

## **Representation, Identity and Self Esteem.**

A study of Disability, Arts Education and Self-Identity, with particular reference to students with physical and sensory impairments who are studying, or who have studied, at Hereward College.

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### **Abstract**

This study examines the processes by which disabled young people who have studied, or are studying, the visual arts at Hereward College have resisted oppressive perceptions of impairment and disability in the production of empowering images that counteract negative representations of disabled people. Hereward College is a national, residential, general college of further education that has extensive specialist resources for students with impairments. Central to this study are the students' own reflections, thoughts, feelings and opinions, and their experiences and artwork are the primary means by which the relationship between disability and impairment, self-identity, and visual arts education have been investigated. It is from their accounts that the significant factors that have impacted on these experiences have been identified. Ultimately it is intended that this research will contribute to a greater understanding in the field of arts education in general and the arts education of young people with physical and sensory impairments in particular.

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## Introduction

For the last 20 years my work has been concerned with the arts education of disabled young people post 16. During this time it has become apparent that there is the potential for a process of self realisation to occur wherein negative and oppressive perceptions of disability can be identified and addressed via the visual arts. The period of my employment has coincided with significant developments in disability policy and research, prompted, from the 1980s onwards, by the Disability Movement and Disability Arts. However, despite such advances there is not a literature that deals specifically with arts education and disabled children and/or young people, and links between this and the possible enhancement or development of self-identity are largely unexplored.

At the core of this research is the artwork produced by young disabled people at Hereward College who are being enabled to acquire the skills and competencies of a visual language within a context that promotes Disability Arts. This encourages a cultural response to what Thomas describes as, 'those disablist social processes and practices which damage our quality of "being", that is, which undermine ... our psycho-emotional well being' (1999a:3). Thomas's work contributes to an extended social theorisation of disability that encompasses not only social processes and practices that 'prevent people from doing things (for example, getting paid employment, succeeding in education, accessing suitable housing)', but that also highlights the importance of cultural matters in 'explaining disability' (p.3). The focus of this research is on such questions of culture, representation and meaning, and of how the voice of disabled people, increasingly recognised as central to disability studies, can be expressed through visual images in addition to, or instead of, oral or written accounts. However, this has raised the dichotomy that has emerged in response to the social model of disability between a collective, or essentialist disability identity, and an individual one which is fluid and which, it has been suggested, better represents the diversity of the disability experience (Reeve 2002:493). Questions concerning the function of the arts as a political instrument of social change that neglect the individual's lived experience of impairment and disability, as opposed to the arts as a means of personal expression that are inclusive of such individual experiences are highlighted as a consequence.

Arts education and Disability Arts, in theory, provide disabled young people with the means to creative, cultural and personal expression. However, mainstream arts provision for disabled people has been condemned as 'limited and limiting', with the additional concern that they are often 'disempowered if not excluded, by arts training' (Barnes *et al* 1999:207). Disability Arts, which is an established subculture formed as a response to the absence of positive cultural identities for disabled people to draw on, has been developed 'by disabled people, for disabled people, in environments controlled by themselves' (p.182-210). Disability Arts has emphasised political content at the expense of technical competence and the rejection of what has been seen as the 'imposition' of non-disabled criteria. Humphrey (1994), editor during the early 1990s of the first glossy *Disability Arts Magazine* (DAM), suggested that strictures that have been handed down from the political movement to the artist have effectively narrowed and restricted the discourse, maintaining that 'Disability Arts has to be good art first and foremost otherwise it will be ignored' (p.66). He suggests that there is a cost to ignoring mainstream criteria of what constitutes 'good' art and certainly whilst Disability Arts has constituted an empowering 'voice' for disabled people its dislocation from mainstream contexts, including educational provision, delayed the emergence of cultural theorisation.

Both Disability Arts and arts education should be inextricably linked if disabled people are to be empowered by the arts. An understanding of Disability Arts and the social model on which it is premised is critical in providing the starting point for disabled students to begin to articulate an individual self-identity that is inclusive of impairment. It is this awareness, combined with the competencies of a visual language that can result in the production of powerful images that have the potential to counteract the negativity contained within images of impairment and disability that are embedded within mainstream culture.

In the first chapter of this study, therefore, the origins of the negative perceptions that have accrued around people with impairments are made transparent through an analysis of the social construction of disability and the conceptualisation of disabled people as 'other'. Chapter two presents an historical account of the ways in which these perceptions have been reflected and expanded through the representation of disabled people. These continue to seep into the mass media despite the developments in disability awareness that have occurred in the last two decades and which have given rise to very recent contemporary images that may be considered to

be affirming. These chapters form the starting point for this study; for disabled young people in the creation of alternative images; and for the teachers who are educating them. Hevey (1992) states, 'knowing what isn't acceptable doesn't produce what is', however, in terms of the visual arts it certainly informs the process wherein disabled people can begin to determine their own self-image (p.84).

Subsequent chapters engage with this question and chapter three suggests that images constitute a visible 'voice' that can represent the thoughts, feelings and experiences of disabled young people. It goes on to investigate the factors that influence the development of such a visual 'voice'. The impact of popular culture's preoccupation with a particular and narrowly defined concept of the body is introduced in this chapter to illustrate the dilemma that this poses in making explicit, through self representation, a body that does not come within the sphere of this ideal. Essentialist and constructivist theories of identity formation and the paradox inherent in adopting a collective disability identity are noted. Comparisons are made with a more reflective individual sense of self that acknowledges the fragmented nature of identity and that encompasses the additional features of gender, class, sexual orientation, age, ethnicity, and so on. The chapter focuses on the self, developed as a response to social experience, in the context of psycho-emotional dimensions of disability (Thomas 1999; Reeve 2002). Some discussion on the critical phases of adolescent individuation follows, and the impact that having support needs might have on this process is noted. The potential of the visual arts to generate a substantive statement of self identity, where other means may be limited or inaccessible, is highlighted as are the effects of skills development (in the arts) in enhancing the concept of self.

Chapter four considers whether disabled people constitute a cultural group, and whether a post modern approach to education that embraces difference and the commonalities of human experience has the potential to include disability within a multicultural agenda. The traditional exclusion of disabled people from high western artistic traditions is compared with their potential to be included in, or access, popular culture by virtue of Information Communication Technology (ICT), television and the Internet. The role of the arts in education *per se* is examined with particular reference to the work of Harland *et al* (2000) who have investigated the effects and effectiveness of arts education in secondary schools. The many disadvantages that disabled children and young people experience in addition to those that are currently

impacting on the arts education of their non-disabled peers are highlighted and the importance of teacher training in addressing some of these is emphasised.

The next two chapters, five and six, provide the context for the case study chapters. Chapter five gives an account of the methodological framework used to collect and analyse data pertaining to students' experiences. It begins with an account of the ethics involved in doing disability research and describes how these have been addressed in the execution of this study. The methodology and rationale for adopting a case study approach is outlined, with particular attention given to the work of Hodkinson (2001).

Chapter six gives an account of Hereward College and the radical developments that have brought students into the art room who previously would have been excluded, or whose experience would have been limited to art as a 'leisure' activity often with them as passive observers. The practical and material barriers that disabled people have faced historically in the production of artwork are described, as are the developments in Information Learning Technology (ILT), enabling support, arts curricular and disability awareness that have changed the cultural climate and enhanced the potential for disabled young people to access and achieve in the arts.

The four case study chapters, seven to ten, are based on the accounts given by Hereward College students, both past and present, who are studying, or who have studied the visual arts. They have physical and/or sensory impairments and a number are wheelchair users. The college accepts students with many different kinds of impairment; however, students with cerebral palsy, spina bifida and the muscular dystrophies make up a constant and significant proportion of the student numbers. These impairments are often exacerbated by other medical conditions that have developed since birth, such as asthma, epilepsy and diabetes. In addition, Hereward has increasingly accepted students with head injuries, often the result of road traffic accidents, and, in recent years, students with mental health problems, behavioural difficulties and Asperger's syndrome.

These four chapters investigate, through the accounts that students give, the link between arts education, self-identity, disability, empowerment and the development and expression of a positive sense of self through images. The interview data and the images that students have produced combine to 'give voice' to their experiences

in ways that effectively render the personal political. Thomas (1999a) describes this 'bringing in of the personal' as a 'hallmark of feminist approaches' (p.68). She states that this is not only important in centring women's [disabled people's] voices but that 'it gives rise to new ways of understanding what knowledge is and how it is produced'.

Chapter seven, the first of the case study chapters, investigates how disabled students can explore new ways of understanding what knowledge is and of how, through their art work, they can discover new ways of producing it. It examines the ways in which negative social perceptions of disability have coloured students' sense of themselves and it relates this to early experiences of the arts, both in terms of family perceptions and educational experience. The students whose accounts are featured in this chapter were at an early stage in their college arts education (GCSE level two or the beginning of level three Foundation Art and Design). Nevertheless, an understanding of the purposes of art and the ways in which they can employ this in articulating the lived experience of impairment and disability, given an empathetic learning environment and appropriate learning support, are clearly emerging.

Chapter eight adds breadth to these themes through an in-depth analysis of one student's experiences at level three. Her account details another stage in the continuum of arts education that is being described in this study. This student, who is non-verbal, has complex and high-level support requirements that demand a particularly effective marrying of practical enabling, communication support, and ILT to enable her to study the arts at level three (pre-degree). The ways in which this has been achieved to create access for her is described, and the significance of a visual language to a student for whom other forms of expression and empowerment are not possible, is emphasised. Images provide evidence of her growing concerns with self identity which are expressed in a narrative format that is characterised by a Timeline.

Chapter nine is based on the accounts given by two students who have progressed to study in higher education (level four). The chapter begins with an analysis of the difficulties that many disabled students, and particularly those with high level support needs, encounter in going to live and study at university. It goes on to look in detail at the very different accounts given by the two students who are studying BA degrees in Fine Art and Textiles respectively. The part that factors other than impairment and disability play in shaping their experience is particularly apparent.

Class and family background, gender, personality and material circumstances also significantly affect their experiences despite the similarities of having the same impairment, special school education and education in the arts at the same college and university.

The final case study chapter (ten) presents insightful accounts by three artists who have progressed from Hereward College, completed their higher education degrees and are continuing with their work as practising artists. It draws together the strands that have emerged in the previous case study chapters and elucidates the themes and issues identified in the early chapters of this thesis. As mature young disabled people they identify and reflect on their experiences of living in a disablist society, Disability Arts, the impact of impairment in their lives and the practical and intellectual rewards of their arts education. The different ways in which they have transposed the negative connotations of being labelled 'disabled' into positive and empowering images, leads us to the conclusion that arts education has served each of them in developing and articulating a positive self-identity. The shifting of allegiances between an empowering, 'collective' identity that subsumes the individual, to one within which there is the potential to develop a fluid personal narrative that expresses the individual lived experience of impairment and disability, is a dilemma that occupies all three artists. This chapter engages with the dynamic between these two dimensions of experience and acknowledges that both are critical in enabling the disabled young artist to create meaningful images.

The conclusion sets out the ways in which the visual arts education at Hereward College has enabled disabled students to develop and express a positive self-identity. Deductions are made about the impact that enabling support and ILT have had in the realisation of this and disability awareness and the interrelationship of this with teacher training is highlighted. Further areas of inquiry that have arisen as a result of this research are identified.

## Chapter One

### The Social Construction of Disability and the Conceptualisation of Disabled People as 'Other'

This chapter provides the starting point in the process of enabling disabled young people to create their own self image, by setting out the roots and historical development of the concept of disabled people as 'other' and the challenge that was made to this concept in the 1980s by the Disability Movement. It gives an account of the ways in which non-disabled people have transferred their fears and prejudices onto the body of people with impairments in a disabling process of marginalisation. Negative and stereotypical attitudes towards people with impairments have circulated within social and cultural discourses, and eclipsed individual qualities and characteristics with the assumption that it is the impairment that limits and therefore defines the whole person. In this chapter an analysis is given of the concept of 'other' and the enduring links between charity, disability and the perception that impairment is synonymous with pity, helplessness and tragedy. The politicisation of disabled people in the 1980s, following on from the upsurge in civil rights and feminism and the formation of the Disability Movement and Disability Arts, empowered disabled people through solidarity, the social model of disability, and an alternative cultural forum from which to challenge prevailing representations of disabled people.

The re-conceptualisation of disability as a social construct in the 1980s as a consequence of the Disability Movement highlighted, through Disability Arts, the importance of images in the expression of these new meanings particularly within an intensifying mass media dominated by increasingly sophisticated imagery. However, arts practitioners and cultural theorists, and the analyses of images, particularly within popular culture, that reproduced the processes of objectification of disabled people were slower to appear. The 'burgeoning literature on many different aspects of disability' which Barnes, Mercer and Shakespeare (1999:2) describe as emerging from the sociology departments of academic institutions from the mid 1980s onwards, was initially concerned with the political and social aspects of disabled people's experiences. (Abberley 1987; Oliver 1990, 1993, 1996; Swain, Finkelstein, French and Oliver 1993; Campbell and Oliver 1996). Barnes *et al* (1999) note the early neglect within disability studies of the impact of cultural influences stating that 'the significance of culture, both in the oppression and emancipation of disabled



people, is a comparatively recent phenomenon in the field of disability studies' (p.182).

### **Definitions of Disability**

Central to the work of academic disability theorists and fundamental to any analysis of sociological or cultural issues is the definition of disability. Gilson and Depoy (2000) recognise that achieving a satisfactory definition that encompasses the complexities of impairment and disability is not an 'easy task'. They state 'many definitions have been advanced, founded on diverse values and theoretical propositions' (p.207). However they organise the definitions that have evolved through disability studies under four headings that, with the addition of Thomas's (1999) psycho-emotional dimensions of disability and Swain and French's (2000) affirmation model of disability, constitute a succinct frame of reference for the issues considered within this thesis. The first is the Medical Model, which Gilson and Depoy describe as a 'form of biological determinism' whereby the focus of disability is on 'physical, behavioural, psychological, cognitive and sensory tragedy' (p.208). Within this model 'the individual who cannot be 'fixed' by professional intervention ... remains deficient'. In contrast with this they outline the Social Model of disability in which the 'locus of the 'problem' to be addressed by services and support [is] within the social context'. The Political Model of disability is described as being 'closely aligned with the Social Model' but relates to the marginalisation that occurs when disability is seen as 'a condition that interferes with one's capacity to work and make contributions to a social group' (p.208). Fourthly, they identify the Cultural Model of disability in which it is suggested that 'all individuals who define themselves as disabled belong to a unique group which shares experiences, tacit rules, language and discourse'.

All of these definitions are referenced in this study but Thomas's psycho-emotional dimensions of disability have a particular relevance in that she identifies 'a form of disablism [that] undermines the emotional well being of disabled people' and, which she maintains, is just as disabling as structural barriers.

Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being (1999a:3).

Reeve (2002) draws on the work of Thomas to develop the concept of psycho-emotional dimensions of disability with their influence on identity constructions. She describes the ways in which 'the gaze and self-surveillance operate on the bodies of people with impairments and leave them feeling worthless, unattractive and stressed' (p.493). Barnes and Mercer (2003) describe 'unease when writers call for studies of the psycho-emotional dimension of disablism'. The fear is that such an approach will lead to a 'descent' into 'a discussion of 'internalized oppression' in which 'disabled people dwell on the pain and the fears, the negative self-images and the low expectations,' which, in turn, may 'eliminate any sense of agency to resist disablism' (p.78). However I have found, in the context of teaching and learning, that disabled young people are liberated when oppressive attitudes become transparent, enabling them to bring an objective perspective to their experiences which, in turn, has empowered them to resist such notions through their artwork.

This process of resistance through arts education results in the affirmation of disability that Swain and French (2000) draw to our attention. They argue that a new model of disability is emerging most notably from disability culture, namely Disability Arts, wherein disability or difference is not viewed as a tragedy for disabled people but that on the contrary it can enhance life. Encouraged by the Disability Arts Movement, disabled people are creating positive images of themselves, and are 'demanding the right to be the way they are – to be equal, but different' (p.578).

### **The Construction of the 'Other'**

Those who are non disabled and therefore by implication 'normal' have, until recent years, dominated perceptions of impairment or bodily difference. The word normal is not merely a descriptive or neutral term but has evaluative aspects, rendering the body that is perceived as 'abnormal' as a receptacle for the displaced fears of non-disabled people. Essentially non-disabled people have consistently transferred their prejudices and fears onto the body of impairment. An explanation is given by Morris (1991) quoted by Shakespeare (1994) in which she states 'It is fear and denial of the frailty, vulnerability, morality and arbitrariness of human experience that deters us from confronting such realities' (p.286). These prejudices, which historically have underlain the cultural representation of disabled people, have supported and endorsed 'practices and ideologies that are built into the bricks and mortar of our formal institutions and seep into our personal encounters and observations' (Read

2000:102). The differently formed body has represented 'otherness' in all times and places.

Because such bodies are rare, unique material and confounding of cultural categories, they function as magnets to which culture secures its anxieties, questions and needs at any given moment (Garland Thomson 1996:1).

Shakespeare (1994), in his analysis of the notion of 'other', cites Jordanova (1989) who sees this perception as 'the distancing of what is peripheral, marginal and incidental from a central norm, of illicit danger from safe legitimacy' (p. 290). She describes

the treatment of the "other" as more like an object, something to be managed and possessed, and as dangerous, wild, threatening. At the same time, the "other" becomes an entity whose very separateness inspires curiosity, invites enquiring knowledge. The 'other' is to be veiled and unveiled (p.290).

The perception of the body as a moral statement is integral to Western European culture. Garland Thomson (1996) explores this concept of corporeal diversity or 'Otherness' in American Culture and examines attitudes towards what she describes as the 'extraordinary' body stating, 'the cultural intolerance of anomaly is one of the most pervasive themes in Western thought' (Thomson cited in Barnes and Mercer p.96). Through the representation of the human form as perfect, the ancient Greeks synthesised spiritual, mental and physical values as constituting a moral as well as an aesthetic experience. Impairment therefore was the signifier of a moral or mental deficit and was regarded variously with confusion, fear, amusement, pity and horror, but invariably with fascination. In the medieval period, children who were impaired were regarded as 'changelings' whose mothers had been involved in sorcery and witchcraft (Evans 1999:275). Hughes (2002), however, who explores the cultural representation of disabled people with reference to the work of Zygmunt Bauman, suggests that the 'volatile' medieval body, subject to the 'ubiquities' of the plagues of medieval Europe, meant bodily difference was 'part of the fabric of daily existence' (p.574). As such 'the happy negation of uniformity and similarity' was more readily the case (Bakhtin 1968, cited in Hughes p.574). It was the notion of the Protestant

modern body, 'marked by discipline and control,' that transformed difference into 'the realities of discrimination and disadvantage' (pp.572-574). Hughes states 'Modernity is at the heart of the transformation of impairment into disability' (p.571).

Hughes describes Modernity as a 'normalising' culture referencing Bauman's (1997) claim that at the heart of Modernity one finds a 'dream of purity' (p.573). The physical and spiritual integrity of modern people was seen as dependent upon the expunging of impurity. The 'other', or the 'stranger', to use Bauman's term, becomes the 'antithesis of cleanliness, rationality and order' (p.575). In response to the fear of contamination or 'incorporating impurity into the body,' barriers, both literal and philosophical, were created to separate and confine the stranger (p.573). Hughes describes this confinement of the stranger as suiting 'the bourgeois predilection for boundaries clearly drawn, absolute categories that legitimated the hierarchical separation of 'this' from 'that' (p.575). 'Difference is to be severed or corrected, exiled or normalised'. Hughes cites modern medicine as the vehicle for achieving this end (p.575).

This shift in ownership of impairment from 'God to the scientist' was predicated on the 'refinement of techniques of correction and self-correction' (Garland Thomson 1996:4, Hughes 2002:575).

As the early custodial institutions became medical spaces and the legitimacy to identify and correct pathological bodies became embedded in them, then disabled residents became the fleshy testing ground for rehabilitative practices (Hughes:575).

The discovery and development of photography provided 'evidence' and a powerful yet inconspicuous means of categorising and documenting impairment for the purposes of segregating people into the major social institutions created in the nineteenth century and pertaining to psychiatry, medicine and criminal justice (Evans and Hall 1999:275, 277).

A finer and finer 'grid' of observation is placed over the population in order to create a whole series of 'functional discriminations' between different types of people (p.277).

Physical features were believed to hold the key to inner pathologies, and biological traits identified through the body, became key signifiers of physical and moral qualities. Those who did not meet the increasingly standardised criteria for the type of work needed for industrial purposes were also highlighted by these processes. Industrialisation demanded workers who conformed to a given physical norm (Oliver 1993:51-52). Impairment disqualified people although their circumstances were regarded as a personal tragedy deserving of a sympathetic and philanthropic response. However, to ensure that provision was made only for those who were unable to work because of sickness or impairment, the unemployed were categorised into those who were infirm and those who were considered indolent, criminal or lazy. The diagnostic process of screening needed to create these distinctions led to a growth in professional expertise and officialdom, and the establishment of institutional provision for people with impairments (Humphries and Gordon 1992).

This charitable response of segregating people with impairments into institutions, asylums and hospitals, continued well into the first half of the twentieth century, sentencing disabled people to punitive regimes whose inhumanity sprang from the 'normalising culture of modernity' and the ideals of Social Darwinism and Eugenics (Hughes 2002:572). Hughes refers to

deeply ingrained cultural fastidiousness and its excessive remedies which, if they were successful, returned the 'cleansed' individual to the orderly world. If not, they were confined forever in the invisible spaces behind the high walls where the 'others' lived in what Bauman describes as a 'state of suspended extinction' (Hughes p.575).

The Eugenics Movement drew support in particular from among the new administrative and professional classes that serviced the institutions. They believed that the existing social hierarchy resulted from innate differences in the qualities and capacities of individuals and that rigorous segregation of those with physical and mental impairments who were regarded as evidence of 'bad stock' was crucial in maintaining and improving the human race (Evans and Hall 1999:277). These ideas reached their apotheosis in Nazi Germany in programmes of mass sterilisation and the extermination of a quarter of a million disabled people. Hughes sees the holocaust as a similar, if more extreme response than institutionalisation to 'the

problem of political hygiene' and 'the need to purify the body politic' (2002:576). Through such propaganda notions of idiocy, disease, pauperism, the criminal mind, the poor and the sick were linked with that of heredity and 'defective' families. These generalised assumptions were coloured by moral overtones that were to distort perceptions of impairment for decades.

### **The Charity Trap**

When they were established in the late nineteenth and early twentieth centuries, impairment specific charities, such as The Royal National Institute for the Blind, and The Spastic Society (Scope), assumed guardianship not only of disabled people's well being, but of their views, opinions and representation. This monopoly of 'expertise' by those who are non-disabled is intrinsic to the experience of impairment and disability. 'People in each historical era had no doubt that they understood not only the origins and nature of different handicaps but also what were the best ways of responding to the afflicted' (Salford and Salford 1996:2). Salford and Salford describe charity organisations as 'inherently patronising' and as ostensibly established in a spirit that was intended to bring people together across social classes in an harmonious society, but that acted principally 'as elaborate systems of protection from the "dangerous classes" ' and as 'a principal means of maintaining these divisions' (p.54). The status of the donor and recipient is inevitably defined by the largesse of one and the apparent need of the other and the act of charity has traditionally been subject to hidden, as well as overt motives (Nightingale 1973:100).

Charitable motives are primeval in origin springing from the notion that evil is kept at bay by placating the Gods (p.100). Hughes (2002) similarly cites 'the fear of the ominous presence or lightening strike of physical or mental transformation and its tragic consequence' as promoting charity (p.577). He describes 'pity and alms' as 'the stuff of modern bourgeois compassion, the olive branch offered to those who have been deemed unworthy to live with the blessed and beautiful' (p.581). Swain and French (2000) describe the notion 'there but for fortune go you or I' and the fear of the possibility of crossing that divide as fundamental to understanding non-disabled people's tragedy view of disability (p.573).

Charity, or the giving and receiving of 'gifts', has long had associations, in the etiquette of all societies, with notions of competition, power, and vanity. Within the Christian religion, motives for charity are bound up with forgiveness, the clearing of

consciences and atonement for the sins of the departed. It was the donor's passport to salvation in the form of a bribe to God (Nightingale 1973). Evans and Hall (1999) in questioning the motives which these, and the proliferation of further charity organisations inspired, suggest 'it feels like bad faith or just plain cynicism to criticise the whole edifice of a culture increasingly dominated by charity practice and ethos, cast as permeated by unimpeachable motives' (p.278).

Victorian philanthropy introduced the concept of pity as an appropriate response to impairment. Certainly freak shows in the late nineteenth century, had rarely exploited pity as a profitable way of presenting impairment. 'People used their leisure time and money to be entertained not to confront human suffering' (Bogdan p.34). It was within this construction of disability that impairment and helplessness became synonymous, and the dependence of people with impairments on the benevolence of those who beheld them as unquestionable. Shakespeare suggests that this positioning of disabled people as objects of pity and therefore aid, could be specifically identified with masculinity and to the threat to the

order, or, to the self-concept of western human beings – who, since the Enlightenment, have viewed themselves as perfectible, as all knowing, as God-like: able, over and above all other beings, to conquer the limitations of their nature through the victories of their culture (1994:298)

### **Political Changes in the 1980s**

Early twentieth century advances in science and medical techniques fostered the medical model of disability which dominated perceptions of disability and impairment until the 1980s. It continues to influence professional policy and institutional practices and to linger in popular culture. Impairment is seen as a problem that can be rectified by medics and associated professionals who manage and treat the impaired individual in an attempt to bring them into as 'normalised' a condition as is feasibly possible. However this was challenged in the early years of the 1970s, when there was an explosion of political energy, accompanied by a growth of political movements (Parker and Pollock 1987:3). Disability awareness and disability rights developed in the radical atmosphere created by the political momentum of women's liberation and the civil rights movements. Thomas (1999a) describes how the original and now 'classic' formulation identifying disability as socially caused, is to be found in

*The Fundamental Principles of Disability* document written in 1976 by the Union of the Physically Impaired Against Segregation (UPIAS) (p.14). She states that UPIAS played 'a critical intellectual and political role in disability politics in Britain in the 1970s.' In a move to accommodate all impairments, the British Council of Organisations of Disabled People was founded in 1981 and, from the mid 1980s onwards, the work of the Disabled People's Movement, formalised by social model theorists (e.g. Barnes 1991, Morris 1991, Swain, Finkelstein, French and Oliver 1993, Oliver 1996) began to have a significant impact. Disability Arts quickly emerged as the cultural strand of the Disability Movement and, at the launch of The London Disability Arts Forum in 1987 Finkelstein, one of the founders, stated that his hopes for the future were; 'disabled people presenting a clear and unashamed self-identity' (Swain and French 2000:577).

The 'social model' formulated 'disability' as a political category, redefining it as a social process in which people with impairments are disabled by the failure of the social environment to accommodate them. They are excluded through lack of access to the environment, to education that is inclusive, and to the universal provision of facilities such as Braille, subtitles and sign language. The social model created a new perspective on the ways in which disabled people's experiences could be interpreted and validated. It had the potential to counteract the oppressive features of disabled people's lives that are socially and politically constructed, with demands for social and political solutions. Thomas (1999a) describes it as 'a touchstone of disability rights, politics and disability studies in Britain' (p.15).

From the social model of disability and shared disability politics a collective disability identity emerged. Thomas (1999a) states that 'supposedly "despised" and stigmatised social attributes were reclaimed, owned and transformed into positively valued ones' and encapsulated in the term 'celebrate the difference' (p.102). Thomas describes the paradox that is inherent in identifying and celebrating 'difference' and division, in that there is a danger of reinforcing and sustaining defining socially constructed distinctions (p.103). In addition, empowering as it was for disabled people to unify under a collective identity with its focus on changing society, it ignored the self as an 'unformed, unfixed concept' that evolves through the reflexive process (Giddens 1991, cited in Watson 2002:510). The tensions and personal dilemmas within this paradox emerge in the words of the students in later chapters.



The social model also contains a dilemma in that it diminishes, if not ignores, the fact that the nature of impairment itself can often, to a greater or lesser extent, be both painful and debilitating and difficult to 'celebrate'. Read (1999) suggests that 'some find that it can be a significantly restricting and painful part of their experience as disabled people - though not always in the way supposed by non-disabled people' (p.182). This area of difficulty arose from a hesitancy to acknowledge characteristics that would confirm negative attributes to impairment, and thereby undermine the important efforts of disability theorists and activists to 'affirm the authenticity of impaired modes of being' (p.183). Shakespeare described the 'materialist' approach that focused on 'societal structures' as in some part a reaction to psychological research on attitudes to disability that have as their resolution the 'adaptation' of individual people with impairments to their 'misfortune' (Shakespeare 1994:283). This dilemma extends to the arts when they are employed solely as an agency of resistance and the lived experience of impairment is suppressed by the need to project a forceful political stance.

Disability Arts recognised that through the arts there is the potential to engage in the transformation of social relations of power and in so doing to address issues of self-esteem and a sense of self. *Graeae*, a company of actors with impairments (founded in the late 1980s by Nabil Shaban) and *CandoCo*, an integrated dance company (founded by Adam Benjamin and Celeste Dandecker in the early 1990s) are examples of early Disability Arts practitioners who successfully brought the disability agenda to mainstream audiences. This reconstruction of disability identity was in line with the 'identity politics' which had come to public consciousness from the late 1960s and been associated with new social movements such as black power, feminism, lesbian and gay liberation' (Rutherford 1990:88). Within a climate of an intensifying and increasingly sophisticated consumer culture, feminist, ethnic, gay, lesbian, and from the 1980s disabled people, were examining and challenging the ways in which they had traditionally been represented.

However, the assumption that disabled people all have a common culture brings into question the comparison with black art and feminist art. Humphrey (1994) states 'black arts and feminist arts are evidently not exclusively about oppression, they also celebrate the cultural inheritance of being black or being a woman' (p.66). He poses the question 'How can Disability Art be seen as a celebration of disability? - nobody wishes to lose a sense or a faculty' (1994:66). Barnes *et al* (1999) propose an

ambivalence towards impairment wherein whilst the value of people with impairments is recognised there is a refusal to 'glorify incapacity' (p.207). Humphrey suggests that Disability Arts should be seen as part of a celebration of a multi-faceted humanity which people should not be disqualified from because of their impairments (1994:67).

### **The Impact of Feminism on the Development of New Meanings**

Feminist struggles to reclaim the images of women from the representation of others, namely men, emerged in the 1980s (Parker and Pollock 1987; Rutherford 1990; Isaak 1996;). In this sense it was a shared agenda, although for disabled people the task was to reclaim their representation from those who were non-disabled. Feminism has been particularly relevant to disabled people's quest to reconceptualise disability. It had an enormous impact on contemporary art but it also changed contemporary thinking about value systems that extend far beyond the art world (Isaak 1996:2). Shakespeare (1994) describes 'feminist concerns' as being with 'social representation of femininity, cultural stereotypes, norms of beauty and so forth'. He compares them with 'the particular situation of disabled people, women especially, [and] as a more extreme version of the general experience of all women' (p.284). He describes the prevailing focus on beauty and normality as 'deeply divisive for all women' but as 'particularly oppressive for those whose bodies do not fit the stereotype' (p.284).

Feminism prompted women to endeavour to understand how institutions operated, how ideologies worked and how images produced meanings. They analysed the ways in which advertising, film, television, journalism, literature, fine art, and the education system contributed in the interlocking network of images and values that saturate our daily lives and are read as a reflection of the natural order of things, as a 'common sense' (Parker and Pollock 1987:79-81). These new assessments of how meanings are produced, of how reality is shaped even identities formed, motivated women to utilise the flexibility that a variety of diverse media, such as photography, text, video, performance, etc could offer. By reworking images from contemporary art, art history or media, new ways were created with which to realise the 'dislocation of existing and dominant regimes of power and knowledge' and with which to create new and alternative imagery (Parker and Pollock:81).

The revealing and analysing of aspects of life that had traditionally been veiled in shame and silence were part of this process, and were one with which people with impairments could identify. For women this related to childbirth and menstruation and was expressed in the work of artists such as Monica Sjoo's *God Giving Birth* (1969). For disabled people, it was impairment and its implications. Disability artists such as Brian Jenkins, in his installation *Wound* (1990), explored and exposed, via explicit self-representations, the limits of what could be expressed about impairment within the mainstream culture (see Fig 1). Not only does he uncompromisingly present the viewer with his naked, unconventional bodily form, but he also does so in a way that dominates the space in which he confronts the viewer. He is unavoidable in that his linear dimensions fill and embrace the room, drawing the viewer in with an outstretched and oversized hand. Fridha Kahlo, whose work is germane to both Feminism and Disability Arts, represented, in the early years of the twentieth century, her experiences of being both female and impaired (see Fig 2, 3). In the representation of socially taboo subjects such as miscarriage, childbirth and impairment, she defied the authority of patriarchy, the boundaries and exclusions enforced by the art world, the catholic tradition, and also the hierarchical medical profession in which she was so caught up (Adler and Pointon 1993:5 -19).

Importantly, feminism engaged with the question of the personal as political, it discarded the conventional ways in which works of art had functioned as commodified objects and stressed the circumstances that influenced its production. Emphasis was focused upon the conditions within which the work was received, where, by whom and against the background of what inherited conventions and expectations (Parker and Pollock 1987:82.). Feminism was not simply a struggle for women artists to achieve greater representation, it was 'a struggle about meanings, a fight against dominant and established systems of meanings and the positions and identities which they attempt to secure' (p.118). Feminism reclaimed the images of women from the representation of others and in so doing created the climate within which disabled people could also begin to do so.

### **Summary**

This chapter has explored the social construction of disability and the ways in which non-disabled people have distanced themselves from people with impairments by adopting the concept of a generic 'disabled' group, projecting ideas, beliefs and customs onto them, and characterising them as dependent and helpless.



Fig 1

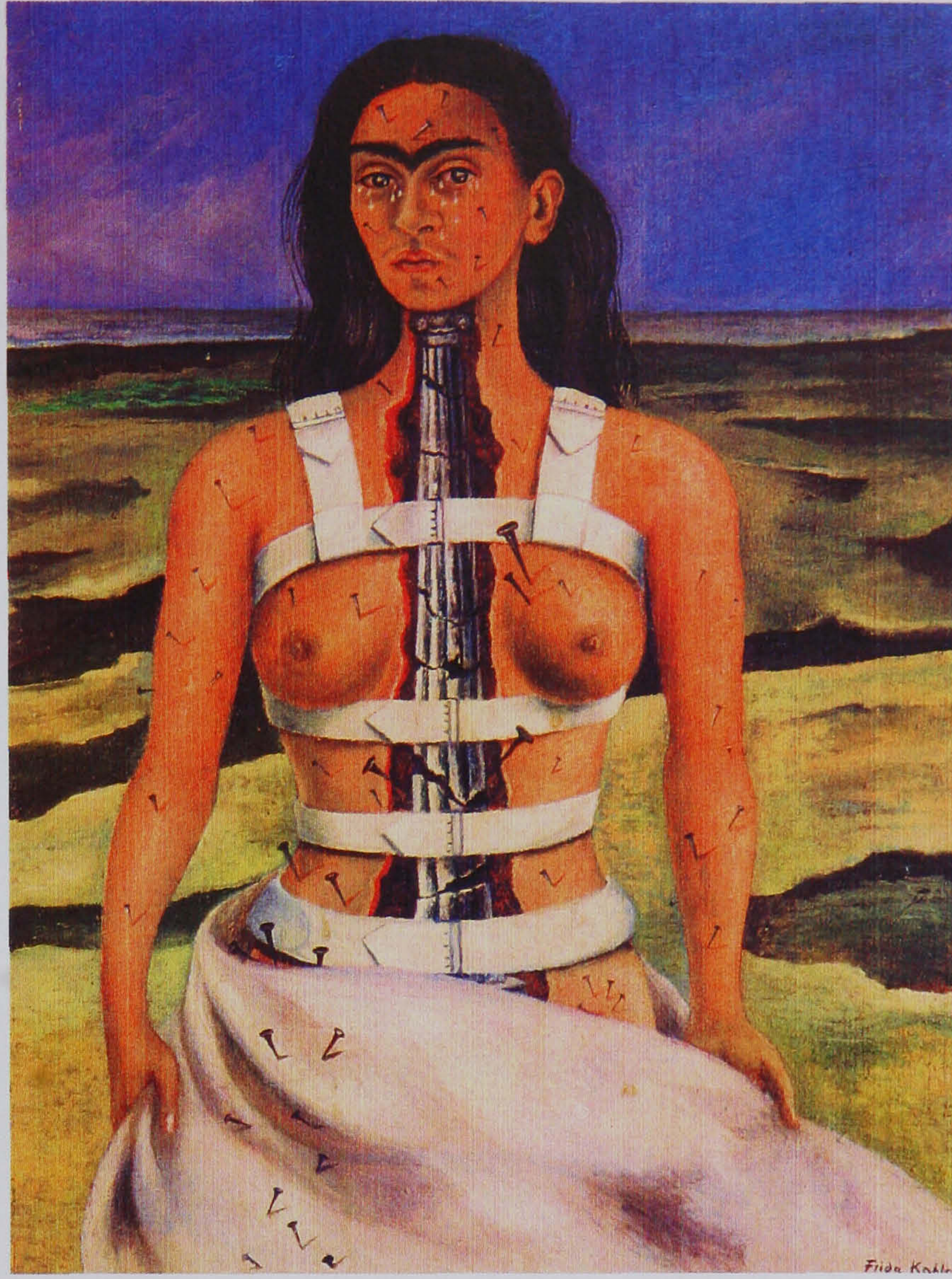


Fig 2



Fig 3

This uniformity of response, justified by a charitable ethos, has ensured that these perceptions have been self-perpetuating, seeping through time and generations and proving powerful enough to continue to resonate in contemporary popular culture. It is through the vehicles of the mass media, Television, film and advertising that young people with impairments encounter and internalise concepts of disability that can undermine their self-esteem and sense of self.

This chapter has shown how the politicisation of disabled people and the development of new meanings through the Disability Movement and Disability Arts have begun to change social and cultural perceptions of disability. Although slow to appear and still few in number, some examples of images that associate disabled people with contemporary mainstream contexts and values, such as glamour, celebrity, lifestyle choices and 'real life' drama, can now be found in the public domain. The following chapter contrasts the earlier stereotypical images of disability with these new representations, in preparation for an analysis of the development and expression of self-identity.

## Chapter Two

### The Representation of Disabled People in the Mass Media

This chapter acknowledges the primacy of the image in promoting the values of contemporary culture, and the phenomenon whereby we are living in, what Berger (1972) describes as a 'concentration of visual images, such a density of visual images' (p.129). An account is given of the ways in which within this 'density of images' disabled people have been, and are represented by non-disabled people. The advent of lens-based media facilitated the process of objectification by manipulating disabled people through their image and the simple expediency that 'the camera never lies'. Charity organisations adopted this power of the photograph to persuade through its authenticity, and television and film up until the closing years of the twentieth century have ensnared disabled people as the negative foil to their heroes and heroines, and as an embellishment to the story line wherein 'good' and 'bad' are made synonymous with appearance. This chapter analyses the ways in which images have determined perceptions of impairment and disability for non disabled and disabled people alike, contrasting earlier images with some recent examples that indicate a growing sensitivity to the representation and inclusion of people with impairments in the mainstream mass media.

#### Representation and Meaning

Academic analysis of the meaning of images of disability in the media only began to appear in the early 1990s however there is now a significant literature that analyses the ways in which disabled people have been represented by non-disabled people in literary and visual forms, including TV, film and the media (Morris 1991; Hevey 1992; Cumberbatch and Negrine 1992; Norden 1994; Shakespeare 1994; Pointon and Davis 1997; Barnes *et al* 1999; Barnes and Mercer 2003). Disabled people have always been perceived as providing 'rich' subject matter for spectacle, curiosity and metaphor but the authority of the image in encoding and endorsing generalised and negative perceptions of impairment, and securing them as an accepted norm, escalated through the twentieth century as the technologies of photography, cinema and television developed. Hughes (2002) refers to 'an "ocularcentric" culture', describing its 'preference for physical and mental perfection [as] ... a source of aesthetic discrimination that invalidates and excludes people with impairment' (p.580). Giddens (1991) similarly describes disabled people as having been 'lost'

behind images over which they have had no control, in a 'society dominated by appearances' (p.172).

### **The Photographic Shaping of Impairment**

Photography, from its inception, supplied tangible images that could function as a focus for the voyeuristic gaze, and position the disabled person as 'other'. 'Photography transformed the subject into an object, which could be individually possessed', 'a still, which allows one to linger over a single moment as long as one likes' (Scherer 1992:33, Sontag 1973:81). The *Carte de Visite* produced in the mid nineteenth century as souvenirs of a visit to a circus or 'freak' show provide early examples of the ways in which disabled people were manipulated through their images. (Pultz 1995; Bogdan 1996:27; Ostman 1996:122). A variety of devices were employed to intensify impairment and construct and manipulate identity in terms of this single defining feature. This might involve, for example, placing the disabled person against a domestic backdrop to heighten and contrast difference (see Fig 4). People who displayed extremes of stature were posed together to maximise their disparity, and it was common practice to aggrandise the social position of the subject in absurdly inflated titles such as *Captain, Princess* or *King* (Bogdan p.29). Thus in a 1915 postcard representation of a woman of restricted growth, a vase of flowers of similar size is placed beside her with the caption, 'Princess Wee Wee, the smallest perfectly formed little woman in the world' (see Fig 5). The anecdotal text that directs comments in a familiar or sensationalist 'aside' to the viewer becomes a constant in the objectification and exclusion of disabled people, an enduring device that appears later in tabloid newspapers and television documentaries.

Photography, which it was believed offered empirical, objective knowledge, was 'notoriously at the centre of scientific initiatives to classify physiognomy and impairment, as well as central to the Nazi promotion of the classical 'Aryan' body (Barnes and Mercer 2003:94). Edwards (1992), Ewing (1994), Evans and Hall (1999) describe how the medical model of disability was authenticated through documentation facilitated by new photographic technology. This systematic separation, sorting and classification of impairment is characteristic of the Modernist approach to rationality and order and it was used extensively to collect documentary evidence of people with impairments and people of non-western ethnicity.



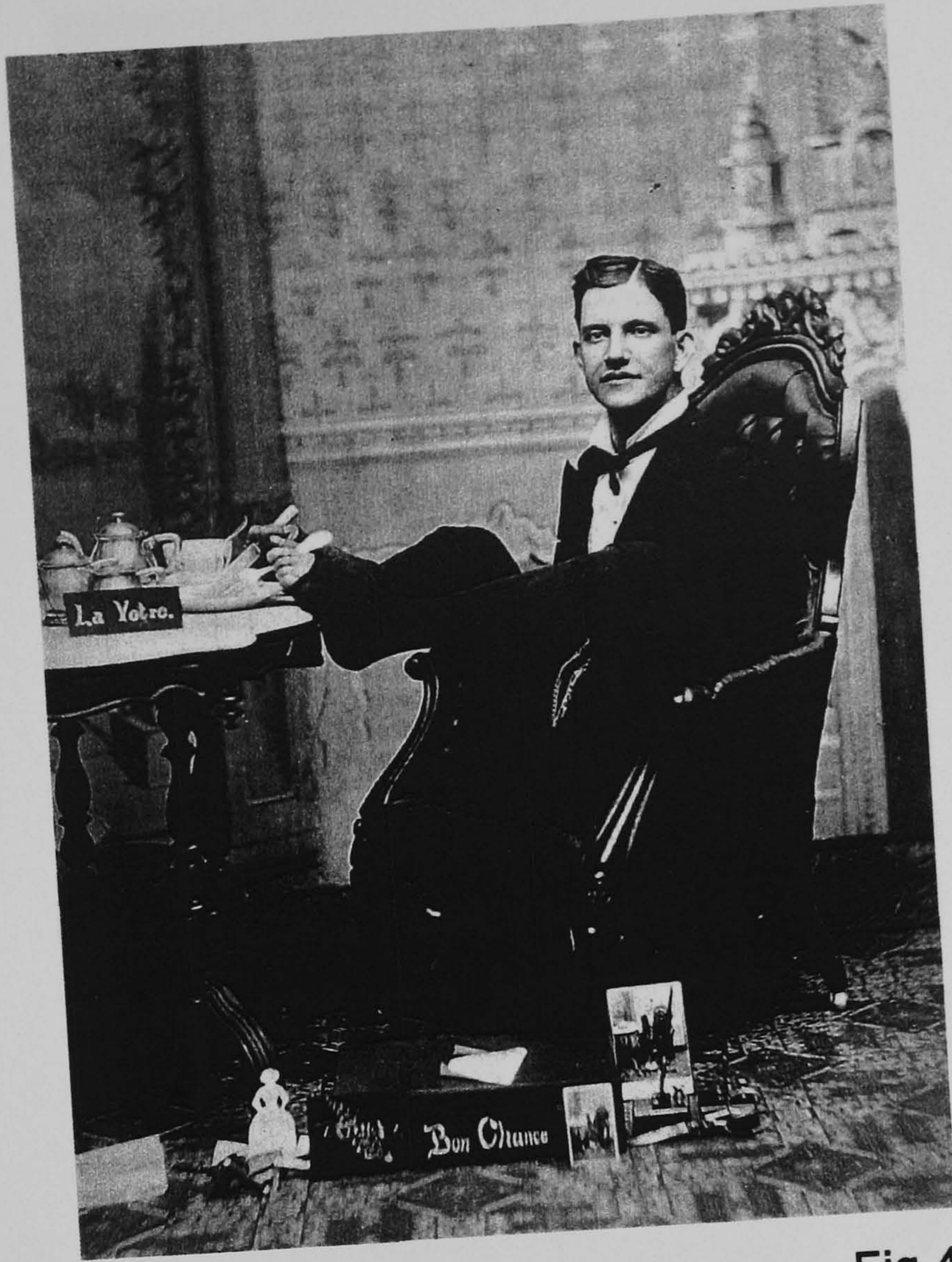


Fig 4



Fig 5



Fig 6

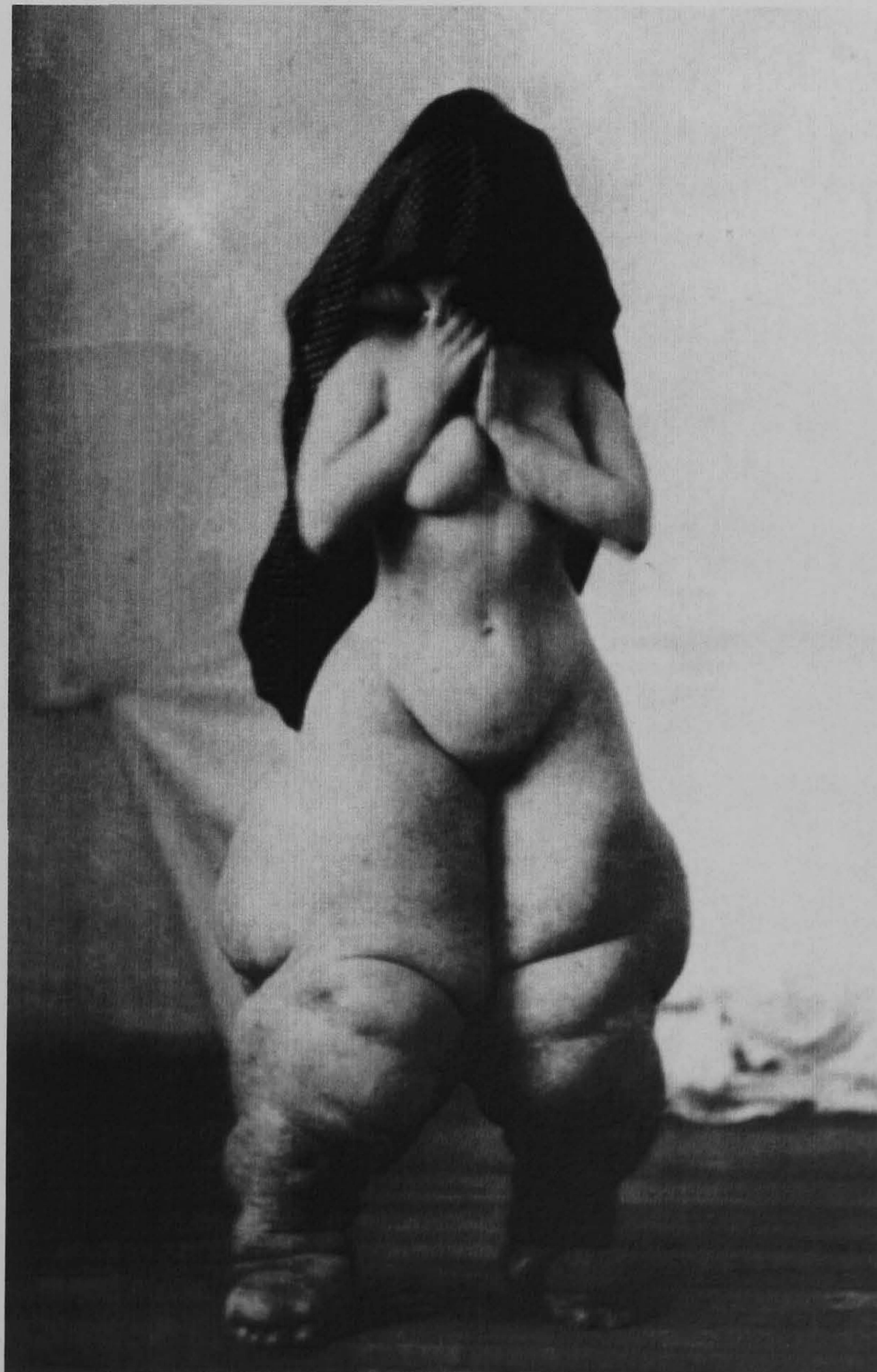


Fig 7

This collection was made in the belief that 'the type, the abstract essence of human variation could be perceived as an observable reality' (Edwards 1992:7). The ensuing images, intended as an objective record of impairment or ethnicity, resonate with the social, political and moral ethos of the age (see Fig 6, 7).

### **Charity Advertising**

The charity advertising campaigns of the 1980s (the decade in which many of the students interviewed for this research were born and grew up) left an enduring legacy in terms of oppressive images that became synonymous with disability. Hevey's (1992) analysis of such images is seminal and had additional significance in that it was cultural theory that was produced by an artist who had an impairment, who was a political activist and who was working with disability representation as an overall strategy to create social change with the use of photography in a directly interventionist approach.

In the 1980s and 1990s there was a shift in emphasis towards a greater reliance on private charity organisations. By the 1960s Campbell and Oliver (1996) point out that

We were faced with the choice of a range of dependency creating services or nothing at all, and a plethora of disability organisations, which spoke in our name, but neither represented us accurately nor [in the political or democratic sense] met our needs (p.45).

As these organisations grew into multi-billion pound businesses, fierce competition to boost products within an intensifying market economy meant that professional advertising agencies were employed to use the same devices as those that large corporate companies and professional public relations people adopted to sell their products. This meant that, in terms of charity advertising, they promoted tragedy, pity, and helplessness on the basis that this was the necessary prerequisite for giving.

The impairment became the 'unique selling proposition' for the charity product, in a construction which represented disabled people as a particular kind of person subject to a process of 'image specialisation' (Evans and Hall 1999:279). The disabled person had become a commodity owned by the charity. They 'marketed'

them using the assumed general negativity of public perceptions, against which only they provided the defence with specialised understanding and knowledge. For example an image of a young person in a wheelchair reaching for the buttons that operate a lift is accompanied by text that presumes to represent her voice - 'Everyone assumes I won't want to get to the top' (see Fig 8). The Spastic Society at the bottom of the poster 'answers' her, and us, with the response - 'Our biggest handicap is other people's attitude' (Hevey:11). Hevey describes how these closed circuit processes by passed disabled people completely

Non-disabled image-making, beginning and ending with a non-disabled photographer, directed by non-disabled art director, commissioned by non-disabled employing ad agency, working for non-disabled-controlled charity, appealing to the assumed to be non-disabled public (p.11).

Charity advertising assumed people with impairments belonged to an homogenous dependent and powerless group. A number of devices which Evans and Hall (1999) refer to as 'the various paradigms of the signifying tool kit - clothing, lighting, camera angle, facial expression etc. were employed in the construction of disabled people as 'outsiders' (p.281). The use in early charity images of stark, grainy black and white photographs taken with deep shadows, placed the subject in a world drained of the colour used in all other forms of advertising to denote the richness and vibrancy of the world that the rest of society ideally inhabit. Monotone created the shadowy ambience that gives a heightened sense of alienation of someone who is 'neither dead nor alive, neither out of society nor in it' (Hevey :34) (see Fig 9).

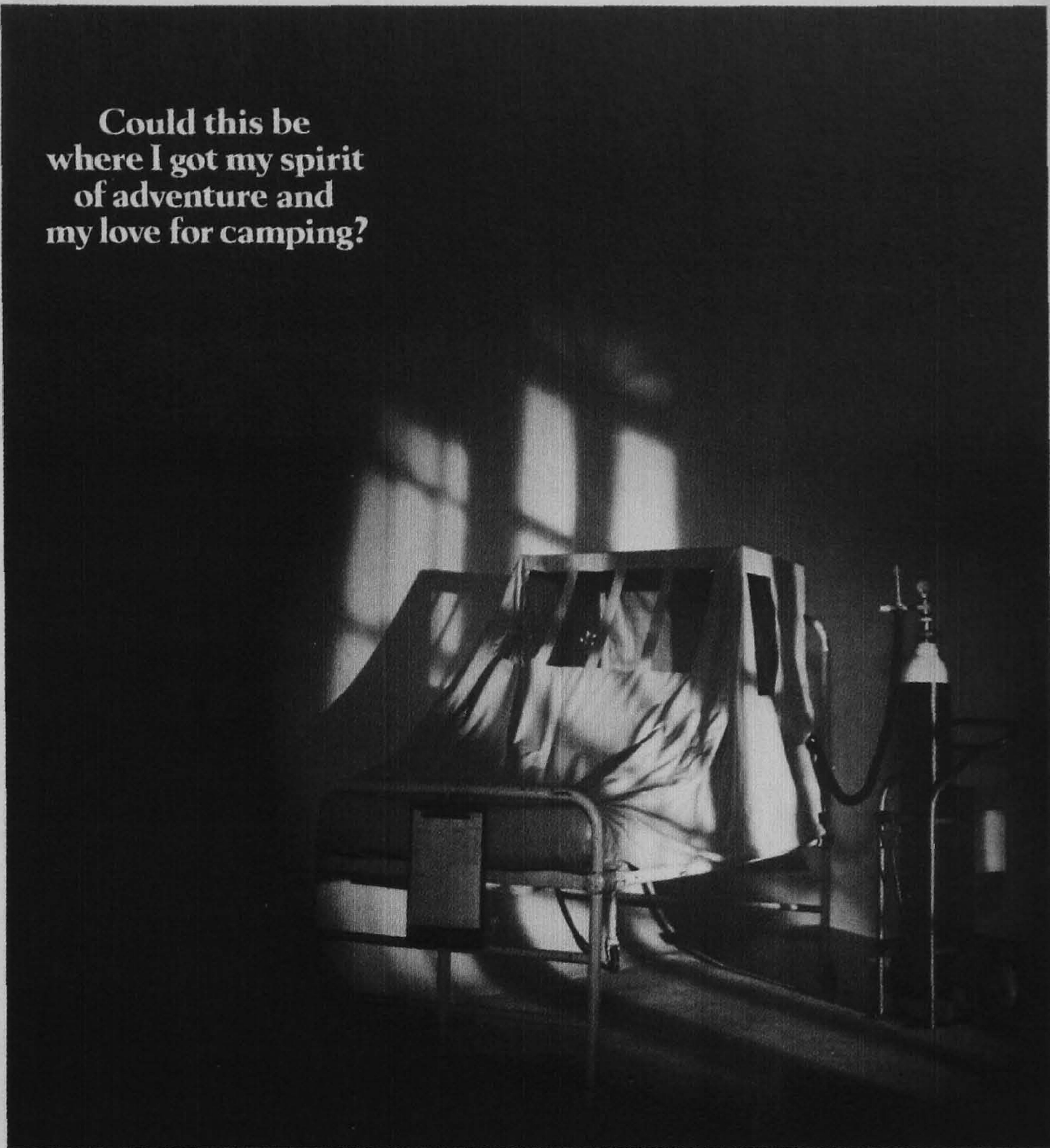
Images were designed to encourage the observer to 'look in' benevolently at the disabled person's predicament. Their gaze is not returned, allowing avoidance of disturbing notions of individuality and personality. Shakespeare compares the objectification of disabled people in charity advertising with the objectification of women in pornography in the sense that 'in each case, the gaze is focused on the body, which is passive and available' (1994:288). He suggests that 'in each case the viewer is manipulated into an emotional response: desire, in the case of pornography, fear and pity in the case of charity advertising' (p.288).



Our biggest handicap is other people's attitude.  
**THE SPASTICS SOCIETY**

Fig 8

Could this be  
where I got my spirit  
of adventure and  
my love for camping?



The only reason I've got cerebral palsy is that I couldn't breathe when I was born.

A week in an oxygen tent could not prevent the fact that every time my brain tells my body to do something, my body makes like a demented octopus.

But it's only a disability (yes, only), something The Spastics Society understands.

So much so that when I went to two of the Society's special schools, by far the most important thing I learned was how to

stick up for myself and to organise life the way I want it.

They positively encouraged independence. And the time you really feel you have won is when you forget the Society is there at all.

Like when you're camping, which I do regularly. In fact, I'll never forget the time I once rolled out of my tent, accidentally and at three in the morning.

The moon was shining and everything

was still, except for the odd high speed train that whistled past my ear on the main Exeter to London line.

My childlike instinct was to call out for help. Luckily nobody heard.

So I told myself not to be so stupid and for once my body responded.

I crawled and crawled up the hill till I got back to the tent.

Because there's nothing like doing it yourself. Is there?

FOR HELP INFORMATION OR TO MAKE A DONATION WRITE TO THE SPASTICS SOCIETY AT 12 PARK CRESCENT, LONDON W1N 4EQ TEL: (01) 436 5020.  
NAME \_\_\_\_\_ POSTCODE \_\_\_\_\_  
ADDRESS \_\_\_\_\_ SIGNATURE \_\_\_\_\_  
AMOUNT £ \_\_\_\_\_ FOR ACCESS OR VISA DONATIONS PLEASE STATE CARD NO.

**THE SPASTICS SOCIETY**  
FOR PEOPLE WITH CEREBRAL PALSY

Opening minds by opening doors.

Fig 9

Shakespeare references Jenny Morris (1991) in remarking on the legitimacy, in respect of disabled people and women, of 'stares, comments and unwanted attention' that would be considered inappropriate in any other context. He furthers this comparison with a quote from Coward that 'the ability to scrutinise is premised on power; women's inability to return such a critical and aggressive look is a sign of subordination, of being the recipient of another's assessment' (Coward 1984, cited in Shakespeare 1994:288). The issue of unwanted scrutiny or the 'gaze' and how disabled students have dealt with it emerges in the case study chapters.

### **Representation in Film and on Television**

Norden (1994) considers film to be the 'most pervasive and influential of the media arts, functioning as a reflection of the values of the society from which it has arisen, and which society then takes up in an unquestioning way and reaffirms' (p.1). Certainly cinematic technologies have raised the quality of image and sound to make film a 'particularly intense experience' for the audience which, Abercrombie (1996) suggests, makes identification with what is going on in the film possible (p.10). In listing the differences in the experience of television and film, he describes television as 'an ordinary, domestic, everyday medium' to which its audience is fairly inattentive at times. Film on the other hand demands sustained attention, its narrative moves from a disordered state of some sort through to a resolution that, it assumes, its audience awaits in a state of 'pleasurable anticipation' (pp.10-11).

Impairment has been used to enrich this narrative, based on the premise that has long associated good and bad with particular physical characteristics. It has served as a metaphor for a variety of moral statements in stereotypes so durable and pervasive that, for people with and without impairments alike, they became the authentic model of disability. Norden (1994) summarises these stereotypical characterisations.

The extraordinary (and often initially embittered) individual whose lonely struggles against incredible odds make for what are considered heart - warming stories of courage and triumph, violence-prone beasts just asking to be destroyed, comic characters who inadvertently cause trouble for themselves and others, saintly sages who possess the gift of second sight and sweet young things whose goodness and

innocence are sufficient currency for a one-way ticket out of isolation in the form of a miraculous cure (p.3).

The representation of people with impairments as villain, or the personification of evil, has been a particularly compelling and enduring motif for film makers, implying that, 'deformity of the body is a sure sign of deformity of the mind' (p.32). From the 1930s onwards increasingly sophisticated special effects have been used to endorse this association epitomised by Charles Laughton's early portrayal of *The Hunchback of Notre Dame* in the 1930s, the evil megalomaniacs of the 1960s James Bond films, and the fantastical figure of Darth Vader in the 1980s film, *Star Wars*. Literature, which has provided the narrative for many films, also has a history of manipulating the association of impairment with malevolence as for example with Richard III, Long John Silver and even Disney's Captain Hook. Norden depicts this stereotype of 'disabled person as villain', as 'obsessive avenger', or the 'ego maniacal adult male intent on executing his revenge on those he deems responsible for his disablement or who have transgressed his moral code in some way' (p.53).

The film industry seldom if ever represented disabled people as sexual beings recognising that romance, sexuality and impairment have always been taboo or controversial issues. Impairment has been used more readily as a metaphor for dependency and vulnerability and as a vehicle for exploring such experiences, particularly from the male perspective (Morris 1991:92-101). Gender stereotyping has meant that disabled men have been significantly more in evidence in films than women. Dependency and vulnerability have traditionally been associated with femininity, regardless of impairment, however, the relationship between physical attractiveness, sexuality and impairment disqualifies disabled women on the basis that their impairment, in conventional terms, renders them sexless. These popular assumptions about gender and impairment are summed up by Morris.

To be a disabled man is to fail to measure up to the general culture's definition of masculinity as strength; to be a disabled woman is to fail to measure up to the definition of femininity as pretty passivity (p.92).

Morris describes two films that are ostensibly about disability, (*My Left Foot* and *Born on the Fourth of July* 1989) as actually about the horror for men of physical and emotional dependency. She states 'the films rely on the general association of



impotence with disability, and on the association of heterosexuality with a stereotyped masculinity' (p.94). Paradoxically, even roles that required the characters to be disabled were invariably taken by non-disabled actors and, in these films, are played by Daniel Day Lewis and Tom Cruise respectively. Disabled people have also seldom appeared in roles where their disability is a secondary characteristic (Morris 1991:112). It would seem that directors have been reluctant to cast disabled people in such roles, perhaps because they lack the necessary training and experience which traditionally has been either inaccessible or simply not considered appropriate for disabled people. An even greater influence, however, is the powerful meaning that is given to visible impairment on the screen.

Because disability has such strong meanings for non-disabled people, it is difficult for any play, film, book, television drama - even an advertisement - to include a disabled person as a character who just happens to be disabled (Morris:112).

It is this notion of having characters that just happen to be disabled that the media industry, dominated by non-disabled people, is so slow to embrace. If, as Abercrombie states, television 'seems to be describing the world as it is,' it is a world in which disabled people have largely not been included or have been represented only in particular ways (1996:26). Morris commented, at the beginning of the 1990s, 'I could watch television for years, possibly a lifetime, without seeing my experience reflected in its dramas, documentaries, news stories' (1991 p.84). Abercrombie states 'some 97% of households own at least one television set, with television watching occupying more time than all other leisure pursuits combined' (p.2). He suggests this would imply that television is 'perhaps the most important source of common experience for the British people' (p.2).

Cumberbatch and Negrine's (1992) detailed analyses of images of disability on television highlights the issues that arise in making comparisons between television and real life populations. They revealed that in 1992, 95% of the television population was white, 65% was male and over 50% was between the ages of 25 and 40 (p.16). Within this unrepresentative profile, they demonstrated that disabled people were under-represented or absent across the range of television genres and when they had appeared they were portrayed in particular and limiting ways. For example in dramatic fictional programmes, where the potential exists to include disabled people

in everyday settings, Cumberbatch and Negrine indicated that 0.5% of the characters represented were shown as disabled in contrast to the 6.81% that could be expected (p.36).

Despite the limited representation of disabled people in everyday settings across the television channels on offer, examples of changes in *how* disabled people are being represented, particularly on BBC2 and Channel 4, have begun to appear. Until recently their representation has largely been limited to 'specialist' disability programmes, charity appeals, human-interest stories on local news programmes and documentaries that explore the medical and social narratives of disability. These documentaries have allowed the audience, as the photographic image had done at the beginning of the century, an opportunity to gaze, as detached spectators, in the privacy of their own homes. Even the textual voice remains a constant, with dialogue that 'speaks' directly to the non-afflicted and within which certain values are assumed.

The social narrative documentary features disabled people successfully fitting into a 'normal' life or achieving 'against all odds'. As the generation of thalidomide children grew up the television documentary allowed its audience to eavesdrop on the disabled person performing small tasks in an unusual way in much the same way as the *Carte de Visite* had. Admiration is invited for the inner strength and stoicism of people depicted as brave, courageous and plucky. Disabled people themselves refer to this characterisation ironically as 'super crip' (Pointon and Davies 1997:81). A sympathetic and congratulatory response is encouraged from the viewer who, from the implied superiority of their own condition, can indulge in the 'emotional enjoyment of their generous sympathy' (p.141). Reference is seldom made to social arrangements, attitudes and values and the bearing that these have on the disablement of the impaired individual (*Thalidomide: Life at 40*. BBC 2 Oct. 2002).

The medical documentary often merged scientific medical procedures with highly personalised and emotive narrative. This is illustrated in the television programme *Living Proof* (BBC 1 Oct. 1999). This series documented the unusual circumstances of impaired children and the resources employed to remedy or 'normalise' their situation, with the emphasis on a charitable, as opposed to human rights, response. For example one of a number of programmes that demonstrated the continuing fascination with conjoined twins, featured girls joined at the top of their heads, and the operation, funded by a charitable appeal, that would separate them. The

following emotive preview epitomises the merging of notions of tragedy with hope, and of spectacle with medical enquiry.

With that extraordinary adaptability of children, the conjoined twins learned to move, even to play as one, but the medical prognosis was not good. Charities in the twin's home town of Karachi raised money to send them to Toronto's Hospital for sick children, and this moving film follows the pioneering operation to separate them (*The Guardian* Oct.1999).

The impact that these ways of representing disabled people has had on disabled and non-disabled people is difficult to ascertain. Gauntlett and Hill (1999) who carried out a five-year longitudinal study, gathering data from the viewing diaries of 427 respondents, are guarded about the extent to which people's individual identities are affected by watching television.

In trying to consider the ways in which people's identities were formed and changed in relation to television, we found that in most cases any such influence would be so subtle, and spread so thinly across a broad band of time, that we could not comment on it without indulging in an unforgivable amount of speculation (p.137).

The exception was with the disabled diarists where the researchers reported people 'making connections between their personal identities and media representations' (p.133). They reported several diarists' concerns that television should 'reflect their lives in a fair and unsensationalised way' for their own sense of self identity as well as other people's perception of disabled people. Self-esteem was similarly undermined by the tenor of 'human interest' current affairs stories, documentaries and news items on disability which were designed to elicit an emotional response. The donations that were forthcoming as a consequence were resented and seen as an excuse for inadequate government funding.

Cumberbatch and Negrine (1992) see the hierarchical organisation of television and its economic structures as barriers to any change in the assumption that non-disabled is the base line criteria for inclusion across the full range of television programming. They believed it had precluded any changes in the representation of

disabled people as signifiers for a range of patronising and sentimental attitudes or stereotypical portrayals. By the end of the 1990s Gauntlett and Hill, however, are more optimistic. 'Identity politics has made familiar a list of categories – gender, ethnicity, sexuality, disability and (to a lesser extent) age which are now "up for grabs" in identity terms.' This is certainly borne out by programmes such as *Freak Out* (Channel 4 2000) and the BBC 2 (2002) season of broadcasts *What's Your Problem?* These were intended to reflect the disability experience, 'challenge traditional assumptions about the supposed markers of identity, and ally themselves instead with new social movements or new modes of everyday lifestyle' by offering what Gauntlett and Hill describe as a 'selection box' of identities and 'ways of living and being in the world' (p.132).

Channel 4's disability advisor describes how 'everyone [commissioning editors] is encouraged to "own" disability, rather than having disability programmes coming out of only one department' (Walsh interviewed by Minty:2000). She states 'we have moved away from the idea of the non-disabled film-maker peering in at the life of a disabled person some years ago. It is the disabled person's take that we are interested in'. This can be discerned in programmes such as *The Boy Whose Skin Fell Off* (Channel 4 March 2004) and *Every Time You Look at Me* (BBC2 April 2004). In the first of these programmes the subject, Kennedy, collaborated with the filmmaker to create an account of his experience of living with impairment and preparing for his death. Although it is unsparing, in that he leads us graphically through the implications of an impairment that had profound consequences, the film is nevertheless 'a celebration of a life lived to the full' (Collerton 2004). Kennedy, described as having a 'devilish humour, acute intelligence and unwillingness to suffer his fate or fools gladly', forestalls stereotypical responses of pity or perceptions of him as helpless, through his success in finding profound meaning to his life in a way that eludes many of his non-disabled contemporaries.

The second programme, a romantic drama, challenges the notion that disabled people are asexual whilst acknowledging the difficulties inherent in a relationship between two people who both have a physical impairment, not least because of their struggle with internalised stereotypical and oppressive perceptions of disability (Mickery 2004). It is described as a 'searching insight into a relationship that is both painful and liberating'. The producer, Marshall, describes how the script was written specifically for, and in consultation with, the two main characters, played by Mat

Fraser and Lisa Hammond. He states 'the most important thing was to write something inspired by the actor rather than go on a trawl for an actor that might fit a preconceived part'. Significantly it represents a commitment by the BBC of a tenth of their entire drama budget and to working collaboratively with disabled people in order to represent their lives in ways that are affirming.

These programmes are indicators of changes that have occurred in the last four years since Walsh stated her intention, in an interview in 2000, of trying to revolutionise television in terms of how they see and deal with disability (Minty 2000). She explained how this task is compounded by the need to change how television currently operates in terms of the personal recommendations, nepotism and referrals that Cumberbatch and Negrine highlighted in 1992. She described 'constantly looking at ways to push the boundaries and break new ground by finding new ideas in disability programming, new ways of including disability in mainstream programming and new disabled talent', however she admitted that 'commissioning editors under a lot of pressure to make progress on multicultural diversity, tend to make disability the second phase of the great diversity battle'. She also expressed concerns that disability was doomed to be a 'string of brave new experiments' and she was aware that the barrier that seems to prevent directors casting disabled actors in roles not actually written as disabled has yet to be broken.

Darke (2004) suggests that the 'mainstreaming of disability', the placing of disability within the mainstream of programme production, by the BBC and Channel 4, has had negative consequences for the representation of disabled people in the media. He argues that disability has not been 'mainstreamed' but rather that impairment has, with the specialist disability television programmes (which he describes as 'politicised output made by disabled people with a belief in the social model') replaced with impairment imagery which he believes more than ever is 'linked to a charity or "freak" philosophy [that is] fundamentally voyeuristic and exploitative' (p.100). He suggests that a significant depoliticisation of disability has taken place with political significance replaced by political correctness – 'the language has changed but not the politics behind it' (p.101). He describes this growing political correctness as a sanitising process which masks the fact that there is as little understanding of the 'genealogy of oppression through culture' as there has always been and that a distinction has occurred between what he describes as the

'normalised' and the 'un-normalisable' disabled person; 'the 'good' and the 'bad' cripple (disabled person)' (p.101).

In contrast Hughes (2002) sees the emergence of a post-modern change of mood, as a 'counter culture' which is

first and foremost a celebration of difference, a festival of despised identities, a coming out of all those unruly elements who refused to be purified, suburbanised, made into the image and likeness of a sterile and unimaginative sense of responsibility, and an overbearing sense of order and duty (p.578).

He describes modernity as starting to 'dissolve, or rather show signs of a condition of post modernity within itself' (p.577). 'The stranger could be cool and disorder could be interesting or pleasurable' (p.578).

### **Fashion and 'Lifestyle'**

This concept of the 'stranger as cool' was expressed in an initiative led by Alexander McQueen which brought before a mainstream audience a set of radically new and contemporary images of people with impairments. The images, which comprised photographs taken by top fashion photographer Nic Knight and which appeared in the ultramodern magazine *Dazed and Confused*, featured disabled people modelling glamorous clothes designed especially for them (September 1998 No 46). Fashion conventions, easy class distinctions, ugliness, beauty, fantasy and reality were challenged in images that were devoid of all the traditional associations that accompany representations of disabled people (see Fig 10, 11). The difficulties of disabled people maintaining such a presence in the fashion industry were, however, noted by Knight who stated

the bottom line for many companies is that fashion imagery in glossy magazines and advertising campaigns, however directional it is, is about selling clothes. With the amount of money involved becoming ever larger – tens of millions, sometimes even billions, of pounds are at stake – the industry responds by appealing increasingly to the mainstream ...anything even slightly out of the ordinary frightens people (*The Guardian Weekend* Aug. 29 1998).



Fig 10

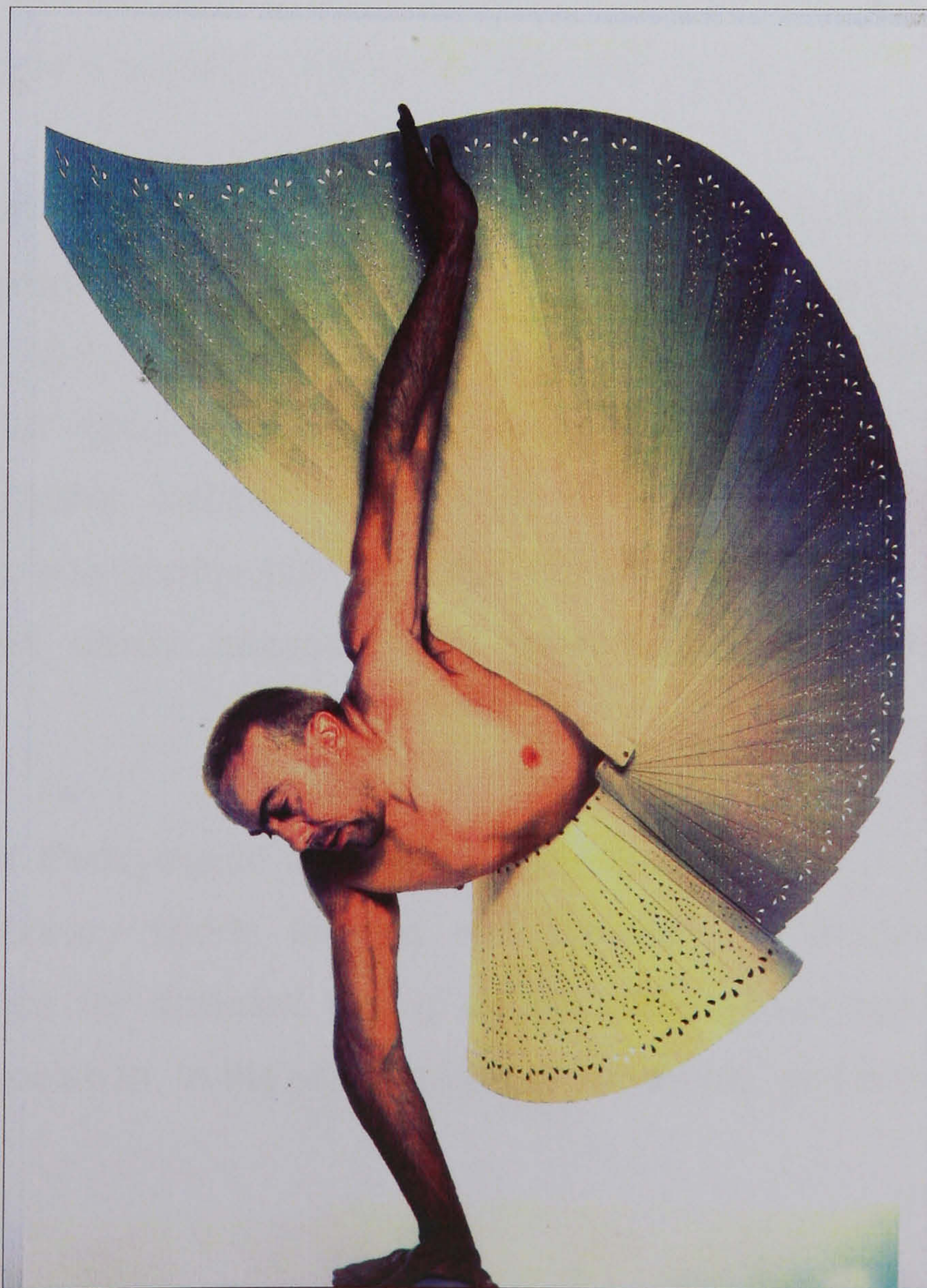


Fig 11

However, the images provided an example of how effectively disabled people, traditionally excluded from the spheres of fashion and style, could be included. It raised the profile of disabled people through cutting edge fashion wear, coverage in a leading fashion magazine and as a photographic exhibition, in the form of a large banner, in the entrance hall of Tate Modern, in the Spring of 2001.

Fashion, advertising and sport are all areas that advance the notion of 'lifestyle' in the promotion of 'commodified consumption' (Giddens 1991:5). 'Lifestyle' has taken on particular significance in modern social culture with leisure and Sport an important 'badge of identity and status in late twentieth century culture and society' (Barnes et al 1999:185). New technology has had the potential to transform the wheelchair into an aerodynamically designed extension of the athlete's body which is far removed from the conventional grey National Health Service wheelchair. This has led to a high profile and celebrity status for some notable disabled athletes (see Fig 12, 13). This notion of embodiment and the transformation of the wheelchair into a fashion/lifestyle item is described by Iwakuma (2002).

the body extends to an object, ... so that it literally becomes a part of the body. ... This extension of the bodily synthesis is a process of embodiment and this search for equilibrium also seems to be the core of adjustment by a person to his/her impairment (pp.78-79).

The basketball players were spending considerable time adjusting the basketball wheelchairs before the practice. They seemed fetishistic and particular about their chairs. A choice of colours, from dark blue to vivid pink and various models were available, and each person customised his/her fashion and identity. The players mended the chairs just as one combs hair in a specific way. ... Their obsession makes perfect sense because they have embodied their chairs (pp.79-80).

Dynamic images of Paralympics competitors like Tanni Grey are comparable with any other contemporary sports images and provide role models and celebrity prestige by inference for disabled young people. Prestigious sponsorship is also contributing, by association, to the status of disabled people, as for example in *The*



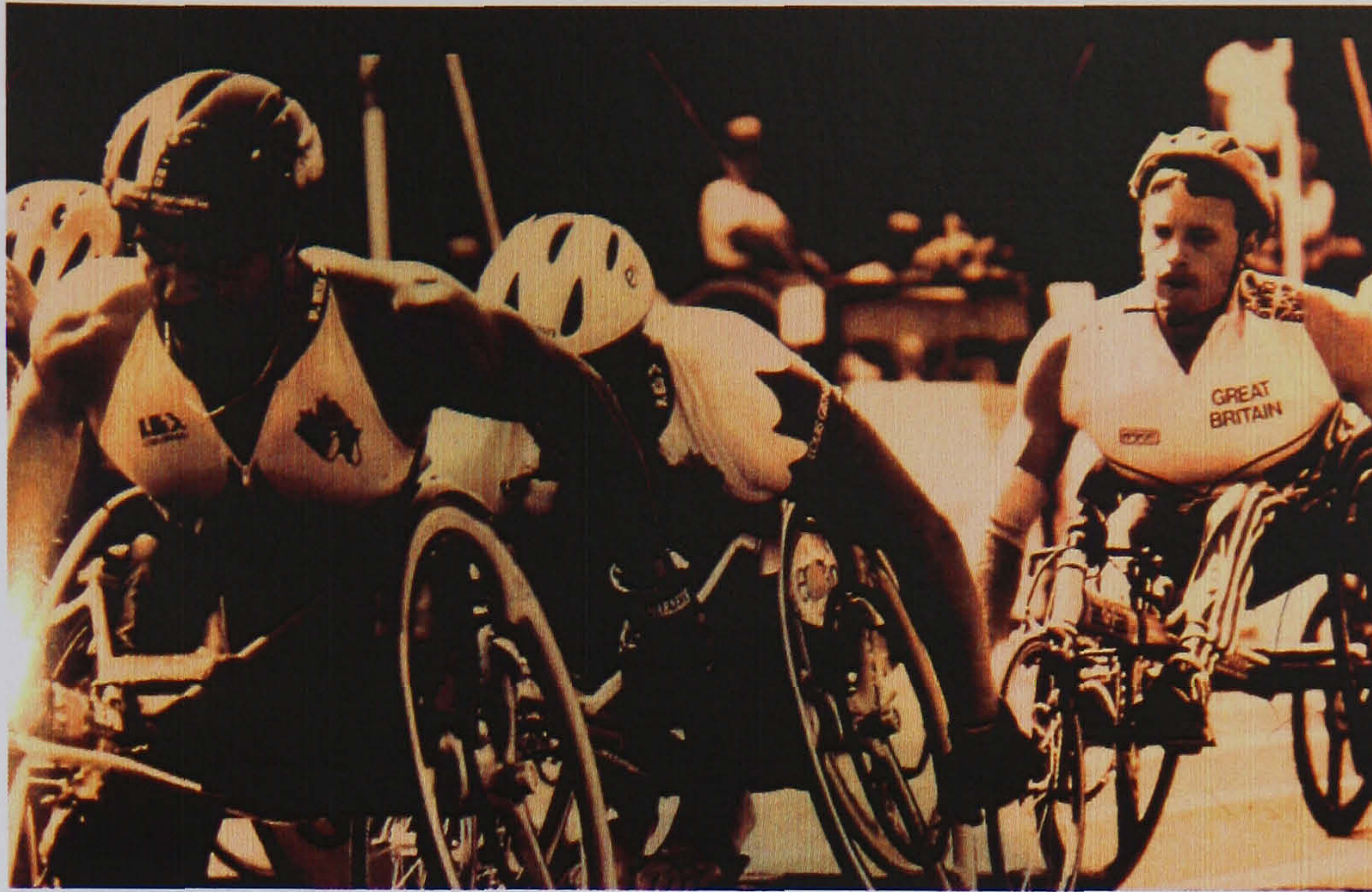


Fig 12



Fig 13

*England Disabled Football Squad and One 2 One's Football Association Charity Shield advertisement Supporting Disabled Footballers* (Channel 4. 8.August.2000).

A number of initiatives appeared at the end of the 1990s in an attempt to counter discrimination and represent disabled people more fully in advertisements. As part of a government-backed campaign a series of DfEE posters began to appear that parodied stereotypical responses to disability. One, for example ran the headline 'Kathy is hard to control', implying the stereotypical notion that disabled people are 'uncontrolled' and disconcertingly unpredictable when in fact the reference is to a stereotypical female shopping habit – 'If it's leather I have to have it' (see Fig 14). These advertisements were limited, in that the desirability of inclusion and equality was acknowledged through references to mainstream tastes and lifestyle options, but disabled people are not portrayed as simply part of that, without reference to their disability.

From 2000 onwards, a flurry of advertisements represented disabled people mainly through the expedient of including a wheelchair user (*Lloyd's Bank, British Telecom and McDonalds* January/February 2000). From 2002 the frequently seen 'link' between BBC programmes that highlighted different dancers and dance styles, has included three wheelchair dancers (see Fig 15). Most notable, however, was *Freeserve's* advertisement featuring Aimee Mullins (June 2000 Channel 4). Mullin's model potential first achieved media attention when she appeared on the front cover of *Dazed and Confused* (September 1998 No. 46) (see Fig 16). A double amputee, she had challenged conventional notions of prosthetic limbs with her glamorously realistic 'mannequin legs', complete with nail varnish. An alternative pair of bespoke carbon-fibre, curved prosthetics enables her to move with speed and grace. The advertisement for *Freeserve* created an impression of style and power by interspersing shots of a leopard running, with Mullin's appearance on the catwalk wearing a dazzling feline mane. As she moves from walking to running, the applause of the audience matches her increasing speed and confidence (see Fig 17). This inspired advertisement marked a break-through in the long history of oppressive imagery of disabled people, with a representation that recognised the strength and beauty of the whole person, providing a role model that added some much needed glamour to the representation of disabled people.

# Kathy

is hard to  
**control.**



“If it’s leather,  
I have to have it.”



See the person



Fig 14

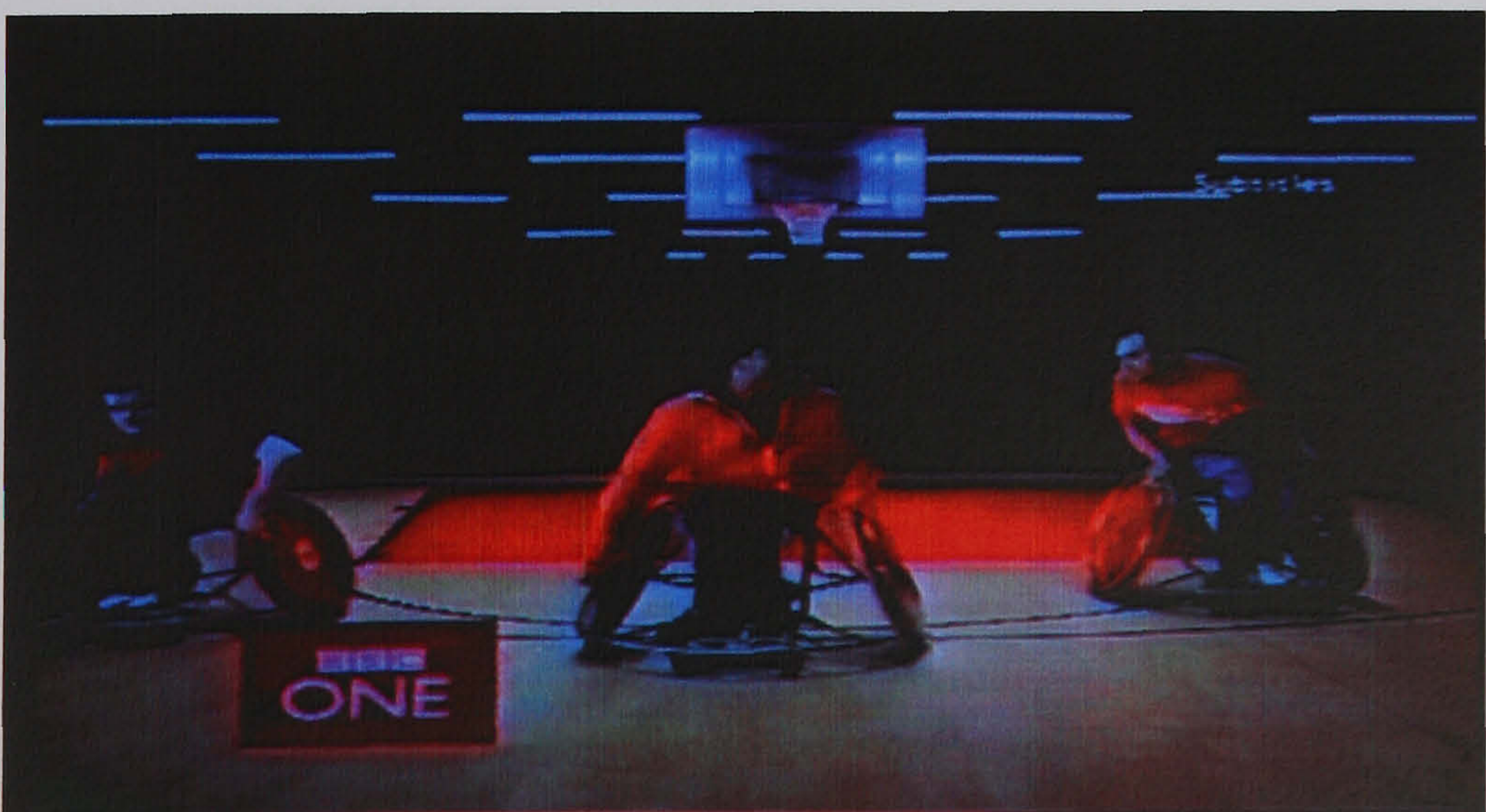
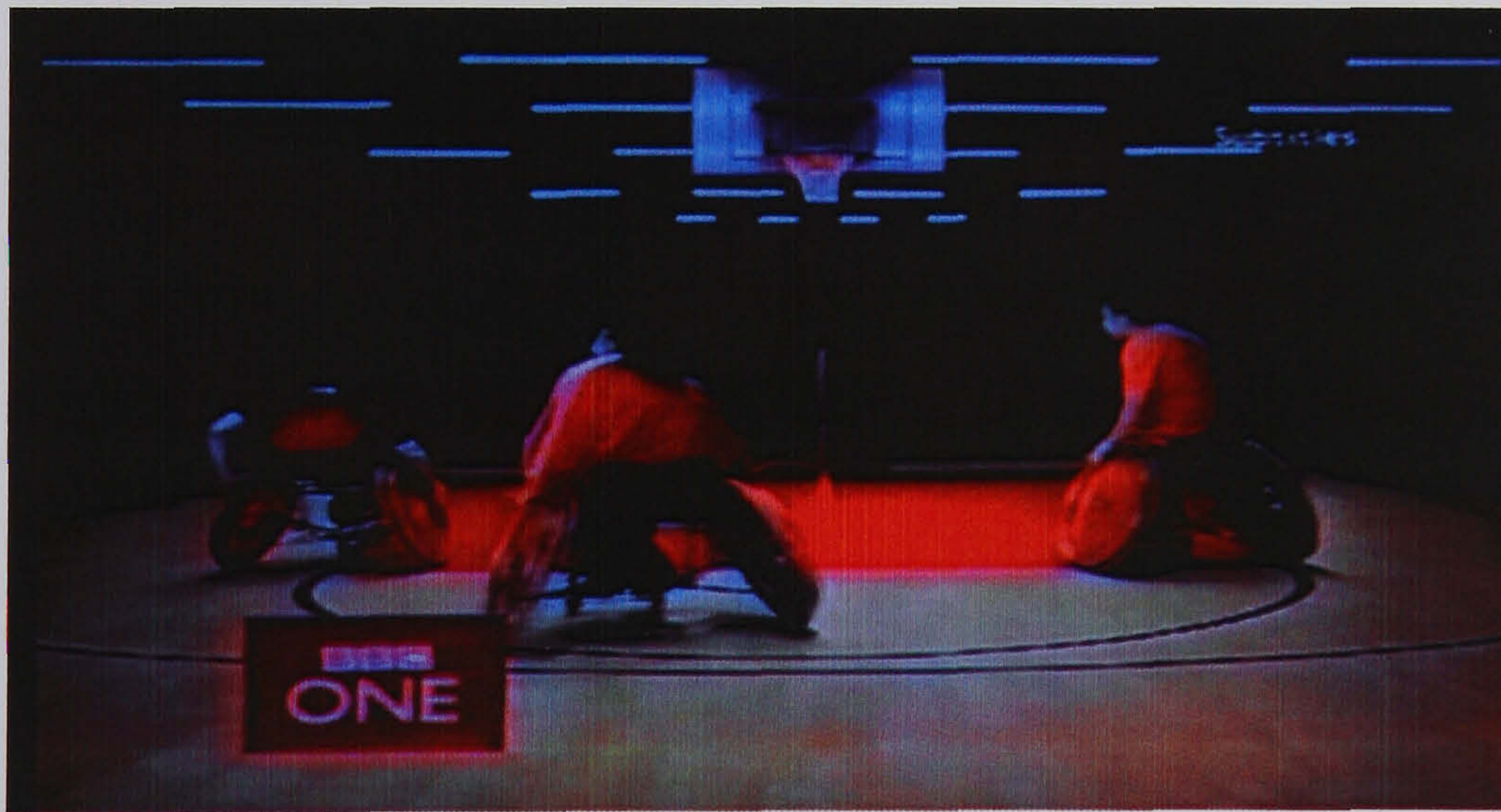
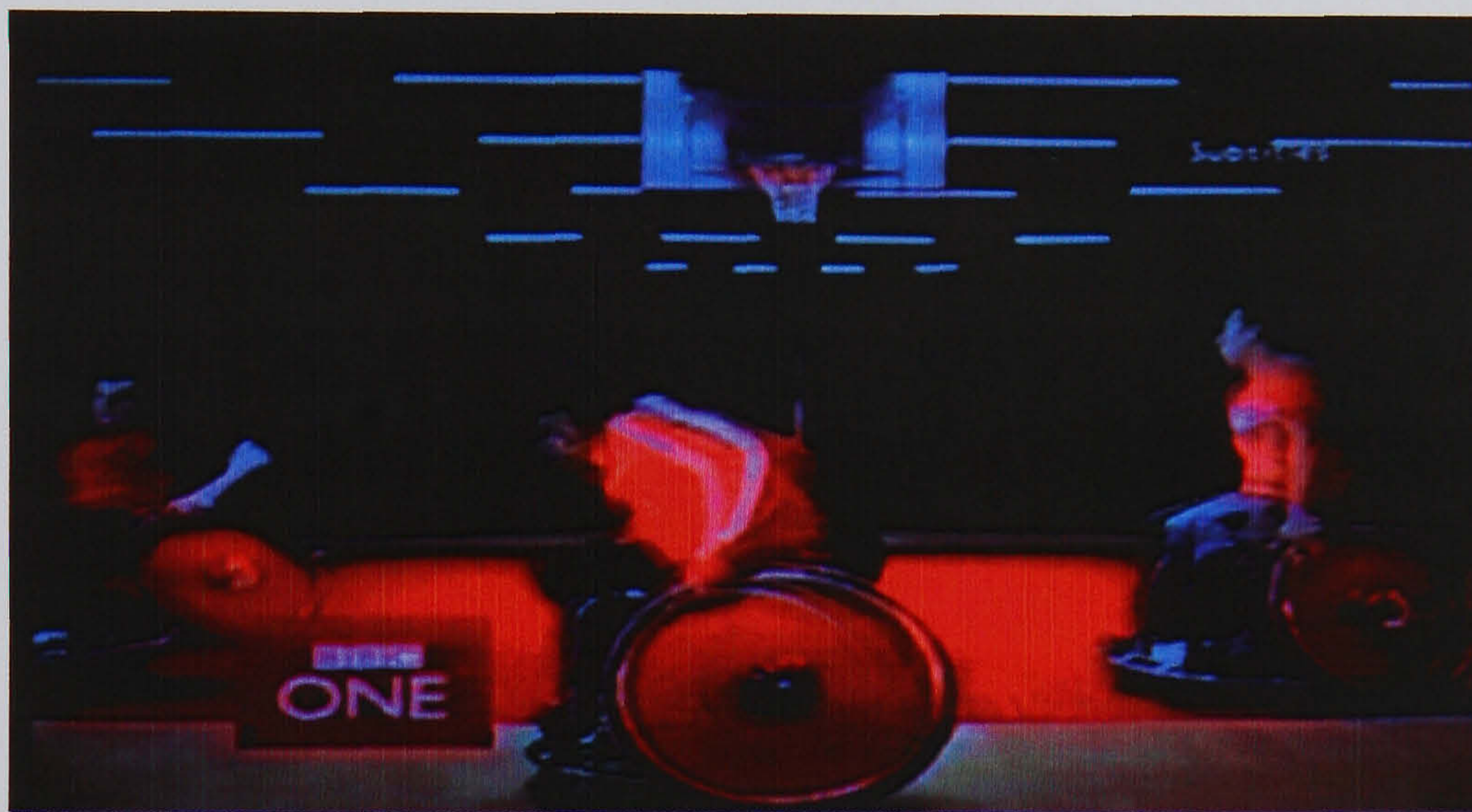
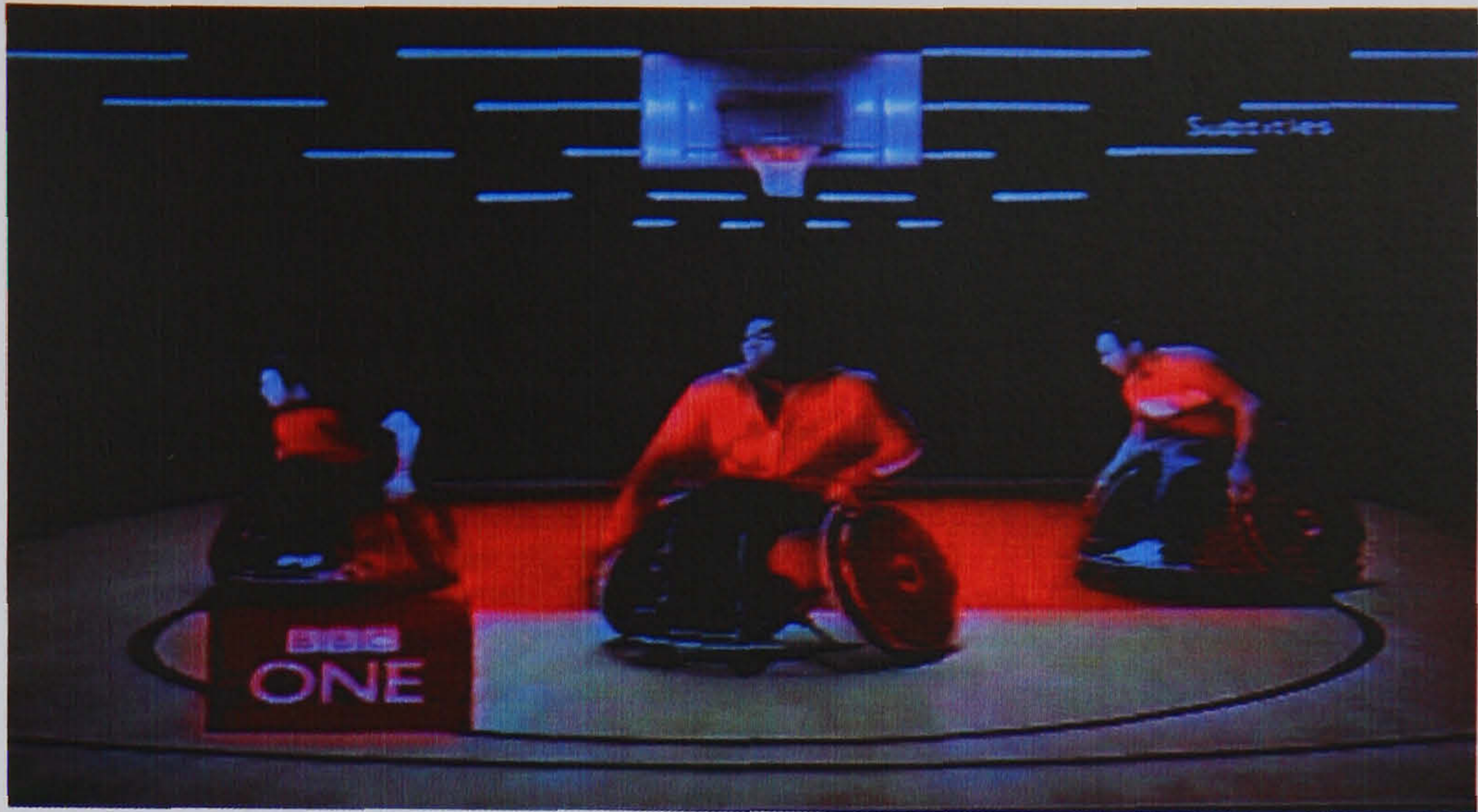


Fig 15

DAMNED

FASHION ABLE?

ALEXANDER  
MCQUEEN  
JEST  
DIRECTOR  
SERIES



Fig 16



Fig 17

The inclusion of disabled people in the advertising campaigns of big corporations acknowledged them as potential consumers and as contenders in the process of buying into an 'exciting' and 'aspirational' lifestyle. It is, as for everyone else, a mixed blessing. Celebrity has been achieved by a small but growing number of people with impairments (Mat Fraser, Aimee Mullins, Shanon Murray, Ade Adepitan) all of whom can, despite their impairments, be seen to meet conventional standards of attractiveness. Barnes *et al* point to 'the dangers of the advertising industry moving from selling the beautifully sculptured non-disabled body to selling the beautiful and sculptured disabled body' (p.196).

Darke (2004) is more emphatic in his condemnation of such notions of 'positive' images as opposed to 'negative' ones and the role that they play in reinforcing the dichotomy that he perceives in current representations of disabled people in the media, as the 'good and bad cripple scenario'. This he sees as 'the enhancement of the normalised disabled person over and above the valuation of disabled people *per se*' (p.103). He states

One has only to think of the pretty Para-Olympian or the pretty disabled ex-model or dandified karate-kicking disabled television presenters, who the main charities use in their advertising, in order to see their increasing dominance as the (stereo)type used in the "positive" representation of disabled people on television (p.103).

His concern focuses on the ambiguity that he associates with these disabled celebrities, that they are seemingly politicised whilst, he suggests, 'entirely wrapped up within the mainstream oppressive structures of media and charity alike' (p.103).

Gauntlett and Hill (1999) suggest that 'the validation of complex identities is currently acting as 'merely a spring board for the imagination', and is still in its infancy' (p.132). Hughes warns that judgement on the depth of post-modern tolerance must be qualified by the acknowledgement that there are 'still barriers, places and spaces where disabled people cannot go' (Hughes 2002 p.580). This is epitomized by the debate that has been generated in the media (March 2004) concerning whether the fourth plinth in Trafalgar Square is the 'right' place for Marc Quinn's 4.7 metre high marble sculpture entitled 'Alison Lapper pregnant', which is to be installed from the spring of 2005 for 18 months (see Fig 18).

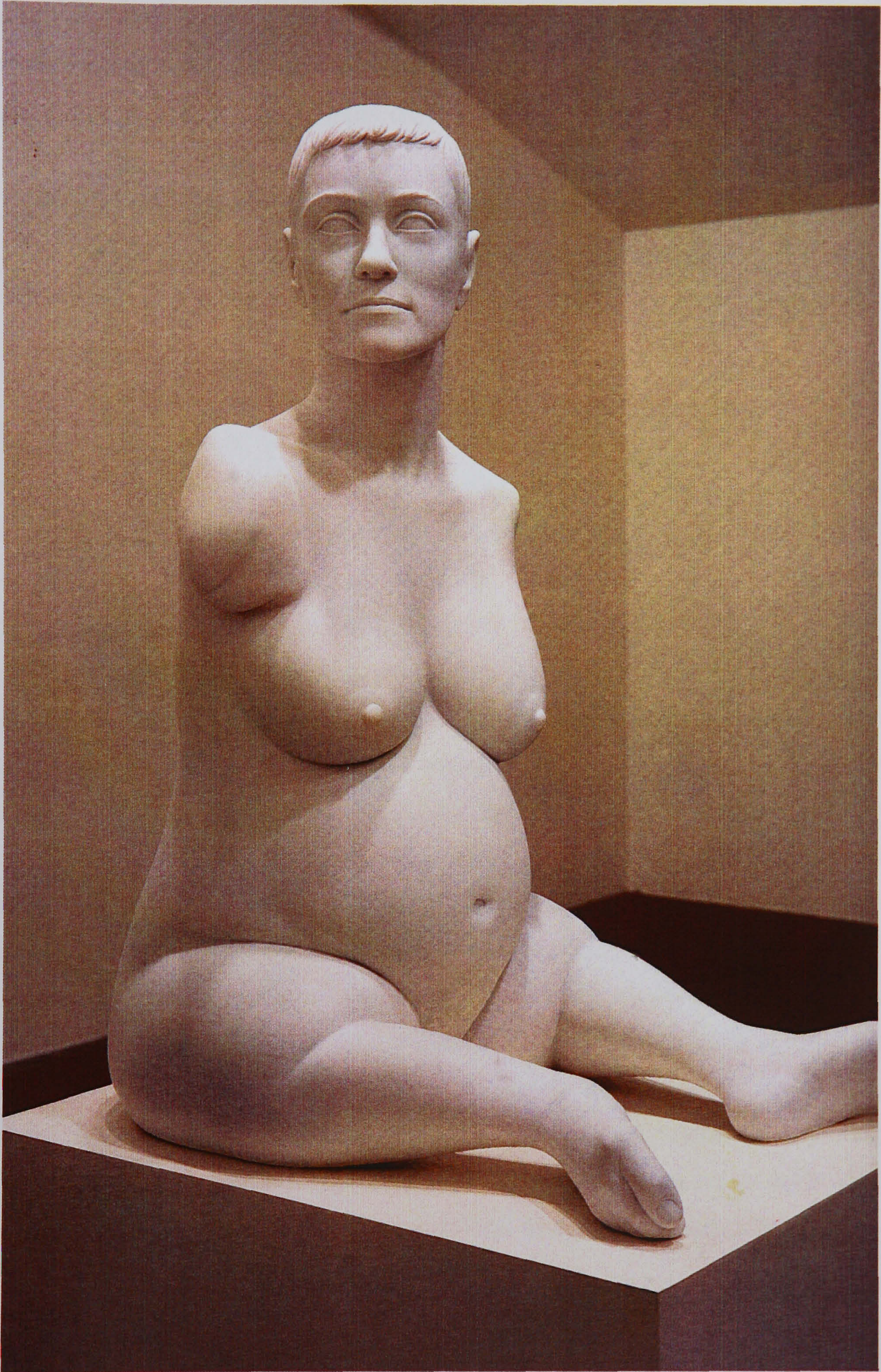


Fig 18



Quinn, a non-disabled contemporary British artist, came to prominence in the 90s with work that explored issues of the self and mortality. The use of his own body as a primary source has included the use of several pints of his own frozen blood cast in a mould of his head. Additionally he created a series of marble sculptures of disabled people born without limbs or who have lost their legs or arms because of accident or illness (Quinn catalogue 2002). Quinn explained

It was only when I saw the fragmented sculptures in the British Museum and the people looking at them that I realised that the reaction of the visitors would be the exact opposite if you had a real person like that.

Alison Lapper is one of the subjects in this series and at the centre of the controversy that arose over the decision to place the sculpture that represented her on the fourth plinth. The debate that ensued provoked media attention with Nairne, director of the National Portrait Gallery who chaired The Fourth Plinth Commissioning Group, justifying the decision on the grounds that the work has 'extraordinary artistic value and merit' (Nairne 2004). He believed that it would encourage powerful responses from Londoners and visitors and would enhance London's reputation as a leader in the visual arts. Hilty, director of visual arts and literature at Arts Council England described the work as 'consider[ing] questions of idealism, heroism, femininity, prejudice and identity' (Hilty 2004). In contrast, Hattersley in the *Daily Mail* (17 March 2004) objected that 'it is the wrong statue in the wrong place', maintaining that 'Trafalgar Square ought to immortalise the great moments in our history' as represented by its current, more illustrious occupants, Lord Nelson, Sir Charles Napier, Major General Sir Henry Havelock and George IV. Street-Porter, (*Independent on Sunday* 24 March 2004) references Thomson's comments in the *Telegraph* in which she states that the statue is rendered in a 'chillingly impersonal way' and that Lapper's own achievements as an artist 'don't get a look-in'. Street-Porter, however, suggests that Quinn has managed 'to touch on a raw nerve with his depiction of 21<sup>st</sup> century feminism'.

Quinn himself whilst drawing our attention to the scarcity of public sculptures of people with disabilities reminds us that 'Trafalgar Square is one of the few public spaces where one exists: Nelson on top of his column has lost an arm' (Quinn:2004). He states:

Most public sculpture, especially in the Trafalgar Square and Whitehall areas, is triumphant male statuary. Nelson's column is the epitome of a phallic male monument and I felt that the square needed some femininity. ... Alison's statue could represent a new model of female heroism. In the past, heroes such as Nelson conquered the outside world. Now it seems to me they conquer their own circumstances and the prejudices of others, and I believe that Alison's portrait will symbolise this. ... I realised how hidden different bodies are in public life and the media. Her pregnancy also makes this a monument to the future (Quinn 2004).

It is unclear how these contemporary representations of people with impairments will develop and cohere with the emerging cultural analyses within Disability Studies, Disability Arts, and the inclusion agenda in education. Darke (2004) argues that the representation of disabled people currently is much as it has been for the last ten years, namely 'clichéd, stereotyped and archetypal'. What is certain, however, is that mainstream producers of imagery have become more perceptive to the ways in which disabled people are represented and more committed to an inclusive approach.

### **Summary**

This chapter has traced the ways in which, as the mass media intensified throughout the twentieth century, images endorsed and emphasized the social construction of disability, perpetuating negative and oppressive perceptions which have dominated the representation of disabled people up until the turn of the century. The cultural exclusion of disabled people has been challenged by the Disability Movement and Disability Arts and the creation of alternative representations has raised the self esteem of disabled people and the awareness of non-disabled dominated, media institutions. Supported by government initiatives, new ways of representing disabled people in the mass media have begun to appear in recent years. As yet these do not represent a substantive response to the inclusion of disabled people across all mainstream cultural contexts, but rather a conscious response to the diversity agenda.

Unresolved questions of culture and identity have arisen from the social model of disability and, for the disabled young person, these have been made more

complicated by the challenges of a complex, rapidly changing and consumer driven society. The arts have the potential to provoke debate and promote changes in attitude in both non-disabled and disabled people alike, but they have particular significance for disabled young people in resisting the social identity that has been imposed on them by non disabled people. However, identity formation is complex and the following chapter examines in depth how impairment and disability impact on such processes and what factors influence the expression of identity through the visual arts.

## Chapter Three

### The Visible Voice: The development and expression of self-identity

This chapter takes a closer look at the impact that living within a social context that continues, in the main, to understand disability in predominantly negative terms, has on young disabled individuals and the difficulties they face in rejecting or embracing disability as an identifier. The powerlessness of disabled people to challenge another's construction of self is contrasted with the resistance that people with impairments effect to the identities foisted on them by non-disabled people. The importance, within these contexts, of listening to the 'voice' of disabled people themselves is emphasised and it is proposed that visual images can be considered a viable response to the concept of 'voice'. The notion of narrative, or story, and the degree of opportunity available to disabled children and young people to develop visual literacy is developed in relation to self identity and the social narrative constructs that relate to disability. This chapter highlights the two-fold difficulties that challenge disabled young people in the development of a visual 'voice', namely disabling perceptions about the nature of impairment and about the function of art.

#### Identity Formation

The question of whether disabled people know who they are

because of the fact that they have an impairment, because of the fact that they face discrimination or because of who they, ontologically, believe themselves to be is a complex one that has until recently received little attention (Watson 2002:512).

Giddens' (1991) constructionist approach describes this process of determining individual identity as evolving as a consequence of the reflexive process which we engage in throughout our lives, but which he acknowledges is multiple and fragmented. Within this process Watson (2002) maintains that choice operates in terms of whom we identify with and what we do. However Giddens notes the numerous influences on these choices.

In the reflexive project of the self, the narrative of self identity is inherently fragile. ... The task of forging a distinct identity may be able to deliver distinct psychological gains, but it is also clearly a burden. A self identity has to be created and more or less continually reordered

against the backdrop of shifting experiences of day to day life and the fragmented tendencies of modern institutions (1991:178).

Cooley (1964) suggests that in order to achieve this sense of self we are heavily reliant on the opinions that others hold about us and in his theory of human nature and the social order he suggests that without social experience the self cannot develop. Goffman's (1963) work on stigma and the notion of 'spoiled identity' is expanded by Lenney and Sercombe's (2002) research into the nature of interactions that take place between disabled and non-disabled people in a specific social context. Their conclusion is that non-disabled people operate from a constructed belief system about disability and impairment that is culturally derived and has little to do with disabled people.

Watson references the work of Hall (1996) in identifying the two historical and strategic approaches to the production of identities. The first is based on 'a shared social experience, origin or structure' through which individuals claim membership of a group distinct from the rest of society i.e. essentialism or 'a belief in true essence, that which is most irreducible, unchanging and therefore constitutive of a given person or thing' (Fuss 1989, cited in Thomas 1999a:103). This gives rise to 'the notion of a female [disabled] subject and hence a female [disabled] identity to form the bedrock of feminist [disability] politics' (Watson 2002:509). The second model for the production of identities that Watson cites denies the existence of any identity based on a shared origin or experience. The constructionist model sees the self as 'multiple and temporal' (p.511). Within this it is the production and organisation of difference that is of central concern and the idea that any 'essential or natural givens precede the processes of social determination' is rejected (Thomas 1999a:104). It is an unformed, unfixed, evolving concept that is the product of the fact that 'there has never existed a human being who has not been aware not only of his body but also of his individuality, both physical and spiritual' (Mauss 1998, cited in Watson 2002:510).

Thomas similarly draws attention to the fact that identities are 'not singular but are multiple and fractured'. There are many 'fragments' in addition to disability and impairment i.e. gender, age, ethnicity, class, sexuality that constitute identity. She cites Price (1996) and her co-authors who state that 'the boundaries of sameness and difference are not fixed but are fluid and continually in the process of

construction and maintenance through discursive practices and performativity' (p.112).

Referencing Giddens's theorising, Watson maintains that we are able to 'choose our identity, and can ignore or reject identities fostered on us as a result of ascribed characteristics'. That 'who we are, who we choose to identify with, what we choose to do are more often experienced as matters of choice' (p.511). These choices are incorporated into our 'creation of narratives about the self' which, provided we can sustain, 'maintain our sense of self' (p.511). However, there are theorists who claim that the self arises as a result of self-objectification, that a sense of self is created through knowledge about the self built up from others' opinions.

Social interaction, the link between self and society, is the substance of Cooley's (1964) theory of human nature and informs our understanding of the social order itself. According to Cooley, 'the body becomes a self only when it imagines itself in relation to others; without social experience, the self cannot develop. Social communication is thus fundamental to selfhood' (Reiff 1964 p.xix). Cooley's theory argues that the idea of 'I' is developed in response to a reflection of the ideas about ourselves that we attribute to others; an idea developed by association and communication. Hence we imagine our appearance to the other person, we imagine his judgement of that appearance and this is followed by some sort of self-feeling such as pride or self-mortification. Thus we compare and measure ourselves against the standards of our community and culture and 'respond positively or negatively to the real or imagined evaluative responses of others' (Hewitt 2001:43).

Burns (1992), in his analysis of Goffman's work, states that 'we confer a "social identity" on an individual on first acquaintance. He states 'we assign him, on the evidence immediately available - principally his appearance, the social setting and nature of the encounter - to one category or another' (p.216). It is through this process of categorisation or 'grading', this 'aesthetic scaling of bodies', that Young suggests we place an individual on a hierarchy of 'humanness' and that life chances are defined and to some degree determined by that scale (Young 1990 cited in Corker & Shakespeare 2002:12).

As has been noted in the first two chapters of this study, the 'meaning' of disability is embedded in society and reproduced for disabled and non-disabled people alike.

Burns (1992) references Goffman's concept of the 'stigma trap' and the fact that critically:

the stigmatised individual shares the beliefs about identity and normality, of the "normal" beings he encounters. Those who carry their stigma from birth learn about their disadvantaged situation at the same time as they learn about the standards that define it as such, and through the same socialisation process (p.218).

He draws our attention to the 'notion of non-acceptability' and the 'extent to which judgements which relegate individuals to an inferior category of human beings are essentially moral judgements' (p.217). Burns suggests that the implications in learning these identity beliefs, which prevail in society at large, are that the stigmatised individual also actually acquires them or adopts them. Work carried out with disabled children by Davis and Watson illustrates that:

some forms of bullying carried out in "special schools" involve disabled children utilising adult abelist discourses against each other and that very often these discourses relate to ideas concerning hierarchies of impairment (2002:163).

Corker and Shakespeare (2002) cite this hierarchy for dividing people, 'through deep linguistic structures' into two states, impaired and 'normal,' with the latter as privileged (p.9). A dilemma then arises for the impaired individual of 'how far to go in identifying himself with those who share the same stigma' (Burns 1992:222). This is amplified by Corker and Shakespeare.

'The entire concept of identity takes place through the repression of impairment, in such a way that people with impairments cannot affirmatively identify with others like themselves' (p.9).

Ambivalence is the outcome, when stigma carries the perpetual threat of non-acceptance among normal people. 'This ambivalence shows itself typically in an oscillation between identifying with his "own" in general, or with those less obtrusively stigmatised and relatively normal. In brief, he can neither embrace his group nor let it go' (Burns 1992:222).

Lenny and Sercombe (2002) sum up the powerlessness of such a position in their research into interactions across difference in a public place.

The capacity to challenge another's construction of "self" is a function of power. Consequently, people with disabilities are often at the mercy of the other's construction of what it means to have a disability (pp.5-18).

Lenny and Sercombe's research explores the nature of the interactions that take place between disabled and non-disabled people. Whereas most research in this area has focused on the way that people with disabilities are de-humanised during the interaction process, they, in contrast, explore the possibility that non-disabled people are unsure of how to interact with disabled people. Their findings led them to identify several themes that they perceived to be in operation in these interactions, which were conducted in a public place with a young man with cerebral palsy who is non-verbal. They named these themes; 'the chosen one', 'public education', 'pity or tragedy', and 'sexually safe'.

The reasoning behind these approaches encompassed quasi-spiritual associations, the opportunity for a public demonstration to show other people that a disabled person is 'safe' to interact with and feelings of pity towards the person with a disability producing a concomitant obligation to interact. Lenney and Sercombe discovered that everyone who interacted with the disabled participant did so out of a frame of belief that actually had very little to do with that participant. They observed that the disabled participant who was limited, in this instance, in his capacity to give real feedback, became 'a clean sheet on which thoughts about disability, human life and the universe in general can be written' (p.16). It is this constructed belief system, based upon cultural and life experiences including dominant ideologies, that people draw on when interacting with others who are perceived to be different from them.

They describe this interaction as a process of negotiation, where the 'other', can actively feedback acceptance or rejection of the construction being used. However, they acknowledge that power differentiation in such encounters is critical, particularly when direct communication is impossible. They reason that if public awareness of disability correlates with favourable attitudes then interaction between non-disabled people and people with disabilities should be enhanced by closer contact and that



this premise has been the rationale behind the policy of placing people with disabilities into the community setting. They point to the success of positive individual interactions taking place between non-disabled and disabled people as the foundation for successful integration. However, they suggest that strong evidence supports the conviction that community acceptance has not developed as human service professionals had hoped it would. 'The literature indicates that interactions between people with disabilities and people with able bodies continue to take place using socially constructed codes couched in negativity' and that 'people with disabilities certainly continue to be aware of them' (p.6).

Thomas (1999) and Reeve (2002) refer to these negative attitudes as the 'psycho-emotional dimensions of disability'. Reeve defines this as a 'form of disabilism [that] undermines the emotional well being of disabled people and [that] can be just as disabling as structural barriers' (p.493). The emphasis, she states, within disability theory has been on 'socio – structural' barriers or the public experience of oppression. The 'cultural and experiential dimensions of disability' or the more personal experience of oppression have been ignored (p.494-5). The profound effect that this can have is summed up in a quote that she uses from Barnes *et al* (1999). 'Dealing with anger, self-loathing, and daily experiences of rejection and humiliation are amongst the hardest aspects of being a disabled person' (p.493). She defines the psycho-emotional dimensions of disability as the emotional response that disabled people have to being excluded socially; to the social response of other people such as being stared at; and to internalised oppression in which the notion of inferiority, is built into the mind of the disabled person. She states 'internalised oppression relies on disabled people internalising the prejudices and stereotypes held by a non disabled majority' (p.496).

### **Foucault's Disciplinary Power**

Foucault's concepts of how the body has been constituted with respect to power have particular relevance to the theorising of a sociology of impairment. He describes the 'pervasive disciplinary power' of continuous scrutiny which affects a process of self surveillance whereby behaviour is modified in the attempt to become more acceptable (Reeve 2002:496-497). 'Foucault provided a definition of power as being induced in the body and produced within every human relationship with "relations of power" being the key point' (p.496). Rather than being seen as 'localised in the hands of one person', a sovereign power, it 'permeates throughout

[society] with individuals being the vehicles of power not its application' (p.496). This shift produces what Foucault sees as a 'pervasive, disciplinary power' which 'classifies and documents individuals and places them under continuous surveillance' (p.496). An example is the disciplinary power of the gaze by which 'the object of the gaze becomes known to the viewer, and the observer gains expertise and control over those being gazed at' (p.498). Shakespeare (1994) likens the gaze that is directed at disabled people to that which women receive in a process of objectification in which 'her [a disabled person's] own sense of being in herself is supplanted by a sense of being appreciated as herself by another [non-disabled person]' (p.288). This can leave the disabled person feeling 'ashamed, vulnerable and invalidated' (Reeve 2002:499). The disciplinary power turns its subjects into objects of power/knowledge. Reeve (2002) states:

Foucault developed the concepts of power and knowledge to show how knowledge makes people subjects because they make sense of themselves (and others) by referring back to various bodies of knowledge (p.497).

To expand on the notion of being observed and to advance the concept of self-surveillance, Reeve refers to Foucault's Panopticon. He devised this model for describing the experience of living 'in permanent, potential visibility', an experience which leads to the 'internalising [of] the scrutinising gaze', and effective and efficient self policing by the individual (p.500). Reeve states,

Self-surveillance is therefore linked to the gaze – people develop an awareness of how they are seen through the gaze of another and then modify their behaviour via self-surveillance to attempt to make themselves more acceptable (p.500).

She describes self-surveillance of the body as affecting everybody in a society that considers 'healthy' and 'unhealthy' as markers of moral worth, but for those with impairments it can constitute a critical and oppressive aspect of daily existence. Failure to carry out 'self-surveillance tasks' and render differences from the norm invisible is considered unacceptable or further evidence of the individual's abnormality (p.500). Reeve draws attention to the fact that the unconscious level at

which this operates makes it very difficult for the individual to identify and challenge it.

### **Resistance to an Ascribed Disability Identity**

The experience of psycho-emotional disablism is not, Reeve states, inevitable suggesting that 'the possibilities of radical resistance of 'individual agency' and the individual's capacity for 'autonomy, reflexivity and critique' should not be underestimated in their potential for emancipatory action' (p.497). 'Resistance emerges out of and in opposition to power', and were referred to by Foucault as 'technologies of the self' (p.501). Davis and Watson (2001) demonstrate that this resistance can be present from an early age. 'We soon came to learn that, whatever the physical impairment attributed to a child they were capable of exhibiting agency and resistance' (p.163). They suggest that disabled children 'resist the imposition of identities founded on notions of impairment, the everyday value systems of other children and adults that differ from their own; and the processes of organisation which structure their lives' (p.170). They draw attention to the heterogeneity of disabled children and to the fact that whilst some resist internally, an example of which might be withdrawal, others resist overtly and this might take the form of verbal and active resistance.

Their research emphasises the need to acknowledge that disabled children do not constitute an homogeneous group. Children who experience the same impairment do not behave in the same way, although many of the children that they interviewed described how people 'only saw them in terms of their impairment' (p.166). The capacity that many children have to 'resist identities foisted onto them by others' is seen as various and individual and situated in both locality and time (p.166). Importantly, they make the point that 'we need to understand the complex web of issues that underpins disabled children's behaviour and the complex identities that lie within each child' (p.170). They see as unhelpful the maintenance of a fixed characterisation that 'writes out the diversity of their lives' and implies that they all 'simply experience the same forms of oppression' (p170). They maintain that the children they worked with were 'neither solely the victims of impairment, nor ... always silent victims of a society that is structured so as to exclude them'. They did, however, comment that, 'we often encountered angry children both in and out of school' (p.171 and p.170).

Watson (2002) reached similar conclusions, concerning resistance to constructions of the self, in his research with twenty eight adult disabled people. Despite daily experiences of oppressive practices, only three of the disabled participants in his research sample incorporated disability within their identity (p.514). This led him to the belief that 'many disabled people do not see themselves as disabled and do not identify as disabled people' (p.509). He cites a variety of ways in which resistance to cultural perceptions of disability, and rejection of impairment, occur. For some physicality is sidelined with the emphasis instead on what the individual can do. In the instance where something can't be achieved, the causes were perceived as being societal and environmental in origin. Whilst the self is, of course, embodied, in that it is through the body that the individual is able to prove to others that identity is not determined by impairment, identity becomes disembodied. The self, Watson describes as 'constructed away from the body' (p.514). In this way the narratives that others hold about impairment and disability can be rejected and challenged and through an interpersonal and social process, the ideas of others can be adjusted to fit with the individual's own idea of self-identity.

Watson's research also found that the idea of normality, 'of leading a normal life', of 'just getting on with things', was present in many of the participants' responses (p.514). Being impaired was 'a fact of life' for many of the informants, it was perceived as an everyday condition that, as such, did not impinge on their sense of self. They had created a biography that incorporated their impairment into their sense of identity in such a way as to normalise the impairment. In this way an explanation of difference from others is not sought so much as others difference from them. Watson makes the point that it could be considered that, 'through a denial of disability and impairment they are rejecting and distancing themselves from other disabled people and are merely 'reproducing disablist practices' (p.520). However he maintains that they are taking choices and actions despite social constrictions and this includes distancing themselves from the potent image that society holds of disabled people as weak and disempowered. Instead they are creating an idea of themselves, for themselves.

Being disabled for many of Watson's informants was not about 'celebrating difference or diversity' (p.521). The individual did not see him/her self as different and disabled. They did not take pride in a disability identity. Watson states that one interpretation of this could be that they were not 'subverting stigma, taking a negative

appellation and converting it into a “badge of pride”,’ (Shakespeare 1994, cited in Watson 2002:521) but were ‘reinforcing a stigmatised image of disability by denying they [were] part of that’. In this sense these disabled people were in effect ‘stigmatising themselves’. By not ‘self identifying as disabled’ they could be described as living in a state of ‘self alienation and inauthenticity’ (p.520). However, Watson maintains that it could be equally reasoned that ‘they [were] not reinforcing oppression, but trying to make difference not matter’. They were ‘defining disability in their own terms, under their own terms of reference’ (p.522). Who, he queries, is being the more radical: those who reject disability as an identifier or those who embrace it?

### **Identity and the Artist**

The stereotypical identity of the artist as someone that challenges convention is an attractive one for disabled people to identify with. Shakespeare (1994:296) refers to people with impairments as ‘the ultimate non-conformists’ - the artist is also synonymous with resistance and the romantic role of exile. Traditionally, the artist shuns material wealth and would not compromise his/her ideals for recognition of his art which furnishes him with a life long *raison d’etre*. The artist’s ‘special gift’ is believed to be inherent and their ‘difference’ from humdrum society is tolerated because of their unique perception of the world. The contemporary novelist Coetzee (2002) however, suggests that the artist’s position conceals the hope for ultimate recognition.

For he will be an artist that has long been settled. If for the time being he must be obscure and ridiculous, that is because it is the lot of the artist to suffer obscurity and ridicule until the day when he is revealed in his true powers and the scoffers and mockers fall silent (p.3).

It is even anticipated that the artist will look different from ‘ordinary’ people, something that does not detract from but enhances their status. Grayson Perry, winner of the 2003 Turner Prize, is uncompromising in appearing as his alter ego Claire, an idiosyncratic and eccentric persona that has become an extension of his creativity and reflective of postmodern and radical perspectives on the notion of identity. Price and Shildrick (2002) state

the trajectory within postmodernism has been to fragment the concept of identity in general and to substitute a fluid, shifting notion of a process of becoming that defines neither its own corporeal boundaries nor a fixed concept (p.62).

They set this fluidity against what they describe as ‘the ingrained tendency for disabled activists and scholars to claim a clear set of identities as disabled people’. The artist as non-conformist, in whatever guise, makes it an identity that can be mapped effectively onto the ‘difference’ that impairment represents and, as such, offers an important role model in the quest for individual personal identity that challenges the disabled adolescent.

### **Adolescence and Disability**

This identity dilemma is at the heart of the transition to adulthood that disabled adolescents and young people, the subjects of this research study, experience. The process of adolescent individuation is completed when ‘the confluence of physical, cognitive and social aspects of development and the ensuing crisis of self-concept are satisfactorily resolved’ (Dusek 1987:370). Kroger suggests that adolescent individuation is complete ‘when one can return to parents in a new and equal relationship’ (Kroger 1996:74). To demonstrate this can pose obvious difficulties for disabled young people and particularly for those with high level support needs, and, where it is achieved, can take longer than the teenage years and may continue into the early twenties and beyond. The achievement of adult status, against the traditional criteria of paid employment, independent living and sexual relationships, is fraught with difficulties and uncertainties and, in addition, and like their non-disabled peers, they must also encounter the phenomenon that Cushman describes as the ‘empty self’. In the absence of community, tradition and shared meaning, Cushman describes the contemporary sense of ‘I’ that has arisen for adolescents and adults alike as ‘experie[n]c[ing] chronic emotional hunger’. This, he states ‘attempts to be soothed, to be “filled up” by consumer products, advertising and psychotherapy’ (Cushman 1990, cited in Kroger 1996:3).

Social science research into issues of adolescent development began to expand at the beginning of the 1990s, but within this burgeoning literature there is little that investigates the impact that impairment and disability has on the adolescent’s developing concept of self and the phases of the individuation process. There is no

reason not to assume that disabled adolescents, in addition to issues of impairment and disability, are not subject to the same factors in this process as their non-disabled peers. Some of the more important of these have been identified as parental influence, child rearing techniques, social class influences, maturational influences and cognitive influences all of which are, in themselves, coloured by impairment and disability (Dusek 1987:385 –397).

Adolescent estrangement, the struggle he/she has in order to find himself and his place in society', is made more critical and complex for the disabled adolescent by virtue of practical, material and attitudinal factors (Kroger 1996:4).

Dependence on others for physical care needs when, as is so often the case, the primary care providers are parents, financial constraints, access issues, transport and social isolation makes 'the adolescent process of shedding family dependencies,' a difficult one to achieve (p.53). In addition the disabled adolescent has to meet in a particularly critical way the crisis of body image that Matteson (1975) describes as 'usually the first of the identity issues to be experienced (by all adolescents), although it is not necessarily the first to be resolved' (p.138). He describes the early adolescent question 'who am I?' as invariably bound up with the body. Although he concedes that 'many adults – perhaps most adults - in our culture have not accepted their own bodies', he cites healthy identity formation as including an affirmation of one's unique body.

### **The Body as a Central Construct of Self Identity**

A primary influence on the identity and self-esteem of disabled young people is perceptions of physical normalcy. Wendell 1996; Seymour 1998; Morris 1998 and Burkitt 1999 describe how the body maintains its cultural centrality in terms of its impact on the construction of self-identity and the ways in which concerns about race, gender, sexuality, nation, the impaired body and technology are reflected in representations of the body and the body politic. Wendell describes 'disciplinary practices of physical normalcy' which, derived from a Foucault model, she likens to the disciplinary practices of femininity and which she presents as 'internalised by most of us, and socially pervasive' (Wendell 1996:88). Such disciplines of normality she posits as preconditions for participation in every aspect of social life. Children she characterises as being acutely aware of the requirements of normality and of

setting and enforcing from an early age by teasing, taunting and social ostracism, 'standards in body size, carriage, movement, gesture, speech, emotional expression, appearance, scent, ways of eating, and especially control of bodily functions' (p.88). Those of us who can learn to be, or seem to be, 'normal' do so, those of us who cannot meet the standards of normality, usually achieve the closest approximation we can manage' (p.88). The consequences of failing to meet such standards or the stresses involved in concealment and secrecy, she identifies as being 'manifested in shame and self-hatred' (p.88).

For the disabled person this understanding - of the processes in force which have in conscious and non conscious ways influenced and moulded their perceptions of themselves - needs to extend to the powerful media messages that are promoted as part of popular culture. Wendell (1996) describes the cultural idealisation of the body as 'related in complex ways to the economic processes of a consumer society' and relating not just to appearance but to an expanded market which includes 'ideals of strength, energy, movement, function and proper control'. She describes these as 'unnoticed assumptions for those people who can meet (or approximate to) them,' but as 'leap[ing] to the foreground for those who are sick or disabled' (p.86). As such these ideals constitute a threat to the self-esteem of disabled people unless they can be identified and extracted from dominant narratives and understood and addressed in the personal establishment of a positive self identity.

Popular culture, which Morris (1998) describes as 'the image - saturated discourse of television, film, advertising and commerce', with its focus on youth and the pursuit of beauty, strength and speed, has never been more observable.

Never before in history have images of real people who meet the latest cultural ideals of beauty, health and physical performance been so often presented to so many people (Wendell 1996:86).

It impinges on us all relentlessly with images that circulate through the popular media and insistently define the attributes of what is considered to be the beautiful, desirable and thus acceptable body. Wendell makes the point that the diversity of real human bodies is driven out by the conflation of these body ideals with our concept of what is physically normal (p.86). Morris (1998) states that:



with the sphere of social life imploded, with politics reduced to fund-raising and the clash of special interest groups, utopia in the post-modern era has, in effect, transferred its location to the solitary, private, individual body. Self and body have become identical, so that paradise on earth now requires simply the glowing, gym fit look revered in Hollywood as the perfect size ten (p.137).

The processes that the disabled person must engage with, in order to develop, articulate and assert his/her own 'story' as valid against those already circulating within the dominant culture are, therefore, doubly complex.

Meaning ascribed to the body is central in the process of self-presentation. 'The body is seen as "inscribed" (the verb rarely varies) with whatever meanings, shapes and constraints the dominant social discourses of the day imprint upon its surface' (p.146). Morris describes these as the scientific, medical and cosmetic interventions of increasing sophistication that, with the addition of diet, exercise and cosmetic enhancement, dispel the notion of a body that is 'fixed' and allow for an individual fashioning of the self (p.138). Seymour (1998) similarly describes modern consumer society as inviting us to celebrate the possibilities of pleasure derived from a cultivated and enhanced embodiment (p.v). Morris refers to the 'utopian images' of bodily health that dominate popular thought creating the cultural paradox that denies the realities of ageing, illness and impairment. Bodies are 'reinvented strictly as objects of vision' (p.137).

This cultural preoccupation with the perfect body as a project that the individual undertakes elevates the appearance of health and fitness to a moral statement. Those whose bodies cannot possibly conform and are resistant to such efforts, will, Morris asserts, 'register as vaguely disreputable signs of personal defeat, too often met with silence and denial' (p.159). Wendell refers to this 'myth of control' as 'the belief that it is possible by means of human actions to have the bodies we want and to prevent illness, disability and death' (p.93). She refers to the illusions about safety and control that people maintain in the belief that 'bad things' can be accounted for within the actions, specific or moral, which those who are afflicted have perpetrated and which consequently can be avoided by others in the adoption of 'correct' behaviours (p.107).

Wendell (1996) describes the disciplinary power that drives the cultural idealisation of the body as 'invested in everyone and no-one in particular', as not enforced by anyone in particular but appearing to be natural or voluntary and as something 'peculiarly modern' (p.88-87). Morris (1998) acknowledges the damage inflicted on individuals by our 'cultural fantasies of bodily perfection' (p.160) and Middleton (1999) reports 'a common mixture among the [disabled] students, of low self esteem and an acute, arguably unhealthy preoccupation with bodily image' (p.2). Seymour (1998) notes this increased susceptibility of the body to stigmatisation as a consequence of the multitude of stylised images of the body that consumer culture provides (p.31).

In conjunction with this obsessive cultural preoccupation with the body as a measure of aesthetic excellence, the body of the disabled child and young person has also been the focus of anxiety, of medical inspection, of attempts to alleviate the impairment and also, of attempts to 'convert them into 'normal' subjects' (Seymour:v/vii). Middleton's (1999) research indicates that students had experienced 'an excessive concentration on their body and its imperfections during childhood' (p.8). This concentration also inculcates the notion of embarrassment and shamefulness that is associated with the failure or disruption of parts and functions of the body. In a society in which, Seymour states, the body has become the metaphor for 'mediating the tensions and insecurities of modern life', 'difference', therefore, is equated with crises and disorder in society (p.19). This impetus to conceal evidence of the body's vulnerability Giddens describes as

the sequestration of experience [which] means that, for many people, direct contact with events and situations which link the individual life-span to broad issues of morality and finitude are rare and fleeting (1991:8).

In complete contrast to the taboos that operate to conceal unusual and unacceptable features of appearance and body function, sexuality, relationships and suffering from the public sphere, is the contradiction that Morris (1998) refers to as the 'unspoken rule of post-modern confession that nothing is unmentionable' (p.63). He describes the ways in which 'once stable categories such as gender and sexuality' (and I would suggest increasingly, notions of bodily normalcy) have 'come under pressure from discourses and images ordinarily either suppressed or located at the margins of

culture'. Swain and Cameron (1999) describe the process of 'coming out' or the self declaration of belonging to a devalued group within society that some disabled people effect, as a response to the pressures 'to pass as normal or to aspire to some approximation of normality, on non disabled terms' (p.68). Barnes and Mercer (2003) describe disabled artists as deliberately adopting a tactic of 'outing' impairment in response to the social conventions that impairment should be kept hidden (p.107) and a comparable process of coming out is described by Bovey (2000) in which the implications for women of being fat in a culture that values thinness are considered.

### **Constructing the Embodied Self**

Giddens (1991) defines self-identity as, 'the self, reflexively understood by the person in terms of her or his biography' (p.53). He refers to the, 'reflexive project of the self' in which self-identity becomes a 'reflexively organised endeavour' (p.5). Seymour (1998) similarly refers to 'the process in which we all engage throughout our daily lives in constructing the embodied self'. The making, unmaking and remaking she describes as 'on - going activities' (p.xiii). It is the adequacy of this biography or narrative, linked, Giddens suggests, 'fatefully' to the appraisal of others through the attentions of early caretakers that determines the levels of self esteem and confidence of the individual (p.38). It is also dependent on the individual's capacity or opportunity to 'keep a particular narrative going' and must integrate events which occur in the external world and sort them into the ongoing 'story' about the self. He states 'in order to have a sense of who we are, we have to have a notion of how we have become and of where we are going' (p.54). He describes how each of the small decisions made by a person every day, need to be decisions 'not only about how to act, but who to be' (p.81).

The notion of 'voice' is linked with that of tale or story in the sense that 'different individuals construct their worlds in the way that storytellers construct their narrative' (Clough and Barton 1998:9).

It is through narrativity that we come to know, understand, and make sense of the world, and it is through narratives and narrativity that we constitute our social identities, (all) of us come to be who we are (however ephemeral, multiple, and changing) by being located or locating ourselves (usually unconsciously) in social narratives rarely of our own making (Somers 1994, cited in Thomas 1999b: 49-50).

In her critique, *'Narrative Identity and the Disabled Self'*, Thomas offers an analysis in which three of the four dimensions of narrativity that Somers identifies are relevant to the 'visual' voice. Ontological narratives are used to define who we are and therefore determine how we will act. These are formed in response to social narratives, defined as public narratives and metanarratives.

Thomas lists a number of public narratives, (those narratives, cultural and institutional, which are larger than the 'single individual') which are of particular relevance to disability and impairment as, for example: the 'personal tragedy' story, the 'lives not worth living' story and the 'shame of the imperfect body' story (and its opposite the body beautiful narrative.) Metanarratives, or the 'master narratives' in which we are 'embedded as contemporary actors in history,' (progress, decadence, industrialisation, enlightenment etc) and which Thomas describes as 'encoding sociological theories and concepts', usually operate beyond our awareness. She describes the metanarratives of importance in the context of disability as 'the grand narratives' which underpin the disablist public narratives listed above, involving as they do, the very demarcation of what it means to be impaired (the social construction of impairment) to be a 'whole' or 'less than whole' human being and thus to be an acceptable member of the community (pp. 49-54).

Social narratives remain stacked against the disabled individual's endeavours to develop an authentic ontological narrative. The Disability Movement has significantly influenced public perception in the establishment of a collective voice for disabled people, but the processes of revelation and skills acquisition needed to articulate the disabled individual's voice and story and to express it coherently and forcefully, are complex and frequently inaccessible. Educational provision for disabled children and young people should inform, encourage and facilitate the development of personal narrative and self-identity.

Seymour advocates 'encouraging disabled people to be empowered in this process - to be aware of this process and to gain control and ownership' (p.xiii). Disability articulated competently by disabled people themselves may provoke reflection on the body and also present opportunities to perceive the body differently and in less restrictive ways.

The anarchy of the disabled body, may provide respite from the tyranny of the body which is continuously produced by means of unlimited consumption of goods and services (p.5).

### **The Visible Voice**

If, as Cooley (1964) states, the self cannot develop without social interaction, then the importance of having a 'voice' that is 'heard' cannot be overstated. Increasingly, in research terms, the importance of centralising and learning from the 'voice' of disabled people themselves is being recognised and the effectiveness and suitability of employing traditional methods, based on scientific processes of investigation in the study of disability, have been questioned (Barnes and Mercer 1997; Clough and Barton 1998). In the development of a more democratic disability research paradigm, the emphasis is placed on the 'subject' of the study by enabling their 'voice' to be heard directly through the research.

In research terms, the concept of 'voice' has more readily suggested a verbal language with meaning constructed through words. In terms of the arts, the 'voice' can also be conceptualised as visual and as part of an expressive, therapeutic, creative and ultimately empowering process in which meaning is articulated through imagery. Images constitute a visual language with all that that implies in terms of communicating feelings, experiences and opinions and constitute a particularly significant 'voice' where the child or young person is non verbal or where impairment has impacted on the development of literacy skills i.e. intellectual ability may far exceed literacy skills.

The concepts of 'voice' and 'narrative', however, present methodological problems in the sense that - 'voices may be far from clear and narratives far from coherent'. Decisions must be made about 'which "voice" is to be taken note of and whose "tale" is to be told' (Clough and Barton 1998:9). Furthermore, when considering the image as 'voice', questions arise around issues of interpretation, the reading of meaning, and the ways in which that which may be produced subliminally is recognised and explained, and, critically, by whom. Production of imagery that constitutes an informed, aware, articulate and significant voice for the disabled person depends upon their ability to recognise and transcend both disabling perceptions (social narratives) about the nature of their impairment and about the function of art. It is

these processes that have the potential to become an intrinsic part of creative arts education.

In general terms the concept of 'voice' implies an audience who hears or sees what is being communicated and who has an opinion about its validity. For disabled children, during the early stages of visual and verbal language development, this is usually and variously their family members, friends and teachers, who, in the main, will be non-disabled. Opinions about what constitutes 'art' and what does not, and understanding of what being disabled means in our society, may or may not allow recognition, endorsement or encouragement of the disabled child's 'voice', as and when it emerges in their art work. In her research into childhood experiences with disabled students from the University of Central Lancashire, Middleton (1999) notes the misguided approaches that they encountered as children. She states that they all experienced 'damaging reactions and behaviours from other children, from adults and from members of the caring professions. These were not necessarily, nor even usually, intentionally malicious. Indeed, some were thought to be helpful behaviours' (p.1-2).

Similarly, Matthews (1994) emphasises the importance of adult attitudes in his investigation into the development of children's visual language (drawings and paintings) and the inter-relatedness of movement, representation, verbal language and literacy in this process. He notes the profound effect that the attitudes of the people around the child have on this development, and elicits the significance of the social and interpersonal context in which children make meaning as they draw. He states the

overall direction of the child's developmental journey, and each twist and turn from moment to moment, is influenced by the responses of surrounding people and by society at large (Matthews 1994:20).

These responses are made more complex for the child with an impairment who, to even begin creative activity, may require innovative and sensitive interventions to overcome the practical challenges that restricted mobility, impaired motor skills, co-ordination or vision might imply. Impairment is not conventionally associated with the subject matter of drawing or painting, there are few precedents, and, unless the child is encouraged otherwise, conventional or 'normal' subjects will prevail. The attitudes

of the people that surround him/her are crucial in the disabled child's early ability to develop and take ownership of a unique, personal, visual language.

The processes by which children acquire a visual language are described by Matthews as 'a naturally unfolding sequence of development, which is universal, and which is initiated from within the child' (p.21). Drawing actions and the shapes they make are imbued with emotion and representational possibilities (p.58). However, Matthews describes this beginning of drawing as having been, 'undermined by a peculiarly limited version of a Western ethnocentric approach to visual representation' (p.63). He states 'it is often the adults who are the most rigid and limited in their understanding of the arts' (p.87). He describes as limiting the effects of teachers who adopt 'a highly prescriptive approach, with a fixed end in mind (and often of the most banal kind).' He depicts a process in which 'children are reduced to slaves in a "cottage industry" production line, mass producing stereotyped trivia' which 'completely cuts across vital processes of symbol formation' (p.87). He highlights the negative impact that uninformed adult intervention can have on children's drawing and painting activities *per se*.

In addition to the teacher, the disabled child may often be assisted by a non- arts specialist classroom assistant. They are particularly susceptible to the insensitive intervention which Matthews refers to as

the "hands-on" type of interaction. Manipulating and interfering with the children's work to an overwhelming extent; sticking things on it, cutting it up, repainting it and generally communicating to the child that his or her efforts are inadequate (p.87).

The disabled students interviewed by Middleton (1999) spoke of their experiences of 'possessive assistance' and the need to give appropriate training so that assistants 'learn to facilitate not control' (p.17).

The power relation between classroom assistant and child authorises the adult, who may themselves be subject to a limited understanding of art as a narrow interpretation of traditional realism. There may also be a misguided commitment to enabling the child to produce 'conventional' artwork in order that the perceived gap in competence between them and their non-disabled peers is narrowed, and as

evidence that they are 'just like everybody else'. The line that a child with, for example cerebral palsy, draws, is not necessarily recognised and valued for the vitality and uniqueness it displays, but seen as further evidence of difference and therefore inferiority. The adult intervenes to rectify the shortfall.

The experiences of disabled children in the development of visual language are very varied, as are the implications of impairment itself. Educational experiences may have been varied with children moving between mainstream and special provision, or the experience may have been solely at a special school often from nursery up until 19 years of age. Teachers they encounter within infant, primary and special school may or may not have had specialist art skills. Family attitudes may reflect an interest and understanding of the arts and recognition of their importance that they then endorse with time and resources. Alternatively the money, energy and optimism to create access for their children might be limited, particularly in the light of more pressing difficulties. Parents may only have their own traditional experiences of art at school to draw on, an education which perhaps petered out when the 'serious' business of choosing options occurred. What does seem to be the case is that luck and being in contact with the right person at the right time has a significant bearing on the opportunities that disabled children have to develop imagery as a language with which to represent themselves. The consequences of such an arbitrary situation would imply that a significant number of disabled children miss out stages of development which most children pass through and the opportunity therein to develop, and the option to use, the visual arts as a meaningful 'voice'. Morris (1998) suggests that; 'Silence and the loss of voice may eventually constitute for some a complete shattering of self' (p.201).

### **Summary**

This chapter has examined the very complex circumstances that pertain to identity formation in disabled young people. Central has been the ambivalence that occurs in the acceptance or rejection of an essentialist disability identity and the resistance expressed to other's perceptions of the disabled self. The ways in which this struggle can crystallize into what have been referred to as the 'psycho emotional dimensions of disability' has been elaborated with reference to social identity or interactions between the self and society. The critical nature of these in the adolescent processes of individuation are of particular relevance in the context of this study, as are Post Modern concepts of identity that embrace difference and offer disabled



young people opportunities for a more liberal interpretation of impairment and disability.

Concepts of narrativity and identity, or the individual 'telling' of the story of who we believe ourselves to be, have been considered in the context of negative public narratives about disability. These are embedded in social discourse and have to be overcome if the process of creating a self identity is to be affirming. Disabled young people, whose accounts are given in later chapters, have developed a self narrative and 'visual voice' in spite of preconceptions about disability, art, and obsessive cultural idealisation of the body. Morris (1998) states that 'we must each become the authors of our own narratives, no one else's will do' (p.45). The following chapter explores disability in a cultural context, investigating the dichotomy that arises from the solidarity that a collective disability identity offers as opposed to individualised identity formation that incorporates experiences of impairment and disability. The significant part that arts education can have in this process is investigated.

## **Chapter Four**

### **Cultural Identity and Arts Education**

The social model of disability provided disabled people with an empowering way to formulate their experiences. Potentially they were able to 'remove' the stigma that had been associated with disability away from their bodies and to relocate the 'problem' within a disablist society. However, central to this empowerment is the notion of a collective disability identity which ignores the lived experience of disability and impairment and other critical aspects of self such as ethnicity, gender, age etc. This chapter examines questions of cultural identity and whether disabled people constitute a cultural group likened to other minority groups and, as such, whether they could be included in a multi-cultural educational approach. Disabled children and young people experience the varied educational settings of special and mainstream schools and segregated, integrated, and inclusive environments. In the absence of literature that specifically investigates their arts education in these different contexts, an analysis is developed from the literature that has examined mainstream arts provision with the addition of information that relates to specialist arts provision where it is available.

Disabled children, like their non-disabled peers, have been affected, since the introduction of the National Curriculum, by the erosion of the arts in schools but in addition to this they also have very different and disadvantaged starting points. As well as confronting issues of access they have the added challenge of understanding and confronting the negative and generalised perceptions of disability embedded in mainstream media. This chapter highlights the importance of teachers in the processes of inclusion, in realising the arts as an expressive and positive force for disabled children, and in preparing the way for their future progression where appropriate, to higher levels of study.

#### **Cultural Alliances**

The question of whether disabled people constitute a cultural group, likened to other minority groups distinguished by ethnicity or sexual orientation, introduces the question of whether the shared experience of a 'disability phobic' society constitutes a cultural identifier that takes precedent over gender, class, age or sexual identity (Wendell 1996:11). Whilst the experiences of disabled people (marginalisation, limitation of civil rights, anger and rage) can be said to constitute cultural

'belongingness' and thereby the political and social advantages of community; 'placing cultural boundaries around a group [also] ... creates symbolic incarceration' (Gilson and Depoy:212).

In the 2001 DfEE Report, the social definition of culture is described as hinging on the 'concept of values' or 'the ideas, beliefs, attitudes which the group considers worthy and important, and which it holds in common as a group' (p.41). Barnes and Mercer (2003) similarly state that 'the definition of culture has shifted from a location in the artistic and intellectual ideas and activities of an elite to incorporate the pursuits of the whole population' (p.89). Barnes *et al* (1999) maintain that 'the growing collective awareness of disabled people and their differential treatment secures their redefinition as a "minority group",' which they see as akin to other oppressed minorities (p.72). They point to the common experiences of separate schooling, rehabilitation agencies, medical experiences, day centres, oppressive institutionalised settings, and ultimately the 'shared culture of resistance' as constituting an overall culture of oppression (1999:204). This viewpoint suggests a 'single identifiable community of concern', 'we have found one another and found a voice to express not despair at our fate but outrage at our social positioning' (Linton 1998, cited in Gilson and Depoy 2000:209).

There are, however, arguments against this attempt to theoretically unify people with impairments into a cultural grouping in the sense that there is 'no unifying culture, language (with the exception of Deaf people) or set of experiences; people with disabilities are not homogeneous, nor is there much prospect for trans-disability solidarity' (Linton quoted in Barnes and Mercer p101). Humphrey (1994) states:

Disabled people are assumed to be an homogeneous mass united in the face of society's oppression, and with a culture of oppression. I am a middle class, middle aged male diagnosed with M.S. 15 years ago. I have little in common with a working class, young woman blind from birth. When we include people with learning difficulties, mental disabilities and mental impairments with us, the differences in cultural identity become even greater; and this is setting aside the differences between people disabled from birth and those people who have become disabled. ... I am arguing that disabled people are people with vastly different experiences and varied cultures of which the cultural

implications of being disabled are perhaps a minor and variable pattern set within the major patterns of society, gender and class (pp.66-67).

Middleton (1999) reports that the disabled students she interviewed did not identify as disabled, with some seeing it as a 'negative identity'. She describes instead their wish 'to belong, to be valued, to mix with able bodied people as well as in a disabled world' (1999:27). In contrast, deaf people, whilst similarly resistant to a disabled identity, self - define as a 'cultural minority,' by virtue of the shared language of signing. They prefer to compare themselves with other minority ethnic groups, seeing their exclusion as similar, in that it is based upon their linguistic differences and the fact that English is not their first language (Barnes *et al* 1999:204). In contrast with disabled people they prefer to retain separate schooling and social organisations such as Deaf Club and, in many instances, raise objections to cochlea implants and genetic screening.

For people with impairments, there are a number of material and ideological barriers that militate against them coming together to share and maintain a common cultural involvement. Barnes *et al* comment on the particular difficulties that disabled people have in identifying themselves as socially oppressed and comparable to women, black people, lesbians or gay people, because of the ways in which their oppression has been 'generally submerged within the rhetoric of benevolent paternalism, professional altruism and philanthropy' (p.179). This ideological stumbling block is compounded by material circumstances that are related to economic considerations, geographical distance, transport difficulties, the tendency of medical, welfare and charitable institutions to divide up the disabled population into various impairment specific groups, and as residents in institutions. All of these factors contribute to 'inhibit the possibility of the disabled population cohering as a unified political force' (p.179). In 1999 Barnes *et al* concede that the disabled people's movement has been relatively unsuccessful in reaching out to the disabled population as a whole, i.e. 'beyond specific groups, notably, those with physical and sensory impairments who are both relatively young and active' (p.179). However, by 2003, Barnes and Mercer are confident that 'a disability culture is emerging' (p.109). They acknowledge, however, that disabled people (and this is certainly true of the young disabled people in this research), are ambivalent about whether they want their own [disability] culture or whether they want to be fully integrated into society (p.102).

### **Creativity and Self Esteem**

Bloomfield (1998) considers that the arts' 'humanizing potential has been grossly undervalued' in educational terms (p.50). Its value to the individual in terms of self-esteem, self-identity and to enhance a sense of being is, in general terms, rated of secondary importance with Harland et al's (2000) study providing one of few investigations. Finding out, or discovering, about your self as a result of arts education was a common theme identified in the research study, commissioned by the National Foundation for Educational Research, which carried out an enquiry into the effects and effectiveness of arts education in secondary schools. The study identified a range of broad effect categories, of which Personal and Social Development was one. This documented accounts that included developing a sense of one's self and one's emotions, enhanced self-esteem and self worth and increases in different forms of self-confidence (p.141). They noted the 'process of self-discovery and the crystallisation of one's own identity' that pupils report (p.142). The report indicated that numerous references were made to the capacity of the arts to foster positive self images in pupils. However the authors warned

It is worth remembering that the evidence to support such outcomes from the arts is drawn from (the case study) schools that have a reputation for high quality provision in the arts, and from pupils within them who were known to be performing well in at least one art form (p.177).

They described evidence from a more representative sample of schools and pupils (schools in the questionnaire survey which were more indicative of secondary schools in general) to show that large numbers of pupils perceive no such effects. Moreover, even in the case study schools, there were sufficient signs that not all pupils enjoyed positive developments in self-esteem to warn against any complacent belief that personal and social development through arts education can be guaranteed. However they did conclude that 'we should not lose sight of the fact that the achievement of these effects is highly dependent on effective teaching and learning in the arts' (p.177).

Skill development theorists have studied the relationship between self-concept and school (educational) achievement. They state that 'doing well in school results in self concept enhancement and that doing poorly results in a lowering of the self concept'

(Dusek 1987:393). Whilst acknowledging the need for more research into cognitive competence and self concept, undoubtedly the feeling that one is competent is seen as important to school (educational) success. Dusek suggests that with increasing cognitive competence, self-concepts become more abstract and complex, equipping the adolescent for stronger self-concepts. He states that 'adolescents with stronger self-concepts are better adjusted psychologically, have higher career aspirations and conform more appropriately to generally accepted social standards' (p.397).

Harland *et al* make no reference to disabled young people in their research and one must assume therefore that either they were not represented in the school population or that they have been integrated into their findings. Middleton (1999) reminds us that 'there is essentially little difference between how disabled children learn and how non-disabled children learn' (p.84). However, against this shared background is the requirement that disabled students have for practical and technological solutions, disability awareness and cultural context. Philip's forward to Paine's (2000) book, which explores fluency of drawing, its beginnings and the personal, social and cultural circumstances which help or hinder its development, suggests that 'drawing can offer an avenue of expression where words fail' which, for disabled young people both literally in the case of non verbal students and metaphorically in the case of those students who have not had the opportunities to be 'heard', has particular significance.

### **The Visual Arts as an Alternative Mode of Expression**

The possibility of being 'heard' renders alternative non literary modes of expression of greater importance when the acquisition of literacy skills poses difficulties. The relationship between movement, where that movement is restricted or impaired, and the significance that this has for the development of mark-making and subsequently the representation, language and literacy skills of the disabled child is neglected in research terms and worthy of further investigation. Matthews (1994) describes the way in which, within children's development, 'writing and drawing flow into each other' with letter forms used 'almost interchangeably with more pictorial images' (p.96). Where the child has limited motor control or is non verbal this presents further challenges the extent of which are highlighted by Moyle's (1976) comments.

Reading and writing ... are both entirely based in our spoken language. It is probably true to say that the child will not remember

any word met in print unless that word is linked with a sound value which has meaning within the child's speech experience (p.59).

The development of visual literacy, therefore, is critical in its potential to provide an alternative means of communication and expression. Cooley (1964) emphasises the links between communication, thought processes and the very process of being.

thought and life (are inseparable) from communication since ... the need to impart is of this primary and essential character, we ought not to look upon it as something separable from, and additional to the need to think or to be, it is only by imparting that one is enabled to think or to be (Cooley 1964:94).

### **Arts Education**

Much arts education literature, (Feldman and Abrams 1992; Abbs 1994; Bloomfield 1998) is concerned with the debate that exists, in educational terms, around the significance of the arts. 'They [the arts] exist not necessarily on the margins but always in an uncertain state, constantly distorted by extraneous demands, curious expectations and fundamental misunderstandings' (Abbs 1994:41). The value of art education *per se* is weighed against its value in developing skills and competencies that are transferable to other areas of the curriculum whilst the DfEE (2001) Report, *All Our Futures – creativity, culture and education* suggests that:

The National Curriculum has imposed a prescriptive model of art education which emphasises technical skill at the expense of creative and conceptual innovation (p.180).

The arts education of disabled children and young people *per se* is a neglected area in research terms. In an attempt to arrive at an understanding of what their experiences might be it is only possible to consider mainstream trends in arts education with the awareness that some integration/inclusion into mainstream provision, or segregation in specialist provision, colours the experiences of disabled children. Robinson (1982), whilst acknowledging the particular significance of the arts for disabled pupils for the 'extra opportunities they provide for communication' and 'the exercise of physical skills and abilities which are involved,' identified three special difficulties in making provision. He lists these as

The problem of identifying an artistic gift may be complicated by the nature of the disability; this requires special attention in the guidance to teachers given by an education authority.

There is a shortage of teachers with adequate training in this field and of artists with the ability and commitment to give time to help the disabled. The former can be resolved within an authority only through appropriate in-service training.

There is the problem of segregation...generally we think the weight of evidence is against segregation. It is wiser, we think, to provide substantial supplementary help in ordinary schools (Robinson 1982:105).

How the first two of the difficulties he cites have been addressed in the intervening years is difficult to assess. However, the inclusion agenda (Tomlinson 1996) appears to be giving far more disabled children and young people mainstream opportunities in the arts, although the quality and frequency of the 'substantial supplementary help' is under researched.

Robinson also cites two misconceptions that placed the arts at risk within the terms of the 'Great Debate' which had been gathering force since the late 1960s and which, in the 1970s, brought into the open the conflict between 'progressive' and 'traditional' styles of education. He describes these misconceptions as 'persisting' and in particular they have resonated within the arts education of disabled young people.

The main role of education is to prepare young people for work, arts education evidently seemed unnecessary except for those looking for arts jobs ... .Through the emphasis in some teaching on creativity, self-expression and personal development, the arts had become associated with non-intellectual activities and therefore seemed to lie outside the priorities of those who argued for a return to "traditional" academic values (1982:xii).



Traditionally the emphasis in special school provision was not centred on preparing its pupils for employment. Qualifications in the arts were not available as part of the curriculum which focused, in the main, on non-intellectual activities that supported independent living skills. Art was neither preparation for employment nor an intellectual activity that referenced the social, political and personal context of impairment and disability. It was regarded as an appropriate 'therapeutic' leisure activity relegating it to 'the screwed-up tissue paper syndrome' that Matthews (1994) so roundly condemns (p.87). Chalmers similarly notes that 'unfortunately this perspective [the equation of the arts with leisure] has remained dominant – particularly for people with impairments' (1996:28).

An exception, which illustrates the potential that the arts can have for disabled young people, is to be found in the work of Overton, co-ordinator of the upper school arts programme at Mere Oaks Special School in Wigan in which IT is being used creatively to make the arts accessible to disabled young people. An account in the *Times Educational Supplement* (TES) (17<sup>th</sup> January 2003) entitled 'The Power of Pixels', describes the development of the competencies of a visual language, enhanced self esteem and assertion of self identity that is occurring as a consequence of enabling disabled children to access an expressive arts curriculum. In addition to the extensive use of video for drama and dance, the article describes how pupils, and in particular one pupil who has cerebral palsy with limited fine motor control as a consequence, use the interactive whiteboard for producing images.

Joe takes digital pictures of other students and loads these stills into the computer, which is connected to the interactive whiteboard. On the whiteboard Joe has the space to "paint" over the pictures, using them as his template. Using a pointed stick and his hands, he can manipulate the original picture, paint using bright blocks of contrasting colours or express himself with fine swirling brushwork that gives his self-portraits a resemblance to Van Gogh's (McLean 2003:TES) (see Fig 19).

The artwork that Joe produces includes self-portraits which he manipulates with various effects and colours and which represent early stages in the exploration of self (see Fig 20, 21). These initial attempts at self discovery and the impact that his artwork has had, have undoubtedly impacted on his self-esteem.

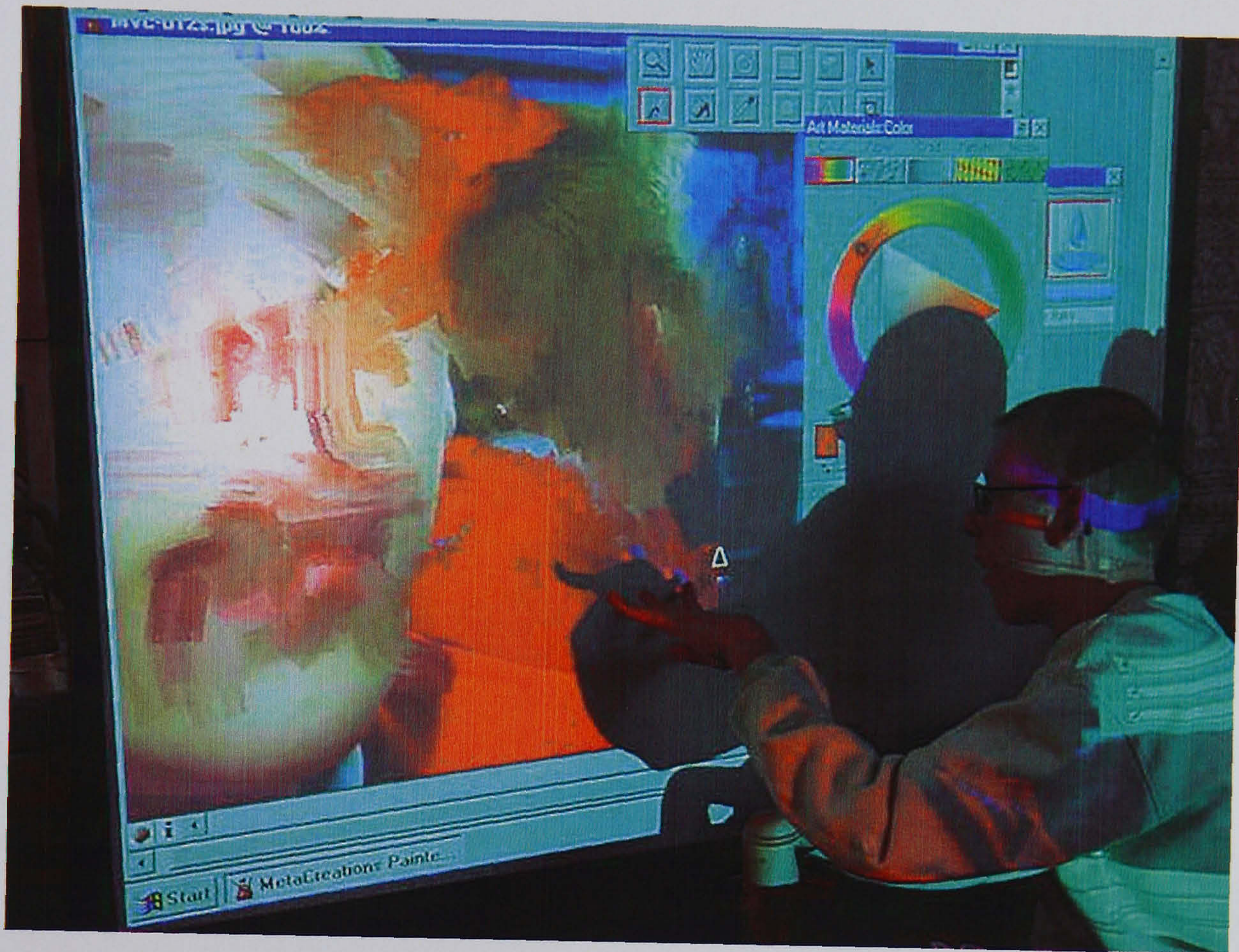


Fig 19

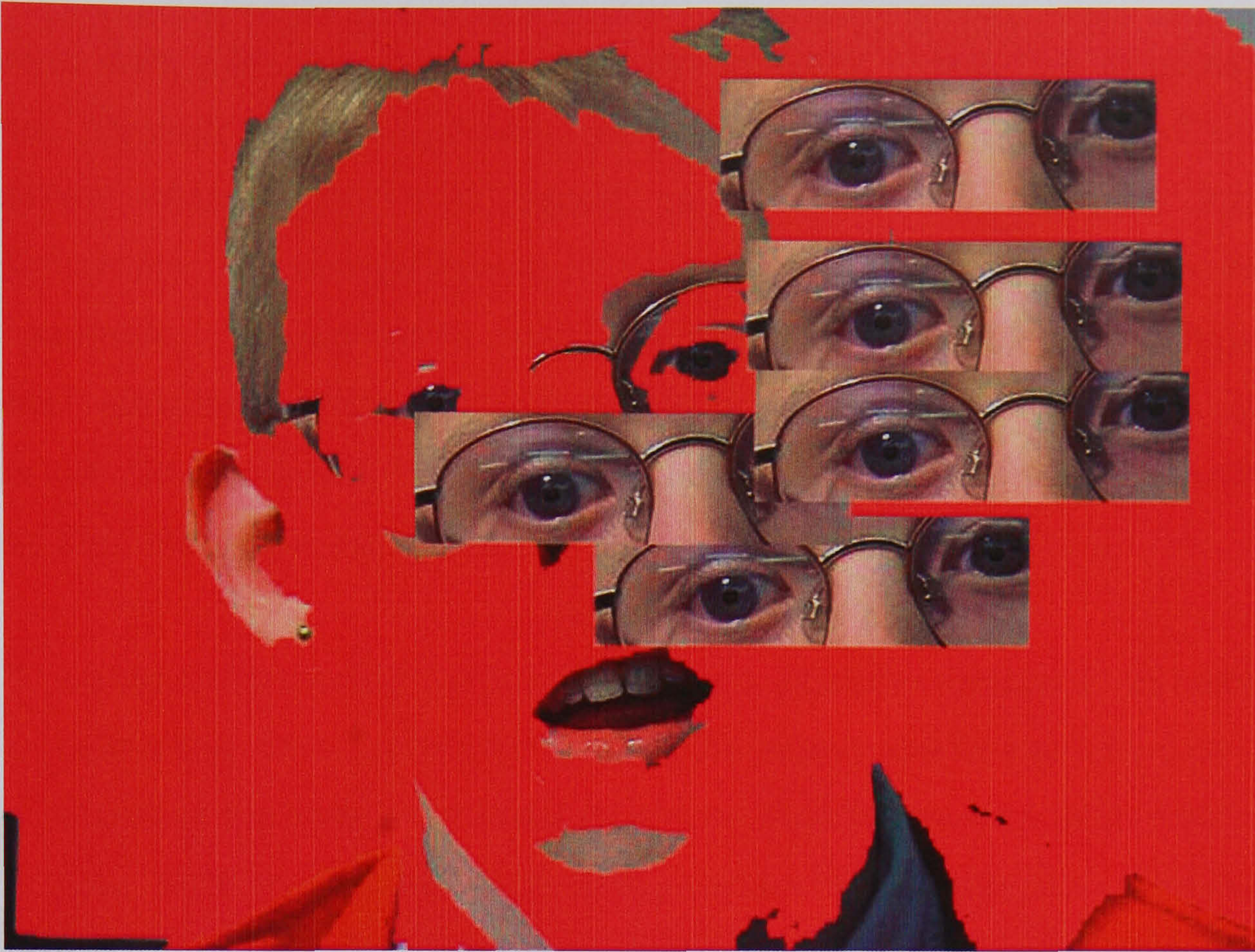


Fig 20

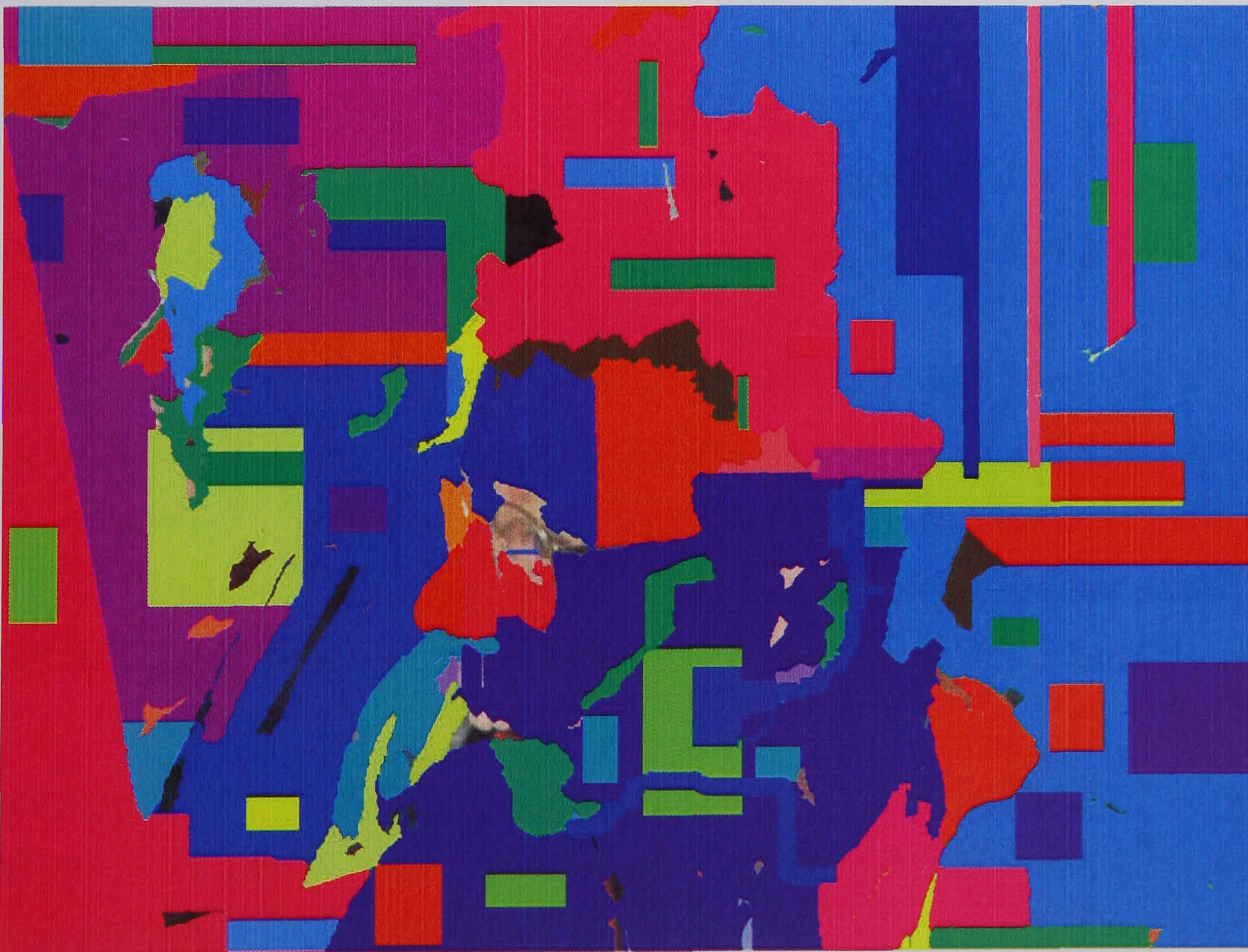


Fig 21

He has been to London to showcase his digital photography art at the Victoria and Albert Museum as part of the DfES's museum and galleries education programme. His father remarked that he had 'never seen Joseph speak so much in his life. He's vociferous with this new impetus'. Overton similarly states 'the emphasis is on students, [through their work] having an increased sense of value, self worth and ownership'. Interestingly in a report prepared for the British Educational Communications Technology Agency (BECTA) from whom the resources had been made available, the pupils are described as 'in a sense having "technologically mediated" identities'. Blandy (1996) writing on *Gender Reconstruction, Disability Images and Art Education*, suggests ways in which disability and self-identity could be integrated more specifically into the curriculum.

Art educators could...present dominant disability images to students, examining the relationship between the image and its explicit purpose, enacting the images in order to inhabit their oppressiveness, creating new texts for images, and finally producing images through which students with disabilities can reclaim their experiences and their gender on their own terms (p.75).

### **MultiCulturalism and Popular Culture**

The proposition that 'art education can be a form of social inquiry' places it within a multicultural agenda which, in the main, has neglected the cultural implications of disability due, largely, to the absence of disabled people in most cultural forum including the institutions of mainstream education (Chalmers 1996:xii). Consideration of the arts education of disabled students within a multicultural agenda again raises the question of whether the experience of disability and impairment implies a collective cultural identity. Chalmers' (1996) statement, 'multiculturalism, as I use the term acknowledges all aspects of cultural diversity', recognises that for disabled people 'the honoured aesthetic exemplars of European male-dominated high art culture', from which they are largely excluded, may also hold little meaning (p.7).

Certainly the need to provide young people with an arts education that enables them to 'find meaning and to make sense of themselves and their lives' is central to the recommendations of the DfEE report (2001). And, although it identifies that for some 'the need is acute' the reference is limited to those young people who have emotional, social and behavioural difficulties or mental health problems (p.23). The

report also acknowledges the increasingly diverse nature of British society and complexity of cultural identities within which all young people 'have to find their place' and it also considers the impact of information and communication technologies and the role of popular culture on identity formation.

The result is an increasingly heterogeneous culture which is global and complex, and which potentially offers new contexts for disabled people. The cultural education of young people with impairments is, however, made more complicated by the need to juxtapose an understanding of the perceptions of disability that have permeated our culture with these new expanding cultural perspectives. The report sets the cultural agenda for education as 'enabling young people to recognise, explore and understand their own cultural values and assumptions' (2001:97). He makes the point that although sometimes we consciously recognise the values and opinions we hold, 'as often, we are not conscious of them' (p.97). People with impairments often absorb and internalise popular perceptions of disability which continue to resonate with history's prejudices and which, with material factors, continue to undermine and limit their potential for achievement. It is of equal importance that non-disabled young people have the opportunity to gain awareness of disability issues through an increased understanding of diversity. Chalmers (1996) states that:

A mainstream-centric curriculum has negative consequences for mainstream students because it reinforces their false sense of superiority, gives them a misleading conception of their relationship with other racial and ethnic groups [and disabled people] and denies them the opportunity to benefit from the knowledge, perspectives and frames of reference that can be gained from studying and experiencing other cultures and groups (p.10).

Multicultural education offers opportunities to bring Disability Arts onto the mainstream agenda (where it has been, and continues to be, largely ignored) and to explore its functions as both a political and social tool and as a means of expressing the diversity of the human condition. Chalmers makes the point that 'multi-cultural education can serve as a means of social reconstruction, it can address persistent forms of racism and prejudice' (p.ix). Certainly the term multi-cultural has, in the main, referred to people from ethnic minorities and not as Green (1996) states 'everybody who inhabits this increasingly frail world' (p.41). However, the emphasis

of people from ethnic minorities within multi-cultural education is enhanced by virtue of their presence, in increased numbers, in mainstream schools and colleges, whilst many children and young people with impairments have continued to be marginalised by educational provision in specialist, segregated institutions.

This conundrum is further compounded by the traditional exclusion of disabled people from the canons of 'high' Western culture, and the current phenomenon whereby technology is creating increased and unprecedented access for everyone to a highly conspicuous popular culture. Tomlinson (1990) speaks of a 'television-saturated and television-centred cultural formation', which he describes as providing a major point of access to cultural forms that were previously separated from the television system thus 'reinforc(ing) its command over experience and debate' (p.78). In addition, the DfEE report (2001) describes the Internet and telecommunications as providing 'unprecedented access to ideas, information, people and organisations throughout the world' (p.8).

Disabled people are not excluded in the sense that television and the media, computer technology and the Internet are as accessible to them as to everyone else. Tomlinson's (1990) comments, 'watching television is most people's major leisure activity and the main source of the information, images and arguments through which they make sense of the world' highlights the universality of the experience (p.77). Although disabled people are under represented on television and in the media, (see Cumberbatch and Negrine 1992), nevertheless they are not debarred from absorbing the subtleties of a consumer culture in which the individual is encouraged to 'read the differences in signs, to decode the minutiae of distinctions in dress, house, furnishings, leisure lifestyles and equipment' which are promoted indiscriminately (Tomlinson p.21). Provided they or their families have the money, disabled people are at liberty to buy into consumer culture and 'the construction of the image around the commodity', in exactly the same way as their non-disabled peers (p. 21).

Popular culture is taken to mean those forms of creative practice which have mass appeal, including commercial music, popular cinema, television, fashion, design and popular fiction (Robinson 1999:40). Abbs (1994) refers to it as 'a puddle culture so shallow one can hardly get one's toe in' (p.1-2). In contrast, Hill (2001) views the 'languages of commercial culture' as an important and dynamic means by which

young people can communicate 'the identities they are busy creating' (p.49). He describes this process as one in which:

Young people select and discard a huge range of available material, ideas, words and images with impressive speed. The past and other contemporary cultures provide them with the material to create an individual style. Strangeness and difference, aspects of the other, are particularly valuable to them in establishing the unique character that will guarantee their presence in the world (p.49).

The role of arts and cultural education for all students, whilst acknowledging the persuasiveness of contemporary modes of identity formation, must offer a comprehensive understanding of the work of artists, designers, photographers and art theorists whose work informs students' own practice. Certainly a break in the 1960s and 70s, with what Barnes *et al* describe as the 'belief in a single, progressively evolving reality or truth' (p.36), and which Abbs (1994) perceives as 'a nervous unease with high western artistic traditions' (p.86), created the potential for a more relevant arts curriculum for disabled students with a new emphasis on the existence of 'multiple realities, discontinuity and difference' (Barnes *et al* p.36). The ideological climate of Civil Rights and in particular feminism, presented a challenge to the notion of traditional and hierarchical knowledge, in the identification and rejection of aesthetic exemplars generated by a dominant culture, increasingly perceived as characterised by elitist, Eurocentric, white, non-disabled males.

Abbs condemns this 'disruption' of any 'reference to a cultural tradition that stretched back through the ages', perceiving 'most of the children in Britain's democracy [as] hav[ing] grown up in cultural exile'. He states:

From this period children were to express themselves in a growing vacuum, without the means, often, to adequate articulation, without exemplars, without predecessors and without the challenge of great art (1994:79).

He is referring of course to non-disabled children, but interestingly, if this cultural vacuum were the case, it places the majority in the same wilderness that disabled people have traditionally always been in. The exception is that they have also had to

confront inaccessible museums, art galleries and theatres, transport difficulties, non-specialist arts education and a dearth of role models in either the arts or education. Peters (1996) notes the controversy (in the context of post-modern education) that the rejection of the traditional canon for a 'popular' canon has provoked. She maintains that although an acknowledgement of the wisdom contained in the traditional canon remains, there is a new insistence that 'people and groups need to transform knowledge in accordance with their own sociological, historical, and cultural contexts' (p.221). Attention is focused on the complexities and richness of human and cultural diversity, and the expression of these not only in terms of differences, but in articulating the commonalities of human experience and vision.

Gilson and Depoy (2000) concede that 'defining multiculturalism is not an easy task' there being 'many competing definitions and philosophical frames of reference' (p.210). For the purposes of this research I will adopt the view of multiculturalism as 'incorporative' and therefore as 'bring[ing] diversity into the body politic such that it becomes transformed' (p.210). Chalmers' (1996) definition is useful in educational terms; he sees multiculturalism as embracing 'differences in gender, religion, sexual orientation, social class, economic status, language, age, and physical ability' and seeing them all as 'cultural factors to be considered, respected, and celebrated in contemporary curricula' (p.4).

The multicultural ethos which demands, 'respect for behaviours, dispositions, outlooks and values that are not solely from one dominant culture,' provides an educational philosophy which has the potential to be inclusive of disabled people (p.4). However, it is contradictory within a climate that has increasingly adopted a more prescriptive attitude towards achieving standardisation of curriculum delivery and assessment and which has the potential to make the curriculum less accessible for disabled people. Abbs describes this as 'an ideological driven move to make schools more functional, more competitive and more submissive' (1994:14). He depicts a 'take-over', in which 'a handful of politicians and a leaden medley of managers and bureaucrats' determine the content and style of education. He sees this as dominated by a politically driven rhetoric that is characterised by 'a one dimensional language of "total quality control", "customer satisfaction" and "consumer needs" sprinkled with a few words like "excellence" ' (p.222).



He similarly condemns the failure to develop an adequate public conception of the true significance of the arts in our society and therefore a comprehensive arts policy for our schools (p.41). The DfEE report (2001) refers to the existing National Curriculum as 'an explicit hierarchy of subjects'. The foundation subjects, within which creative studies are defined solely as music and visual art, are part of the set curriculum only up until the age of 14, and are thus, from the outset, perceived as of lower status than the core subjects (p.74). It states, 'In the revisions to the National Curriculum since 1988, the requirements for the arts and humanities have been progressively reduced'. All of which contributes to the persistent and generalised perception that associates 'the sciences with "tough" acts of knowledge and the arts to "soft" affects of various kinds' (Abbs 1994:42).

The DfEE report states that 'current priorities and pressures in education inhibit the creative abilities of young people and those who teach them' (p.8). In addition to these current drives within education, Chalmers (1996), who describes much of art education as, 'bland, pleasant and middle class', (p.25) makes the point that the dominance and persistence of particular notions of 'good art' can be traced to 'deeply embedded racism, egocentrism, ethnocentrism and Eurocentrism' (p.22). These, he states, originated in European explanations of diversity and became increasingly evaluative in the 18th and 19th Century. 'The universalistic conception of man' was transformed into a 'view of the gradations of mankind' providing justification for the economics of 'slavery, colonisation and institutionalisation' (p22).

Within current arts curricula, Abbs perceives a cultural vacuum in which 'traditional exemplars and predecessors' have been 'largely discarded as the products of alienation and ideological deception' (p.79), whilst Chalmers maintains that Western canons are still assigned major importance with a few multi-cultural examples cautiously added on (p.25). The challenge of exposing the limited values of traditional Western Art for children as part of a multi-cultural agenda, whilst promoting the intellectual inquiry and aesthetic beauty that have informed it, and in addition addressing an increasingly complex and diverse popular culture, may account for the ambivalence that Abbs currently perceives in arts education. There is no ambivalence, however, in arts syllabus assessment criteria. Chalmers considers these to continue to be based on

Prejudices embedded in approaches to teaching that emphasise particular technical skills, formalist aesthetics, working alone as both maker and critic and even in the dominant choices of media for making art in the classroom (1996:25).

Certainly, for students with impairments, fulfilment of formal assessment criteria in the achievement of accredited qualifications and the processes of discovering and developing a positive identity via the visual arts that is inclusive of impairment, are not necessarily compatible.

Harland *et al* (2000) identify a number of factors which they consider militate against the effective delivery of arts education in schools and which are reiterated in the 2001 DfEE report. These include: diminishing Local Education Authority advisory services in the arts; concerns about the employment of experienced and specialist arts teachers in schools; continuing problems in providing appropriate resources and accommodation; and the decline in the arts content of initial training courses for primary teachers. In addition they also highlight the current drive for literacy and numeracy endorsed by the Secretary of State for Education's announcement in 1998 of a relaxation of the primary school curriculum, as further limiting time allocated to the arts in this phase of children's education. 'For some observers', they state, 'the DfEE's preoccupation with meeting national targets for English and mathematics in 2002, risks undermining the implementation of a broad and balanced curriculum' (p.3).

The 2001 DfEE Report expresses 'deep concerns about the supply of teachers and the extent to which current training takes account of the importance of creative and cultural education' (p.9). It states that, 'on current government plans, only 14% of newly qualified primary teachers will have specialised in an arts subject with 9 out of 10 teachers surveyed stating that they spent too little time on the arts during training' (p.155). It is unclear how this translates specifically into special school provision. However, the quotation in the report by a mainstream primary school teacher who maintains 'we cannot lead children where we have never been ourselves' seems particularly pertinent, in many respects, to the disabled child

### **The Impact of Teacher Training on Inclusivity**

It is through teacher training that an inclusive approach which aims to recognise, value, and accommodate all learners, regardless of the notion of 'disability' or other forms of difference, may be achieved. It is also within teacher training that an innovative approach to enabling support that has integrity and an understanding of the social construction of disability can be developed. Evans' (2002) research into the ethnography of teacher training has led him to warn against the inclusive argument becoming a mantra for those constructed as 'other', and illustrates how 'socially constructed norms in relation to behaviour and achievement are reproduced in the classroom' (p.38).

At the training institute that was the subject of Evans' research (2002), two postgraduate courses were being offered - one for inclusive education and one for the teaching of a specific subject. Evans noted that 'inclusive philosophy was being offered as an "option", seen from the outset as 'different from' general education' (p.37). The differences that emerged from these two groups (the education group and the inclusive group) confirmed a 'noticeable disparity' in the values and attitudes towards education of the inclusive group and the education sessions (p.44). Evans states:

In the education sessions, the focus was on how to deliver the curriculum as smoothly as possible and assess the effectiveness of teachers by quantitative analysis of performance. In the inclusive setting the focus tended to be on the 'valuing of difference' and the importance of adapting the learning environment to the learner's needs. These two contrasting positions aimed to achieve similar goals (quality education), but embarked on achieving these aims with contrasting philosophies. The inclusive setting advocated teachers being aware of the inherent politics that were operative within teaching establishments and the consequences to the learner of our attitudes. ... In contrast, the education group was primarily focused on making assessments and evaluating curriculum in terms of quantitative performance of both learners and teaching staff (p.44).

From this Evans concludes that 'how a young person would be perceived and treated by teachers would depend heavily on the context in which the teacher is trained, rather than the qualities of the learner themselves' (p.45).

This disparity is evident in the responses that young disabled people gave in a study by Pitt and Curtin (2004:387-399) when discussing their experiences of staff in mainstream schools. Ten participants described a spectrum of responses whereby although they had encountered exceptionally supportive staff they had also encountered staff members that they described as 'isolating and bullies'. Eight of the ten participants gave examples of being treated negatively by teaching staff, from simply being treated differently to being verbally abused. Pitt and Curtin remark that 'disabled students in school are reliant on the good intentions of individual teachers' (p.397).

Evans acknowledges that his research, which relates to a year-long study at a single institute, cannot be seen as representative of post graduate teacher training courses in general. He notes that since this study the institute has withdrawn its separate inclusive education postgraduate course, with inclusive approaches being taught on a single postgraduate course. However, the research that he has carried out suggests that student teachers 'whether in a general teacher training setting or that of the inclusive approach to education, ... are trained to "experience" difference in contrasting ways' (p.45). He suggests that 'ways of understanding difference in the traditional approach centre around a culture of "normal" and "abnormal", and these notions reinforce discourses of exclusion and oppression'. He concludes that students were trained to 'adopt ways of working that support exclusionary and damaging approaches to education. The political environment in which student teachers are trained (in the non-inclusive setting) encourages dividing practices based on educational policy that is intolerant of difference'.

Evans (2002) supports his findings with the research into inclusive education carried out by Barton and Slee (1999). This demonstrates that 'the prevailing ethos of education in schools remains one of selection, competition and exclusive practices' (p.46). Evans concludes that the 'political environment that student teachers are trained in heavily influences how they react to certain forms of difference in the classroom'. He highlights the need for further research across institutes to provide a fuller picture and analysis of the process of teacher training and inclusion.

### Higher Education

Teacher training is significant not only because it supports inclusion and affects the grass roots understanding of impairment and disability for new generations of disabled and non disabled children, but also for the potential that it has for raising the aspirations of disabled children in the classroom. The influence of disabled people will only significantly be felt when they have achieved the academic status that qualifies them for employment in the arts and media professions. It is only in recent years that the effective transition of disabled people to higher education has become an increasing priority for the organisations and agencies involved in this process, including universities, schools, colleges and other disability related agencies, and that their presence has received any considered analysis (Riddell 1998; 2003). This has been prompted by the Special Educational Needs (SEN) and Disability Act (2002) which extends the Disability Discrimination Act Part IV to ensure that discrimination against disabled students is unlawful (Skill 2002). The implications of the act are far reaching and embrace course content, learning materials, resources such as sign language interpreters and note takers, adaptation to buildings, additional support and staff development.

Despite this new emphasis it is difficult to arrive at a clear picture of the representation of disabled people in higher education for reasons that are set out by Riddell (1998:203-222). However, the percentage of first-year undergraduates claiming a disability has risen in recent years as has total undergraduate enrolment. The largest increases have been in students with dyslexia and mental health issues. Whilst it is likely that the numbers of students disclosing a disability are increasing, it is also probable that these numbers reflect an actual increase in the numbers of disabled students in higher education (Viney 2004). Analysis by Riddell (2003) reveals that disabled students participating in higher education are 'more likely to be white, male and to have come from the more advantaged end of the social class spectrum' (p.16). It would seem that the numbers of disabled students and particularly those with high level support requirements, including personal care, who access higher education in the arts is either extremely small or non existent (see Appendix 2).

### Disabled People as Professional Artists and Designers

The Introduction to the *National Report from the Inspectorate 1990-00 Aspects of Art and Design in Further Education* states 'Throughout the twentieth century, the United

Kingdom has produced some of the most talented and innovative artists, designers and performers in the world' (FEFC p.1). How many of these artists are disabled is unclear. It is probable that the lack of information is not born out of the assumption that a significant proportion will have impairments, in the same way that there is an assumption that both males and females will be represented in this statement. The scarcity of disabled arts professionals and in particular those with support requirements, means that disabled people continue to have little impact in mainstream arts forum.

Disabled children and young people aspiring to a career in the arts are doubly disadvantaged. Not only have they usually had little or no opportunity to make sense of a culture that has a long history of representing them negatively but they must also contend with formal arts education that is limited for all young people. A recent National Union of Teachers survey describes art and music in primary schools as being 'squeezed almost out of existence', by the government's testing regime, with art in some schools dropped altogether for year six pupils until their tests have been completed (Galton and MacBeath 2002). For all young people the business of becoming 'the most talented and innovative artists, designers and performers in the world', rests not only on developing the visual literacy to develop and articulate creative ideas, but also on having some knowledge of who they are, or what they could become. For disabled young people this presents particular and complex challenges.

### **Summary**

Overall, little is known about the ways in which disabled children and young people produce artwork, about the adaptations that they and their families might effect to access practical involvement in the arts, and it is not known to what extent strategies are devised, developed, lost or ignored as they progress through their arts education. There is no research available that records the strategies that teachers develop, in terms of effective technologies and adaptations, which enable children and young people with impairments to make art. Any sensitive, innovatory and effective enabling by classroom assistants in the production of artwork is undocumented and does not provide continuity in the development of self expression and individual creativity. Neither is it known to what extent, nor at what stages in their arts education, the disabled child and young person will encounter an arts specialist,

innovative use of computer technology, or lens-based media as an additional or alternative way of producing artwork.

This chapter has outlined the insufficiency of knowledge and, in the main, provision in the arts education of disabled children and young people. It has also summarised the complexity of cultural identity for disabled people, and emphasised the important links between creativity and self esteem and the expression of self through the arts. As a potentially social act of communication the visual arts offer a way of developing understanding for both the creator and the viewer. The following chapters explore the ways in which this potential has been developed as an empowering force by students at Hereward College and enabled them to resist the negative and oppressive experiences that they have encountered.

## **Chapter Five**

### **Disability Research Ethics and the Methodology**

Out of my involvement with teaching art and design at Hereward College I became aware that processes of identity formation that challenged oppressive constructs of disability were taking place, epitomised in a process of 'coming out' that was expressed in student's artwork. I began to archive images and to seek deeper reasons for what was occurring. In this sense an emergent research design has been adopted in a project that has, in effect, emerged over the last 20 years. Similarly, during this time, the concurrent developments in Disability Studies, the Disability Movement and Disability Arts emphasised the attention I must give to ethical contexts and I was concerned to ensure that the study I wished to conduct acted as a vehicle for the voice, both verbal and visual, of disabled young people.

A qualitative approach has been adopted as the most appropriate tool of investigation with which to gather data concerning the experiences, values, beliefs and feelings that disabled students recount in relation to their arts education, their impairment, their sense of self and their status as disabled people. This chapter describes the methodological framework within which the interviews and questionnaire were carried out and this, with the addition of the students' artwork, will provide the evidence for investigating whether these students have expressed a positive sense of self-identity via the visual art. Prior to this an analysis will be made of the ethics concerned with doing disability research and in particular the appropriateness of collecting case study data in the context of this study.

#### **Ethical Disability Research**

The ethics of doing disability research came under increasing scrutiny from the beginning of the 1990s and Oliver, himself a disabled academic, was at the forefront of a discourse that developed on the problematic nature of doing such research (Oliver 1992, 1996, 1997, 1999). Clough and Barton refer to his contention that disability research had become 'part of the disabling barriers within society in that too often it has been undertaken in ways that have been alienating' (1998:31). They elaborate with a further quote from Oliver (1992) in which he states that for disabled people, research has been 'a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances' (p.31). Certainly, by the



late 1990s Oliver had moved to a more emphatic position, describing disability researchers as 'parasitic upon disabled people, for without the host body (disabled people) there would be no disability research' (Oliver 1999:184).

Cook, Swain and French (2001) substantiate these views with their observation that in the main research on disability has reflected the perspective of non-disabled researchers and that the views and experiences of disabled people themselves (including disabled children) have been ignored (p.294). Oliver (1999) predicts that as a consequence disabled people will no longer be prepared to cooperate with what he terms 'exploitative investigatory research based upon exclusionary social relations of research production (p.191). Certainly this is confirmed by the degree of disillusionment people with cerebral palsy revealed in a survey which found that:

People with cerebral palsy appear to be more reticent than most to participate in questionnaire completion or other forms of field - based research activity. This could be either because of feelings of over exposure or saturation to such approaches or because their experiences of contributing to past research initiatives, gives them little cause to believe that participation is worth while (Stevens and Williets 1999).

This disaffection has prompted an increasing recognition that the voice of disabled people should be central to disability research. An example of this is to be found in the work of Cook, Swain and French (2001) whose research recognises the need for representation and they draw their conclusions from the experiences articulated by disabled children themselves.

Oliver's discomfort with the role of social researcher led him to expound upon strategies concerned with re-conceptualising and creating a different research paradigm that allowed disabled people, treated as 'passive research subjects,' to be actively included. The distinction between what is termed participatory and emancipatory research is defined by Zarb (1997) as a 'crucial but often poorly understood distinction' (p.51). He describes the former as 'simply involv[ing] disabled people in research, while the latter means that the research is actually controlled by them as a broader process of empowerment' (p.51). It is probably the case that truly emancipatory, as opposed to participatory research is currently difficult to realise

given the lack of access to the research agenda that most disabled people experience. However, one suggestion that we cannot afford to await is that emancipatory research

will only be achieved when the material as well as the social relations of research production are overthrown, in other words when disablist late capitalism has been replaced by a different kind of society (Zarb 1992, cited in Oliver 1997:26).

Oliver himself speaks of ‘improving the existing social and material relations of research production: not challenging and ultimately eradicating them’ (p. 26). There are signs that the climate for this to occur could develop through firstly the increase in higher education and, by implication, inclusion in the research ethos by disabled students themselves. Higher Education Statistics Agency data would suggest that the traditional exclusion from the higher education agenda, at least for people with some types of disability, by virtue of social, economic and political factors impacting on their education, support and funding, is gradually being addressed. Secondly, the increase in delivery of higher education in further education colleges should ultimately lead to a broader based and less elite approach to research production. The Learning and Skills Council, through its research and development agenda, places significant emphasis on the extension of research from a hitherto exclusively university based tradition. Hereward College is an example of these developments. Funding from the Learning and Skills Council has enabled disability research to take place within a large community of predominantly disabled students (*Widening Participation in Higher Education for Disabled Students Project 2000-2004*). It has paved the way for the development of a research ethos at the college that is participatory and that has the ultimate goal of facilitating emancipatory research.

This study cannot be described as emancipatory in that disabled students have not had control of its construction and implementation through either its design, analysis, or dissemination of findings. However, neither does the disparaging description of ‘researcher-experts’ moving between projects like ‘academic tourists’ and using disability as a commodity to exchange for advancing their own status and interest’, seem applicable (Barnes and Mercer 1997:6). Oliver’s concern is that, ‘The researcher’s responsibility stops with the provision of an accurate account of experience - what to do with this account is always someone else’s problem’ (Oliver

1999:187). Whilst serving as a cautionary reminder, it can be countered, in this instance, by the existence of a continuum of reflective practice in the arts that has been developed at Hereward College over a number of years, and has been advanced by this research.

Barnes and Mercer (1997) note that:

the primary issue for those who have focused on the 'social relations' [of disability research production] has been the asymmetrical relationship between researcher and researched. This is seen as a major reason for the alienation of disabled people from the research process (p.6).

This has to be a consideration within this case study research where, as a non-disabled person with responsibility for the arts curriculum, I could be perceived as representative of institutionalised authority and a disablist society. However, I consider that this research is distinct, in that it has its roots in my art teaching background and in day to day contact with students with physical and sensory impairments. It does not fall within the parameters, of those

other areas of academia and key positions of power, (where in the main) the academic high-ground of disability analysis is dominated by men who have focused on the structural aspects of disability such as employment, income, housing etc (Vernon 1997:161).

During the 20 years that I have been employed at Hereward College I have been able to develop provision within which disabled students have discovered how to represent themselves in ways that are positive and empowering. I had trained in the Arts at a time when women's 'liberation' and civil rights had come to the fore and my first teaching post was in a south east London boys' secondary school comprised of a high proportion of children from ethnic backgrounds whose socio-economic and cultural status placed them at a disadvantage. Many of these children had unacknowledged learning support needs and were forced to access the curriculum on offer as best they could. They gravitated to the art room where they could achieve successful outcomes that allowed for a more positive reassessment of the self to take place. Further experience of teaching in 'special' schools increased my

awareness of the marginalised status of those with support requirements. The potential of the arts in the education of young disabled people at Hereward College in the mid 1980s was underdeveloped, and I was initially employed to teach for the few part time hours that constituted the arts curriculum. This provision expanded as the important role that the arts could play in the education of students with physical and sensory impairments became apparent.

I had, therefore, already built up a sympathetic rapport with the research subjects and had a basis from which I could create an interview situation that limited the potential for hierarchical constructs that can operate across the researcher/researched interaction, although I was aware that the teacher/student dynamic was still in operation. I tried to minimise the power relations inherent in this by conducting the interviews in as relaxed and informal a way as I could. They took place in a quiet and private space, in the spirit of a participatory project. I endeavoured to make clear that the interview not only informed my own research, but would also ultimately inform the delivery of the students' arts programme within the department, and that it was an extension of an ongoing dialogue with them.

When I approached students with the request for an interview, I offered them the option of refusing, and I also encouraged them to feel that they could decline to answer any question at any point. I made the purpose of the research clear and encouraged students to be objective in their responses. I emphasised the fact that I was not looking for 'right' answers, or answers that necessarily reflected well on the college, the art department, or my role within that. I made it clear that I was genuinely interested in their thoughts, feelings and experiences and that I was appreciative of the time they gave in answering the questions. Students were told that they would be informed and consulted as the research progressed. Issues of confidentiality were discussed with students and they were given the option of being represented in the research with their own names, or of remaining anonymous. In what I perceive as a move towards securing and retaining ownership of their own accounts, they all elected to be known by their real names. This decision would seem to reflect a wider, growing concern by disabled people to be individually identified and heard.

At the conclusion of each interview when I thanked students for their time and outlined future plans for the research or invited further participation, I asked them to

reflect on the request I had made for them to take part in the interview. Responses varied from the cavalier, 'doesn't bother me, got nothing else to do today', to the more tentative reply that indicated that the student had been subject to interviews before and that this held certain anxieties for him, despite his apparently positive reactions to taking part.

I've never minded answering questions to people. I've done it a few times in the past so I'm used to it. I was a little bit worried about the questions I'm going to be asked - am I going to be able to answer these?

This statement contrasts with the more confident reaction from other students who stated 'It made me feel important' and 'I'm very happy, I'm happy to talk about my experiences and how I feel about art'. Overall these comments are representative of students' responses. I had the sense that students were pleased to be asked to participate and enjoyed having the opportunity of designated time out with me in which to individually express their personal opinions and experiences in some depth.

The interview outline and summary findings were presented to the students who have participated in the research interviews, at each stage, and their confirmation and validation of meaning that has been construed, has informed the study. Similarly, meaning that has been derived from students' artwork has been confirmed and permission for its use as an exemplar has been sought. When students had had the opportunity to read the chapter in which they featured, they appeared intrigued to see themselves reflected in what I had written and were gratified to see their experiences given formal status. The research interviews also reminded me of the importance of allocating specific time, in addition to the formal and informal contact that the studio environment allows, to listening in greater depth to students' thoughts, feelings and experiences. The opportunity to take time out informally provided much greater insight and valuable detail of how students perceived themselves and how this translated into their arts practice. It revealed the student voice in ways that can so easily get lost in the everyday activities of a busy department.

### **Methodology for the Case Studies**

Impairment is specific to the individual and even people with the same impairment, whilst sharing some similar characteristics, are often affected in differing and specific

ways. The degree of disablement experienced by the individual is similarly varied and made complex by an array of factors. These might include the nature of the impairment, parental circumstances, attitudes towards disability that are encountered by family, friends and teachers, the medical profession and social services, material barriers, economic circumstances, support available and experiences in education. Stake's comment that 'Issues are not simple and clean, but intricately wired to political, social, historical, and especially personal contexts' is particularly apposite to this study (Stake 1995:17). Given that this research seeks to investigate cultural, expressive and esoteric issues of self identity, representation and self esteem through the medium of the arts, the case study interview will be employed as the appropriate method of research investigation. It will be the means by which holistic and meaningful characteristics of multiple realities can be explored and different and even contradictory views of what is happening can be captured.

Hodkinson (2001) refers to case studies as grounded in 'lived reality'. He expresses this as the case study being able to 'retain more of the 'noise' of real life.' Whereas, 'other forms of research base their success on the ability to exclude such noise ... in some circumstances the excluded noise may be a highly significant part of the story'. He considers that:

This particular facet of case study research brings it closer to the experiences of teachers and trainers than is possible with some other forms of research. For teachers always work with "noise". Their contexts and conditions are always complex ... they cannot exclude unwanted variables, some of which may only have real significance for one of their students (p.4).

The fact that case study investigations can facilitate the examination of the exceptional is seen as valuable by Hodkinson, particularly in the context of the practice of teaching and particularly those with support needs which, he states, 'has to engage, on a regular basis, with "non-standard" students'. He maintains that 'examining the exceptional case can itself throw valuable light on the nature of the more normal processes' (p.4). It is debatable whether there is any such thing as a 'normal' process and therefore by implication an 'abnormal' process in education. Stake instead emphasises uniqueness, and by implication knowledge of others from whom the case is different. He places the first emphasis on 'understanding the case

itself' and from this to '[using] the uniqueness of the case to illustrate ways in which each case is likely to be complex, not what cases have in common' (Stake p.7, p105).

There is no such thing as a typical process or, in fact, a typical student at Hereward College and there is much in the teaching and learning that is highly complex, subtle and intuitive and that is based on experience and observation. Hodkinson considers that case study research is at its strongest when, 'expertise and intuition are maximised' however he also acknowledges that this raises doubts about objectivity (p.4). Stake comments '[we] recognise that case study is subjective, relying heavily on our previous experience and our sense of worth of things, our observations cannot help but be interpretive' (1995:134). This raises the question of whether, or how, case study findings can be generalised, or whether it is as Hodkinson maintains that, 'people can learn much that is general from a single case' (p.4). This case study research will provide a sample that is small and idiosyncratic and, therefore, the extent to which the data represents the larger population of disabled people and their experiences of arts education, or, that similar issues of self-identity and self esteem are germane is uncertain.

However, despite the fact that case studies cannot be seen as representative, Hodkinson considers the issue of 'what case studies can tell us about situations beyond the actual case that was studied' (p.4). He sees theory as transposed beyond the original sites of study so that where new thinking has been generated, that thinking has 'a validity that does not entirely depend upon the cases from which it is drawn' (p.4). This implies that, in this research, the theories that link disabled students, arts education and self identity can be judged in other contexts and settings with students with differing learning support needs. This research therefore can be considered as more than the story of some of Hereward College's students and as a theory of arts education and empowerment. It establishes a provisional truth even though it is based on the direct experiences of only 15 students and should stand until contradictory findings or better theorising has been developed. Certainly it is anticipated that it will be possible to draw an initial set of conclusions from the research findings that are worthy of a much broader survey and critical analysis.

### **Methodological Framework**

The method employed to explore the relationship between the visual arts, disability, positive self-identity and representation was semi-structured interviews which were carried out with students, Hereward College staff and some parents. Interviews with students and analysis of this data have been simultaneous and ongoing activities that have allowed for important understanding to be discovered along the way and then pursued in additional data collection efforts. This research did not have the resources for a longitudinal study, but was designed nevertheless to investigate a 'slice' through the sequential levels of Hereward students' development in the arts. It sampled their disability awareness and the development of their visual literacy at various points in a process of post 16 education. Some students were interviewed at the beginning of what has the potential to become a process of self-realisation. Some were interviewed at critical points within this process and some students' development was traced at a point at which they could reflect retrospectively on the process. The case study chapters together, therefore, are designed to move from a more generalised account by a number of students which establishes the main issues, to more detailed accounts that, in exploring the students' narrative in greater depth, traces and illuminates these issues more fully.

All participants attend, or attended, Hereward College as residential or day students following arts programmes part or full time. Enrolment at the college records a higher proportion of males to females (58.3% male, 41.7% female) with creative studies reflecting a slightly higher percentage of female enrolments than the college overall (45.2% female, 54.8% male). People from ethnic origins other than white are represented in the college and the creative studies department as 10.7%. There are currently 115 residential students at the College, 200 day students with additional learning support needs and 203 standard students who are in the main enrolled to part time courses. Enrolments in creative studies (which includes visual and performing arts) accounts for 14% of the total college enrolment (Hereward CMIS 2002).

Semi-structured interviews were conducted individually, because of the individualised nature of impairment, and response to it, and to the experience of disability. Group interviews were deemed of lesser value, although some experiences in terms of schooling and the medical profession are shared. All participants have a physical and/or sensory impairment and, at the time of the interviews, are studying, or have



studied, at Hereward College. The inclusion, in this small study, of those students at the college who have head injuries, mental health problems, emotional social and behavioural difficulties and Asperger's syndrome, alongside students with physical and sensory impairments, would have comprised too complex and diverse a group from whom to draw meaningful conclusions. Hereward's provision does not currently include Art Therapy as such, and the college makes limited provision for students who have psychological difficulties. 'Outsider' (psychiatric) art, or art of the mentally ill, is characterised by visual references to an internal narrative that is based on a highly idiosyncratic view of the world and the human condition. Ferrier (1998) comments:

They all portray the desperate attempts of man – traumatised, agonised, or irreparably shattered – to reconstruct, with the help of a few colours or the odd piece of stone, his unique, distinctive identity (Ferrier:Forward).

The complexities of the expression of self-identity by the mentally ill or those with mental health problems are seen as a separate research project and as such are not included in this study. The artwork and experiences relating to self-identity of those with learning difficulties are similarly not included.

The inclusion of overseas students in this study would also have introduced disparate variables and made valid and meaningful conclusions unrealisable. Cultural attitudes towards disability vary, as do educational and artistic philosophies. This study will, therefore, be focused on students with physical and sensory impairments, of whatever ethnic origins, who have been educated in Britain. This research is confined to a study within the visual arts and does not include the performing arts, as once again, the field of study would be too extensive for this project.

### **Data Collection and Sampling Criteria**

The rationale for the number of students interviewed for each case study chapter was based on my estimation of what would provide the greatest insight into considerations of self identity, self esteem and disability at the various stages of their arts education. In the early stages such considerations are more tentatively expressed, verbally and through artwork. I decided that in the first of the case study

chapters (seven), a more generalised account by a larger group of students (9) would provide an initial overview and establish commonalities of experience and of the issues involved and I therefore interviewed all of the students available that fitted the control criteria. The focus narrows, in the following chapters, to a more in depth account of the experiences of 1, 2 and 3 students.

Interview participants were selected based on maximum variation, within the control criteria. The similarities of the participants were that they all have a physical and/or sensory impairment, and have studied, or are studying, at Hereward College. The ways in which the participants vary are by impairment; whether their impairment has been present from birth or acquired; whether they are residential at Hereward College or attend on a daily basis; the length of time they have studied in further education; their focus and level of study; their educational background (special and/or mainstream provision); and age, gender, and ethnic background.

### **Data Analysis**

Each individual interview was transcribed in full. Data analysis was conducted using the constant comparative method (Maykut and Morehouse 1994). This method is designed to identify themes and patterns in qualitative data and is preceded by the collection of data which is categorized and grouped together in this study, to demonstrate similar thoughts, experiences and opinions. This systematic sorting and organisation of data revealed salient links between impairment and disability, representation, identity, self esteem and the educational experience of students in the visual arts. Material was compared to look for nuances and variations of meaning and emergent themes from the first interviews were developed in subsequent interviews. Any new data was constantly compared with earlier data. Propositions were formalised from the themes and patterns that emerged.

### **Pilot Interviews**

In 1998, in the very early stages of this research project, I carried out some pilot questionnaires with a small group of Hereward students (see appendix 1.1), and an interview with the mother of one student in her home when the questionnaire provided the basis for the interview schedule. These constituted an exploratory exercise that determined the areas of investigation that I was considering and informed subsequent interview schedules. Data collected from the pilot questionnaires has not been included in this study however the interview data with

the student's mother (Mrs Chamberlain) has been used. Mrs Chamberlain was selected because of my involvement with her daughter Bonnie's art education and because I had observed that despite difficulties with fine and gross motor control and verbal communication, her approach to the visual arts was confident and enthusiastic. The impact and importance of parental attitudes to creative activity and the part that Bonnie's mother had played in her daughter's assurance only became transparent through the interview process. The interview that was conducted with Mrs Chamberlain and which was guided by my areas of interest and the things that she considered significant to the generalised area of her daughter's involvement in creative activity, proved to be key in identifying where my areas of investigation should be taking place.

### **Interviews with Students at the College**

The interviews that were conducted for the first and second case study chapters (seven and eight) were with students on level 2 and 3 courses. Of these students, some were new to the study of the visual arts at Hereward College and some had already successfully completed courses at level two and progressed to level three. At level two (GCSE Art and Design) 18 students were enrolled for the academic year 2001/02. Of these, 3 withdrew. The remaining 16 comprised, 5 non disabled students, 3 that had emotional, social and behavioural difficulties, 2 with Asperger's syndrome, and the remaining 6, who were interviewed for the purpose of this study, had physical and sensory disabilities. Of these 6, 5 were male and 1 was female.

At level three (The Diploma in Foundation Art and Design) 11 students were enrolled. Of these, 2 were non-disabled students, 2 had emotional, social and behavioural difficulties, 1 had Asperger's syndrome and 6 had physical and sensory disabilities. Of these 6, 2 were female and 4 were male. One of these female students is the subject of the in depth case study that forms the content of chapter eight. In total 11 students were interviewed and the data collected from 9 of these interviews was analysed for the first case study chapter. The data collected from two of the interviews was not included. One of these interviews was with a female student who had sustained a head injury as a result of a road traffic accident. It became clear that it was not possible to trace a coherent narrative of her arts experience in the context of disability and impairment and her account was contradictory and impossible to analyse in any meaningful way. The other account was by a male student, in his first year at the college, who was born in Britain but

whose ethnic origins are Indian. In addition to his physical impairment, he has some undiagnosed social/learning difficulties, and his interview provided data that was very confused and inconsistent.

### **Arts Practice and a Sense of Self**

This chapter (seven) draws on interviews carried out with a group of 9 students (eight males and one female). The uneven distribution of gender reflects the fact that Hereward College enrolls an extremely diverse group of students in a small college setting. To achieve an even distribution of gender that was more representative, a research study would have had to have been carried out at Hereward College over a number of years. Alternatively data could have been collected from a more representative group of male and female students by including those studying in other specialist post 16 arts provision. However this would have introduced other variables and students would not have been giving an account based on shared experiences of the arts curriculum and environment at Hereward College and from which common meaning about the relationship between visual arts education and self-identity could be identified. It should, however, be noted that such a comparative research study of disabled children and young people's experiences of arts education in both specialist and main stream provision could provide very informative data within the disability arts, arts and disability discourse.

Of the 9 students interviewed, 5 were studying at level 2 (GCSE) and 4 were at the beginning of a level 3 (Diploma in Foundation Art and Design) course. They are representative of the wide range of physical and sensory impairments that Hereward College accommodates and their impairments include cerebral palsy, muscular dystrophy, spina bifida and sight impairment. Additional impairments such as epilepsy, asthma, dyslexia, and emotional social and behavioural difficulties are also represented across the group. Seven of the students have had their main impairments from birth; two had acquired impairment as a consequence of accidents sustained in early childhood. Five of the group were residential students and the remaining four attended college on a day basis. The students' support requirements are diverse and include ICT responses, assistance with practical tasks and support with study skills (organisation, planning, prompting and reinforcement) and with behavioural difficulties (anger management, educational psychology, counselling and mentoring). Four of the students are wheelchair users and five have personal care requirements.

The interviews were semi-structured and were chronological in the sense that they invited the student to develop their own narrative from their earliest memories of their involvement with art through to their present experiences as students (see appendix 1.2). The questions covered the influence of family on artistic development, role models and perceptions of art. Students were also asked about what they thought the purpose and definition of art was and whether this was pertinent to them specifically as disabled people. They were asked about their schooling and their awareness of the Disability Movement and Disability Arts. In the initial interviews with students who had only just begun their arts education, questions about the specific concept of self-identity, were posed obliquely. Students did not at this stage have an objective concept of disability that was not damaging to 'self' and their thoughts about disability were reflected mainly through their experiences of mainstream/special schooling. I was aware, at this juncture in the interview process of a dilemma between my roles as researcher and teacher. The authentic student 'voice' would have been lost if I had proceeded to give them the information they lacked, but there was also a professional obligation to do so. It was reassuring to note that in the interviews with the older students who had completed their arts education, they were able, from an informed position, to draw their own conclusions retrospectively from experiences that they now had the insight to view more objectively.

Through this process it was possible to identify the themes/issues/significant events/individuals etc. that had impacted on student's sense of themselves and whether this had been or was mediated through their artwork. Additional questions, or encouragement to elaborate, were made when it was clear that important or relevant information was emerging. It was felt that a tighter interview structure would have impeded the flow of narrative and intervened in what were individual accounts that reflected the diversity of personalities and family circumstances, the nature of impairment and disability and the fluidity of self-identity.

### **Access and Support in the Development of a Visual Language**

The second case study chapter (eight) gives an account of a non verbal student, Samantha (Sam), who is studying on the Diploma in Foundation Art and Design at level three. The rationale for including a detailed account of her experiences was based on a number of factors that I considered would elucidate this study. Over a period of time it had become clear through observation of Sam herself, her lifestyle

choices, clothing and hairstyle, and through her artwork, that concerns about self-identity were of central importance to her. I considered that she could provide a valuable insight into the significance of the development of a visual language for someone who is non-verbal. The ways in which she uses visual language, particularly given that verbal and literary forms are not attainable for her, make her visual statements about self-identity particularly germane to the development of this research thesis. It would seem that the difficulties of including non verbal people in research terms means that they are under represented (Cook, Swain and French 2001), however, the particular circumstances of this study, whereby I had known the student over a number of years, presented an opportunity for her inclusion. In addition the complexity of her learning support needs (communication, technology, amanuensis) presented an opportunity to investigate the interrelated and critical part these play in the production of her artwork and their importance, therefore, in varying degrees, to other students with impairments who study the arts.

An understanding of the experiences, thoughts and ideas of Sam herself were built up over the period of time she was at the college, not only from many conversations and tutorials but also, and critically, from observation of her work, how she was producing it, what she was researching as source material, how she was communicating and working with enablers and staff and also from Sam herself, her expressions and intent and how she was choosing to present herself. However, in order that a comprehensive picture was achieved, that included the complex inter-relationships that exist between her and the individuals who support her, the student and I agreed that her parents (with Sam herself present), the manager of the enabling support team, the speech therapist and her art tutors would also be interviewed (see appendix 1.3a - d). In addition, and with Sam and the enabler's agreement, video recording was used to capture the subtleties and nuances of Sam's interactions in terms of eye contact, expression and body language. Data was gathered from Sam's artwork, working journals, sketchbooks and teaching records and assessments.

Hodkinson states that a case study approach will 'facilitate the construction of detailed, in depth understanding' (2001:4). By studying Sam's experiences, feelings and opinions and the circumstances under which she is working as a non verbal student, I will be, in Stake's words, 'trying to establish an empathetic understanding for the reader' (1995:39). Stake describes case study as 'highly personal research,' a

'vicarious experience' (p.135, p.63). It is through the construction of this 'vicarious experience', from observation, communications with Sam herself, and the accounts of those closely associated with her education, that a better understanding of her impairment and disability and her construction of a positive self-identity will emerge.

### **Disabled Students, Higher Education and the Visual Arts**

The third case study chapter (nine) is based on interviews with two disabled students, Daniel and Aharani, studying at level four in higher education (see appendix 1.4). Their inclusion in this study was based on the similarities that provided a measure of control when analysing their experiences, they both have the same impairment, they both studied at Hereward College and they both progressed to the same University. Their differences emphasised the additional influences in identity formation and the interpretation of experience. They differ in terms of class, ethnic origins, gender and the specialist area of the arts that they were studying. Daniel was interviewed twice for this research, once at the end of the Diploma in Foundation Art and Design and once in June 2002. Aharani was interviewed at these points but also at stages in between. At the final interviews in June 2002, Aharani had, after an extension period of one year to the customary three-year degree programme, completed the practical elements of her BA degree in textile design and had an October 2002 deadline for the submission of her dissertation. Daniel had just successfully completed the second year of his BA Degree in Fine Art. Daniel was happy for the interview to be tape-recorded but Aharani preferred it not to be, and so the interview was constructed with notes taken at the time.

### **Three Artists**

For the final case study chapter (ten) interviews (see appendix 1.5) were carried out with three ex Hereward College students, Eddy, Colin and Ruth, all of whom are now in their early to late 30s and have completed their arts education. I had known all three of these students throughout their arts education post 16 and beyond, and we had maintained, throughout this period, a dialogue that had included issues related to this research. Their inclusion was essential in terms of their ability to express verbally and visually issues of disability, impairment, self identity and how this is represented in their work. Their differences and similarities had the possibility of not only confirming and elaborating experiences that had already arisen in the other case study chapters from a mature, informed perspective, but also of exploring this through their professional artwork.

They all, at different times, completed the Diploma in Foundation Art and Design at Hereward College and subsequently progressed to BA degree courses in Fine Art at Coventry University. Eddy and Ruth have successfully completed an MA. All three have made impairment and disability the subject of their artwork but they differ in that Eddy and Colin have impairments that are congenital and they use a manual and electric wheelchair respectively, whereas Ruth is ambulant and acquired her visual impairment as a consequence of diabetes when she was 32. Colin is the only one of the three who has personal care assistance. Both Eddy and Colin were educated exclusively in specialist provision although at different periods influenced by different integration/inclusion agendas. Their first experience of mainstream provision was at university. Ruth as a non disabled child was educated in mainstream provision until she started the Diploma in Foundation Art and Design at Hereward College as a mature student. Ruth and Colin are both Coventry born and continue to live in the city. Eddy, who is originally from Liverpool, now lives in Durham.

#### **Interviews with Staff**

Semi-structured interviews (see appendix 1.6a - d) were carried out with several long standing, members of Hereward College staff who represent a significant body of expertise in their specialist area. These included the director of Teaching and Learning, the Manager of IT Support, Head of Residential Education, the Speech Therapist, the Head of Basic Skills and the Manager of Educational Enablers.

#### **2003/04 New Residential Students Questionnaire**

The questionnaire (see appendix 1.7) carried out with all of the new residential students at the beginning of the academic year 2003/04 was designed as a measure of how changes from government initiatives, disability research and generally raised awareness might be impacting on the educational opportunities and arts experiences of disabled children and young people in the five years since I had begun this research. The 33 interviewed, of whom 22 were male and 11 were female, represented a national cohort within the age range 16-22 with the majority (70%) in the 17-19 age groups. They are representative of the range of impairments that Hereward College supports.

I supported students in completing the questionnaire to eliminate difficulties with literacy and/or communication, to ensure understanding, to investigate fully the



responses that they gave and to elicit a 100% response. The questionnaire was designed to capture information regarding educational experience, the achievement of arts qualifications, how support requirements for arts activities had been met in terms of IT and classroom assistants, and levels of awareness about the Disability Movement and Disability Arts were also investigated.

### **Additional Data**

#### **James Lancaster**

Data has been included from the artwork and coursework documentation of James Lancaster who joined Hereward College in the 1990s as a Foundation Course student. He had come to the college with exceptional achievement in A-level art and it soon became clear that he was a potential HE student. However, his high level support needs and complex medical and nursing care precluded him from mainstream provision. The Hereward College/Bretton Hall partnership described in chapter nine was largely inspired by his potential exclusion from this higher level of study, despite clear evidence of skilful progression in his artwork. He provides important data for this study as his artwork records the development of his understanding of the lived experience of impairment and the powerful ways in which he has incorporated this as an intrinsic part of his identity without recourse to stereotypical notions of pity or tragedy.

### **Workshop and Project Data**

Data is included in this study from two important workshops that were carried out at Hereward College, one at the beginning of the 1990s and the other a decade later. Both were externally funded and presented opportunities for disabled artist in residence placements at the college. Both projects dealt with issues of disability and self identity and had a lasting impact on the students that were involved, and on the arts provision in the college. Data was collected from workshop notes, evaluations, interviews, publications and artwork.

### **Photographic Project 1992.**

The photographic project that was carried out over a ten week period in the Autumn Term of 1992 was a watershed in terms of the impact that it had on the arts provision at Hereward College. Supported by the Ikon Gallery Birmingham, with funding from Marks and Spencer, the Onnely trust, the Alan Edward Higgs Charity and the West Midland Arts, it was the first time that a professional disabled artist (Brian Jenkins,

see chapter one) had worked with a group of disabled and non disabled Foundation Course students on issues of self identity and disability.

### **Craftspace Touring Project 2000/2001**

Craftspace touring is a touring and development agency based in Birmingham. The project that was carried out at Hereward College over a number of weeks was funded collaboratively by West Midlands Arts, Birmingham City Council and The Baring Foundation. In addition to a number of agency staff and a free lance professional photographer who documented the project, two artists were employed to work with the students. These included a wheelchair user and a professional textiles artist. The project, which was entitled *The Politics and Poetics of Cloth*, was carried out with a group of disabled and non-disabled students from across the creative studies curriculum and explored issues of identity and disability through textiles and text. The work that was produced was shown in a touring exhibition – *Ikons of Identity*.

### **Barriers to Higher Education for Disabled Students Report 2000/02**

Data from Hereward College's Widening Participation initiative has illustrated the difficulties that disabled students encounter in accessing higher education. The report is based on interviews carried out with 20 ex Hereward College students studying at university, but not necessarily in the visual arts.

### **Higher Education Statistics Agency Data**

The Higher Education Statistics Agency (HESA) categorises disability (or impairment) data under a number of headings. Their categories indicate the type of disability that a student has on the basis of their own self-assessment, and are consistent with those used by the Universities and Colleges Admissions Service (UCAS). For continuing students, where the information is not already known, institutions have the option of recording the student's disability as not sought. As a result, some institutions have not returned disability data for all of their students. In addition, students are not obliged to report a disability. HESA therefore advises that the figures reported in their analyses are derived from a subset which may not be representative of the total student population. However, in the absence of any other data, and based on the assumption that students with support requirements are more likely to declare their disability I have selected those categories which most closely approximate to Hereward College students who have physical and sensory

impairments i.e. deaf/hearing impaired; blind/partially sighted; wheelchair users and those with personal care needs. Disabled students' presence in the areas of Fine Art and Textiles has been noted as a comparator for the two students' accounts in chapter nine. The areas of Graphic Design and Multi Media Design have been included to demonstrate that even where increased participation could be expected because of the potential accessibility of IT based areas of study their numbers remain small or non-existent.

### **The Artwork and Images**

The images that are included as data in this research are derived from a number of sources. These include the work of artists who are working from a feminist or disability perspective; images from the media including television, government and charity posters; sports and fashion images and historical images, including those associated with the medical documentation of disability and those produced for amusement like the *carte de visite*. Also included, where this contributes directly to the subject of this research, is the work of contemporary non-disabled artists namely Marc Quinn and Freddie Robbins. In addition students' artwork, which includes paintings, drawings, photographs, textiles, installation, 3D and computer generated images, is included as data that I considered exemplifies the thesis as it is being developed. This work has been produced as a specific response to an educational agenda with the exception of some of the work that two of the artists (Eddy Hardy and Colin Marsh) have produced post graduation. For the first two case study chapters I selected images for inclusion with the consent of the student. In the latter two case study chapters the students selected those images that they considered to be representative of their work and that they had talked about with me.

### **The Impact of the Study on the College Arts Curriculum**

The interviews carried out for this study provided an opportunity to gather in-depth and detailed information about specific students, their views, interests, opinions, their awareness of the social, political and economic impact of disability, their preferred learning styles and subtleties of communication and language. It has directly benefited those students who are still studying at the college by highlighting for individuals the social construction of disability and of the ways in which this can be addressed via a visual language. It has also informed the ways in which the arts curriculum can be refined further to more closely meet students' needs and will be disseminated in an ongoing process to departmental teaching staff and taken up with

other support staff where appropriate. For example, the interviews that took place with the student who has non verbal communication prompted review meetings between the speech therapist and arts tutorial staff when it became clear that there was scope for further refinement and development of the student's communication systems. A framework exists at the college to ensure that the information necessary to effectively support students in the attainment of academic and personal goals is co-ordinated and known. However, this research has acted as a reminder of the complexity of students' support needs and that vigilance is needed to ensure that the student's voice continues to be central in a process that has the potential to be experienced as fragmented at an institutional level. Similarly there is a need to guard against complacency and the assumption that students' learning support needs remain constant when in fact they are subject to change.

As the interviews have progressed, the extent that the positive impact of working with disabled artists has had on students and their importance as role models has emerged. Efforts have been redoubled to ensure that this practice is maintained, increased and developed. The interviews with the three ex-students have prompted a resurgence of involvement with the college in the form of workshops, presentations etc. The interview process has also revealed students' lack of awareness about the Disability Movement and Disability Arts and as Disability Studies is not taught formally as part of the curriculum at Hereward College, it would seem that, with the exception of the arts, disabled students rarely have the opportunity to place their experiences within a social, political, economic or historical context. It is intended that this research will be relevant not only for the visual arts education of disabled children and young people, but potentially as a point of reference for addressing the more generalised issues of self-identity and self-esteem that arise in a multi cultural and increasingly complex society.

### **Summary**

This research has emerged out of existing teaching and learning in the arts at Hereward College and has its roots in the commitment to empower disabled students. The methodology is centred on a qualitative approach which, with the inclusion of their artwork, maximises the potential for the students' voice to be heard. Attention is given to the ethics of doing disability research, with recognition made that improved arts education for disabled young people is an important outcome of this study, not only at the college but in a broader context. The following chapter

gives an account of Hereward College, its provision and the developments in arts curriculum, enabling support and IT that have radically enhanced opportunities in the arts for disabled young people.

## Chapter Six

### The Arts Provision at Hereward College

This chapter will provide the context for the four chapters that follow and that focus on the accounts that students' give of their disability, arts education and self identity. A description of Hereward College and its arts curriculum will be given, including the significance of course syllabi and the cross-college Disability Arts programme. The central and important role of support provision (educational enabling and IT) will be examined in detail and the potential that this has for disabled students to become self-determining in the production of visual imagery will be outlined. An analysis of the historical involvement of disabled students in creative activity, and the traditional linking of disability with craft and the notion of therapy, will provide the frame of reference within which current provision can be considered. The development of approaches to arts education that took place in the mid 1950s, and which culminated in the establishment of the Foundation Course in Art and Design, will be traced, and the impact on the arts education of disabled students at the college, after this course was instigated in 1987, will be noted.

Hereward College opened in 1975 as a specialist college funded by the public sector. Its independence from charitable support and the integration of its students into the local community made it unique. The college was located on a site shared with a mainstream college adjacent to a main road leading to the city centre. Historically specialist provision for people with impairments was placed on green field sites away from the mainstream community harking back to the early twentieth century practices of sequestering disabled people away from the public eye, ostensibly on the principle that people with impairments needed fresh air. The shared site offered opportunities for shared courses, but it was not until the early 1990s with the enrolment of local non-disabled students onto Hereward's courses that the college aspired to a singularly inclusive learning environment. The result, potentially, is educational provision that reverses the *status quo*, although those that promote single mainstream education for disabled people would still call it a compromise. An analysis of provision, in terms of this integrated status, reveals that only a very small number of non-disabled students are currently (2003) enrolled full time at the college, although a more significant number are enrolled for part-time evening courses.

The college was designed as sector provision for students with physical and sensory impairments, and was designated a general college of further education under the 1992 Further and Higher Education Act. The case for the existence of Hereward College remains the same today as when it was opened: to meet the needs of those students for whom the sector, or mainstream colleges, cannot make provision. McGinty (1993) states:

The concept that was enshrined in the 1970 Education Act, which was that no child is in-educable, has meant that young people with more complex and multiple disabilities have had their expectations raised. The trend has been for colleges of further education to gradually provide for more young people with disabilities and learning difficulties. This has led to Hereward College catering increasingly for those with profound and complex needs (p.3).

The 'inclusiveness' that Hereward promotes would suggest a more open and diverse cultural ethos and, in theory, this should militate against institutionalisation and the introspective paternalism that can colour specialist educational provision for disabled people based on a charity model.

However, the analysis carried out by Davis and Watson (2001) and their findings, with regard to the social and cultural exclusion that disabled children experience in special and mainstream schools, are pertinent to the Hereward College context. Whilst acknowledging the rapid changes in the past two decades and the increased possibility of disabled children attending mainstream schools, sitting public examinations, and moving onto further and higher education, they assert that disabled children's integration and inclusion is far from complete (p.671). They identify factors over and above the barriers to inclusivity that have been explained in terms of structural influences and 'market place educational policy which essentialises difference' (p.671). Their findings suggest that in addition to these

disabled children encounter discriminatory notions of "normality" and "difference" in both "special" and "mainstream" schools, and that these experiences relate not simply to the structural forces that impinge on schools and teachers, but also to the everyday individual and cultural practices of adults and children (p.672).

No parallel study exists for Hereward College or indeed for other general or specialist FE colleges. It would, however, seem reasonable to assume, until it is proven to the contrary, that such notions must also be present within Hereward, and that, as in schools, 'very few adults ... question the processes and social contexts in which they construct notions of difference' (p.684). Disability as represented by the employees of Hereward College and compared with general further education colleges in England, raises an interesting anomaly. Currently out of 234 Hereward staff, 14% have a declared disability compared with 2% of college staff in England in 1997/98 (Hereward CMIS2002/FEFC 2000). In terms of Hereward staff this figure does not translate into a higher presence of wheelchair users, sign interpreters, guide dogs etc. It can only be surmised that the higher levels of awareness at Hereward College encourages staff to declare disabilities, which it would seem in the main are hidden, in a way that they would not declare them in a mainstream setting. The governing body currently includes one member who is a wheelchair user.

### **The Arts Curriculum**

In 1986 when I started teaching at Hereward College, mainstream arts provision for disabled people had traditionally been, and still was, difficult if not impossible to access. Some students were not perceived, and therefore did not perceive themselves, as having the required level of physical or sensory skills to participate in a practical activity. Students at this time reported that the impact of cerebral palsy on manipulative skills, or sight impairment on the potential to work in a visual medium, was seen by their teachers as prohibitive and they were urged to find other options. Special school provision in the arts was often perceived as a leisure or therapeutic activity with few or no opportunities to gain accredited qualifications. Opportunities to gain qualifications leading to higher education or employment were limited.

Mainstream provision at level three, Foundation Art and Design, a course whose status in terms of location within higher or further education was uncertain, was perceived within education spheres as the 'poor relation' to 'academic' courses. It was often housed in old, inaccessible buildings and delivered in cluttered and unconventional studio settings that were particularly difficult for disabled students to access. Funding for equipment, general expenses and a helper's allowance were not available until the introduction of a modest Disabled Students Allowance (DSA) in 1991/92, making access to higher education prior to this unobtainable for those



students who had minimal learning support needs, let alone significant and complex ones. People with impairments were marooned within a 'basket weaving' or 'Christmas card' interpretation of the arts.

Visual arts provision at Hereward College had had similar limitations, although some accredited courses were available for a small group of interested students at this time. Music, the performing arts, photography, video and media courses were not part of the curriculum. There were, however, several factors that were going to impact significantly on the accessibility of the arts for people with impairments in the coming decade and which rendered the arts at the college ripe for development.

The first of these was the groundswell of disability awareness and political activity that, from the mid 1980s onwards, had permeated thought on disability at a public, institutional, cultural and political level. Increasingly people with significant impairments and complex learning support needs, for whom provision had previously not extended to further education and for whom day centres had been the only option, were coming onto Hereward's courses. In addition, and of critical importance, rapid developments in Information Communication Technology (ICT) had the potential to revolutionise the life of disabled students. This was accelerated at Hereward College, by computer technicians who customised students' equipment and software. Furthermore educational enablers, who provided practical support for students in creative studies, were developing a subtler, more sophisticated service than that of the traditional classroom assistant. These developments, which are discussed more fully in the latter part of this chapter, ensured that, theoretically, no area of study should be inaccessible to students regardless of the nature of their impairment. As a consequence the arts curriculum at Hereward College expanded, and continues to do so (145.7% increase in the last four years: Hereward CMIS 2002). With the unique inclusion, from 1987, of Foundation Art and Design as a route to higher education from a specialist college, creative studies was 'opened up' for disabled students to achieve to their highest potential and aspire to qualifications that would potentially enable them to achieve a professional presence in the Arts.

The freedom to express concepts and imaginative ideas practically in work that was achieving success by mainstream standards, often led to a rational re-assessment of the self, to the questioning of who this creatively autonomous person, capable of such unanticipated achievements, might be. In this new light, issues of individual

identity emerged and were given expression. It was evident that the development of this surer sense of self was reflected in a heightened self-esteem. Within arts programmes, in addition to the important gaining of technical skills and competencies, something more profound was taking place. There existed the potential to, 'centre issues of identity, which are crucial to the lived experience of disability by individuals' (Shakespeare 1994:293).

In the report of a disability project which took place at the London Institute 1997-2000, the distinction is made between 'Disability Arts' and 'arts and disability'. The report states

Disability Arts is crucially informed by a disability identity with the intention of challenging and communicating ideas and issues about disability; arts and disability is concerned with ensuring disabled people have full access and representation within the arts (Fink, Thompson and Williams 2001:13).

At Hereward the fusion of these two distinctions enabled students to acquire the skills and techniques of a visual language, within an environment that encouraged and informed their understanding of the attitudes that conspire to keep them fixed within a given and particular, negative, disability identity. The process of creating new empowered self identities and of articulating the lived experience of impairment can become an enduring preoccupation, or one that is transient and formative, or indeed may not be addressed at all. The point is that opportunities are available via the arts for all students at the college to address issues of self-identity. Identity, and its relationship to disability, can constitute for many disabled individuals a stumbling block to progress. In the visual arts the processes of establishing a positive self-identity can coexist with the business of achieving the skills for developing a coherent and accomplished visual language and for realistic employment within the arts professions.

The London Institute report also states that

Art and Design covers a vast subject area and range of courses that encompass a variety of teaching styles and modes of curriculum delivery. This diversity of approach is fundamental to delivering such a

fluid and personal area of study (Fink, Thompson and Williams 2001:11).

The matching of this 'diversity of approach' creatively to the diversity of preferred styles of learning for all students, but more particularly to the diversity of impairment, marks out art and design as a potential leader in inclusive learning. In addition, radical changes in the nature and perceptions of arts education, (described later in this chapter) and the impact that this has had on the accessibility of arts syllabi, have, in recent years, rendered the arts curriculum more accessible and relevant to greater numbers of disabled children and young people.

Firminger, a long standing member of the college staff, describes the limitations of the early arts provision at Hereward College.

Well, there was a teacher for arts and craft who was also responsible for all the assessments of students and for woodwork. I don't think until 1984 that I saw any evidence of any artwork that was going to take an art student anywhere (Firminger 2001).

At this point, Hereward typified the association of disabled students with handicrafts, and with the arts as a mainly leisure based or therapeutic activity.

### **The Historical Context of Disabled People and Creative Activity**

Humphries and Gordon (1992) trace the origins of disabled people's involvement in what can only loosely be described as creative activity. The association of disability with the notion of training, therapy and handicrafts, which became inextricably linked through the practices of institutions and later day centres, persisted until the Disability Arts Movement claimed the arts as a medium or 'voice' for disabled people in the late 1980s. 'The training they received in the institutions where they grew up and the workshops attached to them prepared them for a lowly role in society' (Humphries and Gordon p.118). Carpentry, basket making, mat making, needlework and embroidery are all given as examples of the training which was given in preparation for entry to a very narrow range of occupations and which also formed the basis of therapeutic activity associated with convalescence.

The therapeutic use of crafts was first established in Chicago in 1908 and was followed by 'curative workshops' in Britain (Salford P and E 1996:214). Occupational therapy was developed as a mode of rehabilitation via the teaching of handcrafts to convalescent soldiers and was intended to provide activities that were to help clients 'work through conflict, redirect aggression and gain self esteem and ego strength' (p.214). The extension of these services to include the rehabilitation of children with orthopaedic impairments created enduring links that associated any sort of creative activity by disabled people as essentially therapeutic. This association is reflected in the final school report of a Hereward student entering the college in 1974. She is commended for her 'special aptitude' in housecraft and needlework, in the execution of which she is described as 'very capable and extremely neat' (Hereward Archive).

A number of factors were to evolve throughout the latter half of the twentieth century which ultimately had the potential to change opportunities for disabled people and overcome the inherent practical and philosophical difficulties which they encountered in accessing education in the arts. In addition to developments in technology, and the impact of the disability movement, a fundamental shift occurred in the perception of art and design education that was to create the flexibility and student-centred approach that the arts education of disabled people demands.

What prevailed before the 1950s was a system devoted to conformity, to a misconceived sense of belonging to a classical tradition, to a belief that art was essentially technical skill (Thistlewood 1992:152).

Early arts education was founded upon Henry Cole's Victorian National Course of Instruction. Initiated in 1853, it was based on the premise that the central role of art and design was to serve a 'strategic economic necessity' (pp.8-9). Industry's requirements dictated a specific and material training which was in direct contrast to the cultural experience advocated by William Coldstream in 1960, and which compared art and design to other arts and humanities and worthy of study for its own sake (*The Coldstream Report* 1960).

The purpose of early art school education up until the late 1950s was to create a route to Fine Art or commercial design. All manner of regional vocational certificates and diplomas provided trade qualifications in art schools which trained or prepared students for craft-work industries which, as the century progressed either

disappeared or evolved into new disciplines. Window dressing which preceded exhibition and interior design, sign writing which paved the way for commercial art and later graphic design, and typography which consisted of the literal, physical manipulation of type, were all examples of disciplines which were reliant on the preparation of hand wrought material. Lettering, illustration, graphic layout and type-setting all demanded a high level of manipulative skill and dexterity. Even if disabled people had not been confined to institutions, workshop training, or day-centres, the high level of physical dexterity and manipulative skills demanded by these early art school courses would have excluded many.

Even Fine Art, with its seemingly more fluid parameters than design, was rendered inaccessible for many disabled people by criteria that had their roots steeped in history and in a particular type of classical measured drawing that still lingers in perceptions of art today.

For decades there had been a preoccupation with drawing and painting according to set procedures; with the use of traditional subject matter - the Life Model, Still Life and the Antique; with the "application" of art in the execution of designs; with thorough knowledge of selected precedents, such as historical ornamentation; with above all, the monitoring of progress by frequent examinations (Thistlewood 1992:152).

Now the validity of these began to be questioned in the search for a legitimate alternative that culminated in 'a general devotion to the principle of individual creative development' (p.152).

The leading figures in the new innovatory approaches to art education - Victor Pasmore, Richard Hamilton, Tom Hudson and Harry Thubron - were committed to an exploratory approach in which it was realised that 'permutations of shape, location, character, accident, system, material property, visual energy, growth, gesture ... were infinite' (p.166). The emphasis was on the developing process, with highly disciplined beginnings that explored the properties of simple graphic marks and the creation of a visual vocabulary that would form the basis for subsequent study. Studies were open-ended, encouraging eventual research of the most personal kind but in which the 'ease of passive learning was to be replaced by

difficulties of self motivation' (p.164). Teachers were required to work one-to-one on individual programmes of learning instead of on the single traditional one, which in essence is the principle that is guiding current notions of inclusive learning. These ideas were developed over a series of summer schools that took place in Scarborough from 1954-56. Existing practices were completely revised prior to their incorporation within full time courses late in the 1950s and were consolidated in the establishment of the Foundation Art and Design course in 1963.

### **The Diploma in Foundation Art and Design**

The Foundation Art and Design course (currently entitled The Diploma in Foundation Course Studies - Art and Design) was significant in that it was a diagnostic course that prepared students for a higher level of study in their chosen area of specialism and culminated in a nationally recognised qualification. Its introduction to the arts curriculum at Hereward College in 1987 was a response to the need for a route to higher education in the arts for disabled people. Its location within specialist provision guaranteed that the difficulties around physical access, finance and resources, which largely excluded those disabled students who did make it to the door of mainstream art colleges, were addressed. However, what was probably less well understood at that time was the significance, for Hereward students, of exposure to the experience of developing self-awareness and individual creativity that characterised the programme. It involved them in the personal resolution of issues related to their disability and self-identity which unexpectedly, but almost inevitably, arose.

These new approaches permeated level two arts courses and certainly from 1988 the new GCSE syllabus, revised in line with the more liberal approach to arts education, has enabled more disabled students to gain the level of attainment demanded for progression to courses at levels 3 and 4. Old rules and approaches to drawing had endured in school curriculum and had characterised the old GCE O-level arts syllabus. The school report of a student applying to Hereward College in 1974 categorises art work as still life drawing from a group of objects; portrait and figure drawing; and outdoor drawing from nature. It praises the student's 'neat, careful and decorative style' (Hereward Archive). The revised GCSE represented a shift away from these traditional themes, towards free drawing, and the creation of a broader range of options which had less emphasis on the formal theory behind drawing and more emphasis on experimentation, problem solving and analytical and creative skills. Encouraged to find outcomes from a range of specialist areas,

disabled pupils had a far greater chance of finding a mode of expression that was suited to their preferred learning style, interests, capabilities and practical ways of working.

Released from the tyranny of attempting to reproduce a particular type of realism and to compete within a very narrow frame of reference, students' practical work, in particular their drawing, could become more personalised and reflective of their individual physicality. This frequently produced original, unexpected and highly creative results. Moreover, the course syllabus emphasised the process that informs the final artwork. Realised through preliminary studies based on research, and the gathering of visual information in a variety of formats, and from a variety of sources, it created a fruitful context for the development of personal skills related to autonomy. As the student progresses through the GCSE course, the initiative gradually passes from teacher to student until, finally, the ownership and dynamics of the work rests solely with the student as practitioner in what is often a novel experience of choice and control that is experienced as personally empowering.

The ethos of Foundation Art and Design studies is liberating for all students but it has a particular relevance for disabled students who, at Hereward College, usually take the course over an extended period of two years. Demands are made which compel students to question and challenge precepts and ideas in ways that they have never previously had to undertake. Even life drawing, traditionally part of Foundation Course studies, becomes an opportunity for personal growth and raises questions around the use of disabled/non-disabled models. The difficulties of securing disabled models and the assumptions and taboos that continue to inform the revealing of the impaired body can provoke enlightening discussion amongst an inclusive group of learners. In addition, students have to develop organisational skills and take on the management of their own time and, in some cases, their stamina and energy. They are required to independently explore and utilise all areas of potential resource and support and, in so doing, refine and extend their communication skills. Within an atmosphere of positive expectation, they are required to be self motivated and innovative, develop skills in problem solving and accepting increased responsibility - all in addition to, but inextricably entwined with, the new processes, media and disciplines that they are exploring as part of their creative development.

Foundation Art and Design students study critical and contextual studies as a formally taught element of their course and are required to undertake a lucid rationale for their work. This may be spoken or delivered through alternative methods such as signed interpretation, an amanuensis reading a prepared text or an electronic communicator, but significantly it is before others in tutorials and seminars. The course, in particular for fine artists, engages students in a process of introspection and analysis of what is informing their work and why. For the physically and/or sensory impaired student, this has proved to be of special significance and, for many, has precipitated the 'coming out' process and acknowledgement and exploration of issues of self-identity and disability previously discussed.

The Foundation Course at Hereward College is delivered by staff who are arts specialists involved in their own professional practice, and who teach in other FE and HE institutions. This created a change in the educational ambience of the whole department, elevating the status of the arts and establishing creative studies as a key area of provision within the college. It also attracted non-disabled students to the arts courses, although the numbers of 'standard' students enrolled remains few in comparison to those who are representative of groups disabled by other social factors than disability, and who are drawn to the supportive environment that the college can offer. These have included students with mental health problems and/or challenging behaviour, women returning to education or from strict religious groups, people from ethnic minorities, mature students, and those who have not achieved through mainstream routes for a variety of social or economic reasons.

### **Information, Communication Technology (ICT).**

The last decade of developments in ICT - computers, the Internet, networks, Intranets, video conferencing, and managed and virtual learning environments - have revolutionised the world for everyone, but have held the potential to emancipate disabled people. The creation of an individually designed package of assistive technology can enable independent mobility by allowing freedom of wheelchair movement, and can substitute a simulated voice where verbal speech is absent. The electronic communicator, linked to the college network, gives the disabled student the autonomy to communicate with everyone within that environment. Connected to the Internet, it creates not only the freedom and self-determination to communicate with family, friends, health and social services, the entertainment and travel



industries and shopping etc, but also the capacity to reach world-wide services and information.

The application of ICT to learning has radicalised and enriched education for many disabled students. It has enabled them to overcome problems with slow writing speeds, fatigue, legibility, production of plans, symbols and diagrams and the storage and organisation of materials. The freedom to communicate, acquire information, even to be 'transported' via video conferencing offers a potentially holistic approach to learning, within a system that can make adaptations for individual and complex learning support needs. Increased magnification, low or high contrast screens, colour variation, signed translation, key-guards, adaptations to hardware and software and input devices are all examples of how, in effect, all students can be facilitated and their learning potential maximised. Access to computers is designed to utilise any controlled movement that the student may have and, as such, many adaptations are created around the conventional mouse. Glidepoint is a small pad, 4cms x 4cms, the control of which gains coverage of the entire area of the screen and facilitates those with limited finger and/or arm movements. Trackerball moves a cursor on screen by rolling the ball with the palm of the hand where there is an inability to grip the mouse. Keyboard guards enable students to press keys accurately, whilst the Microsoft Accessibility software programme enables access via the arrow keys on the keyboard, substituting directional for freehand movement on screen. A foot switch can operate an on-screen keyboard with the addition of the software programme *Ke Nex*, a miniature keyboard with five categories and menus for all options appears on screen with sub-directions for functions of the computer. Similarly, a head switch can create access to any of these permutations, as can Voice Recognition software such as Dragon Naturally Speaking.

Information available on CD Roms and the Internet overcomes the disadvantages that a disabled student may encounter in the manipulation of books, and resources are not restricted to the college but are available from other national and international sources. In addition, environmental technology can enable control of the physical environment (lights, doors, curtains etc.) potentially offering disabled students freedom from dependence on a carer. All of these developments have the potential to free disabled people to interface with the world in ways that are unprecedented.

### ICT and the Arts

At Hereward College the computer arts/graphics suite is adjacent to the practical arts studios, thus facilitating and encouraging the smooth transference of material from one medium to another. This location also encourages an understanding of technology as a 'tool', rather than as an end in itself. Work may originate on the computer in the form of plans and diagrams for example, which may then provide the basis for development in the arts studios as a piece of 3D sculpture or theatre design. Alternatively, work may be generated practically (with the support of an enabler or technician) in traditional ways or with lens-based media, and then be scanned into the computer for further manipulation or design application. Technical solutions that facilitate a student may be as simple as a crayon attached to a long stick or a moulded splint that supports or effects grasping a drawing implement. However, embedded within a broader, richer context, computer technology has proved to be an extremely diverse enabling tool in the practice of art and design and software packages such as *Photoshop*, *Freehand* and *Illustrator*, have created the means to produce highly professional artwork.

National recognition of the potential of ICT for disabled people in the arts occurred in 1999 in an Arts Council digital arts and disability bursary scheme, entitled 'Digitising Disability'. The overall purpose was to encourage disabled artists to develop the practice of digital arts, to influence the development of the technology and to look at how they would inform the future of arts practice as disabled people using digital technology. It also sought to encourage collaborations between disabled artists, digital arts organisations and where appropriate, disability arts agencies (Scott 1999).

The artists who had taken part in the scheme disseminated their experiences via the Internet, a series of conferences and an Arts Council booklet. In this they highlighted the potential that digital technology has to involve them in a mutual flow of ideas and participation in a process of contemporary experimental art making. The Internet offered them available source material from a range of other media and an environment which one described as being 'about constant flux - hundreds and hundreds of changes; layers not representing one constant. I'm interested in how the image can be seen as "change" rather than set: nothing stable, absolute' (Philips1999:6). Complex questions were also posed by another participant around whether 'computer - disembodiment offers an attractive "liberation" from the body for

the disabled individual or whether it effects an effacement of an essential condition of identity' (Williamson 1999:10). He suggested that a society of 'disembodied' agents presents us all with a 'rich territory for speculation and experiment'.

As this initiative demonstrated, technology has changed the culture of art and design and created instant access to the capture, manipulation and printing of images. Images can be gathered from anywhere, including significantly, the Internet. Popular imagery and culture which Richard Hamilton, as part of the vanguard of the new Foundation Course in the '50s and '60s, promoted as 'worthy of respect', is effectively made accessible to disabled students (Thistlewood 1992:153). Opportunities for spontaneity and immediacy are created via, for example, digital cameras which allow the user, regardless of their ability to handle the camera, immediate review of the image he/she has captured, or been enabled to capture, on the display screen. The old courses were not conducive to spontaneity, based as they were on the precise art. Any deviation was regarded as an error rather than a creative opportunity. Now ownership for a set of values is based on current experience. It can be immediate with no history, no reference to past histories, and expertise can become a purely digital experience. The understanding and good eye for design awareness currently demanded in visual communications, demonstrates that in this respect students with impairments are no different from non disabled students. All students learn in similar ways because they are using similar mental processes. Design education focuses on knowing which image is the right one, where to find it and how to process it.

In his investigation into the relationship between technology and student learning in art and design Jobson (Tutor for Graphics courses in the college) cites drawing as the most important activity in a process of personal discovery and the development of expertise in visual thinking, perceptual skills and aesthetic judgement (Jobson 2003). He suggests that 'many disabled students have never had the tactile experience of drawing due to their difficulties with manipulative skills'. I would qualify this by drawing attention to the preconceptions and interventions of others that have also contributed to circumscribing this activity for disabled children and young people. However, whatever circumstances make drawing inaccessible, digital technology, if managed appropriately, has the potential to be a powerful enabling tool for aspirant disabled artists and designers. He describes it as, in effect, a

universal technology, in that when a mind is interactive with a computer, disability is unidentifiable.

He goes on to comment on the growth in computer technology that has enhanced learning.

there are increasing instances where selective and discovered user advantages of computer technology, that are realised through a sound, managed understanding of educational theories and shared innovative educational strategies ... are producing demands for and further developments in ... technology for the benefit of the student user.

However he does question whether in the discipline of art and design this is resulting in the use of technology in a 'creative and meaningful way'. He interprets the notion of technology widely and includes in his definition those 'technologies' that a tutor brings to the learning environment and which include 'theoretical knowledge, imagination, experience and judgement'. He argues that

The tutor's flexible learning strategy (technology) employed in organising and making available the widest possible opportunities and resources, is the key factor in facilitating learning.

The importance of ICT in the arts education of disabled students cannot be overstated; however, the option of complementing the access and independence that technology offers with enabling support is a vital one. In addition to the important, but more routine, tasks of note taking, keying in text, assistance with tasks requiring dexterity, manipulating learning materials, photocopying and support with reading, educational enablers are involved in the more esoteric aspects of supporting individual learning, facilitating communication, advocacy and independence.

### **Educational Enabling Support**

The majority of Hereward's students will have had experience of working with non-teaching assistants in special and/or mainstream schools and this colours their approach to enabling support when they arrive at the college. *The Alliance for*

*Inclusive Learning* reported on these experiences in a report published in February 2001. The Alliance was formed in 1990 by disabled people, their parents and friends, with the objective of promoting a single mainstream education system based on the principle of inclusion. A consultation, that was carried out by the Alliance with young disabled children and their parents, highlighted the difficulties that they had encountered within a system that has been reliant on the low payment and limited employment benefits of assistants who have few opportunities for training and development. Non-teaching assistants are assigned to individual young people in response to their statement of special educational need. They have different titles ranging from 'helpers' to 'classroom assistants', and are often untrained, working for a local education authority who set their pay scale in line with that of a manual worker.

Inevitably the poor pay, low status and ambivalent position within the school leads to a rapid turn over of staff which in turn leads to problems with the continuity of provision. Parent's comments in *The Alliance for Inclusive Education Report (2001)* highlight the issues.

If we constantly have new learning assistants then Anthony has to spend a term training someone up to the point where they can understand his speech clearly ... if they then leave or are moved within the school he's got to start again (p.29).

With the situation at high school at the moment where in the first three weeks of school he had 10 different assistants working with him, he is now extremely frustrated, he can't function and he comes home with a pile of work that hasn't been completed in school (p.30).

In contrast to these fragmented experiences of classroom assistance, Kendrick (Head of Residential Education) describes the experiences of a pupil interviewed for entry to Hereward College in September 2001 that raised a different set of problems in terms of his autonomy. He had had the same classroom assistant from the age of 7 until he left school at 16.

He didn't go into school for the first day of term because that was all time-tabling and running around, all hectic and confused. His support

worker went in and did that for him and he would go in the next day when he was on timetable. So 9 o' clock Tuesday morning he was in his lesson and he didn't have to think or worry about it (Interview 2001).

For the majority of disabled children with high level support needs, their continuing placement in mainstream schools is often reliant on the extensive pro-active support of one of their parents. These parents and their children experience assistance as variable in its consistency, haphazard in the level of disability awareness that an individual assistant may have, and driven by what is available rather than needed. They stated their baseline requirements for effective assistants as - improved pay and terms of employment; extra hours for homework support; training in inclusion and disability equality; and training in basic computer skills including the use of specialist software and facilitated communication. The Alliance does not believe that these problems relate only to mainstream education and that levels of resources are any better in special schools.

Bradley *et al* (1994), in a review of research carried out by the National Foundation for Educational Research into students with disabilities and/or learning difficulties in further education, make the point that 'support lies at the heart of the relationship between students and educational institutions' and yet they also state 'the evidence suggests that, alongside funding with which it is inextricably linked, support is possibly the least researched aspect of special needs in education' (p.29). An exception is a report highlighted in *The Times Educational Supplement* (September 13<sup>th</sup> 2002) which raises more concerns about what is described as, the 'ambiguous' relationship between learning support assistants and the students who receive their support (Veck 2002). In this it is suggested that 'learning support assistants (LSAs) may be acting as a barrier between pupils with special needs and their peers, and can inadvertently undermine their ability to work independently'. Assistants quoted in the report admitted finding it difficult not to cross the line between enabling students to do the work and doing it for them. The study examined the role of LSAs in two further education colleges. It warned that their 'desire to protect and the student's desire to maintain a friendship [with the LSA], conflicted with the development of student's independence'. The author of the report states that 'LSAs are being asked to support students emotionally and socially as well as supporting them with their learning and, in many cases, teaching them'. He comments on the irony of placing

responsibility for such a diverse and complex role that requires constant professional judgement upon LSAs who are in all other ways made to feel of secondary significance.

Hereward College has been largely successful in maintaining consistency and continuity in educational enabling support through the recruitment and retention of a significant core group of staff. It is a service that is enhanced through the college staff development and training programmes and college policies and procedures. However, rates of pay are similar to school assistants and employment is for term times only. Enablers are drawn from different backgrounds, including teaching, nursing, the arts, care, psychology and administration and their interaction college-wide, with students with diverse learning support needs, gives them a broad based wealth of experience. Information and enabling strategies are centralised, thus students benefit from learning to work effectively with different technicians and enablers.

*The 2000 Inspection Report* for Hereward College stated that 'enablers are careful not to hinder students' learning by doing too much for them' (p.14). Certainly help will be given with the processes of learning, with reinforcement of tasks, organisational skills or breaking a task down into smaller stages. They will develop strategies with students to improve memory and to develop communication skills, but in addition to these a primary and critical objective is that students will also be encouraged to develop their skills in learning how to use and direct support competently and to study and work independently. Enablers need to be aware of the influence that they can unwittingly exert on a disabled student and know when to help and when to assess that the student can do the task themselves and of encouraging them to do so. All are key elements in a role that is central to the empowerment of disabled students. This development of autonomy is crucial if students are to make successful transitions in becoming the employers and managers of personal assistants and in using the Direct Payments Scheme or Disabled Students Allowance that supports an independent lifestyle, employment, or study in higher education. 'Learning to train their helpers and negotiate a mutually satisfactory working relationship is a fundamental life skill' (*The Alliance for Inclusive Education Report 2001:33*).

### **Education Enabling and the Arts**

Educational enabling support for art and design at Hereward College was not considered a requirement in the mid 1980s as this consisted solely of 'woodwork type' activities for those that could manipulate materials effectively (Firminger 2001). However, the tradition of an artist working with a technician is a long and respected one, reaching back to the Master painter and his apprentices and encompassing such artists as Renoir, Matisse, Paolozzi, Henry Moore, Christo and more recently Damien Hirst. However, for the purposes of curriculum assessment, the division between the mechanical tasks of manipulation and the creative, conceptual element of the work must be a clear one. This raises questions around the interconnectedness of process and technique and creative realisation, which in turn must inform the subtleties of the working relationship between enabler and student. A support role that can incorporate the involvement of students with ongoing process and spontaneous activity, within which creative possibilities are inherent, whilst ensuring that the ownership of the work remains unequivocally with the student, is a challenging one for teacher, enabler and student to achieve.

The role of enabling support in the visual arts raises further questions. These are concerned with whether it is preferable for the enabler to have an arts background and thereby bring specific skills to the task, or whether the role should be carried out by someone acting strictly as a pair of 'untrained' hands. On the one hand, specialist knowledge of the arts by the enabler in effect streamlines the process because everyone is moving in a direction that is understood. However, further questions are raised concerning the desirability of a student working with the same, or a series of enablers throughout the duration of a particular project or scheme of work. If the student has ownership of the work, then in theory, it is not essential for the enabling to be consistently carried out by one person. And yet it could be argued that the relationship between enabler and student/artist mirrors that of, for example, architect working with engineer, conceptual artist working with technician and in these partnerships the expertise of both parties is considered paramount. Certainly the architect/artist would seek out a single 'best maker' to realise his ideas. On the other hand, it could be argued that in the learning process, the development of student ownership and responsibility for the continuity of the work could be compromised by any creative expertise the enabler might have. In this context perhaps the pair of hands should be just that, any more could constitute an unwelcome influence. In reality the match of enabler and student occurs between diverse human beings, with



communication as the key element. Solutions are varied and each student is engaged in an individually devised enabling process that develops and evolves as creatively as the work that is being carried out.

Some students have initial difficulties in accepting enabling support in the arts, believing that any form of practical assistance compromises the integrity of their artwork. Their preference, at first, is to stay securely within the (often limited) boundaries of what they have learnt and what they can do physically. Slowly, they move towards two realisations: firstly, an appreciation that an activity that might cost them a significant expenditure of energy and time can be carried out equally effectively by another under their direction; and, secondly, of the potential that can be realised in their work through the added dimensions that enabling support can bring. More often the student has been conditioned by an arts experience in which they have implicitly understood their efforts to be inferior, and are prepared to accept a passive role in which they will defer to those around them. They are therefore particularly susceptible to even nuances in enabling support and will search for 'the right answer' in the expressions, words and actions of their enabler. The enabler's role is often to build confidence in independent thought. A significant part of this process is to learn by making mistakes or by taking advantage of the 'happy accident'. This demands that the enabler resists the temptation to necessarily direct the student away from possible trouble or problems, but supports them through what can be a very valuable learning process.

Renoir's response to questions concerning his ability to paint beautiful works from a wheelchair with his brushes strapped to his hand was that 'One does not paint with one's hands' (cited in Canaday 1962:221). This realisation, that creativity is not blighted or confined by physical limitations, is an empowering one for students. For example, a fine art student at Hereward College, whose impairment significantly restricted his movement and thus his freedom to explore scale in his art work, worked with an enabler to photocopy his small, thumb nail drawings onto acetate. Using an overhead projector it was possible to enlarge the drawings (and for that matter, any plans, texts, sections of drawings etc) to the size he considered appropriate. He chose to reproduce his small drawings to fill the walls of the studio and directed the enabler closely and meticulously in all aspects of this process, checking positioning, line, tonal values, shading, detail, etc. Thus he was able to

achieve work where considerations of scale were freely conceptualised, rather than dictated by his physical limitations.

Educational enabling has a similarly liberating effect within courses at entry level and level one where profound impairment may be accompanied by some level of learning difficulty. For these students the production of artwork that specifically addresses issues of self-identity or that could be considered expressive may be difficult to realise and possible outcomes that reflect students' individuality difficult to imagine. However, the following scheme of work gives an example of how, with enabling support, entry level students can create subtle and sophisticated work that can be viewed as reflective of a level of achievement that is commensurate with their age group.

The project was introduced via an initial exercise in which a set of white cards and coloured shapes was prepared for each student. They were required, with the support of an enabler, to arrange the shapes into a design on the card. The particular way in which this was carried out was very important. The leading question 'Shall I place this here?' was replaced with a statement that facilitates and encourages independent choice. 'I will scan the card with the shape whilst you watch, and then when I do it again you indicate to me where you want me to stop and place it'. When these arrangements had been completed the designs were all different. Students were then asked to consider which one they 'liked' best. Invariably, in this and similar exercises, a consensus is arrived at as to which one 'works' best. From this, and further exercises of greater complexity, basic discussion about symmetry/asymmetry, balance, use of space, colour harmony etc took place.

From these simple beginnings, based on the principle of the considered placing of elements, students went on to develop large-scale pieces of environmental art. They referenced the art of Andy Goldsworthy and Richard Long, and manipulated an aesthetically pleasing variety of natural objects (driftwood, stones/pebbles, bamboo, pine cones etc) against a background of contrasting natural surfaces (peat, sawdust, sand, shale, earth etc.) Each student, working one-to-one with an enabler, had ownership of an individual element of the overall piece of work. An outdoors site was chosen from which the work could be viewed from inside in various weather conditions, and photographic evidence gave each student a permanent record of what had been achieved (see Fig 22).

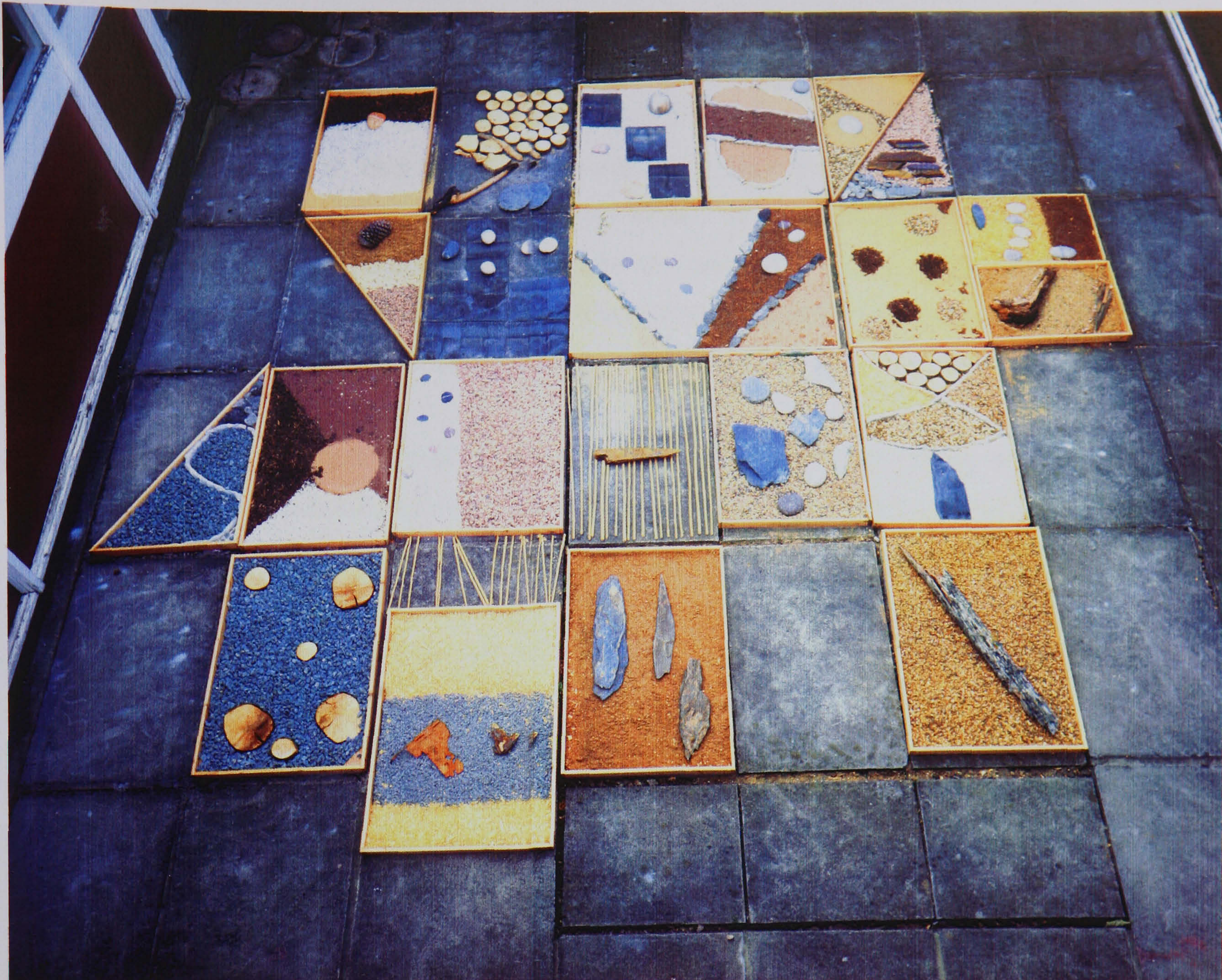


Fig 22



Fig 22a

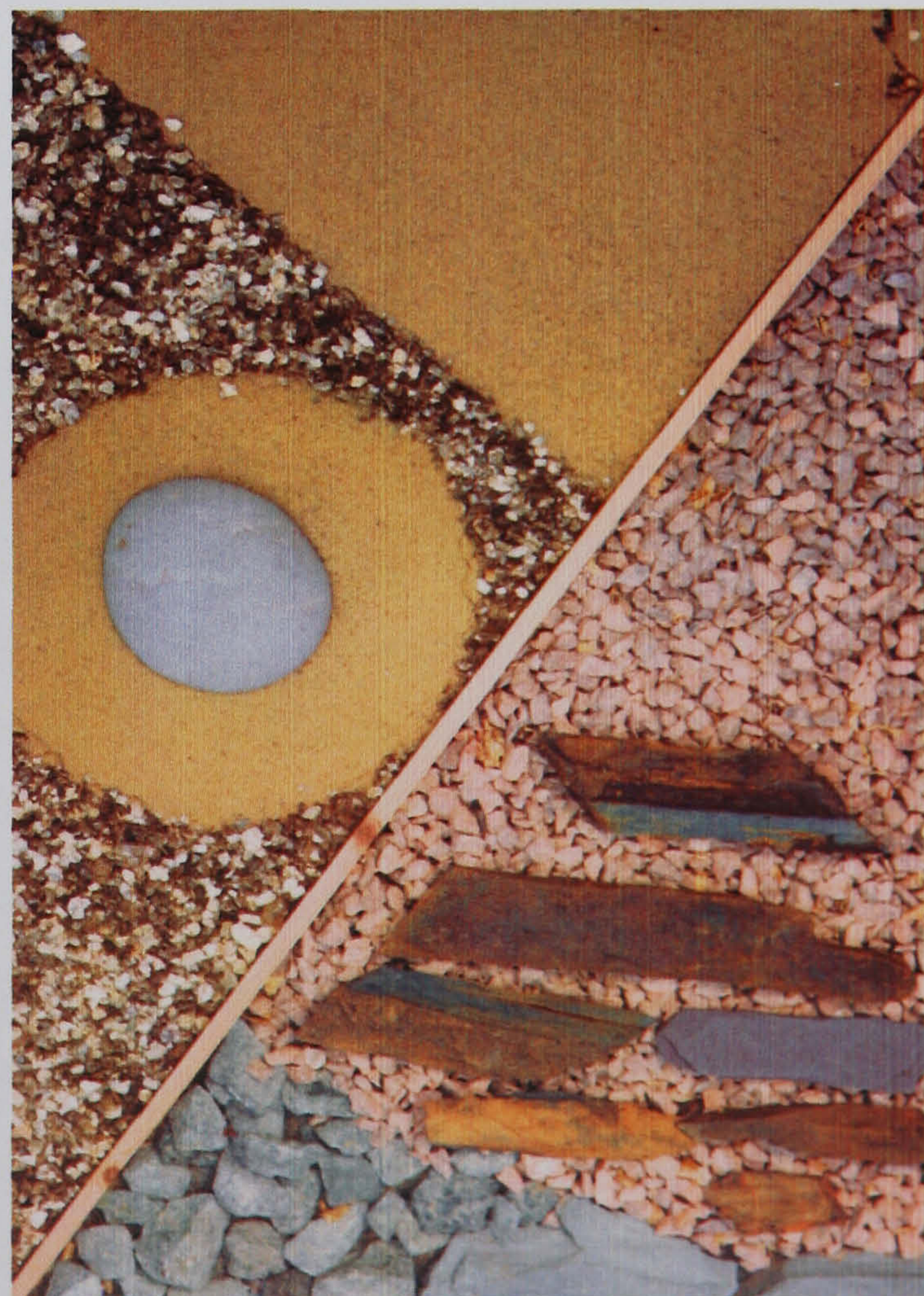


Fig 22b

Further work with the students capitalised on wheelchair movement to create line. Salt drawings were created on the straight, plain, surface of a corridor carpet using a pierced bag of salt tied to the wheelchair, and painted wheelchair tyres printed coloured tracks of movement onto large sheets of canvas. The generation of an individualistic mark, however modest, can be captured using a digital camera or if appropriate scanned directly into the computer and provides original, student created material that can be further manipulated.

The central importance to all disabled students, but in particular those with complex and high level support requirements, of effective enabling in support of practical arts activities is clear. However, it would seem, from the questionnaires carried out with the 2003/04 new residential students, that the unhelpful interventions raised in this study, about the ways in which disabled students are enabled in the arts prior to coming to Hereward College, continue to be of concern. Enabling support was used by 64% of the new intake of students for arts activities at school (course work and leisure activities) with 48% of students reporting that the classroom assistant 'helped them with drawing and/or ideas'. One can only speculate on the interpretation of these interventions and whether the student is being assisted with processes that will lead to the generation of ideas or being given direct solutions to visual arts problems. Students reported assistants 'drawing in guidelines', 'drawing fine detail' and 'doing the main outline', implying perhaps a narrowly defined interpretation of the visual arts curriculum with a continued emphasis on skills based criteria and traditional materials employed in the pursuit of a particular type of realism.

### **Disability Arts and Popular Culture as part of the Arts Curriculum**

Disability Arts awareness is critical in strengthening the operational position of students with impairments, whether as a basis from which to develop their creativity, succeed in professional arts practice, or as the reference point for other aspects of their lives. Few students coming to Hereward College from a mainstream or special school background are politicised or have an affiliation with Disability Arts or the Disability Movement and it would seem that they have had little encouragement from family or school to become informed. Reasons for non-involvement have been explained by the perception that the Disability Movement and Disability Arts are 'an extension of special schools'. Students perceived Disability Arts as implying that art done by disabled people should be isolated from mainstream art whilst they believed

that, 'art by disabled people should not be separated' (comments by students in response to questions about the Disability Movement 2000).

The Disability Arts Programme was set up as a cross-college initiative with the intention that it would raise awareness and inform disability identity through the arts. It offers all disabled and non-disabled students an involvement with disability issues, culture, and role models. It has taken the form of specific disability arts projects, with external agencies such as *Craftspace Touring*, and it is significantly part of the broader experience of visits to exhibitions and performances at various venues. It is embedded in the curriculum as has already been described, with the whole staff and student body as witness to the visual or performing arts work that students produce. It is also significantly realised through the artwork and workshop activity of professional disabled artists and performers such as *CandoCo* and *Graeae* and through the involvement of ex-students who have graduated in the Arts returning to work with current students.

The Disability Arts programme is probably best epitomised by the fashion show that takes place at the end of the summer term as the culmination of the enrichment module 'FashionAble' that is run throughout the year as part of the extended curriculum. It was introduced into the arts curriculum in 1999 inspired by the fashion images of disabled people featured in *Dazed and Confused* (September 1998 No 46), described in chapter two, to create opportunities for students to explore disability identity and popular culture. Students were encouraged to consider issues of disability and fashion and invited to create a 'look' for themselves that they then modelled for a photographic shoot. These images, which they had constructed, showed them as contemporary, glamorous and fashionable. Importantly they demonstrated their involvement with, and inclusion in, popular culture and significantly depicted them as sexual beings. The fashion show is an extension of this opportunity to express a contemporary identity and to have the 'look' endorsed through public display. Themes have been very varied from the 'wedding set' (with many brides), to 'East meets West'- a fusion of traditional Asian culture with contemporary western fashion realised in a very individualised style and as an expression of ethnicity which, in this instance, subsumed disability identity.

Accessing and exploring the interface between identity and popular culture is a priority for the majority of students at Hereward College. Hill (2001) describes this commercial, popular culture as

Recorded music and images, broadcast and printed material, consumer items mainly made mechanically, live entertainment, digital information, games and recreation, educational aids, food and drink, travel and holidays, drugs and cosmetics: these are the languages of commercial culture as spoken to young people (p. 49).

Disabled students, prior to their placement at the college, have often had limited opportunities for independent (supported) social contact in the contemporary environments that their non disabled peers enjoy. Difficulties with care requirements, transport, developing a circle of contemporary friends outside the special school environment, finances and parental concerns can be restrictive and isolating. In addition to dealing with the practical challenges that living in a disablist society presents, they also have to cope with the fears, feelings and concerns of parents and the authority of the range of professional experts who have frequently advised them and their parents from an early age. Moreover, adolescence is a critical period for the development of the sexual activity that Middleton (1999) refers to as 'a sign of adulthood'. She discovered that disabled students reported that their parents made 'false assumptions' about the nature of their impairment in terms of puberty, sexuality and parenthood. Deferment of adult status for sons and daughters with personal care needs makes a more 'acceptable' context within which parents can manage and present their needs. The result is a tendency for young disabled people to experience a 'perpetual childhood' (1999:3-4).

Middleton also found that the childhood experience of the disabled students she interviewed was of not being in control. In terms of the larger decisions about educational options, career choices and independent living, they and their parents have often been socialised into the belief that non-disabled professionals are better equipped to make these decisions than they are. Middleton states: 'Paths were chosen for them because of tradition, from lack of imagination, mistakenly to protect them from disappointment or conversely to enforce normality'. What emerges from her research, 'is a picture of childhood during which there is a steady stream of negative experiences that have a cumulative effect' (p.30).

Certainly, young disabled students, given the opportunities for potential self determination that Hereward College offers, increasingly display evidence of their engagement with contemporary forms of popular identity formation in their

possession of mobile phones, use of the Internet, purchase of designer label clothes, CDs and fast food. In the support and involvement with the narrative of 'their' football team's success and failure, and the vicissitudes of television soaps and reality TV, they are aligned with the 'hyper-real' allegiance forged with a hundred other fans. They become members of the critical 'audience' that the media and television addresses unselectively, with the assumption of certain values, beliefs and attitudes that have become culturally embedded and which they are then at liberty to live out through their relationships and lifestyle choices. In this construction of self, having an impairment can become a secondary feature or only a part of the young person's perceived sense of self in which 'style becomes the device of conformity' and the mode by which 'we judge - and are judged - by others' (Ewen 1990:43).

Money dictates the extent to which the expressive dimensions of a commodity culture can be explored and employed by any individual and many people are disenfranchised. Traditionally disabled people have been economically powerless and certainly statistics highlight the continued disproportionate numbers who are unemployed.

Involvement in productive economic activity of people of working age with disabilities is half that of those without disability (40% compared with 83%). Unemployment rates (on the *International Labour Organisation* definition) among people with disabilities are approximately 2 1/2 times those for non disabled people (21.6% compared with 9%) and this is about the same for men and women (FEFC 1996:7).

Barnes *et al* (1999) state that 'government figures show that disabled people receive much less than the average national income, and the overwhelming majority do not have sufficient income to cover their impairment - related expenses, let alone leisure pursuits' (p.186). They concede that there are 'some opportunities for some groups within the disabled population, most notably, the younger better educated minority' (Barnes *et al* 1999, cited in Hughes 2002:580).

However, Hughes (2002) goes on to make the point that:

Unless disabled people have the resources and wherewithal to participate in cultures of consumption, then they will continue to be marginalised. ... If ... post modern culture is organised around consumer freedom, then those who are not able to exercise it will be recognised as outsiders. Many disabled people will become ... the 'new poor' (p.580).

A window of economic opportunity is created for students at Hereward College. Fees are paid, on average, for three years but often for longer periods substantially by the Learning and Skills Council but frequently with contributions from Social Services and The Health Authority, depending on circumstances. Funding is inclusive of all academic and living expenses during term time including food, laundry, transport and 24 hour care assistance. The benefits, which students are entitled to, potentially gives them an average weekly income of approximately £100. It is difficult to generalise about student income in the context of varied family financial dynamics. However, during their time at Hereward, a climate is created in which disabled students are encouraged and enabled, not only academically and practically but also financially, to explore various cultural contexts.

### **Summary**

This chapter has given an overview of Hereward College and its position within the spectrum of educational provision for disabled students, post 16. Further to this the development of the arts curriculum in the college, from the mid 1980s onwards, has been described with reference to the impact that external factors such as legislation, curriculum development and support mechanisms like ICT have had. The significance of developments in enabling support and applications of ICT on the accessibility of the arts curriculum for disabled students has been stressed. This relatively recent increase in accessibility of practical arts courses has been set against an analysis of arts provision historically. Despite the advances that distinguish contemporary arts practice from conventional methods, there remains, in mainstream and specialist provision, residual perceptions about the traditional nature of arts activities and physical and sensory impairment that mean that some disabled young people continue to be dissuaded from taking part. The ways in which issues of self-identity have emerged from the arts provision at Hereward College, where Disability Arts and popular culture have been linked to the delivery of formal arts education, has been described and this paves the way for the following case study



chapters within which the students themselves give an account of the development of their artwork, experiences of impairment and disability, and issues of self-identity.

## **Chapter Seven**

### **Arts Practice and a Sense of Self**

This is the first of four case study chapters that draw together the themes from the earlier chapters and link them with the experiences that Hereward College students recount. This is achieved through an investigation of the students' 'art biography' including early memories of the arts in a family context, their schooling and arts education, their understanding of the purposes of art and their experiences of impairment and disability. Links between their artwork and self-identity are explored through the students' own comments and artwork. At this early stage in their arts education the image constitutes a 'visible' voice that is often more powerful than the student's ability to articulate verbally, a rationale for what they have created. In several instances clarity has emerged during the time that this study and their arts education has progressed and this has been included in the chapter to date.

In addition to exploring the contexts within which students understand disability and self-identity, the interviews also explored whether students' interests or skills in art, as reflected through theirs and other people's appraisal of their talents, constituted part of how they thought about themselves and whether this contributed to their self esteem. The students' artwork was analysed, and it was accepted that the concept of self might have been rejected as specific subject matter for expression at all, and that some students were at too early a stage in their arts development to bring together these complex strands and to make a meaningful account of this as subject matter.

#### **Earliest Memories**

Philips' (2000) statement that 'Most children enjoy drawing and use it to express a wide range of experiences and emotions,' reminds us of the commonalities in the arts experiences of disabled and non disabled pupils alike. Certainly the earliest memories of arts activities that the interviewees reported are consistent with the experiences of most children and are related, in the instance of boys particularly, to the drawing of cars, and to all of them as crayoning, colouring in, scribbling and doodling. For all of them art was remembered in its earliest phases as something that they engaged in with enjoyment and interest.

Several of the students reported drawing on the wallpaper, with Ashleigh giving an account that recalled the tactile quality of the experience.

My Grandma got really cross with me 'cos I couldn't find any paper. I started drawing "accidentally" on her wallpaper. It was old fashioned, furry, velvet wallpaper, it all had pattern over it and I was just filling the bits around the edges (Slater 2001).

There was recognition that art could, as in the case of the wallpaper, constitute a subversive act of rebellion, and interestingly Ashleigh was the only student who had grown up to identify with an activist approach to oppressive perceptions of disability. Students also recognised that art was an activity that could draw praise and admiration from their family and, overall, they were actively encouraged although this was described variously as a source of inspiration and/or frustration.

Matthews (1994) has drawn our attention to the significance of the social and interpersonal context in which children make meaning. Drawing, he states, is not a developmental process which simply occurs on its own but is profoundly affected by the attitude of the people around the child. Students cited fathers as the main source of encouragement, perhaps because the sample group was predominantly male. Sachin recalls, 'My Dad said to me with drawing, "you are very good at that, keep doing that" '. It would also seem that art was perceived as a viable activity for children whose options for other, more physically demanding activities were limited. Colin, whose account is featured in Chapter ten and for whom hospital visits were a frequent experience when he was growing up, demonstrates the particular importance of the arts where other activities might be curtailed. 'From being in hospital when I was very young and then not kind of being well enough to be outside, and then drawing – [I] sort of found drawing that way'. Sam's parents, whose case study follows this chapter, describe drawing as a therapeutic activity, in which they encouraged her to use her hands to try and improve physical dexterity and manipulative skills. Chris recalled his father's encouragement as a means of engaging him in a more productive activity.

My Dad was very interested in me drawing and whatever, 'cos as a young kid I used to watch the telly an awful lot and he pulled me away from that and started drawing things around the house (Knight 2001).

In families where fathers were proficient at art the memory is characterised by ambivalence and a degree of competitiveness. Katy's step-dad was an artist and she recalled:

he always used to draw with us when I was little. I used to get so angry because I couldn't draw like him and I wanted to draw like him so much, but then we always thought that I was the one that couldn't draw and my brother and sister could, but they can't. They can't draw (Lowe 2001).

Similarly, Nicky's recollections of his father's skills produced a discouraged response. 'My Dad's an artist and looking at his pictures I thought I couldn't do as good as that, so it just really annoyed me'. Perceptions of what constitutes 'good art' are at play here with the emphasis on a limited and limiting type of realistic representation (Chalmers 1996). Nicky described how his father

used little dots to do his pictures and he done the front cover of *Silence of the Lambs*. He drew one of his girlfriends when he was young, he drew me and my older brother, he drew my little brother and loads, he done loads (Sapsford 2001).

In effect Nicky's father, albeit with well meaning intentions, was building his own self esteem by impressing his son with his artwork. In contrast Bonnie Chamberlain's mother was building her daughter's confidence by facilitating and valuing her work. Bonnie, whose cerebral palsy impacted on her mobility, motor skills and spoken communication, had had very good opportunities to develop her drawing and painting skills at home because her mother valued her creative activity and had herself had aspirations to go to art school. She recognised the importance of seeking out and providing a range of exciting and appropriate materials, of encouraging the creative process in unconventional ways and of endorsing the outcome by displaying the child's work (they created an art gallery on the walls of the hall). Bonnie described how 'Mum used to put a big mat down [in the hall] and lots of paint and tools and big sheet[s] of paper and we just went for it'. She stated 'I believe it helped with my movement control and self confidence'. This student's early experiences in drawing and painting at home were not overshadowed or subject to constraints. The content of what might be expressed was not prescribed, and encouragement to

continue to develop and search for the 'voice' with which to say it, was not lost and given up in frustrated attempts to conform to traditional expectations or through the misguided interventions of others.

These early experiences at home were critical in establishing a confidence that was not shaken when she came up against less enlightened approaches at school. She recollected that the drawing of herself that she undertook at school as part of her class 'tea towel project' was considerably 'tidied up' before it was considered good enough to be included and printed onto the finished design, recalling the 'manipulating and interfering' that Matthews refers to (1994:87). She recalled 'they changed it loads - it was nothing like what I did – [I was] really gutted' (Interview with Bonnie and her Mother 1998). Significantly at a later date, as a Hereward art student, her 'extra - ordinary' GCSE artwork was viewed with great enthusiasm by specialist art teachers at an examination area moderation meeting. There was recognition that the work met the course criteria, constituted a valid representation of the world and constituted a good pass mark.

In these ways the parameters of what constitutes a visual language are set, as are expectations in terms of competencies and subject matter. For the students interviewed for this study, school experiences contributed little that challenged essentially conventional perceptions of art and disability. Impairment and self-identity did not appear, for any of the students, to constitute subject matter or any part of their visual arts experience before they came to Hereward College.

### **Educational Experiences**

Of the 9 students interviewed for this chapter (2001/02), 6 had experienced both mainstream and special education, usually as an integrated experience, and the remaining three had been educated solely in a special school environment. All had come to Hereward directly from special schools. Their experiences had been diverse and had included attendance at a special school with integration into some classes at the nearby mainstream school, private education in a girls' convent school, and home tuition. Educational experience was characterised in some instances by fragmentation, and a shifting between systems, whilst others experienced an unchanging special school continuum from nursery, at 3 years of age, until they left school at 19. The questionnaire carried out with the 33 new residential students (2003/04) revealed that the number of students experiencing inclusive education is

encouraging with over half (54%) having spent time in mainstream schools and 18% having had this as their sole educational experience. 36% had moved between provision, however, 45% had experienced only special school provision. Although it is difficult to draw conclusions concerning educational experiences between these two groups because of the disparity in numbers nevertheless it is useful as an indicator of trends. The Tomlinson report (1996) has had an impact on inclusion although conversely still high numbers of disabled children are experiencing special schools as sole provision.

The Disability Movement has condemned the argument that supports segregated, specialist, educational provision that separates and excludes children and young people with disabilities from their peers, unjustifiable on humanitarian grounds. In 1991 Barnes stated that for disabled people their experience in special schools 'largely conditions them into accepting a much devalued social role and condemns them to a lifetime of dependence and subordination' (p.28). Barnes *et al* reiterated in 1999 that 'historically, children with perceived impairments were socialised into low expectations of success in education and work' (p.103). This is reflected by students in this research and Anthony expressed a preference for mainstream provision, as opposed to the special school he experienced, based on his perception of what would be expected of him. He stated 'the work would have been harder than it was at [his own special] school. They didn't give us hard enough work. It was always easy'.

Certainly, statistics on employment and qualifications gained by disabled people in comparison to those who are non-disabled confirms their disadvantaged status with regard to educational qualifications.

Two fifths (41%) of disabled people of working age have no educational qualifications, compared with under one - fifth (18%) of non-disabled people, but for those who are economically active, the proportion is 26% (compared with 16% for non-disabled) (The FEFC 1996:7).

The intensifying debate around the ideological, practical and financial implications of specialist versus mainstream provision for those with learning support needs has been informed by a number of sources, which have included disabled people's organisations, parents' groups, educationalists and sociologists but rarely disabled

students themselves (Pitt and Curtin 2004:387). Barnes *et al* summarise the arguments that have been generated both for and against the provision in special and mainstream schools and present the ideological argument that the disabled people's movement has put forward (1999:106-107). In essence this asserts simply that, 'the special school system is fundamental to the disabling process and therefore must be abolished' (p.107).

Regardless of the validity of these arguments and the role that segregated schools might play in 'sustaining ideologies of essential difference' (Riddell 1996:100), it must nevertheless be noted that the impact that physical and sensory impairment may have on developmental milestones and achievement is neglected in these propositions. Physical and sensory impairment can have as their consequence ill health, hospitalisation and time consuming medical treatment or therapeutic programmes. There may be effects on cognitive development because of restricted movement, impaired motor control, or sensory impairment, whilst implications in the accommodation of head injury or degenerative impairments with reduced life expectancy cannot be discounted. A comparison that employs standardised criteria and comparable time frames ignores the fact that impairment, in itself, can have negative consequences in terms of academic achievement.

The arts education that the nine students interviewed had experienced had yielded one achievement of GCSE at a grade B, two Certificates of Achievement and one GNVQ Foundation Art and Design qualification. Ashleigh recalled taking 'little module exams and other qualifications that I can't remember', and four had not achieved any qualification in art at all. Students' comments demonstrate the importance of qualifications as evidence of the achievement that Dusek (1987) links to self concept enhancement. Mushraf, whose expectation was of failure and 'just another failed grade', expressed the relief he felt when he achieved his GCSE in art. Chris, who had created artwork throughout the seventeen years he had been at the same special school without the option of gaining a qualification, exemplifies the senselessness of this experience in the following comments.

Disappointed in a way because I feel like I've done a lot of work through all those years in art and I would like to come here [Hereward College] and say, look what I've done, this is what I'm capable of – things like that (Knight 2001).

Where achievement was reflected in qualifications, students were positive about their teachers, highlighting the centrality of teachers to achievement in the arts (Robinson 1982, DfEE Report 2001). Sukvinder who had achieved a GCSE recalled 'they liked my work, you could tell it from their faces'. Sachin, who had gained a GNVQ qualification, remembered that his art teacher had been really encouraging. He stated 'she used to say to me, if you keep at it, your drawing and painting, you could do a fine art degree if you wanted to'. He added 'she wasn't joking she really meant it'. This setting of expectations and building self esteem would seem to be variable and yet significant in the context of achievement in the arts.

The number of students in the 2003/04 questionnaire (78.7%) who reported that arts qualifications were available at the schools that they had attended reflected what would appear to be greater access for disabled students to appropriately accredited and varied courses. 42.5% had achieved an arts qualification, including Certificates of Achievement, GNVQ Foundation Art and Design, GCSEs, and A-level art (one student). It is, however, of some concern to note that a number of the questionnaire students continued to give their impairments and a negative perception of their skills (gleaned perhaps from others) for not having taken qualifications in art even though they would have liked to have done so. Comments included

I would like to have done it but I didn't because my hands aren't very good.

Because of my hands. I am wobbly.

I'm no good at art.

I missed too much school.

I didn't have the co-ordination to do it.

The 1988 Education Reform Act, which introduced the National Curriculum, promoted 'normative attainment targets' which have been seen variously as either an entitlement to a common curriculum (Oliver 1996) or as restricting the freedom to respond creatively to the needs of children with learning support needs (Riddell 1996:96). In terms of art education, the 2001 National Report condemns the imposition of 'a prescriptive model' which 'emphasises technical skill at the expense of creative and conceptual innovation' (p.180).



### Self Identity, Impairment and Disability

It must be noted that for the students interviewed for this research, disability and impairment are part of a lived experience that is 'rich and multi-dimensional' wherein, Thomas (1999a) states, 'already complex features of impairment effects and disability meld together with other facets of ... social identity (such as gender, ethnicity, religion, class etc)' (p.48). However, Thomas believes that 'for most disabled people disability constitutes a dominant aspect of their experiences, maintaining that for most disabled people 'there are times in their lives when disablism succeeds in severely undermining their psycho-emotional well being' (p.47). She describes this as 'feeling 'hurt' by the reactions and behaviours of those around us, being made to feel worthless, of lesser value, unattractive, hopeless, stressed or insecure'. She suggests that

the "inner world" dimension of disablism is closely bound up with socio-cultural processes and that the "agents", or "carriers" of this disablism may be close to us: husbands, wives, partners, parents, other family members; or they may be individuals with whom we have direct contact, such as health and care professionals and workers (p.47).

It became clear from the accounts that students gave that decisions concerning their education (mainstream/special school) had prompted, in effect, an initial crisis of identity when disability became an identifier to be resisted, accepted or registered as an ambivalent part of the individual's self-identity. Watson (2002) proposes that choice is in operation in terms of whom we identify with and what we do but for disabled children for whom there is often no element of choice, special school automatically brings with it a disability identity which some find difficult to view positively (Middleton 1999). Katy describes her difficulty in 'negotiating' the identity crisis that choice of school generated.

I didn't want to go to a special school 'cos my mum had always brought me up - not as normal, but do you know what I mean, not disabled. Even though like, I was always in hospital, I wasn't disabled. It was basically, my mum didn't want to face the fact that I was disabled (Lowe 2001).

Her ambivalence is clear as Katy expresses her fear of disabled people, from whom she distances herself, separating them into an homogenous group who are unable, unlike herself, to operate in 'normal' ways.

the thought of being surrounded by them [disabled students] just scared me basically. I thought I'd have to be like [them.] I wouldn't be able to do stuff that I would normally do at home (Lowe 2001).

Wendell (1996) describes children as applying rigid 'disciplines of normality' in determining all aspects of appearance, behaviour, movement etc. These constitute a code that has been internalised by Katy herself and leave her with the task of reconciling the fact that she knows she has an impairment and therefore can be perceived as disabled, with the associations that she has with a group that she discerns are stigmatised. The result is the ambivalence that Burns (1992) describes in which Katy finds herself trapped and unable to either embrace her group or let it go.

It's still hard. I mean I don't class myself as disabled. I mean it sounds stupid but I walk around and I think all these people are disabled, I'm not. I know I am (Lowe 2001).

Both Katy and another student reported bullying in mainstream schools as a consequence of their perceived 'difference.' Richard recounted, 'the others were discriminating against me. I think it was awful. I broke one of my teeth because someone tripped me over'. Katy stated 'I was bullied when I was little because of what's wrong with me and because I was always different in class'. These very physical attempts by other children to distance themselves from those that they perceive do not conform to a central 'norm' illustrates the very powerful ways in which the notion of the 'other' or 'stranger' permeates our culture and institutions (Morris 1991, Shakespeare 1994, Garland Thomson 1996, Hughes 2002). Clearly both students felt marginalised by the other children and unwanted by the mainstream school which they believed wanted to 'get rid of them,' reporting respectively, 'they kicked me out', and, 'I just thought the school was trying to kick me out'.

In comparison, Nicky perceived the mainstream environment as a preferable option but this was similarly predicated on the stigma he felt was associated with disability and the confirmation of this status that attendance at special school conferred. Of primary concern to him was the added indignity that the special school made provision for nursery through to senior school without apparent distinction.

I hated the special school compared to the mainstream school 'cos in special school they had a tiny playground and at lunchtime they used to keep you inside the playground. It was one of these combined schools, from first school up to year 11 and it really annoyed me at break having loads of little kids running around your feet. So I hated it. So as soon as I went over to the mainstream school I absolutely loved it (Sapsford 2001).

In contrast some students benefited from moving into an environment where they were not in the minority and contact with other disabled students gave them, through a sense of belonging, an opportunity to view their impairment in a positive light. Mushraf remembered

As I started to progress into [special] school, I started to meet new friends with disabilities and I started to learn that my disability is part of me and it's who I am and it doesn't matter (Rafiq 2002).

A number of the students interviewed for the case study chapters recounted negative experiences that they had encountered as part of social interaction and they understood implicitly the impact that this had had on their sense of self (Cooley 1964, Lenney and Sercombe 2002). For disabled people the process of developing a positive sense of self is compounded by the negative connotations of disability that Goffman (1963) described as the 'spoiled identity'. Physical impairment is listed in his categorisation of abnormal roles and status positions and students gave examples that illustrate the negative ways in which they believed they were perceived as disabled people. Sukvinder, referring to his experiences in a general further education college, stated:

It's an integrated college. We went there for a week, a kind of induction thing to see what it was like and it was really crap. It was

integrated but not integrated - it was like able-bodied students were there but they didn't interact with any of the disabled students. It almost felt like there was a hierarchy and you were kind of like in a department, a disabled department. It wasn't defined but you had the feeling that it's not integrated in the sense that everybody was talking to one another, it was just separate (Kang 2002).

Sachin and Richard clearly described the discomfort that negative social interaction and exclusion had had on their lives but they had no developed way of thinking about disability that would remove what they experienced as stigma (from themselves). Sachin had, throughout the interview, constantly referred to his lack of confidence, expressing frequently his need to have his confidence and self esteem endorsed by others. These anxieties were particularly focused on going out and encountering people he didn't know.

I think when I was smaller I was walking along the street one day and someone said, "can't you see?" Or something like that and from then I can go out, but sometimes when I go out I feel that because my eyesight, my left eye won't focus properly, it shakes a lot. So sometimes when I walk down the street sometimes I think to myself that people are looking at me so I get a bit nervous. It's upsetting because that's what it is (Nayee 2001).

He made it clear that it was not the physical danger from knocks or falls that might be incurred because of his visual impairment that made him nervous, but that people might notice and comment on something different in his appearance and that this was beyond his control (Wendell 1996).

Richard similarly identified social effects for the reticence he felt in going into new situations. When asked if he thought that people looked at him he replied 'I know they do, they always stare at you', indicating that he felt himself, as do other students in later chapters, to be subject to the disciplinary power of scrutiny that Foucault defines (Reeve 2002). This student's resistance is expressed through a defensive limiting of his social interaction, firstly through the economy of his speech which he explained was a response to his concern that he 'didn't know what the others would say if he said the wrong thing', and secondly by not risking new and unknown social

situations. 'That's why I only go to one pub in the village because I know them and they know me and I don't get discriminated against'. Davis and Watson (2001) describe two forms of resistance, one that is internal and characterised by withdrawal and the other that is a more active, verbal, overt resistance.

Ashleigh had adopted an activist approach and had formalised his resistance to disabling perceptions through subscription to the Disability Action Network (DAN) at the age of 15. He undoubtedly drew strength from embracing a collective disability identity and a militant approach, active politicisation and fighting rhetoric had given him the means to express his own anger and frustration. However, he has also internalised negative perceptions about disabled people and also directs his invective against those he himself perceives as the 'helpless' disabled, urging them to a more proactive stance which was the one he saw himself as taking.

And people just say, "Oh all right I'm disabled, sit back and let the world carry on by". That's not for me - you've got to stand up for your rights! I've got myself a flat. I've had to fight for that because it's difficult to say "I want the doors adapted", because they don't really give a shit basically. They just think you can sit back and wait for somebody to do something about it. You've got to do something about it yourself and chase things. See if you just sit down and you're a disabled person and let everything go by, nothing's going to happen with you. But if you start chasing it up and saying, "I want to do this, I know I'm disabled but I'm still doing it", you start getting sides where people are getting annoyed with you because you're pushing them because they don't understand. "Well I thought we could just pass this by, I didn't think they'd be worried about it". But we are (Slater 2001).

Although students had been aware of these discriminatory practices and negative attitudes only two of those interviewed had heard of the Disability Movement, and they could not articulate the social model of disability. Students, therefore, with the two exceptions, were not empowered by current disability theory to hold different perspectives on their experiences. This lack of awareness has remained constant with 88% of the new residential students questioned at entry in 2003/04, also not having heard of the Disability Movement. The remaining students who had heard of the Movement had, with one exception, only a very vague perception of what it might

mean. A slightly greater number had 'heard' of Disability Arts with just one student describing people visiting the school to talk about it. Both of the students interviewed for this chapter who knew about the movement had learnt about it through school. Unusually for one student, it appeared to have been discussed as part of a broader social, political context.

I've always had an interest in social issues and politics, before coming here. I think school was where I got my knowledge of social issues (Kang 2002)).

The full significance of disability theory articulated through the Disability Movement however, appeared to have been obscured because of the cursory nature of the discussions that had taken place and Sukvinder qualified his comments by admitting that although they used to talk about disability at school 'we never went into anything deeper about it'.

### **Arts Education**

The accounts that students gave of their education in mainstream and special schools indicated that the quality of experience in the arts is still dependent on good fortune rather than a basic right and there were references by several of the students to the limited curriculum they had experienced in specialist provision. Chris felt that

after a while I was doing a lot of the same things, it was starting to get quite repetitive and I was almost glad to leave in a way and go onto new challenges (Knight 2001).

Sachin, who had achieved a GNVQ Foundation Art and Design, had benefited from his teacher's positive approach and encouragement, but his account reveals a somewhat formal structure of delivery based on Western artistic traditions (Abbs 1994, Chalmers 1996).

When I had Mr Stannier I really enjoyed him. We used to go around drawing still life and painting. We used to watch TV programmes on art. That really helped me getting ideas. He used to set us homework every week telling us to draw different objects and that. We used pencils and crayons to create light and shade and that (Nayee 2001).

For other students regardless of their interest, the opportunity to do art qualifications simply wasn't addressed. The options for Nicky, who attended a special school and accessed some areas of the curriculum at the nearby mainstream school, were dictated by others, echoing Middleton's (1999) findings that disabled children experience a lack of choice, with larger decisions made for them.

I don't know they couldn't fit it [art] into the timetable. Just didn't give me a choice, they had to fit me into the slots that they had free, so I never really got to pick which lessons I did (Sapsford 2001).

Regardless, in some instances, of the inadequacy of their experiences, it was from year seven onwards that students started to identify with art as a subject that engaged them with some significance. Chris stated

Well, I was always drawing things off shelves, like plants and stones and things like that, looking at different colours and shades. I didn't like the way I was set to do certain things; like sometimes they'd put a plant in front of me and a piece of paper and [say] "can you draw this please". It was starting to bore me really, going to art, and I actually spoke to my teacher and asked if I could do something different and eventually after time I was moved onto different things (Knight 2001).

The 'something different', however, was interpreted as leaving the student to his own devices, from which he was able to salvage a more positive activity that had evidently given him much satisfaction.

Well, I was given this huge piece of board, absolutely huge, and I was told just to paint anything I liked. I went to the school library, got a pile of books, looked through them and just painted a really long picture. In the middle there was a moon, a full moon and different shades of blue around and it started at the top as black and it was coming down different shades of blue - it was - I was really impressed with it (Knight 2001).

Students' recollection of successful artwork that was produced in this stage of their education was, despite evident limitations in the projects set, remembered clearly

and recalled with satisfaction. Katy recalled as notable, albeit mainly in terms of the length of time that it had taken, an extended project that she carried out about *Winnie the Pooh*. Despite her obviously considerable efforts it did not appear to have been significant in terms of identifiable objectives or accreditation. She described it as 'a massive project that took months to do', remarking, 'there was a lot of time in that'.

It is difficult, with some of the activities that students describe, to resist the conclusion that they had been designed as anything more than simply a way of filling the time. The following account by Anthony appears to have had no merit other than the superficial impact that reproducing a familiar image on a larger scale produces.

In the art class everyone had a go at making the Mona Lisa and everyone did a bit of her on a piece of material then stuck it up in the school and so that was quite good. I did all the face. I did the hardest part (Chamberlain 2001).

#### **IT and Lens-Based Media**

Significantly very few of the students had had access to what might have been more accessible lens-based media, with only one student declaring an entry level qualification in digital photography and one having used a video camera at school. For the majority of students, art was interpreted in terms of traditional materials although Ashleigh refers to the use of a digital camera and others refer to an initial and modest employment of IT. Ashleigh had identified at an early stage the significance that computers might have for him and was characteristically subversive in his quest to secure for himself the skills that he required. He stated

Then we had some PCs come in with art packages. I used to play on them with the art packages without the teacher's permission, because the teacher said, "don't touch this because it's a new piece of equipment, it's expensive, you don't know what you're doing" (Slater 2001).

In the short space of time that separates the schooling experiences of the cohort of students interviewed in 2001/02 and those who responded to the questionnaire in 2003/04 there appears to have been a marked increase in the use of IT with (70%)



reporting that they had created images using computer technology. In 2003/04 students were able to name a variety of software packages and had scanned in images and manipulated them often in the production of posters, leaflets and flyers for school initiatives such as citizenship, school newsletters etc. However, this did not appear to be linked to an integrated approach to art and design. This is supported by the findings of the DfEE survey of ICT for 2002 that reported 'a pattern of generally poor and rapidly declining use of ICT in art' (Arts Council 2003/ *Times Educational Supplement* 07.11.03). Schools were asked to record the level of 'positive benefit' ICT had in each area of the curriculum. Almost a quarter of all schools reported 'little or no benefit' from using ICT in art (primary 23%, secondary 26% and special 27%). This represents a marked decline in substantial use of ICT in art when compared with the 2000 survey with a 31 % drop at primary and a 14% drop at secondary level. However, they also report that in spite of this evidence, research commissioned by the Arts Council (Creating Spaces Group) shows that there are 'clearly pockets of really exciting practice in this area' as for example with the work at Mere Oaks school described in chapter four.

### **The Effects and Effectiveness of Arts Education**

Given the unimaginative approach to subject matter that frequently characterised their art classes, student responses to questions concerning the meaning and purpose of art, produced replies that were surprising. All the students identified art as a vehicle for the expression of emotions, feelings and personal creativity and it was evident that it was linked to their self esteem (Harland 2000). Sukvinder stated, 'To me art is expressing your feelings and emotions. To me that's what it's all about – emotions'. Students also recognised the power of communication in the visual arts and Nicky in particular expressed this view of art's purpose.

If you can do a piece of artwork and get that message across it'd be brilliant. I suppose in every painting there's a message the artist is trying to get across and if you can really understand a painting and what the painter is trying to tell you, you start feeling better in yourself (Sapsford 2001).

Katy appreciated the autonomy that her art work gave her and had realised that she was free to interpret the world as she wished. 'You can make that drawing what you want it to be. You don't have to draw exactly what you see. So you can turn it around

'til you like it'. This power, implicit in the self-referential experience of producing visual art, is tempered by the response of the audiences that receive it, and from whom a whole range of reactions may be anticipated. Students had experienced the rise in self-esteem that admiration of their artwork produced and had little difficulty expressing how this felt. Sachin reported:

It was good because I brought my work and showed them [his family] and they were really pleased you see, and my dad, when I got my art report home, was very pleased with the progress I was making and the comments of the teachers and I really enjoyed it (Nayee 2001).

The distinction between level 2 and level 3 studies in terms of the production of imagery specifically concerned with self identity was sharply defined. With the exception of Anthony, it was only in the artwork of the students who were studying at level 3 that images relating to self-identity appeared. Of the 5 students who were interviewed at level 2, Anthony had chosen to involve himself in additional activities such as life drawing and the Disability Arts programme. During his GCSE course, his initial self-portrait represented a conventional response in the simple recording of his features (see Fig 23), however, he progressed to a more fluid, interpretation in which the image becomes fragmented and less tightly constructed (see Fig 24, 25). Ultimately, he returned to the original image. By scanning this into the computer, he was able to add text and a collage of other images, both photographic and drawn, that he felt were more representative of the more complex notion of identity that he was developing (see Fig 26). It is interesting to note that his subsequent progression to Foundation Art and Design studies in 2003/04, has prompted him to address aspects of his identity that relate to his impairment, through images that represent the rods in his spine (see Fig 27). His confidence to express the 'hidden' feature of his impairment has grown and he adopts a broader, more explicit notion of self-identity that demonstrates the early stages of the process of 'coming out' that Swain and Cameron (1999) describe.

In contrast Ashleigh did not feel the need to empower himself through a process of 'coming out' but rather developed an understanding of his social identity by locating it within a family context and creating a visual narrative approach to the expression of self (Clough and Barton 1998).

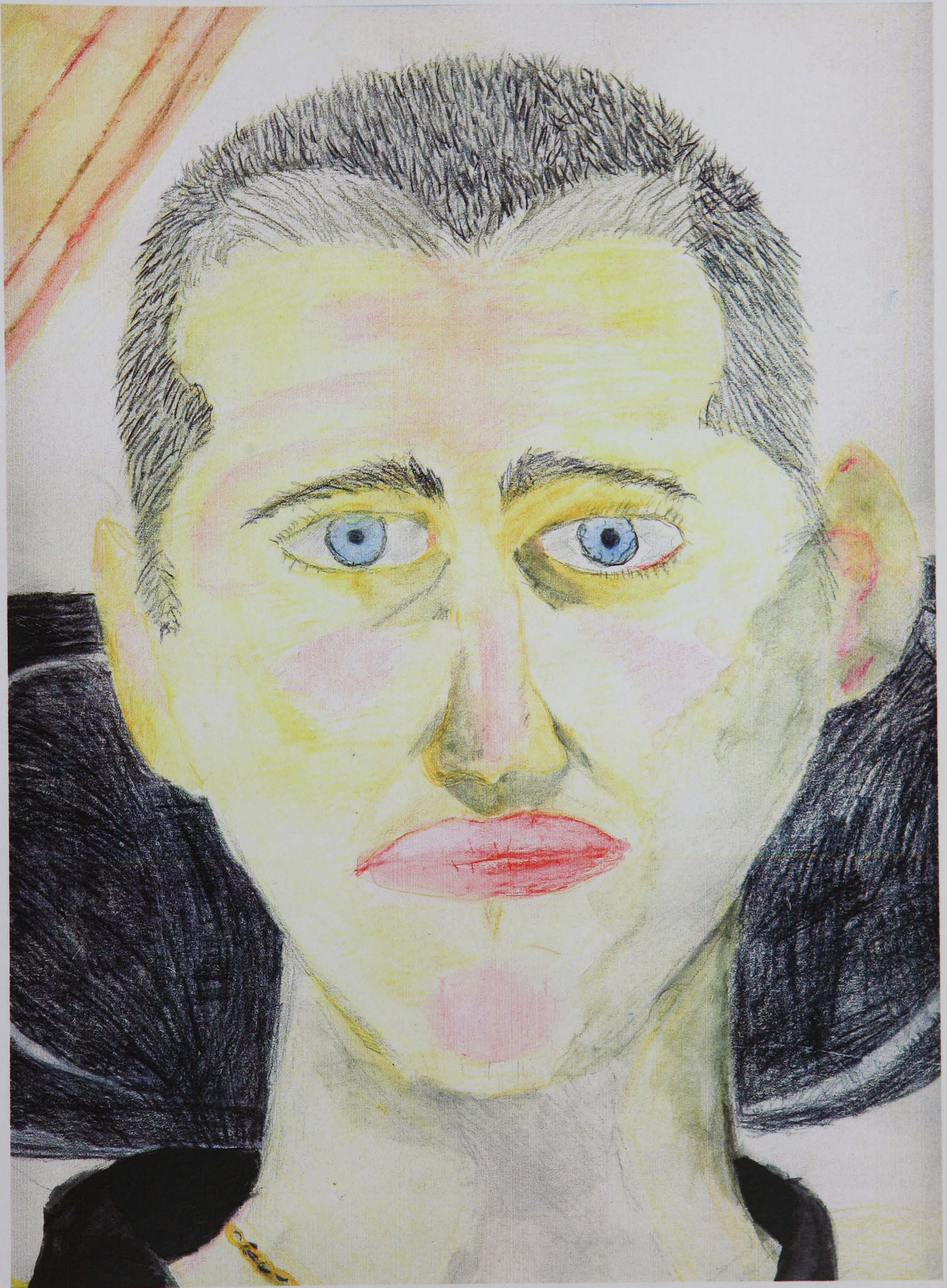


Fig 23



Fig 24



Fig 25

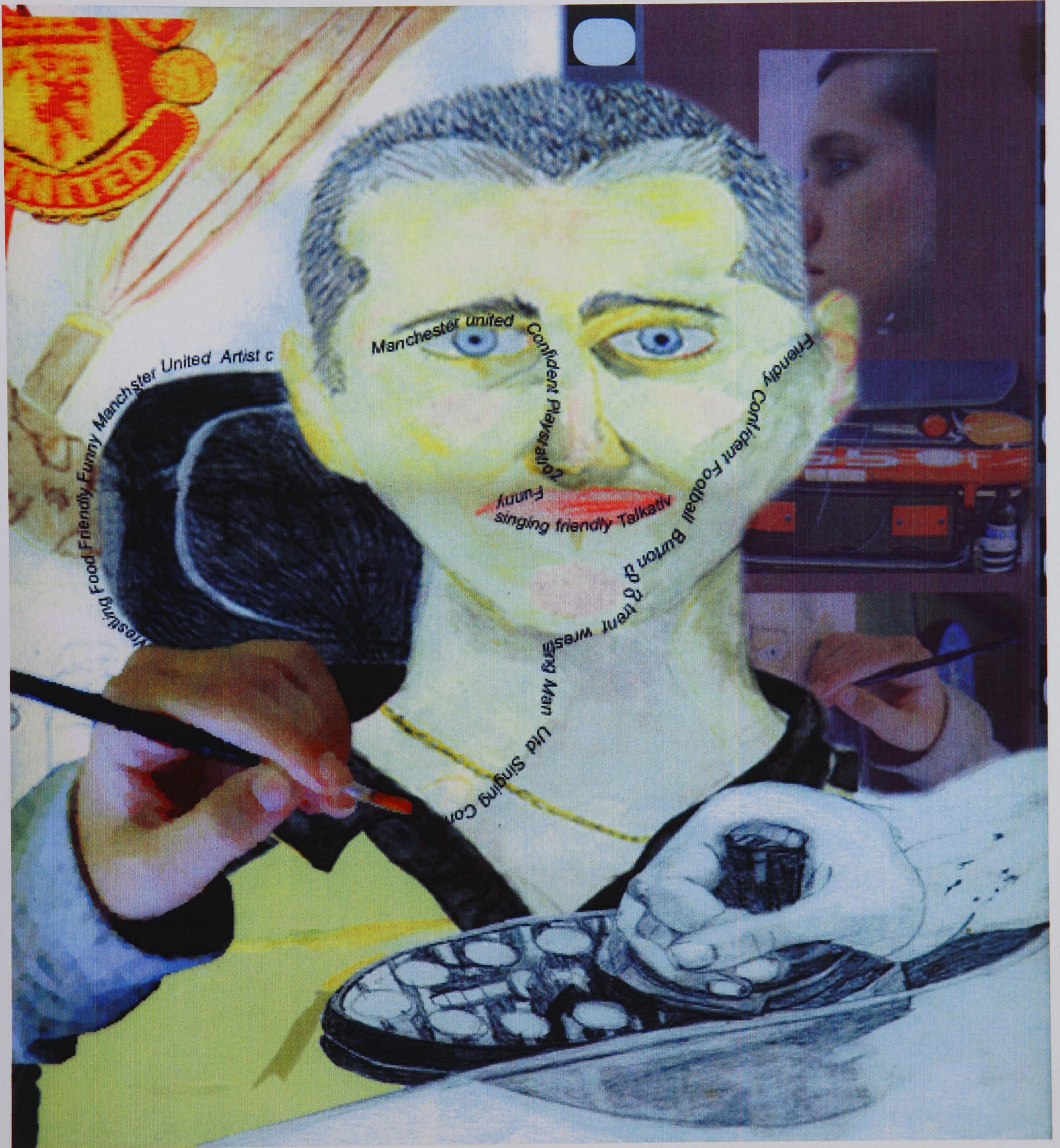


Fig 26



Fig 27

This he did in the form of a 'quilt' which he entitled 'Woven Emotions' and which he intended to depict his family's genealogy/identity and his own personal history (see Fig 28). He stated

In designing my own quilt I will be using ideas based on the ways in which families can constrain, or are a major foundation/framework for the way you live. As well as this I will be influenced by my own feelings of emotion, disability, my family and my art (Slater 2001).

His research for this project led him to investigate American home made quilts including the AIDs quilts. He used a wide variety of media and materials, including computer generated images, to integrate objects, photos of his family, and text to reflect his memories, personal history and emotions (see Fig 29, 30). He stated

Family is always there. This quilt is a framework of my identity, of my life. Using a quilt design I will be building my life back together. This will include memories, my history and the things I really miss (Slater 2001).

Richard, who started later in the year and had not at this stage engaged with issues of representing the self, was, nevertheless, and despite his taciturn nature, beginning to make connections between his artwork and self-esteem. He commented 'I'm doing a silk screen. I've done quite good at it I reckon'. Of the remaining 3, level 2 students, all had, within the year that they had been interviewed, left the course for various reasons - 1 was long term sick and 2 left for other establishments that focused on psychiatric and rehabilitation issues. This again demonstrates the often, fragmented nature of disabled young people's education and the difficulty of establishing continuity throughout their educational entitlement and creative development.

### **Ethnicity**

Of the 4 students interviewed studying at level 3, although all had been born in England, 3 were of ethnic origins other than white and Christian; 2 were Muslims and 1 was a Sikh. Although this is a very small sample and therefore cannot be considered as representative of disabled young people from Asian backgrounds, the differences that became apparent and that related to cultural attitudes would make





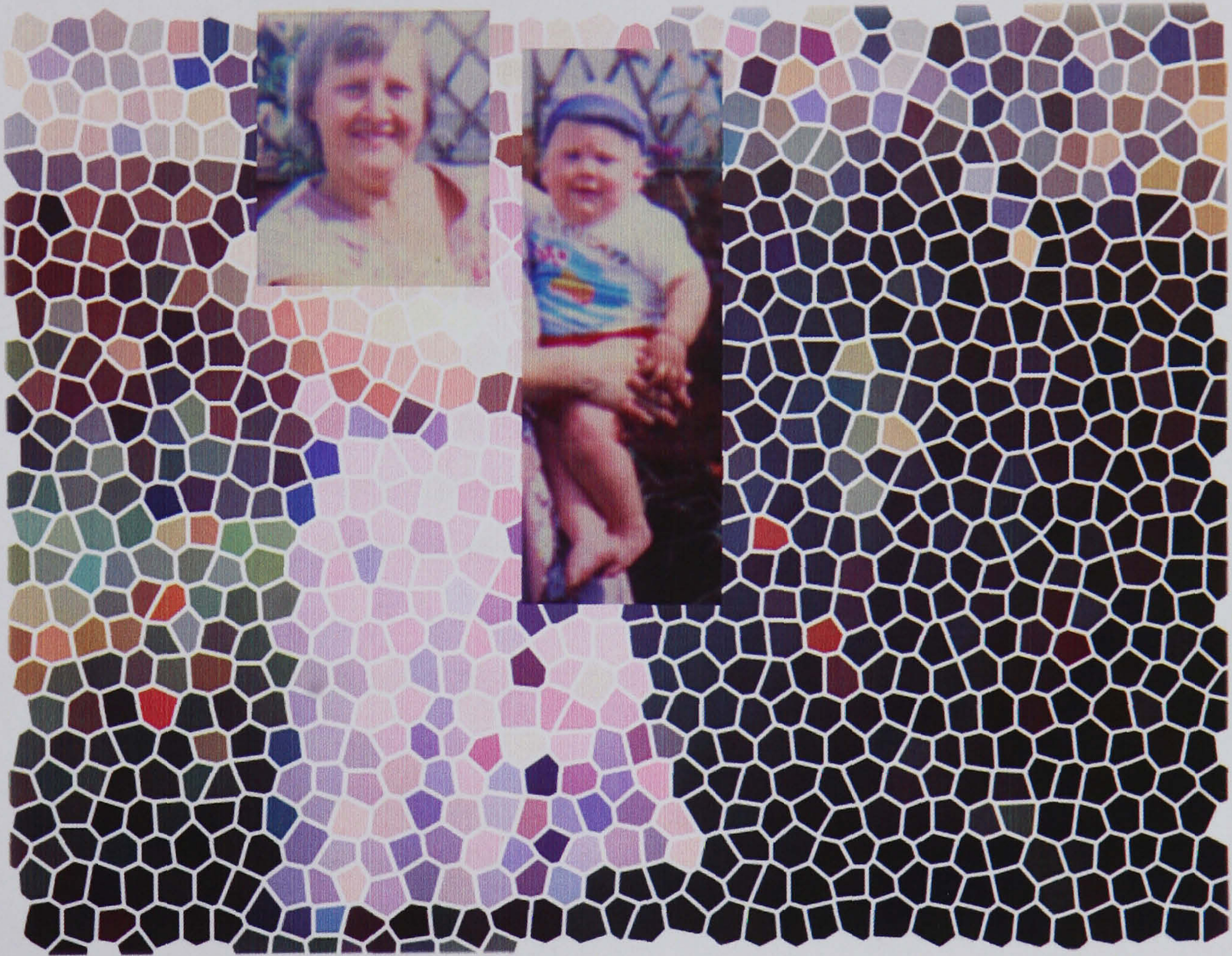


Fig 29



Fig 30

further research in this area valuable. Mushraf and Sachin were adamant that their artwork was separate from the development of self identity, although the artwork (that is described later) belies this assertion. Sukvinder who had through his description of himself as interested in social and political issues demonstrated a higher level of awareness, was more analytical in his approach. He commented

Because I come from a very traditional background, especially coming from an Indian background, art isn't really considered a very "job worthy" kind of thing. It's kind of considered just fun and my parents are concerned with the academic side, obviously a job that's on a desk, or maybe a lawyer, a doctor - that's just a typical Indian thing and they weren't really that bothered. I mean they didn't really push me to do art, I just liked doing the subject (Kang 2002).

He was also very clear that his ethnicity was an important part of his work.

To me definitely it is and when I leave [for a university place in Fine Art] I want to explore that a lot more. I've only just scratched the surface at college with it but hopefully I can develop that a lot more (Kang 2002).

The other two students made a clear, if somewhat ambivalent distinction of their art as 'work' rather than concerned with self-identity with Mushraf asserting that although he saw art as expressive it was not an expression of his identity (ethnic or disabled) and that this was a deliberate choice. However he then went on to describe how he was currently working on masks and recognised that this did actually have something to do with his impairment and identity.

It's actually more hiding than showing. Some of the thoughts I've had is when I was younger I used to find that I was always wearing polo-necks and things that would cover my neck and I always used to pull them over my face just a little bit to cover up the burns. So in my mask project I'm going to take that bit and add to it what I was like for so many years. A polo neck that actually covered the neck a bit and some kind of mask that covered the lower bit of my face and I shall

have some kind of message there of what I'm trying to do, get across  
(Rafiq 2002).

Mushraf appears to have compartmentalised his life as a Muslim, as a person who has an impairment and as an artist, although clearly there is seepage between his carefully constructed divisions. His community, family and religion provide him predominantly with his sense of self-identity and this was common to both of the other students.

On one level this may reflect the demands that Asian culture makes for men to demonstrate the ability to work, preferably in a profession. However, Sachin, whose confidence had been shaken by the experience of a stranger querying the effectiveness of his eyesight from his appearance, had used his artwork as a process for developing and constructing a representation of himself based on his good looks. In this he fused eastern/westernised male at his trendiest creating a photographic self-portrait in which he appears as a glamorous 'Bollywood' type matinee idol but in which he has overlaid images of himself as a vulnerable small child (see Fig 31, 32). It would seem that he is using the currency of his good looks to counteract his fears about himself and it could be argued that these are represented in the image of himself as a child. It is interesting to note that when Sachin progressed to level 4 studies in graphic design (2002/03) he continued to find opportunities to explore issues of self-identity in a very expressive way. Figure 33 shows a painting in which he combines text and image in ways that allude to his sight impairment. He references the blurring and movement associated with his nystagmus, creating a highly tactile surface that draws on the decorative and colourful qualities of his culture.

### **The Alternative Self Portrait and Role Models**

The Alternative Self Portrait, a project that is set for students as part of Foundation Art and Design, has frequently proved to be a catalyst for issues that relate to the representation of impairment and disability. This project requires students to analyse the concept of self-portrait and to create an image of themselves that is observed, true to life and reflects their personality. However, prior to this they are encouraged to research self portraits throughout history and to discover, despite the differences in media and styles, their commonalties. Having assessed these characteristics it is left up to the student, as an artist, to employ them in their own work.

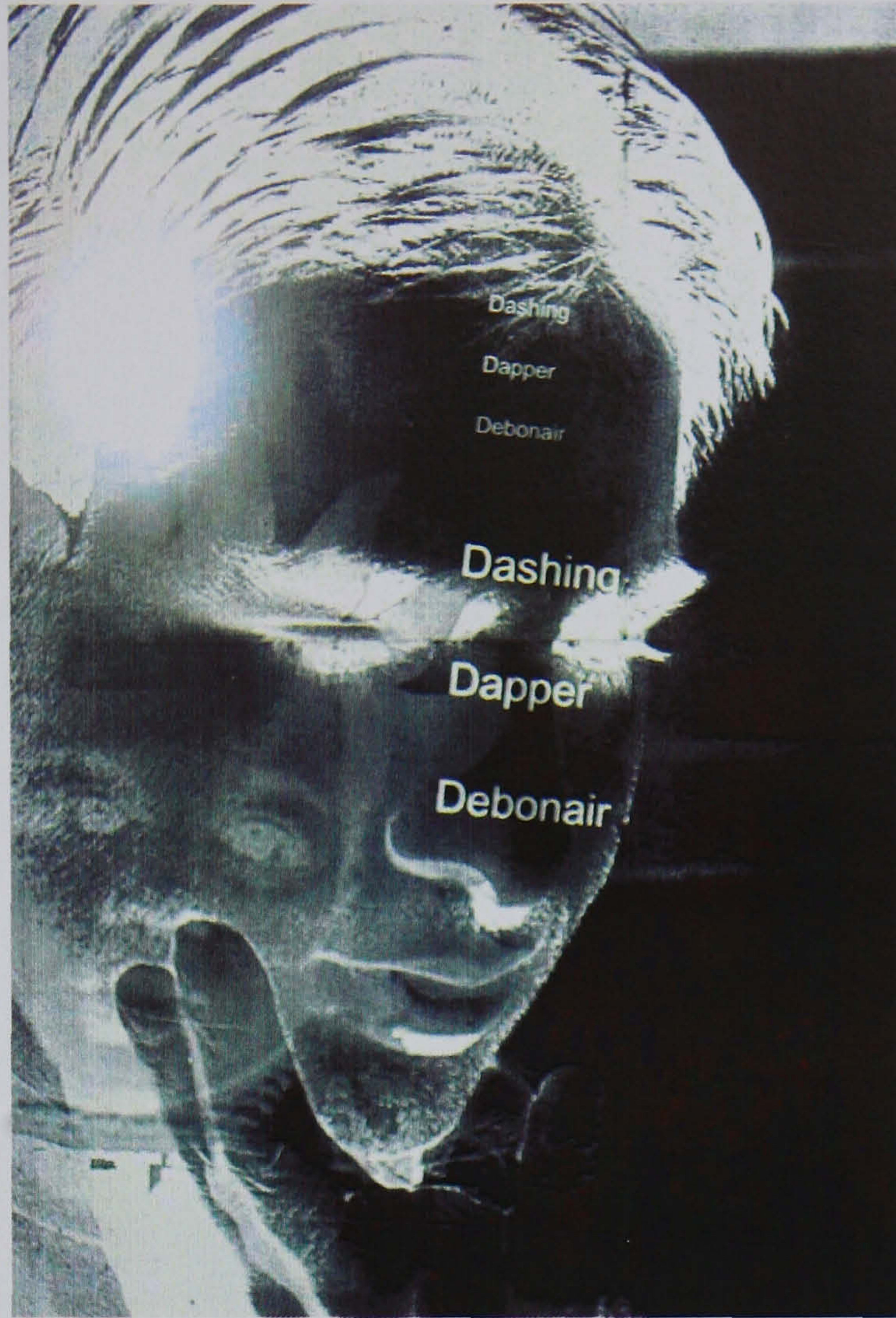


Fig 31

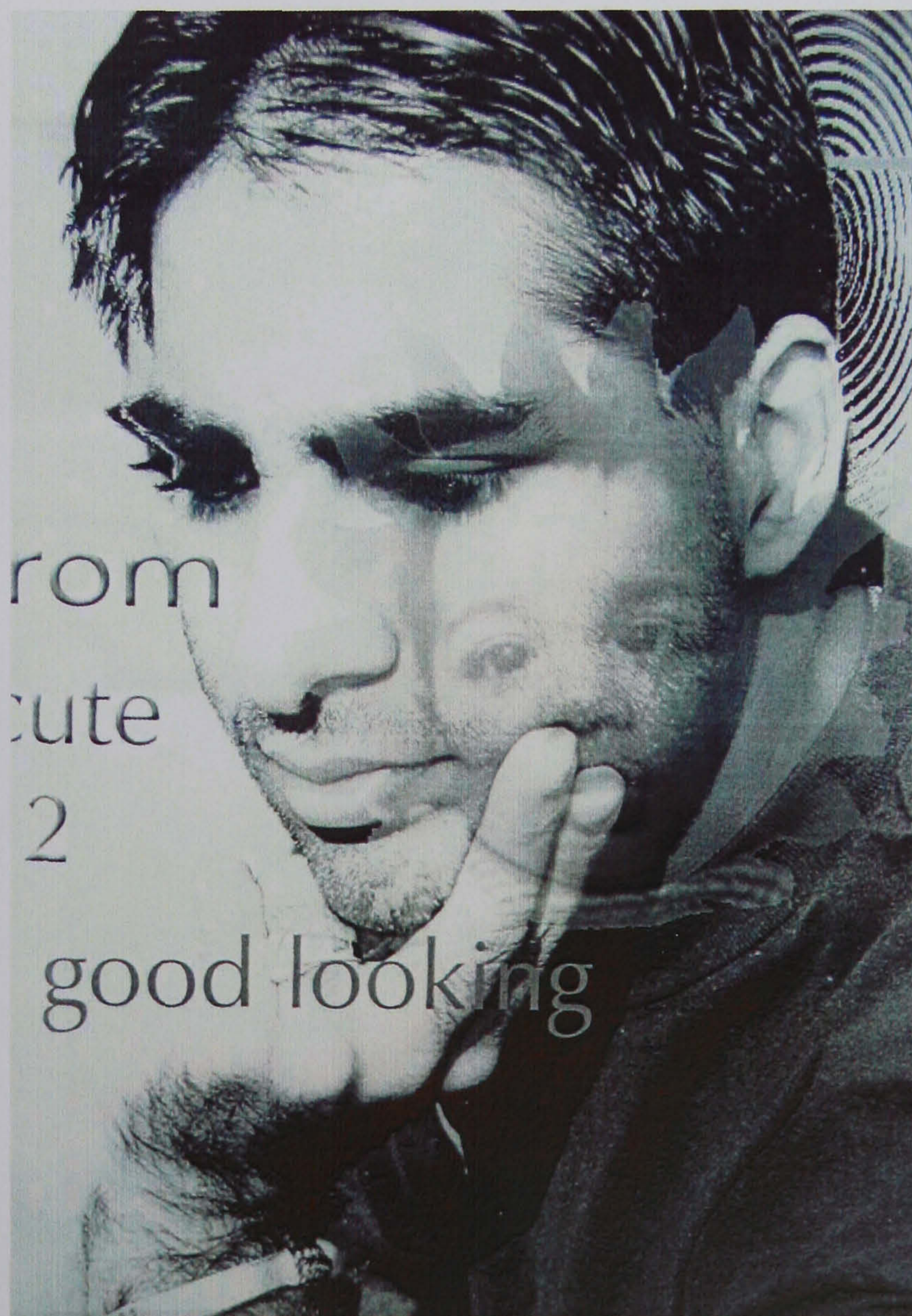


Fig 32



Fig 33



Fig 33a

In this brief, the self-portrait that is required is located within a mainstream tradition and students are encouraged to research and analyse those examples that they consider relevant. Disability and impairment are not written into the brief. However, the student is encouraged to use the phrase 'self portrait' to explore the notion of working directly from themselves - the 'self' being the subject matter and theme for this project. Students are encouraged to use a multi media approach, exploring the potential of mixing and experimenting with media such as paint, text, photography, digital media, video, drawn imagery, graphic media and textile techniques. It is suggested that they consider themselves in three dimensions, looking beyond the surface and employing drawing aids to help them such as overhead projectors, spatial grids, and, of course, lens based media. Above all they are required to document every stage of the project in both their sketchbook and their reflective journal.

Sukvinder described the process he had engaged with and how it was influenced by the work of a disabled artist-in-residence, in the college at that time, who, like Sukvinder was a wheelchair user.

And then I did a series of paintings which delved a bit more deeply, like emotional stuff, like what feelings I get sometimes and that kind of thing, low self-esteem and all of that (see Fig 34, 35). That [Hardy's work] made a huge impression on me, even with my work now I'm doing stuff on a large scale, and I thought I wouldn't be able to do it in a wheelchair and reaching up and everything. But seeing his work, the method that he uses, influences me with my own work, with my alternative self portrait which is a really massive piece (see Fig 36) (Kang 2002).

The artist-in-residence was an ex-Hereward College student (Eddy Hardy) whose work, which is discussed in greater depth in Chapter ten, had a profound impact on students, both because of his status as a disabled artist who uses a wheelchair, and also because his work represents an 'outing' of impairment in uncompromising and in some senses shocking ways (Barnes and Mercer 2003, Swain and Cameron 1999).



Fig 34



Fig 35



Fig 36



Students were inspired and exhilarated to discover the potential for themselves in such a role model and were empowered to be part of a 'collective' response (disabled students plus disabled artist) in creating representations of impairment and disability. Sukvinder was particularly impressed.

I did find it empowering. Seeing his work, kind of made me a bit more confident, that you can be quite alternative especially being disabled and exploring that when he showed his work, self portrait nudes. It was just like a real eye opener kind of thing and it showed me how broad you can be. As an artist your work can be very powerful if you want it to be, so I just really want to explore that really, how work can be really powerful (Kang 2002).

The work also had an impact on the level 2 students and Richard in particular, although giving his customary economic verbal response, made it quite apparent, through his body language and expression, that this had impressed him and made him feel stronger about himself.

Other students had similarly been inspired by role models, particularly when they could identify with the impairment.

Well, when I saw his work I was pleased you know [because] he is partially sighted and I couldn't believe that he could draw like, accurate. I was very pleased 'cos it helped me 'cos I'm partially sighted. It's good to look at other people's work and think I can do this. (Nayee 2001))

The Internet also provides another source of inspiration for disabled students as Ashleigh discovered, fuelling his militancy and radicalism through the declaration of impairment in uncompromising images.

For disabled people it's their feelings. It's stepping out of the boundaries and showing people what we are really like. We're not just wheelchair users, stuck in boring institutions. We are gay! We are drug users! It's like Ju 90 [the artist]: she shows her work through the

Internet and she doesn't just step back. She does her braces, she shows her orthopaedic equipment (Slater 2001).

### **Disability Arts as part of the Curriculum**

Clearly politicised disabled role models have constituted a significantly empowering aspect of the students' arts education, as have discreet projects and workshops that have taken place at the college. One of these is described in detail to illustrate the primary importance of developing positive and confident self-identity as a precursor to political involvement. Peters (1996) describes a situation in which after years of activity in the Disability Rights Movement she felt the need to search for a self-identity that was 'more complex and personalised and more grounded in a sense of physical and psychological self image than in political identity' (p.215). An example of how these dual aspects of disability identity can be addressed in an educational environment is demonstrated in a project that took place at Hereward College in the academic year 2000/2001. This was designed to encourage students to focus primarily on their sense of self, whilst acknowledging that disability exists as social injustice and societal oppression.

### **The Politics and Poetics of Cloth**

The project arose out of a partnership between the creative studies department at Hereward College and *Craftspace Touring*. The aim of *Craftspace Touring* is stated as 'the desire to play a leading national role in the development, presentation and critical appraisal of contemporary and design-led crafts' (*Craftspace Touring* Handout 2000). Traditionally crafts practice has been strongly associated with the development of technical skills, and certainly the historic association of disabled people and crafts has been limited and limiting, linking them to culturally low status activities such as basket weaving, raffia work etc (Humphries and Gordon 1992). *Craftspace Touring*, however, take as their remit an interpretation of crafts in which the development of creative, social and personal skills are also given high status. They regard designing and making as

a creative process that may include the development of a wide range of skills including discussion and negotiation, investigation, analysis, lateral thinking, speculation, and problem solving, as well as the manipulation of tools and materials. (Handout 2000)

Central to *Craftspace Touring's* policy is a commitment to making its exhibitions and services accessible to all people, including those with disabilities. This is interpreted not just as good physical access, but also extends critically to intellectual and emotional access, with recognition of the respect for self-identification as key. The purpose of the project that was introduced to Hereward students was the use of contemporary crafts to explore issues surrounding the representation of the body in contemporary British society and to challenge traditional stereotypes in relation to body shape and disability. The framework for this exploration was a textiles project which examined clothing (including headwear and accessories) in terms of social and cultural significance. Students were involved in making new garments and reconstructing old ones to serve as metaphors for their personal desires, opinions, ideas and experiences. As such, it enabled students to take control of the process of representation within an encouraging and critical framework.

In support of the project, *Craftspace Touring* funded two artists-in-residence to work alongside Hereward staff. Freddie Robbins is a textiles artist who employs traditional knitting techniques to create garments which in their unconventional interpretation of seemingly familiar items such as gloves and jumpers subvert expectations of normality. For example a pair of gloves with further gloves knitted from the end of the fingers, a jumper with no head space or hand space, a jumper with long sleeves finished as socks, explore function, fiction and stereotyping in design, and in their non-conformity, resonate with meaning for disabled people (see Fig 37). She has also experimented with knitted text, designed to question the viewer and challenge assumptions about the wearer (see Fig 38).

This integration of text and garment was an important part of the project as it gave disabled students ownership of the words that are usually spoken across them by non-disabled people, to non-disabled people (Hevey 1992) This was facilitated by the second artist, Semba Jallow-Rutherford, a poet and performer from a Caribbean cultural background, who draws upon his own experiences as a wheelchair user to create poems which are both personal and political. He sees disability as 'a teacher, which can teach about self and other people, making the person richer by the awareness of the world and the people in it' (workshop diary 2000). In addition to these two artists, a professional photographer was employed to work with students and enable them to gain creative control over their photographic representation.



Fig 37

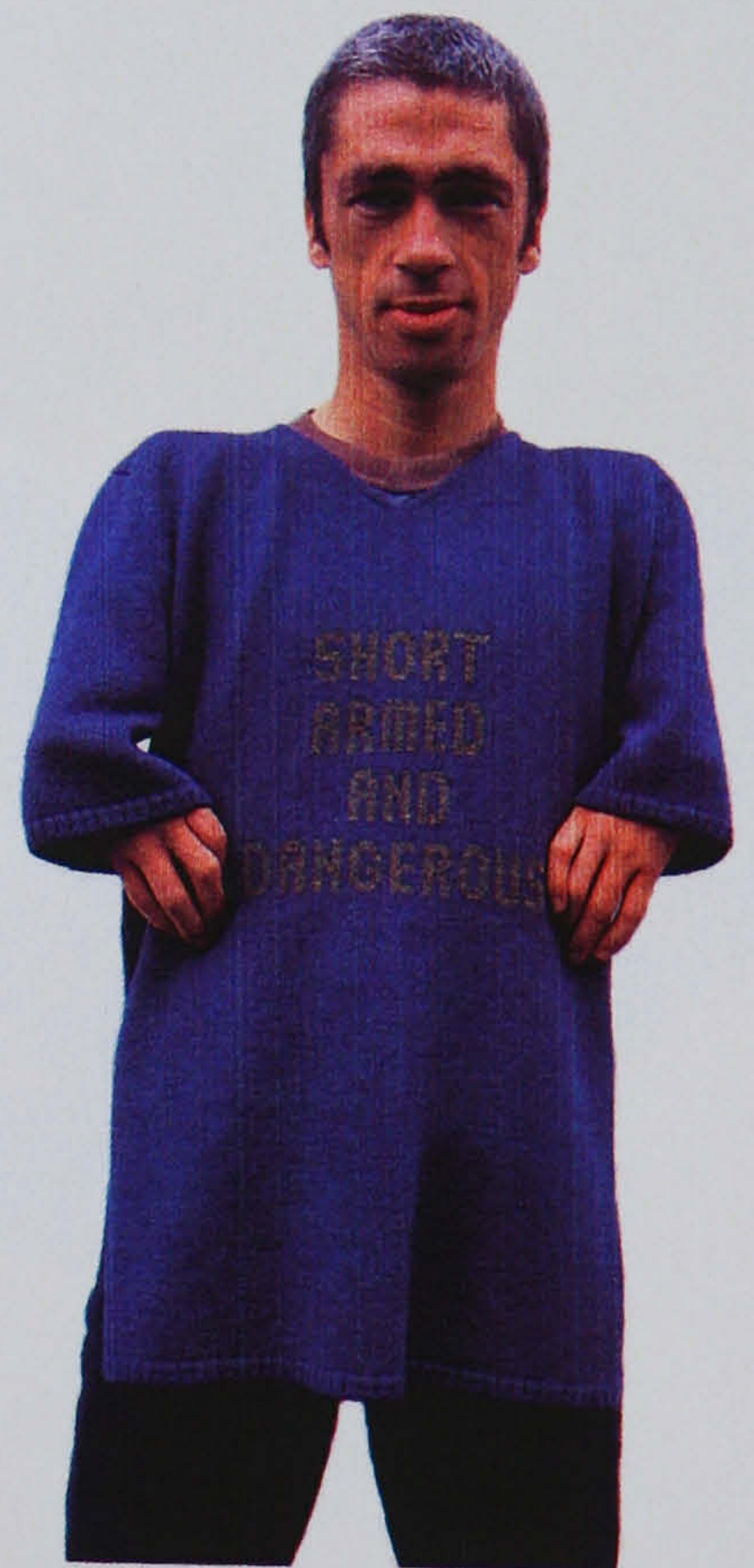
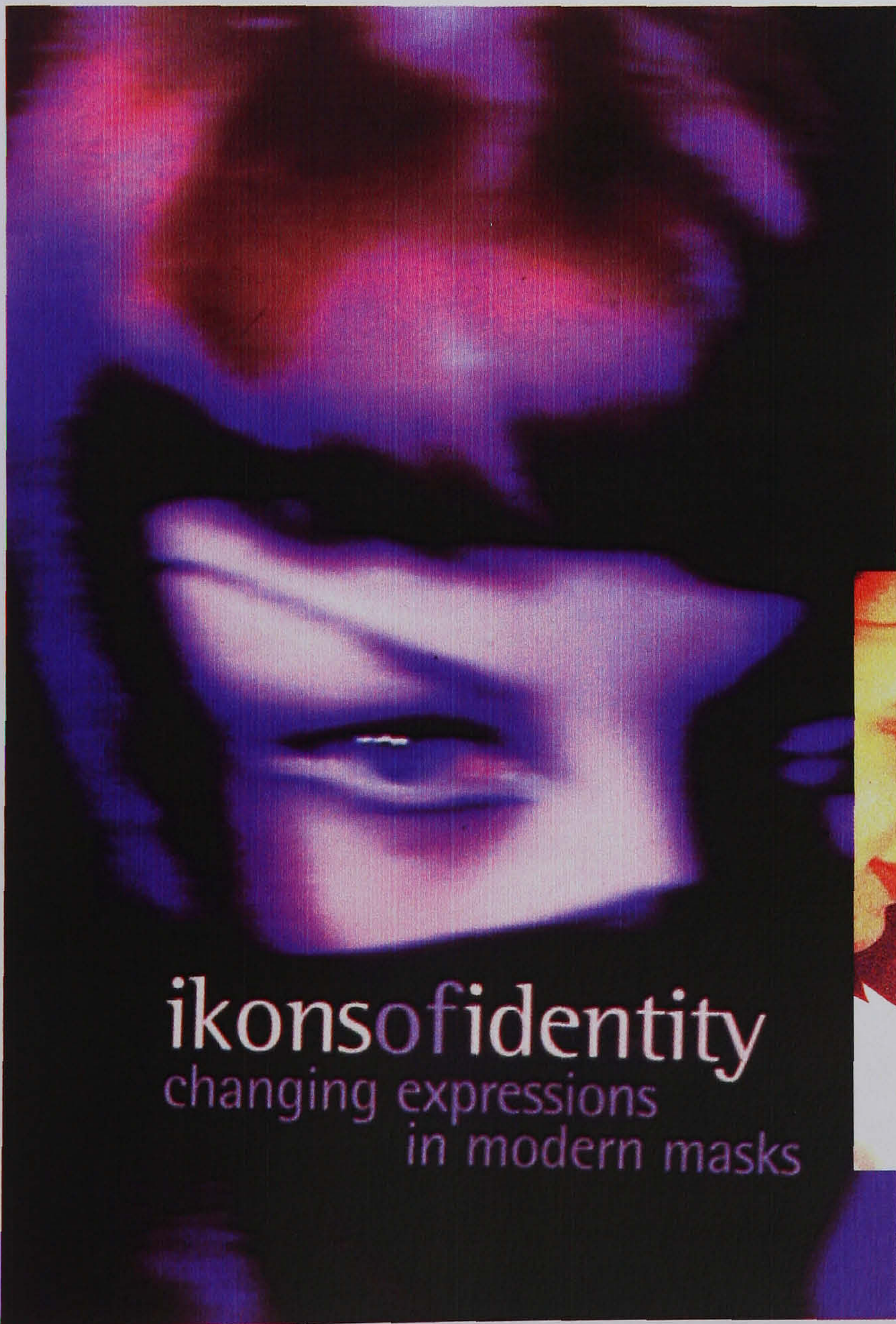


Fig 38



Fig 39



ikonsofidentity  
changing expressions  
in modern masks

Fig 40

**thepoliticsandpoeticsofcloth**

The Politics and Poetics of Cloth was a project that took place at Hereward College in Coventry during the autumn of 2000. Working with textile artist Freddie Robins, poet Samba Jallow-Rutherford and photographer Karen McConnell over a two month period, students made and wore a series of garments, exploring their personal identity in the process.

**the setting**  
Hereward College, Coventry is a well used specialist secondary school specialising in the education for students in the physical and mental health care services. The main school building is a large and modern building with a large courtyard area.

**who am I?**  
The project was a two part project. The first part was a series of workshops where students explored their own identity and the way they see themselves. The second part was a series of workshops where students explored their own identity and the way they see themselves.

**a fusion of text and textiles**  
The project was a two part project. The first part was a series of workshops where students explored their own identity and the way they see themselves. The second part was a series of workshops where students explored their own identity and the way they see themselves.

**customized T-shirts and vests**  
The project was a two part project. The first part was a series of workshops where students explored their own identity and the way they see themselves. The second part was a series of workshops where students explored their own identity and the way they see themselves.

**My identity is something I tend to forget about because it is a part of my everyday life. My disability is deep inside but I forget about it. But if you take the time to pull it out then I'll really get going and get really fiery - just because my legs don't work does not mean that I can't do anything.**

**I want to challenge society in this way, as I don't feel it is challenged enough. I think that all the students involved in this project feel equally strongly about the way in which disabled people are seen in society. The project has really got me thinking and made me realise that this is what I want to do as a career.**

**Kim O'Brien, student**

**a textile artist, a poet and a photographer**  
Freddie Robins is a textile artist who works for Coventry and Warwick University. Samba Jallow-Rutherford is a poet who works for Coventry and Warwick University. Karen McConnell is a photographer who works for Coventry and Warwick University.

**it's thinking, breathing space**  
The project was a two part project. The first part was a series of workshops where students explored their own identity and the way they see themselves. The second part was a series of workshops where students explored their own identity and the way they see themselves.

Fig 41

In this way high quality evidence of what students had made was obtained, and opportunities were created for students to subvert and reinterpret the tradition of the glossy glamour shot and fashion advert.

The group of students, who came together for the project, was drawn from visual and performing arts courses. All appreciated having the opportunity to work together united by an overarching theme, in contrast to the usual framework that dictates that they follow the curriculum according to subject areas and specialisation. The result was a rich alliance of young people who, although familiar with each other, nevertheless had a lot to learn about each other and who were increasingly drawn together by the project's common purpose. The group included some non-disabled students, who, despite the project leader's initial concerns that the activities might be too weighted towards disability to be of relevance, demonstrated its universal significance by exploring how isolating it can be, to be in an environment where they were actually in the minority. A non-disabled, female, Muslim student similarly benefited from the scope of the project, by articulating her thoughts and feelings in relation to the impact that religious codes have on clothing, appearance and identity.

An important element of the project for most students was the group discussion, and the forum that this created for the sharing and acknowledgement of feelings and experiences. It was reflected in remarks such as; 'the workshops help you to come out and say how you really feel' and 'you can let out all your emotions that are pent up inside, through using words and materials'. Discussion sometimes became emotionally charged as students experienced the cathartic effects of expressing suppressed and unspoken feelings about themselves (Thomas 1999, Reeve 2002). Uncertainty about exploring the theme of identity via the project was felt by one student, who stated 'I don't think it is good for disabled people to always think about their disability - they should concentrate on having fun and looking good'. Another student who had been empowered by the experience, commented

My disability is deep inside but I forget about it. But if I do take the time [have the opportunity] to pull it out then I'll really get going and get really fiery. I enjoy expressing this because it shows people that I have a mission.

Another student describing the hidden or invisible nature of her experiences, suggested 'Sometimes I feel as if I have a veil over me as a disabled person'.

Students translated these feelings into garments (see Fig 39). They combined devices such as the employment of restraining fasteners including zips, chains and buckles, pockets which carried messages, the attachment of textile constructed arms and hands to the garment, and masks and veiling embroidered or painted with words, or the features of facial expressions. Text was applied in a variety of ways from graffiti-like scribble, to words that were carefully printed, appliqued and stitched. Colour was achieved through dyeing, printing and stitching, with technicians and enablers acting as amanuenses at each stage to ensure that what the individual designed was realised.

The processes that the creation of such garments demanded encompassed additional skills to those creative abilities related to textiles. These included: the development of critical skills in the interpretation of visual images; the ability to work creatively with words; and an understanding of the social and cultural significance of catch phrases, slogans, labels, jargon, slang and in particular with those that relate to the body and disability. Critically, students were given the opportunity to redefine for themselves what constitutes clothing and to explore the links between clothing and identity, leading to a deeper understanding of their own identity and a stronger sense of control over their own representation.

Recognition and endorsement of the work was crucial in raising students' confidence and belief that what they had achieved was valued. This was affected with the inclusion of a representative selection of the garments and documentation of the project within *Craftspace Touring's* exhibition, '*Ikons of Identity*' (see Fig 40, 41). The theme of the exhibition was the contemporary mask. Craft objects by makers and artists, that veiled or masked the body either literally, metaphorically, or symbolically, were featured. The exhibition was inclusive not just because it featured the work of disabled and non disabled artists, but in its emphasis of the universality of the concerns that Hereward's students had been exploring and of which disability is but an integral part.

If the options of our physical appearance develop, as we become adults, so too do the concerns of personal identity and self-awareness

- physical, sexual and emotional. We talk about masking our emotions, making a veiled response, suppressing a smile, covering our heads in shame, a language of hiding and revealing that reflects as much what we choose not to show as to how we might wish to be seen (*Ikons of Identity Catalogue 2001:6*).

### Summary

Earlier in this study I detailed the social construction of disability and the ways in which this informs social interactions and seeps into the perceptions of disabled and non disabled people alike through the mass media. Students interviewed for this chapter clearly perceived their underprivileged status and recounted how this was manifested through their early schooling and through the attitudes of their non disabled peers and the adults they encountered. The concerns that they express are reiterated, with some additions, by all the students in this study. This chapter has drawn attention to the resistance that has been effected to what Thomas (1999) describes as barriers to 'being' (p.60). This has been variously carried out as angry militant rhetoric, a withdrawal from social interaction and, by some, as empowering statements about impairment and disability via their artwork.

There is much in what students recount about their early experiences, to support Barnes *et al's* (1999) observation that arts education for disabled pupils is 'limited and limiting' (p.207). Nevertheless students had maintained a positive attitude towards the arts and a number had derived pleasure and self esteem from what they had achieved at school. Contact at Hereward College with disabled role models, and opportunities to participate in workshops that address issues of disability and representation have clearly been seen as empowering by students. These have directly influenced their ability to make connections between the visual arts, self identity, impairment and disability, in images in which, increasingly, they are demonstrating technical skill and aesthetic competence which not only authorises the message but places the work within mainstream accreditation frameworks. The next chapter moves from this collective account to focus on a single individual and to explore, in detail, the ways in which a non verbal student with complex and high level support needs has made the expression of a positive self-identity the focus for her artwork and how she has been supported in doing this with IT, enablers and tutor input.



## Chapter Eight

### **Access and Support in the Development of a Visual Language.**

This study has given much attention to the psycho emotional dimensions of disability and the last chapter has begun to explore the ways in which arts education, and the acquisition of the techniques and competencies of a visual language, in conjunction with consciousness raising around issues of disability, has the potential to offer disabled students a means of expressing a positive self identity that includes the lived experience of impairment and disability. This chapter focuses on questions of access and support and is based on an in-depth study of how access to the arts curriculum has been created for a student who is non-verbal and whose fine and gross motor skills, with the exception of her left foot, are significantly affected by cerebral palsy. A gradual process is recorded whereby communication, IT, enabling support, creative techniques, practical activities and design of the curriculum and teaching, are refined and merged to create seamless access to the visual arts for this student. This chapter describes the narrative approach to identity formation that the student has engaged in, in a 'reflexive project of the self' that Giddens (1991) describes and Seymour (1998) elaborates on as a process of 'making, unmaking and remaking' (1998:pxiii). The student has developed this, mainly through the use of lens-based and digital media, and attention is drawn to the particular significance that the acquisition of a visual language has for disabled young people who are non-verbal and for whom text based systems, as a means of expression, are problematic.

People using augmentative communication aids pose particular problems in research terms and they are marginalised from conventional research study because detailed information about how the person communicates is a necessary prerequisite for their inclusion. Their communication may be complex, subtle, involve various modes and be extremely time-consuming and it can be open to misinterpretation if the interviewer is not entirely familiar with the student's preferred means of communication or has the assistance of somebody who is. The knowledge that facial expressions and involuntary sounds cannot necessarily be read in a conventional way, yet can still be highly significant is important. We are well versed in picking up subtle inflexions of expression and intonation but these can be misread until such time as there is familiarity with, and understanding of, individual communication.

The difficulties, in research terms, that are posed by the inclusion of non-verbal students and the moral dilemma that is presented by their exclusion, is described

with reference to a research project that Cook, Swain and French wished to carry out (2001:293-310).

All the children in this small sample were able to communicate verbally. Children using augmentative communication aides or with whom participation in standard communication would be difficult, were not included. We were acutely aware of not being able to listen to these children at this point, and hope to work with them in the future (p.301).

They point out that:

Children were suggested by their class teacher in terms of who they believed would be appropriate for the project, and therefore we relied upon their understandings of appropriateness (p.301).

Time constraints, and a lack of opportunity to develop data collection methods using alternative communication systems with non-verbal pupils, were cited as reasons for their exclusion. We are not told the criteria for the teachers' perceptions of who was 'appropriate' for inclusion, nor whether consideration was given to using those who were familiar with the non-verbal children's methods of communication to act as facilitators in the inclusion of their 'voice'.

### **Alternative Means of Communication**

In comparison, a non-verbal young person is the subject of a Lenney and Sercombe (2002) study that investigates interactions between non-disabled people and people with physical disabilities (pp.5-18). However, his involvement was made possible by the fact that Lenney had known him for four years and was familiar with his means of communication. Similarly Samantha (who prefers to be known by the shortened version 'Sam') and who is the subject of this case study, has been known, by me, for the four years that she has been a student at the college. This has allowed refinement of the understanding of her communication methods, by a number of people, to take place. Her residential status at the college as a full time student made clarification or expansion of data gathered possible, her activities and progress in the studio were observable on a day to day basis and it was possible to develop a

broader and richer understanding from the accounts of those who had worked with her over the four years.

Sam is a 21 year old woman who, in addition to an electronic communicator, uses eye contact and direction, head movement and facial expressions to communicate. She uses her left foot to access the switches that drive her electric wheelchair and operate her communicator. She is able to make soft, high pitched utterances which she uses to draw attention to things and as an affirmation. It is also possible to communicate with Sam through a process of elimination, taking cues from her body language as described by Lenney and Sercombe (2002). Once the non-verbal person has indicated that he has something to say, Lenney describes working through a process of guesswork. Levels of questioning are carried out in which the subject area is narrowed by offering potential options from which agreement is established or further options offered. Lenney states 'this process continues until I have put into words what it is that he wants to say, and he has agreed on the content' (p.10).

He also describes the way in which communication can be effected by watching, as in Sam's case, the person's eye and head movements. He describes a simple system of eye signals to denote agreement, i.e. looking up for 'yes' and looking at an item when it represents what is required, i.e. the radio when he wants music. Sam's communication is also characterised by a 'positive intent' and expressiveness that 'wills' understanding. The college speech therapist commented, 'This comes with always having had a communication means. 'I have always been able to communicate and I will [continue to do so]. She has always communicated one way or another' (Weekes 2001). Lenney, however, draws attention to the fact that it is a system that is 'not always reliable' (p.10). Certainly it is a system that requires tenacity and patience from both participants in the exchange and in particular in the production of art work where intention could be open to interpretation. Ultimately it is only the student's insistence on establishing exact intention combined with the enabler's sensitivity to the task, which can generate confidence in the integrity of the artwork.

An enabler comments on this critical exchange in which it is vital that the student is not swayed or deflected by the suggestions that the enabler/class room assistant presents in the process of establishing meaning (Matthews 1994, Veck 2002).

That's where you have to be careful especially with students you offer options to and not take instructions from, that you don't offer them options that lead them down a certain path. That's where maybe you do need people with more subject knowledge because they are more aware of the options they can offer (Faulkner 2001).

The issue of Sam's assertiveness and determination to arrive at her intended meaning is illustrated by her parents' recollections of communicating with Sam when she was a child. They describe her independence and insistence on even nuances of meaning as being evident from a very young age. As an example they describe her assessment by various medical and social work professionals. When asked to identify 'television' she looked at the physical object in the room, from which the assessor believed that she hadn't understood, when the request was changed to identifying the 'picture' of the television she looked at the image on the set of picture cards. In response to questions about the independence of her decisions and whether they ever felt that she was influenced by what they wanted her to do, her Mother's emphatic response was, 'No. Never swayed Samantha, never, ever swayed Samantha' (Chambers 2001).

### **Schooling and Early Arts Education**

Sam had been educated exclusively in special schools and her parents described what they saw as the limitations of some of this (Barnes *et al* 1999). They were willing to promote her decision to change schools and were aware of the potential for under-estimation of her abilities that could result from her communication difficulties. Her father stated:

She wanted to learn all the time that was the trouble. And at the first school she had to go over things and she'd seen it as an insult to her intelligence. She was getting asked silly questions that people who didn't know her would ask. At Grove Park she refused to do it because she had an attitude that was, "don't insult my intelligence". That was funny really (Chambers 2001).

Sam's interest and involvement in art at school was nurtured in the same erratic fashion that many disabled students describe as part of their special school experience. The productive, but it would seem arbitrary, encounter with creative and

enlightened teachers of art, occurred as a significant bonus. Sam's parents described her as 'good at art' citing in evidence her design of the ubiquitous Christmas card. However they also recognised the importance for Sam of a teacher at one of her schools whom they considered to be particularly good at teaching art.

Her philosophy was if she can put her hand in a tin of paint then she can draw something and she used to come home really messy. I mean they had computers as well so that Sam could design colours, print it off and then they'd make papier mache earrings and things like that. But she always made Sam the supervisor, and I think that's where the main part of her art designing came from, when she was really encouraged (Chambers 2001).

Sam's initial interest in art, when she first came to Hereward, was focused around fashion and textiles, influenced no doubt by the fact that she had always been clear about what she wanted to wear and that this independence had been encouraged by her parents. Her father stated:

We never chose her clothes. I'd never buy her clothes as a present because she went out and bought clothes. And you'd think, "well I don't know" and when you saw them on her it clicked. She had good taste and it all looked good when it was on her, but it was her choice. She didn't want that; "I want that and that". You couldn't talk her into anything (Chambers 2001).

Many disabled young people have to be accompanied on shopping trips by their parents whose influence may limit their individual choices and sense of being in control (Middleton 1999). Sam and her parents, however, appear to have established her independence in this respect at an early stage. Through her choice of clothes Sam is able to resist the imposition of an identity by either her parents or by the conventions that dictate how a disabled person should appear i.e. understated and inconspicuous. By maintaining control over her appearance she distances herself from the stereo typical notions embedded within the public narratives that Thomas (1999b) cites as linking disability with 'lives not worth living', 'helplessness' and 'shame of the imperfect body'. Clothes symbolise her

individualism and the sense of 'self' that was to develop and be expressed more fully in her artwork.

### **Sam's Further Education**

The options for disabled students post-16 and for Sam when she had finished her special school education, are between their local mainstream further education college or, if provision cannot be made locally, in specialist provision in one of a number of residential colleges. Sam commenced her programme of study at the College with GCSE Art and Design (specialising in textiles) which was followed by the Diploma in Foundation Art and Design which she studied over a two year period. In addition she has followed a basic skills programme in literacy and numeracy. Her support needs include enabling and IT, personal care, physiotherapy and speech therapy. Sam uses a powered wheelchair fitted with a tray on which her electronic communicator is positioned. A wooden 'step' attached to her left foot-plate is fitted with a blue button which she operates with her foot to direct the tracking device that operates her communicator, her computer and her wheelchair.

### **The Studio Environment**

As a Foundation Art and Design student Sam's working day takes place, in the main, in her designated studio space. The area currently used for creative studies and practical arts activities was not intended as such in the original design of the building. Neither was the building designed to accommodate the requirements of students whose high levels of support requirements meant that traditionally they were not educated beyond the age of 16, i.e. the large electric wheelchairs with additional communication devices that are now used by many students. The need to allocate designated spaces that could accommodate students on a full time course, their wheelchair, their art equipment and maybe their personal computer and enabler could not have been foreseen. The option of carrying out, if not large, at least moderately large-scale work, was also not envisaged. The art department has evolved by annexing teaching rooms of various sizes along a single corridor and using them as studio spaces as demand has grown. An open door policy encourages the perception of this allocated space as open plan and encompasses the linking corridor. Students and staff move freely from studio to studio with due consideration to the nature of teaching that is taking place at any given time.

Sam's work space is in a studio shared with five other Foundation Course students which is delineated by a structure of 6x6 foot white boards that gives each student an individual area. Each space is personalised. Images, information, photographs, drawings, swatches, colour samples, in short any material or objects that pertain to students' current, individual and personal line of inquiry and that they have selected, are pinned up in a visual collage that juxtaposes information from many different sources. This creative 'nest' enables students to create their own customised visual resource. This is added to and changed, in the organic process of their creative activity, within which connections will be made between the various strands of information, and from which new and original creative outcomes will be synthesised. The atmosphere in the studio is of informal but purposeful industry. A radio plays quietly in the background, people move around in the processes of working with different materials and techniques interspersed with conversation with tutors and each other.

Sam's space contains a trolley on which her personal computer is mounted and which she can access with a simple cable connection to her communicator. Her display space, like the other students, is covered with images, diagrams, notes, instructions and photographs that pertain to her current project. On her table are stacked her records, working journals, sketchbooks and a number of shoe blocks and paper patterns that relate to her current project on footwear. A pink ballet shoe which has been customised to hold a grip for drawing materials, and which Sam wears to capitalise on the control that she has in her left foot and with which she can generate graphic marks, lies ready for her use.

### **Enabling Support**

An enabler is frequently present, working with Sam and communicating with her in a fluent, seamless interaction that efficiently and effectively integrates eye contact, eye direction, affirmative sounds, head movement, verbal inquiry by the enabler, the electronic communicator and reference to material and lists of instructions pinned up. Sam draws attention to her communicator with a small sound. The enabler moves around to look at the communicator and back to face her for confirmation. She reads her expression and Sam nods and raises her eyebrows. The enabler holds a sheet of contact prints in Sam's range of vision for her to examine and from which to make a selection of images. Sam scrutinises the enabler to gauge the accuracy of her understanding. A further image is taken using the digital camera and the enabler,

after lining up the shot, holds the camera so that Sam can see what has been framed. The photograph is taken. Sam uses eye direction to indicate her computer. The enabler connects Sam so that she can work independently from the Internet or in the manipulation of images. The enabler, glancing towards Sam frequently for confirmation, summarises for the tutor, what they have been doing. In this way the communication process between Sam and her teacher is streamlined and he/she can respond to her promptly without the barrier of her laboriously recounting what she has been doing and wishes to do next.

The effective level of communication/enabling that has been achieved with Sam is the result of much sensitive and patient hard work by both Sam and her enablers. It requires constant vigilance and attention to ensure that the artwork progresses according to Sam's intentions and that her ownership is always central. Arriving at this point however, was not without difficulty. Enabling support requirements became more complex as Sam moved from the relatively straight-forward amanuensis demands of GCSE textiles, to the more esoteric and less clear cut demands of the Foundation Course diploma. In the early stages of the course there was much to learn in achieving an effective match between enabling support based on Sam's communication and the new, higher level of work. One of her tutors comments:

There was a lot of confusion around the extent and limits of Sam's communication and literacy. There were lots of people making decisions about what they thought Sam was capable of and not capable of, and for a year, as a college, we weren't really working together (Johnson 2001).

Interviews conducted with enabling support reveal the initial doubts that they had about their role in supporting Sam and in so doing, indicate how relatively new it was for someone with the level of support requirements that she had, to be studying a practical arts subject at level three.

It was a very difficult thing to do; everybody was tense about going down and working with Sam. They found it very difficult. They felt a big sense of responsibility. "Is it mine, is it Sams?" And still going down there with the fear – "I'm no good at art". Feeling that they had to be good at art otherwise what they did wasn't going to be good



enough. Was it what was in her head? Was it what the teachers wanted as an end result and who was going to get the blame for it, if it all went wrong? (Faulkner 2001).

To add to this initial confusion, 'what was in Sam's head,' was also being challenged by the Foundation course experience. It is designed, as it is for all students, to question conventional ways of thinking and in addition is delivered by a number of tutors who will put forward differing perspectives and challenging ideas. Combined with this is the fact that a number of enablers would be working with Sam at different times. Enabling policy is not to allocate an enabler to a student but to ensure that students develop the skills to direct different enablers. However, this can generate initial difficulties at this level of study in a creative subject. An enabling viewpoint is put forward by Faulkner.

Very often you have started something and you've done some work and then you go away. You come back next week and you can't actually see [what is happening,] because it's moved around so much in a totally different direction to the way you thought it was going, and it's almost like picking up a completely different task (Faulkner 2001).

### **The Foundation Course**

Sam was prepared for the Foundation Course in the sense that her experience on the GCSE course had taught her about process. She had learnt how to move through the processes of research and the gathering of information, to experiment with various materials, to develop her ideas and to understand how to work towards a product or outcome. However, there was also the issue of the fine balance between raising Sam's awareness of what was possible by directing her activities, and encouraging an independent response. Her tutor describes this process at GCSE level.

As with all students, when students are being brought through a process, they have to be directed. Sam, like any other student, had to be encouraged and directed initially to give her the opportunity to make something that she could then see was possible. It was building her expectations up of what she could produce and this was very guided and directed. It was only towards the end that we really did pull back and then she just about managed to get through the controlled

test. She'd created three very good pieces of work but when it came to the controlled test she struggled, yet she understood the process, which was the most important thing. But she did get through it. She made a good response (Johnson 2001).

It became increasingly clear that the transition from level 2 to level 3 studies was going to be a complex one. Setting Sam off from a common starting point, or project brief, alongside the other students and encouraging developments from a range of traditional and contemporary media and materials was not going to be the way that she would access the course effectively. An individual learning plan was devised to capitalise on the accessibility of lens-based and computer-generated imagery. A subject that was of fundamental relevance to Sam herself needed to be adopted as a starting point, if her programme of study was to be relevant and accessible. Sam was indicating in a number of ways what that subject matter should be. Influenced by a feminist approach, which had been made apparent to her through the college 'Women's Group', she was increasingly able to challenge value systems and how meanings are accepted as 'normal ways of being' (Parker and Pollock:1987). Her tutor recognised her developing interest in self-identity.

She was making statements about herself in terms of the way she dressed. She had cut her hair. She had joined a woman's group and she had been through a very difficult relationship with another student which had provided the catalyst for her to begin this process of maturity and independence (Johnson 2001).

Observation becomes a critical teaching strategy in the education of students who are non verbal. The tutor had observed the changes that Sam was making to her appearance with her choice of clothes, and the rejection of her 'little girl' haircut for a contemporary adult style. Sam was clearly demonstrating that she was 'remaking' herself in response to the new independence that she was experiencing at the college and a desire to be included in the fashionable mainstream contexts that were becoming more accessible to her. She was unable to address issues of impairment and disability, through a verbal account of her experiences however she was able to make statements through how she presented her body that challenged stereotypical notions concerning the attractiveness and desirability of disabled people.

### **A Narrative Sense of Self**

The visual arts provided Sam with the means to extend and develop this process through the production of images and an engagement with the narrative sense of self that is expressed through the 'writing' and 'rewriting' of individual biography (Giddens 1991, Clough and Barton 1998, Seymour 1998). An assignment was written that encouraged her to carry out an autobiographical investigation and to explore her experiences, her background and her relationships and the impact that these had had on her sense of 'self'. Johnson states:

And she found that very interesting, we all did, but she found that very interesting in the sense that she was collecting and assembling sets of images that plotted her life and her development to this point in time (2001).

To ensure the continuity of this narrative for all concerned, a daily journal was maintained in which each part of the process was recorded in a visual or written form and which logged the ongoing dialogue as it took place between Sam, the teacher and the enabler. Faulkner describes the effectiveness of the book in terms of enabling Sam.

It developed into a multi-faceted communication system. I think lots of the areas of uncertainty were taken out when she had the book to record things. People would come along, pick up the book and say, "Oh this is what you did yesterday, so you need to do that today, OK, that's the piece you're working on, I'll get the stuff out", and she can clearly think and use her time more effectively (2001).

This initial imagery was mainly gathered from photographic sources that Sam then manipulated by directing enabling support to photocopy what she had selected onto acetate and then to alter scale, juxtaposition, colour, etc. through the use of an overhead projector. In addition to this photomontage it was considered equally important that Sam did not lose the sense of making her own mark. Johnson describes how this was achieved.

We put paper all the way along the edge of the corridor and she worked with a brush. She held the brush and trailed the brush along

the paper, down the corridor whilst moving in a backward direction in her electric wheelchair (2001) (see Fig 42).

This would have enabled Sam to see the line as it travelled along the paper and the brush would have 'trailed' fluidly without sticking which would have been the case if she had tried to move in a forward direction. In this sense Sam had to 'journey' along the corridor creating the line behind her as she progressed, thus producing the Timeline that was to symbolise her journey through life.

It took quite a few tries to develop a line that Sam was happy with. She worked with black on white and white on black. We encouraged her to look at other ways of manipulating that line and so she scanned it into the computer. So having got to the point where she had created some nice quality lines that she was happy with, then the next stage was what can we do with that line? How can we manipulate it to describe or represent the idea of her life as a "life line" and how would she start to add to that, take away from it, cut it up, reassemble it, whatever. So she started to build up the photomontage along that line. Images of her family, of her background, people, places she'd been to, memories, birthdays, holidays and it all seemed to bring Sam right into focus. We started to develop all sorts of ideas along that line, she looked at birth, marriage. She looked at the cycle of life (Johnson 2001) (see Fig 43).

In addition Sam started to explore the juxtaposition of text with her imagery. The importance of the ownership of text for disabled people in the context of disability imagery has been noted in the last chapter as a feature of the Craftspace touring project. It has double significance for Sam who as a non verbal young person has difficulties with text based material (Moyle 1976, Matthews 1994). As a natural consequence she went on to explore the scope that orchestrated 'sound' could offer as part of the installation that was developing around the idea of the Timeline. Working with music technology equipment she sampled sounds that were evocative of, and could be associated with, the images that she had selected and she mixed into these snippets of conversation and comments that her peers made in conversation with her about her work. The Timeline was traced onto the walls of a room so that it circumnavigated the entire space.

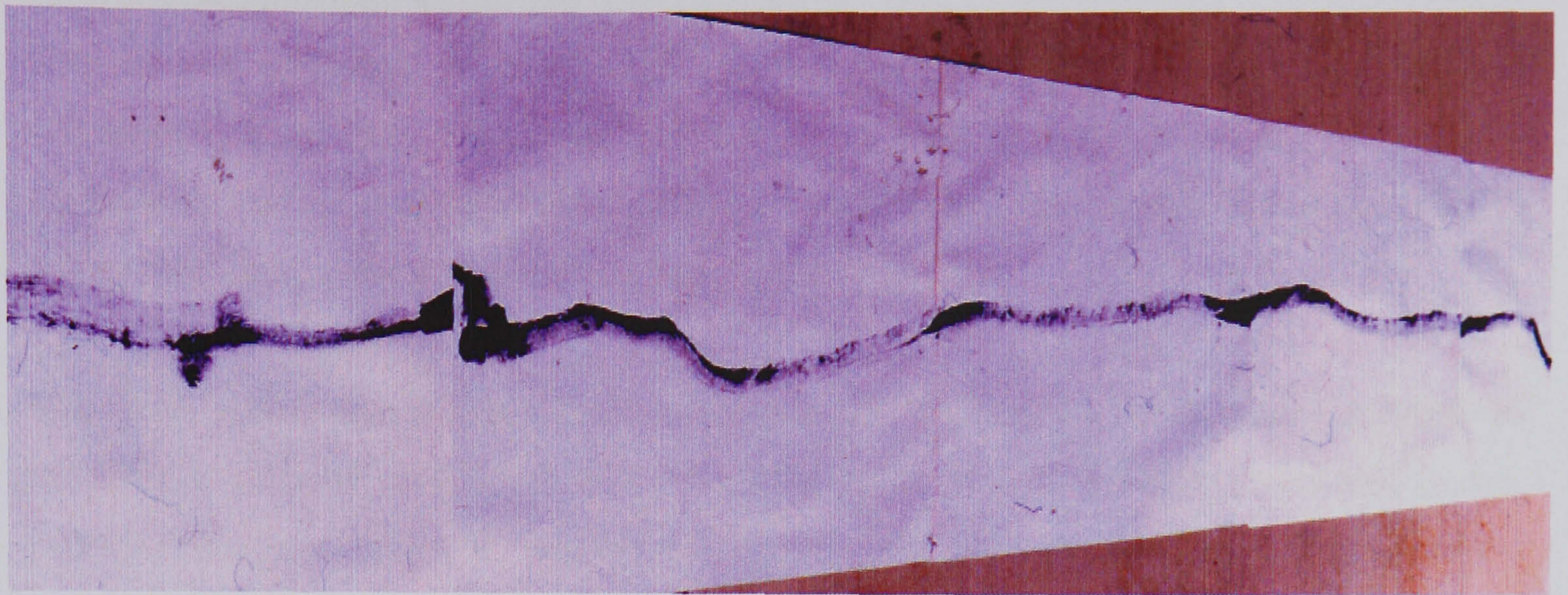


Fig 42

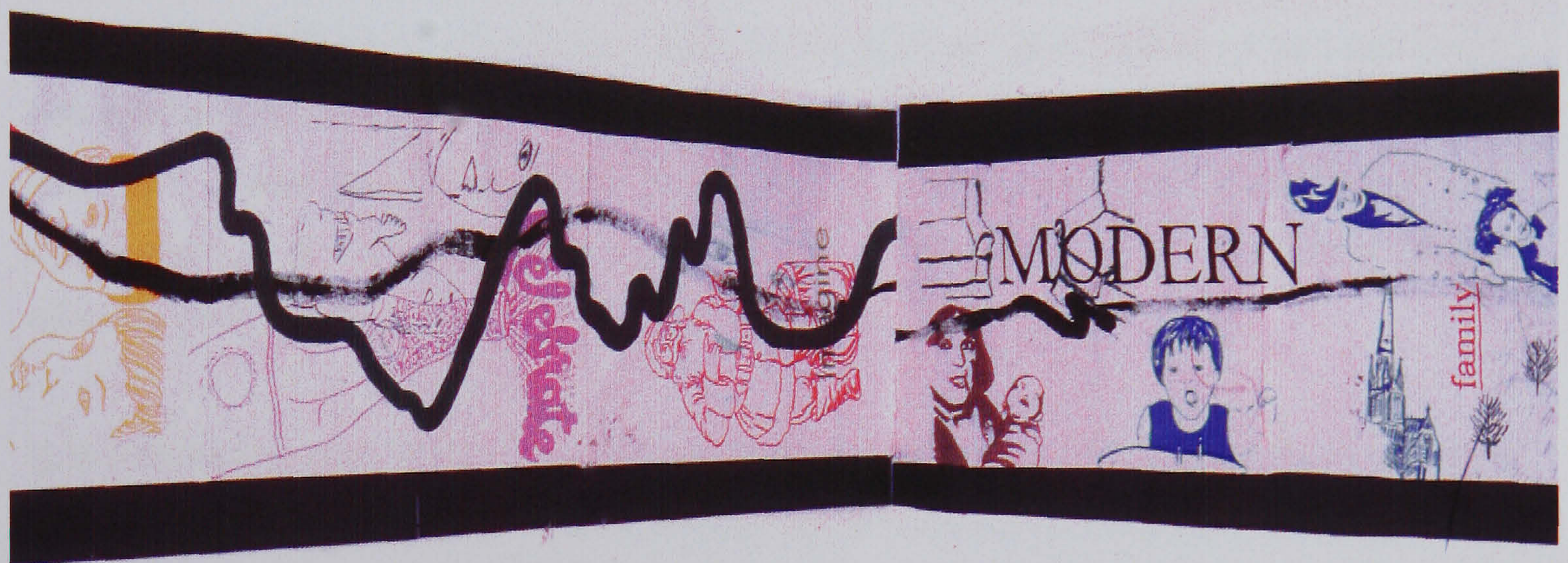


Fig 43

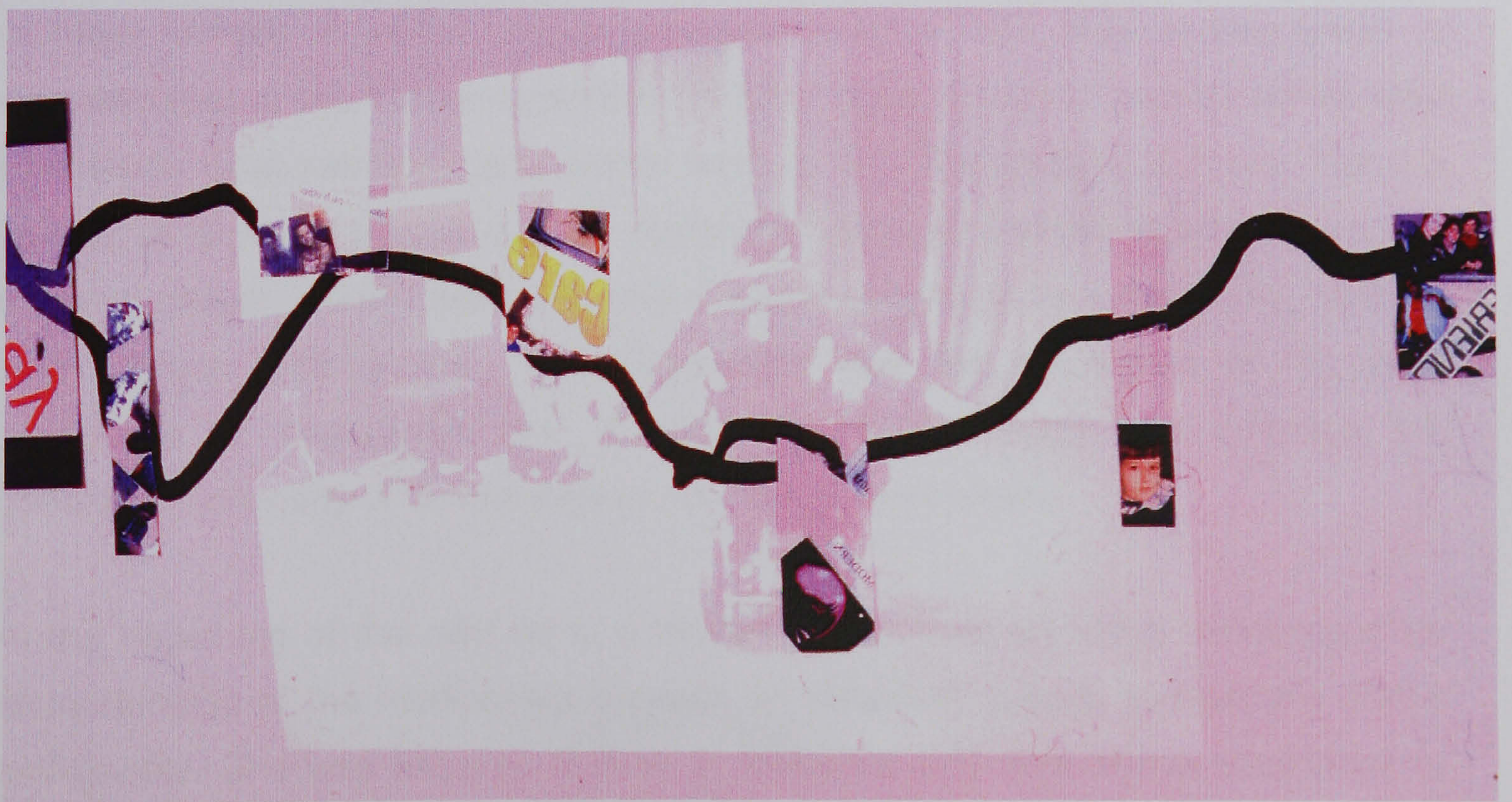


Fig 44

Little pockets of information, assemblages and photomontages of different times and different experiences in her life were placed at, and projected onto, strategic points. The sound provided a back cloth to the visual information. In the resulting installation, Sam had effectively dominated a space in both a visual and auditory sense and had been able to communicate eloquently to the viewer about her 'self' in a way that was novel and empowering (See Fig 44).

The work, which was shown at the college in the summer of 2001, was a watershed for Sam in terms of raised self esteem and the self concept enhancement that Dusek (1987) describes. This was the first time that she had been part of an exhibition and had had such a high profile in the college. Her increased confidence enabled her to perceive her artwork as a powerful means of personal expression. Her work was seen by students, staff, friends and family. Johnson comments 'I think they were bowled over. I think they were shocked at the level of work that Sam had achieved'. Her Mother stated 'I was impressed with that Timeline that she did, when we came to see that. I was quite impressed really'. The social interaction that occurred as a consequence of her installation gave her the positive feedback that Cooley (1964) cites as critical in the sense of who we are.

It is interesting also to discern the assumptions with regard to the content of Sam's artwork, implicit in the comments of one of the enabling support team. 'And what Sam's doing now is about Sam, which is what most people go through at an early stage to establish their identity and I think she's getting the opportunity to express that' (Faulkner 2001). Although the perception is that work done on the 'self' is normally located in earlier stages of development a high level of awareness is demonstrated in the further comment. 'A lot of them [disabled people] spend their time being what someone else wants them to be'. The enabler is aware that the identity of disabled people is often hijacked through the representations of non disabled people, leaving them with only negative constructs to choose from, such as tragic, brave, pitiable etc. The appreciation that the expression of the lived experience of impairment and disability in visual images can embrace the generalised diversity of human experience comes more slowly.

At the beginning of the next term, a textiles project was set which encouraged an understanding of the relationship between an historical, cultural context and Sam's self-identity. She was required to look at foot-ware and from her investigations to

create her own designs. She took photographic images of her own feet with text projected on to them (see Fig 45). She manipulated these images in ways that indicated the controlled movement that she has in her left foot and that is so critical in terms of her potential to move around the world and communicate with it (see Fig 46). From these she went on to explore the work of feminist arts practitioners Sam Taylor Wood, Cindy Sherman and Judy Chicago and also a broader context of cultural practices. These included the practice of foot-binding in China in the 19th Century, and contemporary fashion and fetish foot-ware which both effectively and painfully cripple and disabled women to various degrees (see Fig 47, 48). The irony of this deliberate disablement of women via their feet was central to Sam's interest. The fact is that shoes have no practical application for her, she cannot walk in them and they can therefore, for her, have the potential to become outlandish, impractical, decorative items that are signifiers of her personality, self-identity and empowerment, as opposed to subjugation. Her tutor remarked 'Don't see the wheelchair, see these gorgeous pair of shoes' (Johnson 2001).

In the main Sam uses photography, digital media and video to create artwork, capitalising on the flexibility that these media offered and that women working from a feminist agenda recognised (Parker and Pollock 1987). A decade ago there would have been a paucity of information for her to reference; however, these media are now recognised as key in contemporary Arts. Collins, presenter of Channel 4's The Turner Prize 2001, announced, if somewhat provocatively, that 'Installations have become the new oil paint'. Certainly all the finalists offered work exclusively carried out with lens-based media or installation work for consideration. Sam's work can be viewed in the same contemporary context as the photographic work of, for example Richard Billingham and her worksheets, in which she juxtaposed images that explore her personal identity with contemporary cultural references, echoes the work exhibited in the exhibition '*DREAM 2001*' (see Fig 49). This showcased in photographic terms, the work of a number of contemporary Chinese artists whose socially driven art reflects the upheavals in China's culture in recent decades (Leitch 2001;70) (see Fig 50).

It would appear from the images that Sam is selecting, and being encouraged to select from contemporary practice, that her awareness of the position of her work contextually is growing and is enhanced by her understanding of the work of such artists.

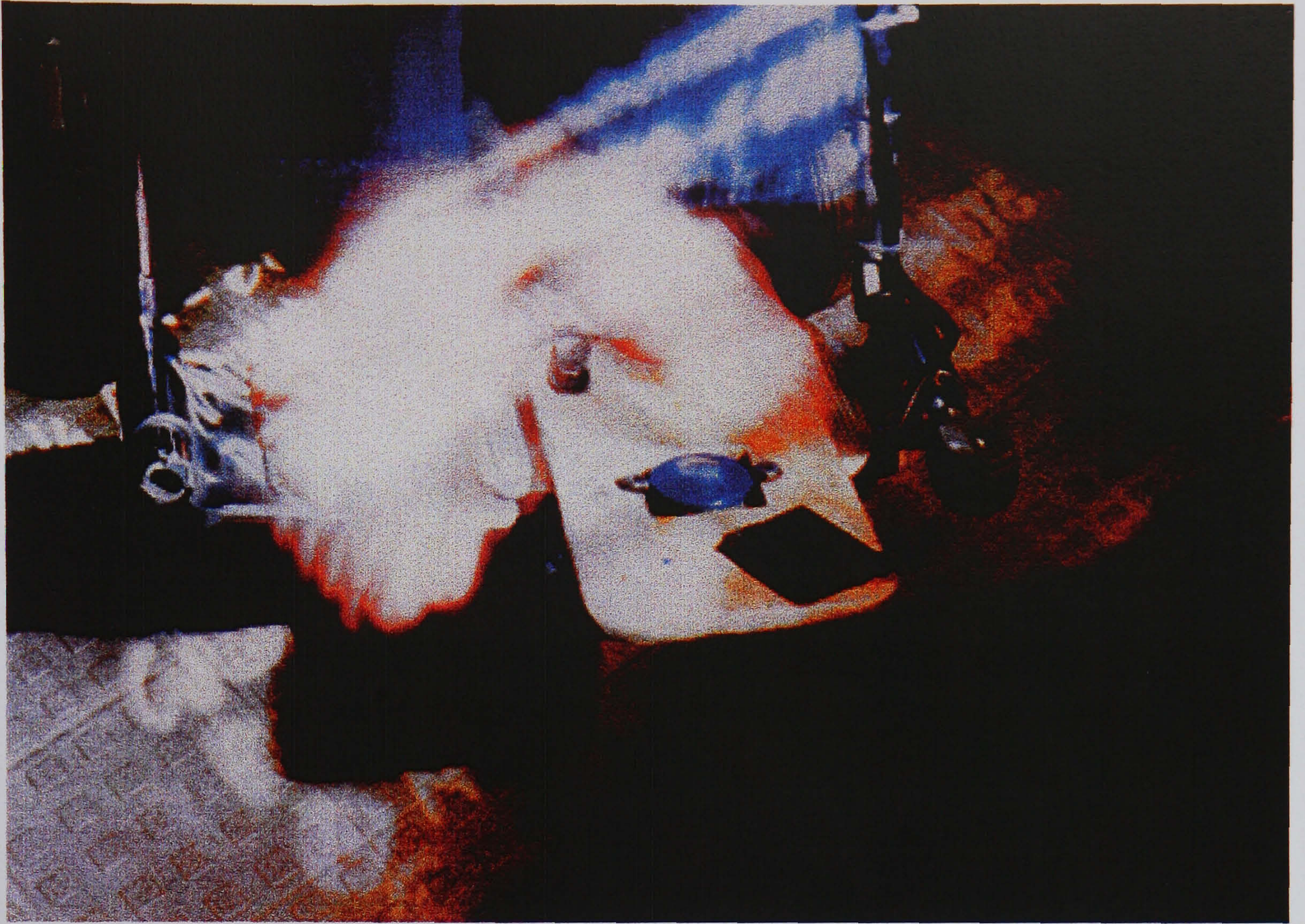


Fig 45

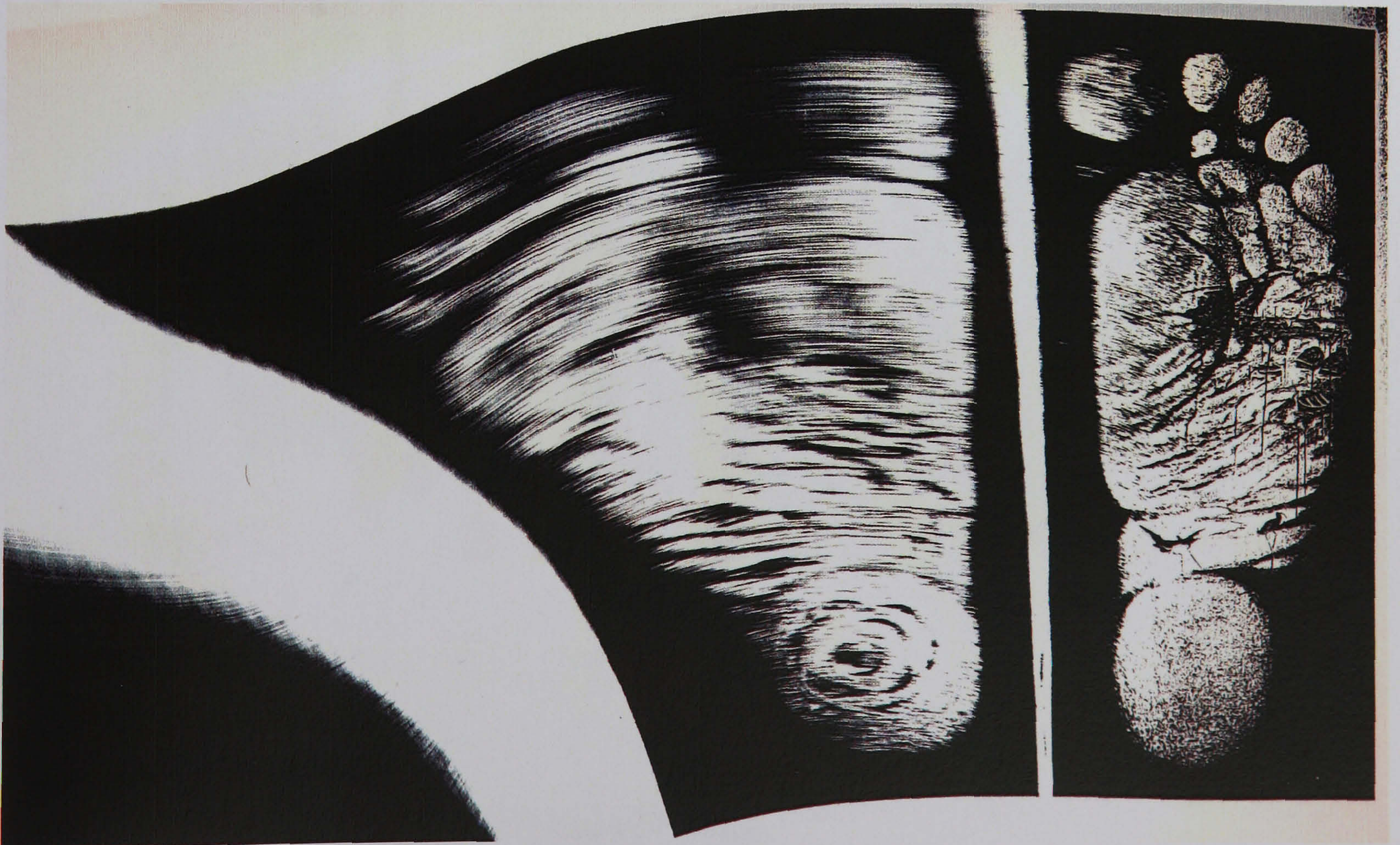


Fig 46





Fig 47



Fig 48

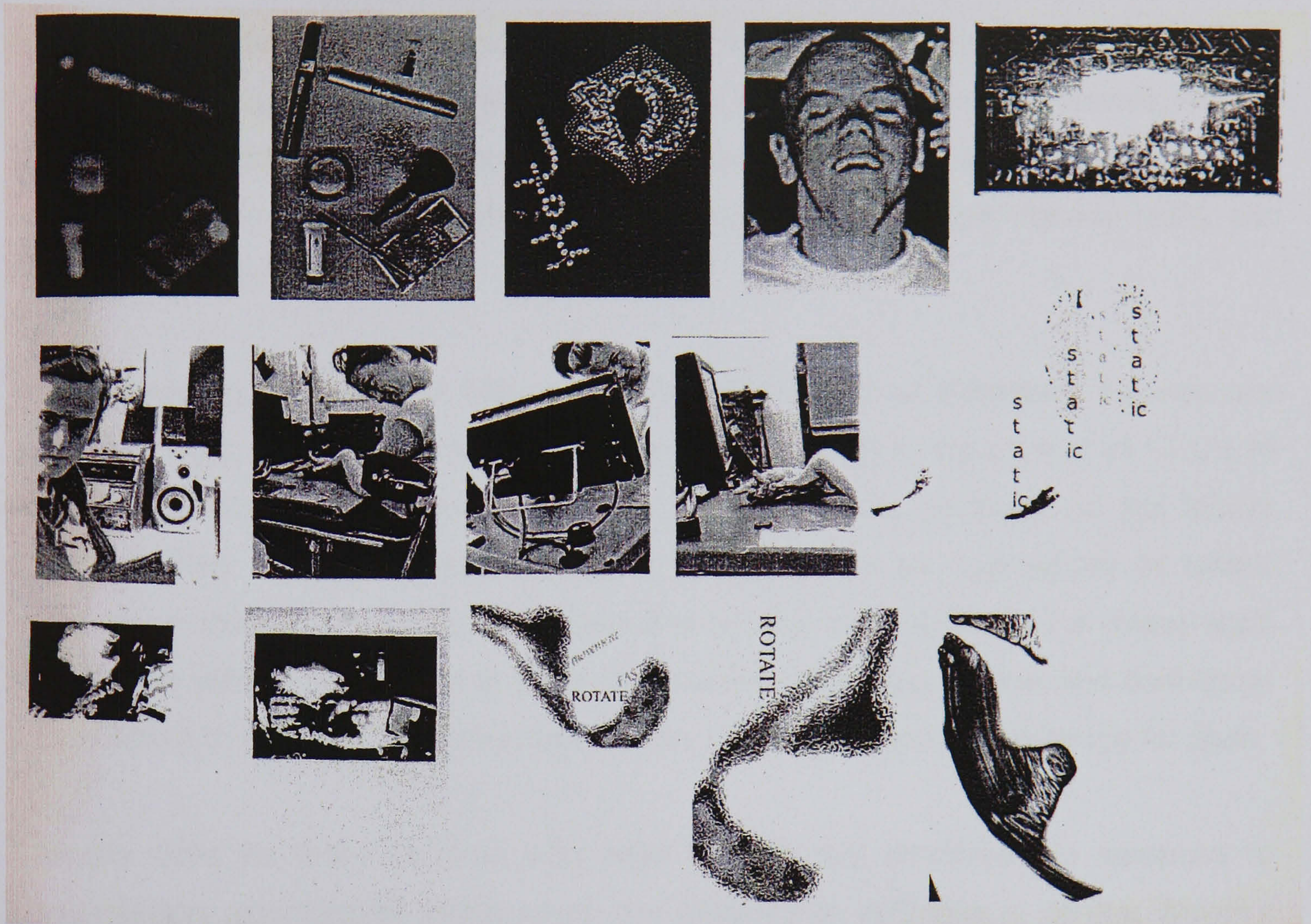


Fig 49



Fig 50

Access is facilitated by the use of the Internet, which enables her to find and look at the work of other disabled artists, many of whom are producing work using these media with the Internet as a site to showcase the results. However for educational purposes, traditional criteria and assessment for assessing knowledge of context and theory in support of practical study remains rooted in a strictly academic, literary based framework - the conventional text based, essay. This creates significant barriers for Sam and many other disabled students for whom literacy skills are problematic (Moyle 1968).

It is interesting to note that 44% of residential students at Hereward College are following Basic Skills programmes (Hereward CMIS 2002) in the context of 12.5% of the Adult National population identified as having literacy problems in the Moser Report (1999). It is debatable whether reading age is an appropriate or useful measure or indeed can be reliably measured at all in the instance of a young adult who is non verbal. However it is clear that seeking to assess critical and contextual competence in terms of the conventional essay sets a formidable challenge for Sam.

Literacy skills for those children who have speech, are developed in response to multi-sensory approaches within which the capacity to verbalise is central. Moyle's (1968) assertion that 'learning to read should be preceded by an understanding of the total language situation and the use we make of language', would suggest that radical methods would need to be employed in developing the literacy skills of non verbal children (p.21). These would need to be based on a very thorough understanding of their communication and language skills. There is no evidence to confirm or question whether this is the case. Given these difficulties, and the additional disadvantage that lack of consistency and continuity of information creates (little is known of the approaches to literacy taken with Sam, prior to Hereward College) the progress and competencies that the non verbal person has developed can often be unexpected. Alternative and compensatory skills and strategies can develop, around for example memory and the ability to carry out complicated operations mentally, but may be difficult to ascertain and difficult to assess in a conventional way.

Moyle refers to the 'use we make of language, not only as a communication art, but also as the vehicle of our thought processes' (p.21). Sam can hear and understand verbal language and therefore has this system as the basis for thought, although she

cannot verbalise these thoughts and is limited in her expression of them in literary based forms. However, visual art forms provide her with an alternative language and a comparison might be made with the cognitive development needed to articulate theoretical understanding in written form and that needed in the production of visual images. Both necessitate a similar process of selecting information, extrapolating meaning and developing a new outcome whether that outcome is text or image based. The difference is that one process manipulates these ideas through a verbal or written language whilst the other does so through a visual language. Sam is able to manipulate information visually but written outcomes continue to present challenges which are difficult to overcome and involve her in slow and laborious processes that are not reflective of her ability. The value of the primacy of a visual language for Sam is clear.

The processes of generating written outcomes and the difficulties that arise in meeting the demands of the compulsory theoretical components of art courses from level 3 onwards, even though these carry significantly less marks than the practical work, are described by the enabling support.

The theory side is a bit of a problem. She needs specific language to produce these sorts of essays and it's very difficult for the staff to work on these, because they're always conscious of how much they should or should not be putting into it. They're also very conscious of the fact that they don't really know what they're doing either so they might be trying to help Sam and not helping her in the right way.

And then it's doing the research, which again is enabler driven because it's, "shall we go and look for some books? Shall we look for books on this?". "Yes". "Shall I look at this book?" "Yes". And then the enabler will flip through it, find something that they think might be relevant, go over it with Sam. "Do you think this might be useful?" It's very led and it has to be because you aren't going to read out a bit, you know darn well isn't useful. That's a waste of everybody's time really. The selection of material is mainly done by the enabling staff. She wouldn't have the ability [literary skills] to scan all the book titles, look down the index, flip through and select the information and make that accessible (Faulkner 2001).

These problems of co-ordinating and developing the processes of theoretical understanding with enabling support and basic skills are made more acute by the difficulties that non verbal students can experience when they are seeking to express new concepts. Often they simply do not have the vocabulary that is developed through reading and discussion. The enabler, working with Sam on her Timeline, describes just such a problem.

Sam knew what she wanted and she knew it wasn't a baby, she wanted the concept of an unborn baby but she didn't actually know how to express that, or know the word "foetus" and therefore she couldn't begin to spell it or give clues on her communicator. It was really difficult and it was "Eureka" when we actually got there [through question and answer] - but the amount of time it actually took to get there. How far do you take something before you start to give input? Just by not understanding what someone is trying to say you can make them make choices that perhaps they wouldn't really understand (Faulkner 2001).

In addition to the production of practical and theoretical work there is also a need to organise the working process.

It's very difficult to organise paper if you can't use your hands, and to organise artwork so that the process is clear. Her files need to be organised on the computer and her floppy discs filed and labelled, the same with her audio visual material. Sam needs to direct all of this and in these terms being a disabled artist, has significant implications in terms of keeping herself in touch with the development of her work. She has to direct people to organise her work so that she can see what she is doing (Johnson 2001).

The future presents significant obstacles which have the potential to disenfranchise Sam from a place in higher education. To be successful she needs 24 hour personal care; enabling support that is a continuum of the methods that have evolved out of the 4 years she has been at Hereward College; an understanding and awareness of her methods of working and communication by higher education lecturers; an accessible HE curriculum and the willingness of staff to deliver it in alternative ways;

an accessible and realistic way of fulfilling the theoretical component of the course; and, last but not least, access to student life. In preparation for such a transition, however, the establishment of a positive self-identity is critical. Her tutor states:

It's about understanding yourself first and foremost. And it's about utilising that life experience and understanding yourself as a working artist and disabled woman, and then from that being able to move on and move out and look at other wider issues. But until you can understand who you are and what it is about art that is particular to you, you can't really start to look outside. Being a disabled person is a very complex starting point in life. I mean there are complexities for all students, but I think it is more difficult for students with disabilities because of the ways in which they have experienced life up until that point in time where they start to question it, understand it, and see it in ways that are not based on a deficit model (Johnson 2001).

### **Summary**

This chapter, based on the account of a student whose impairment might, in conventional terms, have suggested that the visual arts were not an option for her, has provided an opportunity to consider a number of salient issues in the context of access, support, arts education and disability and self-identity. An analysis has been presented of the ways in which a combination of responses from enabling, technical and communication support, tutors, family, and Sam herself have rendered the visual arts fundamental as a mode of expression for her. Sam's art education, combined with access to feminist and Disability Arts discourses, has facilitated the emergence and expression of a positive sense of self in a process, described by Kendrick (2001), of 'becoming her own woman'.

The impact that restricted movement and communication difficulties have on Sam's literacy skills have been outlined to emphasise the importance, for many disabled students, of non literary formats in the expression of concepts and ideas, and the difficulties of meeting the formal, written requirements of accredited art courses at the higher levels. The importance of including non verbal students in research agendas and extending the data collection to include a circle of significant others has been emphasised. Subsequent to these interviews Sam has progressed to study a Higher National Certificate and Diploma in Fine Art at a local college of Further

Education, she has remained a resident at Hereward College in order to do so. The following chapter explores Higher Education through the experiences of two further students who progressed from Hereward College to study honours degrees in the arts at university.

## Chapter Nine

### Disabled Students, Higher Education and the Visual Arts

For the disabled student who may have had an arts education that was subject to many inconsistencies and conflicting influences, and who needed to access appropriate and effective human and technological support, a place on a BA programme in the visual arts represents no small achievement, particularly if their support requirements are high. This chapter is based on interviews with two students (Aharani Sivapalan and Daniel Rooney) who progressed from Hereward College to the same university to study Textiles and Fine Art and in this respect their accounts are exceptional in that they both have personal care requirements and followed practical arts courses at university. In addition to these two students, the work of James Lancaster, who was also a Hereward College student, is included in this chapter for the purposes of contrast and comparison. The chapter begins with an analysis of the commonly shared difficulties and barriers that disabled students face when studying in higher education (HE), regardless of their subject area, and is based on the data collected as part of Hereward College's widening participation (WP) initiative and within which students were given pseudonyms (*Barriers to Higher Education for Disabled Students Report 2000/02*). From this a picture emerges of a varied response by universities to disabled students which colours these critical years of study.

#### The Higher Education Experience

The *National Audit Office Report on Widening Participation (2002)* suggests a wide discrepancy in institutional response to disability. 'The proportion of full time entrants reported as receiving the DSA in 1999-00 varies among higher education institutions from 0% to 8%. There are 34 higher education institutions recorded as having none' (p.8). The report makes reservations about 'some problems with the quality of this data' but broad variation in the degree of response that universities make to disabled students is consistent with the Hereward College findings. From the interviews carried out as part of the Widening Participation initiative the impact that structural and attitudinal barriers in higher education have had on the educational and social experiences of disabled students became clear. In addition, the extra efforts that they have had to make from the beginning, to arrive at the same starting point as their non disabled peers, are highlighted. One student remarked:



I was a bit upset that it was all so easy for them, whereas I had to sort out care and finances and a suitable place to live and medical stuff and everything like that. (WP Research Data Hereward College 2000/02)

### **The Physical Environment**

The physical environment of campus universities and access to buildings were frequently cited in student's accounts of their difficulties, and Riddell's (1998) report states that 'none of the HE institutions were entirely accessible to disabled students and that most were generally inaccessible' (p.212). The impact that this can have on aspiration and self-esteem is apparent in the following student's account (interviewed for Chapter seven) of the interview visit that took place in the spring of 2002 as part of his application to an arts degree course.

Well the place had no disabled access whatsoever. I had to be carried because they had 4/5 steps. Workers, site managers whoever it was, lifted up my chair and carried me in. They said to me, before even I had my interview it was going to be difficult. It felt really awkward, like it was my first choice and I did really want to go there. I thought it gave kind of a bad impression of myself, because I thought I want to be an independent person as much as possible so that I can be regarded as just a student not having special stuff or anything like that. I didn't want to be like that, to be the only disabled student there. I just wanted to be like everybody else. It's hard to describe the feeling. My self-esteem wasn't good (Kang 2002).

In contrast, where good access exists, it can be summarily dismissed as an issue. Another student stated

I am in a new building so it's all kitted out with ramps and things I need. I live on campus too and that is all adapted for me (WP Research Data Hereward College 2000/02).

This 'lottery' of physical access should be addressed by the new legislation that sets a 2005 deadline for adjustments to physical features.

### **Academic Staff and Disability Officers**

Students also reported varying attitudes from academic staff and disability officers that included positive responses but also those that appeared to be insensitive or to arise from misunderstanding and misperceptions. Where students experienced difficulties with support from the disability officer, it varied widely from over zealousness to apparent indifference depending, it would seem, on individual responses and interpretation of the role.

At first it was really annoying because the woman from the disability office was always e-mailing me to see if I was managing OK. This is probably good, but it took me back to the days when everyone treated me like I was wrapped in cotton wool and it got to be quite intrusive after a couple of weeks and I wasn't sure how to tell her to leave me alone. Eventually I asked her if it would be OK if I could call her if I needed anything and she was OK with that. I did feel like I was her 'special project' during the first few weeks. I was only having the same problems as everybody else – work, money and where to go out, so I didn't need her really bugging me every day. I probably sound really ungrateful but it spoilt the first months of university for me (WP Research Data Hereward College 2000/02).

In contrast another student reported

Before I went I had an interview with the disability officer, so I knew I could go to her if I wanted to. But I thought it quite interesting that, apart from my first day, I never saw her again.

Similarly the response of academic staff varied from the insensitive – 'one guy even said to me in the middle of class in front of everyone "I suppose you will be needing a bit of support" ' – to the apparently uninterested.

The attitudes themselves weren't bad, it was just that they didn't really pay attention to me or my needs so I felt a bit ignored. I think a few of them didn't really know how to talk to me and so didn't really bother. And that is bad in itself, but not necessarily a thing done with malice by the staff. They probably just need more training or guidance on the

matter. But no one was specifically rude or unprofessional because I was disabled and I never felt like I was being a burden on their time, just not significant (WP Research Data Hereward College 2000/02).

In contrast there were also more positive responses, 'I got on really, really well with them, and they were always willing to help out wherever they could'. It would seem that the 'lottery' principle also applies to students' experiences of staff attitudes and that tutors' understanding of students' needs is inconsistent and that some are unsure of how to go about interacting with disabled people (Lenney and Sercombe 2002). The impact that individual goodwill played in the success of students, particularly in the instance of those with high level support needs appears to be significant.

Recognition of the inconsistent response that disabled students experience in education is made in the DDA, which states that, the duty to make reasonable adjustments is an anticipatory one (section 3: Oct. 1999). Thus education providers must think ahead to the type of adjustments that may be required and, where feasible, put these adjustments in place. Included within this notion of 'adjustment' is training staff to work with disabled people and employing a disability advisor to meet with students to determine what adjustments may be appropriate in individual cases.

### **Social Relationships**

The everyday contact with other students that university life affords creates a forum in which potentially positive social relationships can be forged. For many disabled students the move to University places them for the first time in an environment of predominantly non-disabled people. For many non-disabled students it is the first time that they have encountered a disabled person in any context other than a charity appeal. It was quite evident, after some initial 'sizing up', that the resulting friendships were often beneficial to both parties. One student described how

When I got a group of friends and they realised I was the same and they could have a laugh with me, then they realised that it is not the disability that defines the person but what they are like inside. The tutors never really saw that which is a shame I think, for them and for me, and anyone else that gets stuck with them (WP Research Data Hereward College 2000/02).

Within these disabled students' accounts there were also comments that revealed how they had internalised negative perceptions of impairment and disability. Although they reported no specific comments or actions to prompt their concerns, nevertheless their fears were of being seen as 'different' recalling again Thomas' (1999) definitions of public narratives and psycho-emotional dimensions of disability. One student recalled

lectures really scared me at first because I was a nobody and I really panicked that I would start shaking and that people would think I was some sort of freak!

Another student believed that people's perceptions of her were constructed around 'the burden thing', imagining that her peers' reaction to her was, 'ah, she's quite nice looking, what a shame about her legs'.

In addition to these issues there are further potential areas of difficulty that need to be considered, resolved or prepared for, in enabling the disabled student who aspires to higher education in the arts or any other area of study. The Further Education Development Agency (FEDA) report, *Preparing Students for Transition from FE to HE 1998/99*, lists these. They include the need for students to gain an understanding of study skills, independent living skills, time management skills, general coping skills; how teaching and learning is assessed in higher education; and the differences between the culture of higher education and that of schools and colleges. The report emphasises the importance of the preparedness of disabled students for the University experience. 'Under preparedness often leads to non-completion and/or negative experiences' (p.35).

The report goes on to state that there is a paucity of information on the transition of disabled students into HE but that there is much anecdotal evidence to indicate that the drop out rate of students with learning difficulties and disabilities in HE is high. Unfortunately it is difficult to get a full picture of the drop out rate of disabled students, as Higher Education Funding Council of England (HEFCE) statistics relate directly to University Central Admissions Service (UCAS) applications and many disabled students do not declare a disability at the application stage. Higher Education Statistics Agency (HESA) asks HEIs to record non-completers under one of ten headings including: death, academic failure, health, exclusion, employment or

other. In one study, 79% of non-completers were classified under 'other', highlighting the limitations of these statistics' (HEFCE 97/29).

The increasing number of disabled students applying to university annually has prompted a growing interest in transition planning which the report states is firmly on the agenda in many FE and HE institutions as part of an inclusive approach to learning. Much of the provision that is currently on offer is at an early stage of development, there is little co-ordinated planning and most current practice is not incorporated within an accredited framework. Some colleges and HEI have more developed transition arrangements than others but the report also states that, 'most examples of good practice are the result of individual initiatives and are heavily reliant on the individuals involved' (p.9).

### **The Bretton Hall/Hereward College Partnership**

Both Daniel and Aharani studied Foundation Art and Design at Hereward College before progressing to BA Degree courses at Bretton Hall in West Yorkshire as part of a partnership arrangement formalised between the two institutions in 1996. In response to the Secretary of State for Education's directive, which followed the 1992 Further and Higher Education Act and emphasised the importance that the government attached to provision for disabled students, an advisory group on Widening Participation had been established. Funding for special initiatives was made available in 1993/4, with a second funding stream in 1994/5 (Hurst 1996:126-129). Two of the initial 38 projects were concerned with disability and the arts, and one of these, *Creative Mobility*, was located at Bretton Hall in Wakefield.

The focus was on creating physical access for students with disabilities to the buildings and facilities of what was a specialist college of the arts and performing arts and extensive work had been carried out to make its campus accessible. It had not, however, anticipated that only small numbers of disabled students nationally had the opportunity to qualify to a level appropriate for progression to graduate level study in the arts, and applications, therefore, were negligible. Hereward College had a well-established Foundation Course from which disabled students, at an appropriate level of achievement, were seeking higher education places. The course had, since its inception, provided a significant route for disabled students onto mainstream higher education courses nationally, however, in recent years students

with increasingly complex and high level support requirements had come onto the level three courses at the college.

Several factors had influenced this. These included an increasingly inclusive ethos in colleges (*The Tomlinson Report 1996*), whereby those with lower level support needs could be accommodated in mainstream provision; and also developments in IT and enabling support had made the visual arts a more accessible and therefore more viable option for students with high level support requirements. However, the complexity of these students' learning support requirements and the implications of some impairments in terms of medical and nursing provision, was making transition, from the highly resourced and supportive environment of Hereward College to a higher education environment, difficult. It could even, where students' levels of nursing and care were high, effectively disenfranchise them from progression. This prompted the forging of a partnership arrangement that linked the specialised support of Hereward College with the academic expertise of Bretton Hall. The bringing together of these two institutions in a partnership was fortuitous but also random in the sense that it relied on the coincidental meeting of parties who would later be committed to making it work (Pitt and Curtin 2004).

The objective was to create a 'seamless transition' between the institutions in which shared delivery, expertise and experience could offer students a number of options. These included some students moving directly to the higher education institution but with opportunities created for effective pre-planning and assessment, monitoring, continuity and review of support arrangements, and continued co-operation between the institutions. Some students would effect a staged transition, progressing to Bretton Hall after a first year of degree study at Hereward, thus creating a 'bridge' into higher education and an opportunity for support to be refined and established. There would be the opportunity for the student to familiarise themselves with the higher education ethos and expected levels of study, within a continuum of delivery that was intended to enhance achievement and ensure retention. Those students who needed the medical and nursing support services that mainstream provision could not deliver would register with the University College and follow the course as residential students at Hereward College with joint delivery, visits for assessment, group tutorials, presentations, shared exhibitions of work etc. There was also the option for students to return to Hereward College, if their impairment was degenerative and more specialised support became necessary. The partnership link

was successful in that I believe that both of these students (and several others) gained access to an arts education in higher education that they would not otherwise have had at that time. It failed in that many of the difficulties they encountered could have been resolved within the original spirit of the partnership agreement that ultimately, and for a number of reasons, did not translate into practice.

### **The Students' Experiences**

The following account outlines the experiences of Aharani and Daniel in the context of this partnership link. Many things that they recount are common to the experiences that have been described by students at the beginning of this chapter. However, although both students had the same impairment (spinal muscular atrophy, a progressive, degenerative condition of the spinal cord), were wheelchair users, had completed the Foundation Course at Hereward College as residential students and progressed to the same higher education institution, their experiences were quite different. Personality, family influences, gender, class and ethnicity also coloured the ways in which they experienced university, highlighting the multiple and fractured nature of identity and the many parts, in addition to disability and impairment, that contribute to a sense of self (Thomas 1999a).

### **Family Background, Resistance and Self Esteem**

Aharani and Daniel come from very different social backgrounds but share the common experiences of having the same impairment, of being disabled, of having attended special schools and of studying the arts. Both described their families as very supportive of them and proud of what they had achieved. But whereas Aharani comes from a family ethos of higher education – with her father, sister and extended family all noted for their academic achievements – Daniel is the first in his family to have gone to university. As the youngest of three brothers, who afforded him a degree of introduction to, protection from, and access to, their peers, Daniel was accustomed to being out and about in Birmingham, where his family lived.

He rejected the ethos of the special school that he attended because there was 'no-one there that was prepared to act in, what he termed, 'a risky fashion'. He arrived at Hereward College as a rebellious student who resented what he felt to be a loss of autonomy. He had been aware when he left school that friends around him from the local community were all leaving to go into employment, the army etc. and that his option, which he believed was decided by agencies other than himself, was to go into

residential college. 'I was thinking to myself that I was put there, instead of wanting to be there'. His first year at Hereward was characterised by resistance and rebellion. He stated 'I had a bad first year. I got suspended because I wouldn't get out of bed and I drank a bit too much as well'. He rejected any aspects of the college that applied to gaining independent living skills – 'I never did it. I said to myself I can already do it'. And he resented the structures and procedures that he perceived as curtailing his independence and freedom.

Before you go out, you've got to put your name in a book. You've got to be back before half past eleven. At weekends, if you're staying out past half eleven you've got to fill in a form and take it to three different people and if you're going out for the night you've got to fill in another form and if you're going home for the weekend you've got to fill in another form. I don't like filling in forms and I won't do it – that's what made it hard. Then in the third year, they gave up on me. That's what made it easier (Rooney 2002).

Daniel's frustration and resistance to the situation he found himself in, mirrors Nicky's experiences in chapter seven and Middleton's (1999) findings that disabled children and young people experience of not being in control, and of having the larger decisions about their lives and futures made by others, namely non disabled professionals. His resistance (Watson and Davis 2001; Watson 2002) takes the form of non-cooperation and anti-social behaviour designed to thwart the institutional mechanisms that he sees as denying his rights to autonomy and self direction. Daniel's frustration was also compounded by his difficulties with literacy (he had been diagnosed as dyslexic) and he was also resisting the status implications that resulted from his problems with achieving in all areas that were text based. His rejection of the college and its curriculum (before he engaged with the visual arts) expressed his anger at being required to submit to institutionalised based measures that he considered were not appropriate as indicators of his level of ability.

In contrast Aharani's resistance was characterised by a quiet determination to achieve her objectives and, although she conformed to institutional demands, her achievements and increasing independence confounded the expectations that her school and even family had of her and released her from the constraints that a disability identity implies. Aharani had come to Hereward College, like Daniel, from a



background that was predominantly in special education. She described how she used to hide her work away believing that it was 'not as good as the others'. It is perhaps indicative of her own and other's sense of her as still childlike and therefore helpless, that when she arrived at Hereward College at the age of 19, the cushion that she used to support her posture in her wheelchair was printed with a teddy bear design. This image provides a graphic symbol of the 'perpetual childhood' that Middleton (1999) cites as being the experience of many disabled young people.

As her education in the arts progressed, it validated an activity that had previously been seen by her family as something that, 'she simply did in her spare time', and this enhanced her standing within the family. She commented that her Mum and Dad liked 'showing off her and her artwork'. Aharani's family were more overtly protective than Daniel's and Aharani spoke of the need she felt to reassure her parents as well as cope with her own fears about her future. They had come to Britain from Sri Lanka and settled in Leicester and the family work ethic and endeavour to achieve was discernible in Aharani's description of her father as someone 'who had come from a modest background and worked very hard to gain the academic qualifications that would enable him to come to Britain'.

The enormously positive influence on self esteem that the university experience has had *per se* is shared by both Aharani and Daniel, and clearly evidenced by remarks that reflect the increased status and positive sense of self that they both felt. Daniel's remarks, 'If someone asks me I say I'm an artist. I'm a painter definitely', indicate that he felt justified by the university experience to ascribe this status to himself. His artist identity has taken precedence over his disability identity and he has aligned himself comfortably with the unconventional artist fraternity that challenges society's stereotypical view of the world (Coetzee 2002). Aharani's comments 'I am now considered to be one of the daughters at university' signify that she can now consider herself on a par with her siblings status-wise and that she has transcended the educational background of 'special school' that is not ranked highly in terms of educational status. Research by Filsinger and Anderson (cited in Dusek 1987:390-391) has focused on the concept of self-efficacy, the feeling that one is capable of achieving some desired goal.

Self-efficacy theory predicts that individuals interacting in social class contexts higher than their own are more likely to have higher self-

esteem. ... These predictions are based on the assumption that the social class level within which one acts influences the individual's view of self competence (p.391).

The research suggests that 'late adolescents gain a sense of social status and a feeling of competence from associating with close friends of higher social status, perhaps because they have greater confidence in themselves' (p.391). From this point of view the impact on the self-esteem of disabled students who have experienced disability as a negative status category and who have then achieved a university place against all the odds, is profound.

### **Creative Development and Educational Background**

Daniel's and Aharani's learning is affected by their impairments. Both experience low levels of stamina and physical weakness and posture. It is difficult for them to produce significant amounts of written work in limited time scales and there are restrictions for them on tasks that require carrying, reaching, handling and manipulation of resource materials. Both rely on personal one-to-one assistance for note-taking in class and directed study activities, such as practical art and design activities, handwriting, assignment work, page turning, research and organisational work. Study equipment for both includes computer-based word-processing with built-in word prediction, computer-based drawing and image manipulation, and Aharani requires an on-screen keyboard and a touch-pad pointing device for mouse movements and tap or click selection (Hereward Access Centre Assessment Report 1998/2000). Both students require 24-hour personal care assistance.

The residential aspect of Aharani's education at Hereward College and the foundation course experience gave her unprecedented access to disabled and non-disabled peers and the local community. Living away from home gave her significantly more independence and freedom, as she did not have to rely solely on her parents anymore. She made friends with other Foundation Course students with whom she would dress up and go out to clubs and bars. She was able to go shopping independently accompanied by her friends or young volunteers and she could buy her own clothes, which she soon identified as a significant way of creating and expressing self-identity and status. As she progressed through the Foundation Course, it was evident that textile design was to become her specialist area of study. It could be accessed very effectively through IT, and, most importantly, was an area

through which she could explore her growing interest in her cultural identity. The end of year exhibition raised her self esteem and expectations providing the impetus for her to begin to think of herself as a potential textile designer from a position where she had, 'never imagined seeing my work anywhere other than in my sketchbook'.

Daniel had similarly identified the visual arts as an area within which he could achieve and also make unconventional, 'risky' statements. The scale and freedom that he was offered contradicted his special school experiences of art and the more liberal relationship and positive social interaction that he established with the tutor, obviated the need to resist in terms of non cooperation, allowing him to 'conform' enough to 'get out of bed', attend his lectures and achieve something specific. He describes this turning point.

Come to the second year we had a new lecturer in. Got on with him, and we had a laugh. He just gave me a big piece of canvas about the size of the studio floor. I started getting into abstract expressionism, and started finding out about putting the paint on the canvas (Rooney 2002).

### **Transition to Higher Education**

Daniel's single choice for higher education application was within the partnership link. He was accepted to go straight onto the Bretton Hall campus, possibly because at the time he made his application (which was 2 years after Aharani's), there was more confidence in the receiving institution that they could and should accommodate students with high level support requirements. Daniel was also clearly eager to seize the opportunity for independence and educational challenge at this higher level that he felt he could meet, that was not predominantly text based and was in a mainstream environment.

I want to move, I just want to go. I want to be more independent, independence that's what I want. A bit more inspirational as well, working with people that are actually working on what you're doing, having people around who are on the course with you. It's somewhere new (Rooney 2002).

Aharani, who was similarly keen to move on from Hereward, made two choices on her UCAS application form. Her first was to a university that she knew was accessible and that she believed had established a good network of care support for students with impairments. She had been encouraged by the fact that several Hereward students had studied at the university before and made use of this care support. Her second choice was to Bretton Hall as part of the partnership arrangements. She was rejected by her first choice institution, which she believed was because her work was too constructional for a surface pattern course and she therefore had to fall back on her second choice. By the time that decisions are made by institutions in the UCAS cycle, particularly if the first choice is rejected, there is relatively little time left to put complex support arrangements in place with the receiving institution. Aharani began her course as a resident at Hereward with the intention of transferring to the Bretton Hall campus as soon as possible. However she was caught up in a tangle of shifting circumstances that thwarted her aspiration for the next three years. It was only the fact that her programme was extended by a year to compensate for the physical rate at which she could produce the work required, that she was able to experience higher education in a university setting at all.

Daniel's first year at University proved to be extremely difficult as neither Daniel, nor the institution, was sufficiently prepared. His difficulties reflect many of the issues identified by the larger group of students in the earlier part of this chapter but in addition difficulties with personal care and enabling support are raised which the Hereward study confirms continue to bedevil disabled students in HE. When a student needs personal care and support with studying, it is usually the case that social services fund the care provision and funding for educational enabling comes from the non medical element of the Disabled Students Allowance (DSA). Currently this is £11,015 as the yearly maximum amount which comprises allowances for non-medical care support, personal assistance to assist with communications/note-taking etc and up to an additional £4,355 for technology. It became available for part time study in 1999. There are several ways in which this support can be provided. Some universities run their own schemes and will manage the money aspect of employing assistants. Some students are expected to advertise, recruit and employ their own support workers. Community Service Volunteers are another option, although some disability co-ordinators have been known to advise against them as being 'unreliable' and 'offenders'. Students can approach the university disability co-ordinator and their

social worker for advice and assistance and, ideally, they will work together and with the student to put their support package in place.

Daniel's support was interpreted initially as a requirement for 24-hour personal care and as a consequence there was no provision for the enabling that he needed with his studies in the studios. He recalled

The carers were coming from an agency. They were travelling in to me from anywhere around the country and then it meant that from 9-5 during the day they were not doing anything. I was having people coming in and saying, 'I'm not coming in the studio, it's not in my job description', but still expecting to be paid. So that meant that the money that was supposed to pay for my enablers from Birmingham Education Authority was put in to top up the wages for the carers in the day. I did what I could on my own, but I was quite behind and so it all started getting pretty bad. It was a mix up, a proper mix up (Rooney 2002).

In addition to these practical difficulties Daniel was unprepared for the higher education ethos.

It was a big leap of difference [from Hereward College]. There was not a great deal of support [from the academic staff] which I was expecting anyway because I knew basically that you were going to be left to your own [devices]. But I was expecting a bit more than what was given. Yeah, that was a bit of a surprise because I left here [Hereward] on quite a high note and I was expecting to go on with this high note and start off quite well and I just didn't, it didn't work out (Rooney 2002).

Daniel was able to make friends quickly in an environment where he knew nobody, and he was soon part of a group, but the more liberal mainstream approach, his natural inclination towards non-conformity and student ethos of drinking and late nights, which he wanted to be part of, not only jeopardised his continued presence on the course but endangered his life. By Christmas the situation had become critical and Daniel was forced to consider leaving.

I got a bit too much into the drink, but then that put me into hospital at Christmas because then it was quite serious and they thought I was going to die. It was my own fault. It was a wake-up point really (Rooney 2002).

Daniel's tutor intervened at this point and things improved to the extent that Daniel passed the first year of the course. He was allocated dyslexia support and enabling support a few months after the Christmas break. However his disappointment with his first year achievement is evident.

He [the enabling support, a recent ceramics graduate] started working with me and he knew what the course needed and that I needed to catch up and what I needed to get in, to get my year passed. So basically I caught up and I got everything in – minimal, very minimal. I wasn't happy with my first year there, I was disappointed (Rooney 2002).

Aharani had anticipated leaving Hereward at the end of the first year of her textiles degree programme which had in effect run smoothly on from her Foundation Course studies. As a resident at the college her care support continued as part of Hereward's provision. Although she could now employ her own enabling support, a process she initially found daunting, Hereward was able to support her through this and make good any shortfall in provision that occurred in the initial stages. The course was delivered to her jointly by the two institutions, with the Textiles tutor from the University College travelling to Hereward for individual tutorials and Aharani travelling to him occasionally for assessments. Ultimately, his part was to prove crucial in the coherence of Aharani's course (Pitt and Curtin 2004). A merger between Bretton Hall and Leeds University occurred in 2000 and, with the additional year that had been added to her course, it meant that when Aharani eventually transferred to the university campus she became the only student in a fourth year, completing a course that had been superseded by Leeds University's own textiles course. All the Bretton Hall students had been re-located from a new and accessible building adjacent to the adapted accommodation that it had been envisaged Aharani would inhabit, to studios on the Leeds campus, and these were only accessible by

the service lift. There were no designated studio spaces and, with the exception of Aharani's tutor, different lecturers staffed the course.

Establishing the necessary support team of suitable personal assistants for the 24-hour care and enabling that Aharani required also proved to be extremely problematical. It was exacerbated by changes in the disability co-ordinator personnel, and the fact that once she had recruited one or two personal assistants they were reluctant to wait until the full complement was employed. The merger created upheaval and uncertainty and Aharani felt that she was being passed from one institution to the other without any action being taken. Meetings were particularly frustrating as the positive light the situation was painted in inevitably evaporated into intransigence the next day. As her course progressed Aharani felt the lack of contact with the other students on the course acutely. Isolated as the only BA degree student studying textile design in the context of Hereward College, she described herself as 'a little in limbo', rightly maintaining that contact with her peers was necessary to 'keep her on the right creative track'. Aharani finally made the transition from Hereward College to the university for her last year of study. She described this experience as 'exciting' and the 'best move I made'. A young Asian woman that Aharani had employed as a personal assistant at Hereward College moved with her to the university and this provided Aharani with a familiar face, ethnic solidarity and continuity of assistance in the new environment.

### **Social Interaction**

Aharani described it as hard to make friends in the first instance because no one from her course was living in the same accommodation. She was located on the ground floor and everyone was in a different year group doing different things and they didn't have the same things in common. Daniel described how rapidly groups are established in the first year based on common interests and maintained thereafter, making it doubly difficult for Aharani.

You've got all your trendy students that stick together and then you've got all the ones that are into skateboarding and the baggy clothes stick together, and then there are the ones that are sort of odds and ends from everywhere (Rooney 2002).

Ironically Aharani described the final exhibition as the catalyst for making friends with whom she is still in touch.

The fact of Aharani's and Daniel's impairment generated various responses from their non disabled peers ranging from curiosity and preconceived ideas of the meaning of impairment to, in the instance that Aharani describes, well meaning, if misplaced, liberalism and solidarity (Lenney and Sercombe 2002).

When I was out and about in the evening I was made to feel that I was clever because I'm in a wheelchair; I was put on a pedestal. Some people asked me about my disability. There were very many incidents. There was an evening when we went to the union club night. There were three floors, dance floor, bar and lounge. I was in the bar and I wanted to get to the dance floor half an hour before the end. I had to ask the porter to get the lift down and this made me feel different. My friends tried to make an issue about it on my behalf and complained about it. I didn't want to make a fuss and told them to forget about it. They were being advocates for reasons I'd rather they didn't (Sivapalan 2002).

Daniel's response to interest in his impairment appeared to be equable and unconcerned.

I had people ask questions, but I'd rather they ask questions than sit and wonder. It came up at first about a week after [the beginning of term] from one lad I was living with. He came up to me and said he didn't know how to take me at the start because he'd never met anyone in a wheelchair. But I ended up on the first night going to some castle with him at 4-o clock in the morning and he just says he was surprised that I was up at that time. So he did look at me quite stereotypically. I think I changed his views quite early on (Rooney 2002).

The university experience that placed Daniel and Aharani in the centre of a large and dynamic city had a significant impact on both of them. It gave them full and



unrestricted access to the community and culture of a large and vibrant city. Aharani commented:

The world is your oyster – theatre, music, shopping. I went into town every week. I could be out every night if I wanted to. I had to balance things out. I found it difficult. Hereward restricted me doing exactly what I wanted to do. In Leeds I could do whatever, whenever (Sivapalan 2002).

Daniel also welcomed the release from special school and residential college.

I prefer it like that [living as part of the mainstream community] not because I'm being slack to other people with disabilities, but doing what I enjoy doing. I like going out and getting stranded at 4/5 in the morning and not knowing where you are and looking for a taxi, I like that. I don't like to sit back and have everything done. I like to get out there and do it. It's given me that, more than I've ever had before. It's shown me what life can give you. And I think being next door to Leeds is a big, big opportunity. I will most probably end up staying there (Rooney 2002).

### **Artwork**

Neither Daniel nor Aharani felt the need to 'come out' as disabled people through their artwork, neither subscribed to a politicised collective disability identity or aligned themselves with the Disability Movement or Disability Arts but, for both of them, their creativity and visual artwork was essential in their struggle to address their status as disabled people. Daniel's artwork gave him a positive mode of expression that was acceptable to both him and a mainstream educational framework, and he was empowered by the development of a 'voice' that could be heard positively in mainstream and conventional settings. Aharani was able to achieve levels of design skills and competencies that contradicted conventional expectations of someone with her level of support requirements. She was also able to explore her ethnicity in a Westernised context and to make allusions to disability that were subtly contained within her textile designs.

During his first year at university, Daniel struggled not just with the practical difficulties he was experiencing with personal care and enabling support but also with understanding what was expected of him in terms of his visual artwork. He summarised his first year's work as 'Nothing. I did what had to be done, the very minimum that had to be done basically. It wasn't there'. However, by the second year he was starting to think more deeply about the meaning of art and how he could subvert traditional expectations of what constituted a painting. He described how he tried to

get away from the traditional canvas. Started working on plastic, still stretching it (see Fig 51, 52). But then I went from plastic to just working on the frame. Painting frames. I wanted to look at what the frame was and what it was supposed to do. Whether it was just to support the painting or whether it was to separate the painting from the wall. To distinguish what art is and what art isn't or whether it was a piece of art in itself. And then [if you] ask for a deeper meaning of it, it was, as humans we've got to put something in a category before we can accept it. If we can't categorise it we can't sort of accept it. So I was trying to use frames to portray that (see Fig 53, 54) (Rooney 2002).

The link that this might represent with the categorisation of disabled people was not raised. It seemed inappropriate to label Daniel's work in a way that he himself was not suggesting directly. However, I would suggest, that he was making connections with the ways in which people, and specifically disabled people, are subject to various categorisation processes. In the interview with Daniel in the summer he completed his Foundation Course, he made reference to his 'hidden self' and the notion of camouflage. He stated that his work was about his mind or inner life, not about his external person or world. Although this was in his paintings and *he* knew it was there, others would only see a part of that and would not really see him. At this point he asserted that he didn't like people to know what he was doing even in terms of ordinary activities. He returned to this theme again, describing his presence in his work.

It had me in it all over. It's part of me. Someone that's not close to me, they'll only see what I want them to see (Rooney 2002).



Fig 51

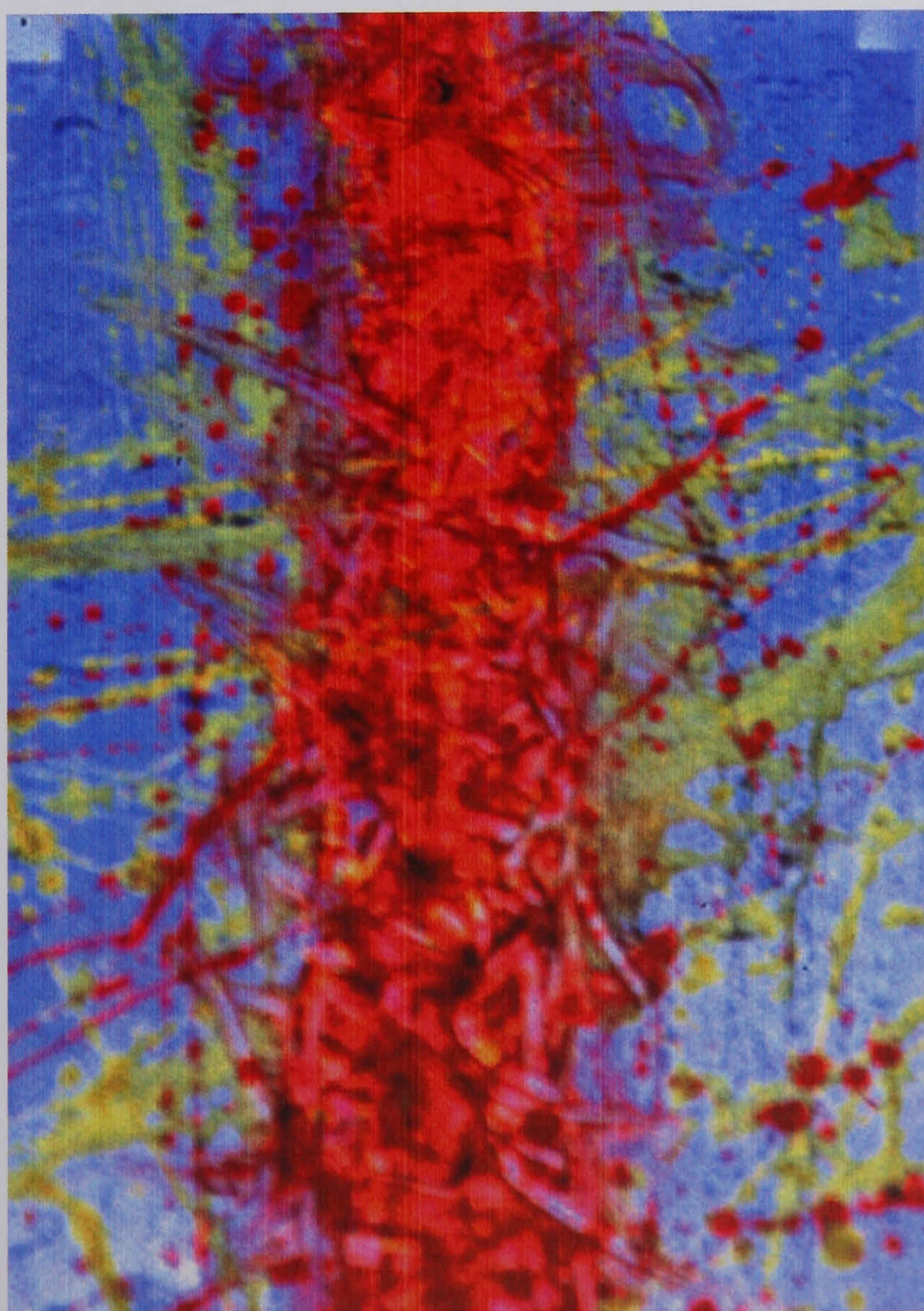


Fig 52



Fig 53

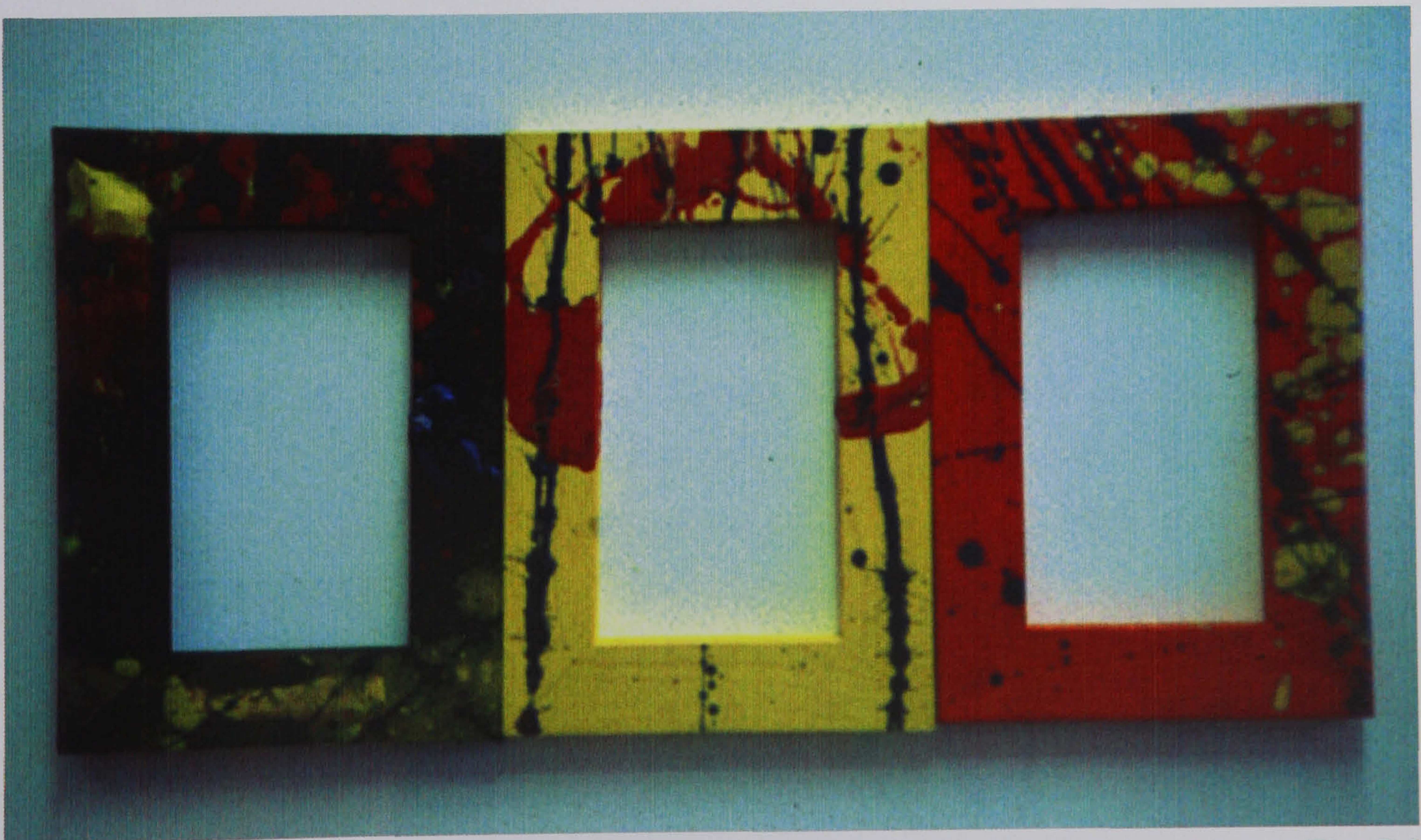


Fig 54

An opposite and contrasting approach is demonstrated in the artwork of James Lancaster who preceded Daniel as a Hereward College/Bretton Hall student, and who revealed in his artwork the lived experience of the unspoken pain of disability, whilst resisting the narrative of victim-hood and tragedy. His impairment had a profound impact on his life and his artwork provides a rare glimpse of a life lived differently.

James has Duchenne Muscular Dystrophy, the implications of which constitute a significant limitation in all his muscular activities and limits life expectation. He studied at the college for a period of five years, first on the Foundation Course and subsequently as a BA Fine Art student registered with Bretton Hall. During this time he explored and articulated the lived experience of his impairment, and developed increasingly eloquent visual imagery with which to describe the processes and activities which comprised this critical aspect of his self identity. His early drawings were of bleakly powerful images in which he transformed his experiences into skeletal figures caught by corkscrew devices, or between the teeth of spiky, jagged edges (see Fig 55, 56, 57, 58). One of these images entitled *The Screw*, he described as, 'the way I view my body being twisted and distorted through my disability. I think it was self-therapy' (*Disability Now* July 1999).

James explored the dimensions of this newly found 'voice' or mode of expression through his effective use of amanuenses and the process of scaling these small, hand-drawn images of a few inches in diameter, into imposing, large scale drawings. These six-foot high drawings dominated the room in which they were shown. He also, at this stage, experimented with images that had become more 'design like' in their representation of the areas of pressure and discomfort in his back, pelvis and shoulder (see Fig 59, 60, 61, 62). These he also printed on fabric onto which bandages, elastoplast and safety pins were collaged together. These challenging and shocking images were stark and in many ways uncomfortable to view, but could not be read as pitiful or tragic.

From these initial statements, James moved to a subtler, intellectual concern with the contrasts and connections – the borderland, between mind and body. His paintings and drawings became uncompromisingly abstract. One series of canvases, relating to breathing and the use of a ventilator, produced initially in response to a period of illness, are dominated by vertical bars (see Fig 63, 64, 65).

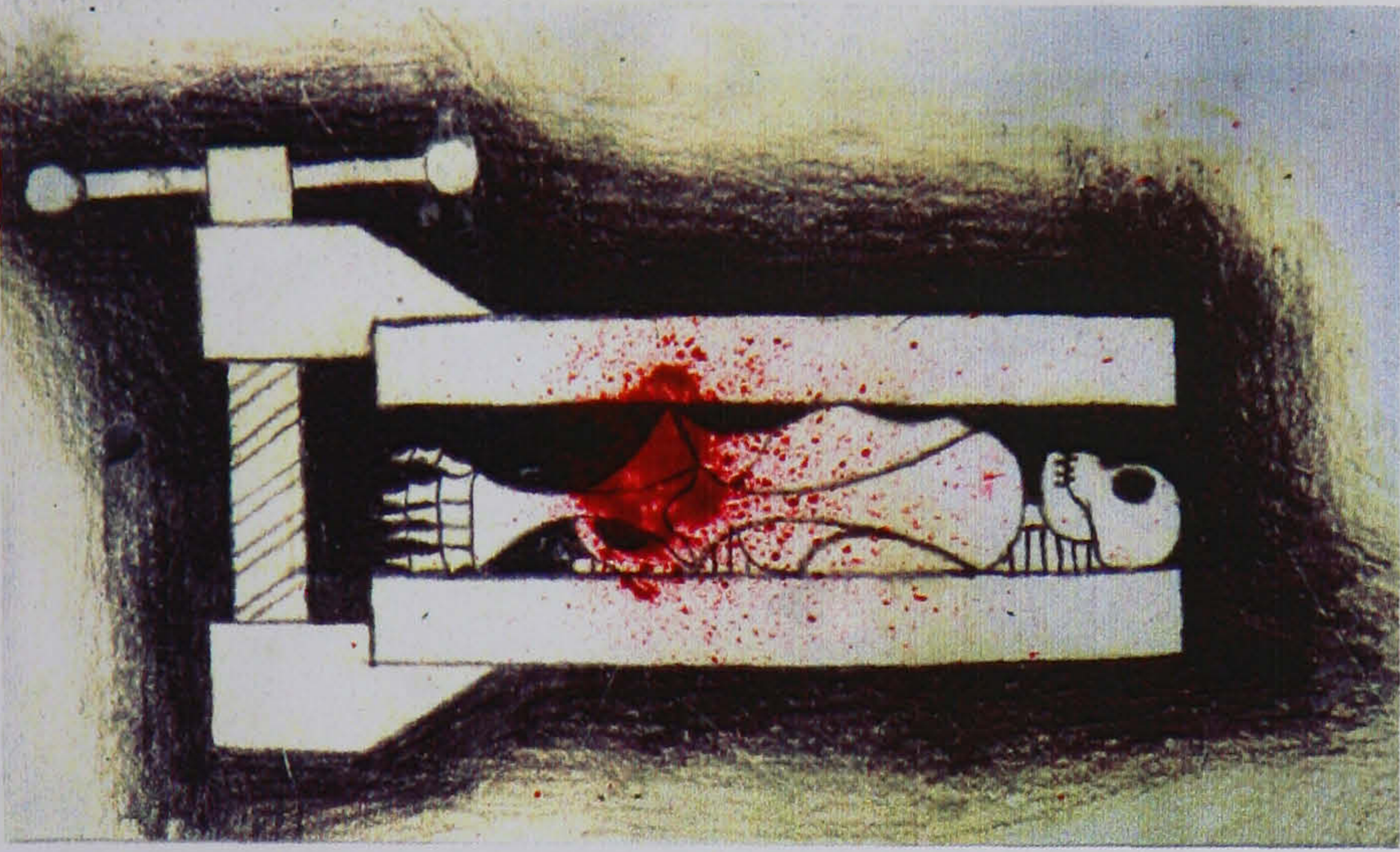


Fig 55



Fig



Fig 57

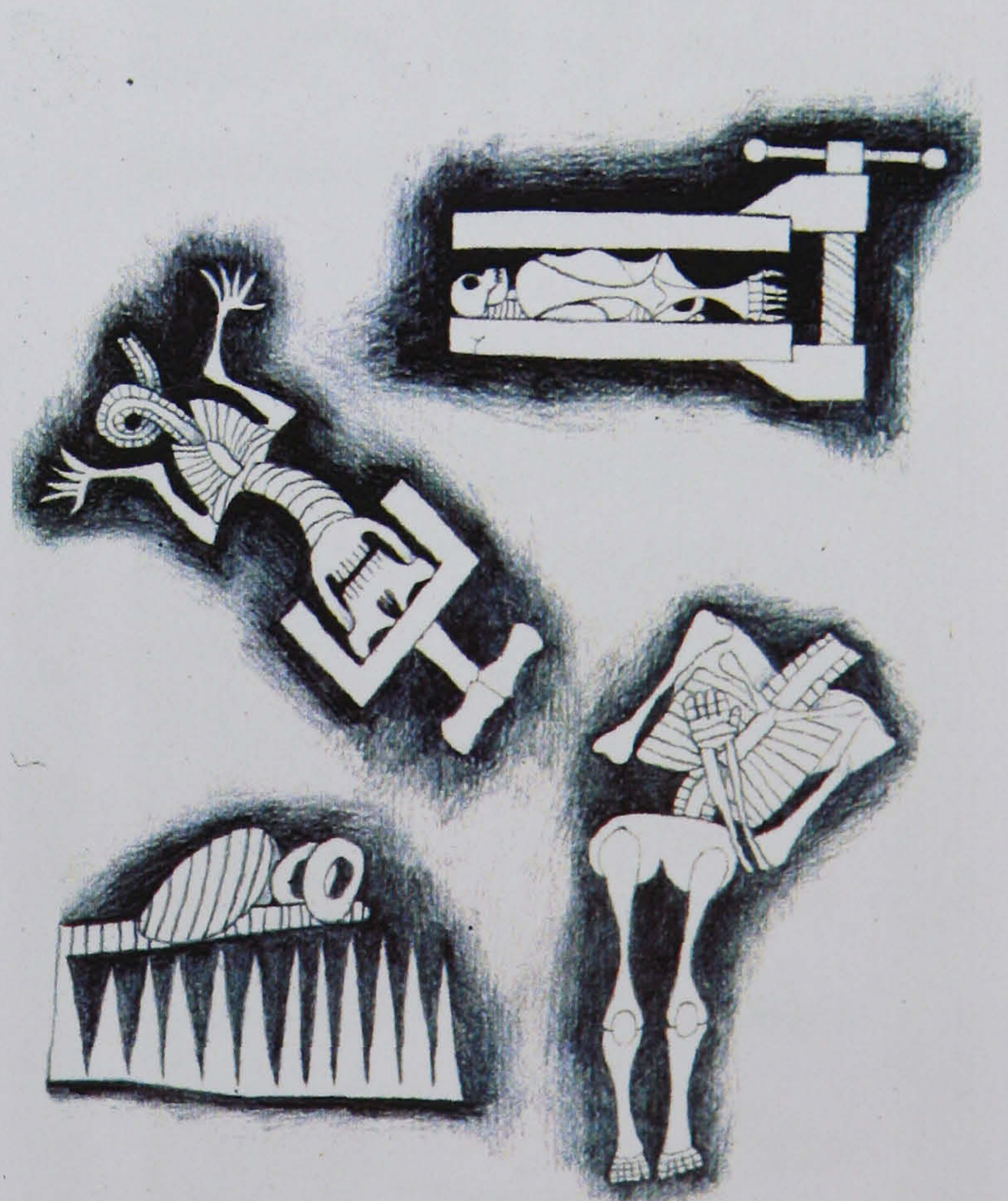


Fig 58



Fig 59

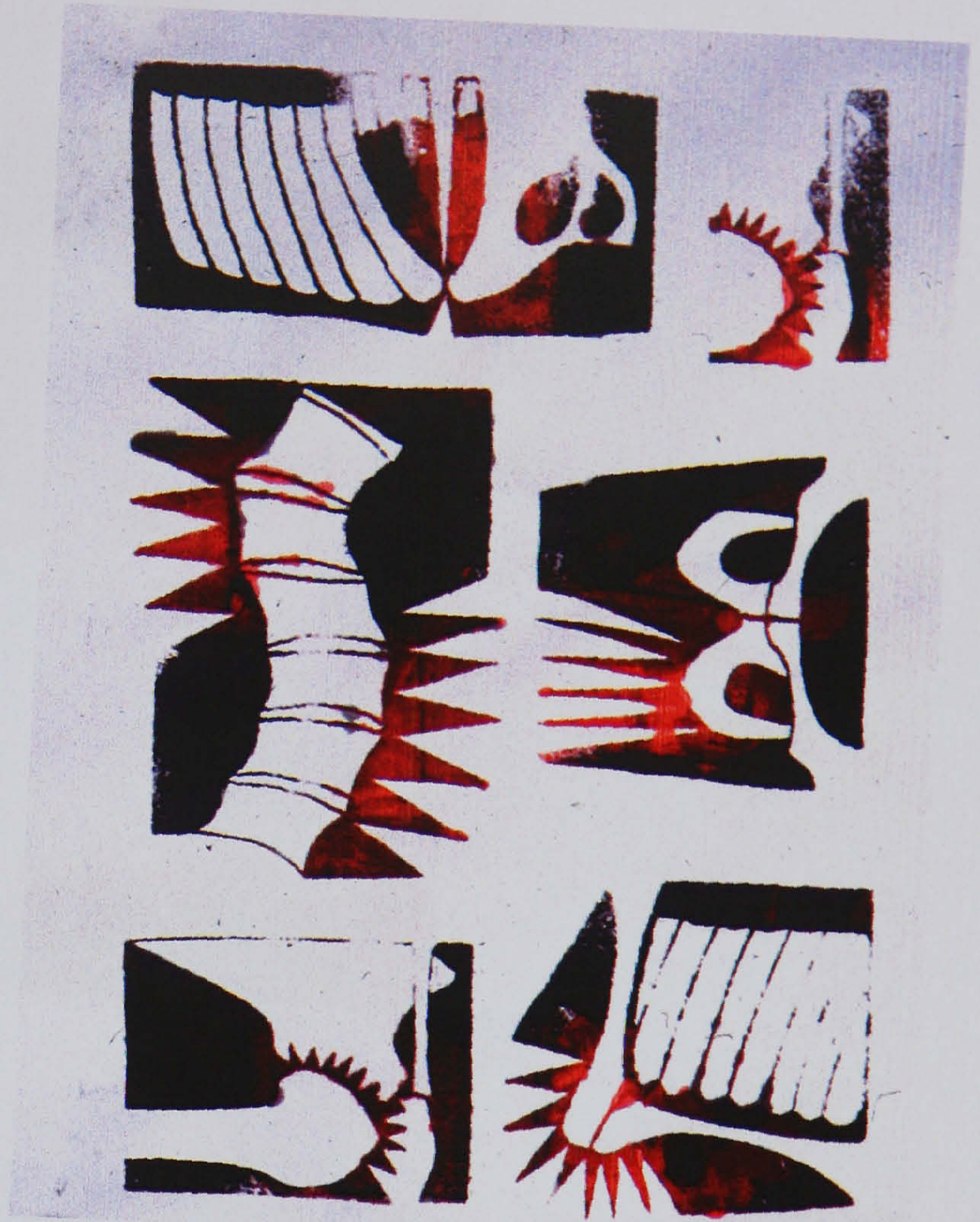


Fig 60



Fig 61

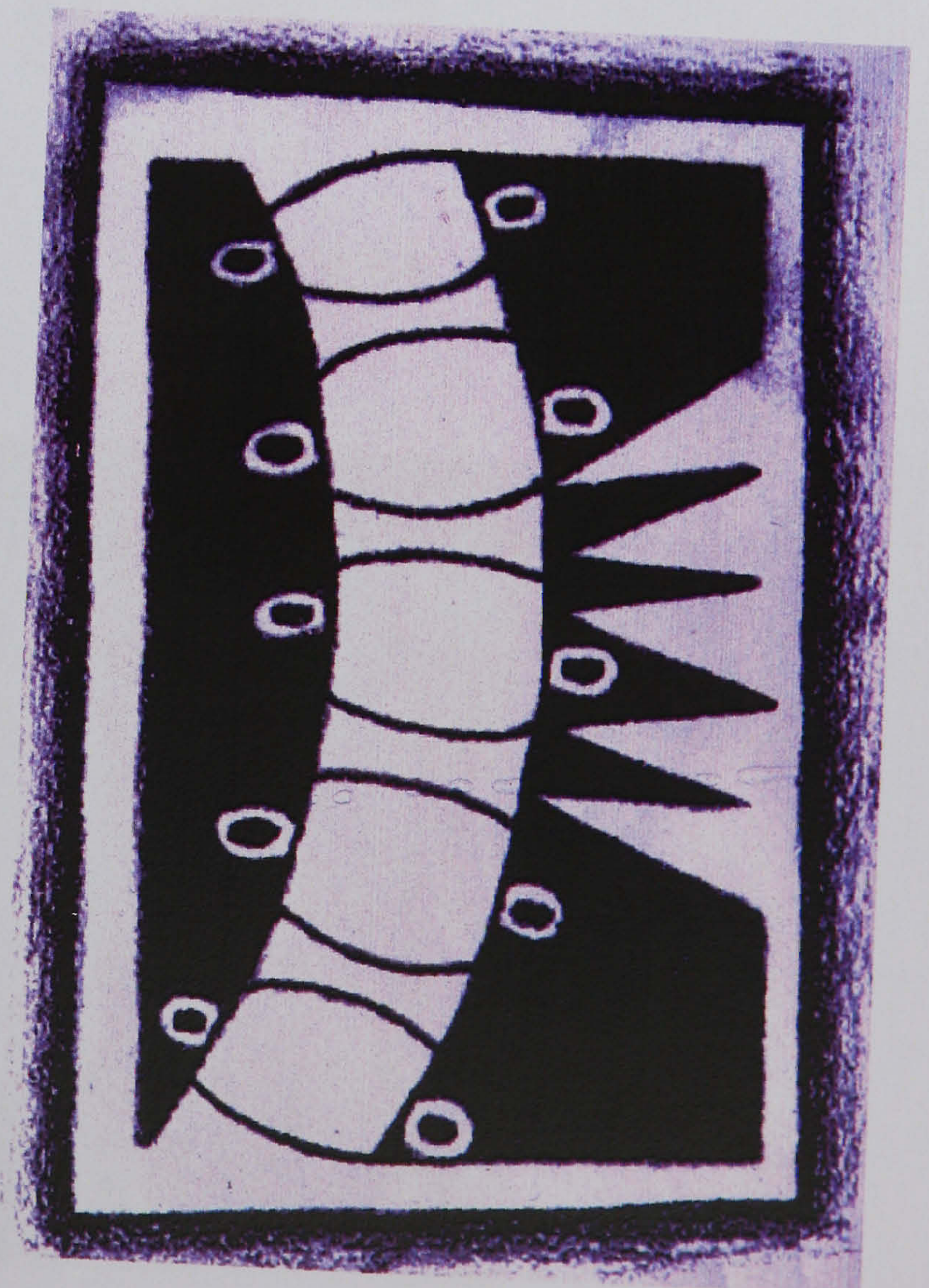


Fig 62

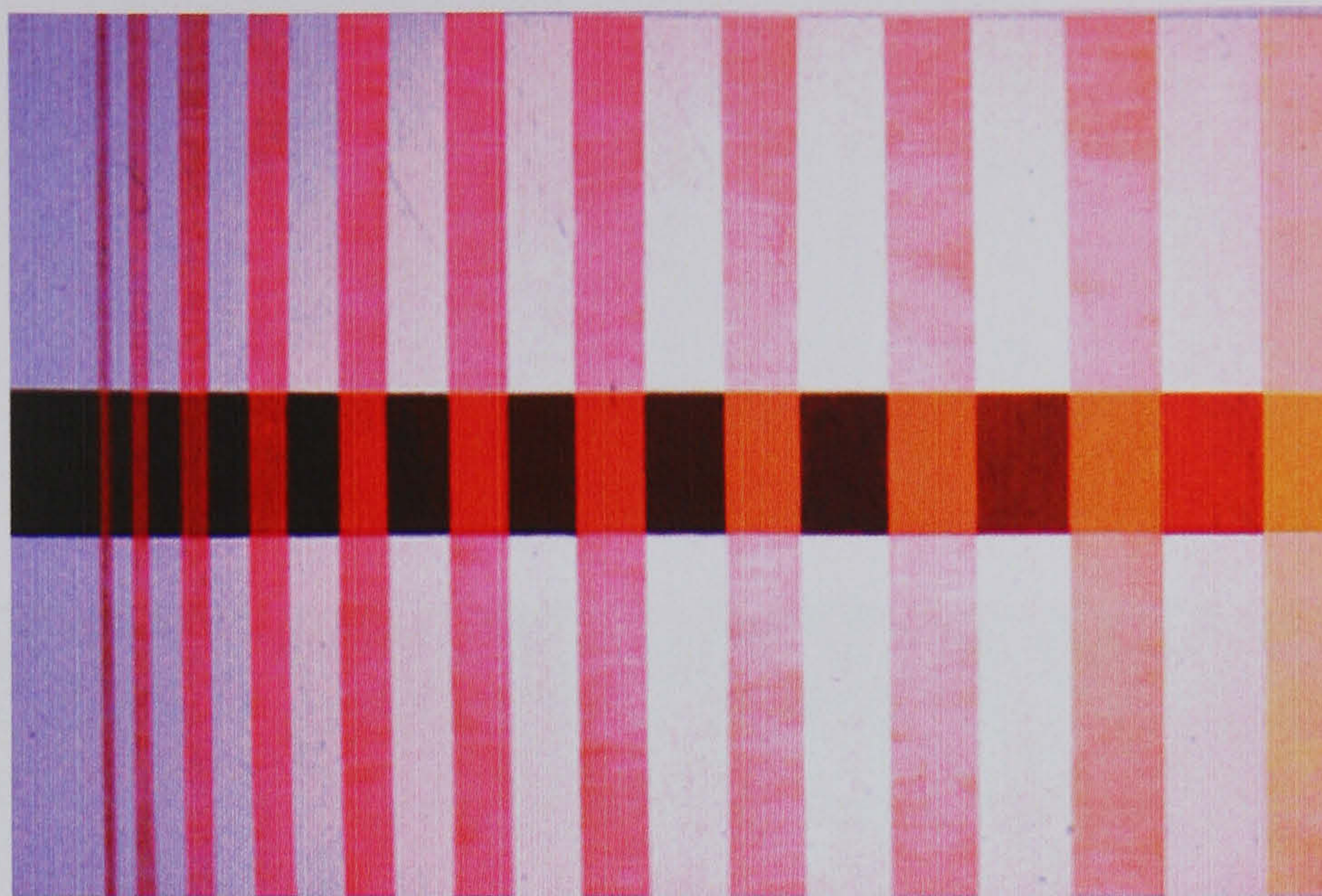


Fig 63

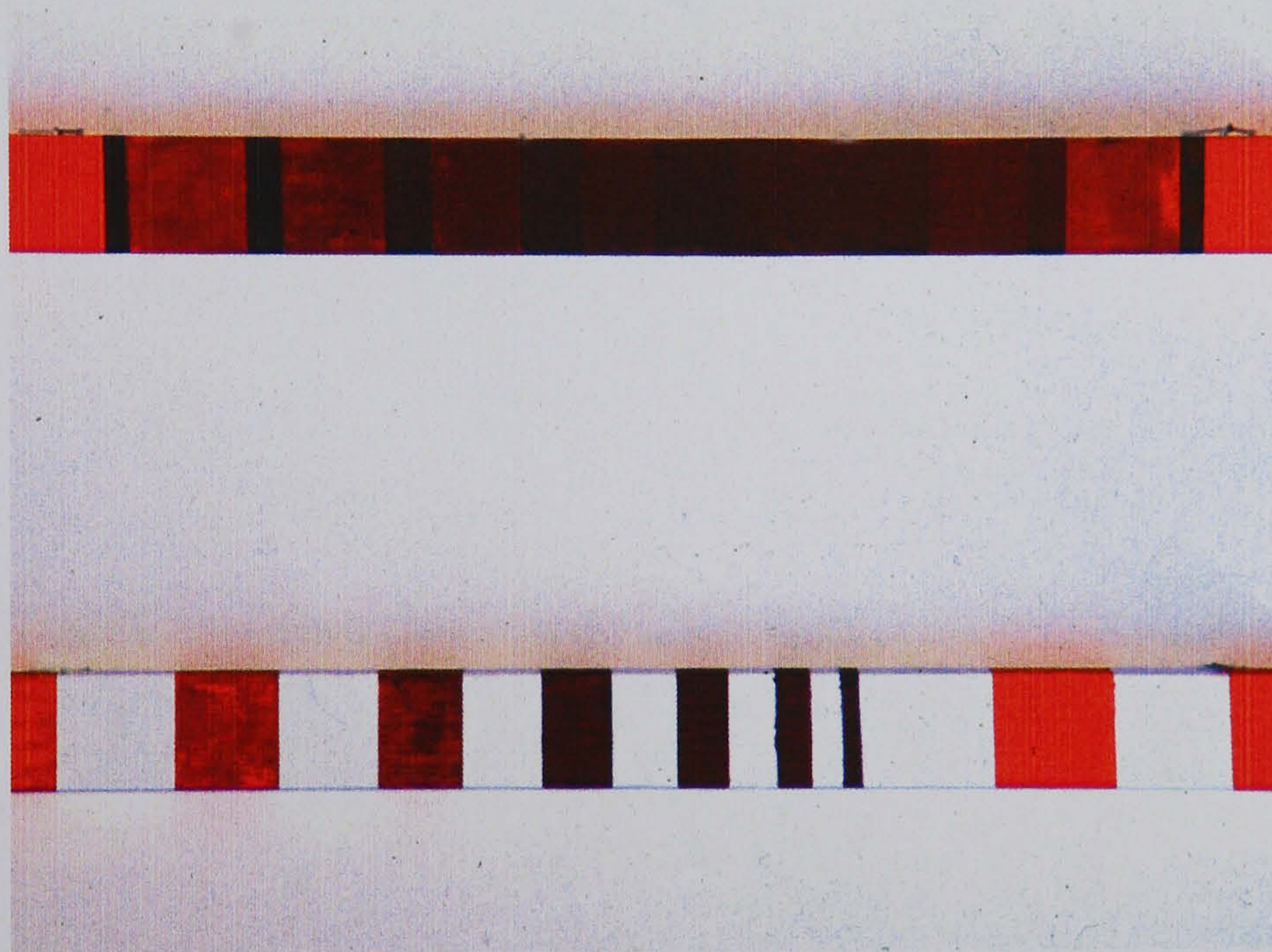


Fig 64

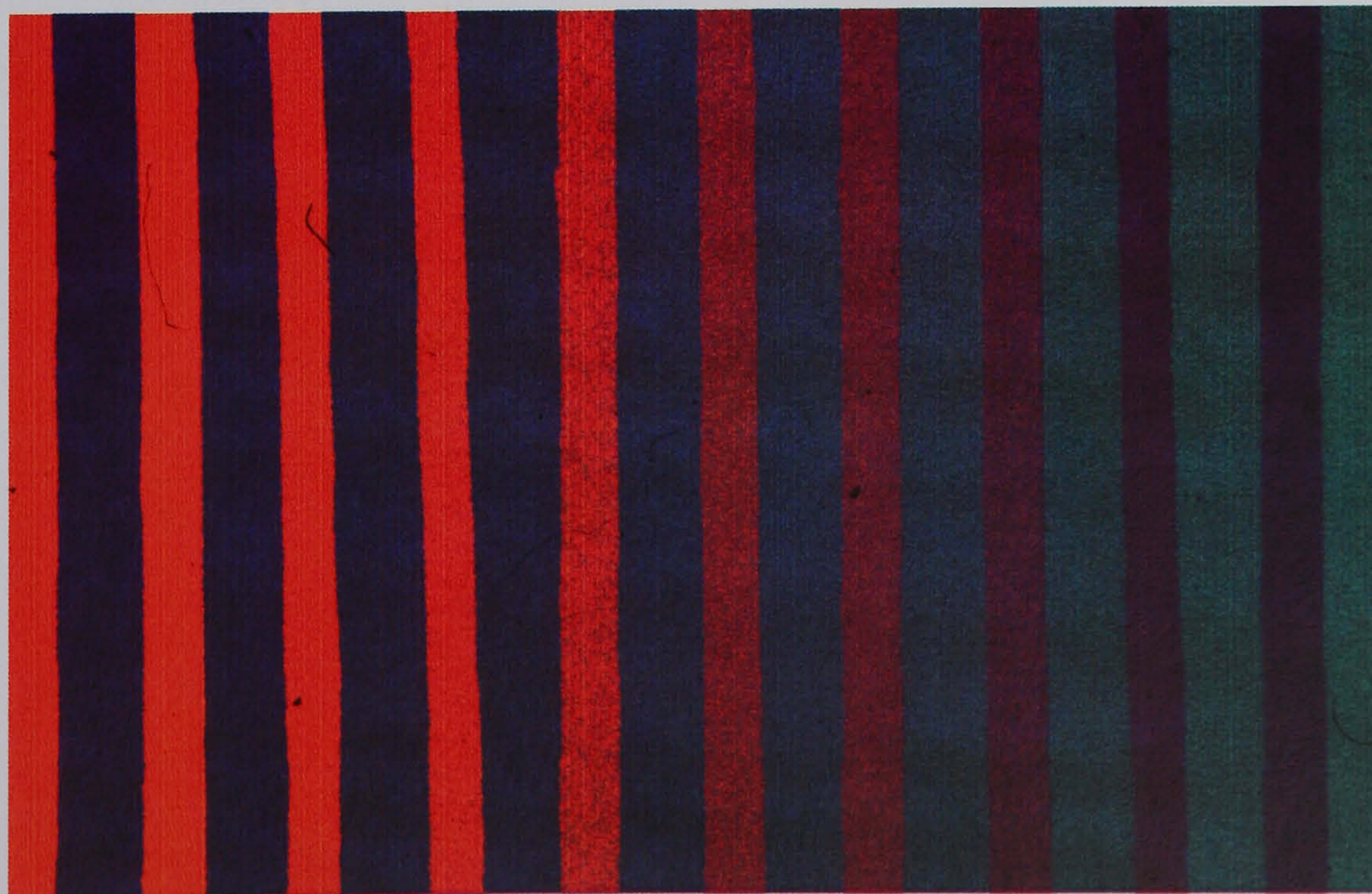


Fig 65



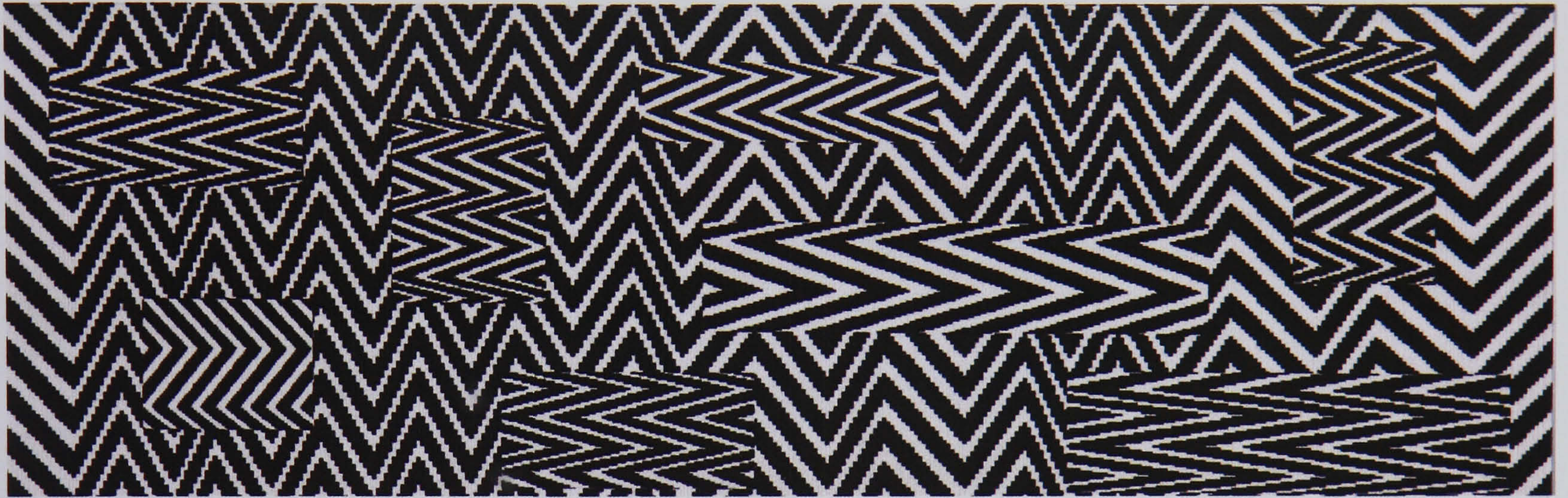


Fig 66

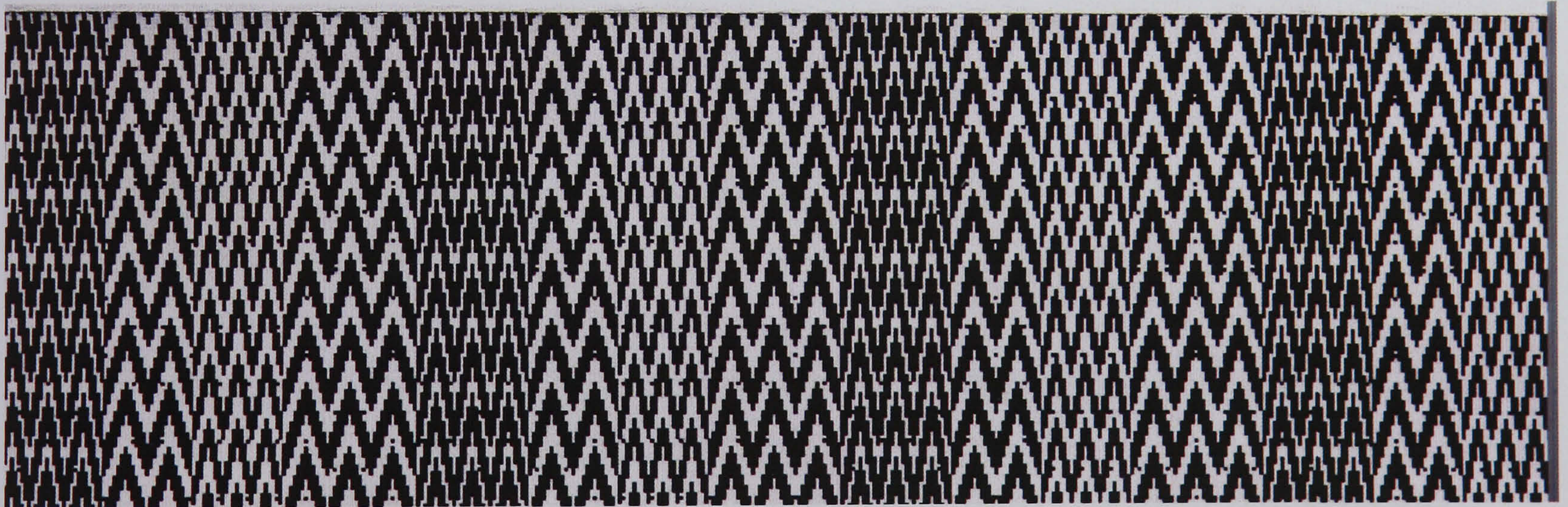


Fig 67

Each bar represents a breath, its width corresponding to the depth of the breath. The final work that he did for his BA Degree in Fine Art, took the form of an installation in which he covered the walls of an enclosed space with a black and white optical effect. This effect appeared to make the walls vibrate and resonate (see Fig 66, 67). These visually disturbing images, in which the viewer was contained, were difficult to look at for any period of time and were intended to convey the persistence of pain.

James stated:

Being in a body that is not capable of the full physical potential of most human beings makes me want to explore the full potential of the mind. Having a body that is in discomfort and pain for a majority of the time leads me to look at ways in which extreme physical sensation (pain) can be used to develop spiritual awareness and understanding. In my work I want to help people understand the experience of not being able to escape a genetically given physical state. I wanted to produce an understanding of “being-in-the-body” of a person experiencing persisting physical pain, through the use of sight and three-dimensional space. The desire is to transcend the body into a disembodied mental realm, free from the physical restraints of the body. The body is a vehicle for the mind (brain). The body in pain distracts the mind from thinking clearly. You want the mind to be freed from the physical restraints of the body, but the body nourishes the mind through the senses (Lancaster. 1999).

James’s artwork offered him the opportunity to develop, articulate and express his self-identity. The embarrassment associated with the sensitive topic of pain, which if ignored would ignore a central part of his lived experience, has been circumscribed. Wendell (1996) refers to the ‘cultural silence’ about pain that increases our fear of it. She suggests that ‘if we knew more about pain ... about what it is like to be ‘too far’ from our cultural ideals of the body, perhaps we would have less fear of the negative body’ (p.109-110). James has represented himself with images that are devoid of the pity that characterises the traditional response of non-disabled people confronted with an experience they do not understand or fear. This is not to say that his work is not emotive, because as Morris (1998) states ‘It [the narrative employment of voice]

can also infuse suffering with an unusual power to capture attention, to move emotion and to compel a response' (p.200).

The effective articulation of a different way of being that James's artwork represents has significance beyond the individual in that it convincingly de-stabilises the social categories within which disability is located. It suggests the possibility that, as Seymour (1998) states:

In their living bodies, people with disabilities may hold the key to promising new bodies freed from the restraints of old orthodoxies with their associated inequalities (p.18).

Daniel did go on, as his arts course progressed, to make more overt references to the lived experience of impairment in a series of digital images that he carried out in response to a module that he had to complete for his second year. In the first instance it seems likely that he chose to work from his own x-rays because he needed to generate something quickly to meet the deadline and that he may have drawn on the area of disability arts simply to do this. He comments:

It started off with, I've got to get something in or I'm going to fail but it took an interest. It was x-rays of my back and spine, of my operation and the rods that are in my back. I scanned them in and manipulated them with *Photoshop*. You could see what they were, I just made them look better than the x-rays. It's quite personal. I was surprised because none of my work really shows it is personal (see Fig 68, 69, 70, 71) (Rooney 2002).

These images of his spine match a similar response from Anthony, described in chapter seven, and represent a concern with the operation that strengthens but fixes the spinal column of students with degenerative muscular impairments. However, the expression of his impairment within his artwork is, for Daniel, only a part of how he perceives himself and is more a nuance or reflection rather than a specific politicised statement aimed at stating a disability identity or shocking, enlightening, or raising the awareness of his audience. He is creating an idea of himself for himself not celebrating difference or diversity (Watson 2002).



Fig 68

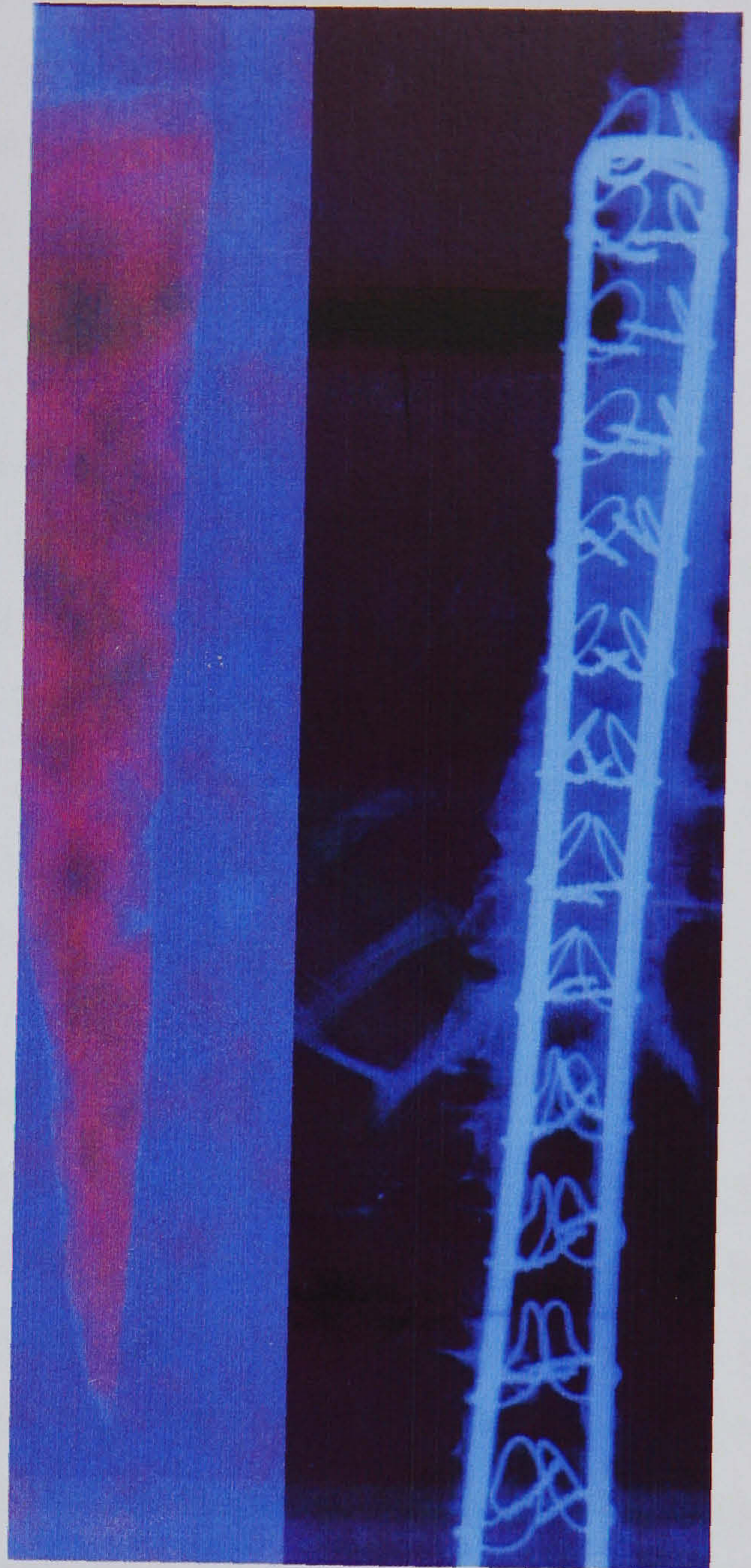


Fig 69

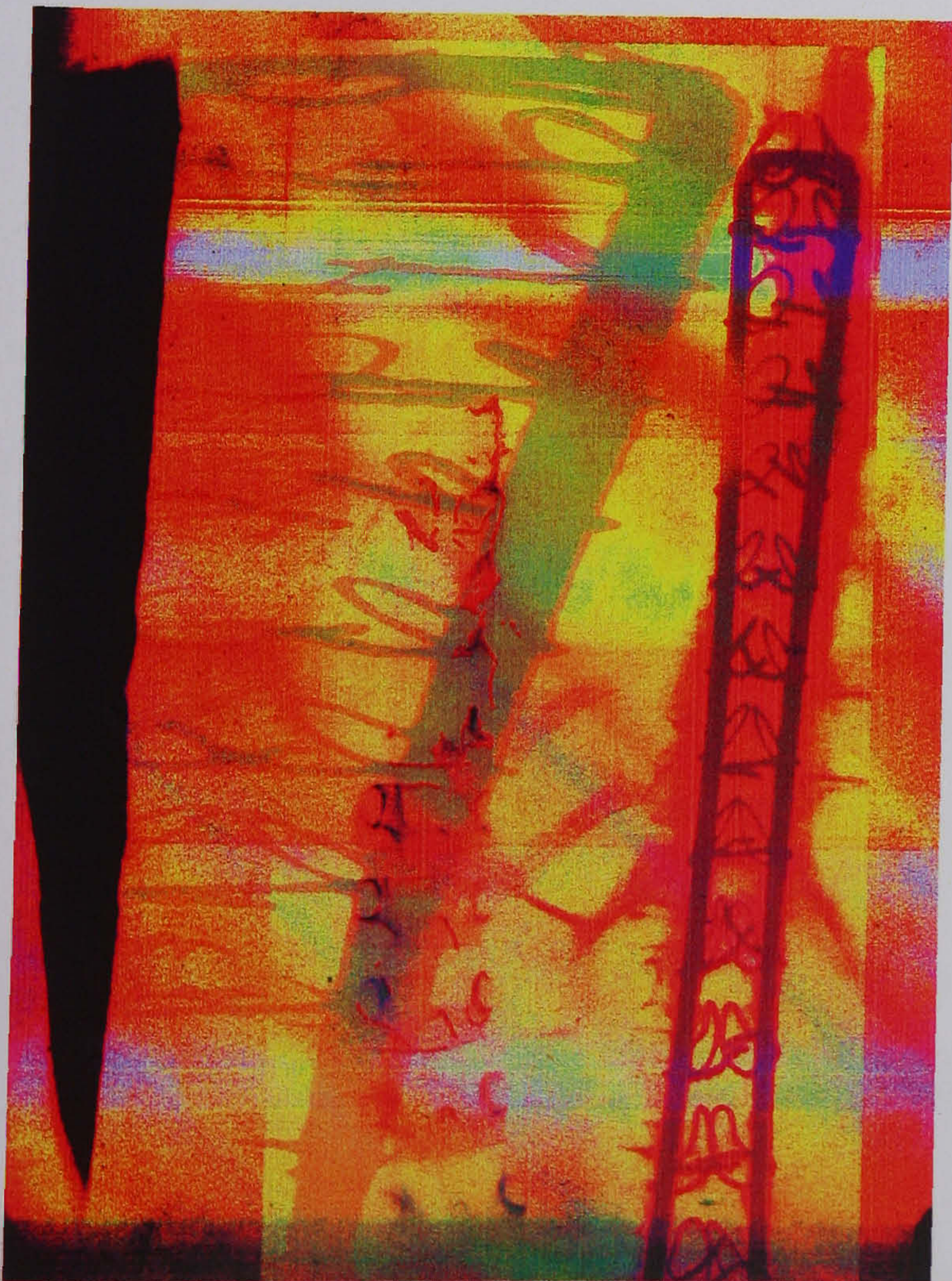


Fig 70

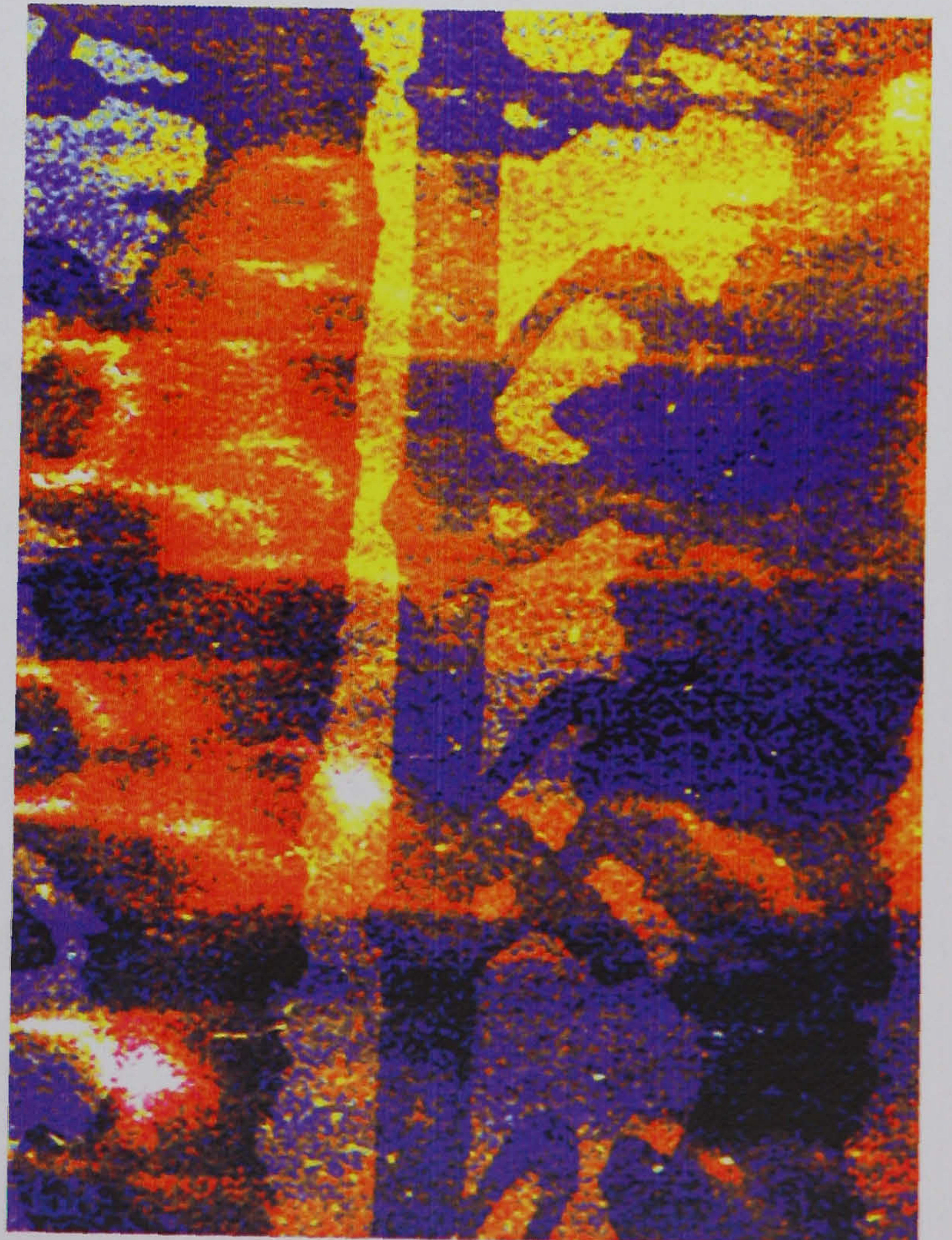


Fig 71

His focus had shifted in preparation for his third year, towards inclusiveness, youth culture and graffiti. His plans for his future after university, highlights his intuitive empathy with disaffected people, the outsider, the 'other'. He identified readily with the homeless as a marginalised group who reject society's conventions mirrored perhaps by the marginalisation of disabled people. He sets out his plans.

I went to a squat party and I got given a leaflet by this homeless person to do with art workshops. You don't get paid or nothing, it's voluntary and I was thinking about doing that. They travel the country and put illegal parties on but they have to have someone to decorate the place before they can do the party. And they have mad paintings put on the wall. I was thinking I wouldn't mind getting into that. Going around with the homeless and painting them (Rooney 2002).

### **The 'Gaze'**

It is interesting to note the different responses that Aharani and Daniel made to the issue of the 'gaze' or being looked at by other people. People with impairments endure the tyranny of unsolicited scrutiny (Shakespeare 1994; Reeve's analysis of Foucault 2002). Aharani commented 'it is something I deal with every day of my life'. In contrast Daniel had accepted it as 'a fact of life' although he had intuitively made the connection that Shakespeare cites of the male 'gaze' that rests upon women. He stated

You're aware of it. I wouldn't say everyone does but you're aware of it. But you could say that's the same as a pretty girl isn't it? They're going to be aware of people looking at them. It doesn't bother me. But they were all very sound, I'll give them that (Rooney 2002).

A response appears in Aharani's work in which, characteristically, she addresses the issue but subtly and in a way that creates a pleasing textile design. The project brief required her to design a headscarf and she selected her eyes as the subject for photographic images in which she effectively returns, to the spectator, the gaze that she so often knows is upon herself. In these photographs her eyes are veiled and partially concealed with exquisite gauzy material or beautifully patterned foliage but in ways that do not lessen the impact of the 'look' (see Fig 72, 73).

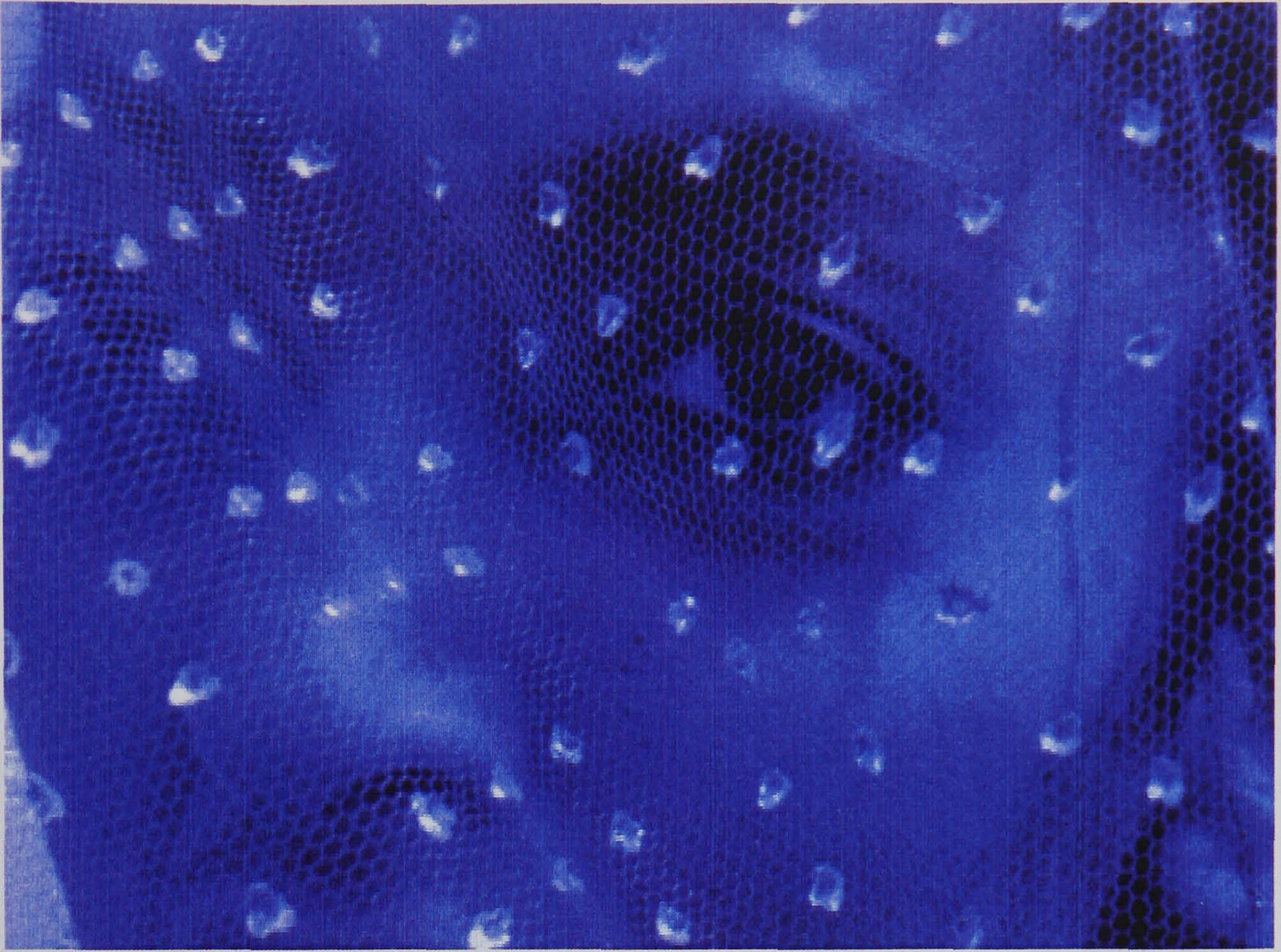


Fig 72



Fig 73



Fig 74

Her work in this respect echoes the challenge of the look returned in Fridha Kahlo's self portraits or it could be read as symbolic of the 'artist's eye'. In this representation she has control of how she is seen and the meaning that can be construed from the images of herself that she has made and presents. However, the images are not overtly about disability, although this has been incorporated into a textile design that very successfully meets the course criteria and demonstrates the potential for a mainstream commercial product (see Fig 74).

### **Ethnicity**

Ethnicity increasingly became the focus of Aharani's work and her interest shifted to exploring her 'dual' ethnicity in the context of modern popular culture. Her work grew from a self initiated project that had developed around her sense of herself as a British-born Asian who was also subject to the influences of her parents, her extended family and their cultural background. Drawing on Eastern and Western cultures she created a fusion of symbolic imagery realised as textile outcomes. Designs combined and merged iconic images such as the famous *Coca-Cola* bottle, *Barbie* dolls, money (dollar bills), Tamil writing, Buddhas and Indian goddesses (see Fig 75, 76, 77, 78). The colours reflected the red, white and blue that characterises America and Britain, and the more subtle shades and decorative qualities of the textile legacy of Sri Lanka. Aharani had quickly understood that she could use elements of her mixed cultural background very successfully from a design point of view and that IT, the Internet and digital printing straight onto cloth made a career as a textile designer realisable. Her work was a manifestation of her self-identity that was also expressed through her developing and overlapping interest in fashion and what she wore. Throughout her arts education this new sense of herself has emerged and she has discovered a resonance in the popular culture of mainstream East-meets-West fashion.

### **Summary**

Ultimately, the partnership arrangements between Hereward College and Bretton Hall that provided an area of good practice in the visual arts education of students with high-level support requirements has not endured. Critically further funding bids to support the initiative were rejected and an appeal by the two institutions to the Higher Education Funding Council to continue and develop the partnership arrangements failed.





Fig 75



Fig 76a



Fig 76b

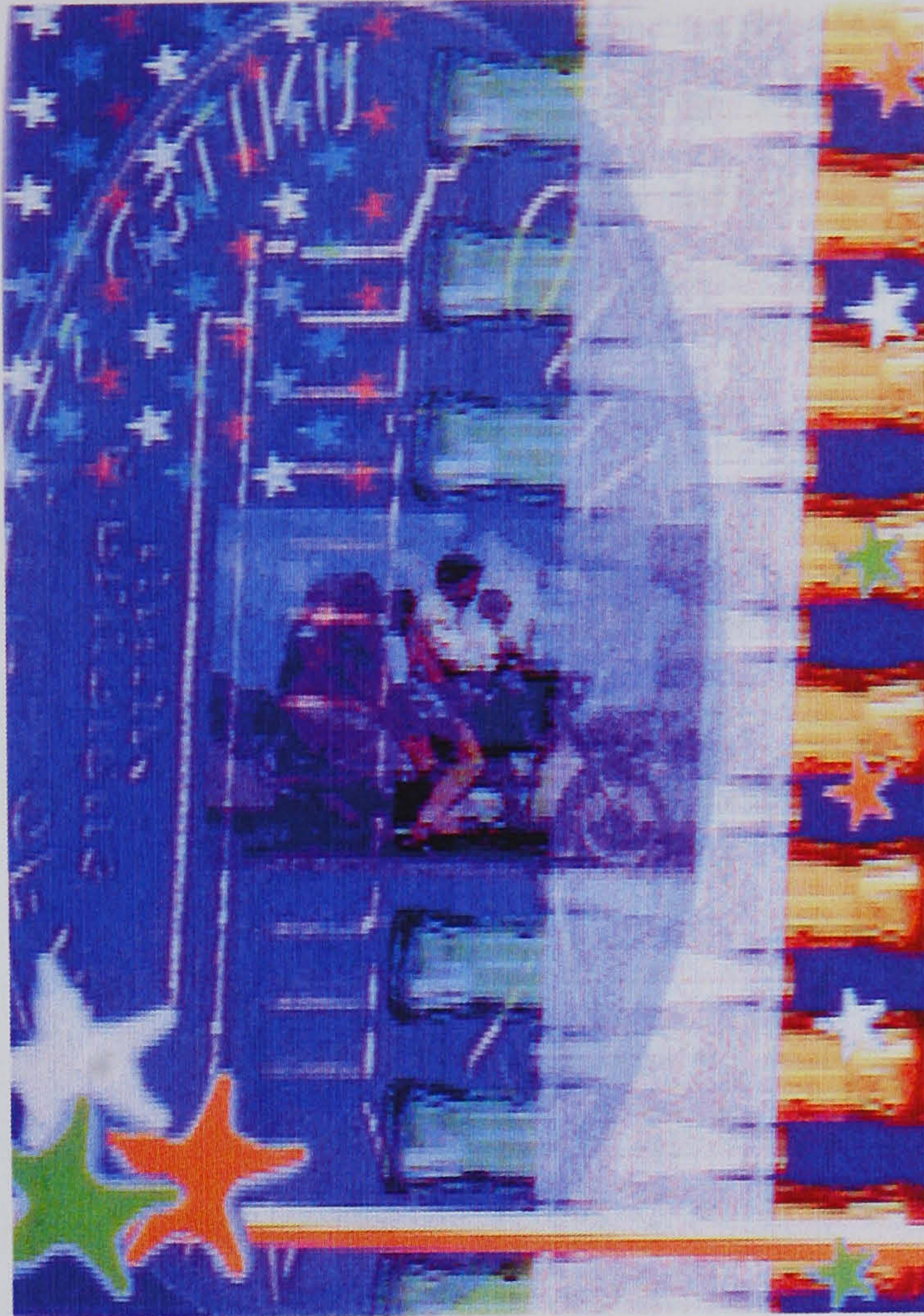


Fig 77



Fig 78

The individual goodwill that had launched the project and supported those students who did achieve was not sustainable over the longer term without specific financial support. The merger of Bretton Hall with Leeds University resulted in a change in the senior management who had instigated and promoted the partnership arrangements. As a consequence, Hereward College students came under the same standard arrangements that the university has in place for all disabled students and the notion of a seamless transition was lost.

The FEDA report, (*Preparing Students for Transition from Further Education to Higher Education 1998/99*) states that where transition is most successful, the most important factors are collaboration between and within the sectors, and collaboration between individual further and higher education institutions (p.53). The report also suggests that:

non completion is an important factor but the “whole” experience of those disabled students who survive higher education must be considered, as again anecdotal evidence suggests that the barriers disabled students face on entering a university raise a whole range of issues (p.36).

This chapter has outlined the difficulties that can arise for disabled students in making the transition to higher education, both through the generalised accounts collected from a number of Hereward students as part of the college Widening Participation initiative, and specifically, and in relation to arts education, through a detailed account of the experiences of two students at the same university. The latter is characterised by the myriad nature of the difficulties that arose for reasons as varied as financial organisation, personal care, institutional circumstances, communication, understanding of the HE ethos and individual personality and family background. Clearly there are issues that are common to all young people making the transition to HE, however, these accounts highlight the additional difficulties that disabled students can face and that, in their resolution, can give rise to delays and fragmentation of the learning experience that they can ill afford.

That disabled students, whatever their support requirements, should benefit from higher education is recognised in the DDA which should undoubtedly create more opportunities for disabled arts students to gain the qualifications needed to place

them in mainstream professional contexts. Aharani, who has successfully completed her textile degree is currently teaching part time at Hereward College, having completed the first stage of a City and Guilds 730 teaching qualification. Not only does she make an important contribution to delivery of the arts curriculum but provides a significant role model for other disabled students who aspire to teach.

This chapter has examined the circumstances that disabled students experience as they seek to achieve professional qualifications. It is followed by the final case study chapter based on the accounts of three young disabled people who have achieved this status, through the completion of their formal arts education, and who are now practising as professional artists.

## Chapter Ten

### **Three Artists: the effects and effectiveness of visual arts education.**

This chapter completes the case studies and also represents the culmination of the formal arts education process that I have been tracing. The three ex-students interviewed for this chapter have completed their degree courses and postgraduate studies. All three are now working as artists, showing work in public spaces and carrying out workshops and residencies. Their accounts have a more mature, reflective quality than those in the previous chapters, and all three are more able to make connections between the ways in which their artwork expresses their self identity and addresses issues of impairment and disability. These three individuals are able to look retrospectively, and from an informed position, at their experiences of schooling, the medical profession, the attitudes and actions of other people and the part that these have played in their understanding of the social construction of disability. All, via their arts education, have achieved the skills and competencies of a visual language at a level that gives them a presence within both Disability Arts and mainstream agendas, and, through the medium of visual images, the resolution of a 'way of being' that has empowered them.

Although no hard theory about artistic development and disability can be formulated, commonalties in experience and outcome can be traced. Paine (2000) maintains that although family background and educational opportunity seem to offer insufficient explanation for the development of 'strong artistic fluency', it is mediated by the effects of 'gender, cultural and social background, family life styles, parental involvement with art, physique, personality, education, development [and] professional objectives' (p.141). She rightly asserts that it is difficult in any case to distinguish 'cause from effect', however, for the students in this study, impairment and disability constitute additional and primary factors in the development of their artistic identity (p.2).

### **Earliest Recollections and Family Influence**

Eddy and Colin were both born with their impairment whereas Ruth acquired hers at the age of 15 when she first became ill with diabetes. However, it was not until the age of 32 that she had to accommodate, as an adult, the impact of her impairment as it became apparent and the social status implications of disability. As a mature student her account begins with her experience of managing an acquired, hidden,

sensory impairment that, whilst avoiding the attention that Colin and Eddy's more overt impairments have always attracted, nevertheless has implications, in terms of social interaction, that are less readily understood. These and her educational experiences in further education and university are described later.

The influence of others in identity formation and self esteem has already been stressed in this study (Cooley 1964; Thomas 1999a; Reeve 2002, Lenney and Sercombe 2002) and both Eddy and Colin also identified class distinctions as significantly influencing their early understanding of disability. After the death of his mother when he was 4, Eddy grew up in an exclusively male environment as the youngest of 5 boys. He recalls

I was from a very basic working class family and I wasn't molly coddled. My Dad brought me up just the same as my brothers. I was treated exactly the same. I got no special favours. If I misbehaved I would get a belt just the same as the others (Hardy 2002).

In this sense he was inculcated into conventional notions of working class masculinity defined as 'competitive, strong, aggressive, independent [and] stoic' (Collins and Sandell 1996:71). He resisted proactively and aggressively, public perceptions that often intertwine the experience of disability and gender negatively, seeing the disabled male as 'weak, pitiful, passive and dependent'. 'Studies are demonstrating that self esteem plummets in relation to the degree to which man or boy fails to conform to the perceived norm' (p.72). Eddy states

I didn't see myself as a disabled person. I suppose I had it in my head that one day I would wake up and not be disabled. Disabled, was part of childhood and then you grew up and became [non-disabled] because I never saw any disabled adults when I lived at home. There was nobody on the telly apart from *Ironsides* maybe. So I hadn't kind of thought of it in disability terms. I didn't actually see myself as a disabled person at all. I ignored the chair (Hardy 2002).

Gradually, however, he learnt about his 'disabled' status. Primarily from outside his home through the attitudes of others towards him and certainly through the 'gaze'

that he experienced as a constant in the same way that Aharani describes in the previous chapter (Shakespeare 1994; Reeve's analysis of Foucault 2002). He stated

not just in terms of people staring at you but you'd be going up the road and there'd be someone coming down the road with their kids and they'd cross the road until you went past and then they'd cross back again. Little things like that. Right from an early age people stared at me, you were constantly stared at and it was usually my Dad they spoke to. They wouldn't speak to me directly. When you went into a place, it still happens, everyone, kind of looks at you (Hardy 2002).

His resistance was active and he used to attack. 'I used to get into fights because a lot of the kids in the street used to call me 'spastic' or 'cripple' and I learnt to fight'. In contrast, Colin summarised his family background as 'typical English middle class; my parents were church goers and all that sort of thing'. Certainly, Colin's impairment resulted in physical characteristics which influenced the type of activities that he could engage in. Although he describes his parents as forward thinking, encouraging him to integrate with the other children in the street, he reflected that he felt protected at home, describing it as a 'cocooned environment'. As an only child with both parents at work, he spent a lot of time with his grandparents. His grandfather bought him sketchbooks from when he was very young and he describes how this, and his impairment, influenced his interest in the visual arts.

I sort of picked drawing up that way really. When I was growing up my parents' and grandparents' [attitudes] were kind of, well you've got to make the best of what you've got. I think they were concerned about what I was going to do when I grew up and then I started drawing (Marsh 2002).

Eddy's earliest recollections relate to the intensity of his drawing activities. He recalls the 'reams and reams' of old computer paper that his father would bring home, that he would fill with his drawings and when he had exhausted that, drawing on any old envelopes and scraps that he could find. Paine (2000) suggests that

Many individuals who show exceptional skill in artistic creation do seem to have been empowered from the beginning, as though (and according to the most enduring popular notion) they have been specially selected and equipped prior to birth (p.1).

The prestige that their creative achievements generated, raised the self esteem of both Colin and Eddy. Eddy recalled that 'it was always seen that I was quite gifted at art' by family and friends, and Colin remembered that his artwork, entered at Summer Festivals by his father, was regarded as 'really good'. Paine's (2000) remarks on these effects are doubly important in the context of disability.

It is easy to see how the first experience of feeling talented and admired can have such a strong effect upon self image and can generate artistic ambition (p.146).

Colin's recollection of the significance of this to him however, is more pragmatic than passionate.

I don't think it was like a bolt of lightning – I'm going to be an artist. You think, well, I enjoy drawing, and then you get to a certain age and think, what am I going to do? I suppose when I got to about 14, it was the turning point really (Marsh 2002).

### **Experiences of the Medical Profession**

With maturity the three individuals interviewed for this chapter were able to reflect on their experiences of the medical profession and comment on the negative effects that these had had on them (Gilson and Depoy 2000). Ruth's comments highlight not only the insensitivity of the medical profession but her fears about the implications of her impairment, giving substance to Humphrey's (1994) assertion, concerning the Disability Movement's exhortation to 'celebrate the difference', that 'nobody wants to lose a sense or a faculty' (p.66).

It was clear that it was going to affect my life and I have a vivid memory of an horrendously out of date book that they gave me which absolutely terrified me. It was the way it was written. It really



frightened me. I was only 15, but they put me in an adult ward, which was quite a scary thing (Pejcic 2002).

It was at the age of 32 that she began to lose her eyesight.

One minute it was OK and then all of a sudden it wasn't. I was told I had a very aggressive eye disease. Basically I woke up one morning and I couldn't see out of my right eye. It really frightened me. It turned out I'd had a haemorrhage and my retina had detached. I went through a stage of being scared to open my eyes in the morning in case I couldn't see. Then I realised I'd got to stop it. I'd got to stop being like that (pejcic 2002).

Medical professionals eroded Eddy's self esteem more insidiously. Their unquestionable power negated his rights, and he was given no option other than to collude, unwittingly, in the sense of his own inferiority and the positioning of himself as powerless.

I'd go into a room and they'd say, "here's the Spina Bifida" and they'd call you by your medical name and that's how you were labelled. I've got a scar on my head and whenever I went to see a doctor, the first thing they would do was they'd check my head [for a valve] without asking me, then they'd say, "have you got one?" And I'd say, "no". But I had the scar on my head because I'd had one put in and taken out again because I never needed it. And so they were doing all this kind of stuff without bothering to ask me about things.

I would be in a hospital bed, and the doctors would come in, they wouldn't ask your permission or anything, they'd whip back the sheets, male and female doctors in front of you, and there you are naked and you might be 12/13 years old. They'd turn you over, pointing at you, prodding at you and showing the students just like a piece of meat. At the time it didn't have that much effect on me, it was kind of what happened. It was only afterwards when I became politicised that I realised how badly I'd been treated in the past because at the time it just seemed like that's the way things were (Hardy 2002).

Colin had similar memories of being 'inspected' by the medical profession when he was young which he realised in a painting that was produced post graduation. This shows him laid-out on a table with an unidentified female wearing black gloves, standing over him with a knife and fork (see Fig 79). Her role is ambivalent and we are unclear whether her intention is to carry out an operation on him or eat him! Colin explains

My work takes cinematic references. I saw Peter Greenaway's, *The Cook, The Thief, His Wife and Her Lover*, also Da Vinci's, *The Last Supper* which is biblical and rich. It made me think about lying on a table, not cooked, but lying on a table being looked at, being inspected. What that was like, having people look at me and say, "this is an arthrogyrosis". And lying there as a kid going, I want to play with my cars now, I don't want to be here, this is a bit boring. It never really upset me as a kid. I never thought why are they all staring at me? I just thought it was really boring. It was only when I got older I thought, is that really necessary or not? I don't particularly think it's good for anybody (Marsh 2002).

Elliot (1999) describes this dislocation of the disabled body from the 'self' in a process which excludes the disabled person's own comprehension of his/her state, as a consequence of modern medicine choosing to see the human body as 'a vast, elaborate and sometimes mysterious machine'. Implicit is the notion that only the expert can respond with confidence (cited in Scully 2002:49).

### **Special School Experiences**

Eddy and Colin's schooling was in special schools although at different times. Eddy's experiences were of segregation in the late 1970s, whilst Colin experienced the integration initiatives of the late 1980s. Ruth, as a non disabled child, attended mainstream education and she felt strongly that her early mainstream experiences had been of particular significance in equipping her for the experience of disability.

It definitely makes a difference, knowing both sides. I consider myself fortunate that I've got the skills that I acquired in mainstream education that enable me to cope, not necessarily 100%, but cope better with what happens (Pejcic 2002).



Fig 79

Eddy's recollections reflect the devalued social role and low expectations associated with special schools that Barnes (1991) and Barnes *et al* (1999) highlight. Eddy attended the same special school, as is still the experience of many disabled children, from nursery through to 16 years of age. He remembers querying why he could not go to his brother's school and realising that, 'it wasn't accessible so I couldn't go to school with my brothers, I had to go to special school and I hated it'. Segregated from his brothers and non disabled peers, and as he increasingly absorbed the stigma attached to disability, Eddy's response was to distance himself from it. 'I thought I don't want to be around here with all these cripples' (Burns 1992; Middleton 1999).

From the comparisons that he made with the curriculum that his brothers were following, he was soon led to the belief that his was a second-class, less demanding educational experience and his disaffection turned into intransigence.

I remember we were doing a form of algebra, but it was very, very basic. I was about 12 years old and one of my brothers said, 'we did that in school when I was 9'. And I suddenly realised that the standard of education was lower and because of this I reacted in a way, I played truant from school. I wasn't interested any more and I got into all sorts of problems (Hardy 2002).

Although Colin experienced the same continuum of special school provision, the later period of his education gave him opportunities to take qualifications and also to attend mainstream school. As an only child he did not have a point of comparison or competition with any siblings and was therefore comfortable and happy to be with his friends in a special school environment. It was his experience of periods of integration into the local mainstream school that he found disquieting as he tried to cope with the expectation that he could function seamlessly in both areas of provision.

I think the authorities were just getting to grips with integration and so it was like being a stranger in town really, after being at Sherbourne [special school] since I was 3. And it was the shock of it. You were going there for one lesson and leaving in a mini bus and going back to school so I felt really sort of excluded, it didn't really feel inclusive.

Some [of the other children] I got on with really well and some I just felt intimidated by really. I mean I'd tried. When I was growing up I did things like cubs and scouts and stuff and my parents were quite switched on to the fact that I'd have to be in the big wide world eventually. I wasn't intimidated because they could walk and I couldn't. I think it was just the fact that they'd all grown up with each other and I hadn't grown up with any people there and I just couldn't relate to them at all. I never really got to grips with it, so I quit before my GCSE classes started (Marsh 2002).

This study has highlighted the historical status of art education in special schools as largely a leisure/therapeutic activity. Eddy's perception of how art was regarded in his special school and by implication how this reflected on his skills, is particularly negative at this time. 'The art class was there for kids that were no good at anything else, that's what it was seen as. I was still seen as very good at art which obviously meant that I wasn't much good at anything else'. Paine reflects on the fragility of artistic development and the fact that 'self image and individuality can be sacrificed or wasted at any stage, through inflexible, inappropriate, untimely or inadequate support' (p.4). This negativity was redeemed, for Eddy, by his encounter, for a period of time, with a positive and encouraging art teacher (Robinson 1982, DfEE Report 1999). However his self esteem was raised more significantly by a commission that he carried out when he was in hospital. For this, he reproduced a black and white image of a tiger on a large piece of scraper board which generated much praise and, at that time, the impressive sum of £35.

Berlin (1949) is cited in Paine (2000) as stating, 'the circumstances, more than the individual, bring about development as an artist' (p.17). Certainly Eddy's conviction that 'he wasn't much good at anything else' came at the point, which Paine describes as the 'impasse of adolescent inhibition in drawing', when there is a tendency to 'deflect their energy into other activities where their performance at the time seems stronger'. The 'scraper board tiger', shown to his careers officer by his father, at this time, was pivotal in that it raised Eddy's self esteem and determined the future direction of his studies.

Colin's struggle focused more specifically with resolving effective ways of producing his artwork with his particular physicality. There had always been a dichotomy

between being in his electric wheelchair and moving around on the floor, and initially, between using his hands and using his mouth to draw and this was compounded by the authoritative 'expertise' of the special school. He described how

a floor is freedom for me, the chair confines me in certain respects because it doesn't allow me to move around without a machine (Marsh 2002).

Colin initially drew with his hands. He described the transition to using his mouth, and his initial reluctance to tell them about his new way of drawing.

Well I used to draw with my hands until I was 13. I used to have a tray on my wheelchair. When I was at home I used to draw on my side [on the floor] and draw with my hands but then I got to the stage where I couldn't see what I was doing very well. So I thought, no, this isn't working. And it began sort of getting where I could only draw for limited periods of time and limited sizes of things and they were sort of saying, "well if you are going to do your GCSEs that way you may have to give it up". I thought I don't want to, I always enjoyed being in the art room, so I just experimented at home. I knew when I ate, I ate on the floor and I could feed myself and I've always been able to do that. I thought well if I can eat custard without getting it everywhere then maybe I'd be able to put a pencil in my mouth and start to draw that way and it just came within weeks. But I didn't tell anyone for about a year. When I put homework in I didn't tell them I'd written or drawn it with my mouth. They started noticing the difference because when I was drawing in my wheelchair with my hands then it wasn't so good so they said "what are you doing differently?" Then I told them (Marsh 2002).

Colin's reason for secrecy and resistance was his perception of the culture in special schools. This is in line with Salford and Salford's (1996) claim that throughout history non disabled people have been convinced that they undoubtedly understand the nature of impairment and how best to respond to it (p.2).

You're sort of taught, this is how you will sit in the wheelchair and you'll sit up straight, this is what it is and you won't move out of it apart from swimming and physiotherapy and all that. I thought they might think it was a bad idea for me to do it that way because I'd be losing the strength that I had in my arms so I just didn't tell them for a while (Marsh 2002).

This element of quiet defensiveness about painting with his mouth remains.

I still have a point to prove about painting with my mouth, that I want it to look good and in a way I need to show some technical excellence (Marsh 2002).

### **Hereward College**

Eddy started at Hereward College in the early 1980s at the beginning of a slow transition in the college's culture, away from old systems based on the medical model towards a social model approach. The art curriculum was in a similarly transitory stage although Eddy's initial experiences were of the 'soft' approach that characterised so many young disabled people's experiences of art education.

When I first got [to Hereward College] there was an art teacher and he was a lovely guy and a lot of the time when I had art I was kind of copying pictures and that's kind of what it was (Hardy 2002).

The changes at the college brought about development in the curriculum which presented Eddy with new challenges. He had to balance the prestige of doing advanced study with the demands posed by the new rigorous approach. In addition he had to address the threat that this posed to the values that he had long held about art, and that he had been able to rely on for self esteem and status.

For the first time I'm doing an A level which is quite a thing for me because I'm doing similar things to what my brothers did. I was working more intensively and we were doing stuff that was a lot different. I was working with other people who were also quite a high standard as well. I'd always been the best one in the class so most of the time I didn't really think about what I was doing because what I

was doing was pretty good anyway, but at A-level you did start to have to analyse what you were doing. I had a fixed view of what art was about which I needed to have bashed out of me (Hardy 2002).

The 'fixed view' that Eddy is referring to is that which Chalmers (1996) describes as middle class notions of 'good art' wherein technique takes priority over content and a narrowly conceived form of representation takes precedence over creative expression. Eddy could demonstrate conventional technique and draughtsmanship with some facility and this had always been instrumental in gaining him prestige. The need to develop new creative ideas and concepts was threatening to the fundamental perception that he had of himself as being 'the one that was good at art.'

I think my idea was that I could draw things and make them look like them. It was almost like I had an obsession. I *had* to make it look like a photograph. When something looked realistic, that's what it was about. It was trying to reproduce reality in a photographic sense. When I looked at somebody like Picasso I couldn't get my head around that. I'd kind of been brought up, [to accept the popular media myth] and they tell you that this [contemporary art] is a waste of money or you can't understand it. You get told that it's a mysterious thing and therefore you think it's rubbish. But while I was on the A-level I started looking at other stuff and becoming more interested (Hardy 2002).

Progression to Foundation Course studies challenged Eddy with a level of serious critical appraisal that he had not encountered before although Colin, whose education in special school was at a later date, had received what he describes as his 'wake-up' call from what had been a somnolent leisure activity.

My first art teacher had been the art teacher there for many years. I don't think we were really properly taught. That sounds a bit controversial but I think it was still a leisure activity even up to when we started our GCSEs. Then a teacher took over who was teaching graphic design at Coventry University and had taught on Foundation courses and so on and so that was our first big sort of wake-up. We



liked it as a leisure activity, we were a bit sort of smug about it and she would say, “well actually I don’t like that”, or “you could draw that better”. And it was like, oh my god, this is a proper teacher. It all started getting a bit serious then and that’s really the first time that I thought this could be something that I really want to do and not just something that I like doing (Marsh 2002).

Eddy describes the somewhat more aggressive interaction that took place between his Foundation course tutor and himself but which he felt at home with, perhaps in the context of his working class background and identification with a more direct, conventionally masculine approach.

Charlie would come in and say, “What are you trying to do? That’s rubbish”. And I could react to that. I loved that because I was aggressive back and at the end of it all, that was what I needed because it was something that I could understand. The thing was that when he said “that’s rubbish” he justified it. It wasn’t just that he came up and said “that’s rubbish” and walked away. It was not that, but it was constructive criticism. I think that it was what I had always wanted. And I didn’t want people saying “that’s nice”. I did want to be pushed, secretly. It made me really think and try to justify what I was doing. And it was difficult because sometimes I’d get different messages [from tutors] and they’d conflict, but that’s kind of the beauty of it really. But what it really did was fire me up in terms of my passion for art. It gave me an intensity about working that I’d never had before (Hardy 2002).

Colin’s first year at the college was dominated by the development and refinement of the practical activities of the visual arts and ensuring that he had ownership of the working process through independence in working methods. This was achieved through maximising freedom of movement and effectiveness of enabling support. His exhilaration with the sense of empowerment that this autonomy gave him is evident.

I originally just started painting with brushes in my mouth and then when I started being in my chair a lot more, physiotherapy made some special grips, mouth moulded things so that the brush wouldn’t move

around in my mouth. I used extensions, [the brush attached to long, light weight sticks] so that I could reach further.

I remember one afternoon Charlie [the tutor] spent the whole afternoon with me. He said, "right this is how you set your palette up. This is the first and only time I'll do this, after this you get other people to do this for you. I'll show you how to set your studio up and this is what you do and then you're going to paint". It was really good. I was painting on the little easel attached to my wheelchair, so we did small sheets and stuck them together to make a big painting. It's no longer a leisure thing. Things were happening, this sort of magical thing that goes on. I wanted to do it more (Marsh 2002).

For many people who paint with their mouths, technique dominates perceptions about their art, and attention focuses on *how* the work is carried out rather than its content. The Association of Foot and Mouth Painting Artists is a world-wide organisation of 500 members that organises exhibitions selling original artwork and producing work for greetings cards and calendars. The association considers itself to be 'an extended international family' that aims to promote 'artistic development' and 'a large degree of financial independence' (Association of Foot and Mouth Painting Artists 2004). The patronage is not something that Colin finds acceptable. In this he differs from Tom Yendell, one of the subjects of Marc Quinn's series of sculptures of people without limbs, who also paints with his mouth and runs a gallery for the Association of Foot and Mouth Painting Artists in Hampshire. Tom had had a mainstream arts education which he considered he had been fortunate in gaining, however his comments about his current artwork locate him firmly within the context of therapy and handicraft that has traditionally characterised disabled people's creative activity (Humphries and Gordon 1992). He stated in conversation with Marc Quinn

In one way that is why I am really lucky, because ... I had a formal training in art, where a lot of our artists don't get that, because they get their disabilities later on in life. For example, they break their necks or get ill, and they take up art as a hobby to start with.

It is very boring. I paint a lot on silk, and it's definitely for the commercial market, for birthday cards and Christmas cards. I tend to try to do things that are a little bit livelier than the other artists, who tend to stick to landscapes and robins on snow covered branches, and snow scenes. I try to do things that are a bit more colourful and brighter (Celant. 2000:188).

Colin's view raises an interesting comparison between Tom's educational experience of the arts in a mainstream setting, and his experiences that had been informed from a Disability Arts perspective. He states

What put me off is when you get the Christmas cards, you get these little labels which say, "these cards were lovingly made by people with their mouths" – it's that sort of text. I want to be a good artist because I'm good at it not because I'm categorised. I wanted to steer away from that (Marsh 2002).

Ruth clearly perceived the environment at Hereward College as a respite from her struggle with people not understanding her difficulties. She perceived the college as being 'separate' and apart from the mainstream environment and described her progression from Hereward to university as 'going back outside' and 'seeing what everybody else was doing'. Revealed in these comments are deeply rooted notions of institutionalised provision in which the 'other' is confined in 'invisible spaces' (Hughes 2002). Her concern about trying to evaluate her own impairment in comparison to others was an enduring preoccupation.

I came here and it was like a breathing space really. It allowed me to feel safe with other people who had difficulties and to know that people knew I'd got them. If I'm honest I still found it difficult because I didn't feel as if I was as obviously disabled as a lot of the people that were there. That's another issue because some people's disabilities are very "in your face" and you don't need to ask, I was aware of that feeling, but I still felt safer (Pejcic 2002).

### Artwork and Self Identity

The fact that Ruth's impairments are hidden has been, and continues to be of considerable concern to her in terms of how she is perceived by other people. The impact on the establishment and maintenance of social networks as one of the less obvious implications of a visual impairment particularly when it is partial, have posed additional problems for Ruth. Cooley (1964) emphasises the part that the opinion of others has in the construction of self and the part that social communication plays in the processes of comparison and evaluation whereby we locate ourselves socially in terms of identity and status. Disabled people face a de-humanising struggle to overcome other people's perceptions of their impairment and this is made more difficult for Ruth because there are times when her impairment limits her responses in terms of social conventions (Lenney and Sercombe 2002).

I sometimes feel that it looks like I'm making things up or people don't understand what I go through every single day. I mean it sounds a bit like paranoia but I am aware that until somebody gets to know me over a long time, why should they take it at face value when I am saying, "it's been this, this, this". [and they think]"well, you look fitter than me!"

I'm constantly missing people and I don't smile at them or make eye contact. Or I stare at them. It seems a stare to me, because it's longer than most people would do. I've said to friends, "some people must think I'm really ignorant". And I'll make a point of saying, "oh, I'm sorry I didn't see you there". They could be standing beside me in the lift but what people don't realise is that you use your peripheral vision a tremendous amount. If you go in a lift you might see someone out of the corner of your eye and say, "oh, hi!" I could be standing in the lift with someone I knew and I haven't even acknowledged they're there. And to say, "I'm sorry I didn't realise you were there", sounds a bit feeble but it's true.

And then the other issue is at what point do you tell people? If you tell them straight away then you both know where you stand, but it sounds like a load of rubbish because I look fine – I haven't got a stick and I don't wear glasses. That's another thing people say, "oh you don't

wear glasses". The thing that's wrong with my eye has got nothing to do with a lens. It takes a long time to understand, so when I say "I'm partially sighted", and they see no glasses, no stick, no dog and I don't go feeling my way around the room, then it's just like, "yeah I can't read a book without glasses, it's the same thing". So you can only acquire understanding through knowing people for a long time and then, I've got to be honest, I still think that several people don't really understand. I sometimes think I should take them with me when I go to the hospital because I've got four files now, with all the different complications that have arisen from my diabetes and other medical problems. And take them [with me] when I go to the chemist and they give me a carrier bag of drugs, because nobody sees these things and it's like look, see, it really does exist (Pejcic 2002).

As part of her course work and for the first time, Ruth started to make images related to her impairment. She commented, 'I think that was the start of looking at the way people see you and what they assume from what they see'. Her imagery was, and continues to be related to the physical body with no specific visual references made which link her to the impairment, to the social implications, or to her experiences of this. She describes the first images she made at Hereward College concerning visual impairment.

I did some large pastel drawings of circles, well they were eye-balls really but they didn't have the pupil and everything (see Fig 80). They were representational so they were large circles. I looked at a healthy eye, an eye that has started to deteriorate, and one that's badly deteriorated. I did a 3D piece using latex and red paint to depict the blood vessels bleeding and there was wire in it. So it was a more tactile piece (see Fig 81) (Pejcic 2002).

She realised in retrospect that references to her social self were absent in her work. However she did recognise the cathartic potential of issue based work.

Interestingly enough, if I look back on mine there was no indication in my piece of work that I had any disability at all.



Fig 80

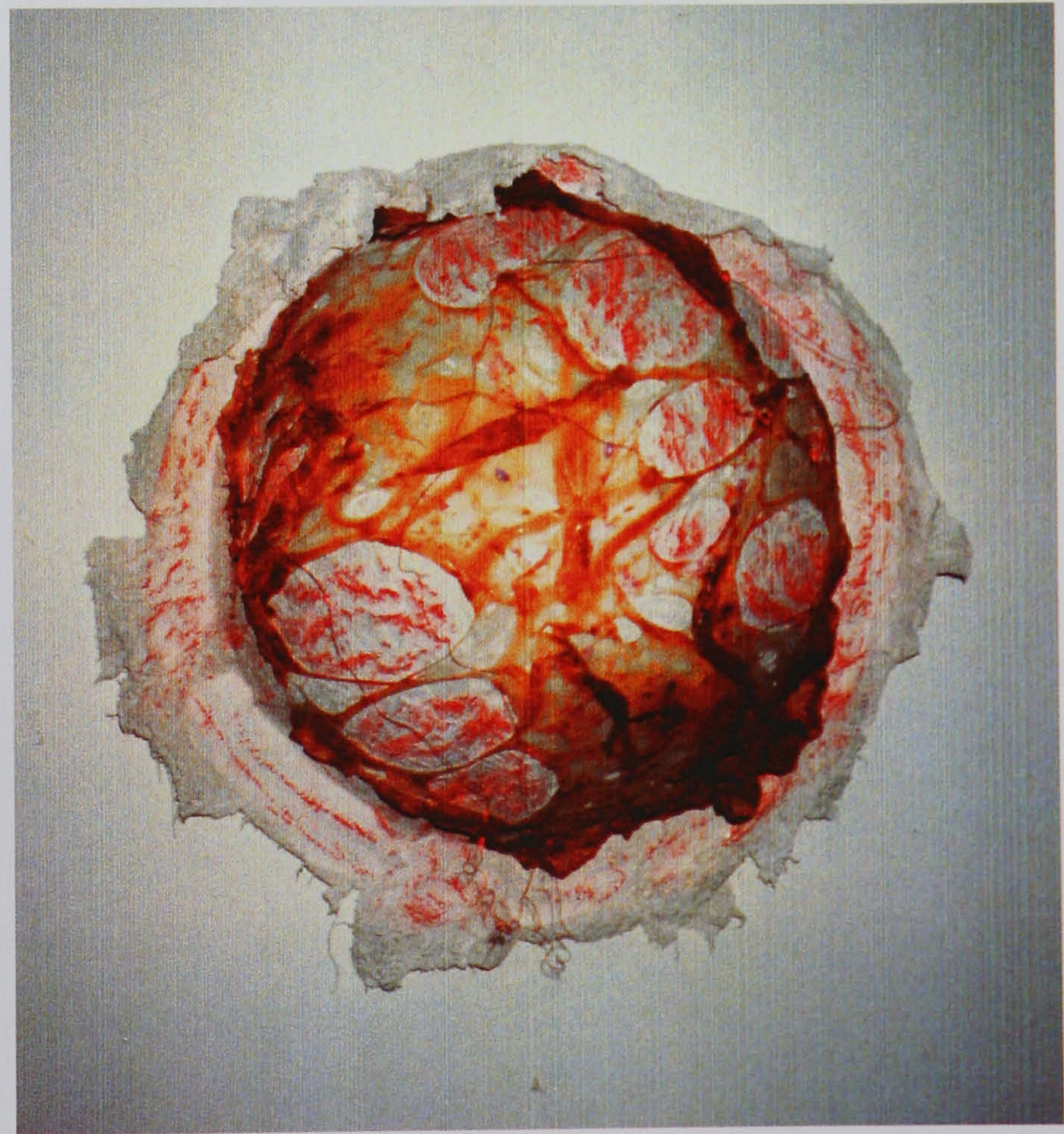


Fig 81

I've just realised that now, none at all. There were photos in my work that I had started to lose my eyesight but it wasn't obvious because of the way I'd presented it. It was there, you just couldn't see it.

Perhaps in retrospect that's why I enjoyed it so much because it was releasing things without me even realising. So it wasn't just the process, it was actually sort of almost "tipping" things out. I suppose really it was a way of telling people about things that I felt they didn't know because it represented what was going on behind the eye (Pejcic 2002).

In contrast, Eddy's struggle was with the psycho-emotional dimensions of disability and the internalised notion of the 'spoiled identity' which he didn't initially associate with disability because he knew that his impairment did not prevent him from doing the things that he wanted to do (Goffman 1963, Thomas 1999, Reeve 2002). In addition, the management and nature of his impairment posed difficulties for him in the demand that it made for constant vigilance in maintaining acceptable standards related to personal hygiene (Wendell 1996).

As a young lad I didn't particularly have an exceedingly high opinion of myself, because I'd always been fairly overweight. I would look at myself and see myself as being kind of ugly. I didn't look at myself and say, "Oh I'm disabled, I can't do that", and so it wasn't directly linked with that, it was just I didn't like myself. I let myself go in many ways and I used to get called into a room and told that actually I smelt a bit. It was very painful, because to be taken into a room and told that you smell was horrible. The moment it was ever mentioned, no matter how gently anybody did it, I knew what it was and I hated myself because I used to let this happen to myself because I hated myself and it wasn't nice.

I was drinking, gambling a lot. I was also going through a few forms of self-abuse. I used to hit myself a lot and also go out and get into bother and get hit. It was about control, about having power over my own body. A lot of reasons why I hurt myself was because I could

choose to have a swollen eye, a bruise here. It was the one thing I could control (Hardy 2002).

The self portrait project carried out as part of Foundation Course studies presented Eddy with an enormous challenge, but also with an opportunity to address the excessive negativity and denial that he was experiencing in terms of his self identity. He started to make many self-portraits, limiting his area of representation to his head or what he perceived as the only acceptable part of himself (see Fig 82, 83, 84, 85). These images grew considerably larger in scale and more dominating, as he changed the superficial aspects of his appearance – moustache, beard, hairstyle, glasses etc. The wheelchair was acceptable only when it was objectified and represented in separate drawings, often upside down or from an unusual angle, although Fig 86 represents a later, rather more conventional response.

I started to do the stuff about identity. We had a project that was to do a full-length self-portrait that I did from the chest up because that was “full-length”. I could have done a full-length self-portrait. I could read. I knew what it meant, but I didn’t and I think I didn’t because I wanted to be challenged on it. I wanted a kind of psychiatrist to kind of pick my brains because I needed it sorting, but I couldn’t do it on my own. At the time it was just my head [that was represented] and that was it. And then there was the thing about doing this wheelchair and there was no bloody way that I was going to paint a wheelchair. And then Charlie turned it upside down and said, “paint that”, and it was abstract shapes and I could do it because it was no longer a wheelchair. And I did it, and once I’d done that, I knew in a way I’d confronted this big ogre, this wheelchair.

Whenever you do a self-portrait, you’re kind of analysing who you are, your position in the world and all the rest of it. There was a time when I couldn’t go past full-length mirrors, now I was dealing with it in my work. I was starting to learn about things and disability. Very slowly, little things were starting to seep in and I had a direction. I think from then I realised this is what I want to do and that’s how it kind of started really (Hardy 2002).





Fig 82



Fig 83



Fig 84



Fig 85

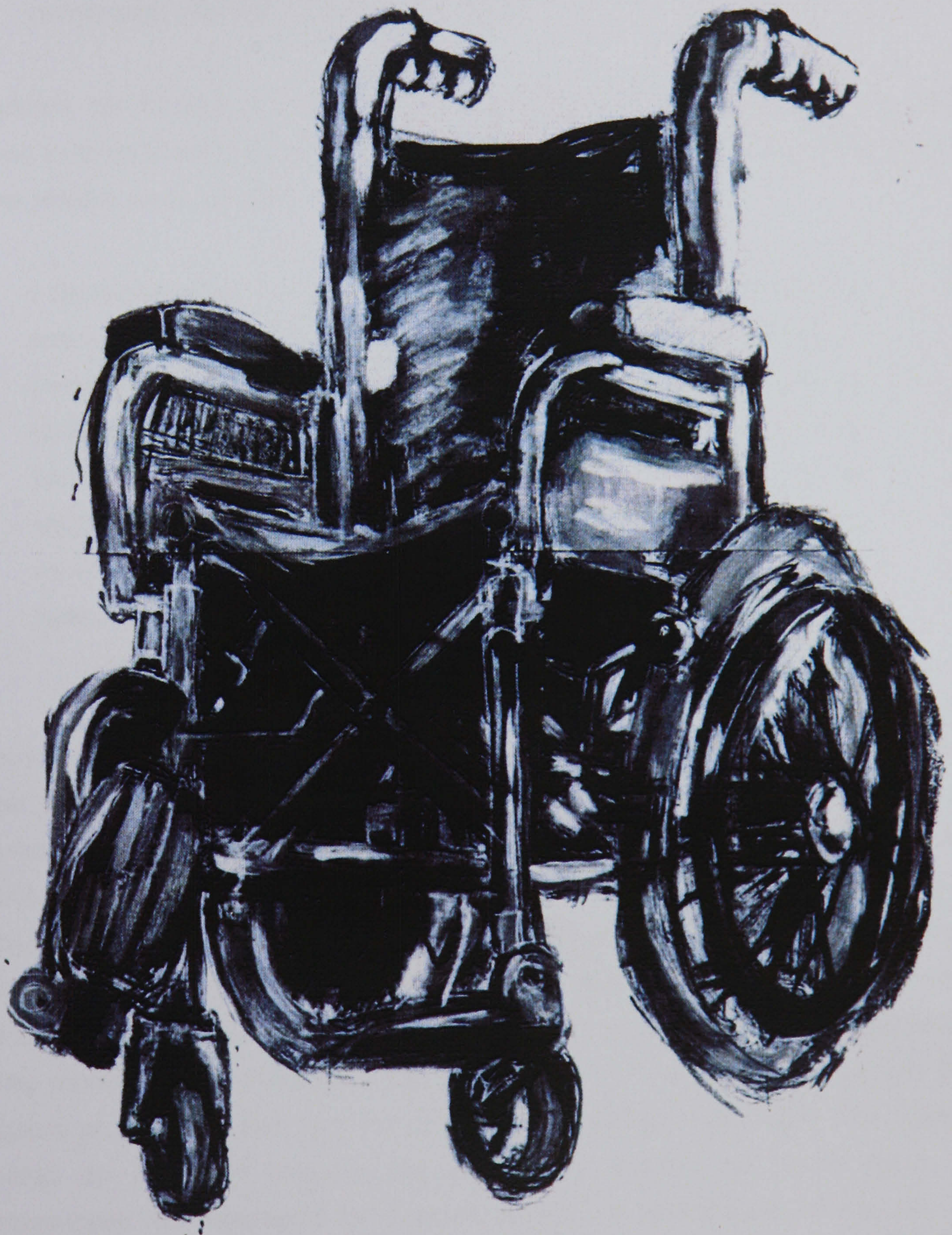


Fig 86

By the time he started at Coventry University, Eddy was depicting himself in full-length self portraits, which included his wheelchair.

I was doing hundreds of them, I was churning them out and each time I was doing it I was analysing myself and after a while I became very comfortable with who I was (Hardy 2002).

Gradually the therapeutic nature of these activities and his life as an art student began to bring about changes in how he perceived himself allowing him to develop a more positive sense of self.

I started going to Gamblers Anonymous because of my addiction and eventually I stopped drinking and I'd started to become a nicer person. I wasn't doing any of the things I used to do. I was self-harming less, so things were starting to get a bit better. I was starting to have a little bit more respect for myself. I was happier in terms of my work. I was starting to be happier in terms of who I was. I threw myself totally into my work. I used to get up in the morning, go to the studio at 8.30 and leave at 9.30 at night. I was happier all round (Hardy 2002).

### **'Coming Out'**

'Coming out', by revealing aspects of life that have traditionally been hidden, has been adopted by Disability Arts as a process of empowerment in response to oppressive images of disability (Swain and Cameron 1999, Barnes and Mercer 2003). Swain and Cameron describe 'coming out' as different, and integrating a sense of that difference into a healthy self-concept, as one of the key tasks of identity formation for the person who is oppressed (p.68). A project that was carried out at Hereward College in the autumn of 1992 had as its objectives the exploration of the representation of disability, the empowerment of those who are normally the subjects of representation, and the provision of a positive role model. The project created an ambience whereby the process of 'coming out' could occur. It demonstrated the importance for disabled students of having such experiences as part of their arts education and the impact that role models like Brian Jenkins (see chapter one), a wheelchair user and professional artist who led the project, could have. The focus was on an exploration of the self, and whilst the fact of impairment and disability was seen as important, it was not considered to be the single defining

characteristic of the students' lives and identities. Newbury (1992) who documented the project commented

Neither the work produced during this project, nor the approach used, are simply about disability. They are about exploring the role of visual imagery in the construction and reconstruction of social and cultural identity. Although because of the restrictive nature of the way they are represented disabled people may be more conscious of this construction than most, the approach has universal relevance (p.29 - 34).

One student, working directly from observations of his own body, from photographs and from x-rays of his spine that showed the scoliosis that had curved his back, created a series of powerful black and white drawings (see Fig 87, 88). These describe a fluid, organic form, reminiscent of a natural element, such as drift-wood, that has been subject to the forces of nature. Newbury, writing about the student's work, states

His comment, "my body is quite sculptural" is both a beautifully positive interpretation of the drawing's visual statement about himself as well as a reversal of the way in which society defines people with disabilities (1992:31).

This questioning, deconstruction and reconstruction of images of disability enabled the student to consider ways to represent his own body as different, but not in some way lacking.

The project had a similarly empowering effect for Colin. He describes the way this occurred. 'I took some photographs of me lying on the floor (see Fig 89), then did a huge drawing. I started experimenting with scale'. Brian Jenkins' large scale work had had a significant impact on Colin's awareness of the ways that he might represent himself and he remembered this as a 'real turning point'.

When I saw him [Brian Jenkins] in the physical space, the person himself and how small he was, I thought you are smaller than me and your drawing is on the side of a building.



Fig 87



Fig 88

I thought there's a real element there of confrontation with the spectator, and to play on that is a really powerful thing to do (Marsh 2002).

Large-scale work and the association that it has with large scale movement, domination, and being difficult to ignore, has been identified with independence, power and strength by many of the disabled students at Hereward College.

Faced with the concept of identity, Colin was presented with the challenge of considering how individuals fit into the community and social world. Woodward (1997) suggests that 'identity can be seen as the interface between subjective positions and social and cultural situations' (p.1). Colin was aware that his hands attracted the attention of others in a social context.

The first thing that they see and they [think], those hands aren't quite right are they? So I thought it was a suitable avenue to go down really. I think in a way, I'm more aware of what it was about now than I was at the time (Marsh 2002).

He began to make images of his hands in the context of his oppressive experiences of the medical profession.

I started thinking about symbols of disability and I thought I would do some work about my hands because my hands are quite symbolic of my disability. It was very personal because when I was smaller I used to get dragged into medical clinics just for student doctors to have a look at my hands because they are quite a rarity. (Newberry 1992:73) (see Fig 90, 91).

The 'revealing' of impairment empowers by giving the disabled person control of how they are seen, by whom and in what context. Green (1996) maintains that the choice of a specific aspect of identity is associated with the strongest part of experience, the characteristic that is most obvious is the one for which the individual has been 'most punished'. She describes it as 'the most assailed part of your identity, and the one most singled out by others', suggesting that 'it may also be the one, that you are most in need of exploring' (p.41).



Fig 89



Fig 90



Fig 9

It is interesting that the drive to 'come out' can surface even when no such empathetic environment exists, such is the powerful urge for some disabled young people to liberate themselves from the oppression of the 'pervasive disciplinary powers' that control and modify behaviour in the attempt to become more acceptable (Reeve's analysis of Foucault 2002). Tom Yendell, who had received a mainstream arts education that focused on formal elements (although it is evident that as part of this he had also done some research into the history of disabled people) felt compelled to stage a dramatic and empowering 'coming out' in the final part of his course. It does not appear to have been integral to, or substantiated by, his wider art work.

I had a real problem, when I was at art-college, admitting that I didn't have any arms. It was a subconscious thing, I never realised I was doing it. For instance I always wore a jacket with long sleeves and I had a mate who was a big black guy who had no arms and little flippers and he was always wearing tank tops and things and showing it. When I did my final theatre performance at college, it was a piece about a performing, theatrical freak in the 18<sup>th</sup> Century who was exactly the same as me, with no arms – the only thing that was wrong with him. Right at the beginning of this performance I had a massive pair of arms made out of foam. I had them pinned up against the scenery and I jumped out with nothing on except for a pair of Y-fronts. That was my way of 'coming out', showing all the people that had been with me for the last 3 years exactly what I looked like under my clothes. That was a big point in my life. From that moment I never had a problem. I also think that I am actually quite beautiful because I haven't got bits and pieces sticking out: I am very flat, I haven't got little fingers or anything like that. (Celant 2000:188)

The shedding of society's negative perceptions of disability along with their clothes is an empowering tactic that disabled people and other marginalised groups have used as an extreme measure that shifts the discourse from the 'struggle against self to struggling against the disabling society' (Swain and Cameron 1999:78). Eddy's preoccupation with issues of identity, impairment and disability, continued into his university education and reached a watershed when he took the radical step of painting himself as a nude.



Then I came up with an idea that I could do a nude self-portrait. I thought, “cor, that will take a bit of bottle like!” The nude image was very liberating for me. Once I’d done that, once I’d painted a 6x6 foot nude image of me with a urine bag on, I was really confident about my own identity because I couldn’t afford not to be then. I was there in all my glory. I was making no bones about things. This is me (Hardy 2002).

In this painting, reminiscent of a classical nude, Eddy reclines on a dais swathed in white drapery, returning a direct and defiant gaze to the viewer (see Fig 92). It parallels Manet’s painting of Olympia which, with a similarly defiant ‘look’, challenged the traditional averted gaze of the female nude that was intended to make men feel powerful (see Fig 93). Eddy had adopted an uncompromising stance in the portrayal of himself as nude. He had revealed his differences as a challenge and as a demand to be acknowledged.

A similar refusal to conceal or hide the body that society fears has also been employed by fat women to challenge negative perceptions. Pollard (2000) cites one such woman as stating

I am fat. Very fat. Indeed it is the first thing that people see when they meet me and very often the first thing they remark upon. I am often abused, disliked, excluded and discriminated against for this reason. ... In knowing this one thing about me – that I am fat – people hold assumptions and judgements about every aspect of me. I have received unsolicited comments on my physical and intellectual abilities, my mental health, sexual responsiveness and even my honesty. I cannot think of another issue that raises such wide-ranging and unchallenged assumptions and prejudices (Pollard p.22).

Drawing strength from solidarity, the Fat Woman’s Group arranged an exhibition of positive nude images in 1997 which were intended to celebrate ‘the incredible diversity of the human form and the manifold ways of expressing this diversity’ (p.29).



Fig 92

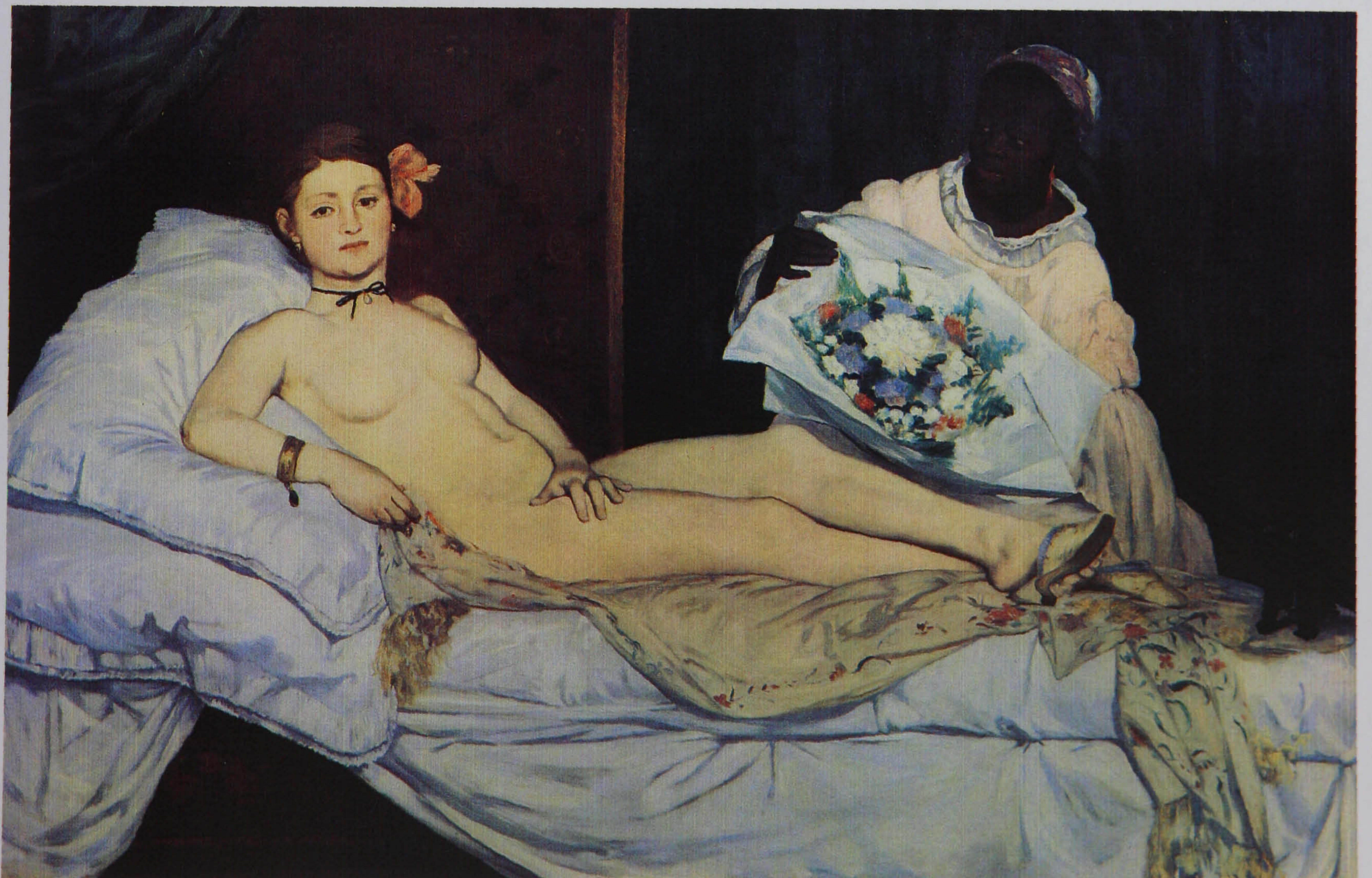


Fig 93

No such exhibition of nude images of fat people had ever been shown and Pollard's comments about the representation of fat women also clearly mirrors disabled people's experiences of representation (Morris 1991), although Pollard states 'ridicule is more likely to be evoked than pity'.

The images of fat people that I usually see are stereotypes. I rarely see fat woman advertising fashion or anything else. When I see a fat woman in the media, it is usually an item about dieting or in some way they are being ridiculed. There are very few fat women in the media ... for the most part I can go through my life seeing no positive reflections of myself as a fat woman (pp.35-36).

However, such bold statements do not always bring a positive response from the audience. On the contrary, confrontation with images that challenge conventional perceptions of what constitutes a functioning body in terms of appearance, body control and physical strength and fitness, produces common responses that include shock, outrage, anxiety, fear and insistence that the image is removed. Eddy enjoyed the controversy and media coverage that his nude images, which he intended should shock and challenge, generated when they were exhibited in the Disability Arts Defiance exhibition in Derby in 1992.

Somebody sent me the centre pages of the local newspaper with the headline, "Is this art?" They had two columns, two members of the public and one saying "yes" and one saying, "no". People felt really uneasy about it. I liked that because I thought this work is engaging and I did that (Hardy 2002).

### **Embodiment**

In the early stages of his arts education Eddy was adamant in his refusal to include his wheelchair in his self portraits. When he did agree to include it as subject matter, it was distanced from himself through the simple expediency of drawing it without himself in it. Thomas (1999a) describes the process that arose from the social model of disability and the Disability Movement whereby despised and stigmatised social attributes were reclaimed and celebrated. Certainly as Eddy's awareness grew an example can be found, in the artwork he carried out for his MA, of just such a reconciliation with his wheelchair and the notion of embodiment that Iwakuma (2002)

describes in the context of disabled sportsmen and women. Eddy has realised that without the wheelchair he would lose who he is. Similarly, he ‘celebrates’ the marks on his body that his impairment has incurred by gilding them with gold, the most precious of materials.

I did a painting of me, nude and I made a video and I did a body cast from the waist up and the scars on my back are gold leafed and I did that as a comment on the operations I’d had and how I felt about my body. The video is edited so that one moment you see me taking the chair apart, next minute you see me undressing. You see me cleaning the chair with oil then you see me washing part of myself. There was a film called *‘Blue Steel’* with Jamie Lee Curtis and she’s getting her gun ready and all you can see is the hands and the gun and nothing else. So it was kind of based on that. You didn’t see all of my body. You only saw parts. It was in the shower, you saw little bits. The other thing was I was trying to do something to say the chair is not separate. Don’t think of me and then the chair as being separate, we’re all one. I don’t want you to think, “well he’s thick because he’s disabled”. At the same time don’t ignore the chair, it’s part of my identity. Also it’s not a negative thing. If I don’t have the chair I can’t get around anymore. It’s a positive thing (Hardy 2002).

In contrast Ruth consistently rejected the use of the white cane that she had been offered as an ‘indicator’, not she explained because she needed it to find her way around but to inform people and enable them to accommodate her impairment in certain situations. It was the reaction of others and by implication the stigma that was attached to the cane as a signifier of disability that deterred her from using it. Ruth’s response to issues of identity, impairment and disability had not involved her in processes of ‘embodiment’ or ‘coming out’ but to a reflexive project of the self whereby she tells the on going ‘story’ of her sight impairment through her artwork (Giddens 1991, Seymour 1998).

### **A Narrative Approach**

As a mature student, Ruth, whose impairment was hidden and acquired, had to assimilate disability into the sense of herself that was already established. She did not feel the need to address the social implications of disability and impairment by

making a declaration, but absorbed her impairment by objectifying her experience through images that were concerned solely with the physical eye and brain, the organs of vision. In effect she tells the ongoing 'story' or narrative of her diabetes and sight impairment, through aesthetically interesting images that are not immediately recognisable as being about disability and impairment. In the early stages of her work at university she described exploring and questioning notions of normality and beauty and whether that which was not considered to be 'normal' could still be considered beautiful. These investigations led her to data-collecting images such as scans which record and monitor the inner workings of the body and in particular the brain which she used as a basis for her artwork.

By the third year of her degree course she was looking at the issue of diabetic hyperglycaemia when blood sugar level drops and has an unseen effect on the brain (see Fig 94, 95). She described how she had arrived at these images.

I made up a series of ten steps, they were my steps, they're not medical steps, but they all happen to me and they went from stage one to stage ten, which is a coma. Some people thought they looked like I'd really scanned a brain and I said, "no they're my interpretation of a brain – my brain going through hyperglycaemia" (Pejcic 2002).

Ruth continued to integrate the narrative of her sight impairment through her MA artwork in which she extended her studies to scans of the eye. She described this development of her work.

I thought I'm going to start looking at retinal scans. I'm using exactly the same circle every time and at the moment I'm looking at difference. Every single time I print the mono-print it's different, even though it's exactly the same circle, exactly the same materials, exactly the same paper (see Fig 96, 97). I'm looking at the issue of what's going on behind the eye how potentially it can look beautiful, because people have said "I really like your prints. They're nice to look at. They're interesting to look at". They're all different and I'm looking at the issue of individuality because everybody's retina is different, like a fingerprint.



Fig 94



Fig 95

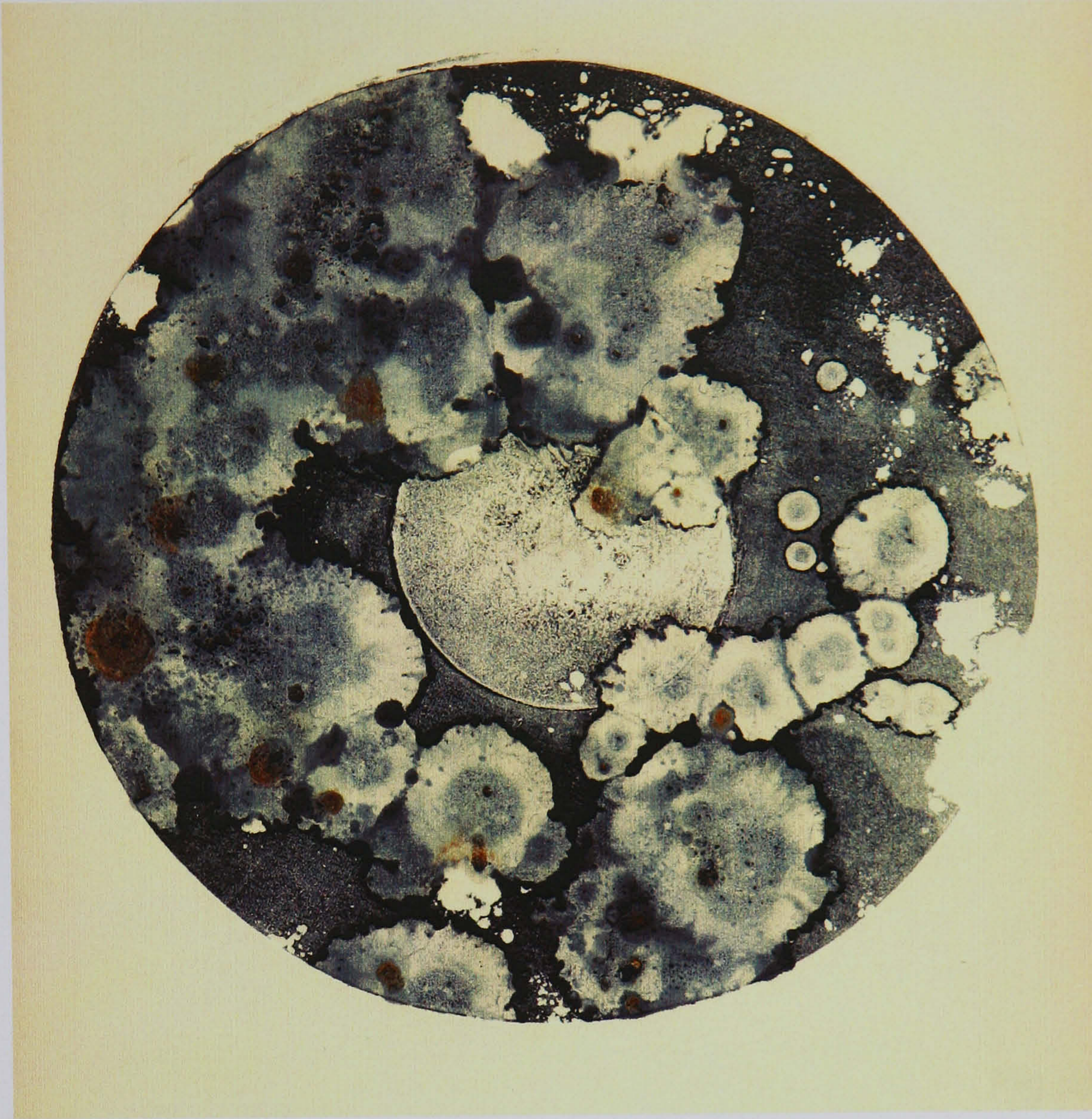


Fig 96



Fig 97

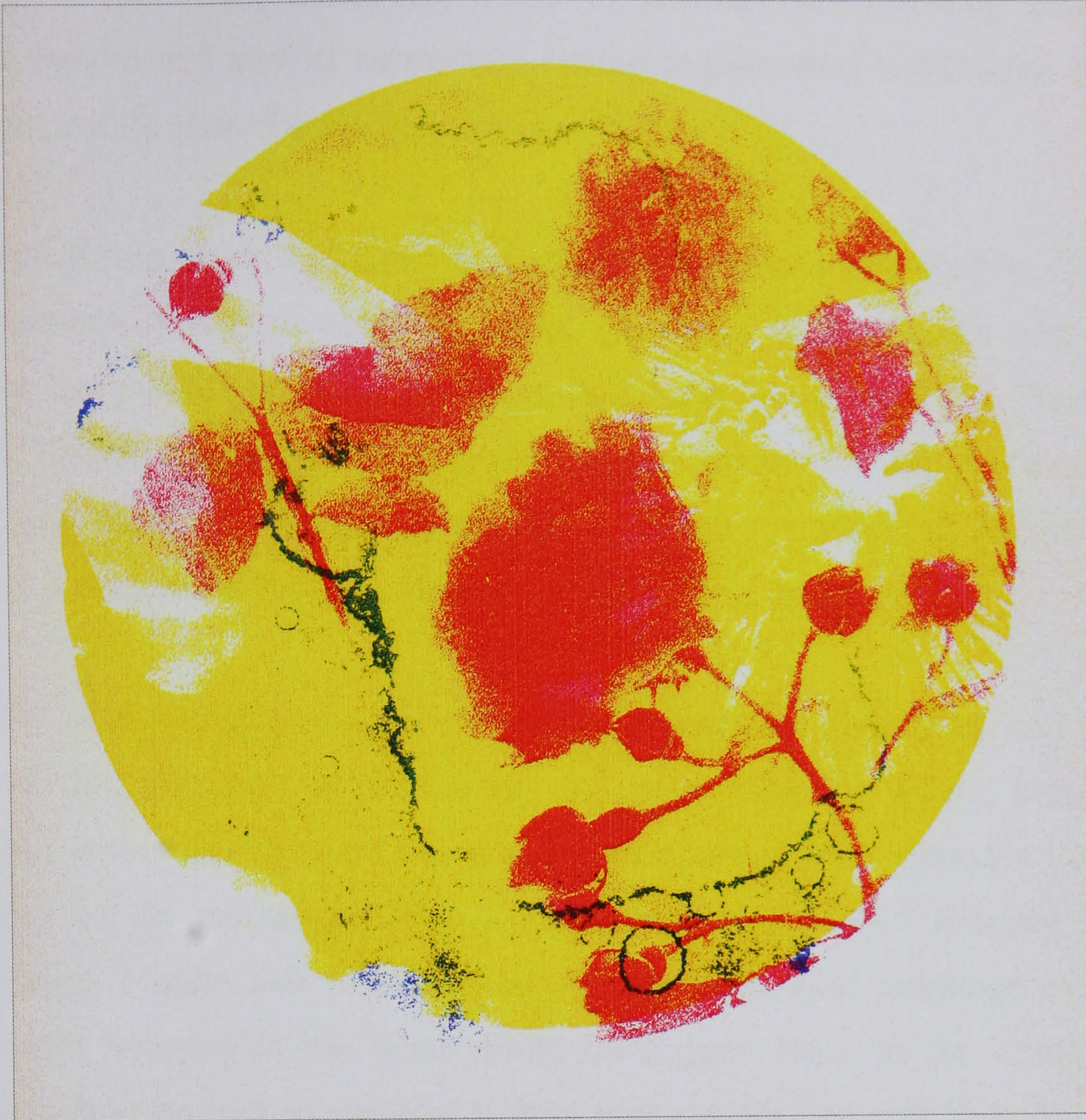


Fig 98



Fig 99



They're just really attractive, beautiful, aesthetically pleasing images but they're still saying something [about impairment] but they're a lot more subtle (see Fig 98, 99) (Pejcic 2002).

The narrative approach that Colin has adopted contrasts with Ruth's. Colin explores the interactions that take place in social situations and contexts and in so doing addresses the public narratives about disability and impairment that Thomas (1999b) identifies. Specifically he chose to make images concerned with the 'disabled people are asexual' narrative but in the context of modern notions of romance, and the seeking of a soul mate through the media and a blind date.

I was watching telly and *Blind Date* and the screen goes back and you have that first look at somebody and what happens. And I thought about when people meet me and what happens. And I thought I was going to do something in my wheelchair and then I thought no, because I quite like Francis Bacon's *Hanging Meat* paintings and I thought hanging in the hoist would be a good thing to do. Thinking about how people would feel if they met me for the first time being, like, crucified in this contraption. In the hoist paintings I was kind of advertising myself for a *Blind Date* (see Fig 100, 101, 102, 103) (Marsh 2002).

Four individual paintings that show tightly cropped areas of a larger image make up the series and are reminiscent of the cartoon strip format of popular comics. The impression, however, is voyeuristic; of something hidden that is revealed momentarily through a half opened door. Colin explained, 'I decided not to show the whole thing because I wanted it to look as if the viewer was stumbling in on something'. The banality of the conventional text abbreviations associated with 'lonely hearts' adverts incorporated in these paintings, force the viewer to confront not only the possibilities of disabled people's sexuality but also that this might occur in the farcical context of mainstream popular culture. He also explored the situation and response, as he imagined it, if he were to go on a blind date. The painting shows us a girl waiting with her face turned away from Colin, who is trapped soundlessly behind her.



Fig 100

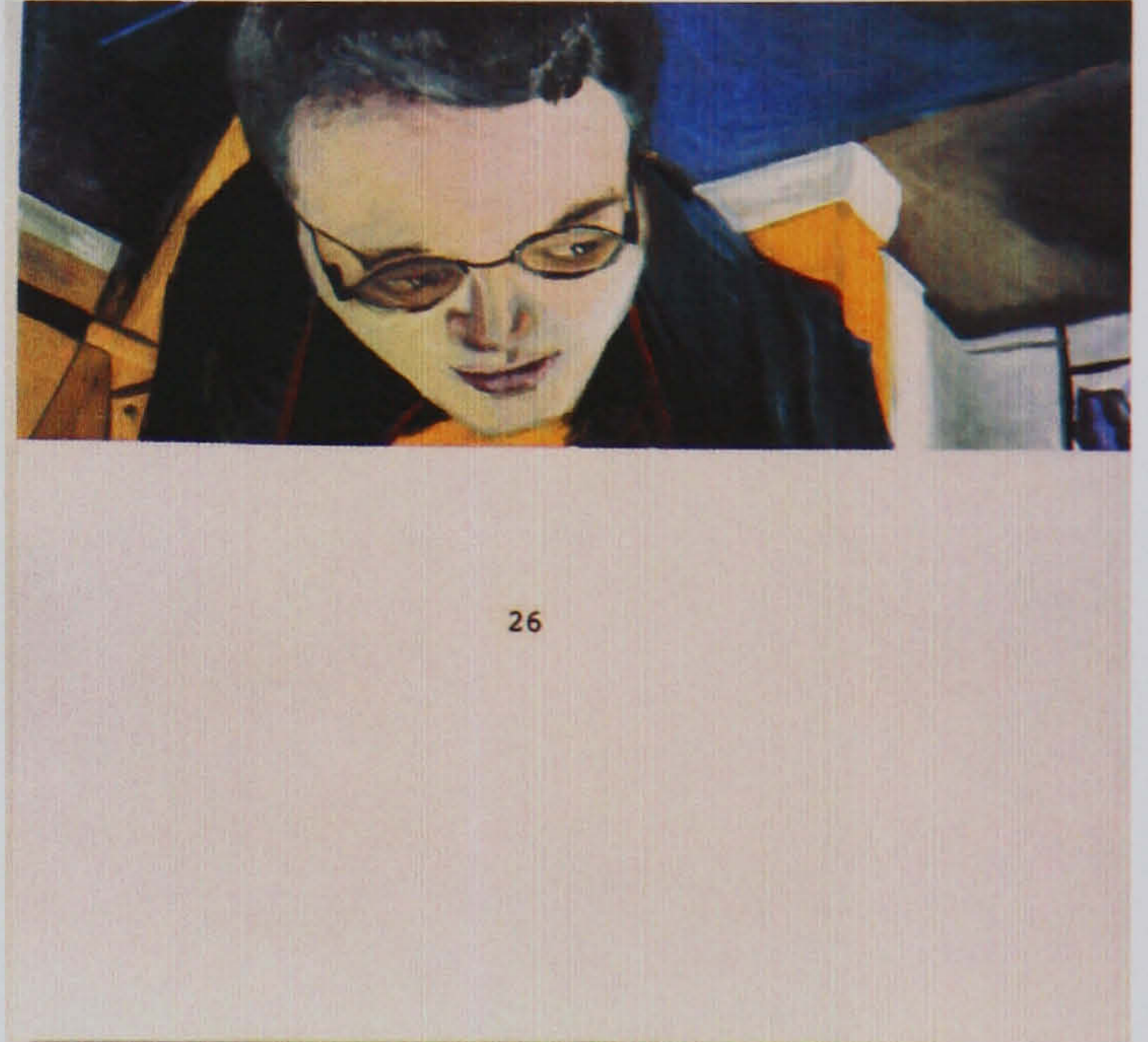


Fig 101

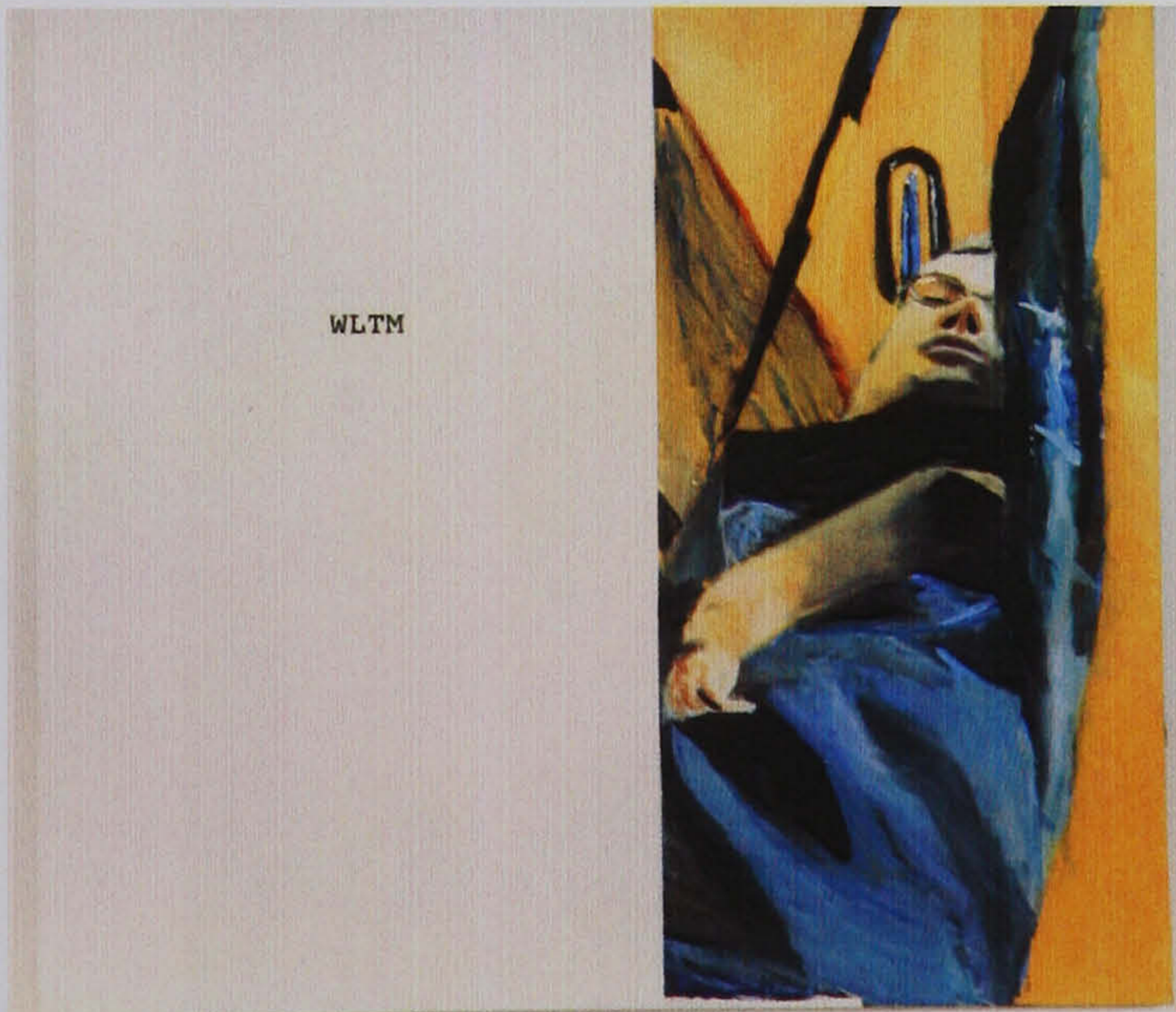


Fig 102



Fig 103



Fig 104

I thought what if I went on a date and couldn't get in? I was somehow trapped behind something. I could see what there was but I couldn't get in. I photographed myself underneath 3 inches of safety glass. I wanted something really heavy to press on me and that feeling of being closed in. It's an invisible barrier. It's a representation of the wheelchair in a way, but it (the wheelchair) isn't there because it doesn't need to be (see Fig 104) (Marsh 2002).

He developed what he described as 'the confrontational style' and the theme of disquiet and unease inherent within certain social contexts for disabled people, with a painting of himself in the line up in a man's toilet. Colin has personal care requirements that render some situations rich in potential for amusement but also for misunderstanding. This image recalls Lenney and Sercombe's (2002) study into interactions across difference in a public place and the possibilities that non disabled people are unsure of how to interact with disabled people: Colin describes the meaning contained within this painting.

Its about that going in as a disabled person and taking someone in with you and that moment when [the other] fellows sort of think, what are you doing exactly? (see Fig 105) (Marsh 2002).

### **Disability Arts**

The Disability Movement and Disability Arts were very significant for Eddy in his struggle to develop a positive sense of himself. Ruth associated herself with Disability Arts but in a measured way that did not appear to have had a fundamental impact on her sense of herself, and Colin located himself in a mainstream context, expressing a degree of ambivalence about Disability Arts. This difference in attitude may reflect an age differentiation in the sense that although Ruth and Eddy were of the same generation, Eddy had always had to address issues of impairment and disability, in contrast Ruth had come to this later in her life. Eddy had had involvement with the Disability Movement and Disability Arts in their early stages and he saw himself as an activist and pioneer, whereas Colin's later perspective seems to indicate the uncertainty about a collective disability identity that characterises the current generation of young disabled people.



Fig 105

They appear to want to establish themselves more within an inclusive mainstream setting, although it would seem, from the 2003/04 questionnaire concerning student's awareness of the Disability Movement and Disability Arts, that this is not an informed choice.

The Disability Movement provided Eddy with solidarity and a politicised concept of disability that empowered him. Disability Arts provided him with the public forum within which he could express this through his artwork. He described, what was for him, an epiphany, as, through his growing awareness of the social model of disability, he was able to shift 'blame' from himself to society.

Then I seemed to realise something about an access kind of thing. Normally you would say, you can't get on a bus because you are in a wheelchair and suddenly I realised it was because the bus wasn't accessible. The moment that happened years and years of guilt – because everything was my fault – went. It wasn't me it was them. It was the environment (Hardy 2002).

At this time Eddy was one of only a few disabled people who were producing issue based work from a formal arts education background (see Fig 106, 107, 108, 109). There were, however, issues that arose that highlighted tensions between mainstream art criteria and the intensely political agenda of Disability Arts. The first distinction that Eddy came up against was between Disability Arts and art done by disabled people. He described how he challenged this with the radical images of himself nude.

They called it Disability Art but basically it was art done by disabled people. It wasn't issue based, it was bowls of fruit. I was really disappointed. There were certain people who would come to these exhibitions and say, "ah isn't that nice, aren't they clever, isn't it amazing that because they are in wheelchairs they can draw". But then there was the Defiance exhibition in Stoke on Trent (1992) and I put in the nude image and I remember thinking, right, say "ah that's nice" to that then! (Hardy 2002)



Fig 106

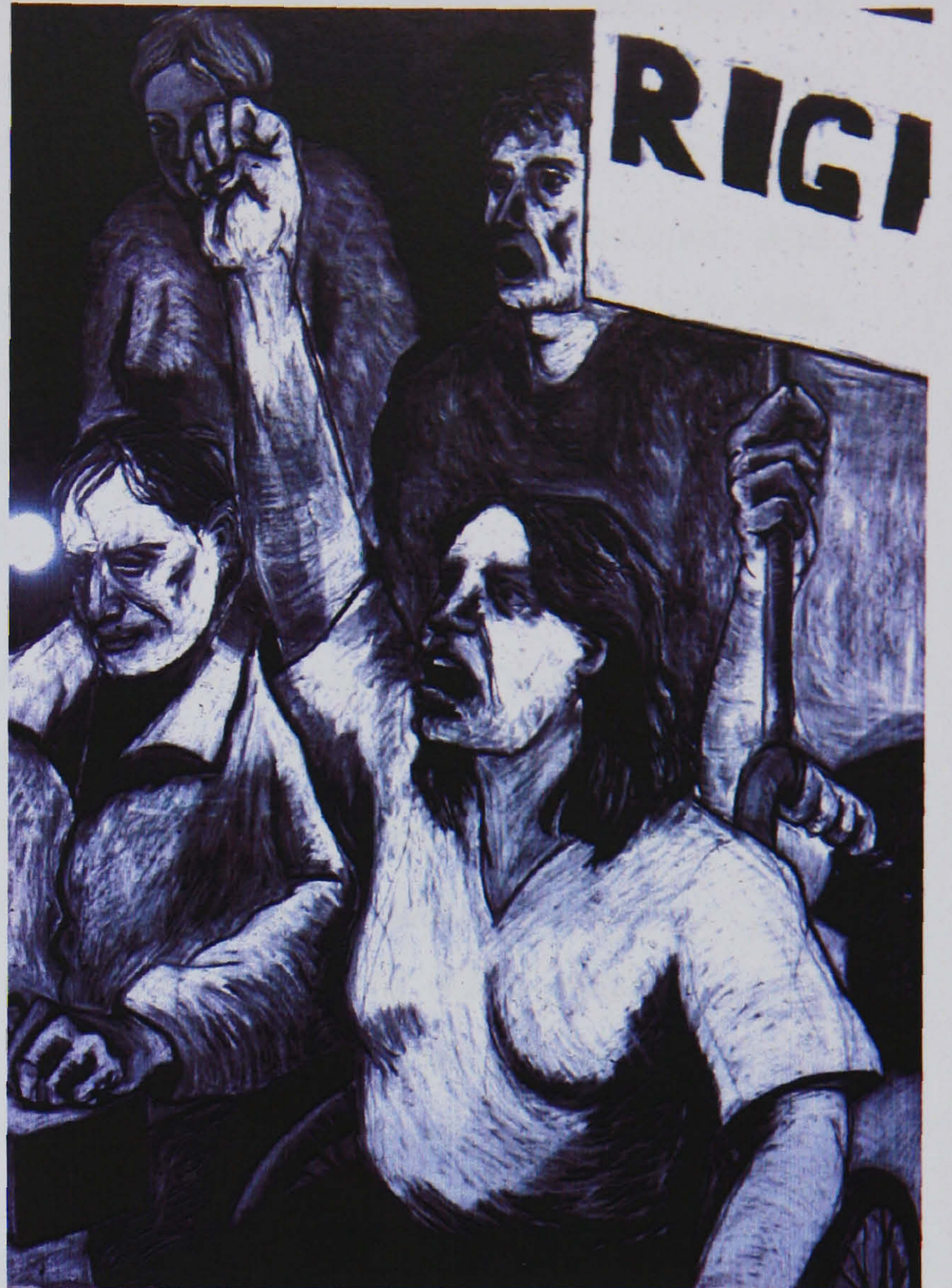


Fig 107



Fig 108



Fig 109

Woodward (1997) makes the point that political identity defined either within a movement or as part of a political statement is often characterised through the emphasising of difference, by 'the marking of us and them' (p.24). However, an area of contradiction arose for Eddy from his location within both arts education and Disability Arts and this was the question of technique versus content. Disability Arts prioritised political content over artistic technique and this compromised Eddy when work, that he considered was not of a very high standard technically, was received with enthusiasm.

I think the quality is a lot better now, but at the time a lot of Disability Arts was about the issue. And there have been occasions when I've put work in for a Disability Arts exhibition that really was quite crap, as a painting it's quite weak, but everybody raves about it and I was not tested at all. What tends to happen, is that people will make issue based work that's accepted and that's it. It can become formulaic, like making a cake and the Disability Movement eats it up. For the Disability Movement the issue is the most important criteria, the technique is secondary. They don't know if it's technically good. A mainstream environment is important because the feedback you can get is less wrapped up in cotton wool, so your development as an artist is going to be better. There would be far more constructive criticism of a Disability Arts exhibition now than there used to be (Hardy 2002).

The Disability Movement and Disability Arts were pivotal in enabling Eddy to empower himself by confronting oppressive attitudes and demanding acceptance of who he is. His identity as an artist is intrinsic to his sense of himself, as is his politicised identity as a disabled person. Ironically it is the relationship of these that present him with challenges in terms of his future artwork. In personal terms the battle has largely been won and the word 'battle' accurately describes his struggle. The dilemma is where he goes from here.

Sometimes I think I don't always want to make issue based work. Then I think well if I don't do that what am I going to make work about? That's something I have a problem with. If I took away all that, what would I make work from? It might be that I draw whatever is in



front of me, but is that still valid? And I go through that thing again, should I be a painter and all the rest. I don't know. I did a statement that said, my work deals with disability, sexuality and identity, and so that meant I couldn't go out and draw a decrepit old house or an old lady whose face I'd look at and want to draw. I thought I can't because it doesn't have anything to do with disability, sexuality and identity. The issue-based work is always going to be a part of me but I've got an exhibition coming up of landscapes and portraits. It's dramatic scenery, not pretty pictures (Hardy 2002).

Although aware of the Disability Movement and Disability Arts, Colin has not drawn strength from a collective disability identity or exhibited his work in a Disability Arts context. This is despite the impact that individual politicised role models that he encountered as part of his arts education at Hereward College, had on him and the development of his work.

There's quite a lot going on with disability rights. There's still a tendency in society [to think] people with disabilities are different, and there's a kind of, "what can we do for that person?" There's still a lot of it about. My thoughts are more towards, is my work any good? Is it progressing? Am I happy with my life? Not where am I in the evolution of disabled people.

I think to go down that [disability] route wholeheartedly forever, then you lose who you are. There's a danger, of trying to represent too many people at one go. If your work is about disability then suddenly you've got the consciences of thousands of people behind you. And I thought I don't want that responsibility. I want my work to be about me and I was very conscious about that. I'm not fussed about meeting people with the same disability as me. I do meet other disabled people but I don't go out of my way to meet disabled people. When I meet people, I just meet people as me and that's it. I don't really think about it (Marsh 2002).

Ruth has moved seamlessly and with apparent ease between aligning herself and her artwork with Disability Arts and seeing herself as an individual who produces

artwork as part of mainstream practice. She first became involved with the West Midlands Disability Arts Forum when she was required as part of the degree course to do work on an independent study. It is interesting to note the use of the word 'ghettoised', implying segregation with a socially deprived minority, as a perceived danger that needed to be guarded against.

For that module I was involved with the International Day of Disabled People in Birmingham and they used some of my artwork for their posters and they made postcards of my work and also I helped out on the day in the reception area. I went onto the committee for a year but then I came off because it was getting near to my finals. At the same time I was also advised by someone at Birmingham City Council to "be careful not to ghettoise yourself as well, you're not just a disabled person and you need to be doing work apart from that". This is the dilemma with specifically Disability Art. It's a group that's formed to have a voice in mainstream, but sometimes in order to be part of a group you end up dividing yourself. I personally feel it's healthy to be in both camps, to be involved with Disability Arts but to make sure you're getting your work into mainstream. Otherwise all you're doing, you're just keeping it separate again (Pejcic 2002).

#### **Increased Confidence and Self Esteem**

Both Eddy and Colin made comments that specifically referred to their sense of increased status and confidence and how this was related to their changed perception of themselves as they progressed through their arts education. Colin clearly drew status from incorporating the notion of 'Artist' into his identity and this association had importance for him in resisting the insistence of others in ascribing him primarily a negative disability identity (Coetzee 2002).

This is going to sound a bit self important, but when you're out and about, and there are still people who sort of go, "hello" [said in imitation of a patronising voice], it's important to me to know what I do. I know who I am. It's funny because you don't really think that you're an artist because you're studying it. Then when people go, "what do you do?" And you answer "oh I'm a visual artist". And when you first say it, it's oh my god am I really that! (Marsh 2002)

Eddy's increased confidence had enabled him to resist the objectification that he had experienced as the subject of the 'gaze' and describes how he had done this.

Now I've got the personality [confidence] to stare back and stare back in such a way as to say, "what the hell are you looking at and do you want to make an issue of it?" And usually they don't. The only way I learned to cope was the ways in which I started to treat myself in terms of getting my tattoos done, shaving my head so that it shows my scars off. Things like that. Almost drawing people to want to look at me and showing that part of me wants to be looked at because you can see I'm now in a situation quite different from before where I was just a disabled person that was stared at all the time. Now I'm somebody who is a bit more kind of outrageous in a way, in terms of my appearance and attitudes. I'm saying, "well yeah, you can look at me", because that's kind of what I want and it doesn't bother me and so I feel more in control of that situation. I've kind of thrown it back at people and I'm not going to kind of notice that people are looking at me and feel bad about it. They can look at me and here I am and it's for them to deal with not me (Hardy 2002).

### **Summary**

Eddy's formative images that were produced from the mid 1980s onwards constituted a politicised challenge to the prevailing value system. The sense of self that he had developed as he grew up required him to incorporate something that he had learnt, from the reaction of others, from the medical profession and from his schooling, had a stigma. He had attempted to suppress, deny and reject his impairment, although clearly, by his comments and actions, it was ever present. His negative feelings were manifested in self harming actions and behaviours that only ceased as his awareness of disability issues grew and he was able to find expression through the development of an articulate visual language. He was able to 'come out' in bold images that exposed his body and revealed his impairments to the scrutiny of others, but in ways that he determined and over which he had control. This resulted in enhanced self esteem and the development of a positive sense of self.

In contrast, and for reasons of family background, schooling, temperament and the raised awareness that occurred from the mid 1980s, disability had not presented Colin with such raw and painful conflicts. His experiences and artwork were influenced by the move towards integration and the content of his work, produced from the early 1990s, incorporates impairment as a part of the expression of his self identity, producing ironic rather than confrontational comments on the lived experience of disability and impairment. His more pragmatic approach whilst addressing negative experiences, of, for example, the medical profession, produce images that juxtapose his impairment with the ordinary events of life – having a meal, visiting a toilet, subscribing to lonely hearts – but in such a way that we are forced to confront the ways in which impairment disturbs social conventions. Colin perceives himself as part of the continuum of mainstream arts practice and his identity as an artist gives him status.

Ruth's work, produced in the late 1990s into the early 2000s is reflective of a more inclusive approach and explores impairment in a more objective way that invites the audience to view the image as both beautiful in itself and also informative. This fusion of impairment and aesthetics, which is not concerned with the social, lived experience of disability, has produced images that can be read at many levels and that span Disability Arts and art and disability. Her arts education has played an important part in her empowerment and self esteem by enabling her to transform her impairment in artwork that is aesthetically pleasing, and is shown in both mainstream and Disability Arts contexts.

## Conclusion

This study has investigated the social construction of disability, the social context of identity formation, the notion of stigma and the spoiled identity and the embedding of these concepts into the social narratives that disabled and non disabled people alike internalise. A main aim has been to give the reader a sense of the disabled young people involved, of their experiences of living with impairment and disability, of the difficulties that they have encountered, and of the ways in which they have been able to resolve those concerning identity and self esteem through the visual arts. The accounts that students gave indicated that issues of disability and impairment are felt at a profound level; that negativity is associated not with any limitation that impairment may impose but with social interaction and the perceptions that others have, or that they think that they have, about them. The endorsement of these perceptions in images in the media is highlighted as a precursor that young disabled people must engage with if they are to recognise and challenge these oppressive concepts through the processes of art education. It is this process of empowerment that is at the centre of this research and is revealed in the images that students have created.

The particularly empathetic environment that developed around the arts provision at Hereward College from the mid 1980s onwards has been detailed. The analysis of this provision suggests that it has facilitated processes of positive self realisation and this has highlighted the critical significance that the visual arts can have for all disabled children and young people. Attention has also been drawn to the greater importance that a visual language can have for non verbal students or where literary modes of expression present difficulties. However it is still the case that disabled children and young people are being denied access to arts education because of assumptions that professionals, family, and students themselves make about physical impairment and/or art.

The innovative ways in which access to the arts can be created have been described and a detailed account has been given of the support that ensures that no disabled child or young person need be excluded from the creative arts curriculum. However, this study has also revealed that inclusion in arts activity does not guarantee 'serious' intent and too often 'art' has been interpreted as a leisure or 'therapeutic' activity for disabled children at school.

The acquisition of skills and competencies that are commensurate with mainstream criteria and accreditation are important if disabled people are to develop a 'voice' in the arts that will be heard. In focusing on education, and whilst recognising the importance of Disability Arts in the empowerment of disabled people, this study challenges the emphasis that Disability Arts has traditionally placed on content at the expense of technical competence (Humphrey 1994). The 'voice' of disabled artists is made more powerful where they are accomplished in expressing their thoughts and ideas.

This study has demonstrated that study at a higher level is significant in producing professional artists and role models for disabled people and yet none of the students interviewed for this study had encountered a disabled art teacher or known of a disabled artist before they came to Hereward College. Attention is drawn to the small numbers of disabled students, particularly those with high level support needs, who attend university courses in the arts and the difficulties encountered by those who do progress to this level of study. The under representation of disabled students in higher education in all areas of the creative arts, including those IT-based areas that might be considered to be more accessible, implies that the arts education of disabled children and young people is not preparing them for this progression. This, and the account of students' arts biographies featured in this study that describes their experiences from early involvement at home through what is often a fragmented and limited arts education, supports the supposition that their experiences can be seen as more generally 'representative' of the experiences of other disabled children and young people.

Despite these findings the evidence is that there have been several developments in the last twenty years that have the potential to radically enhance the arts education of disabled children and young people. These include the politicisation of disabled people and changes in social, cultural perceptions of disability and impairment; new legislation; disability studies and developments in ICT. This study has demonstrated that enabling support (at Hereward College) is also a significant factor in creating access to the arts for disabled young people. However it has also highlighted that it is more generally experienced in special and mainstream schools as varied, and that there are discrepancies in the interpretation of what practical assistance for arts activities should encompass throughout the continuum of school, college and university. At Hereward College, where the option exists for arts trained enablers to

assist creative studies students, the question of whether this is desirable or whether the enabler is merely a 'pair of hands' that the student instructs in response to the teacher led learning programme remains unanswered. Within schools the arts background of assistants working with disabled children and the effects of their attitudes towards disability, impairment and the arts, is also unknown. Similarly an investigation of how disabled children and young people are actively encouraged to develop the skills (communication, assertiveness, independence) that are needed to effectively direct support in the creation of artwork that has integrity is overdue. The question of enabling disabled children in the making of 'mistakes' and how this can be an essential and positive part of arts education (and other areas of the curriculum) is also a field of interest for further research investigation.

The factors which characterise the arts provision at Hereward College and which have been seen to empower students can be summarised as high levels of disability awareness stimulated by the cross college Disability Arts Programme; employment of teachers who are art specialists; an accessible arts curriculum that is delivered innovatively; constructive criticism and relevant contextual studies; an accessible environment; highly developed enabling support; high levels of IT support; and critically, disabled artists as role models. A number of components of the arts courses that students followed at the college were influential in the processes of self realisation. The alternative self-portrait project provided a vehicle for developing a sense of self by encouraging an investigation that went beyond the mere recording of facial features. Opportunities to explore scale, particularly in terms of very large pieces of work and the mapping of the body onto large spaces, including walls, along corridors, and entire rooms was important in the empowering process. Students were exhilarated to discover, often for the first time, the power of dominating a space, exerting a presence, and insisting on being seen. Role models, in terms of visiting disabled artists, also had a profound impact on raising students' expectations and self esteem. They experienced a shared disability identity and sense of solidarity and empowerment that they might not have accepted so readily, in a different, non educational context.

The accounts that Hereward College students have given has brought to the fore the oppressive effects that the psycho-emotional dimensions of disability have on their well being. However despite the burgeoning of an academic literature within Disability Studies the evidence that has been gathered as part of this study (from

both the accounts that students studying the arts have given and the questionnaire carried out with the new cohort of residential students 2003/04), it would seem that young disabled people are leaving special and mainstream schools with little or no knowledge of the Disability Movement or Disability Arts. New generations of disabled children and young people who would most benefit from being recipients of the theorisation that has produced new and empowering meanings are not receiving it, leaving them to struggle, 'on their own', with identity formation and oppressive perceptions of disability and impairment.

The importance of education in these processes of enlightenment cannot be overstated. The complexity of teaching and learning, where high levels of learning support are also a factor has been detailed as part of this study. Each disabled student brings a heterogeneous experience of disability to the learning environment that has been forged in various ways by family, friends, the media, the medical profession, schooling and social encounters with others. This demands a high level of awareness in teachers and a particularly sensitive response. Hodkinson reminds us that even where disability is not a factor 'teaching and learning are incredibly complex, interactive and reflexive processes, which are inherently social, cultural and contextual' (LSDA Conference 2001). Increasingly disabled young people are being educated in mainstream schools and colleges. Assumptions about placements in specialist provision were revised as a consequence of *The Tomlinson Report* (1996) which set out a concept of inclusive learning where providers match their provision to the needs of the learner. However, a commitment by the government to more training for staff in mainstream schools (Department for Education and Employment 1997) does not yet appear to have filtered down to the level of practice (Pitt and Curtin 2004).

As more disabled students experience mainstream provision, the question that needs to be raised is whether their arts education will be informed by the levels of awareness that this study has demonstrated are essential if the arts are to become a meaningful and empowering force in their lives. Teacher training and staff development should focus on addressing these issues. An investigation of the perceptions of teachers and professionals regarding art, disability and accessibility would identify how teachers could be supported in developing an inclusive approach to arts education, as would research that examined the innovative use of IT in the delivery of arts education for disabled young people.



This analysis of the complex relationship between self identity, impairment, and disability has raised the conflicting questions of cultural identity that disabled young people at Hereward College face concerning allegiance to an empowering collective disability identity as opposed to the development and expression of an individual identity that might include impairment and disability as part of a broader concept of self. This study has described disabled students' growing ambivalence, from the latter part of the 1990s, with images that function exclusively as a declaration or 'coming out' and involve a direct confrontation with the viewer. The advantages of subscribing to a collective disability identity, as an important psychological support and vehicle of solidarity, are tempered by, in effect, being relegated to what they perceive to be a sub-culture of relatively low status. Being associated with 'special' and separate spheres has, in the main, negatively characterised much of their lives and educational experiences. A collective disability identity ignores the narrative, or lived experience and sense of self, which incorporates myriad factors which, in addition to disability and impairment, include class, gender, ethnicity, religion, sexual orientation, personality and family dynamics. The young disabled people interviewed for this research strive for inclusion and 'non disabled' culture is seen as more desirable.

What is clear from this study is that popular culture is as powerfully influential in the lives of disabled young people as it is in the lives of their non disabled peers. It probably, if superficially, constitutes more available, easy and acceptable ways of developing concepts of self identity. I think at one level the students in this study do not see themselves as disabled or identify as 'disabled people' but rather are engaged with everyday life in the same way that all young people are. They demonstrate their concerns with popular culture and the trappings of a consumer society through their allegiance with mainstream contemporary trends, with designer clothing, mobile phones, audio-equipment and lifestyle choices. However, powerful media messages promote cultural preoccupation with the body as an aesthetic measure of worth and this study has drawn attention to the greater anxieties that this may hold for those who cannot approximate to these, albeit unrealistic, standards of physical beauty.

This research has demonstrated that an informed visual arts education, based on the provision of effective support, can offer disabled young people a vehicle for including the lived experience of impairment and disability as part of a multi-identity

perspective of positive concepts, in ways that are not pitiable or tragic and that they can share through the images that they produce. In so doing they are empowered and able to resist negative perceptions of disability and impairment that continue, insistently to define them. As this study demonstrates, the arts as a visual 'voice' can facilitate students, disabled and non-disabled, in the expression of human diversity and can promote an inclusive approach through the recognition that we are all part of a spectrum of difference, including those individuals with physical and sensory impairments.

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**Appendix 1**

Pilot Questionnaire	1.1
<b>Chapter Seven - Arts Practice and a Sense of Self.</b>	
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<b>Chapter Eight – Access and Support in the Development of a Visual Language.</b>	
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**PILOT QUESTIONNAIRE 1.1**

1. Name \_\_\_\_\_
2. How old are you? \_\_\_\_\_
3. Gender \_\_\_\_\_
- Male
- Female
4. What nationality are you? \_\_\_\_\_
5. Does anyone in your family have an involvement in art? Comments
- Your brothers or sisters are doing art qualifications
- A member of your family paints or draws for leisure
- Someone in your family earns their living with an art activity
- other
6. Were you interested in Art when you were a child?
- yes
- no
- don't remember
7. Did you do any of these activities at home when you were a child?
- drawing
- painting
- making things
- visiting art galleries
- none
- other
8. Has anyone encouraged your interest in Art?
- |                                  | A little                 | A lot                    |
|----------------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> Mum     | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> Dad     | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> friends | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> no-one  | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> other   | <input type="checkbox"/> | <input type="checkbox"/> |



15. Are you interested in Art now?

A lot

A little

Not at all

16. If yes are you doing it as part of your course of study?

yes Level

no

17. If yes, what has encouraged your interest?

I have enjoyed art before

People say I am good at art

I have achieved in art before

The facilities are good

Seeing other people with disabilities doing good art work has made me want to try

Friends or family wanted me to do it

A teacher encouraged me

The support I have needed has been available

I think I could gain employment

Other

18. Has anything prevented or deterred you from studying art?

Art is difficult for me to do practically

Art was never presented to me as a "serious" subject

There are no employment prospects in art

I think of art as a leisure activity

Art was not taught as a formal subject at school

The art room was not accessible at school

19. Would you consider applying to University for an arts course?

yes

no

perhaps



20. If not, could you state why?

- Not interested
- I don't have the qualifications
- I don't think I could keep up
- I don't want the pressure
- I can't afford to go
- I don't know how to make an application
- Other

21. Do you participate in any of the following activities in your own time?

	Often	Sometimes	Never
Drawing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Painting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Writing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dancing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Photography	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Making music	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Playing music	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Watching T.V.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sewing or customising clothes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going to the theatre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going to the cinema	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## **Arts Practice and a Sense of Self 1.2**

Guide for interviews with students on level 2/3 programmes.

### **General**

- Name of student
- Age
- Programme of study.

### **Questions related to earliest memories.**

- What are your earliest memories of doing art?
- What encouragement did you receive?
- Was there anybody in your family or extended family that was interested in doing art?

### **Questions related to schooling.**

- Tell me about your experiences at school
- Who made choices about the school you attended and the courses you did (careers officers, parents, teachers, you)?
- Tell me about doing art at school
- Were there opportunities to take/did you gain any qualifications in art?
- Did you have enabling support for art?
- In what ways did they help you?
- Did you use IT to do art work at school and if so describe how you used it?

### **Questions related to the arts and self identity**

- What do you think is the purpose of art?
- Do you remember something that you did in art that you, your parents or others thought was very good?
- When did you decide that art was something that you were really interested in?
- When you think about who you are, is art a part of that?
- Tell me about what you hope to achieve in the future with your art?

**Questions related to disability, impairment, ethnicity.**

- Invite comments about disability and impairment with reference to the responses that have already been given re. schooling, family, identity, self esteem etc.
- Have you heard of the Disability Movement/Disability Arts?
- Have you ever seen any work done by disabled artists, performers, on the television etc.
- Is ethnicity an important element in your work? (Explore issues of culture, community, religion)

**Questions related to leisure/popular culture**

- Tell me about the sorts of things you do in your leisure time.
- Tell me about your friends at school and in your local community.

## **Access and Support in the Development of a Visual Language 1.3a**

Guide for interview with Sam Chamber's parents

### **Communication**

- Can you tell me about how you communicate with Sam and how that communication has been developed?
- Do you feel confident in her independent decision making and how did you encourage this?
- What involvement did she have at home with art (drawing painting etc)?

### **Schooling**

- Can you tell me about Sam's early schooling?
- Can you tell me about Sam's experience with classroom assistants?
- Can you tell me about Sam's involvement in art at school?
- Can you tell me about her art teachers?

### **Hereward College**

- What are your thoughts about Sam's progress since she came to Hereward College?
- Do you see the development of a visual language as having greater significance for Sam because she is non verbal?
- Has Sam talked to you about what she wants to do in the future?

### **Disability Arts/Disability Movement**

- Have you heard of the Disability Movement and/or Disability Arts.

## **Access and Support in the Development of a Visual Language 1.3b**

Guide for interview with the manager of enabling support.

### **The role of enabling support in art education**

- Could you identify the key issues on both sides in the enabling process
- Do you think that enablers who work with students on higher level arts courses should be arts trained?
- How does enabling in the arts accommodate the fact that outcomes can evolve through process and experimentation?
- How do you prepare enablers to help students to develop the skills needed to use the enabling support effectively?
- Do you think that enabling support helps students to develop a sense of the other person?
- What are your thoughts about enabling students to take 'risks' with their artwork, to make mistakes and/or recognise the 'happy- accident'.
- Can you comment on the three- way dynamic between the enabler, the student and the tutor and what enhances this?

### **Sam's enabling support**

- What enabling support does Sam have?
- Do you think that this has changed in the time that she has been here?
- What are the issues in enabling a student who is non verbal?
- Do you have any thoughts about the ways in which Sam's artwork has developed?
- Do you think that Sam's ability to conceptualise ideas has developed in terms of her artwork?
- Can you tell me about the difficulties of enabling Sam with the theoretical elements of her course?

## **Access and Support in the Development of a Visual Language 1.3c**

Guide for interview with the speech therapist

- Can you outline how Sam communicates and the differences that occur in a social as opposed to a 'formal' context?
- Can you tell me what issues you have been addressing with regards to Sam's communication and communication aids since she has been at Hereward College?
- How have Sam's communication strategies at school been translated into the college situation?
- How are you working with Sam to develop her communication?
- Can you tell me how independent you consider Sam is in making decisions, given that communication is largely based on the presentation of a series of possibilities from which Sam makes a choice?
- Can you give me your assessment of Sam's understanding of language?
- Can you comment on the significance of expression, eye contact and intent in Sam's communication?
- To what extent do you think her communication difficulties affect her cognitive ability?
- Can you describe for me how Sam's difficulties with literacy impact on her use of communication aids?
- How did you work with Sam and staff to develop her specialist arts language?
- What are your thoughts about Sam's visual arts work as a medium of communication?

## **Access and Support in the Development of a Visual Language 1.3d**

Guide for interview with tutors.

### **Content of work at level two and three.**

- Can you describe the progression from level two GCSE studies to the level three Diploma in Foundation Art and Design?
- Did you have any misgivings about whether level three studies in the visual arts was a realistic choice for Sam given the nature of her difficulties?
- How do you ensure that her work has integrity?
- How are you making the course content accessible for Sam?
- How are you devising her individual learning programme at level three?
- How is Sam using media and materials?
- The focus of Sam's work is self identity can you outline how this is being developed and facilitated?
- How are you maintaining the balance between fulfilling the criteria for the course and involving Sam in an empowering, expressive process?
- How can Sam's work be located in terms of contemporary practice?

### **Enabling support and technology.**

- How have you worked with enablers to develop effective strategies to support Sam in producing her artwork?
- What difficulties have there been and how have these been overcome?
- Have the processes of Sam's enabling support changed?
- Can you describe how IT is supporting Sam in the production of her artwork?
- Can you outline the potential for Sam in the use of multi media approaches?

### **Communication and literacy**

- How were consistent communication strategies developed between Sam, her enablers and tutors in the context of the visual arts?
- What issues are raised for Sam in the production of written material and how do you resolve these?

## **Disabled Students, Higher Education and the Visual Arts 1.4**

Guide for interviews with students

Note - References to impairment, disability/ethnicity/class and identity were taken up and explored individually as they emerged through student's accounts.

### **Early experiences of art and family influences**

- Can you tell me about your family background?
- What are your earliest memories of the significance that art had for you?
- How are your interests/skills in art perceived by your family and friends?
- How do your family support your ambitions?

### **Schooling**

- Can you outline your school experiences (special/mainstream, integration/segregation)
- What are your thoughts about this provision?
- What was the content of your artwork at school?
- What qualifications did you/could you take?
- Do you remember any art teacher in particular?
- Can you describe the support that you had at school?

### **Hereward College**

- How was the choice to come to Hereward College made and how did you feel about it as a next step?
- How did your artwork develop at Hereward College?
- What support did you have?
- How was the decision made for you to go to university and how did you decide where you wanted to apply?
- What difficulties did you encounter in making the transition to university?

### **University**

- Do you think that going to university has enhanced your status?



- How has the enabling support/personal assistance been arranged, what difficulties have you encountered, how have these been resolved and what have you gained from these experiences?
- How did you cope with the differences between the academic environment at university and that of Hereward College?
- Can you describe the social environment at university and how you fitted into this and related to your peers?
- What perceptions did non disabled students have of you as a disabled student?
- How did your artwork develop?

### **Artwork**

- What do you understand by the Disability Movement and Disability Arts?
- What do you think is the purpose of art?
- Can you describe for me what your artwork is about?
- How does being an artist impact on your sense of self?
- Where do you see yourself and your artwork going in the future?

## **Three Artists: the effects and effectiveness of visual arts education. 1.5**

Guide for interviews with students

### **Family background and early experiences of art**

- Can you tell me about your family background?
- What were your first memories of doing art?
- Were you encouraged?
- When did you become aware that this was something that you were good at?
- Did other people perceive you as being good at art?
- Did your perception of yourself as being good at art become a part of how you thought about yourself?

### **Schooling, Hereward College and University**

- Can you outline your school experiences? (special/mainstream, integrated/segregated)?
- What are your thoughts about this provision?
- What do you remember about doing art at school?
- What was the content of your artwork at school?
- What qualifications did you/could you take?
- Do you remember any art teacher in particular?
- How was the decision to move on to Hereward College made?
- Did your working methods, support requirements change?
- How did you cope with the transition to university?
- How did you feel about moving into a mainstream university environment where as a disabled person you were in the minority?
- What was the attitude of tutors/peers towards you?

### **Artwork, impairment, disability and identity**

- Tell me about your experiences on the Foundation Art and Design Course.
- Could you trace the development of your artwork through the Foundation Course and onto degree level studies?
- Have other disabled artists had an influence on your work.
- Did the disability arts projects at Hereward College have any impact on your work?

- Tell me about the significance of scale in your work?
- Is disability an intrinsic element in your artwork?
- How significant is impairment/disability in the way that you think about yourself?
- How have you incorporated your impairment into your sense of self?
- How important is it to you to meet other disabled people?
- Have you heard of the social/medical models of disability?
- Do these have significance for you?
- Has the Disability Movement and Disability Arts had any significance for you?
- How have you formulated your thinking on disability, and what has impacted on this?
- Can you tell me about references you have made to the medical profession in your artwork?
- Can you tell me about your experiences of the medical profession?
- Can you tell me about references you have made to social contexts and disability in your artwork?
- Have you experienced the gaze, being looked at?
- How have you responded to this?
- How did you cope with the transition after university?
- Can you tell me about the content of the work that you are producing now?
- Is your degree/artist identity important to you in terms of status?
- Is it important to you to be part of the fraternity of artists?
- Where do you see your work going in the future?

## **Interviews with Staff – 1.6a**

Guide for interview with the Director of Teaching and Learning

### **The College**

- Can you describe for me the early cultural ethos in the college and whether and how this has changed?
- Can you outline the changes that took place as the college moved from specialist/integrated to inclusive provision?
- Can you describe how the student profile has changed?

### **Support Services**

- Can you outline for me the development of enabling and IT support services in the College?
- Can you tell me how enabling support in art and design developed?

### **The Arts provision and Disability agenda**

- Can you tell me about the early arts provision at the college?
- Can you compare the degree to which students were politicised in the early days of the college to now?
- How has the external disability agenda impacted on the college and its students?
- Can you describe the early arts initiatives i.e. The formation of Graeae Theatre company

## Interviews with Staff – 1.6b

### Guide for interview with the Manager of IT

- Could you outline the significance that the convergence of computer technology and communication technology (Information Learning Technology) has had for disabled students?
- Could you define the term multi media and outline the potential that this has for disabled students?
- Could you give examples of assistive technology and outline its potential applications for disabled students?
- Could you give examples of adaptations that have been made to computers, communicators, software, hardware and/or the learning environment that have created access or enhanced provision for disabled students?
- Could you outline the difficulties facing a single switch user with particular reference to Sam Chambers and how her wheelchair, communicator and computer have been set up?
- How are disabled students who have difficulties with literacy supported by the use of IT (communicators, icons, predictive technology)?
- Could you describe the IT provision that the college has for graphic design?
- How has the IT provision in the college changed in the last 5 years?

## **Interview with Staff – 1.6c**

Guide for interview with the Head of Residential Education

### **The College**

- Can you describe for me the early cultural ethos in the college and whether and how this has changed?
- Can you outline the changes that took place as the college moved from specialist/integrated to inclusive provision?
- Can you describe how the student profile has changed?

### **Support Services**

- Can you outline how enabling, care and medical services have developed at the college?
- Can you outline the development of residential education?

### **Students and the disability agenda**

- Can you compare the degree to which students were politicised in the early days of the college to now?
- How has the external disability agenda impacted on the college and its students?
- Can you outline the development and role of the youth worker provision at the college?
- Can you describe how the influence of family impacts on student's autonomy?
- What forums are there in the college for the student's voice to be heard?

## **Interviews with staff – 1.6d**

### Guide for interview with the Head of Basic Skills

- What are the main strategies that are used to teach children literacy skills (phonetic, multi sensory)?
- What are the issues for a student who is non verbal in the acquisition of literacy skills?
- Is assessment an important starting point?
- How might a non verbal student compensate for their impairment in the acquisition of a language (visual, auditory, memory)?
- Is there a difference between language and communication?
- What do you do with students to develop memory?
- What alternative skills might a non verbal student develop?
- How could a non verbal student demonstrate cognitive skills without verbal or written language?
- Why is it so difficult for disabled students to express their ideas and experiences?
- Can you comment on the implications for a student who has difficulties with literacy on the expression of emotional, cultural issues?

### **Sam Chambers/Basic Skills**

- How did you assess Sam Chamber's literacy skills?
- What information do you have about the ways in which Sam was taught literacy skills at school?
- How will you progress Sam's basic skills?

## **New Residential Student Questionnaire 2003/04**

Name

Age

Special/Mainstream School

Art Qualifications (Art, Photography, Graphics, Video)

Art Qualifications on offer

Use of IT for Artwork

Enabling support/classroom assistant

Disability Movement

Disability Arts

Comments



**Appendix 2**

Table of Higher Education Statistic Agency data 2002/03.

## HIGHER EDUCATION STATISTICS AGENCY DATA 2002/03

<b>FINE ART</b>	
13,892	No known disability
99	Deaf/Hearing Impaired
29	Blind/Partially Sighted
83	Wheelchair users
4	Students with Personal Care Needs

<b>TEXTILES</b>	
1,588	No known disability
10	Deaf/Hearing Impaired
0	Blind/Partially Sighted
3	Wheelchair users
2	Students with Personal Care Needs

<b>GRAPHIC DESIGN</b>	
4,022	No known disability
16	Deaf/Hearing Impaired
10	Blind/Partially Sighted
10	Wheelchair users
0	Students with Personal Care Needs

<b>MULTI MEDIA DESIGN</b>	
962	No known disability
8	Deaf/Hearing Impaired
3	Blind/Partially Sighted
2	Wheelchair users
0	Students with Personal Care Needs

Number of students at UK HEI's by subject area, principal subject and full JACS subject (for Creative Arts and design only) and disability for 2002/03