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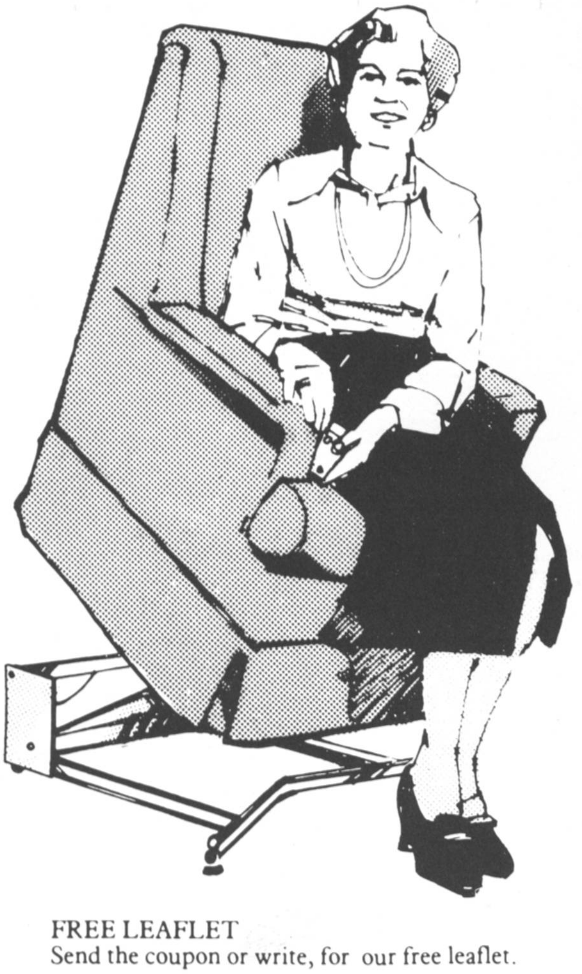

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Timetable for Research

	Nov 13	Dec 13	Jan 14	Feb 14	March 14	April 14	May 14	June 14	July 14
Ethical approval			■	■					
Redraft and rework literature review and methodology chapters	■	■	■						
Contact possible participants /Advertise			■	■					
Pilot interview			■						
Collecting resources for documentary analysis	■	■	■	■					
Begin re reading and initial coding of documents- coding will also be used for analysis of transcriptions			■						
Transcribing of pilot interview (time dependent)			■	■					
Reflect on pilot- make any changes necessary				■	■				
Interview 1/ transcription					■				
Interview 2/ transcription					■				
Interview 3/transcription					■				

Interview 4/transcription					■				
Interview 5/transcription						■			
Interview 6/ transcription						■			
Interview 7/transcription						■			
Interview 8/transcription						■			
Interview 9/transcription							■		
Interview 10/ transcription							■		
Begin coding of transcripts from interviews using NVivo							■	■	
	July 14	Aug 14	Sept 14	Oct 14	Nov 14				
Draft data analysis chapters	■	■	■						
Feedback on chapters/redrafting	■	■	■	■					
Hand in					■				

Chapter Outlines

Title: "Organising for Spina Bifida: Exploring the history of Spina Bifida organisations from 1960 to the current day".

Introduction (2000)

Chapter 1 – Literature Review (10,000)

The literature review will explore the historical experience of those with various medical conditions as a way to understand the reasoning for resistance to those who have sought to identify, categorise and manage their bodies. The role of science and medical science research into preventative and curative research will be considered as one such means through which the variously defined "abnormal" bodies.

The chapter will be used to suggest that there have been numerous attempts to categorise and broadly deal with those with pathological bodies. It will be suggested that although those methods and practices employed to manage the pathological have been various; there has persistently been acts of resistance from those targeted by such methods and practices, the institution and the medical science being prominent examples. The chapter will consider the changes and transformations in the methods and practices used upon the pathological, and then move to explore specific instances of group resistance to this treatment of them based on some bodily difference of pathology. This exploration intends to show how various collective groups of those with medical conditions and impairments have become active in pursuing certain specific objectives. Against this background of on the one hand, control of the abnormal body, and on the other, the active resistance and actions taken by groups of those individuals, the position from which organisations for specific conditions began to emerge, such as Spina Bifida.

Chapter 2- Methodology (5,000)

This chapter will discuss the methodological stance being taken and the methods to be used thereof for the research project. The approach taken to the research, as a project aiming to explore and examine a history of an organisation, there is a Foucauldian influence in the approach being taken. The examination of archived materials produced by the organisation will be used, to explore further the developments and transformations in the work being undertaken in these organisations. The use of interview semi structured interviews will be used in conjunction with documentary analysis, in order to fully explore these historical developments. I will therefore have to consider in the chapter, the difficulties of interviewing those considered to be "elites" in some sense, as the interviewees will be professionals working in the organisations.

Chapter 3– Data Analysis 1-initial stages of association (10,000)

This chapter will draw largely upon interview data, and secondly on that evidence of the beginnings of the association from user magazines, which were first published in 1966. Central to this chapter will be establishing who was involved in the initial setting up of the organisation, for what reasons and with what objectives. Secondly, it will be investigated to what extent professionals in medical science and medical professionals were involved or were sought for involvement in the organisation in these early stages. It will be necessary to establish the development from an informal parental support group to a formally established charity with Professor Zachary as Chairman and Mary Oughtred as General Secretary.

Chapter 4- Founding of ASBAH Moyna Gilbertson CEO 1977- 1991 (10,000)

The chapter will draw on analysis of the content and themes expressed in both documents analysed and transcriptions of interviews being analysed and interviews (depending on availability etc) with Moyna Gilbertson and relevant staff from that period. The chapter will begin with the emergence of ASBAH formally in 1966, which began as small, informal support groups of parents with children who had Spina Bifida. It will be necessary in this chapter to consider the influence of social change occurring simultaneously as these collective groups came together. Therefore there will be discussion of deinstitutionalisation broadly, and specific medical and technological developments which enabled more successful medical management of Spina Bifida (although considering issues like Baby Jane Doe case in 1983, NYC). It is of interest therefore, that these groups emerged at the same time as various politically motivated groups were forming and at the same time as much medical scientific research was being undertaken. It is of interest therefore, to explore the existence and discussion of these sorts of developments in the work of the Spina Bifida organisations and their approach and stance on these ethical debates around treatment as they develop. By the 1980's, those children who had been able to benefit from the development of antibiotics and the shunt in the 1960's had reached adulthood, it will be interesting and important to consider how the presence of those children as adult members of the organisation impacted on the work, focus and constitution of the organisation.

Chapter 5 - Data Analysis 2- 1991- 2009 CEO- Andrew Russell (10,000)

This chapter will consider the period from 1990 onwards, thus it will be necessary once again to consider how the influence of developments in science and medicine pertaining to the curing and prevention of the condition (especially the 1990 Human Fertilisation and Embryology Act- Section 37 on abortion provision, the Genome Project -2001, and Groningen Protocol in 2004), national financial constraints, and a professionalization of medicine impacted on the work of the organisation in this period. Changes and transformations in the way the organisations run and are structured in terms of the involvement of professionals, parents and individuals with the condition, will be discussed and examined.

Chapter 6- Data Analysis 3 – 2009-2013 – (Move to SHINE) CEO Jackie Bland (10,000)-

GoFolic! -2011 -Shine50Plus- SilverDreams

ASBAH organisations took the decision in 2011, to take on the new name of SHINE- Spina Bifida Information Networking and Equality. This chapter will explore the most modern period of the organisations life, and the increasingly professionalised and research led aspects of the organisations work. Central to this will be the campaigns "GoFolic!" SilverDreams and "SHINE50Plus"; including focus upon maternal health, prenatal testing innovations and disability activism for services, rights and treatment. These will be explored through the fracturing and bifurcation of the organisations, considering especially the online communities which are developing, as begun by young adult members in 2012/13- Global Friends and PUSH (People United for Spina Bifida and Hydrocephalus).

Chapter 7- Conclusions (3000)

Conclusions will be drawn about the developments made in the work and character of Spina Bifida organisations, as drawn out throughout the thesis.

Possible participants-

Moyna Gilbertson (CEO)

Andrew Russell (CEO)

Jackie Bland (current CEO)

Joan Pheasant (NORTH regional manager)

Gill Yaz (Health Manager, SHINE)

Roger Bayston (Mid 70's-current- Research fellow into shunts and infection)

Trafford and Salford people-?? (Need to research more with JP)

Theresa Cole- ASBAH services (several roles) latterly Services Director- Retired

Angie Coster (Silver Dreams Co-ordinator)

Gobi Ranganalthan- (current Membership Officer, SHINE)

Richard Astle- Chairman OF Board of Trustees SHINE (current)

Background

The research seeks to explore the history of organisations for Spina Bifida, in the UK context, in which they now operate under the association name, SHINE (Spina Bifida Hydrocephalus, Information, Networking and Equality)[1]. The associations of SHINE are now registered charities, having formed in 1966, to support families of affected children. The SHINE organisation in its entirety now has 75,000 registered members, including parents and relatives of those with Spina Bifida, friends of people with Spina Bifida, and professionals working in related fields, and those with Spina Bifida themselves[2]. Running through central headquarters, and through four regional associations, spread throughout the UK, the SHINE regional teams seek to offer support services, in four key areas; support and development, health, education and occupational therapy. The organisation, however, has gone through a sociologically interesting development; having begun as small parental support groups, the organisation is now a registered charity, whilst simultaneously operating as a group for individuals with the condition. Considering the ways in which those people defined as disabled have been classified, controlled and treated, it is interesting to question why and how this organisation has developed from one where those with the condition were not active participants, being infants during the groups' creation, are now active members, and indeed the focus of the organisations work. Furthermore, it is critical to this examination, to consider the ways in which the organisation has co-operated with and continued to work with scientific research communities and sectors.

Of particular interest in this research, is the development and growth of co-operative work between this organisation and those scientific research sectors who are concerned with curative and increasingly, preventative research. Whilst there has been an abundance of research considering the activism of disabled people as active community members, and into those forms of health social movements and their co-operation with scientific research communities, there has been little consideration of the development of a specific organisation, concerned

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[1] From 20th October2011, SHINE became the name for those local associations previously named ASBAH (Association for Spina Bifida and Hydrocephalus).

[2] www.shinecharity.org.uk Last accessed: 20/10/2013

with a condition which has once been life threatening, treatable and presently, preventable, from a support group for parents, to a group which both supports scientific research and which supports those with the condition.

In order to explore these developments, qualitative research will be carried out. Multiple methods will be employed; documentary analysis of the organisation's magazines combined with individual, semi structured interviews with individuals who have worked in the organisation throughout its life. In doing so, it is the intention to be able to generate a rich data set, through which an understanding of the historical development of the organisation can be gained.

LITERATURE REVIEW

INTRODUCTION

The purpose of this literature review is to provide a discussion of those literatures which have dealt with similar areas of research, to the one being pursued in this research project. Therefore, the review will provide an examination of literatures which have explored the ways in which those with variously understood defective bodies, have been understood and thus the subject of control as such. To understand the position in which these organisations for Spina Bifida have emerged from, it is necessary firstly, to understand the position which people with specific medical conditions, including those with Spina Bifida, have been in through recent history and the ways in which these groups of people have reacted to their position. Specifically this research is concerned with the role of medical science and associated forms of research, which are largely preventative and curative. Whilst there is a great deal of research within the growing sub field of health social movements, into the role of scientific research on the work of these sorts of organisations, these have not considered the influence of those forms of involvement with medical science research and the impact of such on the participating individuals with that condition. Nor have they considered the reasons for developing from an informal support group, to a charity and to a group representing and advocating for individuals with the condition.

Therefore, the historical trajectory of these movements; the control of the abnormal body in the first section, and the emergent activism and action of those with a specific shared diagnosis in the second section, will be examined to present questions about the emergence of such a diverse range of activities being undertaken within one group. By conducting a historical study of the ways in which collective action has emerged from the oppressive treatment of their bodies previously, I am demonstrating the importance of examining historical development in order to understand the present, a Foucauldian influenced position. This approach will be carried through into the methodology and the methods of qualitative research to be employed, which aim to understand the history of the organisation, in order to shed light on the present activity being undertaken.

Section 1: The changing position of the impaired

i. The Dangerous

The organisations for Spina Bifida to be examined in this research initially emerged in the 1960's. To understand the context in which they emerge, it is necessary to consider the historical treatment of those with so called "abnormal" or "deviant" bodies in those previous periods. Those parents who had a child born with Spina Bifida in the 1960's, were the first to benefit from developments in postnatal surgery on the spinal lesion and in developing the shunt which aids draining of hydrocephalus. Furthermore, more broadly and historically, from deinstitutionalisation, better understanding of individual disease aetiology, and the use of community care. Thus, this initial section will consider those scholars work who have examined the historical treatment and subsequent reactive action of those who were deemed to have deviant, and then pathological bodies. Firstly, I will explore the institutionalised and thus deinstitutionalisation movements, followed by the deaf and their resistance to the oralist education system.

Anthropologists, sociologists and medical historians have been central to exploration of the ways in which those deemed "abnormal" in various ways, have been treated by their peers and by those in some position of authority (c.f. Braddock and Parish, 2001, Rosen, 1993). Shifting concern from prevention of an ill-defined notion of dangerousness to a rationalised and calculated risk (Beck, 1992, Lupton, 1999, Rose, 2007) is exemplary of the enabling relationship between power and knowledge, suggested by Foucault (1977). As will be demonstrated, there has been activism from those who have been subjected to these sorts of categorisation and segregation. As Foucault argued, it seems that these forms of medical power practiced over the variously abnormal, is met with instances of resistance. Many scholars in medical sociology have therefore explored the various relationships between the science sectors and the general public as society in general (Conrad, 1992, Gabe, Kelleher and Williams, [1994], 2006, Zola, 1972). As the following exploration will demonstrate, these sorts of resistances to medicine as a form of social control can be traced back historically.

. It is with the initial prevention of dangerousness, in the 1800's forward, to the emerging management of risk, in the twentieth century, which I will briefly discuss now. Resistance to medical social control which only seems to have grown since its beginnings has been variously problematized, and it is the impact of this control, the reception it receives by those who are the target of such control, and the resistive actions this control has caused, which will be explored throughout this review.

Deinstitutionalisation of those who would now be considered to have various physical and cognitive impairments, and those with mental illness or addiction issues, became widespread in the 1970's, in line with the social change of the period (Crossley, 2003; 653). Groups of the variously defective have not only benefitted from deinstitutionalisation, but also from developments in science, medicine and technology, and also in governing practices more generally. These widely noted transformations and innovations across sectors, act as a backdrop against which those defined "at risk" diagnostic groups of individuals, could begin to interact with the state, at a more interactive and empowered level. Simultaneously, as these diagnostically similar groups emerge, those with these conditions became important sites of intervention and curative research from those medical sectors which pursue treatment, cure and the future modification out of those conditions, out.

Foucault's studies of psychiatry (1988), and the ways in which the so called "mad" have been the subject of governing power; have become a cornerstone to studies of psychiatric history. Foucault defines the asylum, the prison and the clinic (1988, 1977, 1973), as specific sites in which the prevention of dangerousness was practiced. Medical knowledge of the symptoms of "lunacy" and "madness" collected together various groups, of the poor, the addicted, the sexually deviant, and those suffering mental illnesses (Mental Deficiency Act,1913) and prescribed the use of widespread institutionalisation in various locations, including; criminal prisons, workhouses and public asylums (Busfield, 1986, Rosen, 1993). Thus, the available knowledge, which was lacking, into the correct aetiology and treatments to be used later, resulted in the use of the singular method of preventing the danger of these individuals to the rest of the population, institutionalisation.

The deaf faced similar strategies of control by those professionals seeking to simply prevent their dangerousness from affecting the rest of the population. Seen as essentially unable to speak, and thus, be taught through using mainstream methods, the deaf, were subject to what has been described as a "colonisation" of the education service (Ladd, 2005). Oralism, a method based on coaching on speech, rather than on teaching of academic subjects became the uniform method, meaning those deaf groups of individuals, could not develop their use of sign language as they previously had. These methods of dealing with the pathological through the prevention of their supposed dangerousness, illustrates the enabling interplay between power and knowledge; when the available knowledge of psychiatric aetiology resulted in the institutionalisation of many who would not now be treated in such a way. Lack of medical knowledge having yet to be gained, similarly affected the deaf, who were segregated from mainstream education, in a bid to remove the uncertainty and danger their lack of speech posed to mainstream teaching (Ladd, 2003, Lang, 2005). Thus, the dangerousness of those diversely termed "abnormal" or "defective" were simply prevented from posing a danger to the rest of the seemingly normal and health population through widespread use of the institution. Fear of the dangerousness of the defective, was further emphasised in wider traditions of the period, such as ideologies and philosophies popular at the time, including Bentham's utilitarianism and Malthus' theory on population control (Haraway, 1991). As such theories of the control of life, that is, bodies, developed, the management of bodies, became a process which necessarily needed to become more calculated and rational.

Rose suggests (2007), in his analysis of the reasoning behind the operation of this power, a shift from the initial, prevention of dangerousness, embodied in the "defective", to a recognition that management of the risk posed by certain defective forms of life was more effective .Thus, as suggested by many sociologists taking an historical perspective on medicine, such as Zola (1972), the concern of the medical sector, moved and, indeed, has remained over more far reaching areas than simply the management of the pathological. For Zola (1972), and Haraway (1991) the motivation of the medical sector, became focused upon the creation and control of a productive stock of labour for the market. Nevertheless, the development of knowledge and skills in the medical sector, that is specialisation in areas such as diagnostics (Jutel, 2009, 2011, Rosenberg, 2002), were seen as critical to the management and prevention of the dangerousness of the defective and ill.

i. The impaired as a calculable risk

As advances in medical science enabled the professional to better diagnose the individual, noted by Jutel (2009, 2011) and Rosenberg (2002)and calculate the risk associated with an individual, diagnostic groups of the "at risk" become identifiable and numerous. More generally, and broadly, the Post War period, has been characterised as one of great transformation, with technological development, liberation movements beginning and developing (Kerr and Shakespeare, 2002, Kevles, 1995). Alongside new medical abilities to specialise, diagnose and treat, the emergence of a concern within governance, with the provision of "healthcare" as a sector, through which the management of risk could be dealt with, becomes evident. Central to the operation of governing power through the healthcare sector, was the emergence of the welfare state, following the 1942 Beveridge Report, which held the National Health Service as a central part of its aims to challenge the "Five Giant Evils", and which was formally implemented with the National Health Service Act in 1946 (Rosen, 1993). Here, we can see the beginning of formal recognition from those within governing sectors, of the necessity and importance of calculating the risk the individual poses to society. As diagnostics has grown as an area of medicine, the group of the individually diagnosed can be targeted, measured and prevented from posing too much risk to themselves and to the rest of the population.

Ex-mental health institutions liberation

As discussed, those subjected to institutionalisation on account of mental illness, have long been vocal about their dissatisfaction with the care and treatment received, through collective action and organisation at a grass roots level, one of the earliest being noted as the Alleged Lunatics Friends Society (Hervey, 1986). Such activities are illustrative of lay resistance to those managing techniques employed to manage the risk these patient supposedly posed to the rest of the healthy population.

Prior to that which has been explicitly termed the 'survivor led' or ex-patient liberation movement, ex-mental health patients and interested parties had collectivised as the National Association for Mental Health in 1939 (Cohen, 1983). The Association emerged within the wider mental hygiene movement (Cohen, 1983), framing mental illness as purely pathological. Hygienists were concerned with dealing with mental illness as a threat to capitalist success (Cohen, 1983, Crossley, 2001). Concern with moral degeneracy of the poor echoed previous eras, and allowed "science to dictate social policy" (Crossley, 2001; 46 7). The Association criticised mental hospitals and brutal psychiatric treatments, framed as a matter of a violation of individual rights as upheld in the UDHR 1948. The Association promoted public education of understanding of mental illness as treatable (Crossley, 2001). Further, the Association worked with Parliament to meet its aims, again suggesting these networks of professional and voluntary sector organisations have been long running, which are relevant to later exploration of various groups, and are central to my concern with Spina Bifida organisations.

The 1960's and 70's witnessed large scale deinstitutionalisation (Cook and Jonikas, 2002) and a rise of opposition to medically grounded psychiatry and the first user movements (Rismiller and Rismiller, 2006), with both the Mental Patients Union (MPU) and the Community Organisation for Psychiatric Emergencies (COPE) being established within the decade (Cook and Jonikas, 2002). Professional optimism in the beneficial role of institutionalisation for patients was not ubiquitous, and closures began in 1973 with the Paddington Day Hospital (Crossley, 2003; 653). According to Crossley (2003), this was the catalyst to the formation of the Mental Patients Union in 1973. Access to treatment and the rights of patients to this treatment, were both influential in this moment, as is suggested as a driving factor throughout a number of the movements discussed into the current moment.

SECTION 2: THE PATIENT ACTIVIST

Groups of those diagnosed individuals who emerge as specifically diagnosed as having a particular condition, have been variously examined as contributing to their own experience of healthcare, it is these, which I will focus on now, as this work raises some important issues and questions relating to the activism and alike which those with particular medical conditions have enacted. Four examples of those "at risk" groups acting in such a way can be emphasised and explored briefly here; the ex-mental health patients liberation movement, the HIV/AIDS activists, women's health activists and disabled persons empowerment.

Each case demonstrates an element of the "active" uptake of health and the provision of specific healthcare. Furthermore, in terms of this Foucauldian notion of an enabling relationship between power and knowledge (1977,1982), discussed earlier, these examples of lay activism, demonstrate the dissemination of power, and the creation of subjects through such pervasive power, which Foucault (1982) and Rose (2007) allude to. Knowledge at the professional level, results in biomedical innovation, which firstly allows the lives of those with previously fatal conditions, to live a fulfilling life (Barf et al, 2007). Thus, an expansion of "ways of being" to use Rose's term (2001), is seen. Furthermore, the active way in which these lay groups have sought to interact in more complex ways, in order to gain knowledge to a professional level, presents an illustration of the enabling ways in which knowledge gained, translates into an increase in power held at the lay level. In the health care sector particularly, this relationship has been popularly considered in that work alluding to and examining the practice of "lay expertise" (Arksey, 1994, Epstein, 1996, Goven, 2008, Kerr, Cunningham Burley & Amos, 1998, Prior, 2003).

a) HIV/AIDS activisms

The AIDS virus, in its short history, has been victim to much misunderstanding of its aetiology. In the 1980's HIV/AIDS was framed as amongst other hypothesis, a lifestyle related condition, or as Kaposi Sarcoma (Epstein, 1996). The disease was recognised in individual cases, and since some of these instances appeared in actively homosexual men across the USA, it was widely speculated among medical professionals, as a "gay disease" (Epstein, 1996; 46). Professionals and the public largely attributed the virus to gay men, intravenous drug users, Haitians and those with haemophilia, providing a discourse of blame against which those diagnosed could resist (Epstein, 1996; 11). As Epstein (1995, 1996) shows, it was Haitian populations and gay men who were most vocal in resisting stereotyping imposed by the medical profession and increasingly the public. The main challenge mounted, as suggested by Epstein (1996), was to counter the partial knowledge base built up in medical professional sectors, which attributed the aetiology to these groups of individuals. Gay activists' resistance shows a number of interesting trends, from varying the relationship between professional and lay knowledge, to protection of a collective identity.

The AIDS activist movement was one of the earliest example of the emergence of activist-experts according to Epstein (Epstein, 1996; 8). At the time of the AIDS outbreak in the USA, homosexuality was a much prejudiced lifestyle, deemed to be pathological by some. Prejudiced views of homosexuality and scapegoating by policy makers and biomedical research sectors in the initial stages of the outbreak resulted in a slow start to research being conducted any further into the aetiology of the virus. Therefore, activist groups firstly sought to forge a group identity and reconceptualise the idea of homosexuality as 'normal' and finally, to gain expertise (Epstein, 1996). Unlike other movements, Epstein argues, the HIV/AIDS movement, were particularly concerned with engaging with knowledge production on the level of scientific, rather than opposing the sector, and as such have been regarded as a "pro knowledge" group (Epstein, 1996). AIDS activism was unique in its ability to take its critique of medical practice into the arena of methodologies of biomedical research (Epstein, 1996; 10). Gay physicians set up the Physicians for Human Rights, thus playing a crucial role between the gay community and the medical sector (Epstein, 1996). Furthermore, in line with those actions suggested in new social movement literatures (Melucci, 1985, 1989, 1994) HIV/AIDS activists sought to take on a group identity of HIV positive, homosexual men. Collective identity enabled the de-medicalization of homosexuality, which was thus far deemed some kind of pathological state, and to promote their rights as equal citizens. Community identity, as Gould shows (2001) focused on a "gay" community, building on those gay and lesbian movements in the 1960's.

Accordingly, grass roots organisations of HIV/AIDS patients were set up for fellow patients. The first grass roots service groups set up were the Gay Men's Health Crisis and the Kaposi Sarcoma Research and Education Foundation, and were concerned with providing necessary services and information (Epstein, 1996; 54). In this instance we see the diffusion of power from the very centralised to the more diffuse, resulting in partnership between professionals of the medical sector, and the lay group affected. Both agreed safer sex was sensible in relation to one's individual sexual health. Support for safer sex was thus promoted by groups led by gay men, (Kegeles, 1996), rather than only the professionally led. HIV/AIDS lay activism encompassed a number of the purposes of lay activism, which I stress as important throughout. The attainment and provision of services and treatments was regarded as being inadequately researched initially by HIV/AIDS patients, and later, to be unfairly distributed and available. Thus, activists sought to tackle the issue, taking on board an agreement made with the medical profession, through a lay led process. In my later research on IF and SHINE, I am interested in this progression which was seen in HIV/AIDS activism from grass roots, self-help, to a research led organisation, which attains a place in international research networks. Both similarly and contrastingly, the disabled person's movement has engaged with the medical profession, in order to fulfil certain aims (Hughes, 2009). This variation in engagement with medicine is a central consideration to be pursued in the research.

b) Women's health activism

Women's health activism was broadly concerned with three goals; reconceptualising women's health as important and needing specialist attention, asserting their rights to decision making and ensuring choice in treatments. Women's health rose in importance as a result of focus moving to the importance of infant health, as recognised in Beveridge's Report (1942) and in the rolling out of the welfare state during the 1950's (Banks, 1982 ;174). Despite women's health being increasingly recognised in its own right, it became increasingly medicalised as a result. The areas of contraception and pregnancy were specifically controlled. Specialisation and to a large extent, medicalization was met with resistance, to a perceived patriarchal medical sector limiting women's autonomy over their own bodies (see Hutter and Williams, 1981; 10, Smart, 1981; 40). The development of ultrasound scanning and the contraceptive pill are incremental to control employed by the medical sector. I will briefly discuss the control, and the forms of resistance mounted to this by groups of women.

The lack of availability of choice, in terms of contraception and in the seeking of an abortion, meant that women's health was largely controlled or its needs left unmet. In resistance to this control and lack of attention, women's health activism, can be seen to have addressed these inadequacies. The extent to which women's health activism was instrumental to the introduction of the contraceptive pill in 1961 and the Abortion Act 1967 (Joffe, 2004), has been a point of disagreement among academics (Joffe, 2004, Kolker, 2005, Morgen, 2002, Soloway, 1995). Soloway (1995) for example points out that the initial motives behind the drive for effective contraception were partly eugenically driven, with a major concern being the control of the population and fertility and thus reproduction of those deemed "unfit" (Soloway, 1995). In addition, although enactment of the Abortion Act 1967 did mark an element of choice, male dominance in the enacting of such practices, means that the exact extent of this "choice" and self-determination remain questionable.

Significantly, the enactment of this legislation illustrates negotiation between the professional and the lay. Pro-choice physicians and the growing number of feminist and women's groups supported legalisation of abortion (Joffe, 2004). The 1960's saw the advent of influential consumer or pressure groups in maternity services (Oakley, 1993), e.g. the Association for Improvement in Maternity Services (AIMS), established in 1960. During the following twenty years, numerous pressure groups were founded including the Maternity Alliance, Stillbirth and Neonatal Death Society (Oakley, 1993). This together with the establishment of The Foundation for the Study of Infant Deaths and the Preeclamptic Toxaemia Society, made this period the "era of the consumer movement in maternity care" (Oakley, 1993; 148). Driving much discontent among the women in these groups were the rising rates of induced labours, which tripled in the period 1965-74, worrying both women and physicians (Oakley, 1993; 56).

AIMS were concerned with provision of resources for the NHS, and maternity services specifically (Oakley, 1993; 53). AIMS pointed to three areas for improvement; number of hospital beds needed to be increased for maternity patients, more midwives needed to be available and finally, improvements in domestic support for women around childbirth (Oakley, 1993; 53). In line with Lupton's discussion of consumerism in healthcare (1997), pressure groups were driven by a consumerist move in society more widely post 1960 (Oakley, 1993; 54). These groups were equally concerned with male dominance in giving advice on "how childbirth is best done" and in medicine generally (Oakley, 1993). Resulting, there was a growth of mutual self-help groups for expectant and new mothers to share knowledge, experience and information, to counter the dominance of medical advice (Oakley, 1981) thus, women have been described as "lay consultants" (McKinlay, 1970). This rhetoric is echoed in British NHS policy (Department of Health, 2001), and literature on lay expertise (Epstein, 1996, Prior, 2003). I will now discuss the activism mounted by HIV/AIDS activists in the USA, toward the increasingly professionalised and homophobic actions taken in the early stages of recognition of the virus.

c) Disabled people

Similarly to those who were institutionalised due to a mental illness, some disabled people felt that the use of segregation was ignorant to their specialist needs and denied them fundamental rights to choice, freedom and treatment. Like the deaf, the disabled child was likely to be segregated in education, if not entirely institutionalised prior to the 1960's. The de-institutionalisation of the disabled in the 1960's onwards then, resulted from the direct action of those who had been institutionalised, including initial individual cases; Paul Hunt, Ken Davis and Maggie Hines (Oliver, 1990). These individuals, and increasingly, *groups* of likeminded individuals aimed to establish independence, autonomy and choice for themselves and others in a similar position. These aims were largely undertaken by disabled person's organisations, the first notable one, being the Union for the Physically Impaired against Segregation. Accordingly, care in the community was preferred by groups of variously impaired individuals, as a way in which they could retain some autonomy in decision making over one's own care (Morris, 1993; 19). Furthermore, community care, can be understood as specifically and more effectively offering particular care and treatment for those who need specific interventions, in ways which the prevention of the dangerousness of their pathological states, were not dealt with in the previous era.

Hope and enthusiasm for community care, that is, specialised treatments administered in out-patient services, allowing those with various impairments and chronic conditions to live independently to varying levels, in the community, was supported by the de-institutionalisation of prominent individuals and subsequent establishment in 1974 of the first movement of disabled people, The Spinal Injuries Association (Oliver, 1990). The establishment of these collectives of those with varying impairments, in this period, had benefitted from increased power following de-institutionalisation. Furthermore, they collected around a mutual concern, in line with a general concern internationally, with human rights and their rights to live independently. By pursuing independent living, these groups asserted their rights, to live in the community with the help that they need, in order to live the way in which they desire (Morris, 2004). They were not, as later collectives to be discussed, were, concerned with a mutual diagnosis, and as such, specific concerns pertaining to that condition. They were concerned rather, with those issues suggested in the social model of disability. As such, they viewed disablement as a social process that was distinct from the biological impairment which affects their body. These collectivisations, of variously impaired, but similarly politically concerned acted as a way in which these groups of people could collectivise and become a coherent group. The influential Union of Physically Impaired People against Segregation (UPIAS) was among the most prominent and active group of this sort. A growing number of disabled peoples organisations (DPO's) followed UPIAS from 1970 with the aim of providing services run by disabled people, to reduce the need and dominance of what Albrecht termed the "disability business" (Albrecht, 1992) is demonstrative of resistance being generated to the management of their dangerously pathological bodies. Thus, a certain collective "identity" became emergent from these activities, although not based, as Novas and Rose's later work, to be taken up, on "biological citizenship" (2000).

Despite such moves by certain groups of disabled people, the 1960's was also a period where prenatal biotechnologies developed as did treatment for certain conditions in infants, such as hydrocephalus and Spina Bifida. Resulting, a number of parent led or parent founded "support" groups began to emerge, including those Spina Bifida organisations to be examined in this research. Thus, although it has been asserted by Bill Hughes (2009) for example, that the disabled persons move has divided into two distinct strands, those who propose adherence to promoting the social model of understanding disability, and those who identify as biological citizens, it is the contention to be examined here, that there remain a novel and under researched hybrid condition specific groups, which began in this period by concerned parents. It is the intention in this research then, to understand how these groups began as parent led support groups, and to consider what sort of organisations they have developed into in the current moment. Of specific interest, is the relationship and dialogue the organisation has pursued with medical research sectors, which have otherwise been opposed by similar condition specific groups in the twenty first century. Furthermore, the influence of the political aims and concerns of the DPM on these more recent collectives, has been little explored,

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Such actions aimed to overturn previous prejudice disregard for their abilities to be productive members of society. These aims were largely undertaken through the growing number of Disabled Persons Organisations (DPO's), established in the 1970's alongside the establishment of the Union of the Physically

Impaired Against Segregation in 1974 (UPIAS). The aims undertaken; the reconceptualization of life with a certain condition, the gaining of knowledge, and the provision of service and treatment as a matter of rights, are all taken forward in the literatures to be reviewed in the following section, which will deal with the sub field of sociological literature upon health social movements and associated collectives. The earlier manifestations of these aims indicate the sustained relevance of the issues throughout the twentieth and twenty first century, which will be shown to be exacerbated by the proliferation and brutal application of neoliberal policies in the Western context, of which this research will take as its case study.

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It is clear in exploring those different instances of group activisms, that these collectives have been variously conceptualised and the object of study. The concerns which they have raised have been numerous and different in each instance, however there are some general similarities in those concerns raised. Generally, the concerns have been around the provision of services, as a matter of good governance from the state, following the incorporation of the National Health Service in the Beveridge Report in the 1950's. This inclusion brought about the ability for there to be concern raised as to the just distribution of this.

Ex-mental health patient activism and to a certain same extent, disabled people, following the 1950's instances of de-institutionalisation (Oliver, 1990), present an active opposition to management of their lives, through a political standing for empowered living arrangements (Potts and Fido, 1993, Braddock and Parish, 2003). HIV/AIDS activism, explored in Epstein's work (1996) presents one of the most complex and interesting cases of lay activism through the utilisation of lay expertise, as a way in which to challenge the professional response, which they deemed incorrectly grounded and homophobic, (Epstein, 1996). Thirdly, women's health activisms attends to those advances and implementation of more equal rights for women in the preceding decades, and developments in prenatal technologies saw; a reconceptualization of women's health as a necessary specialisation, the introduction of the contraceptive Pill and the legalisation of abortion in the 1960's (Joffe, 2004, Kolker, 2005, Morgen, 2002, Soloway, 1995). Fourthly, disabled persons movements, following the deinstitutionalisation already mentioned, sought to establish their rights to equal citizenship (Oliver, 1990, Morris, 1993), characterised by moves such as Independent Living (IL) pursued in the 1970's (Barnes, 2003).

Section 3- Contemporary health activisms

The previous sections have explored forms of resistance as those with various medical conditions and impairments have become more able to participate actively in society. Specifically, the review has shown how those with such conditions have been studied as being active in collecting together with similarly diagnosed individuals to be able to pursue shared objectives. Those objectives have been against or in reaction to various forces of control mounted through numerous aspects of society; such as institutionalisation in the earliest period, to a lack of provision of services or provision of treatments on a just basis. Although these objectives remain central to some of that work being carried out in these collective groups, the contemporary moment brings with it a particular set of challenges which are worthy of exploration and examination here. Specifically, there is a concern with the growth in preventative and curative research being done into conditions which are defined as disabilities, but which are not necessarily life threatening, progressive or particularly difficult to live with, providing that there is a fair provision of medical services and alike. These forms of research are a small part of a broader rapidity in curative and preventative intervention.

A number of specific examples of health activisms have been examined by those concerned with the broad area of health social movements as initially conceptualised by Brown and Zavestoski (2004). These scholars have sought to categorise and theorise certain types of collective action by those with a shared condition. In doing so, they have variously considered the ways theses collectives formed, how they operate, and what it is that they are aiming for. Despite Nguyen's suggestion (2005) that health related activisms such as that being examined in this research, are more complex and dynamic than an example of health activism, and suggesting instead that they are in fact more accurately seen as "complex biopolitical assemblages" (Nguyen, 2005), it is worth turning to the body of work concerned with health activism .In this body of work, a number of differences and unique aspects of health activist groups work have been unpacked.

Within this broad category, branches of these have been variously conceptualised as; "health consumer groups" (Allsop, 2002, 2004), "emergent concerned groups" (Rabeharisoa and Callon, 2008) and "patient organisations"

(Rabeharisoa, 2003). These studies have thus far been interested in various conditions, such as muscular dystrophy (Rabeharisoa, 2003, Rabeharisoa and Callon, 2008), PXE (Terry et al, 2007), Huntington's Disease (Novas and Rose, 2000), HIV/AIDS (Esptein, 1996) and breast cancer (Braun, 2003, Kolker, 2004, Lerner, 2001, 2002, McCormick, Brown and Zaestoski, 2003) women's health (Hayden, 1997, Joffe, 2004, Morgen, 2002) and mental illness (Cook and Jonikas, 2002, Crossley, 2001, Nelson, 1998). Thus, it is clear, that such investigations have been either into the very specific conditions, such as PXE, or concerned with the very general, such as mental illnesses or consumer choice.

Literatures exploring these groups have noted the central aims of these groups variously, as being, to support those with the condition, to lobby for services, treatments and research, and to promote awareness and dispel prejudice. These bodies of literature, do not however, attend to the diversity of actors within these organisations, the diversity of their aims and purposes within the organisation therein. The diversity of the works being pursued in these organisations, becomes particularly pertinent where the medical condition of concern is disabling, congenital and in apparent "need" of research. In such circumstances, there is a need to understand the complexities of the relationship between these organisations which perform multiple roles for multiple types of members. Considering the relationship these organisations have developed with those sectors responsible for medical research is particularly important. Where these organisations seek to perform both a role of leading in research into preventative medicine and treatments for the concerned condition, yet where they also seek to advocate for better services and treatment for those with the condition, the tension between pursuing both, needs further critical examination and unpacking.

Thus far, those studies of health social movements mentioned have tended to present such movements as cohesive and have not attended to the distinctions in the work being pursued within the organisation. Furthermore, the focus has not been upon the inclusion of those with the condition as being attached in any way to their identity as an individual with a particular diagnosis. The influence of diagnosis on one's identity has long been noted following the initial work of Goffman (1963) (c.f. Bury, 1982 Hacking,1995). Furthermore, the influence of holding onto such an aspect of identity, has been suggested as encouraging the pursuing of certain activities and actions, that is, biosocial activities, as Rabinow terms it (2008) or as biological citizenship as Novas and Rose argue (2004).

Where there has been a concern with the antagonisms between pursuing cure and treatment for congenital, non-progressive conditions such as deafness and autism, there is acknowledgement that these conditions are seen as identity forming for those born with them. Such literatures employ those arguments made by the likes of Bumiller, 2008, Gray, 2001, Hacking, 2009, Orisini, 2009, 2010, Shaw, 2008, Sparrow, 2010 and Tucker, 1998. It is the intention therefore, to examine the ways in which the relationships between Spina Bifida organisations and medical research sectors concerned with preventative research have developed as such research progresses in its abilities to prevent those forms of life from ever being born again.

Having been the subjects of prevention of dangerousness and having become the sites of calculation of risk they pose, those groups of the specifically diagnosed as "risky" due to a certain pathological state, have been able to capitalise on that ever increasing power and knowledge available to them, in the increasingly innovative and pastoral medical sector. These groups, as demonstrated through the use of the above examples, have long raised questions within and between authorities responsible for governance and increasingly, governance of health. These questions, as Rose suggests in the notion of "the politics of life itself" (2001, 2007) have brought into question, the value of these increasing number of viable types of lives, enabled by the advances in biomedicine suggested. Those with these pathological bodies, who are increasingly able to be treated, and thus, to live fulfilling lives are however, still faced with instances of political question over the value of their lives, versus the economic value of public health initiatives, including preventative interventions and curative research. The protection and value of different "ways of being" (Rose, 2001) has been presented by specific groups, which I will turn focus to. This discussion will consider three cases; those who consider the expressivist position in relation to prenatal intervention upon foetal abnormalities, the Deaf culturists who oppose the cochlear implant, and finally, those activists concerned with the preservation of individuals with autistic spectrum disorders, who consider themselves simply not "neurotypical", but nevertheless, living a valuable life.

Specifically, in considering what can be congenital and non-life threatening conditions such as deafness and autistic spectrum disorders, there is a complexity of issues at play. Rather than those conditions such as HIV/AIDS and cancers, deafness and autism can be present from birth; have been reimagined by some of those who have these conditions, as part of their individual "way of being" (Rose, 2001). Thus, there is a complexity of negotiations being undertaken around those operating in these activist groups where identity, ways of being (Rose, 2001), the right to be different, and lobbying for the right to services and treatment, are important. These complexities all contribute to difficulties in understanding and thus theorising exactly what it is these groups or mutually concerned individuals constitute. Rapp and Ginsburg (2001) have noted the contradiction in the rise of this sort of activism alongside the growth and development of medical technologies and scientific research, of which prenatal and genetic medicine were amongst them. There have been certain specific examples of condition specific activism which have sought to challenge these developments in science, medicine and technology and the resulting shifts in the valuation of life in both the moral and economic aspects. It is thus crucial to consider the underlying and pervasive rhetoric remaining today; through which value continues to be attached to life both morally and economically, which are mutually reinforcing of one another. Therefore, this research will seek to explore, how and why these organisations for Spina Bifida negotiate and actively co-operate with research sectors, and whether there has ever been any antagonism between the multiple objectives and actors involved in these groups.

Initially however, I will turn to the impact of the positivism placed in scientific research on the ways in which we value life, both morally and economically. It is suggested therefore, that the influence of the medical science research and its growing ability to intervene upon life, alters the way in which we think about the value of a life, and particularly impaired life, as it becomes ever more a matter which we can prevent and modify. I will firstly discuss the ways in which the moral valuation of life has been impacted by such, and then the economic.

a. Moral Value of "life"

As the language of science becomes to be regarded in the contemporary as the "truth" (Greenhalgh, 2005; 356) in our modern society that scientific knowledge discovered thus becomes informative and influential upon the moral value which we subsequently attach to life. A large body of literature in anthropology and sociology exists (Rapp, 1999, 2001, Rothman, 1986, Williams, 2006) regarding the position that pregnant women are situated within regarding the decisions they are faced with where a foetal abnormality is detected prenatally. Rapp and Ginsburg suggest that women in these situations are increasingly becoming "moral pioneers" (2001) as they are required to make decisions about the value they place on the life of the impaired (Rapp and Ginsburg, 2001). Thus, the pathological becomes regarded as not only the presently "Ill", but also the possibly future "ill" can now be prevented, or modified out of future existence. It is argued by some therefore, that the technological contemporary moment, sees a necessarily neoeugenic approach being taken in pregnancy (Rapp and Ginsburg, 2001; 535). These are, according to some writers, being implemented in the most mundane manner, through the notion of care in pregnancy, rather than in creating a discourse of value around the "health" of the foetus. Thus, not only is the foetus the site of valuation, but the maternal body, becomes the target for population level preventative interventions. Such actions are extremely pertinent in the case of Spina Bifida, as a foetal abnormality, which is a legal justification for selective abortion.

Both actions can be seen to illustrate a certain devaluation of the lives of those living with impairments, according to writers such as Parens and Asch (2000), who suggest that these mundane practices illustrate a value judgement about the lives of those living with these impairments. Furthermore, it is suggested by some, that the widespread and pervasive nature of these biotechnologies have become viewed as mundane and neutral in value to many who use them (Parens and Asch, 2000 Rapp, 1999, Shakespeare, 2006), and as such a general ambivalence about the actual choices available to women and parents, and indeed toward the realistic value of a life with impairment, now exists (Asch, 2000, Schwennessen, Svendesen and Koch, 2008, Williams, 2006).

The variously impaired, are thus faced with this "double telos of modernity and technology" (Rapp and Ginsburg, 2001). In this sense, advancing medical intervention generates a population of lay individuals who are increasingly able to resist both the moral or ethical management of their lives and the economic and financial reasoning employed to justify intervention upon so called problematic life, have been thus challenged by specific groups of those affected. Those individuals living with conditions which are no longer fatal, such as Spina Bifida, yet which can be removed prenatally are now negotiating the negative value judgements outlined, in new "biosocial" ways as Rabinow would suggest (2008).

Although it has been demonstrated throughout how advances in medical expertise result in increased abilities of the medical profession to hold managing power over the "ill", the democratisation of these forms of knowledge (Prior, 2003), noted in that work illustrating the growth of "lay expertise" (Arksey, 1994, Epstein, 1996, Goven, 2008, Kerr, Cunningham Burley & Amos, 1998, Prior, 2003) becomes pivotal to the emergence of lay groups as active participants in the orchestration of healthcare. I will suggest that and explore the active role of these previously dangerous and risky individuals as being faced with two scenarios. Firstly, those affected personally, who live with some of those conditions which are now "preventable" in the age of biomedical intervention, who thus have to protect the value of their lives through novel action. Secondly, in the increasingly commercial and market led healthcare sector now present, those with certain medical conditions, prospective mothers of affected children, and professionals engaged with offering these forms of intervention are now all embroiled in a particularly complex situation of politics of impaired life. They necessarily become negotiators in the politics of life, as both biomedical innovation and economic, namely neoliberal, concerns, deem their "ways of being" of less value than those apparently normal, healthy states. In this contemporary situation, where advances in prenatal intervention become possible, the moral and the economic value of life, become crucial questions which the individual is faced with negotiating. This will consider the increasingly neoliberal influences over healthcare, which recast the notion of value over healthcare in relation to the moral and ethical value of the diverse range of "ways of being" (Rose, 2001) which emerge as possible resulting from biomedical advances in research and innovative technologies. Through the exploration of these two examples, it will be suggested that the impaired or "ill", professionals operating variously, and prospective parents, are being faced with political questions, framed as both moral and financial, which challenge the very right they hold to their life.

Taking into consideration those arguments which have been made concerning the impact of biological status, illness or disability on identity formation, from early works by the likes of Mike Bury (1982) and more recent considerations by Novas and Rose (2000, 2004), Hacking (1995), it is necessary to consider the relationship that organisations for these conditions have carved out with sectors concerned with preventative and curative research. It will therefore be possible to question the reasoning behind pursuing such relationships with, with a strong history of politically driven mobilisation, focused on appropriating disabled people's lives as valuable. Therefore, it is interesting to question, whether the persistence of research into prevention and cure can be seen as compatible ethically with the aims of advocacy, removing stigma and promoting wider understanding of disability. I will consider the influence of biological status, identity and the impact of this on collective action in the third section.

i. Autism as a way of being

Representations of autism have been widely discussed (see Murray, 2008). As a highly complex psychiatric disorder which has multiple implications and symptoms, for both the affected child and their parents (Gray, 2001, Murray, 2008, Orisini, 2009, Ryan and Cole, 2009), as such the nature of activism undertaken has been similarly diverse in its aims. Whilst it is clear that there are a diversity of opinions as to what action should be pursued, this is still evolving. Even within a certain group of activists, there are likely to be a diversity of opinions as to how best mobilize and act. There have been studies of those who agree that there should be engagement with research in general, still vary in their opinions in the particularities of this research are contested variously. For example, some support research on treatment interventions, whilst some stress the importance of finding the cure for autism (Orisini and Smith, 2010). As these authors note, the US Autism Society and Autism Foundation, both support working in partnership with those in biomedical research with the overall aim of curing autism (Orisini and Smith, 2010; 43). The autism rights movement is part of the broader neurodiversity movement, which generally opposes projects undertaking research into cure, and supports struggles for a collective identity and lobbies for rights and access to services (Bumiller, 2008).

In resistance to curative research, these groups of affected individuals and advocates support the construction of a positive collective identity for those with autistic spectrum disorders (Bumiller, 2008). Their work largely focuses upon online communication and building of an online support group, but also supports activist events such as Autistic Pride Day, The Joy of Autism and Runman Autistic Celebration Run (Bumiller, 2008). Significantly, in the support of a positive autistic identity, was the founding of the Autism Network International in 1993 (Bumiller, 2008). Their organisational identity was conceptualised largely in distinction from the neurotypicals (Bumiller, 2008). Such work, has fundamental implications, Scully argues (2003) for the way in which disability, difference and personhood are configured.

ii. Deaf culturists against the cochlear implant

There is distinction to be made here between those who identify as "deaf" and those who identify as "Deaf" (Beckett, 2006, Davis, 1995; xii, Tucker, 1998). Those who identify as "deaf" accept to an extent, the medical diagnosis of deafness, and thus as different to the large majority of the population, and therefore they attempt to assimilate into hearing society (Tucker, 1998). "Deaf" people, on the other hand, argue that because they largely communicate through American Sign Language (ASL), they are therefore a cultural-linguistic minority, and therefore their Deaf culture must be protected (Davis, 1995, Ladd, 2005, Tucker, 1998). These communities of the Deaf have had to negotiate particular difficulties in the wake of the development of the cochlear implant. The first cochlear implant was taken home by a deaf individual in 1972 (Blume, 1995; 105). Uptake has now risen rapidly, by 1995, 12,000 patients were reported to have received an implant (Wilson and Dorfman, 2008; 5).

In resistance to approaches "curing" deafness there has been a strengthening in the concept of Deaf culture in the past twenty years (Tucker, 1998). Deaf culturists argue that processes of research and funding of such research, is a disservice to the Deaf population (Tucker, 1998; 8) as is placing the cochlear implant in a child's ear. They argue that, there is nothing negative to "cure" in Deaf children, in much the same way that racial minorities are not "cured" of their differences (Tucker, 1998; 8). However, some deaf respondents in Tucker's work (1998) disagreed, arguing that to be given the implant, would only increase their opportunities in life, and the opportunities available to their children. Culturists, respond, arguing that provision is the missing piece here, and that such a negative view of a Deaf life, would not be necessary if proper provision were made for Deaf people (Tucker, 1998; 10). As healthcare is now a central provision of the state, it is increasingly driven by financial constraints. Economic cost of "difference" becomes the central question here, as raised by Tucker and echoed by those in disability studies more widely. Specifically, the cost of accommodation for a deaf individual, much outweigh the cost of the implant. Furthermore, the work productivity lost due to deafness is estimated to be around $5 billion (Tucker, 1998; 10). The value of the individual in productivity and essentially economic terms therefore appears to override the moral worth of acceptance of difference and identity. Those with a diagnosis of autism, and indeed cognitive disorders broadly, have faced similar challenges to the conceptualisation of their condition as part of a diverse human race.

As Scully suggests (2003), taking a feminist stance, in theorising embodiment and the boundaries of normalcy, we should endeavour to include a more diverse range of characteristics, even those out with the "neurotypical" (Scully, 2003). Thus, in seeing a reconceptualization of autistic spectrum disorders as part of neurologically diverse population, would result in a reconfiguration of the way in which policy was framed in terms of the services and treatments, and therein, the rights of access to these, for those individuals with the conditions. It is clear then, that the provision of health services for the chronically ill or impaired is an inherently financially driven issue for those with the responsibility for such provisions. Where the financial costs of providing necessary services and treatment for those with such conditions, is considered to outweigh the quality of life that individual will experience, then the value of that cost. The moral value of life discussed previously then, is inherently informed by the economic value which we attach to life. For example, much research has confirmed that when making a decision of whether to continue with a pregnancy in which a foetal abnormality is detected, a number of parents consider the financial strains of having a child with a long term health condition. Furthermore, the value of supporting life which requires above "normal" levels of support in the form of treatment, health services and alike, is weighed against the cost of researching curative and preventative medicines and interventions. In the case of fatal or terminal conditions which are debilitating, the value of such research cannot be reasonably contested. However, where a condition is compatible with life, say in the case of autism for example, the moral value of such economic investment in research becomes questionable, as Shakespeare has suggested (2003). Forms of collective action by those with varying medical conditions have thus resisted the valuations being made regarding the investment in research into the cure for their respective conditions. I will seek to question, how and why certain calls for funding in both public and private spheres, are deemed "worthy" and others are not. I will demonstrate instances where those lay organisations I am concerned with, have acted to resist the funding agendas and priorities being supported by governing powers. Thus, these organisations will be considered in terms of how they conceptualise their "cause" into a "worthy" one, in terms of value. Resulting, the reconceptualization of a specific condition, which is undertaken by activist groups, which I have stressed throughout, is employed as a central tactic in improving those groups' rights to access treatments and services. This is particularly relevant to my later exploration of Spina Bifida organisations, as I intend to question their dual approach taken toward both preventative and curative research going into maternal health issues and fortification legislation, as simultaneously supporting provision of care and services to people living with Spina Bifida currently.

b. Economic value of life

Various forms of resistance by collective groups of the similarly diagnosed have been discussed thus far. It is suggested in this section, that in the contemporary moment, the moral and inherently economic way in which society values "life", provides a new form of control and classification of bodies and forms of life, that specific condition groups are now reacting to. An abundance of research points to a reaction to medicalization of the body, from various levels, one being the rise of self-help groups (cf. Kelleher, 2006, Nayar et al, 2004). The concern of the medical profession with the financial value of providing appropriate support versus, funding large scale curative and preventative research is one area which various condition groups have taken on. Epstein's seminal work examining the HIV/AIDS activism undertaken in the 1980's is one such example (Epstein, 1996).Those activists were concerned with in the first instance, the reconceptualization of homosexuality, as a means to reconfiguring research agendas and funding of more appropriate research (Epstein, 1996). In this later period, I am concerned with the financial climate of austerity in which these decisions are being treated by government and policy makers. Therefore it is necessary to explore the lay resistance to such professional decision making.

i. Breast cancer funding activism

As Gibbon (2008) discusses, breast cancer activists had to drive for de-stigmatisation of the disease, in order to be able to reshape the disease as a risk to public health which requires understanding and action (Gibbon, 2008; 19). Further, breast cancer funding activists in particular resisted and attempted to change how funding should be configured around breast cancer. Kolker (2004) discusses resistance breast cancer funding activists raise toward the professional sectors approach, which they felt had ignored the need for more research into cause and treatment. In much the same way that Epstein (1996) suggests that HIV/AIDS activists mounted such resistance, through acquiring their own expertise and thus becoming what Epstein terms "lay experts" (Epstein, 1996). In much the same vein, the breast cancer funding activists sought to reconceptualise how the public and medical sectors viewed breast cancer, in order to raise funds for research, which they framed as a right to treatment. Establishing rights to treatment and services, across both HIV/AIDS and women's activism and in the case of breast cancer activism, can be regarded as supporting choice, against a dominating force in governance of healthcare sectors. In the case of breast cancer activism, this was white male physician (Lerner, 2002) who predominantly placed force upon women to undergo mastectomy (Lerner, 2002).

Resistance began to take shape in the 1970's when the US federal government allotted less than 5% of the money it had allocated to HIV/AIDS activism, standing at just $74.5 (Kolker, 2005). Not denying the seriousness of the condition, it is nevertheless interesting that breast cancer receives such levels of funding over other women's cancers such as ovarian, which kills more women (Kolker, 2005). It is interesting to question the role played by the cultural acceptability of the cause being fought. The way in which the disease was reconceptualised as a "threat" to central features of society, such as the family, and to the reproduction of the population more generally (Kolker, 2005). Breast cancer is deemed a more "worthy" cause as it is seen as the disease which "women fear the most" (Lerner, 2002) and breasts being culturally framed as sexual organs and as representative of maternal relationships (Kolker, 2005, Lerner, 2002). Resulting, as Lerner (2002) shows, funding for breast cancer had jumped to $700 by 1996 and can be seen to be an especially prominent charitable cause in the UK and USA.

Reflecting upon how breast cancer funding activists sought the reconceptualization of their cause as a worthy one, thus enabling them to mount claims to rights, services and treatments is a fundamental comparison to my research, in which I will question whether there are conflicting agendas being pursued in SHINE, attending to both research agendas and improving the current living situation for people affected by Spina Bifida in the present moment. The demonstration of these groups asserting their "worthiness" and "value" we can see two things. In the case of autism, being autistic is not regarded as a valuable way of being. Thus, like deafness, it is a condition which is "Problematic" and thus needs to be treated. However, this is not the case with breast cancer. The individual is not undervalued here, in fact it is the pathological "cancer" which needs to be removed, and rather than a more significant part of the way that individual lives or is. As we will see in the following discussion, the funding of curative and preventative research is situated in a far more complex position, where a condition is not fatal.

ii. Disability and preventative research

Shakespeare succinctly argues (2005) that this ubiquitous positivism placed in the promises of genetic science, point to a similar issue for those living with specific impairments. He suggests that, the financial value of investing high levels of financial investment into innovative preventative and curative research in the case of conditions which are non-fatal, become morally questionable to many of those living with these conditions, who view such investment as devaluation of their way of life. Such an argument is made across disability studies (). It is therefore, interesting, to question the presence of any co-operation between an organisation such as SHINE, which holds support for those with Spina Bifida as central to its work, with medical science, which seeks preventative and curative interventions, which purely focus on helping future generations, rather than those individuals themselves. Thus, there is suggestion raised by a number of scholars, that there is "new modern/counter modern eugenics "(Kerr and Cunningham-Burley, 2000). Such an agenda, is most clearly perhaps seen in the prenatal scenario, in which women are now able to decide whether or not to continue a pregnancy where a so called foetal abnormality is detected.

A large body of literature in anthropology and sociology (Rapp, 1999, 2001, Rothman, 1986, Williams, 2006) exists regarding the position pregnant women are now situated within with regards to the decisions they are faced with where a foetal abnormality is detected prenatally. Rapp and Ginsburg suggest that women in these situations are increasingly becoming "moral pioneers" (2001) as they are required to make decisions about the value they place on the life of the impaired (Rapp and Ginsburg, 2001). Thus, the pathological once again becomes regarded as not only the presently "Ill", but also the possibly future "ill". It is argued by some therefore, that the technological contemporary moment, sees a necessarily neoeugenic approach being taken in pregnancy (Rapp and Ginsburg, 2001; 535). These are, according to some writers, being implemented in the most mundane manner, through the notion of care in pregnancy, rather than in creating a discourse of value around the "health" of the foetus. Thus, not only is the foetus the site of valuation, but the maternal body, becomes the target for population level preventative interventions. Both actions can be seen to illustrate a certain devaluation of the lives of those living with impairments, according to writers such as Parens and Asch (2000), who suggest that these mundane practices illustrate a value judgement about the lives of those living with these impairments. Furthermore, it is suggested by some, that the widespread and pervasive nature of these biotechnologies have become viewed as mundane and neutral in value to many who use them (Parens and Asch, 2000 Rapp, 1999, Shakespeare, 2006), and as such a general ambivalence about the actual choices available to women and parents, and indeed toward the realistic value of a life with impairment, now exists (Asch, 2000, Schwennessen, Svendesen and Koch, 2008, Williams, 2006).

Conclusions

In exploring the collective resistance of those with so called defective or abnormal bodies, it has been made clear that there have been various causes for resistance from these groups of individuals. In presenting some of the causes, from the earliest forms of institutionalisation to asserting rights to and value of certain forms of treatment and service provisions, the varying forms of collective action or resistance by those defined as "patients" has been explored and examined, to situate the emergence of the Spina Bifida organisation, that this research will focus on. Despite the study of specific forms of collective action such as deinstitutionalisation and specific patient activism and health social movements and the study of disabled person's activisms being abundant, there is a dearth of research specifically considering the diverse nature of some of these forms of activism. The relationship between condition specific groups and medical science, has been considered in particular instances, where there is either a purely antagonistic relationship, in those activisms such as Autism Speaks and certain disability groups (). Additionally, there is consideration of those forms of condition specific activism which focuses wholly on the pursuing of curative research. Research considering the interplay of both representation, provision of services and treatment, alongside preventative and curative medical science research, through an organisations history, however, is lacking. Therefore, the following research questions have been formulated in order to attend to this lacking knowledge:

1. How have individuals with Spina Bifida historically participated in SHINE?

2. Since the establishment of these organisations, how have they incorporated offering support firstly to parents, and then, those with Spina bifida?

3. How important have the following been to the work of SHINE?

i. The promotion of individual rights and empowerment for people with Spina Bifida

ii. Research regarding flour fortification, maternal and public health strategies regarding the reduction of Spina Bifida incidence?

iii. Relationships and networks between SHINE with the International Federation for Spina Bifida and Hydrocephalus

-How has their importance fluctuated through time?

4. What does this tell us about the constitution of SHINE from the 1960's to the present day

This research therefore, will attempt to initiate a discussion of how these seemingly diverse objectives can be pursued within one seemingly unified group. This research project will utilise qualitative research methods to do so. The methodological standpoint influencing those methods being used will now be considered in the next section.

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METHODOLOGY

Introduction

The research aims to explore and contribute to understanding of specific aspects of the historical work of Spina Bifida organisations in Britain. In the main, the method to be employed is documentary analysis of archive materials produced by the organisation, from the 1960's to the present day. As the focus is the historical changes in the work of the organisations, I am deliberately considering this historical trajectory as influenced by Foucauldian way of conceptualising history as less straightforwardly developmental in a positive nature. In keeping with this, I will conceptualise the history of the work of the organisation as being efficacious in building an understanding of the present. This is particularly the case in examining critically the utility and effect of science, medicine and technology, which is often discussed historically as "developing" in positive linear fashion.

In aiming to uncover the historical work and character of the work of these organisations, I will use individual interviews in conjunction with documentary analysis, using professionals involved in these organisations as interviewees and their interviews as a way of gaining understanding of the historical trajectory of the work. Using multiple qualitative methods, and then analysing them thematically, I intend to be able to gain understanding of the organisations work in particular focusing on how they have responded to transformations in medicine, science and technology. Specifically, I will focus on the presence of direct response from the organisation to developments made in medical science and research concerning the condition.

Methodological standpoint

It is commonly suggested that qualitative methods are most suitable to research which seeks to gain a range of views in particular (Gaskell, 2005; 42).The research will employ multiple qualitative methods to explore the historical work of the organisation, as I am working from the understanding that the organisation can be understood as existing in multiple places. Thus, the examination of multiple forms of data will be used to explore the historical work of the organisation. Through examining both official documents from varying historical points in the organisations life, and conducting individual interviews in addition, will hopefully gather a rich data set, which provides multiple perspectives and understandings of the historical work of the organisation. By seeking to understand the multiple ways in which the organisation can be understood and thus constructed, I will use multiple methods to access these, combining documentary analysis with individual interviews.

Thus, the methods to be employed on one level draw inspiration from constructivism (Manning, 1997), holding the position of the social actor, i.e. In this case, the individuals who have worked in the organisation being examined as to the influence of their position in the organisation as having had impact on the work being undertaken by the organisation. Furthermore, as suggested in the literature review, there have been numerous transformations in the way in which those deemed biologically abnormal or problematic have been treated by society and authorities in particular. Thus, it is clear that the reality of disability, the abnormal body and alike, are constructed in terms of that situation in which they exist, including society, economy and technology as influencing factors on the construction of such phenomena. Therefore, it is the intention to be able to understand the influence of such factors as evident in data sets, on the changing work of the organisation historically.

The Case Study

Although a prevalent condition, affecting 2.4.-3.8 live births per 1000, the experience of Spina Bifida for the individual (Sav, 2008), or the actions of those with the condition, have not been studied in much depth in the social sciences. Much consideration instead, has been given to the medical aspects of the individual's condition, in public health and medical research (Akalan, 2011, Bebbington et al, 2011, Bunch et al, 1982, Danzer, Johnson and Adzick 2012). These fields of research have been considerable in their pervasiveness across society in terms of presenting a certain views of the condition, and life with the condition. As such, the condition is variously framed as a public health or maternal issue, as a foetal abnormality, and as a serious disability. Little, if any consideration has been given to the ways in which those with the condition have collected together in groups such as SHINE. Furthermore, little research, despite health social movements becoming a growing sub field of sociology, has considered the collective actions of Spina Bifida organisations. Additionally, disability studies scholars have attended well to exploring and examining the ways in which the disabled person's movement has developed over time (Anspach, 1979, Barnes, 2003, Beckett, 2006, Evans, 2003, Hughes, 2009, Scotch, 1989). Furthermore, disability studies scholars have commented upon the problematic relationship between themselves and new innovative biotechnologies and medical research, and those writing about health social movements (cf. Brown and Zavestoski, 2004), have discussed the relationship between these groups and medical science sectors (Skinner, 2003, Tucker, 1998). However, those groups have not been studied in terms of the historical development of these relationships with medical science and research, nor has there been consideration of the diversity of agendas being pursued within a single organisation and the diverse range of individuals targeted and involved in these organisations.

SHINE therefore offers a specifically interesting case study for examination, due to its diverse range of aims and its diverse range of members and networks in which it is involved. Having developed from a condition which was life threatening before the 1960's to one which can now be treated both in utero and post nattily,

Multiple qualitative methods

It is commonly suggested that qualitative methods are most suitable to research which seeks to research individuals experience (Morris, 1991) and to gain a range of views in particular (Gaskell, 2005;42). As the research seeks to explore the work of Spina Bifida organisations, it is necessary to view the organisations as existing in multiple locations, and as such, the investigation of their work, must explore multiple sources of data collection. Therefore, to explore the questions proposed, two methods of qualitative research generation will be used; individual, semi structured interviews and documentary analysis. The research questions proposed require the collection of data from across various sources; publications and resources from the organisations and individual interviews. As it is the intention to build up the richest account of the organisations work, the use of multiple forms of data gathering will be efficacious.

Using archive documents

Documentary analysis of an archive of the organisations monthly magazines will be carried out initially. This will allow me to code popular themes initially and to identify a proportion of the key informants whom will be contacted regarding participation. By using both methods, the 'story' of the organisations work, can be read from the official pieces of publications from the organisations, and these can be contrasted with the stories told in the individual interviews. In order to build the richest account of this history, no more value will be attributed to either source of data generation, as both are legitimate presentations of the social reality of the organisation.

The historical development of the organisation is likely to be well presented in these documents, as is the presentation of the historical character and aims of the organisation. These documents are significant, as they are examples of the ways in which the organisation situates themselves in terms of their history, purpose and current character and stance on various issues. However, it is worth noting the limits of only using this site of data collection would be too restrictive to fully explore the research questions proposed. Therefore, it will be beneficial to use individual interviews with individuals who have held different roles in the organisation at various points throughout tis lifespan.

Individual Interviews

In addition to examination and analysis of the content of the documentary sources outlined, I will also aim to conduct a small number of individual interviews with individuals who have previously worked in these organisations. In doing so, it is the intention that the realities portrayed in the documents can be enriched, contrasted and clarified with those accounts given by individuals involved. Narratives are useful for participants as they allow them to organise their thoughts and make sense of them (Rhodes and Brown, 2005). Furthermore, as the research aims to explore the historical changes through which the organisation and its work have gone, the use of narratives will be useful in being able to track and understand these changes (). In addition, using a narrative approach to research has been noted as being valuable as it allows plural accounts, views and experiences. These multiple accounts should and will be considered as equally important as one another in demonstrating the meanings and realities which are constitutive of the organisation. In this sense, the individual interviewees will be valuable as they will present different accounts. In considering these multiple accounts, a rich picture of the organisations history will be able to be constructed by the researcher. The temporal position of the work of the organisation will also be identifiable and open to examination through the use of narratives, as they highlight the importance of the time in which the behaviours and actions of the organisation have taken place. The interviews will allow access to the meanings which managers and those who have held professional positions within the organisation (Rhodes and Brown, 2005).

As shown in the literature review chapter, the negotiation and presence of different levels of power, is crucial in understanding the actions undertaken by individuals who have been previously managed due to their pathological body. Thus the concern through my data collection, will be negotiating power dynamics between myself, those deemed "vulnerable" and those classified as being in an "elite" position, a much considered aspect of social research (Blaikie, 2007, Finkelstein, 1980, 1981, Naples and Sachs, 2000, Scott, 2008, Smith, 2006), although some argue that these relationships are constantly fluid, and thus not necessarily in favour of the researcher (Tang, 2002). It will therefore be crucial to negotiate these power imbalances sensitively, in order to have an efficacious data collection.

In exploring the perspectives of the individual actors involved, I am necessarily taking an approach to knowledge production aligned with a rejection of a single objective knowledge, as suggested by, amongst others, Donna Haraway (1988). I intend to explore the multiple perspectives, of participants and therefore, gain insight into the multiple "knowledge's" available relevant to the position of the participant concerned.

Conducting interviews with those who have previously or presently work in the organisation, it will be necessary to bear in mind the role of power within the organisation. Due to their diversity, I will term them, as Desmond has (2004) a "Hybrid elite", moving away from the notion of a centralised, governing elite. Those being researched are part of an International Non-Governmental Organisation (INGO) and thus, do not fit into the traditional notion of elite (Harvey, 2011). In addition, it is argued by Puwar (1997) that power held in an organisational setting, does not always transfer to the interview setting, however, I would foresee their being an element of power imbalance to be negotiated. As the interviewees are likely to have or continue to hold varying levels of authority within the organisation, it is necessary to consider the power relations which are likely to exist within the organisation, thus the data which I gather may be somewhat shaped depending on the individuals position within the organisation. However, the use of documentary analysis will offer a further opportunity to explore the way in which the organisation publically presents itself. However, it should be made clear that these sources of data are specific to that professional level, and thus do not offer an opportunity to explore the understandings of such work from differing points of view, such as parents or those individuals within the organisation who have Spina Bifida. However, the importance of understanding the professionals understanding of the organisations work is significant and thus far not comprehensively or critically examined in literature. In order to examine the ways in which the organisation has approached different types of work, and differing objectives, I will use thematic analysis when analysing interview transcripts and archive documents. Thematic analysis has been employed successfully across organisation documents and interview transcripts in the work of Fereday and Muir Cochrane (2006)

Analysis

Thematic analysis holds central to it, the significance of "themes" as important parts of a description of a certain phenomenon (Fereday and Muir-Cochrane, 2008).Therefore, thematic analysis will allow me to explore the possible answers to the research questions posed. Firstly, those publications from the organisations will be thought of as "virtual documents" (Bryman, 2012; 654) which, in an era with the proliferation of internet usage, have been increasingly accepted in social life and thus social research (Hardey, 1999, 2001, Ziebland, 2004). Written and visual materials are fundamental materials in the formation of the realities of certain aspects of society (Perakyla and Ruusuvouri, 2011; 530). In this research, the analysis of these documents will be complimentary to the analysis of qualitative interviews

Following data generation through interview and documentary analysis, the transcripts, magazines and meeting minutes, will be analysed together. I will use qualitative thematic analysis when analysing the documents, in addition to also using this approach to the analysis of transcripts from focus groups and interviews. In the analysis of all of these sets of data, I am concerned with the presentation of certain themes as a way of understanding the history of the work of the organisation.

Thematic analysis holds central to it, the significance of "themes" as important parts of a description of a certain phenomenon (Fereday and Muir-Cochrane, 2008).Therefore, thematic analysis will allow me to explore the possible answers to the research questions posed. Firstly, those publications from the organisations will be thought of as "virtual documents" (Bryman, 2012; 654) which, in an era with the proliferation of internet usage, have been increasingly accepted in social life and thus social research (Hardey, 1999, 2001, Ziebland, 2004). Written and visual materials are fundamental materials in the formation of the realities of certain aspects of society (Perakyla and Ruusuvouri, 2011; 530). In this research, the analysis of these documents will be complimentary to the analysis of qualitative interviews conducted.

Analysis of documents will involve firstly reading and re reading the archive of magazines and documentation to gain familiarity with the materials. Then, as suggested by Huws and Jones (2011) analysis of newspaper coverage of autistic spectrum disorders, I will investigate a number of questions, such as "How is life with Spina Bifida presented?" and "how are developments in curative and preventative research presented?" using these questions as codes initially. Coding can be understood as examining patterns of language and content to understand a certain phenomenon. Initial coding will be used to develop overarching themes (Fereday and Muir-Cochrane, 2008). Coding could include the following ideas; reference to prevention/cure, services/treatment and empowerment/rights, references to the past and changes, quality of life, value of life, prenatal testing, and research[3]. Coding will therefore be both inductive and deductive, taking elements from theoretical work and from participant's contributions (Fereday and Muir-Cochrane, 2008). In examining the excerpts labelled with each code, it will be possible to develop overarching themes and to then discern the patterns of use throughout the documents in differing periods of time. To order the content for analysis, I will use coding of themes present in the data.

Through using thematic analysis I will be able to understand the themes of discussion which have been important to the organisation through its life, and how

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[3] These are examples of possible codes, it is not possible to generate the final ones until fieldwork is undertaken.

these have altered in relation to biomedical and biotechnological innovations. In particular, I will be able to trace the changing content in line with biomedical understanding of the condition historically. Furthermore, I will be able to interpret the meaning behind the data generated by interviewees, in relation to this same themes and ideas. Using thematic analysis will allow me to gain an understanding of the themes of discussion which have been important to the organisation through its life, and how these have altered in relation to biomedical and biotechnological innovations, according to those different actors involved. In particular, I will be able to trace the changing content in line with biomedical understanding of the condition growing. In using online and print publications and user group magazines as data, I agree with Loizos (2005), who stresses the importance of these sources as real records of real time actions and thus views held therein (Loizos, 2005; 93).

Although there are a number of risks and limitations of using qualitative methods of data gathering and analysis in research (Loizos, 2005) such as misunderstanding the meaning behind an image or publication, it is the multiplicity of understandings of the history of the work of the organisation and its changing structures, according to these multiple actors, which are important to being able to fully understand the history, and thus be able to answer the questions posed. Therefore I will not define responses as “misunderstandings”, but as individual actors with individual experiences and understandings subsequently. Documentary research lends itself to gaining insight into the historical trajectory of the organisation, as shown in both Epstein’s study of HIV/AIDS activist groups (1996) and Kolker’s (2004) exploration of breast cancer funding activism

Thematic analysis has not been utilised in much of that research into the sorts of organisations investigated in the health social movement literature or patient organisation literature. Therefore, it is the intention that by doing so, I will be able to fully explore the aims and work of these organisations in the current moment, from a number of actor’s perspectives, and explore how these aspects of work have been perceived to have developed through time. Therefore the structure of the analysis will take into consideration the changes in the presentation of these themes through the time periods suggested in the layout of the literature review. Through the analysis of the multiple forms of data I will be able to gain multiple perspectives on the phenomena under consideration in my research questions.

Through using thematic analysis I will be able to understand the themes of discussion which have been important to the organisation through its life, and how these have altered in relation to biomedical and biotechnological innovations. In particular, I will be able to trace the changing content in line with biomedical understanding of the condition historically. Furthermore, I will be able to interpret the meaning behind the data generated by participants in interviews, in relation to this same themes and ideas. Using thematic analysis will allow me to gain an understanding of the themes of discussion which have been important to the organisation through its life, and how these have altered in relation to biomedical and biotechnological innovations, according to those different actors involved. In particular, I will be able to trace the changing content in line with biomedical understanding of the condition growing. In using online and print publications and user group magazines as data, I agree with Loizos (2005), who stresses the importance of these sources as real records of real time actions and thus views held therein (Loizos, 2005; 93).

Foucauldian Influence

Although Foucault's work is not specifically methodological in its focus, nor does it comment upon the utility of any specific methods in particular, there has developed a body of literature around the use of those methods employed through his work and those comments he does make, have influenced a certain approach to social research, namely, his philosophy around history as a social phenomenon. Rather than viewing history as a process which can be broken down and viewed as "epochal", Foucault's work suggests we view the past and present as far more intertwined and continuous. In this sense, Foucault has encouraged a questioning of the exact developments which we positively attribute to the present. Such an approach is valuable in considering the current situation in which disabled people find themselves, despite the number of seemingly "progressive" moments seen over the past fifty years in science, medicine, technology, and in synchrony, law and public attitudes. It is now common in medical sociology, disability studies and certain aspects of bioethics, for there to be concern raised as to the negative impact of some of these moments, and the continuation of what has been described as "proto eugenics" (Kerr and Cunningham-Burley, 2000). In seeking to understand the historical trajectory through which those organisations for Spina Bifida have come will be a consideration of the presence of the organisations responses to these moments of change.

Foucauldian influence is evident in such an approach, as it is suggested that statements and visibilities of certain social phenomena are mutually reinforced (Kendall and Wickham, 1999). Foucauldian work takes such an idea on in those genealogical works produced. These and similar works have been termed "histories of the present". An analysis of the operation of varying levels of power is central to these histories, which is a consideration that will be important to the study of Spina Bifida organisations. Examination will be focused upon the influence of certain types of individuals within the organisation and their influence on the production of an approach and discourse of the value of life with Spina Bifida. In addition, focus will centre on the changes in the presentation of the organisations constitution and content of their work in relation to changes in science, medicine, technology and law. By focusing on this history, the importance of understanding mechanisms of calculation will be shown. It is for this reason that the literature review has focused upon the ways through which the abnormal human body has been variously calculated and managed. Furthermore, I will follow those who have been influenced by a Foucauldian approach, including Hacking (1986), focusing on the "making up" of certain phenomena through discursive practices of human discourse.

It is the intention therefore, to present a historical exploration of the work of Spina Bifida organisations, focusing on the presence of certain sorts of phenomena throughout its lifespan. Specifically, this examination will pay attention to the ways in which the organisation has presented scientific, medical, technological and law developments. To this end, an archive of the organisations magazines, will be analysed thematically, as will transcriptions from around ten individual interviews with individuals who have been professionally involved in the organisations work at various times. The research is concerned with exploring and understanding the history of the organisation for Spina Bifida, as a means to understanding the present ways in which the organisation operates the goals and agendas it undertakes, and the positions that different individuals hold within it. Organisational Studies as a discipline, has been less concerned with the place of historical analysis in the past, however, it is suggested by some in the field now, that the place of history in organisational studies, needs to be revitalised and should stand as important (Clark and Rowlinson, 2007). As Usdiken and Kieser (2004) accurately reflect, the use of history in organisational studies, is efficacious as it allows us to reflect on the historical development of organisational structures as historical processes, rather than as necessarily resulting from particular actions (Clark and Rowlinson, 2007).

Sampling, Access and Recruitment

The sample for the research is fairly small, and to a large extent, has already been specified. The research is necessarily aimed at interviewing professionals who have, or presently do work in SHINE or ASBAH associations. This sample is fairly narrow, and is one which requires the expert knowledge of those individuals who have worked in SHINE. Therefore, there will be no formal recruitment process, through advertising, as is usual. This is largely due to the majority of participants being individuals with whom I am already in contact with, and therefore direct contact via email or letter will be employed as recruitment methods. In some cases, where the participants are not known to the researcher, SHINE staff have agreed that they will contact those professionals on my behalf where possible and appropriate. In addition, I have already discussed the opportunity to write a small piece on the research for the user magazine "Together".

As has been noted (Goldstein, 2002) it is useful if the researcher has access to the "elites" whom they wish to include in their research. In this context, I am regarding the position held by those professionals working in IF and SHINE as elites, who I fortunately have pre-existing contact with. Therefore, I use purposive sampling to an extent, as in formulating the research strategy I have already made decisions around the key informants to be recruited (Silverman, 2011; 141). In the research I am concerned with adults only and do not intend to interview any participants under eighteen years of age.

Although the case studies to be researched are specified, it is still necessary to consider issues of diversity within the sample (Curtis et al, 2000). Therefore, I will make note of the diversity of the sample during the research process in terms of age, gender and profession. This will be reflected upon, and consideration of the reasons for this diversity will be given. I am aware, the sample will be made up of professionals, which is likely to result in a certain story being told about the organisation. However, it is hoped that the use of narratives and semi structured interviews will encourage a reflective and open discussion of the history of the organisations.

Ethical considerations[4]

The research proposal has been submitted for ethical review by the University of Leeds Ethics Board, in order to ensure the processes of research which I will use, are sound and do not harm participants. It is essential that the process of data gathering is done in a way in which participants are fully informed and comfortable with. In this sense, Manning (1997) stresses the importance of "authenticity" being upheld, in terms of employing a data gathering strategy such as recording and production of results, in a way in which participants agree that it is an authentic representation of the research process. This is particularly important in the case of this research project, which intends to present an accurate representation of the work of the organisation historically.

Avoidance of harm to participants is of the upmost importance in the research process. Therefore, all participants will be provided with an information sheet and informed consent form, and transcription will be done fully and carefully, and these scripts will be given back to participants for editing before further work is done. All participants will be anonymised using pseudonyms in the written work produced. This process is intended to protect participant's identity, however, due to the small size of the organisation and it being the dominant organisation of its type, it is possible that some participants could be identified. However, the impact of participant's identity being made public will be explained beforehand. Participants will be free to withdraw from the research at any point if they so wish. Whilst this research is not directly recruiting any of individuals who necessarily fall into a "vulnerable" category, it is possible that some of those who have worked for the organisation may be affected by Spina Bifida and/or hydrocephalus, thus making them somewhat vulnerable. However, it will be ascertained whether each individual has capacity to consent before they are involved in any of the research process. If concern is raised as to an individual's capacity to understand the research or vulnerability during the research, all participation of that individual will be ceased.

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[4] Further exploration and explanation of ethical considerations and procedures put in place to reduce risk, are explained in the attached Risk Assessment (Appendix B) and Ethical Approval Application (Appendix A).

However, it is reasonable to assume that few individuals who had held a significant role in the work of the organisation could be considered particularly vulnerable due to their position and influence.

Dissemination

The work produced in this research is primarily for the academic setting, contributing to the examination and award of Masters of Philosophy Sociology and Social Policy. However, the dissemination of this research is not limited to examiners in this setting. In addition, the research will prove relevant to the Spina Bifida organisations, public health and maternal health issues and policy makers where relevant therein. Furthermore, and crucially, the research will be disseminated amongst participants and associated parties (Chen et al, 2010). Due to the constraints and requirements of the academic examination process, it is necessary for the research to be written using appropriate technical and academic language, and to be compiled in a way fitting with the requirements of academic examination. However, it is crucial that the research is subsequently accessible to those concerned and participants. Therefore, I will produce a key note summary, written in accessible language for the lay person. This summary will be sent to all participants, along with a full copy of research if requested. This summary would also be disseminated amongst organisations involved, and key policy makers. In addition, following completion and grading of the MPhil, and dependent on the outcomes, the research will be used to submit to academic journals for publications.

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Appendix E

Possible participants-

Moyna Gilbertson (CEO)

Andrew Russell (CEO)

Jackie Bland (current CEO)

Joan Pheasant (NORTH regional manager)

Gill Yaz (Health Manager, SHINE)

Roger Bayston (Mid 70's-current- Research fellow into shunts and infection)

Trafford and Salford people-?? (Need to research more with JP)

Theresa Cole- ASBAH services (several roles) latterly Services Director- Retired

Angie Coster (Silver Dreams Co-ordinator)

Gobi Ranganalthan- (current Membership Officer, SHINE)

Richard Astle- SHINE Chairman (current)

Interview Guide

These are the research aims:

1. How have individuals with Spina Bifida historically participated in SHINE?

2. Since the establishment of these organisations, how have they incorporated offering support firstly to parents, and then, those with Spina bifida?

3. How important have the following been to the work of SHINE?

i. The promotion of individual rights and empowerment for people with Spina Bifida

ii. Research regarding flour fortification, maternal and public health strategies regarding the reduction of Spina Bifida incidence?

iii. Relationships and networks between SHINE with the International Federation for Spina Bifida and Hydrocephalus

-How has their importance fluctuated through time?

4. What does this tell us about the constitution of SHINE from the 1960's to the present day?

Early work/ background

1. Please tell me about why you started working for ASBAH/SHINE (when, why?) and in what capacity?
2. What did you do before this role?
3. How long have you been working in your current role?
4. Can you tell me about that role specifically? (responsibilities, aims, colleagues)
5. What sort of position was the organisation in at that time? (Size, aims, set up, public perception?)

The organisation

6. Can you tell me a bit about how the organisation was when you first began working? (I am thinking about how it operated, size, what sorts of people were involved and its main aims)
7. Why do you think the organisation was needed/is needed? By whom?

8. Could you talk a bit about how you think the general public understood/understand Spina Bifida and those with the condition? How do you think this compares to how those working in the organisation view and understand people with Spina Bifida? (Do they differ? - in what ways?)

9. What was life like for people with Spina Bifida and their families at this time? What difference do you think the organisation was trying to make? (Who was being particularly targeted in this work- parents or affected individuals? Why?)

10. Did the organisation hold other groups or movements as important at the time? Could you tell me a bit about those?

3. Objectives and aims

Now I want to move onto discuss the particular aspects of the work being undertaken by the organisation.

11. Did the political and social setting in which the group emerged influence the organisation in terms of how it positioned those with the condition?

12. Who do you perceive the organisation being for? Do you think this groups needs are being met appropriately?

Thinking about a specific objectives-

13. When and why did the support of medical science research into SB become important? How do you think the membership felt about the importance placed upon research? How does the organisation view research? (Valuable, positive?)

14. As I understand, the organisation was initially informal parental support groups, How do you understand the development of these groups into

internationally connected networks, particularly in relation to the work they do in relation to medical research?

15. Having developed at around the same time as disabled persons movements such as UPIAS (Union of the physically impaired against segregation), could you discuss how the protection of individual rights and empowerment for those with SB/H is part of the organisations work? (If this was not the case at the time of involvement- for what reasons was this the case?)

4. Influences-

These questions are focused upon exploring what factors have influenced the work of the organisation

16. Can you reflect on how you think the disabled person's movement has influenced the work of the organisation and its inclusion of people with Spina Bifida?

17. Can you tell me about how the organisation has worked with medical science; this could be the involvement of professionals such as doctors or physiotherapists or with research networks related to Spina Bifida?

5. Transformations –

I would now like to move on to consider how the organisation has developed through the past 50 years or so.

18. Overall, can you explain how the organisation has developed its identity- is it primarily a charity? An advocacy group? A support group?)

19. Since the establishment of these organisations, how have they incorporated offering support firstly to parents, and those with Spina bifida?

(How has their importance fluctuated through time?)

(How have individuals with Spina Bifida historically participated in SHINE?)

20. How do you understand the development of the organisation from its small informal parental support group to its current constitution?

- (Is this a positive or negative change?)

21. Generally, how do you think medical science research is received by those with impairments? Is this different/the same for those with Spina Bifida?

Closing

22. Is there anyone in particular you think would be useful for me to interview?

23. Is there any other comments you think are important to the history of the organisation which we have not already covered?

24. Is there any comments or questions you would like to ask about the research?

Opinion

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Association for Spina Bifida and Hydrocephalus/ASBAH

Correspondence to ASBAH at the
National Office:
Tavistock House North,
Tavistock Square,
London WC1H 9HJ.
Registered Charity No. 249338
Tel: 01-388 1382/5

Patron:
HRH The Duchess of Gloucester

Chairman: Mr D M Bryant

Hon Treasurer: Mr R H Smith

ASBAH has an experienced staff ready to help with any problems relating to those with spina bifida and hydrocephalus.

Executive Director:
Miss M P Gilbertson, MCSP

Finance Officer:
Mr F G Armour, FCA

Appeals Director:
Miss Judy Kay, MIPR

Services Director:
Mrs B Newman

Administrative Assistant:
Paul Dobson, BA (Hons)

Disabled Living Advisers:
Miss Mary Barton, MCPS
Miss Andrea Robinson, RGN, SCM, HV
Miss Mary Small, Dip OT, SROT

Fieldwork Co-ordinator:
Mrs T Cole, MICA

Accommodation & Development Officer:
Ms Siobhan Rowe, BA, Dip HA

Project Leader at Five Oaks, Ilkley, Yorks.
(Tel: 0943 609468):
Mr Jim Stanton

Information Officer:
Miss B Holland

Link Editor:
Mrs Susan Gearing

LIFT (Young **ASBAH**) **Organisers:**
Paul Cooper BA, Vivian Harper, BSc

Coming of age — ASBAH's first eighteen years

ASBAH began its legal existence on April 28, 1966 and so it 'comes of age' in a few months time. They have been eighteen years of significant growth.

In the 1960's, important developments in surgical techniques began to produce growing numbers of parents surrounding the main treatment centres such as Sheffield, London, Belfast, Glasgow, Cardiff, and it soon became obvious that some permanent form of support and help for these families was needed.

A series of meetings was held to try and formulate something, the main centres of activity being in Sheffield and London in 1964-1966. The first Annual Meeting was held in November 1966 under the Chairmanship of Professor (then Mr) Robert Zachary with delegates attending from most parts of the UK.

The emphasis then was on guidance for parents and on the needs of infants and young children, together with the need to publicise the problems amongst the public and government and to finance research.

With these tasks in mind, the structure created was that of independent local associations which would be responsible for the needs of families in their areas, and help them in dealing with local authorities and the medical profession, etc. These local associations in turn would receive help and guidance from the national charity, which would also be responsible for raising money for research projects of all kinds, and be a strong voice when dealing with Government departments.

Within a year or so of 1966 the first office was opened alongside Charing Cross Station, and within two years an Appeals Organiser and the first full time General Secretary had been appointed.

LINK first appeared and has been published continuously ever since reaching a steady circulation of just under 10,000 with many overseas readers. Important, too, have been the series of publications on all aspects of the problems of spina bifida and hydrocephalus.

Inevitably some local associations have strengthened, some have hardly got off the ground at all and many have followed a chequered career, depending on the strengths and abilities of those local people involved with them. So it is no surprise to find that 18 years on we have a very uneven pattern in the country as a whole.

The development of national ASBAH itself has been more even, but not without its own problems, and the emphasis has changed over the years. As needs arose various specialist officers were appointed — to deal with equipment, education, traning and employment, social work, information, and more recently to form a young people's organisation, LIFT.

Large sums of money have been needed over the years, especially to purchase and equip Five Oaks in 1975/6 and to finance its running as a care and leisure centre and holiday home, as well as to pay for the various other aspects of ASBAH's many-sided work.

Independence training is now an important feature of work and Study Days for professionals have recently started up in which ASBAH provides the expert knowledge about spina bifida and hydrocephalus to different groups of professionals.

In 18 years ASBAH has established itself as a national charity with an international voice.

As it comes of age, so, too, do many of those it serves. As a result the emphasis of the work is turning more and more to the needs of young adults.

FRANK ARMOUR

ASBAH's Finance Officer who is the parent of a spina bifida daughter and helped to form the Sussex Association in 1965.

CONTENTS

Parents must have a say in schools

AS PART of the Government's policy to encourage the involvement of parents in the education of children with special needs, under the Education Act 1980, an Order has been made under Section 2 of the Act regarding the governing bodies of all maintained special schools. It comes into effect from April 1 next year.

It will have two main effects. The governing body of every maintained school will have to include elected parent and teacher governors, and the Local Education Authority will be required to establish a separate governing body for each of its special schools, if it has not already done so. If it wishes to establish or retain a joint governing body covering more than one special school, it will have to obtain approval from the Secretary of State.

Key scheme passes the '100' mark

THE NATIONAL Key Scheme now has 100 local authorities taking part — the 100th (Eastleigh) joined in August. An up-to-date list of toilets in the scheme is available from the Housing/Access Department of RADAR, 25 Mortimer St, London W1N 8AB. (Please send a large stamped addressed envelope.)

Since the beginning of August British Rail has been issuing a £1 voucher towards the cost of the key with every Disabled Persons Railcard.

DHSS spreads the word

ADVICE on benefits for disabled people is being extended by the DHSS. The Edinburgh Central Office has a special team visiting adult training centres to advise staff and residents about benefit entitlement. The Birmingham Regional Office has a new member of staff in the social services department to offer advice to handicapped clients attending adult training and social welfare centres. Freephone advice centres are now operating in Basingstoke, Birmingham, Cardiff, Leeds, Newcastle, Sheffield and Stockton.

Planning fees are axed

REGULATIONS come into force on December 1 amending the system of fees for planning applications. There will be an exemption from fees for house alterations required to enable a disabled person to move into a house. Planning applications to cover improved access for disabled people for any kind of public building will also be exempt from fees.

Researchers need 'your' help

YOUR help is needed for two current 'research' projects.

If you have a swivel or rotating seat fitted to your car and would be willing to complete a simple questionnaire about its comfort, design, etc., please contact Miss Sarah Bulstrode, Research Therapist, Royal National Hospital for Rheumatic Diseases, Upper Borough Walls, Bath BA1 1RL. Tel: 0225 65941 ext 47.

She is working on a hospital project to evaluate car adaptations as part of the DHSS Aids Assessment programme. The results which will give guidance on choice of aids will be published by the DHSS and will be free to disabled people and professional workers.

Research Assistant at RADAR, Peter Keeble is investigating the way in which aids are provided to disabled people by social services and health authorities. He would be pleased to hear from you if you have had difficulties in obtaining aids, or have decided to buy your own aids privately because of difficulties. He can be contacted at RADAR, 25 Mortimer Street, London W1N 8AB.

TV presenter wins Snowdon Award

ROSALIE Wilkins, the presenter of Central TV's LINK series for disabled people, has won the 1983 Special Snowdon Award for her outstanding work for the benefit of disabled people. Rosalie has been confined to a wheelchair since a tragic accident whilst a student at Manchester University.

David needs a loving home

BARNARDO'S Home finding project aims to find homes for children of all ages, from many different backgrounds, and with a variety of mental or physical handicaps.

One such boy, is 13-year-old David who has spina bifida and relies on his wheelchair. He has lived in two residential homes as his parents have been unable to care for him since he was a baby. Barnardo's who have got to know David well feel that he would benefit greatly from a secure and loving home of his own.

"He laughs a lot and readily shows his affection and pleasure. He enjoys school and works hard to overcome his learning difficulties. He will continue to need special schooling as his abilities are at present at the level of a seven or eight-year-old.

"Although David can wash and dress himself, he needs help with bathing. He is incontinent but this is well-controlled.

"Full advice, preparation and support services, including finance will be given to David's new family" say Barnardos.

If you would like further information you can contact the Homefinding Project at Barnardo's London Division, Tanners Lane, Barkingside, Ilford, Essex. Tel No: 01-551 0011.

City Limits gives access guide

THE LONDON magazine City Limits — from the October issue — is carrying an access symbol guide alongside its cinema and theatre listings. This is thanks to Artsline, the telephone advice service on arts and entertainment in Greater London. Eventually the symbols will be extended to other listing sections in the magazine. The symbols show places with unstepped access, wheelchair spaces and adapted lavatories, venues with incomplete facilities (ring Artsline for details) and venues with difficult access (ring Artsline), and venues where hearing aid systems are installed.

Would-be drivers put to the test

A DRIVER assessment unit capable of coping with a wide range of physical handicaps has been introduced by Lions International in conjunction with The Mobility Information Service.

Consisting of a specially designed simulator with a range of adaptations to accommodate various disabilities, it is housed in a towable module for ease of transportation, making it especially suited to schools, colleges and homes for the handicapped, as well as for exhibition use.

The unit is completed by the addition of the towage vehicle, a fully automatic transmission saloon car suitable for, and driven by, a wheelchair user, fitted with hand controls. Thus not only will disabled people be given an opportunity to assess their potential as a driver of the machine, but also if found suitable, they will be able to see and try the real thing at the same time.

FURTHER INFORMATION: from Mobility Information Service. Tel: 0743 68383.

Special buses on offer

DETAILS of 15 specially converted buses and coaches that are available for hire by disabled people through the National Bus Company are contained in a new leaflet 'Your Next Move'.

It has been produced by the NBC's Advisory Group on Disability and is available from local National offices or from the head office NBC, 172 Buckingham Palace Road, London SW1W 9TN. Tel: 01-730 3453.

Calling motor sport followers

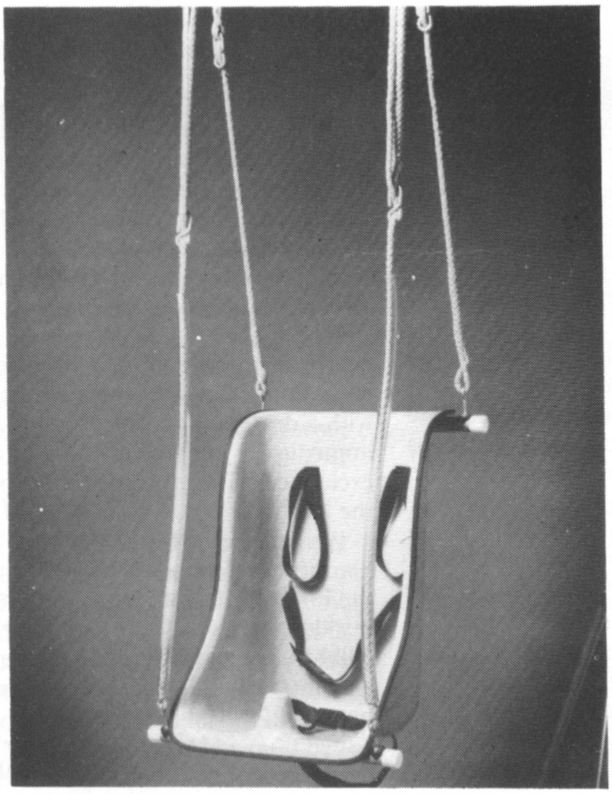
MOTOR sport enthusiasts, disabled or not, who are interested in starting up some kind of club or association for motor sport for disabled people are asked to get in touch with Ronald Cottrell, 87 Cedar Road, Strood, Rochester, Kent ME2 2JN. Tel: 0634 78601. Ideas and suggestions are welcomed, too.

Payment covers external decorations

DISABLED OWNER OCCUPIERS on supplementary benefit can now get single payments to meet the actual cost of redecorating the outside of their homes.

The Disability Alliance Rights Service helped one disabled owner to win his appeal to a Supplementary Benefit Appeal Tribunal. The Benefit Officer has now decided not to try and overturn the decision by appealing to the Social Security Commissioner. So all owners can now get this help if the outside of their homes need redecorating.

There is no upper limit on the cost of the works. Nor is there the usual capital limit for single payments. This is because external redecoration is an ordinary housing cost that should be met within weekly supplementary benefit, but as the cost cannot be known in advance and the need arises at irregular intervals, there is no practical way to work out an average weekly amount. Instead a one-off payment is made when the need arises.



Caroline meets the real Santa Claus

'Santa appeared at the cabin doorway, tall, majestic and smiling. He was dressed in red velvet edged with white fur, his thigh boots made of Reindeer skin and embossed with Lapp symbolic design. . . .'

AS CHRISTMAS approaches we wondered if you would be interested in learning about our disabled and very adventurous daughter Caroline Walsh. This chapter of her life involves meeting the real Father Christmas in Finland this summer.

After some deliberation we decided to combine our adult adventurous nature together with our daughter's Santa Claus dream and visit Finland.

Every Autumn my daughter, now seven years, writes to Santa Claus, Arctic Circle, Finland and she always receives a reply. With this in mind we wrote to the tourist board in the Arctic Circle at Rovaniemi, Finland, who arranged for Caroline to have an audience.

The holiday was split into two major parts. The first was a 19-day packaged self-catering motoring holiday in a traditional Finnish pine cottage with private sauna in a forest on the edge of a large lake all arranged by the tourist operator Europlan. This turned out to be rather magnificent in possibly the best cottage in Finland. The second part we arranged directly with the travel agent Finlandia and the Lapland Administration in Finland.

We should at this point say that Caroline is disabled due to being born with spina bifida and after explaining the problems and our fears the holiday companies made every effort to ensure all foreseeable problems were overcome before the event.

En-route to Finland we stayed at Gyllene Uttern Hotel standing like a fairy castle on the shores of Lake Vattern in Sweden, giving the spirit of the whole holiday.

The Scandinavians cater for the disabled person in every way but what we found particularly encouraging was that they treated you as an individual and not as a special case.

At Rovaniemi, the administration capital of Lapland, we stayed at the Polar Hotel. By purchasing Finncheques before our departure we stayed in the 4-star hotel for half price.

Upon our arrival we visited the Tourist Information Centre who notified us that Santa Claus would meet Caroline the following day and we would have an interpreter provided.

On Monday our interpreter took us to Santa's Arctic Circle cabin and Caroline drove her invalid carriage to where we hoped to fulfil her dream. To our surprise five Finnish national newspaper photographers and reporters were present taking many pictures and asking numerous questions. Then with the awe of his position Santa appeared at the cabin doorway, tall, majestic, and smiling. He was dressed in red velvet edged with white fur; his thigh boots made of Reindeer skin and embossed with Lapp symbolic designs.

He approached Caroline. Lowering to his knees he greeted his visitor and her dream had been fulfilled. They continued to talk by way of the interpreter for over an hour.

Caroline wanted to know why his beard was so long. He replied that he was 550 years old.

He showed her the reindeer and told her all their names. The herdsman was dressed in very impressive traditional Lapp custom.

Upon their conclusion of the audience Santa explained that visiting Caroline was his summer holiday from the North, and he would give her a Reindeer sleigh ride the next day. At this he mysteriously disappeared as he had arrived.

The following day the meeting had been recorded in the Finnish newspapers with many photographs under "The most important news item of the day". We were to discover later that Caroline was the first person to have an audience with Santa during his summer holiday.

For the Reindeer ride Santa had covered a small sleigh in Reindeer fur, harnessed a large animal and the herdsman to lead; all dressed in traditional Lapp custom. Santa mysteriously appeared again in his fine clothes and took Caroline for a long sleigh ride.

At the end Caroline asked how he travelled South to the Arctic Circle? He explained that the weather was too warm for Rudolf and his team so he travelled by spaceship and the gnome who controls it is called Apollo. The two parted good friends after about one hour.

Whilst seated in the restaurant nearby after the event an Air Force jet swooped low over the building with a deafening roar. Caroline immediately jumped up and exclaimed "There he goes back to the North".

We cannot start to explain the kindness and the spirit with which the Finnish Authorities entered into our daughter's dream. It was and will be a true holiday of a lifetime in a country of natural beauty and true paradise.

Caroline's Father.

WELSH BORN international singing star Tom Jones with two members of the South Wales Association, Robert Thursby and Leeanne Jewell, after a concert which he gave in aid of several charities including ASBAH in Cardiff in September. It was the start of a British tour, and this concert will be televised nationally on December 30. Also appearing that night was the Treorchy Male Voice Choir.

The South Wales Association was delighted to be chosen to benefit from the concert, and at the reception given by HTV Wales, members were able to meet other celebrities including Max Boyce and Viscount Tonypandy (better known as George Thomas, former Speaker of the House of Commons). South Wales Association agrees it was a night to remember.
Photo: HTV Limited.

Independence 1984

THERE ARE now only a few names on the waiting list for ASBAH Independence Training Courses. I would therefore like to hear of any young people with Spina Bifida or Hydrocephalus who might benefit from attending a course in 1984. I will be arranging the venues for 1984 courses at the beginning of December and it would be helpful to know which areas the students live in before then in order to arrange courses in the most appropriate places.

If you think you know of any possible students of any age please write or phone me at National Office as soon as possible.

Vivien Harper
LIFT Organiser

Study days

IN ORDER to help parents understand better the workings of the new Education Act, ASBAH is planning to hold 'Study Days' on the act in various parts of the country, starting in the New Year in the London area. More details in a later LINK.

Meanwhile ASBAH would be pleased to know what aspects of the Act you would like covered and any queries you may have.

THE WINNING float in the Lincoln Water Festival Carnival this year — entitled 'Gardening for Leisure; Gardening for Pleasure', built and manned by members of the Lincoln and Mid Lincolnshire Local Association.

They are pictured here after hearing of their success. Members had great fun not just taking part but also with the making of the float and costumes. The children helped in the making of over 2,500 paper flowers.

MSC fund field worker in Kent

KENT NOW has a Field Worker in the county concerned with the needs of those with spina bifida and hydrocephalus.

She is Mrs Pat Edser who started in September, and who is working for spina bifida families in Kent but has been employed through a Manpower Services Commission agency in West Malling, after consultation with ASBAH.

ASBAH is hoping to get a similar scheme underway with the MSC in the North, and LINK will publish details as soon as possible. It is a partnership which ASBAH hopes will prove successful.

NEW PUBLICATIONS

Motoring and Mobility for Disabled People

Available from RADAR, 25 Mortimer Street, London W1N 8AB. Price £2.50 (including p&p).

THE FIRST edition of this publication was a sell out, and this follow up, which contains even more information than before, should be as popular.

The authors Ann Darnbrough and Derek Kinrade have completely rewritten this edition. Parents can discover a deal of information on mobility for children in a new section on "Children and Personal Mobility'.

A chapter on Finance includes details of the Motability scheme and goes into detail on many other possibilities.

A new chapter shows how voluntary organisations have taken the question of transport into their own hands and organised Dial-a-Ride services.

Citizens Band Radio for disabled motorists is given its own chapter, and the book also gives information on some of the initiatives which have been taken to provide accurate assessment facilities.

There is a great deal of other valuable information about wheelchairs and holiday motoring, car hire, conversions, specialised and standard vehicles, road safety, driving tests, etc. . . .

Are you sitting comfortably, correctly and safely?

A guide to the right kind of cushions for wheelchair users

by
R. L. Nelham, B.Eng., C.Eng., M.I.Mech.E., M.B.E.S.
Technical Director
Rehabilitation Engineering Unit
Chailey Heritage Hospital

ANYONE who has to sit for long periods of time will soon experience discomfort as a result of the blood being squeezed out of the skin where it covers the protruding bones of the bottom (ischial tuberosities). For those who are wheelchair-bound and consequently spend the majority if not all of their day in the sitting position, and in addition have impaired or total lack of sensation, discomfort is unlikely to be experienced and the restriction of blood flow to this or any other area of tissue may lead to the development of "pressure" sores.

Whilst the danger of the development of sores exists, or the use of hands and arms is required for posture control, the potential for maximum functional ability and, perhaps, prospects of employment are markedly reduced. If a sore does develop the person will need to take their weight off the affected area and maybe spend some time in a prone position. This is far from a desirable position and leads to further difficulties in functional activities and results in a decreased quality of life. Prevention of skin damage is therefore of the highest priority.

Inspection of the skin over the bottom for the presence of red marks at the beginning or end of each day is a wise precautionary measure. If any red marks take longer than approximately half an hour to fade, then the skin is in danger of breaking down into a more serious sore.

The first step to alleviate this situation is to choose a cushion if one is not presently being used, or to question the performance of an existing cushion. DHSS wheelchair cushions are made of either latex or polyurethane foam, which degrades over a period of time. It should be checked frequently for its ability to distribute seating pressures adequately. The cushion should be replaced if the performance has deteriorated.

If the standard DHSS wheelchair cushions, with or without a sheepskin cover, are not adequate to prevent red marks from developing, it may be possible for a therapist or doctor to prescribe one of the large number of commercial cushions. A limited number of these can be supplied by the DHSS for use in their wheelchairs and there are many more which can be purchased from the manufacturers.

A comprehensive report written by Peggy Jay entitled "Choosing the best wheelchair cushion for your needs, your chair and your lifestyle" has just been published by RADAR and is intended to help those involved in the provision of wheelchairs and wheelchair cushions as well as the users. In includes information on the causes of sores, designs and performance of cushions and a chart to assist in the choice of the most appropriate type.

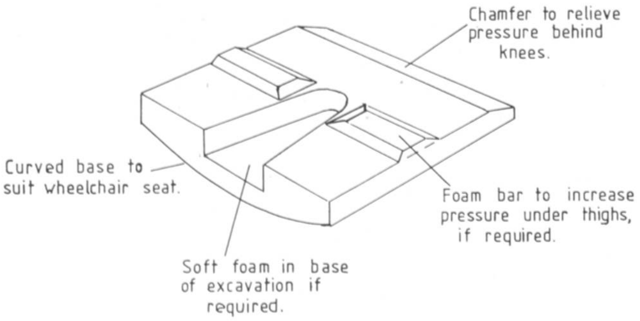
The main function of the majority of cushions is to distribute seating pressures over the largest area possible in order to reduce the maximum pressure and so preserve the skin. A cushion will also provide a stable platform for the pelvis in order to assist with hand function and should also be able to control humidity and temperature at the skin surface to prevent accumulation of perspiration or excessive heating of the skin. Both moisture and high skin temperatures will contribute to the development of a sore if the pressures are already reaching a point where blood flow to the skin is restricted.

There is no single design of cushion that can be considered as a solution to everybody's problems, which is reflected in the wide variety currently available. It is not possible to float on a cushion as in a water bed since the body weight is being supported on a much smaller area. A compromise solution is therefore achieved through the design of the cushion such that it allows the user to sink in, which maximises the area of support and hence minimises the pressure. The final support is derived from a combination of the tension of the cover on the cushion and the internal pressure or indentation hardness of the contents.

The most practical way of choosing a cushion is to obtain several types on approval and, if possible, measure seating pressures with the pressure transducers marketed by Talley Surgical Instruments Limited, or carry out skin inspections to determine the speed with which red marks disappear when weight is removed from the bottom. In general, those with protruding bones are likely to require thicker cushions than those who have a good quantity of flesh covering their bones. No design of cushion will overcome the need for frequent "press-ups" throughout the day to periodically relieve the pressure from the bottom.

Many people with spina bifida will have curvature of the spine and related tilting of the pelvis. This tilting of the pelvis results in a high pressure being taken on one side of the bottom which is likely to result in a pressure sore developing on that side. Several clinics throughout the world have established that certain areas of the skin are able to tolerate higher pressures than others and specially shaped cushions can be manufactured to distribute the pressures away from the ischial tuberosities, which are the most vulnerable areas for those with paraplegia, to the more tolerant areas such as the thighs and hip joints.

A sketch of such a cushion is shown in figure 1 and there are now some commercially available cushions which use this principle in their construction. Invariably, for those with a pelvic tilt, the cushions have to be made purpose made. This can be readily achieved by cutting the correct shape into a block of reconstituted polyether foam (chipfoam) of the appropriate density (norminally 6lb/ft^3) and the construction method is soon to be



published in the Physiotherapy Journal.

Having constructed a special cushion, or if difficulties are experienced in using a cushion with a PVC cover, it is preferable to use two way stretch covers in order not to mask the properties of the pressure distributing materials within the cushion. Two way stretch towelling used as slip on covers over the foam, with or without a two way stretch polyurethane film to waterproof the foam underneath, will often produce a more satisfactory solution than a thick and inelastic PVC cover.

Some users of DHSS wheelchair cushions turn them upside down in order to sit on the canvas surface, thus avoiding the perspiration accumulation that is likely to occur whilst sitting on the PVC coated surface.

Posture control is not a frequent requirement of those wheelchair users with spina bifida, but where it is required relatively simple solutions are usually the most effective. These include the addition of special designs of harness to support the trunk in a functional posture and these may have to be used in conjunction with side pads to support a spinal curvature where bracing with orthopaedic appliances is not appropriate.

Some modern designs of wheelchair have adjustable side pads built in and further information on these chairs may be obtained from the manufacturers, which include Everest and Jennings, Meyra and J. and A. Carter. The Disabled Living Foundation has a comprehensive list of wheelchair manufacturers and suppliers.

For those who require a great deal of postural support in order to achieve the required degree of hand function some individual seating inserts may be required, such as padded plywood box seats or moulded seat shells shaped specifically to the user's body profile. These are provided through specialist seating services and a list of manufacturers may be obtained from the DHSS at Blackpool. Moulded seats may also have an application where a very prominent spine requires protection when surgery is not indicated and horseshoe shaped back cushions have not worked.

Whichever solution has been found to be most effective it should be kept under constant review since new cushions are constantly being developed and the user's requirements will often change. The advice of therapists or other health service staff with experience in solving seating problems may be necessary to obtain the most effective solution and the Disabled Living Foundation or the manufacturers of wheelchairs and cushions may be able to assist with the choice of the most appropriate equipment. No one who spends a great deal of time in a wheelchair can expect to reach his or her full potential unless correctly, comfortably and safely seated.

Editor's note: The Disabled Living Advisers at National Office are available to help with advice, and full addresses, etc.

All kinds of everything at the LIFT Conference

WHAT'S ON the Agenda for LIFT's first weekend Conference next year? . . . Talks and discussions on sex, personal relationships, the role of LIFT, workshops, sport, education and a fancy dress disco.

This weekend for the members of LIFT (young ASBAH) should prove a lively occasion. The more people who go the merrier, so send for more details now and get your name on the list.

It will also be a celebration marking ASBAH's 'coming of age' — its 18th birthday.

The Conference will be a great chance to meet other members from all over the country.

The date is March 30-April 1, and the venue is Owens Park, Manchester University.

For more details and a form contact Paul Cooper or Vivien Harper at LIFT office, ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. Tel: 01-388 1382.

Sex, Water Sports, Driving, the National Health Service

Sex for Young People with Spina Bifida or Cerebral Palsy

Available from ASBAH National Office: price £1.25 plus postage.

I WAS very pleased to see this edition of *Sex for Young People with Spina Bifida or Cerebral Palsy,* and I was especially interested to see what changes had been made to the original book in order to include the very different problems caused by cerebral palsy.

The preliminary sections dealing with basic anatomy and the physical side of sex are in fact virtually unchanged, and I feel they give a good general introduction to the subject. I was pleased to see that the very important difficulties handicapped people may have in forming relationships were seriously considered, as well as the possibly unpalatable fact that not everyone either wants or will be able to achieve an active sex life.

I'm sure its at the back of every disabled person's mind that their handicap may adversely affect their chances of having a sexual relationship, and of course the greatest worry of all is how and when to tell a prospective partner about incontinence. While its obviously impossible to give concrete advice, I think the emphasis on mutual trust and understanding is right, as well as the important observation that this can only be achieved by people who are interested in each other as *people,* quite apart from sexual partners.

In view of this, I think the book does well to stress the importance of getting on well with people generally, and making the most of the positive side of ones character.

The chapter devoted solely to spina bifida is good, and the problems of incontinence are dealt with in the sympathetic but matter-of-fact way that every handicapped person appreciates.

However, I do think maybe a little more could have been said about the difficulties spina bifida people may encounter in having sex, which may be quite specific. For instance, there can be the simple physical problem of a greater than usual height difference if only one partner has spina bifida, or if both are disabled, a lack of sufficient flexibility in some positions.

Granted not everyone will have these problems, but I think many people would have taken some reassurance from discovering that they are quite common. I also found the vague reference to "alternative forms of love making" rather coy. I'm sure I'm not the only one who will be curious about what was being referred to!

I found the chapter on cerebral palsy interesting, but I must admit I did still feel that these problems were so different to those of spina bifida, that they did not combine particularly successfully in one book.

However, that apart, I do think it is a very valuable book, and one which will be read with interest by many disabled people. It succeeds very well in presenting the facts, and young disabled people will be much reassured to read that although they may well face various difficulties, they are nevertheless just as capable as anyone else of enjoying satisfying sexual relationships.

ALISON DAVIS
Chairman LIFT Committee

Water Sports for the Disabled

THIS book should be read in the context of 'I am going to participate' and not 'I do not think I am capable'. You have got to be as positive as the book.

I say this because the book starts from the premise that water sports are not too difficult for disabled people.

If you are an instructor reading the book you will find it very helpful.

The book gives a brief breakdown of disabilities. It also stresses that an instructor must know about these disabilities and not shy away from them — because it could cost one of 'your' students their life.

The book also tells potential participants to stress the extent of their disability and not to try to cover it up. For example, unreported epilepsy could and has, resulted in someone drowning.

A very important message contained in the book is that if you, as a participant, are unsure of how capable you are or, if you as an instructor, are unsure of a student's capabilities — informed medical opinion should be sought.

Thus, as you can see, the book is very positive whilst very safety conscious.

The correct balance has been achieved. But, to put another angle to the book, it also pulls no punches. It does stress that risks are involved. It also points out that *you* take the risks, not your instructor or friend. When your canoe tips over, there will not always be somebody there to help. *You* have to know how to help yourself!

The book does not romanticise. It puts the truth in print. You will not be able to participate in every water sport: there are limits. However, on the other side of the coin the book points out that barriers have often served as a stimulus to enterprise and inventiveness.

So, if your problem is purely technical — don't give up — think about it — you may beat the problem.

The book does give good practical advice — try and learn a sport in a controlled situation. For example, try and learn the basics of canoeing in a swimming pool and not in the river or lake.

The only criticisms I can level at the book are, firstly, in the fishing section, for example, tackle is described, how to stop a wheelchair running away is dealt with, but what about the fish? Fishermen are always interested in them! A reference or two to a few fishing books would have helped just to wet (sic!) people's appetites!

The second criticism is that although training courses are suggested, there is no mention of where to find a course, any idea of the length and contents of a course, and most importantly, the cost involved!

In summing up, the book does fulfil a great need for guidance in an area where there are many who are eager to participate but who lack the knowledge and often the confidence to do so. One last word of advice from the book:

Don't be put off by problems or setbacks — try and try again (if at first you don't succeed!) For me, the purpose of the book is to get people involved. If it does this then it will be a success! I think it will be.

PAUL COOPER
LIFT Organiser

This book covers angling, canoeing, rowing, sailing, coastal cruising, sub-aqua, water skiing power boating, model yachting and swimming.

It is available from bookshops or direct from: EP Publishing, Bradford Road, East Ardsley, Wakefield, West Yorks WF3 2JN. Price £9.95.

Putting My Foot Down

Available from the publishers: New Horizon (Transeuros Ltd), Horizon House, 5, Victoria Drive, Bognor Regis, West Sussex PO21 2RH. Price £4.50 (plus 50p p & p).

JANE Stewart-Smith has written this book with enthusiasm engendered by her great love of driving. She sees it not only as a means to an end, but also an art. Very rightly, she wishes to share this enthusiasm and, hopefully, to spark more alertness and genuine pleasure in driving in others.

The general impression is of a fresh and unusual presentation. Whereas it is not intended as a text book on the subject, a few more diagrams in place of photographs could have been more helpful.

This book is probably more useful to the qualified driver, but there is also a wealth of tips for the learner. Perhaps the young spina bifida/hydrocephalic driver could find a more structured book of greater help.

If you buy this book please do not follow the suggestion of allowing your dog to occupy the front seat. Not only is it dangerous if the dog sees a cat, but also the dog could get hurt in an accident. Although it technically isn't an offence, the police certainly advise against it.

This book will certainly make you think about your standard of driving and should, as Jean Stewart-Smith hopes, improve your performance.

Physical Education for Handicapped Children

'Physical Education . . .' is an addition to the very popular Human Horizon series. Available from bookshops, price £4.95 (paper back), £7.95 (casebound).

THIS book written by Sarah George and Brian Hart, outlines some of the handicaps found in a Physically Handicapped School; in this instance, the Cedars PH School, Southampton, and describes a form of Physical Education known as the Circuit, which is used in that school.

It also includes detailed accounts, freely illustrated with diagrams of indoor and outdoor games to play with handicapped children.

There are some good 'straight from the shoulder' comments about attitudes toward the disabled child, with a strong message to all in contact with them to allow them to integrate with the able bodied and to think positively: for instance — before one says 'this child can't because . . .' one must think 'is there a way?'

The book includes 'thumb nail sketches' of various handicaps and their problems. The school has a predominence of spina bifida children and therefore is most helpful for groups dealing with spina bifida and hydrocephalus. A failure of the book is the out-dated information of the key help "Useful Addresses" . . . even ASBAH's address is given incorrectly!

MARY BARTON
Disabled Living Adviser

A Patient's Guide to the National Health Service

Available from bookshops or from: The Subscription Dept., Consumers' Association, Castlemead, Cascoyne Way, Hertford SG14 1LH. Price £3.95 including p&p.

THIS guide published by the Consumers' Association and Hodder and Stoughton was produced in collaboration with the Patients' Association*.

"It helps you get the best from the NHS with the least difficulty" says the Patients Association Chairman, Dame Elizabeth Ackroyd.

The guide explains how the NHS structure works, who is responsible for what, who go complain to if things go wrong and what you can reasonably expect of, say, a health visitor, a doctor or an optician.

It also suggests when it might be worth going outside the NHS for treatment. The guide advises on where to get specialised information, whether about visiting children in hospital, making provision for the elderly or hiring a nurse. It also explains how to find out what surgeries and health centres are available near you; and what to take into account before making your final choice.

Free prescriptions and other benefits are covered, as are maternity and child services.

A Patient's Guide says that there are a 'number of reasons' for considering private treatment but 'it is not generally true that going privately leads to "better" medical care'. Bear in mind, it adds, that unless you're referred by your GP it's up to you to find out how well qualified your non-NHS practitioner is, as there's nothing in English law to stop someone calling himself a doctor, or an acupuncturist, or a cosmetic surgeon.

The book looks at a number of services for which you might consider private treatment; and, as private patients do not have recourse to the NHS complaint system, it outlines their legal rights.

The role of district nurses and people in professions that are supplementary to medicine, such as physiotherapists, occupational therapists and dietitians, are explained in the book, and there's a section on the controversial question of access to medical records. There's also a useful list of addresses at the back of the book.

** The Patients Association is an independent organisation offering advice to patients and representing their interests. It is financed by donations, by a Government grant, and by members' subscriptions.*

1983 . . . ANNUAL MEETING . . . 1983

ASBAH was delighted that its President, Lord Maybray King was able to be at the Annual Meeting held this year at St. Thomas's Hospital, London. He was unable to attend last year because of ill health.

His warmth and genuine interest in ASBAH's work together with his irrepressible humour got the meeting off to a good start. He praised the work of ASBAH and its staff, and paid special tribute to the devotion of parents of children with spina bifida and hydrocephalus. He gave ASBAH his very best wishes for the future as it 'comes of age' next year.

Finance: It was "hard going"

1982/3 was a tough financial year for ASBAH. Total expenditure exceeded normal income by some £183,000, a situation which gave cause for concern.

However, ASBAH again benefited from a number of substantial legacies which reduced the overall deficit to £46,000.

Mr R H Smith, the Hon Treasurer, told the Annual Meeting that the deficit was partly due to a 42% increase in expenditure incurred as a result of carrying out the new 'forward plan' of development.

At the end of the day ASBAH was still fortunate in having a fairly strong capital of £362,000.

Another factor contributing to the deficit on the year, said Mr Smith, was that donations were down by 6%. He felt that one of the main reasons for this was the postponement of the usually successful Summer mailing appeal because of the Falkland Islands Appeal.

He commented on the welcome success of the new space selling department of ASBAH, and the increased level of support from the Local Associations.

As part of ASBAH's 'forward plan' there was increased expenditure on specialist welfare work, fieldwork and grants and ASBAH's contribution to research was up, too.

Publicity and promotion costs had risen and Mr Smith said how to continue to raise money each year was a source of concern to all charities.

The only sure way to reduce the debt, he said, was by a drastic reduction in services, which wasn't desirable. Fortunately there had, from year to year, been a recurring pattern of legacy money, and it was to be hoped that new and successful ways of raising money would be found. He emphasised that saving money, where possible, was important.

Later in the day Mr Smith reported on the financial situation after the first four months of this year (to the end of July), and said the situation looked brighter. There was a 12% increase in income over the same months last year compared with a 4% increase in expenditure.

THREE new members have been elected to the Executive Committee of ASBAH: Mr Douglas Endersby, Chairman of Greenwich Association, Mr Alan Dale who has been associated with ASBAH for many years and is a member of the Management Committee, and Mr Brian Henley, the active Chairman of Worcestershire and a former member of Executive.

Busy ASBAH is coming of age

NEXT YEAR will be a significant one for ASBAH said the Executive Director, Miss Moyna Gilbertson, in her speech at the Annual Meeting.

"It will mark ASBAH's coming of age, and we look forward to emerging into adulthood and grappling with the challenges that will no doubt bring", she said.

It will be 18 years on April 28 since ASBAH's Memorandum and Articles of Association were signed, and Miss Gilbertson said that suitable celebrations would be arranged around that time.

"Already the search is on for someone born on April 28."

Miss Gilbertson referred to the young people's organisation LIFT which will be arranging its first ever Annual Conference in March and which would be one very suitable way of marking the occasion.

She made other references to the participation of young people in the growth of ASBAH and ASBAH events, notably the Spring Conference earlier this year. The LIFT committee was now a strong one with seven young LIFT members with spina bifida out of a total of 10 on the Committee.

Miss Gilbertson said: "Just a couple of weeks ago an activity holiday was held at the Calvert Trust Adventure Centre. Thirty-two young people — if you include the staff, Paul, Vivian, Siobhan and Andrea — including 17 LIFT members enjoyed a week of rock climbing, abseiling, canoeing, sailing, riding, fishing, orienteering and generally relaxing.

"The holiday was partly funded by a £1,700 grant from the Royal Wedding Fund. We hope that this will be the first of many such holidays and are delighted to have established firm links with the Calvert Trust.

"Leisure activities are becoming an increasingly important element of courses at Five Oaks. Six young men have recently enjoyed a fishing weekend with companions from the Ilkley Angling Club. Each one landed a catch and somehow the torrential rain didn't seem to matter! We have sixteen other leisure and sports courses at various stages of planning ranging from wheelchair dancing, archery and gardening to rather more gentle weekends learning about flower arranging and jewellery making.

"The Treasurer has emphasised the worrying financial situation we face. In an effort to improve Fieldwork cover throughout the country without incurring increased expenditure we are hoping to be involved with Manpower Services Commission schemes (see page 00).

"Study days have become acknowledged as an

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MR DENIS Bryant, ASBAH's Chairman described the Association as 'vigorous and active'. He added "It is clear about its aims, but doesn't feel it has achieved them all. There is so much to do and it is only possible to tackle a portion."

He pointed out that this year ASBAH has had to tackle and face up to the problems of insufficient funding, and had also had 'a soul-searching time' looking at its own internal structure and various committees.

"We have restructured and streamlined the organisation in a way which we think will make the way ahead clearer", he said.

Mr. Bryant chaired the afternoon's Council Meeting in his familiar and efficient and cordial style.

important part of the programme of both the Education Training and Employment, and the Disabled Living Advisory departments. They are a satisfactory way of reaching large numbers of professionals. Each one we have organised so far has been oversubscribed indicating an urgent need, especially from staff of ordinary schools who are now beginning to accept responsibility for disabled pupils. We have been lucky in attracting financial sponsorship to help defray the costs of the study days so far held, and are actively seeking sponsors for the future.

"A few years ago we were pleased and somewhat surprised when the first edition of *Sex and Spina Bifida* sold out very quickly. Subsequently the Spastics Society asked if they could collaborate in the production of the next edition. It is a great relief to be able to report that after a longer gestation period than we had hoped *Sex for Young People with Spina Bifida and Cerebral Palsy* is now available — and we did welcome this opportunity to work with another charity and avoid duplication of effort.

"*Life and Death* — some thoughts on bereavement was also published this year and *The Handwriting of Spina Bifida Children* has been reprinted. Work on *Spina Bifida and You — a handbook for young people with Spina Bifida or Hydrocephalus* is almost complete and should be available early in 1984. This means our publications programme is almost back on schedule."

Miss Gilbertson referred to the increased links with overseas. Through ASBAH's membership of the International Federation and Mobility International, it hopes to develop courses at Five Oaks which will include some overseas students — initially students from EEC countries.

"Barbara Newman and I attended a meeting in Brussels on the problems of employment, and this Autumn sees the second Conference and General Meeting of the International Federation when Mr Duncan Forrest and Mrs Leonie Holgate will present papers".

Miss Gilbertson described the past year as "busy, and stimulating, and I hope, constructive". She thanked the Chairman and Committee members for their support and paid tribute to the 'good humour' of National ASBAH staff who had been working under difficult cramped conditions.

AT THE Annual Meeting, Staffordshire Association presented its annual cheque to further the work of ASBAH. It donated £500 for the Professor Zachary Fund and £1,000 for ASBAH's work.

"IT IS with brothers and sisters that a child has fun. It is with brothers and sisters that a child grows. It is with brothers and sisters that a disabled child develops and reaches maturity and achieves the complete life, or as nearly complete as possible, which will certainly be more complete than we guessed at the beginning."

The importance of Happy Families

Duncan Guthrie, Founder and Director of the Disabilities Study Unit and well known for his work concerning disablement spoke to the Annual Meeting on the subject of Happy Families — the relationship of children to their handicapped brother or sisters.

Much of what he said was based on a survey that he conducted earlier this year on the attitude of non-disabled children to their handicapped siblings. Mr Guthrie pointed out that a number of ASBAH members and LINK readers took part in the survey.

"EVEN if I do not consider the family the be-all and end-all of personal relationships I am staunch believer that our modern family is the nucleus from which the total person — child, adolescent, adult — develops and that a happy and satisfied childhood is more likely to produce a happy and satisfied adult.

"I am the administrative director of the CHILD-to-child programme. Although this programme was primarily designed for the developing countries it is worth our while to have a look at is for it also has relevance, I believe, to our own society.

"In the Third World, as all who have worked or travelled in the developing countries know, children, even quite young children, look after their younger brothers and sisters in a way quite unknown to us in the industrialised countries. We appear to believe that if we ask a child to look after little brother or sister both are immediately run over by a bus or both immediately fall into the canal. It is not true! Even little children have an inborn capacity for caring for the yet smaller child in the family group — a capacity that our culture has stupidly done its best to eliminate from our own children.

"I suppose everybody who is listening to me knows that terrible book 'The Lord of the Flies'. I say 'terrible' advisedly. It is, as you will remember, the tale of a group of British school children who are ship-wrecked and who, separated, revert 'naturally' to a state where social

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responsibility and ethical standards no longer exist. The children become absolute horrors and the message of the book is that this is what happens to immature minds when the controls are relaxed. This denigration of the child is indeed 'terrible' — especially since the book has become 'required reading' throughout the educational system of almost all the United Kingdom and of a great part of the English speaking world.

"Many million children are being told 'This, dear child is what *you* are really like'. Not only is it a terrible message for children it is also quite untrue! In 1965 six teenagers from Tonga, who had gone fishing in an open boat, were caught in a hurricane and after eight storm-tossed days ship-wrecked on Ata, an uninhabited island, their boat in smithereens. There they were marooned for 15 months until an Australian fishing boat, the 'Just David', rescued them.

"When they found themselves naked and bleeding on this island, thickly forested and with precipitous cliffs, they sat down and vowed that, no matter how great the provocation, they would never quarrel. They promised each other too that no one would ever go alone — they would always be paired lest one should hurt himself or get lost. And they agreed that two would be on watch night and day, in case a ship were sighted. (Four times ships came close but in spite of frantic signals, sailed on. What must have been the youngsters' feelings!) But they kept their promises to each other — and survived.

"As Alec Dickson, the founder of VSO and the man who drew my attention to this story, said 'Is theirs not a more remarkable — and nobler — story than Golding's novel?'. Is it not, I would add, also a reminder to us that our children — and when I say 'our children' I mean British children, Tongan children, American children, Chinese children . . . — are pretty remarkable, pretty reliable, pretty admirable and pretty lovable — notwithstanding their clothes, their hair-do's, the noise they make and the strange things they sometimes get up to.

"It was because of the success of my CHILD-to-child programme in the developing countries that I started thinking of its application to children in our own society. I had the honour of calling on Mrs Carter when she was still in the White House to explain CHILD-to-child to her, 'But you know' she said to me, 'this could be very useful to our own disadvantaged populations — in the inner cities, for instance, and country folk in the Appalachians'. Also, I thought, among so-called comfortable, middle-class families. But, most of all perhaps, among 'disabled families' of whatever social class, for their childhood has more than its fair share of difficulties.

"The Disabilities Study Unit commissioned a little booklet for the non-disabled siblings of handicapped children — 'One of the Family'.* It explains in very simple terms, what handicap means and suggests ways of developing better relationships between non-disabled and disabled siblings.

"This led me to start looking at the existing relationship between non-disabled and disabled siblings. To this end I set up a little study, based on a postal questionnaire.

"I must admit that the study was not as scientifically designed as I would have wished. This was chiefly because the resources available to me were very limited. . . ."

Mr Guthrie enlisted the help of voluntary organisations like ASBAH to get the questionnaire out to non-handicapped children. He was able to collect questionnaires from 258 children with disabled siblings (115 boys, 141 girls and two 'not known'!).

Not only was a great deal of valuable information obtained from the questionnaires, said Mr. Guthrie, but he felt that many of the children benefited from having to analyse their own feelings and behaviour.

He found that the 'lower' the social class, the more likely that the handicapped child had been kept within the family. Children from this class were more easily able to accept the situation of having a disabled member of the family, and felt less than other children that it had changed the family or made a difference to their own lives.

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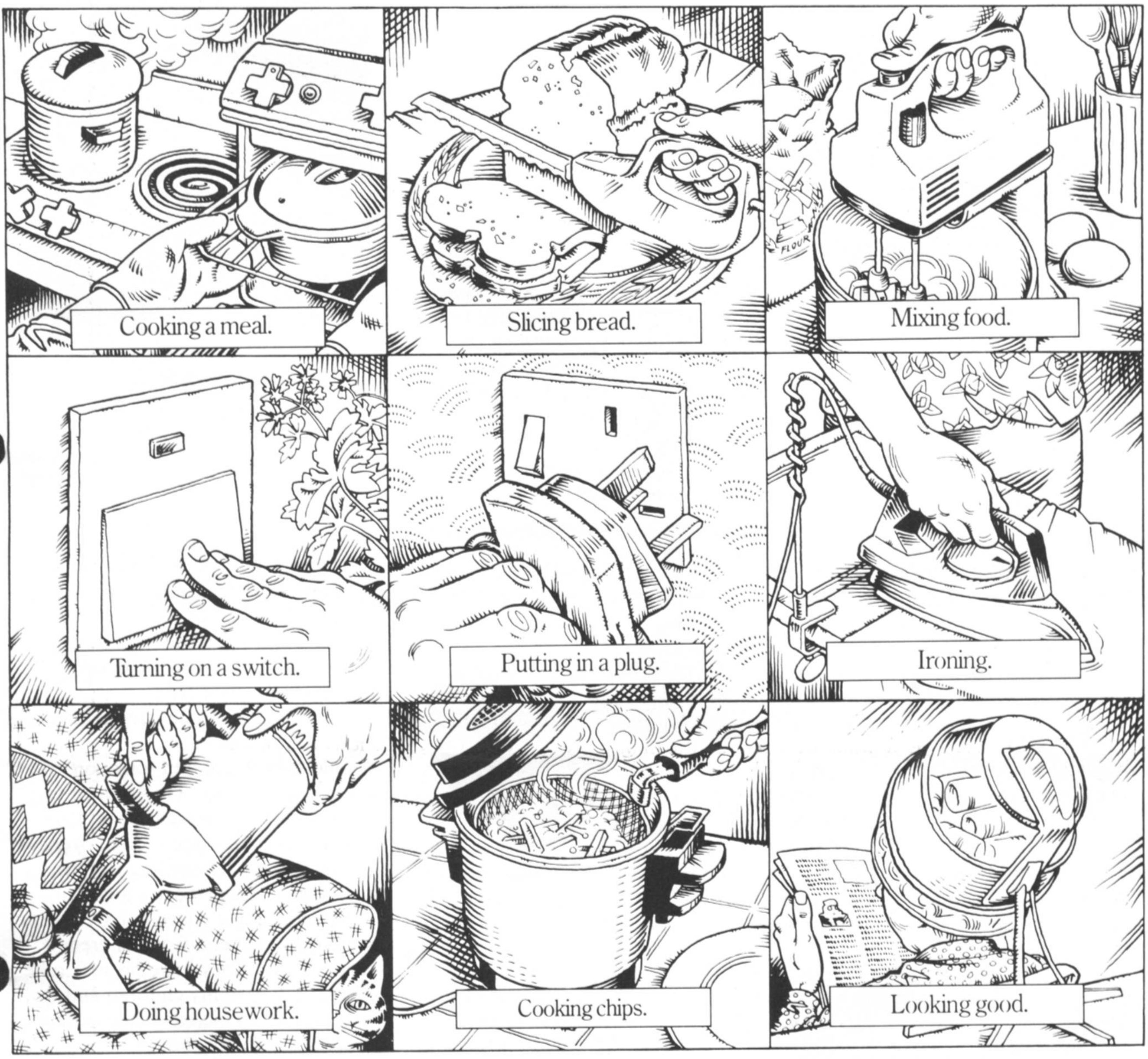
What brothers and sisters had to say . . .

- *"I find that because he is handicapped, he is different and, therefore, I like him best."*
- *"We have a special rapport not based on words so much as a shared childhood."*
- *"I wonder how God can be so beastly to make my brother handicapped."*
- *"I think it is so sad when I hear handicapped children singing 'Yes . . . Jesus loves me' when they are the way they are."*
- *"I think God has put handicapped people on this earth for a reason — to show us that life is not meant to be easy. . . ."*
- *"Having a handicapped brother has made me think that he once lived but has come back in a different soul."*
- *"I get on with my sister better than anyone else in the world."*
- *"I will look after him if he doesn't drive me mad, but I think he will."*
- *"I enjoy looking after him now . . . I hope he will be more able to look after himself in the future."*
- *"I like looking after him now as he is my friend, but if I want to do something else I get annoyed."*
- *"If my mother died I would be the sole person who could continue the care and love my mother gave, so I would be prepared to look after him myself under any circumstances."*

**'One of the Family' is available from the Disabilities Study Unit, Wildhanger, Amberley, Arundel, W. Sussex.*



Is it this easy in your home?

At your Electricity Board, we have a leaflet called "Making Life Easier for Disabled People".

It contains lots of helpful ideas and lists many electrical appliances which can make life easier.

Appliances such as table-top mini cookers. Electric knives which require only a slight pressure to operate. And small, hand-held vacuum cleaners which can be used for dusting, too.

The leaflet also gives details of brailled controls that can be fitted to certain electrical appliances. And specially designed attachments for plugs and switches which afford easier handling.

The leaflet is free, from your Electricity Board shop. Or you can write for a copy to the Electricity Council, Information Centre, 30 Millbank, London SW1P 4RD.

THINK ELECTRIC

The Electricity Council, England and Wales.

Trikes and carts that help put the fun into play

OVER THE past few months in the Disabled Living Advisers' Office at National Office, we have received a flow of enquiries concerning the various pieces of mobility equipment on the market. There are many carts and trikes available which many spina bifida youngsters enjoy playing with and we thought, therefore, that we should describe a few of them.

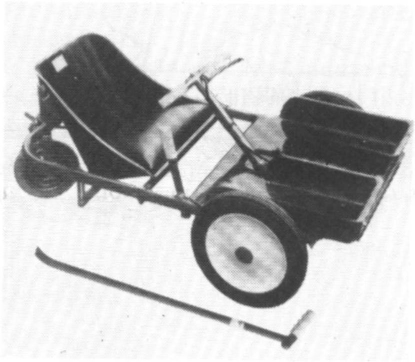
Shasbah Trolley

THE STANDARD model is 23″ long x 11″ wide. This is thought to be suitable for children up to the age of 5 years, but, of course, this depends on the size of the child. The standard model and the very similar Chailey Trolley are available from the DHSS. The Shasbah Trolley is now being made by the Midland Association, 14 Court Road, Sparkhill, Birmingham 11. Tel: 021-771 0371. (See advertisement on page 9).

Byrd's Buggy Car

BYRD'S SUPPLY a range of buggy cars — the Mini Bug is designed for children aged 20 months to 5 years. The Mini Bug is more advanced than the trolleys. A back rest can be fitted to these buggy cars for added support. The two hand levers can be slightly difficult to master as the youngsters have to pull and push them alternately in opposite directions.

These toys offer fun play and, at the same time, youngsters feel comfortable and many will happily play in their calipers.



The Prindus Hobcart

THE HOBCART is propelled by means of forward and backward movements of the centre lever. A gear lever enables the child to easily change to and from reverse. There is a detachable long handle which fits on to the rear of the cart which enables an adult to help the youngster propel himself if necessary.

This cart's normal speed is a slow walking pace, and it requires a fair amount of effort on the centre lever to go a short distance. It is, however, a very safe and practically unspillable vehicle as it sits so near the ground.

It can take children from about 3 to 12 years of age and is also available from the DHSS. The vehicle can be ordered from: PRINDUS, c/o Directorate of Industries and Supply, Home Office, Tolworth Tower, Surbiton, Surrey KT6 7DS.

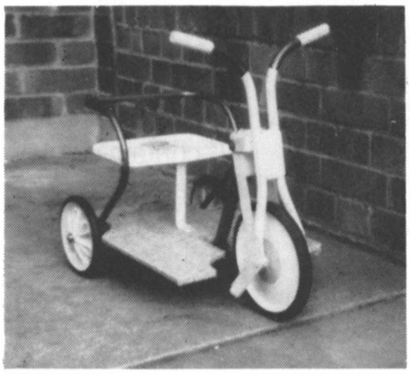
The Thistle Tricycle

THESE tricycles come in three sizes to suit disabled people from infants through to elderly adults. The smaller size of tricycle is designed to meet the needs of children aged 4/10 years and is available with alternative leg-rests.

Those children who have calipers without knee-locks can have the original design, but those who are able to bend their knees can have a tray, mounted lower down, on which to rest their feet.

Like all three-wheeled vehicles, these trikes had been known to topple over if children took corners and kerbs too fast. Tri-Aid now fit an adjustable steering lock on the trikes which prevents sudden oversteering to the left and right, thus making the trikes more stable.

Many of these tricycles have been supplied to spina bifida children in this country. They have proved to be a great joy to many children and have helped to increase their outdoor mobility and their independence, especially when playing with other children. They are also available from the DHSS.



Small Trikes Adapted for Hand Propulsion

AN ADAPTED trike for the child under 5, that's the aim of Mavis and

Adapting Small Trikes

Ken King in Kent, who together with Mr Fred Walton a retired craftsman in Somerset, adapt the Raleigh Mini Trike. It is particularly suitable for spina bifida children and is a robust 3 wheeler with a good wide seat. The work is done on a non profit-making basis. The total cost of a trike with conversion, package and sending etc. is about £45-£50. The platform fixed to the base of the trike will need a little simple work done on it by the recipient to make it fit the individual child — adding sides, building up or screwing on shoe plates.

Enquirers should first visit their local toy shop and see if they consider the Raleigh Mini Trike the right size for their child.

For more details contact: Mrs Mavis King, Sycamore Cottage, Swan Street, Wittersham, near Tenterden, Kent. TN30 7PH.

ACTIVE Leeds and District Branch

THIS adaptation is similar to above. However, Leeds Active use various ordinary trikes and adapt them to the needs of the individual. Anybody who is interested must discuss his requirements with the converters beforehand.

The price of conversion varies with the model of trike selected. The converters are: ACTIVE Leeds and District Branch, 3 Roxholme Terrace, Leeds, W. Yorkshire L37 4JH. Tel: 0532 622339 (evenings/weekends).

We will be pleased to supply manufacturers' leaflets to those interested in mobility equipment for youngsters with spina bifida. We also have further information about carts and toys not mentioned in this article. Please do not hesitate to contact:

MARY SMALL or ANDREA ROBINSON at ASBAH National Office on 01-388 1382.

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The less advantaged more readily 'closed ranks' and worked together to deal with the family problem, and the children appeared to be more willing to look after their handicapped brother or sister.

One of the questions producing a wide range of replies was 'Has having a handicapped brother or sister made any difference to your religion or your ideas about religion?'.

Dr Guthrie referred to another finding — the relatively small percentage of children who knew or did not know whether their brother or sister's disability was hereditary. "A case could, perhaps, be made for not telling very young children, but of the total of the children in the survey there are only 18.6% under 11 years" he said.

"There were many other questions and many interesting replies which I have not had time to report to you today. I can say however that the research, as a whole, has reinforced my belief that it is within the family that the seeds of a lifetime are sown and that within the happy family the seeds of a happy lifetime blossom.

"Ogden Nash in his own ironical way reminded us that —

> One would be in less danger
> From the Wiles of a stranger
> If one's own Kin and Kith
> Were more fun to be with.

"Do not let me suggest that parents cannot be 'fun to be with'. Some certainly are. When I was a boy I envied those other boys whose parents were 'fun' — my own were sadly sedate — and as a parent myself I tried to laugh and lark with my own children. But there always was and there will always be something of a generation gap.

"It is with brothers and sisters that a child has fun. It is with brothers and sisters that a child grows. It is with brothers and sisters that a disabled child develops and reaches maturity and achieves the complete life, or as nearly complete as possible, which will certainly be more complete than we guessed at the beginning.

"In 'Integrating the Disabled' — the report of the Snowdon Working Party on the Integration of the Disabled — Lord Snowdon speaks of the 'two nations out of whom in the name of humanity and the greater benefit of all we should strive to make one'.

"Families are seldom divided, certainly not happy ones. Why cannot the integration that exists within the family, disabled child with non-disabled child, be maintained into adulthood, on into life in its widest sense?

"If at times integration fails, I blame those who claim that the disabled are special as much as those who claim the non-disabled are special. An elite of the disabled is just as bad as an elite of the non-disabled, and a society which excludes the non-disabled has replaced integretion with segregation as much as one that excludes disabled people.

"To sum up my paper . . . which is a mixture of my own thoughts backed up by the replies: 1. The childhood family has a strong influence on a child. 2. A *happy* family has an even stronger influence on a child. 3. A *happy* family has the greatest possible influence on a *disabled* child. 4. In a child's development, brothers and sisters are as important as — and often more important than — fathers and mothers.

"And so it is up to us who are parents (and grandparents) to help all our children, disabled or non-disabled, to develop as integral parts of the whole family.

"I am reminded of one of our young respondents with a mentally handicapped sister who wrote that at first she 'thought everyone had a handicapped person in their family and was very surprised to find they hadn't. I, therefore, felt that her handicap was normal'. Perhaps she was not so wrong after all."

INTEGRATION OF HANDICAPPED PUPILS: Following the introduction of the 1981 Education Act more handicapped children are likely to be integrated into ordinary schools. Here Sheila Waldron describes how two handicapped girls, Allison and Lesley, have already joined a comprehensive school.

How Allison and Lesley became part of the School

I AM A school nurse employed by the Nottingham Health Authority in a comprehensive school of about 1,040 pupils. Situated in a large mining village the school also serves the smaller villages within a radius of 12 miles.

A radio programme about the difficulties in placing physically disabled sixth form students stimulated our head teacher to invite the heads of the local special schools to visit. Two years previously we had accepted a handicapped pupil and the head thought it would be interesting for them to see how readily David had been accepted.

David, who came as a second-year pupil, has a congenital condition of the central nervous system and alternates between wheelchair and crutches. He is continent, and therefore manages to use the school toilets.

Our visitors saw that most of the building is on one level with the exception of the craft block. However, there are alternative craft facilities on the ground floor.

A year later the head visited a special school in our district to see the children at work and their facilities. He was introduced to two nine-year-old spina bifida girls who were considered to be capable of a full senior school curriculum and of taking part in ordinary school activities. The venture was discussed by our head teacher, the director of lower school, deputy head for pastoral care and myself. Everyone was interested and keen, but had reservations about the practicalities.

In March 1980, the parents of one of the little girls visited the school to look around and talk to the head and myself about their daughter. We had a general discussion with special reference to mobility, continence and aids. The doctor, headmaster and school nursing sister from the special school also visited.

Following a tour of the buildings we discussed the practical implications for each of the girls. Six months later a case conference was held at the special school, including both head teachers, medical and nursing staff and the educational psychologist. It was agreed that the girls were suitable for a normal school.

THE various departments met to discuss the necessary structural changes. The sister from the special school and I spent a morning investigating and discussing the possibilities of the proposed alterations to the school. The ramps, hand-rails and access to class rooms were relatively uncomplicated. It was more difficult to decide on toilet facilities.

Access from my room was essential, thus a separate door was needed on the main corridor to facilitate easy access and encourage independence. The special school sister offered advice on the height of the toilet, positioning of rails, hand basin, mirror and shelves. During the next few weeks the clerk of works and surveyor arrived to measure and plan.

I visited the special school which was itself undergoing changes so I was unable to meet the girls on that occasion. However, I was able to see how they dealt with spina bifida children, and, in particular, how they managed their incontinence.

During February the proposed alteration costs arrived — approximately £2,500. The following month the alterations and financing were approved. During June the builders, heating and ventilating engineer made a final check and promised that all the alterations would be completed during the school holidays.

On my nursing officer's advice, the paediatric liaison officer arranged for me to spend a morning with the physiotherapist responsible for spina bifida children.

A useful morning was spent in the physiotherapy department's hydrotherapy pool seeing the children handled. I talked to their parents and saw the children in action. We discussed swimming, boots, jackets and appliances, particularly those related to intermittent catheterisation.

Four months later Allison and Lesley came to school with other potential pupils, to acquaint themselves with the surroundings and to meet the head, their tutors and myself. Before the end of term they spent another morning in school using their wheelchairs and finding their way around. They were bright, cheerful and full of optimism. In the meantime I visited them at their special school where they introduced me to the nurses and teachers.

ON the first day of the autumn term Allison and Lesley arrived with their mothers. After a quick word of assurance from me they joined their peers in tutor groups and arranged to see me at break.

Although both girls have spina bifida, Lesley has an ileal loop and is able to cope with toileting herself. At this time Allison's bladder was manually expressed. I had discussed the possibility of Allison learning intermittent catheterisation with her mother and advised her to ask the consultant's advice. It was crucial to sort this out as it could have proved a problem if I were absent from school. Allison's mother agreed that if necessary either she or her husband would come to school and attend to Allison at lunch time.

The need for continuous assessment and flexibility has been shown in the control of their urinary incontinence. Both girls have undergone major spinal surgery during the last year. Lesley, who has always emptied her urostomy bag, did have a little difficulty when she returned to school encased in a plaster jacket. However, more frequent emptying of the urostomy bag and a lot of encouragement soon solved the problem. The urostomy bag is changed at home.

Allison's bladder was expressed by me manually at lunch time and again during the afternoon, if she was staying after school. However, following spinal surgery, she too was in a plaster jacket and applying pressure to the pelvis was not practical.

It was decided to use a self-retaining catheter. We tried intermittent emptying of the bladder but there was leakage around the catheter. Continuous bladder drainage using a Uri-bag has solved the problem and Allison now empties the urine bag herself twice during school time.

It is hoped that once free of her plaster jacket she will learn to catheterise herself.

The extra door leading to my room easily enabled me to be on hand when the girls were adjusting their plaster jackets. The extra toilet in my room is available for handicapped adults using the school for night classes and social functions.

The teaching staff and I discussed the girls Spitz-Holter valves, continence and mobility. The major concern was the valves. I suggested that should either of the girls complain of headaches, nausea or disturbed vision, to contact me. If I was out of school they should contact the girls' parents at their work.

I did point out that everyone is entitled to have a headache and nausea from time to time even without a valve! In practice we have had no trouble though I find it necessary to reassure new staff.

Two female games teachers visited the special school and worked out a programme within the girls' capabilities and our facilities.

Swimming has been very successful. We have our own pool and I help the girls to change and, with the pool attendant, lower them in. Two sixth-form students join them in the pool and the attendant and I remain on the side. This has proved beneficial both socially and as a form of physiotherapy.

> 'Integration is possible — most problems are solved when they appear'

The girls take part in all lessons including games. They are also able to take part in some ball games which improve their co-ordination. Of course they are also able to take part in swinging to shape from their wheelchairs!

The first term ended with a first-year disco. Both took part and one said, 'This is the happiest evening of my life!'

WARNOCK was born from the desire of parents to have children with special educational needs educated in normal schools. They may not be practical or even possible in many cases. Probably there is no best solution and each case must be examined considering the child's family and the community's ability to provide help.

For success there needs to be maximum co-operation between nurses and teachers to make the best use of existing facilities and to keep costs down.

We have found that integration *is* possible, and most problems are solved when they occur. From the outset the school has had help and co-operation. All the staff at the special school have been supportive throughout. The nurses, physiotherapist and occupational therapist have always been willing to offer support and help when asked.

The parents of the children involved have been both adaptable and of practical help, particularly in the early days. We learned that they know and carry out what I would consider to be nursing procedures.

The teaching staff responded with enthusiasm and a desire to make the venture a success. When I asked the director of lower school about the problems encountered by the teaching staff he replied, 'What problems?'

The pupils responded in different ways. After the initial interest most of the children take very little notice unless, of course, they are Allison's and Lesley's friends.

Allison and Lesley will remember their 'Special School' with affection, but as they have gained confidence in themselves their needs have changed.

Puberty can present problems with any child. One of the girls had already learnt to cope with menstruation before she came to the school. It is hoped that should there be any problems, the parents, teachers, girls and I will be able to resolve them between us. If necessary, we will seek advice.

It is now over a year since they joined us and we have had few problems. They toilet themselves and take part in all lessons. They move freely around the school asking for help only when it is necessary.

Both girls have friends who take their wheelchairs from reception to the car park in the morning. This enables their parents to get away quickly. This fulfils a need in some children to be of use to others.

SIXTH-FORM debates on 'The place of the physically handicapped in our community' take on a new dimension when personal experiences can be used.

The girls' presence in the school has stimulated some fourth-year boys to design a wheelchair suitable for going up and down kerbs. For this they were awarded the third prize of £30 by a local engineering firm.

Another group of children participated in a sponsored swim by a local Lions Club and consequently helped to raise the money for a new wheelchair for one of the girls.

One of the handicapped pupils has been seen helping her able-bodied friend with her homework — an exercise that must have benefited them both.

We have recently had an inquiry from a parent of another child who is suitable for integration.

The best way to learn is through experience. Perhaps the children now in daily contact with their handicapped peers will grow up with a healthy attitude to handicap.

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L/7/C

It's the rugged types who win through

THE CURRENT economic climate is not always kind to fundraisers. Not only has the public grown reluctant to dip into its pockets; there is also less enthusiasm for glamorous events such as balls and theatre nights. On the other hand, there has been a notable increase in public interest in sponsored events of a rugged, athletic and outdoor nature.

Mountain Express — Some of the walkers set off on their 40-mile trek

Col. Sam Roberts gives the troops their 'cycling' orders at the start of their marathon ride to Sicily

Picture: Les Wiggs, Soldier Magazine

ASBAH's programme of events during the late summer of 1983 has clearly reflected this trend.

For the third year running, we have successfully organised one event that even our most rugged supporters can find daunting — the Mountain Express. This 40-mile trudge through the Brecon Beacons took place over the weekend of August 21 and 22 and attracted nearly three hundred contestants. On the night before the walk, our base camp was almost saturated by rain.

However, came the dawn and the sun was shining brilliantly on our gallant walkers as they strode boldly on their way. As night fell, the skies clouded over and a second drenching was in store. Nevertheless, our stout-hearted contestants all made their way back to base without serious injury and were greeted by a well-deserved champagne breakfast.

Hitherto, the Mountain Express has attracted large numbers of members of the armed forces. This was again true of our 1983 event. However, this year, we were also pleased to welcome many more civilians and female contestants. The winning team came from RAF Lyneham and more than honourable second place was gained by a contingent of Welsh Guards.

The Mountain Express was organised for ASBAH by one of our newer members of staff, Jane Hayman. Having won her spurs on so tough an enterprise, Jane immediately proceeded to organise a totally new venture called the Odd Ball Rally.

On Sunday, September 25, 45 eccentrically dressed volunteers assembled in the grounds of Knebworth Hall in Hertfordshire. Their task was to push a collection of wheelbarrows, lawnmowers and go-karts around a quarter mile course and — when this was accomplished — to go round again and again and again and . . . This process lasted for three hours, after which prizes were presented.

Throughout the day, the sun beat down on what turned into a most enjoyable event which should raise considerable sponsorship for ASBAH.

Meanwhile, others were seeking the sun further afield. . . . Six young soldiers from Princess Marina College, Arborfield Garrison, were cycling 2,000 miles towards Sicily in aid of ASBAH. The incredible aspect of this cycle marathon is that the soldiers undertook the 2,000 mile cycle non-stop working on a two man shift system and meeting up at pre-determined locations when the next two cyclists took over.

Co-ordinator of the event, Madeleine Legg, breathed a sigh of relief not only because they reached Sicily safely in a very fast time of six days, but because thousands of pounds will now come in as a result of sponsorship money from fellow soldiers and families.

We hope these tidings of outdoor summer events will keep our readers warm during the long winter months. We would also like to take this opportunity of wishing you all a Merry Christmas and a Happy New Year.

IAN MORRISON
Assistant Appeals Director


AFTER USING MY ROHO CUSHION FOR TWO YEARS- PRESSURE SORES ARE A THING OF THE PAST. IT'S CERTAINLY GOT TO THE BOTTOM OF MY PROBLEM!
I SIT IN MY ROHO NOT ON IT THAT'S HOW IT WORKS-BY SPREADING MY WEIGHT WITH NO SINGLE PRESSURE POINT.
MY ROHO IS EASILY CLEANED AND MAINTAINED- SOMETHING NOT POSSIBLE WITH SOME CUSHIONS
I CAN NOW SIT FOR HOURS & DO MANY THINGS I COULD NOT THINK OF DOING BEFORE!
MY ROHO GOES ANYWHERE WITH ME - EVEN IN MY CAR.
I THOUGHT MY ROHO WAS EXPENSIVE AT FIRST - BUT NOW I KNOW IT'S WORTH EVERY PENNY. ROHO WORKS!

CLASSIFIED 'ADS'

THE CLASSIFIED ADS page offers Local Associations a great opportunity to "put across" any services, goods or holiday accommodation to LINK readers, and at a very reasonable rate.

Please note that there is a 10% discount if you book six advertisements in advance.

The advertisement rate is:
£2.25 for up to 30 words. £3.30 for 30-45 words.
£4.50 for 45-60 words.
Please send remittance with your advert.

Adverts for the next LINK (Jan./Feb.) should be in by Dec. 5. Send to the Editor Mrs. Susan Gearing at home: The Gables, Long Lane, Wrington, Avon. Tel: Wrington 862279.

HOLIDAY ACCOMMODATION

HEYSHAM, Nr. Morecambe. Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 5 Roman Way, Whitchurch, Shropshire. Tel: Whitchurch 3691.

MABLETHORPE. 2 fully equipped cedar chalets on Links estate. Sleep 6. Further details: Mr B. Guest, 57 Bloxwich Lane, Walsall. Tel: Walsall 31725.

BORTH, Nr Aberystwyth. 6-berth de luxe holiday home. Licensed site. Suitable for wheelchair users who live independently. Details: J. Carter, 1 Meadow Road, Craven Arms, Shropshire.

WINTERTON-ON-SEA, Nr Gt Yarmouth. Fully equipped chalet. Sleeps 6. Indoor heated pool, shop, amusements, take-away snacks, club room, play areas. Details: Mr R. Morris (0494) 32184.

JOHN GROOMS HOLIDAYS

All facilities specially adapted for wheelchair users (family friends and escorts welcome)

Seaside Hotels: Llandudno and Minehead. (Bargain Winter Breaks for only £10 per day, incl. VAT)

Self-Catering Units: Near the sea at Barnstaple, Borth, Poole, New Milton, Tenby, Looe, Maplethorpe and Camber Sands. Also in the Cotswolds. Ramps and other aids

Holiday Chalet: Near Skegness (Lincs)
London Holiday Flat: London, N.4.
Motor Caravan: Hire for one or two weeks. Tail lift, wheelchair, WC/Shower unit, etc.

Bungalow: In the heart of the Norfolk Broads

Canal Holiday: In adapted narrow boat.

For further details contact: John Grooms Holiday Department, John Grooms Association, 10 Gloucester Drive, London N4 2LP. Tel: 01-802 7272.

ASBAH booklets, etc . . .

Your Child with Spina Bifida, by J. Lorber, MD, FRCP	35p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP	35p
Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH	50p
Sex for young people with spina bifida or cerebral palsy	£1.25
The Nursery Years by Simon Haskell & Margaret Paull	35p
Little Joe (A Grandmother's story) by W. Foster	50p
Life & Death—thoughts on bereavement	75p
Information leaflets	100 for £4.00

Asian language translations of a Fact Sheet about spina bifida and hydrocephalus and ASBAH's work are available free from national office. Translations into Bengali, Gujarati, Hindu, Punjabi and Urdu. Welsh language sheets are now ready too. All available from ASBAH. (Special rates available to Local Associations.) Please allow 20p per booklet postage.

Scottish Spina Bifida Association Booklets

Growing up with Spina Bifida	35p
The Spina Bifida Baby	35p

both by O. R. Nettles, McSP, ONC.
Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

FUND RAISING AND PUBLICITY MATERIAL
Posters

Best Foot Forward 20 x 30 in	**10p each**
Best Foot Forward 15 x 30 in	**10 for 40p**
For local publicity 15 x 10 in	**10 for 40p**
Car Stickers	**13p each**
Plastic Lapel Badges	**8p each**

All available from Appeals Dept.—postage extra.

Film 'Appeal for ASBAH' 10 mins 16 mm Colour/Sound	**£4 Hire**

The Appeals Dept. carries a range of fund-raising and publicity items, i.e. posters, pens, key rings, games. Send for list and order form.

Flag Day equipment can be obtained direct from: Angal, 48a Holmbush Road, London SW15 3LE (01-788 5464).

EXCHANGE & MART

Leisure Wear: White cotton **Tee Shirts** with green family symbol and words 'Support Spina Bifida'. Adult sizes, small, medium, large: £3.75 each. **Sweat Shirts** in reverse colours. Adult sizes, small, medium, large, XL: £7.50 each, postage included. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

To you it's a discount card,

Support is a fund raising association whose members support National Charities by purchasing a privilege Membership Card and National Directory for an annual subscription of £13.80 (£12.00 plus £1.80 VAT). **Not only is 75% of this sum a direct donation to the Association of Spina Bifida and Hydrocephalus but also members can recover the total subscription from the discounts available.**

Full information on how to use the card and purchase bonus vouchers is given within the directory.

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APPLICATION FORM

To: **ASBAH (The Association for Spina Bifida and Hydrocephalus), Tavistock House North, Tavistock Square, London WC1H 9HJ.**

I wish to subscribe to ASBAH in order to become a member of SUPPORT.

I enclose my annual subscription of **£13.80** (£12 plus £1.80 VAT) and understand that within ten days I will receive my Membership Card and Directory with full information on how to use my card. **I acknowledge that 75% of my subscription constitutes a donation to ASBAH.**

☐ I enclose my cheque for £13.80 made payable to ASBAH
OR
☐ Please debit my Barclaycard number
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☐ Please debit my Access Card number
with this amount.

NAME (Mr/Mrs/Miss/Ms)

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Signed **Date** 19

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