LEARNING DISABILITY AGAINST ITSELF: LOST IN SELF-INJURY

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Andrew Lovell – Learning Disability Against Itself: Lost in Self-Injury

Abstract

The primary purpose of this piece of research was to investigate the role of self-injury in the lives of a group of individuals with significant learning disabilities, some of whom have experienced institutional life whilst others have always remained with their families, though all now live in community settings. The case study methodology was chosen because of the nature of the questions being explored, which revolved around issues of the connections between professional discourses, the negotiation of reality by different members of the group, and the process by which they became engaged with self-injury. The historical context was considered important, encompassing the period 1960-2000, because it was over this time that the transition from an institutionally-based service to a community one effectively took place. The case study approach necessitated multiple sources of data collection pertaining to the lives of fifteen individuals, all of whom had significant difficulties in communication to the extent that very few engaged in any spoken language, and all had a life-long relationship with self-injury. The methods comprised analysis of archive material, including medical and nursing case note material, assessments, reports, and professional correspondence, interviews with parents and qualified learning disability nurses, and brief periods of directly observing each individual in the study group.

The results of the study suggested an early affiliation of each member of the group with self-injury, the gradual emergence of a complex repertoire of behaviours as the years passed by, and the difficulties inherent in professional attempts at ameliorating the situation. Professional discourses effectively met at the juncture of the multi-disciplinary team, whereby each member would be expected to present their own definition of the situation. The remoteness of the consultant psychiatrist, embodying the biological discourse, served the profession well, with power being retained over time despite the changing circumstances, which would appear ill-suited to its continuing dominance. The other primary discourse, behaviourism, initially resided with the clinical psychologist, but proved irresistible to other groups of workers working with this complex client group and accordingly came to assume the most dominant position. The discourse surrounding the communicative intent of self-injury, though maintaining a discrete presence in the shape of the speech and language therapist, came to be absorbed into behaviourism, with a consequent loss of credibility as a separate entity. The consequences for parents of self-injuring individuals, regarding the way in which self-injury has been socially constructed, were sometimes immense. There was frequently a failure to listen or understand the reality of others' lives, particularly as the post-institutional world was taking shape and there being an absence of expertise and knowledge relating to the needs of families with never-institutionalized members in extraordinary circumstances.

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IN MEMORY OF MY DEAR MUM AND DAD
ROYSTON W. LOVELL (1925-2003)
JOYCE LOVELL (1933-2002)

LEARNING DISABILITY AGAINST ITSELF: LOST IN SELF-INJURY

CHAPTER ONE: LEARNING DISABILITY AND THE SOCIAL CONSTRUCTION OF SELF-INJURY

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(i) Introduction

My interest in self-injury in individuals with learning disabilities is one that goes back many years, something that I initially regarded as puzzling and shocking, but was content to dismiss as arising from the 'brain damage'. When I was growing up in the 1960s my family used to make regular excursions to visit my father's relatives, who continued to be based in Bristol, whereas he and my mother had made a life for themselves in Cheshire. His younger brother had three sons, all of whom were a little younger than myself, and the elder two had phenylketonuria, a metabolic disorder, which had not been detected and consequently resulted in quite considerable 'mental retardation'. Neither of my two cousins developed spoken language, though the family developed effective communication strategies and never considered anything other than them living at home. During our visits, though I was never uncomfortable, their 'difference' was very pronounced, and the younger one in particular would sometimes sit for long periods in a comfortable chair bouncing violently against the backrest. He did not strike me as being discernibly distressed, though on reflection the ways in which some individuals with learning disabilities convey emotion can be more complex than I would ever have known.

Nevertheless, without realizing it, my first encounter with self-injury was taking shape and this first image would be one that would become a significant point of reference.

From the early 1970s onwards, when I first began doing voluntary work in a hostel for children considered 'mentally subnormal', I slowly acquired more and more experience of this propensity to self-injure. The hostel was clean and bright, some of the children were permanently living there until they reached such an age as they would transfer to adult services, and some were there for short-term care only. Temper tantrums and emotional outbursts were quite frequent, but most of the children could express themselves to some extent through language, which meant that they could usually explain an emotion, even if it did not resolve the distress. There was some self-injury, which again tended to take the form of throwing oneself against a wall or to the floor, and occasionally slapping the face or pulling the hair. These behaviours I could again explain, though, through frustration and the individual not having the emotional capacity for preventing this being translated into anger and then violence. Other factors were certainly at work, such as the child being aware of his/her 'difference' from others, and all of his/her relationships involving a considerable power differential. It was and is extremely difficult to assess the contribution of such factors on the emergence of self-injury, and in retrospect these are issues that all people with learning disabilities need to negotiate and slowly come to terms with as they start to make their way in life.

In chapter two I will discuss my initial impressions of encountering and re-encountering three particular individuals, who self-injured violently and consistently to the extent that they caused themselves regular and sometimes quite horrendous harm. I initially met these three members of the study group whilst working in an institutional setting, before re-acquainting myself with them following their community resettlement. It was consequently the question of the development of the self-injuring over the passing years, as they reached maturity and beyond, that I found of interest. There seemed to be no real explanation of why the pattern of self-injuring adopted the shape that it did, or why sometimes the individual would hurt him/herself but appear generally content with life, whilst at other times seem driven by a desire to do real damage. This was the motivation for this research, to try to follow the path of the self-injury within the context of changes occurring in the individual's life, whilst simultaneously looking at the ways in which we, as carers, professionals, and as a society respond to it. Consequently, the study needed to be based on the lives of real people to see whether there were specific phenomena occurring, such as shared experiences and circumstances, which could help to explain why self-injuring had become so important to them.

(ii) The study's questions

The central question that I wanted to address in starting out on the research concerned the cause or causes of an individual with a learning disability engaging in the sorts of self-injuring, which seemed so characteristic of this group of people. I had always found that many of the approaches employed over the years to try to reduce an individual's self-injuring seemed to me to be less than satisfactory. This was not because of the degree of control that was exerted though this was frequently excessive, but related more to a belief that the dominant approaches (medication, mechanical restraint, behaviour modification) did not really address the cause of the self-injury. Furthermore, the 'functional analysis' approach (see chapter four), though offering a practical and sometimes effective way of addressing self-injury, failed to concern itself with what I considered to be some important issues. These were mainly concerned with the course of self-injury through the individual's life, and the changing social context within which it occurs. Nevertheless, this notion of cause remains at the heart of my study, albeit significantly modified, since it is the one that is the most difficult to answer.

A number of secondary questions emerged from this central question and sought to address the issues about cause that I felt needed answering. These questions tend to link into each other and centre on the development of self-injury and the predominant responses to it:

- What particular factors have contributed to the emergence of self-injury in an individual's life?
- Why are these factors of significance?

- How do different professional groups construct their own 'definition' of self-injury?
- How do such definitions relate to the sorts of treatments/interventions advocated by such groups?
- How do non-verbal self-injuring individuals negotiate the reality of their lives?
- What are the key differences in the development of self-injury between those individuals experiencing institutional care and those experiencing family care only?

These questions are predominantly concerned with 'how' and 'why', which guides the research, according to Yin (1994), towards an 'explanatory' approach. Furthermore, one of the two remaining 'what' questions is concerned with the identification of key differences between the constructions of self-injury in the differing contexts of institution and family. All of these questions, then, suggest that a case study design with multiple methods of data collection would be the most fruitful. Only the first question, requesting information about specific factors, might indicate the value of an alternative approach, such as a survey; but when this is located within the context of an individual's life, the merits of face-to-face interview emerge into focus. The study's questions, according to Yin (1994), constitute the first step in the case study approach to research, which will be explained in detail in the following chapter. I have included this brief discussion at this point in order to emphasise the particular focus of the research, and illustrate why an alternative methodology would have been less pertinent.

In my investigation of these questions I have, throughout this thesis, tried to employ the pertinent term of choice in describing people currently considered to have learning disabilities, so as to reflect prevailing views about their relationship with society. Similarly, I have tried to draw on the literature of the period, from textbooks and practical handbooks aimed primarily at nurses and other direct care staff, to the more academically orientated research and discussion articles. In doing so, I have tried to address the extent to which contemporary thinking about learning disability and self-injury influences the practicalities of the delivery of care, and how much is affected by other, possibly more pragmatic, factors.

(iii) The problem of definition of self-injury

There is something quite unique about the ways in which people with a learning disability and associated communication difficulties engage in self-directed violent behaviour, which sets them apart from other groups seeking to harm themselves. It is frequently regarded as a poor relation to similar behaviours where no such learning disability is in evidence. For example, one of the most comprehensive textbooks on the topic, written in the late 1980s, identifies it as a sub-category of the preferred term self-mutilative behaviour (SMB). In the context of learning disability, four defining characteristics are identified:

- the behaviours indulged in are considered more ‘primitive’ because of their very nature;
- there is invariably a higher frequency rate;
- the most influential factors are the level of stimulation and the availability of reinforcement;
- sometimes there is an underpinning of identifiable organic problems (Walsh & Rosen, 1988, 131-2).

Walsh & Rosen acknowledge that the term of choice when discussing such behaviour in people with a learning disability is self-injurious behaviour (SIB), since this is the expressed consensus of writers and researchers in this field. They do, however, acknowledge that the two terms are virtually interchangeable and essentially refer to “self-inflicted injuries that may be performed either as a method of communication or as a means of discharging emotions” (1988: 131). This association is considered as being unquestionable, and probably relates to the view of people with a learning disability engaging in self-injury simply as a means of dealing with the frustration of being unable to express themselves effectively in alternative ways. The features identified above are intended to enable us to differentiate between the self-injury of people with a learning disability and the more 'sophisticated' SMB of people with mental health difficulties.

Another influential book, first published in 1987, was Favazza's 'Bodies Under Siege', which again was primarily concerned with the self-mutilative behaviour of some people with psychiatric problems. Once again, people with a learning disability are identified as a sub-group of the wider population of people who engage in SMB. Favazza divides SMB into two major categories, which serves to emphasise and illustrate the socially constructed nature of the phenomenon, through inclusion of what he refers to as 'culturally sanctioned self-mutilation' (1996: 225). This relates to rituals and practices, which are considered to be reasonable and rational in the context of the particular social group within which the behaviour takes place. Favazza spends a considerable amount of time in his book exploring the very nature of SMB and demonstrating the appropriateness or inappropriateness of the behaviour depending on such contexts.

Culturally sanctioned rituals refer to "activities that are repeated in a consistent manner over at least several generations and that reflect the traditions, symbolism, and beliefs of a society" (1996: 226). Favazza is concerned about the role that such behaviours play in helping to maintain stability and promote shared values in social groups. He approaches and explores the consensual nature of SMB rituals and how they can serve to preserve traditions and promote the health of the community.

The second group that Favazza identifies relates to 'deviant-pathological self-mutilation'. This is clear and distinct from the first category and underlines his position in viewing SMB as a clinically identifiable phenomenon, which includes very specific features. His approach has been criticized as "one that pathologizes self-mutilation, seeing it as an aberration, a maladjustment, a disorganization of normal functioning, or illness" (Babiker & Arnold, 1997: 14). Favazza's work is extremely comprehensive and is influenced by his own theoretical background; though he nods towards social constructionism and is concerned with acknowledging the acceptability or otherwise of SMB, he is primarily a clinician drawing on practical examples to illustrate his thinking.

Under the category of deviant-pathological SMB, Favazza talks of three distinctive clinical types – major, stereotypic, and moderate/superficial. Moderate/superficial is then further sub-divided into compulsive, episodic, and repetitive, according to the features presented. People with a learning disability are considered to engage primarily in stereotypic SMB, though they are not entirely excluded from the other categories, particularly when the learning disability is less severe. Major SMB involves isolated incidents of extreme violence, such as the amputation of a limb, the removal of an eye or self-castration. Favazza is eager to differentiate between such dramatic behaviours and those that represent an attempt at suicide. In his view, such "bona fide suicide attempts should not be regarded as self-mutilation" (1996: 235). He goes on to raise issues of religion and sexuality, which he argues frequently underpin major self-mutilation and reinforce his view that it should be considered separate and distinct from the other two categories. Favazza is also concerned to draw attention to the fact that, for many people, who self-mutilate, despite its pathological nature, the activity is rewarding and may be even beneficial to their wellbeing.

> "The deliberate destruction or alteration of body tissue without conscious suicidal intent... (and if habitual)... may best be thought of as a purposeful, if morbid, act of self-help" (Favazza & Conterio, 1988: 27).

Moderate/superficial SMB refers to:

> "(H)air pulling and skin scratching, picking, cutting, burning, and carving, (which) are the most commonly encountered forms of self-mutilation" (Favazza, 1996: 241).

He equates our understanding of such behaviours as being similar to our understanding of eating disorders a few years earlier, prior to the increased awareness of public and professionals alike. But now, as with people engaging in the abuse of food, many people from a range of backgrounds are admitting their association with these self-mutilating behaviours. Favazza argues that there is invariably a link with mental health conditions, such as anxiety disorders, dissociative disorders, depression, personality and borderline personality disorders (1996: 246-9).

Repetitive self-mutilation occurs when episodic SMB, “becomes an overwhelming preoccupation in those persons who may adopt an identity as a ‘cutter’ or ‘burner’ and who describe themselves as addicted to their self-harm” (1996: 250-1). Favazza goes on to discuss how he believes that this then constitutes a distinctive clinical syndrome, which is essentially a disorder of impulse control. He argues that it should be classified along with intermittent explosive disorder, kleptomania, pyromania, pathological gambling and trichotillomania on Axis 1 of the American Psychiatric Association’s *Diagnostic and Statistical Manual* (Favazza & Rosenthal, 1990). He also argues that the diagnosis should not be made when there is an underlying organic condition, “such as serious mental retardation” or identifiable syndromes like Lesch-Nyhan, de Lange and Tourette’s (1996: 253). Consequently, people with a severe learning disability or syndromes that have been linked with repetitive SMB are effectively excluded.

The term that has become the one of choice in describing violent behaviours directed towards the self is self-harm. There does, however, continue to be a lack of a clear consensus concerning which term refers to which behaviours, though self-harm is the one that is used most widely and most commonly. The argument for a self-harm syndrome has gathered pace over recent years and it is less all-inclusive than when it was proposed in the mid-1970s (see Morgan et al, 1975). Four years later, Morgan forwarded the most comprehensive definition of Deliberate Self-Harm Syndrome (DSH):

> “A way of describing a form of behaviour which besides including failed suicides embraces many episodes in which actual self-destruction was clearly not intended. The general meaning of self-harm is also well suited to cover the wide variety of methods used, including drug overdosage, self-poisoning with non-ingestants, the use of other chemicals such as gases, as well as laceration and other forms of physical injury” (Morgan, 1979: 88).

Other authors have sought to develop this initial thinking about self-harm and emphasised the need for recognition of a specific clinical syndrome (Pattison & Kahan, 1983; Harris, 1992). But differences of opinion amongst writers on the subject are commonplace and the adoption of one particular term in preference to another does appear to be at least partly arbitrary. For example, Walsh & Rosen prefer SMB to DSH by virtue of the fact that, "(S)elf-mutilation is a direct, physically damaging form of self-harm, generally of low lethality, often repetitive in nature, and commonly employing multiple methods" (1988: 29-30). Furthermore, they are critical of Morgan's definition because of its all-inclusiveness, whereby the inclusion of attempted suicides and self-cutting "unnecessarily blurs the distinction between genuinely suicidal acts and self-mutilative acts" (1988:31), a differentiation noted also by Feldman who stresses the "intentional" element but "without the conscious intent to die" (1988: 252).

Sometimes the different terms employed to describe the behaviours engaged in appear to be chosen randomly, whilst at other times, as in the previous discussion of Walsh & Rosen's approach, the term is meticulously chosen. In addition to self-harm and self-mutilation, other terms include self-destructive behaviour, used frequently in relation to behaviours involving the abuse of food, alcohol or drugs (e.g., Miller, 1994), self-wounding, which largely corresponds to Favazza's notion of 'major' SMB, self-attack (Sinason, 1992), and, of course, self-injurious behaviour.

Perhaps the most interesting contribution to this issue of classification comes from a study of cutting behaviour in a Canadian correctional school for adolescent girls during the 1970s. The researchers argue against the need for an elaborate behaviour classification system because of the implications for establishing the motivations for the behaviour prior to undertaking the research. As they put it:

> "...we decided that it would be useful to adopt a behavioural-descriptive rather than an explanatory-based classification scheme. Such an approach makes it possible to at least approximate the classification stage of research. At the point of classification we wish to avoid the complexities and problems in attempting to examine the mutilator's motives or intentions or to determine the environmental or interpersonal conditions which may have preceded the act" (Ross and McKay, 1979: 15).

In contrast, Babiker and Arnold's (1997) approach is a definitional one, which sets out to compare self-injury (used interchangeably with self-mutilation) to other forms of self-destructive behaviour. They argue that self-injury cannot be entirely separated from other behaviours characterized by harmfulness to the body, so consequently must be contextualized along with these other behaviours. This classification of self-injury is illustrated in box 1.

1) **Somatic expressions of feeling** e.g., skin disorders; pain; accident-proneness
2) **Factitious disorders** e.g., Munchausen's syndrome; simulated illness; polysurgery
3) **Self-destructive behaviours** e.g., eating disorders; substance abuse; sexual risk-taking
4) **Self-injury/mutilation** e.g., cutting, scraping; burning; banging, hitting
5) **Other/marginal self-injurious behaviours** e.g., smoking; reckless driving; workaholism; danger sports
6) **Body 'enhancement'** e.g., cosmetic surgery; tattooing; piercing; bleaching
7) **Self-harm** e.g., suicide; para-suicide; overdosing.

Box 1 – Babiker & Arnold's (1997) classification of self-injury

Babiker and Arnold go on to point out that, despite the criteria of harm to the body that unifies these behavioural categories, there are a number of ways in which they might be considered different. These include, "lethality, social construction, intention, purpose, directness and immediacy of injury, whether illness is a focus, and whether there is any deception involved" (1997: 3). People with a learning disability are absorbed within the category of self-injury/mutilation, though, interestingly, Babiker and Arnold avoid simply including them as a sub-group and briefly address their complexity. After mentioning the usual reasons linking learning disability to self-injury – organic, communication and stimulation – they say:

> "In our experience, it is far less often recognized that learning disabled people may also self-injure for similar reasons to those attributed to non-learning disabled people" (1997: 50).

(iv) Learning disability and self-injury

Favazza's discussion of SMB in relation to people with a learning disability revolves around his category of stereotypic self-mutilation, which, as we have seen, he considers to be 'deviant-pathological'. The whole tone of the section suggests that these behaviours have low status in the hierarchy of SMBs; as he says, and as the term he employs suggests, stereotypic SMBs "are monotonously repetitive and even may have a rhythmic pattern" (1996: 237). As with Walsh and Rosen's 1988 work, there is little attempt to explore the connection between the behaviours exhibited by people with a learning disability and those exhibited by people without a learning disability. Favazza suggests that there is little in the way of symbolism, cognitive process or emotional disturbance in the presentation of these behaviours in people with a learning disability and they are likely to engage in it regardless of the presence of others. In fact, for Favazza, "(S)tereotypic self-mutilators seem to be driven by a primarily biological imperative to harm themselves shamelessly and without guile" (1996: 237). This is a school of thought advanced by many people concerned with attempting to explain SMB and one that I will explore in some detail later. In essence, the biological argument cannot be ignored, but its examination certainly needs to be more exhaustive.

The over-arching term of choice in exploring SMBs in people with a learning disability is 'challenging behaviour', which has come to replace other terms such as problem, disturbed, disruptive, aggressive, destructive, violent and anti-social over the course of the last decade. The term is attributed to the work of the South-East Thames Health Authority, who established the first team specializing in challenging behaviour in the late 1980s and defined it thus:

> "Behaviour of such intensity, frequency or duration that the physical safety of the individual or others is placed in serious jeopardy; behaviour that denies access to or delays use of ordinary community facilities" (Emerson et al., 1987).

The longevity of the prominence of this definition relates to the dominance of the behavioural approach within the field of caring for people with learning disabilities over the last two decades. The definition is a working one and can be applied to most behaviours that might be considered challenging, and is useful in that the behaviour to be addressed can be measured according to the criteria of intensity, frequency and duration. The role of the behavioural approach in relation to people with a learning disability who self-injure will be identified later and then discussed in greater detail in chapter four. It should be noted, however, that the definition was altered in the mid-1990s in order to exclude certain behaviours, such as the abuse of tobacco or sport, and focus the emphasis more clearly on the contravention of important social or cultural norms or expectations (see Emerson, 1995: 3-5, for a more detailed rationale).

Challenging behaviour thus covers physical aggression towards others, violence towards property and self-injury; these are the three primary categories of behaviour associated with it. A number of miscellaneous behaviours are also covered – severe non-compliance, prolonged screaming, compulsive and obsessional behaviours, stripping and a number of others. The term provides a useful umbrella term for the various behaviours identified and has proved attractive to service providers because of its lack of emphasis on the behaviour being located within the individual. Instead, the challenge is placed with the service, the professionals providing the expertise and the direct care staff to help the individual to behave in ways, which are more acceptable in community settings. It is for this reason, though the term is not without its critics (see, for example, McCue, 2000, who argues for 'behavioural difficulties' as a more inclusive term, and Baker, 1991, for a more general critique), that it can be considered to be a progressive one and one that is in keeping with the contemporary values-based philosophy of care within learning disability services.

For the purpose of this study, however, the term to be adopted is self-injury, which is not incompatible with the afore-mentioned challenging behaviour. The main reason for this is that it is the term, which is most associated with the particular client group being researched. A good case can be forwarded for many of the other terms considered, particularly self-mutilation and self-harm, but self-injurious behaviour (or SIB) is the one that is used most widely with people with a learning disability. In particular, it does appear to be the term of choice for professionals working and writing about the care of people with a severe learning disability, who cause themselves regular bodily damage. There is no real justification of my preference for self-injury to self-injurious behaviour other than a personal dislike of the way in which SIB seems to me to dehumanize the behaviour and isolate it from the life context of the individual.

Tate and Baroff (1966) made one of the earliest attempts at a definition of self-injury. It was, however, rather too broad and lacking in sufficient detail. These writers talked of, "behaviour which produces physical injury to the individual's own body" (p.281). But, though they were referring to people with a learning disability, this does not come across from the definition. Their definition remains popular, though, and some researchers continue to use it (see, for example, Morgan and Mackay, 1998). Ten years later, a better definition was put forward by Baumeister and Rollings, but this was criticized for being rather restrictive in its scope (Borthwick-Duffy, 1994: 4). Their definition concerned "acts which are highly repetitive or stereotyped in character which result in direct physical damage to a person" (Baumeister and Rollings, 1976: 2). But the later criticizm appears valid, in that not all self-injurious behaviours are necessarily repetitive or stereotypical, even in people with a very severe learning disability. Nevertheless, there is some attempt at addressing a specific population of people, who engage in very particular behaviours.

In 1983 the American Association on Mental Deficiency used self-injurious behaviour and self-mutilation interchangeably in their attempt to devise a contemporary 'Classification in Mental Retardation'. They defined self-injury simply as "to damage or disfigure a body part by one's own action (e.g., biting or hitting self)" (Grossman et al, 1983: 195). The emphasis was thus on the process of engaging in the behaviour and the intention to cause damage. This provided a little more focus than the previous definition, but was still lacking real consideration of the consequences of the self-injury. Two years later, Murphy and Wilson proposed an improved definition:

> "Any behaviour initiated by the individual, which results in physical harm to that individual. Physical harm will be considered to include bruising, lacerations, bleeding, bone fractures, and other tissue damage" (1985: 15).

One of these authors, fifteen years later, acknowledged the definition as being less than ideal. This is primarily because of its failure to include such behaviours as self-induced vomiting and trichotillomania, but also because of the confusion that may surround a behaviour, that may be self-injurious in one instance, but if done with less intensity in another is unlikely to be so (Murphy, 1999).

A less comprehensive, but possibly more precise, definition took shape more than a decade later, reflecting Murphy and Wilson's concerns about the type of damage being inflicted as well as the increased awareness about self-injury, but also stressing the transient or otherwise nature of the phenomena:

> "Repeated, self-inflicted, non-accidental injury, producing bleeding or other temporary or permanent tissue damage" (Schneider et al, 1996).

This later definition captures the purposeful, frequently ritualistic nature of the self-injury as well as suggesting that the violence can be so extremely severe as to be life threatening. It is this definition, which will be adopted for this study, though it will be extended to take account of issues such as age, ability and communication. This will be discussed further when the people, who constituted the sample, are introduced in the next section.

The usual way in which self-injury is discussed in the literature is in relation to its 'topography', whereby the particular area of the body, such as head, hand or face, is linked to the method employed by the individual, that is, banging, biting or slapping. And more importantly, in diagnostic terms, this is the way in which it has been included, as 'stereotypy/habit disorder', within the acknowledged authority on classification criteria, DSM-III-R (American Psychiatric Association, 1987, though the system was updated in 1994 as DSM-IV). It is included on the Axis I descriptive syndrome axis and three specific criteria are identified:

1) Intentional, repetitive, nonfunctional behaviours, such as hand-shaking or waving, body-rocking, head-banging, mouthing of objects, nail-biting, picking at nose or skin;
2) The disturbance either causes physical injury to the child or markedly interferes with normal activities (e.g., injury to head from head-banging, inability to fall asleep because of constant rocking);
3) Does not meet the criteria for either a pervasive developmental disorder or tic disorder

Self-injury is also included within the category of 'pervasive developmental disorder' (Axis II), as a particular dimension of that condition, but the two cannot be diagnosed together.

One of the arguments raised by this research is that self-injury in people with a learning disability is not as difficult to understand as initially might appear to be the case. It has been interesting, however, that the literature has been contradictory in this area. The work of those inclined to regard the behaviours as 'primitive' and arising directly from the learning disability, for example, has already been mentioned. These authors address the issue of learning disability, but it is not their main area of interest. For Walsh and Rosen, "self-mutilation is an especially complex problem...one of the most puzzling and intriguing riddles that clinicians encounter" (1988: viii). In a similar vein, Favazza asserts that, "self-mutilation... is a profound phenomenon that defies ready comprehension and rational response" (1996: 4). But, presumably, such statements are compromised by the introduction of the notion of learning disability. For them, the issue becomes less, not more, complex, puzzling, profound or irrational when the individual has a learning disability.

In contrast, writers on the subject, whose primary intention it is to explore self-injury in the context of learning disability, tend to view it differently. "SIB is a devastating chronic condition for which there is no known cure" (Thompson and Schroeder, 1995: 87). It is also, "the most severe behaviour disorder affecting people with mental retardation", according to Mace & Mauk (1995: 104) [mental retardation still being the descriptive term of choice in official academic circles in the U.S, despite the use of developmental or intellectual disabilities by service providers]. The rhetoric continues with Sandman & Hetrick's observation that self-injury, "is among the most unmanageable, expensive, destructive and unpredictable behaviours exhibited by human beings" (1995: 130). The cost implications are mentioned here, possibly hinting at concerns over the expense involved in community care. Some of the clients involved in my research, for example, had 'packages' of care, which were far more detailed and comprehensive than would ever have been previously imaginable. It is entirely likely that the voluminous literature on self-injury in people with a learning disability over the last decade has come about, at least partly, because of community care's tendency to reveal the true nature of self-injury in terms of its implications for family and care providers. This is not necessarily to suggest that the care provided is always preferable, indeed some of the clients' lives investigated have deteriorated markedly as they have been affected by community care policy. But self-injury is a little easier to conceal within an institution than in a small house.

A further general comment about self-injury comes from Thompson et al (1995), who allege that the, "compulsive and deeply disturbing character of self-injurious behaviour makes it one of the most difficult behaviour problems to understand scientifically and treat clinically" (p.137). This, of course, raises the question of the extent to which it is necessary to fulfil these demands when working with people with a learning disability, who self-injure. The same authors pass the comment that self-injury by this client group, "seems alien" (1995: 137), thus increasing the already considerable distance between researcher and target population. In sum, the language used in much of this work does tend to emphasize difference rather than similarity. However, as Oliver and Head point out:

"It is difficult to introduce an article on self-injurious behaviour (SIB) in people with learning difficulties without repeating the observations of others that it can be a severely disabling and often intransigent problem" (1990: 101).

One of the goals of this research has been to attempt to reduce the gulf through the emphasis on the rational nature of the self-injury, particularly when examined in the context of the individual's life story.

(v) Selecting the group

The research framework, including issues such as data collection and analysis, as well as the life history/case study framework adopted, will be explained in the next chapter. The purpose of this section is to generally introduce the selection criteria, and provide some general information about the construction of the overall profile. My overall intention in undertaking the research was to examine the role of the self-injury when taken over a period of time in the individual's life. This necessitated contacting a number of individuals, who fulfilled the necessary definitional criteria, were accessible, and differed from each other in terms of specific life circumstances. One of the questions that interested me was the transition from institutional to community care; so I needed some of the group to have experienced life in the old 'mental handicap hospitals' and some not to have done so.

The operational definition employed was to be the one proposed by Schneider et al (1996), which gave me some idea about the descriptive nature of the sorts of self-injuring engaged in. The pervasiveness of severe communication difficulties in the client group was also a major consideration. The vast majority of people who self-injure in this direct way have little, if any, formal language, which must be fairly critical in terms of shaping the nature of the behaviour. The whole relationship between self-injury and communication will be discussed further in chapter three.

The most common forms of self-injury indulged in by people, who have severe learning disabilities and associated communication difficulties are as follows. Headbanging with fist or palm of hand or against hard surfaces; banging other body parts; repeatedly biting self; scratching or picking at the skin; hair pulling; placing inedible objects in the mouth or placing fingers in body cavities (Rojahn, 1986; Oliver et al, 1987; Schroeder, 1991). Between half and three-quarters of individuals engage in more than one behaviour (Windahl, 1987).

Fifteen individuals were selected for the study group and ranged in age from 20 to 46-years. There were ten males and five females, which is fairly representative of the incidence of self-injury within this population (Read, 1997). The work of Griffin et al (1987), for example, estimated that approaching 60% of individuals indulging in daily self-injury were male. In my group, four were living at home with parents, one with grandparents, one in a residential community for people with autism, two in assessment and treatment facilities, and the remaining seven in ordinary dwellings being looked after by nursing staff or care workers. Each member of the group engaged in more than one type of self-injury, about two-thirds had additional stereotypical behaviours and about the same number were also aggressive towards others and/or property.

The specific nature of the self-injuring engaged in is fairly typical of that described in the literature of the wider population of people with learning disabilities, who fulfil the necessary criteria. Headbanging is by far the most common type of self-injury in the group and encompasses head to wall, floor, doorframe, knees, other people and objects. Face slapping and punching closely follows. Two-thirds of the group indulge in these types of behaviours. Eye gouging/poking, knocking the chin and jaw with the fist and pulling hair are other behaviours observed that feature the head. Other behaviours are biting of the hand, picking at wounds, throwing self against walls and the floor, and eating foreign substances (pica). However, many of these are engaged in as a secondary self-injury, in addition to the main headbanging. Many of the individuals self-injure in a rhythmic, repetitive and ritualistic manner; frequently, there appears to be little aggressive intent and the face slapping and headbanging seems to represent a device for self-comfort. However, they all do have a time when the intention behind the behaviour is entirely serious. Relatives interviewed talk of a particular look or demeanour, which translates as 'I mean business now'. The individual then engages in severe self-injury, frequently choosing a favourite section of the wall to headbang or punching him/herself with markedly increased ferocity.

Additional associated information about the behaviour of the group relates to aggression towards other people and stereotypical/self-stimulatory/bizarre behaviours. Ten of the fifteen have a history of being aggressive towards other people. This ranges from pinching and scratching others when physical contact has been initiated, for example in dressing and bathing, to more expressive violence involving kicking and head butting. The same number, ten of the group, include stereotypical behaviours in their overall repertoire. Rocking is probably the most common, which can be from one foot to the other, rolling from side to side while lying down or backwards and forwards whilst seated. Rocking can take place with varying amounts of energy and may appear to be an expression of agitation or may not. Twirling around, finger twiddling and hand flapping are other stereotyped behaviours indulged in, though these are less common.

Additional physical and sensory difficulties were quite widespread within the group. Five have some degree of cerebral palsy, of which one has spent all of his life dependent on wheelchair transportation, another has left side hemiplegia following a stroke when he was in his early-20s and now uses a wheelchair full-time and three others are restricted in their movements. Only one of the group has a recognizable clinical syndrome – Wolf-Hirschorn – though there is no suggested link between this and the self-injury displayed. The syndrome does, however, bring quite debilitating physical problems so that, in addition to distinctive facial and other features, the individual has significant spinal curvature (scoliosis), which makes mobility painful and awkward.

In terms of sensory difficulties, the mother of one of the group contracted rubella during the course of the pregnancy, which had a detrimental effect on the baby, who was born profoundly deaf and with tunnel vision. She is now deaf-blind after being afflicted with glaucoma, which took her remaining sight. She and her family are still coming to terms with her becoming blind and I will discuss the circumstances surrounding the whole incident in a later chapter. Two of the others have only residual vision as a result of cataracts, which is currently considered inoperable because of the risk of self-injury during the post-operative period. Several of the group have drifted in and out of epilepsy over the years and have been consequently treated with anti-epileptic medication over a long period, but only one seems to suffer with regular seizures. Similarly, more than half have been considered to be autistic or display features associated with the autistic spectrum disorder, but only one has retained a firm diagnosis beyond the age of twenty.

The period of institutionalization covered by the group is 1960 to 1998. This covers the time from when 'mental handicap hospitals' were pretty much at their greatest capacity, through their gradual retraction, to eventual closure in the mid-1990s. This is the context for examining changes in thinking, conceptualizing and reacting to self-injury. Ten of the group have spent a significant period of their lives in 'hospital', including three for more than thirty years each, four for between twenty and twenty-five years and three for between ten and twenty years. Considering that the eldest is only now in his mid-forties, these are quite lengthy periods of time. Furthermore, one of the remaining five, currently living with her parents, has experienced respite care over more than a thirty-year period, which includes time spent on the children's ward of a nearby 'hospital'. Finally, one more currently resides in a community for people with autism and has spent regular, relatively brief periods of his life in assessment and treatment 'hospital' facilities including a period under a compulsory section of the Mental Health Act 1983. So, despite the relatively youthful profile of the sample, only three have no connection at all with the institution. However, it should not be ignored that the care of these three is closely monitored by the consultant psychiatrist responsible for their wellbeing, and it is not implausible that they will spend time in a 'hospital' facility at some point. Table 1 below provides comparative information relating to the group profile.

(vi) Theoretical explanations of self-injury

A number of different theoretical approaches to explaining self-injury in people with learning disabilities have been developed since it was identified as a specific phenomenon in the post-war period. Prior to that time self-injury was generally regarded

GROUP PROFILE

NAME	AGE	SEX	TIME IN HOSPITAL	SELF-INJURY	ADDITIONAL DIFFICULTIES	AGGRESSION TOWARDS OTHERS/PROPERTY	STEREOTYPED BEHAVIOURS	RESTRAINT *	ESTIMATED AGE AT START OF SELF-INJURY
ALAN	40	M	24 YEARS	SLAPS & PUNCHES FACE / BITES HAND		HITS OUT	ROCKS FROM SIDE TO SIDE		7 YEARS
ALISON	32	F		HITS HEAD WITH FIST / BANGS HEAD ON WALL	LEFT SIDED HEMIPLEGIA, CATARACT	SCREAMING / URINATES INAPPROPRIATELY	ROCKS TO AND FRO	ARM SPLINTS	2-3 YEARS
DANIEL	44	M	30 YEARS	BANGS HEAD ON KNEES AND WALL	WEAKNESS TO ANKLES AND LEGS		ROCKS WHEN SEATED	HELMET	< 7 YEARS
JAMES	46	M	23 YEARS	HEAD BANGS / PULLS HAIR		KICKS OUT, LEAPS UP & DOWN, SHOUTS	FLICKS PAPER OF CATALOGUE	BODY SUIT, HELMET	4-6 YEARS
JANINE	31	F		SLAPS HEAD / KNOCKS KNEES ON SHIN	PERIODIC WEIGHT LOSS		ROCKING, PAPER RIPPING, EATS SOIL		2-3 YEARS
JASON	45	M	31 YEARS	HEAD BANGS / SLAPS FACE	RIGHT SIDED HEMIPLEGIA – USES WHEELCHAIR	SOMETIMES PINCHES AND SCRATCHES ON APPROACH		HELMET	2-3 YEARS
LESLEY	20	F		KNOCKS JAW AND CHIN WITH FIST	WOLF-HIRSCHORN SYNDROME – SPINAL SCOLIOSIS		TEETH GRINDING, ROCKS HEAD FROM SIDE TO SIDE	ARM SPLINTS	3 YEARS
MELANIE	35	F	21 YEARS	THROWS SELF AGAINST WALL AND FLOOR					7-8 YEARS
ROBERT	25	M		BANGS HEAD AGAINST WALL	AUTISM	HEAD-BUTTS, KICKS OUT, SMASHES FURNITURE			3-4 YEARS
RONALD	41	M	30 YEARS	PICA / THROWS SELF TO FLOOR	AEROPHAGIA				2-3 YEARS
SAM	26	M		BANGS HEAD / POKES EYES / BANGS CHIN	CATARACT, MOBILITY PROBLEMS – USES A WHEECHAIR	SCREAMS, THROWS OBJECTS AROUND	ROCKS WHEN LYING, SUCKS BLANKET	ARM SPLINTS	5-6 YEARS
SARAH	35	F	14 YEARS	HEAD BANGS AGAINST WALL, FLOOR, KNEES	RUBELLA BABY – NOW DEAF AND BLIND	HITS OUT, KICKS AND BITES	ROCKS TO AND FRO		5 YEARS
SIMON	23	M		SLAPS HEAD / BITES HAND		SCREAMING, PINCHING, BITING	KNOCKS TEETH, ROCKS		7-8 YEARS
STEWART	40	M	16 YEARS	BANGS BACK & FRONT OF HEAD / PICKS WOUNDS		CAN PUNCH & PUSH OTHERS	FINGER TWIDDLES, GRINDS TEETH	HELMET	7 YEARS
TERRY	38	M	22 YEARS	SLAPS & PUNCHES FACE	CEREBRAL PALSY – USES WHEELCHAIR		SUCKS FINGERS		14 YEARS

TABLE 1.

* NOT ALWAYS USED AT THE PRESENT TIME

AL/KC

as simply a difficult behaviour directly linked to the individual's brain damage (Emerson, 2002). Certainly, the literature has little to say on the subject prior to the 1950s and it is notably absent from the textbooks of the period, though there were studies discussing self-injury in relation to animals and non-learning disabled infants going back to the 1920s. Three particular theories have been put forward, one biological and two psychological. These will only be identified and briefly discussed here, and then the two most influential explored in more detail in future chapters. These three primary explanations emerge at a similar point in time and quickly become rival, rather than complementary, explanations.

a) Biological

This explanation of self-injury places emphasis on something within the individual's biological constitution significantly contributing towards their propensity for damaging themselves. It emerged in the early 1960s, with a few studies suggesting links between the self-injury and a clearly identifiable clinical syndrome (e.g., Lesch and Nyhan, 1964; Bryson, Sakati, Nyhan, and Fish, 1971), and quickly consolidated itself as an area worthy of extensive investigation. The focus in this strand of the biological approach is on the self-injury representing a specific characteristic of the overall syndrome, something that the individual is unable to resist. A second more recent strand concerns the role of the mechanics of the brain, particularly the contribution of neurotransmitters in compelling the individual to self-injure or rendering him addicted to the opiates produced as a response to pain (e.g., Mace and Mauk, 1995). Chapter six will explore both strands of this overall approach as well as investigating other less influential biological possibilities.

b) Behavioural

The behavioural approach to self-injury currently represents the most influential theoretical perspective, both within the discipline of psychology and more generally. In chapter four I will explore how it grew to dominate the field of learning disabilities over the last half of the twentieth century, with its simplistic approach to human behaviour gradually being regarded as ideally suited to such a vulnerable target population. Behaviourism is most associated with the work of Skinner (1953), who issued a "direct challenge to traditional psychotherapeutic concepts and methods" (p.11) and sought to explain an individual's actions in terms of its reinforcing consequences. Consequently, self-injury could be rationally explained by reference to it achieving certain goals for the individual, and then subsequently tackled through an attempt to alter the behaviour's consequences. Recent years have witnessed the development of applied behavioural analysis, a recognition of the multi-factorial basis of self-injury (Emerson, 2002) coupled with a renewed desire to present practical but more humane interventions (e.g., McBrien and Felce, 1992; Donnellan, LaVigna, Negri-Shoultz, and Fassbender, 1988; Zarkowska and Clements, 1994).

c) Psychodynamic

The third approach to explaining self-injury, as already suggested, comes from the tradition of psychotherapy, which was the first theoretical approach to be used to influence practice in 'hospitals' for people with learning disabilities. It has enjoyed something of a minor revival over the last few years, after a period when behaviourism's dominance threatened to eliminate it as a fruitful approach with this group. A recent article by Hernadez-Halton, Hodges, Miller & Simpson (2000), for example, explains the work at the Tavistock Clinic and outlines the treatment services provided there to people with learning disabilities. These comprise individual psychotherapy, group psychotherapy, brief therapy, family therapy and consultation. Interestingly, the service does not automatically exclude people with severe learning disabilities, minimal verbal communication and self-injury, though the inherent difficulties in working with this client group are acknowledged. According to the authors:

> "(T)he service clearly encourages patients to express themselves in whichever way they can, and where appropriate, this includes the use of drawing and play material, particularly with children" (2000: 122).

They do continue, however, by acknowledging the limitations that this can introduce, stressing that:

> "(T)he staff do believe that the most important instrument of change in their work is verbal communication, whatever the patient's degree of language difficulty. By means of putting the patient's feelings and

> thoughts into words in a simple and direct form, the service believes that it can encourage the development of this capacity within the client" (2000:122).

The purpose of psychotherapy, generally speaking, is to clarify an individual's recollection of their early experience and to place some psychoanalytical interpretation upon it. As Sinason puts it, referring to her own approach at the Tavistock Clinic:

> "Central to this book is the factor of trauma as a handicapping agent – the damage done to the emotions and intellect when we are crippled by emotional knowledge. Some people have memories of incidents that are so traumatic that they become numbed with grief, stupefied. In order to protect themselves from painful memories, they throw away part of their brain, their memories" (1992: 2).

She goes on to relate psychoanalytical concepts to a number of case examples of people with quite profound levels of learning disability, and tries to demonstrate the value of prolonged, in-depth, work.

The use of psychotherapy in people with learning disabilities is extremely difficult to evaluate, just as it is also difficult to assess the extent to which it was utilized in therapeutic approaches at the time prior to the rise of behaviourism. Clarke & Clarke's *Mental Deficiency: the changing outlook*, originally published in 1958, and extremely influential in the direct provision of care within institutions, contains a whole chapter on 'psychotherapy with the feeble-minded'. The chapter is written by Gunzberg, one of the foremost thinkers in the field of 'mental deficiency' during the period of debate in the 1960s and 1970s about the future direction of care. His argument is based on the need to address the many neurotic problems afflicting the institutionalized population, because of the previous tendency for these issues to be "overlooked or suppressed" (1965: 417). This is supported by an earlier work by Jolles, who suggested, after studying the level of emotional maladjustment in a group of 'mentally deficient children', that:

> "mental deficiency of the familial and undifferentiated types is, in many instances, a symptom of personality disorder, and it is unlikely that in such cases it represents a failure of the intellect to develop normally. It is quite probable that many mental defectives may be treated successfully by psychotherapeutic techniques" (1947).

Ten years earlier, Chidester and Menninger had made a similar claim, suggesting that it was because psychoanalytical approaches hadn't been really applied to the problems presented by people with learning disabilities, that was the real reason for the lack of progress. As they put it:

> "(M)ental handicap has long been looked upon as an organic condition, therapeutically hopeless, and probably for this reason few psychoanalysts have attempted to apply their methods to the study of retarded children" (1936: 616).

One of these writers', Menninger, would go on to write one of the seminal psychoanalytical texts on self-mutilation in the general population (1938), which would consolidate his earlier exposition that it arose because of a conflict between "destructive influences aided by the superego", and the will to live, "whereby a partial or local self-destruction serves the purpose of gratifying irresistible urges" whilst simultaneously averting the likely consequences (1935: 465). Others have variously noted the possible 'auto-erotic' dimension of behaviours such as headbanging (Greenacre, 1954), its 'auto-aggressive' nature (Freud, 1954), the desire to trace ego boundaries (Bychowski, 1954), the idea that the 'mentally handicapped' child may regard her body as an object because of ego regression (Zuk, 1960), and stereotypical head rolling and body rocking being linked to difficulties in the mother-baby relationship (Richmond, Eddy, and Green, 1958). Murphy and Wilson, however, point out the lack of direct observational evidence in this last study (1985), and Freud and Burlingham (1944) counter claims of links with the ego, since headbanging may occur prior to its development. Such disparate explanations ensured that there would be little psychoanalytical cohesiveness or consensus towards its role in 'mental subnormality' (Wilberforce, 1999), which would later provide ammunition for the behaviourists because of its tendency to be used simply as a mechanism for occupying institutionalized populations in the guise of 'treatment and training' (e.g., Tredgold and Soddy, 1963).

An additional difficulty for psychotherapy in its attempts to gain widespread acceptance as a successful approach to the 'mentally subnormal' concerns the belief by many that it would prove of little value. Tredgold and Soddy (1963), for example, quote Sarason as asserting that "it is generally assumed that the mental defective individual is unable to benefit from a psychotherapeutic relationship", something that they consider a "caustic phrase" (p.448). They go on to discuss how techniques such as group therapy and counselling had to some extent taken its place" and achieved some success within institutions, particularly when used in conjunction with the structure provided by a work schedule and a programme of social activities (1963: 448).

Group therapy is identified as the most promising strategy with its emphasis on simply improving relationships between those living on the wards within institutions. It is described as being best used in conjunction with some sort of a work schedule and programme of social activities. Deeper-seated problems are not entirely excluded, but considered to be unlikely to be resolved within this situation; in fact, the whole approach is identified as being little more than common sense.

> "In most cases all that is needed is an open attitude, occasional encouragement or disapproval and a flexible system of incentives and rewards in which effort as well as success is recognized" (Tredgold & Soddy, 1963: 449).

Such an approach would appear to have more in common with the behavioural than the psychoanalytical, but there does appear to be some differences of opinion over the role of group therapy between writers of the period. Slavson, for example, suggests that its role with people with 'mental deficiency' relates to the, "discharge of emotions through anger, rage, disgust and quarrelling" because of the need to act out emotions when articulating problems in words is not possible (1950). It is clear from my own data that attempts at group therapy were made within institutions during the 1960s, though it is difficult to assess the extent to which they were implemented or the level of success achieved.

<u>Example 1</u>

Daniel Cotterill had been in 'hospital' for three years and was nearly eleven years old when he was involved in group therapy sessions. The emphasis seems to be on equipping him with basic social and personal hygiene skills, which will make him acceptable to those caring for him. The nursing entries for

September 1967 initially suggest that there is some success in this area; for example, Daniel is described as, "attempting to feed himself and (using) a potty although he remains wet and dirty". In April of the following year the notes continue in a similarly positive vein, wherein Daniel's "general movements appear to be more co-ordinated in the last few weeks", and he is "beginning to show signs of returning affection and responds better to name". The successes continue through to the end of August 1968 with progress being emphasised in a number of areas:

- hand/eye co-ordination – "will now hold a cup in both hands and drink himself";
- continence – "has now become clean and dry in the daytime if 'potted' regularly;
- self-stimulatory behaviours – "stereotyped movements less pronounced";
- receptive communication skills – "beginning to respond to certain commands, i.e., 'stand Daniel', 'sit down'.

The final entry of the summer suggests the culmination of an intensive period of nursing input with group therapy being supplemented by a technique identified as 'sense training', to which Daniel is reported as "becoming more responsive".

This period of success is short-lived, though, and from December 1968 the case note entries emphasize his failure to progress coupled with increasing concern over his self-injuring. The repeated, abrupt statement, "no marked improvement in sense training" signals the change in tone. Then, in June 1970, a bout of severe headbanging, which would be linked by the nurses to physical problems that Daniel was experiencing, effectively ends his involvement in group or any other form of therapy.
(Source: 'Hospital' medical and nursing notes, September 1967, April 1968, August 1968, December 1968, June 1970)

In considering the approach adopted with Daniel, there may be some validity in the claim, made by Sternlicht (1966) after reviewing the literature, that the use of group therapy with children in institutions has resulted in improved communication and social skills, better self-esteem, self-control, and a reduction in anxiety. Others were less impressed, however, emphasizing that such interventions were largely attempts to assert "group control and uniformity", because institutions for the 'mentally retarded' were essentially "*countertherapeutic* and particularly dehumanizing" (Slivkin and Bernstein, 1970: 436). It is the context of care, therefore, that is at fault for these authors, rather than the strategy of group therapy, which they acknowledge may have contributed towards "diminish(ing) hyperactivity in response to emotional distress", thus ameliorating the impact of familial rejection on an individual's "impoverished" personality (1970: 436). Ackerman and Menninger concur that "early psychodynamic distortions" may warrant the use of "a therapeutic method based on psychoanalytical technique", but point to the pre-requisites of an I.Q. between 75 and 90, co-existing mental health difficulties, and the suspicion that intellectual development has been restricted by childhood experience (1936: 294).

The use of these modified versions of psychotherapy largely seem to reflect the absence of effective, practical alternatives, which might prove suitable to the needs of the institution. They are also indicative of the relatively high status of psychoanalysis during the middle decades of the twentieth century, pointing to the reality of the rejections and emotional deprivation characteristic of institutional populations. Many of the writers already mentioned in this section clearly recognized these factors, but a continued belief in the role of the institution by those with a vested interest ensured that such voices were either marginalised or restricted to a role of helping the individual adjust to 'hospital' life. As a theory to explain self-injury, psychotherapy might be of some value, particularly if Babiker and Arnold (1997) are correct in their claim that the reasons for people with learning disabilities hurting themselves are not dissimilar to those without. As an intervention strategy, however, it is difficult to ascribe any success to it, particularly since it is so resource heavy, prolonged, and difficult to implement with the majority of non-verbal, learning disabled individuals. It was eventually displaced by behaviourism as the institutional approach of choice, and despite claims by more than 40% of psychologists to have psychotherapeutic skills in working with people with learning disabilities (Nagel and Leiper, 1999), there appears to be little evidence of widespread, consistent, and effective use (Sinason, 1992).

(vii) The social construction of self-injury

The adoption of a social constructionist approach to try to explain self-injury, in the context of the life of a group of individuals with varying degrees of learning disability, was always going to be problematic, not least because there is little consensus over its most important characteristic (Burr, 1995). There are, however, a number of key assumptions associated with it, and if one or more of these constitute the foundation of an approach then it can be considered social constructionist (Gergen, 1985). My starting position in employing social constructionism, therefore, is to examine whether my own study of self-injury satisfactorily accounts for these key assumptions. Though I have looked at each of the four assumptions in turn, there is very clear overlap between them and it is difficult to discuss one without addressing the others.

a) <u>A critical stance towards taken-for-granted knowledge</u>

One of the most important elements of a social constructionist approach towards any phenomenon relates to its suspicion of the way in which it is described in terms that suggest that it cannot be conceived of in any other way. We should be critical of the rational, objective approach to the acquisition of knowledge through the collection of empirical data under controlled conditions, because it is reliant on a particular set of assumptions. These assumptions constitute the background knowledge of the investigator, who approaches his/her study with the aim of adding to existing knowledge but is inadvertently confined by the boundaries of the represented profession. Gergen (1999) explains further, in the context of everyday assumptions:

> "(E)ach of these professionals employs a different vocabulary for understanding what I call my desk. Physicists speak of it in terms of atoms, biologists of cellulose, engineers of static properties, art historians in terms of Victorian style, and economists in terms of its market value. None of these vocabularies is simply derived from individual observation. I could not read them from nature. Rather, the vocabularies seem to spring from the professional disciplines; they are the forms of description and explanation particular to these traditions of practice. A physicist as such will never 'observe' cellulose, nor a biologist a static property, and so on. If this seems reasonable, then scientific truths might be viewed as outgrowths of communities and not observing minds. Likewise, to extend the logic, objectivity and truth would not be byproducts of individual minds but of community traditions. And too, science could not make claims to universal truth, as all truth claims would be specific to particular traditions – lodged in culture and history" (p.14).

In relation to the topic under investigation in my research, the critical stance towards taken for granted knowledge relates to the ways in which different professional groups construct their own particular truths about the nature of self-injury. If consultant psychiatrists and other medical personnel favoured a biological explanation of self-injury, then this would be as we might expect, since their training predisposes them to this position. It may go no further than an association made between the individual's learning disability and their self-injuring behaviour, with the first being considered to give rise to the latter. In which case no particular treatments are likely to be prescribed, other than those aimed at minimizing the extent of the injury, but nor would there be any expectation of the behaviour changing in any way as the person grew older except as a response to treatment. The learning disability was a fixed, lifelong entity, and some degree of behavioural difficulty would be considered quite likely.

Similarly so with the clinical psychologist trained in behavioural methods in the 1960s and 1970s; these practical techniques not only explained how self-injury could be modified in an individual, but they also appeared liberating and life-enhancing. Furthermore, behaviourism challenged the dominant psychological orthodoxy within 'mental subnormality' of the testing of intelligence, which was considered by some as anachronistic (see, for example, critiques by Clarke, 1956 and Gunzburg, 1965) and excluded those failing to score the necessary points on the scale from important services such as education. Behaviourism also provided those clinical psychologists suspicious of the continued dominance of psychotherapy during the 1950s and 1960s, with an alternative view of the development of self-injury as a learned response (e.g., Beech, 1969).

Other professional groups working with people with learning disabilities, who self-injure, include speech & language therapists, social workers, occupational therapists, physiotherapists, educational psychologists, and learning disability nurses. This is not an exhaustive list but one that comprises the most likely professionals to have regular input with this client group on the evidence of this study. The extent to which those professionals closely involved with the individuals in this study construct their own discourse about the reality of self-injury is one of its main aims. But more importantly, it is an examination of the consequences of such discourses, in terms of the interventions and treatments advocated and implemented, that is of greater interest. And finally, it is in the context of multi-disciplinary working that these different discourses meet and offer support to each other. However, if these different professional groups construct their own truths about self-injury according to their own assumptions, how can the multi-disciplinary team work effectively? This is a question that pervades this study, and one that is examined in some detail in chapter seven.

A final point about the critical stance adopted towards the construction of self-injury by different professional groups comes from the social constructionist concern, with why particular models of understanding come to be accepted as valid and true in preference to other (equally plausible) explanations. In the context of self-injury, there certainly appears to be some support for the notion that scientific rationality and the positivist project served to propel psychiatry and behaviourism to the forefront of providing credible explanations. In fact, the way in which psychiatry continues to influence events in the field of learning disability more generally, coupled with the widespread influence of behaviourism on other professional groups besides psychology is quite difficult to explain. Since most self-injurers with learning disabilities have little, if any, spoken language, it would not be stretching credibility to argue that speech & language therapists have just as strong a claim to being the dominant profession. I will explore this a little further in chapter three when the relationship between communication and self-injury will come under close scrutiny. Another claim for hegemony could be made by social workers, who have acquired the role over recent years of co-ordinating the multi-disciplinary approach to clients with learning disabilities through the assembly of a 'package' of care. However, since there seems to be evidence that many learning disabled people, including self-injurers, continue to experience problems of poverty and social inclusion (see Rooney, 2002), it might be surprising that the dominant discourse does not come from those such as social workers. But, somehow, the explanations of psychiatry and psychology managed to come to dominance rather than those of speech and language therapy and social work.

b) Historical and cultural specificity

One of the fundamental aspects of the social constructionist view of the world concerns the way in which phenomena vary according to time and space. How we view self-injury, therefore, depends on the particular historical and cultural context, and how this influences our explanation of why an individual would hurt him/herself. In relation to people with a learning disability, it is only from the 1960s onwards that self-injury seems to have been considered worthy of detailed investigation. It is possible that this was a reflection of the general view regarding other behaviours such as aggression towards others and property, hyperactivity, and stereotypies. These were behaviours, which arose in some individuals with learning disabilities, because of their emotional, intellectual, social, and psychological 'retardation'. Little concern was expressed about individuals' self-injuring, other than in the employment of mechanical restraint, either makeshift or purpose-made, because they did not have the capacity for rationalizing the implications of their actions. There may well be alternative, more plausible explanations to the absence of concern expressed in the literature, but these also would reflect the general societal and professional attitudes towards people with learning disabilities.

The historical context of this research covers 1960 to 2000, which generally corresponds to the period of de-institutionalization, in practical terms, in Britain. Not all of the 'hospitals' for people with learning disabilities closed during this time frame, just as many individuals, regardless of the level of their disability, never experienced institutional care. But, nevertheless, as discussed in the next section, this was a period, which witnessed the increasing critical awareness of the role of the institution, its gradual demise, and the beginnings of a more sophisticated service framework geared towards accommodating even those presenting the most complex of challenges. In the context of social constructionism, the phenomena of self-injury in relation to learning disability took on new meanings and prompted different service and professional responses. Furthermore, such meanings and responses were the products of the ideological and social forces that shaped the post-war period. The changing view of people with learning disabilities, reflected in the changes in terminology, the rise of the mechanisms of 'normalization' (later social role valorization), advocacy, and integration, as the means for achieving community care, could only have arisen within the particular vicissitudes of the late twentieth century. The discourses discussed in the previous section reflected the ways in which different professional groups, encompassing varying degrees of tradition, responded to these ideological and social changes, so that they could respond to self-injury in progressive and innovative ways, whilst retaining maximum credibility.

c) Knowledge is sustained by social processes

The rise of the multi-disciplinary approach saw an attempt to achieve some degree of integration of the ideas and practices of different professional groups, sometimes when they had markedly different constructions of the issue at hand. Despite the expected differences in the ways in which professional groups construct their own truths about self-injury, there are also some striking similarities. One such similarity relates to the shared experience of the broader social context within which different professional groups' work. That is to say that consultant psychiatrists and clinical psychologists might well be operating within different conceptual frameworks for examining a phenomena such as self-injury, but they nevertheless share the changing circumstances surrounding the critique of the institutions and the gradual acceptance of the ideology of community care.

The broad consensus with regard to the advantages of multi-disciplinary working is another case in point. Advocates of a bio-behavioural model of approaching self-injury (e.g., Mace & Mauk, 1995) demonstrate some recognition by some professionals of the need to embrace other disciplines when conceptualizing and intervening in self-injury. The generally accepted way of working with people with learning disabilities, despite considerable regional and even intra-regional variation, involves considerable consultation with other professionals. Consequently, it does not seem unreasonable to suggest that, not only is there greater tolerance of other professional groups, but also that there is increased sharing of knowledge, with the overall aim of enhancing the life of the self-injurer. This will all be explored in terms of the evidence in chapter seven, but for the moment it is worth emphasising that, even if this is so only superficially, it is the broader social processes supporting the developing reality of community care that must be acknowledged.

> "The goings-on between people in the course of their everyday lives are seen as the practices during which our shared versions of knowledge are constructed. Therefore what we regard as 'truth' (which of course varies historically and cross-culturally), i.e. our current accepted ways of understanding the world, is a product not of objective observation of the world, but of the social processes and interactions in which people are constantly engaged with each other" (Burr, 1995: 4).

d) Knowledge and social action go together

This final principle relates to the implications of knowledge, such as facts about self-injury, being defined in a particular way by an influential professional body. Not only do different professional groups produce different discourses about self-injury, which might become established and accepted as 'truths' about the reasons that people engage in it, but also this goes on to influence the formation of local and national policy. The way in which self-injury is explained gives rise to the sorts of treatments and explanations that are then considered permissible by those in the position to make decisions. One of the key purposes of this research was to investigate the validity of this position, and assess the sorts of approaches available and whether these reflected the dominant discourses.

A related point concerns how our explanation of phenomena changes over time; in this case the changing context is the implementation of community care policy and the retraction (and closure) of the institutions between 1960 and 2000. A social constructionist position would expect such a time period, particularly one, which witnessed such dramatic changes in the way in which people with learning disabilities have been perceived, to reveal significant changes in approaches to self-injury. Several chapters in this thesis are concerned with the construction of different discourses about self-injury, namely behavioural, biological and as a communicative act. Along with the psychotherapeutic approach, which I have briefly addressed, though it is no longer of major influence, these explanations are well documented and govern the direction of therapeutic interventions. However, with the emergence of the multi-disciplinary team, there has been considerable need for tolerance and, indeed, embracing of alternative explanations. It follows that if the multi-disciplinary team is successful in its integrated approach towards self-injury then a new definition should emerge, one which reflects consensus rather than competition. The relationship that professionals have with self-injury, according to social constructionist thought, should change according to the social, economic, and political contexts of the last forty years. A comparison of these changing contexts on the self-injuries of those experiencing institutional care and those not will be made in the final chapter. The changing construction of self-injury in the light of multi-disciplinary working is the topic of chapter seven. The predominant aim is to identify which professional constructions of self-injury sustain which forms of social action, and, moreover, which have been or are likely to be excluded.

Key differences from traditional theoretical approaches

These are the four broad social constructionist tenets discussed by Burr (1995) and applied here to self-injury in people with learning disabilities. There is considerable overlap between each of the four and it is difficult and probably less fruitful to consider each entirely in isolation. Burr, however, goes on to elaborate further by identifying within these tenets a number of characteristics of social constructionism, which are in sharp contrast to other social science approaches. There is a need, I think, to consider these characteristics in the context of my own study:

1) The social constructionist position rejects the idea that there is a pre-determined nature to the social world or the people who inhabit it; there is no essential basis to individuals or things arising from biology or the environment. This is not concerned with historical and cultural specificity, arguing, for example, that an individual's propensity for self-injury is created by their biology or their life in an institution, since whichever argument adopted is *essentialist*. Self-injury, regardless of the observable biological reality of the behaviour and our responses to it, is constructed by the various discourses, which dominate over time and have no given reality.

2) The second point concerns the denial that knowledge, such as what is known about the causes of self-injury, arises as a consequence of our perception of reality. The *reality* of these causes is constructed through discourses, since each

profession adopts a particular perspective for observing the phenomena and providing an explanation for it. Such professional knowledge is relative to the historical period and particular culture that gives rise to it, so that each lays claim to particular 'truths' about self-injury. Furthermore, each truth serves the interests of the particular profession abiding by it, and they subsequently lay claim to resources, privilege, and power in relation to responding to the phenomena. The extent to which this principle operates in practice was something that the research set out to investigate, particularly in the context of multi-disciplinary working.

3) The purpose of researching the role of self-injury in the lives of the fifteen individuals selected, because of the social constructionist position adopted, cannot be concerned with uncovering the truth about the phenomena. Consequently, it must concern itself with the historical emergence of self-injury and the social practices involved in its creation. Self-injury in individuals with learning disabilities is not a phenomenon, which emerged during the 1960s and was responded to accordingly by pertinent professionals. Prior to 1960 there was little literature on the subject, because, I think, it was associated entirely with the 'mental deficiency' or 'idiocy' criteria, which was employed to define the individual. Its emergence as a phenomenon of interest lies in the changing relationship that transpired between the individual with a learning disability and society, which saw him/her increasingly recognized as a 'functioning being'. Furthermore, this changing relationship saw an increased awareness that, if this were so, then there was a need to respond in more sophisticated and imaginative ways, which reflected the emerging discourses.

4) The question of language, and communication more generally, will be discussed in chapter three, since it is hugely significant in any study of self-injury. I will also address the issue of whether people with learning disabilities, who have no spoken language, can be considered as social actors. Suffice it to say, at this point, that I seriously challenge the social constructionist position of language being a pre-condition for thought, as we know it (for example, Burr, 1995).

5) Social constructionism calls into question the position of psychology, with its emphasis on individual motivation, cognition or attitudes as explaining social phenomena, such as whether an individual engages in self-injury. However, it also raises questions about the traditional role of sociology in countering this position through its emphasis on social structures, like those of the family and the institution, in giving rise to self-injury. Instead, the social constructionist position is to concentrate social enquiry on the different social practices that people engage in, and their various social interactions; these are the places where explanations can be found. In relation to self-injury, therefore, it is in the interactions between different interested parties that we can see negotiations emerge as to how the behaviour should be responded to and the nature of the care 'package' to be devised. Appropriate strategies for intervening with an individual who self-injures arise through these different interactions, for example, between medical personnel as to the most appropriate medication to employ. Furthermore, these interactions are bound by the particular dominant discourse within the profession at that time.

6) A final point relates to the dynamics of social interaction, which social constructionists' emphasise in preference to placing the focus on static entities like the role of intelligence or the institution. By drawing attention to *processes*, the intention, therefore, is to consider how knowledge of self-injury is achieved by people through interaction. Rather than being something that doctors' have about the nature of self-injury, for example, knowledge is something that they do in conjunction with the individual and the family. Another example relates to the appropriateness of 'hospital' admission during the 1960s, which was something encountered by a number of individuals in the study. The decision to seek admission would have been initially considered by the family, maybe in conjunction with the mental welfare officer. The process would then have been negotiated according to the arrival of a particular crisis, the availability of a bed, or the opinion of the mental welfare officer concerning the fitness of the family to

cope with their 'mentally subnormal' member. Many additional factors may also have been of considerable significance in determining the appropriateness of admission. A decision would not simply have been made on the fulfillment of certain objective criteria, such as the existence of severe 'mental subnormality' compounded by a tendency to self-injure. Therefore, it is the process of making a decision about 'hospital' admission, which is of interest to the social constructionist, rather than the existence of specific criteria resulting in admission.

A word about discourse

The decision to utilize the term 'discourse' to explain the different approaches of the various professional bodies involved in the care of self-injuring individuals with learning disabilities requires some clarification. This is because of the lack of consensus concerning the meaning of the term, which, as van Dijk (1997) points out at the beginning of a two-volume introduction to the subject is "essentially fuzzy" (p.1). My own employment of the notion of discourse derives from the work of Foucault, who was referring to the development of bodies of knowledge, which necessitated reducing the traditional emphasis on language and moving towards the concept of discipline (McHoul and Grace, 1993). In relation to self-injury, the key discourses identified have been medical/biological, behavioural, psychoanalytical, and communication, which are respectively embodied in the disciplines of medicine, psychology (behaviourism and psychoanalysis), and speech and language therapy. These are all scholarly disciplines, which were located within the 'mental handicap hospital' before transferring to community settings, and necessarily altering the relationship with the overall purpose of 'social control'.

However, it is the relationship between such a discipline and the complexities of social control of certain 'deviant' segments of the population, which lay at the heart of Foucault's work, such as of the 'mad', (1967) and the 'criminal' (1977), and how this occurred within historically specific conditions. Foucault was concerned with identifying the conditions that existed within a particular historical period, which enabled a discourse to emerge and then establish itself as truth. Consequently, in the context of learning disability and self-injury, I am concerned with how a particular discourse, such as that constructed within medicine, developed over the last forty years of the twentieth century. Furthermore, this period also embodies the policy change from care provided for this particular group of individuals within institutions to almost entirely within the community. Therefore, since medicine has been correspondingly challenged by the re-appraisal of the appropriateness of the 'hospital', there is a need to examine its changing discourse surrounding self-injury to see how it has managed to maintain significant involvement within the multi-disciplinary team framework.

> "(Discourse) is regulated and systematic. An important proposition is related to this recognition: the rules are not confined to those internal to the discourse, but include rules of combination with other discourses, rules that establish differences (for example scientific as opposed to literary, etc.), the rules of production of the possible statements. The rules delimit the sayable. But (except for axiomatic systems such as chess) they do not imply a closure. The systematic character of a discourse includes its systematic articulation with other discourses. In practice, discourses delimit what can be said, while providing the spaces – the concepts, metaphors, models, analogies, for making new statements within any specific discourse... The analysis which we propose regards every discourse as the result of a practice of production which is at once material, discursive and complex, always inscribed in relation to other practices of production of discourse. Every discourse is part of a discursive complex; it is locked in an intricate web of practices, bearing in mind that every practice is by definition both discursive and material" (Henriques, 1984: 105-6).

In relation to self-injury and learning disability, though different discourses have developed within different traditions which arise from entirely different starting points, such as 'brain damage', childhood experience, and learnt behaviour, the shared historical conditions of the late twentieth century allow for one to articulate with another. The biological approach might continue, for example, to locate its discourse within the mechanics of the brain or the genes, but multi-disciplinary working demands some degree of acceptance of alternative approaches and an integration of the available intervention approaches. This is consistent with Foucault's examination of the complex coming together and departures of the discourses of medicine, economics, and linguistics in *The Order of Things* (1970). Sometimes they are examined in isolation, whereas at other times he is concerned with how each discipline contributes to the creation of a historically specific world-view ('the Western episteme'). Between 1960 and 2000 the discourse of community care came to underpin the general approach of many 'advanced' societies, who were grappling with how to look after their institutionalized learning disabled populations. I will consider the practicalities of this social policy context a little more in the final section of this chapter. In relation to the current discussion, however, it is how this ideological shift towards community care policy allowed for more serious consideration of the relationship between learning disability and self-injury. The gradual acceptance that such individuals were not 'subnormal', for example, and the recognition that they were 'educable' required that the strategy of life-long segregation and the mechanical (restraint) control of behaviour be seriously questioned.

(viii) The social policy context

The historical period covered in the research is from 1959, the year in which the first of the study group are admitted into 'hospital' and the first reference to self-injury is made in the case notes, to the completion of the field work in 1999. Furthermore, the practical transition from institutional to community care, encompassing 'hospitals' at full capacity to widespread closure, occurs within this time frame. Nine individuals, 60% of the study group, experienced institutional life, many for several decades, though all were living in the community at the time of the research. The various discourses surrounding self-injury, briefly introduced in the previous section, developed within the context of this gradual critique of the institution and policy change towards care in the community. The historical conditions, which enabled this critique to take place, were also the ones, which facilitated such discourses, so that by the end of the period in question self-injury had been transformed as a learning disability phenomenon. In other words, behavioural and biological discourses on self-injury, for example, required the vicissitudes of the late twentieth century, in order that they and the respective professional groups develop in the ways that they have.

The gradually changing relationship between society and the 'mentally deficient', both in Britain and the United States, illustrated particularly by the critique of IQ testing as a definitive instrument of reliability regarding individual capability (Castell and Mittler, 1965), elicited distinct unease about the future of policy. This was added to further by concerns about the misdiagnosis of 'mental deficiency', so-called 'pseudo-feeblemindedness' (Clarke and Clarke, 1955), and the relative success of a number of social 'experiments' aimed at demonstrating that significant learning could be achieved if the environment was stimulating and the necessary support was provided (Claridge, 1961; Clarke and Blakemore, 1961; Gunzburg, 1961). Signs that such evidence was beginning to influence the establishment came with the then Minister of Health advocating institutional retraction for all long-stay populations, though no funds were immediately provided and the 1963 'Blue Book' on community care issued only general advice to Local Authorities (Race, 2002). Shortly afterwards, a wealth of sociological and psychological studies (Barton, 1959; Goffman, 1961; Morris, 1969; Rosen, 1971; King, Raynes, and Tizard, 1971), drew attention to the 'hospital's' insular workings, the small and untrained workforce, poor physical conditions, and the dehumanizing and depersonalizing effects on the inmates. The institution had also been opened up by a series of scandals resulting in official inquiries into care practices at Farleigh (1971) and Ely (1972), and following a fire at Coldharbour 'hospital' (1972), all of which received considerable media coverage (see Clarke, 1982, for a review). The role of the liberal critique of the asylum has been exaggerated, according to Scull (1977), albeit in the context of mental illness whose history is intertwined with that of 'mental deficiency'. He points to the fiscal crisis of the state as being more significant. Others have expressed little sympathy for this view and emphasized the unprecedented period of welfare expansion that provided the context for debate (Busfield, 1986). Scull (1977) also questions the view that the advent of antipsychotic medication helped to usher in the 'open door' policy of the post-1959 mental health act era, since de-institutionalization had begun in the 1940s. Furthermore, the use of powerful tranquillizing medication has proffered "a new treatment technology, adaptable without strain to the general hospital, the outpatient clinic, and the consulting room" (Scull, 1993: 394).

Irrespective of which factors were the most significant, the requisite societal conditions were consequently being created whereby the role of the institutional framework for service provision could be seriously questioned and pressure for change placed on policy makers. The 'hospital' system would persist for many years to come, in fact the institutional 'careers' of my study group were beginning as the debate was taking shape, but it's shelf-life was now limited. The white paper, 'Better Services for the Mentally Handicapped' (1971), provided a time-scale for closure and advocated the expansion of community services to accommodate both those being resettled and the majority, who would never experience the institution. The Education (Handicapped Children) Act of 1970 provided a second strand of policy with its rejection of the notion of 'ineducability', dismantling of junior training centre provision, and transfer of 'hospital' schools to the education service. The children concerned, including several of my study group, were redefined as 'severely educationally subnormal' [ESN(S)], and consequently entitled to be educated, albeit within a segregated service. According to Whittaker and Kenworthy (2002), the problem lay with the all-encompassing medical model approach to care:

> "From experiments in the death camps to 'subnormality hospitals' and 'ESN' schools, medicine has a great deal to answer for, not the least of which is the legacy of segregation that is still embraced by our education systems" (p.73).

The massively influential principle of 'normalization', with its stated aim "to let the subnormal obtain an existence as close to the normal as possible" (Bank-Mikkelson quoted in Nirje, 1970: 29), was ideally suited as a mechanism for guiding the practical development of policy. The principle has subsequently been most associated with Wolfensberger (1972), who developed the means for translating it into practice (1975), and later re-conceptualized it as 'social role valorisation' (1983). It was not until the 1980s, however, that this philosophy began to affect models of care provision (following O'Brien and Tyne, 1981), and it was initially regarded as being of little relevance to services (Flynn and Lemay, 1999). It would be disingenuous to suggest that 'social role valorization' remains anything other than the bedrock of service delivery in many parts of the world, despite the intellectual critiques of recent years (Ramcharan et al, 1997), and confusion over its interpretation (Kay, 2003). Normalization/social role valorization constituted a key statement about the rights of the 'mentally retarded' and their relationship with society. It required the social conditions of the 1960s, and discussion of 'pseudo-feeblemindedness' and the inadequacy of IQ measurement, before it could be said, and a few more years before it was seriously adopted.

The 1970s, therefore, witnessed the consolidation of the ideology of community care, with the issuing of the United Nations Declaration of the Rights of Disabled People' in 1971 (Skelton and Greenland, 1979), which along with the normalization principle underpinned a radical service strategy proposal by the end of the decade (Jay Committee Report, 1979). The government response, however, was to acknowledge that the proposal was laudable, but unrealistic because of public expenditure constraints (DHSS Press Release, 1980), so that the "ground breaking inquiry" was "quietly buried" (Ryan and Thomas, 1987: 153). The pragmatic advice given to policy makers by bodies such as the National Development Group, established in the mid-70s, and relating to initiatives like the establishment of the 'Community Mental Handicap Team' (Sines, 1985), was considered more acceptable and certainly less threatening to both the state and the professions of medicine and nursing (Race, 2002). Ironically, the current blueprint for care, the 'Valuing People' White Paper (DoH, 2001), "reveals an amazing number of similarities" to the principles governing the Jay Report, "from ideals of lifestyle planning, through joint working to social inclusion" (Race, 2002: 43).

The reality of community care started to take shape during the 1980s, amidst fears about how to bring together the various providers of care for people with learning disabilities and not alienate one particular group, such as the 'hospital' care staff, who had no vested interest in facilitating its decline. Criticisms were increasingly voiced about the slowness of the 'hospital' retraction programme, the lack of community alternatives (Short Report, 1984), and the general failure of government implementation mechanisms (Audit Commission, 1986). The Thatcher administration commissioned the Griffiths Report (DoH, 1988) to assess how best to utilize public funds in the pursuit of community care. Some of its recommendations were then embodied in the 'Caring for People' White Paper (1989), which would be part of the basis of the NHS and Community Care Act (1990). In effect, a way for achieving community care had been conceived, which didn't have the cost implications of the Jay Report, but did stay true to the values-based philosophy. The main devices were the increased use of the voluntary and private sector to provide the care for individuals being resettled from 'hospital', and the provision of support structures to maintain people at home and reduce the need for long-term care

(Atherton, 2003). The necessity for institutional closure thus started to become a reality by the early-90s, even for those in my study group, who few had been considered candidates for community care only a few years earlier.

> "The institution that is contracting in size should not, however, fear its complete demise. There are those in large hospitals who will have problems that will make rehabilitation into the community a particularly challenging step. For years to come the traditional hospital could with benefit identify its role as to provide specialist rehabilitation services so that no one need be excluded from the exciting new era of community-based living and caring" (Bicknell, 1985: 14-15).

The NHS and Community Care Act (1990) provided the final impetus for the disappearance of the 'hospitals' that had provided care for the individuals in my study, although there was prolonged negotiation before final decisions about closure were made. Each institution had attempted some sort of reinvention during the 1980s as it attempted to grapple with the constantly changing circumstances, and the gradual realization that its days were over. One geographically diverse 'hospital' closed in the late-80s, but established a smaller, more compact institutional complex within the same vicinity, so that the clients with the most challenging and multiple needs were transferred there, along with a secure unit for those legally detained. This project, however, was not considered a success, particularly as community care became increasingly advocated for the more challenging client group, and with the exception of the secure facility was on the verge of closure within a few years.

Two other 'hospitals', each housing around 800 'patients' at their peak, wound down very slowly over the course of the '80s, with several of the individuals in my research moving wards on a regular basis, and being cared for increasingly by agency staff. Closure was sudden, however, with the private sector accommodating the majority of the remaining 'residents' within a network of houses spread around the locality. The 'hospital' sites were quickly purchased by large building firms for the development of expensive, up-market housing, a significant component of the politics of institutional closure. The remaining two smaller 'hospital' facilities were located in a different part of the region, and had originally only accommodated women, since the men, as had been the policy of the period, had been dispatched to the larger institutions. One of these, a dilapidated building housing around eighty individuals, was taken over by a private firm, who initially replaced it with a bungalow complex before deciding on closure and dispersal throughout the area. One of the members of the research group originally resided in one of the larger 'hospitals', moved to the smaller institution with news of the larger one's imminent closure, lived briefly in the bungalow complex, until it's own closure was decided, was offered a place more than 200 miles away, which would have necessitated markedly reduced parental contact, and eventually moved home to her parents when nothing else could be offered. This is an extreme example within an extreme study group, but several of the others experienced considerable upheaval, as the institutions were closed and alternative accommodation provided.

The other smaller 'hospital' did successfully re-invent itself, but not before it had survived several closure scares and entered into an era not entirely as averse to the idea of institutions. In the early 1990s it changed its focus to 'assessment and treatment', accommodated the various community nurses and other specialist professionals in another part of the complex, and diversified to provide further specialist nursing input in forensic care, health promotion and epilepsy. It consolidated its position in the late 1990s with an increased emphasis on security, the provision of conference and other facilities, and exploiting a market niche.

CHAPTER TWO: THE RESEARCH

- Methodology – the case study approach
- The fieldwork process
- Reflections on 'three I had known earlier'
- The emergent themes

(i) Methodology: the case study approach

The choice of method for examining the role of self-injury in the lives of people with learning disabilities, particularly in the context of the questions identified in the previous chapter, appeared ideally suited to that of the case study. This approach necessitates "totalizing" the "observation, reconstruction, and analysis" of the cases selected (Zonabend, 1992: 52), the need for qualitative, in depth study of the phenomena to be investigated. The most detailed exposition of the case study approach comes from the Chicago School of sociologists (see Bulmer, 1984, for a detailed review), who specialized in the investigation of marginalized groups such as juvenile delinquents (Shaw, 1930; Shaw and McKay, 1942), the homeless (Anderson, 1923), suicidal (Cavan, 1928), those living in the ghetto (Wirth, 1928), or pursuing a life of crime (Sutherland, 1937). My research is consistent with these studies in the sense of undertaking research into the experience of one of, if not the most, disempowered and oppressed social groups, but differs in its emphasis on the focus of inquiry, self-injury, being constructed through professional discourse.

More elaborate approaches to the case study have occurred over the ensuing years, each of which emphasize a particular research 'unit of analysis' (the phenomenon under investigation), and is likely to influence the way in which it will be organised and the approach to data collection. Hakim (1987) describes five approaches to the case study, wherein similarities and differences vary according to the specific purpose of the research. The purpose of the community study is primarily to describe and analyse phenomena such as the family or work, though theory testing may also be significant. Studies of social groups are similarly concerned with description and analysis, though in the context of relationships and activities that are bound by common interest and identity. Organizational or institutional case studies set out to examine events, roles, and relationships within these systems, identifying significant factors in the negotiation of reality and formation of practices. The individual case study favoured by the Chicago sociologists provide detailed accounts of the relationship between the person and the social phenomenon, with a view to uncovering causes, processes, and experiences. A variation of this is the multiple case study, my own approach, whereby the 'unit of analysis' is identified as self-injury, which is subsequently examined in the context of the lives of a number of individuals (the cases).

This approach accords with Robson's (1993) assertion that the case study constitutes "a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real life context using multiple sources of evidence" (p.146). Furthermore, it may be utilized to analyse wider forces such as the social system, political ideology or religious persuasion, and has been employed within fields of study as diverse as education, medicine, history, anthropology, psychology, politics, psychiatry, counselling, criminology, social work, and sociology (Bromley, 1986). In the context of my own approach to self-injury, I have attempted to fulfil the criteria identified by Robson. The research adopts a critical and evaluative stance, and can be considered 'empirical' since it involves the collection of evidence relating to what is occurring. Multiple methods of data collection are employed comprising the investigation of archive material, interviews with significant others, and some direct observation of the individuals studied. The particular phenomenon concerns the emergence and incorporation of self-injury within the real life context of a group of individuals over a sustained period of time, between 20 and 46 years. Finally, the theme of the transition from institutional to community care over the same time frame within changing political and social circumstances constitutes the wider context to the study.

There would appear to be considerable justification, therefore, to utilize a case study methodology for research into the lives of a group bound by their propensity for self-injury. It has been referred to as the "bed-rock of scientific investigation" (Bromley, 1986: ix), and according to Valsiner, "the study of individual cases has always been the major (albeit often unrecognized) strategy in the advancement of knowledge about human beings" (1986: 11). It does appear, however, that there continue to be critics of the case study, and it is interesting that there is an element of justification in some writers' explanation of the mechanics of such research (e.g., Robson, 1993; Hammersley, 1992). The laborious and meticulous collection of huge swathes of information, with the inevitable replication and unnecessary collection of data has been the target of those most critical of the case study:

> "Such studies often involve tedious collection of specific detail, careful observation, testing and the like, and in such instances involve the error of misplaced precision. How much more valuable the study would be if the one set of observations were reduced by half and the saved effort directed to the study in equal detail of an appropriate comparison instance. It seems well-nigh unethical at present to allow, as theses or dissertations in education, case studies of this nature" (Campbell & Stanley, 1963: 177).

Harsh words indeed, though one of the authors has since accepted that the case study is fundamentally different to the experiment and the survey, and should be judged according to the criteria that the researcher sets out in his or her strategy and particular designs (Cook & Campbell, 1979). The point of departure lies in the researcher's immersion in the data collection process, and the subsequent impact on the way in which the material is subsequently analyzed and conclusions drawn. My own experience of going through a series of Local Research Ethical Committees (LREC) demonstrated the continuing concerns by some members as to the primary purpose of research being to demonstrate the relationships between variables. This emphasis on objectivity and the need for 'scientific' criteria to be satisfied is explained in the following way:

> "Scientific knowledge is proven knowledge. Scientific theories are derived in some rigorous way from the facts of experience acquired by observation and experiment. Science is based on what we can see and hear and touch, etc. Personal opinion or preferences and speculative imaginings have no place in science. Science is objective. Scientific knowledge is reliable knowledge because it is objectively proven knowledge" (Chalmers, 1982: 1).

Contrary to being an assault on interpretive research, however, Chalmers goes on to dismantle the argument presented, particularly the assumptions of an intrinsic hardness to experimental research, the nature of 'scientific knowledge', and the dubious possibility of achieving complete objectivity. An interesting contribution from Hammersley (1992) demonstrates how cases might be effectively utilized within the experiment and the survey, with theoretical sampling (following Glaser and Strauss, 1967) being employed for analysis. Furthermore, methodological issues in sociology cannot be resolved through qualitative/quantitative conflict (Hamel, 1993), since this simply perpetuates what Pires (1982) refers to as "failed debates".

The most disconcerting criticisms of the case study concern representativeness, reliability, and validity, the 'so-called classic problems' (Plummer, 2001: 153), albeit somewhat unjustified on closer reading of some of the Chicago school studies (Hamel, 1992). Plummer (2001) suggests consideration of a 'continuum of representativeness', whereby "insights, understandings, appreciation, intimate familiarity are the goals and not 'facts', explanations or generalizations" (p.153). I set out to select cases, individuals, who would act as a point of observation of a particular social phenomenon, self-injury, which consequently does suggest a need to consider the adequacy of representativeness. Furthermore, this is particularly so when the quantity and diversity of the material to be collected is taken into account. I have already considered this issue earlier in relation to the selection of the study group, and though there were considerable differences between them as individuals I remained confident that the cardinal criteria were satisfied. The data generated by the group, which will be discussed in the next section, proved extensive, and the similarities in treatment and intervention responses tended to confirm their representativeness.

The issues of reliability and validity provoke concerns about a lack of rigour in the collection, construction, and analysis of the empirical case study data, wherein there may be inordinate subjectivity and bias. This may appear excessive as a general comment about the method, particularly since they might not necessarily provide the most effective mechanisms for evaluation (Atkinson, 1998). They might be pertinent, however, to specific instances, because "case studies are sometimes carried out in a sloppy, perfunctory, and incompetent manner and sometimes even in a corrupt, dishonest way" (Bromley, 1986: xiii). There is an obligation, therefore, for case study researchers to at least address the key question of the construction of safeguards to demonstrate reliability and validity, and not to approach it as an easy option without the burden of objectivity Robson, 1993). Reliability relates to concerns of technique and consistency, whether similar findings would arise if another researcher replicated the study, whereas validity addresses the appropriateness of the technique to the study of the phenomenon (Plummer, 2001). An examination of the nature of self-injury over the life course, its construction through differing professional discourses, and the context of changing approaches to care delivery would appear suited to case study methodology. I have tried to address the issue of methodological rigour throughout this study by ensuring a systematic approach towards the collection of data, despite the implications in terms of time spent and the ultimate discarding of substantial quantities of material. The construction of an interview schedule, for example, which followed an initial informal discussion with some of the relatives of the group, was aimed at ensuring consistency of questioning, whilst allowing for the freedom to pursue productive lines of inquiry as they arose. The multiple methods of data collection provided instances of contradiction, which warranted further investigation, and illustrated the need to approach the data cautiously during analysis. The clinical case notes, for example, did not always accord with the retrospectively accounted experiences of parents, just as the definition of specific situations varied between professionals in the ways that information was recorded and the importance placed on different factors.

Yin's (1994) elaboration of case study methodology, developed and refined over a period of more than two decades, constitutes something of a response to the criticisms surrounding objectivity through its emphasis on logic, structure, and consistency:

> "In general, case studies are the preferred strategy when 'how' or 'why' questions are being posed, when the investigator has little control over events, and when the focus is on a contemporary phenomenon within some real-life context. Such 'explanatory' case studies can also be complemented by two other types – 'exploratory' and 'descriptive' case studies. Regardless of the type of case study, investigators must

exercise great care in designing and doing case studies to overcome the traditional criticisms of the method" (1994: 1).

He goes on to outline the core elements of case study design as being the initial questions, propositions (if any), unit of analysis, the logic linking the data to the propositions, and the criteria for interpretation. These are further underpinned by consideration of quality safeguards – construct validity, internal validity, external validity, and reliability. I found it a useful exercise to apply Yin's methodology to my study of self-injury, since it necessitated a clarity of focus and consideration about analysis, though ultimately the framework proved too restrictive to adopt in its entirety. The initial questions have been identified in the first chapter, as has the theoretical framework of social constructionism, which describes my particular stance in embarking on the study. The need to deconstruct various professional discourses surrounding self-injury, locate them within a specific historical time-frame to demonstrate change over time, and examine the relationship between knowledge and practices were key assumptions arising from my stated position. Furthermore, I was seeking to explore both the emergence of the phenomenon of self-injury in particular individuals' lives and how it subsequently related to their negotiations of reality. My position was that self-injury was a reasonable and understandable response to such negotiated reality, and suggested that it would be a permanent if variable feature of their lives. The relationship between self-injury and the institution I knew was significant, but had to be ultimately an unsatisfactory explanation because of those in the study group never having been in 'hospital'. The role of the family was therefore a vital component of the study. In effect, by forcing me to consider such propositions I was guided in the construction of interview schedules and the identification of the information I should seek when accessing historical and contemporary records.

The unit of analysis of the study, the multiple-cases of fifteen individuals (Robson, 1993), followed the classical tradition of then accentuating one dominant characteristic, such as vagrancy (Platt, 1992), though in my case self-injury. I should point out, however, that I did seek to collect data on each of these individuals simultaneously and not, as Yin (1994) suggests, successively. The characteristic of self-injury varied, of course, in terms of its degree of dominance in the lives of those studied, wherein it could sometimes be considered as a defining characteristic but with others presented as ever-present but more benign in its overall influence. Nevertheless, the group were bound by their propensity to self-injure purposefully, repetitively, persistently, and with resultant, sometimes severe, physical consequences. There was a temptation to collect everything that might seem remotely useful, which Yin (1994) warns about. It seems to me, however, that because case study work is an essentially fluid activity, there is a need to immerse oneself in the detail of an individual's story, with some difficulty inherent in knowing whether data might later be of use. A final point concerns the families and carers frequent requesting of specialist assistance in seeking to ameliorate self-injury, acts of desperation that served also to demonstrate a certain commonality of experience.

Yin (1994) advocates that case study researchers consider the analytical issues of linking the data to the propositions and establishing the criteria for interpretation at the time of constructing the research design. He suggests a number of analytic techniques comprising pattern-matching, explanation-building, and time-series analysis, which might fruitfully focus the researcher during the collection of data on how it is likely to be of value. None of these techniques appeared pertinent to my study of self-injury, with the chaotic nature of these individuals' lives precluding inordinate structure, though it was useful to think about analysis from the early stages of the research. Analysis was enhanced by the employment of the time period encompassing the transition from institutional to community care, and the social constructionist stance, which necessitated consideration of variations in time and space of responses to self-injury. The changing context of care provided an opportunity to examine the phenomenon within institutional, post-institutional (community residential care), and familial contexts. The theoretical approach provided a means of understanding professional descriptions of self-injury, identification of suspected 'causes', and subsequent recommendations. The extent to which professional discourses conformed to my expectations, or otherwise, would emerge in clinical notes, assessments, reports, and general correspondence.

Yin's (1994) mechanisms for ensuring quality in the research design begin with the need to identify the specific types of changes to be studied in relation to the original objectives, and to demonstrate that the measures of these changes adequately reflect the specific types of changes selected (construct validity). My examination of the development of different professional discourses surrounding self-injury over a forty-year period, and the implications of these for the treatments and interventions advocated, necessitated the employment of the multiple sources of data collection already described. Since I was not concerned with establishing a causal relationship through the research, such as 'institutional living results in the propensity for self-injury', there was little need to fully consider the second safeguard, internal validity. I did, however, seek to make inferences about the developing nature of self-injury over the life course, which meant dispensing with or accepting the possibility of rival explanations.

An illustration of such inferring concerns my belief that as the individual negotiated major life events, such as being given the opportunity to attend a school containing the expertise to help her move forward, then the abrupt withdrawal of the same can result in the anger and disappointment experienced being translated through a deterioration in self-injury. It is not inconceivable that an observation such as this may have coincided with something else occurring, such as an as yet unknown medical complaint, and that this was of greater significance. My defence is that the evidence suggested that factors such as major and traumatic instances in an individual's life did seem to constitute key moments in a self-injuring career. Furthermore, such key moments related to prevailing conditions and beliefs about the relationship between 'subnormality' and self-injury, the contexts in which care should be provided, and the interventions considered most appropriate. Another consideration related to the exploration of a perceived logical chain of events, such as in the decision-making process over 'hospital' admission and confirmation or rejection of a diagnosis. These were major issues in tracing the development of self-injury, though not representative of absolute causative effects, and so warranted the need for accuracy in the reporting of how decisions were negotiated. Consequently, there was some necessity to consider the concept of internal validity, despite its general inappropriateness to my application of case study research, since it provided me with a means of trying to avoid disingenuous or erroneous inferences.

Similarly, during some of the interviews with parents the issue of their experience of medical appointments in general hospitals would arise. Sometimes it was evident that this experience had frequently been unpleasant, but the parent may be a little guarded about describing their experience to me in derogatory terms. In another interview a parent may exude the same fury about her treatment as she had experienced at the time of the hospital appointment, but there is no guarantee that the treatment received was worse than that of the previous parent. The internal validity issue, therefore, requires me to be suspicious of the evidence, particularly my own construction of events from the available data. In this case, there can be a marked contrast between particular interpretations of an incident by the parents and the different professionals involved, as well as between these professionals. The clinical notes tended, usually but not always, to be described in bland, unemotional terms, with an emphasis on revealing factual information only. Setting such data against the explanation proffered by parents might increase the likelihood of inferences being plausible and emerging as far as possible from the evidence. It should be noted, however, that, though there is much to be recommended in making the research as airtight as possible, there is also the concern with parental interpretation. In other words, there was an implicit need within the research to believe the information given to me during interview, since the parents' own construction of self-injury was an important aspect of the study. Furthermore, the establishment of different 'truths' about self-injury provided by parents and the different professional groups' feeds in to the social constructionist framework. That is to say that the way in which the parents' interpret the self-injury of their child is significantly influenced by their experience of professional support.

The critical point of the research was the extent to which it is possible to generalize from those individuals studied to the wider population of learning disabled self-injurers, external validity. This is a burning question within case study research, to the extent that an entire volume of sometimes contrasting articles spanning several decades has recently been published on generalization possibilities (Gomm, Hammersley, and Foster, 2000). The study was not going to be conducive to statistical analysis, which would have appeased the criticisms of those unconvinced of the claims to validity of case study research (Tellis, 1997). A number of analytic techniques have been suggested, including the arrangement of the evidence in a matrix of categories, devising a system of flowcharts or data displays, and examining the relationships between variables through the use of means, variances and cross tabulations of the frequency of different events (Miles and Huberman, 1984). Though I have seen the need, for presentation purposes, of tabulating certain information about the individuals under study, none of these methods would be of value in trying to generalize from life history data.

Yin (1994) argues for an analytic strategy, which will yield conclusions based on an analysis of the data. He suggests that a case description might be used as a framework for organizing and influencing the direction of the case study, and that this has proven useful in the study of a neighbourhood or an organization. For research into the lives of a group of learning disabled individuals, I have found it preferable to establish a number of theoretical propositions relating to the establishment and development of self-injury and its interpretation by professional groups. Such propositions can then be analysed within the context of social constructionist theory, which would contend that the progress of self-injury would vary according to time and place, and intervention approaches will emerge from the most dominant discourses.

The final test, reliability, refers to the issue of whether another researcher, following the same procedures as those undertaken in the original study, would arrive at the same findings and conclusions. The predominant concern, therefore, was with ensuring that the research design was logical, consistent, and as accurate as possible.

> "The general way of approaching the reliability problem is to make as many steps as operational as possible and to conduct research as if someone were always looking over your shoulder" (Yin, 1994: 37).

The issue of reliability did cause me some cause for concern, particularly since there were multiple sources of data collection, and there was a temptation to collect any piece of information that seemed remotely relevant to the individual's life. There was a need, therefore, to ensure that there was a logical process involved, which would clarify and give direction to the different stages in the development of the research. The construction of the case history constituted the first stage and was largely concerned with the collection of the data from the medical and nursing notes. Reports submitted by speech & language therapists, occupational therapists, and educational and clinical psychologists tended to be stored within these notes rather than kept separately. A fairly thorough record of the chronological events in the individual's life, including input from different professionals, episodes of illness, and deterioration in self-injury therefore resulted in the formulation of the case history.

The second stage involved the interviews with the parents and a selection of learning disability nurses, which resulted in the production of a number of transcripts. This information would complement the case history, sometimes providing contrasting information, confirming occurrences, and detailing specific incidents. These would serve to flesh out the case history and could have been carried out by anyone with sufficient knowledge of the purpose of the research. The purpose of the research itself has been discussed in some detail earlier in this chapter, and the study questions and propositions are available to guide the researcher in the collection of pertinent information. Consequently, the construction of the fifteen case histories constitutes the mid-point in the overall research process. The final stages, however, would be more difficult, and in one area, virtually impossible, for another researcher to complete.

The application of the theoretical framework, social constructionism, would necessitate understanding of the implications of the propositions outlined earlier, particularly the notion that different professional groups construct differing discourses surrounding self-injury. However, once this has been achieved, then the structure of the thesis, and the logic of the different chapters should transpire. Furthermore, this is really a prerequisite for undertaking the research in the first place, since the social constructionist stance is an important factor in the collection of the data. The final point, however, is less easy to resolve, since it involved the process of reflexivity, whereby I try to reflect on my prior relationship with three of the individuals participating in the study. This also involved a degree of self-questioning about my own role within the institution, my changing view of people with significant learning disabilities, and, in particular, the individual's relationship with his/her self-injury. The point of such self-questioning was to assess whether this exercise would enable me to utilize this information in examining the role that self-injury played in the lives of these three people, whom I had known many years earlier.

> "Thus, in self-questioning, we relinquish the 'stand fast and firm' posture of conflict, and open possibilities for other conversations to take place. Such self-reflection is made possible by the fact that we are polyvocal. We participate in multiple relationships – in the community, on the job, at leisure, vicariously with television figures – and we carry with us myriad traces of these relationships. In effect we can speak with many voices. For example, with effort we can typically locate reason to doubt virtually any proposition we otherwise hold as true, and see limitations in any value we think central to our life. Suppressed at the moment 'I speak my mind', or 'say what I believe' is the chorus of internal nay-sayers. If these suppressed voices can be located and brought forth within the conversation of differences, we move toward transformation" (Gergen, 1999: 162).

The issue of generalization, however, did pose something of a problem, particularly since I had chosen not to rely on Yin's (1994) 'analytical' rather than 'empirical' strategy, and yet had considered the application of much of his case study framework. Furthermore, there seemed to be little to be gained from 'logical' rather than 'statistical' inference (Mitchell, 1983), or generalizations tantamount to the claims made by exponents of the survey method (Schofield, 1990), or results being transferred to other settings on the basis of 'fit' (Lincoln and Guba, 1979). This led me to a different notion, one which suggested that there might be other possibilities besides the need for more purposeful generalization (Donmoyer, 1990). 'Naturalistic generalization' is best associated with the work of Stake (1978), who argued that the most important skills for researchers studying 'human affairs' were "the natural powers of people to experience and understand" (p.5).

The social constructionist stance of the research provided me with a loose framework for exploring the process by which the laws or 'truths' about self-injury had come to be established within different theoretical discourses. This did not mean, however, that there was a need for me to provide an alternative explanation, and the gathering of information could consequently be used for a different purpose. In the selection of the study group, for example, though I have tried to consider criteria for representativeness, this was of lesser importance than accurate and thorough description of the individuals concerned. In so doing, "(A)s readers recognize essential similarities to cases of interest to them, they establish the basis for naturalistic generalization" (Stake, 1978: 7). The boundaries of the case enable the individuals studied to be considered distinctive from others within the learning disabled population, an essential, yet initially misleading, characteristic of the approach. This is because people with learning disabilities are not a homogenous group and many individuals have similarities, such as communication difficulties and level of perceived functioning, but do not engage in self-injury. Similarly, many others share the capacity for self-injury, but vary markedly in other areas of their lives including skills, abilities, and personality attributes. The boundaries establish the criteria by which individuals can be included or excluded from the study, provide clarity about what is to be studied, and contrast with other studies where the content is determined by the hypothesis or previously targeted material (Stake, 1978).

> "(M)ost case studies feature: descriptions that are complex, holistic and involving a myriad of not highly isolated variables; data that are likely to be gathered at least partly by personalistic observation; and a writing style that is informal, perhaps narrative, possibly with verbatim quotation, illustration and even allusion and metaphor. Comparisons are implicit rather than explicit" (p.24).

The purpose of my own foray into case study methodology appears best suited to such goals, where voluminous data is generated, and there is a need to be expansionist rather than reductionist, to proliferate not narrow, and to be idiosyncratic as opposed to pervasive (Stake, 1978). The ultimate aim, therefore, is to add to existing experience and understanding of the human condition by attempting to be intentional and empathetic, and by seeking information that is both holistic and episodic.

> "... the only understanding we ever reach in history is but a refinement, more or less subtle and sensitive, of the difficult – and sometimes deceptive – process of imagining oneself in another person' place" Butterfield, 1951, cited in Stake, 1978: 8).

(ii) The fieldwork process

The practicalities of setting up the research were extremely time consuming; more than a year was spent gaining access to the representative group of self-injuring individuals and satisfying the demands of the various Local Research Ethical Committees (LRECs). Three geographical areas were chosen, all of which served populations of similar size, but varied in terms of the service framework for caring for people with learning disabilities. Each area was located in northwest England, south of both Liverpool and Manchester. Initially the intention was to select a total of eighteen individuals, six from each area, some of whom would have spent time in long-stay institutions whilst others would have lived primarily in the family. But they would all be in contact with local health authority services. In effect, fifteen people eventually formed the study group, six from each of two of the areas and three from the remaining one. The consultant psychiatrist was the first contact point and the main source of access to the group.

Successfully fulfilling the criteria of the various LRECs provided varying degrees of difficulty. Three committees in total needed to be negotiated each representing the particular geographical area. One area was satisfied with a written explanation of the proposal and a few queries with regard to where the information was to be stored and who had access to it. The second area, on the other hand, requested attendance at the LREC meeting, and was concerned with issues such as the proving of the hypothesis and how I was to ensure that the research was 'scientific'. The third area constituted a sub-committee of the second one and erroneously requested my attendance at their meeting. But after a few initial difficulties concerning their differing expectations, they said that they would honour the decision reached by the main LREC. I provided information to satisfy the LRECs with regard to medical permission to access the case note material, guarantees of confidentiality and anonymity, and written information to support the consent forms given to clients and parents.

Three methods of data collection provided the practical tools of the research. Firstly, access to the clinical case notes of the different individuals, going back in some cases to the early 1960s and being stored in a number of different places. Once accessed these would supply the bulk of the raw data to be drawn upon in the construction of the case studies. The range of case note material was surprising, though variable, in quality. Case notes of people, who were formerly resident in a particular 'hospital', remain the property of the particular health authority. When the individuals returned to their area of origin following the closure of the institution, the case notes were placed in a storage facility in the former area and could only be accessed with the permission of the consultant psychiatrist formerly responsible for their care. Even the notes of individuals who remained in the same health authority were placed in these facilities. Only one member of the group's notes were returned with him when he moved to his new home following 'hospital' closure. This was at the insistence of his parents and followed protracted discussions between them and the 'hospital' managers.

All the consultant psychiatrists contacted were more than happy to enable me to access the case notes. Frequently they went out of their way to help me, including incurring financial costs in relation to providing access and transferring the notes. This proved more difficult in one area where two of the group had spent time in a relatively small 'hospital' complex. The 'hospital' had closed three years earlier and the clinical notes had been randomly stored in two adjoining rooms in the administration block of a nearby 'hospital' for people with mental health problems. Though the appropriate authority was more than willing to provide access following a written request, this proved to be virtually impossible since only a small number of the notes could even be reached. The notes of all former residents had been left in huge piles throughout the two rooms and there was insufficient space to even manoeuvre around the room without causing chaos. Nevertheless, for the most part the notes were available and provided masses of useful information about the former lives of these people.

The bulk of the clinical notes were divided simply between whether they were medical or nursing. These were frequently written simultaneously by medics and nurses and subsequently provided different interpretations of the same phenomena, such as the introduction of different medication or the monitoring of an illness. These notes were to form the backbone of my data and provided useful information relating to the development of self-injury during the course of the individual's life in care. A data collection checklist was devised, which focused on a number of factors, and which could then be used as a mechanism for acquiring the necessary information from the notes.

Key questions in the checklist included:

1) What sorts of self-injurious behaviours did the individual indulge in?
2) At what age did admission into 'hospital' occur?
3) What were the circumstances of admission?
4) What was the effect on the family?
5) At what age did self-injury begin to feature in the individual's life?
6) How was the self-injury described by the professional making the entry?
7) What sorts of interventions and treatments were proffered?
8) If mechanical restraint was used, how was it described?
9) What other behaviours did the individual engage in?

This would then provide me with background biographical information so as to begin assembling a raw case construct, which chronologically highlighted the significant, and not so significant, times in the individual's life.

Though the nursing and medical notes were the most complete documentation and provided a daily account of the life of the individual whilst in 'hospital', they were extremely variable in terms of quality. Some of the group's notes were comprehensive and included extensive anecdotal material from both the medical and nursing workers. However, other notes were very meagre and sometimes nothing would be stated about an individual for months or even years. Because of the complexity of their problems – profound learning disability, significant communication disorder, daily self-injuring and, frequently, associated sensory or physical difficulties – they carried no weight on the ward and were rarely popular or influential.

Additional material stored in the case notes was to prove extremely useful, in terms of providing different voices from administrators, teachers, social/welfare workers, psychologists, speech and language therapists and occasional others involved in care. Such material was in the form of official correspondence between the GP and the 'hospital' administrator discussing the possibility of admission on both a short and long-term basis during the early 1960s. Written communication from parents with regard to the effect on the family of having a child with major needs to fulfil on a daily basis was also significant. It became clear very quickly that the process of admission into one of these institutions was one of protracted, subtle and not so subtle negotiation. These letters would then provide me with evidence of such issues as the relative importance of the individual's self-injury in relation to gaining admission. The letters involving the GP were always the most valuable in terms of providing factual information. Sometimes the GP would play a passive role in these exchanges and other times would be more active, but (s)he invariably would be the key player. For example, the community nurse would normally be the individual involved daily and directly with the individual during a period of crisis. Information about their progress, referrals to other disciplines, admissions for assessment would all be clearly explained in correspondence from the community nurse to the GP. Sometimes, this would not warrant a response, because the emphasis of the input would be behavioural and the GP would have no comment to make other than passively concur with the approach implemented. On other occasions, (s)he would contribute more robustly either through the prescription of a particular drug, the undertaking of a medical checkup or referral to a specialist for investigation. So that, if the individual had visited because of a deterioration in their self-injuring, the medical contribution toward the construction of the phenomenon could vary greatly in its significance.

Besides these letters of correspondence, reports from class teachers, psychologists and speech therapists also proved to be of value. In the clinical notes of the older members of the group such reports were few and far between, though not completely absent. People admitted into 'hospital', for example, during the 1960s were unlikely to have a comprehensive assessment made and subsequent report written. Such things were more likely to be undertaken during the 1980s and have become more sophisticated and thorough in recent years. It was not until the early 1970s, in the wake of the publication of the Education Act (1970) and Better Services for the Mentally Handicapped White Paper (1971), that children with learning disabilities were considered educable at all. Prior to that time, children attended junior training centres (JTCs) and the emphasis was one of simple occupation. Correspondence between JTC supervisors and 'hospital' administrators or ward personnel did, however, figure in the negotiations for institutional admission and proved a useful source of information.

Over the last decade, particularly since the NHS & Community Care Act (1990), 'packages' of care have become increasingly complex and involved. This era has witnessed multiple assessments being undertaken as a matter of course by a variety of professionals. The multi-disciplinary team has become one of the mainstays of contemporary care for people with learning disabilities and forms the centre of the 'package' being organised ad implemented. I will spend more time considering the role of the multi-disciplinary team and how it has evolved over the time covered in this study in chapter six. Here, it is just worth mentioning that sometimes many of these professionals contribute to the overall care of an individual with a substantial report, which serves to interpret the situation through the particular language of the profession. It is not always apparent how these various reports and professional discourses relate to each other in the construction of a multi-disciplinary interpretation of the situation.

The bulk of the information gathered about the study group was thus acquired from clinical notes, professional reports, and the various letters of correspondence. The second data collection method was to be observation of the individuals in the group. Initially this involved the use of a detailed observation chart, which was to record the intensity, frequency and duration of the self-injury (following Emerson et al's 1987 definition discussed in chapter one). On reflection, however, and in the light of reservations forwarded by one of the LRECs negotiated, it was decided that the period of observation should be extremely informal and, in some cases, no more than spending a little time in the individual's company. There seemed to be little point in making extended behavioural observation when detailed descriptions were consistently available in the notes. Furthermore, there was an ethical issue surrounding the notion of sitting and observing an individual engaging in headbanging, whilst simultaneously taking notes and determining things such as the level of intensity.

Finally, interviewing the carers of the group seemed to be a useful way of completing the data collection and also gaining the perspective of the people involved in the care (see appendix 1 for a copy of the semi-structured interview schedule used). At first this concerned interviewing the staff currently involved in the care process, one qualified and one unqualified nurse for each person. The unqualified staff in this initial batch of interviews were more than willing to be interviewed, but had little to really contribute to the study. They did provide some information with regard to the relative interpretation of self-injury by unqualified and qualified nurses, but they failed to enlighten with regard to the development and maintenance of the behaviour in the context of the individual's life. Consequently, I decided to change the focus of the interviews to the relatives of the self-injurers. A small number of interviews with qualified nursing staff working with individuals in various settings and not just in residential care would then be supplemented by interviews with parents. In sum there were three interviews with staff nurses working in residential care, two with community learning disability nurses supporting people in their families, one with a behavioural support nurse, and one with a staff nurse working in an assessment and treatment facility providing care in a relatively secure setting. Two of the nurses each provided information for two of the individuals being studied, so that though only seven nurses were interviewed they provided information relating to nine of the study group (see table 2).

Interviewing the parents then completed the data collection. There were six in total and these were concerned with the never-institutionalized members of the study group. Consent had already been obtained and an information sheet provided (see appendices 2 and 3), so that contact had been established prior to the initial meeting. One individual had been considered capable of giving his own consent and the legal guardian's consent had been sought in the case of one with no family contact. Only one individual's relatives declined the request to be involved in the study. Each family had been sent an information sheet detailing the nature of the research and the implications for themselves prior to actual consent being requested. The permission of the GP had also been gained in response to the recommendation of the LREC and the consultant psychiatrist's permission had also been necessary for gaining access to the case notes as previously discussed.

All the families requested to be involved readily allowed me to visit them and informally discuss their particular relative. On this first visit I would make handwritten notes and try to make the encounter as informal and conversational as possible with varying degrees of success. I would then request that I return with a tape recorder and a list of more focused questions (see appendix 4). This would provide me with the opportunity to reflect on what they had said during the initial encounter and subsequently assemble what transpired to be a semi-structured interview schedule. Except for one family where the grandparents had been the primary carers, the interviewees were always the mother of the self-injurer. All of them welcomed me back for the second interview involving the tape recorder, though some did express a little anxiety at this idea. On one occasion both the mother and the father participated in the recorded interview. There was a temptation here to alter the focus of the research and concentrate on the experience of those caring for offspring who engage in self-injury, but this would have involved moving in a completely different direction. The emerging data did, however, seem to be complementary to, and occasionally contrasting with, the data derived from the archive material. These interviews were conducted with the relatives of those individuals who were currently living with them. They may have spent time prior to this in institutional care, have been in the midst of a transitional phase in their lives, such as child to adult services, or, in one case, be splitting the week between home and residential care, but they were currently living with their parents.

The fieldwork process of collecting such a wide variety and considerable quantity of written material, as well as conducting the necessary interviews and meeting the individuals concerned left me with one quite important issue to consider. The requisite assembly of the fifteen raw case records, which would provide me with the basis for translation into more refined studies also informed me of an emerging fact. I was in the process of instigating my own social construction of self-injury through examination of the life histories of the study group. The necessary culling of large amounts of information in order to move from case record to case narrative meant that I needed to carefully select what I considered to be the most pertinent material for the story I was to tell. The building of this case narrative constituted an interim measure between the chronological case record and the eventual case study. The final step was then to utilize these case studies as effectively as possible, so as to demonstrate the development of various discourses surrounding self-injury, which necessitated the discarding of even more material. I was trying to pick out those quotes from parents and that information recorded by professionals, which appeared to demonstrate my argument best. In so doing, however, I would be producing my own social construction of self-injury in the context of the fifteen individuals. Furthermore, the marked difference in the employment and relative use of each of the fifteen compounded the issue. In effect, I don't believe that there was any real solution to this difficulty, but it is necessary, I think, to refer to it as being a key consideration. Similarly, the exercise in reflection on the lives of three of the group I had known many years earlier, which completes this chapter provides a further element to the process of construction. Table 2 shows an overview of the methods of data collection in relation to particular individuals in the study group.

(iii) 'Three I'd known earlier' – an exercise in reflexivity

One issue did, somewhat inevitably, influence the collection of the data and my relationship with the people in the population sample. This concerned my own former role as a learning disability nurse working in a large 'mental handicap hospital' during the 1980s. I trained as a 'Registered Nurse for the Mentally Subnormal' (RNMS), though the profession would change this in the mid-1980s to 'Mentally Handicapped' and again most recently to 'Learning Disability'. There is continuing debate, both in relation to the most pertinent terminology for the client group, and the appropriateness of nursing involvement in their care. Anyway, during this period I encountered some of the people who would later participate in my research. I had developed some sort of a relationship

SOURCES OF DATA COLLECTION FOR MEMBERS OF THE GROUP

NAME	CASE NOTE MATERIAL	OTHER WRITTEN MATERIAL	INTERVIEW – PARENTS	INTERVIEW – NURSES	OBSERVATION
ALAN	MEDICAL AND NURSING (ARCHIVE & CURRENT)	RUDOLF STEINER SCHOOL REPORT		STAFF NURSE (GROUP HOME)	IN GROUP HOME
ALISON	BEHAVIOURAL SUPPORT TEAM NURSING NOTES	SPEECH & LANGUAGE THERAPY REPORT, SOCIAL WORK REPORTS	MOTHER		AT DAY CENTRE
DANIEL	MEDICAL AND NURSING (ARCHIVE & CURRENT)			COMMUNITY NURSE	IN GROUP HOME
JAMES	MEDICAL AND NURSING (ARCHIVE & CURRENT)	JUNIOR TRAINING CENTRE AND SOCIAL WORK REPORT			IN GROUP HOME AND ASSESSMENT AND TREATMENT UNIT
JANINE	ASSESSMENT AND TREATMENT UNIT MEDICAL AND NURSING NOTES	SPEECH & LANGUAGE THERAPY REPORT		STAFF NURSE (ASSESSMENT & TREATMENT UNIT)	IN ASSESSMENT AND TREATMENT UNIT
JASON	MEDICAL AND NURSING (ARCHIVE & CURRENT)			STAFF NURSE (GROUP HOME)	IN GROUP HOME
LESLEY	COMMUNITY AND BEHAVIOURAL SUPPORT TEAM NURSING NOTES	SPEECH & LANGUAGE THERAPY REPORT, PSYCHOLOGY ASSESSMENT	MOTHER		AT HOME
MELANIE	MEDICAL & NURSING (ARCHIVE & CURRENT)			STAFF NURSE (GROUP HOME)	IN GROUP HOME
ROBERT	RESIDENTIAL COMMUNITY NURSING AND ASSESSMENT & TREATMENT UNIT	SCHOOL, PSYCHOLOGY, AND SPEECH & LANGUAGE THERAPY REPORTS	MOTHER	COMMUNITY NURSE	AT HOME IN STAFFED FLAT
RONALD	MEDICAL & NURSING (ARCHIVE & CURRENT)	PSYCHOLOGICAL TESTING REPORT		STAFF NURSE (GROUP HOME)	IN GROUP HOME
SAM	MEDICAL NURSING & BEHAVIOURAL SUPPORT	SOCIAL WORK REPORTS	MOTHER		AT DAY CENTRE
SARAH	COMMUNITY NURSING & MEDICAL NOTES	RNIB REPORT, SOCIAL WORK REPORTS	MOTHER & FATHER		AT HOME
SIMON	BEHAVIOURAL SUPPORT TEAM NURSING NOTES	SCHOOL REPORTS, SOCIAL WORK REPORT, SPEECH THERAPY REPORT	GRANDMOTHER		AT HOME (GRANDPARENTS)
STEWART	MEDICAL & NURSING (ARCHIVE & CURRENT)	SPEECH & LANGUAGE THERAPY REPORT, PSYCHOLOGY REPORT		BEHAVIOURAL SUPPORT NURSE	IN GROUP HOME
TERRY	MEDICAL & NURSING (ARCHIVE AND CURRENT)			STAFF NURSE (GROUP HOME)	IN GROUP HOME

TABLE 2.

with three of these individuals during my time as a student and then, later, as a staff nurse, before finally working as a charge nurse directly responsible for the care of two of them. All three, Daniel, James, and Stewart, have been introduced earlier in the chapter; this exercise is one of reflection, and is more concerned with broad comment than the specific detail of their lives.

The social and political context of the early-1980s reflected the gradually changing view towards the care of the 'mentally subnormal', which I have discussed in the first chapter. The practicalities of care, however, particularly the realization of community care with its underpinning philosophy of 'social role valorisation', were only just starting to take shape, and the implications of institutional living were to make an indelible impression on me. When I first commenced nurse training the occupants of the wards were regarded as 'patients', since their mental subnormality or handicap was regarded as an illness of some sort. The gradual critique of the medical model was well underway with this particular group-incipient of institutional care and a social model was being developed. For example, the Jay Report (1979) had advocated that social care should be the predominant type of provision, that this should be provided entirely in the community by appropriately qualified professionals, and that nurses in this discipline should cease to be trained. Though learning disability nurses have survived and become increasingly specialist in their work, the legacy of this original critique cut deep into the psyche of the profession. Anyway, with this emphasis on social care the term of choice for 'hospital patients' was changed to 'residents', which remained until the demise of the institution. Once outside of the 'hospital', the term was altered again to accommodate the fact that the community nurse would bring the service along with them rather than be based with the individual, though some, of course, continued to receive full-time care from nurses. But those who didn't became 'clients', a term which remains the one of choice for many service providers and professionals alike. Tierney's book, *'Nurses and the Mentally Handicapped'*, published in 1983, demonstrates the challenge to the medical model, which characterized this period and the consequent soul-searching that absorbed those concerned about nursing's future in this field. A chapter by Fraser, a consultant psychiatrist and senior lecturer in rehabilitation studies, reflects, somewhat generously, on the medical model's previous dominance:

> "An example of a previously effective working model is a mental deficiency hospital with a physician superintendent looking after 200 people, he being in administrative charge with non-specific overall 'responsibility' for the hospital, being its leader and representative in all matters. Fine, for a short period if he was charismatic, dynamic, and did not meet another charismatic, dynamic leader. 'His' hospital, however, would eventually destabilize. This institution would have a children's ward where trained nurses would carry out the day-to-day feeding and toileting tasks. There would, however, be three times as many profoundly handicapped children in the surrounding community receiving no services. The family doctor would seek help traditionally only when the family was breaking down or ill, or the child becoming grossly behaviourally disturbed. Admission might, or might not, be possible because of bed shortage (not necessarily, nowadays, staff shortage). The nursing staff would have many skills in behaviour therapy, child development, but the physician superintendent, however well-meaning, would have to say 'No' (having final say because of blocked beds)" (1983: 135).

Fraser goes on to discuss how the institution might become more progressive in the future with the nurses developing specialist roles in areas such as behavioural approaches and portage. A corresponding reduction in the role of the doctor is then envisaged, which would release him to use his skills "for more precise use" (1983: 135). Fraser then goes on to consider how the multi-disciplinary team might take shape in the immediate 1980s future, though firstly he gives emphasis to a doctrine that was becoming, and remains, influential in terms of determining the nature of services:

> "To repeat, *the mentally handicapped have primarily a learning disability: they are not primarily ill.* When they become sick this model is inapplicable. They are then primarily patients and the doctor is indisputably in charge" (1983: 136) [italics in the original].

The fact remains, however, that the lives of many of the 'hospital' residents were largely untouched by these developments, and this was particularly so for those individuals with 'severe subnormality' and a tendency to self-injure. Daniel, living on the children's ward, where the residents were moving into their teens and twenties together, passed his time engaging in his pursuits of eating cigarette butts and expanding his self-injuring repertoire. Though I always had a 'soft spot' for him and believed that he liked me in return, in retrospect it was clear that, as a young, enthusiastic student, I represented the possibility of going for a walk or the opportunity for an extra cup of tea. Residents, particularly those without speech, tolerated each others company but rarely developed meaningful relationships. Daniel was fully aware of the transient nature of our relationship and had developed the capacity for some sort of emotional neutrality, whereby my coming and going would be of little importance to him. When I was to meet him again, nearly 18-years later, in the capacity of researcher, he would remember me but I didn't stir up happy memories for him. Now in his early-40s Daniel lived in more comfortable surroundings, had a more extensive daily routine, and enjoyed the company of caring staff. He was, however, still an ardent self-injurer with a complicated selection of self-stimulatory exercises, and he remained largely oblivious to those sharing his bungalow. His recognition of me was sharply apparent, then almost immediately consigned to the past where it belonged. My attempts to talk to him and make some sort of contact were irritating to him, particularly when it transpired that I wasn't going to take him anywhere or give him anything. Daniel effectively controlled the situation, dismissing me quite quickly and returning to his rhythmic rocking to music interspersed with occasional bouts of self-injury.

My involvement with James and Stewart took place during the mid- to late-1980s and saw me mainly as a charge nurse over a ward for 22 'mentally handicapped' men with 'disturbed' behaviour. This meant that I had considerable power over their lives in terms of the decisions that would be made about their care, taking them on annual holidays and, in the case of Stewart, close contact with his parents. Consequently, I developed a close relationship with James with occasional moments of real affection, though not with Stewart since the ward was literally a place to stay in between his weekends home. When I left the ward to further my career both relationships were abruptly terminated, and I would see nothing more of them for nearly a decade. Contact was renewed with the undertaking of the fieldwork, and again both individuals had moved on in terms of their material surroundings. Both were still self-injurers, a pre-requisite for the renewal of our acquaintance, and both were clearly identifiable as the characters I had known earlier. Stewart allowed himself a moment's recollection as we made eye contact, before casting it from his mind and gesturing for me to switch the television on. James, who was going through a particularly difficult period of self-injuring and escalating aggression, also retrieved me from his memory bank before continuing his demands for a new catalogue to flick through.

It was not only clear to me when I reflected on these encounters, that Daniel, James, and Stewart had moved on with their lives, but also that each of their lives had been full of such brief encounters. Daniel and James, I think, had inured themselves to being emotionally battered, since their early experiences of rejection, so that they played out their lives in as safe a way as was possible. Self-injury may be one strategy amongst many for dealing with various aspects of such lives, including counteracting boredom, expressing frustration, gaining some sort of sensory sensation, and indulging in a bout of self-hatred. Their complexity as individual characters was demonstrated through their ability to cope with the poverty of their institutional existence, followed by adapting to the quite different pressures of living in a small house where it was less easy to bide time quietly. Their lack of interest in my renewed involvement in their lives showed an ability to assert some degree of control over what was happening and what they wanted to happen. Their understanding of 'being different' with the consequence of having little real choice over events and occurrences may also have been a factor in opting for a refuge in self-injury. Stewart's continued rich experience of family life both during his time in 'hospital' and in a small community house provided him with an escape from tedium, and yet he was just as obsessive in his behaviour when he was at home. Though this may be partly explained by his relationship with autism, which seeks to explain his emotional detachment and ritualistic behaviour. For me, Stewart's intelligence manifested itself in his pursuit of the feud when residing on the ward, epitomized by his capacity for biding his time before striking, and the deeper relationship he established with another client who joined him in transferring from ward to house.

(iv) The emergent themes

The two dominant explanatory perspectives towards self-injury by people with learning disabilities identified in chapter one, the biological and behavioural approaches, constitute two of the anticipated themes to emerge from this piece of research. It is of little surprise, therefore, that chapters four (behavioural) and six (biological) explore the pertinence of these two perspectives to the lives of those in the study group. Both chapters seek to trace the development of these approaches within the field of learning disabilities more generally, and towards self-injuring individuals in particular. The significant involvement of a consultant psychiatrist in the lives of each member of the study group, especially in relation to issues such as responsibility for major decisions about care and the likely value of complex medication regimes, indicated that this was an area worthy of separate consideration. Other factors outside of the biological emphasis on syndromes and neurotransmitters, such as the relationship between self-injury and both physical illness and sexuality consolidated the need for a discrete chapter.

The pervasiveness of the behavioural approach within the field of learning disabilities, influencing as it does the work of clinical and educational psychologists, learning disability nurses, teachers, and speech & language therapists amongst other professionals, was amply demonstrated within the study's voluminous data. Each group member's propensity for self-injury was greeted with varying attempts at amelioration through a behavioural programme; chapter four seeks to examine the implications of such approaches as behaviourism sought to establish itself as the key player in the self-injury business. This chapter also seeks to examine how the behavioural approach came to be established as the dominant framework, at least in theory, for organizing the lives of individuals with learning disabilities through its emphasis on structure and measurement in care delivery.

The inclusion of an entire chapter devoted to autism may initially appear unwarranted and is the only one to have transpired entirely through analysis of the data. It is justified on the basis that a number of the study group were considered to be autistic, or more latterly fall within the autistic spectrum, but such a possibility in the cases of all but one were either later withdrawn or more likely never attributed diagnostic credibility. It is the implications of the provision of a diagnosis of autism that necessitated chapter five being devoted to the subject, since this had a direct impact on both the social construction of self-injury and the practical realities of the individual's ensuing life. The chapter seeks, therefore, to investigate the consequences of having a diagnosis rejected, the sometimes convoluted and traumatic procedure of being identified as autistic, and the role of self-injury within this overall process. As Trevarthan, et al point out more than forty years after Kanner's initial description of the condition:

> "It is a pervasive condition affecting most aspects of a child's life, and our understanding of what it is like to be autistic is far from complete" (1996: x).

The penultimate chapter pertaining to the role of the multi-disciplinary team in the life of a self-injuring individual was also not entirely pre-conceived, but emerged because of the need to examine how different professional discourses related to each other through their different bodies of knowledge. Since each individual in the group was the recipient of services provided by different professional disciplines, whether it be within the context of the institution or the community, it became necessary to consider how the emerging multi-disciplinary consensus influenced their lives. Initially, the study's interest revolved around the relationship between the two giants of medicine and behavioural psychology and how such differing perspectives could tolerate the other's radically different explanation of self-injury. Later, however, it would be the organized 'package' of care that would be the focus, and particularly its role in adequately addressing the needs of the individual and her family. In fact, a sub-theme transpired in relation to the family, since there was much to consider that I had previously not realised, such as how they regarded professional input over time and the value, and sometimes dismissal, of their own expertise about their son/daughter's self-injury.

The immediate consideration, however, is the next chapter, chapter three, which seeks to consolidate an aspect of the selection criteria of the study group, namely the issue of communication, which effectively pervades the entire research experience. The chapter sets out firstly to explore the implications of the widespread academic association between language and being recognized as a participating social actor. The development of speech & language therapy is then considered, particularly in the context of those in the group, which proved to be several, who experienced assessment and interventions. Finally, the issue of self-injury as a communicative act is addressed, an argument which would appear to have some substance, but has not resulted in it acquiring the acceptance and credibility that would have seen it rival alternative biological and behavioural explanations.

CHAPTER THREE: COMMUNICATION

- Language, learning disability, and sociology
- Recognition of the importance of communication
- Improvements in approaches to communication
- Communication and self-injury

One of the most influential features of each of the individuals in the group under study, in fact a cardinal part of the selection criteria, relates to the difficulties that they all have with respect to verbal communication. This absence of speech, except for one particular individual, who has developed some effective language, has the implication of significantly increasing the likelihood of some degree of exclusion in the general course of their lives. Each of them, having said that, have developed fairly effective methods of ensuring that their needs are met, either through gesture, the use of particular noises or sounds to indicate something, or, indeed, specific approximations of words. But the role of communication takes on a different meaning for people without effective verbal strategies, to the extent that each encounter with others is likely to be dominated by the party with verbal reasoning. Their own acts of communication are thus necessarily very simple and direct, being geared towards a specific purpose, with only rare instances of communication for the sake of it or to display affection. The purpose of this chapter is to examine the relationship between learning disability, communication, and self-injury. The first section sets out to explore the implications of the absence of language with regard to my study group fulfilling the roles of 'social actors'. The gradual recognition by academics and other writers looking at 'mental deficiency' during the post-war period of the importance of communication is the subject of section two. The third section traces the consolidation of these ideas through the emergence of the speech and language therapist and the development of alternative and complementary systems of communication. The relationship between communication and self-injury, particularly the notion of the latter being an expression of the former is the subject of the final section. The main characters in this chapter are Sarah Houghton and Robert Clayton, both of whom have a complex and sometimes ambivalent relationship with communication.

(i) Language, learning disability, and sociology

One school of thought about human beings' capacity for the spoken word proposes that a common, formal, symbolic language is the essential characteristic of humanity, and thus separates us from the animals (Goode, 1994). This idea that the absence of language makes us somehow less than human is an ancient one, but it is not uncommon in academic and professional writing. Sociology, along with psychology, anthropology and various other academic disciplines, has embraced the idea of the centrality of language in human society, and yet there seems reason to challenge the notion that it should be a prerequisite for recognition as a participating social actor. Sacks (1989) encapsulates the views of many in his study of sign language and deaf culture, which otherwise is an argument for inclusion and acceptance of difference:

> "Language... is not just another faculty or skill, it is what makes thought possible, what separates thought from nonthought, human from nonhuman" (p.68).

Other writers take the emphasis on the importance of language to being human even further, by drawing attention to its necessity for the development and maintenance of a functioning society:

> "Interpersonal communication is the foundation on which interpersonal and organizational structures are produced, maintained, and modified. It is through interpersonal communication that we construct various forms of social relationships, definitions of reality, and programs of action" (Burke & Miller, 1988: 21).

In the context of the group studied, and learning disability more generally, the situation becomes complicated; the idea of language being an, or even the, essential component of the human condition has profound implications, as the history of this client group bears testimony. It is only very recently, for example, that less than completely disparaging terms have been used with this client group – 'learning difficulties'; 'special needs'; 'learning', 'developmental', and 'intellectual disabilities'. These are all terms of the last two decades, and many remain unconvinced that simply changing the label is necessarily a meaningful development. Nevertheless, until the early 1970's people with learning disabilities were considered questionably human if they had an IQ below 20, which was reflected in the fact that many, including several of those involved in my study, were considered 'ineducable' and sent off to junior training centres. The official term of choice until the early 1980's was 'subnormal', which had been considered preferable to 'deficient', with its three categories of 'idiot', 'imbecile', and 'feebleminded'. But 'subnormal' is most relevant with regard to this discussion, since it clearly emphasizes the idea of being 'below normal' or, more significantly, 'less than human'. And it was the absence of language, which was one of the most important factors in diagnosis and in terms of identifying the degree of 'retardation' (see, for example, Tredgold & Soddy, 1963). During the eugenics debates early in the last century, the notion of some individuals categorized as severely mentally deficient being less than human was tinged with racist overtones. Considering the social constructionist emphasis on the consequences of definitions, it also demonstrates one of the difficulties of using language as a central criterion for being human, as this quote from Penrose (1933) discussing the integration of 'mongols' into a classification of 'idiots' demonstrates:

> "The supposed likeness of their features to the Chinese and other orientals led Langdon-Down to propose an ethnic classification of idiots. The classification made no headway because an insufficient number of convincing types of idiots were discovered which might be supposed to belong to other ethnic groups, e.g. Ethiopian. But the designation of the Mongolian or Kalmuck type has remained, and recently the hypothesis of their descent from Mongol ancestors has been much stressed by Crookshank. This writer has, moreover, added that, in his view both the racial Mongolians and the so-called mongolian type of idiots are closely allied to the orang-utan" (p.96-7).

In sociology, the greatest emphasis on language has been within the theoretical perspective of symbolic interactionism, with its emphasis on agency rather than structure. The emergence of postmodernism, with its emphasis on the acceptance of multiple perspectives, also relies on language in the construction of different, sometimes contrasting, realities. The continuing influence of labelling theory, in particular, in areas such as crime and deviance (e.g., Hester & Eglin, 1992), demonstrates the considerable impact that it has in analysing the uses and abuses of power. The overall approach centres on three key areas – a commitment to 'naturalistic' inquiry, social life as process rather than structure, and the construction and transmission of social meanings in and through interaction (Cuff, Sharrock, & Francis, 1990). It is most associated with the work of Mead, who was concerned with the construction of the 'self', both in terms of 'me' and 'I', whereby the former is objectively reflected on by the latter. According to the argument, the self is mainly constructed through language, which is illustrated by the way in which we learn by interacting with others how to become social beings, and true communication can only occur when understanding is in evidence. Meaningful interaction without language is not really possible, although the role of symbols is acknowledged, because people act in relation to others by accentuating understanding whilst simultaneously modifying their own behaviour according to the response (Harvey, MacDonald, & Hill, 2000).

In essence, human beings need to have the capacity for 'self-consciousness' in order to fully participate within society, which requires seeing oneself from the other's viewpoint. Blumer (1967) developed Mead's work further, critically appraising the absence of 'self consciousness' in the 'so-called variable analysis' approach of positivist social inquiry. He went on to develop the methodology of the symbolic interactionist approach and identified its three most essential points:

- Human beings act towards things on the basis of the meaning that things have for them;
- These meanings are the product of social interaction in human society; and
- These meanings are modified and handled through an interpretive process that is used by each individual in dealing with the signs each encounters (Blumer, 1969).

An important additional point is that people utilize their previous experience, so that in each new situation certain assumptions can be made. In effect, individuals construct meanings within a framework, which is largely taken for granted, and they don't have to be negotiated during each interaction.

The relationship between communication and sociology centres on what is broadly described as the 'interpretivist' tradition, yet according to Leeds-Hurwitz, (1995), there has been no real attempt to summarize the theoretical propositions expounded by this position. The need for greater consistency in the expanding yet diverse field of 'social communication' has thus been strongly advocated (Craig, 1995), particularly since the work of those contributing is inextricably linked to broader social theory (Hall, 1989). In fact, some writers have sought to emphasize that this situation requires immediate remedying:

> "Above all, we need to reconnect the study of communications with the cutting edge of contemporary social theory. This is not an option. It is an imperative" (Murdoch, 1989: 246).

If such a task is therefore taking shape, and there is some evidence that this is the case (for example, the various papers presented in 'Social Approaches to Communication', edited by Leeds-Hurwitz, 1995, and arising from two forums held in the United States in 1992), then one starting point might be a reconsideration of the definition of 'communication'. The one currently relied upon by many of those exploring the role of the social in relation to interpersonal communication regards it as "a symbolic process whereby reality is produced, maintained, repaired, and transformed" (Carey, 1975), thus emphasizing process as well as the final product. However, a new definition might take this considerably further, acknowledging the fact that much communication is unintentional, so that both non-verbal and verbal behaviours are required for a more thorough appreciation of 'communicative behaviour' (Leeds-Hurwitz, 1995). Only by an integration of the two can we appreciate that anything other than this is a complete nonsense; communication cannot be considered in any other terms (Kendon, 1972).

An alternative type of definition, therefore, might enable some of those involved in my research to avoid the usual practices of exclusion, which have been generally characteristic of their lives. Ironically, those caring for these people, professionals and parents alike, as well as the majority of those writing about both learning disability and self-injury, are fully aware of their roles as communicating social actors. It appears that the development of theory, in this particular case, might lag behind some of the more innovative developments in practice, in terms of the development of sophisticated relationships. Though there is great variation in the quality of interaction with non-verbal individuals with learning disabilities, their complexity and capacity for humour and self-consciousness was emphasized by many of those interviewed.

In a fascinating and groundbreaking study of children born deaf and blind, which takes place over a number of years and involves an attempt to establish communication without the aid of language, symbol, or sign, Goode (1994: 97) identifies three major objections to the centrality of language to being human, which I wish now to consider at some length in relation to those participating in my study:

a) "That rich, complex, multifaceted, and maturing social relations with such children are achievable without shared symbolic language".

My observations of the relationships that the parents interviewed had with their self-injuring, non-verbal children provides the evidence for my concurring with Goode's claim, which is based on his own personal experiences with two deaf-blind children with no speech. I cannot say that I developed maturing relationships with those individuals, whom I had known earlier in 'hospital', despite my claim to having got to know them in some depth. This is partially because of the nature of the relationship (carer to resident), but also, more importantly, because of the way in which the circumstances of their lives had mitigated against the development of mature relationships. Relationships with staff would inevitably be transient, either because they would leave for other jobs or move to another ward after a certain length of time. Relationships with other residents were, I think, nearly always considered pointless, particularly since they were very much aware of their own 'difference', and therefore that of their peers.

However, in contrast, it became very clear to me, that the relationships between the mothers interviewed and their offspring were complex, multifaceted and maturing, and the evidence is proffered in the segments of interviews included in this thesis. Each of those interviewed was able to provide me with a portrait of the self-injurer, which demonstrated a variety of behavioural and emotional characteristics. Sophisticated manipulation, extreme anger and frustration, jealousy, profound melancholy, sense of humour, and varying degrees of self-awareness were all described to me in interviews.

Consider, for instance, Mr. & Mrs. Houghton describing their rationale for why they think Sarah, their deaf-blind daughter, is going to be well behaved over the coming week:

Example 2
Mrs. H: "Because she's going in respite care and..."

Mr. H: "It's just the way of the world isn't it?"

Mrs. H: "It's just the way she goes. On Thursday night she slept all night, didn't she? And she got up Friday full of – just the best girl you've ever seen and how could you ever let me go away".

Mr. H: "I mean, she couldn't have had a clue. We don't by any means, or any stretch of the imagination, believe she knew she was going away. It's just one of those things. I mean, I didn't take her this time, did I? I thought she'd be – because if I take her she knows I'm going to go and get her. I thought she might kick off a bit in the car going. She was a good girl wasn't she? Once she got there she was sitting there laughing".

Mrs. H: "I mean, how could you leave an angel? (Both laugh)".
(Source: Interview – October 1999)

Another illustration of Sarah's complex character occurs earlier in the interview, when Mrs. Houghton talks of her manipulation of people, which is in response to a question about the level of their daughter's intelligence.

Example 3
Mrs. H: "Yes, I think so, yes. Her manipulation of people has always been good. You can say that with Craig (Sara's brother), when she was small, she ignored him, but when she realised that he could get her things that she couldn't get herself, like a drink, then he became... She could use it, and I might say – she might come to me for a drink and I'd say 'no, you're not having any more, you've had enough. She'd go to Craig and she'd put Craig behind her and walk past me with Craig at the back of her, thinking I couldn't

see Craig. And its, 'come on Craig, you go and do that, she can't see you'. Its like, as soon as she realised that Craig was useful to her, to get her things. And she's very clever, in that she can manipulate a man, whereas she can't probably manipulate a woman. She worked that out early on".
(Source: Interview – October 1999)

b) "That language is not a necessary precondition for thought and reflection (although the quality or character of that reflection may not be available to us)".

In the previous chapter I discussed my experience of renewing acquaintances with three individuals I had known many years earlier. Two of them have no spoken language and the other employed about half a dozen individual words to quite good effect. There is little point in repeating the exercise in reflexivity here, but it is worth considering Goode's statement with regard to these three individuals. Certainly, there was some degree of recognition on the part of all three, and I am also quite sure that each of them consulted their catalogue of faces in order to place me within a particular context. This last point is significant, since I was a stark reminder of a previous period of their lives, which none of them, I suspect, would be over-enthused with re-visiting. Such a comment is not a reference to abuse or neglect, particularly since one of them continued to live in an extremely close and loving family for part of each week, and the parents would have been aware if their son was desperately unhappy. Nonetheless, abuse and neglect, in varying degrees, were a characteristic of institutional life. But this was different; the institution represented an emptiness, an emotional void, with no real potential for personal growth. It was a place for passing time but not much else.

Unfortunately, all too often, there appears to be an assumption that the existence of a learning disability precludes intelligence, in the sense of thinking quite deeply and reflecting on past events. It seems plausible to me that most of the events in the lives of those being discussed here were hardly worth thinking about. Mealtimes, tea breaks, and whiling away endless hours by wandering around a ward shared by twenty other men, or engaging in stereotypic activity doesn't make for fruitful reflection. The pure tedium of ward existence and its effect on the behaviour of those being cared for has been well-documented (Barton, 1961; Goffman, 1961; Rosen, Floor, & Baxter, 1971). But much of this writing was concerned with those residents of the institution, who were able to use the spoken word. Much of the critique of the institution was concerned with the plight of those who should never have been there or had become severely dependent on the process of 'block treatment'. Those writing about the group of individuals described as 'idiots', or more latterly 'severely subnormal' tended to comment upon only what they could directly observe. For example, Tredgold & Soddy (1963) comment:

> "The most severely subnormal children – idiots – remain at a level of infantile dependence on the mother, and the relationships they form with father and other members of the family are, if any, infantile too. Idiots are never capable of more than a completely egocentric baby-type of relationship formation. Their instinctual needs are weak and simple and, provided they are accorded the infantile type of satisfaction – immediate and complete with a minimum of frustration – idiots are not difficult to look after. Conditioned reflexes can even be established to keep them 'clean and dry under supervision'" (p.74).

c) "That the faculty of language, albeit with a power qualitatively to transform one world or reality into another, is just one of many human faculties that allow us to experience and participate in what Merleau-Ponty (1962) called the human Umwelt and Welt".

Goode (1994) argues that formal symbolic language is strongly based in practices of 'bodily intersubjectivity', which provide the neglected grounds for different sorts of human intersubjectivities, whether they be based on language, non-formal symbolic communication, or non-symbolic communication. Intersubjectivity refers to human understanding, and serves to move the emphasis away from just spoken language, whilst not referring to simple non-verbal behaviours like gesture. Goode draws on the notion of Umwelt, which is not used in isolation, to illustrate the biological reality of having a physical body. Welt, on the other hand, refers to the reflexive, self-constituting, and social character of humans; Goode considers it to be a gloss for the socially created world of institutions and environments designed through the mechanism of language. After dispensing with the idea of a 'biological lexicon', which would equip people with the ability to participate in society, he explains his position:

> "The *Umwelt* is not a state or even a stable set of processes. It is permeable to the reflexive construction by people in society. Thus, perception, expressivity, understanding, and the rest are demonstrably influenced by culture, place, historical time, and so forth. Human biological potentialities are reflexively constituted through participation with consociates, learning of the practices of society through which everyday reality, the world, is socially constructed" (p. 98-99, italics in original).

Goode then goes on to put forward his argument, that comprehending the world and other people requires expressivity and communication, which are ordinarily the grounds for the emergence of language. In the case of the children he studied, however, they developed ways of relating based on 'indexical expression', which refers to it's essential or occasional character in conjunction with the interpretation by the other person. The contemporary interpretation of bodily expression, rather than emphasize the biological or psychological, which characterized former approaches, focuses on its socially constructed and indexical nature. This social construction of bodily expression is discussed by Poole (1975), who draws attention to three aspects – no expressive body activity is specific to one individual; it has no significance without a particular historical context; and interpretation of it will also vary across time and space. The development of intersubjectivity through indexical expression occurs prior to the development of language, and amounts to a "lexicon for the conversation with our bodies" (Goode, 1994: 99). But when language fails to develop, these 'conversations' can become extremely rich and detailed or, conversely, they can be manifested through repetitive, stereotyped, and even self-injurious behaviours. In each case, however, they are not random, surplus behaviours, but instead deliberate, precise and intentional. In effect, sophisticated communication, which addresses both the transmission and receipt of the message, can occur on the various levels necessary for a relationship of depth, without the prerequisite of reciprocal spoken language.

> "Our view of man will remain superficial so long as we fail to go back to that origin, so long as we fail to find beneath the chatter of words, the primordial silence, and as long as we do not describe the action which breaks the silence" (Merleau-Ponty, 1962: 184).

The idea of 'bodily intersubjectivity' can, I think, be related to the actions of several members of the study group, particularly when there has been an attempt to comprehend the individual's enjoyment of the presence of others. A 1995 speech and language therapy report relating to Janine Lewis, for example, discusses her relationship with touch:

Example 4

"Despite the impression that her self-harming suggests, tactile sensations seem to be very important to Janine. She obviously likes the soft and gently touching on her arms and legs which she does to herself – she frequently touches any exposed skin which is not covered by clothing and shows a preference to wearing clothes without sleeves in. Janine also appears to like other people being gentle with her for instance putting hand cream on her (though) she dislikes her head, hair or face being touched. She also dislikes people holding her and will instantly try to break loose".
(Source: Speech & Language Therapy Report – May 1995)

(ii) Recognition of the importance of communication

"Communication problems are common to all mentally retarded persons" (Grossman, 1983: 96). Such a statement reminds us that having difficulties communicating, whether it be in the acquisition of formal language, developing the ability to express oneself effectively, or fully comprehending what is being said by others, is a cardinal dimension of learning disability itself. A London survey carried out in the 1920s by Burt (in Fawcus, 1965) claimed 'severe defects of speech' occurred in just over 1% of normal children, in 5% of those considered 'backward', and 11% of those who were 'mentally deficient'. Furthermore, more than 25% of this latter group of children showed some defect of speech. The influential Government White Paper, 'Better Services for the Mentally Handicapped' (1971) drew on a study of institutions in Wessex to be able to state that one in three adults had speech defects. The National Development Team for the Mentally Handicapped (1979) estimated, on the basis of staff reports in 'hospitals', that 57% of children and 22% of adults had significant communication problems. It should also be noted, however, that speech is subject to great variations, and some children of average intelligence talk prior to nine months, whilst others considered much brighter fail to develop the capacity until three or four years old.

"The development of speech is controlled by several factors – by the degree of intelligence of a child, by the amount he is stimulated by being talked to and played with, by the acuteness of his hearing, and by the rate at which the nerve-fibres in his brain are enclosed within a protective sheath called myelin. Speech is one of those skills in which rapid progress may be followed by a period in which there is no obvious progress. Mental retardation is the commonest cause of slow speech development" (Gibson & French, 1971: 18/19).

Other writers have emphasized other factors, to some extent reflecting the particular period in which the thoughts are formulated, their own professional background, and available knowledge about areas such as the physiology of speech. Sampson (1973), for example, places emphasis on speech developing in three inter-related ways; firstly, through the process of maturation, secondly, as a consequence of life experience; and thirdly, complicating both of the former dimensions, the development of specific linguistic ability.

In the group forming the basis of my study, only one of the fifteen successfully developed language skills, which he was able to use as an effective means of communicating and expressing himself. Robert Clayton was also the only member of the group to retain the diagnosis of autism, after ongoing debate throughout childhood and adolescence (see chapter five), into later life. Furthermore, he was also the only one to come from a middle class background, started special school earliest (2 ½ years old), and encountered the greatest degree of frustration because of his other abilities (i.e., gross motor activities). None of the others have developed any speech, other than one or two approximations of words, and occasional, very basic makaton signs, though they all have at least some understanding of what is said to them. The purpose of this section is, in part, to explore the role of communication in the lives of the group, particularly in terms of its relationship to self-injury. Data will be drawn upon later to illustrate any attempts implemented to enhance communication skills, provide evidence of any association with explicit behaviours, such as stereotypy or self-injury, and explore the developing role of the speech & language therapist. In terms of this last point, I hope to examine the extent to which the speech & language therapist serves to construct the self-injury as a communicative act, possibly to the exclusion of other possibilities. For the remainder of this section, however, it is the relationship between communication and learning disability, and later self-injury, which I wish to look at. The context, of course, is the changing nature of care over the last forty years. One thought on the importance of speech, however, powerfully emphasizes the problems that its absence presents for those studied, along with their families and carers:

> "Speech is one of the essential means whereby the child finds his bearings in the external world; it activates the general connections formed in past experience which play a substantial part in the mediated, specifically human, form of regulation of action" (Luria, 1957, quoted in Sampson, 1973: 122).

The relationship between language development and learning disability is more complicated than it initially appears, which was amply demonstrated by the individuals in my study, who had not only learned to express themselves, frequently with great assertiveness, but also sometimes demonstrated abilities associated with individuals considered much abler. Just as the first, and sometimes only, consideration in examining the relationship between learning disability and self-injury is the degree to which the former directly gives rise to the latter, so this is also the case with communication. As one writer observes, prior to examining the question more thoroughly, in the context of presenting an early case for speech therapy:

> "The high incidence of speech defects would seem to suggest that mental deficiency is the *cause* of many of these disorders of speech and language" (Fawcus, 1965: 452, italics in the original).

Other writers have variously emphasized language being an important clue about future mental development (McCarthy, 1946), the possibility of delayed speech being more significant than potential might indicate (Lyle, 1961), and comparisons between the vocal patterns of a 'retarded' 4-year-old with a 'non-retarded' 1-year-old baby (Irwin, 1942). Sampson (1973) focuses on three particular areas of the relationship between speech and 'severe subnormality' – expression, comprehension, and articulation, all of which can be detected early, though she does acknowledge the roles of additional factors such as socio-economic background, institutionalization, and poor parenting. Furthermore, other factors considered influential in promoting early speech include constitutional, environmental, and psychological (Becky, 1942), which might pertain to glandular dysfunction, hearing loss, and emotional disturbance (Matthews, 1957). Kastein (1956), however, issues a word of warning by pointing to speech difficulties in high functioning individuals and good language in those considered 'imbeciles', an observation that is not lost on Matthews (1957):

> "The well trained speech and hearing therapist should recognize that there may be many explanations of delayed or defective speech which have no relation to intellectual retardation" (cited in Fawcus, 1965: 452).

The post-war period, particularly the 1950's and 1960's, I think it is fair to say, in the context of the care of the 'mentally subnormal', were characterized by a number of debates about general capability. The crux of these debates was the extent to which the individual's 'subnormality' affected his or her ability to develop self-help skills, achieve a degree of independence, engage in productive work, and, in the case of the more 'severely subnormal', develop language. It is clear that there was a general questioning of the continuing role of the current institutional service framework, with many writers advocating the increased use of professionals, such as speech therapists. For those with 'severe subnormality', who had not acquired speech, such as the individuals in my study, there was a challenge being made to the notion of 'ineducability', which would soon result in the demise of the concept in the Education Act (1970). The almost simultaneous rise of operant conditioning/behaviourism and critique of intelligence testing raised the possibility, that there could be potentially viable attempts to develop speech in those who were mute as well as the more able (Sloane, 1968). But probably the main breakthrough at this period was the dawning recognition, that the basic fact of the existence of 'mental deficiency' should not automatically mean the provision of custodial care alone because of low expectations about the potential for development.

> "Current research in the field of mental deficiency has encouraged a more optimistic view of the possibilities of speech rehabilitation, and indicate that speech therapy should be available as part of the total training programme for the mentally retarded patient. Certainly, no patient should be denied treatment simply because he bears the label 'mentally deficient', since he may subsequently prove to have a much higher mental potential, and since the speech disorder itself may be largely, or in part, responsible for his mental retardation" (Fawcus, 1965: 481).

(iii) Improvements in approaches to communication

During the 1970s a body of theory about communication had been developed, which was beginning to influence the planning of services for the 'mentally subnormal'. Increased knowledge regarding speech and language disorders meant that medical professionals could increasingly identify specific organic problems, such as dental anomalies, cleft palate, dysarthria, dyspraxia, and hearing loss, and decide upon the value of clinical input (Fawcus, 1965). The challenge to the notion that those individuals, who were so 'retarded' that they were unable to develop speech indicated that their lives were of little value, also meant the tentative widening of services such as that provided by the speech and language therapist. Greater recognition and consideration of the social background of children, particularly when there was considerable evidence of deprivation, meant that such factors would increasingly be influential during consultations over issues such as 'hospital' admission. Though my own study suggests considerable evidence of such consultations being judgemental and decisions made sometimes arbitrarily, much of the writing of the period contrasts with the earlier emphasis on clinical criteria and total acceptance of the role of the institution (see, for example, many of the chapters in Clarke & Clarke, 1965, particularly the contributions by Gunzburg, 1973).

By the middle of the 1970's, there had been some attempt to translate the general critique of existing services, which was beginning to characterize one aspect of the care of the 'mentally subnormal', into some fairly radical alternatives revolving around the notion of the 'therapeutic community'. This is not to say that most services were not institutionally based, extremely conservative, and dominated by the medical model, which they most certainly were, nor that there are no radical alternatives to the contemporary model of service structure, but for a brief moment, as the critique of the 'hospital' reached its zenith, it seemed possible that such radicalism might influence the future of services. The critique, however, was much more powerful in the care of people with mental health problems (for example, Laing, 1959), where the so-called anti-psychiatry movement (attributed to David Cooper, but rejected by Laing) had been in full flow during the 1960s, and radical alternatives had been established, albeit mainly briefly, outside of the conventional framework (see Burston, 1996, for a review in the context of Laing's life).

In relation to 'mental subnormality', Eden (1976) discusses the role of the Rudolf Steiner education system as one such radical movement geared in part towards bridging the communication divide between children and carers. This system "by its very existence points to possible alternatives to the orthodox 'official' approach to mental handicap" (p.101). Many children, who would previously have been consigned to institutional care because of the predominant belief regarding their developmental potential, were provided with intensive input. Eden goes on to identify six inadequacies of language common to 'mentally handicapped' children, limited comprehension, impoverished vocabulary, primitive grammatical construction, constant repetition of a few words, parrot-like copying (echolalia), and poor articulation (1976: 61).

All such difficulties were discernible in the study group, though minimal or the absence of the spoken word were most clearly in evidence, and the few words that were used were frequently repeated and poorly articulated. There was evidence that some of the group had begun to acquire speech when very young, but this had been quickly lost and had not been helped by the individual's perceived 'ineducability', the scarcity of professional expertise, and the eventual institutional context where the greatest emphasis was placed on 'habit' and 'sense training'. Each of the group did negotiate effective ways of making themselves understood, to some extent rendering the spoken word unnecessary, and learnt to be content by developing a largely locked-in world of self-stimulation and injury. The 'hospital' system had few individuals with the expertise to enable speech acquisition in those such as the majority of the study group, and the emphasis was clearly on helping them adjust appropriately to institutional life. There was, however, occasional evidence of the availability of a more radical alternative such as in the case of the 8-year old Sarah Houghton.

Example 5

In 1973 Sarah gains a place at a specialist unit for 'rubella children' set within a larger residential school. The smaller class size (4-5) and intensive system of working is elaborated by Mr. and Mrs. Houghton, who describe the system that enables rapid and marked progress in their daughter. Unfortunately, however, as with most of this family's story, the school and its system of communication closes after Sarah has been there just eighteen months in preference of a unit for children with cerebral palsy. She is consequently cast back into an ESN school where the emphasis is on occupation rather than development.

Mr. H: "They used to have symbols didn't they? She used to have a bag of things; each thing in this bag meant something. How they did it I don't know. There was some signs as well that went with it. But there was a thing – each activity or something – and if she wanted it she'd pick the particular symbol out. There was all sorts of strange things in there – rubber balls with little bubbly spikes on, I remember that one. There was all sorts of strange things, really tactile things to say what she wanted. But I was amazed, when we went to pick her up after the first term. He got the bag didn't he? Give us this thing before she went the toilet... It wasn't anything like spelling, it was just a particular movement or a touch for a particular thing. I don't think she could have understood sign language because she didn't know any. I think you've got to understand, you've got to have some understanding of words haven't you?"

Mrs. H: "She'd touch her fingers to her mouth if she wanted to eat and then she'd cup her fingers round and put them to her chin for drink. It made it easier for her and easier for us. But if she'd have stayed there longer it would have been a different story altogether I think".

The school she attends on returning home is unable to adopt the 'objects of reference' system and Sarah reaches a crisis not long afterwards when her aggression and self-injuring deteriorate markedly. Contemplating this state of affairs, Mr. Houghton ruefully states: "I think she'd have been a totally different person. If she could have stayed there for a few years".
(Source: Interview – October 1999)

There were a number of other communication-enhancing systems being developed with varying degrees of success by the mid-1970s suggesting both increased awareness of the importance of enabling 'severely mentally handicapped' individuals to express themselves more effectively, and some recognition of behaviours such as self-injury as possible means of such expression. These included the American Peabody Language Development Kit and the Language Master system, the first relying on visual material such as picture cards and plastic fruit, and the latter utilizing an electronic toy (a variant of the tape recorder) to emphasize the association between the spoken and written word (Eden, 1976). The sudden proliferation of such systems, however, didn't guarantee their effectiveness, something that Kiernan (1977), following a review of what was available, advised future research to be directed towards. The increase in specialized units, such as Child Development Centres attached to general hospital facilities, sought to refine the use of such technologies through the mechanism of approaches such as 'group treatment', whereby intensive input would be maintained with 4-5 children (Haig and Hope, 1981). The existence of behavioural problems, however, was viewed as problematic within these units, which were primarily regarded as being most suitable to non-'mentally handicapped' children:

> "Children with speech and language delay frequently display associated behaviour problems, so that another problem in forming such a group is that their behaviour problems may be compounded by bringing them together!" (Haig & Hope, 1981: 156).

One of the study group, Robert Clayton, experienced assessment within one such unit and later in a residential specialist school, with the primary aim to establish the appropriateness of a diagnosis of autism and determine the most beneficial future placement. This illustration focuses mainly on the assessment at the school, a primary component of which was the necessity of establishing the likelihood of progress in the area of language, though it begins with an attempt to discover whether hearing difficulties might be impeding things:

<u>Example 6</u>

In July 1983, when Robert is approaching his eighth birthday, and amidst continuing controversy over whether he is autistic or not (see chapter five), he is examined by the 'hearing impaired service' specialist from the regional education committee. This is one aspect of a comprehensive assessment process, which is undertaken in order to establish the most appropriate school placement for him. This particular report suggests that he "appears to lack many of the qualities essential for natural acquisition of speech and language". Furthermore, he is not only considered to be quite self-sufficient but "perceives people as puppets to be manipulated rather than as humans to come to terms with. Until, and unless, he is able to relate to people, it seems unlikely that even the methods of communication employed at the Royal Schools for the Deaf at Manchester with what might be termed the 'damaged deaf' could be employed".

The debate over Robert's future takes shape over the next few months with differences of opinion being forwarded about, not only the autism diagnosis, but also his level of hearing, his need to be given more intellectual stimulation, and the pertinence of different systems of communication. There is a clear split between those emphasizing his particular strengths, abilities, and behavioural improvement, and those stressing his lack of cooperation, motivation, and slow progress. His class teacher, for example, talks of "his temper tantrums and head butting hav(ing) been almost completely eliminated" and his group participation having markedly improved. Similarly, his mother, during interview, discusses Robert's communication difficulties, and she tells me of her delight when at eight years old, he came out with his first sentence, and she describes the circumstances with great affection:

Mrs. Clayton: "His first little sentence was quite distinctive. We'd gone away one Easter to the Yorkshire dales and he'd never seen any sheep before. And his first spoken words were 'not a dog' (laughs). It was really quite memorable. It had snowed and it was very beautiful. He stood and observed first and then this lovely little smile came and he said 'not a dog'. It was really quite lovely".

Though it is difficult to establish with certainty the reasons for Robert's behavioural improvement, developing the ability and confidence to communicate must have provided him with a considerable sense of achievement. Furthermore, it seems that he is being intellectually stretched during this initial period at his new school, and maybe he is consequently more relaxed and less angry and frustrated. The question of his intelligence, communication problems and frustration arises in the interview:

AL: "It comes out in his notes that he was a lot brighter than most of the other children in virtually every school that he attended. I've wondered how strong frustration is with Robert".

Mrs. C: "Well, I'm quite sure. His other problem is that, although he's visually quite bright, he has genuine difficulties with communication and the written word. He was able to do very simple words like 'cat' and 'dog', reading, but he's never got above that, so he's probably had about 18 years of the education system where he's been taught the same thing (laughs). We gained communication with him by using a model called Blissymbols – sort of penny black lines because he never liked curves (pauses). He always liked straight lines and curves cause him problems, which is why letters cause him problems still".

By May 1984, however, those suspicious of Robert's potential are in the ascendancy when he is the subject of a lengthy 'admissions assessment' at a specialist residential school, which will result in a traumatic moment of rejection in his life. This is a crucial juncture because there is some recognition by the various professionals involved in his care that the decisions made now will determine Robert's educational future. He is fully cognizant of the fact that he is different to other children of his own age, but this is complicated by the fact that he is even more aware of the differences between himself and other 'special needs' children. He is truly stuck between a rock and a hard place, with certain gross motor abilities elevating him to the status of being extremely able, irrespective of the group of peers drawing comparison. His frustration and anger are slowly coming to a head at this time, which I think is demonstrated by the significant progress that Robert makes when he is 7-8 years old and encounters an, albeit brief, period of intellectual stimulation. The decline of this stimulation, the elevated importance of the autism diagnosis, his local reputation as the county public enemy number one, his effective 'downgrading' to 'mentally handicapped' by the assessment process, and his difficulty in making sense of it all, all conspire to consolidate Robert's fury at this time.

The assessment is undertaken by, amongst others, a senior teacher/speech therapist, who starts by pointing out that over the previous year "there seems to have been a significant change in Robert following the introduction of Blissymbolics". Unfortunately, however, a change in teacher resulted in this system being no longer considered appropriate, as it was having the effect of deterring him from using speech. The assessment then goes on to provide a detailed account of Robert's performance, which is significant mainly for the gradual clear revelation that he is destined for rejection. Following consideration of his style of learning, for example, there is mention of him being "very aware of his limitations in certain areas" which suggests a need for structure to curb his "generalised wild behaviour". Many of the comments relate to his behaviour rather than his ability, and sometimes there appears to be little insight into his self-preservative need for not stretching himself intellectually. In terms of receptive language, for example, "(T)here were considerable periods of time when he consciously/unconsciously appeared to 'block' input and did not respond to verbal/visual communication". Furthermore, when he is tested in this area "he gave the pictorial material a quick scan and then looked away, or, up to the ceiling (similar response as in general situations)". Much of the latter part of the report follows in this critical vein, frequently suggesting the speech therapist's own irritation at Robert's handling of the whole procedure. She writes, for example, that, "if he was pressed to repeat a response he shouted what had been asked", and later that "he verbally repeated the given verbal utterance (or part of it). This did not always seem a strategy of positive help". The results of the tests (auditory comprehension and picture vocabulary) identify him at an age of less than half of his chronological age, probably confirming her suspicions that he is simply 'mentally handicapped'.

Following a variety of other tests and investigations, including medical and psychological, over the three-day period, Robert returns home and the family await the outcome. A month later, confirmation of his rejection comes in a letter from the school's headmaster, who describes Robert as "a child with a communication disorder rather than a speech/language handicap in the sense that we at (the school) understand it. He has difficulties in the comprehension and expression of language. For example, his behaviour can sometimes be quite obsessive and perseverative and so interfering with normal learning processes". The recommendation is for an individually tailored programme within a small group setting, which effectively identifies him as being appropriately placed within a 'bog-standard' ESN school.

It is a blow from which, I think, Robert never entirely recovers, having been cast through the words of the experts into the role of being basically 'mentally handicapped' with a few developmental anomalies. A marked deterioration occurs shortly afterwards, as he recognizes his fate, but fails to accept that his needs are the same as his classmates at the ESN school. The next year at the school, for the most part, sees him make significant progress, with a corresponding improvement in his aggression towards himself and others.

During this time various professionals make their case as to whether he is truly autistic, the extent of his 'mental handicap', his capacity for language development, and the appropriateness of his educational placement. But somewhere in this lengthy multi-disciplinary process, Robert's real needs become lost, and he starts to develop his own strategies for coping within circumstances that are not of his choosing. He negotiates around the options available to him, which include skills of manipulation, building a safe 'straight line' rather than 'curved' haven, rejecting those selected as his peers, and throwing tantrums. He moves more and more towards the final option, vying between being violent towards others and violent towards himself; he has had his year of possibilities and now he must make do with increasing frustration and anger. Mrs. Clayton talks of his awareness of his predicament during the interview:

AL: "Was he marking them out?" (referring to the occasion when Robert had painted other, more disabled, children in his class green).

Mrs. C: "Yes. Recognized he was different from a very early age. And didn't like – that's part of the reason he didn't like the place. He had always been 'better' (emphasizes by inverted commas gesture) when he's been with what appeared to be normal children rather than with disabilities as great as his own. He hasn't got that..."
(Sources: Interview – July 1999; Residential School admissions assessment documentation – May 1984)

By the early 1980s, the importance of enabling people with 'mental handicaps' to communicate more effectively was well recognized, and there was much more emphasis on professional involvement to facilitate this possibility. Most of the progress was confined to community settings, however, with only a quarter of 'hospitals' employing a speech therapist, whose work was largely restricted to outpatient clinics, advice to families and special schools, and working with small groups of fairly able adults (Oswin, 1978). This was almost entirely the experience of those members of the study group, who had reached adulthood through years of tedium on outback 'hospital' wards. The increasing sophistication of electronic communication devices during the 1980s, such as the 'Autocom', the 'Handivoice' (Harris & Vanderheiden, 1980), the scanning communication board (Zygo, 1980) and the 'Cathode Ray Tube' (Danjuma, 1979-80), passed them by and they would be fortunate to be taught anything other than occasional sign from either the Paget Gorman or Makaton signing systems.

During the 1990s the emphasis would be on maximizing the use of rapidly changing computer technology, which would revolutionize alternative systems of communication. Sign language and communication boards would continue to be the basis of attempts to enable communication, but there would always be the difficulties associated with too few people understanding signs and many not bothering to use boards. But the problem would be increasing their availability to the individuals most in need, such as many with severe behavioural difficulties, for whom exclusion was a way of life. Only by providing the computer technology, allied to individuals with the knowledge to use them and the motivation to help people with severe learning disabilities acquire the necessary skills, could real progress be made.

In relation to the practical application of such communication systems within the study group during the 1990s, only one individual, Alison Wilson, experienced the employment of computer technology.

Example7

After two years of involvement with the behavioural support team and a consequent recognition following extensive assessment that her self-injuring has a distinct communicative function (see final section), a determined attempt is made to find a mechanism for facilitating Alison Wilson's communication. Yes/no cards are introduced in May 1994 as an interim measure before a more appropriate system can be introduced. This occurs in April 1996 when the behavioural support nurse makes a referral to speech and language therapy for "assessment of communication and development of communication aid for Alison in relation to communication as a function of her self-injurious behaviour". He inquires as to "the possible future development of a hi-tech or low-tech communication aid" suggesting that Alison "would benefit from 'having a voice'". The argument forwarded is that it "might prevent her needing to exhibit challenging behaviour in order to gain the attention of another party for communication". She is currently able to use yes/no cards and the use of an electronic communication aid would constitute a backup. The referral concludes by saying that Alison "should be assessed by a Communication Aid Centre", bearing in mind her visual, auditory and mobility difficulties. She "currently requires 4-8 hours per week speech and language therapy in order to work on developing her communication using the cards".

In the middle of May 1996, the occupational therapist (assisted by the behavioural nurse) devises a care plan, based on enhancing Alison's communication and anticipating her needs for use when she is attending the day centre. The strategy demonstrates some of the benefits of fruitful co-operation between different professionals, particularly when there is clear recognition of their own role along with a common reading of the situation. The need for Alison to develop practical skills, such as using a kettle or preparing a light meal, justifies consultation with the occupational therapist. The employment of behavioural language enables such a task to be broken down into sequential steps, which are clear, precise and easy to follow. And the increased emphasis on communicating more effectively with Alison, empowering her during the course of the activity, and recognizing the communicative function of her self-injuring necessitated close consultation with the speech therapist. The multi-disciplinary framework, therefore, enabled each of the different professionals to utilize the shared professional language of behaviourism to consider how better communication via skill development might come to replace self-injury. The relationship between Alison and her self-injury is, of course, more complicated than this strategy allows, but it does demonstrate multi-disciplinary co-operation through the meeting of different discourses.

Unfortunately, such success is short-lived when it comes to the application of a planned approach being related to direct care providers at the day centre Alison attends daily. The main stumbling block to Alison acquiring the ability to communicate more effectively lies ironically in poor communication between the professionals, particularly the nurse coordinating the strategy, and those involved in direct care. For such unqualified workers the discourses of behaviourism of 'facilitated communication' have not become the established 'truths' on why some people engage in self-injury. In August 1996 this becomes particularly apparent in a report submitted by the behavioural nurse, which emphasizes inconsistencies in staff approaches, such as not consulting her about intended activities, appearing "unable to work through problems with Alison", not using the communication cards, and treating her as a 'naughty girl'. The nurse's frustration is clear in the comment that Alison "must decide when she requires it again <u>NOT</u> staff". However, the dictatorial nature of some professional involvement is also apparent and it seems possible that she may have irritated some of the care staff in comments such as "evidence shows that (her) self-injurious behaviour decreases when away from the (day) centre".

Alison starts to use an electronic communication aid on a month's trial at the beginning of 1997, which she adjusts to quite quickly, requiring "just a physical prompt to press hard enough", and which does serve to increase her independence. The main idea behind such an aid is to provide Alison with a 'voice', which is considered to be quite a significant move in improving her quality of life. Unfortunately, however, the corresponding reduction in her self-injury is short-lived and there are several incidents of aggression in quick succession over the next couple of months. It seems possible, though this is not identified in the nurse's clinical notes, that Alison was responding to the taking away of the communication aid, just as she was reaping the benefits from it. The trial was a success, but there was still a need to secure funding and maybe this had not been effectively communicated to Alison, and even if it had it fails to fit in with the overall strategy of anticipating her needs so as to avoid frustration and, therefore, self-injury. The deterioration in Alison's behaviour is responded to by the development of reactive strategies to respond to the particular context of the self-injury, such as its occurrence in the car or the supermarket.

In April 1997, the nurse attends a session run by the physiotherapist, which turns out to be a "very interesting session with (the two physios) working with each of Alison's arms alternately with minimum speech with Alison. Method involves physically prompting person to carry out set tasks e.g., picking up bricks with alternate hands and place them in a box. (The physio) believes that verbal communication distracts and confuses the person and so throughout the task doesn't speak. (She) has apparently had a lot of success with people who also severely challenge... Alison's palsied arm does appear to have a lot more movement than previous". The nurse reflects about the possibility of going to Manchester to meet the person who devised the method, so as to come up with an individual package for Alison. The downturn in her self-injuring appears to be causing considerable concern to the nurse, who seems to be seeking out any possibility of providing some relief.

At the end of June 1997, the nurse visits the specialist in Manchester to consider the "alternative form of working with Alison. (The) theory incorporates working on set tasks with physical support but without communicating verbally with Alison. Attended session with (physio), (physio assistant) and day centre keyworker. Funding needs to be secured for (the specialist) to work with Alison... there appeared to be no time limit/objectives for the work with Alison... I am very dubious about the programming seeing no positive evidence of it working/aims and objectives of the programme". On this occasion, the initial optimism appears to have been misplaced, which is not entirely surprising since there is considerable conflict with the thinking underpinning the behavioural approach, and particularly facilitated communication. Whereas the nurse had been quite impressed at seeing the approach in practice with Alison, she is less so when addressing the theory, since it appears incompatible with the pragmatic emphasis of behaviourism. Whereas with the nurse's work with the speech and occupational therapists, the three could identify a core discourse that pervaded their daily workings, in this encounter she could ultimately not accommodate the approach within her core professional belief system.
(Source: Behavioural support team clinical notes – May 1994, June 1997)

Speech therapists did become considerably more widespread over the course of the 1980s and were increasingly influenced by the behavioural approach to the provision of care. The emphasis continued to be on comprehensive assessment of both the individual and the environment, followed by evaluation to see whether therapy would be of value, and finally implementation of treatment (Walker, 1980). Walker & Keleher (1985) describe what they perceived to be the role of the speech therapist at this time:

> "Assessment of language comprehension, expressive language and communication skills. Individual and group 'speech therapy' to extend and promote all aspects of language and communication. Advice to parents. Assessment and advice regarding feeding difficulties such as problems in swallowing or excessive dribbling" (p.104).

The reduced likelihood of children being admitted into institutions, however, created something of a problem for special schools, since this strategy meant that they were increasingly likely to encounter those with communication difficulties and behavioural problems. Improved speech and language skills were considered something of a prerequisite for successful integration and greater participation (Anderson & Greer, 1976), but there was no retreating from the need to include children regardless of the degree of 'mental handicap', so the increased appetite for alternative communication systems continued (Odle, Wethered & Selph, 1982). This required not only the availability of such systems, but, more importantly greater awareness of the basics of organizing a language-training programme. Schiefelbusch (1978), for example, identifies essential components of such a programme to include an emphasis on the roles of "simple, stable, and useful" features of language, early intervention, combined speech and non-speech teaching, maximizing the advantages of the home environment and the roles of parents and carers, with the ultimate goal being functional communication (p.15). The ensuing programme would reflect the fairly new (in the early 1980s), but increasingly influential, emphasis on a structured approach, and was implemented by way of a five step plan – assessment, programme development, programme implementation, evaluation, and generalization. Three of the most important aspects of care delivery were thus in place – a structured framework; multi-disciplinary working; and behaviourism, particularly since, "(T)echniques for behaviour management may need to be provided" (Odle, Wethered, & Selph, 1982: 270).

Although the 1980s emphasized the increasing inclusion of children and adults of all abilities in communication skills training, there was, nevertheless, recognition that a number of prerequisites needed to be in place for success to be achieved. According to Bricker & Dennison (1978), for example, formal linguistic skill training should not take place without the acquisition of four particular behaviours comprising the ability to concentrate for a reasonable period, imitate vocal sounds and gestures, discriminate between objects, and associate words with appropriate events. Once it had been decided that the acquisition of such skills was feasible, a choice of programmes were available depending on the level of language that the individual was likely to develop (Odle, Wethered, & Selph, 1982). Some of these programmes would require very little input in terms of training (Guess et al, 1976), whilst others would be aimed at the individual with more complex language needs.

Example 8

The report of a speech and language assessment for Janine Lewis, when she is 25-years old and living at a social services hostel is subsequently presented to the multi-disciplinary team by the speech & language therapist late in May 1995. This illustration suggests quite major advances in the role of the speech and language therapist during the 1990s, but also points to quite significant complications in the application of their work with individuals with complex behaviours. The starting point for this assessment is a consideration of Janine being able to realistically acquire such pre-requisite behaviours before alternative systems are discussed. Once it is decided that such an approach would yield little success the focus changes towards trying to see the world from Janine's perspective. Janine is regarded to be in a fairly distressed state, with bouts of ill health, weight loss, and regular displays of self-injury (the therapist employs the term self-harm throughout). There is also a general belief amongst some of the staff caring for her, that her residential placement may be exacerbating this deterioration. The medical contribution from the consultant psychiatrist relates that "all the activity she uses in banging her head etc. could cause her to burn up the food". The report is not typical of many by speech & language therapists, in that it is extremely detailed and provides numerous suggestions for the future. The report's recommendations are never implemented or discussed in greater detail, however, which might suggest difficulties in a consensus being reached between the professionals involved.

The report initially establishes that she is self-aware but has no real relationships before identifying the main drawback to implementing a strategy of facilitating communication with Janine. "There appear to be some inconsistencies in the way in which other people attribute communication skills to Janine and likewise other people appear to vary enormously in the way in which they communicate with her". In assessing her understanding of language, the speech therapist suggests that she has the capacity but considers that there is great inconsistency, which she associates as a symptom of emotional distress. She goes on to say that there needs to be much a greater attempt by those working with Janine to increase their awareness of her attempts to communicate and their own communication with her. In unstructured situations, for example, some thought needs to be put into the meaning that they are conveying to her through eye contact, facial expression, gesture, and posture. In relation to this last point, the speech therapist elaborates: "As movement and posture are so connected with Janine's self harming, it is difficult at this stage to determine how these are used by her. Other people emphasising posture and body movements towards Janine appears to produce more response from her, although this often appears to be when other people are making demands of her".

In terms of Janine using self-injury as a means to communicate, a theme I will take up in the final section of the chapter, the speech therapist makes some interesting comments. "Some people have observed that occasionally Janine will poke at her eye in a way which seems to be more than just rubbing an itch away – as if she enjoys the stimulation. She also appears to be poking at her eye as part of her way of pointing at something, as if to indicate 'look at that' or 'I'm looking at that'. Because of her self-harming, the use of touch as a communicative tool appears to have become confused. This area will need to be more closely examined and sensitively dealt with so that a more positive use of touch can be developed. It may be necessary to look further at Janine's history to discover whether there is a connection between the use of touch and her self-harming. The difficulties with touch may be linked with a need to feel in control of what is happening to her. It is interesting to note that the section on communicative purpose highlights the focus on request (or control?) in other people's communication towards Janine".

The speech therapist goes on to discuss Janine's apparent lack of empathy with others emphasizing that it is not that she has no regard for other people's feelings. Rather, "it is important for others to know that she *cannot* rather than will not behave in any other way" (italics in original document). She then suggests that there may be some link between her self-injury and the absence of any positive relationships in her life. Later in the report she returns to the question of Janine's self-injury, since this was the primary reason that it was commissioned. In doing so, she describes her actual behaviour: "Self-harming, hitting her ear, kicking her legs etc. She groans as she does it, getting louder as the hitting gets stronger, and with facial grimacing. Her self-harming gets more severe and harder when (she) is distressed: the movements appear to be uncontrolled but gentle when she is relaxed". The report ends with a number of recommendations, the first of which tentatively link Janine's ritualistic, obsessional behaviour with her needing to 'switch off' for a period. Others discuss her need for some structure to her life, the need for personal relationships, which develop her capacity for taking the lead role in interaction, capitalizing on her enjoyment of touch, and "the control element from attitudes of others needs to be recognised and prevented if at all possible".

The findings of the speech therapist's report are detailed and appear to demonstrate considerable awareness of Janine's perspective concerning her situation, as well as several possibilities concerning why she engages in self-injury. Nevertheless, it fails to influence the direction of care being provided and not long afterwards she becomes a resident on the assessment and treatment unit when her social services placement breaks down. Part of the reason for why the report is ignored, though, may relate to its general tone, which is suggestive of an expert informing direct care staff how to develop a relationship with Janine. For

example, in one of the general points made she discusses the possibility of developing greater trust: "It is important that, where possible, staff tolerate Janine's behaviour and not impose on her while at the same time helping to develop a trusting relationship with her. However, care will need to be taken not to become desensitised to her difficulties and so become uncaring". The rest of the report is similarly prescriptive and possibly irritating to direct care staff. There are continued instructions, underlined for added emphasis, relating to how Janine should be approached, the inappropriateness of care in the past, and extensive proposals for further assessment. The passage that seals the reports fate, though, is the one that explores Janine's background: "There is a need to look into and be aware of Janine's past history, especially at the manner in which (she) has been cared for e.g., restraint, aggression, physical force, inconsistencies etc. For example, Janine used to be restrained in a rocking chair, used to be strapped into a wheelchair to go out even though she was (and is) ambulant. These experiences will have had a marked influence on Janine's present difficulties and must therefore be taken into account". This is followed by: "With further consideration of the nature of Janine's difficulties, both communication and otherwise... it would appear that many of the difficulties which have been highlighted are indicators of significant emotional distress of the kind often related to past mistreatment. It would therefore seem appropriate if expert help could be sought from a qualified psychotherapist to help Janine particularly with her difficulty with self-harming and personal relationships".
(Source: Speech & Language Therapy Report – May 1995)

The decision by speech and language therapy to adopt a behavioural framework for their approach to individuals with significant learning disabilities, a lack of language, and a propensity for self-injury has implications in terms of social construction. The decision appears certainly to be fruitful in the sense that behaviourally orientated psychologists would also emphasise self-injury as a communicative act. My research, furthermore, suggests that liaison between the two professions seems to be largely without friction. Speech and language therapy input, however, has entirely been on a consultative basis and, more often than not, their advice has gone unheeded and in some cases dismissed out of hand. The employment of a behavioural framework seems to have had the paradoxical effect of making their advice more accessible to direct care staff, whilst simultaneously appearing remote and, on occasion, preachy. The presentation of a detailed professional speech therapy report may give the appearance of knowing the truth about the self-injury, but by couching it in the language of behaviourism the power of the claim becomes submerged within the discourse of another discipline. Speech and language therapy appears to be content with a brief consultative process, but not only is the success of their work extremely limited within the group studied, they also sometimes attempt to aim for a wider sphere of influence. In doing so, I think, both their influence is diminished and their knowledge base about the association between communication and self-injury considerably under-valued.

(iv) Communication and self-injury

The relationship between learning disability, communication, and self-injury is complex, though it is clearly simplistic to ascribe a formula of the combination of the first two explaining the existence of the third. As many as half of people with learning disabilities have quite severe language problems (Howlin, 1987), justifying communication criteria being included in the process of diagnosis (Abbeduto, 1991). Furthermore, most individuals with learning disabilities engaging in self-injurious behaviour have been found to have no verbal capacity (Shodell & Reiter, 1968). The broader association between challenging behaviour, particularly aggression and violence, and communication has attracted a number of studies (Chamberlain, Chung, & Jenner 1993), with some claims that behavioural difficulties may be underpinned by problems in the development of speech (e.g., Ceci, 1986). Others have emphasized articulation difficulties, particularly being poorly understood, sometimes provoking an aggressive reaction (Gould, 1977). Quine (1986) drew links between communication difficulties and a number of factors, including literacy and numeracy problems, poor social skills, and behavioural disorders. Some studies have shown that, not only is there an association to be made between behaviour and communication, but that the former is actually an expression of the latter (Baumeister, 1978). In other words, some individuals with learning disabilities, who experience great difficulty in articulating their thoughts and feelings, may resort to aggression, in order to put their point across. Behavioural approaches, such as the use of functional communication training, have been used with both aggressive and self-injuring individuals, with some claim to success (Bird et al, 1989).

A comprehensive inventory of the wide range of 'behaviour problems' exhibited by people with 'mental handicaps', including stereotypical, bizarre, and 'sexually deviant' behaviours was assembled in the early 1980s, with the stated aim of being able to categorize them according to particular criteria (Leudar, Fraser, & Jeeves, 1984). The next step would then be to try to identify whether there were any common themes, which may serve to underpin a number of the behaviours within a category, such as the role of the environment or if the behaviour constituted a 'frozen' stage of development. A third factor lay in the area of communication deficits, which may contribute to the development of self-injury, because of the build up of frustration.

> "Such deficits reflect perhaps poor room management of the training centre in which the person works, poor skills at 'reading' the handicapped person's unclear and blurred messages, or simply communicatively insensitive staff, and also the communicative faults which the mentally handicapped person himself may have in expressing his intentions and feelings about the predicament that he may be temporarily or permanently in" (Fraser, 1991: 87).

The development of psycholinguistics over the last forty years has proved to be of some significance with regard to understanding more about the role of challenging behaviours in people's lives. One particular aspect, pragmatics, has been particularly valuable, with some writers arguing that it helps to explain self-injury in some individuals (see Carr & Durand 1985, for a review). Pragmatics relates to the way in which people are socialized into the values of demonstrating tact and sensitivity to the needs of others, and following conversational rules like taking turns, all of which emphasize interpretation and the use of prior knowledge (Fraser, 1991). According to Leudar and Fraser (1985), the emotional problems experienced by some individuals can be explained in relation to difficulties in the area of communication. And in the context of many people with learning disabilities, the damage might relate to difficulties in the way in which they construct a model of the other, based on knowledge, beliefs and actions. This argument has been received favourably in understanding autism, whereby part of the communication difficulties experienced by this group has been associated with the way in which they relate to others without drawing on the rules, which will enable them to 'read' people whilst going about their lives. But at the same time, there should be recognition that this does not prevent communication from taking place:

"In the framework of the theory of the *pragmatics in language*, defining the effects of utterances or gestures between people, what they do to each other with language, the abnormal language of autistic children can still be seen to have a functional role, though a limited one" (Trevarthen et al, 1996: 104, italics in the original).

It is interesting, though, that many individuals diagnosed as being autistic do experience significant difficulties in communicating with others according to the various unwritten rules (see Hobson, 1993, chapter seven, for a comprehensive discussion), but they do still have to 'negotiate reality' at some level. For example, Leudar and Fraser (1985) have demonstrated that many 'mentally handicapped' people, who appear permanently withdrawn, tend to be very brief and sparse during verbal communication, thus breaking a primary conversational rule, because they have learned that helplessness can be a productive strategy. Furthermore, if it is true that all behaviour is an act of communication, then it seems plausible that some individuals without spoken language may draw upon their repertoire of self-injurious behaviours to illustrate a particular emotion.

Example 9

In April 1996, the speech and language therapist linked to the behavioural support team submits her report on the 18-year old Simon James' communication difficulties. The overall context relates to his imminent transfer from child to adult services, which has encountered problems because of his aggressive behaviour, both towards himself and others. In a brief, targetted report, the speech therapist begins by identifying the possible link between communication and his challenging behaviour: "A number of Simon's challenging behaviours seem to be related to communication problems, especially with understanding spoken language, reading situations correctly and making sense of change. Simon has a severe pragmatic disorder combined with poor comprehension and benefits from visual representation together with a known routine in communicating." She goes on to recommend a 6-month trial of a photographic communications diary aimed at reducing his frustration and anxiety. The rationale is described as relating to Simon's previous difficulties in understanding the objects used within an 'objects of reference' system. A subsequent attempt is made to implement the photographic diary, overseen by the behavioural support nurse, though there is no mention of its success and staff in the respite house Simon went to regularly found it of little value.
(Source: Speech & Language Therapy Report – April 1996)

The increased interest in the possible communicative functions of challenging behaviours has witnessed the development of observation tools (e.g., Donnellan et al, 1984), 'special request signs' (Carr and Durand, 1985), environments conducive to communication assessments (Van der Gaag, 1988), and measurement scales (Leudar, Fraser, and Jeeves, 1984). This last scale sought to examine the links between challenging behaviour and the conventional patterns of communication, though the general purpose of such approaches was to establish the possible functional content of the self-injury or other behaviour by examining the likely environmental consequences (Leudar, 1988). Such consequences relate largely to the reactions of those providing care (Emerson, 1992), which reaffirms the communicative intent of the behaviour (Chamberlain, Cheung, and Jenner, 1993). The value of such mechanisms arises also from the analysis of the communication of people with severe learning disabilities as being simple, direct, and predominantly imperatives, such as 'do this' (MacLean and Snyder-MacLean, 1987), whilst simultaneously idiosyncratic and sometimes difficult to decipher (Fraser, 1991).

Durand (1986), in discussing the implications of a communication model of explanation for self-injury, suggests the development of a 'functional classification system', which categorizes behaviours according to attention, escape, tangible consequences, or sensory functions, rather than on the basis of behaviour type. But work since this time has suggested that the self-injury may vary according to its functions depending on circumstances, mood etc (see chapter four). Durand's work is useful, though, in drawing attention to the notion of 'intention' as a way in which self-injury can be explored. Drawing on Bruner (1973) for a definition, he identifies five criteria, which can be used as guidelines in determining the intention of self-injury:

a) the behaviour continues to be exhibited for a short time when the goal of the communicative response is not reached;
b) the behaviour ceases when the goal continues to be withheld for prolonged periods of time;
c) the behaviour ceases being exhibited when the goal is reached;

d) the topography of the behaviour is modified by the individual when certain settings preclude reaching the goal; and

e) if several topographies of behaviour are available to reach the goal, the individual chooses the one topography that maximizes the chance of reaching the goal.

(Durand, 1986: 145).

The formulation of a communication theory of self-injury is an important one, and one that I think offers a considerable amount in understanding the behaviours exhibited by those in my study. There is a difficulty, however, which relates to the conceptualization of self-injury as an intentional communicative act entirely in behavioural terms, so that interventions must be of a behavioural nature. The recognition that the individual's distress is being communicated suggests that the absence of speech is coercing him/her to make a statement through headbanging. For this to be interpreted in behavioural terms alone suggests that the 'message' is not being understood on its own terms, but is being located within a framework, which may not be fully in the individual's best interests.

Example 10

Following referral to the behavioural support team in December 1992 when Alison Wilson is 24-years old, a comprehensive assessment based on applied behavioural analysis (see chapter four for greater detail) is undertaken. One of the key areas to emerge from the assessment relates to her self-injuring having a communicative function, which is suggested also by a speech therapy report commissioned as part of the overall behavioural approach. The speech therapist describes Alison as "appear(ing) to understand all that is said to her in context". She goes on to describe how she uses "banging and chin clicking to gain attention and to communicate", and suggests that she has a "fair awareness of how close to stand and how to approach". She does, however, "occasionally forget the need to approach in order to gain the attention of the individual she has selected". The communication aspect of the report places some emphasis on 'analysis of meaning' of Alison's self-injury, suggesting its complexity and her individuality. "Alison appears to hit herself on the head for a variety of reasons. There is a large communicative function – when she wants someone to do something for her, when she has to wait, when people don't understand her, when she wants someone to move away or come to her. She also hits herself whilst alone or with others, but less so when occupied, laughing or doing some activity she appears to enjoy e.g., swimming, eating. The presence of the day centre keyworker and Mrs. Wilson seems to reduce the behaviour, perhaps due to the greater understanding that they have with Alison of her needs and what she is trying to communicate.

Intervention strategies need to increase the time spent without the splint on, increase functional activities and things she enjoys, increase methods of communication (and) positive interaction".

A speech therapy report complements the behavioural assessment the following month, as well as demonstrating the behaviourist-influenced emphasis on measurement: "(Alison) uses facial expression and a number of words and vocalizations to get her message across, however, she also occasionally uses chin clicking or arm-to-head banging. During an observation period of four hours, she was seen to exhibit one of the aforementioned behaviours on twenty-six occasions. Out of these 18.2% appeared to be for communicative purposes." The behaviours observed comprised chin-hitting shoulder (sometimes with upper and lower teeth clicking together), hitting brow and nose with left hand, hitting right side of head with right splint, and rocking. Nearly ¼ were when Alison was alone and ¾ with others around. The speech therapist determined that 43% of these incidents of self-injury involved no apparent precursor, 26% were "following having been told 'no' to a request", 10% "followed listening to another's conversation", 6% were "in response to a request" and there was uncertainty about the remaining 15%. Behaviours became "more frequent and more severe over time."

The twin assessments (behavioural and speech therapy) point to the necessary intervention programmes concentrating on continuing to 'facilitate communication' and aiding the development of 'functionally equivalent' skills. However, since less than one fifth of Alison's self-injuring is directly observed as relating to communication, it might be that there is a desire to locate her behaviour within a behaviourist framework regardless of its functions.
(Source: Behavioural Support Assessment – January/February 1993; Speech & Language Therapy Report – August 1993)

This chapter has sought to investigate the relationship between learning disability, communication, and self-injury within the context of a historical change in the provision of services. Various communication-enhancing systems have been discussed, and examples from the study group utilized where appropriate. The notion of language being a pre-requisite for thought has been challenged through exploration of the work of Goode (1994), and its application to those comprising my study group. The gradual recognition of people with learning disabilities as developing beings, regardless of the extent and complexity of their difficulties, constitutes one of the core 'statements' within communication discourse. This effectively enabled work to be undertaken by professionals into self-injury being considered as a communicative act, rather than simply a manifestation of the learning disability itself. The chapter has traced the emergence of speech and language therapists as key players in changing thinking about self-injury, and raised questions about the profession's relative subservience to those extolling the virtues of behavioural and biological discourses. The next chapter will explore how one of these latter discourses, behaviourism, emerged and subsequently came to dominate interventions with people with learning disabilities generally and relating to self-injury in particular. This necessitated the incorporation of understanding about the relationship between communication and self-injury within a behavioural framework, which consequently restricted the possibilities for those wishing for a more discrete body of communicative principles to be elaborated.

CHAPTER FOUR: THE BEHAVIOURAL APPROACH TO SELF-INJURY

- The rise of behaviourism
- The consolidation and increasing sophistication of behaviourism

(i) The rise of behaviourism

The behavioural discourse within learning disability services has emerged over a period of half a century, and has gradually come to influence much of the work of many professional groups. These include clinical and educational psychologists, speech and language therapists, occupational therapists, teachers, and learning disability nurses, all of whom have been significantly affected by its pragmatism, clarity, and power (Emerson, 2002). The theoretical underpinnings of behaviourism belong to the early years of the twentieth century, with numerous experiments being conducted on animals to establish the principle of reinforcement. The first published article relating its principles to the 'mentally subnormal', however, was Fuller's 'Operant conditioning of a vegetative human organism', whereby he sought to demonstrate that "by beginning at the bottom of the human scale the transfer from rat to man can be effected" (1949: 590). Further impetus was then provided by Skinner (1953), the individual most clearly associated with the approach, who sought not only to refine the principles he had outlined two decades earlier, but also to challenge the erstwhile dominant perspective of psychotherapy (Beech, 1969), which he "reconceptualized... in behavioural terms" (Agras, Kasdin, and Wilson, 1979: 4). The essence of what came to be known as 'behaviour modification' comprised three elements, the key statements of the early discourse:

- Individuals learn to behave, or change their behaviour, as a result of environmental consequences i.e., reinforcement;
- therefore, 'unacceptable' or 'inappropriate' behaviour develops because of ineffective or faulty conditioning;
- if behaviour can be modified by environmental consequences, then such faulty learning can be rectified through exposure to more appropriate and carefully controlled consequences (Brechin, 1981).

The theoretical consolidation of behaviourism with the 'mentally subnormal' then occurred through the 1950s and 60s with the publication of a variety of experimental articles (e.g., Ellis and Pryer, 1958; Barrett and Lindsley, 1962; Lindsley, 1964). This was then followed by "pilot projects" within "wards, cottages or wings of buildings of large institutions", some of which were considered successful, though failures were not unusual and associated with "problems with funding, staff and administrative support, and sometimes to a lack of understanding of the fundamental principles" (Thompson, 1977: 9).

There is considerable evidence that behaviourism contained elements of radicalism within its armoury, particularly through its challenge to the notion of 'ineducability' by asserting that all individuals were capable of learning, and thus indirectly contributing to the demise of the institution (Lovett, 1996). Furthermore, experimental research was demonstrating that it was possible "to modify longstanding maladaptive behaviour patterns and to establish new ways of responding, even in severely retarded and chronically psychotic patients" (Thompson, 1977: 9). This early emphasis on 'behaviour modification', however, raised considerable ethical and legal concerns surrounding the acceptability of many of the techniques advocated and difficulties relating to issues such as consent. These debates continue to the present day, and range from concerns about the acceptability of doing nothing when an individual exhibits entrenched challenging behaviour (e.g., McBrien and Felce, 1992) to angry condemnation at behaviourism's history of aversiveness (Lovett, 1996).

This history is demonstrated most clearly with self-injuring 'mentally subnormal' individuals, though it should not be forgotten that prior to attempts to modify the behaviour there was a basic reliance on purpose-built or makeshift restraining devices aimed at denying the capacity to strike oneself (Spain, Hart, and Corbett, 1984). The aversive procedure prompting greatest concern was contingent electric shock, whereby a portable battery-operated device delivered a brief and painful, but, according to its advocates, generally harmless, electrical current (Lovaas, Schaeffer & Simmons, 1965: Risley, 1968). These authors argue convincingly that the electric shock rapidly eliminates the individual's propensity to self-injure, and because it can be achieved so quickly it is much more effective than a less aversive approach being used over a period of time. Tate and Baroff (1966) provide a detailed and occasionally chilling account of the employment of electric shock therapy with a partially sighted nine-year-old boy with a long-standing and marked tendency to self-injure. After identifying close physical contact as the most powerful reinforcer and justifying intervention on the basis of the boy's remaining sight being threatened, the authors describe the procedure:

> "The investigators, together with a physician, chatted pleasantly to the child as he lay on his bed with his feet restrained. He was told (with what degree of understanding is not revealed) that if he continued to hit himself he would be shocked, and that this would hurt. Following this, any attempts Sam made to hit himself were greeted by a shock to his right lower leg. This regime was intermittently continued, periods in between the aversive stimulation being spent in playing with toys and being pleasantly entertained by the investigators, who praised lavishly any non-injurious movements by the child" (Beech, 1969: 159).

The authors then report a steep reduction in the boy's attempts to self-injure, though it is difficult to assess the success of the electric shocks against the increase in activities, such as walks and the use of playground equipment, during non-experimental periods. Beech (1969) makes the point that the nature and extent of the self-injuring could be considered "sufficiently serious to justify (such) extreme measures", before pondering the paradox of the pain of the behaviour frequently outweighing that of the treatment, which would suggest that it be extinguished naturally (p.159). The benefit of hindsight, of course, enables us to note that self-injury can be maintained by many different motivating factors, which may vary over time and might be different for the different behaviours engaged in (Emerson, 2002). Other aversive interventions employed within a behavioural framework included the forced inhalation of aromatic ammonia (Tanner and Zeiler, 1975; Altman, Haavik, and Cook, 1978), the application of citric acid to the tongue (Mayhew and Harris, 1979), and aversive tickling (Green and Hoats, 1971). According to Wethered, Troutman & Wilder (1982), these treatments should be judged according to their own merits, with some being considerably less aversive and consequently more justifiable than others, such as lemon juice providing a "practical and acceptable alternative" to electric shock (Sajwaj, Libet and Agras, 1974: 557).

The extent to which such procedures were adopted in practice, beyond such initial experimental research, appears fairly limited, with some evidence that they were employed fairly arbitrarily and with little consideration for the possible consequences (Thompson, 1977). There was little record of their use with the group that I studied, for example, during their time in 'hospital', which suggests that they didn't become widespread, though this may have been more to do with the lack of professionals with the expertise and materials to carry out such techniques. The only evidence that I did come across broadly corresponded with Greer, Anderson, and Odles' (1982) discussion of the value of loud noises, such as a cycle horn, a handclap or sudden shout, which might interrupt the self-injury.

Example 11

A variation of this approach was considered at a 'hospital' case conference in 1987, which sought to identify possible ideas about how to combat 22-year old Sarah Houghton's self-injury. The subsequent minutes describe how the consultant psychiatrist asked Sarah's parents as to why the behaviours were more likely to occur on the ward than at home, which prompts the response that "they used a wooden spoon to bang on the table as the ultimate deterrent". Mr. And Mrs. Houghton successfully employed this approach over the next decade whilst Sarah was spending time at home, but its effectiveness diminished markedly after she returned to live with them permanently and even more so following the loss of her sight.

Mrs. H: "But we had a different way with her, I suppose, and she knew that 'you don't do that madam'. We had the wooden spoon. It was, 'that's a naughty girl's spoon, you know, and if I bring the spoon out, that means you're really naughty, and you're going to behave'. And she did, didn't she? She only had to look at the wooden spoon and, you know, 'I will be good'".
(Source: Case Conference minutes – November 1987; Interview – October 1999)

The ethical argument against these aversive methods, by the late 1970s, was firmly in the ascendancy, though the role of behaviour modification itself had sufficient advocates and an increasing influence in ESN schools, 'hospitals', and other residential establishments for it to flourish (Woods, 1983). Furthermore, a considerable proportion of the techniques advocated, such as extinction, over-correction, and time out were aversive, in a less direct but equally as powerful way, with self-injury being singled out as the one area where punishment could be justified (Gardner, 1985). The predominant justification at this time surrounded the exploitation of the commonsense approach to the care of society's most vulnerable members:

"In spite of its formidable name, behaviour modification does nothing more than apply systematically the methods which parents and teachers make use of every day to persuade children to do what they (the parents and teachers) want" (Eden, 1976: 76).

Behavioural discourse also sought to consolidate its developing power-base by emphasizing the need for any programme to be consistently applied in "school or training centre as well as home, whether home is family or hostel" (Heaton-Ward, 1984: 97). This expansion was necessary for any behavioural success to be achieved, but the practical implications for the family were frequently poorly considered.

<u>Example 12</u>

Mrs. Wilson, for example, talked of the confusion and disruption to family life sometimes brought about by the generalizing of behavioural methods from the day centre to the home. She talks initially of the value of the support of the behavioural support nurse to Alison's care, but then reveals the contradictory nature of her involvement. "Well, she started coming in and letting her (Alison) do breakfast and things like that. And then it got for four weeks, then nobody came at all. Then they couldn't make it for some reason and then Alison got better as time went on. And then they were going to start coming at evening times, and I said, 'Simone, we don't mind the outreach team, but Eric and I don't like anybody intruding on our house'. I said, 'we like our privacy', which they understood. So now what they do is, they do it at school (reference to the day centre) and I expect they go into the bungalow (respite unit), as well, to see if things are alright there. And that's how they've done it. But I said no, we like our privacy and Eric was on shift work and it wasn't convenient".
(Source: Interview – November 1999)

A more complicated illustration involving the necessity for the family's commitment to the behavioural approach, the need for thorough recognition of the implications of such a commitment, and the importance of professional consistency is demonstrated with Sam Morris:

<u>Example 13</u>

By December 1982, a community nurse has been involved in Sam Morris's care for about six months, and has just negotiated a series of short stays at a nearby children's hostel. Sam is causing considerable disruption and distress to the family as he has become more able and mobile, to the extent that they are becoming increasingly desperate. A case review takes place and the community nurse records that those present "discussed the problems of Sam's hyperactivity in all environments and how inconsistent it appears to be, i.e., at times he is very loveable at other times very irritable". He wonders as to whether he "could arrange some observations of type and frequency of behaviours to see if some programmed help could be offered". A simultaneous report from the hostel relates a "discussion about making a more systematic and objective record of Sam's various behaviours, (which) could provide a good baseline to take to a psychologist for help and advice. Sam's behaviour swings from very hyperactive, with volatile outbursts, to becoming quiet and loveable with no known reason for the change".

A decision is subsequently made to devise a simple progress chart, which can be used to monitor Sam's behaviour over a 24/48-hour period. According to the community nurse's notes: "Bearing in mind the parents' anxiety about the forthcoming birth (Mrs. Morris had lost the last baby), it was recognised that they had no energy or commitment to spending much time themselves on Sam at the moment at home. However, if progress were to be made to identify some of the reasons for Sam's disturbed behaviour and work towards tackling this, this would have to be done at (the hostel). It was agreed that the community nurse would devise a programme in conjunction with the psychologist and liaise with (the hostel) over its implementation. Hopefully this would demonstrate a clearer picture of the real problems".

The involvement of the family in behavioural programmes continues to be an important but problematic area, since the parents are the ones, who are most knowledgeable about their son/daughter, but in some ways they are also the least appropriate. This is, I think, because of the necessarily emotional relationship that they have, which conflicts with the behavioural need for consistency and sometimes almost mechanical responses. Many of the parents interviewed found it difficult to marry their caring role as parent, with the expectations of being involved in the carrying out of a behaviour modification programme. Furthermore, as this comment in the minutes of a social services review of Sam's programme demonstrates, the behavioural approach sometimes fails to account for the complexities within relationships. "Mrs. Morris still has strong feelings about her last pregnancy (about two years earlier) as she blames Sam for her miscarriage (when she was sixteen weeks pregnant)".

In January 1983 the community nurse discusses a meeting he has had with the headteacher at Sam's special school, "who was reluctant to agree to (me) organizing any observations on Sam and that problems should be referred through the educational psychologist". He considers this to be "a point of difficulty as I would be unable to make much headway without full co-operation from the school". He then talks of the new baby and the family's new house and reflects that, "I as community nurse should step back and allow matters to take their course". In the early-1980s the majority of 'mental subnormality' nurses were institutionally based, and gaining acceptance within some community services, such as special schools, was fraught with difficulty. Some teachers were unconvinced of the skills of community nurses, believing that they were dominated by the medical model and steeped in the practices of the institution. Also, their involvement with children was not initially encouraged, with the policy of children not being admitted into 'hospital', unless absolutely necessary, stretching back over a decade, and suggesting a lack of pertinence of the role of the nurse.

A new community nurse becomes involved later in the year. The family is more settled but Sam's headbanging has worsened. She says that he is "to be assessed by educational psychologist at school and plan of behaviour to be implemented", though this is deterred by his family, who say that he is "not headbanging to the same extent". A 'progress review' is held at the hostel in November 1983, and in the subsequent report, the residential social worker says that, "group staff have been maintaining thorough accounts of Sam's behaviour although these have not been formulated into a chart as yet. We will be seeking professional advice as to the handling of Sam and the possible modification of his behaviour".

In January 1984, the new community nurse writes that Mr. & Mrs. Morris "are both capable and able parents (and) Sam is not headbanging quite so much at the moment". She goes on to discuss a chart to log the time and frequency of his headbanging and the preceding factors. A fortnight later she records that Mrs. Morris has said that "Sam bangs his head at any time, there didn't appear to be any set times... except first thing in the morning when he doesn't want to get up". She decides to "monitor the bouts of abuse for now". Then, two weeks later, she begins some observations using an antecedent-behaviour-consequence (A-B-C) framework, which lasts over six consecutive days and identifies possible triggers for the headbanging, such as hunger and constipation, whilst also recognizing the complexity of Sam's use of self-injury. For example, the community nurse notes towards the end of her period of observation, "doing it for fun and laughing". The A-B-C approach, at this time in its infancy in terms of application, continues to form the basis of behavioural approaches, because of its emphasis on the direct relationship between causes and interventions (see next section). Unfortunately, as so often appeared to be the case, there is no continuity with the eventual programme because of the withdrawal of the community nurse.

In November 1986 a new community nurse takes on Sam's case, the fourth in four years, and proceeds to make her observations from her initial visit. She begins by observing that "Mrs. Morris demonstrated difficulties in controlling the behaviour of her son who has normal intelligence". The nurse then determines that "(her) method of managing behaviour in her younger son was not adequate". The community nurse is committed to the behavioural approach, but recognises the need for full parental involvement if there is to be any possibility of a reduction in Sam's self-injury. She records her thoughts about the possibility of increasing their involvement in the context of a behavioural strategy: "Sam's parents are only just coping. Any efforts to reduce the banging will need an intense programme, which his parents are aware of, and feel would be difficult for them to implement. For the same reason, any demands made on Sam to learn, results in headbanging, which the parents wish to avoid. It will thus be difficult to implement any programmes into the home".

After six months of involvement with the family, the community nurse reflects on the lack of progress being made in reducing Sam's self-injury, the recent involvement of a consultant psychiatrist, and Mrs. Morris' apparent negativity: "A recent experience of flu, whereby his behaviour became very disturbed (but, nevertheless) Sam appears calmer of late, although the headbanging is still a problem and an excuse for Sam to express his frustration or distress. Mrs. Morris stated despondency over the amount consultant psychiatrists could do for Sam and seemed resigned to the situation that Sam will always have a behaviour problem of a very severe degree". If anything, though, retrospect seems to suggest that a strategy of caution about the likelihood of life with Sam becoming easier was a realistic one. On interview, Mrs. Morris had become more philosophical with age and experience, and it is the criticisms expressed by successive behaviourally orientated community nurses that appear misguided. She appears vindicated from the accusations of having poor parenting skills, being reluctant to implement a programme at home, knowing that Sam's self-injury was not just a learned response, and appearing generally pessimistic. What she has done is learn to live with a son, whose complex self-injury will always be something of a mystery:

AL: "You seem to take it in your stride?"

Mrs. M: "You have to, yeah".

AL: "You don't expect too much".

Mrs. M: "No, no, cos I know – nothing… "

AL: "It's not going to change?"

Mrs. M: "No it's not. And I knew years ago".

AL: "Did you?"

Mrs. M: "Yeah".

AL: "How long ago?"

Mrs. M: "Yeah. Even when he was about ten, that people are trying to do this and that and the other. You let them help and you let them – you go along with it, but you really know that, you know".

AL: "The pattern was set".

Mrs. M: "Yeah. Still going to be the same pattern. Kept banging his head. He'd have ulcers on his head, they'd open. He'd bang his head. We'd be up the hospital. Then he'd have a good couple of months where he wouldn't be banging his head as much. And then it would come back and, you know, try him without his splint and try him without that, but they didn't realize that, when he'd get in a taxi, he could have just hit somebody. So they had to put that splint on and different things, you know, that you know that's best for yourself and him".
(Source: Community nursing notes, December 1982 – May 1987; Social Services Review minutes, January 1983, November 1983; Interview – November 1999)

One explanation for the haphazard and frequently ineffectual use of the behavioural approach during the 1970s and 80s relates to the lack of attention given to it by many of the most influential writers of the period (e.g., Heaton-Ward, 1977; Gibson and French, 1971). Despite the plethora of academic research articles, the first real practical handbook (the EDY Trainee Workbook, 1981) did not really exert its influence until several years later. Even then it didn't really address the research that had revealed the importance and complexity of those environmental factors serving to maintain behaviours such as self-injury (e.g., Bachman, 1972; Baumeister and Rollings, 1976; Carr, 1977). These authors, admittedly, did press the need for further experimental research into the functions of self-injury, but this in turn should have prevented the arbitrary implementation of half-baked behaviour modification programmes.

Example 14

One example of the use of a behaviour modification programme within the 'hospital' school system occurs in the care of Terry Lawson, who had been in institutional care since he was nine, and by November 1979 was sixteen years old. An attempt is made by his teacher to employ a programme to improve his self-help skills, particularly in the area of feeding himself. His school report relates that he "is a popular boy and his appetite and alertness indicate that a good deal may be achieved in shaping his behaviour". Unfortunately, however, his cerebral palsy is extremely restrictive and may have been influential in terms of the lack of success gained from the programme. A later addendum to the report states that, "Terry tends to eat very quickly – drops spoon and uses fingers", and eventually the feeding programme is discontinued "because

(he) started to hit the side of his head which resulted in alopecia". In the case of Terry, therefore, there was no behavioural programme to reduce his self-injury, but instead, the frustration surrounding his difficulty in successfully achieving self-feeding seems, paradoxically, to have precipitated bouts of head bashing.
(Source: 'Hospital' School Report, November 1979)

A few years later it is likely that a 'functional analysis' of Terry's reaction to the behaviour modification programme would identify 'escape from demands' as the reason for his self-injury. However, the work of Carr (1977) (see next section) had yet to influence behavioural discourse by identifying clearly differentiated maintaining factors, and the possible consequences of employing powerfully controlling techniques were not widely discussed.

Example 15

One example of the problematic nature of such a system being increasingly regarded as the solution to all problems arose with Robert Clayton, which also serves to demonstrate factors contributing to his frustration and later violence. The relationship between Robert and the behavioural approach reveals a paradox at its heart. Behaviourism was considered useful with 'mentally handicapped' children and adults largely because of a rather simple view of them blindly responding to the trade off between behaving more appropriately and receiving rewards. However, its success with this client group is reliant on them not understanding or not being concerned about the process of manipulation being undertaken. Robert had started special school when he was only two years old, and by August 1979, the educational psychologist, who will have considerable involvement in his care as his school life progresses, submits her initial report. She considers that he "will respond to behaviour modification techniques and can imitate sounds, and thus structured developmental programmes could be assembled to be worked with in conjunction with his class teachers at school". Towards the end of the school year, in May 1980, Robert's school report identifies him as having "swings of mood with fairly frequent temper outbursts, but he can be pleasant when co-operating". The class teacher acknowledges, however, that he has become wise to the guile of behaviourism, and determined how it might work in his favour. She writes that "responds to some behaviour modification techniques, but now sees 'time out' as a pleasure rather than a punishment. He likes to be cuddled and have adult attention". Later, in his school report she talks of how, when he first moved into the class, there were some difficulties with "severe temper tantrums, throwing anything available, kicking, screaming and often taking his pants down and exposing himself". However, he was "allowed to work his way through them", rather than employ 'time out' tactics, since "I felt this had become a reward in itself for Robert".

During my interview with Mrs. Clayton, she highlights the way in which Robert was able to use his intelligence to manipulate the way in which behaviourism was beginning to become established as the general approach in special education:

Mrs. C: "Well he – certainly by – he went – let me see, I'm trying to think back now. He would have gone – he would have been two just before Christmas and he would have started that January at, what was then, the clinic. It wasn't a proper school. Back in the 70s it was still part of the health service. 'Special needs' children didn't go to the normal school. They went to the old ESN schools. And he went (there). They had some beautiful equipment and they were really very good and very professional and very helpful. But certainly by the time he was three he was already making an effort to get out of lessons he didn't like".

AL: "What did he do?"

Mrs. C: (Laughs) "He found quite quickly he could gain 'time out' – their punishment system was to remove a child, who was being disruptive, and place quietly in the corridor – he found that was much more pleasant. So he manipulated the situation fairly rapidly. I got called out of work on a couple of occasions to remove him because he was being so disruptive. There was one particular occasion where he painted all the children with cerebral palsy green. He'd gone round several classrooms and he'd gone round with the paint pot".
(Source: School Report, May 1980; Interview – July 1999)

Evidence for the possibilities presented by behaviour modification in relation to self-injury continued to escalate, with many researchers claiming significant successes (e.g., Schroeder et al, 1978). The centrality of positive reinforcement to any programme continued to be emphasized (Murphy and Wilson, 1985), particularly when used in conjunction with something more aversive like mechanical restraint (Fleming and Nolley, 1981), the use of which could be later reduced by a process of 'fading out' (Yule and Carr, 1980). Behaviourism was adapting to changing circumstances by increasingly, though not entirely, disassociating itself from the more aversive techniques, whilst refining the elements that would ensure its survival as the ethical debate gathered pace through the 1980s. The changing social climate was also significant and, according to Eden (1976), contributed to the reluctance of teachers to embrace it fully:

"The use of behaviour modification is not yet common in the special schools, partly because such control runs counter to the ideals of freedom and spontaneity which are so important in modern education.

> Nevertheless, the effectiveness of the technique, and suitability for use with the mentally handicapped under the right conditions seem likely to give it an increasingly important place in the future" (p.78).

Perhaps there is a further irony here, since the critique of liberal values characterizing much of the Thatcherite '80s may have paradoxically contributed to the conditions for the essentially controlling behaviourist philosophy to become entrenched within 'mental handicap' services. Furthermore, the 'behavioural model' was better suited to the ongoing social critique of the 'medical model', which had previously underpinned the institutional approach to care provision (Clarke, 1982). There was also a need to change the language, so that 'modification' with its emphasis on targeting specific behaviours evolved into a more generalized 'approach', whereby 'faulty conditioning' (Brechin, 1981) could be addressed within a more holistic strategy of assessment, analysis, planning, implementation, and evaluation (Woods, 1983). The 1980s, in effect, saw the consolidation of behaviourism within the field of 'mental handicap' following varying attempts at re-elaborating Skinner's original principles in a more palatable format (e.g., Carpenter, 1974; Yule and Carr, 1980). The ideal target group had been realized as a powerless and marginalized group, who were susceptible to the various techniques and methods, as well as being unlikely to offer widespread, sustained resistance. Furthermore, the twin-pronged interventions of skill building and behavioural change proved irresistible to those wanting to demonstrate the more humane aspects of the approach, whilst simultaneously stressing its objective and scientific character:

> "In line with behaviourists' expectations it proved possible both to improve levels of functioning (e.g., by teaching new skills such as self care, cooking, literacy) with enormous implications for educational practice and to reduce 'behaviour problems' (e.g., aggressive or non-compliant behaviour and self destructive behaviour, such as hair pulling or eye poking)" (Brechin, 1981: 192).

In practice, however, specific interventions frequently neglected the recommended framework and continued to be arbitrary, ill conceived, ethically dubious, and with little consideration for the implications.

Example 16

By 1980 Daniel Cotterill is 23-years old and has been resident in 'hospital' for sixteen years, and up until this point there is no recorded attempt to modify his behaviour. Then, in February of that year, his medical notes indicate that his "behaviour (is) very disturbed (and he is) shouting and overactive for no apparent reason". His behaviour remains disturbed over the coming months and medical tests do not reveal any abnormality, so a referral is made to the (small) psychology department, which is now beginning to emphasise a behavioural rather than psychological testing approach. Daniel is assessed over several weeks away from the ward in an attempt "to find a way of motivating him". A behavioural technique identified as the 'premack effect' is implemented, "whereby a high frequency behaviour (tobacco) is used to build up a low frequency behaviour (not headbanging and concentrating on work) with a view to a formally agreed treatment programme".

However, Daniel's use of tobacco is an edible one, in that he searches the ground for discarded 'dimps' (cigarette ends) and proceeds to eat them with relish. The employment of tobacco as a reinforcer, incidentally, is quickly withdrawn from use in behavioural programmes, in the early 1980s, as a consequence of ethical concerns from the 'hospital' managers. This further exemplifies the complexity and diversity of Daniel's behavioural repertoire: self-injury (headbanging, hair pulling); self-stimulatory (hand flapping, finger flicking); addictive (tea drinking, eating cigarette ends). Ironically, there is no further mention of this behaviour modification programme, so that it is difficult to ascertain whether it achieved a reduction in his self-injuring or, indeed, whether it was fully implemented. The role of the psychology department, which contained one clinical psychologist and a couple of assistants, was largely to devise the programme and enable the ward staff to carry it out.
(Source: Nursing case notes, February 1980)

For various reasons, successfully implementing a behavioural programme with the required technical skills, consistency and motivation was, and remains, very difficult. These fairly early attempts to instigate behavioural change within institutions failed to fully take into account the significance of the self-injuring, or other such undesirable behaviour, to the life of the individual. Nevertheless, the more systematic approach to the institutional care of the 'mentally handicapped', exemplified by the advent of the nursing process (Kratz, 1979) and other similar frameworks (e.g., Williams, 1980), slowly became a reality. In doing so it reflected increased concerns about individualized rather than 'bloc treatment' and the need to account for ethical considerations rather than simply explain the available behavioural techniques (e.g., Perkins, Taylor, and Capie, 1976). Behavioural discourse was effectively reinventing itself so that it could be relevant to different settings (ward, classroom, hostel, day centre, and home), applied by different people (nurses, teachers, care workers, parents, and more specialized professionals), organized within a generalized framework, and increasingly distanced from its aversive associations. It had demonstrated its effectiveness in the face of the most intransigent of behaviours, particularly self-injury, and had contributed to the 'mentally handicapped' increasingly being recognized as capable of learning. The journey was not yet complete, however, since the behaviourist discourse needed to redefine itself further to achieve complete hegemony.

(ii) The consolidation and increasing sophistication of behaviourism

The continuing need to periodically change descriptive terminology underwent a further change by the close of the 1980s, with 'the mentally handicapped' giving way to 'people with learning disabilities', just as the previous one had replaced the even more disparaging labels discussed earlier. The term is not without its critics, with some writers preferring 'intellectual disabilities' (Emerson, 2001) or 'learning difficulties' (Boxall, 2002), and 'special needs' continuing to be the educational preference. Some reject the need for a term to be employed at all (e.g., Whittaker and Kenworthy, 2002), but many recent influential textbooks on the subject appear content with its use (e.g., Markwick and Parrish, 2003; Thompson and Pickering, 2001; Gates, 2003). The overall context relates to the eventual closure of most of the institutions, some during the '80s and the majority in the '90s, and recognition that those with the most complex of challenging behaviours could be cared for in the community. The role of behaviourism was to ensure that it could continue to be influential in the lives of those untouched by 'hospital' living, whilst maintaining its role in the post-institutional life of those now emerging into the community.

One way in which behaviourism could seek to further consolidate its position in the changing climate related to the appropriateness of the places where people with learning disabilities were spending their time. The manipulation of environmental characteristics, rather than emphasis on behavioural change alone, thus constituted a means of adapting to vicissitudes. Mechanisms for evaluating the environment and services more generally had begun several years earlier (e.g., Wolfensberger and Glenn, 1975), and were well established by the early-'90s (see Cocks, 2002, and Marsland, 2003, for reviews of service evaluation systems). The initial emphasis was on the extent to which various 'service accomplishments' (following O'Brien and Tyne, 1981) could be adequately accommodated, which necessitated objective measurement, a process with which behaviourism was entirely familiar. This meant assessing the suitability of the environment towards maintaining people with learning disabilities in the community (Demaine, 1980), though in practice this necessitated a change in thinking away from individual characteristics determining whether a placement was likely to be successful (Brechin, 1981).

> "A shift in focus from the individual to the environment will allow new possibilities to emerge, more in line with the perspective of disabled people, for the identification and modification of processes which at present produce for them such a disabling learning environment" (Brechin, 1981: 197).

This focus on the quality of services, with its emphasis on performance indicators and measurable outcomes, was perfectly suited to the developing behavioural discourse of observable behaviour, achievable goals, criteria for success, and regular evaluation. Furthermore, there was the realization that challenging behaviour might be maintained but not caused by the institutional environment (Emerson, 2001), just as the individual's 'mental handicap' was no longer identified as the sole source. This determined that, not only could those with the most challenging behaviours be cared for in the community, but there was also a renewed need for the behavioural approach to be employed as an effective mechanism for achieving this aim. Several members of my study group never encountered the institution in any of its forms, enjoyed flourishing family relationships, but still developed seriously debilitating tendencies towards self-injury. The consequences for professionals were immense, since the effects on the family were clearly visible; behaviourism needed to establish more creative ways of intervening, which were simultaneously more acceptable and ethical than the more straightforward option of institutionalization. Other complications, however, were quickly in evidence as the following example illustrates:

Example 17

In 1988 Lesley Anderson is seven years old and a community nurse involved in her care supports her mother in working out an effective approach to dealing with her daughter's self-injuring. Though she reluctantly recommends the use of a glove during times when Lesley is particularly irritable, she does so "coupled with physical and verbal prompting to discontinue the activity". She also writes of the use of "diversionary activity of a favoured nature and gentle verbal reward used for positive response". The community nurse is clearly sensitive to the approach needed at this point, recognizing that it is Mrs. Anderson, who has to manage the behaviour on a daily basis. In order to get a fuller picture, she visits Lesley's class teacher, who agrees that: "(T)he situation has been a vicious circle of Lesley being disturbed and demanding attention, Mrs. Anderson giving her attention on demand but getting more and more tired, and more and more frustrated, hence both feeding each other's frustration". The nurse also suggests to Mrs. Anderson, that if the behaviour continues to deteriorate then she should contact her and "arrangements to see the doctor will be made".

However, with the involvement of a new community nurse, three months later, there is a significant change in approach, which has implications for how things will develop in the future. He visits the home twice before arranging to be accompanied by the clinical psychologist, who recommends that an 'analogue assessment' be completed. This is concerned with creating different conditions for the behaviour to be observed, in this case the home and the school, and is attempted in August 1989. At this time it is one of the most recent and innovative techniques for assessing the 'functions' of self-injury (see McBrien & Felce, 1992, pages 54-65 for a description of the process). He then notes that "due to the high frequency of this chin stroking behaviour and (the) physical condition of Lesley's chin, assessment cancelled until such time as the physical condition of her chin improves". A few days later Mrs. Anderson informs the nurse that she doesn't really want to do the assessment again because "when we had attempted it, she had found it difficult to allow Lesley to engage in the chin stroking behaviour and had found it too distressing".

The following month and the community nurse reports "increased agitation and chin stroking behaviour. Mrs. Anderson brought Lesley to herself to give her physical comfort and calm her. It had the opposite effect and Lesley increased the frequency of the behaviour and it took her mother a while (8-10 minutes) to calm her". In this instance the self-injury is clearly not motivated by a desire for her mother's attention, but again the nurse appears not to consider his own role as a causal factor in Lesley's distress. At the end of the month he talks of how an homeopathist, who had been consulted by Mrs. Anderson, had informed her that: "He would be of assistance in trying to help Lesley. On discussing this further and trying to inquire what he had said, Mrs. Anderson used a great deal of her own 'personal language' and I felt to some extent that she had placed her own interpretation on the doctor's statements".

At the beginning of October 1989, he implements a feeding programme, based on behavioural principles, but Lesley tends to drop the spoon after placing food in her mouth. It also causes her some agitation and she engages in some chin stroking, which in turn causes her mother to become "increasingly annoyed". The relationship between Mrs. Anderson and the community nurse is becoming increasingly strained, and the following week he talks of Lesley being in playful and inquisitive mood, but then "became agitated and began to chin stroke. Mrs. Anderson intervened and used physical control to prevent her from injuring herself", which lasts for fifteen minutes.

In the November, the community nurse writes of Mrs. Anderson's desire to investigate the possibilities of complementary medicine, something, which he is clearly unhappy with. "I considered the difficulties associated with Lesley's eating skills to be connected with her self-injurious behaviour and, as I wasn't offering 'support' for the self-injurious behaviour whilst Lesley is seeing the consultant homeopathist, I couldn't fully utilize my skills appropriately in relation to feeding". He goes on to say that he will retain input and will continue to monitor the self-injuring. At the end of the month, Mrs. Anderson has dispensed with the services of the homeopathist because she wasn't happy with the results. The community nurse then says that Mrs. Anderson "now felt ready to attempt a behaviourist approach to try and combat Lesley's self-injurious behaviour". This would involve an 'analogue assessment' and Mrs. Anderson was "distressed at the idea of allowing Lesley to hit her chin without intervening", despite it only taking a couple of minutes. He continues that the self-injury has increased over the last couple of weeks and that the 'analogue assessment' will take place with the psychologist but without Mrs. Anderson being present. (Source: Community nursing notes, August 1988 – November 1989)

The community nurse's commitment to behavioural principles as being the most effective way of working with the family illustrates how dominant the approach had become by the late-1980s. The principles of establishing a 'baseline' of the behaviour being investigated, consistency of approach by all involved, and reinforcement of appropriate and ignoring of inappropriate behaviours were now integral to the way in which community nurses would work. However, the evidence of success, particularly in relation to self-injury was, at best, negligible. The evidence of this section demonstrates the increased use of behavioural programmes, which would be consistent with this confidence in the employment of the techniques. Yet none of the group seems to have responded particularly well to the application of such behavioural techniques. The 1990s would witness a change of focus by some behaviourists, who recognized not only the power of such techniques but also the way in which they could reduce an individual to an object. The main practical problems related to working with exhausted families, who needed more than their burden of care being increased further, and constant personnel changes, so that there was no shortage of assessments but little success when it came to intervention. There was also a developing recognition that individuals with such complex behaviours required approaches, which were much more flexible, reflected the needs being expressed by the family, and took account of the fact that the behaviour belonged to the self-injurer.

As the pattern of services for people with learning disabilities changed, however, the need increased for community services, which could respond to the needs of clients with complex behaviours, including self-injury. The debate over the nature of the service, particularly the role of a particular residential facility to accommodate those requiring intensive, short-term input prior to returning home, began to take shape. Some services developed without such a facility, arguing that interventions needed to take place within the context where the behaviour is displayed. Instead, they opted for a community based team of individuals skilled in behavioural techniques, who would provide intensive input in the day centre, respite unit, and/or client's own home (see Green and Fraser, 1991 for a discussion of the need for treatment units or community behavioural teams). Eventually, by the early 1990s, most areas had established their chosen direction for service development, in terms of responding to self-injury and aggressive or violent behaviour, though a consensus was never to fully emerge. My study, for example, demonstrated considerable diversity in the sorts of services available for supporting self-injuring individuals and their families, with behavioural methods always being given a central role, but little evidence of consistent application or sustained success.

Nevertheless, behavioural discourse in the '90s did adapt effectively to the changing climate, with a reduced reliance on the more aversive methods discussed earlier, and a more sophisticated approach to self-injury. 'Constructive approaches' came to be accepted as the necessary basis for intervention, though widespread understanding by professionals and carers was uncommon (Emerson, 2001), and "the only imaginable circumstances" for more aversive procedures were with "behaviours regarded as life threatening" (Baker, 1991: 114). Furthermore, critics of existing services were becoming increasingly vociferous, and challenges were being made to behaviourist discourse hegemony more directly and uncompromisingly:

> "The culture around people with severe behavioural disorders is a culture of death. The technology of that culture is behaviourism, which says we are nothing more than crude sets of stimuli and responses. The goal of life for these technologists is control compliance; they force people to obey" (McGee, cited in Brandon, 1990: 62).

Despite this scathing criticism, the essence of the alternative approach offered by McGee, 'gentle teaching', is behavioural; in fact it has been referred to as "behaviourism at its best" (Jones, 1990: 10), though it is only very recently that better understanding of it amongst professionals has been gained. The overall goal is to have all interactions by a self-injuring client, for example, meet with human reward, such as verbal praise and affection, but mainly tactile strokes and cuddles (McGee, 1988). Self-injury is approached through the development of personal relationships, based on trust, tolerance, warmth and affection, and the rejection of chemical, physical and mechanical restraint, as well as 'punishing' behavioural techniques. It's initial emergence, in the late 1980s, was based on an extensive study, which had suggested extremely significant reductions and sometimes complete elimination of self-injury (Brandon, 1990).

Despite such encouraging statistics, there was little enthusiasm for gentle teaching at this time, and it failed to make significant progress, in terms of service delivery and professional influence. Psychologists and nurses, particularly the behaviourally orientated ones, were not especially impressed, which is not entirely surprising given the critique of their own methods that had inspired its development. And some responded with the same level of vehemence, that they felt had been inflicted on them.

> "Gentle teaching claims to be a unique alternative to the use of aversive techniques. Nothing could be further from the truth. Gentle teaching is a collection of well-tested behaviour modification procedures that are all non-aversive in themselves. Gentle teaching has, to date, failed to prove its effectiveness in its own right" (Turnbull, 1990: 65).

In the years since this initial debate about the value of the gentle teaching approach, there have been significant changes within the behavioural approach, particularly the gradual acceptance of a non-aversive model of working. The anger with which many behaviourists responded to McGee and early advocates of his approach, I think, reflected the crossroads encountering behaviourism by the early-'90s. Many behaviourists, for example, did not need it pointing out to them, that people with learning disabilities were amongst the most oppressed of minorities (Brandon, 1990), and neither did they need to be reminded of their aversive history. But what seemed to gall them most, it seems, was the adoption of many of their own techniques, set into a context of intense, unconditional valuing and acceptance. For example:

> "The power of human valuing can be taught to people with seemingly refractory behaviours if it is given unconditionally in a spirit of warmth and sincerity and supported by behavioural techniques" (McGee, 1990: 72).

Even to the casual observer, this statement appears patronizing in the extreme, implicitly suggesting that such 'warmth' and 'sincerity' is absent from the work of straightforward behaviourists. On the contrary, I would suggest that, though the behavioural approach provided a fairly objective theoretical framework, those employing its techniques were committed, caring individuals, who regarded an individual's persistent self-injuring with great personal distress. Furthermore, behaviourist discourse was attempting to redefine itself in a more humane manner, by acknowledging the value of biological factors, the context within which challenging behaviour occurs, and the ways in which it is socially constructed (Emerson, 2001). This was partially because of its increasing role with the families of severely learning disabled self-injurers, but also because of its acceptance of its own aversive past.

One of the key statements in the continually changing behaviourist discourse surrounded the 'functional analysis' approach to understanding the factors that might be maintaining self-injury, though not necessarily having caused it in the first place (Emerson, 2001). In the 1990s there appeared to be an emerging consensus that it was not only essential, but also an ethical imperative, to conduct such an analysis prior to the implementation of a behavioural programme, though in practice this was frequently not the case. Functional analysis had begun to emerge many years earlier, with an initial emphasis on consideration of the antecedents and consequences relating to a behaviour (Kiernan, 1974). The antecedent-behaviour-consequence (A-B-C) chart developed later extended this into a more analytical format (Murphy and Oliver, 1987), and could be employed as an effective way of assessing staff-client interactions (Edelson et al, 1983). It would come to constitute the most favoured tool for analysing a behavioural incident within learning disability services. The evidence of the early use of A-B-C charts with the study group suggested that, though they were embraced with enthusiasm, there was little expertise in the subsequent planning of care.

Example 18

In February 1984 the community nurse involved in the care of 9-year-old Sam Morris over the previous three months employs an A-B-C framework over a period of six days to assess the time, frequency, and preceding factors relating to his persistent headbanging, the behaviour to be observed. Hunger, constipation, "doing it for nothing", and "doing it for fun and laughing" are subsequently identified as antecedent factors. The consequences column of the chart identify "gave him food" and "put on potty" in the case of the first two factors, with "put helmet on for most of the day" and "couldn't do much, just kept stopping him" for the latter two. A subsequent discussion with a clinical psychologist reveals a suggestion of behaviour modification, but no such programme is forthcoming and the community nurse ceases to become involved shortly afterwards.
(Source: Community nursing notes, February 1984).

There are two points to consider, I think, in relation to this example, besides the frequently transient nature of the community nurse's involvement and the tendency not to build on the work that has already been achieved. Firstly, the A-B-C chart is an assessment tool, which should point to contributory factors to the headbanging, so that the community nurse should be observing the usual consequences rather than immediately instigating change and thus distorting the findings. Secondly, there is no subsequent intervention plan to address the possibility that hunger, constipation, and boredom might be seriously contributing to the headbanging.

A second cardinal aspect of functional analysis concerned the identification and subsequent testing of different hypotheses about possible factors and situations serving to maintain the behaviour (Carr, 1977). Such hypotheses related to sensory consequences, positive social reinforcement, positive tangible reinforcement, and negative social reinforcement. The practical consequences were the development of the 'analogue assessment', whereby different conditions were devised for the experimental testing of such hypotheses (McBrien and Felce, 1992), and the Motivation Assessment Scale, which attempted to predict the results of more detailed experimental analyses (Durand and Crimmins, 1988). The value of experimental analyses of challenging behaviours relates to the identification of functional relationships, the ease with which they may be instigated, quantitative precision, and their practical usefulness (Vollmer and Van Camp, 1998; Wacker et al, 1998). Zarkowska and Clements (1994) suggest caution, however, because of the ethical appropriateness of manufacturing a situation, which "'invites' aggressive or self-injurious behaviour" (p.39). Despite Emerson's (2002) report of the markedly increased use of experimental analyses such as analogue assessments over the previous decade, there was only one instance of such an attempt being considered over the period of my study and that was complicated by other factors.

<u>Example 19</u>

In November 1989 the community nurse assessing 9-year-old Lesley Anderson's "chin stroking" writes that her mother "now felt ready to attempt a behaviourist approach", which would involve the analogue assessment that had been considered three months earlier, but was cancelled "until such time as the physical condition of her chin improves". The community nurse arranges to conduct such an assessment with a clinical psychologist, but notes that Lesley's mother was "distressed... at the idea of allowing (Lesley) to hit chin without intervening", so he decides to go ahead without her being present. The notes end abruptly a couple of weeks later, without the assessment having taken place and with the community nurse having decided that he is no longer in a position to offer support.
(Source: Community nursing notes, August – December, 1989).

The development of mobile teams in the late 1980s/early 90s for intervening with clients engaging in severe self-injury allowed for a clear consolidation of the 'functional analysis' approach. The catalyst was the 'hospital' closure programme, which did not at this point mean that the majority of self-injurers were being resettled into the community, but that there was a need for such a service for those never admitted and now reaching adulthood. The basis of these 'behavioural support' or 'specialist resource' teams was 'applied behaviour analysis' (Woods and Blewitt, 1993), a natural development from the more aversive forerunners, 'behaviour modification' and the 'behavioural approach'. It had been developed in the 1960s, consolidating the existing elements of measurement, experimental design, behavioural theory, and specified techniques, whilst placing greater emphasis on social importance, applications across time and settings, and demonstrable effectiveness (Baer, Wolf, and Risley, 1968).

This changing discourse within behaviourism, by the 1990s, was becoming established as the standardized framework for many services to clients with challenging behaviours (see, for example, Carson, Clare and Murphy, 1998). Comprehensive functional analysis was regarded as the essential starting point for mobile teams adopting such a framework, and other integral behaviourist discourse statements included the continuing retreat from resort to aversive interventions, such as 'punishment' procedures like overcorrection, time out, and extinction, and the need to concentrate on the development of 'functional equivalents'. This latter development, regarded by some as the single most influential factor over recent years (Oliver, 1995), concerns the teaching of alternative behaviours identified as serving the same function as the self-injury. Eason, White, and Newsom (1982) described a prototype of this procedure with toy play being used to replace the hypothesized function of self-stimulatory behaviour. Mesaros (2000) took this further by comprising it within the framework of 'positive programming', along with skill teaching, substituting communicative means, and assigning meaning to the behaviour. Woods and Blewitt (1993) extol the virtues of such an approach because of its 'constructional' rather than 'pathological' character, wherein there is recognition that the individual's behaviour represents a "legitimate and logical path to a desired natural consequence, albeit costly and distressful to the person or others" (p.44).

This emphasis on the meaningfulness of the challenging behaviour to the individual is consistent with the acceptance of their being 'communicative intent' discussed in the previous chapter, and represents the continued broadening and inclusiveness of behaviourist discourse. In effect, there was a pressing need in the '90s for behaviourism to continue its trend of stressing less the need for individual change, though this was never anything other than the desired goal, and more an investigation of the role of the environment. The formal arrival of such a discourse statement came with the notion of 'ecological manipulation', which required "a much more global effort to change the general context in which the behaviour occurs or to more generally establish a context that will make the behaviour less likely to occur" (Mesaros, 1986: 26). In many ways this was not a new development, since there had long been recognition of the need to alter the environment so as to effect behaviour change (Menolascino et al, 1983; Wilson and Davison, 1987). The difference now was that behavioural teams were more likely to assess its role with greater immediacy, and prior to implementing a programme geared towards individual change.

The culmination of this developing behaviourist discourse surrounded the advocating of a tripartite system of interventions, whereby procedures to reduce self-injury, increase self-help and social skills, and opportunities for participation in planned activities constituted the recommended approach (e.g., McBrien and Felce, 1992). Evidence for such a comprehensive pattern appears scant, however, with my study suggesting that behavioural teams frequently undertook exhaustive assessments, which incorporated functional analysis and informed consequent interventions. The difficulties, however, related to sustaining such strategies over time, engaging the commitment of care staff, and addressing the complex needs of the family. This study confirms much of the work of others that self-injury is longstanding in many cases (Kiernan et al, 1997), that there is a high relapse rate when initial success has been apparent (Schroeder and MacLean, 1987), and that early intervention and improved facilitation of the necessary skills would appear imperative (Emerson, 2001).

The following more detailed examples from the study group relate to the more comprehensive behavioural strategies adopted by behavioural teams in the '90s, highlighting the complexity of successful implementation over sustained periods.

Example 20

In July 1997, James Simpson is 42-years old and has been living in a small busy social services house, part of a housing network, for the 4-½ years since he left the institution. He is referred to the behavioural support team, who subsequently arrange to visit him at home, consult with staff, and submit a short report. The reason for his referral is identified on the form: "James displays self-injurious behaviour, (which) is becoming more frequent in number and causing injury more often. James' behaviour is changing. He will now run away from staff when out of the home putting his life at risk. Poor road sense. Aggressive outbursts on the increase. There is strong probability this behaviour is tied in with obsession with books".

The team's initial steps are to undertake a 'screening clients' assessment, which seeks to establish suspected causes, communicative ability, effectiveness of previous interventions, and expected input, which is followed by a 'risk assessment' because of the level and intensity of James' violence. This is immediately succeeded by a three-month period of observation and further assessment, a 'functional analysis', which identifies that "extended periods without any interaction" result in his self-injury and aggression "increasing in intensity until response is obtained". Boredom and frustration are subsequently identified as major contributory factors, and a medical examination is sought so as to eliminate physical causes. The subsequent programme is based on the cardinal behaviourist statement of encouraging care staff to "reinforce appropriate behaviour and ignore difficult/disruptive behaviour", which necessitates the identification of key reinforcers. This is accompanied by a recognition of "the inherent dangers of James banging his head against the wall", through a recommendation for "redirecting him to a situation, which involves social interaction". The final part of the programme concerns suggestions that staff refrain from constantly telling James not to do certain things, since this operates as a 'negative reinforcer' by increasing the likelihood that they will occur, recommendations for increasing his opportunities for social interaction, and a need for staff anticipation regarding escalations in his behaviour.

The three-month programme duration yields little success, partially, I think, because of James' insight into his behaviour being manipulated through redirection, so that he becomes increasingly demanding and violent, but mainly because of the lack of congruence between the demands of the behavioural approach and the staff's desire to concentrate on running the house. They become irritated, I think, by a behavioural 'expert' designing the programme, immediately withdrawing, and leaving them to carry it out unsupported, which is not helped by a period of 'role modeling' to demonstrate the practicalities of carrying out the plan. There is, furthermore, a marked reluctance to alter the staff definition of James' behaviour as being "naughty and impatient" towards a perspective, which necessitates trying to see the world from his viewpoint. Something of a standoff results, with a rejection of the behaviourist approach as "impractical", complaints about the detached approach of the consultative 'expert', and some acceptance by the carers that they may not be equipped with the necessary behavioural skills. This is further exacerbated by the frequent use of 'agency' workers with little understanding of the context of James' behavioural deterioration, to provide direct care, and the majority of more highly skilled personnel operating in a more managerial capacity.

Another important complication concerns the results of James' health assessment, wherein a dental check reveals several abscesses, which results in extensive treatment, and blood tests show "an ulcer, which is bleeding, (so) he is therefore extremely anaemic". The subsequent dietary changes and medication prescription, however, fail to ameliorate his behavioural excesses, the behavioural team persist in encouraging reinforcement-based approaches, redirection, and 'reactive' strategies over the next year before the placement breaks down and he is admitted into an assessment and treatment unit.
(Source: Behavioural Support Team notes, July – December 1997)

Example 21
In June 1994, 34-year old Stewart Robinson has been living in his new home after leaving 'hospital' for just less than six months and there have been a few transitional difficulties, which have warranted an action plan being devised by his community nurse. The question of Stewart's adjustment after leaving 'hospital' is significant, I think, in contributing to a sudden exacerbation of his challenging behaviour, which is manifested as "aggressive outbursts towards self, others and inanimate objects". The ensuing behavioural programme is aimed at enhancing "sociable behaviour", but fails to really consider the length of time he has lived in 'hospital'. A second area of concern relates to his tendency towards excessive regard to minor factors, such as the position of a chair or the television being on or off. Such behaviours have been generally established over a number of years living in 'hospital', though Stewart does tend to change them periodically.

The intervention strategy subsequently selected demonstrates the increased emphasis during the 1990s on approaching the issue from a number of different angles. Because of the need for some of the staff to acquire the necessary skills and 'competencies' for 'positive programming', in addition to the need for 'ecological manipulation', the community nurse produces an immediate 'direct action' plan aimed at short-term rapid effects. The community nurse specifically identifies the particular behaviours to be looked at, identifying their unpredictability and occasional intensity, before emphasizing the philosophy of the team: "A non-aversive approach is essential in addressing the complex nature of Stewart's behaviours".

The main objective of the intervention is described in behavioural terms, but also addresses the need to be 'positive' ("to minimize the frequency of the inappropriate behaviours so as to enhance Stewart's quality of life"). The programme then goes on to identify a number of activities for Stewart to engage in, the first strand of the approach, which provides his life with greater structure, so that he is less likely to engage in those behaviours considered less desirable. The emphasis here is also on developing a particular skill and spending some time of each day away from the house. Enhancing communication through the construction of a photograph book, which contains pictures on objects, people, and situations pertinent to his life, past and present, constitutes a second strand, whereby Stewart can look at the contents alone or accompanied by a staff member. A third area relates to a 'reactive strategy', so that staff can respond to Stewart in a consistent and effective manner, revolving particularly around the use of gentle physical guidance, redirection, and protection of the individual targeted by his aggression. The final aspect of the programme relates to the building of relationships, which necessitates his increased involvement in household tasks in conjunction with increased choice and decision making. Some reduction in Stewart's challenging behaviour is achieved over the next few months, but this also coincides with his adjustment to his new life. He does not cease to engage in ritualistic, bizarre or self-injurious behaviours, but they do not occur to the extent that they disrupt goings-on in the house or disturb his living companions.

Nearly four years later, in April 1998, Stewart's self-injury and violence towards others is considered to have deteriorated markedly over a period of several months, to the extent that it jeopardizes his place in the house. The consultant psychiatrist, who also seriously considers compulsory detention under the mental health act (1983), increases his anti-psychotic medication and a referral is made to the behavioural support team. The behavioural nurse subsequently undertakes the usual assessment process, identifying that Stewart is trying to re-establish some degree of control in his life. Two care plans are then introduced, which employ clear, precise behavioural language and require the consistent completion of recording charts. One of the programmes seeks to provide staff with a number of guidelines to be followed during an incident of violence, whilst the other seeks to enable Stewart to regain the control that he seeks. Shorter-term aims of simply reducing the number of occasions of headbanging accompany this longer-term one.

The emphasis is consistently on accentuating the positive aspects of Stewart's behaviour and locating the chosen approach within a context of non-aversive practices and 'normalization' philosophy. The behavioural nurse facilitates the implementation of the care plans with some 'role modeling', because of some initial difficulties being experienced by the staff working in the home. During the summer, Stewart becomes increasingly aggressive towards others, including an incident involving a member of the public, and this culminates in the behavioural nurse carrying out a risk assessment in September 1998. This is subsequently submitted to a meeting with the home leader and newly appointed case manager and a number of factors are identified as possibly contributing to the deterioration in Stewart's behaviour. These are the recent reduction in his anti-psychotic medication, his father's recent retirement (Stewart's father has maintained full involvement in his care throughout his life), staffing changes in the house, and the possibility of bereavement following the death of a fellow 'tenant'. This combination of factors, according to the behavioural support nurse, has resulted in Stewart feeling that he has no control over many areas of his life, and his response is to become agitated and physically violent.

The risk assessment itself is very specific and concise, basically comprising a series of statements relating to a description of the 'identified risk' followed by a response to the question 'how is the risk being managed?' For example, the statement covering his current self-injuring identifies a "significant risk of Stewart exhibiting self-injurious behaviour e.g., banging his head against the wall outside the house". The management of the risk then revolves around the following of the guidelines devised in conjunction with the behavioural support team, along with 'breakaway training' being arranged by the home leader. This latter strategy is in response to concern by staff as to their own safety should Stewart become aggressive whilst being redirected. Other identified risks relate to the possibility of him becoming violent towards his parents when travelling in the car, aggression towards other tenants, flooding the bathroom, and wandering into the road. Each is responded to by very specific instructions to staff about how to react, the following of particular guidelines where appropriate, and persuasive tactics towards his parents about Stewart travelling in the back seat of the car and his mother spending less time talking to the home staff. The programme is effective in so far as Stewart does become less violent towards others, and reduces the intensity of his self-injury, but he continues to retain these aspects of his behavioural repertoire in a reduced form with occasional periods of deterioration continuing to occur.
(Source: Community nursing notes, June 1994; Behavioural Support Team notes, September 1998)

Both Stewart and James were introduced in chapter two ('three I'd known earlier'), and the behaviours illustrated later were clearly in evidence many years before. It is also clear that they did respond to varying degrees to the more sophisticated approach of applied behavioural analysis. The complications relate to biological factors, such as James' poor health, the degree of awareness that he or Stewart are being 'put on a programme', carers being sufficiently skilled in behaviourism to be able to appreciate and implement techniques, and the role of the consultative 'expert'. Behavioural discourse must account for such factors to achieve widespread and sustained success, something that it has proved adept in doing in the past. In the 1970s the emphasis within behaviourism had been necessarily narrow, since "its precision and objectivity depend, in large part, upon its application to single dimensions of behaviour, one at a time" (Willems, 1974: 155). In recent years, however, a number of attempts have been made to try to develop an 'ecobehavioural perspective', (for example, Dumas, 1986; Pyles & Bailey, 1990; Sanders, Dadds & Bor, 1989), though this effectively meant incorporating ecology into a behaviourist strategy (Jones & McCaughey, 1992). The behavioural discourse's great strengths have been it's capacity for self-examination and critique, immense adaptability, and gradual pervasiveness to the work of many of those providing care to people with learning disabilities. The weaknesses, however, are equally considerable and include a preponderant inability to enable carers to implement behavioural interventions successfully, and a failure to adequately address the complex role of the family over the years of inconsistent and sometimes ignorant professional support.

The primary purpose of this chapter has been to demonstrate how behavioural discourse initially emerged and subsequently consolidated its position as the most effective strategy for working with people with learning disabilities. The first part of the chapter examined behaviourism's relationship with its aversive history, which, I have argued, was never as influential in practice as has sometimes been claimed. Rather, it has been the arbitrary and short-lived implementation of poorly thought out behavioural programmes, which has been the main difficulty. The experience of those in my study during the 1970s and 1980s provides evidence of attempts to employ non-aversive behavioural techniques, but there was little regard for the possible consequences of such programmes other than a belief that a reduction in a behaviour such as self-injury would be beneficial for all concerned. The second part of the chapter has been concerned with exploring how behaviourism sought to re-invent itself for a post-institutional world, which would involve greater consideration of the appropriateness of its techniques within family settings. The emergence of specialist input such as that provided by the behavioural support team, where the emphasis was on 'functional analysis' and 'positive programming', suggested greater sophistication. The chapter ended with two substantial examples of the application of this more progressive behaviourism, both of which demonstrate the necessary thoroughness and structure as well as some of the difficulties associated with a specialist being consulted for their expertise.

Every member of the study group at one time or another experienced the behavioural approach being used either to improve self-help skills or, more likely, reduce behaviour that was considered challenging. Similarly, a large proportion of the group witnessed consideration being paid to the appropriateness of a diagnosis of autism being applied to them. Chapter five sets out to explore the phenomenon of autism, particularly in the context of the lives of the study group. It raises questions about the power of diagnosis and the subsequent implications for individuals, just as in this chapter we have seen how dominance can be achieved without the need for absolute effectiveness being demonstrated.

CHAPTER FIVE: AUTISM AND SELF-INJURY

- The 'discovery' of autism
- Contemporary issues relating to autism
- Autism and self-injury

The justification for including a separate chapter on autism was provided in the discussion on emergent themes at the end of chapter two. The continuous debate regarding the condition over the last sixty years has had a marked effect on practice, and was witnessed in the lives of several of the study group. This chapter, therefore, attempts to trace the development of the discourse through two distinct phases, which relate primarily to autism's discovery and consolidation, and then to its establishment as a clinical fact over the last twenty years. Each section ends with a discussion of the impact that the discourse had on the life of one of the group, firstly with Alan Dawson during the 1960s and latterly with Robert Clayton over more recent years. The chapter ends with an examination of the relationship between autism and self-injury, of considerable importance in the context of this study though less so with regard to the establishment of a diagnosis.

(i) The 'discovery' of autism

This first section attempts to chart the initial identification of autism as a discrete syndrome and the subsequent quest to identify the necessary cardinal characteristics. The early discourse on autism revolved around three central concerns, the nature of its relationship with childhood mental illness, the psychiatric desire to be able to establish a diagnosis, and the relationship between parents and children. This discourse required the emergence of requisite societal conditions for discussion of the mental health of children to be able to take place, despite a major implication being some sort of critique of the traditional family unit. Nevertheless, such societal conditions were taking shape during the decades after the war, which enabled a more critical look at 'relationship formation' (following Bowlby, 1955; see Tredgold and Soddy, 1963, chapter 8) and 'maternal deprivation', and which would culminate briefly in the critical excesses of the 1960s (e.g., Laing, 1969; Esterson, 1970). In terms of practice, relationships between parent, particularly mother and child became an important element of diagnosis, despite the lack of professional consensus regarding validity, and will be explored later in relation to some of the individuals in the study. Another concern was with the issue of 'mental subnormality', which as we will see became extremely important in terms of determining whether autistic children were worthy of the extended attention of medicine, with the rich associative rewards of specialist services and resources.

During the 1950s and 1960s many of the early studies of autism regarded the condition as part of a number of illnesses, which together constituted 'childhood psychosis' (see, for example, Tizard, 1958). Barker (1971) employs it as the most effective umbrella term, which includes also "*infantile autism, childhood autism, childhood schizophrenia, schizophrenic syndrome of childhood, psychosis* and *symbiotic psychosis*" (p.68, italics in the original). Even as late as the mid-'80s some authors continued to use the terms autism and childhood psychosis interchangeably (e.g., Walker and Keleher, 1985), despite caution having been suggested more than twenty years earlier:

> "In recent years it has become usual to regard these conditions as being in the field of psychosis, but the main drawback of this approach is that the conditions appear to be heterogeneous in many respects. In the present state of knowledge it may be misleading to attempt to force all these phenomena into a single pathology, and in this connection the current American fashion of referring to these cases as childhood schizophrenia has much to condemn it. This term begs every question of aetiology and pathology" (Tredgold and Soddy, 1963: 152).

The initial paper by Kanner, 'Autistic Disturbances of Affective Contact' (1943), outlines a number of cardinal characteristics of 'infantile autism'. The title also hints at what he considered to be the main contributory factors to its development, which we will address later. The characteristics are 'autistic aloneness', an 'obsessive desire for sameness', 'delayed or abnormal development of speech', and 'onset in the first two years of life'. Some of the ensuing debate has been concerned with whether the condition can be developed a little later, particularly when there is a considerable 'mental retardation'. Many of those in my study effectively flirted with an autism diagnosis, which suggested a complicated relationship between their learning disability and the likelihood of a successful application, one that would 'stick' over the ensuing years. To be more precise, the flirtation is between the consultant psychiatrist, and occasionally other professionals considered able to contribute towards the making of such a diagnosis. The likelihood that the spectre of autism would arise during initial investigations was further complicated by the probability that any such diagnosis would be later withdrawn, along with the promise of resources and specialist services. Though the situation has changed quite dramatically over recent years, with far more people with learning disabilities being clinically regarded as being within the 'autistic spectrum disorder', thirty years earlier it was likely that the very fact of their 'mental subnormality' would preclude diagnosis.

'Autistic aloneness' concerns the difficulties that these children have in relating to others as people rather than as objects to be used for their own benefit and then discarded when not of use. Kanner argued that they were completely oblivious to the needs of others and behaved accordingly. Debate was quick to follow, though, and many writers broadened the range of the condition to include those, whose behaviour was previously regarded as different but not pathological.

> "There is also an imprecisely defined range of children whose remoteness is not so marked and whose behaviour is not so bizarre as in infantile autism, but who are emotionally more or less cut off from other people and who show obsessional and ritualistic behaviour" (Tredgold & Soddy, 1963: 152).

The 'obsessive desire for sameness' has been extremely influential in terms of guiding the psychiatrist towards a diagnosis. Becoming distressed by fairly minor environmental changes or disturbances of routine is the essence of the trait, and there is frequently a further association with the child having a good memory. The 'delayed or abnormal development of speech' dimension also includes speech not being developed at all, which has been estimated to occur in about half of autistic children (Gibson and French, 1971). Kanner talked of speech being developed and then being lost, confusion of the personal pronouns, and echolalia (constant repetition of certain words or phrases). He also emphasised its stereotypical nature and the tendency for some children to use words inappropriately. The role of self-injury may have been significant in the lives of many of the children in his study, but was not felt to be sufficiently noteworthy to be discussed separately.

> "Early signs of infantile autism include unresponsiveness, failure to assume the posture appropriate for being picked up or nursed, headbanging, rocking, and bizarre, ritualistic and repetitive play" (Barker, 1971: 70).

The demonstration of a particular capacity, such as a 'special facility for mathematics' is further identified, as is being easily distracted, having poor concentration, becoming aggressive or emotional without provocation, not recognizing dangerous situations, avoiding eye contact ('gaze avoidance'), resistance to learning new behaviours or skills and becoming excessively attached to objects (Kanner, 1943). But none of these were regarded as essential in terms of making a diagnosis. The existence of bizarre actions in the behavioural repertoire of autistic children, such as smelling and licking objects, finger or hand movements, and ritualistic rocking, has been well-documented (Hilliard and Kirman, 1957; Barker 1971). It is also true, though, that regular 'mentally subnormal' children are equally adept at engaging in such behaviours, which is exemplified by the various repertoires of all in my study group.

The initial employment of the term autism was by Bleuler (1913), who used it to emphasize schizophrenic creativity, though it is most associated with Kanner's work (1943). Mahler (1952) differentiated between the 'normal autism' of early infancy, prior to the differentiation between the self and outside reality, and the pathological infantile psychosis variety, whereby the child regresses and becomes stuck within the former type. The association between 'mental deficiency' and autism was emphasized by Kirman (in Hilliard and Kirman, 1957), who sought to demonstrate the difficulties of diagnosis as opposed to when the child or young adult is schizophrenic. He identified four particular features of 'psychosis of the autistic type' found amongst those considered 'mentally deficient'. These were the irritating contradiction between having the ability and knowing how to maximize the use of it in social situations, the rejection of social contact, the tendency towards negativity, and the display of obsessional and stereotyped behaviour. The negativity feature referred both to a tendency to excessive rigidity, and other occasions where "(T)hey may bang their heads, pick their faces, and bite their hands, particularly if attention is given or the pattern of stereotyped behaviour is disrupted" (Tizard, 1958: 182).

In the years following Kanner's elaboration of the syndrome of autism, there was no immediate consensus forthcoming, with particular controversy surrounding age of onset (Creak, 1951), regression, and deterioration in both speech and self-help ability (Tizard, 1965). There was some agreement, however, regarding the bleakness of prognosis, with little expectation of recovery once the condition had manifested itself (Mayer-Gross et al, 1954; Bender, 1955). The prevailing lack of overall consensus resulted in the establishment of a working party aimed at definitively establishing the criteria for a true diagnosis of autism (Creak, 1961). As Eden remarked a few years later, the "description 'autistic', becoming fashionable, was applied to all sorts of children, until it ceased to have any clearly defined meaning at all" (1976: 79). Nine criteria were identified, which were later modified to seven, and these subsequently became the basis for diagnosis.

1.) Failure to form normal relationships because of the child's emotional remoteness;
2.) The absence or abnormal development of speech;
3.) Ritualistic and compulsive behaviour;
4.) Repetitive actions or mannerisms – "A mannerism is a repeated action performed with the body alone" (Eden, 1976: 80);
5.) Self injury, such as headbanging, biting the wrist or pulling the hair – "Sometimes self injury seems to arise from frustration, but it is often apparently habitual" (Eden, 1976: 80);
6.) Overactivity, which may be hyperactive, aggressive or destructive;
7.) Variations in intellectual function.

Unfortunately, the identification of such criteria provided something of a paradox, since central questions relating to cause and relationships with 'mental deficiency' and 'childhood psychosis' remained unanswered. The term 'autistic tendencies' became popular, partly reflecting the confused boundaries of diagnosis but also expressing a reduced tendency towards emphasizing the 'pathological' nature of the problem (Eden, 1976). Heaton-Ward (1967) captures this uncertainty by including only a minor comment on autism within his then influential textbook, which differentiates it from 'juvenile schizophrenia' because "the history reveals that development has never been normal and that complete integration of personality has never taken place" (p.59). This differed from the argument put forward a decade earlier, that autism was a feature of normal development becoming pathological only in a few cases (Anthony, 1958). Furthermore, Heaton-Ward (1967) suggests that the causes are probably environmental, though unspecified, which illustrates the ambivalence with which autism was regarded by the late-'60s.

This confusion was symptomatic of the ongoing retreat from the theory that it was a consequence of maternal coldness, which had dominated early thinking on the subject (e.g., Kanner and Eisenberg, 1956). Gibson and French (1971), for example, were unable to provide any greater insight into the condition other than describing it as "(E)xcessive concentration on oneself, daydreaming" (p.166), which reflected, I think, the temporary lack of professional confidence in autism actually constituting a recognizable clinical entity. Nevertheless, despite vigorous debate, the consequences of the early emphasis on dysfunctional parent-child relations were immense and clearly in evidence in the diagnostic encounter. Medical interest was wakened on first meetings between the consultant psychiatrist and Ronald Falconer, Melanie Dodd, James Simpson, Stewart Robinson, and Alan Dawson, along with their respective parents, but waned once the pertinent criteria were considered inapplicable.

Example 20

The clinical description of the 3-year old Ronald in 1962, for example, is shrouded by the early language of autism, such as concern about "maternal rejection" and a question asking "is mother bright enough?" He identifies Ronald as a "social problem" and formally writes to the area medical officer describing him as having "little emotional consideration to other people and to this extent demonstrates some element of autism". Shortly afterwards, however, he concludes that Ronald's mother is "rather simple and just does not grasp the requirements of her child" (emphasis in original letter), and he subsequently dismisses the idea of emotional rejection and admits him into 'hospital' where there is no further discussion of autism. James Simpson's brush with autism is similarly brief and again centres on his relationship with his mother, in addition to his failure to reach milestones of development. In 1966 the consultant psychiatrist identifies 11-year old James' overactivity, anxiety, echolalic (repetitive) speech, and general restlessness as promising signs of autism, but eventually identifies him as behaving badly as a result of being given his own way too often. He is not admitted permanently into 'hospital' for several years, but 'mental retardation' is quickly confirmed and autism denied on the grounds of his attachment to his mother.

Melanie Dodd and Stewart Robinsons' relationships with diagnosis are a little more complex because of their initial admissions into a newly established 'hospital' autistic unit during the early 1970s, the former as a 7-year old in-patient and the latter as a 9-year old out-patient. Furthermore, there is more elaborate consideration of diagnostic criteria, with greater emphasis being given to issues of more formal assessment such as "difficulty in making contact", "aloneness", "hand mannerisms", and "visual avoidance". Both receive a relatively short-lived diagnosis of autism, with the associated benefits of residing in the more salubrious surroundings of the specialist accommodation, more intensive educational input in the unit school, and more considerable professional input, medical, nursing, and psychological. The overriding concerns about their violent behaviour, however, in passing towards self but primarily towards others, eventually result in the withdrawal of their privileged status and relocation in basic wards, and in the case of Stewart one for the 'behaviourally disturbed'. The context for both Melanie and Stewart is complicated by issues of transition from childhood to adulthood, which appears not to have been fully considered at this time. There was no 'hospital' service for autistic adults so the options when they reached their late teens seem to have been severely limited.
(Source: 'Hospital' medical notes, 1960s/70s)

The trend towards such specialist units at this time was not without its critics, and was regarded most suspiciously by advocates of a completely different educational perspective. This quote, furthermore, illustrates such suspicion whilst simultaneously demonstrating the paradox at the heart of the relationship between integration and segregation:

"The best possible environmental benefit is probably afforded to an autistic child if he can mix with children suffering from other types of handicap. There is a tendency to establish special units and schools for autistic and psychotic children. Here, however, the autistic child experiences just the duplication and exaggeration of his own problem. But when he can live and go to school with children suffering from entirely different handicaps, he can derive specific and often astounding benefit to his own development... The principle of non-segregation can be extended in a variety of ways all of which will be helpful... Very severely disturbed, retarded and non-communicating autistic children have been helped to learn to live and work, albeit on their own terms, in sheltered and tolerant communities to the benefit of all in the community" (Weihs, 1971: 97-8).

Example 21

The most severe example in the study group of the implications of the process of diagnosis are illustrated in the care of Alan Dawson, who comes closest during these early years to making the grade as autistic. He is identified early, when he is two years old, as requiring investigation by a specialist consultant to establish why he is failing to develop successful relationships. This referral from the area medical officer in 1962 focuses on a more detailed elaboration of early autism discourse in relation to child development. The 'Griffiths Scale' had been employed to establish various responses (locomotor, personal-social, hearing-speech, and hand-eye coordination) to toys and apparatus. This test revealed Alan's disregard of the materials, identified his stereotypical behaviour, and noted his lack of eye contact and resistance to being cuddled. It is these latter elements, particularly his relationship with his mother, which are of interest to the area medical officer and convince him of the need to make the referral. He concludes his observations with reference to Alan's "self-sufficiency", his mother's admission that she withholds affection "because he is a boy", her belief that he is "just like his father', whom I didn't meet", and his own concern regarding "features of psychosis". The clincher, however, is his comment that "it is certainly not the case that it is straightforward subnormality", a concern which Tredgold and Soddy identify as being of such importance to parents, though as this study suggests with good reason:

"The parents of psychotic and autistic children are often bewildered by the strange mixture of retardation, ability and, even, precocity that their children may show. They will, quite rightly, dismiss any statement that their child is just defective and will insist that he has special capacities. It may require months or years of patient explanation and demonstration, on the part of the doctor, before they can reconcile themselves with their lot. The situation is the more complicated because so many doctors fail to recognize this condition and, therefore, conflicting medical opinions are always available to the parents; also, since they so readily tend to pass, dissatisfied, from one doctor to another, confusion becomes worse confounded" (1963: 434).

So begins the search for an appropriate diagnosis with Alan attending the specialist consultant's clinic for a period of observation and correspondence taking place over a period of several years between the various medical personnel (specialist consultant, area medical officer, and consultant psychiatrist). The specialist concludes that Alan's "relationships in the clinic are not those of an ordinary backward child", and that he "was quite outstanding by remaining persistently on his own for the duration of the group, which lasted 1 ½ hours". He is reluctant to confirm a diagnosis of Kanner's infantile autism, however, because of the affection he shows to his parents, but does stress that the home conditions "may be having an effect in colouring Alan's behaviour". Eventually, a compromise is sought and in 1966 he is provided with a provisional placement at a Rudolf Steiner school in Aberdeen ('for children in need of special care') to establish his suitability to such a 'progressive' environment.

Alan attends the school for more than a year and does prompt comments in his term reports of becoming "more balanced" and observant of the actions of others. Unfortunately, however, he does not express the desired emotional reactions and imaginative responses, which are considered imperative in this environment based on an 'alternative educational philosophy'. From a more pragmatic perspective, nor does he begin to develop speech or form relationships, and it soon becomes clear that he will not retain his place. Furthermore, his noisiness and aggression towards other smaller children increasingly cause concern, and it is these areas that come to dominate discussion of his future. He is subsequently excluded early in his second year, which precipitates a crisis concerning where he should go, with his family particularly distressed at the possibility of him returning home. He retains his autism diagnosis during a period of admission into a 'hospital' children's ward, but the absence of any self-help skills coupled with his "uncontrollable and destructive" behaviour result in his gradual downward categorization into a 'subnormal' child. It is three years before Alan is admitted on a long-term basis, a period which witnesses the usual prolonged negotiations between family, professionals, and administrators. The key player, though, is the family mental welfare officer, who emphasises his mother's emotional instability, his father's ineffectuality, and his sister's "mild mental subnormality" (she also spends a period within the Rudolf Steiner school system). His request, however, for a place within the 'hospital' autistic unit is rejected on the basis that he failed to make progress at the Rudolf Steiner school and there is a considerable waiting list, and he is admitted permanently when he is 10-years old. Shortly after admission the nursing notes reveal that he is "extremely overactive, screams and bangs himself quite often", behaviours that will deteriorate considerably over the next few years.
(Source: Medical correspondence, July 1962, May 1964; Rudolf Steiner yearly report, 1966/7; 'Medical Report on Patient Requiring Hospital Care', August 1967)

(ii) Contemporary issues relating to autism

During the 1980s the confusion surrounding the terms 'autism' and 'childhood psychosis' led to the introduction of a new diagnostic category, which would be used in relation to children where there were numerous, discernible distortions in terms of their development (Fraser, 1991). The term 'pervasive developmental disorder' (PDD) was differentiated from 'specific developmental disorders', which focused on a very particular difficulty, such as the development of language. Three sub-categories of PDD were identified: infantile autism, characterized by major problems in the areas of both language and relationships, and occurring in the first 30-months; atypical autism, which occurs before 30-months, but fails to meet the full criteria for autism; and childhood onset of pervasive developmental disorder, which does meet all the criteria but occurs at a later age (Russell, 1984). The most striking change from the 1960s and 1970s in the discourse surrounding autism, however, was the emerging consensus with regard to its existence, though not it's causes:

> "We may conclude that there is no doubt that autism constitutes a valid and meaningfully different psychiatric syndrome; indeed the evidence on its validity is stronger than for any other psychiatric condition in childhood" (Rutter & Schopler, 1987: 184).

The two most written about and generally accepted, on an international basis, systems of diagnosis are the World Health Organization's International Classification of Diseases (e.g., ICD-10, WHO, 1992), and the American Psychiatric Association's Diagnostic and Statistical Manual (e.g., DSM-IV, APA, 1994), both of which are widely employed in the classification of children with autism (Trevarthen et al, 1996). This effective 'medicalization' (following Conrad, 1975, and Conrad & Schneider, 1980) of autism took place over the course of a number of years, but never really settled the continuing debate over the origins of the condition, and hence the treatment. It did, however, provide some degree of consensus over the central criteria for diagnosis, which would provide the focus for research and study during the 1980s and 1990s. Systems of diagnosis developed over this period have tended to be based around the idea of a 'triad of impairments', which are most characteristic of people with autism; these are 'social relatedness', 'communication skills' and 'imagination' (Wing and Gould, 1979).

> "This triad, of behavioural failings in social skills, language and cognitive flexibility, reflects an historical preoccupation with testable disorders that are important in the development and education of school age children" (Trevarthen et al, 1996: 11).

The interesting thing about the way in which the 'reality' of autism has been considerably enhanced, in terms of credibility, over recent years, relates to it's formal acceptance within these two apparently monolithic structures, the WHO's ICD-10 and the APA's DSM-IV. I say apparently, because both systems have contributed to the way in which autism has been constructed since 1980, with changing thinking being reflected in the diagnostic criteria. This period, to some extent, I think, has been characterized by an increasing need to locate the condition within a medical, and thus 'scientific', framework. Whereas in the early work on autism, there was some emphasis on it being a psychological strategy for dealing with a difficult world and complex social relationships, recent years have seen much of the focus be concerned with which part of the brain is not working properly. Apparent neurological signs such as motor abnormalities and late-onset epilepsy have been linked to nervous system dysfunction (Damasio & Maurer, 1978); autism has been associated with clinical syndromes where there is frequently a significant learning disability (Wing, 1988); and in some cases evidence has been presented for a genetic predisposition (Bolton & Rutter, 1990). However, not everyone is convinced of the value of a biological explanation, particularly claims for abnormalities in brain structure and neurophysiological function being related specifically to autism (Dawson, 1989), though research in this area is on the increase.

In terms of the way in which autism has been classified since 1980 (ICD-8), the WHO selected the category of 'psychoses with an origin in childhood', and retained it in updates in 1987 (ICD-9) and 1993 (ICD-10). The main changes that have occurred, in addition to the employment of the term PDD and the focus on the triad of impairments, have been in terms of increased precision of definitions of conditions previously defined within the infantile autism category. In particular, very clear criteria are presented for differentiating between Rett's syndrome and Asperger's syndrome, which enables a more precise clinical definition of infantile autism. Furthermore, the definition is not one, which is in conflict with the criteria employed by the APA for 'autistic disorder'.

The APA's updating of its Diagnostic and Statistical Manual has corresponded with the work of the WHO, and, generally speaking, they appear complementary to one another. Autism has only featured as a specific category since 1980 (DSM-III), and prior to this time there appears to have been little consistency in the criteria used in different research facilities (Trevarthen et al, 1996). Since 1987 (DSM-III-R), when autistic disorder was re-classified as PDD, successful diagnosis necessitated that eight items, at least, were present from three groups of criteria (see Box 2), which revolved around the triads of impairment previously discussed (Bemey, 1997). One point of interest here was that onset during infancy was to be noted, but not considered essential for diagnosis, as was the case in all other DSM systems.

1) 'Social Behaviour': - Qualitative impairment in social interaction (five subsets, scoring on two of which was required for diagnosis);
2) 'Language and Communication': - Qualitative impairments in verbal and non-verbal communication, and in imaginative activity (six subsets, scoring on one of which was required);
3) 'Activities and Interests': - Markedly restricted repertoire of activities and interests (five subsets, scoring on one of which was required).

Box 2 – 1987 DSM-III-R criteria, adapted from Trevarthen et al, (1996)

These criteria were certainly an improvement from 1980 (DSM-III), which emphasized a "pervasive lack of responses to other people", "gross deficits in language development", and "bizarre response to various aspects of the environment" instead of the three descriptions above. This earlier version also listed a number of exclusion criteria, which tend to be associated with schizophrenia (e.g., absence of delusions, hallucinations, loosening of association and incoherence), though none are stated in the revised 1987 edition. But it was the removal of the age restriction, which presented the greatest problem, because the criteria were scored positively only if developmentally inappropriate, which created major diagnostic difficulties if the child was very young, unable to speak or had a learning disability. In terms of my own study, this did not arise directly in the clinical notes, but it must have caused some confusion during the 1980s, which was when much of the debate surrounding the diagnosis of Robert Clayton occurred. According to Aitken (1991), the eight criteria required for diagnosis frequently had to be drawn from a list of only nine possible characteristics. In the context of the emphasis on early diagnosis to achieve effective intervention, this was a major flaw, and furthermore, few of the items were particularly fruitful, with regard to accuracy of the diagnosis (Siegel, Vukicevic & Spitzer, 1990).

The impending arrival of DSM-IV in 1994, after the difficulties which had characterized the previous seven years, was eagerly awaited, and some observers anticipated it as the most rigorously assembled system so far (First et al, 1992). Its predecessor (DSM-III-R) had classified more than double the number of children as being autistic as DSM-III (Hertzig et al, 1990), and was also applied to a more heterogeneous and generally more able group of individuals. All of which suggested a major flaw in the system somewhere, which needed to be immediately addressed and remedied. The advent of DSM-IV saw a more sophisticated approach, with its emphasis on a multi-phase empirical plan, which incorporated a comprehensive literature review, thorough examination of data from the earlier versions, and culminated in exhaustive field trials.

> "It has been validated against both previous versions of the DSM system and against the ICD-10, and has resulted in a return to the diagnostic stability that characterized the period of DSM-III" (Trevarthen et al, 1996: 14).

The new system also set out to enhance its compatibility with European ICD-10 systems, and to reduce the likelihood of diagnostic confusion with other conditions, both of which were additional criticisms of the previous system. In sum DSM-IV established a specific subgroup of autistic individuals, with significant cognitive failings and problems of empathy, who will very probably have stable behavioural characteristics all their life, and who are clearly differentiated from those with Asperger's, Rett's and Heller's syndromes. Furthermore, this system restored the age restriction (before the age of three), and was consistent with various others established in different parts of the world. Though, with regard to the age of onset, diagnosis before the age of three is extremely rare (Baron-Cohen et al, 1996), despite the consistent claim that the condition arises prenatally (Volkmar et al, 1985). The average age of diagnosis is actually over six years old (Howlin & Moore, 1997), an important point in the context of the significant diagnostic problems affecting those in my own study, particularly in terms of the preparation of the family.

It is clear, therefore, that autism and related concepts have continued to change, and that this is reflected in the revised criteria and terminology of continuing updates of both ICD and DSM. The consequence has been that the boundaries for those considered to be autistic have been extremely flexible, with prevailing conditions, such as the availability of resources, influencing the likelihood of diagnosis, though there has been a generally upward trend. A diagnosis alone is insufficient, since there are implications for families and professionals alike, in terms of the availability of specialist services to accommodate the needs of the autistic individual. This was an issue in my study, since, for example, the availability of a specialist school, unit or community was likely to increase the possibility of a considered diagnosis, as opposed to the noting of one or two traits, though reliance on the latter was more usual. A whole battery of techniques, checklists and questionnaires have subsequently been developed for the psychological and behavioural assessment of autistic children diagnosed according to ICD or DSM criteria, and also to avoid the application of an incorrect diagnosis.

(iii) Self-injury, autism, and learning disability

Self-injury itself, as we have seen, is not a specific dimension of diagnosis, but, along with bizarre behaviour, hyperactivity and noise sensitivity, remains closely associated with the condition of autism. According to Berney (1997), something like 80% of people with autism also have a learning disability, though others, such as the National Autistic Society (1997), estimate a figure closer to 70%. Fombonne (1997) reviewed the epidemiological research to find a huge variation in estimates, ranging from 0.7 to 15.5 per 10,000 population, which is significantly higher than the early assessments of 3-4 per 10,000 (Lotter, 1966; Wing & Gould, 1979), though he did stress that it depends on the extent of the 'autistic spectrum' that is included. Whichever is the most accurate, both figures are relatively high, and significantly complicate the procedure of diagnosis, particularly as there is a need to define the symptoms in relation to the 'normal' developmental process.

Three further complications are that the greater the degree of learning disability present, then the more frequent the additional diagnosis of autism, though this is not supported by my own study, where, particularly in the early days, the presence of 'subnormality' would be likely to preclude the application of the autism label. Secondly, many individuals are diagnosed as having 'atypical autism', which is effectively a formal replacement of the former, frequently used title of 'autistic features'. And thirdly, there is considerable overlap with the category of 'Overactive Disorder associated with Learning Disability and Stereotyped Movements', a category created in 1993 with ICD-10, and constituting an "ill-defined disorder of uncertain nosological validity" (in Trevarthen et al, 1996: 12). Alternatively, in DSM-IV, individuals exhibiting similar behaviours, hyperactivity or self-stimulatory, fall within the category of 'Pervasive Developmental Disorder Not Otherwise Specified'.

The proportion of individuals with autism, who also self-injure, has been variously estimated at between 6.5 and 28% (Fovel et al, 1989), though some have put the figure as high as 44% (Hoshino et al, 1983), with particular attention drawn to the difficulties presented in relation to communication. As we have seen in chapter one, a number of theoretical explanations have been put forward to explain the development of self-injury in people with learning disabilities, and these are frequently related to individuals, who are autistic, or fall within the broader spectrum (Hare & Leadbeater, 1998). The behavioural explanation remains the best supported and most influential, though there are considerable variations in emphasis, perhaps reflecting the changing social context of its occurrence. Azrin & Holz (1966), for example, argued that self-injury, as with other stereotypical behaviours, began accidentally and were then shaped and maintained by the contingent responses of others, thus constituting 'surplus behaviours'. A similar theory was suggested by Johnson & Baumeister (1978), though they emphasised greater diversity of environmental control in supporting the continuity of the behaviour. The communicating function of the self-injury, particularly in relation to its meaningfulness to the individual with a learning disability, has been proposed (Carr, 1977; Carr & Durand, 1984), with ample evidence of links between autism, self-injury, and the absence of, or restrictions in, language and speech (Shodell & Reiter, 1968).

Treatment approaches towards people with autism have been quite diverse, though not particularly dramatic, in terms of effectiveness, with ultimate reliance on behaviourism, in one of its various guises, being the usual consequence. But, nevertheless, there have been other approaches, some of which have laid claim to considerable success. 'Holding therapy', for example, with its emphasis on maintaining extremely close proximity to the child during a period of extreme emotion, self-injury, and even aggression towards others, became quite popular around the beginning of the 1990s. The idea is that, even if the child continues to struggle, and becomes even angrier, eye contact and positive facial expressions are maintained (Welch, 1988; Richer & Zappella, 1989). But, as with 'gentle teaching', there is no complete separation from behaviourism, and the central component of the strategy is reward, even of the child's protests and tantrum display.

Auditory integration, another technique, focused on enabling the child to become less sensitive to sounds of particular frequencies (Stehli, 1992), and scotopic sensitivity training involves the wearing of specially constructed spectacles (Irlen, 1995). Different drug and vitamin treatments have also been considered (Rimland, 1994), but largely to little avail. In the case of some of the individuals in my own study, there appears to have been occasional 'fashions', which were implemented in a rather arbitrary manner, and sometimes focused on the features of autism, sometimes on the need to improve communication, and sometimes on the propensity to self-injure. The use of additive-free diets, for example, in the early 1980s, seems to be one such fashion, which was associated with hyperactivity, but frequently applied to other aspects of the individual's behaviour.

> "Unfortunately, on the whole, the more extravagant the promises the more limited are the experimental data on which they are based" (Howlin, 1997: 94).

Another approach, which has attracted considerable attention, is that of 'facilitated communication', whereby the 'facilitator' provides support to the hands of the autistic individual, whilst he or she is engaged in word processing, or some other activity to produce symbols (Trevarthen et al, 1996). The central idea behind it is that autistic individuals are always unable to make the movements intended, and are therefore afflicted with a type of communicative apraxia, but their thoughts can be revealed through support of great sensitivity. Howlin (1997), however, is extremely critical of the approach, pointing out that controlled studies (e.g., Bebko, Perry, & Bryson, 1996) have suggested that positive responses are nearly always under the control of the facilitator. She is also highly skeptical of the claim by Biklen (1993), that this approach can enable the autistic individual to participate in reasoned political argument and indulge in creative writing, hence demonstrating raised intellectual awareness. The official line seems to be that the jury is still out:

> "'Facilitated communication' has the potential for becoming a useful though not new technique for some people with autism most likely found in the group known to be precocious readers, good with computers, signs, and other forms of communication. Current promoters of this technique have been unwilling to differentiate those clients for whom a facilitator is useful from those who can learn spontaneous communication on their own" (Schopler, 1992: 337).

Other approaches to autism have also claimed some degree of success, and sometimes even more than that; the main one being that intensive early behavioural intervention, as much as 40 hours a week, can result in normal functioning (Lovaas, 1993), though evidence for what this is, has been questioned (Mesibov, 1993). The Japanese 'Daily Life Therapy' system, involving a highly structured regime focusing on physical activity, and practised in the Higashi schools (Gould, Rigg, & Bignell, 1991), and the 'Options' method of the therapists, themselves, engaging in bizarre behaviours and rituals, so as to enter into the autistic child's world and enhance the relationship (Kaufman, 1981), have both received considerable attention.

The increased sophistication of methods of functional analysis, as a basis for understanding the role of self-injury in the individual's life, has led to the possibility that it may serve multiple functions. These basically revolve around the notions of obtaining positive reinforcement, such as edibles, activities, and attention, and removing negative contingencies, such as unwanted attention and activities (Carr et al, 1994). The behavioural approach, as we have seen in the last chapter, has been most effective when it has been able to devise intervention strategies, which reflect substantiated ideas about the cause. Specific internal or external stimuli are usually emphasized as being linked to the display of self-injury (LaGrow & Howard, 1987), as is the existence of environmental contingencies (Carr et al, 1976). Subsequent behavioural approaches are then based on the employment of techniques, alone or in combination, such as overcorrection, time-out, differential reinforcements, and debatable aversive therapies.

The success of behaviourism in explaining self-injury, as well as many other behaviours considered a problem, when the individual has autism and/or a learning disability, demonstrates the phenomenal rise of the approach, as we have seen in the last chapter. By 1970, more than a hundred studies of behavioural treatments had appeared in the literature (DeMyer, Hingtgen & Jackson, 1981), with an emerging school of thought noting that the behavioural excesses and deficits characteristic of autistic children were controlled by reinforcing environmental consequences (Ferster, 1961). Behavioural techniques, such as shaping, whereby successive approximations to a target behaviour, such as copying speech were rewarded and, hence, reinforced, proved to be of some value in enhancing the acquisition of language (Lovaas et al, 1966). There seems to be little real significance as to whether the individual was autistic or learning disabled, or both, as to the selection of the specific techniques chosen, particularly during these early days of behaviourism. Both groups were ideal for acting as guinea pigs in the development and refinement of behavioural methods, just as animals had been the first subjects for experimentation. People with learning disabilities encountered every relationship on the basis of dependency, and those with autism found relationships too difficult to fully establish, so attempts at modification could be made, frequently with minimal resistance.

Self-injury in individuals identified as autistic was treated with reasonable success by the use of extinction, whereby the behaviour was continually ignored when it occurred (Lovaas & Simmons, 1969). Differential reinforcement has been employed to treat stereotypical behaviours (Mulhern & Baumeister, 1969), as has the punishment procedures, such as the use of electric shock (Risley, 1968). Such self-stimulatory behaviours were considered to prevent the development of more appropriate ones, particularly self-help and even social skills, and modification was justified on this basis. There is some recognition now that these behaviours are not arbitrarily chosen, but serve some sort of function in people with autism, and decisions to try to eradicate seem to be generally more considered. As Zarkowska & Clements (1994) explain, whilst reflecting on the approach they have advocated in their book:

> "Rather than seeing such behaviour as bizarre symptoms of some unknown illness, it has been stressed that it should be seen as expressing powerful emotions or serving important functions, in particular those of communication and stimulation. It is a means whereby an individual seeks to exert some control over a world which is often frightening, incomprehensible and unresponsive" (p.257).

Evidence for the increasing amount of research into the application of behavioural methods with individuals with autism is provided by the fact that more than 200 studies took place during the 1970s (DeMyer, Hingtgen, & Jackson, 1981). Some focused on the development of language (Lovaas, 1977), whilst others sought to reduce repetitive speech patterns (such as Freeman, Ritvo, & Miller, 1975), and others, still, focused on the development of appropriate social interactions (Strain, Kerr, & Ragland, 1979).

Behavioural intervention approaches with people with autism, therefore, appear to be virtually interchangeable with those employed in the cases of individuals, who have a learning disability, but no autistic traits. And considering the difficulties we have seen in relation to the process of diagnosis, this is not really a major surprise. In fact, the dominance of behavioural approaches, with those with learning disabilities, and those with autism, has accelerated, if anything, over the last few years, as they have become more sophisticated.

> "However, many areas of behavioral treatment addressed extensively with mentally retarded persons have yet to be thoroughly evaluated with autistic persons. This is particularly true in the areas of daily living skills and academic interventions" (Matson et al, 1996: 459).

Despite the sophistication of the behavioural approach, coupled with the increased objectivity of the diagnosis of autism, my own data suggests continuing difficulties in both areas. Essentially, autism has been constructed, in part, by the way in which behaviourism has asserted itself in this field, and subsequently developed a body of knowledge and expertise to consolidate its position. As we have seen in the previous chapter, its other power base has been in the field of learning disability, which has been constructed in a similar way, though the emphasis has been more on control and skill teaching. In relation to autism, however, behaviourism has been more complex, and its route has been more circumvent; it has been aided by the role of the WHO and the APA in attempting to bring order to the chaotic world of symptoms, bizarre behaviours, and remoteness. And somewhere within all of this has been the role of self-injury, which has been constructed by the employment of behavioural techniques and also the frequently transient association with autism.

Example 22

Some of the elements of the gradual re-conceptualization of autism as autistic spectrum disorder are evident in the case of Robert Clayton, who also demonstrates the continuing debate during the 1980s and 90s. He first comes into contact with medical services in 1977 at the age of 18 months, and this is the beginning of the continuous professional interest and contradiction, which will come to characterize his life. The family GP initially lays emphasis on Robert's ability to "shut off" and inattentiveness, which leads him to make a referral to a specialist children's hospital to eliminate certain diagnostic possibilities, though not at this point autism. Once this has been achieved the consultant paediatrician refers him to the senior medical officer, who notes his "lack of eye contact, lack of facial expression or communication... low interest level in his surroundings" and emotional detachment. He concludes from his initial observations that it "smacks of autism" and considers him "a strange retarded child", but he falls short of making a diagnosis since "there was no obsessional behaviour, headbanging or rocking or other clear indication of this and he will be nursed when tired".

The copious documents, memos, reports, and clinical notes retained and given access to me by Robert's mother provide for a detailed chronological record of a discourse within a discourse. His example is an extreme one because of her longstanding dogmatic attempts to both try and explain her son's 'differentness', and thus somehow enable him to receive the best possible care and treatment. Over the next year referral follows referral and Robert witnesses investigation by the senior medical officer, the consultant paediatrician, and a consultant paediatric neurologist. He is also examined by a consultant ophthalmologist, who initially misdiagnoses him as deaf, to assess his suitability for an operation to rectify a squint. The senior medical officer recommends a period of observation and assessment within a specialist nursery service attached to a general hospital in order to establish his 'special education' requirements. He emphasises his lack of emotional response, communication deficits, avoidance of eye contact, and poor self-help skills, and "aimless repetitive movements", but also draws attention to his skills of manipulating objects and ability to lead his father to obtain something he wants. After identifying his parents as "intelligent" but "anxious for a diagnosis", he concludes Robert to be an "interesting retarded child with autistic signs (who) is in urgent need of programmed teaching".

The period of observation within the nursery setting follows quite quickly and has the joint purpose of identifying diagnostic criteria and stimulating Robert's ability to develop language. Robert's parents are fully involved and at least one of them is present for much of the time. The subsequent report establishes that he "screams a lot and doesn't relate to children" as well as "seem(ing) to try to manipulate the situation by crying for long periods". Furthermore, his propensity for self-injury is clearly in evidence, with headbanging and "screeching" witnessed on several occasions, frequently whilst his mother is present, despite the report indicating that she considers him only to engage in these behaviours at school. The report concludes the existence of "definite autistic features", points out Robert's mother's reluctance to accept such a diagnosis, in addition to suggesting that her behaviour is "somehow... superficially affectionate" and his father's own experience of having been "shy and timid as a small child".

The consultant paediatrician's position is one of trying to ascertain the presence of "true infantile autism" as opposed to severe developmental delay with autistic features, and after receiving the report and following several individual consultations concedes that he "suspect(s) that the former diagnosis is more appropriate". The involvement of the consultant paediatric neurologist in October 1978 provides both a significant and poignant contribution to the developing discourse surrounding the appropriateness of such a diagnosis for Robert. It is significant in its demonstration of the powerful consequences of one medical opinion for the life chances of a 3-year old child, and it is poignant in that it marks a point whereby there will be a change in emphasis from diagnosis, though this will continue to be an ongoing concern, towards Robert's behaviour. It also precipitates a division of professional opinion between medicine and psychology, which will continue over a number of years and will never be entirely resolved, as well as provoking considerable irritation in Mrs. Clayton because of her perception of the treatment received. The neurological opinion forwarded, following a short consultation centring on identification of clinical features (i.e., "large head", "rather floppy", likelihood of epilepsy developing) is that Robert is "severely subnormal (not autism) with communication problems". The consolidation of medical opinion begins a couple of months later when the paediatrician and another specialist examine him and record that "autistic features are less marked".

The disagreement between disciplines takes place the following summer with quite a comprehensive assessment (utilizing the Stanford-Binet, Merrill Palmer, and Parnell scales) having been undertaken by an educational psychologist. She accepts his difficulties in expressive and receptive language, and relationship development, but points out his "very developed skills in the fine motor, manipulative and non-verbal reasoning". She also suggests that his "temper tantrums" and "bizarre behaviour pattern" at school and his "shaking and perspiring" at home illustrate an "anxious desire to resist change and maintain sameness". Her conclusion is that "parental bonding with the baby may not have been completely effective" and these identifiable features fit "Kanner's diagnostic criteria for the autistic syndrome". Robert's mother spoke of her son's difficulties relating to others, including his parents, and his problems in developing speech during a response to a question about when he first began to talk:

Mrs. Clayton: "Speech didn't come. He was eight when he said his first sentence. He had one or two – I thought they were words and his social worker thought they were words, but they may have been sounds. He appeared to be saying 'mum' and 'dad' in his first year but by two they had gone. And that was difficult because when he did start talking he called us white car and blue car. Associated us with cars".

The two sides of the debate are thus firmly established, with the paediatrician apparently acting as something of a mediator between interested parties, which is reflected in his observation that the consultant neurologist might "ha(ve) been glib in labelling him after that short, atypical consultation". Robert's "little tolerance or interest in other children", lack of intellectual development, and escalating violence at school provides the backdrop to the debate, which begins to focus on the most appropriate educational provision. The psychologist's stance is clear and detailed, though not necessarily influential, with the paediatrician mentioning her emphasis on Robert's "increasingly withdrawn behaviour and the development of certain ritualistic procedures" when an educational opinion is requested from him. Instead, he returns to the views of the neurologist, so as to clearly establish whether "Robert is autistic or whether he shows a global retardation with autistic features". The neurologist's reply, which does not involve another consultation, comes in February 1981 when Robert is 5-years old and is suitably direct and extremely influential. He does acknowledge certain autistic behavioural features and "some quite good perceptual abilities" before delivering the pay-off line, wherein "I do not think that these alter in any essential (way) the rather gloomy developmental and learning prognosis". In July 1981, the neurologist ends his involvement by writing to Robert's GP and confirming his suspicions following his assessment. "Our formulation is that of a significantly mentally handicapped child who has some autistic behavioural features (and he is) appropriately placed at his present ESN(S) school".

In effect, the neurologist's professional opinion in conjunction with his withdrawal draws a line under his case and results in several consequences:

- Robert is consigned to an educational placement, which will never stretch him intellectually, and will diminish his confidence during interactions with others;
- The school will provide an environment in which his violence will flourish, though he will later generalise such behaviour to the home;
- His resentment and frustrations at his situation contribute towards his violence becoming increasingly self-directed and excessive;
- The educational psychologist becomes Robert's most vocal advocate, which is partially because of the medical rejection of her own professional expertise. It also, however, reflects her belief in the inappropriateness of the ESN school and the likely implications of his placement there.

The debate over diagnosis does continue over the next few years, largely in the context of the pertinence of education, but just as was witnessed with Alan Dawson a generation earlier Robert's status is effectively downgraded to 'mentally subnormal'. Unlike in Alan's case, however, a different climate is transpiring with regard to autism during this time and his reduced status proves prolonged but temporary. Robert, I think, seeks refuge from the tedium of his placement by engaging in increasingly bizarre and obsessional behaviours, which are vividly described in one of his school reports. He engages varyingly in "dribbling down the window and watching it run down in a straight line, (which is then) superceded by touching the floor in a certain place (and) looking under his shoe whenever he went out of the classroom". The possibility of boredom being a consideration is given credence by his appearing "content to play the climbing frame or sit staring into space or twisting something in front of his face". Despite this observation, though, some very real differences between Robert and other children without learning disabilities is made clear when I ask his mother about his milestones of development:

Mrs. C: "Yes. Gross physical difficulties weren't apparent in the first year. It was only fine motor skills that he had problems with. He crawled and walked at the same time. But he had quite a lot of difficulties when approaching things – he couldn't tell depths. And he quite often used to reverse over a step of a quarter of an inch. We were able to teach him how to get down stairs at a normal age by reversing backwards and coming down. But he would reverse over very, very, tiny, weeny, little… "

The educational psychologist's persistence in fighting Robert's corner, which is given some support from another psychologist during an assessment when he is 7-years old, does eventually provide him with an opportunity for more specialist educational input. She describes him as "ha(ving) a specific language disorder overlaying moderate learning difficulties in non-verbal functioning and combined with some obsessional, ritualistic behaviour". Furthermore, she considers him to be "exceptional", his current schooling to be damaging, and his increasing aggression to be a reflection of anger at his association with lesser able children. This opportunity for Robert involves a 4-day assessment period at a residential school, which specializes in children with difficulties in perception and adjusting to traditional education. The assessment involves input from a speech therapist, psychologist, and several teachers, but no offer of a placement is forthcoming because, according to the school headmaster, of "Robert's rather special needs", particularly his communication disorder rather than "speech/language handicap in the sense that we understand it". The recommendation put forward is for "an educational environment where new experiences can be introduced as part of a carefully planned individual programme in a quiet setting of a small group where social, visual and auditory distraction are at minimum levels".

Unfortunately, however, this means that Robert is plunged into an educational abyss whereby his behaviour spirals out of control as he becomes physically stronger, and he suffers the humiliation of several exclusions from both ordinary and residential 'special' schools. One headteacher remarks both tragically and prophetically that he "needs to accept the fact that he must adapt to the world he lives in, with all its inconsistencies, and that the world cannot be molded to suit him. If he cannot do this, then he will become a very unhappy young man". A spree of violent behaviour during 1986 when Robert is 10-years old encompasses window breaking, headbanging, and lashing out at others, and ensures continued medical involvement. The consultant paediatrician refers him to a child and adolescent psychiatrist, and ultimately a referral is made to a consultant psychiatrist and a compulsory placement within an assessment and treatment facility. The paediatrician continues to adopt a position of diplomacy in his description of Robert as having been a "diagnostic puzzle", though now "the general feeling is that he is a child with severe learning difficulties but that he also has certain autistic tendencies such as repetitive forms of activity".

The referral to the child and adolescent psychiatrist illustrates the changing discourse surrounding autism during the 1980s, with a reduced emphasis on the criteria of certain traits being fulfilled. Robert is again assessed in a specialized environment by a number of professionals including teachers and clinical psychologist, and overseen by the child and adolescent psychiatrist. The changes in his life circumstances, including his father's illness, exclusions from school, and issues of personal development, are subsequently identified as contributing towards his descent into violence and self-injury. Furthermore, he is regarded as responding quite well to the assessment process, and the eventual recommendation made, residential specialized education within a "carefully controlled environment with sufficient experienced staff to react consistently and constructively to him", is based on "the opinion that Robert is an autistic child". This does not result in the end of Robert's many difficulties, but it does tend to dispense with the debate that had raged over the preceding years as to whether he deserved the diagnosis of autism.

Unfortunately, however, this new consensus fails to remedy the many difficulties that Robert continues to experience, and though such a residential school placement is eventually achieved his behaviour continues to deteriorate and his frustrations remain unabated. Some of the benefits of a diagnosis, in terms of access to resources and specialist professional support, do transpire as Robert negotiates the transition from child to adult services during the early 1990s, but it is difficult to conclude that this is anything other than too little too late. He is eventually provided with a residential placement in an autistic community, which includes one-to-one support in his own community-based flat, and ongoing community nursing input. The deteriorating nature of his propensity for violence and self-injury results in regular periods of respite in the assessment and treatment unit, mainly informally but occasionally on a formal basis. One side benefit of compulsory detention is the requirement of the consultant psychiatrist to provide more detail regarding Robert's diagnosis, which centres on both mental impairment (see concluding chapter) and the triad of impairments that, as we have seen, came to dominate the changing discourse surrounding autism:

1. "His difficulty in communicating what he wishes to other people and some problems with comprehending complex information;
2. Robert has great difficulty in empathizing with other people or taking their feelings or views into consideration;
3. Robert has a need for routine and an understanding of what is going to happen on a continuing basis. He reacts badly to some changes and especially to uncertainties. Robert also has problems in that he can become very anxious e.g., at certain noises. When Robert is anxious he is likely to become distressed and start injuring himself, particularly by headbanging, or by hurting other people".

(Sources: Medical correspondence, April 1977, September 1977, February 1978 February 1981, July 1981, March 1986; Medical examination report, December 1977; Educational psychologist report, August 1979; Special school report, February 1981; Educational psychologist's testing report, January 1983; Admissions assessment to specialist school report, June 1984; Statement of Special Educational Needs, July 1986; Medical discharge summary, December 1997; Interview – July, 1999)

This chapter has examined the complex relationship that several of the study group have had with autism, particularly in the context of the benefits that a firm diagnosis appear to bring. The examples of Alan Dawson during the 1960s/70s and Robert Clayton in the 1980s/90s tell two very different stories, yet are strikingly similar in demonstrating the fragility of claims being regarded as legitimate or otherwise. Many other individuals' studied initially invoked a transient professional interest before being quickly downgraded to the status of 'subnormal', whereby they were considered worthy of little more than basic care within an institutional ward. The chapter has investigated autism's sixty year history since the initial elaboration of Kanner's cardinal traits through to the contemporary emphasis on the triad of impairments and the condition's re-categorization within the framework of 'pervasive developmental disorder'. The professional disagreement between medical and psychology professionals in the case of Robert Clayton reflects the continued lack of consensus about the appropriateness of the diagnosis. Finally, the chapter ended by looking at the relationship between self-injury and autism, wherein behavioural approaches have tended to predominate just as they have with individuals considered learning disabled but not autistic.

An important aspect of autism's history has been the degree to which biological processes are implicated as causal factors, with current research emphasizing such possibilities being in the ascendancy. The next chapter continues this emphasis on biology, albeit in the context of self-injury without the added complication of considering autism. The completion of the human genome project has given great impetus to biological explanations of a variety of phenomena, and medicine's access to and control of considerable resources has enabled it to make convincing arguments about its future role. The extent to which its claims are credible, however, remain debatable and the chapter seeks to explore the validity of the claims made by reference to the lives of those in my study.

CHAPTER SIX: BIOLOGY AND SELF-INJURY

- From syndromes to serotonin
- Medication and self-injury
- Mechanical restraint
- Physical illness
- The role of sexuality

(i) From syndromes to serotonin

As has been mentioned in chapter four, Carr's hugely influential research article had identified the four most commonly accepted hypotheses relating to self-injury (1977) (there was a fifth, psychodynamic theory, which was less compelling, largely due to the perspective's decline by this point). This effectively set the trend for much future research into 'functional analysis' (see Mace, Lalli, & Shea, 1992, for a review), though none of the explanations were able to assert that they could "explain the phenomenon fully" (1988: p.135). The 'organic' explanation suggested that self-injury arose from the individual's 'mental retardation', a simplistic yet important contribution since this had constituted the basis of much of the early thinking on the subject (Emerson, 2001). The purpose of this chapter is to examine the role of biology in contributing to the origins and development of self-injury, and the subsequent treatment initiatives that may arise. The main reliance has been on mechanical restraint and anti-psychotic medication, and both of these areas of intervention will be considered in the context of the lives of the individuals in the study. The intention then is to broaden the role of biology so as to encompass such factors as the role of physical illness both in giving rise to, and occurring as a result of the self-injury. The chapter concludes with a discussion of the association between menstruation and self-injury, drawing particularly on interviews with parents about their daughters' frequently complex relationship with their own sexuality.

a) Syndromes and self-injury

Some forms of learning disability are regarded as having an identifiable organic cause, which ranges from trauma and head injuries to genetic abnormalities. The organic hypothesis regarding the cause of self-injury states that it arises from the same organic disorder that has caused the learning disability; the self-injury is therefore considered to be one aspect of an organic brain syndrome (Walsh & Rosen, 1988). Many studies advocating this position relate to Lesch-Nyhan syndrome, an X-linked genetic disorder found only in males, whereby there is deficiency of the enzyme hypoxanthine-guanine phosphorobosyl transferase (HGPRT), as a result of which there is a disturbance of purine metabolism, leading to an accumulation of uric acid in the blood and severe brain damage (Dizmang & Cheatham, 1970). It is a sort of cerebral palsy that includes having 'mental retardation' and a variety of motor movement and physiological abnormalities (Lesch & Nyhan, 1964). One characteristic set of symptoms found in these individuals is "peculiar self-destructive behavior", such as the repeated biting of the fingers, tongue and lips (Freeman, 1970: 337). As Nyhan reveals thirty years after the initial publication of the paper on the condition, however, the vast accumulation of knowledge has been, as yet, of limited use in enhancing our approach to self-injury.

> "The Lesch-Nyhan disease is in essence a pure culture of self-injurious behaviour. It exemplifies the most ferocious type of self-injurious behaviour, and it is associated with impressive loss of tissue. It is extraordinarily resistant to the usual measures of management. Aversive methods of conditioning, for example, have been documented to make the behaviour worse. At the same time, it is tantalizing in the sense that the molecular nature of the abnormality is known in intimate detail. This has led to the conviction that there is an underlying chemical cause of the behaviour and that the cause is linked somehow to the basic chemical abnormality. Further, it is likely that if the link could be fully understood that it would lead to rational approaches to treatment. It could also lead us to understandings of self-injurious behaviour in general" (Nyhan, 1994: 181).

There has been a huge amount of speculation since the identification of the syndrome in the early 1960s, that the consistent occurrence of self-injurious biting in these individuals must be related to the biochemical imbalance that produces the condition (Walsh & Rosen). The self-injury is considered a manifestation of the biological condition of the individual and is unrelated to any environment or learned behaviour. It has been described as a behavioural phenotype (Harris 1987), and there seems to be some evidence that, once it has been initiated, it may be at least partially maintained by environmental contingencies (Harris, 1992). Although, according to Heaton-Ward & Wiley, whilst engaging in the behaviour, "children seem to be terrified and are obviously relieved when restrained" (1984: 56). Lesch-Nyhan syndrome undoubtedly provides the most convincing evidence for a genetic basis to self-injury, though it is debatable as to whether the amount of attention it has received can be justified. Cornelia de Lange syndrome has also been identified as being congenital with a tendency to self-injure frequently being in evidence (Bryson, Sakati, Nyhan, & Fish, 1971). In this condition there is usually a severe degree of 'mental subnormality', small physical stature and a distinctive physical appearance.

> "Compulsive self-mutilating behaviour similar to that in the Lesch-Nyhan syndrome has been reported".
> (Heaton-Ward & Wiley, 1984: 37)

There remains uncertainty as to whether the de Lange syndrome is of genetic origin, since no particular cause has been described; furthermore, no evidence has emerged to demonstrate the exact sort of organic dysfunction that has occurred. Though, in reviewing the literature, Murphy & Wilson (1985: 92) consider that the link with genetics is 'likely', and the likelihood of the cause being neurological is 'probable'. After Lesch Nyhan, de Lange syndrome continues to be regarded as the condition most often associated with self-injury, with some evidence that the treatment of underlying physiological disorders is likely to reduce the behaviour (Berney, 1998). Both syndromes are located on the Axis III category of DSM-III-R, along with other conditions sometimes associated with self-injury, such as Fragile-X syndrome, Rett syndrome, congenital insensitivity to pain, and specific causes of blindness, like retrolental fibroplasia (Harris, 1992). The continued interest in the syndrome approach to self-injury revolves around the belief in possible advances in physiological assessment, and the likelihood of determining the exact nature of the relationship between the two phenomena (Walsh and Rosen, 1988). Despite misgivings, largely related to the historical reliance on pharmacological and mechanical restraining treatments if such a cause is suspected, the approach constitutes a significant statement in biological discourse. Some of those in my study group were occasionally tested for a biological cause, though no genetic explanation was subsequently forthcoming bar the eventual discovery of Wolf-Hirschorn syndrome in one individual, which is not associated with self-injury.

b) Neurotransmitters and self-injury

- Serotonin

A second area of concern relating to the biology of self-injury concerns the neurotransmitter serotonin, which has been linked to 'impulsive aggression', whereby the individual seems unable to prevent themselves from self-injuring (King et al 1991). Serotonin, as a neurotransmitter, is responsible for facilitating the passage of impulses between the connections of a few nerves in the brain; the largest amount being found in a part of the brain known as the raphe nuclei. Nerves from this area connect to all areas of the brain but mostly to a region called the hypothalamus, a structure that plays a role in regulating impulsivity and aggression as well as appetite, mood, and the sleep-wake cycle. The dietary amino acid tryptophan is chemically transformed into serotonin, which is then metabolized with a chemical called 5-HIAA (5-hydroxyindoleacetic acid) (Favazza, 1996).

Mace and Mauk (1995) suggest that there may be some self-injuring individuals, who are unable to control their desire to hurt themselves, and this may be associated with, or be a variation of, obsessional compulsive disorder (OCD). Some self-injuring behaviours, specifically repetitive hair-pulling (trichotillomania) and eye gouging, have been described as being linked to this condition in individuals where there is no evidence of a learning disability (Jenike, 1990). Furthermore, it is only in the last few years that there has been recognition of OCD afflicting children and people with learning disabilities, both groups previously having been considered not to be affected (Vitiello et al, 1989). At present, a formal diagnosis of OCD necessitates the presence of intrusive thoughts or 'obsessions', which excludes many individuals with a learning disability, who have problems in communicating, because of the difficulties of verification of such symptoms. Consequently, the compulsive nature of the tendency to self-injure is deduced from two factors, the extremely high frequency with which the behaviour occurs and the high rate of anxiety observed on interruption of the response (Mace & Mauk, 1995). The implication that serotonin neurotransmitters are involved arises from the success claimed in the treatment of self-injury by serotonin re-uptake inhibitor medication, such as fluoxetine and anafranil (King et al, 1991).

Much of the work investigating the association between impulse control, serotonin levels, and self-injury has taken place with people suffering from mental health problems, whereby difficulties with communication are less of an issue. Coccaro et al (1989), for example, found that there was an increased likelihood of impulsiveness and possible violence directed both inward and outward when serotonin was reduced.

> "In other words, a reduction of central serotonergic system function was associated with an increased risk of impulsive aggression against both self and others, probably depending on the circumstances leading up to the act" (Markovitz & Coccaro, 1995).

In the context of learning disability, there have been a number of studies, which have sought to modulate the serotonin levels of self-injuring individuals, by the employment of medication, though these have been fraught with difficulties. For example, there has been something of a reliance on single case studies without proper controls, and also, there are at least six different types of serotonin receptors and it is possible that drugs may have an affect on other neurotransmitters (Schroeder & Tessel, 1994). Nevertheless, there have been a number of claims for the successful, sometimes strikingly so, treatment of self-injuring individuals with learning disabilities (for example, Ratey et al, 1991; Markowitz, 1992; Cook et al, 1992), and it seems likely that research will escalate in this area. The publication of the second edition of Feighner and Boyer's 'Selective Serotonin Re-uptake Inhibitors' in 1996 demonstrated the enthusiasm for the increased application of this batch of drugs to the treatment of depression, OCD, panic disorder, dysthmia, eating disorders, drug and alcohol abuse, and sexual dysfunction. Furthermore, self-injurious behaviour is only discussed in one chapter, and is categorized as a dimension of OCD, albeit, as mentioned earlier, without the preceding obsessions (Stein and Hollander, 1996).

- Dopamine

Some self-injurious behaviours, such as hand mouthing or the repeated rubbing together of body parts, have been proposed as being illustrative of another distinct sub-category of individuals with learning disabilities (Mace & Mauk, 1995). The tissue damage in these behaviours is less severe than in those where the self-injuring is direct and intense, and arises from repeated mechanical abrasion or wetting. There is an association with stereotypical behaviours where there may be no self-injury, so that it is the repetitive and persistent nature of the behaviours that is problematic. The argument emphasizes the role of dopaminergic pathways in mediating the stereotypic behaviours, and is evidenced by the alleged success of dopamine antagonists (such as neuroleptics) and the induction of stereotypies by dopamine agonists (such as stimulants) (Evenden, 1988). Once again, however, there is a difficulty, I think, in clearly identifying individuals who are representative of such a 'type' of self-injurer. Certainly, all of the individuals that I investigated had a wide repertoire of behaviours, some of which were self-injurious whilst others were not. They all engaged in stereotypical behaviours to some extent, sometimes elaborately (finger twiddling; hand flapping) and sometimes simply (rocking from one foot to another; sucking fingers). But the main observable factor seemed to be mood; much of the behaviours seemed designed toward counteracting boredom, seeking physical comfort, expressing rage, and generally passing the time.

- Norepinephrine

The level and extent of the agitation being experienced by the self-injuring individual leads Mace & Mauk (1995) to identify their final category to be considered, in terms of promoting self-injury. Running, screaming, and other physiological symptoms of over-arousal, like breathlessness and rapid pulse, express such agitation. Some observers have noted that this state of being may be responsive to lithium carbonate, which has proven successful in the treatment of general aggression, though less so with self-injury (Chandler et al, 1988). The criteria for success lies in the knowledge that lithium carbonate can be influential in affecting the biological processes underpinning arousal (Sovner, 1981). Norepinephrine is a neurotransmitter, which has been associated with stress and arousal, and has been demonstrated as being abnormal in anxious individuals (Sevy et al, 1989). Unsurprisingly, its mechanism for action remains difficult to determine, but it is believed that lithium may affect catecholamine transmission or may block inositol triphosphate and subsequently reduce the formation of diacyglycerol and inositol triphosphate, which act as neuronal second messengers (Baraban et al, 1989). If this is correct, then other medications which 'down tune' the norepinephrine system, such as propanolol could also be effective (Reudrich et al, 1990).

- Enkephalins

According to Mace & Mauk (1995), there are a small number of people with learning disabilities, whose self-injuring is so severe that the consequent physical trauma is manifested as deep wounds and severe scarring. Furthermore, though such activity might be apparently longstanding and deliberate, prolonged observation does not suggest that the individual is inordinately distressed. The theory has subsequently been elaborated that this small group of individuals, because of the consistently violent nature of their self-injuring, have been rendered partially anaesthetized to the pain. They either have congenitally altered central pain mechanisms or need to indulge in their habit so as to generate increased amounts of their own opiates, with the possible consequence of addiction (Campbell et al, 1988; Sandman, 1991). The mechanism maintaining the desire to self-injure is thus acting as positive reinforcement to the individual, requiring them to continue to self-injure with the necessary force so as to prevent withdrawal.

Some of the studies investigating the possibilities presented in this argument have emphasized altered levels of endorphins and enkephalins in the cerebro-spinal fluid of autistic children and self-injuring individuals (Coid et al, 1983; Sandman et al, 1990); Thompson et al, 1994). Such findings resulted in the development of medications during the 1980s, the so-called 'opiate antagonists', naloxone and neltrexone, which have had mixed success. The argument put forward was that self-injury may begin for a variety of reasons, but over a period of time individuals may seek to repeatedly hurt themselves so often and with such intensity that endogenous opioid release is triggered. These endorphins and enkephalins are produced naturally in the body as a response to painful stimulation; they bind to the same neuronal receptor sites as opiates taken from the outside, such as heroin (Thompson et al, 1994). The results of tests of naloxone have been extremely mixed, with some studies emphasizing no discernible effect on the self-injury at all (for example, Beckwith, Couk, & Schumacher, 1986), and others claiming marked reductions (for example, Sandman et al, 1983; Richardson & Zaleski, 1983). By the end of the 1980s, naltrexone had been proven superior and longer lasting than naloxone (Barrett, Feinstein, & Hole, 1989), and many of the studies in this area over the next decade concentrated on increased testing of this drug with people with learning disabilities (e.g., Buzan et al, 1995).

It will be interesting to see whether the biological discourse relating to self-injury is able to influence practical interventions towards the individuals identified as being biologically driven, though it is currently difficult to envisage the exact shape of such an approach. The identification of a specific biological process, which can be clearly linked to the manifestation of self-injury, would appear to be fraught with difficulties. I will end this section by briefly identifying some of these difficulties:

1) There was no evidence of an underpinning clinical syndrome influencing the self-injury of any of the study group, despite extensive medical investigations in several cases.
2) The attempts to demonstrate some sort of biological causation and the subsequent resources expended appear to vastly outweigh the potential for effective interventions into reducing an individual's desire to hurt themselves.
3) The consequences of the biological approach appear to suggest an emphasis on restricted movement (mechanical restraint) or altered awareness (medication). There appears to be little attempt to engage with the individual or explain the role of self-injury in his/her life. These two approaches have been marked, though, in the interventions employed with many of the study group and it is with these that is the concern of the next section.
4) Another difficulty relates to the role of the recommended medication once the link with addiction has been clearly established. Presumably, the release of the body's home-produced opiates constitutes a source of pleasure for the self-injuring individual, which exceeds the pain that arises from headbanging. The medication is

geared towards preventing the production of such opiates, so that, in effect, the individual is being coerced into a withdrawal situation through having to endure the pain, but without the pleasure that follows. This seems to me to be extremely ethically dubious, even if the claims for reductions in self-injury are correct. It also represents another quite extreme version of chemical restraint, which relies on the notion that the individual will not self-injure if it becomes more painful and less pleasurable.

5) A final point concerns the very real difficulties and frustrations experienced by many of the study group, and which cannot be dismissed in preference of a biological explanation even if that were never the intention. Let us accept that there may be some truth in the relationship between a biological problem and the particular manifestation of self-injury. This does not mean, though, that the individual engaging in a particular form of self-injury is always a reflection of the occurrence of a biological process. This would be a danger inherent in acceptance of a biological proposition, since it may serve to reduce the importance of factors such as anger, frustration, and compulsion as simple emotional expressions of biology.

The possibilities of incorporating the biological underpinnings of self-injury into an approach towards a self-injuring individual may lie simply in an awareness of it as a mitigating factor. Emerson (2001), for example, reminds us how little we know about the initial development of self-injury, but that the behavioural approach constitutes a proven practical framework for intervention. In other words, even if the behaviour is defined biologically, it could be treated behaviourally, something that would appear to be tantamount to an uneasy alliance between perspectives. So far then, though there has been a move towards establishing the basis of a bio-behavioural approach to self-injury, as yet this would appear only to be the recognition of the role of the other and not the elaboration of a set of principles. There is greater acceptance of the idea of levels of analysis, be they biological, psychological, or social, but the development of approaches, which integrate these effectively remains very much in its infancy. Possible contributory factors will be addressed in chapter seven when the multi-disciplinary team comes under scrutiny.

(ii) Medication and self-injury

The advent of neuroleptic (also variously referred to as anti-psychotic, psychotropic, and major tranquillizing) medication in the 1950s was perceived by many as providing the trigger for a "revolution in psychiatric treatment" (Schaal and Hackenburg, 1994: 123). This is mainly because such drugs were considered likely to significantly improve the lives of people afflicted with debilitating mental health difficulties. The employment of this rapidly expanding group of medicines to the 'mentally deficient', however, was not in relation to alleviating a distressing symptom, such as a hallucination, but was justified on the basis that it could be of value in controlling behavioural disturbance (Singh, Singh, & Ellis, 1992). The current continued use of powerful medication with people with learning disabilities is aimed at controlling behaviours in the areas of violence and aggression towards others, damage towards property, self-injury, and perhaps most worryingly stereotypy (Hill, Bralow, & Bruininks, 1985).

> "In the short term they are used to quieten disturbed patients whatever the underlying psychopathology, which may be schizophrenia, brain damage, mania, toxic delirium, or agitated depression. Antipsychotic drugs are used to alleviate severe anxiety but this too should be a short-term measure" (BNF, 1999: 166).

The widespread use of such drugs over time was amply demonstrated with many of the study group, particularly though not exclusively those with an institutional background. The early drugs of choice to ameliorate behaviour disturbance in 'mental subnormality hospitals' were hypnotic (e.g., chloral hydrate), anti-epileptic (e.g., paraldehyde), and barbiturate (particularly phenobarbitone) (Swazey, 1974), though by the late 1960s these had been largely replaced by the neuroleptics (e.g., chlorpromazine, thioridazine, and haloperidol). These did tend to be the drugs favoured by the consultant psychiatrists prescribing in institutions, sometimes in various combinations, sometimes in conjunction with anxiolytics (e.g., diazepam), and sometimes along with drugs aimed at alleviating symptoms of mental illness or epilepsy (e.g., lithium carbonate, carbamezapine). My evidence suggests that they were employed arbitrarily without detailed knowledge of the side effects, likely consequences, or even what they were being employed to combat other than calming the individual down. Furthermore, the consultant psychiatrist or medical officer would invariably have their own preferred drug options, occasionally come into conflict with other doctors, and even more occasionally radically alter a medicine regime that had been in place for several years, with demonstrable consequences for the individual. The propensity towards self-injury, generally regarded as a characteristic of a more general behavioural disorder, was unlikely to be elaborated upon in terms of the desired effect of the drug.

Those in the group not experiencing institutional care were also prescribed medication, but this did tend to be more specific, short-lived, and involved the surveillance by parents. They were less easy to recruit as guinea pigs than those consigned to the institutions, particularly those not retaining ongoing family input. Schaal and Hackenburg (1994) accurately sum up the role of medication as applied to the challenging behaviours exhibited by many people with learning disabilities; furthermore, it should be noted that they are referring to a range of behaviours, not just self-injury:

> "(A)t the present time, the best that can be said about most psychotropic medications is that sometimes they help, and sometimes they do not. Their beneficial effects are often minimal and poorly understood, and their side effects range from annoying and distressing to permanently debilitating. Although it appears that the days of the 'chemical straight jacket' have ended, researchers and clinicians are still largely unable to specify with certainty what a drug should be given for, to whom it should be given, and why it should be expected to help" (p.124).

The use of medication with the study group does reflect the changing discourse relating to both increased knowledge, and greater understanding of the consequences of widespread experimentation with those regarded as 'subnormal'. Schaal and Hackenberg's comments above should appear shocking given the widespread prescription of powerful drugs to this group, but instead simply highlight the reality of the situation. The emergence of the phenothiazine group of tranquillizers, in particular, appeared not only to provide the psychiatrist with a way in which to combat such behaviour, but also almost an obligation to do so. The first illustration in this section typifies the lot of the institutionalized group members, and concerns the capricious but sustained prescription of powerful medication, with little thought applied to age, side effects, or long term effects. This is followed by an illustration of how such medication was not restricted to the 'hospital', which is no less disturbing than the first because of the suspicion of random administration.

Example 23

In 1966, 11-year old James Simpson begins a series of periods of short-term care, primarily because of his increasing use of violence towards children and supervisors in the junior training centre, and his escalating self-injury and tantrums at home. He had been prescribed phenobarbitone for his epilepsy (he hasn't experienced a seizure since he was four years old), though it is maintained for behavioural control, and hydratene to improve his sleep pattern prior to admission. Haloperidol is quickly to follow, and over the next two years this is used interchangeably with chlorpromazine and thioridazine (he experiences side effects of facial rash and folliculitis), to which are sometimes added librium (anxiolytic) and nitrazepam (hypnotic) for his "still frequent temper tantrums". The consultant psychiatrist expresses frustration at James' mother's reluctance to administer his medication when he is at home, and appears intent on demonstrating to her its markedly beneficial effect when he is in 'hospital'. It has a different effect, though, and tends to simply illustrate to her that the family is better off with her son being away from the family.

James is admitted permanently into institutional care in 1972 and retains the combination of antipsychotic and anxiolytic medication, plus the short-lived employment on different occasions of sodium amytal (barbiturate), lithium carbonate (antimanic), and lorazepam (anxiolytic) for his continued night time disturbances. His medical notes also indicate that one of the reasons for the regular changes relates to his occasional tendency to suffer adverse reactions, such as lethargy, vomiting, and unpredictable mood swings. The BNF indicates the use of lithium carbonate for "treatment and prophylaxis of mania, manic depressive illness, and recurrent depression; aggressive or self-mutilating behaviour" (1999: 178), so there may be some possibility that his capacity for self-injury was considered when prescribed. During his 22-years as a long-term 'hospital patient' James core medication regime revolves around chlorpromazine. This transpires as the most 'effective' antipsychotic, despite his continued susceptibility to side effects such as photosensitivity (severe skin reaction when exposed to the sun), and anticholinergic reactions (hand tremors) for which he is prescribed orphenadrine (antimuscarinic). There are occasional attempts to employ a different neuroleptic, such as neulactil in 1980 when James' headbanging is considered to have dramatically worsened. This medication is sometimes prescribed for "violent or dangerously impulsive behaviour" (BNF, 1999:170), and it is plausible that the manifestation of some of his more agitated responses could be interpreted in this way. Towards the end of his institutional life a fairly high dose of zuclopenthixol is prescribed in addition to the chlorpromazine, which is already higher than the usual maintenance dose outside of severe psychosis, and an intramuscular injection of haloperidol is introduced for use should an emergency arise.

The other core element of James' medication concerns the long-term preoccupation with getting him to go to sleep, so that he consequently spends much, if not all, of his institutional life taking a hypnotic, usually nitrazepam. This particular drug is prescribed on an 'as required' basis, but in reality is administered regularly, probably over a period of more than fifteen years. It is difficult to determine the long-term effect of such medication, particularly since his self-injury and aggression seriously deteriorated over the latter period of my research, which resulted in him being admitted into an assessment and treatment unit. Finally, James' last recorded epileptic seizures were in 1973, when he was 18-years old, and yet his anti-epileptic medication, which comprised sodium valproate and carbamezapine, was only withdrawn at the end of 1991. Furthermore, this bout of epilepsy occurred less than a year after his permanent 'hospital' admission, and coincided with a severe bout of self-injury wherein he pulled out much of his hair. It seems reasonable to suggest that these factors, the epilepsy and self-injury, might have been related to his general unhappiness with his life circumstances. I should point out that James' relationship with prescribed drugs is extreme, but not untypical in the older members of the study group, with regular and quite arbitrary changes being quite normal. I am aware also, from my own experience, that it was something of a rarity for an individual to be resident on the 'behaviourally disturbed' ward and not be in receipt of powerful neuroleptic medication.
(Source: 'Hospital' medical notes, January 1966, January 1967, April 1968, January 1972, April 1973, February 1980, August 1982, December 1991, February 1993)

Example 24
My interview with Mr. & Mrs. Houghton provided further evidence about the arbitrary use of medication with many people with learning disabilities even when institutional care was not a factor. They talked of Sarah's problems when placed in an ESN school, and the frustration she experienced from one particular teacher, who, they believed, never really appreciated the complexity of their daughter's needs. The context of Sarah's attendance at the school having occurred because of the closure of a residential school for 'rubella children' in the mid-70s is significant because of the contrast in approaches between that and her new school. After a critical incident at the school when the 12-year old Sarah had begun to self-injure in a more determined and agitated manner, she was prescribed liquid haloperidol (antipsychotic) by her GP. Mrs. Houghton, however, quickly becomes suspicious of the class teacher's casual administration of the medication:

Mrs. H: "Then some days they would just – I knew she'd been overdosed with haloperidol... because she used to get spasms. And I used to say to Mrs. Magill (class teacher). She'd bring her home with Mrs. Wallace, and I used to say, 'why didn't you bring her home before you gave her anything?' Should have brought her home then instead of giving her overdose. And she said, 'we don't', and I said, 'I know you do because it's only when you overdose on the serenace and you don't give her the other medicine that would counteract the side effects'".

The incident is then compounded by Sarah's own frustration with the situation; not only was the considerable progress at her previous school being eroded, leaving her confused at the different expectations, but according to her mother she was not oblivious to the attempts to control her:

Mrs. H: "It's only because she'd had an overdose that the side effects came. But I think Sarah – she knew what they were going to do, and I think that was part of it, you know. She was ticked off, perhaps, because she knew what they were going to do with her. You know, when she was naughty, she knew the reaction, and she'd had these terrible side effects. You know, and I think she resented them slightly".

The continuing close relationship between Sarah and her parents has probably been the most important factor in ensuring that there is no excessive reliance on prescription medication. She continues to be prescribed neuroleptic medication, just as she had been during her time living in 'hospital', but her parents have always been keen to ensure that it was not administered unnecessarily. Furthermore, Sarah's extreme violence towards self and others at the time of my interview with her parents reflected her desperate sadness and bewilderment at the loss of her sight, and the circumstances appeared to warrant the use of such medication. The other parents interviewed demonstrated a combination of suspicion and pragmatism at the role of prescribed drugs, the former because of their awareness of the arbitrary and sometimes experimental way in which they were prescribed, and the latter because of their value in helping to cope with a sometimes seriously violent and self-injurious individual. Despite changes in the ways in which consultant psychiatrists prescribed medication, so that other options were considered and individuals were less likely to take such drugs for years and years, those who retained minimal family contact and had spent much of their lives in institutions continued to be much more likely to be administered combinations of powerful neuroleptic and other medicines.
(Source: Interview – October 1999)

(iii) Mechanical restraint

The employment of mechanical devices to restrict the physical movements of individuals trying to self-injure has a long history, and is an area of care that remains contentious. Some writers continue to advocate it as a practical response to people in great distress (e.g., Luiselli, 1992), while others regard it as an invasion of the individual's rights to such an extent that it cannot be tolerated under any circumstances (e.g., Lovett, 1996). When I first began to work with people with learning disabilities during the 1970s, mechanical restraint was certainly in use but was largely reliant on makeshift restrictive apparatus. For example, one young boy resident on one of the children's wards would thump himself in the face regularly, but he would also scratch at his arms causing a mass of superficial scratches all along the forearms. The response by the ward staff, in consultation with his family, was to place the tubes from washing-up bottles over his arms, thus preventing him from both methods of self-injury.

A second individual, resident on a mixed sex ward for younger and more physically disabled children, would attempt to manually evacuate his rectum whenever he could gain access. He was prevented from doing so by a simple device, whereby his arms were inserted into 'mittened' sleeves, each of which was then tied to one side of the cot, that he rarely emerged from. The use of 'strong suits' to prevent people from indulging in 'anal rooting' or causing injury to the genital area was not widespread, but many wards contained one or two individuals, who would rarely be dressed in anything else. Furthermore, those with a regular headbanging habit would frequently be provided with an 'epileptic hat', a leather skullcap to prevent injury when the person fell over during a seizure. By the early 1980s, according to Murphy & Wilson (1985), mechanical restraint was 'probably' the most widespread approach towards self-injurious behaviour, though there was an increasing move towards making its use more formal and accountable, with homemade devices gradually becoming less acceptable. Concern was increasing about the ethical issues involved, behaviourism was gathering pace, but reduced reliance on mechanical restraint was some distance away.

> "Restraints may range from simply putting mittens on a person's hands to prevent hand biting, through to using bandages or straps to tie an individual to a bed for most of the day and night. In the latter case bone deformities and muscle weakness will inevitably occur. In between these two extremes people can be found wearing helmets, collars, arm splints, and so forth. Restraints of this kind are not used as a treatment to eliminate self-injurious behaviour but rather to prevent the behaviour occurring at all, or to terminate an episode of self-injury once it has occurred, or to prevent tissue damage if the behaviour persists" (p.233).

Spain, Hart, & Corbett (1984) provide a detailed overview of the types of restraining devices employed at a specialist unit for children with 'mental and physical handicaps' at that time (see Box 3). They do, however, emphasize a thorough analysis of the self-injurious behaviour beforehand, and particularly the role of behavioural strategies, before it should be acknowledged that mechanical restraint should be considered.

a) **Protective environments:**
- cot padding
- padded chairs
- plastazote cushion

b) **Minimal physical restraint(s) to prevent movement:**
- muffs
- mittens
- elbow splints
- 'watch' or palm splints
- capes
- lip splint (mouth guard)

c) **Protective helmets:**
- plastazote helmet
- orthotic helmets
- commercial helmets

Box 3 – Variety of 'protective appliances', from Spain, Hart, & Corbett, (1984).

The restraining equipment was developed by occupational therapists (OT), another professional group becoming increasingly involved in the care of this client group during this period. Both OTs' and physiotherapists would contribute towards the construction of self-injury through their relationship with the design and development of such a bewildering variety of mechanical restraints. The changing ethical climate in the 1980s regarding the use of mechanical restraint represents a key moment in the development of both the biological and behavioural discourses, with a number of principles about use being increasingly recommended. Restraining devices were to be advocated only for minimal movement restriction, and then only in conjunction with a behavioural strategy (Rojahn, Schroeder, & Mulick, 1980). There should be consideration of whether the individual actually finds being restrained reinforcing (Flavell, McGimsey, Jones, & Cannon, 1981). Short periods rather than continuous use were increasingly perceived as being more effective (Singh, Dawson, & Manning, 1981). There should be an emphasis on the device appearing as ordinary and pleasing as possible (Spain, Hart, and Corbett, 1984). Finally, the primary goal of restraining equipment should be 'tertiary prevention', a minimizing of tissue damage (Richmond, Schroeder, & Bickel, 1986)

Luiselli (1992) provides a more sophisticated 1990s approach to categorization (see box 4), which continues to emphasize locating the use of protective equipment within a behavioural framework, but attempts also to include this within the descriptive process. They defend the continued employment of mechanical restraint on the grounds of common misperceptions of how it is utilized and a lack of understanding of its therapeutic value:

> "For many individuals, the image of protective equipment is that of the self-injurer physically immobilized at the arms, wrapped in a bodyjacket, wearing a helmet, and unable to participate in any meaningful habilitation activities due to restriction of movement. It is distressing that this impression lingers because it represents a very narrowly defined focus and the least therapeutic utilization of protective equipment. In fact, recent years have witnessed many advances in the ***multiple*** uses of protective equipment for the ***therapeutic management*** of SIB" (Luiselli, 1992:235, italics in the original).

1.) Mechanical restraint: - Physically impedes self-injury through complete restriction of movement

2.) Mechanical restraint with Restraint Fading: - Physically impedes self-injury with attempts to eliminate gradually the protective equipment

3.) Response interruption: - Physically blocks self-injury but only restricts self-injury movement

4.) Response prevention: - Allows self-injury to occur but prevents physical damage

5.) Adapted clothing: - Allows occurrence of 'acceptable' topographies of self-restraint

6.) Sensory extinction: - Removes, blocks, or masks purported sensory reinforcing effects from self-injury

7.) Contingent application: - Protective equipment is applied for special duration, contingent upon self-injury (equipment may interrupt or prevent self-injury).

Box 4 – Treatment approaches using 'protective equipment', adapted from Luiselli (1992)

My research indicated the adoption of several of these approaches, though the only term employed in the clinical notes was 'mechanical restraint', and then only rarely. The ethical principles previously described were contributing to the development of professional discourses, though translation into practice was something of a compromise. Institutions were keen to embrace the increased emphasis on human rights within services for the 'mentally handicapped', which was essential if they were to survive, though ultimately, of course, they would not. This transpired by way of restraining devices having to be medically sanctioned, purpose-built equipment being chosen where possible, stringent recording of use, and some attempt at consultation and consensus prior to prescription. There remained a gulf, however, between gestures of this type and really seeking to understand the purpose of mechanical restraint with self-injuring individuals. This necessitated a more sophisticated understanding of the relationship between the individual, her learning disability, and the propensity for self-injury. The widespread belief that self-injury was simply a product of the severity of the 'retardation', implicit within influential standard textbooks through to the early 1980s, effectively gave license to the use of makeshift preventative equipment as an apparently reasonable and humane response. The use of such devices, both makeshift and purpose-made was illustrated in the lives of many of those selected for the study group, sometimes for purposes of convenience but also as a result of the feelings of helplessness and frustration engulfing formal and informal carers alike. The following examples illustrate the casual, occasionally shocking use of such devices, somewhat expectedly in 'hospitals', but also in community houses, and in the family home.

Example 25

Mrs. Wilson, for example, talks of her daughter, the 3-year old Alison, returning from a period of short-term care at a large 'hospital' in the early 1970s, and in so doing provides an illustration of the use of a makeshift 'response interruption' type of restraining device. This appears to have been employed as an instrument of convenience, or perhaps more generously, one of desperation, to those caring for her:

Mrs. W: "It did start more, really, when she was about three. When she went to (the 'hospital'), and then she came back with that bloody tie belt on, right under her bust. And we had a hell of a job to get it off. And then I told you that she started putting her knee to her chin, when she was thinner. I had to put it on a chair, an ordinary chair, and her foot was tied to it. And I had to get the doctor out and he said it's not cruel. It's not hurting Alison so it's not cruel. Then she started banging her chin to one side, also clicking her shoulders. So she wore a neck support".

There is a suggestion in Mrs. Wilson's comments, that the employment of this makeshift restraining device simply had the effect of provoking Alison into finding alternative methods of self-injury. The use of mechanical restraint, furthermore, largely replaced the need for close observation and care from the staff working on the ward, though it should also be acknowledged, perhaps, that this was still an era in which custodial care was considered the norm.
(Source: Interview, November 1999)

Example 26

In the case of the 16-year old Terry Lawson, who by May 1980 has been living in 'hospital' for seven years, mechanical restraint is a response to him, according to his medical notes, "continually banging top of head with his right hand with a resultant bald patch on vortex". The medical officer suggests temporarily "taping sleeve over right hand to lessen trauma" and wonders whether he is disturbed and needs to see a psychologist. Such a measure, effectively 'response prevention', is employed periodically with Terry over the next few years, before a further medical comment in January 1986 relates that "since father is against restraint of patients right arm, this procedure is to be stopped". This response from Mr. Lawson relates to concern with regard to his son's movements being restricted, but should also be considered within the context of increasing concern within institutions during the 1980s about the arbitrary and casual use of mechanical restraint. The employment of cot sides and wheelchair straps, for example, as deliberate mechanisms for restricting movement because of the likelihood of self-injury, elicited such ethical concern that a medical prescription became necessary. The case notes of Terry and several others studied reflected this concern with mechanical restraint having to be increasingly justified on the medical basis of prevention of self-injury. The changing discourse on the relationship between mechanical restraint and self-injury seems to demonstrate a greater emphasis on the purpose of the device. Previously, it appears that such preventative measures were regarded simply as commonsense since they served the laudable purpose of saving the individual from the consequences of their compunction. The changing social climate, however, particularly the increased concern about the rights of 'mentally handicapped' individuals, and greater suspicion of the notion that self-injury should be considered as arising from within, meant a greater emphasis on legal and ethical safeguards. The overall context, of course, was institutional retraction and the, to some extent misguided, association between mechanical restraint and the 'hospital' setting. (Source: 'Hospital' medical notes, May 1980, January 1986)

Example 27

It transpired during interviews with relatives of those never experiencing the institution, that the relationship between carer, self-injurer, restraining device, and self-injury was never simple, always ambivalent, and sometimes paradoxical. Mrs. Anderson, for example, talked of her resistance to accepting the use of splints, ("mind you, I didn't like them anyway"), but later explained how homemade devices aimed again at 'response interruption' had proved occasionally beneficial:

Mrs. A: "She used to bash – well she punched her chin, but she was kicking at her legs, the worst thing was, like, if whatever she was on, she'd bash her elbows against it. So we used to have to pad everything, because she was covered in bruises, all over her arms, everywhere. As I say, the skin, she punched that much she'd take the skin off it. She deformed her finger through constant punching, it's still deformed now. And if she didn't have her shoes and socks on, she could literally claw her own legs with her toenails. And I've seen it actually with blood dripping down her legs, which she'd done by herself".

Lesley's community nursing notes from when she is 8-years old reveal how her "constant and continual pummeling (of) her jaw with her fist" necessitated professional cooperation in the use of makeshift restraint. The community nurse recommends "gloving Lesley's hands at times of severe irritation", though it is emphasised that this should only be as a last resort and in conjunction with behavioural techniques such as 'verbal cueing'. The lack of success in alleviating the self-injury results in the creation of a 'secure area' being established in the house to make Lesley feel safer, and the purchase of a 'ski mitten' as a more formal restraining device. She quickly acquires the ability, however, to use this as an instrument for

expanding her repertoire of methods of self-injury, and eventually splints are sought, which comes to represent something of an admission of failure.
(Source: Community nursing notes, August 1988; Interview – September, 1999)

Example 28
The employment of other 'imaginative' restrictive devices with others in the group include the use of a long sock with Jason Harvey, which is placed over his 'hitting arm' at night because this was frequently his favoured time for self-injury. This occurred in the mid-90s when he had left 'hospital', and involved his parents' full cooperation. They also suggested, according to an interview with the staff nurse caring for him, that carers "put long pyjamas on him and put his arms down his pyjamas so he can't pull his arm up and scratch himself". The staff nurse also addresses Jason's parents' views on his relationship with his self-injuring tendency suggesting the possibility of it being more complex than previously believed, though she is ultimately unable to reconcile this with her own thinking. "They are under the impression that he slides his arm under his belt in the wheelchair. They are under the impression its self-restraint. I think its comfort personally".
Source: Interview with staff nurse, August 1998)

There has been an increased interest in this issue of 'self-restraint' over recent years, particularly with regard to trying to establish what 'function' such behaviour might serve for the individual (e.g., Fisher & Iwata, 1996; Vollmer & Vorndran, 1998). Schroeder and Luiselli (1992) define it as "the habit of some self-injurers to seek physical restraint devices, to entangle their arms and legs in clothing or furniture, or to sit or lie on their arms or legs, as a means of restraining themselves from self-injury" (1992: 293). Each of the individuals studied had complicated relationships with their self-injury and the restraining devices used, and there were occasional suggestions of self-restraint.

Example 29
Although it is difficult to be certain about the role of self-restraint in an individual's life, Mrs. Anderson was clear that her daughter sought relief from her desire to punch her own face by seeking to make it difficult for herself. She talks, for example, of how Lesley "used to take her hand under a cushion so she wasn't that bad", and when particularly disturbed "she'd put her hands down and tuck them down by the side." Furthermore, when I explore this tendency of Lesley's further with her she responds "yeah, she did that a lot at the time, you know", thus emphasising that it was not on isolated occasions.

Mrs. Anderson's awareness of her daughter's intelligence and sensitivity demonstrated the complexities involved in working out what is likely to be the best strategy to adopt towards a self-injuring child. Lesley's attempts at self-restraint indicated some element of compulsion in her behaviour, a response to what her mother referred to as an expression of "self disgust". It was not unreasonable, therefore, to support her in refraining from hurting herself sometimes, for example through the use of cushions, clothing, or other household items. Mrs. Anderson's reluctance, however, to accept the use of a more formal device such as a splint, which embodied a certain professional legitimacy, suggests a fear of tilting the balance of the relationship away from care and towards control.
(Source: Interview – September, 1999)

Several of the parents negotiated this process of embarking on the use of purpose built restraining apparatus, largely because of the exhaustion involved in continuously trying to coax, cajole, hold, or otherwise prevent their children from self-injuring. There was, however, a more worrying dimension to the use of makeshift mechanical restraint, which transpired in the care of both Alison Wilson and Sam Morris, and illustrates its use as an instrument of control, one of convenience, as well as illustrating its inherent dangers.

Example 30

In relation to the dangers involved Mrs. Morris relates an experience from 1984 when her son, Sam, had spent some time in a children's hostel for short-term care, and which has clearly affected her ever since:

Mrs. M: (Hesitates) "He was in respite one weekend. We had a phone call to say that Sam had been pushed down – been sat in a wheelchair. They'd strapped him down in a wheelchair. Somebody had done... where the staff were... somebody had pushed the wheelchair over and Sam was constantly banging his head on the floor. On a hard floor. And when we got there, he was in a right state. We thought he was going to die that night – we brought him – well he didn't go to (the hostel) again. I said there's just no way – and the social services and everything. And they were ever so lovely, they were lovely with him, but this one incident happened and I thought, well we don't..."

AL: "What were they doing putting him in a wheelchair?"

Mrs. M: "Because he was disrupting everything, wasn't he? He was sort of running around, probably, banging doors, doing this, banging there. And they probably thought, 'right we can't stand this', so they put him in a wheelchair. So, of course, somebody had knocked him over. His head – his head was in a right state. (His brother) was about two then, so Sam was about ten (1984). Yeah, yeah, he was in a right mess. So he didn't go back".

This incident proves to be a critical moment in the family's relationship with professional support, a betrayal of trust from which they never fully recover. Mrs. Morris relates the story as though it had just occurred, and though she does continue to engage professional help, including respite care, it is not until a period of time has elapsed whereby the family receive no help at all. In fact, when the family finally apply for respite care in a different establishment they are placed on a waiting list because of a shortage of available places. The immediate consequences of the incident include the quite extensive injuries, described by the community nurse, who they visit immediately afterwards, as "large bruise and lump on forehead with lacerations. Bruises on nose and left cheek and jaw". Furthermore, despite taking photographs of Sam's face and instigating a complaint to social services, there is no subsequent investigation into the circumstances of the incident. Finally, the consultant psychiatrist involved in Sam's care following referral from the community nurse simply notes his injuries, observes an increase in his hyperactivity, and prescribes chlorpromazine to ensure that there is "no problem regarding Sam remaining in the community".
(Source: Community nursing notes, December 1984; Medical correspondence, February 1985; Interview – November 1999)

Mrs. Morris's experience in this instance, though obviously a major concern, might be less so were we able to confidently state that it was both isolated and relating to a particular set of extreme circumstances. Unfortunately, however, there was evidence that it was neither of these things, and several of the parents interviewed had similar stories to tell.

<u>Example 31</u>
Mrs. Wilson spoke of an almost identical incident occurring in the early 1990s whilst Alison is spending a few days at a respite unit catering for adults requiring specialist input because of their complex needs. She talks initially of having "had a few bits with them", referring to one or two difficulties about the respite care provided, though she is also keen to emphasise her general satisfaction with services received. She then goes on to describe how a particular member of staff "put that scarf round her mouth to shut her up", and then proceeded to defend herself by protesting that she was only joking. On this occasion, the service managers do go ahead with disciplinary proceedings, and Mrs. Wilson does receive a formal apology from the charge nurse of the unit.
(Source: Interview – November, 1999)

The exact extent of such arbitrary use of mechanical restraint within hostels and community units is difficult to determine, but they do suggest a significant difference between the ethical concerns of the official service position and the practicalities of care delivery to clients with extreme needs. It does not seem unreasonable to suggest that for each occasion exposed in the ways illustrated, with the consequent breach of parental confidence and trust, it is likely that there were many others that passed without comment.

The seemingly most progressive of the restraining approaches identified by Luiselli (1992), 'mechanical restraint with restraint fading' and 'contingent application' of specific apparatus, constituted an important dimension of the work of the behavioural support team, who preferred to focus on trying to eliminate the use of these appliances. However, they also came to recognize the complexity of the relationship that some individuals had with their splints, and consequently moved towards an emphasis on the client being in greater control of their use. The relationship between behaviourism and the use of mechanical restraint is an ambivalent one, therefore, with 'empowerment' serving effectively to justify the continued use of such devices, so long as it is within a framework of a behavioural programme employing the appropriate language. Such a move within the discourse of behaviourism is significant, since it enables the approach to remain the dominant one of choice with self-injury, whilst simultaneously improving the acceptability of mechanical restraint by altering its role.

Example 32

A precise description of the nature of Alison Wilson's repertoire of self-injury, coupled with the various restraining devices employed to restrict her from doing so, is provided in an explanatory letter from her GP in 1992, when she is 23-years old, to support her referral to the behavioural support team:

"Alison wears a cricket splint on her right arm restricting her from bending her arm at the elbow to prevent her hitting her head with her fist. She uses the splint, however, to hit her head with, she also hits her head less frequently with her left fist and had until recently worn a splint on this arm. Alison wears a neck brace to prevent her banging her head on her shoulders or upper half of body. These mechanical restraints are under the jurisdiction of the consultant psychiatrist. (She) wears these restraints for 24-hours a day, without exchange i.e., same splint continually. Alison has her splint and neck brace removed when washing and swimming, and at (the day centre) her splint (is) removed at lunchtime and whilst drinking tea. As (she) has limited use of her left arm, the right splint greatly reduces her movement and ability to do many activities. Alison appears to have an obsessional fascination for her restraints and their positions, constantly checking and rechecking them".

This complex relationship between Alison and mechanical restraint is subsequently taken into consideration by the behavioural support team in their attempts to implement an approach to dissuade her from self-injury. Central to this approach is the gradual recognition by the team, that there was a need to integrate Alison's relationship with her splints into the established behavioural approach. She is encouraged, for example, to exchange the splint for another one and to change her mind as to whether she wishes to wear it or not. The idea is to try to empower Alison, so that she is able to assert some degree of control over her life, and to demonstrate recognition that she has been wearing splints for more than 15-years, so that a certain amount of dependence is inevitable. Furthermore, the overall approach, though behavioural in emphasis, demonstrates a greater receptiveness to other perspectives, and is more consistent with the service philosophy of valuing Alison's social role. There is also an attempt here to alter the discourse surrounding mechanical restraint and self-injury, so that it ceases to be concerned entirely with preventing the physical consequences, and demonstrates instead an acceptance of the need for a more sophisticated approach. There is a recognition, for example, of Alison's quite marked 'intelligence', illustrated particularly by her engaging in what the behavioural nurse refers to as the 'splint game', whereby she manipulates day centre staff into spending a great deal of time applying and removing her splints. There is no dramatic reduction in Alison's self-injury as a result of this move towards greater empowerment rather it is one part of a long-haul approach which aims to enhance her ability to communicate and try to facilitate increased independence.
(Source: Medical correspondence, February 1992; Behavioural Support Team assessment report, February 1993)

<u>Example 33</u>

The involvement of the behavioural support team in 1997, when Sam Morris is 22-years old, ushers in a similarly sophisticated approach to the employment of mechanical restraint. The referral has been made because of a recent upsurge in his self-injuring, which is usually responded to by splints on both arms and "a duvet around his neck and shoulders", which, according to the behavioural nurse, "appears to serve as an additional restraint and also comfort". She finishes her report with a list of recommendations, wherein she makes a comment about the changing nature of Sam's relationship with his splints, and how this can be facilitated. "As Sam gains control over areas of his life, then interventions will be put in to reduce the amount of time that he spends in mechanical restraints i.e., splints, duvets". Over the next few months a care plan is put into place, which attempts to put into operation this changed thinking about the use of mechanical restraint. The plan emphasises the splints being kept in a bag, which Sam has control over at all times, their use only in the extreme circumstances of severe self-injury, and a behavioural framework being used, so as to ensure accurate recording and regular evaluation.

The subsequent twelve months witnesses a concentration on minimizing further Sam's use of the splints ('mechanical restraint with restraint fading'), though a severe throat infection over Christmas 1998, which involves a brief period of hospitalization and persistent, severe self-injuring, leads to the suspension of the plan. Otherwise, the long-term aim is that "Sam will not need to use prescribed arm splints other than in an emergency situation" ('contingent application'), and the short-term one is that he will only wear them for 30-minute periods when absolutely necessary. The incorporation of mechanical restraint as an integral part of a behavioural programme is partly a recognition of the ambivalent relationship Sam has with his splints, whilst also reflecting the changing discourse of behaviourism. As we have seen in chapter four, by re-inventing itself as applied behavioural analysis, it established a way of retaining its basic principles, whilst simultaneously selecting elements from other approaches, which served its purpose.
(Source: Behavioural Support Team 'action plan', November 1997 and clinical notes, December 1998)

(iv) Physical illness and self-injury

I have been critical of the emphasis within biological discourse on syndromes and neurotransmitters as contributory factors in self-injury. The main frustration, however, has been, not in the pointlessness of resources being deployed to establish such 'truths' about self-injury, but in the neglect of the possibilities of the development of alternative discursive statements. The evidence suggests that the current biological discourse appears to be of little value to self-injurers, their families, and the majority of professionals and other care workers. It is, of course, influential, however, in constructing a particular view of why an individual might start to hurt him/herself by engaging in, for example, violent headbanging. A sense of the exotic, then, may surround such inexplicable behaviour, which might prove attractive to some professionals with a medical background, and, furthermore, may help to lay claim to resources to engage in research. The point is, though, that such research has little to say to those involved in the lives of people who self-injure. Furthermore, the ways in which we respond to self-injury, both in terms of individual interventions and service strategies, is closely associated with our understanding of it. The continued use of mechanical restraining devices and psychotropic and anxiolytic medication reflects our continued lack of understanding of why people self-injure in the ways that they do.

The relationship between physical illness and self-injury is the area where there is the clearest link between biology and self-injury, as evidenced by the experience of those participating in this study. Furthermore, it is also the area where the link appears to be most established in the working frame of reference of many professionals involved in the client's care. It is easy to understand the connection between somebody being in pain or significant discomfort, and the tendency to headbang or punch one's own face as a response. Most people can relate to this in the context of their own private area of pain – headache, backache, toothache and earache, in particular – and conclude that self-injury could be a reasonable response. The size of the problem is difficult to clearly establish, but the very nature of the serious, continuous self-injury frequently engaged in makes it far more likely that the individual will experience a greater amount of illness than non-self-injuring individuals. The next two sections are concerned with the role of physical aspects of self-injury, firstly in relation to pain and illness, and then in connection to menstruation. Recurring minor injuries including wounds, bruises and fractures, along with increased susceptibility to infections and ailments constitute the two areas of physical illness, which pervade the lives of virtually every member of the group. There were, however, a number of other similarities in their experience of illness, and it is these that I wish to explore now.

Example 34

In June 1970 the 13-year old Daniel Cotterill has already spent almost half his life in 'hospital', but there has been no mention of self-injury since a footnote on his admission document. Then, out of the blue, his medical notes declare "headbanging, screaming. Child is suffering severe pain due to toothache". Daniel subsequently receives dental treatment over a period of months for his severely eroded teeth and daily mouthwashes for his "bad breath". By the October his toothache appears to have improved as a result of the treatment regime, but he continues to have "sessions of banging his head on his hand or chair or floor, now no skin left on the bridge of his nose. Screams at times". De Lissovoy, in an article from the period, primarily concerned with the relationship between otitis media (middle ear infection) and headbanging, argues the "possibility that headbanging may actually be a form of pain relief". He equates the headbanging with the primitive "pepper in the eyes cure for toothache" (1963: 165). It is difficult to be entirely confident that Daniel's headbanging had not arisen as an expression of the pain he was feeling. It was, however, present several years before this episode, which together with the multi-faceted nature of his self-injury, for example expressing both anger and pleasure, suggest that he selects a particular behaviour to suit the occasion.

(Source: 'Hospital' medical notes, June and October 1970)

Example 35

Sam Morris' experience of physical illness and discomfort is such that there is a clear association with the extent and severity of his self-injuring. The initial involvement of a community nurse in 1982, when he is 7-years old, a referral having been made by the family social worker, relates to a deterioration in his self-injuring, and confirmation of dental problems (problems with his lower teeth coming through) is soon made. The community nurse begins with a general observation of the presentation of Sam's behaviour. "He does not violate other children and tends to throw or swing toys around and push, shove or thump anybody/thing that gets in his way. He frequently bangs his head against the floor/hard objects". Sam's dental distress, which is confirmed by the school dentist, provides considerable disruption to the family over the next month, because he becomes increasingly hyperactive, self-injurious, and allows the family little sleep at night. Furthermore, though he does reduce his headbanging once his teeth have come through, this does seem to be a critical juncture in his self-injuring 'career'. As with Daniel, with whom he does have certain parallels, Sam has acquired a taste for self-injury, which will become central to his life.
(Source: Referral by social worker to community nurse, July 1982; Community nursing notes, October 1982)

Example 36

Dental problems are also an issue with Lesley Anderson, who is eight years old in January 1989 when she is prescribed antibiotics for a bout of sickness and diarrhoea. A community nurse has been involved in her care over much of the previous year, because she is "presenting some disturbed behaviour from time to time". The community nurse's notes talk of a recent upsurge in Lesley's "facial beating", which her dentist confirms may possibly be associated with new teeth at the back of her mouth. The following week Lesley is "constantly face banging to the extent that she has again broken the skin on her chin and knuckles". This intensive bout of self-injury continues for several months before finally abating. Furthermore, she continues to have dental problems over the next few years, so that by the time she is 17-years old, the community nurse observes that her teeth have been completely ground down. It is difficult to determine, however, whether this is because of Lesley being in constant discomfort, or whether it is a result of habit, frustration or some other reason. Nevertheless, once the individual recognizes the power of self-injury in disturbing significant others, compensating for being unable to verbally express one's feelings, and providing a mechanism for channeling rage, it becomes an indispensable tool. In relation to Lesley, she is extremely frustrated by the physical consequences of her clinical syndrome (Wolf Hirschorn), which include, besides her small stature and distinctive characteristics, hearing loss, heart defects, scoliosis, allergy problems, and susceptibility to chest infections.
(Source: Community nursing notes, January 1989 and November 1997)

The evidence appears, therefore, to suggest, unsurprisingly, that the pain and discomfort arising from toothache and dental decay sometimes have the effect of precipitating bouts of self-injury, particularly violence directed towards the head and face. Some individuals also concentrate their self-injuring and self-stimulatory behaviours in the region of the eyes, occasionally resulting in visual problems including blindness. Three of the study group, Sam Morris, Alison Wilson, and Sarah Houghton experienced eye injuries as a consequence of self-injury. Their subsequent experience of treatment is variable, with medical decisions presumably made on clinical need and likelihood of success. A general feeling does emerge, though, of lives that are considered of less value because of the self-injury being regarded as a consequence of the 'mental handicap'.

Example 37

In June 1986, Sam Morris is eleven years old and a letter from a consultant ophthalmologist to his GP confirms that there has been "a cataract develop in this severely subnormal lad over the last few months". But he adds ominously, "I do not think it would be wise to try and operate on this as I think the wound would be immediately disrupted by his behaviour in the post-operative phase". The cataracts issue is not an infrequent one with individuals who self-injure by battering their own faces and heads, and was shared by two other members of the group.
(Source: Medical correspondence, June 1986)

Example 38

Alison Wilson is 24-years old in 1992 when she is referred to the newly established behavioural support team because of her persistent and severe self-injury. The nurse notes that she "often has a swollen right side of her face particularly around the eye area and an eye test showed deficiency in eyesight in right eye with external strabismus". The ensuing assessment by the nurse is extremely comprehensive, though behaviourally orientated, and there is only a brief mention of her visual problems. "Alison's self-injurious behaviour has resulted in several open wounds in the past, the right temple area is often reddened and swollen. The vision in Alison's right eye is impaired but this may not be a direct result of her behaviour". Three years later, in September 1995, a routine visit to the ophthalmologist/optometrist confirms that she has a cataract in the right eye, though "it is not possible to consider operating because of Alison's self-injurious behaviour". There is no change over the following six months, so that the ophthalmologist writes that he is happy with her sight, since correction of the left eye strabismus would result in little improvement. He adds, however, that Alison's self-injury "would make recovery from surgery very difficult", though Mrs. Wilson, during interview, proved not entirely convinced at this decision:

Mrs. Wilson: "Well I worry. I mean, she's blind in the right eye – partially. And they say they daren't operate; because of the tantrums that she has, she could knock her right eye out, it could come right out. Because you have to keep your eye very still for so many days to get it used to – and they can't do it. I was devastated when I knew that".

Mrs. Wilson then ponders whether Alison could cope with wearing glasses or having an operation for her cataract:

Mrs. W: "Whether they will, I don't know. We were a bit done about that. But, like our Graham says, when you think, mum, you don't want her eye falling on the floor. That'd make me bad. Cos that's what they said if the strings... See, Alison is continuing to do this (demonstrates self-injuring action) and my argument is this... "
(Source: Behavioural support team initial assessment, December 1992; Multi-disciplinary meeting minutes, September 1995; Interview – November 1999)

<u>Example 39</u>
Sarah Houghton's deafness and tunnel vision presented her with few major difficulties for the first thirty years of her life, but around the end of 1997 (the notes make little reference to what exactly happened) she loses her sight, apparently unnecessarily, and the consequences for the family are significant. In July 1997 the consultant psychiatrist writes to Sarah's GP because of concern about what she regards as symptoms of depression. "She has had further treatment for glaucoma at the Royal Liverpool hospital and she is increasingly distressed and clingy. She does not want to go out and she is not able to enjoy herself at all. Some days she cries and sobs throughout the day. Her appetite and sleep are satisfactory although sometimes she is extremely agitated and eating is difficult. She finds hospital visits extremely traumatic and, for example, when her father took her last time and had to restrain her, she has refused to have anything to do with him since then. It is extremely difficult for her to understand what is happening. I feel that it would be worthwhile giving Sarah a course of antidepressants, although a lot of the problems are ongoing".

An 'emergency meeting' held in the September, because of the continued deterioration, reveals that Sarah has "spent a lot of time agitated and screaming and has become extremely possessive of her mother (so that she gets) upset when other people come to the house or mother's attention is taken elsewhere". The ensuing months deliver no improvement and she is eventually admitted into an assessment and treatment unit in June 1998, where she is assessed by a representative from the RNIB multiple disability services following referral by her social worker. The subsequent report reveals that Sarah did have an operation to remove cataracts when she was very young, and also that a "common later consequence of rubella with congenital cataracts is a risk of glaucoma, which manifested itself while Sarah received services from the (local) deaf society". And then comes a comment, which almost conceals the full force of the unfolding tragedy through its apparent matter-of-fact delivery. "As people working with her at the time and her parents started to notice her sight was deteriorating she was referred to a GP, who treated her for conjunctivitis. By the time the correct diagnosis was made the fluid pressure inside Sarah's eyes had already built up to an extent that she had now lost her sight in both eyes and is now functioning as deafblind".

The RNIB report goes on to clarify some of the concerns about Sarah's behaviour as arising directly from her adjustment to the changed circumstances of her life. Her erratic sleep pattern, for example, "is a common feature of total blindness", because of chemical changes in the brain arising from the absence of light. Her increased obsessional behaviours, such as light switch flicking and curtain pulling, are also explained in relation to her bewilderment and fear, and are then linked to her need to grieve, which may also manifest itself through anger and violence. In effect, the RNIB report locates Sarah's increased aggression, silent fury, obsessional behaviour, suspicion of strangers and intolerance of new situations within a framework of 'how did anyone expect her to adjust to being deaf-blind?' Mr. and Mrs. Houghton describe one such consequence of Sarah's frightening 'new-world' when she attends a routine hospital appointment in October 1999, over a year later:

Mrs. Houghton: "(The community nurse) took...(laughs) Sarah had to have a barium meal on the first of October at the (hospital). A nightmare visit, an absolute nightmare. And it didn't take place. (She) phoned the radiology department to tell them all about Sarah and that she would need sedating. And when we got there, there was nothing. And Sarah – even by the time we'd got to the radiology department, she was really, really kicking off. Terribly violent. And they just stood and looked at us, you know. Three consultants just stood looking, saying 'we're not touching her'. I thought, yeah, thanks, you know. I'm stood here. (The community nurse) and I were knocked about and they just stood there".

AL: "They made a decision there and then did they, not to get involved?"

Mrs. Houghton: "They weren't going to touch her, they weren't going to do anything for her, they weren't even going to give her something to sedate her so that we could take her out of there. You know, lots of violence still. And we were left to try and carry this kicking, spitting creature out".

Mr. Houghton: "Beast".

Mrs. Houghton: "She was a beast as well, she was really, really well off the wall (laughs). We'll not go back to radiology again. She was picking up chairs and hurling chairs in a really narrow corridor".

(Source: Medical correspondence, July 1997; 'emergency meeting' minutes, September 1997; RNIB Multiple Disability Services assessment, June 1998; Interview – October 1999)

Example 40

The 27-year old Janine Lewis, by March 1997, has accumulated a wide range of health problems, which include intermittent constipation/diarrhoea since a bowel resection in 1984, an erratic, heavy menstrual cycle, recurrent skin infections, continuing dental problems, hair loss because of slapping her head, sleeplessness, and weight loss. The opportunity arises during her stay on an assessment and treatment unit based within the ground of a large general hospital for a full investigation into her health. This is particularly so because of a need to break a cycle of weight loss and illness, linked to a worsening of her self-injuring and general unhappiness, and resulting in regular difficulties with her residential placement. Janine's ill health is exacerbated by both the self-injuring, which results in bouts of cellulitis (highly contagious skin disorder), and her penchant for "smearing saliva and eating soil", which lead to frequent infections.

She is referred by the consultant psychiatrist to a consultant physician, who speculates as to the cause of her recent weight loss in a letter: "I decided not to examine her because she would not co-operate. It is a puzzling story and I doubt if we are going to find the answer. The fact that it is very intermittent just could suggest some surgical cause such as volvulus or intussusception etc. and ideally an abdominal X-ray at these times would help but I guess is impractical. I very much doubt if this is peptic ulcer, inflammatory bowel disease etc. An endocrine cause is just possible e.g., Addison's disease (hypoadrenalism) – this can cause attacks of vomiting and diarrhoea in an asthenic person... the last cause I suppose could be intermittent episodes of raised intracranial pressure related to her presumed brain damage".

Collaboration between the physician and GP fails to confirm an accurate diagnosis, so that the former writes that, "our working hypothesis remains one of intermittent sub-acute intestinal obstruction in a person with learning difficulties who has had previous abdominal surgery (?) for volvulus". Both a surgical opinion and that of a dietician is sought, but there is never any conclusion reached during Janine's stay at the unit. It is interesting, nevertheless, that the experience of health care experienced by several in the group studied is less than satisfactory, whereas, possibly because of the informal nature of the referral process, Janine receives immediate attention from a number of medical professionals.
(Source: Assessment & treatment unit nursing notes, March 1997; medical correspondence, May 1997 and November 1997)

Example 41

One final factor relating self-injury and ill-health arises in the case of Sam Morris in September 1987 when he is 13-years old and there is an inexplicable deterioration in his general health coupled with a desire to retreat even further into himself. It begins with worsened headbanging, which results in him having to go into hospital where a severe ear infection is diagnosed. Sam's self-injuring continues to worsen over the coming months, though, so that he is referred to a consultant child and adolescent psychiatrist, who notes his weight loss, reduced appetite, and general apathy and listlessness. She then goes on to suggest possible reasons, which include the "possibility of dietary imbalance/anaemia", a "possible small subdural haematoma secondary to his headbanging", and "some withdrawal and apathetic behaviour (being) sometimes seen in adolescence in handicapped people with severe hyperkinetic syndrome". In relation to this last point, it is interesting that some of the others in the study group, notably Jason Harvey and Daniel Cotterill, also experienced major health changes, which were associated with deteriorating self-injury. Jason suffered what appeared to be a stroke in his mid-teens, after having been very active previously, which resulted in him having to use a wheelchair. Daniel underwent a period of severe weight loss, increased agitation, and an obsession with consuming inedible objects during his early twenties, which was considered to be tantamount to a personality change, though he did return to his former self eventually.

Sam's behavioural and health deterioration continues throughout the remainder of 1988 without an accurate diagnosis being made. Various investigations are undertaken, including "blood for uric acid, electrolytes, LFTS, full blood count, chromosomes (and) EEG", though they are all returned normal a few weeks later. His community nurse records that "he broke his nose by head-butting a wall", which illustrates his continuing passion for self-injuring, particularly when he is required to cooperate during the course of personal care like washing, dressing, and feeding. Sam only appears to be content when he is left alone to either chew on his quilt or soft toy, or rocking happily from one side to the other. There is never any adequate explanation, medical or otherwise, for Sam's change over a period of several months from being so hyperactive to so withdrawn, to the extent that it is not long before he comes permanently to rely on a wheelchair. Mrs. Morris considers the decline to have occurred gradually at first, but is then exacerbated by a specific incident when he slipped over on some ice whilst being escorted towards a taxi to take him to school.

Mrs. Morris: "Well, he did want to sit down more with his quilt around him and lounge around for a lot more before that, but when that happened all one side went weak. That's the left side, it shakes... So he sort of just altered. But then, when he had the fall, you were sort of more worried and he'd lost his confidence in walking. And he had to have either one walking or two with him".
(Source: Community nursing notes, September 1987; Medical correspondence, April 1988; Interview – November 1999)

(v) The role of sexuality

The relationship between sexuality and self-injury in people with learning disabilities is complicated further when there are significant difficulties in communication, since this absence of a spoken voice has historically helped to reinforce powerful images of the 'eternal child' and the 'sexually deviant'. Lovett (1996) contrasts such stereotypical images to the way in which women without learning disabilities are categorized according to their roles as asexual nurturers or being in possession of an inexhaustible sexuality:

> "Instead of being thought of as madonnas, they are seen as asexual 'holy innocents'; instead of being thought of as whores, they are sometimes labeled as 'children in adult bodies', capable of a dangerous and ungovernable sexuality" (p.16).

Lovett's angry rhetoric belongs to the present era and reflects both his frustrations with the historical treatment of people with learning disabilities as well as his continuing concerns about the organisation of services. Tredgold and Soddy, on the other hand, outline the prevailing view towards the sexuality of different 'grades' of people with 'mental deficiency' during the 1960s, a period as we have seen that witnessed the admission into 'hospital' of several members of the study group:

> "The sex life of the most severely subnormal is undifferentiated, it does not reach an anal level, let alone genital. Idiots appear to gain what sensory satisfactions they are capable of experiencing mainly from feeding, thumb sucking, skin stroking, warmth, passive body movements, rocking, swinging, and so on. The sexual activity of imbeciles commonly has some genital component and in both sexes masturbation may occur, though probably without any specific interpersonal relationship formation. It is doubtful how far anything more than a vague comforting sensation will result. Among the feeble-minded, sex life has a much more obviously genital nature. Masturbation has a more erotic component, including orgasm; mutual masturbation occurs both in a lasting interpersonal relationship and more casually, and various types of homosexual and heterosexual intercourse are not uncommon" (1963: p.87).

The influence of the language of psychoanalysis is clearly in evidence, since behaviourism was yet to make its mark, and it appears archaic because of the three level categorization of 'mental deficiency' arising from government legislation at the beginning of the century (1913). Yet it does at least attempt to acknowledge that they are not 'asexual' beings, and furthermore, Tredgold and Soddy, despite their work in many ways belonging to a previous era, do go on to address the need for the creation of an agenda relating to sexuality and 'mental deficiency':

> "The problem of sexual behaviour of subnormals of both sexes, therefore, remains unsolved and largely unstudied. Such public action as there is has been and is still usually directed exclusively at suppression of outward expression of sexuality, by careful social supervision and denying both sexes access to each other" (1963: 89).

The changing social climate of the 1960s and 1970s, exemplified by a more liberal approach towards abortion, contraception, and the expression of sexuality more generally, saw some increased discussion of the relationship between 'mental handicap' and sexual awareness. This was largely quite simplistic, however, and tended to focus on an elaboration of the legal machinery (e.g., Gibson and French, 1971), the sexual offences act (1956) remains the framework to this day, or broad observations about sexual behaviour.

> "The subnormal girl, so often deprived of affection in childhood, is apt to mistake sexual advances from the opposite sex for true affection" (Heaton-Ward, 1967: 56).

In the context of self-injury and sexuality there are a number of pertinent areas for consideration, which include the possibility of sexual abuse, recognition of people with learning disabilities as sexual beings, and the implications of the onset of puberty. In the group studied there was some explicit suggestion of sexual abuse, though this was entirely conjecture, and it would be foolhardy to claim that this could be directly associated with the onset of self-injury.

Example 42

A male staff nurse caring for Melanie Dodd, now in her early thirties and living in a community unit in her area of origin, for example, talked of her sexual awareness ("I think Melanie has a crush on a couple of the male staff who work here and she's a little bit more silly and adolescent when they're on"), and speculates as to possible reasons ("Melanie does express, at times, her sexuality... And was she abused? I'd imagine if anybody – yes, I think she probably was – if we're talking about sexual abuse. Physical abuse and

mental abuse did happen in 'hospitals'... I do think there's something – I wouldn't like to say for definite, but I'm fairly sure of it").
(Source: Interview with staff nurse, July 1998)

Example 43
A second instance of conjecture arose during an interview with a staff nurse caring for 27-year old Janine Lewis in 1997 whilst she is undergoing a comprehensive assessment within a specialist unit to determine reasons for her increased self-injury, rapid weight loss, ongoing gastric problems, erratic menstruation, and recent vaginal infection. The nurse describes the long-term nature of many of these difficulties, before talking of her "poor interpersonal skills (during which she) touches people and lifts clothing to look for belts". She goes on to discuss her evident emotional distress on these occasions, and her "bizarre relationship with her father" whose visits appear "to make the situation worse". There was no direct reference to abuse having taken place, but the nurse, who had known Janine over a number of years, was keen to emphasise that she often wondered whether there was "a lot about (her) past that we don't know about".
(Source: Interview with staff nurse – May 1998)

It is clear that neither of these examples constitute serious evidence, and could arguably be regarded as dangerous speculation, but given the increased evidence over recent years of the sexual exploitation of people with learning disabilities (Brown et al, 1995), maybe such comments deserve not to be completely ignored.

The most significant and clearly identifiable link between sexuality and self-injury emerging from the study concerns the issue of menstruation and the whole process of becoming a woman.

Example 44
The minutes of a multi-disciplinary meeting discussing the care of 22-year old Melanie Dodd in 1987, for example, whilst she continues to reside on a 'hospital' ward, though by this time it is mixed sex, draws attention to the possibility that some of her "behavioural difficulties are related to her menstrual cycle". Furthermore, Melanie "no longer strips her clothes off completely but will occasionally rip the buttons off her blouses but this is usually when she is menstruating".
(Source: Multi-disciplinary meeting minutes, July 1987)

Such references reflect the increased willingness towards greater openness about the issue of sexuality in institutions, albeit within the environmental and structural constraints of the setting. Tierney (1983), for example, mentions how the subject of sexuality "has only recently come to be discussed in relation to mentally handicapped adolescents, but the problem merits the more liberal approach which has now been taken" (p.78). She goes on to consider in the half page devoted to the subject, and within the context of the family, how "managing menstruation can also be difficult, especially if the girl is still incontinent", before advocating input from the health visitor. Another text from the 1980s allots a full page to menstruation alone, largely geared towards parental advice from professionals, and influenced by the gathering pace of behaviourism. Sines (1985) discusses how "(B)ehaviour modification techniques can help with the development of self-help skills in relation to feminine hygiene", and advocates "charting the frequency of behaviour problems" so that "community nurses can help parents to assess how the menstrual cycle influences their child's behaviour" (p. 168/9).

The parents of two others in the study group voluntarily addressed the onset of their daughters' periods, since I had not anticipated it as being significant in relation to self-injury.

<u>Example 45</u>

Mr. and Mrs. Houghton spoke of Sarah starting to menstruate when she was ten years old, in the mid-1970s, which precipitated an increase in her agitation, and coincided with a change of class teacher to somebody less in tune with her (Mrs. H: "Everything seemed to come at one go at her"). The family subsequently consider what options are available to them, seriously investigating the possibility of sterilization before being informed that it was no longer readily recommended:

Mrs. H: "There didn't seem anything anybody could do for her, because until about eighteen months before, they'd been giving girls' hysterectomies, and then they said it wasn't – they said they weren't going to do no more of that. So Sarah and I could sort of soldier on because – she dealt with it".
(Source: Interview – October 1999)

Sines' (1985) advisory approach to care captures this gradually changing discourse surrounding sterilization, which cannot be detached from the increasing concern about 'mental handicap' and human rights, and the social context of institutional critique:

> "If very heavy or prolonged periods occur, a referral to a gynaecologist is recommended. Some parents may request relatively drastic intervention by gynaecologists to solve menstrual problems. In some cases a total hysterectomy has been requested, and following careful consideration this operation has been performed in certain situations" (p. 169).

The Houghtons', for their part, regarded the specific difficulties about what to do about the onset of puberty in Sarah with relative equanimity, particularly since she was later prescribed injections to prevent her from menstruating. This was more because of its relative insignificance in affecting the family's quality of life; to them the furore surrounding the issue had little to do with the practicalities of doing the best for their daughter whilst maintaining a semblance of normality within the family. The loss of her residential school placement, readjustment of the family to having her return home so abruptly, and the poor relationship between Sarah and her class teacher conspire to reduce its overall importance.

Example 46

My interview with Mrs. Anderson reflects a different era, that of the mid-1990s, when her daughter Lesley, then about 15-years old, confronts the bewilderment of the onset of menstruation, and subsequently responds with an exacerbation of her self-injuring. It is only, however, when she mentions that this deterioration had transpired over the previous two years, that the line of questioning pursues her interpretation of events. She begins by attaching a communicative explanation to Lesley's self-injury ("pain – I think it was pain. And the only way she could tell me was to bash herself"), before elaborating a more detailed theory:

Mrs. A: (Thoughtfully) "Being a woman. Her body changes. This is why it was so hard, because she was changing. She was going from a young girl to a woman. And with that you have body changes and you have pain, like, period pain things. She was having the period pains without the periods... She didn't understand what was going on. She knew there was things going wrong with her body. And I kept taking her back to the doctors, because I felt it was something to do with her body changes. And – and then it – because all this goes on, because she couldn't do this, she was having pain. Then she wasn't eating properly, so it upsets her bowels, she couldn't go to the toilet, she got constipated. That was more pain, so she was bashing out, because she's thinking, 'what's going on'. And I kept going back saying 'there's something wrong with my daughter'".

Mrs. Anderson goes on to talk a little about Lesley's reaction to being in physical discomfort, and how her own approach is to be persistent in her pursuit of thorough medical investigations and treatment. This strategy is eventually successful, in that Lesley is prescribed oral contraception and her direct approach ensures that she receives the immediate attention of a gynaecologist. She fails initially, however, to secure the treatment that would put her mind at rest, a thorough medical investigation to determine whether there was there was a physical complication, though her persistence ultimately wins through:

Mrs.A: "...what I was worried about was that the hymen wasn't broken and that she could have a blockage. Because you can have a blockage and each time, every month when she came on, there could be a build up of blood and it can kill you – because this has happened before. That's what my fear was – that she'd got this build up, because the pains were coming, but the blood wasn't. It came once and it didn't come again, but every month – a week or two before she'd start with all this really bad punching and kicking and crying and everything. And so, luckily, he listened to me and, you see, he checked everywhere. He checked her ovaries..."
(Source: Interview – September 1999)

It is clear from looking at each of these examples that the role of sexuality is a complicated, yet significant, factor in the development and establishment of self-injury in the lives of these women. The role of sexual abuse has certainly been considered to be of major importance in influencing the decision for some women to engage in self-harm (Smith, Cox & Saradjian, 1998; Spandler, 1996). Furthermore, some writers have argued that the factors giving rise to self-injury in people with learning disabilities may not be as dissimilar as we think from those in self-harm (e.g., Babiker & Arnold, 1997). However, apart from the exploration of this possibility by the staff nurse responsible for the care of Melanie, there was little suggestion of this with the others in the group. It is, therefore, difficult to consider the association in anything other than speculative terms, which is of little if any value to my study.

The role of menstruation, however, does appear to be a significant, albeit relatively unexplored, dimension of the development of self-injury in the context of an individual's life. In particular, the onset of puberty for several of those studied appears to have been extremely traumatic, exacerbated of course by the absence of spoken language. The varying, though always extremely close, relationships that the women had with their mothers made this particularly evident. Mrs. Anderson talked of Lesley's difficulties with coming to terms with her bodily changes and how this was reflected in an upsurge in her indulgence in self-injury. Her fear, distress, and confusion must have been almost palpable to Mrs. Anderson, who frequently spoke of her ability to anticipate her daughter's anxiety long before it manifested itself. Lesley's emotional reaction to what was happening to her made perfect sense to her mother, and prompted her to vigorously pursue medical intervention. However, medical discourse surrounding self-injury did not take into account the possibility of it being exacerbated by menstruation, which meant that, to be taken seriously, Mrs. Anderson had to become a nuisance. In doing so, appropriate, yet reluctant, medical investigation and treatment was forthcoming, despite the continuing denial of a possible connection between the two.

This chapter has explored biological processes in explaining self-injury in people with learning disabilities, initially in relation to the changing emphasis from clinical syndromes to the role of malfunctioning neurotransmitters in the brain. Evidence from the lives of the individuals studied demonstrated a consistent emphasis on powerful medication to ameliorate behavioural excess, and a frequent reliance on makeshift and prescribed mechanical restraining devices to restrict the capacity for self-injury. There was little to suggest, however, that there was any demonstrable link between the choice of intervention advocated and an underlying responsible biological mechanism. It seems likely that research into this area will continue to proliferate, though it is difficult to predict whether such increased knowledge will reveal increased diagnostic accuracy and subsequent successful treatment options. The evidence relating to physical illness and biological phenomena such as the onset of menstruation appear both more convincing and likely to present more practical possibilities. A life history approach reveals the interrelationship between self-injury and incidents of physical illness and points to the former sometimes being a strategy to deal with the latter just as the latter frequently arises as a consequence of the former.

The following penultimate chapter seeks to examine the development of the multi-disciplinary team in relation to people with learning disabilities. The perspectives explored in chapters three, four, and six are embodied in the work of speech and language therapists, behavioural psychologists and nurses, and the medical profession respectively. Each of these profession's knowledge base provided a clear framework for explaining and intervening with self-injuring individuals, but the extent to which they can effectively engage with the other determines the relative success of multi-disciplinary working.

CHAPTER SEVEN: THE MULTI-DISCIPLINARY TEAM

- The multi-disciplinary approach
- The conditions for change
- The levels of multi-disciplinary working and the NHS & Community Care Act
- The arrival of the contemporary multi-disciplinary team
- The nursing construction of self-injury
- The family experience of professionals and construction of self-injury

The purpose of this chapter is to examine the ways in which the multi-disciplinary approach has been employed in the care of those individuals in the study. Because of the nature of contemporary care of people with learning disabilities, the role of multi-disciplinary working has been considerable in each case. The development and then consolidation of the multi-disciplinary team provides the focus of the first three sections, with a specific emphasis on the professional compromise that has to be made if a profession is to be successful. The interpretation of self-injury within 'hospitals' during the 1960s, with the acceptance of it arising from the 'subnormality' has the implication that professional input would not be directed at ameliorating the behaviour. This tended to be the experience of the institutionalized study group when they were subject to professional input. Self-injury was accepted as a character blemish and there was an acceptance, albeit reluctantly, that restraint and medication would serve only to ease the individual's suffering. The fourth section looks at the interpretation of self-injury by nurses working in community, residential, and assessment and treatment settings both in relation to the study group and from their experience generally. The final section of the chapter concerns the families of the younger members of the group and their own interpretation of the multi-disciplinary support received.

(i) The multi-disciplinary approach

The trend towards multi-disciplinary working becoming an essential ingredient of care for people with learning disabilities covers a period of over 30-years (Mathias, 1991), and even during the dominant 'total institution' structure prior to this time there was recognition of the importance of regular professional consultation (Clarke and Clarke, 1965). Tredgold and Soddy (1963), for example, talked of the uniqueness of the clinical examination for acquiring the necessary information about the 'mental defective', wherein the 'patient's' own story should be considered cautiously and the accompanying relative constituted "a highly interested third party". Furthermore:

> "In the third place there is a continuing need to study the physical, psychological and educational growth of the subnormal child however certain the diagnosis may be. Fourthly, this is an interdisciplinary process, in which the findings require discussion from the medical, psychiatric, psychological, sociological, and educational points of view" (p.357).

Institutional 'interdisciplinary' working was, therefore, clearly advocated, with reports and assessments being submitted by psychiatric social workers and clinical psychologists to assist the decisions about care being made by the consultant psychiatrist and carried out by 'mental subnormality' nurses. This process was significantly compromised, of course, by the need for those with the greatest recognized expertise and clinical credentials being responsible for the care of several hundred 'patients'. The availability of other professionals, such as speech therapists and physiotherapists, was limited, and occupational therapists were occasionally employed in 'hospital' industrial training units. The "ultimate aim" of such training should be "the successful settlement of the patient in the community" (Gunzburg, 1965: 397), though it was more likely regarded as a means of passing the time most efficiently. The individuals I studied, because of the degree of their 'subnormality', received little if any day care, and when they did it would be 'social recreation', usually a means of providing them with a couple of hours in a different environment. The multi-disciplinary approach was largely concerned with the needs of the 'total institution', with liaison being formally arranged and an administrative and bureaucratic preference for professionals occupying a discrete position in the hierarchical structure. Furthermore, as the expectation of contributions from different professional groups increased during the 1970s, there was a simultaneous need for them to adapt to the changing climate of institutional critique by examining and adjusting their own beliefs and methods, particularly, in relation to this study, with emerging discourses surrounding 'subnormality' and the intransigent self-injurer.

The case of clinical psychology – a professional compromise?

The purpose of the 'hospital' clinical psychology service in treating the 'mentally deficient', according to Gunzburg, revolved around the need to assess the individual's personality and both her present and potential mental functioning, and was not a "mere labelling process for statistical or research purposes" (1965: 283). The most widely used assessment tool in the 1960s was the Revised Stanford Binet Intelligence Scale, Forms L-M (Terman and Merrill, 1960), which was used extensively to test general intelligence in areas of verbal functioning and practical performance (Gibson and French, 1971). It was, however, becoming "increasingly recognized as unsuitable for use with the mentally deficient and, of course, quite inappropriate for testing adults" (Gunzburg, 1965: 290). Another influential testing device during this period, the Vineland Social Maturity Scale, developed by Doll (1936), assessed competence in skills such as using a knife and fork, going to the toilet, climbing stairs, buttoning clothes, and managing money, and constituted a "rough guide to intelligence" (Gibson & French, 1971: 24). It was an additional component, to go with intelligence and personality testing, for ensuring that there was, what Clarke & Clarke refer to as the "adequate sizing up of the defective" (1965: 320). The scale, a combination of standardized interview with those who knew him best and detailed observation, was regarded as a useful guide to the progress that the individual had made as a consequence of training in 'hospital'.

Example 47

In December 1963, as Ronald Falconer passes his fourth birthday, preparations are being made for his admission into 'hospital' on a permanent basis and he is subjected to psychological testing. This is a re-test to follow up the first test three months earlier. In the Stanford-Binet test Ronald emerges with a full scale Intelligence Quotient (IQ) of less than 30, and a Mental Age of under 2-years.

In the Vineland Social Maturity Scale he is regarded as operating at an age of 1.62-years. The psychologist reports that Ronald "was unable to talk and therefore could not pass any of the verbal tests in the Binet. He played with the bricks but was unable to build a tower. He played with the movable pieces of the form board but could not fit them into their proper holes". The report goes on to say that Ronald "passed all the tests at the one year level", in relation to the Vineland Scale. "He can run around the house and garden and walk up and down the stairs. He can feed himself with a spoon and drink from a cup unassisted. He will play with a ball but is not interested in other toys. He cannot remove his clothes and is incontinent. Ronald is restless and overactive, and according to his mother, tends to be very destructive".

The second test confirms the findings of the first and the psychologist's psychometric conclusions are that Ronald is "a child of severely subnormal intelligence who cannot talk". A third test takes place in February 1964, after he has been in 'hospital' for a month, which declares that Ronald "could not pass any test at the 2-year old level".
(Source: Clinical psychology report, December 1963)

Both tests, along with a number of others, provided the basis of the clinical psychology approach in institutions for the 'mentally subnormal' in the 1960s and for some time after, though there was no lack of criticism as to their usefulness. Some writers, such as Whitcomb (1945), distrusted the Vineland Scale's emphasis on independence rather than mutual dependence, whilst others warned of the dangers of 'pseudo-feeblemindedness', whereby a mistaken diagnosis was either based on inadequate investigations (Clarke and Clarke, 1955) or applied where the cause is 'atypical' (Benton, 1956). The appropriateness of the Stanford-Binet test for use with 'subnormals' was also questioned (Tredgold and Soddy, 1963), though they ultimately advocate acceptance of the reliability of the results. These concerns about testing were part of a more generalized critique, which had raised concerns about performance bias, standardization errors, cultural 'loading', IQ changing over time (Clarke, 1956), and the role of material deprivation (Roswell-Harris, 1958). Clarke later added a postscript to his original article, whereby he located the context of the IQ debate within the furore caused by the nature-nurture writings of Eysenck and Jensen (Clarke, 1973).

By the late 1970s, the role of clinical psychology had moved on irreversibly from the reliance on intelligence tests towards an emphasis on education and training. Psychological research focused on assessment procedures, which were not intended to result in an IQ figure, but, rather, would be of value in the selection of training objectives, such as the Gunzburg Progress Assessment Charts (PACs), the Adaptive Behaviour Scale, and the Behaviour Assessment Battery (Gardner, 1985). Gunzburg's own thinking is illustrated in this comment on intelligence, which draws on the need to concentrate on the field where the critical meeting between the individual 'defective' and society takes place.

> "Intelligence and personality tests offer a large amount of useful information regarding the individual's resources and the dynamics of his personality makeup, but there is for the mental defective no adequate measure of what is sometimes called 'social intelligence'" (1965: 323).

This gradual change in approach of clinical psychology within the institution, coupled with the development of behaviourism, as the mechanism for moving forward from the assessment process and formulating a plan of action, is pertinent to the care of self-injuring individuals. Psychology was re-conceptualizing self-injurious behaviour in behavioural terms, which necessitated concentrating on the immediate cause or trigger for the outburst. Previously, the 'hospital' had tolerated individuals, who headbanged or punched themselves, through the employment of makeshift or more formal systems of mechanical restraint (see chapter six), if they were required. The construction of self-injury by psychology supported the premise, that these people engaged in these violent behaviours towards themselves as a direct consequence of their brain damage (Woods, 1983). Hence, the development of intelligence testing scales confirmed expectations, the lower the IQ the more bizarre, stereotypical and self-injurious the behaviour. The two fitted together quite neatly and appeared irrefutable, until the radical post-war critique of the institution and the realization that even 'mentally deficient' individuals could develop greater social awareness. Furthermore, behaviourism was to emphasize the contribution of directly observable facts as causes of an individual's headbanging, and rejected the more fatalistic approach of its predecessor. It must be accepted that the role of clinical psychology, in theoretical terms, was significant in the construction of self-injury towards being something, that one could do something about, other than simply devise ways of physical prevention.

(ii) <u>The conditions for change</u>

The changing thinking within clinical psychology about the relationship between 'mental handicap' and learning was set within a philosophical context of a shifting perspective towards human rights (e.g., The Declaration of General and Special Rights of the

Mentally Retarded, 1968), service delivery principles (Nirje, 1970), 'ineducability' (e.g., the Education Act, 1970), and the future of the 'hospital' (e.g., the government White Paper, 'Better Services for the Mentally Handicapped', 1971). This last report, in particular, though provoking criticisms of both idealism (e.g., Shapiro, 1972) and conservatism (e.g., Elliot, 1971), provided a future framework for care revolving around rigorous assessment, integrated planning, and inter-disciplinary working:

> "There should be proper coordination in the application of relevant professional skills for the benefit of individual handicapped people and their families, and in the planning and administration of relevant services, whether or not these cross administrative frontiers" (DHSS, 1971).

One of the key practical moves towards realizing such inter- or multidisciplinary working transpired with the recognition that children should be educated, regardless of degree of 'subnormality', and they shouldn't be admitted into 'hospital' unless in the most intransigent of circumstances. Powerful critiques of the inappropriateness of 'hospital' care for children had emerged as the 1960s ended (Raynes and Tizard, 1967; King, Raynes and Tizard, 1971), which broadly corresponded with the more generalized institutional critique that had been gathering force. The policy of not admitting children, however, was implemented quickly, whereas for adults it would be more prolonged and political. In effect, this meant that systems needed to be put into place, which would help to maintain children in the community, and facilitate the family being able to look after them. The multidisciplinary team would subsequently provide the mechanism for such social and educational support. (Four individuals in my study group, nevertheless, were admitted into 'hospital' during the 1970s, though the process of negotiation was considerable and circumstances at home came to be regarded as intolerable).

The situation was more complicated for 'mentally subnormal' adults where the powerful medical lobby would be necessarily resistant to change, since that was the nature of their history in most areas of care (Turner, 1995). Consultant psychiatrists were not averse to the principle of multidisciplinary working, so long as their privileged status was preserved:

> "The care of the mentally subnormal requires a team approach to which many different disciplines contribute. We believe that the consultant psychiatrist is the most appropriate person to accept responsibility for coordinating the work of the team" (RMPA, in Heaton-Ward, 1977: 75-6).

Their main point of contention related to a perceived lack of consultation over the proposals of the 1971 White Paper, though they accepted a reduced reliance on the institution and suggested assessment of children occur within paediatric units attached to general hospitals. Other medical voices expressed greater concern over the impending changes (Shapiro, 1972), and they were joined by the bureaucrats and administrators (Association of Hospital Management Committees, 1972), and some voluntary groups (NSMHC, 1971). The reluctance of psychiatrists and managers, Goffman's "true clients of the institution" (1961), to embrace change was not unexpected, but the concern of the voluntary sector was more difficult to understand. Once again, however, there was little criticism of the multidisciplinary proposals, with recommendations for "a system calculated to engender a team spirit through staff consultation and involvement at all levels". The 'total institution' model was envisaged as continuing to provide the framework, with administrators and service departments being considered equally as important as those who would come to be regarded as more typical of multidisciplinary working, psychologists, teachers, speech therapists, and physiotherapists (NSMHC, 1971).

The radical element of the white paper had been the proposal that the institutions would be closed within 10-15 years, a statement that could only have been made at the precise moment that the disparate elements of radical reformers, dilapidated buildings, institutional scandals, sociological studies, and government policy apparently merged. The retreat into conservatism was rapid, predominantly because of the cost implications and impending economic crisis, but also as a consequence of the entrenchment and resourcefulness of the critical voices already mentioned. Multidisciplinary working, though, could be equally associated with the critique of the institution as with its defenders, and was ideally suited to the developing service principle of consensus management (Briggs, 1972). Furthermore, 'severely subnormal' self-injurers were not particularly represented in the rhetoric of those most critical of the institution, beyond the notion of 'educability', in fact it was the contrary they were primary targets for its defence.

> "The most urgent cases for admission on the waiting lists of most hospitals for the mentally subnormal are severely subnormal children, often doubly incontinent and with multiple handicaps or overactive or destructive behaviour, who impose an intolerable strain on their parents and often threaten the stability of the family unit. Such cases have usually already defeated the efforts of all other agencies (e.g., junior training centres, paediatric units, and children's homes) to manage them, and it seems highly unlikely that any hospital-type unit would be able to do so unless it had the staff structure and facilities to make it, in effect, a small hospital. With the increased expectation of life, a high proportion of such children survive into adult life without becoming suitable for a hostel providing residential facilities only. Sooner or later, therefore, they must be transferred to hospital type care. The integrated area service should provide day-care for those patients who do not require residential care and who are unsuitable for attendance at junior and adult training centres or are special care problems" (RMPA, 1970, in Heaton-Ward, 1977: 76).

Ultimately, greater acceptance of the social approach to 'mental subnormality' was intrinsic to effective multidisciplinary working, and the medical model would be increasingly challenged during the 1970s, culminating in the ill-fated Jay Report (1979). The conundrum for medicine was how to engender and encourage greater professional cooperation, whilst simultaneously retaining power; for the moment it came with the publication of a 5-year study in the north east

> "Medicine is not now the discipline which calls Psychology, Education, Nursing and Social Service to its aid in the overall treatment of the retarded and that there is a considerable danger that, as a result of the many administrative changes that have been made in very recent years and which are still proceeding, these disciplines which should be a coherent whole led by medicine, are now splitting up into their separate parts, leading to a situation where each discipline is acting on its own and in its own right without regard to the need for total integration of effort, and giving an appearance of being more concerned with the rights and privileges and power of the individual discipline and less with the right of the patient to have integrated total treatment" (McCoull, 1971: 191).

The immediate survival of the 'hospital' lay in its amenability to reform, whereby constructive criticism, monitoring of good practice and conditions would be undertaken by an external source, the Hospital Advisory Service, comprising medical, nursing, administrative, and social work personnel. This body recommended that a "complete multi-disciplinary assessment of each patient, recorded in the notes and repeated at appropriate intervals, is the basis of accurate diagnosis and the provision of a suitable therapeutic programme" (NHSAS, 1971). This was a key statement in multi-disciplinary thinking, one that would be above criticism, but extremely difficult to fully enact because of the inadequate mechanisms for facilitating effective interaction between competing professional discourses.

(iii) The arrival of the contemporary multi-disciplinary team

The advent of the 1980s witnessed the consolidation of multi-disciplinary working as an essential component of service development, irrespective of this absence of real engagement. Heaton-Ward (1984), for example, describes how the process should work and identifies the professional meeting as the point at which subsequent individual plans should be formulated:

> "Each member contributes his or her particular skills and, in the National Health Service, the consultant psychiatrist remains the person with overall responsibility for integrating the many disciplines concerned, and for ensuring the best possible treatment for the patient. All patients should be reviewed at regular case conferences attended by all disciplines, and patients themselves encouraged to participate in decision making" (p.95).

The era of Heaton-Ward, however, was coming to an end, and his "standard students' and nurses' handbook" (Eden, 1976: 119) would soon be consigned to history, just as the influence of other equally significant writers was waning. Craft (1979), for example, continued to carry on the traditions of his predecessors in 'Tredgold's Mental Retardation', but the institutional association marks the book as belonging to the past. He does, however, make a telling comment about the rhetoric of the period:

> "Although there is much lip-service paid to the concept of a multidisciplinary team, it is more commonly talked about than successfully put into practice" (p.18).

Example 48

The 'hospital' multi-disciplinary meeting or case conference, once established, would be conducted annually, chaired by the consultant psychiatrist, and based on a 'ward report' submitted by the charge

nurse/sister. One such report is made about Terry Lawson in April 1978, 15-years old and residing on a ward for 'severely subnormal' and multiply handicapped children for the previous 6-years. He is described as "becom(ing) distressed and irritable when teased by younger boys" and "crying bouts have been noticed for the last few months". The remainder of the report relates to his general self-help skills, mobility, communication, and general attitude towards adults, children, and parents. The meeting is attended by the consultant psychiatrist, ward staff, and 'hospital' school class teacher, though no action is agreed and no record of such a meeting is made in Terry's clinical notes.
(Source: 'Ward report', 26th April, 1978).

The early-1980s economic and political context had also altered, with ideological assaults on welfare provision (Pollitt, 1990), and institutional expenditure cutbacks advocated so as to accommodate community expansion (Allsop, 1984). The 'Ideal Type' service structure proffered by Jay (1979) (see box 5) was increasingly gaining unofficial acceptance, despite the irony of the essential conflict between its idealism and the new economic realities within 'mental handicap' services.

1. Mentally handicapped people have a right to enjoy normal patterns of life within the community;
2. Mentally handicapped people have a right to be treated as individuals;
3. Mentally handicapped people will require additional help from the communities in which they live and from professional services if they are to develop to their maximum potential as individuals.

Box 5: The Jay Committee's philosophy of care, (1979) – the basis of an 'Ideal Type' of service provision.

A second irony lay in the 'managerialism' of the Griffiths report (1983), whereby decisions were made quickly and precisely by key individuals, representing a clear retreat from consensus (Pollitt, 1990), and also resting uneasily with the unique 'negotiated order' of the NHS (Cox, 1991). The multi-disciplinary team needed to adapt to the new language and rhetoric of cost-effectiveness, quality assurance, and the variously defined concept of 'managerialism' (Cutler and Waine, 1997), by demonstrating its applicability to the different levels of care. The 'new right' ideology placed great emphasis on the bloated nature of health services, and the consequent pressing need to reassess the use to which resources are put (Harrison, Hunter, & Pollitt, 1990). Multi-disciplinary 'case conferences' took place within this changed economic and political climate, and there was greater emphasis on their regular occurrence, 'residents' being represented, and achievable targets being established and subsequently evaluated.

Example 48

In 1987, a 'panel assessment' relating to Sarah Houghton, 22-years old and living on a 'hospital' ward following transfer from a larger institution, demonstrates the move towards a more focused approach to multi-disciplinary working. She is described as engaging in "occasional headbanging", but the report is generally more objective, identifying the specific nature of her daytime activity, physical and sensory 'handicaps', and skills identified from assessment including those pertinent to community living. Attendance at the meeting includes the consultant psychiatrist, senior registrar, service manager, nursing staff, clinical psychologist, and social services representative. The minutes of the meeting end with 'recommendations for action', which include "more stimulation from occupational therapist, ward, and physiotherapist", liaison with social services "regarding the blind and deaf societies", and a long-term goal of "small group home with 24-hour staffing".

(Source: 'Panel assessment' minutes, 23rd April 1987).

The emergence of the idea that institutional quality of care could be measured had occurred in the 1960s, when features such as rigidity of routine, degree of 'block' treatment, extent of depersonalization, and social distance between carer and cared-for were evaluated using a 30-point scale (King, Raynes & Tizard, 1971). Staff training and institutional structure and functions were subsequently identified as the main factors preventing quality, rather than the institution's size and staffing levels (Tizard, 1974). Subsequent quality measurement procedures would focus more on factors such as skill acquisition and the elimination of behaviour problems (Whatmore, Durward, & Kushlick, 1974; Durward & Whatmore, 1975), which was both more consistent with the increasing influence of behaviourism and represented something of a departure from the influence of sociological studies. Quality was temporarily being redefined in individual terms, and was greeted enthusiastically by some observers:

> "The research... is an extremely sophisticated method of evaluating and measuring the quality of care in a residential setting. It involves the classification of child and staff behaviour, the coding of these behaviours by specially trained observers and the interpretation of the collected data in terms of discriminative indices. It represents a breakthrough in enabling a scientific measure of the abstract concept of quality and care" (Clarke, 1986: 248).

The burgeoning of quality measurement systems went on to encompass the establishment of residential facilities (HCAT, 1977), the influential PASS system's emphasis on the extent to which they conformed to the normalization principle (Thomas, Firth, & Kendall, 1978), and guidance checklists for parents seeking to assess residential accommodation (NSMHC, 1978). The impact was equally discernible within the establishment of community services and in the slowly retracting 'hospital' sector, where 'quality circles' and 'performance indicators' were becoming the norm. As many have pointed out, however, quality is to some extent determined by the standpoint of the individual in relation to the service being offered (Pfeffer and Coote, 1991; Ovretveit, 1992; Harrison and Pollitt, 1994). This is a moot point for my study, since many of the parents interviewed had much to say about the quality of care that they had experienced over sustained periods (see final section of chapter).

The doctrine of multi-disciplinary working, nevertheless, adapted to the changing climate with some equanimity, since it was increasingly coming to be regarded as unassailable, and the subsequent new batch of textbooks (e.g., Clarke 1982; Tierney, 1983; and Sines & Bicknell, 1985) sought to identify the new principles upon which professionals would need to work. These would underlie the emerging relationship between community nurse and social worker (the basis of the proliferating 'community mental handicap teams'), and consider how the skills of the consultant psychiatrist and clinical psychologist could be generalised to community settings. Multi-disciplinary working was struggling to establish a presence in the emerging complicated climate of the 1980s, with the problems of professionals being narrowly trained and socialized within their own disciplines (Hilton, 1995). This was further compounded by the pervading climate of protectionism and distrust, which could hinder individual practitioners engaging successfully with each other (Weinstein, 1998).

The result for the individuals that I studied, who had always lived at home, was a sometime lack of preparedness by professionals about the implications of working with families caring for a self-injuring member. Only a few years earlier, many children with such complex needs would have been cared for permanently in 'hospital', and the necessary experience and expertise in maximizing multi-disciplinary working had not yet been acquired. There was also a difficulty in the transferability of institutional skills from institution to community, which resulted in some conflict between the consultant psychiatrist reliance on powerful medication and parental reluctance to administer medication to their children. Side effects of medication were recognized far earlier than in 'hospital' and the numbing impact on behaviour, despite the relief that it could temporarily provide, rested uneasily with family life. Furthermore, the shortage of consultant child and adolescent psychiatrists in the areas studied during the 1980s exacerbated the situation significantly, with desperate parents frantically searching for the required professional assistance.

The care of those remaining in the, by this time, rapidly retracting 'hospital' system was geared towards eventual closure, and multi-disciplinary assessments were increasingly geared towards establishing the options available in relation to assessment.

<u>Example 49</u>

The 'hospital' multi-disciplinary assessment of the early-'90s revolved primarily around the recognition of impending closure, and a consequent need to identify the most appropriate future placement for the individual. Self-injury was no longer, therefore, regarded as necessitating institutional care, but the availability of suitable residential accommodation posed something of a problem. A March 1992 multi-disciplinary meeting for 31-year old Stewart Robinson, for example, identifies his obsessional behaviours and tendency towards "headbanging or biting himself" if his compulsions are not satisfied. 24-hour care is recommended, but with carers being equipped with the necessary behavioural skills to work with him successfully.

(Source: Multi-disciplinary meeting minutes, 30th March, 1992).

<u>Example 50</u>

A similar procedure occurs in the life of 34-year old Daniel Cotterill, with a multi-disciplinary assessment attended by the consultant psychiatrist, medical officer, clinical psychologist, staff nurse, and social work assistant. Apologies are conveyed from the 'hospital' social worker, and the community nurse and social worker from Salford, Daniel's area of origin. His challenging behaviours, comprising his consumption of "cigarette ends, grass, paper, and other inedibles", in addition to "rock(ing) and headbang(ing)", are central to the report because of the need to escalate the discharge process. Fully staffed care provision and

involvement in structured daytime activities are considered prerequisites for such a move, since it is "not clear how Daniel might cope in different environments, or indeed how he might cope in a physically more restrictive situation". Targets are established to quell such concerns, and Daniel remains for 3 further years in the 'hospital' before joining an NHS trust residential network, though not in his area of origin.
(Source: Multi-disciplinary meeting minutes, April 17th 1991).

(iv) The levels of multi-disciplinary working and the NHS & Community Care Act

The life of the institutional multi-disciplinary team was coming to an end by the beginning of the 1990s, and the main concerns occupying 'hospital' managers were efficient retraction and finding a suitable community placement. There was a need, however, for greater consideration of how those with extremely complex needs like self-injury could be facilitated in the community. Inadequate co-ordination of services had contributed to the provision of some fragmented services (Hornby, 1993), and clients and their families could be inadvertently excluded because of bureaucracy and culture clashes restricting co-operation between professionals (Biggs, 1993). Families sought professional help ordinarily when the informal support system was exhausted (Golan, 1981), and the majority of the parents I spoke to had negotiated the hierarchy of support (Sugarman, 1986), before embarking on professional assistance in a state of desperation.

Mathias (1991) analyses the specific levels of multi-disciplinary care available once the decision to seek help has been made (see Box 6), though he acknowledges that there may be circumstances in which it might be preferable for one individual to take full responsibility. These levels of multi-disciplinary working were designed in anticipation of the new legislation, the NHS and Community Care Act (1990), which set out to put an end to the endless debates over the meaning of the concept (for a review, see Land, 1991). According to the act:

> "Community care means providing services and support which people who are affected by problems of ageing, mental illness, mental handicap or physical or sensory disability need to be able to live as independently as possible in their own homes, or in 'homely' settings in the community. The Government is firmly committed to a policy of community care which enables such people to achieve their full potential" (Dept. of Health/Dept. of Social Security, 1989: 3).

1. Level I concerns parents or clients in receipt of separate services from a number of disciplines and who themselves integrate the advice and translate it into a programme of activity informed by various disciplines;
2. Level II is an extension of level I in which parents or clients effect the integration with the help of someone else, a named person, a guide or a counsellor;
3. In level III activities professionals adopt a more central role in managing the inputs from different disciplines and have formal responsibilities to do so – as in case management or the management of a service or unit the staff of which come from different disciplines;
4. Level IV activities describe the work of teams, groups or committees in which the responsibilities are vested at group rather than individual level, although there might be a formal leader.

5. Box 6: levels of multi-disciplinary working – from Mathias, (1991)

One of the key issues emerging from the act, the cornerstone of high-quality community care (Shaughnessy and Cruse, 2001), and emphasized within the earlier white paper, 'Caring for People' (1989), was the expectation of clearer differentiation between an individual's need for 'social' or 'health' care (Harrison, Hunter, & Pollitt, 1990). The community 'trusts', which would be created during the 1990s (there was a period of respite of 3-4 years so that each service could establish how it might develop) consequently needed to determine the sort of care best suited to their clients. In effect, this meant an increased targeting of resources to those considered in greatest need (Manthorpe, 2003), and an end to any hopes of equal access to services for people with learning disabilities (Statham and Timblick, 2001). The act effectively consolidated the shift from 'hospital' to community care (Matthews, 1996), and there was considerable variation in its implications for the individuals that I studied. One 'trust', for example, claimed successfully for significant 'health' needs for many of their clients, since the majority had been resettled following periods of institutional care in neighbouring areas. In the other two areas studied, it was more difficult to envisage how the post-institutional internal market world would unfold, or what the implications might be for the younger group of self-injurers, whose contact with health services was less pronounced than their predecessors. The introduction of 'care managers' (level III of Mathias's categorization) in the act constituted the mechanism for addressing the complexities of these individuals more adequately. The remit of such an individual, anticipated as the social worker, would be to assemble a care 'package', which would involve coordinating the input of the various multi-disciplinary professionals and accessing such services as respite and day care.

> "This model is buttressed by changes in the social security regulations aimed, firstly, at removing the perverse incentives towards residential care, secondly, at making the use of private sector residential accommodation financially more attractive to local authorities, and thirdly, at encouraging the provision of home-based care where appropriate" (Harrison, Hunter, & Pollitt, 1990: 174).

The employment of this new system of care delivery can be illustrated in the care of Sarah Houghton and Robert Clayton, whose care 'packages' demonstrate both the advantages and disadvantages when applied to those with such extremes of behaviour.

<u>Example 51</u>

Sarah Houghton's experience of this emerging system of care delivery demonstrated both its advantages and its disadvantages. The 'package' was assembled in 1995 whilst she was still living in residential care following the transfer of responsibility for provision from the NHS to a private non-profit making organisation. Deterioration in her self-injury, possibly as a consequence of the recent upheaval following the closure of her former institutional residence, resulted in a referral to the community learning disability team in order to establish a more coordinated approach. The referral, as the nurse points out in a letter to Sarah's GP "does not include automatic involvement of our consultant psychiatrist (for which) the normal consultancy referral should be made". In learning disability services, the consultant psychiatrist has tended to remain formally detached from the other professionals providing input, which has served to illustrate their continuing importance and helped to consolidate their continued position of power in the community. The consultant confirms the situation in a subsequent letter to Sarah's GP. "It seems that Sarah has been constantly hitting, punching and scratching (her accompanying keyworker) throughout the clinic appointment. She was agitated and wanted to get away from it all. (Her keyworker) described her behaviour to be deteriorating. It seems that she dictates the daily routine, and this is being done in order to contain her. She has also started urinating in the bed and coming out with counterproductive behaviour". He ends by outlining a management plan, which involves the prescription of antipsychotic medication and input from the community nurse, psychologist and speech and language therapist.

Over the next two years Sarah's circumstances change significantly, as she is initially provided with a residential placement, which proves too disorganized and arbitrary for her parents, and, amidst considerable frustration, they welcome her back into the family home. The loss of her sight (see previous chapter) occurs round this time as well, which consolidates this extremely traumatic period of her life. Throughout this period, as things spiral downwards, the multi-disciplinary team becomes increasingly involved, but circumstances are conspiring against them. An 'emergency meeting' in September 1997, when Sarah is now 32-years old, describes her as being treated with anti-depressant medication for her continuing low mood. The social worker talks of a one-to-one strategy being implemented by a private sector organization to provide her with regular intensive support, the use of the 'snoezelen' (purpose-built recreation area) to facilitate relaxation, and ongoing family support being provided by the community nurse. The community nurse describes the 'clinical interventions' currently being offered by the community team as being concerned with the monitoring of Sarah's mood and behaviour, particularly in relation to the medication, support and counselling her parents, advice to care workers, and liaison with speech and language therapy.

The involvement of a speech and language therapist, clinical psychologist, and RNIB representative, all of whom conduct comprehensive assessments of the situation, completes the multi-disciplinary approach. Unfortunately, however, Sarah's aggression and self-injury continue unabated and she enters a downward spiral, which necessitates emergency admission into an assessment and treatment unit, though this is more than anything to provide her parents with some respite. Some awareness is demonstrated by the consultant psychiatrist, who records that since July 1997 "when Sarah had treatment for her eyes, which she found very traumatic…there has been a marked deterioration in her – she is unhappy, agitated, continually screaming and demanding her mother's attention". He is, however, unable to provide anything other than monitoring of her antidepressant medication and recommendations for increased family support. The application of this more coordinated approach to Sarah's care fails, unfortunately, to properly consider the family's real needs, and attempts instead to manage the crisis. The 'package' of care being assembled is unable to take into account Sarah's obvious intelligence, her anger over the loss of her sight, and her fear of the motives behind change.

The disappointment in the care 'package' being offered to the Houghton family is entirely justifiable when the ongoing circumstances of Sarah's care are fully considered. A life history approach enables us to witness the unfolding of a tragedy of almost mythical proportions, since it stretches from when she is a young girl attending a residential school for 'rubella children' right through to the current situation. Key events of significance have been Sarah's transfer between and within different institutions before ending back with her parents. The unnecessary loss of her sight exacerbated the situation further, and the absence of the necessary structures and expertise to facilitate her entry into a deaf-blind world remains significant. The social worker is unable to draw on the expertise available and establish the necessary trust with Sarah that might address the real issues. Unfortunately there is no happy ending for Sarah and she remains bewildered, frustrated and angry at what has happened to her; yet she is an intelligent girl and this adds further to her parents bitterness. Sarah's self-injury has been constructed by the events of her life, which have been unforgiving and sometimes unnecessary, and the provision of a 'package' of care has been thus far inadequate. Mrs. Houghton discusses the effects on Sarah in quite graphic terms: "(S)ometimes she's so overcome with this rage, in her bed, watching her on her bed, and she's absolutely beside herself with terrible, terrible rage. But you don't feel you can step into her bedroom because you don't want to get in the way. Because, you think, if she turns on you, that she will hurt you quite bad. So – make sure she's not really hurting herself, because the bed is soft, isn't it? But even sometimes when she's in a terrible rage in the bath and you give her a cup, she's so rigid in her rage that she can't take the cup to her mouth. Her hand's shaking like that, she's so, so beside herself. We've given her more and more medication". (Source: Referral letter to community learning disability team, February 1995; Medical correspondence, June 1995 and September 1997; Minutes of 'emergency meeting', September 1997; Interview – October 1999)

Example 52

The complexity of adapting an individual to what services are available is further demonstrated in the care of Robert Clayton when, in July 1992, as he approaches his seventeenth birthday, a 'review meeting' is held at the assessment and treatment unit. The level of violence that he is displaying, both to himself and others, means that the unit is the only facility with the necessary structure to be able to accommodate him. The context of the meeting is the need to coordinate the input from the various agencies contributing to his care (social, health, education, and voluntary) in order that he makes a successful transfer to adult services. The key stumbling block arises from deciding the level of financial responsibility applicable to each agency and this makes for prolonged negotiations. The meeting fails to establish a consensus but it does result in the various representatives accepting that there needs to be increased coordination and the need to search for a compromise.

Over the course of the next year social services assume the dominant role in trying to guide Robert into adult services, but they find it difficult dealing with the complexity of his situation. A review summary in January 1993 states, with what appears to be more than a trace of irony, "(S)uch were the cause of great turmoil and further meaningless meetings and letters from Mrs. Clayton to all concerned and replies thereto. The procession of letters and poor understanding only served to exacerbate all parties concerned". Robert's progress is considered to be quite good, with him having settled into life at a local 'autistic community' with no real episodes of violence, but there is some concern about his father's predicament. "Mr. Clayton, it would seem, has been pushed to the periphery. It must be difficult for Robert to understand why his father is not living in the family home. I am informed that he does see (his father) once per week and that the mobility (benefit) is partly needed for this purpose. I do not think, therefore, that we should be thinking of closing the case just yet, for there is still disharmony around. In my opinion it should remain active until at least the fifth review of Robert's placement and then neatly closed, if all is well".

The complicated nature of Robert's family life, with his father being afflicted with a rare neurological disease that will shortly kill him, and the messy divorce between his parents, has, I think, a considerable impact on his negotiations into adulthood. The difficulty relates to the conspiracy of silence that surrounds the whole issue of his father; it is as though he had been air brushed out of Robert's life, never to be spoken about again. On interview with Mrs. Clayton, she responds to my references to him, but is clearly uncomfortable with the subject yet, in all other areas she demonstrates acute insight into Robert's displays of anger:

Mrs. C: (Finds this extremely difficult and uncomfortably, talking hesitantly throughout) "Well, it was very difficult – Con's speech started to deteriorate from about '82 onwards, and his ability to write and walk was visible in the early '80s, and Robert would only have been five then. But Con was already visiting the doctor with his own problems in the late '70s/early '80s, so he'd been deteriorating as Robert grew up. I think one of the worst problems was that Robert was trying to copy speech patterns, when he did start to speak, of somebody whose speech was deteriorating very rapidly".

AL: "Did they have a good relationship?"

Mrs. C: "No, they were (laughs) – they were very similar. I mean, this was one of the difficulties, in that Con and Robert were very similar in a lot of the things they did. They both liked collecting cars and railways, you know, they had hobbies that are the same. They had a lot of mannerisms that are the same. A lot of their personality was the same (hesitates). Desperately sad".

In October 1994, little has really changed and Robert, having just turned nineteen, remains in this transition to adulthood period. The senior registrar (for the consultant psychiatrist) writes to Robert's GP. "I understand that his father died recently but that Robert showed little reaction". Unfortunately, however, by the beginning of the following year (February 1995), there is a clear change in Robert's behaviour, which is becoming increasingly unpredictable but more self-directed. A meeting is called "over concerns regarding the deterioration in Robert's behaviour, which was becoming more self-injurious, and was increasingly being directed at staff and residents, as well as to the fabric of the building. The past has shown the pattern would continue until Robert took such actions that would cause exclusion from wherever he was placed. The causes of these behaviours (although these were not always clearly identifiable), were noises made by other residents, or any sudden noise".

The central component of the deterioration in Robert's self-injury is identified by his mother as being his desire to live at home rather than within the 'autistic community'. There is no further discussion of his father's death as being a possible contributory factor and the emphasis is placed on maintaining him in his placement and having a backup plan for when the level of his violence becomes intolerable. This latter

approach is identified as a structured one based on behavioural principles within the confines of the assessment and treatment unit. Extensive ongoing input from the multi-disciplinary team (consultant psychiatrist, clinical psychologist, social worker, community nurse, and 'autistic community' manager) constitutes the approach of choice in achieving a stable residential placement. There is also continuing concern with regard to funding with a submission to a 'learning disability panel' pending about additional finances. The financial situation is eventually resolved, though not before the 'autistic community' threatens to withdraw the care provided. Furthermore, Robert continues to present considerable management problems and spends the next couple of years fluctuating between his own flat within the 'community', the assessment and treatment unit, including a period detained under the terms of the mental health act (1983), and the family home.
(Sources: 'Review Meeting' minutes, July 1992; 'Review Summary' report, January 1993; medical correspondence, October 1994; multi-disciplinary meeting minutes, February 1995; interview – July 1999)

The multi-disciplinary process became more and more complex during the 1990s because of the expectations of the NHS and Community Care Act (1990), which necessitated closer working between different professionals and coordination by a 'care manager' (social worker) when the need justified it. The younger members of the research group were the ones benefiting mostly from these changes as they negotiated adulthood, whereas many of those, who had spent many years of their lives in institutions, were resettled as the 'hospital' closed and retained their 'health status'. Difficulties for those receiving the more coordinated approach arose when their violence to self and others demanded intensive support and a fine balance within the 'mixed economy' approach. Sarah and Robert's cases amply demonstrate the need for coordination to be pragmatic and circumspect when things go less smoothly than anticipated. Level III of Mathias's analysis was the only one witnessed with any of the individuals researched, partially because of its appropriateness but also because of the reluctance for professionals and agencies to accept that the parental role could or should be developed to such a degree.

The transition from children to adult services demonstrates issues of multi-agency care, which are clearly different from those of multi-disciplinary care. In the latter, the discourses surrounding self-injury relate to the way in which the professional body adopts and develops a particular way of thinking about and defining the issue, which then influences the intervention approach. In the former, however, the constraints on the role of the particular agency with regard to finance, manpower, and resources are much more likely to influence the construction of the care 'package'. An individual's 'package' of care tends to be assembled three or four years prior to his/her leaving school, and proceeds without problem, until he starts to exhibit challenging behaviour. Each of the agencies involved, social services, health services, and the private/voluntary sector, define the situation in terms of the impact on their own service. The negotiation of respite care, according to 'health' or 'social' criteria, for example, illustrates the rather arbitrary nature in which these decisions are made. The private sector placement is reluctant to increase entitlement of respite, because of the resource implications of challenging behaviour, so the process of needs being redefined in 'health' rather than 'social' terms begins. It is also important to note the political context of the NHS & Community Care Act (1990) which emphasised differentiating between the two types of needs, as the internal market established itself in the mid-1990s.

(v) The construction of self-injury by learning disability nurses

The role of learning disability nurses in the lives of people with learning disabilities has been the subject of considerable debate for many years, particularly since they were associated with institutional working. Nurses working in this field have subsequently had to continually defend their role in moving away from the 'hospital' and into the community. Very few clients being resettled were considered to be in need of ongoing health care by nurses in a residential setting. Most residential care was therefore provided by the voluntary or private sector, meaning that nurses needed to justify having a continued role. One of the key areas that was considered to warrant specialist nursing intervention was in the area of challenging behaviour, and all of the individuals looked at in this study received nursing intervention for this reason. The purpose of this section is to examine how nurses working closely with individuals from the group constructed their ideas about the causes of self-injury.

Only one of those interviewed had trained very recently, the rest had experienced working in the institutions during the early years of their careers, and this was clearly in evidence in some of the answers. Two were currently working as community nurses, two more were employed as staff nurses within a residential network catering largely for clients with significant challenging behaviours, and one was also working as a staff nurse, but in an assessment and treatment unit. The question of cause constituted the focus of the interviews, particularly those factors, which had contributed to the nurse forming her/his beliefs about the nature of self-injury.

Only one of the nurses really touched on the possibility of the role of biology in underpinning self-injury, although it transpired that she was really referring to the actual existence of the learning disability. She was a nurse of about forty with more than twenty years experience, and she was currently caring for and talking about Jason Harvey. Initially the nurse surprises me by making the simple association between learning disability and self-injuring, but her position becomes clearer as she responds to my query as to whether she means that its genetic:

Example 50

S/N: "Yes. Yes. I mean there's loads of stuff in that. He's got no reasoning skills, has he? I say 'no' he can't have something, I can't reason with him because he hasn't got the intellectual capabilities of understanding that reasoning. Now when I worked on the unit (for more able individuals with learning disabilities), I could sit down with somebody and I could reason with them and explain. They have the intellectual capabilities, Jason hasn't got that intellectual capability. He doesn't comprehend reason... Yes it stems from the learning disability, doesn't it? Well, I think it does".

The nurse's argument with Jason revolves around him becoming irritable as a consequence of impatience, intolerance, or frustration, and then expressing this through self-injury or scratching and pinching others. But she sees the solution, not in biological terms, but by the use of a structured behavioural approach, whereby Jason learns that there are consequences to his actions. This is a logical response to the question and one which was fairly influential within the institutional system, but it is also one which suggests that people with severe learning disabilities and communication difficulties are incapable of mature responses. Though Jason's behaviour may be unreasonable, it is also the consequence of a lifetime of dependence and frustration at his inability to exert much influence over what happens in his life.
(Source: Interview with staff nurse – August 1998)

In relation to Robert Clayton the community nurse (C/N) interviewed is in her late thirties and trained originally as an RGN before converting to learning disability nursing. She talks of "anxiety, frustration (and) insecurity" being the principle contributory factors to Robert's self-injury. She doesn't discount the possibility of a biological cause but sees no evidence of it and rejects the notion that Robert may indulge in such violent headbanging, at least in part, because he is less sensitive to pain:

Example 51

C/N: "But Robert will actually say it hurts. Maybe the pain is part of it, but I've never really looked at the pain part, I'll be honest. Because he's never really given me any indications of that. I think mainly it's the insecurity with him that's the main reason. I think it's very deep-rooted, I think he's done it from a young baby. He was also sent away, as well, for his education in residential (care) and stuff. And when he was moved away from home, out of the area, his behaviours were really bad. He set fire and, you know, things, so there's an element there".

Her view of self-injury is influenced less by a general theory about the subject and more by a detailed knowledge of Robert's difficulties in reacting to stressful situations and capacity for becoming obsessional about something. This, I think, reflects the very practical role of the nurse and her need to be able to explain self-injury in terms which provide her with a platform from which she can plan her response.
(Source: Interview with community nurse – February 1998)

A more elaborate explanation is provided by a community nurse, also in her late thirties, who talks affectionately of having known Daniel Cotterill many years earlier when he was in 'hospital'. She discusses the role of biology in giving rise to self-injury, particularly the relationship with sensory stimulation:

Example 52

C/N: "I think people who've got bad physical or sensory loss and self-injure – the type of self-injury we see, it very much seems to be head based. Either banging the head or injuring the eyes or picking the face. It seems to be very much in that sort of area where the senses are... (B)ecause you and I are open to a lot of stimulation, whether you like it or not we're experiencing something. And very often it's not just deprivation of one sense, it's one or more. We've got people who are deaf and blind, so I think, it's sort of, at times in the past people haven't had that sort of input. So people will amuse themselves as people do, in order to get something for themselves. It's like going back to the old saying of feeling pain is better than feeling nothing at all".

The community nurse's knowledge of Daniel is again the most important factor, and she demonstrates the ability to try to explain his behaviour in terms of his own view of the world. She sees him as primarily responding to the boredom that has been such a major feature of his life over the years of his institutionalization. She talks of his tendency to seek the privacy of his room when he doesn't want company, but also how the general improvement in his life and increased attention has led to some reduction in his self-injuring. This detailed knowledge is demonstrated when I ask whether she thinks there is a link between self-stimulatory behaviour and self-injury:

C/N: "I don't know really, a lot of it seems to be – I think they're two different things in a way. When he's doing his behaviour stuff, but when he's hurting himself or attempting to, it's usually when he's not happy with life or when he can't do something, or when he wants to do something and it's not possible or when there's a lot going on. There was a time when a gentleman passed away so there was a lot of activity, things like that, whereas the other things... "

In addition to the role of stimulation in precipitating Daniel's self-injury the community nurse considers the role of other factors and, in doing so, illustrates one of the key shortcomings to the behavioural approach:

AL: "What do you think is the reason for Daniel's self-injury?"

C/N: "Haven't got a clue (laughs). I definitely think there's something regarding attention, and also for stimulation. But I don't think we can actually provide that stimulation and think it's stimulating for Daniel. One thing is, Daniel is Daniel's man and he's seeing life on his terms and he lets you know. You can have people who self-injure who can still be manipulated. Daniel's not one of them. Daniel's his own man and I think probably always will be".

The community nurse effectively pinpoints the main difficulty with behaviourism in effecting change in an individual, who self-injures in the way that Daniel does. In its reliance on the manipulation of behaviour through the use of rewards, it fails to account for intelligence. Despite his lack of communication skills and the appearance of having a severe learning disability, Daniel has always retained a degree of control in his life, which may not be apparent to many. Through her own experience of working with people with learning disabilities spreading over a number of years, added to an extensive knowledge of Daniel, the nurse realizes that the self-injuring belongs to him. She is, however, probably inordinately critical of the role of the institution in Daniel's life, expressing considerable surprise when I tell her that his headbanging pre-dates his admission. But the main contributory factor to her explanation relates to her ability to put herself in the position of another, albeit someone without speech and with a significant learning disability:

AL: "Do you think that Daniel's self-injury is a means of expressing himself then?"

C/N: "I agree with some of that, I do. You only have to think of how you feel sometimes if you can't get your point or how you're feeling across. How frustrated you become and that's something that happens to us occasionally. But with these people it's something that's constant. You imagine sometimes, day in and day out. You can't get across, some people, how they feel about something or that you're in pain. Or you want to go out or you want to whatever and you actually can't".

The nurse's construction of self-injury appears initially to be somewhat arbitrary, with a variety of factors being considered, including sensory stimulation, boredom, frustration, and a reaction to him feeling particularly unhappy with life. In the context of Daniel's life over more than forty years, however, there is considerable insight demonstrated into this process of negotiated reality. This is illustrated further when I ask her whether she thinks that Daniel's self-injuring might vary in its intensity according to his mood or the particular circumstances:

C/N: "Yes there's definitely a tendency to put his hands on the wall and then there's other times the hand isn't there... I could be wrong but there are times he shows frustration or anger. And sometimes it's 'there's something I'm not happy at and I'm letting you know about it'".

AL: "(Can you divert him) when he's doing it angrily?"

C/N: "No, that's when you can't. There are certain times – you can catch him as he's sort of 'tinkering', you know, because if you – but then it's like hit and miss. But if he's not happy with life or whatever's wrong, then he's got to work it through or retire to his bedroom, something like that".
(Source: Interview with community nurse – July 1998)

The role of the institution in giving rise to self-injury also arises in an interview with a staff nurse caring for Ronald Falconer and Melanie Dodd in a small bungalow, part of a large residential network. A 38-year old man, who has worked in a number of institutions in Scotland and the north of England, he does not demonstrate thorough knowledge of the clients because he has only worked with them for 18-months. He does, however, demonstrate a capacity to understand how he became the person that he is today. He dismisses the biological approach, tending to favour a combination of behaviourism and the environment:

Example 53
S/N: "I think that we would have to look back and – it's a way of gaining attention. I also think it's a learned behaviour, and I think that from the days when they were in the institution. Because they were both

in institutions from a very early age. I think it's gone beyond – I think its just part of them now. Certainly the pica with Ronald is just part of him. And with Melanie it's banging herself against radiators or sitting very, very heavily on the toilet. It's like they're making it known that they're here. I think that if you took it right back, I would imagine that Melanie, she wasn't born to do that, but it is, from my own experience on some of the long-stay wards that I've worked in, the abilities of these people here would pick up challenging behaviours or exhibit behaviours than others".

AL: "You think it's more learned than any other theory?"

S/N: "Yeah. I don't think it has much to do with the genetics, and if we say that, why doesn't Phil White act like somebody who has Downs syndrome? I think that the people with Downs syndrome exhibited less challenging behaviour because they looked quite cute. The people who exhibited more challenging behaviour were the ones who were ignored on the ward, who weren't the cute little children. I've often felt that. People like Ronald, who doesn't give much, were left in the corner – 'oh that's Ronald isn't it?'"

When I push him on the causes of Ronald's pica behaviour, the staff nurse demonstrates a pragmatic approach coupled with something of a philosophical approach to the role that it plays in his life:

S/N: " I think it started off when he was a young lad for whatever reason. Did he see somebody else doing it? Did he get comfort from it? Yeah – and I think it started off as a comforter and it has continued as a comforter. I have tried to work out how much he actually eats, but it's impossible to say. I think that it was a comforter and it's developed on and it is now a habit. He does it. It's there. And if Ronald could speak, we'd be asking why he does it. He wouldn't know. The same as I don't know why I bite my nails. I don't think he gets anything from it. I believe if a person does it because he's short of paracetamol or various other things. I don't think it's got anything to do with that. It's a hobby – it's something that he does. He gets some pleasure from it. He ain't got much in the world. I know it doesn't do him any good, and it's just a case of monitoring".
(Source: Interview with staff nurse – July 1998)

A 36-year old staff nurse caring for Janine Lewis in an assessment and treatment unit provides the most informed explanation of self-injury of all the nurses interviewed. She talks of the results of a 'functional analysis' undertaken over a period of weeks, in conjunction with a clinical psychologist:

Example 54

S/N: "The psychologist was working with us at one point and we were looking – he came in frequently to see her and observe her to see why the behaviours arise. And it was found that on three occasions – three types of incident would instigate it. One of them was pain – dental pain, stomach pain, headache, earache. Because Janine has no verbal skills, the only way she has to tell you is – she does that sort of behavior. Then we were working blind because we couldn't really tell from that whether she was just bored, frustrated – that and manipulative. Because if you wanted her to do something, she would start banging if she didn't want to do it, banging her head, stomping – basic temper tantrum. She would do this to try and avoid it. And the more you tried to get round it the more she became…"

The three major factors are thus identified as pain, boredom, and the manipulation of circumstances to avoid something Janine perceives to be unpleasant. This is consistent with the expectations of functional analysis, which as we have seen previously emphasizes 'sensory stimulation', 'attention seeking', and 'escape' as three of the four possibilities. The nurse demonstrates considerable knowledge of self-injury, just as she does about the role of illness in Janine's life, but not the understanding of the role that it plays in her life that some of the others are able to.
(Source: Interview with staff nurse – May 1998)

The nursing construction of self-injury is influenced most significantly by the extensive experience that many of the interviewees had of working with the client group. It was notable that several of the nurses were able to consider how the individual's behaviour had developed over the course of his/her life. In so doing they were able to relate to the idea that self-injuring might make perfect sense to someone whose life circumstances had not always been the most favourable. The only surprise for them was that the self-injuring frequently started at a very young age and frequently preceded their admission into 'hospital'. The role of the institution in precipitating self-injury, largely through the boredom and monotony of daily ward life had figured quite highly in their own explanations. The nurses did not, however, entirely condemn the institution but, rather, were more likely to adopt a more reflective posture, which struck me as being more realistic than defensive. They demonstrated a detailed practical knowledge of working with complex people, which balanced factors such as the effect on the family against what was best for the individual.

(vi) The family experience of professionals and construction of self-injury

According to Byrne, Cunningham and Sloper (1988) there are a number of significant factors influencing the degree of satisfaction that families have of their experience of the multi-disciplinary team. These include their general receptiveness to professional input, prior knowledge and expectations, degree of disruption to family life, and perceived improvements to quality of life. These authors used interviews to examine the views about the input of different professionals of a number of parents of Down's syndrome children. Their findings indicated that 23% received support from five or more professionals, all of whom were helpful, 56% with between two and five, 14% with one, and 6% with no helpful professionals. Nearly half (48%) were entirely content with all the services received, whilst the remainder (52%) expressed some reservations and unmet needs, and some of these (varied between 7 and 38%) viewed the professional input as very unhelpful. One difficulty related to the separate experience of the various professionals, rather than an integrated and coordinated approach, so that the parents needed to vigilantly extract the different bits from the various professionals to effectively create their own multi-disciplinary experience.

This section relates entirely to those individuals of the group, primarily the younger ones, who have continued to live at home and have experienced the changing care context of the developing community multi-disciplinary system. There are a number of areas that I think are worth exploring in relation to the parental construction of self-injury, which might be of value in considering the nature of the future delivery of services. The extreme nature of the behaviour of the group suggests that they do not conform to the usual expectations of service providers. This is, of course, not something that most professionals are unaware of, but the occasional unintentional exacerbation of the situation is something that should be given greater attention. Another related issue concerns the detailed knowledge of the individual's relationship with self-injury, which includes understanding its complexity, accepting it as a character trait, and adapting family life to the requirements of maintaining some semblance of normality.

On interviewing the parents of the group, it became quite clear that there were major differences, in terms of their satisfaction with the professional input that they had experienced. Generally speaking, we can say with some degree of confidence, that services have improved as they have diversified, and there is a greater tendency to consult with and take the views of the family into account. It is also true, however, that some of those interviewed perceived themselves to have been in receipt of quite a poor service. There is a pressing need, I think, to explore how those interviewed have 'negotiated' the reality of their experience, and subsequently come to terms, or not, with the massive impact of having a learning disabled, non-verbal, self-injuring dependent. Critical to our understanding of this is the extent to which the 'package' of care on offer is appropriate to their needs, and how the family accepts this, or indeed is unable to do so. Furthermore, it should also be recognized that these families were coping with individuals with the most extreme of difficulties, and services generally are geared towards catering for far less demanding situations.

- Judgements made about parenting

Example 55

Mrs. Clayton provided an unnerving specific example of where she considered herself to have been unreasonably judged by a medical professional, since the circumstances were beyond her control.

Mrs. C: "... there was one occasion when I actually saw a consultant's note – 'this woman isn't bothered' – because I hadn't turned up for an appointment. And on that particular occasion, we'd been waiting an hour and Robert was screaming and beginning to dismantle chairs. So I had to leave a message to say that I really couldn't sit any longer under these circumstances with him. And all that the consultant had written was this offhand comment and no understanding of the very real nature of the problem... I think they thought initially that it was mother complaining". A handwritten note by the senior medical officer from 1977, which Mrs. Clayton had kept since this time, confirms the experience. The memo says that Robert was "seen at (the consultant paediatrician)'s request at (the local) health centre". It continues by referring to the state of the family on arrival, whereby "all children eating crisps and spilling them". They were "half an hour late because car wouldn't start". One interpretation of Mrs. Clayton's experience of some of the professionals, whom she encounters over the years, relates to her refusal not to be related to on equal terms. It appears that sometimes this approach can invoke a critical and somewhat dismissive response in the professionals concerned, and appearing articulate and informed might not always be more effective than appearing cowed and deferential.

Another example of the power of reputation is illustrated when Mrs. Clayton talks about her son's school experience: "He was once memorably told that he was the worst child ever to be educated in the county. He'd been excluded from more schools than any other child at one stage of his school career, which is awful because he's handicapped – you shouldn't have to exclude kids, who are handicapped". It is notable that Mrs. Clayton's overall view of services is significantly influenced by these two experiences, which are recollected with great clarity and considerable despondency.
(Source: Interview – July 1999)

Example 56
The involvement of a new community nurse with Sam Morris in September 1989, when he is 14-years old, provides another example of an absence of professional insight into the factors that may have contributed to what is encountered. The nurse reflects in her notes that "Mrs. Morris says everything is okay (but she) does not ever seem to have come to grips with controlling Sam's unacceptable behaviour at home and now that the arm restraints he has actually stop him self-mutilating then Mrs. Morris is quite happy". She concludes by saying that she is "considering closing the case", which she does and it will be eight years before it is re-opened. It does appear that this new community nurse approaches the situation without full regard for even the immediate history of Sam's propensity for self-injury, seemingly identifying it purely as a behavioural problem, and not considering the effects on the family. Furthermore, she fails to take into account the number of community nurse changes over recent years and the level of Sam's mother's exhaustion arising from the lack of progress being made with her son.
(Source: Community nursing notes, September 1989)

- Experience of professional support

Each parent tells a different story about their experience of professional input, which is modified further by their current level of satisfaction. In terms of the construction of self-injury this is an important point, since my interpretation of the parents' words would be affected by what was going on in their lives at that particular time.

Example 57
This is illustrated with Mrs. Clayton, whose summary of her experience of professional input reflects both her disillusionment with the current care 'package' and disenchantment with the accepted wisdom of notions such as the orthodoxy of early intervention:

Mrs. C: (Laughs) "I'm not sure that, between us all, we've helped him. He's no better now than he was. I think he's worse because he doesn't like where he is – and to be quite honest, I think between us all – I

mean, I have followed professional advice because I am a professional myself and felt I ought to, but I wish I hadn't. It would have been much easier if, at five, I hadn't gone out to work. I went out to work because I'd been advised that Robert ought to start school early. So, I then took myself back to work, but I would have stayed at home with him, and I'm sorry I didn't in retrospect, because he may well still have been mentally handicapped, but he might not have been so aggressive. I don't know. It might well have been easier for me, because this way has been no joy at all (laughing). A purely selfish comment".
(Source: Interview – July 1999)

Example 58

Mrs. Morris's revelations about professional involvement were similarly mixed, with a general emphasis on people having been very caring and helpful, but not especially effective. Though, significantly, her reflections are those of a woman without major expectations or inside knowledge of how the system works. The effects of Sam's behaviour on the family become quite marked when he gets to twelve years old (1987), and is continuing to display both hyperactivity and self-injury. The community nurse involved at the time records her thoughts about the effect, particularly on his mother: "Mrs. Morris appeared to be resigned that there was little that could be done to help Sam improve his behaviour and admitted freely that she was tired of trying different things. Looking through Sam's notes Mrs. Morris is correct that many things have been tried with Sam. Mrs. Morris is saying that her skills and reserves are not strong enough to be able to give the intensity of behaviour modification, which is required to improve Sam's behaviour in any way. Unfortunately, it will probably be a crisis, which will cause the parents to think either more positively about Sam's placement within the family, or they will relinquish care of Sam altogether. Mrs. Morris openly stated that she found Sam very frustrating and at times unrewarding and this was one of the reasons why she felt so pessimistic about his place in the family in the future. At the moment the parents are not even attempting to take Sam out any more with them when they go on family outings".

The community nurse's fears appear justified shortly afterwards (April 1988) when the family seriously consider applying for a place for Sam at Beech Tree, a residential school for children engaging in severe self-injury (see Jones, 1983, for a detailed explanation of the philosophy, principles, and development of the project). They eventually decide otherwise because of doubts about the likelihood of any success being achieved and a belief that it should have been done much earlier.
(Source: Community nursing notes, August 1987 and April 1988)

- Lack of support

Example 59

Sarah Houghton's story, as we have seen, is the most tragic of the whole group, and the frustration and anger was very evident when I interviewed her parents, though this was probably outweighed by the resignation that they also felt in great measure. The family's recent experience of Sarah's escalating violence had met with a comprehensive 'package' of care (social worker, community nurse, one-to-one worker, and consultant psychiatrist amongst others). Unfortunately, however, this had been unsuccessful in reducing the level of aggression and self-injury. It subsequently became increasingly difficult for the family to contact anyone when the occasion arose. As Mr. Houghton says, when they try to get in touch: "It's an answer phone or they're not available or, like Jim Shankley (social worker), he's been promoted – I mean, Sarah's supposed to be a *client*. They've never bothered to let us know".

Mrs. Houghton then expands her husband's point: "I think that they don't let us down, but they let Sarah down. Their complete indifference, sometimes, as to what's happening to her, is just amazing, I think anyway. And they give you lists of phone numbers, crisis – phone. And if you haven't got a crisis, you just want to ask somebody something, can you get them on the phone? No. And you think, if I was in a crisis now, we'd just have gone under. Because it can take you five days to get somebody on the phone, you know, who'll actually answer the phone". The main difficulty in this situation is that the care 'package' in place is inappropriate to the needs of this particular family because of the extraordinary nature of the circumstances. Sarah's anger has been fuelled by the loss of her sight and the changes in her place of residence, so that she has finally returned home. She is suspicious of the input from the one-to-one worker, who tells me of her inability to form a relationship with Sarah, and she is wary of the involvement of most others. The social worker, however, avoids being a target by virtue of his role as organizing things behind the scenes and appearing to Sarah as a friend who drops in for a cup of tea.
(Source: Interview – August 1999)

- ## The parent's voice

Example 60

An example of a more successful approach was provided by Mrs. Anderson, who talked of her own strategy in gaining the attention of professionals, particularly when she is not satisfied with the service being offered to Lesley. A variety of professionals continue to be involved in Lesley's care, but Mrs. Anderson's strategy is to remain in control and work out what is in the family's best interests:

Mrs. A: "Well, the thing is, I've probably had as much of the service, because I've fought for it. Unfortunately, it wasn't given to me. I've had to fight and fight really hard. Because a lot of my friends haven't got part of what I've got. And, as I say, I'm fortunate in the fact that I don't keep my mouth shut. And I will shout, because I don't want my family breaking up. So I feel that I've got quite a good service, and if I don't, I shout. And they do things for me. And when I ask for things I tend to get them. Because they know I won't keep quiet till I do get them. So they might as well give it me now. And that's what happens, you see. And that's what happens – I didn't want the wheelchair they had, so, I mean, I wasn't happy. I said 'I'm not having that'. So they said to me, 'we'll give you a voucher, you can find one'. So I found my own wheelchair. So its 750-pounds but they paid for it. Because I said, 'what you're offering me isn't suitable for Lesley'. And not a lot of people know about that, you know, they don't let you know these things. You have to find them out and then you have to fight for it".

Mrs. Anderson had eventually learnt the best way of caring for Lesley and safeguarding the interests of her family, but it had not come easily and she talked of numerous devastating experiences before improvements came.
(Source: Interview – September 1999)

- Explaining self-injury

Another issue concerns the family's own interpretation of the self-injury presented by their child, which demonstrated a detailed knowledge of the circumstances that were more likely to exacerbate it, and the sometimes contradictory way in which it might be expressed. It is ironic that the professionals involved never effectively utilized the level of expertise conveyed. The parents would be invited to attend and contribute at multi-disciplinary meetings and sometimes their words would be seriously heeded, but there was always a significant gap between the parents' and professionals' 'definition of the situation'. The example of Mrs. Clayton, a professional lady equipped with the skills of being articulate and also having a reasonable understanding of the nature of service provision hints also at a further difficulty. This is that there sometimes appears to be a need by some professionals to cast the parents into a clearly defined role of 'recipient of services' rather than fellow care provider. Mrs. Clayton sought inadvertently to blur the boundaries between professional and parent and was subsequently regarded as somewhat troublesome, and sometimes as being the cause of Robert's difficulties.

During the course of my interviews with the parents, it became clear that their own understanding of their own child was, in each case, the most significant element of the relationship. Even though there were differences in terms of priorities and expectations from services, there was a shared knowledge base that was largely unexplored by the professionals involved in the care. This vast, relatively untapped, reservoir of knowledge and experience transpired in each case, despite the frequent lack of confidence, the concern with practicalities and minor details, or the years of frustration and anger at not being listened to. This was a humbling experience, and led me to consider how they had all 'negotiated the reality' of caring over a long period for an individual, who persistently engages in violence towards the self. How did they explain the emergence and maintenance of this constant headbanging, punching, biting and slapping of the face?

Example 61

Mrs. Anderson provided an account of the many difficulties she faced when Lesley was born, which included discussion of professional misdiagnosis, considerable ignorance of prognosis, and blunt recommendations for her daughter to be put into care. She then goes on to describe Lesley's first venture into the territory of self-injury. "I would say she started chin banging round about the age of three... I've got pictures of her with her head up on her chin, and then she'd be kicking at herself, making bruises on her legs". She continues by elaborating on the circumstances of the self-injury, which necessitates her considering the relationship between Lesley and her younger brother.

Mrs. A: "When Lewis (younger son) was perhaps 12-months old or so and Lesley would be what, three and a half. Then, I remember him sitting on the pot and Lesley used to sit on the pot too. And I had, like, used to give him a piece of toast, give her a piece of toast. And that's what I did and they were smashing, and they were getting on the floor. She couldn't crawl then, like, but she used to sit on the floor but just fall over. You know she just propped herself up with her knees against her. And Lewis used to be crawling everywhere. And once she couldn't – she used to just fall on the floor, because he used to always knock her over. So she used to think, well he's coming now I'll fall to one side, so she was getting things with him, interacting with him a lot, you see. And they were playing with box toys and he'd get a toy and, you know, give it to her. And they were playing well, and it was after that – when they started walking, running around. (Becomes more softly spoken) She couldn't do that and that's when she started getting angry, I think, and annoyed and that's when she started getting mad and hitting and kicking. I think, because she wanted to do what her brother was doing. She couldn't do it, and that's when she got angry and things started going then". Mrs. Anderson identifies, I think, a major contributory factor to an individual's discovery of self-injury. The sheer frustration that Lesley experiences through her physical complications, particularly those of mobility and development, compound her dilemma. She recognizes her difference from her brother and quickly negotiates the things that might make her life more tolerable. These revolve around the centrality of her relationship with her mother and the knowledge that her self-injury can be a useful tactic for both obtaining her attention and deterring the advances of those who might exert pressure on her. She refines these over the years so that they can be drawn upon when required.
(Source: Interview – September 1999)

Example 62

When I talk to Mr. and Mrs. Houghton about the onset of Sarah's self-injury, I refer back to something that she told me during our previous discussion, which concerns a specific incident at school. Mrs. Houghton had been very clear that this had been the point that the self-injury started and I ask her to repeat it, particularly since it is so different to the experiences described by the other parents. The incident occurs in the mid-1970s when Sarah is about 11-years old.

Mrs. H: "Mrs. Magill (teacher) wanted to take her shopping for ingredients for a meal and then come back and prepare the meal. But Sarah had got no understanding of that – that raw ingredients produced a certain meal. And Mrs. Magill would take her shopping and Sarah had got no idea of what she was doing. And Mrs. Magill got frustrated with Sarah and Sarah knew Mrs. Magill was frustrated. So she'd get frustrated as well. And in the end it just really... She was just so beside herself – on a mat on the floor".

AL: "What was she doing?"

Mrs. H: "She was just – just sort of shaking and banging herself and her feet were smacking on the ground. And when I went to try and pick her up to let her know I was there, she jumped up and she hit me on the cheek and knocked me out. It was just like a nightmare... She was throwing herself – that day I went to see her – she was throwing herself back and banging the back of her head on the floor. It was just like her whole body was, like, in a convulsion. She never seemed to lose it then did she?"

Mr. H: "She couldn't express herself much before that, to be angry and frustrated. But then she'd suddenly learn how to do it. It was like that wasn't it?"

Sarah's parents go on to discuss how this was a critical moment in her life because she now had a tool (violence and self-injury), which she could employ to devastating effect. Sometimes she would engage in violence to avoid going to school and other times it would be to express her frustration at being unable to communicate since all the others in Sarah's class could speak. Both parents demonstrate an ability to understand Sarah's perspective and are able to explain quite clearly the logic of her decision to adopt a violent strategy. Ironically, though, when asked directly about their own explanation of Sarah's self-injury they look toward a different sort of explanation. As Mr. Houghton says:

"I think there's something to do – there's something. I wish we could find the happy pill that would hit. Because when she's – she's great really, isn't she, when she'll sit there

laughing? Different person. And then (clicks fingers) gone. You think, what the hell is this, there's got to be something, you know, that's doing this. There's no use poking her with a stick or annoying her – it's something inside herself that's doing it".
(Source: Interview – October 1999)

- ### The contradictory nature of self-injury

Example 63

Mr. and Mrs. Houghton's understanding of their daughter's frustration and anger at her predicament is at odds with this biological explanation of the self-injury arising from within. It reflects, I think, both their desperation and the inherent difficulties involved in trying to combine professional and parental expertise. In effect, it is the lack of service flexibility with its need to provide only that which is available, that determines that real progress cannot be achieved. Consider, for example, this description of Sarah about to embark on a spree of violence and self-injury:

Mr. H: "You can see it – you can sometimes see it starting over a couple of days, when she's been good. Well she's been brilliant (the) last week, hasn't she? But then, she'll be good for a few days and then you can see it gradually change. And you know she's gonna get grumpy about something".

Mrs. H: "Yeah, sometimes we can be eating our tea, can't we, and I'll look at her and I'll say to Jack, 'the monster's crawling out of the pit, look'. And you can tell because her face changes, doesn't it? And you can tell that the monster's coming... And you can look in her eyes. Her eyes have changed. I know she can't see, but suddenly she's giving you a staring look. But as I say, sometimes, like over half an hour, you can see her sat at the table and you can see the monster's out of the pit. And you can see all her face sort of changes. She's got a different look and off she goes".
(Source: Interview – October 1999)

Example 64

Mrs. Wilson also talks of the contradictory nature of Alison's self-injury, talking first of its unpredictability, in that "it seems to come as forceful as what it went really (and) doesn't give you no warning, she just starts really banging hard". In contrast, she then goes on to describe the gradual build up of the behaviour: "Well, I can see when she starts banging her feet or she'll kick out or something like that". A little later, though, Mrs. Wilson complicates the situation further: "She doesn't really give you any warning at all, she just sits there and she'll go 'byah, byah' and I'll say 'that'll do'. And then

she'll get up and bang the wall and then she'll – she doesn't touch furniture or anything. She doesn't – only her own chair she sits on. She'll get on it and bang hard on it. But I don't know – she'll sit down if she thinks to herself. Now the other day, she banged her head three times on there. Well she knows she does five, so she went up again, but instead of doing the extra two and that'd be five, she did five again. As if to say, that wasn't proper, I'll have to do the right number".
(Source: Interview – November 1999)

<u>Example 65</u>
Mrs. Morris, an essentially pragmatic lady, who mentions several times during the interview about her role in keeping the family together when Sam was small, recalls with great clarity what he was like at this time: "A live wire. Running around kicking everything over, pulling curtains down, banging doors, going round in circles, breaking things, anything. Wouldn't bother about the fire or danger". She goes on to talk about the onset of Sam's self-injury: "He slapped and banged his head with his hand more when he got to about five, or six, seven".

Mrs. Morris is unable to identify what she considers to be a specific cause for the self-injury, though when I explain that the mother of another of the group thinks its just part of the individual's character she agrees immediately: "That's it. It is, it is. I'd say the same. I don't know why he does it. I think he gets enjoyment out of it as well. I do".
(Source: Interview – November 1999)

Mrs. Wilson, similarly, is describing the reality of her experience, which is that she is unable to explain her daughter's behaviour but she is clearly able to understand it. At one point she likens the self-injury to smoking, in that it is a habit that Alison has come to depend upon. The dramatic, vivid, and sometimes contradictory nature of these parents' descriptions should not conceal the wealth of knowledge and understanding that underlies it, and the possibilities for multi-disciplinary input necessitate engaging with this expertise.

- Self-injuring in anger or contentment

The fact that many self-injurers appear to pursue self-injury without always being seriously distressed led me to follow this line of questioning with my interviewees, so as to explore the extent and nature of the issue. Each individual studied seemed to have a time when they were intent on serious self-injury and a time when they engaged in it in an almost passive, contented way. Mrs. Wilson, Mrs. Morris, and Mrs. Anderson all provided insights into the nature of the self-injury engaged in by their children. In the first instance Mrs. Wilson describes both the banality and gathering intensity of Alison's self-injury:

Example 66

Mrs. W: "Oh she does cry. But the banging isn't always associated with crying. It's just like a habit. She can sit here and she doesn't make a murmur, all you'll hear is (makes squealing noise)... When she's banging her head on there. It's just something for her to do, or if something – and then she goes another way if things aren't going her way. She'll do the same thing. So she sort of, seems to get herself all uptight, and we used to say, she's got things wrong because (pause). Like London Bridge is Falling Down and there was another one as well, that we thought she liked (pauses). So when she was in a bad mood she used to sing it, cos she can hum tunes by the way, very good with that (impersonates her humming London Bridge). And I think, oh aye, we're in for something. Oh aye, the opposite way round".

AL: "Like a signal that she was angry?"

Mrs. W: "That's right. Yeah. But she sort of had it twisted, because when you're singing, you're supposed to be happy aren't you? But hers is the opposite way round. When you hear her do London Bridge, you know. Quite strange really, because there's no crying with it, not all the time. She does cry and she does the same things. But she does the same things when she's not crying".
(Source: Interview – November 1999)

Mrs. Morris similarly describes the ambivalent relationship that Sam has with his self-injury, varying dramatically between great intensity and as a matter of routine, with the only thing guaranteed being its regular occurrence.

Example 67

Mrs. M: "He will sometimes bang his head or slap his face and he will laugh and get enjoyment or just do it anyway. He'll try to head butt the door, sometimes he won't, you don't know... He can get off the chair laughing and still do it".

AL: "What's the longest period that he's not bothered to self-injure?"

Mrs. M: "Oh no, every day he likes to do a bit of something. Even if it's just that (demonstrates punching self) when his splint's removed. But at one time he would have carried on. That's the thing that's changed".
(Source: Interview – November 1999)

Mrs. Anderson also mentions the contradictory nature of her daughter's self-injury, which appears largely to be characterized by intense frustration. Her description also demonstrates the lengthy process of negotiation, which has enabled her to work out which strategies are most effective in both managing the behaviour and simultaneously preserving the mother-daughter relationship.

Example 68

Mrs. A: "Yeah. She'll laugh. She'll be sitting watching telly, laughing, and all of a sudden she'll start crying and hitting herself. (Talks quietly and more deliberately). We don't know why, I can never understand that. You're sitting talking to her and she's laughing like mad and she just whips off and cries. Weird... She used to bash her head on the floor. When she was little, she used to head bang on the floor, yeah. But, I mean, if she was angry and she was sitting by you, she'd throw herself against your body".

AL: "Is that rather than go against the wall?"

Mrs. A: "She wouldn't go against the wall. Mind you, she was like, if she was by the wall. It depends, that, because a lot of the time she isn't on the floor. It's when she chooses. I mean, once upon a time – she's here and she'll go where she wants to go. I'll put my hand out and say, 'do you want to go somewhere, Lesley, then go'. If not, if she wanders round for too long, I'll say, 'Lesley, if you can't make your mind up, you know, you can sit in the middle and find your own'. I said, 'we've been in this room, we've been in that room'. We go everywhere sometimes, when she starts messing about. But after a while, I say, 'that's it, I've had enough now Lesley'. And I'll put her in the middle of the lawn and walk off and leave her, and say, 'find your own space now'... She might moan at me or cry. Or she might lie and bang her head, maybe. I say, 'well you carry on girl'. I say, 'I can't be fairer than that, I took you everywhere'. She looks at me, she knows she's not going to win. And then she does her own thing. You'll hear her muttering and having a little chatter to herself. Oh yes, she's clever, she plays on..."
(Source: Interview – September 1999)

This chapter has set out to trace the emergence and subsequent consolidation of the multi-disciplinary team as a consensual framework for working with people with learning disabilities. The broader political context over more than thirty years has been significant since successive legislation has emphasized the need for increased multi-disciplinary co-operation. There has been an element of contradiction, however, in that such multi-disciplinary working escalated even during the 1980s when there was a heightened tendency towards professional socialization and self-interest. The final two sections have been concerned with the ways in which learning disability nurses construct their own beliefs about self-injury, and how parents negotiate their own reality according to their experience of professional support. Examples from the study group have been employed throughout, which have served to demonstrate the proliferation of multi-disciplinary working, as well as illustrating the process of negotiation involved in care being delivered simultaneously by different professionals to individuals with complex needs such as self-injury. The concluding chapter begins with a discussion of the implications of such arrangements in the context of social construction, before exploring the value of the concept of discourse as employed in the study and the role of case study methodology in enhancing knowledge of self-injury.

CHAPTER EIGHT: CONCLUSION

- Social construction and the multi-disciplinary team
- Discourse and the historical context
- The legal construction of self-injury
- The case study approach to understanding self-injury

(i) Social construction and the multi-disciplinary team

The idea that there are a number of competing discourses surrounding self-injury, namely behavioural, psychoanalytical, biological, and communicative, has pervaded this piece of research. Alongside it has been concern about the consequences of such discourses for self-injuring individuals with significant learning disabilities and their families. At the beginning of the 21st century the multi-disciplinary approach has come to be seen as the way forward in the organisation and delivery of services. Furthermore, it is in the formation of the multi-disciplinary team that these various discourses come to present their arguments for making a telling contribution to the individual's welfare. In doing so, different discourses can seek to influence other perspectives on learning disability and self-injury, whilst simultaneously recognizing the impact on their own way of explaining and intervening in care delivery. Of course, some professionals, such as occupational therapists, physiotherapists, and even learning disability nurses, do not have a distinct and discrete explanation of self-injury. Their involvement with self-injuring individuals, rather than being based on the need for them to consider this to be the priority, is sometimes primarily related to another area of life, such as their potential for acquiring self-help skills, the value of specialized equipment, or health-related difficulties. In contrast, the involvement of the consultant psychiatrist, clinical psychologist, and speech and language therapist in the life of a persistent and regular self-injurer is frequently sought primarily because of this aspect of their lives. Their chosen approach is effectively defined by the profound belief arising from the body of knowledge informing their work, that the self-injury is a consequence of something not working right internally, a learned response to specific stimuli, or a way of communicating frustration, anger, or distress.

The continuing dominance that medicine enjoys in the care of more dependent individuals with learning disabilities might appear to be something of a mystery given its apparent ineffectiveness. The purpose here, though, has not been to analyse professional power generally or medical power in particular, whether or not in the context of learning disability and self-injury. It is, I think, more to do with how learning disability services needed to manage the massive resource implications of moving from an institutional to a community framework. The medical model's influence with this client group had been challenged over a number of years with the gradual establishment of the principle that a more socially orientated care was the correct basis for care of this client group. Consultant psychiatrists, therefore, had much to defend as community care started to become a reality during the course of the 1980s, and their institutional power base began to be dismantled. Furthermore, the behavioural approach had become the dominant discourse within self-injury and was better suited than medicine in providing an effective strategy for enabling these individuals to live outside the institution. Medicine, however, was able to adjust to the demise of the institution and the rise of the social model, to the extent that it was able to reassert itself as the main focus of decision making in the lives of self-injurers.

It is true to say, I think, that some consultant psychiatrists and other medical personnel working in the field of learning disabilities struggled to accept the new emerging framework of their clients' needs being primarily 'social'. The 'hospital' system endorsed their position at the top of the hierarchy and they strove to defend its continuing role with this client group. By the beginning of the 1990s, however, it was becoming clear that the institutional system had no future, which meant that in order to remain dominant, consultant psychiatrists needed to relocate and consolidate their position within the community. For a while during the 1980s, as witnessed by Sarah Houghton's experience, for example, it had appeared that some of the 'hospitals' would wind down to a smaller scale or, indeed, be redeveloped on the same site. It transpired, however, that this was only a temporary measure, the land proving too valuable not to sell, but consultant psychiatrists remained cushioned by a belief by service providers and policy makers that they had a significant role still to play. Once the institution disappeared, there would appear to be little more use for medical professionals to continue to play so important a role as they had done previously. But professions, especially those so used to having the whole system revolve around their decisions, do not give up their power easily, and history demonstrates that "they have a dynamism which allows them to change according to changing beliefs, ideologies and social patterns of society" (Kelly, 1998: 78).

During the 1990s, therefore, medicine set about establishing its position within the emerging community care system, the shape of which was being constructed within the 'Caring for People' White Paper (1989) and then embodied in the NHS & Community Care Act (1993). Individuals with learning disabilities who self-injured would continue to be served by medicine, since they were considered to offer most to the management of behaviour in difficult circumstances. The system that took shape over the course of the nineties, and which was most pertinent to those in the study group, was based on a tripartite structure of community nurse, assessment and treatment unit, and behavioural support team. Because of regional variations, this was not the only, nor was it necessarily the permanent, service system, but all those in the group experienced input from a community nurse at some point, twelve of the fifteen had had access to behavioural support, and nine lived in areas provided for by assessment and treatment. Furthermore, those individuals not living within such an area were experiencing residential care provided entirely through a health trust, whereas the others either lived at home or in care provided by the private or voluntary sectors. In other words, because residential care was being provided directly through 'health', delivered by nurses, and overseen by a consultant psychiatrist there did not seem to be the necessity for an assessment and treatment unit.

For the majority of the group, though, access to health orientated services would be through referral and consideration of the nature of the expected involvement. Self-injuring behaviour would tend automatically to be defined as a health-related issue, because of both the physical and psychological dimensions. The likely response to self-injury, as we have seen, continues to rely on psychotropic medication and mechanical restraint, both of which require a medical prescription, so that the argument for continuous access to a consultant psychiatrist remained strong. The framework for approaching care for the self-injuring individual would best be served through behaviourism, but medicine would be required for the making of significant decisions. In addition, four of the group experienced periods of time within assessment and treatment units, three of whom were compulsorily detained for part of this time. Such detention could only be organised through the responsible medical officer, that is, the consultant psychiatrist, which put the question of the continued need for medical surveillance of this group beyond question.

In sum, then, medical discourse in relation to learning disability was restricted to a reduced role with the majority of the residents of the old institutions, through a system of referral on the basis of clinical need. One such clinical need was subsequently identified as self-injury, despite the fact that medicine had contributed little to the practical care of such individuals, other than dispensing drugs and advocating the restriction of movement. In theoretical terms, as I argued in chapter six, the justification of the discourse offered was even less than the practical solutions offered. Medical discourse now revolves around the roles of 'bad' genes and, more likely, malfunctioning neurotransmitters, despite the lack of real indisputable evidence of both the reasoning and the drug solutions suggested. It is the power that medicine continues to wield that is the interesting thing about its continuing domination within a field where it does not have that much to offer. Furthermore, it is the redefining of the role of consultant psychiatrist, albeit in a way that has not really asked it to change too much.

Some consultant psychiatrists had begun to extend their role into the community during the 1980s, before those living in institutions had been resettled, and so had developed some insight into the needs of those living at home. The cases of Sam Morris, Robert Clayton, and Alison Wilson, in particular, demonstrate how consultant psychiatrists were called upon to support families of self-injurers, who would have been placed in 'hospital' only a few years earlier. The shortage of child and adolescent psychiatrists also consolidated the need for their involvement with such children, though they offered little more than a variation on their 'hospital' role. They did, however, come to recognize that they could not simply prescribe drugs and mechanical restraint, and then see the individual managed within a fairly secure institutional environment. There needed to be a much closer relationship with the other members of the community learning disability team, particularly those most familiar with and least suspicious of the medical model. Such individuals would be nurses, community, assessment & treatment, behavioural support, and residential, who were struggling to emerge from the institutions and secure a community role themselves.

During the course of the 1990s, therefore, medicine set about making the transition from the institutions, which were on the verge of closure, to a location within the community. They did not adopt an integral role within the community learning disability team, but instead retained a consultative capacity, so that a new referral would be made first to the team and then, if necessary, to the consultant psychiatrist. The assessment and treatment unit provided them with a location for self-injuring individuals to go to during times of crisis, as well as a base from which clinics and various meetings and conferences could be conducted. They thus managed to retain power over those individuals presenting with challenging behaviours or diagnosed as having additional mental health difficulties. The demise of the institutions by the mid-90s effectively created a 'service gap' since there was a problem in accommodating those who might need a safer or more secure environment than might otherwise be seen necessary. The 'hospital' had enabled many self-injuring individuals to remain on locked wards, without any inordinate concern for treatment other than drugs and restraining devices. Consultant psychiatrists had ventured into responding to the needs of severe self-injuring children, such as Sam Morris and Alison Wilson, during the 1980s. In so doing they paved the way for their own transition into community settings and ensured that their medication and mechanical restraint approach would be transferable to those living at home within a secure family. The development of assessment and treatment units consolidated this strategy, since it provided a place of safety when an individual's behaviour was such that continued care at home was untenable.

(ii) Discourse and the historical context

There are a number of contributory factors to the changes in thinking and subsequent policy initiatives towards self-injuring individuals and their families. The historical context of the transition from institutional to community care has provided the backdrop to the emergence and varying success of the different professional discourses. The question then arises as to what factors within this policy shift effectively enabled the key 'statements' within each discourse to be said and then eventually become commonsense. The post-war period provided the societal conditions for self-injury by individuals with learning disabilities to emerge as an issue worthy of serious consideration. The embodiment of these conditions has been in the ideological and later policy development of community care. This has been the key process underpinning this piece of research and it is the one, which enabled the discourses surrounding the emergence of the behavioural and biological explanations of self-injury to take shape. As we have seen the way in which people with learning disabilities were perceived by academics, professionals, and other interested parties was transformed during this period, as the search for a more appropriate and enlightened term bears witness. The implications of terms such as, initially 'idiot', 'imbecile', and 'feeble minded', and later 'mental deficiency', 'defective', 'subnormality', and 'retarded' resulted in a policy of widespread segregation and a preponderant belief that there was only so much to be done for such individuals. The gradual shift towards people with learning disabilities being seen as 'developing' beings, who had been disadvantaged by their incarceration within the institutional network, required this changed social and political climate.

Over recent years, however, there has been a need for the behaviours presented to be defined differently, so that they could be looked after in community settings. A view of self-injury that accounted for it in terms of communicating feelings of anger, frustration, or boredom meant that it no longer became necessary to describe it as alien or beast like. This provided the impetus for a gradual re-conceptualization of self-injury, which would be more in line with the view being formulated about the nature of 'mental handicap'. This was the term of choice during the 1980s and it provided the bridge between the more offensive labels of the previous twenty years (e.g., 'subnormality') and the sanitized ones of more recent years (e.g., 'learning difficulty' and 'special needs'). 'Mental handicap' reduced the distance between the individual and those caring for him/her just as the employment of the terms' 'client', 'consumer' and 'service user' emphasised being in receipt of services rather than needing treatment. 'Challenging behaviour', furthermore, by acknowledging the role of the environment, moving the focus 'outside' of the individual, and requesting services to examine their own responses sought to inject a human approach to people previously considered subhuman. Self-injury, within this context, could come to be regarded as something quite comprehensible and even reasonable in relation to the wretched nature of some of these people's lives. The recent trend of attempting to appreciate the perspective of the person engaging in self-injury seems to be a logical development of the 'functional analysis' approach to behaviour. Rather than just identifying the individual's motivation, an examination of the logic of his/her decision to embark on a self-injuring 'career' might provide a true focus for the discourses of communication and behaviourism. These different discourses were able to gain credence because of the challenges being lain down to the assumptions made about the combination of profound 'mental handicap', an absence of language, and a capacity for damaging ones own body. The behavioural discourse enabled the development of a practical strategy and the communication discourse allows for the possibility of a different view of the individuals concerned.

The discourse relating to communication has also been considered in some detail in chapter three, though it is one that has met with less success primarily because of its relationship with behaviourism. Speech and language therapists may suggest that this has never been the aim of the discipline, but it remains significant that their continued employment in a consultancy role effectively limits the likelihood of dominating interventions with self-injuring individuals. The challenge for a more discrete appreciation of self-injury as a communicative act lies in the acceptance of Goode's (1994) elaboration of the concept of 'conversations with our bodies', which argues for appreciation of deaf-blind individuals with severe learning disabilities as participating and contributing social actors (see chapter three). My research leads me to concur with

Goode and advocate greater exploration of the broader processes of communication in enhancing greater understanding of the relationship between the individual and their propensity for self-injury.

It is this idea of the communicative intent of self-injury, which constitutes the key discursive statement but it is yet to be acknowledged as an essential 'truth' about the nature of the behaviour. In fact, there has been a tendency for it to be co-opted as one component of the behavioural approach to self-injury, which has demonstrated the value of the application of a discrete body of theory as the most effective practical response. I have discussed the behavioural discourse relating to self-injury at length throughout the study because it is the one that has become most dominant in providing a framework for intervention. Chapter four illustrated the process by which behaviourism achieved and consolidated its ascendant position in understanding and intervening with self-injuring individuals. The acknowledgement by behaviourists that self-injury might initially have emerged in an individual for a range of reasons, but was being maintained because of its current 'functions' (e.g., attention seeking or escape from demands) actually helped to consolidate their position (see, for example, Emerson, 1995). A practical way of 'managing' the behaviour, addressing the 'ecological' context, and seeking to understand the self-injurer's perspective may prove irresistible to service providers. In practical terms, however, such an approach maintains a discrete hierarchy, which elevates the application of behavioural techniques, along with the use of medication, in a consistent and informed manner, as the most important dimension. Even behaviourism's history of abuse has been somehow used to its advantage, witnessed by the trend towards an apparent "'coming together' of approaches and perspectives" (Zarkowska and Clements, 1994) and advocation of the discarding of the more aversive elements of its armoury (Donnellan et al, 1988). It remains unclear to me, however, exactly how such markedly different discourses can merge effectively, particularly since this would necessitate serious engagement with the other's theoretical exposition. The multi-disciplinary approach might appear to be the ideal place for this to occur, but the evidence of this study suggests that it is simply a practical service strategy where the emphasis is on liaison, referral, and consultation. The increasing trend towards different disciplines sharing training and being encouraged to be less self-interested may remedy this difficulty, although the degree to which medicine will be expected to follow this path is open to conjecture and diluting professional expertise might not anyway be the solution.

Behaviourism's key statement identifies self-injury as being functional for the individual, in that it is "both shaped and maintained by personal and environmental stimuli and consequences" (McCue, 2000: 219). This view of behaviour transpired during a period of societal liberalization during the 1960s and 70s, which enabled a critique of both the role of the institution and the relationship between learning disability and society. The more conservative social and political conditions of the last twenty years have not resulted in a reversal of a view of people with learning disabilities as developing individuals. There has, however, been a changing focus from the idealism of the earlier period towards greater pragmatism and increased compromise, culminating in the criticisms of services raised by the recent white paper Valuing People (2001). Behaviourism has thus moved away from self-injury as a 'learned response' towards an emphasis on those factors 'shaping and maintaining' it, which has essentially enabled it to provide what it considers to be the most effective response without the burden of having to explain it in its entirety.

The ability of medicine to maintain a considerable power base regardless of the validity of its claim has been discussed earlier, with the accompanying suggestion that its continued role as a means of helping self-injuring individuals is more than a little bewildering. It has been unable to demonstrate indisputably that a genetic condition automatically gives rise to a propensity for self-injury beyond the case of Lesch-Nyhan. As we have seen in chapter six, though, ongoing work surrounding the role of different neurotransmitters in the areas of impulsive behaviour, stereotypy, and levels of arousal, in addition to the possibility of individuals becoming addicted to their own opiates has generated considerable interest. The context for this work has been the renewed interest, particularly in the United States, of the relationship between biology and behaviour, particularly in the light of the completion of the Human Genome Diversity Project. Claims about such relationships provoked intense debate in the usual areas of violence, criminality, gender roles, and 'race' (Kohn, 1995), though not in the area of learning disability and self-injury. The furore surrounding these discourses seems to have waned in recent years, though it is as yet uncertain as to what has actually transpired about the influence of genetics on behaviour. There appears to be an emerging consensus about the complex interplay between biology, psychology, and environment, which has been discussed earlier, but there has been no real elaboration of how this process works. The danger in relation to self-injury is that a compromise is drawn between the various discourses, so that there is an acceptance of the different 'truths' submitted. Unless, however, there is greater understanding of other discourses by the respective professions, then there can only be increased tolerance and acceptance without any real benefit for the self-injuring individual. A merging of perspectives requires a full elaboration of the principle tenets of each, and biology is currently unable to do so beyond speculation. There has been, as yet, no biological 'truth' about the role of neurotransmitters and enkephalins to justify interventions other than experimental ones. Biological discourse surrounding these factors has emerged over more than a twenty-year period, but has failed to make a real impact on widespread interventions to self-injury. The interesting thing to observe over the next few years will be the extent to which it becomes established as 'commonsense' about the nature of self-injury. Societal conditions in the United States, and to a lesser extent here, would appear to be favourable for a biological explanation to gain increasing acceptance. The consequence, presumably, would be an emphasis on the increased development of medications aimed at achieving such goals as reducing arousal, reducing impulsive behaviour, and blocking opiate production.

(iii) The legal construction of self-injury

The role of the legal machinery relating to people with learning disabilities was insufficiently influential to warrant a discrete chapter, but does warrant brief consideration because of its impact on the lives of several members of the study group. The legal construction of self-injury revolves around the role of the Mental Health Act (1983) which was applied to three individuals during the late 1990s, and seriously considered though eventually rejected with two others. James Simpson was admitted formally into an assessment and treatment unit following a marked increase in both his violence and capacity for self-injury, which resulted in what proved ultimately to be an irretrievable breakdown of his placement in a community home. At the time of writing he remains formally detained, though it is the absence of a 'package' of care to seriously address his needs that appears most pertinent rather than his need to be admitted for treatment (section three of the act). This situation does indicate the consideration of mental health legislation as a last resort, but also suggests an absence of imaginative service responses to vulnerable individuals with complex needs. Robert Clayton was similarly admitted via section three when he was twenty years old, because of escalating violence towards others and an exacerbation of his self-injury. The difference between his situation and that of James Simpson related to the concentrated effort placed upon finding a way in which he can return to his 'autistic community' placement as quickly as possible. A strategy of establishing distinct boundaries for Robert with a clearly identifiable system of sanctions proved extremely successful, and he is identified as responding well to the unit's structured regime. It is also worth pointing out that he spent some time in the unit several years earlier whilst in his mid-teens, because of the absence of a facility for young people with both learning disabilities and periods of extreme violence and self-injury. Robert feels both safe and not a little important in this environment, somewhat relishing his 'dangerous' status, enjoying good relations with several of the nurses, and not feeling too pressured. This last point is significant, I think, because the simplicity of the regime enables him not to have to behave too responsibly, whilst simultaneously providing him with some of the benefits of the reputation he previously associated with attending a special school. Robert's violent behaviour and self-injury gradually return to manageable levels, though this is by no means a straightforward process, and he returns to his placement after just over a year.

An example of the legal construction process in operation occurred with Janine Lewis early in 1998 when she was continuing to reside informally in an assessment and treatment unit, again because of the lack of alternatives. A recent Department of Health directive had raised concerns about individuals with learning disabilities being unable to provide informed consent. Consequently, if they are to continue to live in a 'hospital' environment, such as an assessment and treatment unit, then they should be subject to the safeguards of the mental health act. A multi-disciplinary meeting follows, which confirms the guidance of the 'hospital' solicitors that the law must be upheld and an assessment needs to take place regarding the appropriateness of formal detention. The minutes of the meeting record the comments of the approved social worker in outlining the complexity of the situation. "The ruling is that the fact that you do not want treatment is not enough, you have to actually say you want or do not want treatment (but the benefits might be that) it might make people think about the length of Janine's stay in hospital, although... there was a certain amount of stigma to being detained under the mental health act".

A decision is subsequently made for Janine to be formally detained, which further demonstrates the construction process, since nothing has altered about her situation other than the consequences of the directive. In effect, two pieces of criteria applying to the relevant section (for treatment) are scrutinized by the responsible medical officer (makes the recommendation) and approved social worker (submits the application) and subsequently considered in relation to Janine. The first of these concerns establishing that she "needs to have treatment in hospital for her own health and safety because of self-injurious behaviour". The other criterion, however, necessitates an official change in Janine's status as an in-patient within the unit. Rather than being considered as having a learning disability with a propensity to self-injure, she is established as being 'severely mentally impaired' in order to fulfill the requirements of the section. This means that not only does she have "a state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning", which would identify her as having a learning disability, but also that it must be "associated with abnormally aggressive or seriously irresponsible conduct". The justification for the responsible medical officer's diagnosis is that Janine has a "severe mental handicap with history of mood disorder and self-injury (and) multiple physical problems requiring treatment".

A further implication of Janine being formally detained is that she is subject to the consent to treatment provisions of the act [section 58(3)(a)]. This means that her anxiolytic and antipsychotic medication require the second opinions of two other professionals, in effect a registered nurse and an occupational therapist. Furthermore, by becoming a detained 'patient' (Janine's legal status) she is provided with a detailed multi-disciplinary 'treatment plan', which she may not have had by remaining informal. It is clear, therefore, that legal detention constitutes something of a double-edged sword for Janine, since despite the problem of stigma raised by the social worker, nevertheless it does secure a framework for interventions and provide an impetus for finding a more appropriate placement. In the event, the period of legal detention is short lived since there is widespread concern about the consequences of this directive for informal patients without the capacity for consent and it is altered shortly afterwards. From a social constructionist viewpoint, however, it does demonstrate how the approach to self-injury may vary according to the legal process, as well as illustrating how, given particular conditions, it can be made to conform to the necessary criteria.

(iv) The case study approach to understanding self-injury

The life history context of the research provided a means of investigating how a group of otherwise disparate individuals sought to develop and consolidate their careers as self-injurers over a period of many years. The aim was to utilize archive and contemporary documents, interview material, and observation as the means of providing "an account of individual experience which reveals the individual's actions as a human agent and as a participant in social life" (Blumer, 1939: 29). One of the primary features of many individuals and groups, who have been the focus of case study research has been their identification as 'strangers', 'outsiders', and 'marginal people' (Plummer, 2001). The institution provided the mechanism over many years for facilitating such marginalization in those described as 'mentally subnormal', self-injurious, and unable to communicate, so that they were condemned to inhabit the two cultures Stonequist (1961) describes as being characterized by both difference and antagonism. In fact, it is more accurate to say that the younger members of the study group, who never experienced the institution, lead lives more fitting to this description, 'strangers' living in society but not of it (Simmel, 1950). Whereas the 'hospital' represented a forthright rejection of the suitability of these individuals to live in the community, the realization of the mistaken and disturbing nature of overt segregation has not necessarily meant that people have become any more 'of' society. This is demonstrated particularly by Plummer's (2001) assertion that life history research, probably more than any other method, requires the establishment of prolonged intimacy between researcher and subject. The repeatedly transient and power-imbalanced relationships characterizing the lives of several in the study group were incompatible with the establishment of reciprocal intimacy, since many had negotiated a certain emotional remoteness necessary for psychological survival. This was so both with those touched by the institution and those not, although the latter group experienced a degree of emotional richness with certain 'significant others'. I was able, however, to acquire some degree of intimacy through understanding of the lives that they had lived and were living, lives that emerged through the construction of case narratives and the words of these significant others.

The key strength of a case history approach to self-injury such as this one, I think, is that it seeks to examine the stories of real people in real situations over an extended period of time. The emergence of self-injury in the context of an individual's life, with a specific emphasis on significant 'shaping' factors was identified at the beginning of the study as the most important question to be addressed. It is difficult to determine with certainty why the 'escape' or 'retreat' into self-injury occurred, or even to be certain of its precise emergence, but it has been possible to clarify how it came to claim its place in the individual's life. Furthermore, there were many factors that were common between the lives of those in the group, but there were many other factors that were unique to that individual, so that ultimately it would be the way in which he or she negotiated these experiences with significant others. A case study approach enables us not only to examine the complexity of the lives of some of the most disadvantaged and inaccessible of social actors, but it also provides a focal point, self-injury, for investigating the various professional discourses and the historical context in which these various constructions emerge.

I think that the best way to proceed in this section is to identify the key players in the study and look at the development of the self-injuring career, which constituted such a central focus of their lives. Sarah Houghton, Robert Clayton, Daniel Cotterill, and James

Simpson were the individuals, who contributed the most in the construction of this thesis. This was not just because of the amount of data available, since others contributed larger quantities of case note material and all of the interviews with parents told a separate story. The reason lies in the individual's relationship with self-injury, which was always something more than a reaction to particularly frustrating or boring circumstances, though both of these factors should not be underestimated. Sarah did experience some time in 'hospital', but it never entirely engulfed her life in the way that it did James and Daniel, and Robert was too young for incarceration but now lives in an 'autistic community'.

Incarceration is of significance not simply because of the sometimes erroneously simple correlation made between self-injury and the institution, but also because of what it says about the role that the 'hospital' played in the lives of its severely 'mentally handicapped' inhabitants. Institutional life demanded that these people develop strategies of passing the days as fruitfully as possible, with occupation (both education and work) providing little more than a change of environment. The complete absence of a sense of belonging necessitated a passivity and neutrality of response to virtually every event in their lives (e.g., Christmas, birthdays, and holidays), and an excessive importance placed on the seemingly irrelevant (e.g., cups of tea, apparently trivial possessions). There were no evidently complex relationships in the lives of these institutionalized young people, so they set about developing the necessary emotional blankness characteristic of those who have been casually yet systematically emotionally battered. The portrait painted of James Simpson at ten years old by the consultant psychiatrist is a reflection of the one I encountered 35-years later, though also having known him at other points in his life (see chapter two). This was not simply the consequence of him having a learning disability, which prevented him from experiencing emotional growth, but represented the most effective way for him to make his way through life when maturing relationships would never be an option. The institution contributed to the development of self-injury in so far as it provided the time necessary for the development of an elaborate repertoire of behaviours to while away the hours, days, and years.

In the life story of James self-injury was a mechanism established early, which achieved a modicum of success in somehow enriching a desperately dull life. It worked for him and would manifest itself in exactly the same ways throughout his life, causing irritation to others because of the noise, sometimes successfully gaining the object of his desires (a catalogue, cup of tea, or walk), and also enabling him to alleviate boredom and express his frustrations. It became meaningful to him in his relations with others, and was a public rather than a private act. His life-long violence towards others also began in childhood, influenced his early introduction to a 'behaviourally disturbed' adult ward, and helped him to come to terms with emotional and physical rejection. I believe that the prolonged period of negotiation resulting in his 'hospital' admission witnessed James' dawning recognition that he was unwanted.

In contrast, Daniel's life in 'hospital', though equally passive, enabled him to develop a different relationship with his self-injury. His was frequently an expression of self-hatred, which revealed itself during his bouts of purposeful headbanging with serious intent. No audience was required when he sought out that favoured area of doorframe or wall. This is not to say that frustration or seeking an object of desire was insignificant, since the opposite was clearly true, but just to say that Daniel had an apparently inexplicable occasional drive to hurt himself. It is possible, of course, that biology had a role to play here, such as through addiction or impulse control, but it seems more likely to me that it was more to do with a consuming rage with his inability to control his life in the way that he wished. There was, however, another dimension to Daniel's self-injury, shared by some of the others in the group, which illustrated something of a paradox. Although his motives were sometimes dark, the self-loathing that I have suggested, he could also use the same behaviours as expressions of both the mundane and something more akin with delight. He had learnt to utilize the same self-injuring and self-stimulatory behaviours to express different forms of emotion, with the underlying motivation being reflected in the degree of violence employed and the level of injury sustained.

Sarah's story ends also in the expression of rage, but should be explained differently because of the way in which factors conspire against her in such a tragic way. Her family relationships provide her with a degree of security, which enable her to know that she has not been rejected despite the amount of time she spends in residential school and later 'hospital'. Her potential, however, so tantalizingly suggested during her time in the school for rubella children, is never realised and, in fact, perversely serves to consolidate her misery. She experiences a growth spurt whilst at the school, which then enables her to recognize the pointlessness of the rest of the educational system. Time spent in 'hospital' provides her with no stimulation or opportunities for growth, but witnesses continued loving family contact, which she settles for, without real resort to violent self-injury. Two 'hospital' closures, a failed community placement, and a stark choice of living 200-miles away or nothing result in her return to the family home at the wrong time in both Sarah's and her parents' lives. Add a dash of medical negligence so that she is plunged into a deaf-blind world and you have, I think, the recipe for complete distrust of the world and anger turning in on itself in epidemic proportions. Sarah's retreat into self-injury is entirely understandable, without recourse to theoretical explanation, and is simply reflective of a conspiracy of a glimpse of the possible, service incompetence, professional mismanagement, and finally too little too late.

I have documented Robert Clayton's life extensively throughout this thesis, particularly in relation to his autism in chapter five. Robert has a necessarily complex relationship with self-injury because of his capacity for the spoken word and the perceptual difficulties arising from his autism diagnosis. In the context of his life story, however, remembering that he was only in his early-twenties, it is the frustration that permeates his life, which is of primary interest. He becomes the subject of considerable professional disagreement between a medical specialist, who considers him 'mentally handicapped' but not autistic and an educational psychologist, who remains convinced that he is autistic and requires specialist input. I think, regardless of professional self-interest, the psychologist has a far more detailed knowledge and understanding of Robert, and she is able to articulate the consequences of the rejection of the requisite diagnosis. She envisages an escalation of his behavioural deterioration should he not receive the help he requires, particularly a far higher level of intellectual stimulation, and this does indeed turn out to be a self-fulfilling prophecy. Robert's resentment towards his association with lesser able individuals, especially since he is physically more able than the majority of those within the non-special education system, is a marked feature of his life. Like the others in the group, though, his negotiation of reality relies on working out what strategies are most successful and reaching some level of compromise. Unfortunately, though he achieves the first part he is unable to do so with the second, partially because what he wants (to live at home with his mother) is no longer considered a realistic option, and partially because of the level of violence he engages in. Such violence is directed particularly towards his mother, on such occasions she says he resembles a 'snarling wolf', and towards himself to the extent that he can run towards a wall and smash his head against it. The family dynamics and early death of his father are certainly factors in Robert's violence, as are the inability to tailor a service to his particular needs. His self-injury is both a strategy to manipulate circumstances not of his liking, such as feeling academically out of his depth, and also a way in which to articulate his impotence to exert control over his life.

'Naturalistic generalization', to return to a theme introduced in chapter two, suggests that it may be possible to draw broader conclusions from a small study group using intuition, experience, and understanding.

> "Naturalistic generalizations develop within a person as a product of experience. They derive from the tacit knowledge of how things are, why they are, how people feel about them, and how these things are likely to be later or in other places with which this person is familiar. They seldom take the form of predictions but lead regularly to expectation" (Stake, 1978: 6).

The individuals in the study group were bound by their learning disability, communicative difficulties, and propensity for self-injury, but they were also separated by each of these characteristics. Their experiences were internalized so that self-injury, biological factors withstanding, was adapted as a strategy for adjusting to the various circumstances characterizing their interpretation of the social world. A form of 'naturalistic generalization' enabled me to attempt to make sense of how each of them became the people they were, and accept, or otherwise, their place within the world. They had developed ways of occupying themselves for long periods, other ways of inuring themselves to disappointment, disillusionment, and, in many cases, rejection and institutionalization. The construction of extensive chronological case records, which were then converted into case narratives, before finally being integrated as far as was possible into the overall thesis, enabled me to acquire detailed knowledge of their life stories and the process by which they became 'hardened' self-injurers. The insights that I have tried to share have required this lengthy process and run the risk of attracting accusations of a lack of objectivity. Similarly, it is difficult to claim with confidence that such insights can be generalized to other self-injurers separated by geography, service structure, and extent of professional expertise.

My defence surrounds the areas of institutionalization, segregation, and classification systems ('deficient', 'subnormal' etc.), which have been historically widespread, and the medication, mechanical restraining devices, and arbitrary behavioural interventions which have dominated treatment even for the younger members of the group. A person's descent into self-injury may appear to be a personal, private act, but the commonality of the life experience suggests that it is also very much in the public domain. Just as I am confident that the telling of their stories reveals individuals living out their lives as best they can, with recourse to self-injury demonstrating boredom, frustration, anger, enjoyment, relief, and self-hatred, amongst many other things, so I believe that the stories of others also reflects these expressions of emotion. The functional analysis approach to self-injury discussed in chapter four demonstrates the basis of a maturing practical strategy for engaging with individual self-injurers. The additional components of communicative intent, appreciating the individual's perspective, and the need for a complex, multi-component set of responses suggest that this is the most pertinent and fruitful approach to self-injury. A life history approach suggests the need for service providers and professionals to recognize critical points within an individual's life, wherein self-injury might begin, become further entrenched, or extended. As Stake (1978) points out, it might be difficult to confidently predict, but through expectation we might understand a little more about how an individual becomes lost in self-injury.

Appendix 1

Interview Schedule (Learning Disability Nurses)

1) How long have you worked with people who have learning disabilities? What sorts of situations and circumstances?

2) Have you worked with many individuals with learning disabilities, who engage in self-injurious behaviour? What sorts of environments and circumstances?

3) What do you understand by self-injurious behaviour?

4) Describe some of the behaviours that you have encountered.

5) What sorts of behaviours, self-injurious or otherwise, does ______ engage in?

6) Are there particular times of the day or night when the behaviours are worse than other times? (Prompt to elaborate if necessary).

7) How long have you known ______?

8) How does ______ spend his/her day?

9) Does this vary much from day to day/week to week?

10) What sorts of things, activities etc. does ______ enjoy doing most?

11) Does ______'s self-injury vary much in the way that it is expressed, for example, is it more intense or emotional at particular times?

12) If ______ could verbally communicate more effectively, do you think that this would influence his/her behaviour? (If yes, ask to expand and address how this might be the case).

13) Has ______'s self-injury changed much, improved or deteriorated, during the time that you have known him/her?

14) Has his/her life changed much during this time? (e.g., changes to the environment; moved to a different house; frequent changes of staff/clients).

15) Does ______ relate particularly well to anybody, such as a member of staff or another client? How does he/she express this?

16) Does ______ have any contact with anyone from his/her family? Does he/she look forward to this contact?

17) Is there any change in the self-injury, such as a decrease or increase, during periods of family contact? (Ask to elaborate if necessary).

18) What do you think might be the reason or reasons for ______'s self-injury?

19) What leads you to think this?

20) Do you think that others would agree with you?

21) What is the general intervention strategy or approach adopted towards ______ when he/she is engaging in self-injury?

22) How successful do you think this approach is?

23) Is there a specific policy in the Trust for dealing with self-injury? (If not, do you think that there should be?)

24) Do you find ______'s self-injury personally distressing? (Ask to expand and explain why or why not).

25) Do you think that there might be any other, maybe deeper-rooted, reasons for ______'s self-injury? (Ask to elaborate if necessary).

26) Some studies have indicated that self-injury is a means of expression. What do you think of this notion? (If the answer is no, then the final question need not be asked).

27) Why do you think that ______ expresses his/her feelings through self-injury rather than express himself/herself by attacking others or damaging property?

Appendix 2

Information Sheet provided with Consent Form

This sheet provides some additional information into the research project that I propose to undertake into self-injury by individuals' with learning disabilities. It follows the letter that I recently wrote to you by way of introduction. I am currently registered for a PhD within the department of sociology at the University of Liverpool. My supervisor is Dr. David Hall. The research aims to explore the subject of self-injury by looking at the case notes of a number of individuals who have received nursing and medical treatment over a number of years. The case notes date back to the time when _______________ resided within _______________ Hospital, and they are now kept within a storage facility outside of the immediate area. I wish to gain access to these notes so that I can build up a profile of the way in which the self-injury developed and was treated during the period in question. My research proposal has been subject to the scrutiny of the Local Research Ethical Committee of the Hospital Trust, who have given their approval for me to proceed. I have already corresponded with the consultant psychiatrist responsible for ________'s current care, and s/he has requested that I contact you with the relevant information and request your consent. I attach a consent form for you to sign if you are willing for ________ to be involved in the research. You may, of course, withdraw such consent at any time that you wish. Furthermore, if you require any more information with regard to the research please do not hesitate to ask me accordingly. Thankyou for your cooperation in this matter.

Yours sincerely,
Andrew Lovell

Appendix 3

Consent Form regarding Research Project into Self-Injury

Participant's name: _______________

____ I give permission for Andrew Lovell to read _______________'s case notes with regard to the research project he is undertaking

____ I do not give permission for Andrew Lovell to read _______________'s case notes with regard to the research project he is undertaking

Please tick one or the other sentences

Signed: _______________ Date: ____________

Appendix 4

Semi-Structured Interview Schedule (Parents)

1) Tell me a little about when __________ was born. How quickly were you told that s/he had a learning disability?

2) When did s/he start to engage in self-injury?

3) What other sorts of behaviour did __________ engage in? (Prompt, if necessary, by mentioning aggression towards others, self-stimulatory behaviour, non-compliance etc.)

4) Were there any particular circumstances from around that time that you think might have been important? How would you describe them?

5) Has s/he always self-injured in the same way or did s/he do it differently at one time?

6) What about when s/he was growing up – did she get on okay with particular others in the family or at school?

7) Were there any people with whom she didn't get on particularly well?

8) How did s/he get on in terms of being able to communicate with others? If s/he could communicate more effectively, do you think that this would influence his/her behaviour?

9) Are there particular things that _________ enjoys doing more than other things?

10) What do you think of the help and support that you receive from professionals and other carers?

11) What sort of help do you receive now? (Mention professional, respite, voluntary, and informal, if necessary.) Which has been the most useful?

12) Has the support improved over the years or not?

13) Who would you say knows __________ best?

14) How does this show itself best?

15) Describe in your own words what __________ does when s/he engages in self-injury.

16) What sorts of interventions have been used to try to stop him/her from self-injuring? (Prompt, if necessary, by mentioning mechanical restraint, medication, and behavioural techniques.)

17) What sort of success have these interventions had?

18) Have you got your own theory for explaining self-injury? What is it?

19) Do you think that s/he will ever stop self-injuring? How long have you thought like this?

20) What has been the impact of __________'s self-injuring on your family?

21) If you could receive any level of support that you wanted, what would it be?

Appendix 5

Recommendations for Service Providers

- One of the most important considerations to arise from the research concerned the frequent incongruity between the family's interpretation of self-injury and that of those providing services. This has been discussed at length in the final section of chapter seven, but is worth reiterating because of the implications for the services currently being offered to family's living with an individual with such complex needs as self-injury. There was often a lack of understanding by professionals regarding the intensity of the relationship between the key carer, usually the mother, and the self-injuring individual. This intensity reflected a deep knowledge and understanding of the nature of the self-injuring, particularly in terms of when it was likely to occur, the associated trigger factors, and how quickly it might subside. Unfortunately, however, there was frequently a tendency for professionals to seek to locate the parental role within their own frame of reference, which effectively meant a desire to relegate the informal carer into a recipient of services. Only by truly embracing this informal body of knowledge and experience can a service be provided which truly reflects the needs of the self-injurer and his/her family. The implications for professional education revolve around the need to understand the negotiated reality of parental experience over extended periods of time, and particularly the informal discourse surrounding the meaningfulness of self-injury to the individual concerned.
- The value of a case study approach to self-injury, which traces its development over the life course, can provide important information with regard to critical junctures in the individual's 'career'. This concept is significant because it highlights the consistency and continuity with which individuals engage in their favoured behaviours, refining and adjusting them according to circumstances, so that they essentially become experts in this area of activity. Professional intervention must seek to understand that it has something to compete with i.e., self-injury, which is much preferable to the individual than anything else on offer. Contemporary behaviourist discourse acknowledges this point and consequently aims to replace the

behaviour by something that might be of equal value or enjoyment. The case study approach provides us with a means for tracing the development of the self-injuring career, and thereby considering the points at which there might have been an opportunity for dissuading the individual from becoming increasingly reliant on retreating into violence. The difficulty for service providers lies in being able to clearly identify when such critical junctures arise and subsequently being able to avoid the ensuing deterioration in self-injury.

- A further point relates to the pressing need for services to develop the necessary flexibility, which would encourage the conditions for the facilitation of truly individualized care. Community care, with its imperative that the individual be maintained within the home under the most difficult of circumstances, requires that services be able to respond to extreme situations. The rhetoric of individualized care seems to be compromised by the preponderance of services, which conform only to specified patterns and systems. Professionals seek only to locate the individual within existing services, so that the much sought after and discussed flexibility fails to materialize. Parents frequently expressed their frustration about services not being designed to provide that which is most required. This revolved around the availability of dependable respite services employing staff with the skills to work with difficult and unpredictable individuals, and imaginative day care services where the sole purpose was not one of providing a sitting service. The provision of small-scale, locally based, and imaginative services, wherein the expertise for responding effectively to the needs of unpredictable self-injuring individuals is readily available requires a significant change from the culture of slotting the individual into existing services.
- The most effective interventions available for working with self-injuring individuals are well documented and belong within the behaviourist framework. These techniques have been refined over many years, and when implemented consistently by skilled individuals demonstrate an estimable record of success. Furthermore, when such an intervention strategy seeks also to provide a regular, well-thought-out activity programme and there is an additional emphasis on enabling the individual to develop self-help skills, then the framework can be considered to have paid serious

heed to ethical considerations. Unfortunately, the lives of the study group are littered with attempts to implement behavioural techniques without any consideration being paid to the ethical implications of these being arbitrary and short-term. Similarly, the practical implementation of such interventions appear to be largely the domain of care staff without the knowledge and expertise to fully appreciate the longer term benefits. The knowledge that behavioural strategies can be successful with self-injury, and the availability of professional experts to design such programmes, is insufficient evidence for reckless implementation. None of the 15 participating in my study were immune to the vagaries of behaviourism, and yet self-injury remained as influential in their lives as it had ever done. Service providers need to be fully aware of the implications of adopting behavioural strategies, particularly consideration of time-scale, the possible effect on significant others such as parents and housemates, and exactly how the life of the individual concerned is going to be improved.

- I have argued throughout the thesis for communication to be deserving of a higher profile as a contributory factor in self-injury. The evidence from my research suggests that there is wide recognition by a range of professionals that this is the case. Despite such a relative consensus, communication continues to attract limited resources, and there remains a dearth of speech and language therapists working with people with learning disabilities. It is difficult to be precise about what services should do to remedy this situation, particularly since there is continued disagreement regarding the extent to which people can develop effective speech or alternative ways of communicating effectively. Maybe it is sufficient to say that the key issue in improving the lives of severely learning disabled self-inuring individuals surrounds the issue of communication.
- Finally, the increasing popularity of espousing a bio-psychosocial model for understanding and consequently responding to self-injury requires greater consideration than has so far been the case. The effective development of such a model is consistent with the multi-disciplinary approach, but greater thought needs to be applied to the ways in which perspectives can engage most satisfactorily with others. Chapter seven explored some of the difficulties with multi-disciplinary working, but the history of professionalism suggests that greater co-operation can

only be beneficial to the individual receiving the service. There has been a recent general tendency towards inter-disciplinary co-operation, with an increased emphasis being placed on transferable skills and shared training initiatives. The development of a bio-psychosocial perspective should be concerned with sharing the most important facets of each approach, and with reducing the evident barriers created through professional isolation. Unfortunately, however, this can also mean that there is less of an emphasis placed on the theoretical underpinning of a professional discipline so that depth of analysis is sacrificed for breadth of response capability. The consequences of developing a model that is appreciative of such collaboration need to be addressed, which also accounts for how a profession is likely to respond to phenomena such as self-injury once it has become less theoretically introspective.

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