

Disabled Women and Socio-Spatial 'Barriers' to Motherhood

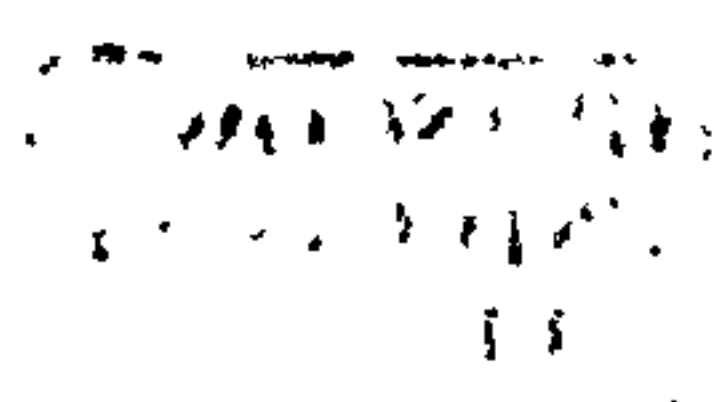
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Abstract

Disabled women's social history of institutionalisation and spatial segregation has, over time and space, set them apart from mainstream society and rendered them invisible in the spaces and places of everyday life. In more contemporary times, when disabled women 'invade' reproductive spaces, their presence as prospective parents, 'becoming mothers' or mothers, is often regarded as 'out of place'. This study hence incorporates a historical review that traces the spatial realities of disabled women's and girl's lives between 1796-1910 in Glasgow and Edinburgh. This reveals the development of social stereotypes and misunderstandings of disabled women's lives and bodies, particularly their assumed asexuality and inappropriateness for undertaking reproductive or mothering roles.

Disabled women's 'voices' are to the fore in the contemporary chapters of the thesis, reflecting the reproductive and non-reproductive experiences of 27 disabled women resident in the Glasgow and Edinburgh areas. These narratives offer an insight into the embodied experiences of 'disability' in private and public space. Being placed sexually 'off limits', and rendered 'out of place' in and by reproductive or mothering environments, constitute some of the social and spatial barriers to motherhood encountered by disabled women.

It is hoped that this study contributes to the process of recovering the forgotten histories and neglected experiences of disabled women, particularly in terms of their social exclusion, infantilisation and desexualisation that have reduced disabled women's participation in child-rearing and motherhood across time and space. The chronological framework of this study reveals slow but positive changes in social attitudes towards disabled women expressing reproductive choices, raising children and creating a 'place' for themselves as mothers in contemporary society.

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Chapter One

Framing the Thesis

A personal journey

Oh I've never worked with a blind woman before - how do you think you will cope with a baby?

During my pregnancy in 1998 I was often greeted with the above remark on initial meetings with health professionals involved in the monitoring of my pregnancy, at both the local maternity hospital and my General Practitioner's surgery. The surprised tone of voice that usually accompanied such a remark made me feel as though my presence was unexpected and 'out of place' in an environment that traditionally welcomes and supports women. Throughout my pregnancy and following the birth of my child, I felt pressured to demonstrate my abilities and capabilities as a mother at every turn, ranging from encounters with health professionals to ones with strangers in the street. I was acutely aware that my competence as a mother was questioned. As my confidence as a mother grew, I became increasingly frustrated and angry at the intrusive probing reflecting society's unease and lack of comprehension of the ways in which a 'blind woman' would undertake parenting¹.

Almost two years on, I still felt angry that the social unfamiliarity and discomfort around disabled parenting would have such an impact on my daily life activities as a mother. I frequently found myself pondering why my pregnancy and mothering role had upset the reproductive and social order of who should or should not have children. At this point, where I was reflecting upon and questioning my experiences, I was invited to participate in an interview as part of a geography doctoral student's field research on employment. During this interview I discussed thoughts, feelings and opinions that I had never actually verbalised until then; as I heard my words, the penny dropped and the floodgates opened. I realised that I had internalised many oppressive attitudes and social controls that placed tremendous strain on me as a woman and a mother. By the end of the three-hour interview, I had begun to consider my experiences in socio-spatial terms, which was a

¹ Although my work is informed by the social model of disability, this study focuses on the experiences of physically and/or visually impaired women. The terminology used by women to describe their

complete revelation to me. From that moment on, I was motivated to undertake PhD research to document disabled women's reproductive choices, influences upon these and experiences of mothering; I felt certain that my experiences were not unique. My profound sense of social injustice served as a catalyst to explore the experiences of other disabled women, to provide space and voice to their untold life (hi)stories concerning reproductive choices and experiences.

Entering an unfamiliar discipline at post-graduate level was daunting. Although I was familiar with disability studies, appreciating the social model of disability and the consequences of 'hostile' environments because of my previous employment in disability-led organisations, the opportunity to consider everyday places and reproductive places in spatial terms did put a whole new spin on things. Kitchin (2000) laid out the meaning of 'space' in very straightforward terms for the study of disability in geography, but I have a very distinct memory of reading the introduction in Butler and Parr (1999) and realising that 'space' could mean anything from the street outside, a maternity unit, a house or a room within a house, right down to the 'space' in your own mind. It all seems obvious to me now, but at the time I had never considered everyday spaces in these terms; it was an incredible turning point in my foray into geography. I began to think in spatial terms, enabling me to make sense of my own experiences, and later those of the women who I interviewed, to a far greater extent than disability studies had offered. These spatial influences play out in the thesis and therefore will not be explained at this stage.

As a disability activist, I felt sure that disabled people's social history of institutionalisation, charitable benevolence and low social status in some way impinged upon our perceived 'place' spatially and socially in contemporary society. This sense was confirmed by a number of academic works. Gleeson (1999) provided the geohistorical foundation of disabled people's social removal, documenting their transition from productive members within rural feudal village communities and their displacement from these roles to that of 'social burdens' brought about by the industrial revolution. This transition framed the supposed 'solution' to 'the problem of disability' arising in the shape of institutionalisation as a solution. Sibley (1995) briefly touches upon

impairments has been retained. Where I mention my own impairment, I use the terms 'blind' or 'visually impaired'.

the spatial removal of disabled people from mainstream space, while Bashford (1998) elaborates on this process of 'purifying' everyday spaces with the removal of groups of apparently unwanted people, including disabled people, from public spaces into various spatially segregated institutions. Goffman's (1961) work on *Asylums* provided me with an analytical lens through which to understand the experiences of institutionalised women. The work of Foucault (1979) enriched this process of interpretation; his work has been a significant influence in my understanding of modes of surveillance and the 'production of docile bodies' within the historical context of the institutions, as well as in the contemporary spaces of every day life (see below).

In the current era, disabled people living in the community has become widely accepted as an alternative to institutionalisation (Fine and Asch 1988). The rise of deinstitutionalisation can be attributed to a number of factors, primarily the implementation of 'community care' legislation. The purpose of deinstitutionalisation was to make an individual become an integral part of a local community, living in an autonomous manner (Fine and Asch 1988:273). Thus, deinstitutionalisation was supposed to facilitate a disabled individual's reintegration into community and family life (Gadacz 1994), offering potential opportunities for disabled men and women to share spaces and places of everyday life, become active participants in their local communities and perhaps for women (who seem to have been institutionalised to a far greater extent than men) to become 'real' women; living, loving, having children and being mothers. Ironically 'care in the community' continues to frame disabled people as 'in need of care and protection' therefore, in some respects preventing their participation in interpersonal aspects of life, particularly with regard to disabled women's participation in intimate relationships. I suggest that the extent of change is rather illusory, and that many socio-spatial barriers to motherhood for disabled women remain (many being inherited in more or less distorted forms from the institutional era).

French (1996), Humphries and Gordon (1992) and Potts and Fido (1991), while documenting the embodied experiences of institutionalisation and the process of de-institutionalisation, make a compelling argument for the value and importance of researching and recording disability history. Such an act of 'recovery' provides a means of interpreting contemporary social misconceptions, opening a critical lens on the social positioning of disabled people, especially women. The work of such authors also heightened my own

resolve to undertake a historical review (1793-1910) to ascertain the places and spaces where physically and visually impaired women in the Edinburgh and Glasgow areas lived their lives. This material does not merely contextualise what disabled women say to me about their present-day experiences, it suggests the many ways in which the weight of the past hangs heavy on more contemporary geographies of deinstitutionalisation and so-called 'care in the community'.

Hence, this thesis incorporates a historical element (particularly Chapters 3 and 4) in a deliberate attempt to blend disability history with disabled women's contemporary experiences of sexuality and reproductive choices. In addition, Philo's (1989) work on lunatic asylums led me to explore the micro-geographies within institutional environments and the manner in which the spatial environments were used to segregate and 'control' inmates (see Chapter 3). Robinson (2000) prompted me to consider the implications of surveillance both within and outwith the historical institutional context. Several of the women who I interviewed (see below) offered narratives across different eras in the societal response to disability, encompassing their embodied childhood experiences of institutionalisation and the process and adjustment to deinstitutionalised lifestyles (see in particular Chapter 5, a link chapter for the thesis between the historical and the contemporary parts). The words of these women offer a unique opportunity to reflect upon changing manifestations of supervisory controls over time. In short, although many of the institutions have now closed, even in the twenty-first century disabled women are nonetheless subjected to various forms of spatial segregation and social surveillance. The extent to which the institution has ever gone away, and the depth of social change really ushered in by deinstitutionalisation, is therefore very much open to doubt. The articulations of the past and the present, the continuities as much as the changes in socio-spatial practices, are therefore central to what follows.

Other literatures focus on the society's formulation of appropriate spaces in the contemporary period for behaviours by particular people, such as women, disabled people and, especially, disabled women. Cresswell (1996) provides the basis of an argument grounded in social displacement and bodies being 'out of place'. Although this is not specifically targeted at disabled women, it is wholly applicable, particularly in sexualised spaces. Gillespie-Sells et al (1998), Shakespeare et al (1996) and Lonsdale (1990) raise the profile of

contemporary disabled women's subjection to asexual stereotypes, identifying negative charitable imagery as a source of disabled people's social and sexual oppression. Gow (2000) and Watson (2000) provide evidence of social and sexual oppression of disabled women through social 'infantilisation' of their bodies. While Valentine (1996) and Bell (1995) do not deal with disability specifically, they argue that mainstream spaces are sexually coded so as to 'displace' non-standard sexualities. Chouinard and Grant (1995) also discuss the marginalization of non-conformist sexualities. Butler and Bowlby (1997) and Butler (1999) then take this further, dealing directly with disabled women's bodies and their peripheral presence in sexualised spaces (see Chapter 7).

Although not dealing with disability specifically, Longhurst's (2001) work concerning non-disabled pregnant women's experiences of everyday spaces was both revealing and inspiring, as these paralleled those of disabled women. Her suggestion that pregnant women are subjected to surveillance by 'societal supervisors' was of particular relevance and significance to this study (see Chapters 2 and 8). Sharpe (1999) contends that the highly medicalised and controlled hospital environment has become naturalised in Western culture as the most appropriate place for childbirth; unfortunately, he does not expand on this by considering the spatial relations between the birthing environment and women's bodies. Meanwhile, Chouinard (1999) talks of disabled women's peripheral presence in ableist space. Although she makes no mention of reproductive spaces, the notion of a marginalised peripheral presence is relevant and can be applied to disabled women's 'place' in reproductive spaces. The pioneering work of Thomas and Curtis (1997), Thomas (1998,1997), Wates (1997), Goodman (1994) and Shackle (1994) has raised awareness and initiated a process of documenting disabled women's experiences of maternity environments in specific geographical areas of England. The first three studies are of particular relevance as they are informed by the social model of disability, and therefore did consider the spatiality of maternity environments in relation to disabled women. In exploring these experiences, Thomas (1999) deliberately underlines similarities between non-disabled and disabled women's experiences of reproductive spaces. While this is valid, the ways in which an inaccessible physical environment distinctly disadvantages disabled women in their mothering roles cannot be underestimated or played down, as by doing so we, as researchers, condone inequitable facilities and services to disabled

women.

Significantly, none of the above studies explores the personal journeys of disabled women embarking on pregnancy; they all start near the end of the journey where women have recently given birth to their children. Many important issues are arguably faced before even reaching that point. Gesler and Kearns's (2002) work raises concerns regarding the overwhelming influence of the medical profession in disabled people's lives; this has particular resonance for disabled women's reproductive choices. This influence is borne out in Begum's (1996) study, which provides an important link between women's studies and disability studies. It is important that, where possible, studies should incorporate a holistic approach to women's reproductive lives. They need to commence at pre-conception or early pregnancy if they are to expose the social and spatial influences exerted upon women (and their partners) during the decision-making process of whether to have or not to have children or, perhaps more pertinently, whether to terminate or to continue with a pregnancy. This thesis thus includes narratives from some women who remain at the start of their reproductive journeys, some who embarked on a journey but did not arrive at the destination they hoped for – motherhood - and others, who despite a circuitous route, did finally arrive as parents.

Methods, voices and me

Initial primary research or 'fieldwork' entailed the historical review (for Chapter 3 and 4), much of which was gathered from service providers' documents, such as Asylum minute books, Blind Mission workers' diary extracts and institutional annual reports. In contrast, contemporary elements (for Chapters 6, 7 and 8) were gained directly from women. Considerably more information about the methods employed in both the historical and the contemporary parts of the research, as well as critical reflections upon such methods, is provided in Appendices 1 and 2. I will nonetheless say a little more here about the contemporary research, and about related questions to do with overcoming the absence of disabled women, and also the disabled author, in both this research and other studies more generally.

In the contemporary research, it was intended to seek the views of service providers. One formal and two informal interviews were undertaken, but it

became apparent that service providers strive to protect themselves in a 'cloak' of political correctness, answering in a 'disability-friendly' way. They often followed up by requesting assurance that they had used the 'politically correct' terminology, indicating the possibility that interview responses did not necessarily reflect the reality of the service offered or delivered to disabled women. It was also obvious that, with one service provider steeped in a history of benevolence towards disabled people, an embedded culture of differential treatment of disabled people was ingrained in working practices and, as such, remained unrecognised by staff members. The ideas underpinning this differential treatment simply reinforced traditional stereotypes of disabled women and disabled people generally. Taking all this into account, I decided not to continue interviews with service providers, and instead to seek disabled women's personal experiences of services related to reproduction, sexual health and family planning as a far more useful route into the subject-matter.

Therefore, the contemporary chapters of the thesis (Chapters 6, 7 and 8) rely heavily upon the narratives of twenty-seven women resident in the Edinburgh and Glasgow areas. I should stress that this study is not a comparative study of the experiences of women resident in Glasgow compared to those resident in Edinburgh, although fragments of such a comparison can be inferred from the findings. This study is informed by the social model of disability; I have hence deliberately chosen not to profile disabled women by their impairments. Where women mention their impairments, or the implications of these, I have retained the words they used. Where some prior explanation is required in order for a reader to fully appreciate or make sense of a narrative, I have, at times, provided a thumbnail sketch.

The framework of this PhD needed an examination of theoretical and substantive issues in relation to disability, disabled women and their reproductive choices. Such issues have already been briefly introduced above, and are examined at greater length in Chapter 2. During my theoretical and methodological reading, however, I was constantly confronted by the absence of disabled women or, their depiction in very much a one dimensional way. There was no texture to their lives as 'real' women with multiple life roles, social lives or sex lives. For example, although Lonsdale (1990) offers a useful glimpse of the first person experience of daily life, it is framed in medical model terms, focusing on women's impairments. I also

became increasingly frustrated that women's narratives often seemed to be tagged on as an afterthought; the author's words take centre stage, while the women's words, at best, were relegated to the wings. I therefore deliberately set out to place disabled women centre stage, to let them 'strut their stuff' and to make their voices heard. It was not easy to do this through the historical record, where the women are almost entirely represented through the words of able-bodied others, but the contemporary interviews – as just noted – can begin to rectify this imbalance. Indeed, it is hoped that the women who participated in this study will be involved in presenting the findings of this research through drama – the 'Vagina Monologues' providing the inspiration for such a venture at a later stage.

Another voice that risked being absent from this project was my own. Influenced by the writing of Chouinard (1999) and Moss (1999), though, I began to realise the importance of writing my own experiences into this thesis. Golledge (1993) wrote poignantly of his adjustment to becoming a blind person and the implications of this on his academic work. Framed in medicalised and as such rather negative terms, I was slightly discouraged from doing so. However, Michalko (2002) has been inspirational, writing of his blindness matter-of-factly. He discusses the implications of his visual impairment positively on his academic work. Hence, throughout the thesis I have made mention of both my own visual impairment and the implications of this, particularly on the fieldwork methods and approaches (see Appendices 1 and 2). I also realised the importance of my own personal motivations for undertaking this study, and that I should indeed give voice to my own personal, and at times painful, experiences of pregnancy and motherhood hitherto kept secret and silent. Following Hansen's (2002) groundbreaking example, my reproductive and mothering experiences are intertwined throughout the contemporary chapters, a pseudonym offering me the anonymity afforded to all the women who participated. Where I am willing to share my own experiences of pregnancy and mothering, I make this explicit (see also Chapter 2).

Research questions and a 'map' of the thesis

To conclude this opening chapter I will sketch out the basic contents of the chapters that follow, but let me first clarify my underlying research questions. Although these are starkly posed here, and may even have a 'policy' ring to

them in places, the implications flowing from them spiral theoretically and substantively:

- What are the historic social and spatial influences on disabled women's social roles and reproductive choices?
- How do these historic influences play out in contemporary society?
- Do disabled women encounter barriers to their participation in social and sexualised spaces?
- Do disabled women encounter social barriers to seeking sexual expression and intimate relationships?
- What factors influence disabled women's reproductive choices and how do these factors manifest themselves in disabled women's lives?
- Are reproductive spaces physically and attitudinally accessible to disabled women?
- Are disabled women well-supported in their mothering roles in private and public spaces?

Chapter 2 establishes the theoretical groundwork for the remainder of the thesis. It deals with disabled women's spatial segregation, introducing the consequences for contemporary society and disabled women through theoretically informed narratives.

Chapter 3 provides an overview of the spatial realities and social restrictions placed upon blind and visually impaired women within and outwith Blind Asylums and those associated with blind welfare agencies in the Edinburgh and Glasgow areas between 1793 and 1900.

Chapter 4 illustrates the social and spatial segregation of physically impaired children and women in long-stay adult institutions and those resident in their homes in the Glasgow area between 1874 and 1910.

Chapter 5 offers a unique insight into the personal reflections of two women

on their embodied childhood experiences of social and spatial segregation within an institution and their adjustment to deinstitutionalisation.

Chapter 6, following the chronology of the lives as narrated by contemporary interviewees, demonstrates the spatial segregation of disabled girls and their social displacement from potential adult roles of lover, wife and mother.

Chapter 7 deals with the social and spatial influences on disabled women's access and opportunities to and for sexual expression, and considers their participation in initiating and sustaining intimate relationships.

Chapter 8 deals with disabled women's opportunities to exercise reproductive choices and their access to reproductive spaces. It also incorporates social responses to disabled women in their mothering roles.

Chapter 9 sums up the main findings from the research process, and notes recent positive developments in the profile of disabled parents.

Appendix 1 details the research methods used, providing a summary of research methods used during fieldwork, in particular the methods used to access archival documents.

Appendix 2 details my personal reflections as a disabled woman involved in disability geography research and my commitment to facilitating an inclusive research process. I also reflect upon the implications of my visual impairment when interviewing fellow blind women.

Chapter Two

Contextualising the Study:

Disability and the Changing Spaces of Reproduction

Introduction: disabled women, sexuality and spatial separation

Throughout my pregnancy in 1998 I was subtly, but more often explicitly, made aware that my participation in childbearing and mothering was not expected or welcomed. I learned of my 'out of place status' through health professionals questioning my ability to care for my unborn child, strangers in the street expressing their surprise at my visibly pregnant body, and all sorts of people enquiring as to the likelihood of my baby inheriting my eye condition. These encounters were arguably all manifestations of social disapproval at my pregnancy, although I was unable to identify or name what was occurring at the time.

For some disabled women, social disapproval at their participation in reproduction may manifest itself in a distinctly spatial response, as Litwinowicz's experience illustrates:

She [ward sister] said they were going to put me in the corner of the ward next to the nursery, so that I would have room to move about in my wheelchair ... So I was moved and the curtains were pulled round me ... After the third day I felt better, I asked the nurses if I could have the curtains drawn back but I was told it would be better to leave the curtains as they were for the time being (Litwinowicz 1999b:78).

It would seem from both my own and Litwinowicz's experiences that our impairments, combined with our unexpected presence in spaces associated with reproduction, evoked fear and unease in non-disabled people (Chouinard 1999). This response may be prompted by a combination of factors, including the historic spatial segregation of disabled women from mainstream society, and the related social conceptualisation of disabled people through the medical and social models of disability.

A medical perspective on disability is synonymous with the nineteenth century. During this time there was a rapid expansion in institutional provision, and admission criteria became based primarily on an individual's (presumed 'deviant') physicality. As the century progressed, institutions and their associated medical professionals became increasingly powerful agents in

the development and adoption of medicalised categories that defined individuals who fell outwith the accepted parameters of normal function and behaviour as 'defective' and 'abnormal' (Thomas 1999b, 2002b, Braddock and Parish 2001, Mason 1999). Disability rapidly gained status as a field of specialist medical expertise as medical intervention to normalise defective bodies became socially accepted and expected. Where normalisation was not possible, individuals were thought to be in need of care (Braddock and Parish 2001, Barnes 1997, Crow 1996, French 1993, Golledge 1993, Morris 1991). The medical model locates disability within an individual's body, but it ultimately rests upon a social judgement (Abberly 1997, French 1994a, Morris 1994a, Finkelstein 1993) based on outward signifiers of 'disability' and social perceptions about the disabling nature of the visible impairments (Dear et al 1997).

This is in direct contrast to the social model devised by the disabled people's movement, which locates disability in society, rather than so obviously in the body itself, and the term 'disability' is used to describe disabling social barriers such as environmental, attitudinal and institutional constructs that may negatively affect disabled people's equality of access to participate fully in society (Barnes and Mercer 2004, Oliver 2004, Thomas 1999b, 2002a, 2002b, Vernon 1998, Crow 1996). In the new vocabulary of disability activism, therefore, 'impairment' is the term used to describe the functional limitation that affects an individual's body, whereas 'disability' now becomes the loss or limitation of opportunities to participate in local communities and wider society as a result of direct or indirect discrimination (Vernon and Swain 2002, Thomas and Corker 2002, Thomas 1999b, Oliver 1996, French 1994a). Hence disability and impairment are inextricably linked and interactive, and disability discrimination is social – and, as will be argued through this thesis, also spatial – exclusion on the grounds of impairment (Thomas 2004, Freund 2001, Swain and French 2000, Barnes 1994).

During the nineteenth century the customary segregation of disabled women into all manner of institutions rendered them part of a population considered to be 'incapable and harmless' (Goffman 1961:16). The incapacity referred to by Goffman is presumably in relation to a lack of expectation that disabled women would fulfil any social roles. As members of the 'cared for' population, these women were hence 'rendered genderless and objectified' (Meekosha 1998:165), a theme to be revisited repeatedly in what follows. The historic

spatial segregation of disabled women, alongside demeaning charitable images produced by institutions, are now thought to have caused disabled women considerable harm by perpetuating demeaning stereotypes and misconceptions (French 1994b). These so-called 'harmless' individuals have thus had serious 'harm' visited upon them as a result. Pitiful portrayals, compounded by a medical model perspective, have resulted in disabled women being widely conceptualised as fragile, weak, passive and dependent. The child-like attributes routinely associated with disability have come to parallel certain social understandings and stereotypes of femininity, but are at odds with accepted notions of adulthood and maturity (Barron 1997, McNamara 1996, Morris 1993b). In Western society, disability and femininity thus end up inextricably entangled (Thomson 1997b), and Lonsdale (1990) and French (1994b) suggest that gendered attributes of passivity and dependency may render perceived impairment more socially acceptable in females. The implications for 'real' disabled women have far reaching consequences. The notion of 'dependency' is underpinned by a social infantilisation of disabled women, and as such, they are not accredited with adult status. Their bodies, perceived as weak, fragile and hence sick, are often not seen as 'beautiful' or 'attractive'. Disabled women are often rejected as potential suitable sexual partners. Moreover, their fragile and weak bodies are often not regarded as suitable or capable of reproduction; of conceiving, sustaining a pregnancy, giving birth or fulfilling a mothering role.

Contemporary society places a high value on physicality, where women are socially identified and defined by their bodies: non-disabled women by the sexualised parts of their bodies, and disabled women by their physical difference or impairments. The emphasis placed on physicality has constructed disabled women as substandard, unattractive and unsuitable sexual partners (Wendell 1997, Vernon 1996, Fine and Asch 1988). Consequently, while non-disabled women have been sexually objectified, on the contrary, disabled women have been asexually objectified (Asch and Fine 1997), indicating a social discomfort or distaste at the idea of disabled women's sexuality (Thomson 1997b, Wates 1997, Wendell 1997, Shakespeare et al. 1996, Morris 1994b, Campion 1990).

While the women's movement has been underpinned by the key standpoints of equality of social status for women and liberation from traditionally feminised divisions of labour, an argument against biological determinism has

been at its core. For many disabled women, however, arguments for liberation from oppression centre around recognition of their embodiment as *women*, as adult sexual beings with a possible reproductive function (Armstrong 1999, Collins 1999, Barron 1997, Meekosha 1998, Kallianes and Rubenfeld 1997, Blackford 1993). In many respects the disabled women's movement and the feminist movement have much in common, as both centre on women's autonomy in their lives and control of their reproductive capabilities. In part, though, the readiness of disabled women to embrace their embodied womanhood, so often denied them in other spheres, can create tensions in their relationship with a 'constructionist' feminism suspicious of any, as they might see them, bodily 'essentialisms'.

Social barriers to (the perception of) disabled girls or young women as potential sexual beings, manifest themselves in a silence about adult aspirations, especially any related to the likes of sexual intimacy and reproduction (Contreras 1999):

... in the whole of my childhood I can only remember one reference to my future adult life. This was a conversation between myself, my sister then aged about 12, and my mother ... a remark was made about my sister becoming an aunty. Her response was 'Oh yes, and *who* is going to make me an aunty?' My mother said 'Sssh!' and that was it - that was the only time my future adult life was ever referred to (Mason 1992:114, cited in Morris 1994b:214).

While the women's movement has campaigned for the liberation of women from sexed stereotypes of mother and wife, disabled women struggle to be recognised as suitable sexual partners, child-bearers and capable mothers (Wates and Jade 1999, Thomas 1997, 1998a, Blackford 1992, Oliver 1990). Although housekeeping, child bearing and mothering are traditionally feminised roles, they are *not* traditional roles for disabled women, who in the main have historically been denied these roles (Asch and Fine 1997, Barron 1997, Morris 1994b, Fine and Asch 1988). Possibly as a consequence of multiple social barriers, disabled women are less likely than non-disabled women to fulfil the sex stereotyped roles of lover, wife and mother (Asch and Fine 1997).

In most societies, non-disabled women's bodies may be reductively understood as 'breeding machines reproducing the species' (Meekosha 1998:170). Non-disabled women are expected, encouraged and subtly

pressured to fulfil their reproductive capacities (Campbell 1999). However, particularly in Western societies, societal expectations in relation to the reproductive capacities of disabled women are inverted, and reproduction is 'not expected, discouraged and proscribed' (Kallianes and Rubenfeld 1997:204, Litwinowicz 1999a, Thomas and Curtis 1997, Thomas 1997, 1998a, Fine and Asch 1988). Non-disabled women who choose not to fulfil feminised roles are often stigmatised as deviant or rebellious (Campbell 1999, Lonsdale 1990), whereas, for some disabled women, the lack of societal expectations on them to fulfil traditionally feminised roles may be liberating, enabling them to lead self-determined life styles (Shakespeare et al 1996, Lonsdale 1990, Fine and Asch 1988). The population of disabled women is nonetheless diverse: while many may have no desire to engage in sexual activity with men, not aspiring to child bearing and mothering (Campbell 1999, Thomas 1998a), there are others who do possess such desires and aspirations. Moreover, an abject lack of expectation may also prompt some disabled women very explicitly to reclaim feminine identities and roles culturally denied to them (Thomson 1997b).

It would seem that the spatial segregation of disabled women, as linked to the medical model of disability, has had far-reaching consequences in terms of cultural treatment, perceptions and understandings of their lives. Spatial segregation and subsequent social absence have undoubtedly contributed to the development of social ideologies that infantilise disabled women, constructing them as unsuitable sexual partners, child-bearers and mothers. In this chapter I intend to illustrate the effect that such ideologies have had on disabled women's access to social space, sexual citizenship, reproductive freedoms and mothering. I propose to confront these issues through three empirical moments:

- 19th Century institutionalisation,
- Mid 20th Century institutionalisation,
- Early 21st Century, institutional legacy

These empirical moments will be reflected upon here through theoretical lenses, and they will then be developed at length, drawing upon a diversity of archival and interview sources, in the chapters that then comprise the heart of the thesis.

Nineteenth-century institutionalisation: sanitising bodies and spaces

The notion of institutionalisation as a spatial strategy for 'problem' populations began before the nineteenth-century. However, the nineteenth-century took the idea of the institution, of socio-spatial exclusion, and turned it into a gigantic conjoint medical and moral experiment – in the course of which it became accepted as 'the norm' that 'misfits' of all sorts are *not* to be found in everyday spaces of living and working, but rather removed to specialist spaces of shelter, provision, care, therapy and correction. Some institutions with the goal of the moral and/or physical reform of inmates prior to their return to the workforce; others with the goal of simply getting the 'nuisances' out of the way of capitalist enterprise. Social policy also implied a notion of removing 'misfits' from capitalist enterprise in the form of the Poor Law of 1601 that identified disabled people as incapable of financially supporting themselves (Barnes 1997). Social policy therefore, contributed to the development of a hierarchy of 'deserving' and 'undeserving' poor based primarily on physicality and (perceived) morality of the potential recipients.

The growth of industrialisation in the nineteenth century simultaneously produced impaired bodies and displaced them from the workforce (Oliver 1990, 1993). By the latter stages of the century, some forms of factory work had become the preserve of non-disabled men, while women, children and disabled people increasingly shared a common social status as non-labour (Gleeson 1999:105). Capitalist society regarded impaired bodies as incapable of competitive productivity. As a result, disabled people were excluded from the workplace. Unable to earn a living, they were regarded as social burdens (Barnes 1997, Oliver 1993) forced to rely on family members, parochial relief or institutions for financial support. While more could be said about the capitalist imperatives at work here, following the example of Gleeson (1999, esp. Chaps.4,5,6), I wish to focus first on the sanitary and eugenic drivers of institutionalisation for disabled people, particularly disabled women. Then I will say more about the experience of institutionalisation itself, introducing the strategies of spatial separation, surveillance and control, proliferating thanks to and behind institutional walls.

The growth of industrialisation, urbanisation and increased population during the nineteenth century combined to create public health problems. The sanitary reform movement arose from public health concerns (Bashford

1998). The sanitary reform movement, initiated in the domestic sphere, involved the participation of women through their roles as wives and mothers in the sanitising of domestic space (and bodies) as the means of producing a healthy family and therefore a healthy nation (Craddock 2001). Women's central positioning in sanitary reform was reflected in their elevated cultural status, predicated upon a supposed superior morality and religiosity (Bashford 1998). At the same time, sanitary reformers likened bodies to houses, both to be sanitised along similar hygienic principles, the two being perceived as synonymous or at least mutually co-constitutive:

The lack of distinction between physical environment, bodily condition, and moral well-being meant that the cleanliness or dirtiness of any of these elements could influence the other (Bashford 1998:17).

Thus, a dirty home threatened the onset of physical disease and supposedly signalled a decline in moral standards, while a dirty body was perceived to be capable of fouling or polluting the immediate environment (Craddock 2001, Bashford 1998, Barret-Ducrocq 1992). The constant conflation of the cleanliness or dirtiness of the domestic environment with the bodily condition of those who inhabited it had consequences for how 'the woman of the house' might be judged. The relative cleanliness of home spaces appear to have been considered a tangible expression of a woman's moral stature, and by implication, a signifier of her femininity and suitability as a wife and mother. A disabled woman unable to undertake physically demanding housework, and hence failing to meet these exacting 'standards' of home hygiene, was hence open to cross-coding as 'immoral' and a likely poor wife and mother.

When women acquired impairments, disease or illnesses, the standard social response was spatially to segregate them in institutions, the ambition being to rid them of their physical 'imperfections' if at all possible and, crucially, to reform their moral characters (Craddock 2001). Sanitary reform, therefore, always involved some sort of moral reform, where physical and moral cleanliness were conflated with health, while physical and moral dirtiness were associated with ill-health (Bashford 1998). Hence, while sanitary reform positioned non-disabled women centrally in the domestic sphere, undertaking sanitising tasks and feminised roles, disabled women were displaced from domestic spaces and associated roles. To put it another way, physically 'deviant' bodies represented agents of contagion, dirtiness and immorality,

and were subsequently constructed as inadequate sanitisers, wives and mothers. Institutionalisation physically removed such women from both the domestic sphere and spaces of everyday life – thus sanitary reform leaked beyond the private domesticated environment to have ramifications for who would be allowed into mainstream public spaces.

While sanitary reform arose out of public health concerns, eugenic thinking arose from concerns about population health (Davis 1995, Thomson 1997a). Sanitary reform arguably heralded the emergence of the eugenics movement as a means of 'perfecting society' (Thomson 1997a:35). In eugenic terms, disabled people were categorised as 'evolutionary defectives' (Davis 1995:31); and this category included both visually and physically impaired people. Eugenics aimed to suppress disabled people by, in effect, artificially aiding or speeding up processes of 'natural selection', since disability was regarded as a mark of imperfection that would – or at least – should ultimately be obliterated by the 'survival of the fittest' (Sibley 1995). Consequently, as eugenics gained social acceptance, its focus on hereditary improvement gained prominence and the elimination of 'defectives' became of paramount importance in the improvement of population health (Fawcett 2000, Thomson 1997a, Davis 1995). While the sanitary reform movement viewed 'deviant' bodies as capable of polluting a room, a building or public space, eugenic thinking perceived them to be capable of polluting genetically, adversely affecting population health. In this context, disabled bodies, especially female bodies, were perceived to be physically, morally and genetically threatening to population health and hereditary improvement. Unsurprisingly, the growing influence of eugenic ideas about the quality of the population identified disabled people as a social problem, and legitimated the development of a system of life long segregation regardless of an individual's impairment (Chappell 1997). The spatial strategy of institutionalisation as a means of managing these disabled bodies then 'leaked beyond the institutional boundaries to influence broader strategies for managing populations' (Philo 2001:2). In essence, the ethos of the eugenics movement may be regarded as a spatial strategy of population management.

Institutionalisation of disabled women facilitated their spatial separation from origins, communities and families (Finkelstein 1993, Shapiro 1993, Humphries and Gordon 1992). Institutional admission tended to result in their life-long spatial segregation from mainstream society. The daily activities of female

inmates, whether involved in education, work, eating or sleeping, all took place within the institutional environment. Goffman (1961) refers to this as the condition of a 'total institution':

... a place of residence and work where a large number of like situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life (Goffman 1961;11).

While the term 'total institution' could be applied to the four institutions cited in this thesis, it seems most appropriate to apply the term to Broomhill and East Park Homes, where there was virtually no opportunity for the physically impaired inmates to leave the spaces of the institution or to escape the view of their guardians. The Edinburgh and Glasgow Blind Asylums might be better described as 'gated' institutions (Hannah 1997), a term that seems more applicable, given that there was some (albeit heavily) restricted access and egress of inmates-. Locked gate entrances still facilitated a control and monitoring of bodies within the institution grounds, but some inmates, predominantly males, were allowed to leave at the end of the working day to return to their family home or lodgings. Revealingly, though, female inmates were expected, and in some instances forced, to remain resident in the institution, and so in practice for them the effect was definitely more of a 'total' than a 'gated institution'.

Sanitary reform, eugenics and the emergence of medicalised categories of 'normal' and 'abnormal' physicality all fuelled the institutionalisation of disabled people, particularly those with physical impairments (Braddock and Parish 2001). Institutions served to classify, organise and control bodies (Holloway and Hubbard 2001); indeed, the nineteenth-century witnessed the rise of well-developed methods for using institutional spaces as carefully managed tools for intervening in the surveillance and supervision of inmates, imposing upon them pressures to 'reform', to adopt versions of what is considered 'proper' conduct on the outside. As Foucault's (1979) scholarship has so persuasively demonstrated, surveillance was widely used within the institutions as a method of disciplinary control. Bentham's infamous Panopticon was primarily adopted in the design of prisons, if never in pure form, but facets of it recurred throughout countless nineteenth-century institutions comprising what Foucault memorably termed the 'carceral archipelago' (Foucault, 1979:297). The circular layout of cells around a

watchtower enabled surveillance of inmates in the Panopticon, and keepers were kept out of the sight of those being watched. Therefore, inmates could never be certain if they were being watched or not. This uncertainty, it was presumed, would encourage inmates to internalise the possibilities of an external gaze, and thereby regulate their own behaviour and actions (Holloway and Hubbard 2001, Robinson 2000, Hannah 1997, Sibley 1995, Philo, 1989, Driver, 1985, Foucault 1979).

Although the blind asylums were not built on or at all explicitly adapted to Bentham's panoptic design, elements of this type of surveillance were evident, creating the somewhat ironic notion of the 'all-seeing eye' surveying an institution in which most inmates could not even properly see one another. Inmates, predominately females, were subjected to three modes of surveillance – silent, chaperoned and noisy – as a means of controlling their behaviour. East Park and Broomhill Homes were former family homes and hence were not built with a panoptic design, although extensions to Broomhill Home reflected a slight panoptic influence in their design. Inmates of East Park were subjected to constant surveillance by the nursing staff. Inmates of Broomhill Home were subjected to surveillance by the nursing staff and members of the Ladies Auxiliary, who from time to time, 'inspected' the inmates and the standard of cleanliness within the Home.

By the mid-nineteenth century, a small number of females lived outwith the blind asylum in private lodgings. In these circumstances women were subjected to a form of silent surveillance, sighted neighbours receiving payment to observe the conduct of the women, and to report any indiscretions to the asylum directors. The silent nature of the surveillance would have rendered it virtually unverifiable by the women, unable as they were to see if they were being seen, which unwittingly created exactly that state of unequal opportunities to see, lying at the heart of Bentham's design. The uncertainty of the observers' gaze most likely contributed to precisely the self-regulation of behaviour, and to the internalisation of institutional rules, that Foucault (1979) reckons to be productive of obedient, docile bodies and minds. Surveillance of female resident inmates' attendance at church was also facilitated by the imposition of a spatial strategy, since they had to sit in particular pews allocated for blind women. This means that, without a word being said, a space on said pews would indicate one of them being absent from the service. The silent nature of the surveillance here increased

uncertainty, and possibly influenced both their regularity of attendance and possibilities for the censure of their (mis)behaviour by female inmates. Therefore, while surveillance had a visual component inaccessible to blind people, it also had a spatial component, where place and space were contributory elements in the surveillance process (as Foucault, 1979, explains when discussing the 'art of distributions' in disciplinary regimes: see also Philo 2001).

Female inmates, resident in the asylum house, were subjected to chaperone surveillance when they were permitted, as a group, to take a walk guided by a sighted servant or subordinate member of staff. Although chaperone surveillance gave a clear indication to the women that their behaviour was being observed, the extent to which this control was exercised by differing staff members created potential opportunities to escape the gaze of the supervisor. For example, some women 'escaped' during the daily one hour walk. Others, considered capable of negotiating the streets, were allowed to go shopping unsupervised. However, changes to the rules of the female asylum ended this limited freedom. From 1842 (this 'rule' was relaxed by 1864), when out on the daily walk, all the women had to remain together for the duration of the walk and be accompanied at all times, 'deviation' from the rule would be reported to the directors (EBAMB 1835-1849:174). Within the institution, surveillance of inmates took a number of additional forms. During financially buoyant times, sighted men and women were recruited to supervisory positions, but in times of financial hardship, inmates were recruited to workshop over-seer positions with associated surveillance responsibilities. By implication, surveillance in these cases was not undertaken solely by visual means, and visually impaired overseers may well have relied upon audible cues to interpret the situation. For example, noise levels within the workrooms most likely acted as an indicator of productivity, quietness equating with high productivity and active conversation with low productivity, although these 'noisy' cues may not necessarily have been reliable indicators of diligence. Since all inmates were visually impaired, audible cues from supervisors let them know that they were being watched. Hence, noisy surveillance relied upon verbal engagement between observers and those being watched (Robinson 2000). Verbal cues from supervisors confirmed their observation, similar to the way in which an inmate's glance to see if there was a figure in the watchtower verified the presence of surveillance. Regardless of the nature of surveillance, blind women undoubtedly censured and self-

regulated their behaviour in response to the supervisory gaze.

Mid-twentieth century institutionalisation: normalising the distance from everyday life

The majority of physically disabled children admitted into institutions came from working-class families. Many came from the poorest of backgrounds; living in the slums with their physical impairments often associated with poverty and deprivation (Humphries and Gordon 1992). Such children were thought, by virtue of their family background, to be ignorant and immoral (similar to attitudes of sanitary reformers). Hence, one of the main aims of institutionalisation was to reform the moral character of the inmates. Within children's institutions visiting by parents was restricted. Any parents considered to be a poor moral influence on the child were prevented from visiting.

Physically impaired individuals' physical appearance or behaviour was often regarded as offensive, therefore, spatial segregation became entrenched as a positive solution to a variety of 'problem' populations (Thomas 2002b, 1999b), disabled people included. This notion, born in earlier centuries, given sanitary and eugenic spins by the nineteenth century, still persists well into the twentieth century and includes both the state and charitable sectors. The pace of institutional change is incredibly slow. The theoretically informed narratives of this chapter are strikingly similar to contemporary experiences of disabled women (see Chapters 5 and 6).

Whether a particular total institution acts as a good or bad force in civil society, force it will have, and this will in part depend on the suppression of a whole circle of actual or potential households (Goffman 1961:22).

Institutions wielded their influence in creating social understandings of the purpose and workings of segregated spaces. These were constructed as absolutely necessary, efficient but nonetheless caring and compassionate places, where inmates lived out their lives peacefully and happily, even when the reality of the situation may have been quite different (see Chapter 5) (See for example French 1996, Humphries and Gordon 1992, Potts and Fido 1991). Something of the horrors of a mid-twentieth century institutional regime is illustrated below:

At seven precisely a loud hand bell rings.
We strip off our beds and collect our wash things,
Then queue up in silence is what we must do,
First for a basin, again for the loo.
Then get dressed in haste; we must each make our bed
Before seven-thirty when prayers will be said.
We solemnly kneel at the sound of the bell
And silently pray for release from this hell
(Extract of a poem by Susan Nicholis 1989, cited in French and Swain 1998:3).

The force exerted by institutions was to translate medical model concepts of disability into cultural beliefs and understandings of disabled people (Barnes 1997, Barnes and Mercer 1996). This force perpetuated ideologies of disabled people as distinctly different from non-disabled members of mainstream society (Linton 1998). Portrayed as dependent upon others, in need of expert care and unable to participate in mainstream society, institutionalisation was presented as necessary, unavoidable and legitimate (Hannaford 1985). This medicalised force fuelled the momentum of institutionalisation that sustained disabled peoples' social removal and consequent absence (Braddock and Parish 2001); in short, while society shaped space, space shaped society (Cresswell 1998). Hence, disabled people's absence from spaces of everyday life, as a consequence of their spatial segregation, became 'normalised' in mainstream society.

Humphries and Gordon (1992) suggest that the main purpose of institutionalisation was to render individuals devoid of their own personalities, to create an obedient group, perhaps what Foucault refers to as the production of docile bodies (Foucault 1979). In a similar vein, Goffman (1961:22) refers to total institutions as 'forcing houses for changing persons'. The internal force within institutions was exerted through regulations and the strictly proscribed daily routine that demanded inmates' total compliance. In order to survive within segregated spaces, inmates had to learn to live within a rigid system (French 1996). Goffman encapsulates the rigidity of regimes and regulations within institutions when he remarks that 'what is prison-like about prisons is found in institutions whose members have broken no laws' (Goffman 1961:11). Studies documenting the embodied experiences of institutional 'survivors' have similar themes of discipline and punishment, where former 'inmates' frequently parallel their experiences to that of prisoners; on admission having their hair cut short, deloused, bathed and

issued with a uniform (French 1996, Humphries and Gordon 1992, Potts and Fido 1991). Similar to prisoners, inmates lived in the institution and had restricted contact with the world outside, whereas staff remained socially integrated in mainstream society. While staff were positioned as authoritative figures, with expertise in the management of disabled people, inmates were positioned as submissive and docile (Goffman 1961). The force of the institutional doctrine that framed inmates as incapable of living independent lives became entrenched in both everyday working practices and staff perceptions of inmates (Oswin 1998). More insidiously, an associated disability industry evolved around the twentieth-century institutionalisation of disabled people, in the form of support staff and suppliers. Where an institution was a local employer, any changes that threatened staff livelihoods were perhaps met with resistance: for example, deinstitutionalisation of inmates would decrease the need for staff in an institutional setting. In effect, staff had a vested interest to keep inmates in their 'place' (Oswin 1998), while inmates themselves may also have resisted change as they had become 'institutionalised' and unable to envisage a home elsewhere. Deinstitutionalisation did not begin in earnest until the late-1950's. Most significantly for those institutionalised at a young age, the segregated environment constituted their world (Oswin 1998, Goffman 1961), and they had little or no idea of life outwith the institution. For such individuals, their social and spatial exclusion meant that they were unfamiliar with the conventions of social interactions and daily living skills. For example, inmates were not in the habit of making decisions or handling money, and this lack of basic life skills effectively rendered them unable to live independent lives. Institutionalisation hence prevented inmates from keeping pace with social changes, and Goffman (1961:22) refers to this as a process of 'disculturation'.

Inmates were subjected to treatment similar to that of social offenders, including enforced removal from their family and wider society for long periods of time or, in some cases, for the remainder of their lives (Shapiro 1993, Potts and Fido 1991). Individuals, particularly children, were sent to residential special schools or, during outbreaks of polio and tuberculosis in the 1950s, were admitted into institutions that treated their impairments or conditions far away from their families and local communities (Oswin 1998). As a result, family ties became broken (Mason 1999), as illustrated by Sadie's experience:

I caught the polio virus in 1934, I was then fourteen months old and like many others my parents did not think I would survive, but I did ... My parents ... were advised to take me to a particular Children's Home in Glasgow. I was immediately taken from them and there started my life in residential care. I do know that it deprived me of my childhood life with my family (CLIG 2000: no pagination).

The emotional consequences for inmates of such separation from home and childhood were ignored, possibly because the individuals involved were regarded as being emotionally as well as physically different. Furthermore, with the emergence of medical interventionist approaches within institutions, inmates were perceived to be partly responsible in the process of altering their own physicality. Those who co-operated by wearing prosthetics or experimental technologies - for example, the wearing of prototype contact lenses - were rewarded as a result of perceived improvements in their physical appearance or function; those whose conditions did not physically alter were deemed to be unco-operative or lazy and therefore deserving of punishment (French 1996).

On admission to an institution, individuals were stripped of their individuality and often forced to alter their physical appearance, as noted by Humphries and Gordon:

When I first arrived ... she [school nurse] cut my hair short, right above the ears (Humphries and Gordon 1992:68).

They were also expected to surrender their personal items of clothing in exchange for one set of plain, usually worn, clothes identified as belonging to the institution (see Chapter 6). In special schools, these clothes formed the school uniform, and therefore everyone was similarly dressed (they were rendered 'uniform'). Moreover, the clothes were marked with a number that was often used to identify the wearer rather than their name, as noted by French:

They wanted us to look very plain. Everything was passed down, you were lucky to get anything new. The shoes were awful, only once do I remember getting a new pair (French 1996:38).

Similar to prisoners, inmates were simply identified as a number:

The first day you got there, you changed into the school uniform and your own clothes were put in the wardroom. And to add insult to

injury, we were each dumped with a number. Mine was forty-three, prisoner forty-three sort of thing, and I kept that number for seven solid years (French and Swain 1998:4).

No wonder that they felt lost, perceived as insignificant beings, as Miller and Gwynne suggest:

... society has effectively washed its hands of the inmates as significant social beings (Miller and Gwynne 1972, cited in Finkelstein 1993:35).

Inmates, including those in children's institutions, were seemingly expected to live out their entire lives within an institutional environment. Inmates were not perceived as capable of attaining adult status, and were therefore given little, if any, preparation or education to enable them to live independently in mainstream society (French and Swain 1998). Long-stay institutions functioned as warehousing facilities for disabled people (Linton 1998), and at worst were 'merely storage dumps for inmates' (Goffman 1961:73). For many disabled people incarcerated in institutions, their spatial corporealities, compounded by attitudinal and physical barriers, prevented them from living ordinary lives in mainstream society (Hannaford 1985).

Twenty-first century: the socio-spatial legacy

The historic spatial segregation of disabled women has nurtured a social acceptance of their absence from mainstream life. This social absence created difference, and, labelled as different, disabled women have been treated accordingly (Philo 1989). Differential treatment of disabled women persists, and it does not necessarily just occur outside everyday communities, but frequently at the very centre of communities, in everyday places and spaces (Ravaud and Stiker 2001), in fact wherever disabled women and men are found in an era that, in principle at least, has accepted the imperative to 'do away with institutions' such as hospitals, homes and schools for disabled individuals. The 'idea' of deinstitutionalisation was prompted by the return of injured ex-service men from the second world war. Hospital wards were thought to be inappropriate places to consign these men for the remainder of their lives (although at the time many disabled people lived in hospital wards for 'young chronic sick', geriatric wards and psychiatric hospitals). This idea of disabled individuals living in the community led to a more formal policy approach to deinstitutionalisation in the 1950's with the implementation of 'care in the community'. However, deinstitutionalisation and 'care in the

community' did not gain pace until the later years of the last century (Morris 1993a). Following Iris Marion Young (1997), we could refer to this differential treatment as a form of 'cultural imperialism', wherein disabled women, as various other non-conforming groupings, are rendered invisible at the same time as they are marked out and stereotyped. Culturally imperialistic groupings, including here much of non-disabled society, 'project their own values, experience, and perspectives as normative and universal' (Young 1997:219, Holloway and Hubbard 2001), to the detriment of anybody who does not square with such supposed norms and universalities. It hence seems that, even in the twenty-first century, disabled women's participation in society and presence in mainstream space remain unexpected and often unwelcome (Chouinard 1999).

It would appear that, along with the deinstitutionalisation of disabled people, some forms of disciplinary control have also leaked out beyond the institutional boundaries (Philo 2001) and are now manifested in contemporary society in everyday spaces. Indeed, Foucault (1979:211) anticipated as much, ironically even using the term 'deinstitutional' in this context:

Disciplinary controls have a tendency to become deinstitutionalised, to emerge from the closed fortresses in which they once functioned and to circulate into a 'free' state; the massive, compact disciplines are broken down into flexible methods of control, which may be transferred and adapted (Foucault 1979:211).

Just as the gaze of the supervisor within the institution conveyed disciplinary power and the 'place' of the inmate, similarly, an onlooker's gaze in contemporary society reflects differential power relations and the dominant culture's interpretation of (in this instance) disabled people's 'place' (or lack of it) in social space and order (Cresswell 1998, Sibley 1995). The gaze today arguably covers just as much freight as it ever did, possibly even more so through being so obviously steeped in negative emotions, suggesting that the recipients of said gaze should, quite simply, not be present in the spaces concerned (the street, the park, the shop, the cinema, and so on). Thus:

The power of the onlooker's gaze to control, limit and patrol the disabled person is brought to the fore. Accompanying the gaze are the welter of powerful emotional responses. These responses can include horror, fear, pity, compassion and avoidance (Davis 1995:12).

The longer-term segregation of disabled people has undoubtedly contributed

to this pervasive social fear of physical difference. The presence of 'deviant' bodies in the spaces of every day life is met with glances, gazes, stares and questioning – and any question can be asked to satisfy the curiosity of the onlooker (Chouinard and Grant 1997, Thomson 1997a, Keith 1996, Davis 1995, Morris 1994a). These bodies require explanation in public space; what is the nature of the impairment, when and how did it happen and what are its effects? (Davis 1995). Etiquette regarding accepted social interaction is dispensed with:

People see a damaged exterior and therefore feel free to ignore the normal social conventions which tell us we must be silent about what we see as negative attributes in others (Keith 1996:73).

For women, the gaze or the intensified form, the stare, renders the disabled female body as defective, unattractive – an 'icon of deviance' (Thomson 1997a:26) – and therefore unsuitable as a sexual partner (Wendell 1997). Moreover, the onlooker's gaze defines disabled women's bodies as out of place in mainstream space, and may influence these women's subsequent behaviour and personal geographies (Longhurst 2001, Keith 1994).

Longhurst (2001) writes of pregnant bodies being viewed as out of place because they may be regarded as out of control bodies (threatening to vomit or leak bodily fluids), ones sometimes considered to be ugly by others, that provoke unease in public spaces. Participants in Longhurst's study spoke of feeling 'under surveillance' in public space, conscious of 'stares' and 'glances' from members of the general public, resulting in the women's withdrawal from public space. 'It seems that being defined by being looked at is central to this sense of confinement' (Longhurst 2001:37). Therefore, for disabled and pregnant women, the onlooker's gaze conveys that their presence in mainstream space constitutes inappropriate behaviour and an unwanted state. Moreover, surveillance as a means of disciplinary control is manifested in contemporary society through so-called 'societal supervisors':

The behaviour of pregnant women is frequently policed not just by health practitioners but also by employers, colleagues, neighbours, friends and loved ones. People frequently regard themselves as societal supervisors of pregnant women's behaviour (Longhurst 2001:58).

The gaze of the social supervisor may cause pregnant women to alter their

behaviour to comply with what is expected: namely, to confine their pregnant bodies in the private domestic space until their pregnancy is over, when they will presumably be free of the supervisory gaze. For disabled women, rarely free of social surveillance, the controlling effects of the social supervisory gaze may have far greater potency, possibly affecting their presence in mainstream space, and ultimately their participation in sexual citizenship, child-rearing and mothering.

Disabled people have only recently entered everyday life through the process of deinstitutionalisation initiated in the late-twentieth century (Linton 1998). Disabled women are hence more likely than before to be living in the community, and to have opportunities to form sexual relationships (Wates 1997). However, the erroneous association of impairment with dependence makes it difficult for non-disabled society to imagine a disabled woman at the centre of family life in a parental role (Wates 1997, Morris 1993a). As Thomas and Curtis (1997:203) put it:

The dread spectre of the unsuitable or inadequate mother is not far beneath much of the discussion about disability and reproduction.

Disabled women may either be encouraged and supported or discouraged and dissuaded in their reproductive choices (Finger 1985, Morris 1994a, Begum 1996) by societal supervisors around them (see Chapter 8). Some women may be deterred or prevented by the supervisory gaze, narrow stereotypes of motherhood and internalised messages of disapproval from pursuing a desire to parent, or even to attain sexual citizenship. Mary Duffy's poem illustrates the internalisation of subtle supervisory messages that result in self-policing and censure of her reproductive capabilities:

i know i am not expected to have children.
i don't know how i know, i just do.
Nobody ever said anything:
It's probably what they didn't say
that made the difference
(Duffy, cited in Keith 1994:29).

Conversely, attainment of sexual citizenship, pregnancy and parenting may be interpreted as acts of defiance; resisting the power of the gaze and the social ordering process that this invokes. By embarking on sexual citizenship, pregnancy and parenting, disabled women enter spatial and emotional territories historically and culturally constructed as exclusive domains of non-

disabled women.

Thomas's 1997 study points towards the nature of the emotional territory of motherhood, and to the power of the social supervisory gaze:

Disabled women really do feel under surveillance, and that feeling is usually well founded because disabled women are often assumed by professionals and lay people (often including close relatives) to be incapable unless they can prove otherwise; guilty until proven innocent (Thomas 1997:636).

In subtle and explicit ways, social supervisors may attempt to preserve the role of mother for non-disabled women who are socially considered to be appropriate and capable. An example of this is illustrated by Jo Litwinowicz's experience when a representative of a family planning organisation advised her to terminate a much wanted pregnancy on the grounds of her impairment and presumed unsuitability as a mother:

You do realise that when your child can walk and talk it will come to you and say 'I hate you mother because you can't talk properly, you dribble and you're in a wheelchair and I want a new mother' (Litwinowicz 1999a:32).

Conclusion: eugenics, a spatial response

Attitudes towards congenital disability per se have not changed markedly. Both pre-modern and contemporary societies have regarded disability as undesirable and to be avoided (Asch 2001:306).

In the nineteenth century, avoidance of disability involved a spatial response that resulted in the removal of individuals from their local communities, and consequently from wider society. While institutions portrayed inmates as asexual within these segregated environments, the potential sexuality of inmates was both acknowledged and repressed by spatial arrangements. Sex separation was a constant feature within institutions, and the repression of sexuality was used as a means of preventing procreation (Ravaud and Stiker 2001). At one extreme, in the case of some people with learning disabilities, the result was sterilisation, but the more mundane solution of the closed institution was enough, in most instances, to render the people concerned, disabled people of all varieties included, effectively 'sterile' (Radford, 1995)

In contemporary society, the spatial response of the set-apart institution with

its own checks and balances, has arguably disappeared, and the prevailing response has shifted from the physical/spatial level to the molecular level in the form of prenatal screening, genetic testing and gene therapy, enabling the *in utero* identification of impaired fetuses. Termination of impaired fetuses may therefore be regarded as a contemporary spatial response in managing populations perceived as social problems. The advent of genetic testing, with a focus on inheritable difference, has further devalued disabled women's bodies and reproductive capabilities (Collins 1999, Finger 1991). The historic principles that underpinned the eugenics movement have seemingly returned with a vengeance, and both then and now the result is a discrimination against disabled women with regard to mothering (Blackford 1993):

While healthy and beautiful bodies (white) signify the reproduction of the dominant race, disabled women's bodies signify the opposite – dangerous reproductivity or lack of fecundity or ability to reproduce (Meekosha 1998:172).

This being said, it is not only a new kind of technological eugenics that is at stake in the world of today's disabled women who might want to go down the route of sexual relations, pregnancy and motherhood. Indeed, perhaps even more insidious, as indicated when discussing the twenty-first century picture, are the everyday social and spatial exclusions that serve to position such women as 'out of place': as, in fact, not really having an accepted place anywhere, even in exactly those spaces of reproduction (ante-natal clinics, hospitals, GP surgeries, and so on) where pregnancy is supposedly a normal state, unlike in the public spaces discussed by Longhurst. There is little documented about the social, attitudinal, environmental and institutional barriers that disabled women encounter when considering having a child, become pregnant, use maternity services or have contact with health service professionals (Thomas and Curtis 1997, Thomas 1997, 1998a, Wates 1997, Wates and Jade 1999). This study hence intends to investigate these social and spatial barriers encountered by disabled women, and to establish the influence that they have had on their life choices in relation to reproduction and mothering, charting in much more detail the empirical story – from the nineteenth century to the present day – that has here been presented in a theoretically-informed schematic outline.

Chapter Three

Out of Sight, Out of Mind

Introduction

Blind Asylums and Missions to the outdoor blind established in eighteenth- and nineteenth-century Edinburgh and Glasgow sought to render blind people, primarily men, useful members of society and financially capable of supporting their families. Working in the asylum workshops, or supported by the blind mission to become street traders, blind men retained a presence and role in mainstream society. The asylums and missions, it seems, did not seek to render blind women as useful members of society in the same way, however, but rather sought to protect them from the rigours of everyday life. The root purpose of this chapter will be to chart this gendering of asylum and mission activity, using a range of primary historical sources to do with the work of the asylums and missions in Scotland's two major cities. The objective will also be to elaborate how the segregation of blind women in heavily controlled and surveyed asylum and even mission 'space' had enormous implications, partly for the women themselves in terms of what they could and could not do, be and become, and partly through growing perceptions of them as less-than-proper women with no role to play in wider family, community and social life.

Women admitted as residents or out-workers of the asylums were indeed subjected to constant surveillance, rules and regulations that acted to restrict their participation in mainstream society, as will be documented shortly. The majority of women supported by the missions lived in the community, but, whether in the family home, lodgings or poorhouse, supplied with knitting and sewing by the mission, they usually remained within the confines of this 'home', rarely participating in their local community. This social and spatial segregation imposed upon blind women severely diminished their opportunities to form relationships, engage in sexual activity, or to undertake child-bearing or mothering roles in society. Blind women's spatial segregation, along with demeaning stereotypes created by the institutions, perpetuated a cultural belief that blind women were unsuitable reproducers, incapable of fulfilling feminised roles or indeed any useful roles in society (Stoddard Holmes 2001).

The Asylums

Local philanthropists established the Edinburgh and Glasgow Blind Asylums in 1793 and 1827 respectively. The directors, drawn from the medical profession, business and church communities, genuinely desired to have what they considered to be a positive influence on the lives and circumstances of blind people

The aim we have in view is to rescue the blind from hopeless despondency and render them useful members of society (GBAAR 1883:5).

These sentiments indicate a commitment to assisting blind people to acquire education and skills to facilitate their participation in mainstream society. The Edinburgh and Glasgow Blind Asylums admitted mainly young people, who generally had been blind from a young age. Entrance criteria favoured those who could be taught a trade and be employed within the asylum workshops, and they did not admit individuals who would possibly become a burden upon the institution (Royal Commission on The Blind 1886(c):44). The asylums proactively created the impression that they accommodated the needs of the majority of blind people in the cities' populations, but, because they only admitted those who could be absorbed as employees into the workshops, they effectively served to assist only a minority of the blind population (Ritchie 1930).

Moreover, it would appear that the directors' intentions to make blind people useful members of society were very much gender-orientated. These institutions were opened with the intention of offering blind males, first and foremost, opportunities to access general education, industrial training and employment within the asylum workshops. The asylums met the requirements of mainly blind males, mirroring the cultural expectations of that time, when men were assumed to have responsibilities as providers for their families. These blind males were enabled to fulfil their expected social roles and served a purpose to society, manufacturing the various goods produced in the asylum workshop, but the directorial intentions for females appear to have been very different. Prior to the 1820 opening of the female asylum in Edinburgh, the directors were particularly concerned with the guidance and development of the moral deportment of their female charges. It seems that the directors perceived blind women to be physically and morally vulnerable,

and in need of guidance and care. Many of the women initially admitted were assumed to originate from the poorest classes, although they were considered to be among the most respectable characters who were very poor (EBAMB 1805-1825:208). It is apparent that the directors regarded blind females as helpless, and that this misguided perception undoubtedly influenced their adoption of a guardianship role in the women's lives.

Contained spaces

The Edinburgh Asylum for the Relief of the Indigent and Industrious Blind, opened in 1793, was initially located in Waterloo Place in the centre of the city. The requirement for larger workshop premises prompted a move to Nicholson Street on the south side of the city. While located in the south side, a female asylum was opened in 1820, situated in the same street as the male asylum. Further expansion in workshop premises and female accommodation involved the erection of new buildings at Craigmillar Park on the periphery of the city: 'This which is a new building, is just outside the town, in a very healthy and beautiful situation' (Armitage 1878:6). Situated just beyond the city boundary, only a few large dwelling houses were present in the vicinity of the asylum in 1876 (Edinburgh 1877, 1881). House-building proliferated, and by 1893 the area had established itself as an affluent neighbourhood, and large detached and semi-detached dwelling houses had encroached on the fields that bounded the asylum grounds (Edinburgh 1893). The Glasgow Blind Asylum, established in 1827 and based in the former fever hospital, was located to the north of the city, occupying a semi-rural location bounded on the north and east by fields and west and east by newly built large residential dwellings (Maps 1828, 1831, 1832). In the mid 1800s the Asylum moved to a purpose-built site in Castle Street, and the new location positioned the asylum in front of Glasgow Royal Infirmary (Map 1860). The Asylum was surrounded by a substantial, nine feet high, perimeter wall. A statue of Christ opening the eyes of the blind stood symbolically at the Castle Street entrance. By 1896 the asylum had become completely encompassed by residential developments, and these were large dwellings as opposed to tenements, which would suggest that the asylum was now sited in an increasingly prosperous residential area of Glasgow (Map 1896).

Peripheral locations contributed to the spatial segregation of blind people. Even when residential developments encroached on the asylum boundary,

perimeter walls, austere, imposing entrances and long tree-lined avenues leading to the main asylum buildings all acted as physical boundaries between segregated and mainstream spaces. These physical boundaries distanced supposedly 'defective others' away from mainstream normality. These physical features contributed to the mystification of both the activities within such spaces and those who inhabited them.

The blind asylums distributed advertising literature to raise awareness of their charitable work, as well as detailing the items for sale produced by the inmates such as, mattresses, baskets, brushes, knitted shawls, stockings and baby clothes. Annual reports frequently carried adverts for these items, with the text always constructing the institutions positively as philanthropic providers and inmates negatively as passive recipients. This exploitation of inmates as a means of increasing legacies and donations was particularly pronounced during times of financial hardship. A trade depression in the late 1840s was identified as the cause of a decline in sales, donations and legacies, and in order to redress this situation the institutions promoted the need for their continuation:

The many pressing applications for admission to the institution, from all parts of Scotland and elsewhere, at once show the great helplessness of the blind. The reputation of the asylum for meeting their wants, and the usefulness of the institution in enabling them to raise themselves above entire dependence upon others (EBAAR 1850:3).

Edinburgh Asylum also projected the fate of inmates had they *not* been admitted into the institution:

Houselessness, uninstructed, blind – helped through this dreary world, as it were, from hour to hour, groping for aid amid the constant embarrassment of their forlorn condition (EBAAR 1852:4).

Similarly, Glasgow Asylum forcefully conveyed the institution's supposed role in alleviating the perceived burden that blind people placed on society:

The Asylum is the only institution in Glasgow or the West of Scotland where a blind person can learn to do something for his or her support, and without which many blind persons would now be wandering about begging or be dependent on their friends, or have to enter the poorhouse (GBAAR1883:8).

A trade depression in 1886 again dramatically reduced legacies and donations to the institutions and once again placed them in a tenuous financial position. These severe financial circumstances were reflected in an aggressive approach to raising public support and funds for the continuation of the institutions. The asylums clearly indicated their supposed role in society and the manner in which the general public were expected to assist them in undertaking their role:

To maintain such an institution necessarily involves a considerable outlay, which can only be provided by subscriptions, donations, bequests and purchases of articles manufactured by the blind (GBAAR 1887: Front Cover).

During financially hard times the institutions kept only profitable lines in production and resorted to using poorer quality raw materials. Inmates were portrayed as incapable of working efficiently and as such their wages required augmentation:

It must be remembered that the work of the blind can never be entirely remunerative. There will always be a certain income required from the public to keep the asylum in efficient state. Considerable expense must be incurred in the industrial training of the blind (GBAAR 1884:9).

Inmates were portrayed as an inefficient, unprofitable workforce who would have little influence on the prosperity of the institutions. The notion, perpetuated by the institutions, that blind individuals worked slower than sighted people meant that blind people were generally considered unsuitable for employment outwith the asylum workshops. Consequently, their association with the asylum tended to span their entire working life.

Institutional literature represented inmates as a human group deserving of sympathy and charitable support, while the general public were regarded and positioned as the main means of providing that charitable support. Thus, the general public were believed to have the capacity to influence the prosperity of the institutions and to alter the life circumstances of blind people, rather than this possibility being in the remit of blind people themselves:

The desire to help the blind was natural in every well-disposed person. The sad loss under which they laboured in the deprivation of sight, and the cheerfulness with which they bore it, commanded the interest and sympathy of those more highly favoured (GBAAR 1888:8).

The Asylums, perhaps unintentionally, created a fearful image of blindness, describing blindness in some Annual Reports as 'one of the severest of human afflictions' (EBAAR 1857:4). Such descriptions were clearly used to stimulate generous donations, and the language used, combined with the spatial segregation of blind people, created societal fear of blindness and blind people. Therefore blindness was something to be avoided, and giving to charity enabled sighted individuals to distance themselves financially and physically from 'the blind'. Where gender was acknowledged, men were portrayed as competent, undertaking masculine tasks despite being blind. Women, however, were not accredited with adult status, and were instead portrayed as dependent, incapable, recipients who needed the institution to protect them.

To allow a female in the helpless state of a blind woman to go by herself unprotected through the crowded streets on a Sunday was inexpedient and attended with risk to the pupil herself (EBAMB 1825-1835:152).

The Asylums thus substantially contributed to the social construction of blind women as helpless and vulnerable individuals, women for whom everyday spaces were positioned as dangerous places.

The notion that blind females needed to be taken care of was reflected in statements from Annual Reports that reinforced the women's supposed unsuitability for work, inferring an incapacity to support themselves within or outwith the institution. Directors promoted their magnanimity towards the women:

The female asylum in a pecuniary sense, may be considered almost entirely unproductive, the expenses incurred for board, clothing of its inmates, absorbing a large proportion of the subscriptions to the institution. The directors have much satisfaction in believing that this great outlay is compensated by the comfort and happiness experienced by their interesting charge, through the mental training and sound religious instruction they receive under the superintendence of their respected Matron, Miss Bathgate (EBAAR 1856: initial page unnumbered).

In general inmates' privacy or feelings were accorded little if any recognition by directors, and in many respects the inmates, especially females, were a commodity perhaps unintentionally exploited (Finkler 2003). For example, in

an attempt to increase legacies and donations, members of the public were invited to tour the asylum on a daily basis. Females housed in the asylum in receipt of benevolence effectively became the property of the benefactors – the public. Giving to charity seemingly bought individuals the right to view, inspect and observe inmates at close quarters. For daily tours, no space was out of bounds. Visitors toured the workshops to watch inmates working, as well as the large dormitories where the women slept two to a bed. Female inmates were constantly on display, encouraged and expected to perform for visitors. As objects of public property, any aspect of the females' lives could be scrutinised or questioned by visitors and directors. As recipients of charity, the women were expected to be passive, diligent, obedient and most importantly, grateful.

The directors welcomed expressions of gratitude, and inmates were often invited into directors' meetings to thank them personally, or letters from inmates were read aloud. Despite the restrictive regimes, female inmates did express their gratitude to both the directors and the public. A letter submitted to the directors' meeting of November 1824 read:

The girls of the female blind asylum beg leave at this time humbly to thank the gentlemen of the management, the kind and indulgent public, and master Johnston in particular, for the many favours that are daily conferred on us: and it shall be our earnest prayer and constant endeavour to merit a continuation of the inestimable blessings both temporal and spiritual, which we have received since we entered the asylum (EBAMB 1805-1825:326).

Containment, morality and purification

The containment of inmates varied considerably depending upon the inmate's gender and the financial position of the institution. Prior to 1820 Edinburgh Blind Asylum admitted only males. The directors considered it highly improper to have males and females living in the same house. Funding constraints and a resultant lack of accommodation prohibited the admission of females for a further 23 years. Boys and unmarried men were boarded within the asylum, and later in a boarding house purchased specifically for the purpose. This arrangement was abandoned in 1830. From this point onwards, boys were lodged with respectable married couples, unmarried men resided in lodgings selected by directors, and married men returned to their families each evening. Therefore, males participated in a segregated working environment

during the day, after which they had, albeit limited, opportunities to participate in the everyday life of their local communities.

Women were accepted as home workers onto the roll of the Edinburgh Blind Asylum from 1796 onwards. Women were provided with materials and visited regularly by the overseer to monitor progress and productivity. At this early stage, differential directorial influence over females' lives became apparent. Where women's living conditions were considered to be very poor, the directors of the Asylum applied to the parish workhouse on their behalf. If women were accepted, but refused to enter the workhouse, they were denied the benefits of outworking for the Blind Asylum (EBAMB 1805-1825:17). By the early nineteenth century, directors resolved to establish a female asylum. In their deliberations regarding the location, they acknowledged 'the importance of females placed under their care in a more reputable situation and where their whole moral deportment would be under one superintendence' (EBAMB 1805-1825:217). It would seem that the directors did, in fact, assume responsibility for the moral correction and guidance of their female charges. The female asylum opened in 1820, and females admitted into the asylum resided within the walls of the institution. It was not until the middle of the nineteenth century that a few women were boarded out in lodgings selected by the directors. Even so, the majority of female inmates remained resident within the institution.

The directors' perceptions of the women as childlike had spatial consequences, chiefly manifested in the large dormitories with no physical divisions as privacy was not considered a requirement for inmates, especially when housed in single sex accommodation. Directors discussed the possibility of dividing the space with partitions, but took the decision not to do so (GBAMB 1880-1884). It was assumed that blindness, or at best partial sight, negated the need for physical divisions to create private space. For example, toilet facilities in the female dormitory were not equipped with doors until 1881 (GBAMB 1880-1884:58).

Moreover, newspaper descriptions of the female inmates at the time centred on their appearance, suggesting recognition of them as females. As with their sighted counterparts, their appearance indicated their moral stature; a dirty, untidy appearance was thought to signify immorality, while cleanliness and neatness equated with good moral standards (Barret-Ducrocq 1992).

However, the description of their conduct also implies an infantile perception of these women:

In appearance they are clean, tidy and intelligent – in disposition apparently contented and cheerful: they appear less talkative than the males, the silence that reigns in the house being very notable in a household of women. The fact that they almost never quarrel among themselves is perhaps equally so (*Scotsman* article 1864:71).

In general, children rather than adults would be expected to quarrel amongst themselves. The article also described the men working competently with complex and potentially dangerous pieces of machinery. Female inmates were depicted quite differently, referred to as girls working quietly and passing the time singing; such portrayals distanced the inmates from sighted women.

The majority of Asylum inmates originated from poor families. Poor conditions and poverty were routinely associated by the Victorians with dirt, disease and also immorality. Directors therefore assumed that the majority of inmates originated from 'families where good example was not known' (EBAAR 1853:4). Inmates were occasionally admitted into the asylum on a conditional basis, especially when they were considered to come from an immoral background, and inmates were often forced to sever all ties or to limit contact with their relatives. For instance, Eliza Lyell was admitted into the Asylum on the condition that she only visited her family with the Matron's permission (RBASMB 1872-1883:20).

Although the directors perceived female inmates to generally be of good character, by virtue of their social class they were still assumed to have immoral and delinquent habits that had to be corrected through a purifying process of strict adherence to religious regimes. The directors professed their responsibilities towards both the moral and physical deportment of the inmates. 'With so great a responsibility [to] the moral, as well as the physical culture of so many of these almost helpless fellow creatures' (EBAAR 1855: unnumbered), worship, religious instruction, reading and recital of the bible were fundamental elements of daily life in the asylum. The reformatory effects of the religious doctrine were considered to have paramount importance, especially in relation to female inmates. Christianity and expressions of Christian beliefs indicated the taming of a savage, animal-like group, and cleansing females of their immoral, depraved, dirty origins was crucial in the purification process. The female inmates were to be rendered as

women of moral stature, living a celibate, moral life and, as such, could more readily gain social acceptability as deserving objects of charity.

Attendance at family worship twice per day, in addition to religious instruction and Sunday worship at the local church, was compulsory for all inmates. Male and female out-workers could choose which church they wished to attend, with their attendance monitored by directors. If monitoring revealed repeated absence, dismissal from the asylum ensued. The directors were convinced of the reformatory effects of religious doctrine:

The benefits of religious and secular education are afforded to those who might otherwise have remained in mental as well as visual darkness (EBAAR 1857:4).

Female resident inmates were held to a far higher moral code than were their out-working counterparts. Regulations dictated the church they were to attend, where they were to sit within the church, namely the seats provided for the blind, and the manner in which they should spend Sunday:

No one living in the house being left to wander about but all to attend the parish church with the mistress and to remain afterwards at home, neither admitting visitors or paying visits (EBAMB 1825-1835:271).

A few women residents made requests to attend a church of their choice. While the directors anxiously denied any desire to control the conscience or religious creed of the female inmates (EBAMB 1825-1835:272), they exerted their power directly in outright refusals to permit females to attend another church:

The directors do not want females wandering from church to church and perhaps about the streets or fields. Wandering on the Lord's day without God or good once influencing their mind (EBAMB 1825-1835:273).

The women's safety and religious ordinance may well have been causes for directorial concern. However, it is highly likely that the directors did not want inmates to be 'aimlessly wandering' in public space, because women whose presence in the street could not be explained by an obvious task, shopping or some other necessary activity, were considered unnatural and their out-of-placeness perceived to signify doubtful morality (Barret-Ducrocq 1992). Also, images of vulnerability and helplessness had been constructed around the

female inmates, women for whom public space was regarded as a thoroughly risk-laden place to be. Blind women independently navigating their way through public space would certainly have challenged this social perception of them. The directors' influence hence appears to have limited women's opportunities to participate independently in mainstream society, perhaps as a means of maintaining the created social images of both the incapable female inmates and the supposed necessity of the asylums.

Controlled and surveyed spaces

Strict regimes, rules and regulations formed the framework by which the Blind Asylums operated. The rules and regulations were initially devised to facilitate the efficient running of the institutions. However, as directorships changed over time, so too did the ethos underpinning both their involvement and attitudes towards the inmates. Regulations were introduced which acted to restrict and to control the choices and activities of all inmates to varying extents: for example, swearing, drinking alcohol, impertinent language, idleness and smoking were not tolerated within the asylum. Rules and regulations were frequently read out to inmates, particularly when they had been contravened. The threat of dismissal was unremitting and presence in the asylum was always conditional, dependent on adherence to the rules and diligence in the workshops. Since expulsion from the institution would almost certainly lead to destitution or entry into the workhouse, these actions perpetuated a climate of fear and conformity.

One of the objects of the Asylum was to 'educate the young, and to instruct the adult to earn his bread by his own industry' (Alston 1846:37). It was assumed that blind men would have families dependent upon them for support, whereas blind women were not expected to have such responsibilities, but rather to be themselves dependent upon their friends and relatives for support. A gender bias hence existed in the facilities provided within the asylum, mirroring assumed responsibilities and dominant social roles. Expansion of male workshops enabled the enrolment of an increased number of males, and the Edinburgh Asylum Annual Report of 1865 notes 106 men and boys in the male asylum, and 28 females in the female asylum (EBAAR 1865:iv). Males outnumbered females at least three to one. Age limits on admission differed, with 40 years as a maximum age limit for men, compared to 30 years for females (EBAMB 1805–1825). Provision for female

inmates was limited to one workroom and two dormitories, accommodating a maximum of 29 women (*Scotsman* 1864:72). The imbalance in provision was somewhat redressed in 1876 when the asylum moved to new buildings in Craigmillar Park, which allowed accommodation for upwards of 100 females (RBASAR 1874).

The directors exerted their influence over all inmates by devising and implementing mechanisms for monitoring conduct and behaviour within and, more significantly, outwith the institutions. All inmates had to seek the permission of the workshop manager prior to taking leave for example, prior to taking a day off work. A regulation was implemented that obligated the inmates to disclose why they wanted time off and where they were going. All out-worker's lodgings were selected and approved by the directors, and a regulation imposed a curfew on the activities of inmates lodged outwith the asylum:

It is enjoined that the blind shall never be from their homes after nine o'clock at night, unless they can give a satisfactory excuse and if the least appearance of drunkenness is discovered at any time it will be visited by the most severe reprehension of the directors and by dismissal upon repetition (EBAMB 1825-1835:338).

Outwith the institution female out-workers' activities and conduct were monitored more closely than males. For example, prior to the opening of the female asylum, a few out-workers sang in a choir along with male out-workers but the directors exerted their influence over the women's activities by instructing the minister that the women were no longer to participate (EBAMB 1805-1825:208). Male out-workers' behaviour was probably observed with a degree of leniency, so that when male inmates McDermid and Watson were found guilty of staying out late with suspicious company, both were admonished for their behaviour but neither was expelled (EAMB1825-1835:292). In November 1827, Paul Ramsay was disciplined for being seen intoxicated, but he was allowed to stay in the asylum on the condition that this would not occur again (EBAMB 1825-1835:80). The directors took this opportunity to remind inmates of 'their determination to punish in the most exemplary manner every delinquency that may arise' (EBAMB 1825-1835:81).

For women, though, the consequences of digressing from the moral limits imposed upon them as females were enforced to a far greater degree. The

minutes of a directors' meeting held on the 21st January 1834 record the dismissal of Margaret Bogle, an out-worker of the Glasgow Blind Asylum. She was dismissed for misconduct that took place outwith the asylum. The minutes do not detail the nature of the misconduct, but the stance and resolve adopted by the directors following this incident implies that the misconduct took place in Bogle's lodgings. Revealingly, they stated that:

... as much care as possible should be taken to find lodgings for blind females working but not boarded or lodged in the asylum. Where they would not only have the benefit of moral example, but observation taken of their conduct and for this purpose authorise the treasurer to allow out of their funds a small gratuity not to exceed £5, to a proper person for finding out such lodgings and taking superintendence and observation of their conduct (GBAMB 1825-1845:175).

It hence became common practice to pay sighted observers to monitor the conduct of female out-workers and to report any indiscretions to the directors. The likely hidden motive of surveillance measures may have been to prevent women indulging in supposedly immoral behaviour.

The conduct, activities and choices of females resident in the asylum were restricted and controlled by oppressive regimes that punctuated their daily lives. Woken at 7am, allowed a limited amount of time to wash, dress, eat breakfast and attend worship before commencing work for the day, the women's working day was then regimented by an inflexible timetable dictating breaks and mealtimes. The inmates were supervised constantly, and they had restricted opportunities to exercise choice, while options were usually set within narrow parameters. For example, women could choose from limited options the way in which they wished to pass the time during the evening in the asylum house: either to return to work, read an embossed Braille book, play the piano or engage in conversation with other inmates. Bedtime at 9pm ended their day. The daily routine, coupled with surveillance, enabled directors disproportionately to exert their influence and control over female inmates, in particular those accommodated within the asylum.

Female residents were rarely permitted to leave the asylum house unaccompanied. During the week, women were permitted to leave the asylum for one hour per day, usually accompanied by a sighted guide. A few of the women considered capable of negotiating the outside environment safely were allowed to take exercise in an area of land adjoining the asylum, which

had been purchased specially for that purpose. Some independent freedom was allowed for a few women, then, but this was highly circumscribed:

At four o'clock the inmates are then taken out for a walk, under the charge of a servant generally straight south to Newington, or round the Meadows. A few who have the inclination and the cash, are able to take care of themselves on the streets, are permitted to indulge in 'shopping'. But all return to tea at five (*Scotsman* 1864:72).

Ritchie described a group of inmates of a blind institution negotiating public space in his book *Concerning the Blind*:

... the inmates of an institution were taken out like a party of rock climbers, united by a rope. Much more recently in vogue was the 'crocodile', wherein each youngster laid his hand on the shoulder of the one in front (Ritchie 1930:32).

Female inmates being guided in such a way in public space reinforced an evolving stereotype of blind women as dependent, helpless and different, but this learned helplessness was precisely *not* an option for female out-workers who had to negotiate their way to and from the asylum on a daily basis.

Directors frequently exerted their powerful influence over female residents by refusing petitions from women wishing to move out of the asylum house. In April 1834, eight females of the Edinburgh Asylum petitioned a representative of the board of directors regarding lodging out of the asylum house (EBAMB 1825-1835:303). Their request was refused. Directors interpreted such requests as insubordination by an unappreciative individual or group. In order to repress such ingratitude, petitions to leave the house were refused and regulation of food was introduced. The gradual erosion of personal autonomy and the necessary support of the directors to leave the house made it extremely difficult for women to change their circumstances.

Women within gender, sexual and eugenic limits

Socially dominant sexual stereotypes influenced female occupations, education, earnings and living arrangements within the asylums. Therefore, on a practical level, in relation to roles and occupations, *females were regarded as women*. Many prevailing social attitudes towards women were mirrored in the asylum. Women pursued socially acceptable, suitably feminine occupations such as plain sewing, knitting, dress-making, shirt making and

fancy needle-work. Over and above their work in the asylum workroom, females were also expected to help as much as possible with cleaning and other domestic tasks in the house. Within the asylum workshops, men had the opportunity to earn between nine to eleven shillings per week (Alston 1846:37), but the comparative insignificance attributed to female earnings within the asylum is evident in the lack of clear indications of the pecuniary reward for work undertaken by the women. Alston simply recorded that 'many of these young women are receiving regular wages from the institution' (Alston 1846:41). Armitage, meanwhile, recorded that women in the asylum were paid far less for their work than men (Armitage 1878:9), presumably making attainment of financial independence and a self-supporting lifestyle virtually impossible. Regulations governing funds established to pay allowances to families of inmates in the event of their death, or to provide sick pay when inmates were unable to work, were based on the premise (as mentioned) that only men would have family responsibilities. In Edinburgh Asylum only men contributed to the fund, whereas in Glasgow both men and women participated, women contributing three pence and men six pence per week. When unable to work due to ill health, men then received six shillings per week and women received three shillings and six pence per week (Alston 1846:40).

Sex-differentiated education within the asylum also reflected the dominant social culture, where a sound elementary education was considered inappropriate for females. In keeping with this ethos, girls were instructed in various branches of female industry, in principles of religious instruction and in elements of general knowledge, whereas boys received religious instruction and elementary education as well as being taught trades that suited their capabilities and inclination. Annual reports recorded inmates educational and industrial activities. The activities of males were separated out into those of men and boys, no such distinction between adult and juvenile was made for women they were simply recorded as 'females' or 'girls'. Women in the asylums continued to be called 'girls' even when older, thus positioning them as potential subjects of schooling.

Female inmates were infantilised by the asylum directors, often being referred to as 'girls' in annual reports, advertising literature and newspaper articles. Crucially for this thesis, these inmates were treated as childlike individuals, asexual and sexually immature. Consequently, they were denied recognition

as women, and were deprived of the social trappings of womanhood: sexual maturity, sexual activity and the reproductive roles of childbearing and mothering. One aspect of this was ensuring that women and men in the asylums, or when out-working, were not allowed to mix in a manner that might carry any kind of sexual charge, such that gender segregation was indeed also very much a *sexual* segregation. Unsurprisingly, a host of problematic assumptions crowded into the imposition of this strict gendered and *desexed* geography of asylum life.

Stringently imposed and monitored measures to ensure gender segregation were implemented in both the Glasgow and Edinburgh Blind Asylums. Prior to opening, the directors of the Glasgow institution took the decision to implement a rigid separation of the sexes:

No intercourse shall be permitted between the male and female branches of the Asylum, nor shall the boys and girls enter the building appropriated to each other's use except when they are attending family worship or religious instruction (GBAMB 1825-1845:57).

Sexual separation was imposed in various ways, but most obviously in the social segregation, close supervision and monitoring of women resident in the asylum. Resident inmates rarely had time to themselves, or in fact, any time where their behaviour was not being observed. This level of surveillance severely limited their opportunities to express any resistance to the rules and regulations.

Separate workrooms indicated a deliberate measure to segregate inmates along gender lines:

Their apartments are separate from those of the males and no intercourse whatever is permitted (Alston 1846:41).

Men were engaged in mattress-making, sack-making, brush-making and rope-making (Alston 1846:37, *Scotsman* 1864:67), while women sewed mattress covers (Armitage 1878:6, *Scotsman* 1864:67). The compatibility of these activities does not indicate a necessity for the tasks to take place in separate environments. In addition, men and women worked different hours, with men starting earlier and finishing later (Alston 1846:49). Women who boarded out-with the asylum were obliged to have dinner with resident inmates each evening, rather than carrying on working (Alston 1846:41). Furthermore, one

of the Edinburgh Asylum regulations specifically forbade male and female inmates from communicating in any way within and outwith the institution

It is hereby most strictly enjoined that the men and boys shall on no account whatever hold any communication whatever with those in the female department of the institution, either on the respective premises or elsewhere (EBAMB 1825–1835:339).

Men and boys were hence strictly prohibited from communicating with the females, but there is no such documented rule preventing women communicating with men. This omission is revealing of the directors' attitudes towards the sexuality of the inmates, in that men were perceived as sexual beings while the women, however, were not. These measures contributed to spatial separation of men and women at times of the day when they could possibly meet, develop friendships or even form relationships, times when men, with supposedly limited control of their sexuality, might take advantage of vulnerable females.

As a means of preventing the women inmates from engaging in any immoral behaviour, sighted observers monitored the women in both public and private space:

It has been found advantageous to have an elderly woman, who has sight to take charge and work along with them [female inmates] (Alston 1846:41).

The Royal Commission on the Blind suggested that:

... the supervision of the blind at night should be obtained by a sighted officer sleeping in a cubicle in the same room, or in one with a window looking directly into the dormitory. We attach great importance to this (Royal Commission on the Blind 1886(a):xlili).

Daily worship in the morning and evenings were the only times when men and women were permitted to share the same space. Even so, women sat in a separate area of the chapel and a sighted elderly woman observed the females' conduct and behaviour throughout the sermon. The sighted observer's principal role was to ensure that women did not engage in any form of communication with the male inmates. The superintendent of the male asylum also observed the men's behaviour throughout family worship.

The various measures to ensure gender and hence sexual segregation

suggests that, despite infantilising the women, the directors did acknowledge the potential for sexual activity between inmates – primarily between men and women, since at this point in time the likelihood of same-sex relationships, certainly between women, was simply not recognised as a possibility by asylum directors. Lesbian sexual relations had not been discovered, identified or named.

Separation of the sexes within the asylums was probably influenced by the attitudes and moral stances of those involved in blind welfare. Notable in this respect was Dr T.R. Armitage, founder of the British and Foreign Blind Association, later known as the Royal National Institute for the Blind (Ritchie 1930). He was a prominent figure of the time who disseminated his views on wide-ranging social and moral issues in relation to blind people as a means of, in his estimation, producing healthy public opinion through sound views and correct information. In a paper, *On the Means Employed for Ameliorating the Condition of the Blind of Great Britain and Ireland*, presented to the Paris Congress in 1878, he indicated staunch support for morally informed sex segregation within institutions for the blind. Dr Armitage, himself a blind person, acquired a visual impairment later in life, and may have taken a moral stance that did not necessarily impact upon his own lifestyle. In relation to arrangements for achieving sexual separation within institutions for the blind, he stated that:

In one or two blind schools, the arrangements are so bad that inter-marriage among the old pupils is of frequent occurrence (Armitage 1878:13).

He made reference to a workshop in London where blind men and women worked side by side, and as a result some formed relationships and married. In the few institutions where men and women worked alongside each other, vigilant supervision was implemented and widely supported by those involved in blind welfare (Wagg 1932). It would appear the key function of sex separation, surveillance and imposition of an oppressive influence over blind women's lives was primarily to prevent them forming relationships, engaging in sexual activity and procreating.

The 19th rule, as it became known and implemented within the Edinburgh Asylum, required all inmates to seek the permission of the directors prior to entering into marriage:

It is expected that when any of the blind think of entering the married state they will intimate their intention to the directors who will be always ready to give their best advice relative the formation of suitable connections. Although the directors do not claim to themselves any power to prevent marriages yet it is to be held imperative that they are to be consulted (EBAMB 1825-1835:338).

Directors were of the opinion that marriages entered into without due consideration could cause great misery. They rendered the 19th rule imperative, an action they believed to be important for the 'good of the charity and comfort, respectability and happiness of the members' (EBAMB 1825-1835:223). However, such an action undoubtedly placed the directors in a position of power where they could approve or disapprove of the blind person's intended spouse. Even when inmates lived and worked a considerable distance from the asylum, the directors continued to exert their influence over the inmates' lives. It would seem that the directors genuinely thought that their intervention would avoid blind people making a decision that they would later regret. The elevated status of the 19th rule from observed regulation to imperative rule implies that the directors may have indeed questioned the abilities of inmates to make considered and reasoned decisions.

One of the earliest records of an inmate seeking permission to marry is recorded in the Edinburgh Asylum minute of a directors' meeting held on the 5th July 1796. Denis McQueen had been sent as an out-worker of the asylum to David Dale's cotton mills in Lanark. Denis's written request sought permission to marry a local Lanark woman, and was accompanied by a letter from a Mr Lamb of Lanark vouching for the woman's good character. The directors resolved that they would give their permission if the woman's character withstood the closest scrutiny. The secretary ascertained the woman's age, current earnings, potential earnings and ability to assist Denis. Only when the directors had satisfied themselves that the woman was of good character, could earn her own bread and assist Denis, did they finally give their approval (EBAMB 1792-1805:110). A thorough investigation of archive documents revealed no documented instances of female inmates requesting permission to marry. The absence of female appeals for permission to enter into marriage may well indicate the restrictive effects of surveillance on the women's lives and social activities. The absence of documented instances of men requesting permission to marry female inmates

similarly points towards the limiting influence of surveillance.

Later in the century, the emergence of a particular social discourse in relation to blind people marrying undoubtedly influenced the attitudes of asylum managers and others involved in the welfare of blind people. Although blind people marrying was not encouraged, it would seem that blind men marrying sighted women was more palatable to those involved in blind welfare as it was assumed that sighted women, if necessary, could 'look after' their blind husbands. Also sighted wives of blind men were considered less likely to produce blind children. Whereas blind-blind intermarriages were presumed to be productive of blind children. Dr Armitage, mentioned earlier, was forthright in his views of blind intermarriage, stating to the Paris Congress in 1878 that:

Of all social questions connected with the blind, there is none perhaps on which those who have studied the subject practically are more unanimous than the evils of intermarriage (Armitage 1878:13).

The Royal Commission on The Blind supported this way of thinking, and their report suggested that:

The intermarriage of the blind should be strongly discouraged (Royal Commission on the Blind 1886(a):xlili).

Directorial stance and morally informed working practices within the asylums were undoubtedly influenced by such external discourses, this being obvious in the opinion offered to the Royal Commission on The Blind by Mr William Martin, Manager of the Edinburgh Asylum. He believed that:

Intermarriage of the blind ought to be prohibited by the State (Royal Commission on the Blind 1886(b):502).

It almost goes without saying that negative attitudes towards intermarriage of blind people, as held by those in a position of power within the institutions under study here, undoubtedly limited inmates' opportunities to marry.

Dr Armitage was of the opinion that 'intermarriages were followed by the usual bad consequences' (Armitage 1878:13). He did not elaborate on what such consequences might be, but Martin, in his evidence to the Royal Commission, offered his opinion on the consequences of intermarriage:

... I have never seen anything but either blind children or dirt and filth

result from the intermarriage of the blind (Royal Commission on the Blind 1886(b):502).

Institutionalisation of blind women and proactive influences on public opinion colluded to engender widespread moral hostility towards the possibilities of blind people establishing relationships, marrying and bearing children, possibly children with inheritable blindness. It would appear that the moral issue of sexual separation was unquestionably charged with eugenic undertones, and the further notion that blind women's bodies rather than men's were more likely to transmit heritable blindness was illustrated by additional evidence presented to the Royal Commission by Martin:

[Sir Lyon Playfair] Was there any hereditary blindness in the family of either the man or the woman in the case to which you have just referred?

Answer: There was hereditary blindness in the case of the female.

[Dr Tindal Robertson] In the case of the man, was his blindness accidental, or had he been blind from birth?

Answer: He lost his eyesight gradually when young. He had a brother whose eyesight gave way also when he was young.

[Dr T R Armitage] Could you state what was the nature of the hereditary taint in the case of the woman?

Answer: There is a difference of opinion in this case, it is a very peculiar and interesting one (Royal Commission on the Blind 1886(b):503).

It would appear that the manager of the Blind Asylum associated the female's body with hereditary blindness, indeed perhaps as the source rather than questioning the male's genetic inheritance. The notion of women's bodies as carriers or sources of inheritable blindness without doubt contributed to a hostile moral climate towards blind women indulging in sexual activity and childbearing. The fear of blind women procreating not only justified precautionary methods of sexual separation, it legitimated their spatial segregation from mainstream society.

Resistance

Resignation and a proper spirit of gratitude for benefits received were the moral postures most highly in favour with the management (Ritchie 1930:33).

The asylum directors welcomed expressions of gratitude from the inmates. Female resident inmates were expected to be particularly grateful for what

they received from the institution: a home, employment, earnings, clothes and food. However, for these benefits women were expected to comply with restrictive rules and regimes.

The directors interpreted acts of resistance to the asylum regime as insubordination, inevitably provoking a hostile or disciplinary response from them. Directors conditioned and convinced inmates that adherence to the rules and obedience was in their best interests. When the directors felt that order within the institution or their authority was being challenged by inmates, they took swift and decisive action to quell such confrontations. Action taken by the directors was dependent upon their interpretation of the gravity of the situation in line with the social moral code of the time. Asylum directors did not want their institution to be associated with immoral, depraved or delinquent behaviour, given the possible ramifications for both themselves (as supposed moral guardians) and levels of donations on which the asylums depended. Directors and the institution as a whole thus had to be distanced immediately from inmates who had transgressed moral boundaries. Instant dismissal facilitated distancing from such supposedly immoral behaviour, and acted as a warning to other inmates contemplating disobedience of the rules.

The age of inmates on admission had a significant influence on whether they expressed resistance to the rules and regimes of 'the house'. In general, the younger inmates were on admission, the less likely they were to test or to contravene the rules. Those who chose to defy the rules expressed resistance in various ways. Some refused to conform with daily regimes, such as attendance at religious ordinance and instruction. Women who absented themselves from religious worship were thought to be exhibiting signs of serious mental instability. When Isabella Gray, an inmate of the Edinburgh Asylum, refused to attend daily worship, the directors considered her to be 'mentally deranged'. They professed her presence in the asylum to be 'extremely injurious to the welfare of the inmates', and she was dismissed for insubordination of the house rules (EBAMB 1825-1835:173). It is reasonable to assume that Gray desired to exercise choice in relation to religious persuasion and attendance at worship, but that the wilfulness displayed in wishing to display such choice – something departing from the infantilised state in which the women inmates were supposed to reside – was perceived by the directors' as a threat to order and morality within the institution. The

directors hence discredited her actions as those of a deranged and dangerous individual.

A hostile moral background within and outwith the asylums did not encourage marriage between blind people. Prior to entering into marriage, as indicated, all inmates had to seek the permission of the directors, but inmates very occasionally defied this regulation by entering into marriage *without* the directors' consent. Records of the Edinburgh Asylum document the case of John Strachan and Jean Miller, inmates who had contracted their marriage without consulting the directors (EBAMB 1825-1835:104). Following the discovery of this marriage contract, the directors delivered a stern address to the inmates warning of the consequences of such actions

That is of those under their protection [who] engage in so serious a contract without advising their best friends [the Directors] – such may expect immediate dismissal (EBAMB 1825-1835:104).

The justification for the imperative nature of this rule was attributed to the welfare of the inmates, and yet the moral enmity towards blind people marrying was more likely a pertinent factor. The 19th rule placed male inmates in a 'no win' situation, since in the process of seeking permission to marry they had to disclose the identity of their intended. If she was an inmate, they effectively admitted to breaching the rules by forming a relationship, punishable by dismissal. Similarly, not seeking permission, marrying and maintaining a relationship in secret also risked dismissal. Considered in these terms, it is probable that the 19th rule deterred individuals from entering into marriage. Resistance to this rule nonetheless affirms that a few inmates were indeed capable of making their own decisions, and were prepared to face the consequences.

With no easy access to contraception or abortion (Barret-Ducrocq 1992), the existence of forbidden relationships tended to be discovered when women became pregnant. Such a discovery was usually followed by an immediate demand by the directors for the name of the father, particularly where the involvement of a male inmate was suspected. An inmate of the Edinburgh Asylum, Agnes Miller, was found to be pregnant to Thomas Manderson, also an inmate, and both were immediately dismissed. Following their subsequent marriage, Manderson requested to be readmitted into the asylum workshops, and he was allowed to return (EBAMB 1835-1849:370), presumably because

he had done the honourable thing by marrying Miller (Barret-Ducrocq 1992) and thereby rendering her pregnancy respectable. Later in the century, the directors' response to behaviour that they considered immoral had not changed, as was evidenced when an inmate, Susan White, requested time off because she was in a 'delicate state of health'. The institution physician confirmed her pregnancy. She was instantly dismissed, with the directors ordering her name to be immediately removed from the roll and her family and friends to be informed of her pregnancy (RBASEMB 1872-1883:35). The directors' reactions indicated a revulsion to the manifest fact that, in a biological sense, the women were quite capable of adult sexual activity. Moreover, the implication is undoubtedly that their real sexuality was indeed being denied, repressed by the institutional regime

Female inmates of Glasgow Asylum also faced dismissal when found to be pregnant. Christina Mypen and James McLatchie, both inmates of the Glasgow Asylum, were dismissed when Christina was found to be pregnant. Directors were disgusted when McLatchie 'admitted intimacy with the girl, with the knowledge of the girl's parents' (GBAMB 1880-1884:28). Such immoral behaviour reflected negatively upon the institution and its directors, so it was thought, and the institutions were perceived to have failed their moral duty to both inmates and society. It would seem that directors interpreted their moral duty to society as one of keeping blind people's behaviour within morally acceptable boundaries, although this duty did not then extend to the welfare of those who broke the rules. Individuals, especially pregnant blind women, dismissed from the asylum for immoral behaviour possibly faced being shunned by their family and friends, or unavoidable entry into the poorhouse.

An institutionalised life for life

Although the main object of the asylums was to render blind people, predominately men, self-supporting, very few inmates left the asylum to enter into mainstream employment or self-employment. The majority of male inmates tended to be associated with the institution for the duration of their working lives. The Edinburgh Blind Asylum Annual Report of 1852 noted of the inmates that 'many of [them] have been there from an early age and have grown grey in the institution' (EBAAR 1852:4). The institutions' founders did not intend to establish a long-term home for blind people. However, the

creation of stereotypes and subsequent construction of blind men and women as helpless, passive dependants in need of special facilities, coupled to the simultaneous portrayal of the asylums as the most appropriate places of expert knowledge to deal with such a group, all meant that the systematic and long-term segregation of blind people became socially acceptable.

Turner and Harris's 1870 *Guide to Institutions and Charities for the Blind in The United Kingdom* contained survey responses from both the Glasgow and Edinburgh Blind Asylums regarding age of admission and potential length of time inmates might typically remain in the institution. Glasgow Asylum indicated an admission age of 8-14 years and that individuals could remain until their education and apprenticeship were complete, an average of seven years (Turner and Harris 1870:23). Edinburgh Asylum indicated five years and upwards as age of admission and that individuals could remain for life (Turner and Harris 1870:21).

Domineering controls and repressive regimes undoubtedly contributed to the length of time females remained resident in the asylum house. For some women their association with the asylum spanned almost their entire lifetime. Margaret Baxter, from Cupar Angus, was admitted into the Edinburgh Blind Asylum in March 1822, aged 15 years old. Prior to admission she had been employed as a spinner. She remained in the asylum for 72 years, until her death on the 21st December 1894, aged 87 years old (EBA Admissions Register 1793-1938: unnumbered, Register of Deaths 1894). Elizabeth Baird from Innerwick, was admitted into the Edinburgh Blind Asylum in November 1832, at the age of 13 years old. Prior to admission she had been employed as a servant. She died in the asylum 73 years later on the 31st January 1905 (EBA Admissions Register 1793-1938: unnumbered, Register of Deaths 1905). Women's long-term association with an institution was not unique to the Edinburgh institution. Glasgow Blind Asylum 1896 Annual Report records the death of Ann Taylor, who had been admitted into the asylum in July 1831, at the age of 9 years old. She became a knitting instructor, and 'passed more than 64 years of her life in the asylum' (GBAAR 1896:10).

Although men may have remained associated with the asylum for a considerable proportion of their working lives, they did have the opportunity to return to their families, to live outwith the asylum, to take control of their own lives and even to participate to a limited extent in their local

communities. Women, as resident inmates, however, had extremely restricted freedoms and little opportunity to engage with mainstream society.

The Missions

Since the asylums only catered for a minority of the blind population, even with out-workers in their workshops, Missions to the Out-door Blind were established initially in Edinburgh in 1857, followed by Glasgow in 1859. The Edinburgh Society for Promoting Reading Amongst the Blind and the Glasgow Mission to the Out-door Blind shared similar objectives:

To seek out the blind, visit them in their homes, conduct meetings among them where convenient, teach them to read with the finger the embossed system of reading, supply them, free of charge, with books from the society's library, and in every way possible seek their spiritual and temporal good (ESAR 1893:2).

The missions employed missionary teachers and volunteer lady visitors to undertake the duties of seeking out and teaching blind individuals to read embossed books. As well as visiting blind people in their homes, the missionaries also visited blind people in hospitals, infirmaries and poorhouses.

The Edinburgh and Glasgow Missions encompassed an extensive geographical area. The Edinburgh Missionaries worked within six counties; Edinburgh, Haddington, Peebles, Selkirk, Roxburgh and Berwick. Glasgow missionaries worked in the counties of Glasgow, Lanarkshire, Renfrewshire and Ayrshire. The missionary teachers of both societies went to great lengths to seek out blind people, note their circumstances, develop a register and keep statistical records of the diverse blind population. By 1882 ten Missions had been established, covering the whole of Scotland and these efforts formed the basis of a voluntary movement of welfare on behalf of blind people. Within ten years of their establishment, the Edinburgh and Glasgow Missions took the decision only to offer assistance to blind people who were unemployed and those not associated with the Blind Asylums. By 1881, 2,747 blind people were on the rolls of the missions throughout Scotland (Auchincloss Arrol 1886:6). The missions claimed to be doing 'All in their powers to help this helpless class' (GMAR 1884(a):9).

The work of the missions was underpinned by a pervasive religious ethos, unsurprisingly given their very name, and they aimed to seek blind peoples'

'spiritual and temporal good' (ESAR 1893:2). Although their priority was to teach blind people to read, a close second was to save their souls, 'bringing them from darkness into the light' (ESAR 1889:2). Blindness, class and morality were closely connected. Individuals from the poorest classes were often considered to have brought illness or blindness upon themselves through immoral conduct, and women's immorality was particularly linked with loss of sight. In some instances blindness was directly attributed to women's inappropriate conduct.

Journal extracts disseminated in annual reports fuelled this ideology, placing emphasis on the ways in which wayward, wanton women had been reformed following the loss of their sight. Two cases illustrate this belief held by the missionaries and internalised by some blind women. The case of a 28-year-old woman, noted in the 20th Annual Report of the Edinburgh Society, indicates the stance supported by the missions:

This young woman was trained in a Sabbath School by a kind Christian lady. She left her home when she was a young girl but wandered far away from the paths of virtue and continued year by year to do so; but the Lord arrested her in her downward course by taking away her eyesight (ESAR 1879:3).

The case of Margaret Wallace, noted in the 1878 annual report, suggests the internalisation of this ideology. The 27-year-old had lost her sight eighteen months prior to the report, and had been taught to read by the missionary. She confessed to him:

I have lived a careless life, and believe God in his love has stopped me in my downward course, by taking from me my eyesight, and through your visits and instruction, I have been taught the way to be saved, and through grace I have taken Jesus as my saviour (ESAR 1878:3).

The implication was that blindness acted as a warning or punishment from God for living a morally careless life. Furthermore, blindness could seemingly be avoided by living a moral, Christian life.

The missions exploited any opportunity to illustrate the reformatory effects of Christianity on blind people, and a conviction that blind peoples' lives and very character could be reformed by a belief in God was evident in all aspects of the missions' work:

The eyes of the blind have been opened, and those who were once in darkness are now light in the Lord (ESAR 1891: initial page unnumbered).

Therefore the rejection of a dark immoral lifestyle and the embracing of a Christian ethos could propel blind people onto a superior spiritual plain. Although they could no longer physically see, they could see spiritually. The reformatory effects of religious instruction subtly hinted at physical transformation: that for those who believed in God and lived a moral life, miracles could happen. In short, those who read their bible each day, prayed and led a Christian lifestyle might at some point have their eyesight restored. The importance of individuals reading their bible daily is shown in one of the few journal extracts regarding a blind woman with childcare responsibilities. The missionary does not focus on her physical responsibilities, but rather on her spiritual ones:

R's case is very interesting. She is the Mother of a number of children, and although she has the work of the house to attend to she finds time to read her portion of the word of the Lord (ESAR 1877:8).

Dissemination of extracts from letters evidenced both blind peoples' gratitude to the society for teaching them to read embossed print and in turn to find salvation, simultaneously publicising the reformatory effects of religious instruction on blind people. Hence one woman was presented as:

Manifesting a cheerful Christian spirit and filled with gratitude for what the mission, and especially the Ladies Auxiliary had done for her (LAGMAR 1888:5).

A relief fund enabled missionaries to provide limited financial support to unemployed blind people in times of extreme hardship. However, increasing demands made upon this fund for financial assistance influenced their supportive role. The missions undertook to assist blind people capable of working to return to some form of employment. The majority of blind people resident in Glasgow in 1881 were not in employment or in a position of independence:

Blind people in the poorhouse	83
Receiving parochial relief	229
Employed	294
Non productive	899
(Auchincloss Arrol 1886:13).	

Returning to work and realising the potential of financial self-sufficiency were considered to be of paramount importance for men. The loss of a breadwinner's income was portrayed in the missions' annual reports as a catastrophic turn of events:

... homes once bright and happy, suddenly plunged into deepest poverty and distress, by the terrible calamity overtaking the father or breadwinner (GMAR 1884(b):2).

Men were generally perceived to fulfil the role of breadwinner, with a family dependent upon him. The loss or deterioration of eyesight did not relinquish men of this role. For women with acquired visual impairments, though, it was assumed that they would have an extended family, friends or husband upon whom they could rely for financial support. On this basis, men and women were assisted into very different forms of employment.

Men were more likely to have served apprenticeships. Where possible, they were helped to return into their trade on a self-employed basis. Men were generally assisted to set up as tea, firewood, drapery and coal sellers (GMAR 1885:14). The Edinburgh missionary, Mr Brown, reported in 1894 that:

I had the privilege of giving a handbag and a quantity of tea to one of our blind men who has a wife and family dependent upon him, and thus set him agoing as an itinerant tea seller (ESAR 1894:5).

Furthermore, such employments meant that blind men remained visible in the streets, participated in their communities and provided a service to others. As such, they gained something approaching an equitable status with others eking out a living selling in the streets. The aim of the mission's support was to enable such men to become financially self-supporting, and so, in general, blind men thereby remained active in mainstream society. Blind women's dependence upon their families and friends was socially acceptable, conversely, and they were rarely expected or assisted to become physically or financially independent. Scottish-wide statistics gathered in 1881 illustrate the emphasis placed upon blind men returning to employment. These estimated that 467 blind men were unoccupied and unproductive, whereas, 1,172 blind women over the age of twenty years were unoccupied and unproductive (Auchincloss Arrol 1886:6). The minority of blind women who were employed tended to be engaged in industrial and domestic occupations.

The Glasgow Mission to the Out-door Blind established a Ladies Auxiliary Committee in 1865, with the purpose of assisting unoccupied blind women. Their objectives were to teach blind girls and women to knit, to supply them with the necessary materials and to assist in the disposal of the finished articles. Members of the Ladies Auxiliary offered knitting classes to blind women. They resolved to brighten the lives of blind women who attended the classes 'by reading to them and providing them with little treats to relieve their gloom' (Dunbar 1989:55). This aim implies an assumption that blind women lived a miserable existence, brightened only by the knitting classes and cakes provided by the Ladies Auxiliary. Blind women, it would seem, were objects of pity and sympathy, women who lived their lives in a darkened gloom who could not possibly be happy. The description of a new recruit to the knitting class exposed some of these attitudes:

She is really very dull in spirits having now to face the stern reality of darkness all through her future in this life, and beginning to experience some of the hardships and disadvantages which surround the path of those in such circumstances (LAGMAR 1882:16).

The majority of women mentioned in the mission's annual reports were portrayed as passive recipients and dependants, living with their mothers, relatives or friends:

BG is about 19 years of age, who has been for years a great sufferer and never will be able to work for herself. She can knit a little and takes great pleasure in reading (ESAR 1877:8).

Income generated from knitting and sewing work was meagre, and the main purpose of such 'diversional' work was to keep women occupied. Even where the quality of work was so poor that items produced were not saleable, the mission continued to provide materials to those individuals. Regardless of previous working experience, these women were presented with knitting and sewing as the main means to earn a living. One woman mentioned in the Glasgow Ladies Auxiliary Annual Report had successfully managed her own business prior to losing her sight. Nonetheless, she was still provided with knitting and sewing as a means of earning money (LAGMAR 1880:6). Although the nature of this woman's business was not documented, it was noted that she managed the enterprise with 'energy and ability' (LAGMAR 1880:6). It would appear that her capabilities as a businesswoman were

taken to be annulled by her loss of sight, and her acquired visual impairment was clearly accompanied by a change in the social perception of this woman.

On the rare occasions where women were assisted to attain an independent lifestyle, their lives were still very much confined to their homes, with little indication of women participating in mainstream society. One journal entry tells the story of a young woman who lived with an aunt. They lived in extreme poverty, and the only prospect for the blind woman was the poorhouse. However, after being taught to read and supplied with knitting, her circumstances significantly altered:

She has now a neat, clean comfortable house of her own: and being fully occupied with her housework, her knitting and her book, is quite contented and happy (LAGMAR 1888:5).

Blind women were not supported or encouraged to become street traders, and instead all were offered work to be done in the home. At the time respectable and moral women's work was strongly associated with the confines of the home, while women's presence in the street was considered unnatural, except where they were involved in tasks such as shopping or running errands (Barret-Ducrocq 1992). Therefore, supplying working-class blind women with work to be undertaken in the home removed them from the streets and may have enhanced their moral stature. Since blind women were generally considered to be delicate and vulnerable, home working was perhaps a means of protecting them. Annual reports of the Outdoor Missions evidence the isolation and loneliness experienced by the women, many of who did not venture outside the familiar environment of their home, as illustrated in a missionary's journal extract for 27th May 1875

On reaching Ms L I found her much cast down and on hearing my voice she brightened up and exclaimed 'o Mr M is that you? Thank God I am not forgotten yet'. Were it not for my visits, this woman would not have a single friend to take any special interest in her (LAGMAR 1876:28).

Conclusions

The Blind Asylums established themselves as centres of expertise and knowledge in relation to the training, education and management of blind people. They proactively created the impression that they met the

requirements of the majority of blind people in the Glasgow and Edinburgh populations, even if in practice they did not. Numerically, the Outdoor Missions probably worked with more blind people. The working practices of the asylums and missions seem to have been influenced by prevailing cultural stereotypes of female morality and respectability. Consequently, through religious instruction, the aim was to reform working-class blind women's assumed immorality to mirror the moral stature accredited to the asylum or mission with which they were associated. The connections and cross-codings between the women and the 'space' of both the asylum and the mission were hence multiple and enduring, having significant implications for both the women themselves and the perceptions of a wider (sighted) mainstream society.

Similarly, within the asylums the imposition of oppressive regimes, rules and regulations, ones manipulating institutional spaces to impose sexual separation, surveillance and monitoring of women's behaviour and conduct, were probably motivated by a desire on the part of directors to protect the respectable reputation of the institution rather than with genuine concerns for inmate welfare. This being said, we must beware of assuming that no directors held genuine feelings of wishing to improve the lot of inmates, but, even so, such feelings could not but have been framed by dominant discourses about disability, femininity and the 'right' ordering of social and sexual relations. As a result, the oppressive regimes, rules and regulations denied female inmates opportunities to sexual expression, childbearing and mothering. Likewise, changing notions of respectability saw the retreat of respectable women from the streets, and this undoubtedly influenced the imposition of institutional regulations that severely limited blind women's participation in mainstream spaces. The localised, but concentrated, spatial segregation of women resident in asylums, along with the limited presence of respectable women on the streets, combined to deter and virtually to eradicate the participation of blind women in mainstream society. With time, the erosion of blind women's presence in spaces of everyday life rendered them invisible to the majority-sighted population. This pervasive invisibility became second nature, to the point where society no longer questioned their absence, a claim with great relevance to what will be discussed in the second half of this thesis.

Chapter Four

Lives Less Worthy

Introduction

The working practices within nineteenth-century 'welfare' institutions were influenced by the external moral culture and associated social attitudes, as informed by the prevailing social sanitary reform movement. Much as occurred in the institutions for the visually impaired (or 'blind') discussed in the previous chapters, these practices had devastating consequences for physically impaired women during the nineteenth century. Constructed as 'invalids', in need of care, disabled females were neither educated nor enabled to pursue any social roles. Rather, they were considered to be suitable candidates for life-long institutionalisation, with much the same consequences as faced the visually impaired women whose experiences have already been documented. Increasingly directed into similarly constrained 'spaces', particularly behind the closed doors of specialist institutions, these women lost their 'place' within wider society as capable individuals, wives, mothers, lovers and workers. At the same time, any sense that they should be part of wider society vanished, and they increasingly became regarded as less-than-human beings with no 'worth' or 'value' for the community at large. The links between the institutions as segregated spaces and such outcomes will be explored further in this chapter, this time with specific reference to physical impairments other than just the visual.

The institutions

During the nineteenth and early-twentieth centuries, philanthropists in Glasgow were responsible for the founding of institutions established to help physically impaired children and adults. Two examples of these were East Park Home for Infirm and Imbecile Children, Maryhill Glasgow, founded by William Mitchell, and Broomhill Home, Kirkintilloch, founded by Beatrice Clugston, for permanently infirm and incurable adults. Archived documents of these institutions indicate directorial motivations for establishing such institutions arising from a genuine desire to help those considered to be helpless or less fortunate in society (*Daily Mail* 1875, Clugston 1881). The sanitary reform movement predominant in wider society at this juncture, particularly in the response to problematic urbanisation (Driver, 1988), may

have influenced their intentions. Poverty, poor housing and over-crowded living conditions were linked with immorality, ill health and physical impairment. Sizeable bricks-and-mortar institutions, ones capable of holding large numbers of people who were physically incapable of participating in the workplaces of urban-industrial capitalism, became widely acknowledged as suitable sanitising spaces where 'dirty, diseased bodies' could be treated medically and morally (Bashford 1998). Institutions gained social status as repositories of expertise in the care of disabled people, and during the late-nineteenth and early-twentieth centuries institutionalisation of physically impaired people became customary. The routine spatial segregation of such individuals meant that the general public and society at large became generally unaware of their existence (Garwood 1957:50).

East Park Home opened on 16th September 1874 with initial accommodation for thirty children, and an adjoining cottage purchased in 1878 enabled the Home to accommodate a further twenty children. The erection of a new building in 1889 enabled the Home to accommodate eighty children in total (EPHAR 1887:2), while further expansion in 1903 increased capacity to 130 inmates (EPH 1974:11). Beatrice Clugston initially proposed the establishment of a national institution equidistant from Glasgow and Edinburgh (BHH Minute book 1874-1878:5), but rivalry between Glasgow and Edinburgh sabotaged the plan (Dow 1985). It was finally agreed to set up a local institution, the argument being that the creation of a number of local institutions would provide even coverage of institutions throughout Scotland. Broomhill Home hence opened officially on 6th October 1876. The Home initially provided accommodation for 49 adults and twelve children (BHHMB 1874-1878:16/12/1876), while the building of a new wing increased capacity to 107 (BHHAR 1884:2). Less than a year later, accommodation had increased to a capacity of 114 inmates (BHHAR 1886:7).

East Park Home admitted children with a broad range of physical impairments, but not children certified as 'imbecile' (an old definition of intellectual impairment). Initially the home did admit children certified as 'imbecile'. In order to maximise accommodation for 'infirm' children those categorized as 'imbecile' were referred to other institutions such as Baldovan Asylum (Hutchison 2000). Many children accepted into the institution had conditions that would respond to medical attention. Physically impaired people considered to be in extreme need, and who had been resident in the

Glasgow area for no less than three years, were eligible for admission into Broomhill Home (BHHLAC 1885-1904:29). Those who lived with, or were cared for by, their families or relatives were enrolled on the Outdoor Relief Fund administered by lady visitors and almoners. The Home did admit those certified as 'imbecile' until February 1891 when it was decided to admit no more as separate provision was available at The Scottish National Institution in Larbert (BHHMB 1883-1899:329). Due to lack of room 'epileptics were no longer admitted after May 1877 (BHHHCMB 1876-1881:11/5/1877). Individuals who were deaf, blind or insane were also not eligible for admission as it was considered that adequate provision existed elsewhere. However, where incurable disease would debar entry into lunatic asylums or other institutions, such cases were considered on an individual basis (BHHMB 1874-1878:2/9/1875). Any individuals who had left the poorhouse, received parochial relief or were considered to originate from the pauper class were ineligible for admission (BHHMB 1874-1878:27/8/1875), which left many of these individuals eking out a living on the street begging or selling small items such as shoelaces, nutmeg and matches (Stoddard Holmes 2001).

A large proportion of men and women either admitted into Broomhill Home or in receipt of outdoor relief had acquired physical impairments as a result of illness or accidents. It would seem that entry into this Home or acceptance of outdoor relief had a greater social significance in relation to men as opposed to women, echoing a theme covered in the previous chapter. An *Evening News* article headed 'Strong men stricken' noted that 'cases particularly painful are those of married men. Several married men who were previously earning a respectable living' (*Evening News* 1885). In a male-dominated culture, where men were perceived to be the main breadwinner, their admission into the Home would probably have serious consequences for their families. Alternatively, the change in circumstances for women who had previously earned a respectable living was perceived to be less significant, possibly because women were generally not expected to fulfil the role of provider. Therefore, altered physicality and dependence upon others was perhaps more socially acceptable for women, as reflected in the gendered facilities of Broomhill Home where more women than men were accommodated (BHHMB 1874-1878:16/12/1876): for example, 42 men and 53 women (BHHAR1891: unnumbered).

Locations, wretched dwellings and clean Homes

East Park Home was located to the West of Glasgow, situated on Maryhill Road, and initially occupying a rural setting. However, by 1887 the City had extended westwards and by 1894 the rate of tenement building was so rapid that the directors purchased an adjacent field to ensure space for future expansion. By the close of the nineteenth century, East Park Home had become part of a sprawling urban environment (Illingworth *et al* 1946). The brick-built wall and iron entrance gates denoted the boundary between the urbanised space of the community and the segregated space of the institution. Broomhill Home was set in the Kelvin valley, overlooked by the Campsie Hills and situated in the immediate vicinity of Kirkintilloch and approximately seven miles from Glasgow (BHHAR 1875:11). The grounds covered 97 acres, which encompassed a mansion house, lodge house, farm and stables (BHHMB 1874-1878:30/4/1875). The farm was used to supply the Home with milk, fresh vegetables and fruit. The back of the Home was bounded by the river Kelvin, and to the front was the Forth and Clyde Canal (*Evening Times* 1898). From the lodge house a long wooded avenue led to the Home (Clugston 1881:73). Imposing entrance gates were always kept locked, admission only being obtained by ringing the bell of the lodge house (BHHHCMB 1876-1881:11/5/1877). A perimeter fence was erected to prevent town visitors to the countryside from straying onto the Home's grounds. The fence, a physical expression of boundaries presumably acted to keep unwanted visitors out and inmates 'in their place'. The first fact of these institutions was their stark spatial isolation from the everyday spaces of the city, then, to some extent because of a declared ambition to create cleaner spaces (medically and morally) than those from which many of the inmates derived. --

The majority of inmates originated from the poorer classes. The social interpretation was very much influenced by a moral code that linked the mixing of bodies in overcrowded houses with immorality (Barret-Ducrocq 1992), on occasion presenting physical impairment as a consequence of such behaviour. Sanitary reformers also identified poverty, over-crowding and poor sanitation as possible underlying causes of ill health and physical impairment. The beliefs and expressions of the sanitary reform movement resonate throughout the literature published by the institutions at that time. Annual reports emphasised the stark contrasts between the physical and moral

environments from which inmates originated and that of the institutions. For example:

Most of the children come from very miserable dwellings, where little could be done to alleviate their sufferings or cheer and brighten their lives (EPHAR 1890:unnumbered).

Reformers identified a link between environmental factors and bodily conditions, and the institutions seized upon this claim to promote the negative environmental effects of inmates' dwellings, contrasting these effects with the implied benefits and necessary continuance of the institution:

So many of these people huddled together in one apartment, subjected to bad air, bad cooking, and a want of those delicate requirements of a person who was incurably diseased (BHHAR 1876:8).

It is significant that most inmates were considered to come from dirty, squalid poverty-stricken dwellings, the assessment of which would presumably have been undertaken by either the lady visitors of East Park Home or almoners who distributed pensions from the Funds of Broomhill Home. These women would most probably have originated from reasonably affluent, comfortable, middle-class family homes. Their judgements about the suitability of home environments in terms of cleanliness and sanitation would very possibly have been measured against their own homes and standards of living, to which the homes they visited would not have compared favourably.

Institutional literature contributed to the construction of physically impaired children as innocent sufferers grateful for charitable assistance and physically impaired adults as morally degraded (Stoddart Holmes 2001). For example, East Park Home described inmates as 'poverty-stricken suffering and infirm children' (EPHAR 1887:3). The majority of Broomhill Home inmates were people who 'had been reduced from good social positions' (BHHAR 1898:11). Nonetheless, they were also perceived to originate from miserable, dirty dwellings. It would appear that the institutions exploited an association between poverty and immorality to create and sustain a notion of inadequate care giving amongst disabled individuals families, relatives and friends. The association of immoral behaviour and neglect was then particularly emphasised where disabled children were concerned, presumably because the neglectful environment legitimated the need for institutionalisation:

... a helpless blind boy who was living with his mother in an unsanitary dwelling in the centre of the city. So dark and dismal was it, that a light had to be got at midday to see the patient. There was no furniture in the house, the child was literally naked, and the mother was helpless through drink (EPHAR 1898:8).

Disabled adults were also depicted as recipients of neglectful care at the hands of families, relatives and friends

In many instances [inmates] have been removed either from miserable dwellings, where they lay scarcely noticed or cared for all the day (BHHAR 1880: unnumbered).

The diffusion of such information perpetuated a notion of disabled individuals in need of care and attention living with uncaring families in the worst of conditions.

On the contrary, the institutions' external and internal environments were constructed as healthy and therapeutic, located in the countryside where the air was fresh, clean and good. An *Evening News* article described Broomhill Home as 'A charming retreat' (*Evening News* 1885). Directors took every opportunity to emphasise the environmental improvements and comforts afforded to inmates:

Cleanliness, comfort and kindness abound in the Home, and the weary invalid from the small country hut or the dingy city apartment, who gets admission within its walls, is privileged (BHHAR 1885:14).

The buildings' internal environments, described as clean, moral, ordered and tidy, were also thought to have a remedial influence. The spacious, well-ventilated dormitories and wards of the homes, as well as the provision of toilet and bathroom facilities, were recognised as measures to combat the spread of disease. Such facilities constituted massive improvements in living conditions (*The Bailie* 1891), and were equated with healing influences, improved physical and moral health. East Park Home reported the healing influences within the home as:

... not only medical and surgical, but sanitary and social, moral and educational (EPHAR 1892:5).

Improvements in inmates' health or physical condition were also attributed to the caring and attentive nursing offered by educated and trained nurses.

Institutions were believed to offer medical expertise, prompt and ongoing medical treatment where and when necessary. Furthermore, institutions emphasised that they offered inmates a standard of living unobtainable to them outwith the institution:

... one can easily understand what a contrast all this presents to the comfortless dwellings from which many of them have come (BHHAR 1895: unnumbered).

As well as a level of care presumed to be unobtainable out-with the institutional setting, it was insisted that attention be given to:

... the looks of astonishment and delight depicted on little faces, and hear the quaint remarks when, perhaps for the first time in their lives, these children creep in between clean sheets and are tucked in comfortably for the night (EPHAR 1908:7).

In short, the institutions and staff represented everything that inmates' homes and families supposedly were not. Consequently, the institutional environment became widely accepted as a beneficial and appropriate environment for physically impaired people.

Evidently, for some, admission into an institution did improve their circumstances:

This was a young woman who, before the institution was opened, had spent all her life in the inside of a box-bed ... her friends being quite unable to do her the least service towards improving her condition. Until she was taken to the Home at Broomhill she had never seen a tree, but she was now able to be placed in her chair and wheeled out to enjoy the delights and gladness of the fresh air and beautiful scenery (BHHAR 1876:6).

Although this young woman's admission into Broomhill enabled her to engage with the outdoor environment, it was physically distant, isolated from the local town and society at large. The crucial factor in this young woman accessing the outside environment was arguably the provision of a wheelchair, rather than removal from her family and friends. Nonetheless, entry into an institution was perceived to offer lonely people the opportunity of company, and more especially company of their own kind, impaired individuals with whom they could relate:

The patients had also company – the company of those who were afflicted in a similar way: and it was well known what solace there was in meeting with those who were likewise suffering (BHHAR 1883:5).

The directors took every opportunity to emphasise the gratitude of the inmates for the assumed benefits of the institution:

The patients were thankful and happy in the greatly improved circumstances in which they were placed (BHHAR 1876:6).

Directors interpreted almost any form of expression to be that of gratitude, possibly because that was the response they expected:

The gratitude of the sufferers from the benefits received is, in many instances, truly touching – the tearful eye often expressing what the paralysed tongue cannot articulate (BHHAR 1892:7).

Spaces of death, insignificant lives and 'impure' physicalities

In both East Park and Broomhill Homes, inmates considered capable were obliged to attend religious services. Although East Park accommodated children up to the age of 15 years old and Broomhill accommodated mainly adults and a few children, it would seem that religious ordinance in both homes served a similar purpose – that of preparing individuals for their death. This was undoubtedly informed by the connection between ill-health and impaired physicality. Many conditions were incorrectly thought to considerably reduce life expectancy. Although local ministers and missionaries visited the Homes regularly, the nursing staff exerted great effort in religiously preparing children for death. This was considered entirely appropriate, both in terms of the nurses' pure moral stature and in the prevailing expectation of inmates' premature deaths. On admission to East Park Home, many children were considered to be close to death:

Of many little sufferers admitted it may at once be said they are not long for this world: the shadow of death comes with them (EPHAR 1895:4).

A similar expectation was imposed upon some of those admitted into Broomhill Home:

Unlike those who entered an infirmary or convalescent home, those who entered Broomhill Home very often did so only to find a place in

which to die (BHHAR 1899:6).

The institutions were equipped to deal with death: Broomhill had its own mortuary and associated cemetery (*Evening News* 1898), while East Park also had an associated lair (EPHAR 1887:7). The directors' and staff members' ambition was to 'let the poor sufferers go down the hill of life on the sunny side' (BHHAR 1894:7). The significance of the supposed link between impaired physicality and pain framed death as a release from life, thought to be filled with suffering, an understanding that was expressed in words such as 'eleven of these little sufferers have been released by death' (EPHAR 1895:4).

Within East Park nursing staff exerted a great deal of effort preparing children for their death, rather than providing religious instruction in the longer-term *living* of a moral life. The Matron of East Park Home wrote in the report of 1892:

How varied and suitable are the opportunities for telling them of the painless land, and leading their young hearts by the green pastures and still waters of a saviour's love (EPHAR 1892:5).

The nursing staff team was perceived to represent cleanliness, moral purity, selflessness and dedication:

Those who carried on the work of the institution did all they could to make lives which seemed essentially hopeless as happy and bearable as possible (BHHAR 1895: unnumbered).

The way in which nurses were thought to make hopeless lives bearable suggests a stark contrast in the value placed upon disabled and non-disabled peoples' lives. The non-disabled nurses' lives had value because they served a purpose, whereas disabled peoples lives were considered to be hopeless and therefore worthless.

As the institutions expanded in size, deaths of inmates and those in receipt of outdoor relief increased. Broomhill Home reported a mortality rate amongst outdoor pensioners to be eight times that of the average death rate of the general community (BHHAR 1876:7). Death became a familiar feature of institutional life, reflected in the brevity of recorded details of inmates. A thorough inspection of the Broomhill Home male and female inmates' journals dating from 1876 to 1901 reveals disordered, inaccurate and incomplete case

notes, perhaps reflecting the lack of significance, value or worth placed upon inmates' lives. It is apparent that, with the passage of time, inmates' deaths became inconsequential, their existence insignificant.

On admission into an institution, individuals were immediately categorised by a dehumanising medical assessment process that conceptually reduced individuals to their medical conditions and bodily difference. Thus inmates became defined, described and labelled in medical terms, as illustrated by the visiting medical officers' classification of female inmates:

Paralysis in various forms, chronic rheumatism, deformity, deformity with epilepsy, spinal curvature and rickets, neuralgia and debility, blindness and debility, heart disease and deafness, debility in lower limbs, scrofula (BHHAR 1884:15).

Deformed and, as they were often seen, grotesque bodies represented pain, suffering, illness and fragility, such that, as implied, physicality and ill health became inextricably linked. The institutions sustained these associations through their literature and the local media:

Human suffering in perhaps its worst form expresses the condition of the large majority of those who are taken to spend the remainder of their lives at Broomhill. Paralysis is the affliction in more than half the cases and in not a few paralysis and the affects of which are almost as indescribable as they are grievous and painful (*Evening News* 1885).

This association was reinforced by terminology used in the institutional literature, where inmates were referred to as 'patients', thus conjuring up an image of sick bodies in need of medical expertise and care. Emotive phrases used to describe inmates such as a 'great little sufferer' (EPHAR 1889:5) and the institution as a 'refuge of pain' (BHHAR 1884:6) strengthened the association of impaired physicality with pain and suffering. The language and imagery used here acted to distance physically impaired individuals from wider society. For example, in describing the therapeutic benefits of the garden, emphasis was placed upon inmates' 'damaged' physicality:

They have a nice garden with playground in front where they sit in the sunshine, or wheel about their little chairs, or race upon their crutches, or ride their hobby horses full of glee, quite forgetful of their crooked legs, or weak backs, or drooping heads (EPHSCL 1894: unnumbered).

Some descriptions hint at the emotive response evoked in the author and

then transmitted to the reader: 'S.S. Only 10 years old, blind, imbecile, and paralysed; a truly sorrowful sight' (BHHAR 1885: unnumbered). Such phrases duly established a repertoire of appropriate emotional responses to physical difference of sorrow, pity and charity.

Institutions thereby sustained the cultural and social divide between physically impaired people and wider society by describing inmates as helpless, and with the level of care necessary for them often being compared to that required by infants. This comparison undoubtedly contributed to the social infantilisation of disabled people, another key theme from the previous chapter. Regardless of an individual's chronological age, they were not regarded as adults, but instead were viewed as dependents. For example,

- She is 25 years of age. She can do nothing for herself, and has to be fed like a child (BHHAR 1875:16).

The cultural divide was widened further by the often erroneous belief that physical impairment signified an intellectual incapacity:

AB aged 19 has since infancy been paralysed in the lower limbs and unable to walk. This is quite incurable, depending on an arrest of the brain development since birth. She cannot read or do the simplest sum in arithmetic (BHHAR 1885: unnumbered).

Individuals who experienced paralysis or did not use the spoken word to communicate were often certified as 'semi-imbeciles' or 'imbeciles'. Certified individuals were often judged to be uneducable, and therefore no attempt was made to offer any form of education. It is probable that the young woman mentioned above had received very limited education, if any at all, and so an assessment based on reading or mental arithmetic would give a misleading indication of her intelligence. Over time physical impairment became inaccurately recognised as a signifier of subnormal intelligence.

The social inscriptions written into images of impaired physicality, child-like dependence on others, ill-health and subnormal intelligence defined disabled people as different, making the institutionalisation of these 'impure' or 'polluted' individuals socially acceptable because they were considered to require and to benefit from specialist facilities such as East Park and Broomhill Homes. Here too was the origin of the 'normalisation' debate that is still prominent in discourses around disability today. Indeed, the medical focus on

physicality within both institutions stripped individuals of their status as human beings: instead, they were regarded as 'deviant' bodies ripe for fixing, as appropriate objects for experimentation in the name of medical advancement. In both East Park and Broomhill Homes inmates were subjected to such treatments as the fitting of plaster and, in some cases, steel jackets to correct curvature of the spine (EPHAR 1894:4, BHHJMF 1876-1900). For others, surgical procedures were administered in an attempt to reform deformed limbs (EPHAR 1890:4). The correction and possible cure of defective bodies gained great significance amongst medical professionals associated with the institutions.

Where surgical interventions were deemed inappropriate, bodily difference was disguised by the fitting of prostheses. The East Park Home medical adviser noted in an annual report the great excitement caused by the arrival of a pair of artificial legs for a young girl:

Her first efforts to use the stumps were amusing, but with the help of crutches she now gets along slowly, and by and by may be able to do without crutches altogether (EPHAR 1899:5).

The apparent intention for this young girl was that she would possibly walk unaided using artificial limbs. By doing so, she would walk in a manner considered conventional, thus gaining superficial acceptability in terms of appearance. For those inmates whose bodily difference could not be surgically altered or disguised by prostheses, they were encouraged to use alternative parts of their body to carry out tasks. One inmate, Emily Callaghan, was encouraged to use her feet in place of hands, with a focus on her undertaking appropriately feminine tasks as a means of normalisation:

Our little armless patient, notwithstanding her deprivation, is proving herself to be very intelligent, and besides being able to read, is learning to write, knit and sew with her feet (EPHAR 1900:4).

Surveillance, regulated routines and limited activities

Within Broomhill Home, inmates had very limited, if any, choice or control over their daily routine, possibly signifying an institutional expectation of them as sick patients to be taken care of rather than as responsible adults. Moreover, the threat of dismissal perhaps coerced patients to co-operate with their passive sick role while the nurses fulfilled their expected responsible

caring roles. With time, these divergent roles became ingrained, manifested in the working practices of the institution, particularly through surveillance measures that restricted admission to only suitably behaved inmates and subsequently limited their contact with mainstream society.

Prior to official admission, inmates had to undergo a three-month probationary period in the Home (BHHLACMB 1885-1904:29). Difficult behaviour or the use of impertinent language towards the Matron or directors would result in admission being denied. The probationary period possibly enabled the Home to admit only those willing to comply obediently with the rules and regimes of the institution. Where admitted inmates were disobedient, restriction of food was implemented as a punishment (BHHHCMB 1876-1881:3/10/1877). Some punishments suggest an infantilised perception of inmates: for example, John Mills was accused of pilfering tobacco from a fellow inmate, and the Matron was authorised to use the strap on him. The strap was nonetheless dispensed with as directors did begin to disapprove of corporal punishment being used on an 'incurable' (BHHHCMB 1876-1881:4/1/1878).

It appears that the passing of time within Broomhill Home was initially punctuated solely by mealtimes: breakfast at 8am, dinner at 1pm, tea at 5pm and supper at 7pm. All inmates who could leave their rooms were expected to be present in their respective dining rooms at mealtimes. Inmates had no control over what or when they ate. The daily routine ended at 9pm, when all inmates had to be in bed with lights out. Similarly, inmates could only receive visits from their families and friends on Wednesdays and Saturdays between 2pm and 6pm (BHHHCMB 1876-1881:26/7/1876), and they were prohibited from entertaining their friends or family at any other time (BHHDR 15 undated). Visiting times may not have been suitable for relatives who worked and undoubtedly led to the breaking of family ties and relationships. Perhaps inadvertently, the institution made it difficult for inmates to maintain any semblance of contact with the outside world.

It would appear that opportunities for inmates to engage in mainstream society were restricted, and in the event were tightly controlled by key staff members. Inmates were not allowed to leave the premises except when issued with a pass by the Matron. The pass issued once per month granted leave of absence for two nights, and this enabled inmates to visit their

families or friends for a limited amount of time. The length of time an inmate was absent from the Home was strictly monitored, though, and the time of departure and return were recorded on the pass. Inmates issued with a pass had to be inside the gates no later than 8.30pm and had to be indoors by dusk (BHHDR 3, undated). These limited freedoms were further restricted by rules prescribing the distance that inmates could travel from the Home:

Patients shall not be away from the home driving for longer than three hours, on any one day, and must be accompanied by an official on every occasion (BHHDR 10, undated, no pagination).

Therefore, even when physically away from the Home, the institutional rules had a limiting influence on inmates rare excursions into mainstream space.

Regardless of inmates' or outdoor pensioners' age or gender, it would seem that institutional directors, staff and consequently wider society regarded disabled people as unable to fulfil any socio-economic roles, assume social responsibilities or indeed contribute to society in any way. This abject lack of expectation conceivably resulted from 'common knowledge' created by the institutions themselves:

... the objects of its beneficence are not those from whom society can expect any return in the way of help or service, on the contrary, they are recognised to be those who are permanently helpless (BHHAR 1876:9).

Inmates were expected to remain 'invalids for life' (BHHAR 1876: unnumbered), and as such simply pass time in their home or an institutional setting. When Broomhill Home opened, inmates were not expected to undertake any work, although they were supplied with books and magazines, and in addition lectures and musical afternoons were laid on to keep them entertained. Therefore, initially it would seem that inmates were regarded as sick, unable to perform any role or task towards the subsistence of the institution. Similarly, pensioners in receipt of outdoor relief were considered incapable of work. Exclusion from the workplace forced disabled people to rely on family members, institutions or parochial relief for financial support.

As demands upon the institutions increased, the perception of inmates as 'those who were hopelessly and permanently disabled from ever helping themselves' (BHHAR1886:7) altered dramatically to that of an untapped

labour force who could indeed serve a purpose for the subsistence of the institution. As a result workshops were built to accommodate work-related activities (BHHAR1885: unnumbered). Thus limited gender-oriented, craft-based education was offered, especially to those institutionalised at a young age. Girls and women were taught sewing and knitting (*Evening News* 1885). Boys were taught woodcarving (EPH1890:5), while men were taught to make wooden tables, chairs, chests and book racks (*Young Herald Magazine* 1901:73). Items produced by inmates were sold at annual sales of work to raise funds for the institutions. These various items were listed in the local press, ranging from tea tables, mirrors, flower pedestals, spinner seats, hall chairs, medicine cupboards, photo frames and kettle stands to stockings and under garments (*Kirkintilloch Herald* 1896). Over and above producing items for sales of work, inmates played a leading role in fundraising concerts where they recited poetry, sang and played various musical instruments. These concerts were held in the Home and attended by members of the public (*Concert Programme* 1888).

The use of inmates' labour was framed in therapeutic terms, stressing benefits to the individuals rather than any financial gain to the institution. Initially, work arrangements were informal and most likely voluntary. However, the Ladies Auxiliary Committee of Broomhill Home implemented a new regulation that obliged every inmate certified capable of undertaking light work to labour each day in the Home (BHHMB 1883-1899:302). Following the implementation of this rule, inmates were regularly checked for suitability to work. Female inmates were involved in knitting, sewing, fancy needle work and later millinery (BHHMB 1883-1899), while male inmates were involved in woodwork (*North British Daily Mail* 1888). Females were also expected to assist with domestic tasks within the Home and, dependent upon educational background, to assist the nursing staff (BHHMB1874-1878:14/11/1876).

Although previously considered to be incapable of socio-economic activity, male inmates now received earnings through woodcarving. They were expected to use this income to contribute to the purchase of new clothes (BHHMB 1883-1899:3). It would seem that, in general, female patients were rewarded for their work with new clothes (BHHMB 1883-1899:315), and it would appear that women did not receive any financial reward for their work. It is probable that the sewn and knitted items produced by the women would

have commanded less status and significance in comparison to the substantial pieces of furniture produced by the males.

Sex segregation and life-long spatial segregation

The main strategy to curb the fertility of the 'unfit' was sex segregation. It was pursued with extraordinary vigour in almost all institutions where disabled people lived (Humphries and Gordon 1992:101).

Strict sex segregation was implemented within Broomhill Home when prior to opening, the mansion house was adapted to fulfil its intended purpose as a home for physically impaired people. The adaptations were made in a manner that facilitated such separation as completely as possible. Women's and girls' facilities were to the north of the building, comprising of a drawing room and dining room, a room for women confined to bed, women's and girls' dormitories and toilet facilities. Men and boys had similar facilities to the south of the building, and the men's apartments included a smoking room (BHHMB 1874-1878:3/8/1875). The complete sex separation within the Home was most likely influenced by the external social culture that regarded mixing of male and female bodies as immoral. In order to retain charitable status worthy of public support the institution and the bodies it contained had to retain their moral integrity. Again, the echoes of what was happening in the Blind Asylums are most striking.

One of the domestic rules delineated gendered spaces within the Home where trespassing was strictly prohibited:

Female patients are strictly prohibited from going near the workshop or smoking room, and male patients from entering the laundry (BHHDR 6, undated).

Many of the inmates who were certified suitable for light work would have spent the bulk of their day in these spaces, females assisting in the domestic tasks of the house and men in the workshops. Inmates engaged in work were presumably physically capable of doing so, and most likely also capable of independent mobility, and thus there was potential here for inmates to 'trespass' and possibly to form relationships. Systematic sex separation implied some recognition of inmates' potential sexuality, and even the possibility of sexual activity, despite the fact that emerging social ideologies of

disabled people as helpless, sick and child-like inferred a sexual immaturity or absence of sexuality.

A thorough search of the Broomhill Home's minute books and medical journals reveals no recorded cases of pregnancy amongst female inmates. This points towards the absolute nature of the sex segregation, since it follows that – even for inmates physically capable of sexual intercourse – they simply did not have an opportunity to act upon their desires. It seems that sexual desire was presumed to be absent in both female and male inmates, with no documented evidence in the medical records of the 'official' administration of sexual suppressants such as bromide. (BHHMCMB 1878-1894).

It would appear that physically impaired individuals were considered to be suitable candidates for life-long institutionalisation. The Lord Provost of Glasgow and Chairman of the Association for Relief of Incurables for Glasgow and the West of Scotland, Hon William McOnie, in his speech to the ninth Annual General Meeting of the Association, talked of:

Those afflicted ones who are admitted to the benefits of the institution, not for a few days merely, not for a few weeks, but for life (Applause) (BHHAR 1883:5).

Emily Callaghan was admitted into East Park Home in 1898 aged 7 years old, her physical condition recorded as 'congenital deformity: no arms' (EPHAR 1905). She was admitted into Broomhill Home on 19th February 1904, aged 13 years old, and she remained in the institution until her death on 20th April 1936 (BHH Register 1876-1943: no pagination). By the time that she died, she had spent 38 years in an institutional environment. Emily Callaghan is just one example of many women, who, on the basis of their bodily difference, spent almost their entire lives spatially segregated, excluded by a social culture that could not perceive of a more appropriate place for what were popularly conceived of as deformed, defective bodies.

The level of staunch public support for institutionalisation during the nineteenth and early twentieth centuries was reflected in the duration of inmates' stay. A random selection of female inmates was made from a Register of patients admitted into Broomhill Home after 1881 and still present in the home in 1915 when the register commenced. Table 1 hence depicts

their degree of institutionalisation.

Table 1. Duration of female stays in Broomhill Home

Name	Admitted	Age	Condition	Death	Duration of stay
Mary Stirling McGillum	February 15 th 1887	14 years	Infantile paralysis	June 8 th 1925	38 years
Maggie Littlejohn	January 19 th 1886	11 years	Paralysis	December 1917	33 years
Elizabeth Davidson Watson	July 20 th 1886	52 years	Paralysis	September 13 th 1926	40 years
Alice Arthur	December 18 th 1886	8 years	TB and leg amputation	February 27 th 1933	47 years
Mary Miller	May 1 st 1896	31 years	Paralysis with aphasia	December 22 nd 1929	33 years
Martha Trellway	August 28 th 1889	38 years	Ataxy	October 17 th 1921	32 years

An inspection of Broomhill Home admissions registers, case notes and medical journals of inmates admitted between 1876 and 1901 reveals only one woman who defied the expectation that she would remain in the home indefinitely. Winnifred Maithers Campbell was admitted into the Home at the age of 7 years on 3rd February 1900, her condition noted as ‘TB and curvature of the spine’ (BHH Register 1915:25). Records indicate that she later left the home to take up employment. Unfortunately, due to the incomplete nature of the records, it is difficult to establish the duration of her stay in the Home, the only clue being that the register was of inmates present in the Home from 1915 onwards. Nonetheless it is admirable and indeed, astounding that an individual institutionalised as a child would have found the resolve to challenge internal and external social cultures. This case is an exception in comparison to the countless numbers of women who remained within the institutional environment until their death.

Outdoor pensioners

In cases where an individual's physical condition was unlikely to respond to medical treatment, it was deemed preferable to assist them financially so that they could remain in their own home. A small grant was paid from the Broomhill Home Outdoor Relief Fund to enable a family member or relative to remain at home to care for an individual. Two factors greatly influenced whether such a pension would be awarded. Firstly, the cleanliness and tidiness of the individual's house was of paramount importance, since it was thought that a clean tidy house equated with good moral stature. Secondly, the family member or relative assuming a caring role had to be 'worthy and dependable' (BHHAR 1876:8). It thus seems clear that the beliefs of the sanitary reform movement also influenced the administration of the Outdoor Relief Fund. Almoners administered outdoor relief to pensioners in Glasgow and the West of Scotland. There were pensioners in the counties of Argyle, Ayr, Bute, Dumbarton, Kirkcudbright, Lanark, Renfrew and Stirling (BHHAR 1898:13). On average, there were 180 pensioners on the roll of the Outdoor Relief Fund at any one time (BHHAR 1887: unnumbered). Dependent upon individual circumstances, each received payments of between 8 and 12 shillings per month (BHHORR 1875-1911). Almoners' journal extracts published in annual reports, often suggested a reversal of roles in that mothers received care from their children:

FC for several years has been getting weaker from general shaking paralysis. She is now confined to bed for the most of the day. Though in humble circumstances, she has evidently been an industrious woman, keeping a shop which paid fairly well, as long as she could. The house is clean and tidy, and her little daughter of nine years is her kind and faithful nurse (BHHAR 1886: unnumbered).

It is possible that the presence of children precluded some women's admission into an institution.

Extracts from almoners' and lady visitor's journals, the latter also being published in annual reports, conveyed a rather bleak impression of disabled people's lives. Although these individuals were not institutionalised, it would appear that many spent their lives confined within their houses, indeed, for some, in just one room of the house. For example:

CB lives with a married sister in a house in the West end of Glasgow.

She has been confined to bed for upwards of 24 years (BHHAR 1875: unnumbered).

Although the houses in which individuals lived were an integral part of a community environment, physically impaired individuals were nonetheless, often excluded from participating in mainstream society. The inaccessibility of the built environment and the lack of affordable mobility aids, such as wheelchairs, available to working class people effectively deterred disabled peoples' participation and presence in mainstream space. The social isolation of disabled individuals was acknowledged in the almoners' and lady visitors' journal extracts:

Many of the outpatients are bed ridden sufferers, known only to a little circle of kindly neighbours and to the institution's almoners (BHH leaflet printed 1882: no pagination, BHHAR 1899: unnumbered).

Disabled people's lives may well have been difficult, but the assessment of life circumstances was subjective, undertaken by non-disabled lady visitors whose voluntary work, distributing grants from the Outdoor Relief Fund, was most probably prompted by pity for those 'incurably afflicted' (BHHAR 1889: unnumbered). Pitiful portrayals of individuals in receipt of Outdoor Relief, too often reciting the stark contrast between their existence and non-disabled peoples lifestyles, undoubtedly influenced emerging social ideologies of disabled people as incapable of fulfilling any social roles. They hence encouraged public and financial support for the continuance of the spatially set-apart institutions.

Conclusions

During the nineteenth and early-twentieth centuries, institutions gained social respectability and status as loci of medical knowledge and expertise in the treatment and care of physically impaired individuals. Conversely, physically impaired individuals became regarded as beings who required expert care and attention. Institutions created and maintained demeaning social images of physically impaired people. These portrayals contributed to the inaccurate social inscriptions of ill health, subnormal intelligence and dependence being attributed to physical difference. It would seem that both congenitally disabled people and those who acquired physical impairments were stripped of their adult status, and as such considered unable to contribute or participate in mainstream society. Perceived as social burdens, institutions

were thought to be appropriate places for disabled people to live out their lives in relative comfort. The invention and ingraining of such spatial segregation undoubtedly denied disabled people the opportunity to contribute to society. Furthermore, morally informed sex segregation denied inmates many, if any, opportunities for sexual expression. Indeed, portrayed as sick, deformed and frail, their bodies were constructed as asexual and undesirable. Spatial segregation not only denied these disabled women their place in society, it deprived them of full social and sexual citizenship, setting a certain cast for the experiences of much more recent years that will be encountered in the second half of this thesis.

Chapter Five

The Big Green Gates

Introduction

As explained over the last two chapters, the history of disabled people from at least the nineteenth century is essentially one of spatial segregation in institutional settings, together with a deep-seated social exclusion rendering disability an absence, at the same time a feared presence, in everyday spaces of living and working (Linton 1998, French and Swain 1998). Little is documented about the lived experiences of institutionalisation from the perspective of disabled people, however, perhaps this is because social and spatial segregation go hand in hand with disempowerment and silencing. This short chapter, acting as a deliberate link between the historical and the contemporary components of the thesis, seeks to recover something of these lived experiences through the memories of two older women with first-hand knowledge of an institutional existence arguably little different from that of their nineteenth-century sisters.

Adele and Melissa (pseudonyms), participants in this study, were admitted into East Park Home for Infirm Children in the late-1950s. Both women, now in their middle fifties, spoke openly of their memories of the Home. These childhood memories, interpreted through their adult perspectives and information gained from conversations with their respective parents in adult life, offer a unique insight into their lived experiences within a children's institution from the mid-1950's to mid-1960's. Adele and Melissa emphasised that they did experience happy times in the Home. They both had very fond childhood memories of Christmas time in the institution and Christmas parties held by large organisations, and both also had happy memories of an annual taxi outing to the seaside at Troon. They spoke with great affection of a Matron who had been particularly caring and kind to children in the Home while she was employed there. Both women cited their meeting and life-long close friendship as a positive aspect of their institutionalisation. Yet many of their experiences were less than positive and had many negative implications for their later lives, and Adele and Melissa's life experiences beyond the institutional walls play out in the contemporary chapters (see Chapters 6, 7 and 8).

Admission

Children were admitted into East Park Home for various reasons, often because of social or financial difficulties (Potts and Fido 1991). Adele was admitted into East Park Home following the death of her mother. Adele had contracted polio at the age of nine months and had spent the first four years of her life in hospital. Her father loved her dearly and did not want to place her in an institution. However, he had to earn a living, and with no one else who could care for Adele in the family home, professionals advised him that institutionalisation was the only option. Similarly Melissa's parents were advised to place her in an institution where she would receive schooling and medical care. Her parents loved her and wanted the best for their only child, but institutionalisation was presented to them as the best option, as Melissa recalled:

... years ago, what parents were advised was that children were much better off in some kind of institution ... What a doctor said was law then. Doctors were kind of gods and you just did what the doctors said and that was it. So I ended up in East Park Home for Infirm Children ... that was a place where there was schooling, there was nursing staff that took care of you; you were there twenty-four seven, you weren't allowed out (Melissa 51-56 years).

This remark also underlines the extent to which the walls of the institution really were impermeable to the disabled inmates, revealing the extent to which this was indeed a spatial shutting away.

Although Adele and Melissa were young children on admission to the Home, both clearly recall early impressions of the place:

... I can remember quite clearly going into this place where there was nurses who were in uniform and in a ward with about another twelve children (Adele 51-56 years).

Adele's narrative reveals memories of a clinical, medicalised environment whereas Melissa, who was three years younger and an only child, had strong memories of other children with whom to play but also of separation from her mother:

... when I was very young ... I never really thought it was unusual that I was there...the only bit I found that was strange was that my mum used to come on a Saturday and then she would go away and that was

really distressing because I couldn't understand why she couldn't stay with me (Melissa 51-56 years).

In addition to medical care East Park Home was supposed to offer schooling, but Adele and Melissa spoke of feeling 'cheated' of their education. Both women felt strongly that their intelligence and their academic potential was not acknowledged and consequently was not nurtured by the teaching staff. It would seem that they equated physical impairment with intellectual impairment, as Adele recalled:

... you were termed educationally subnormal and you were labelled mentally handicapped as the term would be then (Adele 51-56 years).

Melissa and Adele recalled that the 'school day' was shorter than in mainstream schools and that this was further reduced by regular physiotherapy sessions. Melissa felt that more importance was attached to improving physical function rather than education. Both women spoke negatively of the educational curriculum offered and expectations of the teachers:

A lot of the schooling wasn't schoolwork, it was like making baskets and doing sewing and drawing pictures, and not the formal education that other children get..I think that only started in later years when you were about thirteen, fourteen (Melissa 51-56 years).

This claim was echoed by Adele:

... education ... it was really non existent. I was fourteen years old when I left East Park and I wasn't able to read but I could make lovely little baskets ... and tea cosies ... there was just this assumption that you wouldn't really be able to be educated (Adele 51-56 years).

Both women spoke of not being taught to read until they were teenagers, noting the irony that books were awarded as prizes at the annual school prize-giving. The education offered to Adele and Melissa obviously did not prepare them for possible mainstream employment or independent living.

Rules, regimes and routines

Within East Park the three R's of 'rules, regimes and routines', rather than those of 'reading, (w)riting and (a)rithmetic', were strictly adhered to and

constituted the controlling force within the institution. Few non-standard activities or events were allowed to impinge upon the daily routine.

Visiting

The rules regarding visiting, implemented in 1874 when the Home opened, remained in force until the early-1960s. Visiting times were strictly regulated to a set day, time and place. Visiting took place on Saturdays between 2pm and 4pm within the Home. Parents were not permitted to take their children out during visiting time. The restrictive visiting hours, travelling time and cost meant that regular visiting was not possible for some parents. Melissa recalled that some children never received visitors

... there was a boy called [name] and he waited every Saturday from two 'til four for his Mum and Dad to come and she never came and it didn't matter how many times you said "look [name] she's not going to come, they are not going to come and see you," he sat there the whole time. It was heartbreaking, it really was sad (Melissa 51-56 years).

Most institutions disregarded the emotional consequences for children separated from their families. Indeed, some institutions did not encourage parents to visit their children as a participant in one research project noted:

We only had one visiting day a year all the time I was at Chailey. I used to miss my parents so much. I used to cry myself to sleep. The homesickness was really terrible and we were only allowed home in the Christmas and summer holidays (in French and Swain 1998:4).

Adele's father and Melissa's parents lived locally and were able to visit regularly. In the early-1960s a new matron was employed, and she allowed parents to visit two evenings during the week, for one hour, but the time allocated to parental visiting was strictly monitored and enforced.

Chores

The children were expected to participate in the cleaning and maintenance of the institution, and within East Park children were expected to participate in basic chores. The extent to which the daily routine constituted a controlling force on the children is evident in Adele's memories, and the 'geometric'

precision with which the domestic spaces were to be cleaned, arranged and presented is certainly worth comment:

... you had to make your bed. You had to have the beds in line, the wheels of the bed had to be turned a certain way, the locker, everything had to be correct. You had a wooden chair at your bed ... when matron came round to inspect the ward, the chair would be turned over to see that underneath the legs of the chair were clean (Adele 51-56 years).

Melissa recalled the elaborate morning chores and the undertaking practical tasks, as well as how the Matron inspected tasks to ensure they had been carried out to her satisfaction

We all had chores; you had to brush everybody's shoes, the whole ward, all the shoes, and have them all lined up. You had to fix your own bed, you had to sometimes ... clean the bath and do different things (Melissa 51-56 years).

Both Adele and Melissa described where they slept as a 'ward' rather than a dormitory. The nurses in uniform and the emphasis placed upon cleanliness and tidiness of the environment indicate a highly medicalised, clinical approach to the space and its inhabitants. Instances where the tidiness of the ward or physical appearance of any child was unsatisfactory to the Matron resulted in punishments. As they grew older Melissa and Adele undertook some of the nursing duties within their ward: for example, they dressed and changed children as a means of gaining time to themselves, unsupervised by staff.

Food

A static weekly menu and eating times were adhered to strictly. Adele commented that during her eight year residence in East Park, the weekly menu remained unchanged:

I think for eight years for breakfast I ate prunes and porridge and on a Saturday at the Home it wasn't really a meal at tea time because Saturday was visiting day ... they had this belief that ... your visitors came and you ate that much rubbish, so you didn't really need your tea at night. So what you got was a banana and a lump of cheese and that was your tea every Saturday night (Adele 51-56 years).

An ethos of minimal wastage towards food facilitated its use as a method of control and punishment. Inmates were not allowed to leave food, and Melissa spoke of the consequences of leaving food:

... you could have a hot meal. If you didn't eat it you got that meal at the next sitting and until it was finished that was it (Melissa 51-56 years).

Residents of The Park institution spoke of similar treatment regarding force-feeding:

If you didn't eat your dinner – leave it for your tea. And if you didn't eat it for your tea, you had it for your supper and if you didn't eat it for your supper you had it for your next meal (in Potts and Fido 1991:59).

Adele spoke of force-feeding; at morning school break children returned to their wards for a cup of Bovril:

... I wouldn't drink this Bovril, so I was locked in the linen cupboard with a bib on and a tray of Bovril ... this cup of Bovril put in front of me each time until I drank it, and that's one of my memories. I mean it was just, you know, there were good times and bad times (Adele 51-56 years).

Melissa recalled going to great lengths to avoid eating food that she disliked, and the static menu made it possible to try to make alternative arrangements:

I didn't like cheese and tried to swap with a friend to eat it for me and I would eat something she didn't like. Sometimes we were lucky and could get a swap, but if not it was just tough luck and you had to eat it even if it made you sick (Melissa 51-56 years).

Melissa spoke of resorting to bribing other children to eat unwanted food during the summer months, and eating outside in the summer also offered an alternative method of disposing of unwanted food:

... you were frightened, you knew the rules like even if you were sitting out on a summer's day and they brought out food. I mean my other friend {name}, we used to dig the grass up and hide our food under it and pack the grass down so that nobody would find it because you knew that you'd be made to eat it (Melissa 51-56 years).

Melissa and Adele also found ways of getting food they did want by begging at the front gates of the institution, a practice that presumably risked severe punishment:

... we used to sneak out and go down to the gate and shout at people and we used to say "We can't get out, they'll not let us out, and we've got no money. Could you go to the chip shop and get us chips, or could you go to the shop?" and people used to do that, I mean they really did. It was amazing! We used to say "We'll just hide in the bushes here, but we'll be here if you just come back and stand at the gate" (Melissa 51-56 years).

Lack of privacy

Both Melissa and Adele spoke of having no private space within the Home, and particularly in the ward they shared with boys until their teenage years. The mere fact that they were sharing in this way with the opposite sex indicates that they were not expected or supposed to have sexual feelings, thus paralleling some of the bigger claims made in Chapters 3 and 4 (and as will be further developed in the later parts of this thesis). As Melissa recalls:

I was in a big ward with about fifteen other children ... it was a mixed ward so that was really embarrassing because you had to get dressed when there was boys in the ward as well. So you got very adept at dressing under the covers because you didn't want anybody to see you (Melissa 51-56 years).

The general lack of privacy within institutional environments is reflected in French's research on women's experiences of a residential special school, where a participant commented:

There was a total lack of privacy, you were all together in these big rooms, all got dressed together, all in the bathrooms together. Even the toilets had no locks on the door (in French 1996:37)

In East Park each ward had a communal bath area, and children were bathed every other night in accordance with a strictly enforced rota. The bathing of children started at 5pm and finished at 7pm in time for lights out at 7.30pm. It would seem that the bath time regime resembled a sheep dip, as Melissa also recalls:

... there was a bathing area that everyone just went and got their bath and I hated that as well ... you were in [the bath] and the next one

was in and you just kind of got bathed and changed in [front of each other]. I mean loads of people could walk in and out. It wasn't like that you could have this privacy, that's just the way it was, you just went for your bath time ... everybody went in and out and that was just what you did (Melissa 51-56 years).

This lack of consideration for inmates' privacy, especially during adolescence, is also evident in French's research, where a participant remembered:

I didn't like the way we were all in the bathroom together, as you got older it wasn't nice. There was one in the bath, one drying, and one waiting. (in French 1996:37).

In East Park inmates bodily functions were afforded no privacy. For example, Melissa recalled that she became accustomed to using the toilet with other children present. As she approached adolescence, she became increasingly unhappy with these arrangements and took action to create private space:

... when I was about ten or eleven I started to shut the bathroom door and put a ... wedge under the bathroom door to try to keep the bathroom door shut. You used to get shouted at that you were stopping everybody else from going into the bathroom (Melissa 51-56 years).

The Bunting Ward for girls opened when Melissa was a teenager: it had two bathrooms, and the girls were permitted to shut the bathroom doors affording them some privacy. This implies some changing of attitudes, and perhaps a growing recognition of certain human rights to which even young disabled women were entitled. Whether or not it amounted to any deep appreciation of their sexual status, though, is probably dubious.

Punishment

Melissa and Adele remembered living within a strict regime and being well aware of the rules and punishments doled out by the staff. Although there were probably rules, regulations and an associated formal system of discipline set down by the Board of Directors, it seems that the institution developed its own sub-culture where the Matron and nursing staff, charged with the day-to-day care of the children, developed their own covert and informal systems of punishment. Potts and Fido (1991) wrote of such a system:

A system based on punishment and the fear of punishment is always a potential breeding-ground for violence and cruelty (Potts and Fido 1991:65).

Spatial isolation is a precondition that allows abuse to take place, as is known from countless examples historically and in the present. Adele and Melissa spoke of commonly used punishments within the Home, and, while neither referred to these as abusive, the staff evidently did 'abuse' their powerful and trusted positions. Adele spoke of children being 'grounded' as a form of punishment. Children would be 'strained' to their beds from the end of the school day to the following morning, and the children could be subjected to this punishment for a number of days or possibly weeks depending upon the severity of their transgressions:

... strained to their beds, in bed. It was like a bodice that went on you with big long straps and it was tied round the back of the bed, or it was tied under the beds so that you couldn't reach it (Adele 51-56 years).

The evolution of such a sub-culture of covert punishment did result in children being subjected to particularly harsh or cruel punishments. From Melissa's recollections, it would appear that the Matron and nursing staff participated in certain physical and psychological torments:

If the matron didn't like you I mean it was awful. She used to ask you to go along to her office and take her teeth. She had her false teeth in the top drawer, and she'd make you take them out her drawer and give them to her (Melissa 51-56 years).

Melissa as a young child gained the impression she was Catholic and had practised this faith accordingly. A nurse took it upon herself to inform Melissa that she was mistaken, that she was a Protestant, and duly punished her for 'telling lies and for taking communion'. Melissa had very clear memories of this incident because she was absolutely petrified:

... she [nurse] took me into the sterilizer room and opened the sterilizer where they washed the bed pans and put me in the sterilizer [and switched it on] for telling lies (Melissa 51-56 years)

Melissa also spoke of other forms of punishment. For example, if representatives from organisations visited to present the children with gifts, any child that had misbehaved was ignored by the Matron, who 'also

instructed visitors not to talk to a particular child or children and not to present them with a gift. Melissa had clear memories of visitors' adherence to the Matron's instructions. Children were also subjected to solitary confinement in the isolation room for misbehaving.

Neither Melissa and Adele mentioned punishments or their unhappiness to their parents. Melissa recalled:

... there was nobody to tell ... you were frightened. I know I was always kind of nervous because I never wanted to let my mother down by getting into trouble for things. So it was like a two fold if you were unhappy, there was nobody to tell, you could only tell your friend (Melissa 51-56 years).

Deaths

Adele and Melissa recalled that a few children received preferential treatment; staff were more lenient towards them. They were allowed to choose what they wanted to eat at suppertime, got the best hairbrushes, toys and the nicest party dresses. Melissa and Adele were teenagers when they realised that this preferential treatment was bestowed upon children with limited life expectancy. Although death was part of institutional life, children's deaths were never discussed. Both women thus spoke of their childhood fear and confusion when a child 'disappeared':

... she was just another child and then one day she just disappeared but nobody said where she was. I was terrified that I was going to disappear one day too because children did disappear. Nobody explained where they were going and I couldn't understand; am I going to disappear as well? Nobody going to talk about you or mention you? It was dreadful, it was dreadful, they just disappeared (Melissa 51-56 years).

Their parents, rather than institutional staff, explained to Adele and Melissa that children had either gone into hospital or had died as a result of illness or the nature of their impairment.

De-institutionalisation

Children were discharged from East Park at the age of 16 years old, and they were either returned to their families (if they had one) or entered an adult

institution. Prior to discharge, children's contact with mainstream society was very restricted, only leaving the confines of the institution for day trips. In the early 1960s a new matron initiated progressive changes that enabled children to return to their families for two weeks during the summer holidays. By the time that this was implemented, Adele and Melissa were teenagers, and Adele recalled the novelty of going home and having choices over when and what she ate:

... the good thing was you could eat what you wanted and my father used to think "goodness me!" But it was just the novelty of being able to have some food when you wanted and have the food that you wanted to have (Adele 51-56 years).

Melissa spoke of her distress when she had to return to the Home after two weeks spent with her parents:

I remember at fourteen, fifteen [years old] I did get home, and I hated coming back and I used to say to my dad "drive slow, drive slow, don't go quick," and when we got there they had to leave you and I remember crying (Melissa 51-56 years).

Although Adele and Melissa had spent two weeks outwith the institution from the age of fourteen, it was totally inadequate preparation for their re-integration into society. Institutionalisation meant that they were unaccustomed to living in a family environment or having the freedom to make choices. Furthermore, they were not equipped with basic life skills, numeracy or literacy skills to enable them to live independently or to participate equally in society with non-disabled peers. Both women had to work extremely hard to fill in the gaps in their academic and social knowledge created by institutionalisation (see also Chapter 6).

Adele was an active agent in her discharge from East Park. At the age of fourteen years old, she had been admitted into a local hospital for treatment lasting nine months, at the end of which she refused to return to the Home. Her father supported her decision and she referred to this as a 'turning point' in her life. Melissa remained in East Park until shortly before her sixteenth birthday. Her father died suddenly prior to her discharge from the Home. She spoke poignantly of her anxiety at the prospect of leaving the institutional environment familiar to her for a mainstream society that was an unknown, unfamiliar world:

It was really, really difficult. It was a difficult period, it was difficult, frightening, exciting, it had everything mixed into the one. I wanted to go because I wanted to go home. I was frightened to go because I didn't know what I was going to do and how I was going to manage, and I was frightened because I was leaving an environment where there was staff, all my friends had an impairment. I was used to being regimented and I just couldn't foresee how I was going to cope in this other life ... and yet part of me was desperate to go to the other life because I wanted to do the things. So it was a kind of mixed up time for me (Melissa 51-56 years).

Melissa amplified this point about the difficult transition from regimented, restricted institutional life to the choices and spatial freedoms of a family environment:

It [living in family home] was difficult. It was very difficult to adjust. I mean I went mad ... I couldn't believe that you could go into the fridge and eat something and not get into trouble because you weren't allowed to do that [in East Park] ... For the first three months I just stuffed myself stupid, because it was like an evolving thing, until I learned that you didn't need to do that – you had then the choice of being able to do it. I used to go out and not come in because [of] all this freedom, being able to come in and go out (Melissa 51-56 years).

Adele and Melissa both recalled the way in which they shared their aspirations and fantasies of their adult lives while resident in East Park. At a very basic level their aspirations involved their presence and participation in mainstream society, living 'ordinary lives'. It is apparent that institutionalisation did not prepare them for life on the outside. Both had clear ideas of what they wanted in their lives, but they were unsure of *how* and indeed *if* they would ever achieve their goals of marriage, child-bearing and mothering:

... I didn't know what to do and I was really frightened. I used to look down ... onto Maryhill Road [from the ward window] and I hated those green gates because it was the gates, and then it was the road, and I used to think "I want the life that they've got. I want to be out there doing what they're doing going to the shops ... I want to be able to drive and I want to have children, I want to do all the things but I couldn't see how that was going to be possible (Melissa 51-56 years).

Adele also spoke of her childhood aspirations

... the main window [of the ward] looked out onto Maryhill Road ... her [Melissa] and I used to sit at the window, and we used to say to each other "when are we going to get out of here, when are we...going to

get our freedom and do what we want?" and I used to think "I wonder what my life is going to be like?" But [for] everybody around you, and I have to say even my family, there was this low expectation and I hadn't a clue, I didn't have a clue what life was going to be like. But Melissa and I used to fantasise; often we used to talk about getting married and having children. It was like a dream, it was like a dream that you wanted to come true, but I think we believed in our hearts then that it was just a dream, it wouldn't happen (Adele 51-56 years).

The extent to which such things could come to pass for disabled women like Adele and Melissa, upon leaving the set-apart spaces of East Park, is an important context for the remaining chapters in this thesis. At the same time, even for the women to be encountered in these chapters who have *never* personally been institutionalised, they arguably still bear the implications of an era that did institutionalise disabled people, particularly disabled women, in a manner rendering them socially and spatially 'out of place' anywhere but behind – as it were – 'the big green gates'. The implications have inevitably rebounded on to their dreams of expressing sexual needs, meeting partners and entering motherhood: these too are not supposed to occur beyond 'the big green gates'.

Chapter Six

Out of Place Bodies

Introduction

Disabled women are chronically 'out of place' (Cresswell 1996) in many everyday scenes of living and working; their participation in education, employment, social and family life is not expected and often unwelcome (Hansen 2002). Michalko talks of the spatial metaphor of 'putting to one side' as a means of understanding 'the place of disability in contemporary society. He suggests that:

... even though society is the place of disability, it [society] is reluctant to give disability a place (Michalko 2002:151).

Disabled women are literally 'put to one side', spatially and socially, in contemporary western society. In this chapter I intend to explore the social and spatial manifestations of being set to one side, considering women for whom society cannot perceive 'a place' other than on the margins, the very fringes of everyday life. Disabled girls and women, it seems, are socially regarded as individuals requiring protection, and removal from mainstream society is reckoned to afford protection in segregated spaces. More pointedly, non-disabled society is saved the awkwardness of dealing with an undesirable, threatening element.

The three preceding chapters have traced the emergence of this approach to the treatment of disabled people, disabled women in particular, from the nineteenth-century origins of institutionalisation to Adele and Melissa's experiences of much the same segregated regime in the mid-twentieth century. This chapter and the next two findings chapters bring the story nearer to the present, drawing upon the in-depth interview research anticipated in Chapter 1 and described in the methodological appendix. In all kinds of ways, the interviews have revealed traces of the past weighing heavily on the present, in that the socio-spatial separations enforced in earlier times – feeding into popular presumptions about what disabled girls and women should be and do (and should not be and not do) – clearly play out in the experiences of the women interviewed (whether they have themselves been institutionalised or not). This chapter takes a chronological approach towards these women's experiences from early childhood and adolescence

through to adulthood. Their experiences cut across time as well as space, ranging from the mid-1950s to the early-1980s.

Earliest years and schooling environments

The birth of a disabled child is often regarded as a tragedy (Mason 1999). In Western society perfect babies are what is expected, valued and celebrated, and indeed some parents may mourn the birth of a disabled child (Avery 1999). Impaired newborn bodies are devalued by society; regarded as tragic, valueless, perhaps in-valid. Moreover, this diminishment encompasses not only the material body but also the mind (Charlton 1998), given that there is an erroneous assumption in society that physical impairment is associated with intellectual impairment. This is borne out in Ellen's childhood experience in the 1950s:

... before I went to school, my mother was told that I was not educable ... they [the Education Department] just looked at my medical condition and said that there was no way I could go to school (Ellen 51-56 years).

The 'tragedy view' well established by the medical model of disability is hence widespread in society, influencing all manner of decisions, and is readily conveyed by medical professionals in their language and suggested interventions (Basnett 2001). Therefore professionals may inadvertently influence parental perceptions and expectations of their child, commonly in a negative way. Veronica felt that forceful medical pronouncements had negatively affected her parents' expectations of her

... doctors told my mum I wouldn't be able to do very much ... "she won't be able to do half the things a kid at her age would be able to do, she won't be able to read, she won't be able to have a normal life" (Veronica 21-26 years).

Veronica commented that her mother 'did not expect anything' from her, and therefore she did not read her story books, accepting that the medical predictions for her daughter's future abilities were correct.

It is apparent from Ellen and Veronica's narratives that the medical model of disability which constructs disabled people as sick, weak, fragile and in need of care and protection (Barnes and Mercer 2003) intrinsically informs and influences social attitudes towards impairment. Socio-medical messages

hence invoke families to 'protect' their disabled members from the rigours of mainstream society and the spaces of everyday life. Often this has led to disabled children being consigned to allegedly 'safe places', the institutions discussed in earlier chapters and their close correlate, the so-called 'special school' or 'segregated education' solution. Historically, special schools have been regarded as places of expertise offering education and medical attention. In many respects Blind Asylums, and in more recent times, special schools developed to serve a similar purpose, the physical containment of one group of 'others' (Holt 2003, Mason 2000). Holt suggests that special schools represent the spatial representation of society's fear of socio-spatially constructed 'others' (Holt 2001:120). In short, special school education sets young disabled people spatially and socially apart from their non-disabled counterparts (Mason 2000).

Special school provision in the recent past was often presented to parents as the best or only educational option available. It is highly likely that parents' decisions were made on the understanding that there was absolutely no other option or, indeed, that special school was the best educational option for their child, often assuming that this would 'protect' their child from potential bullying and believing these spaces to be essentially safe places (BBC 1996).

Fifteen of the women who participated in this study were educated in special school at some point during their primary and/or secondary education. Several women spoke at length of their experience of residential special schools which span the late-1940s to the mid-1980s. Despite separation from their families and strict regimes, to be discussed presently, most of the women had some favourable memories of these institutions. Ellen spoke positively of the special school that she attended for her secondary education, where she was presented with opportunities she felt would have been unavailable to her in a mainstream school:

... they [the teaching staff] believed in education and that was their top priority when I was there and I got to do things I wouldn't have been able to do at a standard school because they would never have let me. They simply would not have let me go camping ... it would just have been a nightmare thought or getting into a canoe or all the things that I like doing would just have been a 'no no' (Ellen 56-61 years).

Most of the women mentioned the camaraderie amongst pupils and a desire to help each other. Katie recalled an act of kindness shown to her by a senior

pupil:

I couldn't find my dormitory ... and this big girl came and she said "I'll show you what to do Katie, count the doors." We counted the doors from the stairs and on the sixth door was my dormitory, and then she showed me that the handle of my dormitory was a slightly different shape from the other ones (Katie 61-66 years).

Myra also spoke of pupils supporting each other by helping younger children in the dormitory and those who required personal assistance to get dressed and undressed each day. Mary, Katie, Boadicea, Jenny and Myra spoke of sleeping in dormitories of eleven or twelve children, but a privilege as they grew older was for the numbers to be decreased to less than ten in a dormitory. Notwithstanding, certain positive assessments arising in the interviews, though, the predominant themes were more negative, amplifying what Adele and Melissa said about East Park Home in Chapter 5, and stressing unease about the isolation and discipline, encouraging docility, that they experienced in special schools.

Places of isolation

During the 1950s, 1960s and as late as the 1970s early admission into special schools was considered to be beneficial for disabled children, and children often started special school before the age of five years old. As a result of this widely held belief, Mary was admitted into a residential special school in the early 1950s, at the age of three years old. Professionals advised her parents that this would be the best educational option for her, with little consideration given to the emotional consequences of removing a child from their family environment at a very young age (Oswin 1998). Katie, Boadicea and Jenny spoke of their immediate removal from mainstream school when they acquired visual impairments. Katie was initially placed in a 'sight saving school' in 1946, the ethos of the schools being to preserve residual vision by restricting the use of sight (for example, reading time was restricted). Katie recalled the school interior was painted blue and cream to 'rest the eyes'. The loss of her sight in 1948 resulted in Katie's admission into a school for blind children.

Boadicea acquired her visual impairment at the age of 12 years old, and she was admitted into a residential special school for blind children:

You were taken out of your home environment, you were taken out of your school environment, you were put into the nearest blind school that was available or would accept you (Boadicea 46-51 years).

Similarly, Jenny's parents had been advised that special residential school was the only educational option available. She recalled the trauma of being removed from her family home:

I was totally unprepared, no clueless. So you're dropped from a very small family, Mum, Dad and one sibling and wee friends ... into this sort of [alien environment] ... It was very scary (Jenny 41-46 years).

Katie, Boadicea and Jenny obviously found their removal from their families traumatic, and the changes in their living circumstances simply added to their difficulties in adjusting to their acquired visual impairments.

Where young people attended segregated education they are less likely to have a circle of friends or extensive social networks as a direct result of their removal from local communities (Hirst and Baldwin 1994, Pearson 1994). Several women spoke of their social isolation when they returned home from residential special school for weekends or during holidays, and the situation was not remembered so differently by those women who had attended special schools as day pupils. It was difficult to meet up with school friends as children came from all over Scotland to attend certain special schools, and all of the women concerned spoke of very limited social networks in their local communities:

... you didn't really have any friends at home because you were away. I mean as I got older I had a couple of friends, but up until I was fourteen, fifteen, I didn't, I had none (Mary 51-56 years).

Although these individuals lived in mainstream neighbourhoods for some of their early lives, they did not attend local schools, a key place where children form friendships and social networks (Mason 2000). Beth felt that her limited circle of friends as a child was a direct result of her attending a special day school rather than the local primary school.

Even those women who went to mainstream schools with impairment specific specialist support units felt a measure of isolation (Holt 2003). Kathryn attended a special primary school and went on to a mainstream secondary with a specialist support unit. Although she shared mainstream classrooms in

the latter, no preparation was made for the integration of disabled youngsters (there was no Disability Equality Training, for instance, to educate and prepare non-disabled children for the presence of disabled children in their midst). Both of these educational settings were a substantial distance from her home and local community, and she felt that they had an adverse impact on her opportunities to develop friendships with school friends and social networks in her local community:

... I had friends but not outwith school because everyone came from miles away so it was hard to have a social life outside school (Kathryn 26-31 years).

From the experiences of women who participated in this study, a small number spent their entire education within segregated environments moving from special primary and secondary schooling onto specialist colleges. Some women spoke of feeling, in consequence, 'totally unprepared for life in the outside world'. Katie commented on having to 'rehabilitate' herself and adjust to living in a sighted society after leaving special education. Other women spoke of feeling 'totally institutionalised' and uncertain of 'appropriate and inappropriate' social interactions and behaviour. In short, within segregated environments, individuals became unaccustomed and uncertain of social interactions with non-disabled people in everyday spaces.

Places of docility

Both Boadicea and Myra likened their segregated school environments to prison. Boadicea commented that while at special school she often asked herself 'what have I done to be incarcerated like this?' Myra spoke in similar terms:

It was just like a prison ... you didn't feel like a normal person, it was like just trying to conform and do what the people were wanting me to do (Myra 41-46 years).

This analogy, as drawn by the women, speaks volumes about the working practices and regimes within segregated environments that suppress individuality and promote conformity, as already demonstrated at some length. The issue has therefore not been solely one of exclusion, segregating this problem population, but has also been about striving to engineer 'conformity' in the disabled inmates, something recognised above by Myra

and also by many of the other women interviewed.

In many respects, visually impaired individuals may be rendered docile by unfamiliar environments. This enforced docility may be prolonged by lack of access to 'mobility training', a formal process of familiarisation that enables a blind person to become familiar with their environment. Blind individuals must memorise, for example, the layout of a special school campus, key building locations and the internal layouts of buildings and classrooms. Mobility training enables blind people to navigate their environment independently. Lack of mobility training within special schools may be regarded as a form of control. Denying individuals the information and knowledge that they require to travel independently undoubtedly impacts negatively on that individual's self confidence, and may quite literally serve to keep disabled bodies in their place. Katie spoke of the anxiety caused by lack of orientation and familiarity with her environment at a blind school that she attended six months after losing her sight completely in 1948:

I was very unhappy there ... nobody ever said to me, "now this is where the toilet is, this is where your dormitory is" ... I couldn't concentrate on my lessons because I was worried about how I was going to get from one classroom to the next (Katie 61-66 years).

Boadicea spoke of mobility training and independent travel being highly circumscribed at the school that she attended in the late-1960s, some twenty years later:

... we had six stages or six routes to learn and that didn't start until you were 15 years old ... but you were not ever, ever, ever allowed outside the school gates by yourself or even with another pupil (Boadicea 46-51years).

French's study of women's experiences and the effects of a residential special school for partially sighted girls found that, after leaving school,

Most of the women were frightened of travelling and going out on their own because they had never been permitted to do so (French 1996:40).

Discussions with women regarding their experiences of various special schools revealed strict regimes that dictated what and when they ate, as well as when they would learn, play, sleep, wash and involve themselves in domestic duties. Without exception, within residential special schools, pupils were

expected to participate in domestic tasks to varying extents. Mary, for example, was expected to make her bed and polish her shoes. The school that Jenny attended had, at one point during her stay, attempted to involve the children in the cleaning and maintenance of the institution, with pupils expected to participate in basic tasks depending upon their level of sight:

... the blind seemed to get the job of washing and drying the dishes and putting the cutlery away. If you could see a fair wee bit you'd ... set the tables (Jenny 41-46 years).

Myra and Jenny spoke of not being regarded or even acknowledged as an individual within the residential special school, citing lack of choice or control over what or when they ate. Lack of choice in relation to food may be regarded as a form of control, as personal preferences are disregarded. Arguably, within a large institution, it would be problematic to cater for individual tastes. It is nonetheless significant that these women did not recall *ever* being offered a choice of what or when they ate, as Myra remarked:

... they never really asked you what food you wanted it was just sort of made from the kitchen and put down in front of you (Myra 41-46 years).

Katie spoke of the way in which pupils were expected to eat their meals at the special school that she attended, and it suggests an infantilised perception of the pupils:

... they didn't give you a knife and fork, you got a spoon. You got a spoon to eat your soup with, then you ate the main course and pudding all with the same spoon. It wasn't until the 1950s that they introduced knives and forks (Katie 61-66 years).

Being issued with just one piece of cutlery may have reduced domestic staff costs to the institution. Most significantly, though, the practice would *not* have instilled in pupils appropriate table manners acceptable in mainstream society. Katie hence commented that she felt this practice 'did not prepare you for the outside world'. Goffman (1961) refers to such practices as a process of 'dis-culturation' where pupils become institutionalised and left unfamiliar with expectations and practices in mainstream society.

A few women spoke of being issued with a school uniform, and in general these were standard issue, plain and usually well worn by previous pupils. In

special schools where uniforms were worn all pupils tended to be dressed the same, and Goffman (1961) refers to the substitution of institutional uniforms for one's own clothes as a crucial technique in what he terms the 'mortification of the self' (the death of the old, pre-institutional self). Jenny spoke of 'surrendering' her usual clothes in exchange for her school uniform, known by pupils as 'field clothes'. Jenny's narrative illustrates the deliberate removal of individuality through the provision of school clothing, even down to underwear. All issued items were returned to the school laundry on a Friday afternoon when the pupils left to spend the weekend with their families. On return to the school on a Sunday evening, pupils once again surrendered their own clothing in return for a laundered set of school clothes:

... you surrendered every personal item of clothing and you were given a bundle of underwear to do you the week, with the school knickers and vest and socks with a number sewn in it and school pyjamas with your number sewn in it; and you had your bed linen ... and you had what they called the field clothes, which were regimented pinnies and frocks ... you were more or less dressed the same ... when you were older you could bring in your own clothes and I decided that one set of underwear for a week wasn't enough (Jenny 41-46 years).

It is significant that each item of the substitute clothing was marked with an identifying number, a constant reminder to the wearer that the items did not really belong to them, rather that it was the property of the institution (Goffman 1961).

The provision of school clothes is echoed by Andrea, a participant in French's research on the experiences and effects of attending a residential special school for partially sighted girls:

The thing that really got me most was having to wear the same pair of knickers all week. We only got clean clothes once a week even when we were teenagers ... we used to wash them out at night and dry them on the radiators, but even then they'd [staff] ask us why (in French 1996:38).

It would seem that the provision of just one set of clothes was in itself a form of control, with the level of personal hygiene dictated by the institution rather than by the individual. Moreover, provision of just one pair of pants each week, especially when girls were teenagers and presumably menstruating, indicates that they were not recognised as feminine. Non-disabled girls nearer the time of adolescence and menstruation are usually instructed or

encouraged to change their pants each day, in line with attitudes towards femininity. Revealingly, within TB institutions, women infected with tuberculosis were thought to have become unfeminine, and therefore moral training to encourage them in the ways of feminine cleanliness and hygienic principles were taught to restore their feminine status (Craddock 2001). The implication would seem to be that disability institutions did indeed deny disabled girls and young women any real recognition as females, with the accoutrements of bodies that could potentially procreate and all that follows therefrom.

Although it appears girls and young women's femininity was not recognised within special schools, strict sexual segregation was practised (cf. what appears to have happened in East Park Home: see Chapter 5). This was not borne out of an acknowledgement of pupils as potential sexual beings, but rather the historical religious and moral beliefs marking an institution's origins enmeshed and manifested in everyday practices. Most special schools were established by charities, with a few established by churches. Jenny attended a school located within a convent, and the pupils were taught by nuns. As a pupil, she was conscious of religious influences on school practices, noting that the Bible was used as a reading book, and that complete sex segregation was practised:

... it was very institutionalised when you had a large dining hall and the boys would eat on one side and the girls on the other (Jenny 41-46 years).

Boadicea also spoke of strict sex segregation at the special college that she attended in the late-1960s to early-1970s, where fraternisation between girls and boys was not allowed, with the female and male accommodation being separated by a door kept permanently locked.

Some women did discuss their resistance to disciplinary regimes or 'breaking the rules' as they put it. Boadicea for instance noted that although strict sex separation was imposed within the special college she attended male and female pupils nonetheless did forge relationships. Mary and Jenny started smoking at the ages of 15 or 16 years old, and both referred to smoking while at school as 'breaking the rules'. Smoking may well have constituted restricted self-expression and autonomy within a highly controlled environment:

... I'd hide them [cigarettes] in my radio. Everyone had a Roberts radio and you took the side out of it and there was just enough room to fit ten cigarettes and a box of matches. [laughs] So we did, sort of, what you would call normal things in a very abnormal situation (Jenny 41-46 years).

The peripheral locations of special schools attended by the women and the isolation that some described within their peer group (Boadicea discussed difficulties forming friendships at special school because her 'sighted past' set her apart from her peer group of congenitally blind children) create conditions where discipline and docility become 'normalised' while pupils' individuality becomes suppressed by the disciplinary regimes. It is noteworthy that despite their isolation, young age and vulnerability many of the women while pupils at special school did retain their individuality illustrated in the flickers of resistance mentioned above.

Early adulthood and practices of protection: for whom?

Regardless of educational background, almost every woman who participated in this study made direct or indirect reference to protective responses instigated primarily by parents, relatives and friends towards them as girls or young women. It would seem that those people closest to them during childhood and adolescence subconsciously, or perhaps consciously on occasion, conveyed their expectations, or more pertinently lack of them, through their protective responses. Although these 'protective' responses were diverse, they probably stem from a set of similar underlying assumptions regarding disabled females' capabilities, sexuality (or lack of it), and presumed unsuitability as sexual partners, child-bearers and mothers (Thomson 2004). It would seem that a desire to protect disabled girls and young women may well be prompted by a desire to shield them from customary expectations placed upon women, expectations that 'societal supervisors' (Longhurst, 2001; see Chapter 2) – parents, families, friends and professionals – assume disabled females to be incapable of fulfilling.

Societal expectations placed upon non-disabled females include presumed (hetero)sexuality, involvement in relationships and the reproduction of children (Campling 1981). Indeed, there is a social expectation that women will choose to have children. Those who chose to remain childfree are often stigmatised as rebellious (Campbell 1999, Lonsdale 1990), regarded as

'selfish, hedonistic, feckless, child-hating and unfulfilled' (Bartlett 1994, Safer 1996, McAllister with Clarke 1998: in Swain et al 2003:66) Conversely, society has quite different expectations of disabled women's bodies, in that they are not expected to participate in intimate relationships, child-bearing or child-rearing (Barnes and Mercer 2003, Gillespie-Sells et al 1998). In fact, disabled women, single women and lesbians are often regarded as unfit to be mothers (Swain et al 2003). There remains a general level of social and professional antagonism towards disabled people having sexual partners or having and raising children (Barnes and Mercer 2003), and various protective responses may therefore be motivated by a desire to protect social roles ascribed to non-disabled women. It would seem that the need to 'protect' disabled women stems from a social discomfort level around sexuality and disability, thereby denying the myth of infantilisation and asexuality.

Parental protectiveness prompted by a concern for their daughter's safety and a desire to safeguard them from physical injury was interpreted by interviewees as a questioning of their mobility skills and competence to navigate the outdoor environment. Women repeatedly referred to their parents being 'more protective towards me' in comparison to siblings. Mary and Veronica spoke of not being allowed out alone, while Katie and Kathryn spoke of the close surveillance to which they were subjected, Katie at the age of 18 years old and Kathryn as a young teenager:

... Mum went everywhere with me. Dad took me to the bus when I went to work in the morning, he met me when I got off the bus at night and the awful thing was if I went to go and see a friend for my tea he'd see me on the bus and if I was even five minutes late off the next bus everybody got into an awful state. It was absolutely terrible (Katie 61-66 years).

I wasn't even allowed like even out to the local shops myself, the same if there was like roads to cross or whatever. I always had to go with somebody or tell someone where I was going and how long I was going to be ... if I was late ... [her parents would be out] checking that I hadn't been hit by a car or something (Kathryn 26-31 years).

Parents tend to encourage their teenage children to become increasingly self-reliant in preparation for adulthood, but it would seem that for these women their parents perhaps could not conceive of them as potential adults. As a result, parental responses undoubtedly limited the young women's personal geographies, and inadvertently fostered dependency as opposed to nurturing

independence. Joy acquired her impairment as a young adult, and she was very clear about the response of her family and colleagues to the change in her status from non-disabled to disabled. On acquiring her impairment, she felt that she was no longer accorded adult status; rather, she was 'infantilised', reduced to childhood status and regarded as a dependent individual in need of protection:

One thing I do think, it [the acquired impairment] did, it ... infantilised me ... my Mum and Dad and brother became very protective of me and people at work almost patted me on the head. It was quite difficult because I was quite an independent and strong person (Joy 36-41 years).

A key set of assumptions underlying protective responses is the presumption of disabled women's asexuality, undesirability and unsuitability as sexual partners. This set of assumptions provoked varied responses by those undertaking a societal supervisory influence in the women's lives, creating some seemingly contradictory situations in which young disabled women ended up being given *more* freedoms than their non-disabled siblings. Beth's narrative illustrates parental differential expectations and protective responses towards her and her non-disabled sister

She [sibling] had boundaries about ... where she could go and what time she had to be in at ... I didn't have any of that ... I now realise what it is to do with: I wouldn't have done anything that I shouldn't have done anyway because I'm disabled (Beth 36-41 years).

Beth's parent's responded to her sister's sexuality by establishing limits and boundaries, presumably to protect her from participating in sexually active teenage relationships and the potential consequences of these in, for example, unplanned pregnancy. Beth's presumed asexuality and unsuitability as a sexual partner led her parents to expect that she would not be interested in sex. Moreover, they probably figured that potential sexual partners would not find Beth desirable or attractive. Therefore they perhaps considered the establishment of limits and boundaries to be unnecessary. Beth used her 'freedom' to explore her sexuality, embarking on a sexually active relationship as a teenager (see Chapter 8).

Family members, especially those in a position of influence, may assume the role of societal supervisors who explicitly or more subtly convey their expectations of their daughters, sisters, nieces or cousins with respect to

future adult lives. These expectations, based upon the presumption of disabled women's non-participation in intimate relationships, childbearing or mothering, may involve attempts to influence women's decisions and self-expectations through supervisory approval or disapproval. Hence, micro-systems of social regulation evolve that exercise normative control over individuals (Turner 2001), and in the case of disabled women normative controls involve conformity with expected 'social rolelessness' (Fine and Asch 1988). To give a very specific example, parents may protect their daughters from potential male attention by dressing them in a dowdy or old-fashioned manner, but in the case of young disabled women the same may be the case for quite other reasons. Where girls or young women require personal assistance to dress, due to a disability, it appears that clothes are often chosen on the basis of ease of dressing rather than style or fashion (Campling 1979, 1981). Boadicea identified her mother as the main person who chose and purchased her clothes, tending to buy items that reflected her own views on practicability rather than Boadicea's own taste or age, but in the process affirming a sense of Boadicea's social rolelessness as someone who might be 'pretty' and attractive to others.

For many of the women, parents and close family relatives undertook the role of societal supervisors. Elizabeth, Boadicea and Beth spoke of the various ways in which parental and professional expectations of their adult lives were conveyed to them, clothes, as above, being one small instance. Elizabeth felt that the local priest had significantly influenced her parent's expectations of her adult life, which evidently did not include intimate relationships, marriage or children:

... he [a priest] always thought I would make a good nun, because I was disabled, that was the reason ... she will never get married, she'll never have a family of her own, she might as well come into the convent and he was always on at my parents ... I think my parents did believe that I would go into the convent (Elizabeth 51-56 years).

As a young teenager in the early 1960s Elizabeth recalled being conscious that the prospect of her becoming a nun was far more palatable to her parents, as the subject was constantly discussed, than were the possibilities of her marrying and having children – possibilities that were never mentioned.

As a teenager in the mid 1960s, Boadicea became acutely aware of her family's lack of expectations for her adult life when she overheard a group of

her female relatives discussing her future prospects:

... [they were] saying that of course she will never get a husband, nobody is going to want to marry a blind girl (Boadicea 46-51 years).

These remarks were evidently made on the assumption that Boadicea's visual impairment rendered her undesirable to potential partners and unsuitable as a sexual partner or wife.

Beth also mentioned subtle expectations for her adult life as conveyed by her parents and teachers. Beth's interpretation of these 'messages' was that her adult life would not include relationships or social roles of wife or mother:

... I wouldn't get married, I wouldn't have relationships and I certainly would never be a mother, that's the sort of message that you got – and sex, but disabled people don't have sex [laughs] (Beth 36-41 years).

Beth noted that teachers in her special school subtly and more often explicitly conveyed their expectations of her adult life (see also Chapter 7). Angie, a participant in Campling's (1981) study, recalled that at the age of fourteen years old a teacher intimated the social expectation of her non-participation in any feminised roles. At the end of a cookery lesson in which Angie had prepared a salad, the teacher remarked:

What a good job you've made of that you would have made someone a good wife (in Campling 1981:9).

The teacher's turn of phrase that Angie *would* have made a good wife conveys to the young teenager that the teacher's expectation is that she will not aspire to or indeed attain the role of a wife, an assumption made upon the basis of Angie's impairment and consequent supposed unsuitability to this role.

A number of women made reference to the fact that their parents and close relatives had never mentioned or discussed the possibility of them marrying or having children. Kent has suggested that it is the subjects that are *not* spoken about which shape disabled women's self-expectations and voice others' expectations of disabled women. Kent has written of her own experience of the way in which unspoken expectations conveyed a clear message to her as a young blind woman:

I was seldom encouraged to say “when I grow up I’ll get married and have babies.” Instead, my intellectual growth was nurtured. I very definitely received the unspoken message that I would need the independence of a profession, as I could not count on having the support of a husband (Kent 1987:82).

It is noteworthy that in Kent’s case there was an expectation that she could be academically ‘bright’ and could have a career whereas, for many of the women who participated in this study neither was considered an option by their families.

Disabled women’s active participation as partners, wives or mothers at the centre of the domestic sphere continues to be regarded as an exception to the rule. Their presence in the capacity of wife or mother is often regarded as extraordinary (Michalko 2002): and, put bluntly and using a construction that should now be familiar, they are matter ‘out of place’ (Cresswell 1996, Sibley 1995) in the context of the domestic environment with an active woman supposedly at the heart.

Despite young disabled women’s exclusion from family assumptions of marriage and childbearing, some are nonetheless taught the basics of housekeeping (Rae 1993). Yet, even here it has been found that low parental expectations of an individual’s ability to contribute to the domestic routine adversely impact upon opportunities to do so (Hirst and Baldwin, 1994). Individuals who require personal assistance or adaptation to the physical environment are likely to have very limited or no experience of managing domestic affairs. Susan was clear that her mother did not expect her to be able to ‘cope’ living outwith the parental home. Boadicea had a similar experience following the breakdown of her marriage: when she was offered a local authority house, her mother voiced her expectation that Boadicea ‘would never be able to manage by herself’, and as a result she agreed to remain in the parental home. Susan noted that the inaccessibility of the kitchen in her parent’s home also presented a barrier to her participation in this space. More telling from her narrative is the construction of the kitchen as a dangerous place, full of potential hazards. Perhaps prompted by her mother’s desire to protect Susan from harm, this approach is arguably more fitting towards the education of a small child rather than that of a young woman. Exclusion from the kitchen created a barrier to Susan’s opportunities to learn to cook, a basic skill required for independent living:

... when I lived with my mother, it was a big 'no no' for me to go into the kitchen because there was so many things that could happen, I could spill pots over me (Susan 41-46 years).

Boadicea recounted something similar:

She [mother] would do the cooking, I would ask her if it was okay for me to do the cooking but she said no (Boadicea 46-51 years).

The exclusion of these women from the domestic space may well have been intended to protect them, but would inevitably lead to their dependence upon others to prepare and cook meals for them, with all manner of consequences later on.

Later adulthood and the difference disability makes

Even though we are all different, not all differences are noticed (Michalko and Titchkosky 2001:202).

Many of the women interviewed talked of developing positive self-identities primarily through involvement in the disabled peoples' movement and disability arts. It became apparent, that as women had grown older, they had begun to work more constructively, more self-consciously perhaps, with the 'difference of their disability'. The conscious creation of positive self-identities was often borne out of a negative 'normalising' past where as girls, women were subjected to normalising assumptions and techniques, persuading them that their bodily difference was bad, inappropriate, in need of correction, rendering invisible if at all possible so that they might be socially accepted.

As girls most had internalised the social message that 'disability' was something to be concealed if at all possible. However, as adults involved in disability activism many had 'come out' as disabled and had developed a more positive sense of the difference that disability makes: to (re)claim a positive self-identify that can be the basis for a fuller adult life, which may well include sexual relationships, motherhood and child-rearing. For some disabled women the messages received about their bodily difference, shape their self-identify negatively to the point where they possibly never do manage to come to terms with their bodily difference; women who for whatever reasons never form positive self-identities.

'Normalising' different bodies

The medical model frames disability as something wrong with the body and thus constructs disability as a medical problem that must be addressed to minimise the noticeable difference such as physical appearance or function of the body (Barnes and Mercer 2003, Swain et al 2003). This 'normalisation' process may be regarded as a form of governance and control; indeed, disabled people may be subjected to medical intervention without being consulted or involved in the decision-making process (Basnett 2001). Normalisation of the body has become naturalised as a logical and advantageous measure as unnoticeable difference equates with ordinary bodies, meaning that ordinariness is inextricably linked with social acceptability and humanness (Michalko and Titchkosky 2001) whereas, physical difference signifies extraordinariness and social unacceptability (Hansen 2002, Bruegemann 2001).

Normalisation of the body's physical appearance or function may be prioritised over all other aspects of an individual's life. For example, Ellen was selected for surgery by an orthopaedic surgeon on a regular visit to her special school. As a result Ellen spent two and a half years in hospital, and during this time her education and relationship with her parents were adversely affected. Societal pressure to minimize physical difference also led to Elizabeth's parents undertaking an extreme treatment widely believed in the late 1950s to improve circulation. Elizabeth had clear memories of the painful and somewhat barbaric practice of applying rags soaked in boiling water to her leg:

I remember lying on the kitchen table, I'd be about four or five at the time, and this went on for years ... really boiling hot, he had to use the washing tongs to get it out. He'd throw this rag on the top of my leg and I would be lying there screaming, covered in blisters, but they thought that they were doing good (Elizabeth 51-56 years).

In an attempt to normalise Hannah's appearance she was advised to hang from the wall bars in her school gym each break-time, and she was also instructed to swim the backstroke. Her PE teacher's words convey a social misconception that disabled people themselves, if they try hard enough in pursuit of normality, can attain acceptance through alteration of their physical form (Philips 1999). Hannah recalled that:

I can remember her [PE teacher] shouting at me "you know you are just not trying hard enough, how do you ever expect to get better if you just don't try hard?" (Hannah 41-46 years).

The normalisation process inherently magnifies physical difference as it focuses primarily on alteration of the body's physical appearance (Tremain 2002).

With so much emphasis and value placed upon physical appearance, the women interviewees noted that it was during their teenage years that they became aware of 'feeling different' from their non-disabled peers. Sara spoke of the moment that she realised her physicality was noticeably different from those around her in the mainstream secondary school that she attended:

I was 11 or 12 ... I walked into the school gym for a dance and I thought, "I'm not like these people," and believe it or not it's the first time I remember and, it's just weird, before that I was totally oblivious to the fact that I didn't move around the way everybody else did (Sara 41-46 years).

Hannah also spoke of first noticing her physical difference as a teenager when she started to dress in a sexualised way, wearing tight fitting clothes:

... it was at that point that I realised my body was a different shape on either side, because I've got a wee short side and I've got a long side so for the first time I really noticed (Hannah 41-46 years).

Hannah also felt 'different' because of her feelings around her sexuality and her dawning sense of sexual attraction towards other women. She felt she had 'buried' this unnoticeable difference, and 'latched onto' her physical difference as an explanation of her feelings of being set apart from her non-disabled peers.

A number of the women referred to their teenage years as a particularly painful and upsetting time in their lives, much of which may be attributed to society's response to their impairment. Kylie's comments reflect disablism in society, and more specifically in the micro-environment of the mainstream school that she attended, where physical difference becomes regarded as a legitimate excuse to subject individuals to ridicule, humiliation and verbal abuse (MacFarlane 1994):

I was always the odd one out. I was always different ... people see you

differently, because I walk differently and they [non-disabled peers] always used to take the micky out of me and I didn't like it (Kylie 31-36 years).

Claire, who also attended mainstream school, talked similarly of experiencing disablist attitudes. She had clear memories of regular humiliation, verbal abuse and ridicule by non-disabled contemporaries, and this treatment had adversely affected her self-esteem and confidence during her teenage years.

The manner in which we communicate may be considered a noticeable difference: for instance, where an individual's speech is impaired or they use symbol boards or books of pictures, sign language or other human aids to communication for example, lip speakers or sign language interpreters. The assumption that speech impairment equates with lower intellectual capacity results in social interactions where people adopt a patronising tone similar to one used by adults when engaging with children (Knight and Brent 1998). Annie spoke of being conscious about the links that society makes between physical appearance, mode of communication and intellectual capacity:

I think people see my impairment and they make assumptions about what I can and cannot do, and I think that, with a speech impairment, quite a lot of them probably see me as being stupid or mentally retarded in some way (Annie 26-31 years).

Annie noted that people often spoke to her in a patronising or condescending manner, negating her status as an adult, and at the same time potentially negating her possibilities for developing relationships and sexual partnerships.

Sara also spoke of societal assumptions that erroneously equate physical appearance with intellectual capacity:-

... people assuming that, [because] I walk differently than they do, that I also think differently than they do (Sara 41-46 years).

Laura spoke of concealing her visual impairment as a means of protecting herself from societal responses to impairment, especially disablist attitudes. 'Passing' as non-disabled facilitates social acceptance and inclusion in everyday life (Bruegemann 2001). The energy, time and effort involved in 'passing' is immense, however, and is usually expended at great personal cost to the individual (Hansen 2002). Passing may be regarded as 'an act of repression' (Michalko 2002:10) where individuals deliberately conceal part of

their identity. To return to Laura, she revealed that:

... from that day on for several, well for the next fifteen years, I kind of denied that I had a visual impairment and actually put myself under a tremendous amount of strain to do it (Laura 46-51 years).

French wrote of her childhood denial of her visual impairment as a means of self-protection from negative responses to her impairment, and as a means of gaining societal acceptance and approval primarily from her family:

By denying the reality of my disability I protected myself from the anxiety, disapproval, frustration and disappointment of the adults in my life (French 1993:70).

Thomas also spoke of concealing her impairment in response to social messages regarding 'noticeable difference':

I was born without a left hand, an impairment which I began to conceal at some point in my childhood (probably around 9 or 10 years of age). This childhood concealment strategy has left a long legacy. I still struggle with the 'reveal or not to reveal' dilemma, and more often than not will hide my 'hand' and 'pass' as normal (Thomas 1999a:54).

Many people act as conduits of social messages, primarily parents, doctors, teachers and friends, but even complete strangers may display a resistance to embracing diversity and in effect 'tell' the disabled person that, in order to gain social acceptance, noticeable difference should be minimised (Thomas 1999). Claire spoke of differential treatment depending on whether she was using her long-cane or not. If she walked into someone when not using it, this would usually be met with a hostile or abusive response, whereas when using her long cane, identifying herself as a blind person, other people tended to move out of her way or treat her in a patronising manner.

'Celebrating' different bodies

Some women spoke of consciously making space for themselves on their own terms, so that they no longer feel obliged to conceal their impairments but, rather, feel able to assert their positive self-identities as disabled women. Adele spoke of using callipers and crutches to coerce her body into the normative standing position, something drilled into her as the right thing to do when younger. Now, she talked positively of her decision to discard these mobility aids in favour of using a wheelchair:

So they [the crutches and callipers] got put in the bin and I just used my wheelchair and that was like a liberation (Adele 51-56 years).

Although Adele's decision was liberating for her, she made reference to her immediate family's disapproval and disappointment at her decision, which was perceived by them to indicate that she had 'given up on trying to be like one of them'.

Laura spoke positively of her decision to stop hiding her impairment, but instead to be proud of her identity as a disabled woman:

I thought "sod it, this not being able to see is part of me and I'm not denying it any more and I'm not going to be embarrassed about it," so I sort of came out the closet and started doing Disability Equality Training (Laura 46-51 years).

Laura had discussed the tremendous strain that hiding her impairment had caused her, emphasising her sense of relief at making a decision to 'come out' as a visually impaired woman. Veronica put much time and energy into concealing her sexuality. As a wheelchair user concealing her impairment was not an option. It would seem that any act of repression may be detrimental to an individual's well being, although in psychoanalytic theory there may be good reasons why an individual may repress things, as part of a self-survival mechanism regardless of whether it be denial of an impairment or sexuality.

Veronica spoke positively of 'coming out of the closet'. Brown suggests that 'the closet' describes the denial, concealment, erasure, or ignorance of lesbians and gay men (Brown 2000:1). The notion of hiding or concealment of those who do not have a place in the world unless they are something they are not can also be translated to disability, as for some disabled women such as Laura who invested time and energy in concealing her impairment to gain acceptance as a sighted woman, gaining a 'place' in society by pretending to be something she is not. By 'coming out' Laura self identified as a disabled person. Choosing to 'come out of the closet' represents a powerful act of positive self-identification (Linton (1998). For Veronica, her self-identification as a lesbian freed her from heteronormative sexual oppression and enabled her to explore and express her lesbian sexuality.

... I used to be anorexic ... when I came out all the kind of things like that disappeared ... I feel like I've come alive within the past four years ... because I feel I can finally be me, I can finally be the person I want

to be (Veronica 21-26 years).

Boadicea spoke of resisting societal expectations of her to glamorise her body impressed upon her by close family members. She considered it ironic that as a blind woman she was nonetheless expected to present a sighted image of femininity. She talked of her decision to stop wearing make-up:

What made it really ridiculous is that I had to present a sighted image, what they thought as beauty, what they thought as feminine ... [The decision not to wear make-up] was a conscious effort on my part to reject all of that sighted stuff (Boadicea 46-51 years).

Although Sara spoke positively of her self-identity, she was conscious that contemporary society remains transfixed by physical appearance. Gill (2001:353) refers to the insider experience of disability as 'a persistent and disquieting sense of mistaken identity', where disabled people find the identities they have forged and present to society are dismissed by others in favour of stereotypical identity ascriptions:

I love living my life, they [non-disabled society] see my crutches, they see that I walk differently, and my friends that are really my friends are the ones that are really clued up: they see the other person that I am ... I don't mind that I walk differently, I just wish they could see who I am, I'm proud of me, every inch of me, I just wish they could get away from the superficial stuff (Sara 41-46 years).

Laura echoed such claims:

They say your impairment shapes you, and I don't think I would want to be a different person, you know I'm happy in my skin now, I'm happy with who I am (Laura 46-51 years).

It would appear that the adoption of positive self-identities enable disabled women to challenge and to counteract the negative identities and stereotypes imposed on them by others (Swain et al 2003).

Conclusion

Lack of social expectation, driven by a need to 'protect' society, confines, narrows and contains the social threat of disabled sexuality. Isolation that is ostensibly for protection is really aimed towards normalisation and correction as to what behaviour should be, as determined by the social mainstream for

disabled people who are degendered and asexualised. During their life course disabled people effectively 'learn' to tolerate socially accepted limited parameters that engender lack of social identity, gender and sexuality.

Fragmented and disjointed teaching methods – for example, mobility training discussed by visually impaired women, where individuals' experiences of mainstream society were limited – thereby help to maintain the spatial confinement that sustains the status quo and social discomfort level of disabled people's social presence.

Chapter Seven

Sexuality and Relationships

Introduction

Disabled women's socio-sexual history of social exclusion, spatial segregation and sexual separation within various institutions facilitated the regulation of women's sexuality, and at the same time the creation of asexual stereotypes that constructed disabled women as celibate 'girls'. These stereotypes remain in contemporary society where disabled women are presumed to be asexual socially, biologically and psychologically (Limaye 2003, Asch and Fine 1997, Morris 1994a, Finger 1985). Disabled females are often thought to be incapable of having the same sexual desires or needs for intimate relationships as their non-disabled counterparts. Indeed, disabled women are often denied the information and knowledge that they require to form a positive sexual identity and to participate in intimate relationships. For instance, 43 percent of disabled women who participated in the Sexual Health Equality (SHE) study had never received any sex education from their families or the education system, perhaps due to assumptions that disabled girls would never have sex or that nobody would want to have sex with them (Gillespie-Sells et al 1998, SPOD 1990a).

Asexual stereotypes of disabled women are sustained by contemporary media images where they are often portrayed in need of care and assistance, being unable to undertake feminised roles. For example, an RNIB 2002 poster campaign to 'raise awareness of sight loss' implied blind women could not fulfil the roles of wife or mother as, amongst other things, they could not host a dinner party, undertake housework, care for children, read their children stories or make their child smile (Jennings 2002a) The very nature of charity advertising tends to fortify negative attitudes towards disabled women's sexual eligibility and capabilities as lovers, wives and mothers.

Positive images of disabled women and men rarely appear in mainstream media such as magazines, newspapers, films or television (Butler 1999). On the rare occasions when they do appear, they are asexually objectified, whereas non-disabled women's bodies are sexually objectified. Women are bombarded with physical images of 'beauty' and 'femininity' through media representations. While these images represent an ideal unobtainable to the

majority of the female population, disabled women are often physically displaced from what constitutes a 'normal' body, let alone from those highly valued as beautiful, desirable and sexually eligible (Gillespie-Sells et al 1998, Shakespeare et al 1996, Wendell 1996, Lonsdale 1990). The body beautiful fixation in heterosexual, gay and lesbian sexualised environments effectively displaces disabled women as potential sexual partners (Watson 2000, Finger 1992), in a similar manner to how pregnant women are placed off limits as suitable sexual partners, being equally regarded as sexually unavailable (Longhurst 2001).

Although attitudes towards sex are more liberal in contemporary society, attitudes towards disabled people having sex have changed at a much slower pace. As a result disabled people are often spatially and socially excluded from sexual expression. Drawing further upon my in-depth interview work, this chapter explores in detail the spatial and social processes that influence disabled women's sexual expression and participation in intimate relationships.

Constructed sexuality: the earliest years

As children we learn of our expected (hetero)sexuality and gendered roles; girls are often encouraged to play houses and play with dolls in a caring mothering way. Non-disabled girls are subtly encouraged to aspire to marriage through stories such as Cinderella and her marriage to the handsome prince. For disabled women, some of this early socialisation is present, but, crucially, not all of it. Indeed, although almost every woman to whom I spoke recalled playing with dolls, none remembered being encouraged to aspire to marriage or indeed to think of themselves as potential partners. These women also recalled that as children there were very few, if any, positive images of disabled children or adults in story books (for some good examples of what can be done, see Letterbox Library). Rather, they grew up with stories that portrayed physical difference as bad and a reason for social ostracism or segregation, examples including 'The Hunchback of Notre Dame' and 'Snow White and the Seven Dwarfs' (SPOD 1990a). Therefore as children they had few points of reference in terms of positive body image or meaningful disabled adult role models.

Disabled girls learn and are reminded of their asexual status in various contexts and social interactions of everyday life from professionals, families, relatives, friends and strangers. A number of women hence had strong memories of others' responses to their physicality, particularly when approaching adolescence and becoming self-aware of their physical difference. The body acts as a 'site of capture' between others' responses to our bodies and internalised interpretations of these responses (Hall 1999:143). These accumulated experiences may influence an individual's present or future self-image and sexual identity, an aspect of how personal pasts weigh upon individual futures (an individualised version of the broader articulation of past, present and future with which my thesis is working).

Parents convey their expectations to children through direct communication, but often it is what remains unspoken that most strongly conveys parental expectations. The non-mention of sex, sex education or the possibility of their daughter having children passes on a clear message that disabled girls are not expected to participate in sexually active relationships. In general parental expectations may subtly pressure non-disabled girls to incorporate marriage and children into their future, while the converse seems to be the case for disabled girls. As Micheline, a participant in Campling's (1981) study, recalled from her childhood at the age of 12 years old:

Sex was distinctly not talked about nor was the issue of my having children which I had started to worry about from that day onwards (Campling 1981:24).

Teachers may also prove significant influences in conveying societal expectations of disabled girls' asexual status. Beth's future expectations were significantly influenced by the comments of a special school teacher:

... my best friend happened to say one day "well when I have children" and she was basically shot down in flames for it by the teacher ... who said "well you know girls you won't, you can't have children, so you will have to think of other things in life because you can't have children" (Beth 36-41 years).

Such comments by an authoritative and influential figure impressed upon the girls that they were not expected to participate in intimate relationships, effectively fortifying the myth that participating in sex is something that disabled people do not do (Cooper and Guillebaud 1999). Thus the girls were not given permission or approval to aspire to an active, enjoyable sex life. The

teacher by implication communicated another social misunderstanding by insinuating that disabled female bodies are incapable of reproduction, and are therefore unsuited to pursuing feminised social roles of wife, mother or homemaker (Lonsdale 1990).

Disabled young people may also learn of their asexual status from their peer group. Sara was educated in a mainstream school where she was the only disabled pupil. She recalled a fellow pupil making an inadvertent comment to her, verbalising her presumed asexuality and implying her unsuitability as a prospective sexual partner:

... one of the boys that I was dancing with said "you know you'll never be able to have babies" ... he wasn't being mean or anything ... that just stuck with me ... I thought it was just hurtful. He didn't say it to be hurtful, but it was (Sara 41-46 years).

This comment conveyed to Sara differential expectations of her adult life in terms of her participation in intimate relationships and social roles.

Boadicea, a teenager in the late-1960s, remarked that, although the '60s heralded the beginnings of a sexual revolution for women, societal attitudes towards disabled girls and young women remained unaffected. Societal responses to her impairment, and the asexual identity imposed upon her as a result, made it difficult for Boadicea to develop a positive sexual identity:

*Disabled young women ... were generally and continue to be perceived as asexual beings ... seen as vulnerable, needing to be protected, **asexual**. Disabled young people don't indulge in sex, they don't need to and, also, it would be totally wrong if they did, it would be immoral if they did (Boadicea, 46-51 years, her emphasis).*

Socially constructed as asexual, disabled females learn of their sexuality initially within their families. Many of the women to whom I spoke recalled that sex or any topics related to sex were never discussed within their family. This led them to understand that sex was not for them; although this was not directly communicated to them, the non-mention of sex evidently conveyed family expectations of them as asexual (Gillespie-Sells et al 1998).

A number of the older women in my study clearly remembered being totally unprepared for the bodily changes that puberty would bring. Some women reported receiving absolutely no sex education from their parents or

preparation for the onset of menstruation, indicating a lack of expectation that disabled girls would experience the physical consequences of being female (Morris 1994b):

I was not told by my immediate family about menstruation even when it happened. I think in fact they were quite surprised that it did happen (Mason cited in Morris 1994b:215).

Ellen talked of her mother making no attempt to discuss menstruation, as a result of which she was totally unprepared for the onset of periods:

I had my periods when I was 11 when before I went to secondary school, I thought I was dying, nobody had told me anything ... I don't know if she thought somebody with a physical disability wouldn't have them. I don't know what she thought, it's not a subject she talks about very much (Ellen, 56-61 years).

Ellen's experience indicates that her family possibly did not expect her body to go through the important change from girlhood to womanhood (Gillespie-Sells et al 1998). Although Ellen thought her mother did not expect her body to develop in a similar way to a non-disabled girl's, the non-mention of menstruation is most likely bound up with cultural reluctance in the mid- to late-1950s to discuss bodily functions. As young girls in the late-1950s to early-1960s Elizabeth, Melissa and Adele also discussed their lack of preparation for menstruation and the fear and confusion that this evoked in them.

In more recent times there still remains a cultural taboo around the subject of menstruation; it is something that must be hidden away and kept secret (Laws, cited in Cresswell 1996:108). Beth remarked on the taboo nature of any subjects to do with sex and reproduction:

I was lucky if she [mother] even told me about menstruation or anything like that. It just didn't get spoken about at all (Beth 36-41 years).

The non-mention of menstruation may result in a hurried explanation when it does happen with 'little thought given to the developing woman inside' (Gillespie-Sells et al 1998:70). It is perhaps these hurried explanations after the event that further conveyed to women the 'fact' that they were not expected to experience these changes. Hurried, necessary explanations may also simply be indicative of a social reluctance to discuss bodily functions that

are culturally taboo rather than a deliberate denial of sexuality or sexual potential; but my impression is nonetheless of a particular intensity or awkwardness bound up in the non-transmission of relevant information on such matters to disabled girls, as revealed by my interviewees.

While at school very few non-disabled or disabled people receive good sex education (SPOD 1990c). Most of the women aged over 50 years old reported that they received no sex education at all, and that it was common for young people to be uninformed and totally ignorant about sexual intimacy. Younger women recalled receiving limited sex education in the guise of 'biology' or 'personal hygiene' classes. Many women referred to gaining information about the 'facts of life' or 'mechanics' of sex but not in a form that was necessarily relevant or useful to them. These were usually just one or two classes and tended to be sex segregated. Only one woman who attended special school recalled sex education being part of the educational curriculum, included in a biology course. It is perhaps significant that for subjects such as science and biology, pupils walked the short distance from the segregated 'special unit' to join mainstream classes in the neighbouring school. Therefore, the special school had no involvement in the delivery of sex education.

Jenny attended a special school where nuns had teaching roles. Sex education was not included in the educational curriculum; instead it was informally delivered by untrained house parents who cared for the children resident during the school week:

... they did tell you about, this is your period and this is how babies are made and you know of course it's a sin (Jenny 41-46 years).

The facts that the school was funded by a religious charity and that all lessons were taught by nuns may have had an influence on the absence of sex education from the formal curriculum, but Jenny noted that even the informal sex education offered by house parents was very moralised. In more recent times Beth, Annie and Myra also reported receiving no formal sex education while pupils at special school. Myra challenged the lack of sex education and direct denial of her potential sexuality:

... when I was getting older, I would say "why don't disabled people get taught about sex education?" She [matron] said ... "that's totally shocking, what would you want to know about that for?" And I thought, what, "after I leave school, ... is my life just going to finish at

17 and I'm not going to have a future?" ... I said the same to the head teacher ... she immediately went to my mum saying I'd been a bad influence on the other pupils (Myra 41-46 years).

Myra's teachers clearly regarded her potential sexuality as disruptive and inappropriate, perceiving her to be a 'bad influence' because she aspired to sexually active relationships in the future. The presumed asexual status of the pupils may have contributed to a rationale that sex education would be an inappropriate or unnecessary element in the curriculum. A search of Government policy documents reveal that sex education has been part of the mainstream curriculum since 1944 and more formally incorporated in 1975 (School Curriculum 1944, Health and Sex Education 1975). Special school policy documents refer to the provision of special education, buildings and premises, with no formal sex education policy apparently in place (Special Education 1964, 1973). Even if there was a policy in mainstream schools, it seems clear from the women's narratives that sex education was not delivered as part of the special school curriculum. The omission of sex education bluntly signals social disapproval of young disabled peoples' sexuality. Conversely, passing on information signals approval to young disabled people to aspire to a fulfilling and enjoyable sex life in a way that suits them, engendering confidence and self-esteem to develop a positive sexual identity and to participate in intimate relationships (SPOD 1990a).

Lack of adequate sex education from parents and the education system may leave young disabled women in total ignorance regarding their reproductive capabilities, denying them the opportunity to make informed choices about, or take control of, their fertility. Boadicea explained that at the special school and college which she had attended, young people were not offered any information or advice about sex:

... they did their best to keep us apart but it didn't work. At [special school], there were two or three girls got pregnant and had to have abortions. And it didn't work at [special college] either ... there were a couple of girls there got pregnant (Boadicea 46-51 years).

Boadicea explained that a young woman was expelled from the special college when she became pregnant, which mirrors the past practices within the blind asylums (see Chapter 3). Claire and Kathryn commented that during the 1980s, when awareness of AIDs and HIV was emerging, disabled young people alongside non-disabled peers seem to have received the minimum

level of information regarding sex, with limited if any information regarding sexual health, safe sex practices, sexually transmitted diseases and methods of contraception. This omission perhaps would have led to some disabled young women and men embarking on risky sexual behaviour without fully realising the consequences.

Since heterosexual relationships and physical perfection are deemed to be the societal 'norm', sex education is most often orientated towards heterosexuality and non-disabled physicality (Butler and Bowlby 1997, Valentine 1993). Legal constraints such as 'Section 28' restrict sex education to heterosexual relationships (Butler 1999, SPOD 1993). Therefore, school sex education does not include same-sex relationships. This omission conveys social acceptability of heterosexual relationships and disapproval of same-sex relationships, and this can cause great confusion for disabled and non-disabled females alike, as Hannah commented:

I only remember getting heterosexual sex education at school. There was absolutely nothing at all about same sex relationships. I actually didn't know there was such a thing as lesbians when I was at school (Hannah 41-46 years).

Ableist and homophobic prejudices can result in disabled girls and women trying to 'pass' on either level by denying their impairment or suppressing their sexuality (Chouinard and Grant 1997, Butler 1999). Hannah deliberately suppressed her sexuality in order to gain peer approval and acceptance by 'buying into fancying boys'.

Initial (sexual) relationships

The Sexual Health and Equality (SHE) study revealed limited expectations placed upon disabled girls. Thirty-seven percent of the women in the study stated that their parents and teachers did not expect them, as disabled girls, to form relationships and be partners or mothers when they grew up (Gillespie-Sells et al 1998). Parents' and teachers' lack of expectations of disabled young people as sexual beings, and a presumption that they will not have sexual desires (Finger 1992) or indeed wish to explore their sexuality, may, somewhat ironically, give them freedom to do so. Beth experienced initial relationships and exploration of her sexuality while at special school:

... we did we used to have some laughs actually, snogging behind the sheds [laughs] ... the [staff] had no idea, they had no idea whatsoever because they didn't expect any of us to ever do anything ... We had a brilliant time! (Beth 36-41 years).

The teachers' lack of expectations about the youngsters engaging in any sexual experimentation resulted in scant monitoring during break-times, and this allowed the pupils to 'get up to no good' behind the bike sheds. Jenny also experienced initial relationships while at special school, although she noted that these relationships did not go beyond holding hands and kissing because female pupils were subjected to close monitoring by members of staff:

I had two boyfriends when I was there [residential special school] ... but I mean it was just kissing and cuddling, it was none of the, nothing any further than that. Probably lack of opportunity rather than anything else (Jenny 41-46 years).

Laura and Beth attended mainstream secondary schools between the late-1960s and the early-1980s. During this time, although the integration of disabled children into mainstream schools was on the increase, their presence remained relatively rare. It is clear from Laura and Beth's narratives that mainstream schools were not 'ready' attitudinally to include disabled young people. As young girls, they were clearly subjected to both negative responses to their impairments and peer prejudice. They internalised and interpreted these responses to mean that their access requirements and physical difference rendered them unsuitable dating material, girlfriends or prospective sexual partners, as their memories reveal:

I never really had a boyfriend from school because obviously nobody would want to be seen to go out with the girl who sat six inches from the blackboard (Laura 46-51 years).

Beth had experienced initial relationships in special schools, whereas in mainstream school she felt isolated and set apart from her non-disabled peers:

... [I] felt quite isolated, nobody wanted to sort of go out with a disabled person or sort of be with a disabled person (Beth 36-41 years).

Laura and Beth's mainstream school experiences mirror a wider societal attitude towards disabled females as damaged goods, substandard, unsuitable sexual partners.

Lack of access to sex education can make it difficult for a disabled woman to form a positive sexual identity, an identity largely taken for granted by non-disabled women in their teens (Gillespie-Sells et al 1998). Adele received very limited sex education while resident in a children's home, and, as a result, when she embarked on a course at a special residential college in her late-teens she did not share the same level of sexual knowledge as her peer group. As for many young students, residential college gave Adele the opportunity to explore her sexuality and gain her first experiences of sexually intimate relationships:

... I was catching up on all my education about sex and partners ... My father couldn't understand why I didn't want to come home and live at home each weekend. Little did he know that I was educating myself in other matters! (Adele 51-56 years).

Adele's father's lack of expectation that she would want to forge sexual or personal relationships enabled her to remain at the college during weekends to pursue this goal, without her father suspecting an ulterior motive (another version of that greater freedom to experiment allowed, if unintentionally, to some disabled women when young, as already mentioned above).

The legacy of asexual stereotypes of disabled women cultivated by the blind asylums and other institutions play out in the physically inaccessible nature of many family planning clinics, conveying that disabled women's participation is not expected or accommodated. Ellen's choices in where to access contraception services were determined and restricted by the physical environment:

... the family planning centres weren't accessible ... I once went to a well woman clinic in [local hospital] but they were just so patronising that I never went back, they were just unbelievable (Ellen 51-56 years).

Boadicea's lack of mobility training resulted in her reliance upon assistance from family members to access contraception services:

But how did a visually impaired youngster have access to contraceptives? ... How was I to get there [GP's surgery] without a sighted person coming with me? ... My parents were very, very over protective at home, so it was a very difficult situation (Boadicea 46-51 years).

Boadicea's reliance upon her family for assistance, together with her mother's likely disapproval of her teenage daughter's sexual activity, prevented her from accessing contraception services and taking control of her fertility.

Adele and Boadicea talked of general practitioners (GPs) being reluctant to prescribe the pill to any women, let alone disabled women, in the late-1960s when the pill remained a controversial social issue. Boadicea talked of her GP's response to her request for the pill in the mid-1970s:

He [GP] ... came to the conclusion that he couldn't possibly give me the pill, because I had a cyst on my ovary. Therefore, he was not going to prescribe the pill ... I came away raging, absolutely raging because I didn't think there was anything wrong with me (Boadicea 46-51 years).

Although Boadicea had physically accessed the GP's surgery independently as an adult, she was prevented from taking control of her fertility once again with serious physical and emotional consequences for her (see Chapter 8). Almost twenty years later, in the mid-1980s, Colette, a teenager at the time, was denied access to the contraceptive pill by a GP who prioritised control of her diabetes rather than control of her fertility. Colette subsequently became pregnant.

Every visually impaired woman who participated in this study mentioned difficulties in accessing information on contraception, sexual health and family planning. None of the women had ever received information in accessible formats, making informed choices difficult or virtually impossible. Some younger women, particularly Laura, Jenny and Claire, did not feel well informed about various methods of contraception. A number of the women talked of being reliant upon GPs, practice nurses, family members and friends to read printed information verbally, effectively rendering control of their own fertility public property, open to debate. Over the counter purchase of alternative methods of contraception may prove problematic, especially for visually impaired people. Insensitive or disrespectful sighted assistance has the potential to render an individual's private life public property in everyday

spaces, for example in shops, as Theresa recalled when she requested sighted assistance to buy a packet of condoms:

... she [shop assistant] stood and read out every packet, I was absolutely cringing, there was a big huge queue and I was, like, this is a nightmare. I was, like, right I'll have those and ran out the door (Theresa 36-41 years).

Bodies placed 'off limits'

Disabled people are not often welcome in contexts where sex is on the agenda. For example, nightclub and social venues may aim to cater for young people, fashionable people and beautiful people. Steps, narrow entrances, flashing lights, smoke and loud noise may all prove barriers to disabled people's participation (Shakespeare et al 1996:88).

The inaccessible nature of the built environment has a significant influence on disabled individuals' presence and participation in social spaces. Factors such as inaccessible social venues and a lack of accessible public transport exacerbate social exclusion. Even today, when affordable accessible transport is available, for example 'Handicabs' (based in Edinburgh) the service does not facilitate social inclusion or spontaneity; it can only be used for two journeys per week, and must be booked forty-eight hours in advance. Taxis, as an alternative mode of transport to social venues or events, may be prohibitively expensive for disabled people, especially for those on low incomes or reliant upon benefits as their main source of income. Therefore, for some women, their opportunities to meet others, form relationships and participate in sexually intimate relationships will be strangely dependent upon the nature of the physical environment to be negotiated in the process.

The advent of the Disability Discrimination Act (DDA, 1995) has positively influenced new build and adaptations to existing venues, and this has resulted in an increase in accessible social venues. Although social spaces are becoming increasingly accessible, disabled peoples' participation in such spaces nonetheless often requires planning. Jenny talked about some of the environmental and practical considerations that had to be made when socialising with visually impaired friends:

... you end up going to the same places because you know it's easy to get to the loo, it's easy to get to the bar, the staff will read you the menu ... You want to sit where there's room for the guide dogs, those

of us that are long cane users getting to the loo, getting somewhere near a taxi rank or near transport and that is a major consideration ... You have got to be psyched up to try somewhere new because you are never really sure of the reaction of the staff (Jenny 41-46 years).

Some adaptations to the built environment may be compliant with legislation, but their design or installation undertaken without consideration for, or consultation with, disabled people may render the facilities unusable. Taken-for-granted facilities available to non-disabled patrons are often not available to disabled customers, a prime example being the provision of accessible toilet facilities, the lack of which restricts disabled peoples' participation in social spaces. As Sara commented:

... most pubs and clubs I can't get into or I can't go to the toilet in, and it's fine to get into some place but you have to be able to go to the toilet in order to be socially free: to go out you have to be able to pee (Sara 41-46 years).

Where accessible toilets are provided, these are frequently unisex rather than designated for use by males or females. Tom Shakespeare cites this as a symbolic representation of the degendering that disabled people are subjected to (Shakespeare et al 1996:87) Furthermore, these facilities are often kept locked, reducing disabled adults to a childlike status where they have to seek permission to use the toilet, which may be regarded as a subtle form of abuse towards disabled people (MacFarlane 1994). Sara stated that she often had to request a key or ask for a member of staff to unlock an accessible toilet, and she found this embarrassing and at times humiliating.

The wider social environment has very much evolved in the absence of disabled people, and as a consequence the presence of diverse physicalities disrupts mainstream social spaces (Chouinard 1999) because non-disabled people are often unsure of how to respond to disabled peoples' presence. Therefore, while changing the physical environment is essential to facilitate the access of disabled people in social settings, attitudes and behaviour towards disabled people also need to change (Butler and Bowlby 1997). As Sara again commented:

... but as far as going out and stuff, it's always a novelty to see a disabled person out ... They are amazed that we're out mixing among the other humans you know (Sara 45 years).

For some disabled women, the very nature of their impairment, for example, a visual impairment, can create difficulties in responding to or even noticing initial contact from others such as eye contact, facial expressions or some other engaging flirtatious communication. Due to a general lack of social disability awareness, a visually impaired woman's lack of response may be misinterpreted by non-disabled men as disinterest, aloofness or unfriendliness (Butler 1999). As Kathryn explained:

A few of my friends I go out with are sighted and they've said to me, "oh! There's a guy there watching you; of course you didn't see' ... You don't see people waving or smiling at you (Kathryn 26-31 years).

The extent to which the difficulties here reside with the disabled woman herself is relatively limited, and for the most part the problem lies with the non-disabled occupants of the social spaces in question (ie. with the attitudes and practices underlying the 'rules of engagement' in the everyday social environment).

The past casts long shadows on the present (Thomas 1998b). Historically depicted as child-like, weak, ill and fragile, disabled women's bodies have acquired cultural ascriptions of asexuality and undesirability. These negative ascriptions are compounded by social understandings of pieces of equipment that enable women to retain their independence. Long canes, crutches and wheelchairs, for instance, are socially ascribed symbols of dependence, confinement and limitation rather than associated with independence, liberation and ability (Thomas 2002a). These cold metallic pieces of equipment are not socially regarded as an integral part of a sexually attractive body. Sara declared that, as a disabled woman, she was conscious that men did not always regard her as a sexual being or as a prospective sexual partner:

... guys ... they think of disabled women as being nice people or whatever, or courageous people, but I don't think that at first glance would think of them as being dating material (Sara 41-46 years).

A participant in Gow's (2000) study was acutely aware that in sexualised social environments, where sex is on the agenda (Shakespeare et al 1996), her presence was peripheral. Although she shared the space, she was not regarded as sexually equitable:

... I wear lipstick, I wear everything. And they still think you're a wee girl. Because you're in a wheelchair, I'm a young child. Because I'm in a wheelchair (Gow 2000:164).

Socially relegated to child-like status, sexuality is considered to be inappropriate or absent. Despite her best efforts to counteract the asexual identity imposed upon her, this young woman was acutely aware of her asexual status through a complex mix of social responses to both her body and her wheelchair.

Leslie, a participant in Watson's (2000) study, noted a change in her sexual status when she acquired an impairment:

... meeting up with guys and things like that – that virtually has not happened since I've become disabled (Watson 2000:147).

In the highly sexualised social scene of Western culture, perfect, glamorous and beautiful bodies are welcomed, celebrated and sought after as sexual partners (Limaye 2003, Gillespie-Sells et al 1998). Disabled women's bodies are not regarded in these terms; rather they are not considered to be sexually available, akin to the manner in which pregnant women's bodies are regarded as sexually unavailable (Longhurst 2001, Watson 2000). Disabled women are similarly placed off limits in terms of sexual availability and are therefore not considered to be 'part of the game' in terms of flirtation, sexual initiation or courtship rules (Longhurst 2001). Disabled women are effectively sexually set aside (Michalko 2002):

In a sense, to be treated as a sexual object is a 'privilege' that non-disabled women have, and disabled women do not (Tremain 1992:26).

The notion of disabled women being 'off limits' in terms of sexual availability, or their assumed unsuitability as appropriate sexual partners, seems to have changed little over time; as Elizabeth experienced in the nineteen-sixties and as Theresa currently experiences:

I was standing at a bus stop this night going out to the dancing at the time, and I heard this guy at the back saying, "Oh! She's all right, but oh! Oh! Look, look she's got a calliper on her leg" (Elizabeth 51-56 years).

Theresa talked of numerous occasions in her local pub where men had approached her, chatted her up and were interested in her. However, when

Theresa harnessed up her guide dog making herself identifiable as a blind woman, men usually responded by sexually setting her aside:

... [he said] "oh I'm so sorry, I'm so sorry", and I'm like "why are you sorry?" I get that a lot people apologising for having spoken to me ... Or they've been chatting me up and they're like "oh I shouldn't have been chatting you up, you're blind", and I'm like "why?" I find that one a weird one (Theresa 36-41 years).

The notion of disabled women as substandard or unsuitable sexual partners is also illustrated in Goffman (1968), where a young woman recalls her realisation of being sexually set aside:

I think the first realization of my situation, and the first intense grief resulting from this realization, came one day, very casually, when a group of us in our early teens had gone to the beach for the day. I was lying on the sand, and I guess the fellows and girls thought I was asleep. One of the fellows said, 'I like Domenica very much, but I would never go out with a blind girl'. I cannot think of any prejudice which so completely rejects you (in Goffman 1968:47).

Similar experiences were recalled by many of the women to whom I spoke, revealing a theme to do with the intertwining of social space and the complexities of 'sexual citizenship', a theme to be amplified in my conclusion (see Chapter 9).

In some instances, non-disabled men who find disabled women attractive may possibly be considered to have deviant sexual tendencies, as Theresa's experience illustrates:

One of the guys in the pub had been chatting me up he was really interested in me ... Another guy had told me that someone was slagging him and calling him a pervert because he was wanting to go out with a blind girl, and I was like "so how does that make him a pervert?" (Theresa 36-41 years).

This being said, a high proportion of blind women who participated in this study also reported experience of domestic abuse, as it seems that men with controlling tendencies or abusive behaviours may pursue a blind woman as they consider her to be easily controlled (Jennings 2002b). Although Jenny did not explicitly discuss domestic abuse, she was conscious of this element in social space:

I'm always suspicious of people who pester us. You do get folk who will come and chat you up ... chatting up the wee blind bird ... Sometime you tend to attract folk that think "oh! Well this is one, I can do her a favour and ask her out and manipulate her" (Jenny 36-41 years).

In social space, disabled women, perhaps more so than non-disabled women, have to be able to decipher between genuine individuals and those with ulterior motives, something that may be particularly problematic for some women who may have experienced sexual rejection in the past and may be flattered by sexual attention and the prospect of a relationship.

Further (sexual) relationships

Although the spatial segregation of disabled children, young people and adults in contemporary society is on the decline, the effects of segregation in limiting social networks can last a lifetime (Harvey 1994). For some the legacy of childhood educational segregation becomes manifested in limited social networks that may remain a constant feature of an individual's adult life, as Kathryn's experience reveals:

I've not, to be honest, I've not had any [intimate relationships]. I think it's purely because of the lack of social life that's been throughout my life right through from primary school, secondary school, even university (Kathryn 31-36 years).

The notion that disabled people need protection seems to include defending them from the joys and pitfalls of forming relationships. Parents and relatives with the best of intentions may try to shield their family member from taking emotional risks or the pain of rejection.

Ironically, the desire to protect can manifest itself in negative or hurtful ways, as Sherer Jacobson suggests from her own experience

The closer you are to the source of a remark, the more impact it has on you in very subtle ways (Sherer Jacobson 1999:83).

Inadvertent comments may be internalised and prompt self-doubt, and such comments may remain with an individual even when they succeed. Ellen vividly remembered a comment made by her mother:

... my mother once told me ... "why would anyone want to marry you?", she once said to me. So, when I asked her about it a few years later, she said she didn't want me to get hurt – well thank you, you just did (Ellen 51-56 years).

Besides being extremely hurtful, the message conveyed to Ellen and other women with similar experiences is that they are unsuitable as sexual partners, wives or mothers. The narrative of a 27-year old blind woman who participated in Limaye's (2003) research illustrates parental manipulation of a woman's expectations of relationships, showing the longer-term implications:

I have a dream of getting married, have a home with children, but my parents told me that marriage is not for me. I was shattered with disbelief (Limaye 2003:97).

It is clear that this woman's parents did not regard her as a sexual being, and, as in Ellen's case, by verbalising that marriage is not for her, they directly communicated that sex is not for her because her presumed asexuality is more acceptable to them. When these messages come from those providing essential care or love, it takes vast inner strength to reject what they imply (Gillespie-Sells et al 1998).

Dissuading disabled women from embarking on sexual activity may also be regarded as a means of protecting society from the consequences of disabled women having sex and perhaps becoming pregnant, arguably an extension of eugenicist claims (which have been widely internalised in many popular discourses). A desire to protect a son or daughter may manifest itself in parental intervention to end a relationship, and Katie talked of a former boyfriend's mother who forced him to end their relationship. Beth's parents' desire to protect their own daughter manifested itself in a verbalised suspicion of her boyfriend:

... I don't think she [Mother] would have approved of anybody. I really don't, and I think people were very, not my friends but maybe like family, were very suspicious about why a non-disabled person would be wanting to go out with a disabled young person. They were very suspicious (Beth 36-41 years).

For many disabled women, disclosure of their sexuality may risk rejection from their family and friends, something that cannot but impact negatively on them throughout further sexual encounters, creating potential problems in the attaining and nurturing of further (sexual) relationships.

The situation is different for women who acquire an impairment, not having had it from birth or early childhood, although in many ways prevailing ableist package of assumptions about disability continue to play an important role in what happens next. In some instances the onset of impairment may also coincide with the breakdown of a relationship, and both Lonsdale (1990) and Shakespeare et al (1996) suggest that this is more prevalent where women acquire impairments:

Evidence suggests that, in heterosexual contexts, disabled men are more likely to maintain their relationships, while disabled women are more likely to find themselves abandoned by their erstwhile partner (Shakespeare et al 1996:95).

Both Islay and Theresa experienced the breakdown of their marriages following the onset of impairment:

... when I lost my sight, my husband didn't want to know ... He changed towards me from that time ... whether that was just because he couldn't cope with blindness ... because it seemed to be from the very beginning that he was telling me that I couldn't do this and you know it's better that I sat down ... but he didn't say it in a kind way. (Islay 61-66 years).

Islay's husband probably assumed that acquired blindness meant that she was no longer capable of fulfilling her role as a wife and mother, an outcome echoed by Theresa's experience:

My marriage broke down because of it [onset of visual impairment] completely. My husband, he couldn't handle it basically, and he just went out and got another life and left me sitting in the house, so I left (Theresa 36-41 years)

Prior to acquiring her impairment, Theresa and her husband had planned to start a family, but her husband may have presumed that Theresa would no longer be capable in this connection.

Disabled women and men are positioned in society as damaged goods (Watson 2000, Gillespie-Sells et al 1998), and therefore relationships between non-disabled and disabled people are subjected to various proscriptions. Pam Evans wonders as follows:

That any able-bodied person who marries us must have done so for one of the following suspicious motives and never through love: desire to hide his/her own inadequacies in the disabled person's obvious ones; an altruistic and saintly desire to sacrifice their lives to our care; neurosis of some sort; or plain old fashioned fortune-hunting (cited in Morris 1991:20).

The assumed saintly selfless status of non-disabled partners is borne out by Melissa and Joy's experiences. When meeting people out socially and being introduced as Jeff's wife, Melissa spoke of reactions that often made her feel devalued:

... "Oh is this your wife, oh how do you manage, oh how do you cope?" [said in a sad tone] (Melissa 51-56 years).

Melissa mentioned that other individuals often verbalised their assumptions of Jeff's role as a carer towards her rather than in a loving role as her husband. Similarly, Joy talked of the presumptions made by her immediate family about her relationship:

I think they think Michael has a hard life. I mean even my parents will say things like, "gosh, I'm so lucky that I've got Michael," and they're much happier now that I've got Michael - that type of comment, which really pisses me off (Joy 36-41 years).

The assumptions and comments of others can serve to negate both the contribution that disabled women make to their relationships and the roles that they fulfil in family life.

The supposed selfless caring role of non-disabled partners may also leave disabled women vulnerable to abuse within their relationships, as Boadicea, Sally and Claire all mentioned. Boadicea described her ex-husband as tall, dark, handsome and charming. His appearance and manner led everyone to believe that he was a 'nice guy'. Before they married he had been violent to Boadicea, but, as she was pregnant with his child, she agreed to marry him; but he was then 'very brutal' throughout their marriage. Sally made reference to an abusive ex-partner who would not give her assistance following an argument:

I was shouting for him to get me out of the bath and he left me in the bath for a long time which was a bit of a not very nice thing to do (Sally 41-46 years).

Claire's husband's abusive behaviours started while she was pregnant, constituting a classic pattern of abuse when women are physically and emotionally vulnerable (SWA 2003):

He always convinced me that it was my fault that I tripped over his things, walked into doors ... then he admitted that when he felt angry with me, he deliberately left things lying about or moved things so that I would hurt myself. It was incredibly difficult and frightening to acknowledge that my husband deliberately set out to hurt me (Claire 31-36 years).

Subtle messages conveyed to disabled women that they are lucky to have successfully attracted a partner – that they are fortunate to have been chosen by someone in this way – can make it extremely difficult for them to escape domestic abuse that, by its very nature, is perpetrated in private space and is often kept secret (Thomas and Rigby 2001).

Disabled individuals forming relationships within the disability community, 'with our own kind' (Morris 1991:21), is perhaps more socially acceptable. Indeed, in many respects disabled and non-disabled partnerships parallel the prejudice, hostility and family disapproval experienced by couples involved in cross-cultural relationships (Diversity Works 2003). Keeping relationships strictly 'disabled with disabled' can be seen as preferable, as somehow more appropriate, even if suspicions remain about the degree of genuine feelings involved. Hence, when Elizabeth announced that she was marrying a disabled man, friends and acquaintances assumed that it was because of their shared experience of impairment rather than because of their genuine love for each other:

... "Oh! You're getting married? Oh! Right so he's disabled. Oh! I understand that, that's why you are getting married." No it's not! [laughs] (Elizabeth 51-56 years).

Sara also talked of the assumption that the shared experience of disability would sustain a relationship:

I never thought I'd date a disabled guy, he uses a chair and, yes, we have the same disability, and no that's not the reason we're dating ... I had a woman tell me I should meet a nice disabled guy and settle down (Sara 41-46 years).

The societal notion that disabled people should marry their 'own kind' can alter at the micro level within families, however, given worries that, by marrying another disabled person, an individual's life will be even more difficult without a non-disabled person to care for them. As Ellen explained:

His parents didn't approve at all, they were okay until they realised we were serious about each other and we were talking about buying a house; they just didn't want him to marry a wheelchair user or a disabled person (Ellen 51-56 years).

It really seems as if disabled people, and particularly disabled women cannot 'win' whatever the form of (sexual) relationship into which they enter, if fortunate enough to do so: whether it be with a non-disabled or a disabled partner, there are negative hurdles to be negotiated in the wider social environment.

One line of possible escape from some of the usual censures, albeit doubtless rarely chosen for this reason, arises when disabled women adopt non-heterosexual lifestyles and relationships. A participant in the Gillespie-Sell et al (1998) study talked of being freer to express her lesbian sexuality when she acquired an impairment, precisely because she was no longer expected to marry or have children. The embodied nature of some women's impairments may unavoidably 'out' them as disabled, whereas electing to adopt a lesbian lifestyle and relationships is something that can perhaps be more easily concealed. Veronica, in the present study, talked of her identity as a disabled person enabling her to express her identity in private space; at one point, for instance, she had shared her one-bedroom flat with a partner and had little trouble passing this off to her immediate and extended family as just sharing with a female 'friend'. This would have been impossible had her friend been male: fears would have been alerted that in this instance were not. Relatedly, for some disabled women their status as (hetero)sexually unavailable may enable them to express their sexuality quite openly in public space, more so than can non-disabled lesbians. Few people would think twice, for instance, about a blind female using a long cane taking hold of the arm of another woman (Butler 1999). This all being said, 'coming out' as either disabled or lesbian involves having to deal with other peoples' prejudices and assumptions, and constitutes a 'significant act of personal resistance' (Chouinard 1999:148), if not to be one taken lightly.

Having a sex life

Historically perceived as objects of charity, disabled women's bodies have been rendered public property where the taken-for-granted boundaries of social interaction are stretched to their limit or are simply non-existent (Mason 1999). Women may be subjected to intrusive, impertinent and offensive questioning about the capabilities of their bodies (Chouinard and Grant 1997). Women in this study hence spoke of being questioned about the sexual capabilities of their bodies. This line of questioning, perhaps informed by a societal understanding of sexual intercourse as a very physical and embodied experience that 'deviant bodies cannot participate in satisfactorily' (Butler 1999:209), leads to women finding their sexual suitability and capacities being questioned in public, social and private spaces.

The usual ground rules of mutual respect that underpin workplace interactions are often not extend to those involving disabled colleagues. Ellen recalled her friend's experience:

Another friend of mine who is also disabled - when she got married, one of her colleagues actually asked her how she had sex ... She replied "how do you?" (Ellen 56-51 years).

These comments indicate a questioning of the woman's suitability as a sexual partner, asking about her physical ability to consummate her marriage. As already noted, mobility aids that enable women to retain their independence often have negative social ascriptions associated with the users' body. In particular, a wheelchair user's ability to have sex is often questioned:

People say "Oh you're a wheelchair-user, this must mean you can't have sex'," and I say "why?" - and they say "you can't walk" and I say "oh do you walk while you are having sex?" (Swain et al with Paula Greenwell 2003:105).

Rose talked of individuals approaching her about her sexual capabilities when socialising in nightclubs:

People come up and ask me "can you have sex?" ... I say "yes of course." I just tell them straight (Rose 31-36 years).

Rose clarified that individuals did not approach her for sex, but simply to ask if she was physically capable of having sex. These comments illustrate the

public property status of disabled people's bodies, as well as the societal hegemony of sexual intercourse as a physical act for which only beautiful, perfect, 'healthy' bodies are eligible or suitable participants.

Even in the private space of their own homes, disabled women cannot escape this voyeuristic approach to their sexual capability, as reflected in the experience of Annie, a participant in Wate's 1997 study, who was asked by a health professional how she had sex – to which she replied:

I jump off the wardrobe, what do you think? (in Wates 1997:30).

Societal questioning of disabled women's sexual capabilities is based upon a presumption of their asexuality and unsuitability as sexual partners. The baseline assumption that relationships involving disabled people do not involve sexual intimacy is manifested in a denial of women's sexuality in public and private spaces by professionals, relatives, friends and complete strangers who, through their language and actions, convey the message that asexuality is the only acceptable sexuality of disabled people (Gillespie-Sells et al 1998, Shakespeare 1996).

Susan talked of the reaction from shop assistants to her presence in a retail outlet selling sex related items. She was acutely aware that the assistants did not expect her presence in the shop or to be making purchases for herself, with the implication that they did not expect her to be sexually active:

When I go into sex shops they kind of look at you as if you're not meant to be in there ... They often do say to me "is this a gift for somebody?" And I'll say yes, "it's for myself!" (Susan 41-46 years).

Sally found her sexuality denied by medical professionals when, two weeks after her wedding, she required treatment for a flare up of her condition. Treatment involved her being bandaged into custom-made full-length plaster splints on her legs, feet and hands each night. The medical professionals involved did not seem to give any consideration to the effect that these splints would have on Sally's sex life, prioritising the management of her medical condition rather than the implications for her private life:

... I was going for check ups and they would say "are you wearing your splints?" and I would say "no" and they would say "well why not?" (Sally 41-46 years).

Susan talked of her sexuality being denied by personal assistants in the supported housing complex where she and her husband live. The personal assistants and support workers assumed that Susan's marriage did not include sex, directly denying both her and her husband's sexuality:

*Well, I always introduce ourselves as Mr and Mrs. Well, a lot of people in here [supported housing], I think it's been the home helps, they think because we've got three bedrooms, they think that Paul sleeps in a different bedroom from me ... And I say "no, we sleep in the same bedroom," because they always say to me, "in your bedroom" and I say "no, in **our** bedroom," because I don't think that they are used to hearing that disabled people sleep together (Susan 41-46 years, her emphasis).*

Bob, a participant in Watson's (2000) study, also spoke of others assuming that his relationship did not include sex:

... she [partner] has a disability herself and I have a disability and everybody thinks how sweet, they're company for one another! You know, this is what we get all the time, Bob's got a new friend, isn't it sweet, and they're staying together, they'll be company for one another (Watson 2000:145).

Disabled individuals' relationships are often assumed to be platonic because their bodies are presumed to be incapable of sexual intercourse. The dominant concept of conventional sex as heterosexual (Chouinard and Grant 1997, Valentine 1993), in the missionary position with the man on top, face to face with the woman, has public approval, while anything else may be considered deviant. Furthermore, non-penetrative sex is not considered to constitute 'proper' sex (Arthritis Care 2001, Gillespie-Sells 1998, SPOD 1990c, Newman 1983, Campling 1979). Shakespeare refers to the societal notion of proper sex as heterosexual and penetrative as 'fucking ideology' (Shakespeare et al 1996:97). These ideas may create barriers to some disabled people expressing their sexuality where conventional sexual positions may be inaccessible, cause pain or discomfort, or where penetrative sex may be difficult or impossible. While conventional sex has public approval, disabled people require 'permission' to adapt sexual positions (Arthritis Care 2001, SPOD 1990a, SPOD 1990b). Disabled people are adept problem-solvers, and for many it is not an issue of adapting sexual positions or finding ways of having sex, but rather of finding someone to have sex with in the first place (Shakespeare 1996). Arthritis Care (2001) and SPOD (1990b, 1990c) propose a fundamental shift in the notion of 'proper' or 'conventional' sex. They

suggest that the embracing of diversity and experimentation in sex would benefit all people who are sexually active, and not just disabled people.

Lack of adequate information about alternative sexual positions or ways of experiencing sexual pleasure may undermine the confidence of disabled people (Costa et al. 1992). It also renders individuals' sex lives public property, as information or advice about sexual issues may have to be discussed with medical professionals. Joy commented on the important role of professionals in addressing sexual issues given the absence of adequate or accessible information:

One of the things that comes up for me a lot in [voluntary organisation] is difficulties in physically getting together [laughs] ... It's something consultants and other people need to be up to talk about ... Often disabled people physically can't make love without some sort of support, and where do you start with that? You know, where do you get support, how do you talk about it? So I think, if you've got consultants that are aware that these are issues, and that young disabled women and men have a right to have a sex life, I think that's really, it's important that it's talked about (Joy 36-41years).

The way in which a lack of information, and then a subsequent lack of knowledge about sexual intimacy, can undermine a woman's confidence is revealed by Sara's candid comments:

... when we first started seeing each other I wasn't even sure how to kiss somebody because I hadn't kissed somebody in ten years, like in that way. I had kissed people on the cheek, but as far as kissing on the lips, I wasn't even sure how to do that (Sara 41-46 years).

For many disabled women, their bodies are exposed and touched by medical professionals, personal assistants or friends, with very limited sensual or sexual contact; indeed for some they are rarely touched in any other way.

Anita, a participant in Lonsdale's 1990 study, observed:

People have gone out of their way not to have any physical contact with me at all ... When I was very ill, I was on one of these machines and developed a migraine. Five minutes of somebody actually holding my hand or rubbing my forehead, doing something more intimate, would have been worth any amount of aspirins and cold compresses and nobody did. I've been really starved of any sensation (in Lonsdale 1990:73).

Sara spoke of the pleasure of the physical contact that she had with her partner:

... it's nice to be held because, when you're a disabled person, people are always sort of moving away from you, so it's nice. I like being cuddled, I like putting my head on somebody's shoulder, I like somebody in my life who cares enough who is not family ... It doesn't surprise me that a lot of people don't know how to react in situations of intimacy, because where the hell do you get the opportunity because most of the time in society our sexuality is denied anyway ... There's just this expectation that we're not supposed to do that stuff; nobody has ever said "no you don't do that," but it's just such a revelation if you do, do it (Sara 41-46 years).

Conclusion

Sexuality and disability are not natural outside the context of accepted or expected behaviour because disabled men and women are generally perceived to be asexual. Hence there are assumptions applied to relationships that involve disabled people: assumptions of care and companionship over and above sexuality, sexual attraction and intimacy of any kind. The only intimacy disabled people are expected to experience is within a doctor's office. There is no outward social acceptance of sexuality and disability, and it is confined, invisible and most of all secret, kept in 'the closet'. The usual cultural taboos around sexuality and sexual activity are accentuated with disability, and the lack of sexual education here reflects mainstream denial of sexuality and a social fixation with the infantilisation of impaired bodies. This results in extreme consequences for disabled women, as in, for example, disabled women's displacement from sexualised environments or perhaps exclusion from expressing reproductive choices and maybe then experiencing the embodied 'state' of pregnancy.

Chapter Eight

Out of Place Parents

Introduction

Institutionalisation removed disabled women and, to a lesser extent, disabled men from the spaces of everyday life. Consequently mainstream space has developed primarily to meet the physical requirements of non-disabled people. Therefore, the presence of disabled individuals in mainstream space is often peripheral, kept on the outer fringes by inaccessible physical environments and attitudinal barriers such as prejudice and ignorance. Inaccessible spaces convey to disabled people that their presence and participation is not anticipated nor welcomed, as is now a familiar claim throughout the disability geography literature, as Kitchin (2000) 'accessibly' outlines.

Mainstream spaces dealing with prospective parents, pregnant women, birthing mothers, baby care and surveillance are often physically and attitudinally inaccessible or hostile to disabled women's participation. A contributory factor perpetuating attitudinal barriers is the manner in which disabled women are represented in media images as vulnerable, asexual and dependent. They are rarely portrayed in everyday spaces as actively involved in mothering roles or tasks. Disabled women and men are not thought of as prospective parents because parents are expected to be authoritative, independent and capable of protecting and caring for others, qualities rarely associated with disabled people (Goodman 1994). Furthermore, the powerful 'statement' of pregnancy for a disabled woman, the visible appearance of a disabled woman showing the physical signs of pregnancy, tends to challenge stereotypical assumptions in a manner that non-disabled society often finds unsettling (McFarlane 2002, Shackle 1994).

As a result, disabled women often encounter social disapproval of them becoming or being parents from so-called 'societal supervisors' (Longhurst 2001). Societal supervisors have now arguably supplanted the institutional supervisors who previously monitored, influenced and controlled disabled women's lives within segregated spaces. Contemporary societal supervisors perhaps subconsciously assume a role of monitoring socially acceptable or unacceptable behaviour and roles for disabled women (Begum 1996). These

supervisors range from hospital consultants, nurses, general practitioners (GPs), health visitors, social workers, relatives, friends and even strangers who to varying extents and in a variety of ways exert their influence on disabled women's reproductive choices (Gesler and Kearns 2002, Lee and Jackson 2002). The ways in which these spatial and attitudinal influences play out in disabled women's reproductive and non-reproductive lives is explored in this chapter. The lack of a 'place' for disabled parents in much mainstream thinking and practice and in some instances, women's exclusion from reproductive environments by the physical nature of the space will also be explored.

This chapter will in effect follow the chronology of becoming and being a parent, I deliberately trace what interviewees claimed about pre-conception, sterilisation, pregnancy, termination, miscarriage, birthing and post-natal experiences of dealing with a newborn child. I then consider various pressures on disabled women to 'give up' their young children, reaffirming that the 'place' for children of disabled women is often reckoned – completely contrary to the usual discourse within contemporary society – to be *away* from the mother's side (a spatial removal imagined as what *should* be the case).

Unplaced parents

The natural (and normal) female body is widely considered to be one that has the capacity, and chooses, to bear children. Women are expected to experience their bodies as childbearing bodies (Longhurst 2000:460).

This is not the case for disabled women, as reproductive spaces and social supervisors give disabled women a very clear message that they are not expected to have children, that their bodies are not expected to experience childbearing, a specific example of this is demonstrated in the omission of a disabled woman from a research project as it was assumed by the researchers that she would not have children (see Underhill-Sem 2001a:205). Furthermore, impaired bodies are not regarded by mainstream society as natural or normal, and this social judgement of physicality may present barriers to women forming sexual relationships and ultimately exercising their reproductive choices (Thomson 2004, Gillespie-Sells et al. 1998, Shakespeare et al. 1996, Lonsdale 1990). Kylie and Kathryn, two of my interviewees,

expressed a desire for children. Both were clear that they would prefer to raise children within a stable relationship, but at the time neither woman was in a relationship and they cited the lack of a sexual partner as a barrier to fulfilling their reproductive aspirations. In the previous chapter, the whole issue of disabled women entering into sexual relationships was explored in considerable depth, and need not be revisited here.

Society expects disabled women not to cope with childrearing, and in effect provides no proper 'place' for them as parents, the key theme to be examined in various ways through the present chapter. It is often assumed that others such as grandparents or social care services will have to care for a child (Lonsdale 1990). Support service professionals, medical professionals and relatives may coerce women to accept long-term contraceptive injections as a means of avoiding pregnancy or, for wheelchair-users or women with learning difficulties, as a means of avoiding menstrual management (Collins 1999, Cooper and Guillebaud 1999). This intervention to control disabled women's fertility is wholly acceptable to professionals and wider society. However, when a leading adviser to the Scottish Executive (Neil McKeganey, Professor of Drug Misuse Research at the University of Glasgow) suggested in a newspaper article that female drug addicts should be paid to accept long-term contraceptive injections, given that children of addicts often end up being taken into social care services or are cared for by grandparents, his comments sparked outrage regarding human rights and the intervention of the state in controlling women's fertility (*Glasgow Herald* 13th March 2004). It is doubtful that a similar claim about disabled women would have elicited such an outcry, which does indeed imply differential societal perceptions regarding disabled and non-disabled women's rights to parenthood.

Many disabled women themselves do not aspire to motherhood, suggesting that they internalise many of the assumptions prevalent within wider society. This is not always the case, and the individual agency or capacity for choice on the part of certain disabled women must not be ignored. Sara, for instance, was very clear that she had never considered having children:

... because looking after me is enough work. When I say that I have never ever wanted to change my situation, but my situation requires a lot of time and effort and work for me ... I don't want to look after a child because that's one responsibility and I'm already doing enough in my life ... Nobody has ever said "no don't have a child" or anything like

that, I have just never wanted one ... I've never felt less of a woman just because I never had a child (Sara 41-46 years).

Sara became sexually active 'later on in life', and this fact may also have influenced her decision to remain childfree. What is also evident, though, is that in response to others' verbalised concerns a significant number of disabled women question their own capabilities to care for a child, so much so that some make the decision not to have children (Gow 2000). A number of women who were childfree when I spoke to them hence talked of both their own self-doubts to care for a child and those expressed by others. Theresa had decided to stop considering having children because at the age of 38 years old she was not in a relationship, and felt it was now 'too late' for her to embark upon motherhood. However, she did also hint at self-doubts about her caring abilities:

... that always worries me about how capable I would be at looking after a kid (Theresa 36-41 years).

A number of women used the visual metaphor of 'looking after' children, which implies a need to retain visual contact with or a constant surveillance of a child in order properly to take care of him/her. It is perhaps such beliefs that cause society to bring into question the caring capabilities of many disabled women, for whom their ability to see or to move sufficiently to maintain sight of their child may not be in doubt. For some women, medical professionals may directly question their ability to care for a child, to be a competent parent, on precisely these grounds. For example, in Gow's (2000:200) study, a participant considering becoming pregnant commented that her consultant always 'wants to know who'd be there to look after the bairn'. The woman's comments imply that the consultant had completely disregarded her capabilities to care for a child. Similarly, in my research Susan found her caring capability questioned by her relatives:

... she [adoptive mother] doesn't think I could take care of a baby ... I think I could and my natural mother she says "well, I don't know how you would go about looking after a baby" ... it's just my parents that have put a damper on it, saying that I couldn't look after it. But my carer, she says she would look after the baby (Susan 41-46 years).

Susan's (adoptive and biological) parents' questioning of her mothering capabilities suggests an infantilised perception of Susan as a care recipient, rather than herself as an active caregiver. Moreover, the idea that a personal

assistant should care for a baby if Susan were to have one seems to relinquish Susan of her potential mothering~ responsibilities, effectively displacing her from this role before it even exists (and see below for more on this point).

On breaking the news of pregnancy, other people's responses, especially those of close relatives and trusted friends, can have a significant influence on a woman's self-confidence. When Elizabeth became unintentionally pregnant at the age of 21 in the late-1960s, she was determined to keep her baby. Her parents' reaction may be explained by their abject lack of expectation that Elizabeth would become pregnant, but even so it is akin to the response that a pet owner would have towards puppies or kittens:

Four months down the line I discovered that it was twins that I was having. The first thing that my mother said was "well, we can't keep two, one will have to be adopted out" (Elizabeth 51-56 years, children twins aged 31years, and one child aged 27 years).

Negative responses such as outright disapproval of a pregnancy or questioning of a woman's ability to cope with pregnancy, birth and childcare may therefore cause a woman to doubt her decision to become pregnant

I said to my mum [that I was pregnant] and she said "that's all you bloody well need." I was really, really disappointed ... And I thought "oh! God maybe I have done the wrong thing here" (Melissa 51-56 years, child aged 17 years).

This attitude was echoed in more recent times by Nettie's mother's response to her pregnancy:

My mum was quite a bit upset, I think, delighted but a bit upset. I think just because she was frightened about how I was going to cope (Nettie 36-41 years, children aged 8 years and 5 years).

Pre-conception

The medical profession has a disproportionately significant influence in disabled men's and women's lives. The paternalistic approach of the medical profession has contributed to denying disabled individuals the right to make decisions about their own lives and bodies (Gesler and Kearns 2002). The medical model concept of disability renders impaired bodies public property,

and thus intensely private decisions become the focus of public debate. Medical professionals; doctors, nurses, GPs and information workers, perhaps subconsciously, take on this role as social supervisors (Longhurst 2001), categorising bodies, either rejecting deviant bodies as unsuitable reproducers (Longhurst 1994) or subjecting their motives to reproduce to intense scrutiny and public debate. These social supervisors have the power to facilitate or deny disabled men and women's expression of their reproductive rights by withholding information and access to services.

The powerful influence of social supervisors is illustrated in Myra's comments:

I went to the medical profession to try to seek help. They didn't actually welcome the decision [to attempt to conceive] ... I was still met with the question "oh you're disabled and so is your husband?"... we wanted to go for it ... they kept saying "think long and hard about it, try and fill in a questionnaire and tell us the reasons why you want a child and then we'll come back and have another meeting about it"(Myra 41-46 years).

Non-disabled individuals are rarely asked to justify their reasons for wanting children, but rather to explain and defend why they do not want them (Campbell 1999). Myra and her husband were expected to justify why they wanted to have a child, however, making a private decision a matter of public knowledge with professionals who obviously had prejudicial and discriminatory attitudes towards them as prospective parents in terms of their motives for wanting a child in the first place and perhaps doubting their ability to care for a child (SCOPE 1992). Therefore, Myra's participation in reproduction is very much dependent upon the approval of social supervisors (Hansen 2002).

The significance of the influence exerted by the medical professions on disabled women's decision to pursue their reproductive aspirations is apparent in Sally's experience:

I remember being in the pool getting my physiotherapy and I'm saying to people ... I was really kind of rejoicing and I know other disabled women who have done this, when you are told by the doctors "yes, it's okay for you to get pregnant," you go round telling everybody ... But it's that thing about having been given the permission (Sally 41-46 years).

Sally's exuberance in being 'given permission' to go ahead with her plans to

become pregnant may also be explained in terms of social acceptance of her as a potential reproducer and mother, both of which are taken for granted by non-disabled women. Social supervisors within the medical profession may advise women to 'wait' or delay attempting to conceive for various reasons, well aware of the possible effects of their advice-giving (Longhurst 1999, Goodman 1994); notably that waiting for medical approval may take women beyond their most fertile years to a point in their life cycle where natural unassisted conception is greatly diminished or improbable. Such advice-giving may be regarded as a means of controlling disabled women's fertility and reproductive choices. Myra was advised to 'wait' for medical approval before attempting to conceive her experience, an experience that poignantly illustrates the controlling effects of this advice:

... it's making my husband very unhappy because all he's wanted from day one, since we got married was to have this child, now eleven years later you say to yourself "is it going to happen?" (Myra 41-46 years).

For many disabled women, the delaying tactics of social supervisors, whether meant for the 'best of reasons' or concealing a tacit agenda about the non-suitability of such women for getting pregnant, results in a negative answer to the question 'is it going to happen?'.

In vitro fertilisation (IVF) has become a routine method of assisted conception in Western society. IVF is generally only available through the National Health Service (NHS) in exceptional circumstances, and there are often lengthy waiting times to access such services (Cooper and Guillebaud 1999). The wait to access such services may diminish the chances of success, while the cost implications of private treatment may create a barrier to disabled people in a similar way to anyone with low or limited incomes. Disabled men's and women's participation in reproductive technologies such as IVF remains unexpected, and consequently access requirements are rarely accommodated. In order to attend an NHS Assisted Conception Unit (ACU), Susan and her husband, both wheelchair users availed themselves of the hospital transport service. The ACU was not a recognised drop-off point for this service, though, and as a result Susan and her husband were taken to a general reception area and had to seek the assistance of hospital porters to reach the ACU. Once at the unit, the physical environment conveyed to them that their participation was not anticipated, since the space was not accommodating of, or welcoming to, them as wheelchair users:

My husband and myself couldn't get into the waiting room because we are both wheelchair users ... It was just a normal surgery room and we could get in there alright. Again, I had to ask the doctor to wheel my husband in ... He did it okay, but you shouldn't have to ask (Susan 41-46 years).

The hospital transport service collected Susan and her husband from their home three hours prior to their appointment, and then they were transported home two hours after attending the ACU. The ACU lacked accessible toilet facilities, and as a result Susan and her husband did not drink any fluids during the seven hours taken up in attending the hospital appointment.

Sally had also used IVF as a means of assisted conception. This had adversely affected her general health, and after two attempts her consultant refused to administer further fertility treatment. Sally and her husband described being relinquished of the final decision to continue with IVF, or not, as a relief. Sally and her husband now remain on an egg donation waiting list as a 'last option' towards assisted conception, and the likelihood is that they will remain childless. For Susan, mixed messages from medical professionals have caused confusion, and imply an infantilised notion of her:

... they [Doctors] say "hope you have a family" and all that, but they don't think it's likely ... It's the cervix, they can't find the opening to the cervix with me. So that they don't know whether it's going to open or what's going to happen ... They have said they can't do anything, so that's how it's been left ... You feel half of a woman, you know, when you can't [have children]. Well I do anyway (Susan 41-46 years).

For Susan the experience of enforced childlessness makes her feel less feminine, in which case she arguably (but understandably) internalises certain general expectations about a woman's role, whereas Sara, who has made a lifestyle choice to remain childfree, did not regard herself as 'less of a woman'. It would seem that, for women with a strong biological drive to reproduce but who for various reasons do not conceive, the difficulty in fulfilling the desire to experience their bodies as reproductive may adversely affect a self-perception of their womanhood (Petrie 2002).

Sterilisation

An extreme dimension tied up with the pre-conception 'phase' for some

disabled women was being confronted with pressures to be sterilised. The biomedical gaze reduces non-disabled female bodies to their reproductive function, viewing women's bodies as 'bodies that are waiting for babies' (Longhurst 2000). Non-disabled women's requests for sterilisation are often met with medical disapproval at their reluctance to fulfil their reproductive obligations, and women may have to justify their reasons for wanting to be sterilised and to 'prove' that they have no doubts about not wanting children (Campbell 1999:xvii). Non-disabled women are often not considered for the procedure until they are in their early-30s (Campbell 1999). The reductive gaze views disabled women quite differently, however, since it categorises and rejects them as appropriate reproducers. These out of control bodies (Longhurst 2001) must be brought under control, rendered compliant, docile, unthreatening and unproductive. Non-therapeutic sterilisation is hence the ultimate social supervisory intervention in the control of disabled women's reproductive capabilities. In Begum's study, a participant wrote as follows:

GP refused to refer me to gynaecologist when I wanted to marry. Refused to prescribe the pill – advised me to obtain sterilisation privately – which I did – reluctantly. Feel very bitter as other women with my impairment have had support and encouragement to have children. Did not know I had ... any other choices (in Begum 1996:189).

The disproportionate influence of the GP in this woman's reproductive choices indicates an infantilised perception of her. It seems that the medical professional considered her unfit to reproduce; by withholding information about reproductive choices, denying access to contraception and through advice-giving, the GP guaranteed that this woman would not reproduce.

Six women who participated in this study had encountered medical professionals who regarded sterilisation as a means of controlling their fertility. Sterilisation was suggested to Elizabeth because her husband was haemophilic and any female children could be potential carriers, but she refused to be sterilised. Sally had been very clear with medical professionals that she wanted to have children, but despite this she discovered she was to be treated with a drug called Azothioprine that may have rendered her irrevocably infertile:¹ in other words, she was confronted with drug-induced

¹ When the drug manufacturer's information line was contacted regarding the effects of Azothioprine on women's fertility, they were aware of one clinical study relating to the drug's effect on ovarian function. In contrast, numerous clinical studies exist on possible effects on men's fertility.

sterility. A few years later, while actively involved in an IVF programme (see above), Sally developed complications that required emergency surgery. Although she clearly wanted to have children, somewhat ironically, barely an hour before her operation, the consultant from the ACU who had administered the IVF treatment suggested that she make a decision regarding her future fertility:

... he [ACU Consultant] said to me, "will we just sterilise you while we are at it? ...Thank God, I said to him, I think that decision is too big a decision for me to make at this moment."(Sally 41-46 years).

For some women the suggestion of sterilisation was at particularly inappropriate times; without prior warning or information, they were expected to make decisions about their future reproductive capabilities. The notion that sterilisation is a preferable option to reproduction reveals a dehumanisation of the women to animal-like status, akin to family pets incapable of controlling their own fertility. Similarly, where it is seen as 'fair' to let an animal have one litter of puppies or kittens, disabled women likewise are often regarded as candidates for sterilisation often following the birth of their first child.

When Joy attended a routine six week hospital check following the birth of her baby, she hence did not expect the consultant to have his own agenda regarding her future reproductive capabilities:

[I]n essence what he was doing was telling me that, that was it, no more children, and he was wanting to, actually that day, he was talking about sterilisation ... it was such a huge assumption ... He wrote to my doctor to say he'd strongly recommended sterilisation ... It was so presumptuous and judgemental and controlling (Joy 36-41 years, child aged 5 years).

Adele was 22 years old when she had her first child delivered by caesarean section, and as she was wheeled into theatre the gynaecologist made a passing remark:

"We'll just sterilise you," and I said "no, no I don't want to be sterilised," because I knew I wanted more than one child (Adele 51-56 years, children aged 29 years and 24 years).

When Adele's second child was delivered by caesarean section, sterilisation was again suggested to her. On both occasions, the consultant in charge of her care was furious that she had not agreed to be sterilised following the

delivery.

At 22 years old, Beth had a very similar experience to Adele. As she was wheeled into theatre for the caesarean delivery of her second child, she was asked (without prior warning, information or discussion) about being sterilised:

... he [consultant] said "I meant to say, do you want me to sterilise you while we're at it?" I said "no, I'll maybe get sterilised in a few years time if that's what I want to do." "Oh no, we can do it while we are in delivering the baby." I said "no, I don't want that." ... I was thinking I don't want to go to sleep, what if they sterilise me and don't tell me because I was convinced they were going to do it (Beth 36-41 years, children aged 24 years and 20 years).

At the age of 23 years old, a year after the birth of her second child, Beth did finally agree to be sterilised, as she felt that this was what was expected of her. She was far younger than the age at which sterilisation is considered for non-disabled women, where the '120 rule' applies; a woman's age is doubled and multiplied by the number of children that she already has (Campbell 1999:129). Therefore, Beth, in her early-20s with two children, scores 92, falling well short of 120, and by this 'rule' was an unsuitable candidate for sterilisation. On the basis of medical advice, Hannah had made the decision to be sterilised after the section delivery of her second child. She found following through with her decision very emotional, but the medical professionals around her were seemingly oblivious to this distress:

I could feel the tears rolling out of my eyes and into my ears, and the consultant came in and slapped me on the leg and said "so we'll just be doing the sterilisation at the same time Hannah," which I had agreed and signed up for, but when he said it I just suddenly panicked and thought "oh! My god! What's this about?" (Hannah 41-46 years, children aged 13 years and 9 years).

Hannah and Beth underwent sterilisation procedures on the basis of advice from medical professionals, but in retrospect both women regretted being sterilised as they felt they were given insufficient information about the procedure and any long-term effects.

Pregnancy

The way in which society influences space and space influences society is

apparent in the places where reproduction is monitored, processed and ultimately delivered (Cresswell 1996). These places have developed in the absence of disabled women, and this invisibility is reflected in the attitudinal and often inaccessible physical environment of antenatal classes, antenatal clinics, antenatal wards, labour wards, post-natal wards and baby clinics – almost any space where the surveillance of reproduction, birthing and mothering takes place. In short, the maternity system constitutes an ableist space that is challenged, disrupted and made uneasy by the presence of disabled women, considered to be 'out of place' within the reproductive arena (Underhill-Sem 2001b, Chouinard 1999). Consequently, within the ableist maternity system physical difference or diversity is not welcomed, encouraged or accommodated.

Melissa experienced hostile attitudes reflected in the physical environment towards her pregnancy and presence in reproductive spaces:

The difficulties that I had, it wasn't my difficulties, it was other people's perception of being disabled and being pregnant ... the hospital service, they had nothing. I mean, it was as if you were from a different planet ... There were no facilities within the hospital for disabled women to have children and especially if you were using a wheelchair (Melissa 51-56 years, child aged 17 years).

The hostile antenatal environment is apparent in a lack of adaptation to the service and subsequent integration of disabled women, who are expected to 'fit in' to what is offered rather than enjoy provision that includes them. For example, Melissa had to rely upon her husband to lift her on and off inaccessible examination tables. Visually impaired women, meanwhile, highlighted a lack of essential basic information on pregnancy, childbirth and rearing that made it particularly difficult for them to be well-informed about their pregnancy and to make informed choices regarding the delivery of their babies (Campion 1990). Jenny experienced difficulty accessing information when she was pregnant almost twenty-three years ago:

... my husband read me what he thought was the important things. I never independently read (Jenny 41-46 years, child aged 22 years).

In more recent times, Claire experienced similar difficulties accessing information:

... information on pregnancy and childbirth in accessible formats was

simply not available ... I felt really excluded from a lot of information that other women took for granted ... I wanted the same information that all other women had been given by the hospital (Claire 31-36, child aged 4 years).

Hospital staff suggested to Claire that her husband read the information to her, which conveyed an assumed and acceptable dependence on others to access information. More importantly it clearly revealed a lack of commitment to take action to supply the information in an accessible format as an integral part of the service provision.

The rejection of disabled women's bodies as suitable reproducers, and the medical profession's seeming disapproval when they do become pregnant, is all illustrated in Annie's experience when she attended her first antenatal appointment in the early stages of her pregnancy:

... [At] my first consultation that I had, abortion was mentioned, and I was like "what? Abortion? Have I come to the wrong place?" And they were like "we could book you in next week" and I said "bloody wait a minute, I want this baby." [The consultant replied] "How can you have a baby?" (Annie 26-31 years, child aged 6 years).

Begum's study of disabled women's experience of GP services also found women who had encountered the medical professionals' disapproval of their pregnancy. One participant early in her pregnancy was invited to attend an out patients appointment at a local hospital:

When I arrived I was told that a letter had been sent by someone (whose name could not be divulged), who had suggested that I should be offered an abortion. I was unable to ascertain who had written the letter but at this early stage only my GP knew I was pregnant (in Begum 1996:188).

The suggestion of a termination without prior consultation with women indicates social disapproval and fear of women's pregnant state. Moreover, disabled women's bodies are often regarded as public property, so that the foetus also gains status as such becoming a matter for surveillance and public concern (Longhurst 2001). Public concern may manifest itself in the questioning of women's abilities to care for their unborn child. The suggestion that Annie and the participant in Begum's (1996) study should terminate their wanted pregnancies indicates social supervisors' misgivings regarding their care-giving abilities. Adele and Claire experienced a similar questioning of

their caring abilities by social supervisors who, arguably, should only have been worrying about the specifics of their pregnancies:

... she [ward sister] said "well who is going to look after this baby you are having?" I was quite offended by that ... I said "well, I'm going to look after the baby" (Adele 51-56 years, children aged 29 years and 24 years: note earlier remarks about the 'looking after' issue).

In more recent times Claire also encountered social supervisors who were negative towards her visual impairment and her ability to care for her unborn child. Sometimes, moreover, those closest to women take on an equivalent social supervisory role during pregnancy:

... one of the biggest doubters was my husband, that was extremely difficult when the person ... that's agreed to have children with you then begins to question your ability to care for your unborn child ... that did really, really upset me (Claire 31-36 years, child aged 4 years).

The unsupportive stance adopted by Claire's husband had a profound effect on her self-confidence in her own abilities, and by the time she was six months pregnant she felt intensely pressured to prove that she could care for her unborn child.

The flexible arrangements made around Hannah's antenatal care indicate a more positive attitude towards her as a prospective mother, and a willingness to meet her access requirements in a person-centred way. Hannah found her pregnancies difficult because her mobility dramatically decreased, but she was offered antenatal care geared towards her home situation in a supportive and flexible way:

... [T]he first time round I went into hospital during the week when Steve was at work and I got home at weekends ... when he was there to do things ... The second time round ... I stayed out during the week and I went into hospital at the weekends, so he [husband] could look after Jack at the weekend (Hannah 41-46 years, children aged 13 years and 9 years).

It should be noted that there are indeed some positive stories in the accounts of women interviewed, it is important to include such 'voices' to avoid creating a 'totalising' (negative) account. Throughout the writing up of this research I have been acutely aware of this methodological issue and have endeavoured to demonstrate the diversity of women's experiences and

include their 'voices' throughout the thesis (see Appendix 1).

Termination

The issue of termination has already been mentioned, but it is worth elaborating a little more in light of interviewees' comments. The social surveillance of disabled women's participation in reproduction is undertaken primarily by medical professionals who, through advice-giving (as already explained) may exert a disproportionate influence over women's reproductive choices (Lee and Jackson 2002). For example, when Ellen married in the early-1960s, none of her disabled friends had children, but despite this she 'had every intention of having children'. She recalled the GP's disapproval when she phoned to get the results of a (positive) pregnancy test:

... he said "Oh! You can't have it" ... I remember immediately thinking what? I think he thought disabled people shouldn't have children (Ellen 56-61 years).

Ellen's husband was advised by their GP that to continue with the pregnancy would endanger her life, but her husband did not disclose this to her at the time. Most likely prompted by his love for Ellen, he perhaps subconsciously assumed a social supervisory role from which to exert his influence over her reproductive choices:

... I found I was pregnant and David [husband] didn't want me to have it ... So I went through the most awful months of my life convincing him that I could have it, and he just kept telling me that I couldn't, and at the end of the day I gave in so [starts to cry] I agreed to have an abortion (Ellen 56-61 years).

Some years later, Ellen decided to be sterilised so that she would not become pregnant again.

Physical and attitudinal barriers denied Boadicea access to contraception services, and as a result she became pregnant while a pupil at special school in the late-1960s. Initially she had considered continuing with the pregnancy, but was met with resistance by her boyfriend's family, and so she reluctantly agreed to terminate the pregnancy. At that time terminations had recently (1967) become available through the NHS, but required approval by two medical professionals. Boadicea recalled that her young age or personal circumstances were not recognised as grounds for the procedure, but rather

her visual impairment was identified as legitimating termination. In her mid-20s, Boadicea was again denied access to contraception when her GP refused to prescribe the contraceptive pill, claiming that she had an ovarian cyst. A hospital examination a few weeks later revealed that she did not have a cyst but that she was actually pregnant:

... the consultant said "Now, do you want a termination or not?" I thought, I can't go home with a baby, and I said "I don't want it, but I've got to have it" ... I was homeless, I was totally, totally homeless, I did not have the support of the father, I didn't feel in a position to negotiate, I didn't feel in a position to argue, I had no money, I was destitute. So I went through with it (Boadicea 46-51 years, child aged 27 years).

Although the medical approval for termination was on the basis of her visual impairment for Boadicea, her difficult decision, as with many women, was influenced by the social circumstances in which she found herself at the time of the pregnancy.

For any woman, the decision to terminate a pregnancy is extremely difficult and emotionally charged, and the long-term effects that these decisions may have on women are rarely discussed or documented. Boadicea talked of the effects that her first termination had on her:

... [I] didn't realise the psychological effect it was going to have ... For many, many years afterwards, I considered myself to be a murderess (Boadicea 46-51 years, child age 27 years).

Following the termination of her first pregnancy, Boadicea was expected to resume life as usual, and she returned the next day to special school where none of the staff had been informed of her termination. The secret nature of her termination and subsequent lack of support had serious consequences for her, and shortly after returning to school she attempted suicide by taking an overdose.

Ellen also talked of the personal effects of a decision to terminate her wanted pregnancy. Following the termination, Ellen was not offered any support or counselling. She recalled that there seemed to be an unspoken understanding amongst medical professionals that, as a disabled woman, she would not be affected emotionally by the procedure in perhaps the same way as would a non-disabled woman. Prior to participating in this study, Ellen had never

talked about the termination that took place thirty-five years ago. Her words give a chilling insight into the social isolation that accompanies silenced bodies:

I still lie awake at night and cry about it. After I had the abortion, after that nobody said to me "how do you feel about it?", nobody ... I didn't get any support from anybody and didn't know where to go (Ellen 56-61 years).

For Ellen, Boadicea and the participant in Begum's 1996 study, quoted above with reference to sterilisation, compliance with social supervisors' approval and advice-giving was at great personal cost to themselves; these women were effectively coerced to relinquish control of their fertility and to surrender their reproductive capabilities.

Miscarriage

Miscarriages in the early stages of pregnancy are common, but even so such events constitute deeply painful moments in women's lives. The emotional impact of miscarriage seems unacknowledged by medical professionals, who tend to inform women in a distanced and insensitive manner. Non-disabled women tend to be informed in private environments of a consultation or scan room, but Beth was informed of her miscarriage, fourteen weeks into her pregnancy, in the public environment of the ward and in a brutal manner:

... she [doctor] ... stood at the end of the bed and at the top of her voice she said "well, Mrs Jones's baby is dead, and you are going to theatre tomorrow morning to have the contents of your uterus removed," and walked away ... I said "excuse me, can you just repeat what you have said to me?", and she ... said [slowly] "your baby is dead and you will be going to theatre in the morning, is that clear?", and she walked away again (Beth 36-41 years).

The insensitive treatment experienced by Beth is reflected in the experience of a participant in Wates's (1997) research. When the participant, Annie, started bleeding at ten weeks, she was admitted into hospital for a scan:

The doctor said "Are you sure you were pregnant? If there was a baby it's not there now." Then he walked out of the room (in Wates 1997:32).

An unease at the presence of disabled women in reproductive spaces, and

insensitive treatment at an emotionally difficult time, is also echoed in my study by Annie's experiences. An initial routine scan revealed that her baby was not moving, so she requested a second scan a week later, and this confirmed the results:

... it took three weeks to get me in [for a D&C] I had no support in those three weeks ... So I had to carry my baby for three weeks knowing it was [dead] (Annie 26-31 years).

Following the operation, Annie was very distressed. A hospital counsellor was sent to speak to her, but the counsellor could not understand what Annie was saying, and she felt that the counsellor 'did not have the right attitude' towards communication with disabled people. Annie remarked that in the end the counsellor broke down in tears, and left without finding a way of communicating with her. Sadly, Annie did not get the opportunity to talk about the various reasons for her distress. Indeed, the insensitive treatment experienced by Beth and more recently by Annie had a devastating impact, with both women attempting suicide following their experience of miscarriage.

Birth

Disabled women's choices of *where* to birth is perhaps restricted by a medicalised perception of their bodies as unpredictable, thus equating physical difference with risk of complications (Sharpe 1999). In Western society, hospital has become the taken-for-granted space for childbirth, yet it is a space from which disabled women are attitudinally and physically excluded (Chouinard 1999). Medical uncertainty as to the way in which an impaired body, regardless of the nature of the impairment, will respond to the labouring process may result in interventions to deliver the baby without fully consulting the woman. For example, when Katie had her baby twenty-nine years ago, she was simply told that her baby would be delivered by caesarean section; indeed, she was not presented with any other option. Conversely, Claire, in anticipation of potential barriers in the birthing environment, developed a detailed birth plan to ensure that her access requirements were met during labour; for instance, midwives were requested to say their name on entering or leaving the delivery room, and Claire asked to be informed of any monitoring of the baby's condition throughout labour. Midwives complied fully with Claire's birth plan throughout her long labour, and she recalled the positive impact of this:

I felt in control of the situation, empowered and respected. I will always remember my labour as something quite positive (Claire 31-36 years, child aged 4 years).

Again, it is important to stress that both negative and positive accounts of birthing did arise in the interviews, with some hint that the situation is improving, disabled women who have given birth in recent years experiencing better treatment than did their disabled sisters in earlier years.

During the late stages of her labour, Laura encountered the medicalised gaze which reduces disabled women to 'curios' and legitimates the asking of any question to salve the onlookers' curiosity (Davis 1995). A doctor, carrying out a final internal examination prior to the imminent birth of her baby, questioned Laura repeatedly about her visual impairment

I was thinking I'm about to bloody give birth here, and I said "look, never mind my eyes, just get this bloody baby out," and I felt really angry about it ... It was just so inappropriate so late in my labour to be questioning me about my eyes (Laura 46-51 years, child aged 20 years).

The presence of disabled women in birthing spaces is often not anticipated. Most medical professionals are unfamiliar with sensitively raising the issue of inherited impairment, as Michele experienced when a doctor entered the delivery room as she was about to give birth to her first child:

... she came in and she said "is this the visually impaired woman who is going to have a baby who might be visually impaired?" I mean everyone, all the other medical people were looking like, "what?!" It was just so inappropriate (Michele 31-36, children aged 9 years and 6 years).

Disapproval of her pregnancy, and fear of being forced to have a termination, silenced Beth so completely that she kept her pregnancy secret. She recalled that even at full term her body did not appear physically pregnant. Unbeknown to her parents, she laboured in her bedroom until she recognised that she needed to go to hospital. As she divulged her secret to her mother, her body dramatically altered:

... I said "I am pregnant, I'm in labour" ... at that point, when I told her, my body physically appeared pregnant, it was absolutely amazing, my stomach just went and you could see very clearly then that I was

pregnant, and she then went down and phoned the GP who told her not to be so stupid, I couldn't possibly be pregnant! (Beth 36-41 years, children aged 24 years and 20 years).

Although Beth's body had assisted the concealment of her pregnancy, lack of parental and professional's expectations of her as a sexual being colluded to hide her pregnancy until a moment of 'release' when the fact of going to give birth could no longer be concealed.

Post-natal

The invisibility in, and absence of, disabled women from reproductive spaces is reflected in the inaccessible ableist nature of these spaces. Disabled women often remain pushed to the margins of these places, and societal supervisors within the medical profession rarely perceive access to such reproductive spaces as a matter of human rights and social justice (Chouinard 1999). As a result, disabled women's access to basic facilities, such as toilets, baths and showers in reproductive spaces can be problematic. More generally, it is hardly surprising that women's embodied experiences within these exclusion zones are often humiliating, undignified, devaluing and degrading (Wates and Jade 1999, Wates 1997). Accommodation of access requirements is dependent upon the awareness or willingness of the personnel present within these spaces, and this is only patchily forthcoming.

Mobility training or informal orientation around the post-natal ward enables visually impaired women - to navigate the environment independently, become familiar with the location of stored items such as baby milk, towels and nappies. Awareness and familiarity with the ward or side-room environment makes it possible for visually impaired women to care for their baby without constant assistance. Following the birth of her first child thirty-one years ago, midwives deliberately kept Mary in the ante-natal ward where she had spent a considerable period of time prior to the birth of her baby. This enabled Mary to focus on caring for her child in a familiar physical environment with nursing staff known to her. However, in more recent times the divisions of ante- and post-natal spaces have become fixed, and do not allow for the flexibility experienced by Mary. In addition, the delivery of mobility training by blind welfare organisations has become strictly proscribed to the outdoor environment. Where visually impaired women require orientation or mobility *within* a maternity unit, this is dependent upon the

staff present. Michele found maternity staff helpful in familiarising her with both the layout of the unit and the location of things she would perhaps require:

... they took me round and showed me where things were, like the baby milk, towels and whatever else there was. I'm not quite sure if they did that because I was visually impaired or whether they did that with any new mum ... I didn't ask for that, they just did it (Michele 31-36 years, children aged 9 years and 6 years).

Claire experienced isolation in the post-natal ward as a result of lack of familiarity with her environment, on the other hand, and staff shortages meant that the nursing team was unable to offer her any orientation. Placed in a side room on her own, there were few people she could ask for assistance:

I badgered an auxiliary to show me where the toilets and showers were, and that was it. So I just went between the toilets and the shower and my room, I had no contact with any other women who were in having their babies for the four days that I was in hospital (Claire 31-36, child aged 4 years).

Anyone in a new environment requires familiarisation with the location of key spaces within the hospital environment, but for visually impaired women it is crucial. Without familiarity with their environment, visually impaired women are placed at a distinct disadvantage and are more likely to be excluded from social interactions.

Problems can arise even when disabled women have communicated their access requirements well in advance, and such requests can remain unmet, as Annie experienced:

I hadn't anticipated breaking my pelvis [during labour] obviously [laughs]. I couldn't walk, I couldn't sit up, I couldn't do anything and I needed a bath, a shower or something and I asked for a hoist and they [nursing staff] looked at me as if I was talking in Swahili. I'm like, "a hoist?" So it took them about a day to locate a hoist, and then they got in the hoist [but] it wouldn't fit under the bath, so they then had to get a guy to come up and cut holes in the side of the bath; and I was like in agony. I just wanted a bloody bath ... it was just horrendous (Annie 26-31 years, child aged 6 years).

This experience was echoed by Joy, who had also communicated her access

requirements well in advance of her presence in the maternity environment:

The first day was terrible ... I hadn't had a bath, I couldn't have a bath on my own, I needed help to get in and out of baths, so I couldn't get a bath. I didn't get a bath until the next night [following birth] ... They said "oh, use the bidet," but I couldn't get on and off it. If I got down, I couldn't get off it, but I didn't know any of that until I tried it and I kept getting stuck, and it was just, it was awful (Joy 36-41 years, child aged 5 years).

The combination of the inaccessible environment and staff shortages prevented Joy accessing the basic facilities to wash. When faced with inaccessible facilities, it is often only when women try to use items such as a bidet they discover that these do not constitute a solution.

The inaccessible nature of the post-natal environment, lack of accessible baby equipment, and inflexible hospital protocols in relation to baby care can all make the early days of mothering difficult for disabled women as they find ways of working with their babies. When Melissa gave birth to her daughter seventeen years ago, there were no baby cribs in the hospital accessible to her as a wheelchair user. This made independent baby care impossible, and she had to request assistance each time she wanted to lift or lay her baby. A consultant asked Melissa to bring an accessible crib from home for use in the ward, but this solution was met with resistance by ward staff. In more recent times, Claire also encountered nursing staff resistance to her solutions to baby care. She had found it difficult to change her baby in the crib but found that changing her baby on the bed enabled her to get close to him; she could be certain both that he was clean and his clothes were on comfortably. She did not realise that this contravened hospital policy until informed by a nursery nurse:

She [nursery nurse] was shouting "get that baby in the crib" ... she actually picked up my son and dumped him into the crib and shouted ... "if that baby rolls off the bed that's a stone floor and that would be murder, you will have murdered your baby'." I was just completely shocked ... I explained to her that I was blind, but she just wouldn't listen ... My husband noted her name and we made a complaint (Claire 31-36 years, child aged 4 years).

Claire was forced to comply with hospital policy by changing her baby in the crib, and this made changing and dressing her baby very difficult for her. Forced to work with her son in an inaccessible way did not nurture Claire's

self-confidence in her own caring abilities. Conversely, Beth who had her first baby twenty years earlier than Claire was encouraged to change her baby on the bed. Changing her baby in the crib caused Beth physical discomfort, and a nurse suggested that she change her baby on the bed. This flexible approach enabled Beth to develop her own ways of working with her baby and positively enhanced her self-perception as a young mother.

In recent years a Scottish Executive advertising campaign with the slogan 'Breast is Best' has strongly encouraged all new mothers to breastfeed their babies. Breastfeeding may pose difficulties for women who cannot physically hold their baby in a breastfeeding position. Additionally, women may have taken strong drugs on a long-term basis to treat or to control their impairment, and the residual effects in the body or transition in breast milk is not known or understood. For example, Joy had taken strong medication to control her impairment, and considered it unwise to breastfeed, and so the nature of her impairment made breastfeeding physically impossible. As she recalls, though:

I still feel bad about that [not breast-feeding], I still feel judged. I can remember I had to walk, you know [maternity unit] the corridors are never ending up to the nursery, right through the nursery where all these mothers were breastfeeding, pick the milk out of a cupboard and walk all the way back, and I felt like real daggers in my back, it was so awful. I always remember that walk in [maternity unit] because my hips were just agony and to walk all the way along and all the way back it was horrible ... it was really hard to have this added stigma, it was horrible (Joy 36-41, child aged 5 years).

The segregated location of bottled baby milk within the maternity unit indicates a distain for bottle-feeding, with breastfeeding thereby prominently promoted in mainstream spaces, further marginalising some (if not all) disabled women.

Bathing a newborn baby is a task that any new mother feels particularly nervous about, and in most hospitals first time mothers are shown how to bath their babies. Where women's physicality makes it difficult or impossible to bath a baby in the conventional way, solutions have to be sought (Thomas 1997). A lack of awareness of hidden impairments, compounded by a lack of support and creativity in developing solutions, can leave disabled women feeling inadequate in their caring abilities, as Joy described:

She [nurse] obviously hadn't read my file or anything, and she came in and said "right, I'm here to show you how to bath the baby." I was totally panic stricken because I knew I couldn't do anything with this arm, and she's saying "but it's [baby] not heavy, it's only five and a half pounds," and I was saying "but it's not that, it's that I can't move," and you know her saying "support the baby's head with your hand'." I couldn't do that, it was too painful, and it was just terrible (Joy 36-41, child aged 5 years).

Consultation with Joy about what was physically possible for her, and adopting a more creative approach, would have enabled the nurse to assist Joy to develop positive solutions to the task. Such an approach engenders an acceptance of diversity, and embraces the notion that everyone undertakes baby care differently (but equally diligently). It is instructive to consider Colette's case, following her developing a significant visual impairment prior to the birth of her third child fifteen years ago. Nursing staff supported Colette to develop methods of bathing her child that did not rely upon her limited residual vision, and this positive approach enhanced her confidence in her ability to care for a newborn baby as a visually impaired mother.

Non-disabled social supervisors may find it difficult to comprehend the mothering capabilities of disabled women, and therefore subject them to surveillance and monitoring, indicating a lack of confidence in the women's mothering capabilities (Gillespie-Sells et al 1998). This may then prompt in disabled woman a primitive response that they must constantly 'prove' themselves as capable competent mothers (Bendall 2002, Curtis and Thomas 1997, Thomas 1998, Wates 1997). Annie broke her pelvis during labour, and the effect that such a serious injury would have on her mobility was disregarded by a midwife who assumed that Annie's immobility was a direct result of her impairment. The midwife made the erroneous assumption that Annie's baby would not be safe in her care, and, without consulting Annie, this midwife contacted Social Services to arrange for the child to be placed in care. To prevent this from happening, Annie's mother agreed to 'take responsibility' for the baby until Annie was well enough to look after her child. Nonetheless, the midwife forced Annie to demonstrate to her that she could bath and change her baby:

I still had to sit up in bed and change Holly in front of the same midwife. I did it because I was so fucking determined, but it was so painful. I had to bath her and at one point I said, "see, when other

women break their pelvis, do they have to demonstrate their capabilities with a broken bone?" It was horrendous ... At the time it was like you had to prove you could be a mum and it was horrific (Annie 26-31, child aged 6 years).

Annie's ability to care for her baby was undoubtedly questioned and scrutinised by the midwife. In her role as a social supervisor, she clearly considered Annie's mothering capabilities to be a matter for public debate, without taking into consideration the serious injury that she had sustained during labour let alone the consequences of her own actions as a midwife for Annie and her family.

Some women found that, once they left hospital with their babies, the level of monitoring and surveillance by health professionals in the home environment actually increased along with an intensification of self-monitoring of behaviour by women. It seems that success in the domestic sphere equates with appropriate and acceptable motherly behaviour (Aitken 1999). Claire's observations on the differences between perceptions of her ability as a mother and those of her non-disabled twin sister are telling:

... her competence in terms of being a mother in the early days of parenting and her ability to care for her child ... were not questioned in any way ... whereas for me ... that was something that I had to prove (Claire 31-36, child aged 4 years).

Adele, Beth and Claire identified that the tidiness of their house was used by health professionals as an indicator of how well they were 'coping' with motherhood:

... I was quite paranoid because I knew they had powers, and of course I would be up at six in the morning – you could eat your meal off the floor ... I need to prove to them that I'm able to do this and look after this baby. So that ... put added pressure onto me just in my day-to-day life because I knew they had the powers to take your baby ... I believed that they had the power to do that (Adele 51-56 years, children aged 29 years and 24 years).

... I felt as though I had to be better ... I couldn't have low days, I couldn't not cope with washing and the housework and stuff like that. I couldn't because any wee thing would give them an excuse [to take my baby away] (Beth 36-41 years, children aged 24 years and 20 years).

In more recent times, Claire had similar experiences of a health visitor who called in almost every day to 'see how she was coping'. This gave a clear message that the health professional had little confidence in Claire's abilities as a mother:

... at the time I felt that my ability to look after and to care for my son was being questioned and scrutinised. I found it a real pressure, not knowing when she would just turn up ... I made sure the baby and the house were immaculate all the time, but that was at great personal cost to myself. I mean I think within a very short space of time, realising that I felt quite depressed and that I didn't feel confident, ... I went over board to prove myself as a mother (Claire 31-36, child aged 4 years).

Fear of children being removed from their care in the early days of mothering was a very real concern for most of the women who I met. This fear was so great for some women that it prevented them from seeking or accessing support services. For example, Islay became blind suddenly during her third pregnancy, and following the birth she became a lone parent of a newborn baby and two toddlers. She did not approach any services for support in relation to her acquired visual impairment, or with her mothering, as she feared that the authorities would remove her children from her care. Instead, she developed strategies to merge in with other mothers and to conceal her blindness, especially in spaces of surveillance such as the baby clinic. As she recalls:

... I didn't tell them that I was blind, I just listened. Whereas other people would be maybe sitting having a chat with people, I was concentrating on who was next to me and what direction they were going in and where they were going to and, even if I got it wrong I would just say my eyesight isn't very good ... I just went about following people (Islay 61-66 years, children aged 46 years, 45 years, 43 years).

Fear of her child being removed detrimentally silenced Claire, and prevented her seeking and accessing support services:

I didn't actually tell anyone I was feeling depressed, I certainly didn't tell the health visitor because I felt as though, if I told anyone, they would just take my baby off me ... I felt as though it wasn't safe for me to tell anybody, so I just didn't ... I ended up experiencing post-natal depression for almost three years ... I didn't go and seek help ... until I felt it was safe enough for me to go and admit how badly I had been

feeling, and in a way I feel really shocked and saddened [starts to cry] that I waited so long (Claire 31-36, child aged 4 years).

Laura concealed her visual impairment from health professionals but was 'one hundred percent certain' that, if she had disclosed her impairment, her mothering would have been monitored more closely. It is a real indictment of services supposedly there to support women that they can make them feel so threatened, and in the process silence them to the point where their mental health, confidence and self-esteem are adversely affected (Mason 2003). To varying extents all of the women mentioned in the last two paragraphs felt that they had to prove themselves as supposedly 'whole women' rather than as just *children* playing at being mothers (Shackle 1994).

As with any woman, a number of factors influence disabled women's decision to have more children or not: for example, the woman's age, number of existing children, relationship status, family and financial circumstances may all have a bearing. Reactions to inherited impairments may also be a particular influence on a disabled woman's decision to have or not to have more children. When Jenny became pregnant, she discovered that her visual impairment was hereditary, and that any further child would have a 50 percent chance of inheritance; when her first child was born without the eye condition, she decided not to have any more children. Alternatively, Michele had two children, both of whom had inherited visual impairments, but Michele, her husband or children did not regard this outcome negatively. Indeed, when asked if she would consider having more children, rather than replying with reference to the 'risk' of inherited impairment, Michelle replied that it had been seven years since she had her youngest child, implying that the age gap was perhaps more of a concern to her when deciding on a third child than any 'risk' of inherited visual impairment. For some disabled women, moreover, their decision whether or not to have more children is determined by the medication that they have to take. This was the case for Joy:

... the stuff I'm on now, it's really, really dangerous to get pregnant, and I've been on that before and you have to sign things to say that, if you get pregnant, you will have an abortion (Joy 36-41 years, child aged 5 years).

Also very important in disabled women's lives, however, are the views of others about the 'sensibleness' or otherwise of the decision to try for more children. Those within the medical profession are of course powerfully placed

to monitor and to influence further reproductive choices, while societal supervisors within family and networks of friends may also exert influences through their response to disabled women as mothers. Katie's experience illustrates the over-arching power of such people:

... they told me "don't have any contraceptives when you get married because if you want a baby you have to get on." Then, after Helen came, the rule was that I mustn't have any more children, it was risky (Katie 61-66 years, child aged 29 years).

The influence of medical professionals' advice giving was similarly evident in Hanna's experience when she became pregnant for the second time:

... the consultant did say to me "it has been really difficult at times, and I wouldn't recommend that you have any more" (Hannah 41-46 years, children aged 13 years and 9 years).

It would seem that society remains unprepared for disabled people becoming parents, and particularly disabled women becoming mothers, as this directly challenges the perception of their asexual 'rolelessness' to such an extent that there is often no 'place' (physically, attitudinally or emotionally) left for them in reproductive spaces. Thus, feeling 'unwelcomed', 'out of place' or having to 'prove' their mothering capabilities is experienced most intensively by disabled women. Professionals' misgivings or questioning of their presence in reproductive space; a displayed disapproval of their pregnancy, or verbalised misgivings regarding a woman's caring abilities: all of these become directed at disabled women, precisely because they *are* women. Mainstream society still closely associates women with the fundamental parenting role, and more specifically supposes that the mothering role should be undertaken in a manner that 'traditionally' requires certain physical, visual and verbal means.

Replaced parents

For many disabled people, their parenting aspirations may be determined by adoption agency workers, social workers, hospital doctors or GPs. Disabled individuals' access to adoptive parenting and other basic human rights such as housing and employment often depends upon medical assessment and approval, meaning that the medical profession has a disproportionately greater influence on disabled individuals lives in comparison to non-disabled people (Gesler and Kearns 2002). Disabled prospective adoptive parents may

be denied the opportunity to adopt based on the adverse opinion of a medical professional. Disabled writer and adoptive mother, Denise Sherer Jacobson, in her book, *The Question of David: A Disabled Women's Journey Through Adoption, Family and Life* (1999), wrote of a medical professional who questioned her mothering ability based on his perception of her physical capabilities:

The words he had written echoed my own self-doubts about parenthood but, because I was disabled, I couldn't just worry about my concerns, I had to worry about the implications of his (Sherer Jacobson 1999:83).

Similarly, Eve, a participant in Begum's study, commented on the reports written by her GP when she applied for approval as an adoptive mother:

He was particularly disturbed by the idea of me adopting a child, and seemed to go out of his way to mention my blindness on the medical reports, even in places where it didn't seem to apply. He clearly saw it as an obstacle and meant to portray it as such (Begum 1996:178).

Therefore, judgements regarding suitability as an adoptive parent may be grounded in the physical appearance of an individual's body and professionals' perceptions of their physical inabilities, rather than to do with parenting aptitude *per se*. This physically founded judgement of appropriateness as an adoptive parent is reflected in the experience of television celebrity Dawn French, who was forced by an adoption agency to lose weight before becoming an adoptive parent (BBC One 2003). Her experience implies that there are physical criteria to which prospective adoptive parents are subjected. Two of the adoption agencies contacted in this research did provide criteria for prospective adopters, and this information clearly indicated the importance of medical assessment, health status and an upper age limit of forty years for applicants (Glasgow and West of Scotland Adoption Service 2002, Scottish Adoption Association 2002). Adoption UK, a self-help organisation offering support to families before, during and after adoption, hold a database of adoptive parents throughout the United Kingdom. A search of their database revealed only two adoptive disabled parents in the whole of Scotland registered with the organisation.

Sally's experience of using a national adoption agency may shed some light on the under-representation of disabled adoptive parents in Scotland. The adoption agency used by Sally and her husband was inaccessible, located on

the top floor of a tenement building, and this spatial 'fact' in itself conveyed a clear message about the expected physicality of prospective adoptive parents. A contributor to the journal *Disability, Pregnancy and Parenthood International* (DPPI) noted difficulties with receiving information, particularly children's profiles, in accessible formats from adoption agencies (DPPI, 2003). Where access requirements are not accommodated, this may give an unwelcoming message to prospective adopters. As prospective adoptive parents, Sally and her husband fully expected that every inch of their lives would be probed by the adoption agency, but she found that her life was scrutinised in a one-dimensional way that focused on the physical implications of her impairment for her mothering capabilities:

She [adoption agency worker] just kept bringing it back to how would I cope with ... She said things like "well, you know what toddlers are like they can just run off, dart off suddenly," and I said I would have strategies for coping with that type of situation ... there are ways round it ... I would go somewhere that is safe for them to run around ... I was saying we have a three bedroom flat here, so there would be room for somebody to stay the night if I really wasn't coping well ... it was always those sorts of "how would you cope if?" (Sally 41-46 years).

Anyone disabled or non-disabled has to adapt to parenting, but disabled people are expected to have highly developed 'coping' strategies to hypothetical situations suggested by adoption agency workers or social workers. Sally's experience of being pressured to say how she would cope with the physical nature of parenting is similar to Claire's experience, where she felt forced to develop coping strategies in response to the difficulties of medical professionals in comprehending how a blind woman would approach parenting tasks. Adoption agency workers justified their approach to Sally's impairment, assuring her that they had the best interests of a child at heart and that they had to ensure that a child would be safe in her care.

A recent issue of DPPI also featured the mixed experiences of disabled individuals when going through the adoption process. This included a contribution from a blind prospective adopter, who wrote of the negative manner in which their caring abilities was questioned by the local authority involved:

The point seems to be whether someone who is totally blind can keep a child safe, even though numerous visually impaired and blind parents

are keeping their children safe every day. I've been asked stupid questions, such as how would I know a child was going to stick their fingers into an electric socket? The common-sense answer is that you would childproof your house just as anyone would (DPPI Winter 2003:3).

Claire, a blind woman was also subjected to similar questions during her pregnancy. The contributor to the DPPI article, and in Sally's and her husband's experience, factors such as positive motives for adopting a child, the stable environment that they could offer, their financial security, their educational background as trained teachers, their extended local family network and friends, and the like, all seemed inconsequential in comparison to the significance placed upon Sally's impairment. Prior to entering the medical assessment phase, Sally and her husband hence decided to withdraw from the adoption process, and this is perhaps the case for many disabled prospective parents.

Displaced parents

Everyone caring for a young child needs support, although often in mainstream society the requirement for support is regarded as being wrong. Where women require assistance with their mothering role, it does and should not take away their right to do it. Where women employ personal assistants, this may be to facilitate an independent lifestyle and multiple roles of mother, wife, employee and student. For some women, the nature of their impairment means that they may require support with practical baby care tasks, maintenance of their house or even more intimate personal assistance. Annie employed personal assistants to enable her to live independently, but service providers' misunderstandings regarding the role of personal assistants implied an infantilised view of Annie that displaces her from her mothering role:

We really had it all set up, but of course the Social Work weren't happy with that because they weren't registered child minders ... but we don't employ child minders, I employ personal assistants to assist me to be a parent (Annie 26-31 years, child aged 6 years).

Annie, Joy and Hannah were offered home helps as a means of support. This type of support offered through Social Work community care services is generally geared towards meeting the needs of older people in the community, and is therefore not designed, nor intended, to meet the diverse

requirements of disabled mothers.

Hannah, Joy and Annie had similar experience of the home help service; they were not consulted about either their support requirements or the role of the home help, and nor were they involved in the recruitment process. This paternalistic approach to service delivery resulted in support services that were ineffective, as they did not address aspects where the women required support. For example, Hannah commented that the home help 'was only interested in taking the baby for a walk', and similarly for Joy the home help was only there to carry out baby care tasks:

... I needed support to be a mum, I didn't need support to mother my child. I just needed support to give me a bit of energy and time and to take away some of the things that were killing me, like the washing and the ironing and trying to keep my house tidy (Joy 36-41 years, child aged 5 years).

In the private space of the domestic sphere, individuals intended to deliver support services can sometimes over-step or even abuse their position by effectively displacing the disabled woman from her mothering role:

... she [home help] dictated when she would be there and she bathed and dressed Holly, and I had no choice in that (Annie 26-31, child aged 6 years).

As a means of attaining effective support, Hannah, Joy and Annie discontinued the home help service. Hannah and Joy recruited home helps privately, while Annie negotiated support from existing personal assistants in her employment. When Melissa had her baby seventeen years ago a community initiative was introduced which offered support that responded to an individual's requirements. This person centred approach to support facilitated Melissa in her mothering role. It seems that this initiative was short-lived, as in Joy and Annie's relatively recent experiences, both women were offered a standard home help package irrespective of their support requirements.

Parenthood usually affirms status as an adult (Aitken 1999), and this rite of passage does not seem to apply to disabled women who find themselves infantilised by societal supervisors reluctant to recognise them as competent mothers. These supervisors, believing their actions to be in the best interests of a child, may take steps to displace disabled women from their mothering

role, as Elizabeth, Beth and Boadicea's experiences illustrate. Elizabeth gave birth to twins at the age of 22 years old, but shortly after the birth a nurse tried to persuade her to give up her role as their mother:

...All she [staff nurse] went on about was ... "you're ruining your life, adopt them [twins], look at these poor people that are desperate for kids and you are going to have two. You can't even look after them. Look at you, you're a cripple" (Elizabeth 51-56 years, children (twins) aged 31 years and one child aged 27 years old).

The fears that had silenced Beth throughout her pregnancy began to materialise as she was being prepared for an emergency caesarean section. Before being anaesthetised, she was asked repeatedly if she was sure she wanted to keep her baby afterwards. Despite clearly communicating her intention to keep her child, she awoke from the delivery with a social worker by her bedside:

... she's [social worker] got these papers, and I'm saying "what's this for?" and she's saying "well you won't want to keep this baby? ... This is so you can have your baby adopted" ... I said "do you really think I've gone through what I've gone through to give my baby to you? ... I'm not doing this" (Beth 36-41 years, children aged 24 years and 20 years).

The social worker reluctantly accepted Beth's decision to keep her baby, but for a substantial amount of time Beth feared that social workers or those in authority would attempt to remove her son from her care. For Boadicea, her parents made a key decision without consulting her:

... One day, my mother announced "oh! Your father and I have come to a decision, we're going to adopt your daughter" ... I said "no you are not. There's no way that that is going to happen I will not allow it. You've got no right to suggest it ... just because I'm not in a financial position to fully support her in the way I would like to, it doesn't mean to say I should relinquish all my rights as her mother" (Boadicea 46-51 years, child aged 27 years).

This, for some disabled women, it may actually be those closest to them that consider displacing them from their mothering role.

When disabled women give birth to or adopt a young child, they gain unconditional acceptance as a mother *from* their child, and for most women this may be the first time in their life that they will have gained such a level of

acceptance (Sherer Jacobson 1999). This unconditional acceptance of disabled women as mothers is not shared by wider society, probably due to the relative absence or invisibility of disabled women from mainstream (often inaccessible) spaces. The methods developed by disabled women to get their children (while babies/toddlers) around illustrate a high level of personal endeavour, reflective of women out to prove themselves as competent mothers in public space. Katie, Mary, Jenny and Claire, as visually impaired women, developed strategies to get out and about with their babies. Both Mary and Katie mastered a technique for navigating through public space using their guide dogs –

... I just had my dog on the left hand side and pulled my pram behind me (Mary 51-56 years, children aged 31 years and 27 years).

- whereas Jenny and Claire, both long cane users, carried their children in backpacks:

If we were going out for the day ... I'd have clean nappies, wipes, toddler snacks, clean clothes, a drink for him, you're really going out prepared for any eventuality, so I had to carry all that with me in the backpack. I must admit it was difficult to walk any distance because my son was quite a weight (Claire 31-36, child aged 4 years).

These and other disabled mothers challenge the low to no social expectations of them pursuing any social roles, but, being widely viewed as out of place in public space, they have to deal with society's responses that displace them from their mothering roles. Annie spoke of social responses to her as a disabled mother in public space:

My daughter gets upset with people who just ignore me, and she doesn't understand why people are staring at mummy and talking about her mummy as not being normal, and it's just, I find it really difficult (Annie 21-26 years, child aged 6 years)

As Melissa recalled, meanwhile, her presence as a wheelchair-using mother was totally unexpected when out with her baby daughter seventeen years ago:

I'd have the baby on my knee ... people would come up and say "oh, and whose baby is this?" and I would say "it's my baby." "Oh! What are you doing with a baby," and "oh, I didn't think you would be able to manage having a baby" (Melissa 51-56 years, child aged 17 years).

These disabled women's narratives reveal public responses to them in their mothering roles. In public space these women are 'particularly subjected to the 'gaze' of others and to some degree on display' (Butler and Bowlby 1997:419). This 'gaze' objectifies disabled women as objects of sympathy or curiosity. Hostile responses to disabled mothers are most likely prompted by a social fear of physical 'difference'.

The social relations surrounding the disabled woman in public, medical or other institutional spaces can become quite scrambled in the assumptions made by non-disabled people, with the effect of displacing disabled mothers from their mothering role (if only momentarily). Katie spoke of being displaced from her mothering role almost thirty years ago by a young doctor, who, after examining Katie's child, handed the baby to her acquaintance. Despite the passage of time, Katie still found this rejection painful:

... I feel upset after all this time ... He just absolutely ignored me ... I was trying to ask him questions, and it was as if it was her baby. Now, to this day I wished I'd said "excuse me, can I have my baby back?" ... I know it sounds like a small thing, but to me it really hurt me very much ... He probably thought she ... did all the things for the baby (Katie 61-66 years, child aged 29 years).

Katie also found herself displaced from her parenting role by other peoples' assumptions that her young daughter took on a caring role:

I held Helen's hand right up until she was five, I taught her road sense ... but what do sighted people think? They think they are guiding you around, and they go about saying "oh that brave little girl, oh she must have an awful lot on her plate" (Katie 61-66 years, child aged 29 years).

Twenty-five years later, Katie also finds herself displaced from her grandmothering role by those who assume that her grandchildren have taken on a caring role:

... she [bus passenger] said "you'll be lost without her, getting around" ... I said "she's my granddaughter" ... She said "I thought it was a neighbour's lassie that took you around" (Katie 61-66 years, 3 grandchildren aged 8 years, 5 years and ten months).

Katie's status as a mother or grandmother seems to have been disregarded by others who assume that her daughter, and more recently her

grandchildren, act as sighted guides. More insidious is the underlying implication that the children are responsible for Katie, and that the roles of child and adult are thereby reversed.

In more recent times Claire found the same attitudes prevalent in public space, implying a role reversal between parent and child, regardless of how young the child may be:

I find it very offensive that when I'm out with my son, and if I'm using my cane, they say "oh, are you looking after your mummy?" ... I have the parenting role and not him, he's my child (Claire 31-36, child aged 4 years).

Disabled women are displaced as mothers by social supervisors, perhaps due to their difficulty comprehending the many ways in which disabled mothers do undertake everyday childcare tasks. One factor often overlooked, furthermore, is a child's instinct towards their mother's impairment, and almost all of the mothers to whom I spoke mentioned their child's early and accurate intuition and responses:

I found when my kids were toddlers ... it was amazing how quickly they realised you couldn't see and, if they wanted to show you something, they would come and take your hand and take you to where it was (Mary 51-56 years, children aged 31 years and 27 years).

This theme was echoed by Melissa:

When she was ... seven, eight months ... she would crawl up my chair ... she would sit there [arm rest] and she used to cling on to me and I used to push around. I mean it wasn't that I used to say "hold on to mummy," but she just knew (Melissa 51-56 years, child aged 17 years).

Hannah also mentioned her children's early awareness of her impairment:

They were good at sitting on my knee in my wheelchair as well and also they learned from a very early age ... that I couldn't carry them, so they just walked, they didn't ask me to carry them (Hannah 41-46 years, children aged 13 years and 9 years).

Most of the women spoke positively of the influence that their impairment had on their mothering or grand-mothering style. Most felt that their children and grandchildren would grow up, or for older women that their children

already had grown up, more accepting of human diversity.

Conclusion

Disabled women becoming mothers is often met with disapproval or even resistance on the part of 'societal supervisors', who exert a disproportionate influence on disabled women's reproductive choices. The intervention of societal supervisors (GPs, health professionals, family and friends) often renders the most private of decisions a matter of public debate and as such, public property. Underpinning this debate is the social infantilisation of disabled women, not accredited with adult status, they are *not* expected to be sexual beings and in turn are not expected to embark upon 'adult' relationships, conceive, give birth or fulfil a mothering role.

Society's abject lack of expectation that disabled women will reproduce is reflected in the often inaccessible physical and attitudinal environment of maternity spaces. These spaces are frequently experienced by disabled women as hostile places; giving a very clear message that disabled women have 'no place' in these spaces. In more recent times, where 'space' was created to include and to meet the access requirements of disabled women, these flexible approaches to working practices made the women feel welcomed and respected; most importantly, it enabled them a positive start to their mothering roles.

However, in the main, disabled women's access requirements were not met, even when these had been communicated well in advance. The unwillingness to accommodate women's physical access requirements and/or access to information may perhaps indicate a stubborn resistance on the part of societal supervisors, to acknowledge the rights of disabled parents to establish families and, in particular, for disabled women to exercise their reproductive choices. Legislation will assist disabled women wishing to access reproductive/sexual health/ family planning services as on 1st October 2004 changes to the Disability Discrimination Act (1995) will be ratified, and this will directly affect 'service providers' offering goods and services. Thus, disabled women cannot only expect, but can make demands upon, service providers to deliver an equitable service. These changes will enhance the provision of accessible information and the accessibility of the built environment where a service is offered: for example, maternity services.

These changes will hopefully benefit disabled women greatly along with all other women using reproductive services.

One of the most overwhelming findings of this research requires special mention, and I would hope may prompt a debate about the ways in which services are delivered to new mothers who just happen to be disabled. Regardless of the age of their child/ren, almost every woman mentioned their absolute fear of their child/ren being removed from their care in the early stages of motherhood. This fear had been fuelled for the women by health professionals' frequent visits, including their subtle and explicit questioning of the women's caring abilities, and in, for example, Annie's case (see above), a midwife's erroneous assumptions resulted in a request by the health professional to have her baby taken into care. Therefore, for most of these women their fears were not irrational, but based on a certainty that they were being 'watched'. As has been demonstrated in this chapter, women went to great lengths to 'prove' their capabilities at great personal cost to themselves. Women frequently described feeling 'robbed of a time that *should* have been special'. One woman did talk positively of the support that she had received, noting that this had been offered in a supportive manner to facilitate her in her mothering role. It would seem that a flexible, person-centred approach to service delivery would facilitate both disabled and non-disabled women in their mothering roles.

Although reproductive and parenting rights remain on the outer fringes of the disabled people's movement, women remain determined to make space on their own terms in the reproductive arena (Chouinard 1999). An increasing number of disabled women have a burning ambition to exercise their reproductive rights. Annie expressed a desire to have another child, significantly in a space accessible and familiar to her:

I would like to have another child, but ideally I would like to have it at home in my own surroundings and have no medical intervention (Annie 26-31 years, child aged 6 years).

A number of women spoke of the attainment of motherhood as the realisation of a dream. It is significant that reproduction and motherhood is *expected* of non-disabled women (Campbell 1999), but is largely placed beyond the reach of many disabled women, for whom it is reckoned that these facets of human being are *not* ones that it is their 'place' to consider.

Those disabled women who do realise their goal of becoming mothers will have encountered and challenged serious spatial and attitudinal barriers along the way (Dignam 2003). Joy and Adele spoke of the great satisfaction that they derived from attaining their dream of becoming mothers:

... what I enjoy is the, I thought this would never happen to me ... it was worth the wait! (Joy 36-41 years, child aged 5 years).

Similarly, Adele, along with Melissa, her childhood friend, dreamt of marrying and having children, but she never believed that their dreams would come to fruition:

... but it's true, our dreams did come true, and we often sit and say, "God, Adele, remember that day we sat and we dreamt, you know, and look at it now, we're married, we have children (Adele 51-56, children aged 29 years and 24 years).

Chapter Nine

Conclusion

(In)visibility in time and space?

The absence and insignificance of disabled peoples' lives publicly across time and space has been overwhelming, as I have found while researching and writing this thesis. Regardless of whether disabled people lived their lives within or outwith institutions, very little is documented or known of their social history; their lives and experiences remain invisible (Borsay 2002, Humphries and Gordon 1992).

Archival research has revealed a partial picture of some women's lives. These records kept by institutional directors, medical staff, missionary teachers and home visitors reflect the perspectives of those working on behalf of disabled people, rather than the viewpoints of the individuals themselves. Research conducted by French (1996), Humphries and Gordon (1992) and Potts and Fido (1991) has captured relatively recent histories of the embodied experiences of institutionalised individuals. However, very little exists in terms of Scottish institutions catering for visually or physically impaired adults and children and those who have inhabited them. Furthermore, the lack of emphasis placed upon researching the history of institutionalised peoples conceals the scale of their removal, and arguably symbolises 'our' neglected place and lesser value in wider society

In more recent times, however, disability-led organisations and disabled people themselves have begun to realise the importance of researching and recording 'our' own past. The Centre for Living Independently in Glasgow compiled an exhibition entitled *The Life Histories of Disabled People in Glasgow* (to mark the International Day of Disabled People, December 2000) It featured historical images and contemporary narratives from past residents of East Park and Broomhill Homes, and recorded the embodied experiences of segregation from the viewpoint of those who were institutionalised. This powerful and emotive exhibition affirmed my commitment to research disabled women's life histories. This thesis hopefully contributes to the process of writing disabled people back into social history and public space, by making the lives of segregated, spatially isolated and socially excluded, invisible 'others' visible.

Institutionalisation and its legacy

Institutionalisation led to a host of social and spatial consequences for disabled women, as their separation from everyday life denied them opportunities to participate as citizens in society, local communities or family life. Institutional sex separation denied inmates' sexuality and prevented women's participation in childbearing and mothering. With the passage of time, disabled women's spatial segregation and ensuing absence from domestic, sexual and reproductive spaces became taken for granted (Dodgshon 1998). Their naturalised absence from childbearing and rearing roles became equated with asexuality and inappropriateness as active participants in any aspect of domestic life. Such ideologies have stubbornly persisted across generations and have perpetuated an 'institutionalised' animosity towards disabled women having children (Barnes 1991). The historic 'concealment' of disabled women and men within institutional spaces fuelled popular beliefs that often incorrectly associate impaired bodies with heritable difference, effectively framing disabled bodies as 'sources of contagion' and cited in the recent past as justification to control disabled women's fertility (Cooper and Guillebaud 1999).

These ideologies manifest themselves in historical and contemporary understandings of disabled women's bodies as asexual, incapable of sexual desires, in short as 'sexually dead' (Barnes 1991). This situation was evident historically in the attitudes governing the institutions and special schools; indeed, ironically, a few had greater freedom there, as their sexual awakening was inconceivable to carers and parents inculcated with the prevailing attitudes. Yet such attitudes and related practice have hardly gone away, and, as the contemporary interviews all too often reveal, disabled women continue to be victims of assumptions about both their inherent asexuality and the basic 'wrongness' of them being sexual, conceiving and bearing children, and being mothers. Hence, as bodies denied citizenship and sexual expression as a consequence of spatial segregation, the notion of 'sexual citizenship' (Bell 1995, Evans 1993) may be problematic both to disabled women themselves and when applied to them, a marginalized and oppressed group who historically have had 'no place, no voice and no rights in the public sphere' (Bell 1995:140). Indeed, it was not until the implementation of the Disability Discrimination Act (1995) that disabled people in the United Kingdom gained

equitable citizenship and civil rights, with potential implications for them as sexual equals, able to experience and enjoy sexual activity and its possible outcomes (pregnancy, parenthood), just the same as everybody else. Their 'sexual death' has not straightforwardly been rectified.

Permitted sexualities and bodies

Public space is constructed as asexual, although it is sustained and replicated as heterosexual territories (Valentine 1996). Bell (1995) and Valentine (1996) use the term 'sexual dissidents' to refer to marginalised sexual groups i.e. gay, lesbian and bisexuals; expressions of these sexualities are not straightforwardly permissible in public space, and are policed in a variety of ways both overt and covert (by police officers with the power of arrest, by shop managers throwing out those who dare to attempt 'the gay or lesbian kiss', by routine comments, sniggers and threats). Sexual expression in public space is further limited by society's obsession with the body beautiful (Limaye 2003), as mixed with a strong undercurrent of which bodies can express their sexuality in public space – notably non-impaired ones, those revered as beautiful, fit and healthy bodies. I suggest that disabled people may also be considered as 'sexual dissidents', as sexual expression by impaired (thought to be asexual) bodies is considered distasteful and perverse and remains not for public display. This further restricts the localities where disabled people can express their sexuality, whether straight, gay, lesbian or whatever, to spaces related to disability/sexual activism: campaigning or 'safe' spaces (Myslik 1996) such as dating agencies specifically for disabled people, for example, Handigate or gay/lesbian pubs and clubs. Disabled people may well be unwelcome in ordinary gay and lesbian spaces, particularly those with a strong emphasis on physical appearance and 'looking right', something found oppressive by disabled people (Butler 1999) and individuals living with HIV/AIDS whose physical 'beauty' becomes compromised by their illness (Wilton 1996:80). The inaccessible nature of the social scene conveyed to the women interviewees that they are not welcome as appropriate sexual citizens; they are spatially and attitudinally deterred from expressing their sexuality in public space, particularly mainstream sexualised spaces. It seems that, even when disabled women take space in the social scene, their expression of sexual citizenship by their very presence, through dressing in a sexualised manner, or by glamorising their bodies, is not taken seriously as indicators of their sexual identity or availability in the same way as is true of

their non-disabled counterparts. In the main, disabled women's presence in sexualised spaces is experienced as startling, troubling and sometimes shocking, presumably because of their historic absence and invisibility in these spaces. By being sexually active, they do not conform to their asexual role.

Furthermore, the presence of obviously pregnant disabled women's bodies in public space is an expression of sexuality usually not permissible in mainstream spaces. Indeed, Longhurst (2001) discusses the 'out of placeness' of the pregnant body, whatever the physical status of its bearer in public space. Pregnant disabled women in public space often experience invasive questioning of their reproductive choices, hostility, abuse or ridicule in a similar way that gay and lesbians risk abuse, humiliation or even physical harm if they dare to express their sexuality in public space. Private space, meanwhile, has traditionally been conflated with the domestic, personal life, intimacy, passion, sexuality and reproduction (Duncan 1996). In private space, women's bodies are expected to be sexual, penetrative, passionate and reproductive; but none of these functions are ascribed to impaired female bodies. Hence, even in the sexualised private environment of the home, a place where other sexual dissidents may express their sexuality (Bell 1995), disabled women's sexual expression may be regulated or prevented by others sharing the space. The women reported that parents, personal assistants or care attendants are reluctant to perceive or to acknowledge a disabled woman as a sexual being. Therefore, in order to participate in sexual citizenship, disabled women and men require opportunities, choices and autonomy to participate in private, leisure and lifestyle membership (Evans 1993).

Most participants in this study had expressed their sexual citizenship through forming relationships, marriage and/or ending heterosexual relationships enabling them to establish same-sex relationships. Sexual citizenship may also be exercised and expressed through consumerism; some women made reference to their active consumption of sex-related items as something they had pursued with determination, to gain acceptance on their own terms as sexual beings. However, sexualised spaces of sex/erotic retail outlets are places where culturally non-disabled heterosexuality dominates the scene. Often physically inaccessible, the spatial environment simultaneously restricts which sexualities are permissible and conveys which bodies are expected to

purchase, use and gain sexual pleasure from the items they sell. In line with the prevailing culture, heterosexual non-disabled people are those expected and welcomed into such environments. The spatial and emotional exclusion of disabled women and men from sexual or sensual territories is reflected in a lack of items that accommodate diverse physicalities, a lack of available and accessible information on alternative sexual positions or information on non-penetrative sex (Arthritis Care 2001, SPOD 1990c).

Contested reproductive spaces

For disabled women framed as 'sexually dead', a cultural resistance to acknowledging them as sexual beings, or indeed as competent and responsible adults capable of making their own decisions, has resulted in the development of a social discourse around their reproductive choices and whether they should become mothers or not. Much of this debate has been influenced and informed by medical professionals. The power and influence exerted by the medical profession over disabled women's reproductive choices have been and remain significant. For example, such women have long been requested to justify their reasons for wanting children; and these reasons have to satisfy medical gatekeepers with the power to facilitate, regulate and control access to information and services in relation to sexual health, contraception, conception, pregnancy and childbirth. The power of medical advice-giving is evident in the experiences of women advised or persuaded to terminate much-wanted pregnancies, or to become sterilised to prevent the possibility of pregnancy or further pregnancies. The overwhelming historical influence to deter, rather than to encourage, disabled women to use their reproductive capabilities is perhaps tied up with social values regarding which bodies should or should not be sexual, and which sexualities are publicly acceptable.

Within the gendered spaces of reproduction, birthing and childrearing disabled (genderless) women may be likened to 'space invaders' (Massey 1994), invading spaces that have over time become the preserve of non-disabled women. The inaccessible nature of reproductive spaces reflects disabled women's unnoticed absence. These ableist spaces expect only the presence of non-disabled bodies on the production conveyor belt system that is the National Health Service Maternity Service. The experiences recounted here reveal that women's bodies are expected to respond to pregnancy in a

similar way, to give birth in a certain way, respond to their babies through visual, verbal and physical means, and undertake baby care tasks in a conventional and identical manner. Where and when women's physicality necessitates adaptation to the environment or tasks, it may result in professionals questioning their abilities to 'cope with' or to care for a child and, by implication, a questioning of their right to be a mother.

This questioning reveals non-disabled professionals' perception of disabled women as recipients of (as opposed to providers of) care, combined with a lack of expectation that disabled women will have children. It is further compounded by a lack of comprehension of the strategies and solutions that women may have devised to enable them to perform everyday mothering tasks. Hence, this questioning has little to do with a woman's mothering abilities *per se*, and more to do with professionals' deep-seated antipathy towards the idea of disabled women having children (Olsen and Clarke 2003), borne out of a lack of contact with disabled women becoming and acting as mothers. The understandable automatic reaction of disabled women subjected to such professionals' scrutiny is to demonstrate their mothering competence, prompted by a very real fear of their children being removed from their care. Regardless of whether this is in fact a real possibility or not, it poses a deeply felt threat to the women involved and their future mothering opportunities (Olsen and Clarke 2003, Thomas 1998, Thomas and Curtis 1997, Wates 1997). Faced with such a threat, women may be reluctant to seek support, as the need for such support to undertake tasks involved in independent living or mothering is often seized upon as a reason for removing an individual's right to do so.

Ways forward?

In recent years the profile and visibility of disabled parents has increased dramatically through the development of organisations led by disabled parents; for example, Disability Pregnancy and Parenthood International (DPPI). This organisation, through its Centre for Disabled Parents, information service and quarterly journal, raises the profile of disability and parenting issues. It places disabled parents centre-stage and creates a forum where individuals can discuss and share their experiences of parenting. The quarterly journal encourages disabled parents to write about issues of importance to them such as fostering and adoption, the challenges of lone

parenting and having a second child (see DPPI winter 2003, Summer 2003, Autumn 2003). The journal effectively gives disabled parents the opportunity to make their individual and collective voices heard, to present the realities of parenting, share models of good practice and to challenge negative stereotypes of disabled parents.

The Centre for Disabled Parents also houses the Disabled Parents Network (DPN), a national register of disabled parents offering peer support through telephone contact and local parent support groups. As yet, there are two named contact parents in the Glasgow area, and it is hoped to establish a parent support group in the near future. Through participation in DPPI or the DPN, parents and prospective parents have the opportunity to participate in research initiatives, such as that intended to identify and address the information requirements of visually impaired parents. They can comment upon research assumptions and analysis, and put forward research frameworks that perceive disability as a social construct and parenting as an equal opportunities issue (Olsen and Clarke 2003).

Much of the consultation and research undertaken by DPPI and DPN is intended to inform policy and working practices towards building effective services for disabled parents. Demands made upon a leading Scottish local authority by disabled parents resulted in the authority adopting a model of good practice by pioneering the implementation of direct payments – usually only paying for personal assistants to facilitate independent living – to disabled parents, thus enabling them to purchase support to facilitate their parenting role. Therefore, the active involvement and influence of disabled parents on research agendas and policy development have the potential to effect positive change in the context within which disabled people parent.

The profile of disabled parents has also been raised through academic research and texts (see Olsen and Clarke 2003, Wates and Jade 1999, Thomas 1998, Thomas and Curtis 1997, Thomas 1997, Wates 1997, Goodman 1994, Shackle 1994). Increasing numbers of disabled parents are becoming active participants in setting and executing research agendas with the recent establishment of the Disabled Parents Research Forum, whose members are academics with direct experience of disability and parenting. This research forum has the potential to undertake research from an 'insider' viewpoint, and to facilitate research partnerships across the disability

community at local and national levels. Research on a national basis may give an indication of the numbers of disabled parents in the United Kingdom. As the Census does not make a correlation between disability and parenting, it does not collect relevant information, so that at present there are no formal statistics on and for disabled parents.

The increasing presence of disabled parents in public space at a very practical level is the means by which attitudes towards disabled people having children are challenged and changed. As Corbett O'Toole, a disabled parent and respected commentator on the subject, points out regarding the presence of disabled parents in public spaces:

Sometimes just being ourselves is the most radical act of public education that occurs (O'Toole 2003:5).

I wholeheartedly agree with O'Toole's stance; as a disabled parent, I am conscious that my presence in public space challenges stereotypes about both disabled women and mothers. I hear children, parents and grandparents express their surprise at my presence as a mother when my son and I walk into the school playground, or play parks, museums and cafes. Indeed, almost anywhere we go, my presence is 'radical' and unfamiliar. Despite this unfamiliarity, my presence is increasingly being welcomed and respected – revealing a real and positive shift in attitudes towards disabled women having children. I also hope that the presence of my thesis, as a contribution to the academic and policy debate, will serve in some small way to encourage such advances.

Appendix 1: Methodology I

An Inclusive Methodology: Practicalities and Sensitivities

Introduction

This is an account of the practicalities of the fieldwork research undertaken in the production of this thesis. The initial section outlines the archival research undertaken and methods adopted to facilitate my access to handwritten historical materials, including an explanation of these methods and assistive technology used. The bulk of the chapter, though, is given over to the methodological approach adopted throughout the fieldwork concerning the contemporary elements of the research. The deliberate implementation of an inclusive approach will be explained through the practical measures adopted at every stage of the research process, rather than going into a theoretical explanation of inclusive working practices.

Neither the main text nor the methodological appendices contain statistics relating to either the prevalence of impairment amongst women of childbearing age or the numbers of disabled parents. The primary reason for this is the lack of accurate statistics available on the numbers of disabled parents in the United Kingdom, although one evidently very imprecise estimate puts the figure at somewhere between 1.2 million and 4 million (Social Services Inspectorate 2000). Statistics reflect the medical model of disability, which potentially gives a misleading 'picture' of disabled women's and men's lives. For example, the Census gathers information on physically impaired people under the heading of 'Limiting illness', thus giving the impression that individuals in the 'category' experience ill-health, which may not be the case for many people (to underline, being 'disabled' is *not* the same as being 'ill'). A few local authorities in England have attempted to gather accurate statistics of the numbers of young disabled people in their areas, it is true, but there is scant equivalent Scottish data. Perhaps as more young disabled people become parents, statistical recording linked to service planning and provision will alter, but for the moment there are no trustworthy statistics available in this respect; disabled parents, especially those resident in Scotland, thus remain invisible.

A more specific point is that statistics gathered about visually impaired people tend to be 'age loaded' because the majority of people with 'significant sight

loss’ are usually over the age of 65 years old. Hence, statistics are gathered using the age of 65 years as a benchmark. Scottish Executive statistics of individuals registered blind or partially sighted by Local Authorities provide the following information:

Women registered blind or partially sighted

Edinburgh City Council

Women under 65 years	172
Women over 65 years	892

Glasgow City Council

Women under 65 years	380
Women over 65 years	3,447

(Scottish Executive 2003)

These statistics simply confirm that greater numbers of women over 65 years are registered blind or partially sighted, most likely due to age onset visual impairments. Since statistics are used to plan service provision, it is highly likely that they will continue to be gathered in a way that focuses on the older majority, rather than on seeking accurate statistics about younger visually impaired people and their potential support requirements.

Archival research

It was decided to undertake a historical review of institutions and organisations that offered employment, accommodation or financial support to visually impaired and physically impaired women resident in the Glasgow and Edinburgh areas during the late-nineteenth and early-twentieth centuries. Initial archive research took place in public libraries in Glasgow and Edinburgh; numerous institutions and charitable organisations were identified, enabling an understanding of the major providers of welfare to disabled people resident in the cities at that period. Four key institutions and two blind welfare agencies were identified for further in-depth research via the materials held within private and public archives, alongside public records.

These were:

Private archives:

- The Edinburgh Blind Asylum (later the Royal Edinburgh Blind School and Asylum)
- Edinburgh Mission to the Outdoor Blind
- East Park Home for Infirm Children

Public archives:

- The Glasgow Blind Asylum
- Glasgow Mission to the Outdoor Blind and Ladies Auxilliary
- Broomhill Home
- Death Certificates
- Census records 1881,1891
- Poor Law Records

Historical documents regarding the welfare of blind people were accessed through personal membership of the Royal National Institute of the Blind (RNIB). Its research library held such materials as John Alston's 1846 book, *Statement of the Education, Employment and Internal Arrangements Adopted at the Asylum for The Blind Glasgow*.

Private archives

A written request was made to each of the three private archives seeking access. I made it clear that I was visually impaired and would bring portable reading equipment with me. All three agreed to my request for access.

Edinburgh Blind School and Asylum archive

On my initial visit to this private archive, I was stunned to realise that the vault contained almost every minute book since 1792, Annual Reports, Admissions Registers and financial documentation. I accessed printed Annual Reports using a portable close-circuit television (CCTV: see below), which magnifies print. I attempted to read the handwritten minute books using my CCTV, but the copperplate handwriting was totally inaccessible to me, which was extremely frustrating. I realised that the employment of personal readers would be unavoidable; I will explain later in this chapter how I used personal readers to access handwritten materials. This extensive collection was thoroughly investigated over a six-month period; the information gathered covered 1792 to 1905.

Edinburgh Mission to the Outdoor Blind archive

My previous employment had involved frequent contact with the contemporary form of the Outdoor Mission. I was given open access to their archive collection consisting of bound copies of Annual Reports. Since my reading speed is very slow, I was allowed to photocopy some of the documents and the Chief Executive even permitted me to borrow two of the bound volumes to read over the weekend. This trusting gesture and open access to the archive collection enabled me to complete research on this organisation within a relatively short space of time. The Annual Reports accessed dated from 1858 to 1899 (not sequentially for each year).

East Park Home archive

Initial information about the existence of this Home had been found in a Health Board Archive and I discovered that it held its own archive. Access to the archive was granted; I was also offered the use of an existing static CCTV (see below) to read the materials. Photocopying of relevant Annual Reports was also agreed. I used the CCTV to identify Annual Reports from the earliest available, that of 1889, to 1910. Careful photocopying of these documents enabled a thorough investigation of the archive in a one-day visit.

Public archives

I will say something presently about access issues bound up with these public archives, as well as elaborating on my practical use of both these and the private archives.

Glasgow Asylum and Glasgow Mission to the Outdoor Blind archive

The archive collections relating to the Glasgow Blind Asylum and Glasgow Mission to the Outdoor Blind were held within a major public library. The collection relating to the Blind Asylum consisted of two hand-written minute books (1825-1845 and 1875-1880) and bound volumes of Annual Reports dating from 1838 to 1901. Bound volumes of Annual Reports were also available for the Glasgow Mission to the Outdoor Blind dating from 1876 to 1888, and for the Ladies' Auxiliary of the Mission to the Outdoor Blind dating from 1876-1888. In addition, the contemporary form of the Blind Mission, the Glasgow and West of Scotland Society for the Blind, known since 15th December 2003 as 'Visibility', lent me a copy of Helen Dunbar's book, *The History of The Society for the Blind in Glasgow and the West of Scotland*

1859-1989, about the history of the Society. This text supplemented the information found in the historical documents.

Broomhill Home archive

An extensive collection of primary source materials relating to Broomhill Home was held within a Health Board archive, itself housed within a large public library. The collection contained journals of male and female patients, patient registers dating from 1876-1943, various minute books, Annual Reports dating from 1875-1899 and various other miscellaneous documents. This information was supplemented by documents gained from a limited collection held within a small public library. The main archive (also housed in the Health Board archive) contained various newspaper articles featuring Broomhill Home and its founder, Miss Beatrice Cluggston. This public resource also contained Poor Law records, Census records for 1881 and 1891. All handwritten primary source documents, Census and computerised Poor Law records were accessed using a personal reader.

Death Certificates

These records, held on microfiche, were accessed using a personal reader. These records confirmed the date of death and occupation of female inmates resident for more than sixty years within the Edinburgh Blind Asylum. This exercise was carried out to ascertain the accuracy of the historical documents and to enable further 'tracing' of the women's lives.

Archive access issues

My access to private archive collections was relatively straightforward, involving making arrangements convenient to the archive holder, my personal reader/s and myself. Access to one large public library archive was superb, with the archivists' allowing materials to be removed from the reading room to enable me to use a CCTV or personal reader.

Accessing the main public archive, where a number of relevant collections were held, was far more problematic; inadvertent discriminatory practices denied my equal access to these public resources, resulting in heated exchanges between the archivists and myself. The strictly observed rules did not allow the removal of documents from the archive reading room or allow notes to be taken using a pen, and they asked that users show consideration

to others by keeping any conversations to a minimum. These rules prevented me from taking books to the Visual Impairment Resource Base (VIRB), four floors down, to read materials using a CCTV, and they did not allow me to use a personal reader in the reading room. Moreover, since the books could not be removed from the archive reading room, they also ruled out the use of a personal reader in a study room. Note-taking using a pencil was not an option, as pencilled notes would be far too faint for me to read. Therefore, these rules prevented me from reading the information and taking notes; in short, the rules excluded me from the archive space. As a public resource, disabled individuals' access to the library was legislated by the Disability Discrimination Act (1995). Following my contact with the Disability Rights Commission, the archivists reluctantly agreed to make 'reasonable adjustments' by allowing me to remove books from the reading room and use a pen for note taking.

Some access difficulties were more difficult to resolve. For example, archive protocol dictated that a 'reference request' form had to be completed and submitted for each item any researcher wanted to read. When working alone on materials known to be in a print format, such as Annual Reports, I required assistance to complete the form. Most archivists were willing to assist, but others refused. In these circumstances, I had to go down four flights of stairs to the VIRB, complete the form using a CCTV to read it, and then return to the archive room.

My relationship with one of the archivists was extremely difficult; on one occasion after completing a reference request form for a document, I waited for one-and-a-half hours to receive it because the archivist had 'forgotten' that I was waiting. On three separate occasions on submitting reference request forms to this archivist, they advised me that my selection was not what they would recommend. I disagreed and asked them to source the references I had requested; over the space of three hours (on each occasion) they supplied me with the documents that *they* felt were more relevant and ignored my requests. On each of these occasions I left the library without making any progress, as the information selected by the archivist was not relevant to my research.

The archivist associated with a Health Board archive insisted that they accompany me down the four flights of stairs to the VIRB to ensure that no

'harm' came to the documents. The archivist then handed them over to the Resource Base Manager, making her 'responsible' for the books rather than me. On a few occasions when a study room was not available, I worked with a personal reader in the archive reading room; the archivist insisted that I return the books each time I left the room. I therefore returned any documents each time I went for a tea break or to the toilet; this 'rule' was quickly dispensed with, as I had 'shown' that I was 'responsible' with the materials.

As I have made reference above to my use of both a portable and static close-circuit television (CCTV), it may be helpful before moving on to explain how these work. A static CCTV has a television screen at the top of an adjustable 'eye level' stand, with a camera mounted underneath it. Below the television screen, at the bottom of the stand is a small flat table arrangement with controls at the front enabling auto focus of print, decrease or increase of magnification and colour contrast selection. For instance, I prefer to use bright green text on a black background. The book or documents are placed on the 'reading table'; when the machine is switched on, the camera focuses on the text and displays it enlarged on the TV screen. The 'reading table' moves from side to side to enable reading of a full line of text. A portable system is far less sophisticated; it involves a very small screen incorporated into a battery or mains powered unit, with a hand held camera. The hand held camera is passed from left to right along the line of text, moving it slowly across the page. The print appears magnified on the small TV screen. This is particularly slow and laborious because the smallness of the screen, coupled to the magnification that I require, means that only two or three letters can be read at a time. It is extremely difficult to use on days when I cannot see the print on a page.

Recruitment and use of personal readers

I quickly realised that the use of personal readers was the only means by which I could access handwritten documents. I had never used readers before, and spent a considerable time speaking to visually impaired friends who had relevant experience. Using their advice, I developed a system that I felt would work for me. I had been advised that the average rate of pay for a reader was £7 per hour, with subject specific reading costing approximately £10 per hour. I knew that accessing the archives was going to take a

considerable amount of time. I decided that £7 per hour was a fair rate and manageable within my financial constraints. Although all four readers who I eventually recruited were willing to work with me on a voluntary basis, I preferred to pay them (my family member declined payment) as this gave the arrangement a formality and placed me in a position as an employer of their services rather than a benevolent recipient.

A friend resident in Edinburgh was in-between jobs, and she agreed to read with me; over a six-month period we met regularly to access the private archive collection held at the Royal Blind School and Asylum. I advertised for readers in the newsletter of a Glasgow based organisation working on behalf of visually impaired people. Two women responded, one who had been undertaking voluntary work transcribing Poor Law records, and she hence had extensive experience of accessing historical documents and was well-known to the archive staff in the large public library where the bulk of my research was carried out. The second woman had no experience of reading or accessing historical documents. Following a meeting with the women, I decided to work with both of them. On our initial meeting we made arrangements to start work immediately, as recruitment had taken longer than anticipated. A close family member with a keen historical interest also volunteered to read with me. .

I worked with readers on a one-to-one basis; prior to commencing reading, I explained to the reader the nature of the information I was looking for in its broadest terms. I emphasised to the readers that decisions in relation to what information should or should not be read were entirely mine and that, if I instructed them not to read a section, they should not read it regardless of their own opinion. One reader had suggested that she access information on my behalf. Although this suggestion was made with kind intentions, I clarified that this would be inappropriate and that any reading had to be directed by me.

When accessing the Blind Asylum archive the initial task was to take an inventory of relevant documents to enable a chronological and systematic approach to reading. Once complete, initial documents were selected by me and located by the reader, they then read any headings on pages and/or the first few lines of each paragraph. If the paragraph seemed relevant, I instructed them to read it; if not, I instructed them to move on to the next

paragraph or heading. Therefore, although another individual was reading the materials, I directed and guided the reading process. Reading in this way is very slow, laborious and requires immense concentration on both my part and that of the reader. As a result, I tended to limit reading sessions to four hours per day.

Using readers in the public archives was far more complex due to restricted archive opening times (one archive only opened two days per week), limited availability of study rooms, reader availability and my childcare responsibilities. The bulk of the Glasgow-based research was carried out using the reader with extensive experience of handling and reading historical documents. This woman was extremely hard-working and was willing to work alongside me at my pace; on occasions when accessing the archive that was only open two days per week, we often worked for eight hours per day. This reader was very supportive of my research and responsive to how I worked; I enjoyed working with her immensely. The reader with no previous experience worked with me for two hours; she constantly questioned my approach to the research, and at the end of the session I intimated that we would not be working together again. In the public archives I worked with readers in a similar way as in the private archives, initially taking an inventory of the collections and then making a systematic search of these. When reading documents, contents pages or paragraph headings were read out to enable my selection of what should be read.

All personal readers were asked not to take notes for their own reference, but to focus solely on the reading process. Initially I took notes using black felt tip pens, writing in large print. These handwritten notes were then typed onto a static personal computer and printed out in large print. However, during the archive research my eyesight became unstable and I often could not read my handwritten notes. As a result I then had to use a reader to read my own notes to me while I typed them into my computer. A solution to this problem was the purchase (by the C.K. Marr Educational Trust) of a lap top computer with speech output. The portable lap top enabled me to type up notes directly during the reading process within the archive. Where archive holders had allowed me to carefully photocopy materials, for instance, at East Park Home I accessed the photocopied materials at my own home using my static CCTV and took notes using my lap top computer.

During 'writing up' of the historical chapters (see Chapters 3 and 4) themes and sub-themes were identified in the archive materials. Two electronic files were created; 'Out of sight' and 'Lives less worthy' headings and sub-themes were used to 'sign post' the location of archival materials selected and pasted into these files this then formed the framework for Chapters 3 and 4. This technique of 'cutting and pasting' of selected materials was then implemented during the writing up of the contemporary chapters (see below).

Fieldwork

Groundwork: raising awareness

From my previous employment within a disability-led organisation, I was acutely aware that a strategic and systematic approach to raising the profile of my project would be vital in making contact with possible participants. In December 2001, I re-established contact with five key disability-led organisations with which I had previously had a professional and personal association. These were: Access Ability (Lothian); Lothian Coalition of Disabled People; Lothian Centre for Independent Living; Disabled Person's Housing Service Edinburgh; and the Centre for Living Independently in Glasgow. All five were supportive of my research and agreed to contact women on my behalf in Spring 2002. I was conscious that my identity as an 'insider', a disabled woman known to the organisations in question, meant that my research aims or motives were not challenged, and most likely did afford me a level of trust possibly not extended to a (say, non-disabled) researcher with an 'outsider' status (Valentine 2001, Mohammad 2001). I also began to raise awareness of my work amongst my network of disabled friends; prior to this, I had rarely discussed my work with them. I informally sought their support and potential participation, but was very cautious of taking advantage of the long-term friendships that I had with these women for fear that they would regard me as some kind of research pariah. I will explain shortly the simple strategy that I used to protect the integrity of these friendships, and to ensure that friends *chose* to take part rather than felt obliged to do so.

I also wanted to raise the profile of my work amongst women with whom I had no previous contact; to this end, I wrote articles for four newsletters published by disability related organisations. I identified radio as a means of

reaching women, particularly visually impaired women, and I was invited to participate in a short interview on Radio Four's visual impairment programme 'In touch' in February and September 2002. One woman resident in the Glasgow area contacted me directly following the February broadcast. Various women, who unfortunately lived in England, well beyond Edinburgh and Glasgow, the geographical area of this study, also contacted me. I also gave a presentation at a local club for blind people as a means of raising the profile of my work; most of the women had acquired age onset visual impairment. However, one woman with life-long experience of visual impairment, and who had brought up two children as a lone parent, indicated her interest in possible participation.

A more detailed article about my work and my motivations for embarking on a research project was published in the March 2002 edition of *Disability, Pregnancy and Parenthood International's* quarterly magazine. This elicited a positive response from women. Although I had made it clear in the article that my work was geographically restricted to the Glasgow and Edinburgh areas, all those who contacted me lived outwith the geographical remit. Nonetheless, it was extremely encouraging to be contacted by twenty women expressing their support for my work; this affirmed the relevance of my work in other women's lives and not just my own.

Research process: interview guide

Initially two interview guides were devised, one for use with women, the other for service providers. Although an interview guide for use with service providers gained Departmental ethical approval and was formally 'tested' with a service provider and informally tested with two others, I decided not to pursue the views of service providers (see Chapter 1). My concern was really with the views and experiences of disabled women themselves, as our voices are largely absent in most disability and geographical research (Vernon 1997,1996). Departmental ethical approval for the interview schedule was gained in May 2002, and predated the need for approval from the University Ethics Committee. Interviews commenced on June 7th 2002 and were completed on November 29th 2002.

The interview schedule for use with women proved to be far more complex than anticipated, as the framework through which issues and experiences

would be explored had to encompass diverse experiences of reproduction or non-reproduction. In the end, a chronological approach was adopted, using topic areas – childhood and education, adult life, relationships, children, parenting, peer support and family planning – and with prompt questions under each area. This enabled a flexible format facilitating women-centred discussions tailored to each individual’s experiences, and focusing on areas of particular importance or relevance to them . A number of women commented that they found the semi-structured nature of our discussion helpful in sharing their experiences.

The following interview schedule therefore seems cumbersome (akin to the Spanish Inquisition), as it attempted to pre-empt every eventuality that may have arisen within the interview situation; nonetheless, issues that I had not predicted were still discussed in a few interviews. Throughout the fieldwork the interview schedule was used purely as a guide. As I have a significant visual impairment, it was impossible for me to glance casually at the guide. Once I became familiar with the key topic areas and prompts, and as my confidence grew, I tended not to refer to the guide at all; and this lack of reliance upon the interview guide nurtured an informal discussion that put women at their ease and facilitated discussion that seemed to flow naturally.

This is the interview guide:

Perception of disability Can you tell me how you would describe your disability?
Childhood and education Childhood Do you have any siblings? Can you tell me a bit about what growing up was like? Were you treated the same as your siblings or were you treated differently in any way? Education Can you tell me a bit about your school days, what school/s did you attend? (special or mainstream school) Can you tell me a bit about your friends at school? Did you and your friends do things together, like clothes shopping, for example? Did you pick your own clothes? When did you begin to notice people you felt attracted to? Do you remember getting any sex education or information about sexual health while at secondary school? Did anyone ever talk to you about your future or mention their expectations of you i.e.

<p>educational attainment, type of job or whether you'd get married or have children?</p>
<p>Adult life Did you continue your education after leaving school? <i>If no</i>, what did you do after leaving school? Who did you live with? When did you move out of your parent's house?</p>
<p>Relationships Can you tell me about your first significant relationship? (May not necessarily have been sexually intimate) Did your family and friends approve of your relationship? Do you have a partner at the moment? <i>If yes</i> Can you tell me a bit about how and when you met? <i>If no</i> Can you tell me a bit about your social life, where do you tend to socialise and what social activities do you enjoy?</p>
<p>Children Have you ever considered having children or planned to become pregnant? <i>If no</i>, can you tell me a bit about what influenced your decision? <i>If yes</i> Do you have children? Have you used IVF or adoption services? Could you tell me a bit about using either or both of these services? How many children do you have and how old are they?</p>
<p>Pregnancy and birth</p> <p>Pregancy Can you tell me a bit about when you were pregnant, how did you feel about it? How did your family and friends respond to your news? How about medical professionals, your GP for instance? Did anyone voice concerns about perceived physical/medical 'risk' involved in pregnancy in terms of your own physical condition or the baby's? Was information about pregnancy and childbirth available to you in relation to your impairment or in an accessible format? Was the surgery or clinic where you attended antenatal appointments/classes accessible to you and was it easy to get to? Did you attend parent-craft classes in preparation for the birth of your child? Were your access requirements met? Did these classes help you to address practical issues of baby care?</p> <p>Birth (and early mothering) Following the birth of your baby did the post-natal ward and staff meet your access requirements? Were staff supportive of you in your parenting role or were there some difficulties? Can you tell me a bit about when you brought your baby home and the early days of mothering? Sources of support What kind of support did you receive? Was the support adequate? Were there ever instances of inappropriate support? What kind of support or assistance would have been useful to you?</p>

<p><i>Adoptive parents</i></p> <p>Can you tell me a bit about when you brought your child home and the early days of mothering?</p> <p>What kind of support did you receive? (support questions as above)</p> <p>Would you consider having more children, what would encourage or discourage you from doing so?</p>
<p>Peer support</p> <p>Can you tell me a bit about any contact you have/had with other disabled parents or disabled parent's organisations?</p> <p><i>If no contact</i></p> <p>Do you think it would have been useful to you and why?</p>
<p>Family planning services</p> <p>When you require information on contraception or sexual health issues, where would you get this information? Is it relevant to you and is it available in accessible formats?</p> <p>Is there anything else you would like to add?</p>

The research process: an inclusive approach

From the outset, I considered ways in which this research project could encourage women’s equitable involvement proactively by adopting an inclusive approach. My previous employment, facilitating the educational inclusion of disabled people, had allowed me to gain an in-depth understanding of the barriers encountered by disabled people in their daily lives. This experience enabled me to develop straightforward practical solutions to potential barriers in the ‘traditional’ research process. I listed potential barriers to women’s participation: inaccessible information; inaccessible public transport; inaccessible meeting venues; inflexible personal assistance; and lack of affordable childcare. On a more personal level, I was aware that the small close-knit disability community in the Glasgow and Edinburgh areas would present possible barriers in terms of women’s concerns around confidentiality and anonymity. Additionally, my identity as an ‘insider’ could possibly position me too close for comfort for some women (Mohammad 2001).

As a result of these considerations, I drafted a cover letter to be sent to women via the five disability-led organisations. I deliberately used an informal writing style, and I introduced myself as a life long disabled woman; I consciously used the term ‘degree by research’ as opposed to the more intimidating ‘PhD’, and used the term ‘discussion’ rather than ‘interview’. In an

attempt to breakdown any potential barriers to participation, the letter clarified the following:

- The remit of the study and encouraged any women interested to consider participating whether they had children or not. (Regardless of how old or young their children were)
- That discussions would take place in a venue chosen by women at a time that most suited them.
- That I was available to meet women at a venue and time chosen by them for a coffee and informal chat to enable them to make an informed choice regarding their participation and/or to discuss any concerns or requirements that they might have.
- Women who required to use taxi travel or would incur travel expenses in order to take part in the study would be reimbursed by prior arrangement.
- Women who would incur additional personal assistance or childcare costs in order to participate would be reimbursed for these costs by prior arrangement.
- If women had any other additional requirements to enable their participation, every effort would be made to accommodate these.

The cover letter contained my contact details – my home address, telephone number and e-mail, thereby offering women three modes of possible contact. A copy of the article published in the *Disability Pregnancy Parenthood International* magazine accompanied the cover letter. This article gave detailed information about my work and my own experience of barriers during pregnancy and early motherhood. I felt it was particularly important that women who did not know me had access to information about me prior to meeting – in effect, they were placed in a position where they knew more about me than I did about them. The disability community in Scotland is relatively small, and the visual impairment community is even smaller and close-knit. I became accustomed to visually impaired women asking me 'who I knew?'; it was surprising that, regardless of age or geographical location, I shared at least two direct or indirect connections in the 'community' with women previously unknown to me. I was fully aware that armed with this information, women were in a position to check out my credentials with those who knew me directly.

Access to information is a significant barrier in the lives of disabled people; to avoid this, all information provided to women throughout this study was transcribed into accessible formats and was readily available in Braille, large print, tape, computer disc and electronic formats. I received assistance from the Lothian Coalition of Disabled People to transcribe the cover letter and article into Braille formats. All other formats – standard, large and extra large print, computer disc and electronic versions – were produced by each organisation at this stage. I produced a master tape of the information that organisations copied on their shared tape copying facilities.

Contact, consent, confidentiality and assembling a sample

The cover letter and article in accessible formats were sent to women via the five key disability-led organisations, with a letter of support from each organisation endorsing my work. The support letter clarified that I had not had access to their contact details, nor had I been involved in the identification of women from organisation databases. Although I fully agreed that it would be inappropriate for me to be involved in the contact process, I felt it necessary to impress on staff both the remit of the study and the need to take an unbiased view. They needed to contact a diverse range of service users: i.e. not simply women of childbearing age, or those known to have children. I also requested that the disability-led organisations that shared office premises and memberships cross-referenced women's address labels prior to letters being mailed to avoid any women receiving multiple copies of the information. Although the organisations informed me of when the information had been sent out, they were decidedly vague about how many women had been contacted.

Although I had been happy to raise awareness of my work amongst my friends, I felt extremely awkward when it came to seeking their participation. As mentioned, I did not want any of my friends to feel obliged to participate. My friends hence received the same information as the other women, with the addition of a personalised note informing them that, if they wished to take part, they had to contact me (as was the protocol for any other women), and that I would not contact them directly regarding participation. I reassured them that their non-participation would not affect our friendship in any way. This simple solution offered equitable choice with women unknown to me.

The fact that women had to contact me if they wanted to participate meant that they were in a position to *opt in* rather than being in the awkward position of *opting out* (Valentine 2001). Most women made initial contact with me by telephone and some by e-mail. The women were then asked preliminary questions to ascertain the following:

- Confirmation that they were willing to take part in the study.
- Name, address, telephone number and e-mail address.
- Age selected from age ranges: i.e. 36-41 years.
- Age at which they became a disabled person: i.e. congenital impairment or acquired at a later stage.
- Confirmation that impairment was present during potential childbearing years.
- Agreed place, date and time of meeting.
- Preferred format standard print, large print, computer disc, Braille, tape and e-mail.
- Any additional requirements that a woman may have to enable her participation in the study.

At this stage, women were asked to consent to our discussion being taped; I emphasised that if any of the women felt uneasy or uncomfortable with the idea of a tape-recorded discussion, I would respect their wishes and, as an alternative, would take notes throughout the discussion. All of the women who participated consented to their discussion being tape-recorded. Following initial contact, women were sent a letter confirming the time, date and agreed location for our meeting. This letter also reiterated that any travel, personal assistance or childcare costs could be reimbursed if any of these presented a barrier to participation. As a means of ensuring women's names and contact details remained confidential, a professional transcription service was used to transcribe these letters into Braille formats for two of the women. The letters only contained the women's first names, and the Braille copies were returned by the transcription service to my home address and then forwarded by myself to the women.

This letter indicated to women that our discussion would take approximately one to one-and-a-half hours, that the discussion would be taped and that I would be transcribing all tapes to ensure confidentiality. Women were also informed that any narratives used in the final thesis would be stripped of any

identifying information to protect their anonymity. They were asked to consider an alternative name or pseudonym that would be given to their narratives to protect their anonymity. During discussions, women noted that assurances around confidentiality and anonymity had encouraged their participation.

Twenty-seven women self-selected to participate in the study; 6 women were friends, 11 from disability-led organisations, 5 from word of mouth, 1 from hearing the 'In touch' radio programme, and 4 from coincidental meetings such as a presentation that I delivered at a local blind club, my use of a resource base in a library, a disability-led organisation's AGM and one woman who I literally bumped into at a Glasgow railway station and subsequently became friends. Although this may seem like a relatively small group, in my opinion it is the depth and richness of my encounters with these women that is important rather than the numbers of those who participated (Valentine 2001). Two women took up the offer of meeting informally for a coffee and chat prior to making a decision regarding their participation. One woman subsequently decided to take part, while the other felt that reliving her experiences of a forced termination and sterilisation procedure would prove to be too painful and decided not to participate.

Prior to interview, these twenty-seven women were offered the opportunity of receiving a copy of the topic areas that we would possibly discuss to enable them to make choices about their level of contribution (Moore et al. 1998); almost all participants requested a copy. The dissemination of possible topic areas prior to interview was also a means of disrupting any potential power hierarchy between the women and myself as 'the researcher'. To protect the women's anonymity, Braille copies were transcribed by the Royal National Institute of the Blind transcription service, returned to my address and forwarded to the women. This again avoided disclosure of their full name and address details. A number of visually impaired women requested information to be sent in an electronic format, as this enabled independent access with no need for third party transcription; I produced tape, large print, standard print, computer disc and electronic versions. Information access requirements were as follows:

Standard print	13
Large print	4

Electronic	6
Braille	2
Computer disc	1
Tape	1
Total	27

Although I had little influence on the sample group, those who self-selected came from a broad spectrum of backgrounds and diverse reproductive and non-reproductive experiences. Most women had congenital impairments, while others had acquired their's as babies, young children and teenagers, and all were therefore present during potential childbearing years. The women's ages varied from mid-20s to late-60s, and a more detailed break-down is as follows:

21-26 years	1
26-31 years	2
31-36 years	5
36-41 years	4
41-46 years	6
46-51 years	2
51-56 years	5
56-61 years	1
61-66 years	1
Total	27

The age range of the women has enabled me to capture something of changing experiences over time, reflecting 'real' changes in health, welfare and disability policy and practice. Adele and Melissa's oral histories of the institutional era, their embodied experiences of social exclusion and their transition from institutional life to de-institutionalisation as a result of changes in policy and practice, reflect positive shifts in both policy and possibly broader attitudes towards disabled people (see Chapter 5).

Confidentiality was of great importance to women; although they were willing to share their experiences, they did not want to be identified. Prior to interview I had asked women to consider choosing a pseudonym; I suggested they choose a name not associated with their family and to avoid using a name that could be traced to them. Ironically, a significant proportion of the

women chose to use an abbreviated version of their name, their middle name, their mother's or daughter's name; these choices seemed to fly in the face of concerns regarding anonymity. Prior to interviewing friends, we agreed that the content of our discussion would remain confidential (as with all other participants); we agreed that outwith the interview, no aspect of our discussion would be brought up in conversation between us without prior agreement (for example, if I wanted to clarify a point or the woman wanted to add further comments).

Conducting interviews

Throughout the fieldwork women's preferences of interview location and time were accommodated as fully as possible. Sixteen women chose to meet in their homes, and one woman chose to meet in my home. One woman chose to be interviewed in a neutral location but subsequently invited me to her home for a second meeting, as she wanted to share intimate personal aspects of her experiences. Of the sixteen home locations, only two were known to me; the others were completely unfamiliar territory, which created a potential barrier to me as a blind person. I did not divulge my mobility concerns to women, however, as I felt that this would influence their preferred meeting venue. A solution was to travel to mainline railway and bus stations by public transport, and to use taxis to travel from there to women's houses. Two women, who had their own transport, offered to collect me from their local railway station because there was a limited taxi service; this seemed to facilitate a partnership approach to the interview process. The only access requirement I did mention to every woman who stated her home as a preferred meeting place was my severe allergy to cat and dog fur, as this would have an impact on my ability to conduct the interview. My enquiry regarding pet-owning status caused some amusement to most women and seemed to act as an icebreaker with women that I had not met before. Where women did have pets, I took medication in advance to enable me to meet them at home. Only one interview had to take place outwith a woman's home because she owned a guide dog and two cats. I took the decision not to inform women that I am also allergic to cigarette smoke, as I felt that this would infringe upon their own personal choices within the private space of their home. Instead, I took medication with me that I either took immediately after the interview, once I was out of the woman's company, as I did not want them to know their choice to smoke had a direct impact on my

wellbeing, or where women were heavy smokers I went to the bathroom to use my inhalers.

Five women chose to meet me in their workplace, and a further five women (including the woman who owned a guide dog and two cats) chose to meet me in the neutral venue of two disability-led organisations, one in Glasgow and the other in Edinburgh (my former employer). Both organisations allowed me to book a private room for interviews. My former employer kindly paid the room hire costs on my behalf, and the Glasgow based organisation waived the room hire fee.

In the main, interviews took longer than I had anticipated; for a number of the women, this was their first opportunity openly to discuss issues around reproduction or lack of it. For one woman in particular, it was the first time she had *ever* discussed her reproductive choices after a silence of thirty-five years. I was moved to tears when I received an e-mail from this woman thanking me for my non-judgemental approach (see below). Interviews that took place in neutral or workplace venues lasted on average one-and-a-half hours. Those that took place in the women's homes were far longer; sixteen of the interviews lasted for two hours or more, and four of these took four hours. The average duration of a home interview was hence two-and-a-half hours.

Regardless of interview location, I brought something for the women as a way of thanking them for making time to speak to me and to let them know that I valued their participation. I brought a range of items, mainly flowers and chocolates, and for those I knew as friends I brought a bottle of their favourite wine. I also sent each woman a thankyou card following the interview to thank them for their time and contribution to my work.

Prior to commencing fieldwork, I decided that my role in the interview situation would be to facilitate discussion in a person-centred manner, to listen to and to validate the embodied experiences of the women (Vernon 1997). I did not engage in any form of critical analysis of what women had shared; where I asked questions, these were on points of clarification. As mentioned previously, some of the women I interviewed were friends of mine, this worried me a great deal, I fretted that the information shared during an interview and our altered knowledges of each other would perhaps alter our

friendship (Avis 2002). In these cases, the interview experience both deepened our understandings of each other and strengthened our friendships. Most of the women were not known to me prior to interview, because they had read the article about my experiences they already knew quite a lot about me before our meeting. Hence, women were, in the main, ready to share their life (hi)stories when we met. Most of the women shared deeply personal and painful experiences, interviews were filled with a range of emotions, for both the women and I. Despite the often bumpy 'emotional roller coaster ride' of the interview, many of the women commented that they had found it positive and helpful to talk frankly about their experiences and to make sense of these experiences to varying extents. As the 'facilitator' in these discussions I often felt responsible if women became upset, during one interview a woman became extremely upset, with mutual agreement, the interview was brought to a close with an arrangement made to meet one week later. I frequently felt completely overwhelmed by the emotive contents of the women's discussions, the emotional intensity of the interview situation is explored further in the second methodological appendix (See Appendix 2).

Prior to commencing fieldwork, I had anticipated that dealing with the emotive issue of reproductive choices or lack of them would be emotionally demanding. I have to confess that I underestimated the extent to which, on several occasions, the emotive nature of the fieldwork would affect me. I also knew it would be inappropriate to share any of the fieldwork information with my usual supporters, family and friends especially, since some of my friends were participants. I decided it would be useful to have someone within the Geography Department with whom I could share my fieldwork experiences, how interviews had made me feel (not the content of the discussion) and the strategies I had used to deal with difficult situations. This was regarded as a very unusual request but one that my supervisors considered carefully. I suggested a named person within the Department and my lead supervisor agreed to approach them. The establishment of a mentor was extremely useful, and something I would highly recommend when engaged in sensitive fieldwork. I met with this individual on several occasions during the fieldwork and found their understanding, support and willingness to share their experiences of fieldwork very encouraging. Indeed, their reassurance that emotion is a natural but widely unacknowledged part of the fieldwork process helped me deal with and to manage my emotions during the fieldwork (Burns 2002). Positive feedback on the strategies that I had adopted increased my

confidence and reduced any anguish I had felt about 'saying the right thing' in difficult situations. My increased confidence in my ability to handle difficult situations reduced my reliance upon the mentor. The presence of a mentor, as well as the support of my supervisors, meant that I felt well supported during the most emotionally challenging element of my research.

Transcription and coding

I made the decision prior to commencing the fieldwork that I would personally transcribe all of the taped discussions. This decision was prompted by my own experience of participating in another student's research, where I had assumed the student would be transcribing the tape, but later met an individual who told me that they had transcribed the tape of my interview. I decided that if I transcribed the tapes, I would retain control over confidentiality. I hence made it absolutely clear to the women that I would be transcribing the tapes, and that no one else would hear the full discussion. Most women intimated that this assurance had positively influenced their sharing of information.

Transcribing tapes was carried out in-between interviews in an attempt to avoid tapes piling up. In the main tapes were transcribed within a few days; this meant my memory of the discussions was relatively fresh, and helped me to decipher discussions where the tape quality was poor. I used my own ancient 'state of the ark' tape recorder for both recording and transcribing; however, I began to experience repetitive strain injury in my left hand. This was alleviated by the loan of a foot pedal controlled transcribing machine from the Geography Department. This piece of equipment made transcribing physically comfortable and dramatically faster. The transcription process gave me the opportunity to become very familiar with the content of discussions, enabling the development of a coding framework. Interviews were completed at the end of November 2002, and transcription of tapes was complete by early December 2002.

Butler (2001) and Vernon (1996,1997) advocate supplying women with transcripts of their interviews for comment or alterations. I had considered this option as a means of retaining women's ownership of the research. Although I could produce large print, tape, computer disc and electronic versions of transcripts, I did not have the facilities to produce Braille copies.

This would involve compromising the confidentiality agreement by using a transcription service; I therefore decided against supplying women with copies of their transcripts. Alternatively, I contacted women shortly after the interview by telephone to enquire if there was anything they wished to change or to add with regard to our discussion.

During transcription I had become aware of themes and sub-themes emerging across all of the interviews. A consequence of my visual impairment is that my reading speed is very slow; initial reading of all the transcripts took almost three weeks. Initial coding was done under broad headings of 'public space' and 'private space'. A detailed re-reading using colour-coded themes and sub-themes was then carried out. This became problematic, as I realised I could not differentiate between the colours and had to rethink how I was going to break down the transcripts in an accessible way. After much thought, three electronic files were set up in line with the proposed contemporary chapters (6, 7 and 8): namely general considerations, sexuality and relationships, and motherhood (or not), with chapter headings and sub-themes laid out within each file. I then returned to the transcripts held on my laptop rather than the print versions. Each transcript was re-read, portions of interview narrative selected, cut and pasted into the appropriate file under the appropriate theme or sub-theme. The coding trees below give an outline of themes and sub-themes for each chapter.

The coding process was labour intensive, taking approximately two months; the benefit of the necessary meticulous approach required meant that transcripts were scrutinised in great detail. Even so, during the writing up process, transcripts were continually reviewed for themes that initially appeared to be inconsequential but subsequently took on a greater significance. During the 'writing up' of this thesis, I found it difficult to work with large blocks of text. Although I use large character display, I rely far more heavily on the speech output system and effectively have to remember the sequence of headings and sub-themes within chapters. To ease this memory process and ensure that my writing or arguments did not become confused, I tended to work by writing small separate sections that were then brought together at the last minute to form a larger section. Hence, much of my writing remained in a rather fragmented form until I was familiar enough with the text to navigate around a chapter. In many respects, working in this way prepared me for coding by cutting narratives and pasting them into a

rough coding framework with main headings, themes and sub themes. Below, then, are the coding trees for each of the three contemporary chapters (6, 7 and 8) with themes and sub-themes, many of which are of course closely inter-linked.

Out of place bodies

Earliest years

- Schooling environment
 - o Professional expectations
 - o Parental expectations
- Experiences of segregated school
 - Positive experiences
- Separation from family
 - Residential special school
 - Day pupil special school
 - Mainstream in segregated unit

Places of docility

- Experiences of special schools
 - Mobility training
 - Isolation
 - Regimes
 - Chores
 - Food
 - Uniform
 - o Denial of femininity
 - o Gender segregation
 - o Resistance

Early adulthood and practices of protection: for whom?

- Parental protective responses
 - o Surveillance
 - Infantilisation
 - Freedoms
- Societal supervisors

- Family members and friends
- Professionals
- Parental and professional expectations of adult life
 - Asexual being
 - Marriage
 - Child-bearing
 - Exclusion from domestic space

Later adulthood and the difference disability makes

- Normalisation

'Normalising' different bodies

- Normalising techniques
- Noticing physical difference
 - Physical difference associated with intellectual difference
 - Denial or concealment of impairment

'Celebrating' different bodies

- 'Coming out' as disabled
- 'Coming out' as lesbian
 - Positive self-identities
 - Chores
 - Denial of femininity
 - Resistance

Sexuality and relationships

Constructed sexuality: the earliest years

- Disabled girls learn of their asexual status
 - Parental protectiveness/unspoken expectations of disabled girls' sexual future
 - Professional expectations of disabled girls' sexual future
 - Peer group expectations of disabled girls' sexual future
 - Lack of preparation for menstruation
 - Lack of sex education
 - Denial of sex education
 - Consequences of lack of sex education

Initial (sexual) relationships

- Sexual experimentation in
 - o Special school
 - Lack of professional expectations
 - o Residential special college
 - Lack of parental expectations
- Attitudes in mainstream schools towards disabled girls
 - Inaccessible family planning services and sexual health information
 - Consequences of lack of access to family planning services/advice and/or sexual health information

Bodies placed 'off limits'

- Inaccessible nature of the social environment
 - Accessible toilets degendering of disabled women and men
 - Lack of social disability awareness
- Social and sexual infantilisation of disabled women
 - Sexual unavailability/unsuitability

Further (sexual) relationships

- Parental 'protectiveness'
 - Unsuitability for marriage
 - Parental suspicion toward boyfriends
- Onset of impairment
 - Breakdown of existing relationship/marriage
 - Non-disabled partner assumed to be carer
 - Domestic abuse
- Disabled/disabled relationships
 - Public and private responses
 - Relationships do not involve sex
 - Companionship

Having a sex life

- Private life as public property

Notion of 'proper sex'

- Non-penetrative sex
- Sexual diversity
- Lack of information on alternative sexual positions
- Disabled women's lack of sexual intimacy and lack of sensual contact
- Disabled women and the pleasure of physical contact

Out of place parents

Unplaced parents

- Childfree status
 - Women's choice
 - Enforced childlessness
 - Family influences on women's decisions
- Family and professional responses to pregnancy

Pre-conception

- Medical influence in decision to become pregnant
 - Medical disapproval
 - Medical approval/permission
 - IVF services

Sterilisation

- Medical profession
 - Inappropriate timing
 - Insensitive to women's reproductive aspirations
 - As a means of controlling fertility
 - Young age of disabled women

Pregnancy

- Inaccessible nature of maternity environment
 - Lack of accessible information
- Medical disapproval of pregnancy
 - Suggested termination
 - Professional mis-givings re disabled women's abilities to care for unborn baby
 - Family members as 'societal supervisors'
 - Good practice in maternity care

Termination

- Enforced and elective termination
 - Medical disapproval of pregnancy
 - Lack of access to family planning services
 - Consequences of termination

Miscarriage

- Medical professionals insensitive treatment of disabled women
 - Consequences of insensitive treatment

Birthing

- Positive experiences of birthing space
- Negative experiences of birthing space
 - Concealed pregnancy

Post-natal

- Inaccessible nature of the maternity environment
 - Benefits of orientation for visually impaired mothers
 - Consequences of lack of orientation for visually impaired mothers
- Inaccessible maternity facilities
 - Inflexible hospital policy towards:
 - Baby care
 - Breast feeding
 - Bathing baby
 - Benefits of a flexible approach
- Questioning of disabled women's mothering capabilities
 - Surveillance by health visitors
 - Disabled women's fears of their children being removed from their care
 - 'Proving' mothering capabilities
 - Concealment of impairment
 - Medical influence in women's reproductive choices

Replaced parents

- Influence of medical approval of prospective adoptive parents

Displaced parents

- Inappropriate or rigid support packages
 - Displacement of disabled mother by support staff
- Professional pressure to give baby up for adoption
- Family pressure to give baby up for adoption
- Public responses to disabled mothers
 - Getting children around in public space

- Displacement of disabled women from their mothering role
- Children's responses to their mother's impairment

Notes on technology and final thesis production

Another piece of assistive technology that has enabled me to undertake this research, alongside the CCTVs mentioned earlier, is the use of a lap top computer with simultaneous large character display and speech output. This has been a crucial piece of technology, particularly the latter, as I have become increasingly reliant upon the speech output system towards the latter stages of the research.

A related point is that, as my sight has slowly deteriorated during the course of the last two years, it has become increasingly difficult for me to access handwritten supervisors' comments on submitted work. As a means of meeting my access requirements, final drafts have been submitted electronically; both supervisors have read these submissions, agreed on revisions, and the lead supervisor has then used the 'track changes' facility in Word to incorporate suggested revisions and comments. I can then use the 'accept or reject' changes facility to revise these documents on screen, and where necessary to rewrite passages or to draft new ones. This approach has involved a considerable time commitment on the part of the lead supervisor, but it has dramatically reduced the amount of time it takes me to read through suggested changes on a chapter from two days (using traditional print and pen comments) to two hours.

Tellingly, my inclusive research methodology is somewhat compromised by the guidelines on thesis presentation; the implications of this are that final details of formatting, text layout, presentation and proof-reading will be done by others on my behalf, not entirely but to some extent, because of the visual nature of such tasks. Ironically, the thesis in its submitted form will be almost totally inaccessible to me – although once 'approved', fingers crossed, Braille, large print, computer disc, CD and tape versions will be produced.

Conclusion

My intention with this methodological appendix was to share the very practical measures that were adopted and implemented to facilitate my own

and disabled women's equitable participation in the research process. The simple practical solutions sent a clear message to women that their views and participation would be accommodated and valued, reflected in my willingness to meet their access requirements from the outset. I sincerely hope that, by sharing my thoughts on an inclusive methodology, other researchers will realise that the mystified term 'inclusion' is very simple – it involves adopting a social model approach, identifying elements in the environment and more crucially in the research process that may prevent people from participating. By adopting an inclusive approach, the research process, and ultimately the thesis or findings of a research study, are enriched by being able to include the voices of those usually excluded by 'traditional' methodological approaches.

The second methodological appendix explores more personal reflections on my involvement as a disabled researcher in disability geography research. I discuss the implications of my visual impairment in the interview situation, particularly when interviewing blind women.

Appendix 2: Methodology II

Reflecting Upon Researching from the 'Inside'

Introduction

As a life-long disabled person, I have engaged with this research on a personal and political level, as a disability activist, feminist and mother. This research has prompted me to reflect upon my everyday interactions and experiences 'in the field' of which I am always a part (Katz 1994). These reflections are specifically related to the archival and interview fieldwork phases of this study. Hence, this second methodological appendix builds more personal reflections on top of the 'nuts and bolts' materials covered in the first methodological appendix.

As a disability activist, and more recently as a geographer, I have been acutely aware that my visual impairment, socially identified by my use of a long cane, sets me apart as an 'outsider' from non-disabled society while simultaneously positioning me as an 'insider' in the disability community. As a disabled woman, I am part of what I research (Hansen 2002, Kobayashi 2001); indeed I have positively identified myself as a disabled woman in all aspects associated with this research. Ruth Butler cautions against this identification, though, warning that where authors describe themselves as 'disabled' or 'impaired' the reader may prescribe socially negative constructions of disability upon them (Butler 2001:272). Even so, I proudly self-identify as a disabled woman in the hope that, by doing so, I will perhaps challenge negative stereotypes. In newsletter and journal articles, I openly discussed my reproductive experiences, perhaps in a manner akin to Kobayashi (1994:78):

I do not use other people's struggles as the basis for my research, I use my research as a basis for struggles of which I am a part.

'Disability research often privileges the voices of able-bodied outsiders and excludes those of disabled people' (Morgan 2003:89). In much human geography research the voices of disabled people have been either absent or on the outer margins; although gradually these are moving towards the centre (see, for example, Hansen 2002, Parr 2001, Butler and Parr 1999, Moss and Dyck 1999, Chouinard and Grant 1995). It has hence been my intention throughout this research to contribute to and to continue this

process of centring the previously excluded, and in the process to give 'voice' to the full tapestry of disabled women's experiences.

Moreover, I wish to reflect this tapestry through their diverse voices, not simply to speak with a 'singular voice' (Kobayashi 2001:62). I have deliberately ensured that my own disability politics did not influence the ways in which I used women's narratives. For example, I am a strong supporter of inclusive education, and would dearly like to see the demise of 'special' schools in this country. Yet, some women spoke positively of their experiences of special schools, and these remarks have been included, as it is the views of the women that are to the fore here and not my own political beliefs. I have also deliberately not altered terminology that women preferred to use, no matter how much these went against the grain of my own language. An example here would be that Susan used the term 'carer', whereas I would use 'personal assistant'. In short, I have consciously incorporated the diversity of the women, and have not tried to homogenise or sanitise their narratives in any way. My own experiences are part of this tapestry given voice through narratives; due to the personal nature of these experiences, I have chosen a pseudonym to afford myself the same anonymity as all of the other women who participated. Where I make myself identifiable by using the pronoun 'I', the experiences are ones that I am willing to disclose and should be set apart from any of the other narratives. I acknowledge that in the final analysis it is I who organises everything in the write-up, and hence I cannot but put the voices of all other participants into a pattern that reflects something of my own intellectual project, political beliefs and ethical convictions. I am sincere in trying to create space throughout the thesis where many different voices – not always saying the same as me – can be heard.

Academic elitism

Part of the struggle in which I have been engaged during this research has been my access to academic space. I must clarify that the University and specifically the Geography Department's commitment to accommodate my access requirements has facilitated my inclusion in the Department. For the first time in my academic experience, I have felt truly part of things, participating on an equal basis with my colleagues. However, I have been conscious that my presence in other academic spaces has been disruptive; for

example, as mentioned in the previous appendix, when attempting to access archives held within a large public library.

A significant proportion of the historical research involved accessing two archives held within a public library. I found the difficulties in accessing these resources deeply upsetting; no matter how I tried to rationalise my daily experiences, the (attitudinal and physical) environment smacked of academic elitism. Lack of willingness to accommodate my access requirements and an implied questioning of my 'right' to participate actively in research, and hence to share academic (or at least a certain kind of intellectual) space, was hurtful and at times humiliating. The obstructive attitudes that I encountered made me feel that I had no academic credibility whatsoever. Indeed, the notion of having to show that I could be 'responsible' with the archive documents was insulting; it confirmed that my presence in this space was unexpected and disruptive. My worthiness to share such privileged academic space was something that I had to 'prove'.

My worthiness to share this space was further diminished by the spatially segregated locations – the very geography – of the Visual Impairment Resource Bases (VIRBs). The two large public libraries that I used during archive research both housed VIRBs, theoretically to enable visually impaired users to access information. Both were located outwith the main library; indeed, they were nowhere near the books. In one library (where the majority of my research was carried out), the Resource Base is located on the ground floor tucked away in a corner beside the café. In the other library, the Resource Base has a separate entrance and was only connected to the library by an internal corridor. I felt that my presence in the academic space of the archive challenged stereotypes of who 'should' or 'should not' participate in academic research. I resented being hidden away while I was working, consigned to the VIRBs, and on some occasions I defiantly worked with a personal reader in the archive room alongside other users. Sharing the space on my terms felt like a hard-won victory.

Interviews

The inclusive approach of this research was built upon a methodology that promoted mutual respect by anticipating and accommodating women's access requirements, thus enabling their equitable participation (Nast 1994). I was

acutely aware of my privileged position as 'the researcher'. I wanted interview discussions to take place on an equitable basis; and, in an attempt to redress the balance of power, I consciously introduced elements to the research methodology that would disrupt any potential 'power hierarchy' (Mercer 2002, Oakley 1981, Falconer Al-Hindi 1997) between myself and participants. For example, apart from all information being made available in accessible formats, I shared my home contact details, disseminated an article giving details of my own reproductive experiences and self-identified as a disabled woman or 'insider'. Moreover, the interview location, timing and date was chosen by the women, and prior to interview, I offered a list of topic areas that might be discussed. These elements placed women in a more informed and perhaps powerful position than traditional research approaches. Although it should be noted that many good qualitative (non-disabled and disabled) researchers would enact similar methodological and ethical principles.

Many of the women mentioned that they had strongly identified with the content of the article that they had received discussing my own reproductive experiences. Therefore, for some our lives had shared meanings; we had similar embodied experiences. This seemed to set the scene for sharing personal experiences; and throughout the fieldwork, I gained a real sense of collaboration from the women, such as was experienced by Avis (2002). Similar to Avis I was interviewing women with similar experiences to myself as a disabled woman. Indeed one strong collaborative 'feature' of this research has been 'our' shared experience as disabled women, regardless of the differences in our reproductive experiences or choices. Therefore, much of the collaboration during interviews was in our mutual sharing of experiences. However, on occasion, as mentioned below, 'collaboration' by the women I interviewed involved them assisting me to get to their homes in the first place and/or familiarising me with the layout of their home. This takes the notion of 'collaboration' between myself as 'the researcher' and 'participants' beyond simply the interview situation itself and into the whole process of meeting in person.

The place and space where interviews took place tended to influence the duration of the discussion and in some cases also the depth of the information shared; for example, one woman, who initially met in a neutral venue, then selected the privacy of her own home in which to share more intimate information. Those interviews undertaken in the workplace tended to

remain very focused by the women and myself, and had an average duration of one-and-a-half hours. Although this is nonetheless a considerable portion of a woman's working day, the workspace seemed an alien environment in which to discuss personal experiences of exercising (or not) reproductive choices (Elwood and Martin 2000). In addition, my own consciousness of the demands placed upon women and the time constraints in their employment situations, coupled to a fear of 'taking up too much time', did possibly influence the structure of the discussion. Similarly, interviews held in the 'neutral' location of the disability-led organisations, where meeting rooms were business-like, clinical and devoid of personal items, also tended to take approximately one-and-a-half hours. Again, the added awareness of the demand for meeting space within these premises may have had a bearing on the length of discussions, although it should be noted that the natural 'flow' of the discussion was never affected by this awareness, and discussions were allowed to conclude naturally; the women were not silenced or rushed in any way.

Another consideration regarding these workplace and the 'neutral' accessible venues of the disability-led organisations was the context in which these placed both myself and the women in terms of the relative meanings of these spaces (Underhill-Sem 2001b), with the potential influence of past or present power hierarchies never far away. This circumstance would possibly have had a bearing on discussion during the interviews (Elwood and Martin 2000). For example, women who chose these venues were generally 'users' of the organisations and potentially placed by the environment in the inequitable position as a service recipient. Also, one of the disability-led environments was my former workplace, while one of the women was a former colleague. In our previous employment we had worked within a power hierarchy where I had been her line manager. Therefore, when meeting women in these supposedly 'neutral' environments stuffed full of meaning and constructions of power, I consciously endeavoured to deconstruct any residual power hierarchies. For instance, with my former colleague we asserted our shared status as students; with women positioned by the environment as service users, we sought out commonalities in our experiences facilitating empathy and trust (Aitken 2001). During one of these interviews, a woman became upset and started to cry; I immediately turned off the tape and instinctively gave her a hug, using my body to reassure her and affirm my support (Parr 1998).

Interviews held in the private personalised space of the home, hence in familiar, relaxed, safe environments, were strikingly different. In this environment women were more relaxed; however, domestic etiquette and rituals were more pronounced and lengthened the time that I spent with women. For example, I was offered a hot drink on arrival at each woman's house. This welcoming gesture and the ritual of tea drinking before commencing an interview was important in developing rapport, likeability and trust with women who I had never met or when re-establishing connections with those known to me personally, or professionally, in whose company I had not been for quite some time. In the home environment, women tended to talk in far greater detail and shared more personal and intimate information (Parr 1998). For some of the women, their home constituted the environment in which their mothering and care-giving roles had been performed. For others, the home remained the scene of their role as a mother and/or grandmother, with the environment being used as a point of reference; for example, where the accessible or inaccessible nature of the environment shaped their experiences (Aitken 2001). Women choosing to meet in their homes also contributed to disrupting any potential or perceived 'power hierarchy' between myself and the women (Oakley 1981, Falconer Al-Hindi 1997); this was particularly so for me because I was totally unfamiliar with the location and layout of fourteen of the women's homes. Therefore, I required the women to give me verbal instruction to navigate around their house, so that I could find where the sitting room and the bathroom were located. When interviewing sighted women, I felt that my requirement for 'directions' did create a collaborative approach to the research process.

In everyday interactions personal information is shared as a matter of course. However, an interview disclosure or sharing personal information is a conscious act on the part of those involved (Mohammad 2001). It took time for many of the women to build up to discussing their personal experiences of reproductive choices; for some, these experiences of having or not having children remained raw and deeply painful, regardless of how recent or long ago they had experienced them. Many of the women remarked that they had enjoyed having the opportunity to talk about their experiences. Interviews were filled with mixed emotions, lots of laughter intermingled with sadness, regret, anger and frustration. While most women enjoyed the experience, a few did find it upsetting but cathartic. I invested a great deal of effort putting

women at their ease (Burns 2002); in many ways, the discussions were reciprocal. Sometimes, where I shared the same experiences as a woman, I offered this information to let her know that she was not alone (Vernon 1997). More often, at the end of the interview, women asked me direct questions about my own experiences; I answered these with the same honesty and frankness with which they had answered my questions. Throughout the fieldwork process I constantly fretted about my responses, and worried whether engaging in a reciprocal discussion would be viewed negatively by the academy (Oakley 1981, Avis 2002). Often, where I offered information or answered a direct question, this seemed to 'unlock' women's stories (Avis 2002:203). This leads me to believe that, without reciprocity, there would have been no intimacy within the interview situations (Oakley 1981:49). It is noteworthy that my concerns regarding academic credibility are reflected in the fact that, once 'formal' discussions had ended, I tended to switch off the tape recorder. Throughout the fieldwork, I was deeply moved by the women's personal investment in this research, and also by the trust that they placed in me.

In addition to the 'formal' interview, women often invited me to stay for lunch; and this gave me the opportunity to engage with them on a more social level, and to get to know them as individuals and for them to get to know me. In these instances, I often spent an additional one-and-a-half hours with women over and above the time taken to discuss their experiences. I felt that the women had invested so much of themselves in my work, and that this investment should be respected and reciprocated by my time commitment to them. Additionally, Vernon (1997) suggests that for research to be truly reciprocal, the researcher must be prepared to get involved in matters not directly relevant to the research. I found that many of the interviews involved follow-up, either supplying contact details of support organisations or information that I had discussed with the women (i.e. photocopied chapters from books that reflected the woman's experiences). Some women's participation in the research was dependent on a reciprocated arrangement: for example, one friend asked if she could be interviewed at my home and stay for the weekend as she wanted a break from her own home situation. Another woman known to me had an ongoing housing issue that she had not managed to resolve, and asked if I would intervene on her behalf. I agreed to both these arrangements. As a result of the reciprocal

nature of this research, a number of the participants have become personal friends.

The reciprocal nature of this research will continue long after the 'project' is finished, as two women with experience of institutional life (see Chapter 5) expressed their desire to write about their experiences but felt that their lack of education prevented them from doing this. I have agreed to assist them in fulfilling their aim of writing a book about their life experiences. All the participants have been offered a summary report of the research findings in accessible formats, while two women have requested a copy of the complete thesis. It is my intention to have the full thesis transcribed into various accessible formats.

Interviewing blind women

In reflecting upon the fieldwork process, I have to discuss briefly some implications of being visually impaired, especially when interviewing blind women. As a blind person, I am very conscious of sight as an expected feature of interactional normalcy (Michalko 2002). I am also very conscious of being 'visually available to others' (Michalko 2002:149), who assume a level of familiarity with me based upon my physical appearance. While people might think they know about me simply by looking at me, this is not reciprocal. Although I have some residual vision, it is not sufficient to gain an understanding or appreciation of physical appearance or facial expressions. Although I wholeheartedly regard this as a benefit, it is sometimes unsettling when others assume a level of familiarity towards me that I do not reciprocate.

In many ways, my interactions with blind women were refreshing; as neither of us had access to visual clues about each other, we could not assume a level of familiarity with each other by sight and therefore had to build up a picture verbally. An example of this would be that sighted women would look for the presence or absence of a wedding ring to indicate my marital status, some of the women commented on the unusual design of my wedding ring or remarked 'I see that you are married'. None of the sighted women asked me about my marital status, indicated at that time by my wedding ring, whereas blind women did not have access to these clues. From the outset, communication was therefore on a far more personal level, as we worked to

build up familiarity or rapport with each other. This process of familiarisation was reciprocal, with women usually asking me questions first; for example, asking about my marital status, height and weight, my connections within the blind community, my relationships outwith the 'community', the schools that I attended (more pointedly if I had attended a well known blind school), where I lived and with whom, if I used a long cane or a symbol cane, if I had ever considered getting a guide dog, if I read Braille or not, the type of watch that I wore, whether I used large print, Braille or talking, or if my visual impairment was congenital or acquired. These sample questions may seem rather odd to a sighted person, but what is going on throughout the series of questions is a process of alignment in terms of life experience, level of visual impairment, connections within the close-knit visual impairment community, and level of participation in blind clubs, sports, etc. It went beyond building up a rapport, it was about both the women and I building up a picture of who we were talking to; inevitably, with this process of disclosure, an immediate level of trust and respect was assumed between us. These interactions were quite unusual for me; as I am rarely in the company of other blind people, it was novel to interact on an equitable basis that did not involve visual communication.

During the interviews with sighted women, we tended to sit in separate seats, often physically quite far apart. In all interviews with blind women we sat very close to each other, often sitting on the floor right next to each other. At the time I did not give this much thought, but on reflection I realise that we were possibly 'closing the gap' between the physical and the heard environment (Michalko 2002). During interview discussions, because neither myself nor the participant had access to visual cues, I found it difficult to ask questions on a few occasions, especially where a woman was talking passionately about her experiences. I tried to implement a strategy of taking deep sharp intakes of breath to indicate that I wanted to ask something; this tended to prompt a natural break in the conversation to enable me to ask a question. Usually the woman and I would verbally agree to start the interview; on one occasion the woman unexpectedly launched into a discussion, and I had to switch on the tape recorder rapidly without having a chance to ask her a question. I also wanted to ask if I could use the bathroom; but, despite my best efforts taking intakes of breath, the woman became so involved in recounting her story that she did not notice. It was only after she had been talking for almost an hour, totally uninterrupted, that she realised I wanted to ask something! Usually I

indicated verbally that they had answered the question to my satisfaction, and asked if they were ready to go on to the next section. Any visual cues I would usually use towards sighted women were replaced with verbal ones.

Elwood and Martin (2000:652) suggest that researchers observe the information offered up by the interview location as a means of learning about the micro-geographies of research participants' lives; for example, decorations and personal items in the home may reveal much about a person's priorities, commitments and lifestyle. I did not have access to the information reflected in the personal items in an individual's home. On two occasions I gained a sense that the room where the interview took place, usually the sitting room, was sparsely furnished; on another occasion, I gained the impression that the house was a bit untidy, as a space had to be cleared for me to sit down and I stumbled into a couple of items. I perceive this lack of information about the interview location to be beneficial, as it facilitates a non-judgemental approach to encounters, whereas sighted researchers may be unduly influenced by their reading of the environment and what it tells about the occupants.

I was taken aback by the numbers of blind women who spontaneously hugged me at the end of the interview; Vernon (1997) also reports this. I put this physical affection down to a number of contributing factors in the interview situations where women shared intensely personal, often traumatic and painful experiences. We had quickly built up a level of trust and intimacy; the spontaneous hug was perhaps an affirmation of the connections that we had made on various levels (Parr 1998). I also wondered if this was another means of closing the gap between the physical and heard environment, or simply that, after revisiting painful memories, women just needed a cuddle for reassurance and support.

Although I found the fieldwork one of the most rewarding elements of my research, it was also the most demanding both physically and emotionally. In acknowledging the physical and emotional endeavour involved, I undertook one interview per day with a maximum of three per week. Many of the interviews took place in Edinburgh which involved my departure on the 6.55am train from Troon to arrive at women's houses for 10am/10.30am. Fortunately, most women identified mid-morning as a convenient time to meet, which allowed adequate time for full discussion and still enabled me to

undertake the two-and-a-half hour return journey home so that I could arrive on time to collect my young son from nursery. The frequent commute to Edinburgh and pressure to be back on time to collect my son could be very stressful. I found this stage the most difficult for juggling my work commitments with childcare responsibilities, as at times they conflicted. I often returned from Edinburgh completely physically and emotionally exhausted, but still had to switch into 'mummy mode' with all the demands associated with that role.

Extreme emancipatory research

The possibility of gaining a PhD was not a significant motivating factor in my decision to pursue this course of research. I was motivated by an overwhelming desire to make sense of my own experiences, to hear other disabled women's experiences, and to document these in the hope that by doing so, in some small way, it would effect social change. Within a short space of time, I realised that this desire was somewhat ambitious. However, the biggest change that has occurred in the generation of this thesis has been in me (Pain 1999). Initial reading enabled me to start making sense of my own experiences. During the fieldwork I met women who were positive role models, two blind women in particular who had brought up their children as lone parents and who now played an active role in caring for their grandchildren. Listening to these women's experiences gave me something with which to compare my own (although I did not disclose this so explicitly to the women); what I learned from other women's experiences constituted the final piece of understanding that I required to complete my own life jigsaw. With a clarity of purpose that I had never experienced before this point, I made some life-changing and liberating decisions.

Conclusion

This has been much more than a research project for me, it has been a life line with which I have rebuilt my self-esteem, self-respect, confidence and, most importantly for me, my belief in my abilities as a mother.

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Abbreviations (used in thesis)

BHHAR	Broomhill Home Annual Report
BHHDR	Broomhill Home Domestic Rules
BHHHCMB	Broomhill Home House Committee Minute Book
BHHJMFP	Broomhill Home Journal of Male and Female Patients
BHHJMP	Broomhill Home Journal of Male Patients
BHHLAC	Broomhill Home Ladies Auxiliary Committee
BHHMB	Broomhill Home Minute Book
BHHMCMB	Broomhill Home Medical Committee Minute Book
EBAAR	Edinburgh Blind Asylum Annual Report
EBAMB	Edinburgh Blind Asylum Minute Book
EPHAR	East Park Home Annual Report
EPHSCL	East Park Home Sabbath Collection Leaflet
ESAR	Edinburgh Society for Promoting Reading Amongst the Blind Annual Report
GBAAR	Glasgow Blind Asylum Annual Report
GBAMB	Glasgow Blind Asylum Minute Book
GMAR	Mission to the Outdoor Blind of Glasgow and the West of Scotland Annual Report
LAGMAR	Ladies Auxiliary to the Mission to the Outdoor Blind of Glasgow and the West of Scotland Annual Report LAGMAR
RBASAR	Royal Blind Asylum and School Edinburgh Annual Report
RBASMB	Royal Blind Asylum and School Edinburgh Minute Book
RNIB	Royal National Institute of the Blind
VIRBs	Visual Impairment Resource Bases
CCTV	Close Circuit Television