The 'scenarios' that these children perform are not intended to inform or project to an audience some experience or awareness, like that of a character actor portraying a script, rather they are the child's way of personally encountering these scripts in a 'real' experiential way. These 'performances', then, are not for public presentation but for personal enrichment. They are the creative experiential products of brain injured children who, due to general incapacity, have but few other alternatives to explore, as other children do, the world of experience and potential.

The case studies outlined above could now have much greater analytical meaning if we consider the role play of these children not as mere games but performances, conferring therapeutic benefit to the central character

(self) around whom disability is no longer orchestrated to frustrate embodiment but, instead, to achieve new levels of enactment.

Performance for Self

Over the decades anthropologists have become much more concerned with the notion of performance as a cultural way of behaving. Medical anthropology has played a large part in understanding the possible efficacy that can be conferred by performance in the mediation which socially locates a dynamic for illness and health (Kleinman 1980; Good 1977 and Frankenberg 1986). What Singer (1955, 1968) termed collectively as 'cultural performances' - that is, locally recognisable ritual manipulations of phenomena - no doubt form a substrate for the detail I shall explore here. I shall nevertheless, need to make several shifts in the theoretical framework in which performances are presently contextualised. In *'The Performance of Healing'* Laderman and Roseman state in their introduction that the

shift from viewing such enactments primarily in terms of structures of representation to seeing them also as processes of practice and performance (1996: 2)

This seems appropriate to the present analysis. As I intend to argue, performance may well be a 'practice', primarily targeting the self, even so, it can also be utilised as a narrative for children's experiential encounters. Moreover, this is not the only shift that will be required if I am to adequately explain the performances exemplified in this text.

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Thomas Csordas (1996) has reconstructed the theoretical tenets that underpin performance as healing by taking into account that important, and perhaps crucial, information obtained from the patients themselves. He has demonstrated that there are four approaches to performance, (1) *cultural-performance*, (2) *performance centred*, (3) *performative-utterance* and (4) the *rhetorical-persuasive*, these derive from interpretative anthropology, sociolinguistics, both these and the therapeutic process respectively.

All share a hermeneutic sense of the importance of context, but complement one another in that the first formulates performance as event, the second as genre, the third as act, and the fourth as rhetoric (Csordas 1996: 91).

He goes on to suggest that the convergence of all four of these approaches 'offers the opportunity for something that has been markedly absent from anthropological accounts of religious healing, namely a way to grasp and formulate the experiential specificity of participants' (Csordas 1996: 94). In a similar way we must attempt to understand that experiential specificity, which is responsible for the phenomenology also likely to be accounted for in the brain injured child. For Csordas our perception has tended to focus on what is being done to the participants more than what it actually means for the individuals it concerns. Imagery, then, is not merely the structural elements of the performance but is, in Csordas' words 'performances in their own right, a kind of performance within a performance that may not even be observable' (1996: 94). The point of interest, then, for Csordas, is that patients elaborate an 'imaginal performance' (1996: 95) involving themselves,

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their healer and other important characters which helps them to confront the problems that are believed aetiologic to their illness. This form of charismatic healing in the Catholic tradition posits Jesus and the Virgin Mary as key instigators in the efficacy process. Furthermore, it combines with the psychoanalytic position proposed by Melanie Klein's concept of 'splitting' in which the individual's self may be a compound of several personas occupying the self with differing biographies. For Csordas the process of imaginal performances and memory during the charismatic healing sessions provides the opportunity for traumatic and contented episodes of the self in past, present and future situations to be juxtaposed and synthesised into an embodied encounter with Christ and the community of God.

The specific efficacy within this complementarity lies in the juxtaposition of the divine world of the purely possible and the struggling human world of traumatic autobiographical memory, and the experiential superimposition of the divine imagination upon human memory in imaginal performance (Csordas 1996: 107).

What Csordas offers us here, then, is a way to make sense of the imaginal performances that many brain injured children enact. Unlike those healers in the religio-charismatic tradition who manipulate symbols of the divine in order to effect healing, the disabled children encountered above manipulate television characters or events taken from the past experiences of close kin to extend their experiences into real situations of embodied phenomena. The self performing evocations of brain injured children and the charismatic tradition not only share similar procedures for healing processes (imaginal performance) but the common feature is of embodiment as the genesis for action and efficacy. As Csordas so eloquently argues

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Imagery is a bodily practice insofar as it engages multiple sensory modalities. In addition, the experience of immediacy and self-presence in imaginal performances are reinforced by both patient and healer in the process of autobiographical transformation. Finally, it is relevant that a principal component of imaginal performance is the manipulation of the actors' bodies. Imaginal bodies though they may be, there is an essential kinaesthetic and proprioceptive element in sitting on the lap of the Virgin, holding one's disintegrating mother, merging with one's childhood self, or walking in a imaginal garden (Csordas 1996: 102).

This is equally true for the children presented here. Cindy's utilisation of actual childhood events from her mother and grandmother, Timothy's sanctioning self rhetoric and Tom's restaurant business are not just the imaginary flight of childhood fancy. They are performances of potential within which the imagination and body are exercised to the full. Children can, of course, imagine themselves as animals, Batman or aeroplanes but the important difference lies in the physical actuality of their own bodies. Imagining to be a mouse or a bat (as we saw earlier in Nagel's (1979) discussion, see Chapter 2) would merely be fantasy because the capacity derived from the structure and function of their unique human forms makes behaving as human (in the physical sense) the only real and pragmatic possibility. We can not actually know what it is like to be a bat, or anything else for that matter, because everything that informs a bat about its capacity is derived from the fact that it is a bat, with a bat's body. The difference now for brain injured children is that although their bodies may deviate from normal expression, their imagined activities, evolved from other human experiences, are ultimately commensurate to that genre of human operations that would be available to them if not for a lesion in CNS functioning. The actuality of driving a car, playing limitless games with friends and growing up and having a family are not transpositions into other existencies, they are confirmations of

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a shared humanity. These imagined performances are not only psychologically fulfilling but also provide vital afferent and efferent input to a normally incapacitated body¹². These performances proprioceptively¹³ and kinaesthetically enrich the child's body for, as the streams of imaginative detail flow into their minds, their bodies sensitively engage in motoric and sensory adjustments encompassing the whole child and his or her enacted reality. Jesus and the Virgin Mary, who form the spiritual entity in the charismatic healing process, are replaced by the occupancy of tangible and accountable characters from television or the childhood events of others, in ways that make a juxtaposition from present disability to imaginal or future potentiality not only possible but experientially real. I believe this is what Csordas means when he states

I would suggest that imaginal performances can be understood as a manipulation in fantasy of internal objects in order to resolve developmental stalemates. In other words, internal objects are objectified as the actors in imaginal performances (1996: 102).

As the community of the Catholic Charismatic Renewal provides the bedrock for ritual healers, so too the family serves in inspiring the self performances of enactment that many brain injured children develop as a means of extending their experiences. The role of healer may be played by an unsuspecting parent or sibling whilst that of the of the divinity may, for the children presented here, be some character which occurred in someone else's

¹² Afferent pathways are involved with bringing information into the body, especially the brain whilst efferent processes send information from out of the brain to the body.

¹³ Proprioceptors, sometimes referred to as mechanoreceptors, are located throughout the body in muscles, tendons and joints and respond to changes in the tissues where they are located. In this way the brain gets information about the body as it moves, or is manipulated, in space.

childhood or in a television soap opera. The important point, however, is that the patient in the former and the child in the latter are themselves the main agents of action and enactment. It is only from within themselves that the real opportunities are ever expressed or made possible, be they the healing of some past trauma or the future development of a brain injured child's independence.

Conclusion

My analysis above may offer one way to consider the play which occupies much of the personal time many of these children spend with their family at home. If I have got some of the detail correct then these performances are primarily for the self to exercise a body and mind into a meaningful campaign that confers ability to disability. The real emphasis of this work was to attempt to account for that phenomenology within which the child with a brain injury was enveloped. That personal embodiment and experience exist as the tenable capacities of brain injured children which can be further developed through both an alternative therapeutic method and the child's own performances has been argued throughout this thesis. The fact that orthodox medical enquiry has yet to properly acknowledge this phenomenology of the disabled does not disprove its existence. They may have simply, through a myopic conviction in scientific rationalism, lost sight of all the components that regulate health and illness in their patients. As Sharma states

The contest between orthodox and unorthodox medicine may be between forms of knowledge, but the prize is, in the last analysis the patient. If patients are not convinced that a form of treatment works, intellectual arguments about the validity of the knowledge on which it is based will be of little avail (1992: 123).

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The body, then, may well be born as a biological entity (mechanism for medical exploration) but it requires social action not only to transform it within the context of society but also to enable it to have meaning in social relations (Shilling 1993: 199). In this way personal phenomenology is made by, and at the same time contributes to, the embodied experience of all those with whom the individual interacts. Brain injured children differ little from other children in their basic enactments of embodiment. It is in the interpretation of these bodily experiences that differentiation is to be encountered.

I hope to have shown that these children are indeed the orchestrated bodies of institutions that in every aspect regulate both their behaviour and our expectancy of a potential believed to be confined by disability. As in Csordas's analysis of the invisible elements that occur in the 'imaginal' encounters of patients during their ritual healing sessions, so too is there a great deal of the invisible in my study of brain injured children attending alternative therapy. In my attempt to make apparent these children's essential phenomenology I am aware that I have offered few solutions, but sought instead to define the operational parameters used by professionals and other adults to consider these children by largely dismissing their potential. What this thesis has shown, therefore, is that as far as those children who suffer brain injury are concerned they have yet to be sympathetically accounted for as children in their own right.

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I am aware that I, too, have given but little voice to their expressions, but I hope that my account may have suggested more attentive ways of listening to the murmur of childhood disability. Furthermore, I am equally aware that I have offered no more than rhetoric, be it sensitised rhetoric, as a way of articulating the many issues that are the primary concern of parents. Unless we are willing to explore the invisible worlds that brain injured children are responsible for constructing, we will in fact fail to chart that vital source of human experience which these children's components inevitably enrich. Indeed, ignorance of such detail is not only inexcusable from the point of view of epistemology, but also unthinkingly arrogant to all those confined by their dysfunctional bodies and who are only ever considered in terms of their impairment.

Orchestrated as these children's bodies are, one cannot assume that the manipulations that take place are solely the expression of an institutionalised society acting negatively to dismiss their submerged potential. The fact that many brain injured children's self performances engage with those real world encounters of others, via the assimilation of extra-personal experience, to extend embodiment may suggest that the real orchestrators of these children are perhaps themselves. Learning how to encourage and recognise these processes may not only provide new levels of therapeutic efficacy to traditional treatment programmes, but perhaps more importantly also provide essential biographical information to explore the constructions of reality from which we have been, for far too long, largely excluded.

Appendix 1 **Summary of children: General information.**

Age	Sex	Causation	Diagnosis	Pos in Fam	Siblings	Previous Therapies	Sibling Problems
13	male	birth	non-specific	1	1 brother 1 sister	Physiotherapy	no
6	male	genetic	Chromosomal abnormality	2	2 brothers (1 twin)	Portage	yes, identical twin
6	male	genetic	as above	2	as above	Portage	as above
2	male	birth	Developmental Delay	1	none	Physio, Occupational Therapy	no
5	male	trauma (drowning)	Cerebral Palsy	1	none	Physiotherapy	no
4	female	u/k	Cerebral Palsy	2	1 sister	Physiotherapy, Portage	no
2	female	birth	Cerebral Palsy	1	1 brother	Physiotherapy	no
9	female	genetic	non-specific	1	1 brother 1 sister		no

Appendix 1

Summary of children: General information.

Age	Sex	Causation	Diagnosis	Pos in Fam	Siblings	Previous Therapies	Sibling Problems
5	female	trauma	Encephalitis	2	1 sister 1 brother	Physiotherapy	no
7	female	birth	Hemiplegic	2	1 sister	Physiotherapy	no
4	male	trauma	Viral Encephalitis	1	1 sister	Portage	no
4	female	trauma	Viral Encephalitis	1	none	Physiotherapy	no
5	female	birth	Developmental Delay	2	1 brother	none	no
7	male	trauma (near drowning)	non-specific	1	none	Physiotherapy	no
5	female	birth	Developmental Delay	2	2 sisters	Physiotherapy	no
6	female	birth	non-specific	2	1 brother	none	no
2	male	birth	non-specific	1	1 brother	Physiotherapy	no
5	female	genetic	Dysmorphic syndrome	2	1 brother	Physiotherapy	no
5	male	birth	Cerebral Palsy	1	none	none	no

Appendix 1 **Summary of children: General information.**

Age	Sex	Causation	Diagnosis	Pos in Fam	Siblings	Previous Therapies	Sibling Problems
3	female	u/k	Delayed Myelination	1	none	Osteopathy	no
5	female	u/k	Dystonic Cerebral Palsy	1	none	Conductive Education	no
8	male	birth	Cerebral Palsy	1	1 sister	Physiotherapy	no
7	female	viral infection	Athetoid Spastic, Hydrocephalus	1	1 brother	Portage, Physiotherapy	no

Distribution of Causation by gender

Causation	Female	Male	Total
Birth	6	5	11
Genetic	1	2	3
Trauma	2	1	3
Trauma (Drowning)	0	2	2
Viral Infection	1	0	1
Non-Specified	3	0	3
<hr/>			
	13	10	23

Appendix 1

Summary of children: General information.

Distribution of Diagnosis by gender

Diagnosis	Female	Male	Total
Athetoid Spastic, Hydrocephalus	1	0	1
Cerebral Palsy	5	6	11
Chromosomal Abnormality	0	2	2
Delayed Meyelination	1	0	1
Developmental Delay	2	1	3
Dysmorphic Syndrome	1	0	1
Dystonic Cerebral Palsy	1	0	1
Encephalitis	1	0	1
Viral Encephalitis	1	1	2
<hr style="border-top: 1px dashed black;"/>			
	13	10	23

Appendix 2

Victims or Beneficiaries? 'Magical Thinking' Reconsidered and some general notes on the patterning method of therapy.

Robert Cummins has argued that the Doman-Delacato method of stimulation is unscientific and that parents and professionals who subscribe to this procedure are naively following the 'belief in irrational thinking' or 'magical thinking' even though there is 'not one shred of reliable scientific data to support the existence of such phenomena' (Cummins 1989). The following offers a critique of Cummins' argument, and a personal account of one particular alternative therapeutic setting of which I have some experience, in the attempt to clarify some of the misconceptions that I feel are common to many orthodox professionals.

Scientific Method

Cummins' critique of the Doman-Delacato method postulates that the one science, according to his own rationalism has championed over all other considerations. It is not my intention to assess the full implications for a scientific method and its philosophical postulates here, but rather to suggest that the definition of 'scientific' is not restricted to the rationalist's tenet which accompanies Cummins' critique and those of many others in the profession.

This philosophy considers that there exists a single universal criterion which assesses all rival theories. The distinction between a scientific and non-scientific approach for the rationalists is now straightforward. That is to say any theory whose merits can be clearly assessed by this universal criterion,

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and which subsequently pass the test of the criterion, are scientific.

Knowledge developed by this method will tend to be regarded towards both scientific rationalism and truth.

Science, most basically, often involves two distinct but necessary procedures. The first of these requires that the right questions be asked. The second concerns the problem, where do we look for the answers? Cummins' (1988) work 'The Neurologically Impaired Child: Doman-Delacato Techniques Reappraised' addresses the former concern but, unfortunately, fails to find the answers to the latter. That is, he asks the right questions, but in the wrong places. The responsibility for this simple, but important, mistake may well be found in his rationalistic approach to science. Cummins is absolutely correct to point out the disparity that exists between the theory and practice of the Doman-Delacato techniques. Furthermore, there can be little justification, either scientifically or otherwise, for the excessive daily routines of 'patterning' which they advocate. However, my agreement with the two statements presented above does not contradict the notion that (1) theory and practice, although frequently forming a unified approach, nevertheless need not be indivisibly part of the same phenomenon and (2) 'patterning' (specific programmes involving passive stimulation) can help develop valuable strategies for the remedial treatment of brain injured individuals. Although there may be a tendency to agree with many of the criticisms levelled at the Doman-Delacato method, it is nevertheless felt that the underlying rationalism of the Cummins' argument fails to perceive the real beneficiaries of a moderated approach. That is, this methodology is unable to assess the

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multidimensional nature of its 'true' subject. Such dimensions involve the subjective and objective feelings, experiences, anxieties and hopes that both the child and his or her parents have with regard to their predicament. The scientific tenets which underpin Cummins' reappraisal find it difficult to measure these factors so, instead, they submerge such detail under the drowning dogma of rational scientific superiority. It is simply not good enough to regard the scientific assessments as more important than the sophisticated judgements of the people involved. Generally speaking, parents understand more about their child's problems than do the so called 'specialists'. This knowledge may not be scientifically formulated, but it does involve critical assessments with regard to their child's essential developmental requirements. Parents are not easily tricked, since surely any initial vulnerability, to which they might be predisposed considering their plight, would be eroded away if results on their terms were not achieved. With these considerations in mind, Cummins' reappraisal may well have profited from a 'relativists' standpoint. This approach denies a universal rationality for science, and posits instead that the scientific enterprise should adopt a set of criteria that are more relative to the requirements of the individuals who subscribe to them than to the more scientific method which measures them.

There can be little doubt that much of the theory which underscores the Doman-Delacato techniques is speculative, if not unsound, by any criteria. However, such a disparity between theory and techniques need not always render the techniques obsolete, even when the theory for it is obviously inadequate. For example, science and technology are often seen as being part

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of the same thing. However, they can in fact be totally independent of one another. Consider the technology of the steam engine, which was developed before any consistent theory of thermodynamics was imagined, let alone postulated. Thus, although theory and practice are usually in consort with one another this is not an essential requirement. Cummins' attack on the Doman-Delacato theory with the legion of rationalism may secure a victory for the orthodoxy within the medical community, but he has by no means, won the war.

The problem is that many of the people who are personally involved with the remedial treatment of brain injured children are unaware that a challenge to their beliefs has been made, let alone suffered defeat. This is because they tend not to be convinced by argument alone, especially when it is contradictory to their experience. Many alternative therapists, like Robert Cummins himself, are not convinced by some of the theoretical notions proposed to account for the techniques' application. Several of these techniques, however, have been found to be effective in promoting strategies of positive and purposeful interactions between the child's functioning, his or her family and the environment. These patterns of encouraged motility provide the substrate on which self development (cognitive and physical) can be promoted.

Effective Strategies.

Many of the techniques advocated by Doman-Delacato have been empirically demonstrated to make a valuable contribution in aiding the child to

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gain a relative autonomy over motor control. That is, they provide direct stimulation to both the muscles and their corresponding motor neurons that are responsible for controlled function. Enhancing motor function is also an important stimulant for cognitive and social development. The use of passive limb and body movements is designed to help the child experience where the muscles are, what they do and how this can affect motility. This is achieved by firstly assessing the child's ability and subsequently designing an individually tailored programme of therapy to the child's unique requirements. In this sense these specific techniques have a particular responsibility for the mediation of input from limb to motor areas in the brain. This, in essence is the 'programme'. However, an indirect result of these techniques is that they also help to establish purposeful and positive interpersonal contact between the child, his or her parents and helpers, and the external world. Consider for a moment how enriching these procedures can be to a child so incapacitated that even basic reflexes are distorted and mal-adaptive. The parent's expectations are not, in my experience, unrealistic but positive, and all help is directed at that which the child can do to master that which he or she cannot. During these regular situations of directive contact parents and helpers talk, sing and touch their child, while at all other times the normalising routines that establish family life take precedent. These procedures transform the child's personal environment from one with low expectations, and the often attendant deprivations, to one which is enriched socially and physically. It is also important to consider that the use of volunteers (patterners) in a controlled fashion promotes sociality by providing 'first hand' experience of other people.

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I think the biggest plus factor, besides her improved development, is the social development. ... you know the interaction with all those people (patterners) I don't think any child has the opportunity to see thirty adults a week and to become close to her. Giving their almost undivided attention to her, she loves being the centre of attention.

These encouraged relationships between child and 'patterners' are important since the child must attempt the appropriate social responses during the interactive periods. A failure to acquire these basic social skills could affect not only the helpers' commitment to the child and programme, but also the child's future social development. Another point worthy of consideration is the need for the parents to feel that they are doing something about their child's problems (see Chapter 5). Such techniques not only encourage the child to develop, but also fulfil the need of parents to do all that is possible to help their child increase personal functioning.

One of the major distinctions between the modified approach exemplified here and the original method developed by the Institute for the Achievement of Human Potential in Philadelphia is the excessive programme regimes prescribed by the latter. I would suggest that twelve to fourteen hour per day, spent delivering an intensive programme of stimulation, is incommensurate with regards to familial requirements, let alone those of the child. The adoption of such an extreme regime would do little to provide the child with enough personal time to process and assimilate the information being provided from continual stimulation. Furthermore, it is not difficult to imagine the extent of familial stress that is likely to be the result of this intensive programme. Instead, the system of therapy with which I have had experience

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advocates no more than fifteen hours per week. This is, in itself, a considerable commitment of time and effort, but far more realistic than that proposed by Doman-Delacato.

Conclusion

Although Robert Cummins' reappraisal on the techniques of Doman-Delacato has highlighted the inadequacies of their theory, the adoption of a single minded 'rationalism' is neither appropriate nor constructive in assessing the humanistic ramifications of brain injury. The problem of therapeutic efficacy is not measured by validating the theoretical tenets, but by assessing the objective benefit derived from a particular approach to ameliorate, at various levels, the symptomology of brain injury. That fact that highly efficacious therapies are frequently rejected in medicine because they do not align themselves to current therapeutic trends does much to explain Cummins' criticism of the general 'patterning' approach. This phenomenon, termed the 'tomato effect' has been given much consideration by Goodwin & Goodwin (1984) who suggest that it most likely occurs

when an efficacious treatment for a certain disease is ignored because it does not "make sense" in the light of accepted theories of disease mechanism and drug action' (1984: 2387)

Indeed, the history of medicine is replete with examples where 'tomatoes' such as colchine for acute gout, and gold and high dose aspirin for rheumatoid arthritis (Goodwin & Goodwin 1984), were discouraged even

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though they were known to benefit patients. Likewise, many alternative therapies are ignored or criticised simply because the ideas of mainstream clinical practice do not correspond with those empirical beliefs derived from the alternativists' therapeutic encounters with brain injured children.

It is suggested that if a position involving the relativists approach were to be employed, one would assess more personally the effects therapy has on those who subscribe to it. After all, the beneficiaries of this approach are intended to be the brain injured and their parents, not the scientific community. This is not to argue that scientific validity is not important, but it should attempt to measure the human experiences, behaviour and development of those involved, more than concerning itself with the poorly developed theory that attempts to support a unified methodology with that of medicine. It is also suggested that the techniques developed, initially by Doman and Delacato, and especially those modified by other committed practitioners, can offer an effective alternative to that which even Cummins' himself refers to as 'traditional and outmoded professional thought' (1988: 17). This approach is by no means a panacea for brain injury, however it can help effect positive changes in personal functioning for the injured child while helping to resolve much of the parental isolation and feelings of helplessness that often accompany these situations. Many of the techniques employed can assist the child to develop primary skills that aid not only motor functions but perhaps also those of cognition and social development. 'Magical thinking' may now be reconsidered to be not that naive and unrealistic belief which organises parents to seek an 'alternative' for their brain injured child, but in fact the

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process by which compliance to the medical orthodoxy frustrates the aspirations of both child and family.

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