

Saying no to segregation
Disabled people struggle for justice

Judy Hunt

Access and Participation

An end to exclusion

NO LIMITS

Tackling The Barriers

THE DISABLED PEOPLE'S MOVEMENT

Integration and inclusion

Society for all

A radical history

Fair access to opportunity

An end to discrimination

Celebrating diversity

No Limits

The Disabled People's Movement -
A radical history

Judy Hunt

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26 Chapel Road, Sale, Manchester M33 7EG, UK

*To my late husband, Paul Hunt,
who led and inspired me
and many others
to engage in the struggle
against injustice and oppression.*

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Foreword

At a time when as Judy Hunt writes: “disabled people are finding many of the gains of the 1980s and 1990s being eroded,” this book is a timely reminder of where those gains came from. Indeed it’s vital to know where we’ve come from in order to understand the current realities we face, to work out how to make progress and to learn from the past.

It is also an important book, based as it is on the experiences of someone who was there at the beginning of the struggle amongst disabled people in residential care to have control over their lives, a struggle which gave birth to the movement for independent living in the United Kingdom. It is a valuable addition to Jane Campbell and Mike Oliver’s 1996 book, *Disability Politics: Understanding our Past, Changing our Future*.

At the age of 17 years, Judy Hunt went to work at Le Court, the Cheshire Home which became the crucible of the movement for independent living and in 1970 she married Paul Hunt, one of the key participants in that movement. After Paul died she discovered his private journal and realised that with the passing years it was becoming increasingly urgent to record the experiences

of those who were involved in campaigning for a radical change in disabled people's lives. So she set out to interview many of the people who, together with Paul Hunt, were directly involved and, at the same time, to set these individual experiences in a wider context.

The book therefore starts by examining the origins of residential homes for disabled people after the Second World War, illustrating how such institutions had their roots in well intentioned attempts to prevent people with physical impairments having to spend their lives on geriatric hospital wards. What became a "tidal wave of enthusiasm for residential care" was a 'progressive' movement at the time but, as Hunt points out, in not considering community provision to be an option an opportunity was missed and resulted in the creation of a whole industry of residential provision by charities and local authorities.

However, this also meant that fertile ground was created for disabled people to share their discontent, develop new ideas about how their lives could be improved, and organise to bring about change. In the 1950s and 1960s, at the very point at which disabled people were being moved out of hospitals into residential homes, they started to question the arrangements being made for them - arrangements which embedded a form of social control in the assumption that disabled people

could not have choice and control over where and how they live. As this book chronicles, the setting up of residential homes created “unusual communities” which formed the foundations of the disability movement and of disabled people’s struggle for more control over their lives - which lasts to this day. At the same time, as Hunt shows through interviews with those involved as well as through her research on contemporary written material, the 1960s also saw significant changes happening amongst disabled people living in the community.

This is an important story, much of it told through the personal accounts of those who were directly involved in the origins of an important social movement, many of whom are no longer with us. It is a fascinating read, illustrating not just how far we’ve come but also how the seeds of what we, sadly, have yet to fully achieve were sown.

The book goes on to recount the rapid development of both national and local organisations of disabled people throughout the 1970s and 1980s, detailing how a network of grassroots activity created an independent living movement. By the 1990s, local organisations were starting to have some success working with housing and social services to create real opportunities for (some) disabled people to have choice and control over where they lived and how they were supported, with peer

support being a crucial part of the services created. Nationally, the National Centre for Independent Living, the British Council of Organisations of Disabled People and the Direct Action Network eventually broke through to influence governments to implement both direct payments (cash payments in lieu of care services) and the Disability Discrimination Act. Drawing on written material produced by local and national disability organisations, as well as individual accounts of some of those involved, the book provides an invaluable historical record of how social change was driven by grassroots action carried out by people many of whom, only a generation ago, would have been incarcerated in institutional care.

The book concludes by considering more recent developments - the privatisation of social care, the problems with direct payments, the failure of society to make adequate resources available - and discussing the weakening of the disability movement. Hunt raises questions such as whether pressure group politics at a national level has weakened grassroots activism, whether a civil rights approach has meant the movement lost sight of the emancipatory social model as a basis for struggle. These issues - and how we can make more progress in the future - can best be understood by a full understanding of the origins and context of the disability movement. This book is a valuable contribution to that

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JUDY HUNT (2019)

understanding of our past which should help inform our future.

Jenny Morris, April 2019.

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Special gratitude goes to my friend the late Vic Finkelstein who persuaded me to take this task on. He tutored and encouraged me through the research and writing phases and I found his profound and subtle knowledge and understanding a constant source of strength.

I am also grateful to the late Ken Davis, to Maggie Davis, to the late Ken Lumb, and to the late Peter Lobel, and to countless others who agreed to be interviewed, read earlier drafts, commented, fed me and boosted my morale during arduous phases.

I thank the Kings Fund for a research grant, and Haringey and Waltham Forest Social Services for allowing me periods of unpaid leave to do my research.

Last but not least I thank my son Patrick for his forbearance and I hope seeing this record of his father's contribution to society will be a worthy reward.

JH, London.

Editor's Note

The referencing style used here for citations is name-date, sometimes known as Harvard. This style has

a number of local variations, or systems. The purpose here has been to try and maintain a uniform system, but the reader is asked to tolerate any minor variations in punctuation etc within the name-date system printed here.

Of particular relevance to this research is that the essence of this book is the author's own deep knowledge of the activism of her late husband, including from her own involvement, followed by a dedicated period of research with extensive interviews, which are listed within the references section. This means that some of the citations are from family private papers, from personal recollections, and from research notes while interviewing other activists and colleagues. The system used here has been to cite these as [private papers] and [interview] respectively.

For practicalities in the text, any references to either 'Hunt' and 'Hunt, P.' are for Paul Hunt, and 'Hunt, J.' are for Judy Hunt, the author.

In the references, where web-links are no longer working, readers are encouraged to use the Internet Archive to access saved copies of previous versions, via www.archive.org .

All corrections are welcome and will be applied to future editions.

TB, Manchester.

Introduction

“I think the distinguishing mark of disabled people’s special position is that they tend to ‘challenge’ in their relations with ordinary society.”

Paul Hunt, in ‘Stigma’ 1966 [p146]

How true those words have proved to be in the decades since Paul Hunt wrote them. Back then he and others were seeking answers to why non-disabled society was so contemptuous of disabled people, and why it was so little recognised. Furthermore they questioned what could be done about it. They started to publicise the anger they felt about the widespread discrimination they experienced.

Since then much has changed. Society has been forced to recognise disabled people as full citizens with the same rights as anyone to participate in the mainstream. For many years now, disabled people have been playing their part in reshaping modern society. In our daily lives we can see the evidence of this. Amongst some of the more obvious environmental signs are the audio visual indicators, textured pavements, ramped curbs at road crossings, assigned parking bays, wide or automatic opening doors, wheelchair accessible toilets in public places, and Braille on lift controls. Evidence is also to be seen in the various ways public transport is designed to accommodate people with different impairments.

Many of these changes, of course, benefit people who would not consider themselves disabled. We all benefit from more spacious, well-lit, signposted facilities that enable us to move around more freely and confidently.

By contrast, back in the 1960s disabled people found it extremely difficult to get out and about. It not only required a full-scale planning operation, but was also socially uncomfortable. To venture out meant being faced with a negatively reacting public. There were the stares, the ways people avoided direct contact, there were the pity responses, and sometimes the undisguised hostility.

Since then society has experienced many big changes, including, the rise of a disabled peoples movement followed by the introduction of anti-discrimination legislation. Whilst these brought about significant improvements, the full implications of what disabled people have striven for still remains little appreciated. In writing this historical account of their movement, I have set out to explain; why it originated, how it developed, and consider some of the effects it has had on society.

From a world that was very inaccessible we have come a long way towards trying to achieve a more integrated society. But there is no room for complacency. We live in a society which is subject to the pressures of powerful global monopolies, tough austerity measures,

cuts to public expenditure and loss of many important services. Under these conditions disabled people are finding many of the gains of the 1980s and 1990s being eroded.

Personal reasons

My commitment to the task of writing this history relates back to my earlier life. In 1960, aged seventeen I went to work at *Le Court*, the original Cheshire Home in Hampshire, where I discovered the benevolence of a 'caring charity' was not quite as I had been brought up to believe. A group of very insightful disabled people soon introduced me to their reality of the disability experience and this, I started to learn, was about being on the receiving end of a complex system of imposed restrictions and humiliations that went largely unrecognised.

In 1970, I married Paul Hunt who was, by then, a leading voice amongst the residents at *Le Court* and was also recognised further afield for his writings and outspoken criticisms of the way disabled people were treated in institutions. As our life together progressed, I found myself straddled between two worlds.

On the one side, I shared some of the meaning of disability, in my day-to-day life with Paul. Of course we shared the frustrations of the many barriers that got in our way when we wanted to do things together. But we also became part of what proved to be a historic liberation struggle to remove disability from society. Paul had not

only continued to raise his concerns regarding institutional conditions but also set out to find a way forward to tackle disability more generally.

On the other side, as an occupational therapist, I was employed in a service that I grew to recognise was, ironically, part of the problem disabled people were up against. This faced me with the tensions that came from feeling I didn't quite fit in amongst my peers, of being an oddity and of struggling to make a kind of sense of my world too. I had to ask myself, if and how occupational therapy could be of real value to disabled people. I also wanted to see a day when colleagues, in the business of promoting disabled people's independence, would not be embarrassed to learn that my husband was a disabled man!

After witnessing the unfolding events, I realised some years later that I was in an unusual position to help explain them. Many people who had taken part had died and it was becoming increasingly urgent to record the experiences of events from a diminishing number of survivors, if they were not to be lost for ever. Encouraged by some of my disabled friends and comrades I felt a special responsibility to share this history with people who had joined the movement later and with anyone interested to learn how people can influence social change.

I had my reservations though, about taking this task on as a non-disabled person. Disability discrimination

was not something I had to endure in a personal sense and I had to constantly ask myself how well I was understanding the complexities of the disability experience as a non-disabled person? Disabled people are rightly suspicious of professionals who seek to speak on their behalf, it happens all the time. I have therefore relied heavily on advisers, who were disabled, to guide me through the process of research and writing. I have learnt so much and could not have achieved this without their regular encouragement over the years.

The research and aims

Prior to the 1980s there was a severe shortage of published material about disability by disabled people. The body of literature was dominated by the one sided vision of (mainly non-disabled) professionals influenced by an overtly medical perspective. After 1981 the situation changed. As increasing numbers of disabled people gained access to higher education, both as students and as educators, the debate opened up with a new field of disability studies in the universities.

To address the earlier imbalance, I had to rely on evidence I could find from debates in disability journals, archive material, old correspondence, newspaper cuttings and interviews. This was helped by the care my late husband took to file his many articles and letters that evidenced the debates he and others were engaged in during the 1960s. Amongst these papers I found a private journal of his personal reflections during a particularly

painful period of struggle at the *Le Court* institution. This was the spur that drove me on.

Initially I set out with three broad aims. I wanted to find out the extent to which a medical model, that saw disability in terms of sickness, had been displaced by a social interpretation in which disability was perceived as oppression. I also wanted to look into how the relationship between the providers and users of services, changed, as disabled people increased their level of participation in their own affairs. My third aim was to explore the unfolding differences between services that set out to provide care and those that offered support to disabled people. These themes have become integrated into the overall fabric of the work.

The scope and limits of the study

The constituent group have primarily been physically impaired people of working age with impairments of movement. I have not been able to give so much attention to the specific histories of, or contribution by, people with sensory impairments, learning difficulties or disability through old age. A further group, who have experienced restrictions associated with mental distress, have also not been included. But it is important to note that interaction and common ground were frequently established between these different subgroups of disabled people, and this has contributed substantially to a many faceted pressure put on the services and legislature.

Because the study of disability covers a vast field, and the barriers to participation are all-encompassing, I limited the aspects that I investigated. Whilst the principal objective was to look at how disabled people organised themselves to become a social movement, I focussed on what seemed a core theme of struggle over the last forty years, which was about having more control over where and how they lived. This led me to look at how personal and domestic lives have been affected by welfare services since the Second World War, and at the influence disabled people have had on these services.

Whilst sub-themes running through the work concentrate on housing and personal assistance, dependence and independence and the helper-helped relationship, I also include reference to education, employment, transport and culture.

All this has been looked at against the backdrop of Britain as a capitalist society where work versus welfare provides a constant and complex field for policy reform.

A five phase breakdown of the period under study

The period of study spans between 1950 to our current time. Some exploration of service development prior to and during the Second World War provides contextual background.

When considered overall, there have been five principle phases. The first phase from the 1950s involved the expansion of segregated services for disabled people and their reactions to this.

In the second phase disabled people began to mobilise to address their social inequality, ending with the passing of the Chronically Sick and Disabled Persons (CSDP) Act 1970.

During the third phase, 1970-1980, consolidation took place within the newly formed community welfare services which produced a corresponding reaction from disabled people. As they became more politicised a small radical tendency emerged.

In the fourth phase, 1981-1986, disabled people sought to represent themselves and develop alternative services. A marked change of political consciousness occurred and the social movement took off, ending with the Disabled Persons (Services, Consultation and Representation) Act 1986.

In the final phase, 1986 onwards, the grass roots movement pursued a civil rights agenda to gain access to the personal freedoms and equality that disabled people had come to expect. But in the process some of the strength and benefits of collective practice were lost. Disabled people then faced the risk of losing their combined influence to defend the very rights they had fought so hard to win.

The final chapter looks back and draws out some of the lessons we can learn from this history. If future initiatives in service development are to encompass a more enabling philosophy they would do well to draw on these lessons from disabled people's experience. I make

a few tentative suggestions of how initiatives might grow from a different and more co-operative base because it is my hope that this book will contribute to the ongoing and urgent endeavours of many people to create a better, more mutually supportive, society.

CHAPTER 1 - Providing Historical Context for a Disabled People's Movement

The disability conundrum

Since the earliest days of capitalism, which introduced temporary contracts of labour and fluctuating employment patterns, public administrators have faced an endless (and ongoing) task of finding ways to manage the issue of compensation for unemployment. A constant question has been; how do you devise ways to ensure people remain fit to work whilst making it uncomfortable for the unemployed to live off charity? In this context, disability creates the conundrum of: what support should be given to disabled people who cannot obtain paid work, and how does this impact on unemployment compensation in general?

To live as independent adults; free to travel around, become consumers and participate in the economic life of the community, we require an income. But, for centuries, many disabled people of working age have been denied this and had to rely either on family, or charity, because of difficulties gaining paid employment (Barnes 1991: p15, Oliver and Barnes 2012: pp130-131).

In principle, work should be much more accessible now to disabled people. Labour is physically lighter and by and large more sedentary with sophisticated electronics and computers driving much of what we do. With the aid of computers, it can sometimes be done from home too. This means that, today, many people, who

were once regarded as unemployable, or unfit, are considered fit for work.

However, if you are disabled, employability is never simply a question of being able to do the job, it is also a question of being able to get there in the first place, having an employer who makes appropriate adjustments, and having the stamina to complete a working day as the RADAR (Royal Association for Disability and Rehabilitation) report to government, by Liz Sayce, points out (2011: pp137-40). Additionally, the ordinary things like getting up in the morning and travelling to work (which may require assistance) will have had to be achieved first. Within all this lies a whole raft of issues that disabled people have had to tackle to enable their participation in mainstream employment and society in general (RADAR was renamed Disability Rights UK following a merger in 2012, see chapter 11.)

It is when we look at the surrounding issues that prevent disabled people working, that we see many of the fundamental inequalities that continue to operate in our society (Barnes, 1991: p3; Oliver and Barnes, 2012: p129). Despite the advances that have taken place to bring about more integration, including various political initiatives to improve employment opportunities, unemployment amongst disabled people remains disproportionately high.

In its Disability Briefing of March 2006, the Disability Rights Commission (DRC) reported: that of the 6.8

million disabled people of working age, 50% were in employment compared to 81% of non-disabled people, and their average gross hourly pay was 10% less than that of non-disabled people (Disability Rights Commission, 2006: pp4-5). In 2009, the Labour Force Survey (LFS) similarly identified 50% unemployment amongst disabled people available for and seeking work (Shaw Trust, 2009), and Berthoud's research produced similar results (Berthoud, 2011).

Some of the inherent complexities, that surround the employment of disabled people, and their welfare entitlement, became exposed once the Disability Discrimination Act (1996) was operational. Fast on its heels, the 1997 Labour government set out to reduce unemployment and the associated welfare costs by introducing various New Deal proposals, one of which identified disabled people as one of the target groups to be encouraged to find work (Arthur *et al*, 1999). In the interest of supporting disabled people's desires to be employed rather than remain dependent on welfare the government introduced a positive programme to assist them into work. Less welcome, however, were the stringent measures, it also introduced, to re-assess their capability, and entitlement to benefits.

The sudden implementation of cuts to social security following reviews of benefit entitlement, produced a rapid response from an angry lobby of disabled people and their supporters, including concerned MPs, such as

Kirkwood, Lloyd and Skinner (Hansard, 17 November 1997). They were quick to point out, that however desirable it was for people to not have to depend on welfare handouts, there could be no guarantees of increased employment opportunities, nor the necessary back up support services that people needed, to justify the sudden withdrawal of benefits. The same arguments are very much to the fore in recent web-based debates concerning welfare benefits.

It is in this context, both past and present that disabled people have been striving for the means to a decent quality of life. The main content of this book is not, however, about employment or unemployment, but about how disabled people have responded to the many challenges of an inaccessible society over the last sixty years.

Before going into the body of the struggle, I want to set down a brief summary of the historical context regarding how and what services evolved prior to the development of the social movement for they lay some important foundations for what followed.

Broadly, the story of service development has been one of an emerging partnership. Firstly, between the charities and state, to tackle the employment and welfare issues that faced disabled people. Then about the greater involvement of disabled people as they responded to what was being provided. The first part of this chapter looks at what occurred prior to the twentieth

century and the second part continues the story up to the end of the 1950s.

Industrialisation and the creation of dis-ability – a hypothesis

Vic Finkelstein (1981) produced a three-phase breakdown of the history of how disabled people had arrived at their current situation of social disadvantage, in a modern capitalist society. There, he put forward the idea that people with physical impairments became transformed into dis-abled people, by the dual forces of capitalism and industrialisation.

His argument was that; initially, because feudal society tied workers to the land, the families relied upon the labour of everyone to survive. Home based work, such as weaving, sewing, cultivation etc. had to be shared, and because it was more readily adaptable to the capacity of individual family members, those with physical impairments could be included.

In his view, the first phase of transition for disabled people came with industrialisation. That was when production became centralised into mills and factories and produced standardised working conditions where non-standard people, such as those with impairments, could not function so well or at all. Many, as a result, became excluded from the means of earning a living.

Additionally, because families had to move around in search of work it often meant the so-called crippled members became outcasts, without any other means of

support (The phrase *crippled* is used here as a historical term of reference towards people with physical impairments living as an integral part of their local communities). Forced out, they had to turn to charity and become dependent on others for their survival. It was in this phase that such people were *dis-abled* by the social conditions they found themselves in.

Phase two of this historical breakdown occurred when the people who had become *dis-abled* were placed into special institutions to be cared for by a new profession of workers. It was then that charities and services emerged in response to the many social needs being created by the harsh industrial conditions.

Finkelstein (1981: p63) argued that phase three came much later when disabled people began to strive for a way out of their segregation. They then found their attempts to integrate were thwarted by the many barriers in their way. He posited that; society, so used to their absence, had evolved whole systems that perpetuated exclusion and so had entrenched their *dis-ability*.

This historical summary provides us with a useful basis from which to consider what occurred.

Industrialisation and its impact

If we look at conditions in the nineteenth century, it is evident that the industrialisation of agriculture, land enclosures and the concentration of labour within the cities, substantially changed the conditions of life for vast numbers of the working population (Hobsbawm, 1968:

pp86-95, 102-104), (Thompson, 1963: pp237-243). Not only did it increase the amount of disability through injuries but along with the rapid urban development, were the damaging effects of poverty, overcrowded housing, malnutrition, and the rampant spread of diseases. Describing the grim living conditions around him, Frederic Engels (1844: p128) wrote:

The manner in which the great multitude of the poor is treated by society today is revolting ... they are deprived of all means of cleanliness, of water itself, since pipes are laid only when paid for... they are obliged to throw all offal and garbage, all dirty water, often all disgusting drainage and excrement into the streets ... they are penned in dozens into single rooms, so that the air which they breathe at night is enough in itself to stifle them ... What else can be expected than an excessive mortality, an unbroken series of epidemics a progressive deterioration in the physique of the working population.

Excessive exploitation and poor living conditions then drove workers to establish their own trade unions and along with others, concerned about the deteriorating environment, a movement for political reform developed. Laws were passed to bring about public sanitation, clean water, and a series of Factory Acts, between 1833 and 1864 curbed the excessive exploitation of children and women (Doyle and Pennell, 1979). These attempts to

reduce some of the more destructive effects of industrialisation exposed the situation of destitute disabled people without other means of support.

Poor law relief and the management of labour

An analysis of the English Poor Law by Deborah Stone (1984) provides some important insights into the central and potentially subversive role disability has posed for our society as it evolved welfare legislation through the ages. D.G. Pritchard (1963) provides additional insight into how disabled people became segregated from their natural peers in his history of special education, and Anne Borsay's study (2005) of the history of Disability and Social Policy, another rich resource. Their accounts highlight themes that are particularly pertinent to this story as they relate to the foundations of service development of the twentieth century.

The first laws in Britain to consider payments of assistance to the poor date back to the first Vagrancy Act of 1349 (Stone 1984: pp34-35). Stone argued that as industrialisation increased, disability and vagrancy became inextricably linked. She found out, for instance, that work, and needs based administrative categories first appeared when attempts were being made to control the movements and wages of workers, their unemployment, and associated crime, and begging.

Barnes refers to a further statute from the year 1388 mandating officials to discriminate between deserving

and undeserving poor, and Tanner (in: Wilcock, 2001: p146), refers to subsequent Acts of law in 1536, 1563, and 1601 on the collection and distribution of alms which also laid the basis for the poor law (Barnes, 1991: p14).

When it comes to identifying precisely what happened to physically impaired people, this is difficult to determine prior to the nineteenth century, because of limited records, but there are a few clues. In the Tudor period, for instance, the Poor Laws introduced a Commission for collecting and distributing alms for the poor and 'crippled' and attempted to introduce apprenticeships in craft industries for 'crippled' children (Pritchard, 1963: p62). But Pritchard said he found little evidence of paid employment occurring outside the family until the nineteenth century

By then, the Poor Law had become well established and, in 1834, the Poor Law Amendment Act added further distinctions that made it a watershed in the development of welfare policy. It introduced three new principles, these were; national uniformity in welfare administration, denial of assistance outside the workhouse and deterrence as a basis for setting welfare benefit levels (Stone, 1984: p47).

Two systems of relief existed; indoor relief in the workhouses where incredibly harsh working and living conditions acted as a deterrent, and outdoor relief through charity and legitimised begging for certain

designated categories which largely featured people who were 'blind' or 'crippled' (Stone, 1984).

With reference to these begging restrictions, Henry Mayhew (1851), an interested observer of Victorian England, commented that various kinds of 'cripples', as he put it, were still to be found, begging in the streets of London. As a rule, he said, the police did not interfere with them unless they were known to be impostors (Mayhew 1851, cited in Quennell 1984).

Stone (1984: p40) explains how it was around this time that the law started to use disability as an administrative social category of the legitimate unemployed. For instance, the 1834 Act specified, for the first time, which people could be exempted from certain obligations of citizenship and fostered the idea of the deserving (as distinct from the undeserving) poor. It identified "Children, the sick, the insane, defectives and the aged and infirm" as the deserving unemployed.

Apart from children all the other categories here could be described as relative states of impairment or disability. Doctors played a key role in determining who was sick, whether it was temporary or chronic, and whether an impairment was perceived as genuine or sham. During the process of passing the administration of welfare to doctors, unemployment associated with disability became interlinked with unemployment due to long term sickness, which was significant for future developments (Stone, 1984: pp23-24).

Through the poor laws, and new 'lunacy laws,' many beggars then disappeared from the streets. Some went into the workhouses and others into 'mental asylums.' In the workhouses people were divided into subgroups by 'ability' or 'deficiency' whilst the 'lunacy laws,' categorised people as 'insane' or 'mentally deficient' (Borsay, 2005: p66). Deficiency was a generic term that in the nineteenth century applied to all disabled people with severe learning difficulties or physical impairments. People with physical impairments were also often referred to as 'cripples,' 'infirm' or 'invalids' (Borsay, 2005: p66). The fate for people with learning difficulties and mental illness was grim. They were frequently grouped together and jointly referred to as people of 'unsound mind'. Once classified they were hidden away, often shackled, in the most appalling conditions of the large mental asylums built on the outskirts of industrial cities (Borsay, 2005: pp72-75).

As for removing physically impaired beggars from the streets, this did not seem to be so much of a concern. Interestingly, neither Stone, Pritchard nor Barnes, found evidence of formal institutional provision at that time and this would appear to be borne out by Mayhew's observation of disabled street beggars (Mayhew, 1851, cited in Quennell 1984), when he wrote:

'I am surprised there is no home or institution for cripples of this class. They are certainly deserving of

sympathy and aid; for they are utterly incapacitated from any kind of labour.'

There were, however, specialised wards in the workhouses for different categories of 'deficiency' in addition to the workhouse infirmaries (for isolating people with sickness and fever), which suggests considerable numbers of people with impairments did spend periods of time there. The National League of the Blind (NLB, 1949: p11) reported that the outcome of a survey carried out by *Blind Advocate*, in 1896, estimated that two in every seven of the known blind population were classed as paupers, and the number of blind people dependent on begging, although unknown, was thought to be substantial since only 42 per cent of those trained for employment could find regular work.

The pioneering role of charities

Towards the latter part of the nineteenth century, the appalling conditions facing disabled people started to attract the attention of some social reformers, who set up new charities to help them (Borsay, 2005: p94, Pritchard, 1963: pp151-163).

Charities often represented the first round of disability pressure groups and some played a key role in the development of services for various sub-groups of disabled people. By the end of the nineteenth century they were pioneering a way forward in health, welfare,

education and vocational services including sheltered employment and skills training (Pritchard, 1963).

The first specialised workshops to appear were skills-based set ups for blind children, and adults, designed to give them earning power. They offered little in the way of education for it was only when blind people had access to the tactile reading systems, designed by Louis Braille and William Moon, in the mid-1800s, that legislation made education compulsory for visually impaired children (Pritchard, 1963: p49). This did not yet apply to any other groups.

By the end of the century a handful of charities were also helping sighted disabled people to become economically active. A prime initiator of this was John Grooms who set out to rescue young homeless 'crippled' women off the streets of London. In the 1860s he established a silk flower making workshop to provide them with skills training and employment and also helped them find lodgings within travelling distance.

The venture, which became established as the John Groom's Crippleage and Flower Girls Mission, eventually transferred the employees into more protective, residential accommodation attached to the workshop (Martin 1982). This was a model that was soon being repeated by other charities, The Cripples' Home and Industrial School for Girls Mission, established in 1851, and a little later, one for boys, had similar objectives by

offering three-year apprenticeships in a range of crafts (Pritchard, 1963).

The conditions in these workshops, however, were often harsh. Those for blind people were notorious for their excessively low wages and workers often had to turn to begging to augment their meagre income (NLBD, 1974: p20). By 1899, this situation had driven blind workers to establish their own trade union which was called the National League of the Blind (NLB) (in later years membership was extended to sighted disabled workers from other sheltered workshops, and it then became the League of Blind and Disabled) (NLBD 1974: p3). Following the example of other industrial workers, the NLB set out to tackle the excessive exploitation by organising marches, strikes, and campaigns, for better wages and in 1902 the NLB affiliated to the Trade Union Congress (TUC) (Campbell and Oliver, 1996: p47). It led the way by being the first recorded organisation **of** disabled people to campaign against poor living conditions.

By the end of the century, a trend was growing to provide separate (often residential) schools and workshops, frequently linked to specialist hospitals, for a wide group of disabled adults and children (Borsay, 2005: p95, Pritchard, 1963: p19). These charitable initiatives were clearly practical attempts to help destitute people have more secure lives and be financially self-supporting, but they were also the beginning of a new phase. As

Finkelstein argued above, disabled people were being segregated away from their natural communities because of the impact of industrial conditions.

Rehabilitation - a new paradigm

By the twentieth century the evolution of services for disabled people were entering a new phase, and this time with greater input from the state. Blaxter (1976: p2) noted that the statutory service sector had to be seen alongside a continued history of welfare by voluntary charity. She observed this had often resulted in dual service provision which later became established as a partnership. The evidence of this is all around us today, in the twenty first century.

One of the changes to occur was a new approach to the issue of disability and unemployment with the appearance of rehabilitation (Mattingly, 1977a: p1). This led to a range of developments that held both positive and negative significance for disabled people over the next century. At first these services were driven by the objective of swelling labour ranks, during periods of acute labour shortage (Mattingly, 1977b: p50-58). Responding to these economic pressures, the rehabilitation of disabled people followed two paths of evolution, administered via either, medical or industrial work-based channels (Mattingly, 1977b: pp50-58). The services from both routes arose from partnerships that formed between innovative professionals, specialised charities, and parts

of the state apparatus (Anderson 2011: p47, Mattingly, 1977b: pp50-58), but were largely sporadic until 1946.

Initial developments were tied in with periods of war and peace. An immense loss of life during the First World War and a sudden shortage of manpower led to a search for ways to restore injured men to active service. Rehabilitation then made its first appearance in military orthopaedic hospitals and in sanatoria for the treatment of tuberculosis (TB) (Mattingly, 1977a: p1). Doctors, treating the war injured, started drawing on new types of therapeutic methods to see if this could improve recovery of physical function and looked with interest into the idea of some after care following surgery (Mattingly, 1977a: p1).

Outside the medical field of treatment, returning people to work was becoming of greater concern to the state and so some public funding was invested in vocational rehabilitation. After the war, in 1919, the government established instructional factories run by the Ministry of Pensions, to retrain disabled ex-servicemen. These training outlets, later transferred to the Ministry of Labour, continued to offer limited openings for re-skilling workers for industry (Mattingly, 1977a: p2).

The drive to provide some “after-care” for disabled people, following medical treatment, became a new interest for charitable intervention too. This represented a precursor to the convalescent and rehabilitation services we know today. Several charities set out to

promote the idea of medical rehabilitation (which had more or less disappeared after the war), and a significant organisation to appear at that stage was the Central Council for the Care of Cripples (CCCC).

Established in 1919, the CCCC, took up the health needs of disabled children and adults. It set up local branches to promote services, provided the basis for some basic nursing training and professional certification, and established a network of links with health professionals to support their efforts in pioneering the idea that rehabilitation could improve recovery after surgery (CCCC, 1935, CCD, 1969).

The Central Council for the Care of Cripples was subsequently renamed the Central Council for the Disabled (CCD). Later it merged with the British Council for Rehabilitation and adopted the title, the Royal Association for Disability and Rehabilitation (RADAR, much later renamed Disability Rights UK following a merger, see chapter 11).

The British Council for Rehabilitation of the Disabled and the National Fund for Polio Research, added their weight to the CCCC to promote rehabilitation in the 1940s. Amongst their various activities, they promoted the establishment of training courses and higher education centres, organised international seminars for professionals, and established some working parties to investigate several aspects of disability, both medical and social.

World War Two and the welfare state

As with the previous 1914-1918 war, the conditions that increased the amount of disablement in society were also the conditions that drew more disabled people into employment. Whilst the 1939-1945 war prevailed, the rules of industry were different, and the shortage of munitions workers turned government attention to the employment potential of disabled civilians.

The wartime government introduced an interim scheme to train and resettle people into work and between 1941 and 1945 over half a million disabled people were found employment by the Ministry of Labour (Mattingly, 1977a: p2). Having recognised this hidden potential, the government then introduced Government Training Centres, Industrial Rehabilitation Units, Sheltered Workshops, such as Remploy, and assigned Disablement Resettlement Officers to the Labour Exchanges to promote employment in the regular workforce (Mattingly, 1977a: p2, Randle, 1977: p27). It was clear that when industrial production was for the needs of a society under threat, and when labour was in short supply, industry could and did adapt to employ disabled people as workers.

The development of medical rehabilitation in the interwar years had been limited due to the lack of a coherent funding structure (Mattingly, 1977a: p2) but this was about to change. Towards the end of the war, plans were laid to introduce a national medical service and a

welfare state (Berridge, 1999: p11, Owen, 1988). The Poor Law had to be replaced with something less humiliating and in an increasingly, competitive international market, the state had to take some responsibility for improving the health and education standards of its workers and their children (Owen, 1988). As is usually the case with major social reconstruction, discussions for this had been taking place, over a prolonged period (Owen 1988).

The 1929 Local Government Act had enabled local authorities to replace the old Poor Law Infirmaries with hospitals for the purpose of containing infectious diseases, providing some maternity care, care for the elderly poor and for disabled people with nowhere to go.

In practice, legislating for a national medical service was then both halted and furthered by the war. In 1939, the war forced the government to introduce some state funding, to pay voluntary hospitals for Emergency Medical Services to treat air raid casualties, and, by the end of the war, significant amounts of health care were being publicly funded, either centrally or through the local councils (Owen, 1988). There had therefore been a transition towards a publicly provided service by necessity, and this strengthened the case for a properly structured National Health Service.

Between 1939 and 1945, plans were also laid for a raft of social reforms and a review, in 1942, produced the *Beveridge Report* which laid the foundations for social

security and pensions legislation. The aim was to prevent absolute destitution caused by unemployment, sickness, industrial injury or widowhood (McKay and Rowlingson, 1999).

A whole range of new legislation followed that established the Welfare State. The most pertinent to this account were the *National Insurance Act (1946)*, the *Industrial Injuries Act (1946)*, the *National Health Service Act (1946)*, and the *National Assistance Act (1948)*. These, along with the *Disabled Persons (Employment) Act (1944)* laid the basic framework for disability related services (Anderson, 2011: p177).

‘Once the NHS existed, from 1948 medical rehabilitation services expanded more rapidly to get people back to work, but the objectives were very restrictive,’ as Winona, an occupational therapist recalled to me; ‘It became concerned with industry – returning people to work, others and housewives didn’t get a look in at that stage’ (Winona, 1991).

Apart from a few jobs protected by the *Disabled Persons (Employment) Act (1944)*, once the war was over, disabled people became pushed to one side again. The Disablement Resettlement Service, through the Labour Exchanges, still existed, but people found it was largely ineffective (Topliss, 1976, in Borsay 2005: pp136-137).

In due course, as ideas changed, rehabilitation professionals started to think about other groups they could help, seeing that, if the service was to survive, it had to move away from the purely industrial objective (Somerville, 1958: pp11-17). It started to open up to more disabled people, and many became interested in what it could offer.

Louis Battye (1967: p23), a disabled resident of an institution, attending the tenth World Congress of the International Society for Rehabilitation of the Disabled, wrote:

The whole atmosphere of the Congress was positive and dynamic. It is not enough merely to give medical treatment. When the doctors can do no more, the real work begins – getting the patient back into circulation as an independent fully employed citizen. Rehabilitation is not a privilege; it's a right. Yet in some ways the most rewarding aspect of the whole Congress wasn't the official programme but the people we met, particularly the disabled participants. They were examples of what rehabilitation really means.

People, on both sides of the service divide, were becoming engaged in new ways of thinking and learning. For instance, Dr. Agerholm (1965: pp14-20), a consultant of rehabilitation, placed considerable emphasis on the stimulus given to new thinking by the survivors of the

1947 polio epidemic. She noted they did not wish to remain in hospital, but wanted to make their own choices, determine their own risks and live as full lives as possible. She said they helped professionals to develop principles, standards and techniques for the rehabilitation of severely impaired people in general. This enlightened and somewhat unusual acknowledgement from a medical consultant at that time, and the view of Louis Battye, above, provide a glimpse into the enthusiasm around for the potential opening up to disabled people. From the late 1950s onwards, people had raised hopes that rehabilitation would offer a better chance to some quality of life.

For professionals expanding the service it created new opportunities to develop their skills, for disabled people it offered new hope of freedom from dependency. However, opening the service to more people developed in a very piecemeal way (Mattingly, 1977a, Beardshaw 1988).

Raised aspirations, normalisation and what next

As disabled people began examining what the professionals were actually doing, they started to have some serious concerns, for despite all the good intentions and helpful ideas, there were two fundamental problems. One was the power professionals exercised over disabled people, by deciding for them rather than consulting them about their treatment objectives, the other lay with the basic philosophy they worked with

around the concept of normalisation. The extract below from a 1962 edition of the *Health Horizon* is fairly typical of its time:

In treating the “stroke” patient the Occupational Therapist must consider his problems in relation to his normal environment, since her main function is to help him adjust to his disability, and live to the maximum in spite of it (Keane, 1962).

The emphasis on normality and personal adjustment carried with it the implication that the disabled person had to come to terms with the restrictions they encountered. On the surface, this was true. It was necessary to make massive adjustments to big changes, and it was especially tough for disabled people living in an unenlightened society. But, by placing the emphasis on personal adjustment and acceptance, professionals were, in practice, pressing disabled people to accept the unacceptable. Firstly, they were failing to recognise the disabling aspects of society that might be changed, secondly, they were denying the validity and potential of the disability experience, and thirdly they disregarded the merits of people finding alternative ways to achieve the same end, a theme I shall return to in more depth in later chapters.

In the extract below, Anne Rae gives a small flavour of the affect normalisation had on her experience when she was growing up:

“As a disabled person growing up at that time, there was nothing to identify yourself with. You couldn’t identify with a group or anything like that; but I don’t think I thought in those terms anyway. I think what we were desperately doing, what I was doing and probably all of us were doing, was normalising like mad, and reflecting what was going on around us. The 1960s was the era that people feel most nostalgic about these days. It was exciting, but those of us who were active and mobile in those days started to live in a pale reflection of how non-disabled society was organising.” (Rae, cited in Campbell and Oliver, 1996: p38).

Whilst rehabilitation had started to raise expectations for a growing number of younger disabled people who thought it offered a way forward, there were aspects of the service holding people back. A major factor was the inaccessible environment outside the hospital and the rehabilitation professionals were doing little to tackle that.

Once people left hospital there was often no way, they could return home; there were no community-based support services (Beardshaw, 1988: pp25-5) and there was no help to adapt housing (Buckle, 1971: p122;

Finlay, 1978). Because of this, many left rehabilitation programmes full of ideas about what they could achieve, only to end up in institutions because the support wasn't there. It was this situation that confronted Maggie Davis [known as Maggie Hines at the time], in the late 1960s, when she became disabled:

'I was in an institution at Stoke Mandeville after my accident and I knew something was desperately wrong. I knew that I didn't have rights that other people had; i.e. able-bodied people, but I couldn't figure out quite what it was all about. And I couldn't see why. I mean, being able-bodied before, I couldn't see why I just couldn't go back into society and have a flat and have somebody to help me and get a job. I actually presumed that this is what I would be able to do, and I must admit I had a very rude awakening when there was nowhere to go, nobody would take me back in the job I had before, and there just wasn't any help in the community.' (Hines, 1983, cited in Campbell and Oliver, 1996: p34).

The response to the needs of people like Maggie Davis takes us into the parallel service development that was also taking shape in the 1960s and this is the subject of the next two chapters.

CHAPTER 2 - Finding a Care Solution

In the early post war years, although disabled people had their expectations raised by the offer of rehabilitation, the service could not deliver the independence they really wanted. Unless something was done about the barriers to integration, rehabilitation could only bring limited gains (Beardshaw 1988: pp19-22).

Moving away from hospital presented serious problems for many people with substantial impairments. Because of the inaccessible environment they found themselves living isolated lives, often in poverty, and dependent on their families because the community couldn't accommodate them (Fiedler 1988: pp8-11).

If the family home could not be returned to, some form of care service had to take over and considerable numbers of young disabled people aged 16, or above, landed up in chronic hospital wards (Whitaker 1959: p3) where they faced the prospect of remaining for the rest of their lives, as illustrated below:

At the age of sixteen in 1943, I entered a geriatric ward. There was nowhere else for me it seemed ... for 23 years the geriatric ward of The Chronic Hospital has been home to me. I was told on arrival that as I couldn't walk, I would have to stay in bed permanently. The days were monotonous, the routine unvarying and the rules and regulations in their number and inhumanity might have

been devised for an institution for the punishment of criminals (Gilbert 1967: p20).

These austere hospital wards offered a cruel life sentence to many young people forced to live in them and, additionally, being in medical environments they were treated as being in a permanent state of chronic sickness. Ann MacFarlane (cited in Campbell and Oliver, 1996: p36) describes how this affected her earlier experiences:

“I think disability was very much illness based for me. I was ill. I was perceived to be ill by everybody including the professional people and other people who visited me. I think I perceived myself as being ill, though in retrospect, I certainly wasn't most of the time. I was ill at times but I wouldn't have said that was the predominant feature. The predominant feature throughout my institutional life was the fact that I was left in bed a lot of the time when I could have been up. Because I couldn't dress and wash myself, the staff did for me what they felt was adequate and sometimes it was totally inadequate. I was very much kept where they wanted me to be kept.”

In due course these outdated hospital wards had to be replaced and a new form of residential care entered the scene.

Reasons for creating special institutions

Following World War Two, the post-war Labour government pursued its promises to the nation. These were: to build a national health service, develop a more comprehensive social security system, and set up welfare services through local government departments. In the process, a massive new service industry was created that impacted on the lives of disabled people in a multitude of ways. Significant amongst these were the labour demands of the new services of the welfare state.

The war had broken through the employment bar that had operated against married women during the inter war years and it meant that women were not only drawn into the wartime workforce but were also able to develop their careers in the new care professions afterwards (Taylor-Gooby 1991: p57, Wilson 1977: pp163-5). This, along with the professionalisation of care, started to compete with their predominantly caring role within the family (McKnight 1977).

Furthermore, people increasingly had to move around the country in search of jobs, and this brought about the disintegration of social support networks provided by extended families and the neighbourhood. From then on, the basic units of society became nuclear families made increasingly dependent on the state for crisis support (Rowbotham 1973: p60, Taylor-Googby 1991: pp149-50).

Along with the introduction of the welfare state, it became more commonly assumed that disabled people should be professionally taken care of. I can recall personal accounts of relatives being advised to release their; disabled spouses, ageing parents, or children, to the care of others, and many did so.

In the 1950s and 1960s, there was a dramatic increase in the numbers of young people entering specialised residential centres for physically disabled people (Fiedler 1988: p10). This process of institutionalisation occurred for a range of reasons. Some of the more common explanations were; poverty, long hospitalisation for illness or disability, estrangement from the family, inadequate housing, or social rejection.

The *National Assistance Act* (1948) had given local authorities (LAs) the powers to set up some limited welfare services for the community. But, with a starting point of almost no services, and legislation backed by very few resources, the services on offer to anyone, let alone disabled people, remained scanty. One provision of the Act, that did occur, was the creation of residential care homes for the elderly to replace the greatly feared workhouses. When there was pressure to release beds in the hospitals, many young disabled people became inappropriately placed in these old people's homes (Whitaker 1959).

Following the introduction of the NHS there was a drive, in the 1950s, to move young people out of the old

chronic wards. This started to highlight the awful conditions that significant numbers of young disabled people had been living in for so many years. A few concerned professionals then started to question whether the reasons underlying the permanent hospitalisation of these young people were primarily medical, or social (Nicholson 1958: p10, Whitaker 1959).

At this point, no comprehensive survey of the disabled population had been done. The first national survey by the Office of Population and Surveys did not occur until 1971 (Harris, Cox and Smith 1971), so there were no statistics about the number of people in this situation, nor of the reasons for their hospital admission. Because so little was known, social and medical administrators found it difficult to decide what should be done because they were unsure whether hospitals were the right environment. Once alerted to this as a problem studies started to be carried out to shed some light on the situation.

One of the earliest of these was sponsored by the Nuffield Foundation in 1956-1957 and conducted by a hospital almoner, Ann Whitaker, supported by a medical consultant. Whitaker (1959: p3) explained that their task was to:

discover how many disabled people between 15-55 years were being cared for, here and there, in more or less suitable accommodation in the region. To learn more

about them and their problems, from themselves and from the staffs caring for them, and to make recommendations for a more suitable setting for their care if this seemed desirable.

This survey looked at a sample of 314 people, and 57 establishments, and it reported that the most important findings were that: no one (including those in hospital wards) needed a resident doctor; that 157 people were not receiving treatment of any kind; and that a further 86 were on drugs only. Furthermore, Whitaker found that: of the 191 people who were under the care of fully trained nurses, only 83 actually needed their medical services. She concluded that many people could therefore be cared for by far-less-skilled attendants.

Whitaker reported that the disabled people she interviewed had freely and repeatedly told her there was nothing else for them, that they were entirely cut off from the outside world and were destined to remain so. They were experiencing boredom and extreme unhappiness from being in constant association with people who were very old, deaf and senile. Many had explained to her that they wanted something other than hospital life (Whitaker, 1959: p4).

The study's recommendations were; that mentally alert, young and middle-aged disabled people should therefore be moved from these hospital wards into residential centres, administered by regional hospital

boards but separate from a hospital, and situated in the suburbs, or in small towns. Whitaker argued that disabled people should be given the opportunity to mix as freely as possible with the rest of the community (Whitaker, 1959: p6). The researcher had identified that many disabled people were inappropriately situated but could not yet conceive an alternative to medically supervised, residential care.

Fairly early in the 1950s the Spastics Society (renamed Scope in 1994) also carried out a survey to find out what was happening to people with cerebral palsy, and, like Whitaker, discovered a similar pattern of widespread institutionalisation of young people in units designed for the elderly or other groups.

They found that the use of sub-normality hospitals, mental hospitals and chronic sick wards, to provide long-term accommodation and care, was common. Once the results of their survey became known this Society became very proactive in opening special residential centres for young adults with cerebral palsy, so they could escape the grim hospital conditions. It was generally argued however, that home care was either impossible or undesirable for this group of disabled people (Brown, 1962).

Another example of the discussions going on about this issue of long-term support came from two professionals in a special school who were asking questions about the prospects for their pupils:

Segregation of handicapped individuals in residential institutions is not only economically unsound but also emotionally and psychologically wrong for the individual, his parents and the community in which they live. Yet as the parents grow older ... [they] can no longer care for their sons and daughters at home, most severely disabled individuals must look forward to ending their days in a long stay residential home (Ellis and Hardy, *Spastics Society's Quarterly Journal* 1956 vol 5. no.3.).

It is possible here to detect a growing disquiet about the prospect of young people living in institutions for the rest of their lives, but there were few alternative suggestions being made. Like Whitaker, the plea of these educationalists was not that support should be offered to people in their own homes, but for institutions to be situated in towns close to ordinary facilities, in order to make them more bearable places for young people to live in.

These few examples illustrate the beginning of a debate amongst professionals involved in providing the services and further evidence of this can be found in the report of a limited study commissioned by the Central Council for the Care of Cripples (CCCC). There, Nicholson (1958: p10) drew attention to the existence of "a deep division of opinion" when trying to decide policy in the planning of future services. He found on the one

hand there were those who thought special services were best provided in separate facilities whilst others maintained handicapped people should be helped to live as normal lives as possible within their local communities.

This was a time of transition when new services were being introduced. It meant that the door to discourse about policy and service development was still open. But once a direction in the course of action was decided upon, the debate subsided and a range of possible alternatives to institutional care were no longer considered.

Once having become apparent to the authorities that the long-term hospitalisation of young disabled people was inappropriate, resources started to be directed towards creating an alternative set of institutions. The sequence of reasoning, it seems to me, went something like this; disabled people end up in hospital because the family cannot support them. People who are hospitalised must need professional care. If hospital is no longer appropriate specially staffed units must replace them. It was then primarily charities that took the initiative to create these alternatives. The common ground of concerns around the hospitalisation of people with learning difficulties, mental health issues and physical disability also contributed to the groundswell for reform. The institutional programme that followed, then came about as a spontaneous response by voluntary

organisations wanting to do something helpful, supported by the financial and moral backing of the welfare state (Halliday in: *Cheshire Smile* 1963: pp17-22). As mentioned above a decade was yet to pass before there would be any government commissioned national research into numbers and needs of disabled people in Britain, and so the care service grew in an unplanned way.

Institutions - a period of expansion

The period between 1960 and 1980 saw a particularly rapid expansion of segregated facilities for younger disabled people. Charities, health authorities, welfare and education authorities all became involved in establishing a whole raft of separate services that included residential care, special schools, disability skills training centres, sheltered workshops and day centres as part of a general welfare programme (Borsay, 2005, UPIAS 1976). Separate services became the norm (Finkelstein 1981). This separation meant that, once sectioned off, society effectively ignored all the access issues that disability raised.

In effect, disabled adults were badly let down at that point by an enthusiastic movement that set out to provide specialised residential institutions as the answer to all their housing and other support needs. As it turned out, this was not only a regressive policy that later had to be overturned (UPIAS 1976) but represented the most

extreme end of a whole spectrum of social exclusion that was setting disabled people apart.

Whilst in practice only a minority of disabled people ever had to live in residential care homes (Fiedler 1988), the issue of institutionalisation has been highly significant in the political history of disability. Firstly, this is because it is possible to see, within the institutions, a form of social control in service delivery that became a corner stone for social care policies, later. Secondly, because some of these institutions created unusual communities where disabled people started the struggle for more control of their lives and gained insights that were of benefit to a social movement that emerged many years later.

The two most prolific voluntary providers of institutional care, initially, were the Cheshire Foundation and the Spastics Society (Fiedler 1988). In the case of the Leonard Cheshire Foundation it was the actions of one individual in particular, Leonard Cheshire, that sparked a movement to create residential care homes for disabled people (Russell 1963), and in the case of the Spastics Society it was the action of a small group of parents who were desperate for somewhere for their children to go when they became adults (Brown 1962). Both charities had a major impact on other developments in the care services that followed.

Having argued that residential institutions arose in response to the appalling conditions faced by many disabled people, it might appear that they were a

progressive trend. They were, after all, trying to provide better places of refuge. With hindsight, however, it is possible to see a vast array of segregated services that might have been avoided if the initiators had stopped to study the conditions more carefully before setting out to provide the answers.

The origins of Cheshire Homes

Cheshire Homes derived by chance. Leonard Cheshire was a socially privileged young man searching for a purpose in life. His wartime experiences, as a bomber pilot and as an official witness to the nuclear bombing of Japan, had given him a desire to do something socially constructive when the war ended. On leaving the air force, he had the opportunity to buy a dilapidated mansion in Hampshire, surrounded by a large estate, called *Le Court*. There he tried to set up a mutually supportive commune for ex-servicemen and their families (They were not disabled, but they were homeless).

His vision had been to extend the wartime community spirit by creating a self-sufficient community to help people resettle themselves back into civilian life. This venture very quickly collapsed and when the people moved away Cheshire was left with a large empty mansion. Shortly afterwards he was contacted by a local hospital where an ex-commune resident, Arthur Dykes, was terminally ill with cancer. As *Le Court* had been his last residence, the hospital had approached Cheshire to

seek out somewhere for him to go. In a nationwide search, Cheshire became aware there was nothing, and offered to house and take care of him until he died. So, Arthur Dykes moved back to *Le Court* (Russell, 1963).

In discussion with Dykes, Cheshire developed the idea of making *Le Court* available to others in similar circumstances and in 1948 decided to go ahead with his idea. He opened the house as a refuge to sick and disabled people with nowhere else to go. Before long, requests came flooding in from hospital almoners and others desperately trying to find ways to discharge patients from hospitals. This spontaneous experiment became established as the first Cheshire Home (Russell, 1963).

The extensive praise he received, for turning *Le Court* into a Home for disabled people, and his recent conversion to Catholicism, spurred Cheshire on with a missionary zeal to set up more Homes elsewhere. He was soon travelling around the country, enthusing new groups to set up their own local Cheshire Homes like *Le Court*. Disused country mansions were donated with extraordinary rapidity, and with Cheshire's phenomenal driving energy and determination, groups around the country were galvanised into action to refurbish these places into Homes for disabled people. Meanwhile, Cheshire rapidly moved on to take his ideas to India, and other countries. In a very few years, the Cheshire Homes movement was established as the Cheshire Foundation.

This went on to establish numerous Homes in Britain and around the world (Russell, 1963). Before long, Cheshire had acquired an international reputation as the inspirational leader in a mission for the relief of suffering, rescuing disabled people from grim conditions by providing them with residential care homes.

Drawn from the annual figures, published in *The Cheshire Smile* (sic) magazine of the Cheshire Homes the table below indicates the rate of growth of Cheshire Homes for physically disabled people in Britain between 1958 and 1970.

Table of Cheshire Homes by Year of Opening		
Year of Opening	Number of Homes	Number of Residents as at 31 December 1970
1948-1952	2	84
1953-1957	7	248
1958-1962	22	683
1963-1967	7	205
1967-1970	9	222
TOTALS	47	1442

Source: (*Cheshire Smile*, 1971: p38).

By 1970 there were Cheshire Homes in thirty other countries. By the autumn of 1971 the *Cheshire Smile* recorded there were around 64 Cheshire Homes abroad with new ones on the way, and 47 in the UK (*Cheshire Smile*, 1971: pp38-42). From this it can be seen how rapidly the organisation had become a significant

promoter and provider of institutional care to disabled people.

Group Captain Leonard Cheshire imprinted his mark on the homes in a very particular way. Below is an extract from a talk he gave to the annual conference of the Cheshire Foundation, in 1964, which portrays his idealism and moral zeal.

'I am quite sure we would all agree that the essential spirit that one needs in this sort of work is to be economical, to be willing to make do with what one has got. One wants to have people who are willing to do things, to take their coats off and work, rather than sit down and make decisions and invest money. The strength that your Homes have, comes from the fact that you have had to struggle so hard from little beginnings to build something up, and I think my greatest wish to the future is, that should always be so. Once any particular Home has complete security and can foresee the future in terms of financial security and so on, it must lose something of its spirit. I think that applies to the patients too, because the need of the patients is a human need, not just that they need nursing and caring for, like an acutely ill person in hospital. They have their lives to live and *it is not good for any of us to have too much of material things*. That therefore holds good for the patients in a Home, as well as for us as an organisation.'

(Cheshire, 1964 *Cheshire Smile* 10, (4), 11.) (emphasis added).

To fully appreciate the implications of Cheshire's speech here it is worth bearing in mind the differences of his own social background, the social status of the people he was addressing, and of those he was talking about. From direct experience of working for the Cheshire Foundation, at that time, it was clear to me and many others that his target audience of representatives from the various management committees, senior staff, and the Foundation's Trustees, were not "materially deprived". In fact, it was often quite the contrary. The "patients", (i.e. the residents) on the other hand, were frequently from poor, materially deprived backgrounds, and it is not hard to imagine what they thought about being expected to 'renounce material comforts,' because this was good for them! (The disabled residents were not permitted to attend the Foundation's policy making conferences at that stage).

The Spastics Society's programme

The other major charity, contributing to this programme of creating institutional care, was the Spastics Society. Founded in 1952, this organisation established a network of parents' support groups which went on to set up several services for their young and adult children. Principally these were special schools,

training centres, residential hostels and Homes (Brown 1962).

The growth of residential Homes and Centres, run by the Spastics Society, whilst numerically less than the Cheshire Foundation, was none-the-less considerable. In 1965, Miss M. Richards, the Society's Senior Family Caseworker, reported that between 1952 and 1965 the Spastics Society had established 11 residential centres and hostels, one of which had been founded by the British Council for the Welfare of Spastics. She said that with a further 11 centres in the pipeline she anticipated that, by 1966, there would be a total of 20 with 2 more on the way (Richards (1965: p4).

Given they were catering for a relatively small, very specific group of disabled people, it did mean that residential care was soon housing a considerable percentage of that adult population. Membership groups, led by parents who were frustrated with the poor services provided by professionals, or more often the lack of them, showed a similar zeal to Cheshire's followers and so took the initiative to plan and run their own services (*Spastics News*, 1962: p43).

The tidal wave of enthusiasm for residential care that had been set in motion prompted this senior family caseworker, working for the Spastics Society, to raise her concerns about this rapidly growing trend. Richards referred to the 500 applications received for residential placements by 1965, and to an anticipated 200 more per

year in the foreseeable future. She brought it to people's attention that there was a conflict already becoming apparent between the opposing ambitions of parents and their disabled dependants. Whilst the former were looking for long-term security for their maturing children, young disabled adults were expressing their horror at the prospect of being shut-away to be looked after for the rest of their lives. They wanted to be active and become more independent (Richards 1965: p4).

Based on these observations, Richards (1965) urged members of the Spastics Society to be more cautious about rushing into building residential units and asked them to also consider alternative ways to support people to live independently in the community. She wrote:

'I know that some of you, realising the large numbers waiting for a place to be provided by the Society, are wanting to plan your own hostels. My own feeling is that to provide this sort of permanent care on a local basis is more complicated than is realised and probably more of an undertaking than most groups can afford.

... if we can use more of our energies to helping people stay in their own normal environment by providing the supports they and their families need, we shall not only be using our resources more effectively, and freeing ourselves to provide residential care where nothing else will do, but giving many more people the chance to

develop and perhaps move on to a greater degree of independence than if we were to concentrate all our resources on taking as many as possible into our full time care.’ (Richards, 1965: pp5-6).

This was evidence that the policy of segregation was going ahead despite a growing disquiet amongst disabled people. By the mid-1960s, Richards was able to argue that the Society could gain good ideas about how to set up support systems in the community by looking at how some local authorities were starting to organise community services for the elderly, but she was not listened to. It was a considerable number of years and a lot of grass roots pressure before the Spastics Society conceded the need to explore alternatives.

A new trend let loose

In addition to these two major charities there were a few other voluntary organisations also running institutions for physically disabled people (Fiedler 1988). Some had modified their criteria to accommodate a wider group of disabled people when their original purpose had been overtaken by events. Such had been the case with Papworth in Cambridge and Enham-Alamein, in Hampshire, which broadened their scope following improvements in the treatment of tuberculosis making isolation units unnecessary (*Cheshire Smile*, 1961: p50).

However, it can reasonably be argued that, at this stage, it was the Cheshire Foundation and the Spastics

Society that were the main crusaders establishing residential care and they set a scene that others followed. Their campaigning zeal to promote protective environments added reinforcement to widely held perceptions of disabled people as total dependants within society.

Within the early Cheshire Homes movement, there appears to have been no debate about the rights or wrongs of setting up care services in institutions, or about whether there could be any other way of supporting people to live outside hospitals. Within the Spastics Society, whilst some questioning did take place, it gained little attention. Given the warm endorsement by professionals, relatives and the authorities, it possibly didn't occur to Cheshire or to parents of the Spastics Society that an alternative might be viable or more desirable. There were few ready-made community-based models for them to turn to, at home or abroad, but there was plenty of bad residential care to be improved upon. The euphoria of collective spontaneity and frenzied activity left little room for paying attention to the comments of their critics.

State provision of special institutions

The next phase started in 1963 when the government introduced its ten-year health and welfare plans known as the Blue Books (Ministry of Health 1962). The plans were drawn up by the Ministry of Health, from the results of a survey by Local Authorities (LA) and

Regional Health Authorities (RHA) who had been asked to find out the needs of certain specified groups, including people with physical handicaps. The government also wanted to clarify what these authorities were actually doing for elderly and disabled people, so it could plan ahead for hospital services and community care.

The outcome was a government allocation of £7.5 million, a considerable sum in those days, for a building programme of local authority residential homes and day centres for younger disabled people. Further money was made available to Regional Hospital Boards to develop special residential units for young disabled people, known as Young Chronic Sick Units (YCSU's) for people under 65. The aim was to move all adults of *working age* out of their long-term placements in hospital geriatric wards (DHSS Census of Residential Accommodation, 1973: p1) and so LAs and RHAs went ahead to build their special units.

The social policy of the Welfare State, regarding disabled people, was still ill-thought out, and so when the State began to intervene it jumped on a bandwagon started by the voluntary sector. It too accepted, without much question, the need for special institutions to house people and assisted this with an injection of funding and pressure on the respective authorities.

There was still a lack of comprehensive data about the number of disabled people in the country or their reasons for seeking residential care, so public services,

as with the charities, made assumptions about what disabled people actually wanted or needed. Finding an alternative to paying for people to live far from home, in charity-run institutions, was no doubt one of the arguments used to justify decisions to create more local institutions run by local authorities.

When this state-funded building programme started to happen, the Cheshire Foundation became jittery about the implications for its own future as perceived by this Cheshire Home manager Mr. Laysaght:

‘Monmouth County Council have made known their intention of taking our patients. They have not been sympathetic to us from the start. Now they are going ahead with their own schemes and choosing sites for their Homes. There is a growing murmur in the county about the difficulties in raising funds. People are saying, “We pay rates; why should we contribute to the Cheshire Homes, which are or will soon become redundant?” ’ (Laysaght in: *Cheshire Smile* 1963: p15; Spring Conference).

Because of such concerns, the Ministry of Health was invited to address the 1963 Annual Conference of the Cheshire Foundation to clarify the government’s intentions (*Cheshire Smile* 1963). In this talk a civil servant, called Mr. Halliday, raised several pertinent issues. First, there was his reference to the dearth of

research data available to the Minister of Health, about the unmet 'needs' of disabled people. Second, was his mention of the intention to start planning services on the basis of some evidence rather than responding to rash enthusiasms, (possibly a reference to the Cheshire Foundation's approach) and third, he talked of the Minister of Health's intention to address the issues of inaccessible housing as well as providing more residential care which it was envisaged would continue to grow as a shared service between public and voluntary sectors.

He introduced his audience to the reasoning behind the ten-year health and welfare plan, regarding disabled people and went on to say:

'We anticipate a substantial increase ... [in identified needs for services] ... but how much we don't know ... you see, needs don't really come to light until services are there. People don't register if there is nothing to register for.

Thus, the starting point must always be – what do they really need. The Minister's line on this is ... the enthusiasm that decides in advance what people need has led to many services providing what they don't need or want.

We can discuss the needs of the handicapped under four headings:

(1) Skilled help to enable a disabled person to cope with his handicap ...

(2) A home or some other accommodation ...

(3) Employment within his capacity ...

(4) Recreation and holidays

... Having got the needs clear we can then see what services ought to be provided to meet them. The emphasis is on living at home if you can, and thus there is emphasis on building more homes for these purposes, adapting houses, providing gadgets etc. But in spite of all that, some residential accommodation will be essential. The Blue Book states explicitly that many younger handicapped people are still in unsuitable accommodation [meaning chronic hospital wards], yet only eleven new Homes providing 322 places are proposed in the local authority plans. ... We shall need joint studies by groups of local authorities in consultation with voluntary organisations to determine what further provision should be made.' (*Cheshire Smile* 1963: pp17-18).

In the next extract, Halliday goes on to the difficulties they were having developing their policies because of the confusion that existed about the sort of assistance disabled people needed (or wanted) and who should provide it, i.e. when was it because of medical needs or when was it for social reasons. He put it in the following way:

‘Now I want to touch on the division - I know you are very interested in this - between the care for which a local authority is responsible and the care for which a hospital is responsible. The broad distinction is, I think, that the local authorities are responsible for providing what we call care and attention, i.e. of a sort that does not exceed the type of nursing people can expect in their own homes. But when the nursing need is more than that, you are getting on to the responsibility of the hospital service. The decision about any individual can only be taken locally by the medical and welfare people agreeing that this person falls on this side of the fence or the other.’ (*Cheshire Smile* 1963: p18).

Responding to a question from the floor seeking reassurance that the Health Authorities would fund placements Mr. Halliday said:

‘The regional hospital boards are entirely responsible for deciding how they provide for the young chronic sick, and whether they make contractual arrangements and so on with voluntary organisations like yourselves. If you can convince the hospital boards that hospitalisation is not the best provision for this particular need, perhaps you will be able to come to some agreement.’ (*Cheshire Smile* 1963: p21).

The arguments they were having then over whether care was medical or social and who should pay for it have continued to this day. The fact is, there will be no resolution of this argument whilst disability is regarded in medical terms and whilst divisions are artificially created by professional and funding boundaries. People, and the personal help they need, cannot be subdivided and categorised so neatly.

It was difficult in the 1960s for administrators to move away from the idea that disability was a form of sickness and this caused much confusion amongst the authorities when it came to funding residents in Cheshire Homes. L. Cheshire (*Cheshire Smile* 1963: p21) confirmed this state of confusion:

‘Most of our patients are in fact regional hospital cases (sic), but local authorities are paying for many of them out of the goodness of their hearts. Now if we could really persuade the regional hospital boards that this work can be done, and is being done, more economically, as well as better from the patient’s point of view, in Homes such as ours ... we could establish ourselves on a permanent footing, and there would be a clear distinction between our work and that of local authorities, who would then concentrate on providing Homes for people who were much less disabled’.

It is perhaps worth noting here how the residential solution to accommodation was becoming extended, in the minds of people such as Cheshire, to include disabled people who were 'much less disabled'.

The fears of the Cheshire Foundation, as it turned out, were largely groundless. The government had no intention of making the voluntary sector redundant for it needed their services too much, and so the Foundation continued to flourish.

Some registration requirements had been laid down, in the National Assistance and Health Service Acts, which determined whether medical staff had to be employed. If an institution wanted to register as a nursing home (for health authority funded placements) it had to employ some qualified nursing staff. If it wanted to register as a care home with the LA to obtain their funding for residents, medical staff were not necessary. In practice, a lot of charity homes met the minimum medical requirements and obtained funding from both sources (Williams 1967: p21, pp174-175).

Professionalising the carers

With residential homes becoming a major service stream, staffing became the next issue to gain political attention. A new labour force was being created to provide the personal care which was, by and large, made up of untrained people. Once disabled people had moved out of the hospitals, it became better acknowledged that

'medical' expertise was often not necessary, but the issue of what skills were needed remained.

In 1962 the government set up the Williams committee to investigate the staffing needs of care homes and the ideas from this study were presented in a report *Caring for People*. One proposal was for the creation of a new profession of trained care workers (Williams Committee Report, 1967) and this marked the beginning of a long process towards the professionalisation of a non-medical care service. In the light of this the Cheshire Foundation, had taken an initiative, in 1966, to set up its own service training corps, in the grounds of *Le Court*, and this provided a lead that others might follow (Moore in: *Cheshire Smile* 1967: p10).

CHAPTER 3 - A Critical Response to Institutionalisation

The dynamics of the care relationship examined

Replacing hospital care with institutions opened a new era of service development. There were no specific guidelines for deciding how care homes should be run or what to expect from the staff or residents (Hunt 1965: pp38-39, Miller and Gwynne 1972: pp3-4, Williams 1967: p11).

It was in this climate of experiment that a few disabled people started asking searching questions about the care arrangements being organised for them. Some of these thoughts were explored in a debate entitled 'The role of the residents' published in *Cheshire Smiles* in 1963 and 1964 (The Role of the Residents – Debate, 1964).

In those early days, a broad spectrum of disabled people entered institutions. At one end were people living through the end stage of a progressive illness who depended on others for every aspect of their well-being. They could need help with all the minutiae that physical comfort depends on when unable to do it for yourself.

At the other end were people who just required their meals prepared, and the cleaning and laundry done for them. In other respects, they could be physically independent. Between, were many residents who required as little as one or two hours of assistance a day with personal care. There were large parts of the day

when most residents required little formal help, leaving them a lot of time to fill, often with plenty of drive to make something meaningful of their lives (Personal memories, Richards 1965: p5, Russell, 1963: pp29-31).

In these relatively closed communities life incurred a specific dynamic of interaction between the residents, staff, and management. As this was played out it exposed a disparity between the way managers interpreted their role and how disabled people wished to live, with care staff often caught in the middle (Hunt 1965: p8, 1967: p26). When disabled people took up residence, they quickly found they had to negotiate their way through this social minefield caused by the effects of being caught in a web of helper-helped relationships with those around them.

On the one side there was the management with its responsibility to arrange a service. From their perspective, if a disabled person entered the institution it was because they were unable to manage their own lives and needed looking after. Their task was to exercise the controls they saw necessary to run the organisation.

Disabled residents, on the other hand, often experienced it differently. They found themselves living there primarily because the personal help was not available in their family or local community. With a long future ahead, they often wanted to extract what freedom they could from the situation they found themselves in, to express their individuality, and have a meaningful life.

The struggle to assume more control over their lives, that followed, led people to seek this in various ways.

Dependency and the loss of rights

During the early phase, some residents started to expose the oppositional nature of this dynamic of conflicting interests. In doing so they developed some very important insights, which, years later, acquired new meaning for understanding the complexities of helper-helped relationships in the wider society (Resident of *Le Court* (Anon), 1965: p11).

At this early stage of development, welfare services were being confronted with some uncomfortable questions about their methods of help. For disabled people, when they became inmates of institutions, they were immediately faced with the question of what actual rights they had. Dormitory existence gave little space for possessions, no place to entertain friends and absolutely no privacy to share intimacies with a lover (Hunt, 1968b: p18, Tanner, B. 1962-1963: p10). Lack of privacy seemed inevitable when you must share sleeping, eating, and recreational quarters, with others, twenty-four hours a day and when you found yourself set apart in remote country houses, with little transport, it just reinforced the sense of isolation.

In the face of organisational hostility towards disabled people expressing any form of sexual behaviour, and management policies that were against accommodating married couples, inmates had to ask

themselves what chance there could be of marriage or close companionship? They might ask themselves how staff would react if asked to lift two people into bed for a cuddle, and if they agreed to help, what trouble would follow?

These were living, breathing communities of young men and women, who often had lots of time to spare, and the normal range of hopes and desires. From a management perspective, personal relationships between residents, or between residents and staff, raised ethical and moral questions they were ill equipped to deal with. When charities, such as the Cheshire Foundation and the Spastics Society, set up these homes, they had nothing worked out about how people were supposed to get along together and live. As a result, policies tended to develop in a series of reactive hiccups. A personal experience of this was highlighted in *Spastics News* (Roberts, 1965: p7) and recalled in my interview with Alan Finch who was the warden of *Le Court* in the early 1950s (Finch [interview], 1988).

The Cheshire Foundation's institutions were frequently overseen by a management committee of local dignitaries who had contacts and local influence. The executive officers were often drawn from the retired military or had nursing backgrounds, as was indicated in a 1958 publicity leaflet for *Le Court* and later in the *Cheshire Smile* newsletters. Commonly, it appeared that neither committee members nor chief officers had much

prior knowledge of disability. A major task for them was to keep the organisation financially afloat and maintain local charitable support. They therefore wanted the residents to behave in ways that would reflect well for local fundraising initiatives, and young disabled people enjoying life did not always convey the desired image. Some background information regarding the ongoing changes in the makeup of Management Committees over the years and how they interpreted their responsibilities was provided by the 'patients' welfare committee minutes at *Le Court* (Patients Welfare Committee, minutes 1953-1964).

In the intimate daily atmosphere, young staff and residents freely intermingled and when friendships developed, resisting management interference became a collaborative necessity. For the residents, finding allies could be very important for a range of reasons. Writing or posting a letter might require help and residents were often faced with the dilemma of how much a staff member could be trusted not to pry or gossip, or to be confident that what you wanted to say was written down, especially if it was a complaint. Since it was not unknown, during particularly troubled times, for residents letters to be opened by prying managers fearful of complaints getting out into the open, ways had to be found to get around this (as recalled by several past residents I interviewed).

Living in this situation people found they had few clear rights. They found for instance, that when it came to participating in elections, under section 4 (3) in *The Representation of the People Act* (1949) their right to register had been removed if they were classed as patients (rather than residents) living in long stay hospitals or institutions. Because this was not rescinded until 1983, residents of 'care homes' were often left very unclear about their voting rights (Barnes 1991). The right to vote raised other questions for them too, such as: would the venue be physically accessible? Could they have help with the ballot paper if they needed it? Would an institution's care staff be permitted to escort them to a polling station?

The kind of situations which produced the need for some assistance, outside normal staff duties, during unpaid time, often meant residents had to seek acts of goodwill from staff members. This introduced further elements to the ongoing dynamic existing between staff and residents that could lead to different ways of relating during on and off duty time and the formation of friendships.

Residents' lack of freedoms around undertaking paid employment was often another source of frustration. The system of payments for residential placements was heavily weighted against them earning anything more than pocket money and for the majority this meant that most of their work had to be either non-remunerative or

they had to put much of their earnings into a communal fund. This could be a source of some resentment for people who had the potential to do paid work and wanted to enjoy the rewards. Willmott (1966: p163) offers a summary of the rules around financial assistance that was available to disabled people during this period of the early 1960s.

A struggle for self determination

Whilst grouping people together in institutions might have been administratively convenient, it inadvertently provided a context within which some disabled people started to develop their ideas about how they perceived the disability experience they were living and about the type of services they felt were needed to support them through life. By the late 1960s these ideas were contributing to a wider debate about services for disabled people in general (Hunt et al 1966, Hunt 1968a: p17).

For a range of reasons, becoming self-organised to try and have an influence within an institutional setting, was exceptionally difficult and therefore it rarely happened, but there is evidence of some attempts that occurred from time to time.

Living in residential care, dependent on staff for essential help, made people especially vulnerable. They needed a lot of guts to do anything that might be interpreted as critical and they were quite often isolated from possible sources of independent support. For many, this was reason enough not to rock the boat. But, despite

the difficulties, at *Le Court*, the first Cheshire Home, organisation amongst the residents, not only survived, but also cast a lasting influence and what follows is the story of how that came about.

The story itself illustrates a process in which a considerable breakthrough in learning took place. The residents' experiences provided some of the key foundations upon which others built a framework for analysing disability some years later.

Given the conditions of institutional care which forced so many to keep quiet, withdraw, or give up, it is remarkable that from within one institution there emerged a small group of disabled people with the talents to identify, discuss, and develop ideas, that would have lasting resonance.

Amongst this small group of residents Paul Hunt (now recognised for his founding role in the UK disabled people's movement) (Oliver and Barnes 2012: p21) emerged as a natural leader with the ability to carry influence and bring about change. During his time as a resident at *Le Court*, he, along with others, explored and shared many new ideas about the experience of disability. In doing so, they started to reach out to disabled people far beyond their own institution. Hunt, in particular, was responsible for publishing their ideas through his regular written articles and letters, and he later took these ideas forward to influence an embryonic movement. He was largely responsible for much of the

earlier material that sought to raise awareness of the social implications of segregation and institutional care of disabled people.

During some troubled times, the residents of *Le Court* not only became acutely aware of their lack of personal rights, but, more importantly, they set out to do something about it. It is worth just highlighting here that it was from this most restricted, most backward sector of disability services, i.e. institutions, that insights first emerged about how society was in practice denying disabled people some of the most basic human rights.

The story of *Le Court*

The *Le Court* Cheshire Home had been set up in 1948 as an unstructured community. Role divisions were initially blurred between the helpers, who were mostly untrained volunteers, and the 'patients' who participated in the chores and the decisions of the house (Harding [interview], 1987). This informal experimental beginning was significant when later attempts were made to introduce professional structures into the Home. For many residents who had escaped the rigid confines of hospital chronic wards to experience a more liberal adult environment, any threats to their new-found freedom were likely to be resisted.

When Cheshire first invited disabled people to his crumbling old mansion of *Le Court*, he had no money or financial backing for the project. Many of the new residents (or 'patients' as they were called) previously

had working careers behind them and were there because disability had left them with nowhere else to go from hospital. Cheshire, full of optimism, believed at this stage that if everyone used their skills to make this ad hoc, self-help community work, it would survive (Russell 1963: p44-46).

With these ideas, Cheshire muddled along for a while, but in due course was forced to take some practical steps to make it more secure. He obtained the voluntary services of a social worker who established some funding arrangements with local authorities, and he deferred to his father, a lawyer, who advised that the laissez-faire arrangements be replaced by a proper management structure (Russell, 1963). *Le Court* had a warden and matron appointed and in 1955 became formalised to try and accommodate local authority and health authority requirements, in accordance with the 1948 *National Assistance Act* (W Russell, 1963). Interpretation of this recent legislation was still largely undeveloped and so service arrangements were being devised as they went along.

Prior to this, in 1953, *Le Court* had offered a liberal alternative to life in a chronic ward. The residents established their own elected council, 'the Patients Welfare Committee', and organised monthly residents meetings which were initially open to the staff (Snowy interview 1987). They ran an internal shop the income from which went into an independent residents' fund, and

they set up and ran their own workshop where people could make things to sell (Spath, 1964).

In 1954, the residents initiated a house magazine. A few years later, under Frank Spath's editorship, this became established as the *Cheshire Smile*, the official monthly journal of the entire Cheshire Foundation. The residents at *Le Court*, having set up the magazine, retained editorial control of it for many years and as time progressed this placed them in an unusually strong position to publicise the views of disabled people and have an influence on the discussions about future developments in the Foundation. In 1961, reflecting on their achievement, Spath (1961b: p32) wrote:

By 1961 it [the *Cheshire Smile*] had a circulation of 7000 copies, with far reaching effects – the mouthpiece of the Cheshire Homes has widened the horizons and broadened the outlook of residents and staff all over the world. More than in any other organ disabled people are able to speak and be recognised as people with much to offer the community and the world.

Whilst press freedom was subject to some restraint, the *Cheshire Smile* provide a rich mixture of material in which it is possible to see how interactions between residents and management were being worked out. It is an excellent resource for seeing how people succumbed,

responded to, accepted or rejected the restraints being placed upon them.

Through careful reading, it is possible to trace the emerging discussions and see changes taking place in people's ideas and expectations. Residents from many of the Cheshire Homes contributed to these discussions and the struggles for reform that ensued within the Cheshire Foundation, sharing their experiences in the pages of the *Cheshire Smile*.

Whilst it is important to recognise the breadth of participation of disabled people within the Cheshire Foundation, special recognition is to be given to the residents of *Le Court* who, at this early stage, between 1950 and 1970, played such key and frequently initiating roles in the developments that followed.

At *Le Court*, between 1954 and 1956, discussions were regularly held between the residents and the Home's warden, Alan Finch, and the atmosphere described by Snowy Harding, an ex-resident, as, 'a lot more free and easy then' (Harding [interview], 1987). Alan Finch, recalling his time as warden of *Le Court* recalled that it was still running on a hand to mouth existence which led to debts and it started to acquire a bad reputation with some local traders (Finch [interview], 1988; Russell 1963: pp44-46). But the situation was changing, due in part, to pressure coming from the health and welfare funding authorities, which threatened to withdraw permission to register it as a Part 111

residential home, or as a nursing home, unless it put the house in order (Finch [interview], 1988).

Over the next few years the Cheshire Home's Trustees and *Le Court* Management Committee (MC) responded by trying to impose a more formal structure on the home. They believed it was now necessary to establish more professional relationships between the staff and residents by introducing mechanisms such as; staff uniforms, addressing staff by their surnames, clamping down on informal socialising between staff and residents and restrictions on the popular group outings to the pub. They wanted personal relationships in the Home to be put under scrutiny arguing that those between residents and staff should stop, and sexual relationship between residents discouraged (*Le Court* 1955; [three research interviews with former residents:] Harding, 1987, Mawer, 1987, and Inskip, 1988).

This intention to interfere in their personal affairs in such ways drew the residents' indignation. Initially a storm was averted because Alan Finch said he did not see the need to strictly comply with all these expectations, preferring to continue with more laissez-faire arrangements that allowed residents to treat the place as their home. He therefore tried to ignore the intention to 'hospitalise' the place and continued his practice of informal meetings with residents, to seek their views. He continued to organise trips to the pub and avoided any undue interference in personal

relationships. Finch's (1988) recollection was that he was therefore able to stall the process of turning *Le Court* into a formal institution:

'I acted as a buffer between residents and management, the rules therefore were not an issue for the residents at this time' (Finch, [research interview] 1988).

Within this relatively free framework, the residents built a mutually supportive community, where everyone was encouraged to take an active role. Many had daily jobs to service the community such as; running the shop, managing the workshop, delivering newspapers, helping in the laundry and the kitchen and many other tasks. Their collective philosophy was that disabled people could live an active and socially useful life if encouraged. From the start they were pioneers, seeking to advance the quality of life of disabled people, and not just those within their own institution, as demonstrated in an article by Frank Spath (1959: p2-4) and the films subsequently made by four residents who founded and ran the *Le Court Film Unit* between 1958 and 1969 (Baldwinson, 2019a).

This *Le Court Film Unit* was one of two innovative schemes. It made several short educational films about disability, the two principal ones were *Living Proof* completed in 1962 and *No Limit* in 1964 (copies of these

are also in the Disability Archive UK, hosted by the University of Leeds, and the original film reels are understood to be held in the British Film Institute's (BFI National Archive). The films that set out to challenge negative attitudes towards disabled people, provided audiences with the opportunity to perceive disability in a new light. The residents' crew, along with some professional help, filmed fellow residents engaged in various work or leisure pursuits demonstrating inventive techniques, and gadgets, to overcome physical limitations. The films were then distributed widely for public education (*Cheshire Smile* 1964, Hunt 1962b: pp59-60).

The other innovation was *Independence Unlimited*, a gadget-inventing co-operative, started in 1959. It combined the knowledge and experience of disabled residents to those of local people with engineering and craft skills. Jointly, they would identify practical problems in the Cheshire Home, such as the difficulty opening heavy doors or operating the home's public telephone and develop an electrical or mechanical device to solve it (Mawer 1960).

Under the guardianship of resident Laurie Mawer, *Independence Unlimited* survived through the decades to celebrate its 40th anniversary. In the early days, they had thought it would be a good idea to expand its services to disabled people in the local community and promote the idea to other Cheshire Homes by publicising their

activities in the *Cheshire Smile* (Mawer 1959: p46). Whilst this ambition to extend beyond *Le Court* did not happen, similar initiatives did emerge elsewhere, the most well-known being *Remap* which was set up by the British Council for Rehabilitation in the 1960s.

In 1955, the old crumbling house was replaced by a purpose built two-storey building adjacent to the old one. The new *Le Court* was designed to be a specialised institution and was much more accessible. This was in part helped by having residents invited to participate in its design. However, despite the improvements, the new building soon generated a common complaint that it left them little scope for privacy. With a range of four, two and one bedded dormitories, set alongside communal facilities, it was able to house a significantly larger group, of 39 residents, (Tanner 1963: p10-11, Russell 1963: p229). but this also increased its institutional framework.

Soon after their move into the new building, Alan Finch left, and a new warden was appointed (Harding [interview], 1987). With his arrival, the trustees renewed their attempts to impose some discipline on the residents and staff. The new warden, a retired army officer, was used to being in control, and was aided by a new matron. Ex-resident, Snowy Harding, vividly remembered the sudden change in atmosphere:

‘They (the trustees) started to get the professional people in and that’s when the trouble started. When ...

(the new warden), and a new matron [Betty Clark] came, things started to get worse. She was an assistant matron at Bristol and started to bring in hospital ideas.’ (Harding, [interview] 1987).

By 1956, with the management’s backing, these new heads of the Home tried to impose rules and regulations that eroded the residents’ personal freedom. Introducing hospital rituals, they set about formalising daily routines and marking out their authority (Spath, 1964).

Infuriated by this, the residents tried various approaches to hold on to the informal atmosphere they had enjoyed previously and get the management to see reason, but it did not work. Driven to close ranks, the residents then barred the staff from attending their monthly meetings, so they could talk freely and then, out of desperation, increased their pressure on the management by only verbalising essentials which in effect meant putting all the staff and management into a ‘state of Coventry’. The tension it created in the house made it unbearable, but the strategy worked. The matron became persuaded to communicate with the residents’ committee and build a framework for negotiated agreements instead of issued ultimatums (Patients Welfare Committee, meeting minutes, 2 April 1958).

Two years later, when asked by Spath what she had learnt from her experience at *Le Court* she said:

'I have seen the need – it has been pretty well forced upon me at times – to drop more and more of the defence mechanisms, the armoury, the inhibitions, acquired during seventeen years of conventional nursing.' (Clarke, [cited in Spath, 1962]).

Once she had relaxed her authority and agreed to consult with residents, Betty Clarke became accepted and very much liked. The warden kept his peace and the community lived on in reasonable harmony for a couple of years until broken by further changes in the management. A photograph survives of many residents gathered around her as guests at her later wedding.

Following this change, over the next few years, a series of conflicts persisted between management and residents regarding restrictions on bed times, getting up times, about their freedoms to go out, drink alcohol, remove clothing when sunbathing along with a range of other petty and arbitrary changes to daily life routines. Rules were constantly being made without consultation, and later overthrown (Hunt, [private papers] 1962a).

One bone of contention was over decisions about the spending of money at both the personal and collective levels. There was a period for instance when tight controls were imposed by the management over the residents' handling of their own money. Whilst officially the residents had the right to a meagre clothing allowance, they were not always allowed the freedom to

decide how they spent it. As Laurie Mawer recalled in an interview, at one time, there was the expectation that the male residents purchased all their clothes from a specific local shop which would invoice the home direct. As he put it, sardonically, “it avoided the need for us to handle money!” (Mawer [interview], 1987).

At a collective level too, there were disagreements over how the joint residents’ fund was spent. It was particularly galling to find their attempts to improve their quality of life being thwarted by the different ambitions of their founder, and his supporters when, for instance, money they had raised for specific improvements, was suddenly transferred, by the trustees, to other Cheshire Homes without their knowledge or consent. An ex-resident recalled occasions of this happening around 1957 and 1958 (Harding, [interview] 1987). At other times the Trustees had argued with them to be more charitable with their funds (Patients Welfare Committee, minutes, 30 June 1957). Such occurrences were regular reminders of their dependence and relative powerlessness.

This conflict-ridden relationship came to a head during the mid-1960s over the issue of single bedrooms. After years of coping with dormitory existence, the residents were determined to extend the building so that everyone could have a room of their own and they drove a successful campaign to raise the enormous sum needed to achieve this. Based on experience, they also

planned for the building to offer flexibility, so it could accommodate married couples. Once the money started coming in, as previously, the trustees began to have alternative notions of how it should be spent such as being diverted to create more Cheshire Homes! Paul Hunt (1968b: p18) aptly characterised the positions of the opposing sides in the following way:

‘Practically every Cheshire Home resident or potential resident I’ve ever spoken to would prefer to have his or her own room. Does this mean there is something wrong with us all? Are we specially selfish or anti-social? Do we dislike each other so much? I think not. Yet I have heard it argued that we should be happy to share bedrooms for the rest of our lives, remembering others still in hospital wards, and that it’s better for us to be “all friendly together”.

I must say that this kind of moralistic argument makes me somewhat impatient, particularly when it comes from people who don’t have to live the sort of life they recommend. For one thing it shows such an unrealistic view of the joys and virtues of sharing a bed / living room with other people. I suspect that some of this enthusiasm for communal living stems from vague romantic memories of mid-night feasts in the dorm at school, or being all palls together in the Forces or during a short stay in a hospital ward. The people concerned

forget we are no longer children, and nor are we servicemen or patients.'

The residents were often accused of selfishness if they tried to improve their conditions. This might be for not wanting to hand over money to people *even less* fortunate than themselves or for daring to criticise staffing policies. They met this kind of reaction, for instance, when they raised concerns over the practice of employing emotionally unstable people onto the care staff, which was a very real cause of anxiety, as described here by Laurie:

'Sitting on the bog I could hear him crashing around in the bathroom going through some ritual. Should I ring the bell to call for help off the loo? Dare I? What if S-- comes in, in a state? In the end I have to ring the bell. S-- comes in, he's OK, and lifts me into my wheelchair, it's alright. But the feelings I have been through in those few minutes, they were not alright.' (Mawer, [interview] 1987)

There were no complaints procedures if staff abused their position. As Laurie Mawer (1987) put it: "*if someone dropped you all they had to say was that you slipped through their arms. You couldn't say a thing*". Being left on the toilet, or in the bath, too long, could not easily be proved as staff negligence, or abuse, and residents

seldom felt able to make personal complaints on their own behalf. It was too risky.

There were in effect at this stage, two *Le Court* realities. One was a community of disabled people brimming with creative energy and purpose striving for improvements, and the other was of resident-staff relations which tried to prevent them from making progress.

They continued to be angered by arbitrary decisions imposed on them by managers who refused to negotiate. In 1962, hostilities came to another head when the residents' committee chairman, Peter Wade, was threatened with expulsion from the Home.

Wade had a reputation for his outspoken ways which earned him the respect of other residents, but also intense dislike from the warden. His threatened expulsion had followed an incident in the communal dining room when he publicly confronted the warden's latest unpalatable announcement of a new set of un-negotiated prohibitions and petty rules. Hunt recorded in his diary how he had retaliated to it angrily, shouting; "nonsense!" and the furious warden had then ordered for him 'to be wheeled' from the room. Livid, Wade refused to allow the nursing orderly to physically touch or escort him, but instead wheeled himself from the room unaided (Hunt, 1962a, Mawer, [interview] 1987).

Following this incident, the warden was determined to rid himself of Wade and any other 'trouble makers' who

chose to flaunt his authority. Five of the other residents, who came to Wade's defence, were then also threatened with expulsion (Hunt 1962a). Amongst them was Brian Line a loyal friend of Wade, Barbara Beasley an outspoken and articulate writer in the *Cheshire Smile*, and Paul Hunt, himself, the previous residents' chairman.

As it was, this group of residents had, over the years, earned enormous respect from amongst a wide number of people, for their various efforts to build *Le Court* into a positive community. So, when it came to this hiatus, there was plenty of support around from friends, and staff, who wanted to prevent the expulsions. Some staff, who allied themselves with residents, were sacked, and yet others were given warnings which put the place in a state of turmoil (Hunt, 1962a, Inskip, 1970).

Privately, Paul Hunt recorded the intensity of feeling he and others went through at the time:

'When will they realise that imposing laws on people should be done with the utmost reluctance. And especially so here ... the special limitations that our disability causes set up in us a horror of further limitations imposed from without ... our freedom is so precarious.

Being threatened with these internal divisions, media publicity, and attack on their charitable image, the management committee were soon being forced to climb down. The matron was asked to resign, and the residents achieved another victory.' (Hunt, [private papers] 1962a).

Cheshire's response, to the whole management issue above, then showed up some of the contradictions in his approach. From my interview with Hampden Inskip I gathered that at that time Cheshire and the trustees held to an overarching philosophy of non-interference in the management of the Cheshire Homes. This in turn created a problem for the residents when they wanted some support to curb excesses of authoritarianism from local managers. As Inskip pointed out, there was no policy of national guidance for the management of the Homes, until 1981.

When it came to this crisis, between the residents and *Le Court* management, Cheshire did not support the residents' requests to the trustees for some guiding principles, nor did he subscribe to their developing arguments for resident consultation in the running of the Homes. Whilst he consistently wanted to convey an image of the Homes, as large happy families where everyone had a valued contribution to play, he was also very clear that the management retained responsibility as the 'parent' body.

His own response to the expulsion episode above was interesting because it clearly posed him with difficulties. From a compassionate point of view, and a safe distance, he tried to appease the residents, allow the management to have its way and be seen to be fair and forward thinking, all at once. His proposed solution was

to remove the troublesome group from the home by offering them help with finding another house where they might set up and run a community in the way they wanted it.

Here was a tempting offer, and it was briefly considered by the threatened group before being rejected (Patients Welfare Committee minutes, 23 August 1962), (Hunt 1964 private papers: Peter Wade, Leonard Cheshire correspondence; Miller and Gwynne 1972: p27-28). They decided they were not prepared to abandon their fellow residents or give up the endeavour to reform *Le Court's* management structure on a more permanent basis. For them, along with others, it was not just about *Le Court* anyway, it was about using their advantages, as the first Cheshire Home, to establish some principles for the whole Cheshire Foundation, and for disabled people in institutions more generally.

These struggles may seem small, but they need to be understood in their context, and for their implications. Back then it was relatively unknown for disabled people to protest like this against their providers, either within institutions, or outside. When Peter Wade (and the others) faced expulsion, it must be remembered there were no alternative support services in the community, and Hunt (1962a) recorded in his journal what this would mean for himself saying; 'I shall have to go back into hospital I cannot stay here if Peter goes'.

Like Wade, as a teenager Paul had spent two miserable years living in a chronic ward amongst dying people. This was before he discovered *Le Court* in 1956 and initiated his own transfer there. It was going to be a heavy price they would all have to pay if they lost this fight.

As in most conflict situations, for a period, the likely outcome was very unclear. It tested the community and there were those who found opposition too difficult to sustain. For the minority who were prepared to stick to their principles, it was a frightening time. In the end these conflicts had a successful outcome which bore a significance that went well beyond the immediate gains for the residents concerned, for they set the context within which some fundamental issues were hammered out within the Cheshire Homes, and then further afield.

One of the early outcomes of this more recent conflict situation was a lively debate that was started in the *Cheshire Smile* (1964) on 'the Role of the Residents' which continued over several months. A result of this, and other debates, was the emergence of some theoretical tenets that eventually produced practical change.

The concerns that arose from their discussions fell into three main areas; the care relationship and misuse of medical practices, disability and prejudice, and the issue of gaining control over their lives.

Medicalisation, social control and the struggle for independence

Residents of different Cheshire Homes had been using various opportunities to argue that the use of hospital nursing practices, in this institutional setting, were particularly damaging because they encouraged passivity from residents; devaluing them, and any contribution they might wish to make to society.

A resident of Kenmore Cheshire Home, observing the behaviour of Management Committees, referred to their inappropriate use of a medical approach:

Far too many people use these powers to play at 'Emergency Ward 10' [the title of a television drama programme] even the terms 'ward', 'patient' and the mumbo-jumbo of a real hospital are frequently to be seen and heard. All this despite the fact that, in the official brochure issued by the Foundation, we are told: p ... 'They (the Homes) are run as homes rather than hospitals.' (Kitching, 1964: p25).

Some residents started to make a connection between medicalisation and social control. They argued that it was by implementing a medical regime, using regimental hospital routines, that the management maintained its control of the Homes. Hunt (1962a) had emphasised the debilitating affect this was having on them in the midst of the troubles when his diary entry had stated:

April 29th ... We sense a period of attempted 'regimentation and hospitalisation' – and it takes so much energy to fight.

...

May 4th ... Today most of us felt sick, afraid, helpless, depressed and rebellious, desperate. That is why an authoritarian regime is certain to fail with us especially. If pushed to its limits it might subdue us, crush our spirit; but it will not help us.

Two years later he was pursuing these arguments more publicly whilst pressing the case for residents to have some representation on the management committees:

'It seems to me that many of the troubles and difficulties in the Foundation at this time can be traced to the virtually complete separation between helpers and helped, the "governors" and "governed", and to the lack of proper communications that ensued from this. In contrast to the early days of the movement, the whole authority structure now helps to emphasise and perpetuate divisions and classes within the Homes – especially the main separation between, on the one hand, Trustees, Committee members and staff, and on the other hand, the "patients". This amounts to a return to the hospital-type-set-up which is so unsatisfactory on

a long term basis for physically handicapped people, and which is foreign to the idea of a real “home of your own”.’ (Hunt, 1964: p26).

Looking at it another way, a different resident explored the apparent resistance amongst care workers to the idea of disabled people becoming more independent:

‘There is a saying current amongst those involved in this kind of social work that the intention behind the work is to “help the disabled to help themselves”. But what happens when the recipients of this help make real use of it, and start helping themselves? What is the attitude of those who run such organisations when those they have thought for, fought for, and provided for, try flexing the muscles that have so generously been given to them, and strike out on their own account? It seems that trouble starts as soon as the once dependent are given sufficient independence to pass from the largely receptive to the largely inceptive. Then it is that wills clash and feelings are hurt.

Why should this be so? The reason is, perhaps, that the physical needs of the disabled are comparatively easy to grasp and to cater for, whilst the non-physical needs are more nebulous and difficult to satisfy ... This security, the fact that they are no longer absorbed with mere existence, offers disabled people the opportunity to

form and expand their own ideas; the increasing physical independence enables them to put the ideas into operation. They begin asking questions about what is being done for them; they concern themselves with the quality of the services that are being provided – not necessarily asking for more of them, but perhaps for alternatives to what is being given. They ask for the service to be done with them rather than for them.’ (Resident of *Le Court* (Anon), in: *Cheshire Smile* 1965).

A vigorous debate against being called patients turned into a campaign. To them choosing their own term of reference represented the core of this anti-medical, anti-passive struggle they were having with the Foundation. Starting in 1958, people increasingly referred to themselves as residents (*Cheshire Smile* 1958, 1959, Spath 1961a: pp5-8, p14). Over the next few years, a transition took place within the pages of the *Cheshire Smile*, and, by 1961, the issue had become an openly debated conflict. So much so that many of the residents were enraged with the Foundation Trustees when the Cheshire Foundation added ‘for the sick’ to its title despite these debates (Beasely 1960b, 1961, Line 1968: pp6-7). Once again, their wishes to move away from this sickness model had been ignored.

A constant stream of argument with the Trustees over this issue showed how out of step the organisation was with contemporary rehabilitation trends. Pressing

the residents' case, Beasley referred to a revolution of attitudes taking place indicating a change of emphasis away from the passive towards a more dynamic approach to disability (Beasley 1960b). To substantiate her argument, she referred to the renaming of the 'International Society for the Welfare of Cripples', to the 'International Society for Rehabilitation of the Disabled' in 1960 (Beasley 1961: p29).

The residents' arguments encompassed related issues such as the inappropriate use of formal staff uniforms (Beasley 1959, 1960a), against the exaggerated sense of responsibility expressed in coddling attitudes (Battye 1959b) and devaluing their work by calling it occupational therapy. From all of this, a view started to emerge, that, to see the improvements they wanted, they now had to take responsibility for educating society about disability.

Here we see *Le Court* residents in the forefront of an important struggle with an emergent new profession of carers. They were trying to define what was needed to support them to live full and useful lives and resisting the backwards move to medically diminishing practices was a necessary part of this. Most, at this stage, did not perceive an alternative for themselves other than institutional living unless they found a way out through marriage.

Looking to reduce their dependence on care staff, residents became very interested in the ideas coming out

of rehabilitation, such as the rapidly developing field of technical aids, and discussions about architectural barriers. In the United States, specialists such as Howard Rusk, working with spinally injured people, were gaining publicity (Battye 1959a, *Cheshire Smile* 1959) and this was influencing the better design of gadgets. These ideas were promoted in their films and the *Cheshire Smile*:

We are always willing to publish descriptions, together with pictures and / or diagrams, of specially-designed aids to independence, used by residents in the Homes, that are not included in the various handbooks and catalogues of gadgets, etc. for disabled people (*Cheshire Smile*, 1962: p59).

The care relationship researched

An outcome of all their thinking and arguments was a piece of influential research into residential care. In 1962, much to its surprise, the Tavistock Institute received a letter from a group of *Le Court* residents, asking for its help. This small group had set out to find a more enlightened, collaborative approach to the management of the Home and thought, naively perhaps, that a social work model (coming from this relatively new profession) might be a way forward. The Tavistock became interested and decided to undertake research into this relatively unexplored field (Miller and Gwynne

1972: p16). The outcome was a publication in 1972 called, *A Life Apart*.

The initiating group of residents discovered, to their chagrin, that disabled people would derive little comfort from this research, nor receive the support they were after, in their arguments with management. They had misconceived the function of social research and the discovery was an important one (Hunt, 1981).

In the book's introduction the authors relate how they were invited by *Le Court* residents to listen to the concerns of disabled people. Whilst acknowledging the residents had considerable knowledge and insight from their direct experience, they, as researchers, were clear that when it came to decide their research objectives, it was not the plight of the residents they should be looking into so much as the plight of the staff with the unenviable job of caring for them (Miller and Gwynne 1962).

The researchers gained considerable rewards for their work for it earned them a reputation as experts in a new field. *A Life Apart* became extensively used as a standard textbook for training within the 'caring professions', and, in 1976 gained added prominence when the Open University adopted it as a set book for its new course; *The Handicapped Person in the Community* (Hunt, 1981: p38).

This was a serious set-back for disabled people. With *A Life Apart* influencing the thinking of a new

generation of service professionals, it meant that the authors' version became an authoritative one.

Following its publication, Hunt critically reviewed it in the *Cheshire Smile* and pointed out its limitations from a resident's perspective (Hunt 1972a). Some years later, in 1979, he wrote a more in-depth critique (published posthumously by UPIAS in 1981). In his critique he questioned the objectivity and purpose of research such as this, which failed to consider the merits, or otherwise, of institutional care, or the viability of life outside them. He wrote:

They (Miller and Gwynne) are not interested in the question of what numbers of people with comparable or more severe handicaps manage to live in the community, how this is made possible or what kind of lives they lead. ... it is impossible to devise proper criteria for assessing the quality of life in existing institutions without paying serious attention to the standards achievable in the best alternative arrangements (1972a: pp16-17).

Hunt challenged the value judgements that underpinned their research:

The notion of the cripple as parasite occurs explicitly half a dozen times ... So much of this book implies that the severely disabled drain the 'normal' world not only economically but emotionally and morally too, and they

really have nothing to contribute in return that is worth bothering about. The authors see such a vast gulf between the joys of normal life and the deprived, distorted, hopeless existence of the incurable cripple, that they cannot regard the residents' lives as having any real significance or possibilities for fulfilment (1972a: p17).

Hunt expressed two sides of a question that was facing disabled people, like himself, living in institutions. They needed to understand why society rejected them, and, how they could change this situation by demonstrating their own worth as members of a community. For people like himself the questions these researchers had left unanswered were of more fundamental concern. Were institutions the only way of life open to them, and if they were, then the quality of life within them was of paramount importance. Either way, unless residents' views were considered, the question remained how quality improvements were to be secured? Also, if institutions were fundamentally oppressive places – just trying to make them work a little better, as Miller and Gwynne had tried to do, was not an answer (Hunt 1981).

Studies of institutions such as Goffman's *Asylums* (1961) and Miller and Gwynne's *A Life Apart* (1972) highlighted the negative aspects of institutionalisation, but those who really questioned the validity of

segregating people in special units were disabled people themselves, and I return to this later (chapter 6, here). Meanwhile, the struggle continued for greater control over their lives within the institutions.

About gaining control through a share of power

To counter the medicalisation and authoritarian governance of their situation and ensure their quality of life, residents soon realised they would need to have a formal say in the management of their Home. On this, Paul Hunt took a personal lead to press the residents' case, and wherever he could, he argued for consultation and representation within the management of the Cheshire Homes, and in institutions more generally.

Drawing on their reference to *'the desirability of 'care' becoming a joint exercise between staff and residents'* he made the following observation in his comments on the Williams Committee Report regarding the staffing of residential care homes:

If only the implications of these words had been fully worked out and had informed the report as a whole. They are directly relevant to the question of recruiting and retaining suitable staff. An authoritarian or paternalistic atmosphere, with rigid hierarchical structures and "absolute" power vested in one or two people at the top, where complaints are discouraged and there is no appeal against authority's decisions, where residents and junior members of staff are not expected to participate in the

running except in menial capacities, and where there is no realisation of the staff's work as anything other than custodial and dead-end these are major reasons why many able people are not attracted to residential work and leave it soon after they enter (Hunt, 1967: p26).

Finding it difficult to see how authoritarian forms of care could be described as benevolent, it started to occur to residents that they might be suffering a form of oppression. It also seemed that disability, as distinct from impairment, might be something that could be fought against. This was an insight that represented a new departure. In a book review of *Two Lives* by Peter Marshall, Hunt (1962c: pp19-20) drew attention to this new way of seeing their experience:

Marshall's views on his situation are important because he expresses attitudes and feelings becoming more common amongst disabled people. The emergence of this determination to 'fight' disability is brim-full of possibilities for the future. The handicapped person's efforts to participate more fully in ordinary life should not accept any limitations.

In emphasising this need for disabled people to fight for social participation, Hunt was identifying a key to their future emancipation and it linked in with the residents

struggles to participate in the life and decisions of their Home.

The campaign, by *Le Court* residents, to have representation on management committees and a voice in policy development had been going on for several years. From the minutes of their Patients (later renamed residents) Welfare Committee, set up in 1953, it is clear they had initially broached the question as early as 1958:

At present the Management Committee sees no need for a works council or anything like it. Several of the residents felt there was a need but the matter was left for the present.” (Patients Welfare Committee, meeting minutes, 20 August 1958).

The trade union movement would appear to be the reference point here, for a model towards consultation in decisions about the Home.

Being convinced that the only way disabled people would safeguard their human rights was by being part of the decision-making process Hunt then played a key role in taking this forward. Persuading the Foundation, or other service providers, however, to treat disabled people as responsible adults, proved to be an uphill task. At one-point Hunt (1965) took their arguments to the Guardian National Newspaper and in an article entitled *Patients or People* he wrote:

At last the Ministry of Health have formed a survey team to consider the problem [of people in chronic wards]. So a group of us who come into this “young chronic sick” category, but who happen to live in far more congenial surroundings, decided we ought to put in a word for the consumer. We produced a report setting out some ideas on institutional living that we have formed from our experience in chronic wards and Homes of various kinds. What follows is a revised version of our memorandum.

Presenting the arguments against long term hospital and medical care for permanently disabled people, he summarised the residents’ case:

The only real answer for disabled people who require some kind of institutional care is to have small Homes where they can take a share in management ... The fundamental requirement of this substitute home is that the residents should be able to share in the responsibility for running it. All the desirable freedoms and conditions for a full life really flow from this share. Without it they can be taken away by an administrative whim (Hunt, 1965).

Things started to change soon after this when Hampden Inskip joined the *Le Court* management committee, and his contribution proved to be crucial. In

an interview Inskip talked to me about how he had become involved:

‘In 1965 when I was invited to join the Trustees I was asked to take over the Chair of the *Le Court* Management Committee. I was issued with old Cheshire Smiles, warned of the situation and that it needed bringing under control. Perhaps because of my experiences as a lawyer I had some sympathy for residents wish for representation and their desires to participate in the decisions.’ (Inskip, 1988).

Inskip was the first person really prepared to listen and he worked closely with Hunt, by then chair of the Residents Committee, to find a formula the Foundation, the management committee, and residents, would find acceptable. By the end of 1965, the residents’ long campaign had achieved its goal of representation on the management committee and a place at the negotiating table. From then on they took part in staff recruitment, selection of new residents, and various other decisions (Hunt, 1965, Inskip, 1970).

Developing a network of support

Disabled residents in many other Homes, inside the Foundation and some outside it, followed *Le Court’s* example and established their own residents’ councils. Few however, managed to achieve an equivalent share of power in the management of their Homes until many

years later, but their struggles continued. Some evidence of these is to be found in the correspondence people had with Hunt from who they sought advice and support (Hunt, 1965b).

A considerable amount of networking developed between the more active residents of different Homes and these contacts offered some outside support to residents who were isolated during particular conflicts within their institutions. The debates that were being published in the magazine added further reinforcement.

A stimulus to the debate around power sharing were the contributions in the *Cheshire Smile* on themes of self-management, democracy, and the meaning of disability some of which were pieces republished from other journals. Hunt (1967: p26), as a periodic member of the *Cheshire Smile* editorial committee, observed:

Living in the same house as the editor of the *Cheshire Smile* has its advantages. One of them, for me, is that I usually see exchange copies of almost all the journals and newsletters in the disablement field. With practice I can skim through the miles of print about parties, outings and fund-raising events, slowing down only for the more interesting items and bits of controversy (alas few and far between).

Wherever there was an opening to link ideas coming from elsewhere that supported progressive trends for

disabled people, residents took the opportunity to promote them. In his own articles Hunt was often able to articulate the aspirations of many in ways that made sense, and he therefore enabled others to benefit from the lessons of *Le Court*. From the responses to his articles it is apparent that he was stimulating people to talk about their experience in new ways.

One of the lessons the residents had learnt from bitter experience was that without their perspective the services were likely to get it wrong. They had also discovered their own potential to struggle against repression when they needed to. Research, like Miller and Gwynne's, and the day-to-day dynamics within the institutions had made them realise they had to do their own research and come up with their own solutions. What they had achieved therefore offered some foundations that other disabled people could build on. It was a small start towards having some consumer control in the delivery of services.

Before moving on to what was happening elsewhere it is necessary to note what happened to Peter Wade and Paul Hunt who had played such key roles in these events.

By the end of the 1960s both men had married and moved away to live in the community. They both then took these experiences into the wider society but chose different ways to promote the interests of disabled people. Wade, for instance found that once he was

outside and living in a family home both the Cheshire Foundation and the Central Council for the Disabled (to become RADAR, (incorporated in Disability Rights UK, 2012, see chapter 11) were keen to have him on their committees of management. He opted to do so hoping to exert a positive influence on them (personal memories of discussions between Wade and Hunt, Campbell and Oliver 1996: p57).

Once we were married and living in London, Paul Hunt, too, was quickly courted with invitations to join the management of various voluntary bodies, including *Le Court*. Apart from a brief period of sitting on the *Le Court* Management Committee, with the residents' full endorsement, he decided this was no longer the way forward. He wanted to maintain his freedom to challenge these voluntary organisations, as he saw the need, without compromising himself. The relative merits of the different strategies they chose to adopt become apparent later.

Organised resistance spreads

During this period of rapid institutionalisation, conflicts from the dynamics of the care relationship were appearing in several sites. The evidence became more apparent once people were networking with each other and a few examples now follow.

One such example was a revolt in Norwich, by the residents of the first specialised local authority (LA) hostel to be established, in the early 1960s. They had a

profound impact on the LA management and forced them to review their staffing arrangements (Goldsmith interview, 1991). In the course of trying to resolve this, Hunt was invited to Norwich by the chief welfare officer to give them the benefit of his experience and offer them his views about the hostel (personal recollections).

In 1965, Rosemary Dawson-Shepherd (1965: p5) wrote an article in *Spastics News* about a conflict she referred to as a 'slight hiatus' between those who worked for spastics (sic), and the spastics themselves, at the society's further education centre of Oakwood. From her direct experience, she argued there was a case for a spastics' conference to be organised to enable disabled people to express their viewpoint and sort out some of the problems being experienced (Spastic, used as the term of reference, was current in the 1960s, but now the correct term is cerebral palsy). Dawson's article which was picked up and applauded by Hunt in the *Cheshire Smile*, (Hunt P. 1967: p26) had drawn their attention to this other situation where disabled people were clearly struggling for more autonomy in their lives.

In the next few issues of *Spastic News*, an enthusiastic debate was taken up by its disabled readers but then abruptly curtailed by the editor. Unlike the *Cheshire Smile*, disabled people in the Spastics Society had no voice in editorial policy.

Unlike most of its other residential centres, Oakwood offered further education to young adults who wanted to

live independently. Like *Le Court*, the management's attempts to introduce petty regulations, and unacceptable limitations to personal freedom, such as set bed times, were met with the scorn of the students. Some ex-students recalled how their ambitions were repeatedly frustrated by staff that had low expectations of disabled people or their abilities to make their own decisions (Alice, John, Yvonne, [interviews] 1990).

The students at Oakwood were primarily concerned to meet their educational goals and move on, but they did put up a struggle, and did win some concessions which left them freer than in the average residential unit. They too became seen as trouble makers with a reputation as 'the thorn in the flesh' of the Spastics Society (Alice, [interview] 1990).

During my interviews with people who had lived in institutions, the most common complaints were the lack of regard for people's privacy and their frustration at being denied responsibility for themselves. Within the Spastics Society there was less recorded evidence available, but some disabled people did make their voices heard and, by the mid-1960s, concerns surfaced, regarding the trend of institutionalising people. In the midst of their enthusiasm for creating new hostels, as mentioned earlier, the family caseworker for the Spastics Society had cautioned the need to pause and consider before action, arguing that disabled people, in her experience, did not necessarily welcome being placed in

a Home to be 'looked after', and had often expressed a strong reaction against what was seen as the end of the road for them (Richards 1965: p4). Some of this material reached the *Cheshire Smile*, where the editors were keen to reprint articles that reflected their own concerns and some networking came from this also.

Other managing authorities, particularly those within the health service, were slow to concede to residents' requests for more say. But they too had their protagonists. Some years after the gains at *Le Court*, an ex-resident of a regional health authority (RHA) young chronic sick unit [the phrase *young* in the health sector at the time meant non-elderly, which means disabled people who are aged under 65 year old] recalled her experiences of the intense antagonism that had existed there in the early 1970s. This was between the health authority managers on the one side, and the residents along with their more progressive matron, on the other. The residents had tried to have a particularly offensive staff member removed but all manner of tactics were used to try and intimidate them into silence. The management chose to remove the sympathetic matron rather than concede to the residents' demands and cause of complaint (Maggie Davis, [interview] 1988).

These were the more publicised struggles in institutions. No doubt there were others where people had the energy and courage to fight for their rights. Winning consultation and a place within management

has always been an uphill struggle and the same issues have had to be fought for, time and time again. No doubt there are similar battles today and there will be more in the future, but certain principles were clearly won during this early stage. It is no longer acceptable to expect people to live in dormitories all their life, nor to deny people privacy, or dignity, it is more usual to have resident committees and even though it happens, it is unacceptable to deny people the right to some say in their destiny and choice of personal relationships. The fact is that the gains won during these earlier conflicts have influenced national policies on institutional care and can also still be turned to as a source of inspiration for people who are currently living in institutions.

Amongst the most significant lessons disabled people learnt during this period were that they could win by organised resistance, and that control by professionals was something they had to challenge if they were to establish responsibility for their own lives.

CHAPTER 4 - Response to an Inaccessible Society in the 1960s

The period of restlessness within institutions was seeing a similar mood stirring within the community. Here too, disabled people wanted more control of their lives and began to take initiatives to combat their chronic isolation and enforced dependency. In this chapter, I shall explore the various ways disabled people formed into pressure groups, established networks, argued over campaign priorities and entered a period of fervent activity.

During the 1960s, journals such as the *Cheshire Smile* produced by the Cheshire Homes, and the *Magic Carpet*, produced by the Disabled Drivers Association, and one from the British Journal of Occupational Therapy provide some insight into this burgeoning of interest in technical solutions to overcome physical limitations. Before the 1946 NHS Act, aids like wheelchairs were expensive and it was not uncommon for people to be confined at home and immobile, for much of their lives. If they did own a wheelchair, they would have found them heavy and awkward to manoeuvre and were therefore reliant on others to move about. So, when free wheelchairs and adapted road vehicles became available, through the Ministry of Health, as Denny Denly recalled in my interview quoted later in this chapter, it represented a significant breakthrough.

With the introduction of ministry-issue three-wheel *invacars* there was suddenly a market and a folding wheelchair appeared that could be carried in the vehicle. This meant much greater freedom of mobility and it was at last possible for disabled people to visualise a more expansive future for themselves (Curley, 2001).

Soon after, a range of gadgets came onto the market (CCD 1969: p48), and with advances in electric battery-operated motors, and lightweight construction materials, they offered independence to severely disabled people in a host of ways. This new potential raised the aspirations of disabled people and of pioneering rehabilitation professionals working in the hospitals (Nichols and Williams, 1977: p74).

The technical breakthrough in production of aids to independence raised the question of how they would be paid for and whether the new NHS would take on the costs and disabled people started to argue their own case as we see in this next quote:

Electric indoor chairs are available to those fortunate few who can pay £100 or more to buy one. Doctors, nurses, almoners, physiotherapists and many others can do much to help the disabled to obtain these chairs ... They can also help (along with the Invalid Tricycle Association, and others who are actively campaigning) to change the attitude of the Ministry of Health which at present regards these chairs as luxuries and refuses to

issue them to those in need on the same terms as they do ordinary transit chairs and outdoor 'trikes'.

Only when you have seen the transformation in the life of a previously immobile individual brought about by using an electric indoor chair will you realise the countless ways in which he (sic) has been helped to use all his remaining powers, and to regain a little more independence (Cheshire Smile, 1962).

In this innovative climate, disabled people were waking up to the fact that despite improvements in medical care, rehabilitation and technological support, their hopes were frustrated by the vast array of physical and social barriers in their way (Bull 1963: p12), (Cheshire Smile 1962b: pp62-63). Twenty years later, Vic Finkelstein (1981) argued that it was this paradox, and becoming aware of it, that created the conditions for a change of consciousness to occur:

"The successful disabled integrators have found that society, uncontaminated by their presence for centuries, has designed a world which does not recognise their existence. Such people have been forced to protest, first individually, and then collectively, about their social situation." (Finkelstein, 1981: p63).

Tackling the barriers

At a particularly significant conference in Stockholm, in 1961, on Housing, Transport and Access, where the subject was 'the physically disabled and their environment', this paradox was brought into sharp focus, as Goldsmith recalled in our interview (1991). Building design had been rapidly moving up the agenda as people became more aware of the problems being caused by architectural barriers and in Sweden and Denmark some pioneering research had gone into housing design to suit disabled people. The conference delegates were invited to see these innovations (Goldsmith 1997: p7).

The guest speaker, Tim Nugent, set things alight when he talked about his work on a programme of building design for disabled people at a university campus rehabilitation project in Illinois, USA. Nugent introduced his audience to a new concept. In his view all buildings should be made accessible to disabled people because, as members of the community, they had just as much right to use them as anyone else. Selwyn Goldsmith, an architect from the UK, specialising in disability and design, remembers the impact of the occasion on him:

I was unprepared for the explosive charge that Tim Nugent detonated. As a person with a disability I had for more than four years been a frequent visitor of public buildings, I encountered obstacles, but they did not worry

or disturb me, and they were not, as I saw them, barriers which discriminated against me. They were simply a feature of the normal order of the built environment. It never occurred to me that anyone could be provoked or angered by them, could insist they were universally removable, could show how that was to be done and could assure me that he was not a crackpot (Goldsmith, 1997: p17).

Nugent was a medical engineer, who had been working on making a university campus fully accessible to disabled students. As early as 1959 he had been developing a code of standards, so that buildings and facilities would be made accessible and useable by the physically handicapped in the USA, and in 1961 the authorities were persuaded to officially adopt these as the *American Standard A117.1* (Goldsmith, 1997: p14). This new set of specifications represented just the beginning of a long process towards creating an accessible society.

Goldsmith, along with another disabled delegate, Denny Denly, were profoundly influenced by this experience and brought these ideas back to Britain. Both, in their different ways, were involved with initiatives to tackle the problem of architectural barriers in the UK. Goldsmith had just started work on his first edition of a design guide for architects and planners called *Designing for the Disabled* and Denly, founder of the first user's

mobility group, the Invalid Tricycle Association (ITA), had become fully engaged with problems surrounding the mobility of disabled people. After the conference, both Denly and Goldsmith maintained their contact with each other and with Nugent.

Two years after the Stockholm conference, Nugent was invited to speak for the Royal Institute of British Architects, and once again challenged his audiences. This time he wanted people to consider not only the implications of rehabilitation, but also the idea that responsibility belonged to disabled people to participate in the process of changing society:

The most frustrating to disabled people were the buildings and facilities supposedly created for the public designed in such manner as to prohibit the full participation of the physically disabled. It was equally frustrating to professionals dedicated to rehabilitation to find the barriers prohibiting further progress from following a rehabilitation programme.

Physically disabled people must be given opportunity to educate the public as to the real meaning of disability as they are the only ones who can do the job. Professionals; he added, can only set the stage (Nugent, 1963: p22).

Nugent was well ahead of most of his contemporaries and a breath of enlightenment for

disabled people listening to him. A disabled woman in the audience commented on his affect upon her:

My world changed suddenly ... It was as if, being well accustomed to looking out of one window on a familiar scene outside, all in a moment another window was opened upon the same scene from a different angle ... How many of us although acknowledging the desirability of our being independent, to work to live a full life, have meekly accepted that there were certain things we could not do, many places accessible and taken for granted by the rest of the community, into which we could never go. It had never occurred to me before that we had not only a desire but a right to all the facilities available to the general public and that the mere fact of our disability should not be permitted to deprive us of those rights (Bull, 1963: p12).

Organising at the grass roots

At the same time as these ideas were filtering through the disability community a few pressure groups formed to tackle some of the barriers holding people back. Initially the principal areas to gain attention were; mobility, access, poverty and housing. Concerning the first three, the organisations that became particularly influential were the Disabled Drivers Association (DDA), the Joint Committee for Mobility of the Disabled (JCMD) and the Disablement Income Group (DIG). All were pressure groups founded by and for disabled people.

There had been a few others, such as the League of Blind Workers established in the 19th Century, (chapter 1), but these new organisations marked a turning point.

These early pressure groups were quickly faced with questions of strategy. There was so much to do it was difficult to know where to start and the matter of whether to take up single issue or broad front campaigns was soon an issue for them.

Mobility

The initial impetus for organised activity was principally the vision of greater freedom of mobility sparked off, in 1946, by Denny Denly. As a young naval officer who became disabled during the war, following the contracting of poliomyelitis, he had nurtured an ambition to drive across the Alps single-handed, in a state issue three wheeler invacar, colloquially referred to as the 'trike' (Denny, 1990). Denly recalled:

'All I wanted as a young man of 21 was to travel and see the world and I had this ambition to go to Switzerland because the mountains were there. I got a trike issued by the Ministry of Pensions and set off. Everyone said it was impossible and couldn't be done and I did it, I crossed the Alps in a trike with a 147 c.c. engine. ...

'As a result of the publicity of a BBC broadcast, on the wireless, people started writing to me. In November 1947, more and more people were asking questions, as, in 1948 the NHS Act was going to start the issuing of

trikes as appliances. Prior to this the Charity Aids Association had been the only thing that enabled people to get mobility pre-war. There was therefore a tremendous demand for information.’ (Denny, 1990).

In January 1948, following a lot of correspondence generated by articles he put in the evening papers, Denly and nine others founded the Invalid Tricycle Association (ITA), later in 1963 renamed the Disabled Drivers Association (DDA) (www.disabledmotoring.org).

The ITA had, in Denly’s words, “*originated by accident*”. But in another sense, it was no accident. His trip to the Alps had been the spark that lit a fuse of burgeoning public interest and it had just needed a catalyst to draw people together. Bob Parker, editor of the *Magic Carpet*, the journal of the DDA, described how it was for many like him at that time:

‘People had been incarcerated in their own homes, there was much more isolation then. I was unable to walk after 16, by the time I was twenty-three I had not known any other disabled people, I had lived almost exclusively indoors. It was quite a traumatic breakthrough to have a vehicle and to know others like me and that I wasn’t so odd, so it was a highly charged atmosphere. When I got a trike (back in 1950) the Disablement Resettlement Officer gave me two magazines, the *Magic Carpet* and *The Cord* (a magazine produced by people with spinal

cord injuries). It (the ITA) was a contact group with a range of ideas so I joined.’ (Parker [interview], 1990).

According to Denly [interview], 1990) the ITA / DDA’s rapid growth, (1000 members in its first year and 5000 by 1965), provides some indication of the enthusiasm there was for contact with others. In its founding statement the ITA set out their aspirations as:

Mobility for the disabled means that not only can they take an active part in work and social activities, but it helps them on the road to “normality”, the goal to which every disabled individual, without exception, passionately aspire (ITA 1947).

The ITA / DDA was a national organisation, set up and entirely run by disabled people in which, significantly, non-disabled people had no voting rights. Within the first year, members started to publicise their ideas in a regular magazine the *Magic Carpet*, and, by the mid-1950s the DDA had become an important pressure group around mobility issues. Local branches, having brought disabled people together for social events, provided a base from which campaigns could grow. Another motoring organisation set up in the 1930s, called the Disabled Drivers Motor Club (DDMC), had been founded in 1922 but this served a much smaller number of disabled people because it was for those who could afford private

cars and so the two organisations in practice served largely different constituencies (Denly [interview], 1990).

Once people were mobile, the problem of architectural barriers to public buildings became the next target. The DDA first took this up, around 1963, when some of its branches started compiling local access guides to their communities (Cheshire Smile, 1963: p49). Broadly speaking, these initial guides represented a first attempt to gather information about how to make the best use of what existed.

Another initiative of Denly was to invite several other disability charities to join forces with the DDA, to tackle a wide range of restrictions surrounding mobility. This led to the founding of the Joint Committee on Mobility for the Disabled (JCMD), in 1961. Together, this working group of organisations campaigned for; accessible public transport, better wheelchair design and the removal of architectural barriers in public buildings (JCMD agenda and meeting notes, 1961). Talking about this period Denly recalled:

'I founded the JCMD after a visit to Stockholm ... I modelled the Joint Committee on a Danish set up in Copenhagen which had brought together all the different organisations to pool their knowledge. We had about 18 organisations with a peripheral interest in mobility (about 31 now). We have since become a powerful lobby recognised by governments. The Joint Committee did

produce a much wider forum for debate (than the DDA). A lot happened in the years up to the Alf Morris Act. I was becoming more and more aware of the lack of accessibility' (Denly [interview], 1990).

Alf Morris MP had initiated the government's white paper that produced the Chronically Sick and Disabled Persons Act (1970). Denly added:

'The Joint Committee (JC) would take up anything that concerned disabled people, if anyone had anything interesting in design, they brought it to the committee and we discussed it.' (Denly, [interview] 1990).

Peter Large, who took over the JCMD chairmanship from Denly in the early 1960s told me:

'The JC was I think entirely Denny's stroke of genius because there were all these traditional old-style organisations, not one of them doing anything about wheelchairs or vehicles, or anything – just doling out, basically, charity. He realised it wasn't good enough, it was a clever way to do it, to bring these organisations together.' (Large, [interview] 1991).

Large referred to some of the struggles the JCMD went through to influence change. When parking permits were first introduced, for instance, each local authority

issued its own version and they were not mutually respected between authorities, He recalled:

‘Denny was a start of a lot of things – access, mobility, orange car badge. He got fed up with carrying one thousand [different] local authority disabled parking badges in his windscreen.

‘We managed to get British Rail to accept people in wheelchairs, I think it took us about ten years of struggle and argument with them. It was when they were getting a coach with larger doors to help passengers carrying luggage and it suddenly clicked and they started to consider people with wheelchairs. British Rail’s first leaflet on disabled passengers was produced by the JCMD.’ (Large, [interview] 1991).

According to those who knew him, Denly was regarded as a significant activist who used his strength of personality and his many connections to have an influence (Parker [interview], 1990) (Goldsmith [interview], 1991). However, as Lumb recalled, there was a down side for DDA members, like himself, who saw the need to develop a grass roots approach to campaigning. For them, the leadership style adopted by the DDA was too top down and bureaucratic, and a model they wished to move away from (Lumb, [interview] 1998).

During the early campaigns, of the 1960s, discovering how to work jointly with statutory and

voluntary services carried some problematic implications. Whilst initiatives, such as the JCMD, established a basis for consultation in which disabled people had a role, and, motivated charities to broaden their outlook to tackle issues of more pressing concern, they were also alerting disabled people to some of the pitfalls of working with powerful charities.

The JCMD's brief to promote better public access for disabled people prompted several charities to take up the question of housing as well as access to facilities. Recalling this period Duncan Guthrie explained to me that the major charities involved in these activities were; the National Fund for Polio Research (NFPR), the British Council for Rehabilitation, the Central Council for the Disabled (CCD), and the Disabled Living Activities Group (DLAG) formed by the CCD in 1963. They organised some national and regional conferences, projects and exhibitions promoting; rehabilitation, housing, access and aids to independence (Duncan Guthrie interview 1991). Reports of some of these events appeared in the British Occupational Therapy Journals (BJOT, 1962: p30, Hodgkin, 1962: p36, Wilcock, 2002 vol 2 pp310-311).

In 1967, the Disabled Living Activities Group (DLAG) offered Denly the chance to extend the work he had started in the JCMD by becoming the director of a three-year Access Project (Denly, [interview] 1990).

He was one of the few exceptions to be employed, as a disabled person, by a major disability charity engaged in campaigns for better housing. A key issue was to achieve some access standards to building design in the UK and the British Standards Institution agreed to draft its first code of practice for building design in 1967, which Goldsmith (1967: p387) referred to as CP96 Access for the Disabled to Buildings. This was an important step forward, and was no doubt helped by the publicity given to Nugent's lectures regarding progress in America by his contacts in the UK.

Financial support

A different campaign in which disabled people found a very active role, was the Disablement Income Group (DIG), founded in 1965. Two disabled women, Megan Du Boisson and Berit Moore (later Thornbury), had been incensed by the discriminatory way the benefits system excluded disabled married women – “housewives” – from any financial help. They sent a letter to *The Guardian* national newspaper, drawing attention to the poverty being suffered by disabled people. It prompted an enormous response and this inspired them to form the pressure group DIG to tackle the injustice (DIG 1966a).

DIG's primary objective was to achieve a non-contributory national disability income for civilian disabled people with no contribution record (DIG 1965). People who had become disabled through their work in the armed forces, or industry, were by this time entitled

to some compensatory state income and could continue to earn without affecting their benefits. Others, who had never been employed, were treated very differently. Some could claim sickness benefit but there were penalties for earnings received by the wives of disabled men, and disabled housewives received nothing. There was no consideration given for the high costs of disability (Willmott, 1966: pp163-73).

DIG rapidly became a popular campaign. It captured the interest of the media, drew in many disabled people and attracted a wide range of professionals. A smattering of politicians from across the parties lent their support and DIG also gained the support of churches, voluntary societies, charities and women's groups (DIG 1965). From conversations with people who were involved, a review of DIG internal papers and my own experiences as a DIG member it seemed that anyone with any connections with disability, who regarded themselves as progressive, joined. It became a focus that brought people together from a wide range of disability backgrounds, employed, unemployed, mobility disabled, sensory impaired, living in institutions, living in the community, and from all social classes.

Disabled people were only too aware that if the family supports broke down, they risked ending up in an institution. Poverty was an injustice and in the early days of DIG it was clearly believed that institutionalisation was often its consequence (DIG, 1969a: p5, Owen, 1967). At

its outset DIG's founders invited people to consider, not just poverty, but a wide range of the problems facing disabled people. This was expressed in the broadly worded first object of its constitution (DIG 1965) and more fully elsewhere (DIG 1966c).

Du Boisson then conducted a forceful campaign to secure a better deal for disabled people. DIG's specified objective was to work in particular for:

the provision by the State of a modest basic income, with special supplementary allowances, for all disabled persons ordinarily resident in the United Kingdom, whatever the cause of disablement and irrespective of previous national insurance contributions (DIG, 1966a).

Whilst DIG's primary objective was to see the reform of financial benefits, it is worth noting that, initially, it also took up the pressing concerns around the lack of suitable housing or personal help available to disabled people. It also promoted some research into disability for, like others, DIG urgently needed information to campaign effectively.

Having drawn attention to shortfalls in a broad range of health and welfare services (DIG 1966a), DIG contributed to a report *At Home or in Hospital* produced by the National Fund for Polio Research (NFPR), which promoted the setting up of a home-nursing scheme to prevent unnecessary institutionalisation (National Fund

for Polio Research estimated date: around 1968). Nothing in practice came directly out of their recommendations.

Having started out with a broad agenda, by 1969 it had curtailed this to concentrate on its campaign for a disability income (DIG paper 9, 1969a). Hunt, as a participant in the debate, commented on the choices that were facing DIG, around 1968:

their last AGM showed they are faced with a crucial dilemma... Should they stick single-mindedly to their main task, the obtaining of a proper pension for disablement? Or should they risk blunting the edge of their campaign by taking up the large number of social welfare issues that have presented themselves and urgently require ventilation and action? (Hunt, 1968: p17).

According to Large, their decision to become a single-issue campaign came after the death of Megan Du Boisson, and he thought it was prompted by the experience of its new director, Mary Greaves:

'Mary knew much more of what was going on in the disabled world and politics than Megan did, and she realised that if you duplicated what the CCD was doing for example, it was going to lead to bad blood ... so she really kept DIG on the economic side. I must say, when

branches wanted to do things on mobility and access, I said the same thing, let's concentrate on the one thing no-one else is doing.' (Large [interview], 1991).

The fear of duplication that might cause the displeasure of the CCD reflects the pressures applied behind the scenes. Powerful charities could and often did exert their influence to curtail competition where they thought this was necessary.

DIG was also subject to a range of internal influences expressing differing views on strategy and priorities for the organisation. Amongst them was a strong lobby favouring the single-issue approach (Saunders, 1972: p13) that was variously reinforced by the professional bias of lawyers, economists, businessmen, and social scientists, lending their expertise to the organisation.

A change of strategy is also suggested by the subtle alteration of DIG's aims. Between 1969 and 1972 it dropped the aim 'To work for improvement in the social and economic position of the disabled and chronic sick' (DIG, 1969a: p6) in favour of 'To co-operate with other bodies for the improvement of the economic and social position of disabled people and the chronic sick' (DIG, 1972b: p9).

DIG was part of an influential poverty lobby gaining ascendancy at that time. It had formed close links with the *Child Poverty Action Group* (CPAG) and had invited

one of CPAG's founding members Professor Peter Townsend to be a DIG patron (DIG paper September 1966b). The CPAG was founded in 1965 by a group of concerned professionals and academics who wanted to tackle the wide-scale poverty amongst families in Britain (CPAG, 2012). Professor Peter Townsend was one of a group of professional signatories to a letter and memorandum that CPAG sent to Harold Wilson, the Prime Minister in December 1965 to raise political attention to the issue. This became a strategy of some significance that he returned to a few years later when he took up the cause of disabled people's poverty (I shall return to this in chapter 6).

From various interviews I carried out it was apparent that in DIG, many tasted their first experience of becoming involved in a major political rights campaign, and as a movement of disabled people becoming active on their own account, it was very significant. Highly motivated, members attended conferences, local branch meetings and two major street demonstrations in Trafalgar Square in 1967 and 1968; the first to occur since the marches of the National League of the Blind in 1920 and 1936 (National League of the Blind 1949: p14, 24). A national and heated discussion had opened around disability and injustice which was new.

It was not long before discontent grew amongst the membership (Hunt 1972c: p12) (Wade 1973) arousing

disquiet amongst more conservative elements in the organisation (Saunders 1972: p13, 1974: p14).

As I recalled in notes I made at the DIG AGM in 1973, the refrain of 'DIG is non-political' was an indicator of the attempts being made, at that time, to maintain some control over the rise in militancy in DIG. Hunt in his correspondence to DIG Progress and the responses from the chairman, Dennis Saunders, also give some indication of the attempts being made to veto debate that infuriated the members who believed there was a great need for a disability organisation to be unafraid to have a political consciousness and strategy. Peter Large thought this control of the discussions was in part attributable to being registered as a charity and the constraints this put on it to meet with Charity Commission regulations (from interview with Peter in 1991).

One of the most significant things about DIG's mobilisation was the way it facilitated the growth of contact networks between a wide range of people. For instance as I recall amongst the many it brought together were people who had become established as leading disabled activists, such as Du Boisson, Moore, (DIG founders and campaigners) Hunt (Cheshire Homes – propagandist for rights for residents of institutions and later founder of UPIAS), Fred Reid and Colin Low (activists for the National Federation of the Blind and subsequent disability campaigns), Large, and Greaves (leading activists in campaigns around employment,

disability incomes and mobility issues). It also drew in established experts within disability, such as Goldsmith (housing and design), Dr Agerholm (rehabilitation), Townsend (benefits, poverty, and social policy) and Ann Shearer (a journalist promoting the rights of people with learning difficulties). From the political parties it attracted MPs including Alf Morris and Jack Ashley and Dr David Owen who was an early vice president from which an all-party group for disablement matters emerged. DIG therefore facilitated an exchange of views between disabled people, professionals and politicians. From talking to several disabled people who became instrumental in bringing about later initiatives, it is clear that DIG laid the ground work for the future movement.

Formulating a Disabled Persons Act

At a parliamentary level, having captured public attention, DIG undoubtedly played an important role in bringing about a higher profile for disabled people, and a campaign for an advisory body was finally successful (DIG, 1969b). Given the lack of statistical information to hand, (the first official census was conducted in 1966 and the results in: *Handicapped and Impaired in Great Britain* were not published until 1971) the discussions and studies leading up to the Chronically Sick and Disabled Persons Act (CSDP), called on the knowledge of disabled people from DIG, the JCMD, and the Access Campaign who found themselves being invited to act as consultants to politicians.

Peter Large recalled the key role played by DIG's chairperson, Mary Greaves, in this process:

'Mary chaired the committee set up by Guthrie of the CCD that shadowed the Alf Morris bill. It helped with drafting the Act, briefs, and amendments etc.' (Large, [interview] 1991).

Denly also had a role in these negotiations because of his work on the Access project for the DLAG. He said:

'during that time the Chronically Sick and Disabled Persons (CSDP) Act came along. I spent ages lobbying for various access clauses. I concluded there were five necessary rights, to have a house to live in, educational opportunities, employment opportunities, leisure facilities and good health and treatment facilities. All these involve mobility and are linked.' (Denly, [interview] 1990).

There was close co-operation between the different charities and pressure groups and, in response, the government finally passed Alf Morris's private members bill which became the Chronically Sick and Disabled Persons (CSDP) Act, 1970.

The CSDP Act was in effect the first welfare legislation designed specifically to address the needs of disabled people. It was hailed by many as a great achievement, and by some as a 'Disabled People's

Charter', but on closer inspection was found to have many flaws (Greaves, 1981). The Act still took a predominantly medical approach by focussing on the functional limitations and welfare needs of individuals and gave far less attention to tackling the problem of an inaccessible environment. As Large explained to me, what was there in the Act had only been achieved because of a very hard battle from the disabled people on the advisory group. Compromised by an over rapid passage through parliamentary stages, it adopted a very tentative approach recommending that public facilities be made accessible, '*wherever practicable and reasonable*'. Peter Large recalled:

'I remember arguing with Lady Hamilton who was arguing against legislation for access, she was saying it was better done by education and persuasion, and it was Denly who said 'rubbish' and we went ahead. It was us who drafted those clauses pathetic as they are.' (Large, [interview] 1991).

Another great disappointment was the absence of any recommendations to encourage the development of personal assistance services to avoid institutionalisation (Hunt, 1973a: p1). The government had missed the chance to embrace the newly emerging awareness of the limitations caused by environmental barriers. Because of

this it came to represent the end of an era rather than the start of a new one.

In sustaining a dependency culture, the Act was offering what disabled people were now struggling to overcome. The parts that were potentially more liberating, such as encouraging local authorities to adapt people's housing, remained largely unrealised for a long time because there was no way of forcing the authorities to comply with the Act's intentions. Despite its limitations, the CSDP Act was a milestone for it did represent change in political awareness and some acknowledgement of the ground swell of discontent over the last ten years.

Despite their apparent powerlessness, the grass roots pressure from disabled people was growing in intensity. The national newspapers, particularly the *Guardian*, were reporting the debates in DIG, and also publicising other concerns, such as those raised by the 'Trike Campaign', for the replacement of the accident prone *invacars* with a safer option (Jeger, 1965, Cowdy, 1967: p2, Du Boisson, 1967, 1969, Shearer, 1968, Cunningham, 1973, Hughes, 1973).

Ken Lumb recalled that it was following an angry sit-in at the Guardian offices, by Dick Leaman, (a disabled driver active in the Trike Campaign), that the journalist, Adam Raphael wrote several *Cross-Check* reports between 1974 and 1975, publicising the issues. These reports, along with the direct action and the campaigns

of the JCMD resulted in the introduction of the mobility allowance to replace the *invacar*.

In discussion about some of their achievements at this time Peter Large reflected:

‘You can’t ignore what DIG achieved in the Social Security System. I would claim, the Attendance Allowance and its later extension, certainly largely instrumental in Contributory Invalidity Pension and certainly the Housewives Non-Contributory Invalidity Pension ... it got the disabled married woman, the housewife, who was a non-entity, put on the map for the first time. The joint committee (JCMD) claims for the Mobility Allowance, I was handling that in the JC’ (Large was by then chairing this committee) (Large, [interview] 1991).

Large referred also to a string of other changes to benefits over later years that DIG had a voice in influencing, not least in their efforts to address the ‘invalidity trap’ which consistently penalised anyone on benefits from trying to ease into employment.

Making connections and the spread of ideas

From the above it can be seen how the campaigns of the 1960s were beginning to link up. Within institutions, important questions had been raised about the nature and provision of care services and about the rights of disabled people to some self-determination. Within the

community, pressure had mounted to improve disabled people's mobility and access to public facilities and for all adults to have some income support in their own right.

As will be seen in the forthcoming chapters ideas soon changed from a series of specific campaigns to a growing awareness of the restrictions faced by disabled people in general. There were broadly four ways this happened during this period.

Firstly, the common ground made between residents of institutions and people engaged in various community campaigns, notably the Disablement Income Group (DIG), and the Disabled Drivers Association (DDA). Secondly, there was cross fertilisation of ideas between disabled people in Britain and other countries, such as the US and Scandinavia. Thirdly connections were made with the struggles of other oppressed groups, notably against racial discrimination and segregation. And fourthly, disabled people stopped seeing disability primarily in subjective terms, as personal misfortune, and started to regard themselves as a disadvantaged minority. It then became possible for them to see abuses of their human rights as a form of social oppression.

These changes of political outlook were not happening in a social vacuum. As I see it the 1960s, more generally, was a period when old assumptions on the rule of authority were challenged by many groups of people who demanded more democracy and equality in their lives. There was a desire to be rid of the rigid boundaries

of class, patriarchy, and racial intolerance; in education, work, and personal life and this change of mood, filtering through many strands of influence, gave rise to a series of new social movements.

Complaints being made against racial and sexual discrimination and other forms of social intolerance had resonance for disabled people, also taking issue with prejudice and discrimination.

A social movement in the making

In Finkelstein's (1981: p63) historical perspective of disability, (see chapter 1), this was the beginning of the phase of *re-integration*. Having been set apart in segregated facilities, disabled people were now challenging the society's inaccessibility.

From my investigation into the sequence of events it appears that first it was like-minded individuals or *small* groups that started to network with each other. Finding themselves at odds with the dominant view, they sought out allies to reinforce their arguments and started the fight for change.

The second stage occurred when special interest pressure groups introduced a wider cross section of disabled people to the social disadvantages they had in common. This was later followed by a third stage, in the 1970s, when special interest groups formed a network of organisations. This gave rise to a more rapid spread of ideas and a much stronger sense of identity amongst

disabled people generally, transforming a myriad of groups into a social liberation movement.

There were no guidelines on how a very diverse group, such as disabled people, could organise themselves to take the arguments forward. They had no clear idea about how a seemingly powerless group of unemployed people could gain some influence over those who held the power and resources. One of the first shocks they faced was to realise the weight of resistance, and hostility, towards disabled people having a stake in their own affairs. Part of their early struggle was to understand and surmount this.

Reflecting over the period I believe that already, in the 1960s, key strands can be detected in the developing movement which eventually became consolidated in three campaign approaches. Firstly, there was an emancipatory trend in which people collectively attempted to wrest some control away from the management of a service in order to establish a stake of their own in the policies and decisions that directly affected their lives. An example of this trend was the residents struggle at *Le Court*. By successfully setting up their own democratic frameworks, with elected representation, people found they were more able to challenge unjust practices and introduce some power sharing arrangements into the service.

A second theme was a civil rights approach, such as adopted by DIG and the JCMD which was more about

persuading others to change laws or set up charters in order to protect individuals from abuse or loss of freedom. Again, people organised collectively, to create the necessary pressure to influence the service managers or the politicians.

Thirdly there was the social education approach which set out to challenge prejudice by raising social awareness. The aim here was to change social attitudes as it was commonly believed that discrimination was a derivative of social ignorance. The task was to introduce social institutions to the facts and explain how it was possible to minimise disability if they would only remove the barriers.

In addition to these three campaign approaches there were a number of dominant themes. There were the issues of environmental access and the matter of financial compensation for disability and lost earning power, and a call for accessible housing and appropriate support systems.

In the course of taking up all these issues, and others, it became increasingly clear that their disempowerment would not be overcome by having access to more special (segregated) facilities or specialised rehabilitation. This meant finding themselves increasingly at odds with the professional services, the parent led organisations and the charities, most of which were arguing for more special services and separate facilities.

Developing the debate with the aid of journals

Whilst those who were thrown together in segregated units were able to talk to each other, many more were isolated in their own homes. The few journals produced by and for disabled people were therefore an important place for discussion.

Reading through early *Cheshire Smile* demonstrated to me how it had enabled residents of the various Cheshire Homes to communicate with each other and discuss their ideas for more liberal regimes of care. Similarly, it was possible to see how the magazine of the Disabled Drivers Association, the *Magic Carpet*, enabled a cross section of disabled people to share and promote their new ideas, and not just about mobility. DIG's journal *Progress* provided another means of dissemination and discussion.

There were others; *The Cord*, a magazine produced by spinally injured people, *Responaut*, produced by people who had polio and *Spastics News* (previously *Spastics Quarterly*), a journal of the Spastics Society (now renamed *Scope*) which, although predominantly controlled by non-disabled people, occasionally allowed some debate amongst people with Cerebral Palsy. Also, worth a mention, for its coverage of national and international issues, was a local magazine from a day centre in Rochdale, also called *Scope* (not to be confused with the Spastics Society). In this, disabled people confronted local issues that subsequently fed into

the development of a grassroots movement in Greater Manchester that linked up with national developments, which I will return to in chapter 5.

Because there were so few places where disabled people could express themselves publicly, it was mainly from journals such as these that professionals and other interested parties could gain an insight into what disabled people were thinking. It was through the *Cheshire Smile* and *Magic Carpet*, for instance, that professionals could become aware of the developing criticism towards services and service providers.

An example of the value some professionals placed on this growing source of ideas coming from disabled peoples can be found in the Architects Journal 1970: p1317. In this, Hunt and others were invited to contribute their views on segregated institutions (Hunt 1970: p1317). Having this kind of publicity meant that places, from where disabled people's views were being heard, drew visitors who wanted to learn from their experiences. Goldsmith recalled the value of talking to *Le Court* residents whilst preparing for *Designing for the Disabled*, published in 1963. He said;

'I went down early in 1962 and met Paul Hunt and Barbara Beasley and others. They were a very vital company there and very valuable association.' (Goldsmith, [interview] 1991).

These journals also enabled disabled people to network, not only nationally but internationally. The international exchange of articles and magazines in the 1960s meant ideas travelled, and, in the course of a few years, common causes of complaint were being identified around the themes of lack of rights, complaints about the overbearing behaviour of professionals, the inaccessible environment and the use of technology to overcome barriers to integration.

An example of an early discussion between disabled people in the UK and the US was on the lack of civil rights for residents of institutions. Having identified with what she had read in the *Cheshire Smile*, J. Herman, a disabled woman living in an institution, wrote:

‘Thousands of Americans who live in chronic disease hospitals and nursing homes feel they have been deprived of their basic rights. As patients, they have no opportunity to work problems out, or to give and take in an honest and friendly way with staff members; and they have little or no part in management of their hospital communities or in the direction of their own lives. They feel oppressed by their inactive environment.’ (Herman 1966: p20).

Herman referred to the similar aspirations they had in the States for more control over their lives. They too had set out in 1955 to create an alternative living

environment called 'New Horizons' where people would enjoy creative pursuits and relationships and have a say in the management (Herman 1959: p1). The similarity in their ideas with those of the *Le Court* residents led to a correspondence (Hunt, 1959: p3).

Another useful exchange was between the disabled editors of the *Cheshire Smile* and the American journal *Toomy J Gazette*, later renamed *Rehabilitation Gazette*, which was started by Gini Laurie and Donna Mcgwynne. Both magazines had a limited but worldwide distribution and were mutually supportive (*Cheshire Smile*, 1964).

The *Toomy J Gazette* was primarily interested in imaginative applications of new technology to resolve physical disability which was more advanced in the USA and already enabling a few people to return to their careers, take up their studies and live more independently despite severe physical impairments (*Cheshire Smile*, 1964: pp38-39) (*Toomey J Gazette*, 1965, 1968, 1970). The magazine was invaluable to disabled people in Britain who were also exploring the potential for independence offered by technical aids.

This kind of reciprocal international relationship has been continued by others over the years since. *Coalition*, for instance, a journal of the Greater Manchester Coalition of Disabled People (see chapter 10), established a longstanding relationship with *Mouth*, a journal of disabled people in the US and as Ken Lumb, a long time editor of *Coalition* as was Ian Stanton, stated

this had been highly valued for giving advance warning about the potential implications of importing social policies on disability from the US to the UK.

Other connections were made between the struggles for rights within institutions and the struggles for rights more generally within the society. The *Cheshire Smile* reproduced material from '*Fortitude*' the magazine produced by the Civilian Maimed and Limbless Association in Australia in which disability was posed as a civil rights issue. The Australian group had raised the political stakes by drawing attention to the fact that the UN 1948 Universal Declaration of Human Rights, had entirely overlooked the issue of discrimination against disabled people (Cheshire Smile, 1961: p16).

Taking the trouble to search out and reproduce this kind of material and set it alongside the social chat and trivia that the magazines predominately carried, highlighted the shift taking place in the ideas of some towards an awareness of overt discrimination against disabled people and the need to consider the far-reaching implications of tackling it.

Posing disability as oppression

In 1966 a publication of a collection of essays by disabled people, entitled *Stigma* and edited by Paul Hunt, raised the discussion of society's responses to disability to a new level.

Hunt had set out to provide something different from the more usual autobiographical accounts by

encouraging disabled people to look more closely at the social aspects of their experience. Here the contributors tried to make sense of hostility towards disabled people and explain why there was such resistance towards their attempts to become integrated. The essayists used the language of the consciously oppressed by variously describing themselves as a social minority (Battye, 1966: p9), discriminated against (Gill, 1966: p105), subject to a system of apartheid (Shepherd, 1966: p64) or oppression (Hunt, 1966b: p152). It raised uncomfortable issues that left readers with little room for complacency.

Having originally received sixty essays in response to his invitation, Hunt's reflections below, on the contents of the many contributions, express the point of social awareness that had been reached by the essayists and himself. He wrote:

'The overall picture suggested by the entries was that, despite the advances made over the last fifty years or so, disabled people in Britain are still fighting a battle on two fronts. They must contend not just with the disability itself, but also with the psychological and practical difficulties caused by "normal" people's attitudes, and by society's failure to give the imaginative help needed. And it is these super-imposed consequences of disability that are the hardest to bear, precisely because they are avoidable.' (Hunt, 1966, Introduction to *Stigma*, 1st draft).

Stigma soon became widely regarded as an important contribution towards achieving a better understanding of disability and was, for a time, frequently referred to by other writers in the field. In his foreword, Professor Peter Townsend made the following observation,

This is an uncomfortable book. Firstly, it is uncomfortable because it reveals how inadequate are the existing services for the disabled. Secondly ... because they (the writers) reflect a much deeper problem of a distortion of the structure and of the value-system of society itself (Townsend, 1966: pp.vi.).

Townsend, found himself asking; “Is it possible to secure real gains for those who are disabled without calling for a reconstruction of society?” (Townsend, 1966: pp.vi). In one of the essays, Louis Batty poignantly wrote:

When doing something that is not normally attempted by the severely disabled, I have personally experienced the highly disturbing, almost Kafkaesque sensation that I am merely going through the motions of this act, that what I am doing does not mean the same as when performed by a normal person (Battye, 1966: pp3-16).

What was being highlighted here was the general perception of pointlessness in the lives of disabled people. In another essay, Audrey Shepherd referred to the policy of segregating people as apartheid:

Part of the trouble is that in England today there is an almost total lack of real community life. We have little sense of being bound in one body, a body made up, not only of the healthy and the prosperous, the respectable and the successful but also of the old, the failures, the mentally ill, criminals, the physically handicapped, the emotionally crippled, the misfits, the awkward squad. Because of this, but also because society has a 'conscience' about its less fortunate members, it preserves its respectability by pursuing a policy of apartheid. And so there grows up a community without a heart (Shepherd, 1966: p64).

Hunt set out to disentangle social prejudice:

Our 'tragedy' may be only the tragedy of all sickness, pain and suffering carried to extremes. But disabilities like ours, which often prohibit any attempt at normal living in society, almost force one to consider the basic issues, not only of coping with a special handicap, but of life itself ... it does seem that our situation tends to make us ask questions that few people ask in the ordinary world." (Hunt, 1966: p145).

The injustice and brutality suffered by so many because of racial tension makes our troubles as disabled people look very small. But I think there is a connection somewhere, since all prejudice springs from the same roots. And there stirs in me a little of the same anger as the Negro writer James Baldwin reveals in *The Fire Next Time* when I remember the countless times I have seen disabled people hurt, treated as less than people, told what to and how to behave by those whose only claim to do this came from prejudice and their power over them (Hunt, 1966: p153).

The widely held assumptions, that society was kind to disabled people, were thus being challenged. In this book, which gained considerable publicity, disabled people were pointing out the many abuses they suffered, from the care system, and from wider society.

Early discussions on how to campaign

It was through the journals, mentioned above, that disabled people also started to share ideas about how to organise an effective base from which to speak for themselves. The phases of this particular discussion reflected changing ambitions to achieve some self-representation.

In 1960 Bob Parker, *Magic Carpet's* editor, was the first to take up the issue when he argued there was an urgent need to establish a united approach and stressing

the much time and effort wasted by charities on trivial activities. A more effective solution, he thought, would be to set up a federation of voluntary organisations working for 'the disabled', to focus and co-ordinate their efforts on the key issues (Parker 1961: p24).

Shortly afterwards, in 1961, the DDA did in fact enter into a type of federation with other charities, when it set up the Joint Committee for Mobility of the Disabled (JCMD) as explained by Denly earlier. It did so again, a bit later, when it helped to establish the Disabled Living Activities Group's Access Project. Whilst the JCMD was a broad front organisation, not controlled by disabled people, it was one in which they played a prominent role.

Several years later, in 1968 another DDA member, Nigel Harvey, wrote an article in the *Magic Carpet* suggesting that the DDA, with its national network of branches, had the potential to transform itself into a Disabled Citizens Association to better represent disabled people on a broad range of issues. Leaving aside organisations of blind and deaf people, the DDA was the only truly, national grass roots organisation controlled by disabled people. Harvey made the point that there was a commonality of experience going largely unrecognised and hindered by the special interest approaches. Taking this up in the *Cheshire Smile*, Hunt extracts the following quote from the *Magic Carpet*:

Membership of the DDA has probably demonstrated to most of us that we have far more needs in common than the multitude of 'special' charities would indicate to the casual observer. The inevitable duplication of effort and lack of co-ordination in aims and policies and absence of a united representative voice are all functions of their introvert nature (Harvey, 1968, cited in Hunt 1968: p17).

This proposal had once again emphasised the need for a more broad fronted approach to disability, but this time proposing that disabled people play the leading and controlling role. Hunt develops this idea further by drawing attention to the absence of representation for disabled people within the existing charities such as the Central Council for the Disabled (CCD), and he too felt it was time for disabled people to have their own such organisation which he suggested should be:

What we really need, I believe, is a rather more awkward and less respectable national Association, run primarily by the disabled themselves. For many of the same reasons as Mr. Harvey I feel that until there is something of the kind we cannot conduct our affairs properly in three important respects. ...

Firstly we need a democratic organisation for continuing discussion of the many issues raised by disablement, ... Secondly, instead of the present

uncoordinated inefficient and unjust scramble for government and voluntary resources, we need the machinery to decide amongst ourselves what is the fairest order of priorities and then to organise and campaign together so as to bring pressure to bear where it is most effective (Hunt, 1968: p17).

Thirdly, he argued it would be necessary to enlist the talents and efforts, of the most able disabled people, on behalf of those who were less able to assert their rights for themselves - such as those who lived in institutions.

The idea for a National Citizens' Association was in fact not adopted and the DDA chose to remain an AA [Automobile Association] for disabled drivers but the proposal was of significance in pointing out the need for a more integrated approach.

These pressure groups of the sixties had found it difficult to separate one problem from another when it came to disability. At some point, they had been drawn into looking at the interconnections between one area of restriction and others and by the end of the decade the relative merits of broad front versus single-issue approaches were being debated. The different proposals for a national organisation can be seen in this context as a barometer of a developing political awareness taking root.

Bob Parker's proposal, for example had, reflected the enormous frustration that he and others felt about the

ineptitude of a multitude of competing charities incapable of tackling the fundamental issues facing them.

By 1968, however, people were already moving beyond this towards the idea of disabled people having an organisation from which to represent themselves (Harvey, 1968, Hunt, 1968). They doubted whether major charities could properly represent them or give them a say or power to influence government departments or services. In part, this realisation had come from political debates taking place within the Disablement Income Group (DIG) and, in part, from negative experiences of working with able bodied well-wishers, who were often a class apart and unable to understand what disabled people wanted to achieve.

They still lacked much in the way of skills and experience necessary to organise campaigns and because of this their efforts were repeatedly stifled or overpowered by the activities of non-disabled people. The more powerful charities hung on to their position as mouthpieces for 'the disabled' whilst non-disabled professionals, and others with advantages of education and skills, generally took over leading positions and decided what needed to be done (Bradshaw, cited in Campbell and Oliver, 1996: p56). Such experts, however well meaning, often had other agendas.

By the end of the 1960s, the state was much more involved in the overall management of disability and the larger charities, which had championed disability causes,

competed for centre stage to act as the primary disability organisation. In the process of preparing the CSDP Act the principal charities, formed a closer partnership with government.

In 1970s RADAR became formally recognised as an authoritative organisation, by the donation of a state subsidy (Campbell and Oliver, 1996: p92, p190). Guthrie recalled that it was in the mid-1970s, following the amalgamation of the three main disability charities, and after he left, that RADAR started to receive some state grant aid (Duncan, 1991). RADAR was then in a stronger position to consolidate its role of representative authority and it is perhaps worth considering why the most powerful charity was awarded this advisory role precisely when disabled people were becoming organised and seeking to represent themselves.

CHAPTER 5 - New Services, Discontent, and Organised Response

From a background of very little community-based help, two particular Acts of Parliament (the local authority-related Social Services Act 1970, and the Chronically Sick and Disabled Persons Act 1970), led to the creation of local authority (LA) social services departments (SSDs) and a whole new service sector. What should have been a welcome development soon started to display stresses in the service relationship between the services' providers and recipients.

Plans for establishing welfare departments had been incubating since the end of World War Two. The National Assistance Act 1948 started the process by replacing the Poor Law with a new LA service structure but it left many gaps where help was needed. Then, in the 1950s, a ten-year health and welfare plan led to the publication of the Development of Community Care 1960 (Ministry of Health, 1963), which reflected a growing desire to move away from old style institutionalised care towards localised services.

Subsequently, two related white papers; *Better services for mentally handicapped* (1971) and *Better services for the mentally ill* (1975), set down 20- and 30-year plans respectively for the transfer of large numbers of people from hospitals to community-based services (Byrne and Padfield, 1983: p117).

Additionally, the Seebohm committee report (DHSS, 1968) drew attention to the chaos in the organisation of welfare services. The lack of coherent planning since the war had produced many disparate branches of social work, administered through a multitude of agencies and confusion about responsibility. The committee recommended streamlining professional training and creating a single administration for services, which became the substance of the Social Services Act 1970 (Byrne and Padfield, 1983: p320, Jones, D., 1983). Concurrently, the Chronically Sick and Disabled Persons Act 1970 (CSDP) placed new (but non-statutory) responsibilities upon local authorities to respond to the many housing and welfare needs of disabled people in their communities (Greaves, 1981, Topliss and Gould, 1981: pp281-287).

The former local authority (LA) health, welfare and children's departments headed either by a chief welfare officer or the medical officer of health were then replaced by LA SSDs headed by directors of social services. The appointment procedure for the new directors involved the Secretary of State's approval of all the appointments. Additionally, it stated that they were now required to have a social work qualification along with management experience. In some instances, the new qualification requirements produced open conflict between local authorities, with different ideas, and the Secretary of

State (Jones, D., 1983: p3, pp47-56, Byrne and Padfield, 1983: p320, Borsay, 2005: p191).

Reading between the lines it would seem to suggest that some of the conflict was about the loss of authority for medical officers and welfare administrators in favour of a relatively new social work profession. Taking the lead, to embark on the huge task for creating services where few existed, was a big opportunity.

With statutory responsibilities for the (non-medical) care needs of vulnerable people it was soon recognised that something had to be done about the large numbers of adults and children inappropriately housed in Victorian asylums, orphanages, decrepit old people's homes, and chronic sick wards of hospitals. Public attention had been drawn to these grim conditions by Peter Townsend, and the Williams Committee (amongst others), who emphasised the unacceptability of continuing to use these outdated vestiges of the old Poor Laws (Townsend, 1962, Williams Committee Report, 1967: p15). In order to do so the new SSDs had to identify who was disabled and what services they needed.

After years of being left reliant on the ad hoc arrangements of charity, disabled people and their families could at last hope to see some services in the community. As it transpired, the longstanding partnership between state and charity continued but the public sector received a much larger share of the responsibility.

The helper-helped relationship in the community

For participants bound up in the helper-helped relationships of the new services this became a historically significant period. For those providing the services it was the time for establishing the basic framework from which they determined what was provided, whilst for disabled people it became a period when lessons gained from the grass roots campaigns of the 60s fed into a more politically conscious phase of response to these social developments.

Passing social services legislation and the CSDP Act 1970, (chapter 4) and the abundant evidence of severe disadvantage, gathered by the OPCS Survey Team (Harris 1971), released a surge of campaigning energy amongst disabled people and their supporters. It was as though a river had burst its banks. Having been involved in the consultation process for the Act, much effort had gone into DIG's campaign to steer the new disability legislation in the right direction.

Many people hoped the CSDP Act 1970 would mark the removal of barriers and the start of progress towards a more integrated society (Barnes, 1991: p172, UPIAS, 1981: p2, Welch, G. 1974: pp14-16). They were to be disappointed (Borsay, 2005: pp191-196). For whilst there were some gains in terms of promoting better community services (Greaves 1981: p23) it also furthered more segregated institutional provision (Hunt, 1973a). For on the contrary, in the period that followed there was an

expansion of 'special' segregated services to provide education, employment, transport, housing and day centre facilities, (Barnes, 1991: p31, pp71-74, p168, p179, p190, Durrant, 1981: p220).

These new services brought with them a whole new dimension to the helper-helped relationship which became a central issue for the developing social movement.

Disabled people now found that, in setting up the services, professionals assumed rather than enquired about what help people wanted, determined rather than consulted about what services would be provided, and they, as disabled people, were expected to be passive in their acceptance of what was on offer (Borsay, 2005: pp194-195, Durrant, 1981: pp220-221, Finkelstein 1981: p59).

Two powerful influences were acting upon the services. The first came from the dominant medical model which, by not properly distinguishing between disability and sickness, led the managing professionals to assume supervised care services were the answer.

The definitions of; impairment, disablement and handicap, produced by Amelia Harris for the OPCS survey of disabled people, reinforced this view. There it was stated that disablement and handicap were the direct consequences of, and caused by, impairments of the body (Harris 1971: p2). It was therefore generally surmised that the primary task for the welfare services

was to provide supervisory care (Finkelstein, 1981: p59, McKnight, 1981: p31). The second influence on the services arose from the surrounding industrial world. As the service managers saw their task in terms of processing large numbers of service needs, through something akin to a service factory, streamlining their labour force into service specialisms seemed a sensible way to manage the demand.

This produced a huge power imbalance between service users and the new branch of helping professionals and the inter-relationship between them displayed similar characteristics to the staff / resident relationship people had experienced in residential institutions (Borsay, 1986: pp123-125, Finkelstein, 1993b: p34, Illich, 1977: pp17-18). It was recognising this connection that in part fired the subsequent political development of the disabled people's movement, for it raised such fundamental questions around the nature of the relationship between themselves and professional helpers.

Amidst their uphill battle for integration it was alarming to see new services promoting a dependency creating culture (Oliver and Barnes, 1998: p66, p97). It prompted McKnight (1977: p79) for instance, to ask whether a modern service-based economy had a certain interest in ensuring there was a supply of personal deficiency to justify the employment of ever larger numbers of helping professionals!

However, on the other side, despite all its failings the CSDP Act had put the issue of rights and control more firmly on the political agenda (Greaves, 1981: p23). Having a law that said services must improve, helped to put the spotlight on their inadequacies. Having it stated that public facilities should be made accessible 'wherever reasonable and practicable' raised questions about who decided if they were not reasonable and practical, and on what grounds.

Initially, in part due to lack of financial resources, the environmental aspects of the legislation remained largely ineffective and many of the Act's weaknesses were soon apparent when legal challenges failed to gain enforcements as shown by the various cases cited by Michael Mandelstam (2008: p571, p572, p581, p584, p597, p598, p622). Mandelstam also maintains that the CSDPA has become a centre piece for judicial review and a battle ground for conflict between people's needs and available resources (Mandelstam 1998: p54).

The idea that it was a *disabled people's charter* soon disappeared.

Power and control in the professional client relationship

Providing welfare support via social services should have been a positive development, but in practice the services soon became an alienating experience for many of the participants on both sides. To understand how this form of institutionalised help distorted the natural desires that motivate one set of people to want to help another, it

is necessary to consider what was happening to the helpers as well as the helped.

Some of the reasons can be found in service professionalisation. Formalised working practices that provide new skills and expertise can be useful to society, but when professionals become possessive over their knowledge and expertise to protect their careers, it becomes a problem (Illich, 1977: p20). With a whole group of new professions emerging at the same time there was the added factor of competition between them for authority. When this resulted in a hierarchy, disabled people and their views were frequently stuck at the bottom (Durrant, 1981: pp222-223, Macfarlane, 1996: p7).

Gritzer and Arluke similarly explain how a hierarchy of professions emerged during the early stages of American rehabilitation services (Gritzer and Arluke, 1985: p81) and I clearly recall their parallels in Britain in the late 1960s. I also remember the lack of interest amongst professionals for finding out what disabled people thought about the services (Hunt 1996: p5).

The lack of power experienced by disabled people was exacerbated by the sense of responsibility professionals assumed over other people's lives (Barnes and Mercer, 2006: p74-75). Once responsible for deciding on behalf of those they had determined were vulnerable, professionals also risked the consequences if something should go wrong. Such fears were no doubt

enhanced at times by a situation in which the largely female workforce was answerable to a hierarchy overwhelmingly dominated by men within the social services departments (Walton, 1975: pp235-239, pp258-261, Wilson, E., 1977: pp164-165).

At that time, risk averse and dismissive attitudes from professionals, substantially added to the difficulties disabled people often faced when they tried to leave an institution, or their parental home, to live alone or with a disabled partner. Here Chris Law recalls how professional obstruction made it so much harder for her when she took a major risk in her determined effort to move out of a Cheshire Home towards the end of the 1970s:

‘I was on a six months trial and, if at any time the District Nurse or Social Worker thought I wasn’t coping I could have been sent straight back to the Home. The house wasn’t properly adapted for someone in a wheelchair ... I couldn’t balance on the toilet ... I was allotted three hours home help (per week) and was reluctant to ask for more in case it was construed against my fitness to manage.’ (Law, 1983: p19).

In this instance the professionals were either too reluctant to believe her experiment might work, or too ignorant of the disabling implications of placing her in a poorly designed environment. From a situation of round

the clock support she was suddenly left with almost none and had to cope despite the difficulties. It was only her sheer determination that enabled her to survive the trial period. Things improved for her after that, but from what I remember it was to her credit that, despite the limited support, she continued to live independently for the rest of her life, offering considerable encouragement to others wanting to escape residential care.

Distortions brought about by a social needs industry

Streamlining services by specialisms meant disabled people were shunted off down a side line into special facilities commonly referred to as “services for the disabled” and the whole interpretation of disability became narrowly focused around what “special needs” people had for help (Barnes and others, 1999: p188, Finkelstein, 1993b: p34, Oliver and Barnes, 2012: p55, pp65-66). Instead of looking at how education, housing and public transport might be made accessible, so everyone could use it, they were said to have special education needs, special housing needs, special mobility needs.

As Ivan Illich said, this was: ‘The Age of Disabling Professions ... an age when people had “problems”, experts had “solutions” and scientists measured imponderables such as “abilities” and “needs”.’ (Illich, 1977: p11).

For many, the environment seemed a relatively fixed concept and it was the services that provided the flexible

response to compensate people for disadvantage. As Finkelstein put it, the statutory and voluntary helping services were built upon assumptions that the problems of individual disabled people originated from their deviation from certain essential standards of normality. Once this assumption had been made it was then conceived that helping interventions to compensate disabled people for permanent inadequacy, needed to be introduced and administered by non-disabled people (Finkelstein, 1993b: pp36-37)

Disabled people started to complain about the extremely undermining nature of this sort of help (Davis, 1993: p200). Not only was control of their personal life being steadily eroded, but increasingly large expenditure on segregated facilities was taking away the incentive to invest in the means to enable people to avoid using them (UPIAS, 1976: p3). As time went on the professional decision-making, in its various manifestations, came to be looked upon as the execution of an oppressive policy keeping disabled people powerless. A different way forward had to be found (Finkelstein, 1993b: pp38-41).

Finding a way forward and taking control of campaigns

It was against this backdrop of resentment to the professional services that disabled people underwent a rapid change in their political awareness and new campaigns emerged. In the process they were exploring the best ways to have an influence and the issue of power and control was a primary concern.

Not only was the exploitation of power by professional services questioned but also the undue influence of non-disabled people in their grass roots campaigns (Finkelstein, 1993b: p36, UPIAS, 1976: pp5-6). By this time, many friends, relatives and professional allies were involved (Campbell and Oliver, 1996: pp51-52, UPIAS, 1976: pp5-6), and some of those with direct experience of disability started to question the value of this. It was argued; however well-meaning such help might be, disabled people would not gain skill and expertise if others always took the lead, moreover, they would continue to be unheard, undervalued, and without influence. It was emphasised that however much they needed non-disabled help, disabled people must now take the lead (Campbell and Oliver, 1996: p64, Finkelstein, 1993b: p35, UPIAS, 1976: p5).

With this change of awareness stresses developed within the voluntary groups. Not only did people from different disability experience backgrounds have to learn how to share power with some degree of equanimity they had to work through some acute controversy in groups where non-disabled leaders were reluctant to hand over power.

In an upsurge of activity significant differences emerged in relation to campaign approaches. There were arguments about whether the most effective way forward was through single-issue pressure groups like DIG, or whether a broad-based organisation would be

more effective. Specific campaigns for a reform tended to be more popular, but there were those who chose to tackle a wide range of issues, shifting the focus onto specific campaigns at particular times according to changing priorities.

Most commonly it was thought that it was the negative social attitudes and huge ignorance about disability that were causing many of the problems (Finkelstein, 1980: p8, French, 1996: p162, (Siller, 1980: pp47-51). Examples of this can also be found in articles by (Burn, 1974: p8), and (Herbert, 1975: p12). People argued that ignorance produced prejudice which in turn caused resistance towards providing disabled people with access to the services they needed to become part of the mainstream. It was inferred then that attention should be directed at social education. Once attitudes changed, better facilities and integration would follow.

Counter to this was a view that said negative attitudes were not the creators of social conditions but a product arising from them. Here it was argued that prejudice did not go ahead of exclusion but, on the contrary, exclusion of people produced prejudice. It was the social conditions and inaccessible buildings that had to change. Changing social attitudes would not of themselves create accessible buildings, but accessible buildings that enabled people to mix on equal terms, would bring about a change in social attitudes

(Finkelstein, 1980: pp8-11, Finkelstein, 1993b: p36, UPIAS, 1974: p4).

These countering arguments from within the campaigns started to influence them. It was often not clear which was true. The arguments on both sides seemed to make sense; they all reflected experience. It was clear that the issues were complex.

In fact, all these components, highlighted above, were in embryonic form during the 1960s but moved into a phase of conscious choices about strategy in the 1970s. Becoming aware of these various ways of working was itself a process that had to evolve as part of an ongoing struggle to be effective. This maelstrom of ideas provided the basis for energetic debate and argument that helped people to understand what they were trying to achieve and what they were up against.

As I recall, becoming organised presented many hurdles. There was poverty, and few could afford cars or in some cases even telephones (Barnes, 1991: p98, p101, p162).

Finding affordable and accessible meeting places was a major challenge. People in institutions could be dependent on staff to help them get to and participate in events and others often had to rely on relatives. Any hint of criticism towards the services or non-disabled help could risk a hostile response. A poor standard of education was another common disadvantage and for people with a long history of disablement especially so

(Barnes and Mercer 2006: pp35-36, (Barnes and others, 1999: pp103-108, Campbell and Oliver, 1996: pp54-55, Hasler, 1993: pp282-283). All these factors had to be accommodated by disabled people seeking ways to build their own organisations. To develop a collective voice, they had to find ways to support and encourage each other.

A survey of self-organisation

The escalation of political activity amongst disabled people, at this time, can be seen in the results of a survey I carried out in 1991. There were 105 national organisations, with an expressed interest in improving conditions for physically disabled people, were contacted. I investigated three things; how grassroots activity had increased over preceding years, how the leadership had constitutionally changed in favour of disabled people gaining more control of the organisations and whether the composition of management affected what they regarded as of primary importance for improving the lives of disabled people. The graphs in figures one and two present some of the results of this exercise. The groups reporting disabled people had majority control are referred to here as disabled control organisations. The rest are described as having mixed control.

**PATTERN OF GROWTH OF ORGANISATIONS
1866-1980**

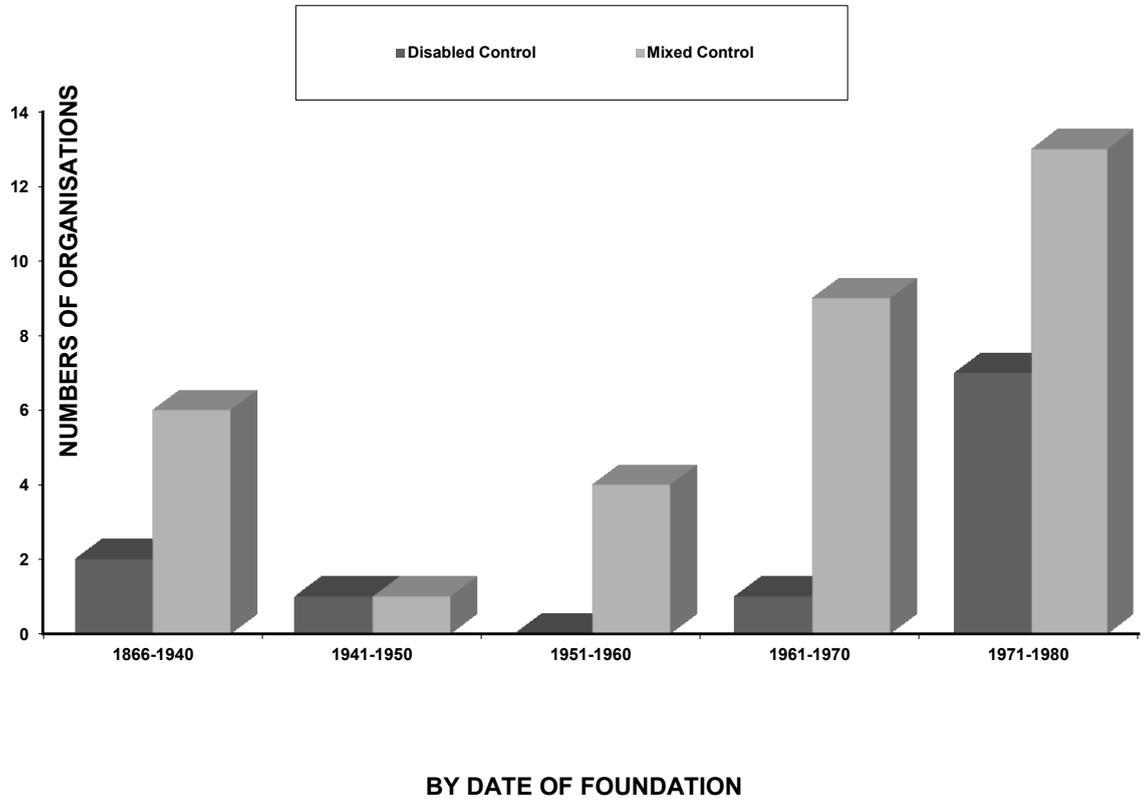


Figure 1: The Pattern of Growth of Organisations by date

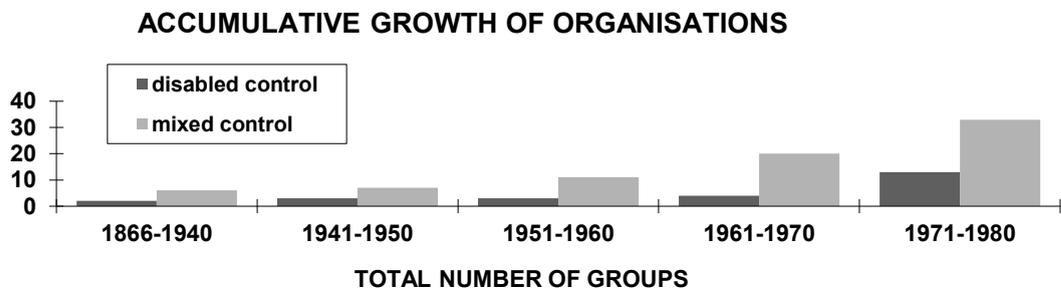


Figure 2: The Pattern of Growth of Organisation, cumulative

Divided into two categories according to their management criteria, these graphs illustrate that from as early as the year 1866 disabled people attempted to better their conditions and, in exceptional instances, set up organisations under their own control. However, the dominant picture was that in general they did not have a controlling say until 1980.

Whilst the overall number of organisations is quite small, the sudden increase in the proportion of those with disabled people in control, in the 1970s, is significant for it reflects the changing interest about who controlled decisions. The surveyed organizations for this group were drawn from the address list of the British Council of Organisations of Disabled People (BCODP) which only accepted membership from organisations controlled by disabled people. The results are backed up by subjective experiences from the movement and more recent research (Barnes & Mercer, 2006: p76.). The term 'mixed control' needs interpreting. In reality, most of the voluntary organisations had a poor history of involving disabled people in their management, and many positively discouraged it. In fact, many had no data about whether any of their voting members were disabled because they had not considered it as an issue. The

organisations for this mixed control group were drawn from the address list of the Disabilities Alliance Rights Handbook which included a wide range of national charities some of which also belonged to the BCODP.

The organisations set up by disabled people tended to have clearer constitutional boundaries and so the figures for disabled control can be relied on as reasonably accurate. The scope of the survey was limited to the organisations that were around at the time. It can be safely assumed that, between 1866 and 1980, a considerably larger proportion of charities would have denied disabled people an active role (some had disappeared whilst others evolved into different organisations).

When looked at for their focus of activity it was found the groups fell broadly into either pressure groups, predominantly engaged in campaigning for social reforms, or self-help groups offering some form of support. Many engaged in both kind of activities with a difference of emphasis. With hindsight one can see that different approaches were also being influenced by two emerging ideological tendencies. Those seeking reforms, to compensate for disadvantages associated with disability, did not tend to challenge the fundamental structures in society. Those who belonged to a political liberation tendency, tackling disability as a discrimination issue, did challenge fundamental social structures. Once these differences of approach became more explicit, all

organisations faced the issue of where they fitted on the new political spectrum.

There was broad consensus about the need for integration, but there was divided opinion about how to achieve it. Some wanted to concentrate on removing the barriers by developing access campaigns others thought compensatory measures, such as providing special transport arrangements or targeted financial aid for disabled people, were needed first, to get people out and about in the community. When it came to education and housing, deciding campaign objectives soon drew people into similar debates about whether they wanted better quality specialist services or full access to mainstream facilities. All this raised questions about what people meant by integration.

As time went on, the different approaches represented something far more significant than just alternative ways of winning improvements. They were based on fundamentally different ideological perspectives. In deciding where to direct their limited resources, it was often a question of whether to build campaigns to relieve the immediate stresses, or concentrate on bigger, more complex objectives of barrier removal. People then questioned whether it was possible, or compatible, to do both concurrently.

From personal to collective struggle; a process of political growth

The following account of political involvement in Rochdale helps to illustrate the kind of social journey that was quite common amongst activists in the movement. I interviewed Ken Lumb, who recalled the contrast between the isolation of his early life, to becoming, politically involved and, in his case, a significant initiator and leader of events:

‘My first experience was the DDA (Disabled Drivers Association). From being stuck in the house to being mobile with a tricycle. Shortly after that I met someone locally who was well known in the DDA and I started to go to Manchester, so I met other disabled people. This was the late 1960s, I was attending meetings, DIG (Disablement Income Group) was being set up. They had huge public meetings initially at the same place as where the DDA met and so I got a look at DIG for a short period.

‘Then I got drawn in locally. This was through the local day centre run in the Social Services offices, and through the disability clubs. They were social clubs basically, mainly trips out and concerts, and at that time they were the main forms of organisation in the country. You know things like ... The Inskip League of Friendship. ... Set up originally because people were that isolated, that it was the only kind of contact they got with other people.

‘When I started going to the Social Services day centre the first kind of thing we did was to set up a magazine. Very soon, in addition to that, there was a small disability access group, set up.’ (Lumb, [interview] 1998).

Ken Lumb recalled their first initiative, in the late 60s, was for some accessible transport. Fed up with being carried on and off the bus they came up with the idea of obtaining a bus with a tail lift. It was a new concept that interested the Local Authority who duly arranged for the Halifax bus service to attach a lift to a second-hand vehicle. Ken Lumb described their first acquisition:

‘A rickety old thing it was, but it had made the point really of having that kind of transport. When the day centre came in a year or two later, buses were being manufactured with tail lifts. But when we got ours, there weren’t any for that kind of purpose.’ (Lumb, [interview] 1998).

When the Ronald Gorton Day Centre opened, around 1970, the service structure was as yet unformalised which gave them room for manoeuvre despite fairly traditional ideas built into the centre’s design. Ken Lumb said:

'The conception, with its medical room, was expecting people to collapse, the ideas were built into the design, but there was room for some innovation. We were able to put a duplicating machine in and get a politicising magazine (called *Scope*), going for a while, so things like UPIAS and DIG material that came in, were addressed in it.' (Lumb, [interview] 1998).

Scope was a small but significant initiative that had a role in the early mobilisation of disabled people in Rochdale. Lumb, as editor, was able to give some coverage to national issues and campaigns of interest to disabled people and draw their attention to shortcomings of the local services.

Scope publicised go-ahead publications coming from abroad. From Sweden for instance there was *Building for Everyone* which put a strong case for environments to be built to accommodate the entire community (Beckman, 1976: p33) and *Life Together*, (Nordqvist, 1972) which argued for disabled people to have normal opportunities for sexual partnerships. Integration, it was being argued, meant that standard literature on sexual education should cover difficulties disabled people might have and not have this off as a specialism. Such publications were rare and a welcome breakthrough in attitudes to disability.

Whilst initially the Social Services Centre did not interfere with their self-organised groups, a change in the

management showed less tolerance and they were forced to move their activities out to the office of the more supportive Council for Voluntary Service (CVS). Lumb explained how their campaigns then progressed through different stages:

‘There was one little access group, and then when another issue came along, there was a reason for another group. So, we started with access, housing then became an issue, and also the support implications. It was because of the lack of accessible housing that we knew people were going to end up in YDU’s (Young Disabled Units) and so that’s why we started to work on it. After that came things like Crossroads. Because, even if you got the housing, people still needed assistance of one kind or another.’ (Lumb, [interview] 1998).

Here was another example, of disabled people pushed into using a segregated service, taking the initiative to find their way out of isolation. As at the *Le Court* Cheshire Home, this group used a collective approach to influence events by developing their role as agitators and initiators. The services, on the other hand, stuck in a groove with their more passive concept of community care, were unable to see the bigger picture or disabled people’s potential as service reformers.

The struggle between disabled people and the welfare services was growing in intensity. By the early

1970s, finding ways to displace institutions and other forms of segregation was becoming increasingly urgent all over Britain. A key, for many disabled people, was to have accessible housing and appropriate forms of personal support in the community, neither of which existed.

Single issue or global approach? A period of transition

Throughout the 1970s, campaigns around poverty, mobility and access continued to be important, but new issues were added to the list. Special education, ineffective unemployment services, lack of accessible housing, and the absence of personal support services all aroused passion. Lack of information about what was available was another major concern as were gross interferences in people's personal and sexual relationships. Against the backdrop of segregated services, these wider concerns led to an escalation of issue-based campaigns which, like tributaries, fed into the overall determination to bring about integration (Barnes, 1991: pp217-225), (Davis, 1993: pp288-289, Disability Alliance, 1976: p22, Hines, 1983: pp5-7, UPIAS, 1976: p4).

Whilst the single-issue attack was often the most popular, as time went on this became more difficult to sustain. Questions arose whether changing society could be fought out by a diversity of single-issue campaigns, or whether a more general, all embracing, approach was required for so often one issue led into so many others.

Could education be separated from employment, could either be separated from access or transport? Could housing be separate from personal help, or employment separate from either? This was so different from the medical outlook of professional services which concentrated on individuals and the specifics of incapacity.

In 1971 the dialogue was being taken forward in another new organisation called the Association of Disabled Professionals (ADP). ADP was interesting for it represented a stage in the political development of the movement. From the outset it was controlled by its disabled membership. Several disabled people, with established credentials in existing campaigns, had taken the lead to set it up with the help of the British Council for the Rehabilitation of the Disabled (BCRD), a principal charity at that time. ADP offered disabled people a new chance to set down a campaign agenda influenced by direct experience of disability.

Like DIG, it was a national organisation and registered as a charity. It offered an open membership to anyone who wanted to join it, (it was never confined to professionals) and like DIG, also attracted liberal politicians and professionals with an interest in disability. But more significantly it became a regrouping of many disabled people who had become active through DIG with its first membership showing many who became leading participants in the disabled people's movement

(Association of Disabled Professionals membership list 1971).

ADP's annual reports and bulletins show that, in addition to its founding aims of pressing for improved employment prospects for disabled people, there were a multitude of interconnected issues that disabled people wanted to take up (ADP Constitution 1972).

The first AGM produced discussion that took off in many directions. The lack of facilities for disabled students in universities, lack of access to public libraries, the barriers to vocational and professional training, high unemployment and their appalling experiences of the disablement resettlement officers (DROs) in the labour exchanges (Association of Disabled Professionals, 1972b). Taking a critical stance on special education, this founding conference overwhelmingly agreed that disabled children should attend ordinary, not special schools, and at the end of the conference, elected sub-committees to look into education and employment (ADP, 1972). The ADP went on to prioritise obtaining disabled representatives on advisory bodies in education and employment and worked closely with major charities to act as a watchdog of government activity. It mirrored DIG's approach of using parliamentary lobbying as its principal way to have an influence.

Although, constitutionally, ADP had made no distinction about who could hold office, by 1975 the association claimed four hundred members of whom

90% were disabled (Association of Disabled Professionals, [publicity leaflet], 1975). By 1975, ADP was also stressing the fact that all its officials, apart from its General Secretary, were disabled people. This emphasis on the management role being taken by disabled members is relevant for it reflected the new mood growing throughout Britain. By 1975, disabled people were more insistent about taking the driving seat of their own organisations (Finkelstein, 1993b: p39).

The ADP was a kind of litmus for its time, reflecting the shifts in thinking taking place. It broadened the base of discussion and ensured disabled people took the helm but in practice remained a single-issue organization around employment. It sought the removal of barriers to employment and some compensation for disadvantage (Association of Disabled Professionals, [publicity leaflet], 1975).

Local associations and a struggle for control

Another strand in the struggle for self-organization was around the development of local associations for the disabled (LADs). These were cropping up everywhere from 1970 onwards. Ken Lumb told me that he thought that the CCD was a major player in this development for it wanted to upgrade its regional representative groups away from old fashioned charities, such as the Crippled Aid Society, such as they had in Rochdale to more modern organizations capable of disseminating its information to the broad spectrum of disabled people.

Borsay (1986: p123) suggests that it was also the element of the CSDP Act encouraging local authorities to increase the participation of disabled people (or people with experience of disability), in decision making, which added to the emergence of local pressure groups in the 1970s. However, she argued, they generally had little actual influence on policy. The common experience at the time was that these LADs were generally initiated and run by non-disabled people (Borsay, 1986: p123, and my interviews with various disabled people).

Lumb argued that in his experience these LADs could be more of a hindrance than a help to the emerging movement. He said, by controlling disabled people's access to information they gained a dominant foothold and frequently this impeded the development of potentially more progressive initiatives by disabled people.

'They [LADs] were paid, would get grants from local authorities and county councils, so they had quite large budgets. They had a director, and one or two individuals employed. With some LADs, disabled individuals tried to take them over; others just faded away and folded' (Lumb, [interview] 1998).

With hindsight Lumb felt Greater Manchester had been fortunate never to have had any local associations for the disabled (LADs) for it had left disabled people

more freedom to take the lead. In their case they had been assisted by Dorothy Whitaker, who had been appointed by Greater Manchester Council for Voluntary Services (GMCVS) to set up the LAD there. However, once she had talked to local disabled people, she interpreted her task very differently. In Greater Manchester, which from 1973 was made up of ten metropolitan district councils, initially with a metropolitan county council 'above' them, she found a number of active minded disabled people who had started to form into small groups, but they often did not know of each other's existence.

She then used the resources of GMCVS at her disposal to put these local disabled people in touch with each other and to support them to set up the kind of organisations they immediately wanted, such as; groups to tackle housing, highways, public transport, and access (Lumb, [interview] 1998).

Despite their limitations, many LADs were responsible for drawing disabled people into local affairs (Barnes and Mercer, 2006: p77). They often set up local access groups that carried out surveys, produced access guides and campaigned for improved access to public toilets, libraries, town halls, cinemas, sports' facilities, restaurants and shops etc, as was the case for example with Liverpool's local association and the Islington Disablement Association (IDA, 1979, Liverpool Association for the Disabled, 1987).

But, without enforceable legislation many of these efforts had limited effect. In some areas disabled people set out to take control of their local associations and an important distinction started to appear. In their terms of reference, they became known as either for, or of, 'the disabled.' It produced plenty of heated debates with examples of considerable hostility shown towards disabled people who, in taking control to represent themselves, questioned the nature of involvement of the non-disabled members (Barnes and Mercer, 2006: pp71-77, Barnes and others, 1999: p158). On the other side there was resentment from disabled people when non-disabled people suggested, as they frequently did, that disabled people were too subjective to represent others inferring that only the 'able-bodied' could be objective (Campbell and Oliver, 1996: p51, Leaman, 1981: pp23-27, Morris, 1991: pp177-178).

In reality it was non-disabled people, trained or otherwise, who were unaware of so many issues. Despite the groundswell, majority control by disabled people was not achieved in most LADs during the 1970s (Barnes and Mercer, 2006: p76-78) largely because of a lack of readiness to risk alienating their non-disabled supporters (Feidler, 1988: p26, Morris, 1991: p177). A related issue facing the organizers around the mid-1970s, as Kevin Hyett recalled from his experiences in Salford, was how to get people to work together:

'we tried to set up an association of disabled groups in Salford to work together to campaign for all disabled people in Salford but it wouldn't work because the mental handicap groups wouldn't co-operate, the blind groups wouldn't co-operate, because they said they each had their own ear to the council and they didn't want to give up their own contact to the council, so the association didn't work.' (Hyett, [interview] 1998).

Self-representation, single impairment groups and the struggle for control

Organising around a specific impairment to provide support where none exists has been an ongoing trend for a long time. Charities for people with sight or hearing impairments go back to the eighteenth century whilst those specializing in other types of physical impairment began to appear in the late nineteenth century (Borsay, 2005: p94, p108, p142). Initially these charities were responding to the effects of common conditions such as arthritis, heart disease and epilepsy, and later it was the impact of poliomyelitis, cerebral palsy and muscular dystrophy, and the need for family support, then others followed suit. This information is drawn from my survey of disability organisations in 1991 which amongst other things looked at their date of foundation.

The purpose of such charities was predominantly to raise money for medical research and welfare support. They might, for instance, provide grants for equipment or holidays. Some charities, such as the Spastics Society

and Muscular Dystrophy Group also established their own schools, colleges, residential homes and workshops.

When disabled people started to set up their own specific impairment organisations the motivation was different. Like the others, improving treatment was important but here disabled people were also keen to share their knowledge gained from direct experience and provide each other with peer support. A particularly successful example was the Spinal Injuries Association (SIA) which led the way in setting up the services that disabled people identified as necessary. The SIA demonstrated how they could not only service each other very successfully, but in some cases, provide services in a way that was preferable to those being offered by professionals, because they were grounded in experience.

The SIA arose out of dissatisfaction with the way the medical establishment behaved towards people with spinal injuries and their lack of understanding of the emotional trauma following spinal injury. The treatment priority within hospital was to improve the patients' physical performance. The worries and fears disabled people had about the future, their relationships, their potential to have children and their employment prospects were not the hospital's concern. Too often, professionals were reluctant to talk to their patients about sexual performance and fertility following paralysis, and

there was precious little counselling for people challenged by dramatically changed circumstances. There was also the need for a lot more information regarding ways to solve practical problems once out of hospital (Barnes and Mercer 2006: p44-45). The SIA produced a book, *So You Are Paralysed ...* to help fill this information gap. Stephen Bradshaw explains the reasons why he and others founded the SIA:

‘People were conscious of knowledge they had of living with spinal injuries and not feeding it back to others and thought sharing experiences could improve the lot of people in spinal units. We set up a link scheme to put people in touch with others. SIA was a means of collecting and sharing information. A number of us were members of other organisations (such as DIG) and could see there was power from getting together.’ (Bradshaw, [interview] 1991).

The medical establishment was not over keen on the idea, as Bradshaw also pointed out, and there was resistance from some doctors when they tried offering each other peer support:

‘We have a lot of examples where consultants have got upset, one got very upset early on, about 1977, at one meeting when he said, SIA was a good idea but two patients had been comparing operations, and

consultants, and he didn't think that such a good idea!' (Bradshaw, [interview] 1991).

In the 1970s doctors expected to have authority over their patients much more than now. Once it got going the SIA provided an information network, a peer counselling service, wheelchair accessible holiday facilities, and in due course, a personal assistance service for temporary periods of help when regular family support was unavailable (Oliver and Hasler 1985).

In becoming a self-servicing organization entirely managed by disabled people, the SIA broke new ground. In several other contexts disabled people had given each other mutual support and taken initiatives that led to the development of new services, but this time was different because the members had decisive control (Oliver and Hasler 1985: p4). Disabled people were not only learning to be the experts of their own experience, but on their way to becoming an authority to which others, including professionals, could turn for well-informed advice and support. By drawing on their collective knowledge the group started to match services to what people wanted (Oliver and Hasler, 1985: p20).

Around the same period other initiatives were being taken by disabled people who wanted to break away from 'parent' charities to have their own independent views on issues they thought important. The National Federation of the Blind, founded in 1947 led the trend (Reid 1974)

Then, in 1976, deaf people founded the National Union of the Deaf (Campbell and Oliver 1996: p23, 9, 70) also, in 1976, people with Multiple Sclerosis formed the Multiple Sclerosis Action Group in Northern Ireland, (xiportal.com / actionms), and in 1989 Muscle Power was set up by people with neuromuscular impairments (GMCDP, 2006: p6; BCO DP, 1997: p20).

All derived from deep dissatisfaction with the way the established charities such as the RNIB, the RNID, the MS Society and Muscular Dystrophy Group ran their affairs. These new peer support groups also became part of the trend, gathering momentum, in which disabled people, learning from each other, were becoming determined to run their own affairs. The charities were failing them by not involving or consulting them, and worse – presenting negative images for fundraising purposes (Barnes, 1991: p202).

Whilst such groups, had specialized memberships with specific concerns, they were soon faced with the need to engage with the emerging general groundswell of disability activism. The campaigns around education, employment, mobility, access, information, and income, were of concern to all disabled people whatever their impairment. But becoming part of a broad-front political liberation movement was not straightforward, as Hyatt, drawing on his Salford experience, pointed out, above, and Stephen Bradshaw also referred to inherent limitations that came from being a service organisation:

‘An organisation such as the SIA is a club for spinally injured people. It takes everyone; we don’t have a philosophy that will alienate members because we are a service organisation. Political awareness has to come by osmosis rather than by conscious education’ (Bradshaw, [interview] 1991).

When asked how much the SIA focused on support for individuals and how much it promoted changes to the general environment, he answered:

‘We have always done both. The SIA’s role is not to help individuals by giving them money, but to change the system and make the system supply’ (Bradshaw, [interview] 1991).

As more people became involved campaigns covered a wider range of issues. Of these, it was education, housing with personal support, and access to information that became particularly dominant during the next phase.

Opposition to segregated education

Feeding into the movement opposing segregated services were the growing concerns about special schools. It was being argued that these regularly failed disabled children by providing education of a very poor standard. Additionally, by preventing these children from

mixing and learning with their non-disabled contemporaries it produced a society of adults who could not relate to each other (Barnes, 1991: p61, Barton, 1995: pp27-37).

Opposition to the system was primarily driven by a lobby of parents, and ex pupils, of special schools. Some professionals and academics became involved including an influential piece of research by Elizabeth Anderson.

Anderson's research findings, published in *The Disabled Schoolchild*, in 1973, gave added impetus to the arguments of the anti-segregation lobby by providing a strong case for integrating disabled children into mainstream schools. She had investigated the experiences of disabled children attending ordinary schools in Britain, and had drawn on the collective experiences of teachers, pupils, and parents, who had explored different ways to tackle the problems that had arisen. Additionally, she had looked at evidence coming from Scandinavia, where integrated education was already well advanced.

In his foreword, Jack Tizzard (1973) drew attention to the evidence Anderson had found of severely disabled children enjoying, and profiting from, being educated alongside ordinary classmates once the conditions had been made right. He also drew attention to the climate of changing attitudes towards special education, highlighting the build-up of grassroots pressure on local

authorities to educate disabled children in ordinary schools.

Critical of a contemporary white paper; *Education: a framework for expansion*, Tizzard pointed out that despite almost no research, the government was at that time proposing an acceleration of the special school building programme and an increase of spending from £11 million to £19 million over the subsequent four years, and had made no mention of provision for disabled children in ordinary schools, nor made any proposal to research the situation.

Government policy was shown to be going backwards. As Anderson (1973) pointed out, even the policies of the past had been more enlightened by recommending handicapped children be educated in ordinary schools wherever possible. In 1954 it was said, for instance, '*No handicapped child should be sent to a special school who can be satisfactorily educated in an ordinary school*'. In 1967, the *Plowden Report* had said; nearly all their witnesses supported the policy of placing physically handicapped children in ordinary schools, and in 1970, the *Younghusband Report* had said much the same, '*We start from the assertion that wherever possible they (physically handicapped children) should be educated in an ordinary school*' (Anderson 1973).

Colleges and universities were also under attack. Education was an essential foundation for entry into employment yet too many universities and colleges

barred disabled students attending. Almost none offered adapted campuses, and even less thought was given to flexible timetables, education aids, or methods of teaching to enable disabled students to participate in the learning process. Many were therefore excluded from the chance to discover their potential and from professional and academic careers (Barnes, 1991: p58).

Several organisations focused their attention on integrating the education system. The primary campaign groups were; the Association of Disabled Professionals (ADP), the Association of Blind and Partially Sighted Teachers and Students (ABAPSTAS) and the National Federation of the Blind (NFB). Over time following repeated representation from different organizations and individuals, colleges and universities took some notice and adapted to take in disabled students (Campbell and Oliver, 1996: p58, Finkelstein, 1993b: p39, Reid, 1974: pp2-3). The government's response to the widespread criticism was to set up the Warnock committee. The brief for this was:

To review educational provision in England, Scotland and Wales for children and young people who were handicapped by disabilities of body or mind, taking account of the medical aspects of their needs, together with arrangements to prepare them for entry into employment; to consider the most effective use of resources for these purposes (Warnock, 1978).

In 1978, the Warnock Committee published its recommendations, amongst which it argued that special provision be made available within mainstream schools for children with special needs. Whilst the *Warnock Report* recommended a movement away from special schools, it still retained the idea that special provision was necessary.

Their proposals favoured a process of assimilation through a variety of means, either by direct placement of children in mainstream classes, or by using special units attached to ordinary schools; suggesting this would create a range of opportunities for children to learn and socialise together across the special needs divide. A further recommendation was to introduce a new statutory terminology of; special educational needs (SEN), and learning difficulties, to replace the outmoded term "handicap".

The Warnock Committee was feeling its way towards a more integrated system for disabled pupils and that was progressive, for it added a spur to improve the accessibility of mainstream schools. But, on the downside, Warnock had been unable to see beyond the idea of a separate specialism within the education system. For disabled people who were determined to get rid of all forms of segregation this was a disappointing compromise. It was becoming apparent that for integrated education to really happen it would need an

entirely new paradigm. This would be one that assessed the schooling system (rather than the individual pupils) to identify the changes needed to enable all pupils to fully benefit.

Alternative approaches to community support – professional responses

Alongside opposition to segregated education was a growing movement against segregated living in residential homes (Davis, 1993: p289), (Oliver and Barnes, 2012: p166). Finding somewhere suitable to live was extraordinarily difficult and tackling this was crucial if disabled people were to have any chance of becoming integrated in the community. The first OPC Survey in 1981 estimated that, out of the three million people it identified as being disabled, nearly a million - 958,000 - were found to need re-housing (Buckle, 1971: p123).

Once this situation had been exposed attempts were made to do something about it. Three publications by Selwyn Goldsmith set down some design standards. The first two, approved by the Department of the Environment, were called *Mobility Housing* (1974) and *Wheelchair Housing* (1975) and Goldsmith also produced his second edition of *Designing for the Disabled* (1976) containing the results of his detailed research into housing design.

A few housing providers started to build some purposely-designed properties, but often they were set within sheltered housing for older people which was no

solution for younger adults (Barnes, 1991: p149-153) (Fiedler, 1988: p39-67). From 1970, as a result of the CSDP Act, SSDs started employing occupational therapists (OTs) to advise and help disabled people to adapt their existing housing (Wilcock, 2002: pp365-368).

Outside the medical authority of the hospital environment, these OTs became more aware of the ways architectural barriers inhibited disabled people's lives and this was a step in the right direction. But, trained as rehabilitators, they could not break free of the idea that disability was a personal issue of dysfunction (Mocellin, 1988: p4-7). This affected the ways their help was offered and introduced some fundamental contradictions to their relationship with their clients.

OTs who were professionally obligated to assess individual's needs for a service, decided what equipment or housing adaptations would help and prescribed solutions. Drawing on my many years of working experience in OT departments I was aware that as with other sections of Social Services they were generally not, in my experience, developing a consultative relationship with their clients and so, despite being employed to reduce dependence, their very control of the resources, and decisions, meant they were preventing people from deciding for themselves. Anne Macfarlane makes a similar observation in her exploration of consultation around service provision (Macfarlane, 1996: p7).

Personalised solutions enabled people to do more for themselves and the resulting huge demand for housing adaptations produced long LA waiting lists. It was soon apparent this was not the full answer to disabled people's housing needs. There was an urgent need for properly designed newly built housing as well and this was only happening in exceptional circumstances (Beardshaw, 1988: pp25-27, CCD, 1974, Fiedler, 1988: p21, Walker, 1995: p46).

It was then the combination of actions taken by individuals and small groups, mostly disabled themselves, who drove the agenda forward. It was these actions for appropriate housing solutions with community-based support that were to provide a way out of institutions.

Alternative approaches to community support – disabled people's responses

There were two ways forward; either to apply familiar compensatory ideas to create a new care service but based in the community or, take a leap into the unknown and establish a service based on emancipatory principles that would enable people to take control of their lives.

Following an emancipatory approach, a series of attempts met with varying degrees of success. The first came around 1970, when news reached Britain of a housing and support service being developed in Scandinavia, by a group called the Fokus society. It was started in 1964 by a group of disabled people who set out

to create a comprehensive integrated housing scheme to replace all residential care (Brattgard, 1972: pp25-40).

By 1973 the Fokus scheme had completed a building programme of integrated, purposely-designed housing, in several Swedish towns, providing a twenty-four hour on-call, personal support service for the tenants, which enabled severely disabled people to live independently of family (Brattgard, 1973). Nowhere else had so much been achieved.

Paul Hunt, from his experiences of institutional living, was quick to see the value of such a scheme and started to promote it. He was attracted by the combined facts of Fokus users becoming more socially integrated and in control of their lives and having representation on the Fokus management committees. Around 1973, the success of the scheme encouraged the Swedish government to underwrite its future plans to release more people from institutions. This political commitment, as Hunt (1973) pointed out, contrasted sharply with experience in Britain where there was neither consultation, nor any proposals to replace institutions.

Concerns at this backwardness, and a growing awareness of Fokus led to a conference in 1973 organised by the Central Council for the Disabled (CCD). Professor Olav Brattgard, an initiator of the Fokus society, and Paul Hunt, as publicist of the idea in Britain, were asked to present the Fokus case. Brattgard explained that in conceptual and practical terms Fokus

was much more than a housing scheme by having an underlying philosophy which maintained disabled people should bear the responsibility of making their own choices. It had already shown that once people lived in the community with aspirations to be integrated, access to the neighbouring environment became a requirement which in turn meant that disabled people became enabled to take up employment, pursue education and enjoy leisure pursuits along with everyone else (Brattgard, 1973). Hunt for his part argued that Fokus represented an exciting breakthrough, not just as a housing solution, nor just a care solution, but as an attempt to tackle disability within an environmental context and promote the integrated solutions that disabled people were crying out for.

Despite their efforts, the audience of housing and welfare professionals remained sceptical. Neither Hunt's reasoning for replacing institutional care, nor Brattgard's assurances that Fokus could prove a less expensive option, could persuade the audience to go away and promote the ideas in their local areas (Central Council for the Disabled, CCD, 1973; Hunt, 1973a, 1973b, 1975 [personal correspondence]).

This was disappointing, but, undeterred Hunt continued to promote the ideas for some years. From my personal recollections of audience reactions at the meetings where Paul was an invited speaker, I know that through his talks and articles he provoked some strong

reactions from audiences and on occasions exposed the gulf that existed in the aspirations of disabled residents of institutions and the assumptions of care staff, towards the idea of replacing institutional care (personal recollection).

Such ideas were filtering through and in due course the Habinteg Housing Association built a scheme of accessible flats scattered throughout a housing complex, on the Fokus design. The Habinteg Housing Association was set up in conjunction with the Spastics Society to promote integrated housing schemes for disabled people. The formal opening by the Prime Minister, Edward Heath MP, of the first scheme, to which Paul Hunt was officially invited, was in the mid-1970s in Tottenham, North London (Heath, 1973). Other Habinteg schemes were subsequently built in different parts of Britain (Habinteg, 1980).

This project produced well designed apartments which thoughtfully included a loudspeaker intercom to call for assistance (Habinteg, undated) but initially, as they had no financial means to provide any on site personal care, it did not necessarily offer people a way out of institutions.

Despite the considerable time and energy by Hunt, and others, to awaken the interest of policy-makers and service providers, and publicity about the introduction of Fokus schemes into a number of European countries, nothing based on this model ever happened in Britain.

The establishment was not ready for anything quite so radical, and the grass roots movement was not strong enough to achieve it.

Grove Road, Nottinghamshire

The next attempt to find an emancipatory way forward was in 1976. This came about because Maggie Davis (née Hines) was seeking her own escape route from an institution. Supported by her friendship with Ken Davis they pioneered a new concept of living that could benefit a few people including themselves. Their initiative led to the scheme known since as Grove Road. It was a small block of purpose-built flats, in Sutton-in-Ashfield, which enabled a few disabled people to move out of institutions into the community with support. Hines describes how Grove Road developed:

‘The idea started when I was at the Stoke Mandeville Hostel. At first just an escape, somewhere to live. We had gone to a housing meeting in London, Selwyn Goldsmith and Malcolm Doney [Director of Inskip St Giles Housing Association] were there. We had already talked to Selwyn, and Malcolm, who was entrepreneurial, said to us ‘if you need a housing association, contact me’. We looked for old houses at first but couldn’t get a mortgage. We had started with the idea – we could live in the community – with the right support’ (Maggie Davis [interview] 1988).

Over several months, and a move by Hines to another institution, the idea continued to grow. A Nottinghamshire vicar, Terry Short, had some church land available and enthusiastically supported their idea. With the aid of a sympathetic housing association, and an architect, plans were drawn up for the scheme. Their proposal included the idea that personal help would be provided by a mixture of assistance from some carefully selected able bodied tenants, in lieu of rent, and additional support from statutory services.

All the management decisions were made collectively by all the tenants and Grove Road broke new ground for it publicised the fact that, in the right environment, severely disabled people could live independently, plan their own help requirements, and achieve a considerable level of control over their lives. Hines, who subsequently married Ken Davis, explained their reasons for incorporating emancipatory principles when setting it up:

‘We wanted to build up a co-operative framework, we didn’t want power over others or others to have power over us, and we had enough of the power structure... We wanted everything to be so right, we were so anti institutions we wanted everything to be equal. It went through different phases and endless discussions. We ended up with six flats, three upstairs for helping families,

three down for disabled people' (Maggie Davis [interview], 1988).

Because they were involved from the outset the building was designed to suit their specific abilities and disabled tenants soon discovered less help was necessary than originally anticipated. It signified another important development towards disabled people having a decisive role in the running of their own services. Grove Road was the first comprehensive housing and support scheme in Britain, to be set up by and for disabled people, and importantly, it incorporated the principle of tenants having control over their lives. Two similar projects were started in Edinburgh and Rochdale (Davis 1981: pp32-36, Fiedler 1988: p58, Priestly 1999: p72)

This approach was a refreshing contrast to the usual pattern of professionally-controlled care arrangements and it was another stage on the road to emancipation.

Crossroads, Rugby

Also, around that time, pioneered in 1974, but taking a more compensatory approach to the issue of care in the community, was another initiative generated by the experiences of a disabled person, Noel Crane. The idea for an independent domiciliary care service in the community run by a voluntary body emerged out of the collaboration between Crane, Pat Osborne who later became a director of the Crossroads scheme, and some people from ATV. ATV was a commercial regional

television company in the Midlands of England which was responsible for making a continuing drama ('soap') programme called *Crossroads* featuring a disabled character, Sandy, which was network-broadcast across the UK. A two-year pilot care scheme also called *Crossroads*, funded by ATV, was then set up in Rugby (Crane and Osborne 1988).

Crossroads grew into a network of local care services and was the first attempt to provide some non-medical personal help to people in their own homes, but it was intended more as a relief service for families caring for disabled relatives, (Crane and Osborne, 1977: p5), falling far short of Fokus. Independent living, the elimination of environmental barriers, and disabled people having some control of the service, were all beyond the *Crossroads*' remit. It was not an alternative to institutions, but it was another important breakthrough.

Then, as the drive to achieve independence gathered momentum, with more disabled people organising their own ways to avoid institutionalization, a new sense of purpose was generated in the organisations. This independent living theme was to prove a core issue for the social movement and it raised a multitude of issues (Barnes and Mercer, 2006: pp29-49).

It was necessary, for instance, to clarify what was meant by independent living, as it clearly did not mean living alone with no help. It had to be spelt out that living

in the community required help from others but the relationship between helper and helped had to be different. Disabled people wanted control of how they lived. Furthermore, it would require a significant policy shift and funding transfer, away from residential services towards community-based support, if their objectives were to be realised.

CHAPTER 6 - Establishing a Base for a Political Liberation Movement

Out of the groundswell of pressure group activity there emerged an overtly political tendency with a much more radical agenda. As new ideas from this took root, a visible leap in political consciousness occurred amongst a broader cross section of disabled people and it was from that point on that it had clearly become a social movement.

The shift away from single issue pressure groups, towards a broad campaign, was significant and the breakthrough for this came with the development of a small, but effective, liberation tendency.

It started off with the founding of the Union of the Physically Impaired Against Segregation (UPIAS) between 1972 - 1974, formally constituted in October 1974 at its first conference (Hunt 1972b, UPIAS 1974b, 1976a). Then came Sisters Against Disablement (SAD) around 1976-77, followed by the Liberation Network of People with Disabilities (LNDP), founded around 1977 (Barnes 1991: p6, UPIAS 1977 C22). Because of its significance for subsequent developments, nationally and internationally, the account of this political tendency is gone into in some depth, starting with the origins of the UPIAS.

Crisis and realignment within the grass roots.

By the early 1970s pressure groups were broadly taking two routes. Whilst the predominant trend had

historically been to press for measures to compensate people for disability, another trend was to focus attention on the disabling effects of architectural and social barriers and the importance of tackling these as the causes of dependence. The initial catalyst driving the debate, and clarification, between these two approaches, occurred within the Disablement Income Group (DIG) where organisational discontent was brewing.

Some of the reasons for the discontent were located in DIG's uncertain early policy and structural origins. DIG had allowed a division of roles to enter its organisational structure that distanced professional expertise from the disabled membership. This had given professionals, few of whom were disabled, a lot of influence to decide policy. As time went on, the views of ordinary members became increasingly marginalized with their role reduced to the tasks of fund raising and mass lobbying. Strategy was being decided by a management elite and ordinary members became increasingly unhappy with the result (DIG Annual Report 1969).

After the sudden death of its founder Megan Du Boisson, in 1969, this rift deepened substantially. In an interview, Peter Large, a long-time activist in the movement, suggested that some of the difficulties rested with the fact that un-elected, non-disabled trustees, with poor disability awareness, had come to assume too much authority. He recalled some of the problems they had

caused for the new Director, Mary Greaves, who was disabled.

‘Mary Greaves found them very difficult on occasions. On the main policies - I don’t think there was too much difference, between Mary’s views to those of the NEC (National Executive Committee), but it was more the marginal activity that was a problem. Occasionally there was friction about press conferences and press releases. They always omitted to learn what she needed. Mary said they knew nothing about disability, never learnt about access. It was fundamentally about who was controlling DIG. They would organise meetings without reference to her, often over-looking her need for wheelchair access for example, and she was Director!’ (Peter Large [interview] 1991).

The executive was so anxious to win over the government they lost sight of DIG’s original objective, which had been to obtain a non-contributory pension for disabled people who had no employment record, no national insurance contributions and no access to any benefits. The executive’s proposal was instead for an earnings-related national disability income (DIG 1972a, NDI), and this became the lynch pin for a revolt. As Hunt (1973) put it in his paper, the new policy was one that reflected the interests of people of high earnings “who became disabled after 20 years or so” which, he argued,

would inevitably mostly favour middle aged men from professional or managerial careers (Hunt 1973c: pp3-6).

The internal turmoil in DIG culminated in a policy conference in 1973, as reported by DIG (1974: pp11-14) and Paul Hunt (1974: p14). This proved to be an important turning point. Amongst the various presentations two campaign approaches, put to the conference, offered very different strategies for solving poverty amongst disabled people (Hunt 1973c 1974: p14, Townsend 1973b: pp4-8). These two approaches subsequently culminated in the work of two new organisations.

The authors of these alternative strategies were Professor Peter Townsend and Paul Hunt, two long standing DIG members, who were amongst a panel of speakers invited to put forward proposals for a new DIG policy. The significance of the differences in their proposals for DIG was not so much to do with the specifics of the pension schemes, on which their papers were based, but more to do with the question of how to take the campaign forward in a manner that would most benefit disabled people.

Townsend placed his emphasis on the need to organise experts to apply more effective pressure on the policy makers. From an alternative viewpoint, Hunt stressed the need for greater involvement by disabled people in the decision-making process itself.

Prior to this conference Townsend and Hunt had in practice already taken initiatives to move things forward and their proposals for DIG reflected this. Townsend (1973a) impatient with DIG's loss of militancy, had taken an independent initiative to draw on the support of many people holding senior positions in society. To shame the government into addressing the benefits issue for disabled people, a round robin letter signed by many professional people of influence, was sent to Prime Minister Edward Heath, and a copy sent to the Guardian newspaper (Townsend & Jaehnig 1973a). It is worth noting that he had not seen the need to involve disabled people in the political process at this stage. For the DIG conference Townsend's paper set out his ideas which, amongst other things, included a re-presentation of his proposals for a functional assessment methodology described in that letter (Townsend 1973b).

Hunt, equally impatient with the inherent problems and weaknesses developing in DIG had already, in 1972, initiated the formation of a new organisation. This was the Union of the Physically Impaired Against Segregation (UPIAS).

In contrast to Townsend, Hunt placed great stress on the failures of DIG to involve its disabled members in its decision-making processes, he drew attention to the lack of democracy in the organisation and argued for this to change. Believing disabled people had to be much more in control of their own affairs, not less so. Hunt said;

“The main lines of any National Disability Income must be devised in close consultation with DIG ordinary disabled members” (1973c: p26).

A further display of their two perspectives was in their ideas on assessment methods for disability pensions. Townsend (1973b) argued that levels of payment should be related to levels of disability – measured according to a person’s ability to perform basic activities of daily living. Townsend was arguing for the State to make wider use of a functional assessment approach that had already been introduced in 1970 to decide eligibility for the Attendance Allowance.

Hunt, (1973c) however, saw it differently, arguing that the functional assessment was anti-rehabilitation as it drove an impoverished group of people to demean themselves by emphasising their physical dependence to gain their financial independence. His alternative proposal was for pensions to be provided based on an objective assessment of physical impairment, such as were used for deciding industrial injuries and war disabled pensions. He argued; objective assessment, such as this, was fairer, avoided social stratification of disabled people, and did not pay people according to degrees of dependence.

Townsend and Hunt were in effect offering the alternative perspectives that came from being on different sides of the helper-helped relationship. Townsend reflected the growing concerns of service

professionals who had the task of managing the care of disabled people. Hunt reflected a growing concern amongst disabled people about how they were to regain control of their lives.

Townsend's ideas were traditional. Linking poverty with (intrinsic) personal dysfunction led him to assume that medical and welfare services professionals, acting on behalf of the State, would be the ones to decide levels of financial compensation. Since they were the experts, they were the ones to approach for support to help bring about financial compensation for disabled people.

Hunt, on the other hand, represented a tendency that linked poverty and disability with a loss of independence that had originated from a variety of causes, many of which were external (or extrinsic) to the person. The logical way out of this situation was for disabled people to become active agents of social change. Hunt believed disabled people had to be the ones making the decisions about how to increase their opportunities for social participation. Anything that set out to emphasise or promote the dependency of disabled people was to be resisted.

In 1974 Townsend also initiated a new organisation by founding the Disability Alliance (Disability Alliance 1974). This, and the UPIAS initiated by Hunt, went on to represent the logical development of their different approaches.

A disabled people's union

Prior to the DIG conference referred to above, Hunt (1972b) had sent a letter to the *Guardian* and various disability journals, inviting disabled people to join with him to form a representative group to take up the issue of disability in its broadest sense. He suggested its purpose should be:

‘To consider what changes in society are required if severe disability is either to be eradicated or to become no bar to full social participation.’ (Hunt 1972a).

To suggest severe disability could be eradicated or become no bar to full participation was a totally radical proposition at this stage.

The respondents to his invitation, first, had to collectively decide the aims and policies of the new organisation, and how they would take the issues forward. This took eighteen months of detailed discussion, mostly done through a written circular.

During the course of this it was realised that poverty was not the fundamental problem facing disabled people, but a symptom of a much greater one. Much more significant was their physical exclusion from every aspect of social participation which put employment and economic independence beyond reach. The group, which adopted the title of “Union of the Physically Impaired Against Segregation”, concluded that

campaigning (as DIG had done) for state charity (in the form of a pension) was not the way to tackle the cause of dependency. By contrast, the finally agreed policy statement, adopted in 1974, put forward the following observation and their proposed course of action:

this society is based on the necessity for people to compete in the labour market in order to earn a living. To the employer of labour, the physically impaired are not usually as good a buy as the non-impaired. We therefore end up at the bottom of this society as an oppressed group (UPIAS 1974b, 1976a: p2).

For its aims it said:

The Union aims to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society. These arrangements must include the necessary financial, medical, technical, educational and other help required from the state to enable us to gain the maximum possible independence in daily living activities, to achieve mobility, to undertake productive work, and to live where and how we choose with full control over our own lives (UPIAS, 1974, 1976a: p1).

Far from rejecting the need for State support, the UPIAS was stressing that it should be used appropriately, to promote active participation in society.

An alliance of experts

Townsend, on the other hand, as a committed campaigner, of many years, against the damaging effects of poverty, perceived poverty as the primary problem and he set out to strengthen the campaign for a state pension. His strategy was to invite individuals and groups to form an umbrella organisation called “The Disability Alliance” so they could press more effectively for a state pension for disabled people. In its initial statement the Alliance argued its purpose was:

‘the payment of an adequate income by right to all disabled persons, to advocate the rapid development of supporting services, and to inform the public, politicians and government about the needs, circumstances and views of disabled people.’ (Disability Alliance [unpublished] 1974).

It was Townsend’s belief that the Alliance would continue the work of DIG, but it would be more effective, by bringing together a strong lobby of professional experts.

Their alternative approaches introduced significant differences in the membership criteria for the two new organisations. The UPIAS was initially only open to

people who were physically impaired. The Alliance on the other hand, called on relevant experts most of whom were not disabled. As Townsend put it, they hoped to draw in:

Paediatricians, geriatricians, academic and other professional workers in community medicine, community welfare and social security and workers in research on disablement (Disability Alliance draft statement of aims 1974).

It is worth noting the different groups of professionals who were then seen as the established voice of authority on disability. It is also worth noting that disabled people were not on this list i.e. they were not initially identified as a necessary source of expertise, although this oversight was soon rectified and a number of disabled people, including Berit Moore, a co-founder of DIG, were amongst its early members.

The struggle against oppression – an emancipatory approach

The foundation of the UPIAS was an important event for the subsequent development of the movement for it placed disability under thorough scrutiny, for the first time. The UPIAS policy statement posed several distinctive concepts that had not been clearly stated before. The first was that the social and technological means now existed to make integration a realisable goal. The policy stated;

Britain today has the necessary knowledge and the advanced technology to bring physically impaired people into the mainstream of life and enable us to contribute fully to society. But instead of the country's resources being concentrated on basic human problems like ours, they are frequently mis-spent, for example, on making sophisticated weapons of destruction (UPIAS 1974b, 1976a: p1).

From this it followed that:

'since the means for integration now undoubtedly exists, our confinement to segregated facilities is increasingly oppressive and dehumanising.' (UPIAS 1974b, 1976a: p1).

Thirdly, the UPIAS argued that disabled people would not overcome their oppression if they were passive. They had to become active on their own account and take control of their lives, what is more, the support of others was only really constructive when it encouraged the self-help and activity of disabled people:

Neither we as a Union, nor non-disabled people, can solve other disabled people's problems for them. Those problems will be correctly tackled *precisely* to the extent that we all as disabled people become involved and active in our own rehabilitation (UPIAS 1974b, 1976a: p5).

Further, it was argued that, to achieve a decent life for themselves, would require big changes to society. Here, the UPIAS recognised disabled people could not do this in isolation. They could, however, find common ground with others, who were also oppressed by social conditions which held them back, and they should endeavour to do so:

... it is fundamental to our approach that we will seek to work with other oppressed groups and support their struggles to achieve a decent life. What all oppressed people share is a vital interest in changing society to overcome oppression, and the Union is therefore anxious to join in common action to achieve such change (UPIAS 1974b / 1976a: p6).

To determine what was meant by “changing society to overcome oppression” still had to be worked out and UPIAS set out to do this.

The formative stages of UPIAS played a crucial part in establishing both the theoretical foundations and a political vanguard for leading the disabled people’s movement that emerged later. Whilst UPIAS’ influence on subsequent events is now widely acknowledged in disability literature, the history of its development is not generally known.

Development of UPIAS

The people who responded to Hunt's invitation were scattered around the country. Some were living in institutions, travel was generally difficult, money was short, and meetings were therefore not easy to arrange. Because of this, working out how to conduct their discussions had to be tackled straight away.

Debate, over the first two years, was in the main carried out through a duplicated internal circular. There the group very quickly came to see the issue of segregation, by institutions, as crucial for understanding what was happening to disabled people more generally. This is clear from Paul Hunt's introduction to the incoming comments from the people who had responded to his invitation to form a group. He had sent them an initial circular setting out proposals for some aims and a policy and a list of questions about the group and its possible functions. The second circular listed extracts of their responses to the questions. Introducing it, Hunt wrote:

The authors of this first batch of letters speak eloquently enough for themselves. With one exception, the letters are from physically impaired people who have either experienced life in residential care themselves, or who dread the prospect. They confirm that segregation of the disabled, particularly in long-stay residential institutions, is an issue of crucial importance which needs

to be taken up by us as disabled people (Hunt 1972c: C2).

Discussion continued, in the main, through the circular and occasional national meetings, throughout the life of the organisation. In addition, some regional branches formed, and these enabled members to meet up more regularly. The internal circular, where all the initial discussions took place, proved to be an important part of the learning process for it provided a constant written record that people studied and referred back to. It was through these circulars that the members explored the meaning of disability, discussed whether they were oppressed, examined the function of segregation and what strategies disabled people needed to emancipate themselves.

With the agreement of ex-members of the now disbanded organisation, material for this section has been drawn from the confidential internal circulars of UPIAS and summarised. But because this material was written in confidence, no names are mentioned apart from the one above by Paul Hunt.

From the outset, a strong lead was given to the discussions by two members in particular; Paul Hunt and Vic Finkelstein. Hunt drew on his considerable breadth of understanding gained from struggles for self-determination in institutions, his concept of disability as oppression and his involvement with the other

contemporary disability campaigns. Finkelstein brought his experience of social movement politics from his engagement in the struggles against oppression and apartheid in South Africa.

Both; had read widely and acquired some grounding in Marxism and socialist literature and they had the skills to be analytical of general social issues. They were a powerful combination, able to draw from each other and lead other members to think about disability in ways that had not been experienced before. Right from the start this produced a vibrant interchange of views between members who were determined to pursue a wide-ranging exploration of the issues and produce a plan of action.

Having insisted that only disabled people could take part in this discussion, and that it should be confidential, gave members confidence, but it also drew some hostility for it also meant their discussions were closed to disabled people who were not members. Very early on, the UPIAS was accused of being exclusive and secretive. Reference has been made to this in another account of the movement's history (Campbell and Oliver 1996: p66).

Few outside the organisation could appreciate why this policy was considered necessary. But, for UPIAS members, confidentiality was vital and a key to their success. The internal discussions they were having in the circulars were very challenging and people had to be able to explore their thoughts freely without fear of intimidation. There were particular risks for members who

depended on others for daily support, and especially so for those living in institutions, when they started attacking the whole concept of institutional care. For all members, it was by recognising the risks they faced for their ideas, that helped them arrive at their understanding of disability (Campbell and Oliver 1996: pp66-67).

The UPIAS policy document (1974) characterised institutions as the “*ultimate human scrap-heaps*” where, in effect, society dumped people who were no longer regarded as useful, and left them to while away their time until the end of their lives. UPIAS maintained that an uncompromising opposition to this service was pivotal in any strategy to challenge the policy of segregation generally.

The members’ determination to both support people struggling in institutions, and promote ways to help people move out, marked UPIAS out as different from the other groups. By and large, campaigns had ignored the institutional issue and utterly failed to see the significance of the struggles residents were having, inside them, around their lack of rights. This issue came up in one of the early discussions, when a UPIAS member suggested that since most disabled people would never live in an institution it had to be less important than all those other things that needed tackling.

It had led to lengthy discussions from which it was deduced there was a significant relationship between the role of residential care and the subtle forms of control

disabled people experienced in the wider society. If UPIAS was serious about tackling the roots of oppression, it had to take up the issue of institutions.

Paul Hunt and I were married by this time and living in London, but he remained absolutely determined to continue his support for residents struggling for more control of their lives. For him this had to be a fundamental concern of any organisation he was part of. Although not the only member of the UPIAS with inside knowledge, the work he had done previously provided the grounding UPIAS needed.

Experience at *Le Court*, (chapter 3) had informed his thinking, and in starting UPIAS, he was already clear that many of the issues facing disabled people living outside institutions were in essence the same as those of the residents. The stage was just bigger and more complex. For him, it was the question of the power dynamics in the helper-helped relationship that had to be changed. This, he always maintained, had to be led by disabled people, as they realised at *Le Court*.

The discussions in the circulars were often experienced as adversarial and uncomfortable. Arguments such as 'I do or don't feel oppressed', or 'I think segregation might always be necessary for some people' were met with robust counter arguments about why subjective feelings, and reasoning based on the current situation, did not explain the true picture for disabled people.

The arguments went to and fro as people wrestled with the need to look beyond personal experiences to the world about them. They were discovering that the true situation could not simply be interpreted through a generalisation of personal experiences, because personal experiences were in themselves a product of the kind of environment, they lived in. If the physical and social environment were changed, then experience would be different. It became evident that to understand the true situation they had to look at the actual relationship that existed between the social group, of disabled people, and mainstream society. The blatant facts were that high unemployment, excessive poverty, isolation, segregation and general exclusion from the public sphere provided ample evidence of social discrimination against disabled people.

People who contacted the Union (which here refers to UPIAS, the two terms of reference being often used interchangeably), were not only unsettled by the challenging ideas that were emerging but also by the rigorous manner of argument they encountered there. It often seemed ruthless, with little concern for people's feelings. Having ones ideas criticised, in print, for all to see (however confidential), was often painful. Belonging to a group, which expressed ideas that conflicted with the dominant ideology, also faced people with potential isolation from peers who found the ideas too challenging. Some people left because they remained unconvinced

UPIAS was following the right course, but, despite the difficulties, others stayed and became much clearer and stronger in their arguments in the process. The attempt to confront the issues openly, and argue them out, was in stark contrast to the prevailing tendency towards consensus politics that so often stifled or muddied debate.

UPIAS members were finding that developing a democratic framework and achieving some unity required hard graft and perseverance. In the discussions that led up to their first conference, they sought agreement about; the name for the group, what the membership criteria should be, and what internal working structure they should have. On its name for instance, there were early objections to calling it a union *against segregation*. Some preferred a less militant sounding title, suggesting that a union *for integration* would be more positive and better received.

The argument about the name was an important one. It raised the fact that lots of people were 'for' integration, but few were prepared to say segregation was wrong. To do so allowed for no exceptions. If it was agreed, that segregation was an aspect of oppression, it followed that to oppose oppression, they had to oppose segregation, openly and explicitly. It was argued that, until segregation was thoroughly rejected, as a service solution, proper consideration would never be given to alternatives, nor would there be acceptance of the

principle of full integration. To achieve full integration, there would need to be major social reconstruction and it was likely that, if left unopposed, the policies of segregation would continue to thrive. They were easier and possibly cheaper to administer.

In 1974 the UPIAS formally established itself and set to work to publicise its ideas in the disability press. The outcome of the discussions was a detailed policy document in which it went straight into the offensive on segregated services. The policy stated:

The Union of the Physically Impaired believes that the reality of our position as an oppressed group can be seen most clearly in segregated residential institutions, the ultimate human scrap-heaps of this society ... The cruelty, petty humiliation, and physical and mental deprivation suffered in residential institutions, where isolation and segregation have been carried to extremes, lays bare the essentially oppressive relations of this society with its physically impaired members (UPIAS 1974b: p2).

Although clearly perturbed by this new development, the first response from the major disability charities such as the Cheshire Foundation, DIG and the Disability Alliance was an attempt to be conciliatory (UPIAS 1975: C15: p3-4: C16: pp2-3). UPIAS (often referred to as “the Union”) started to receive letters of support from a few of

them, in which they said how much they agreed with the union's aims to improve the situation of disabled people. But these organisations did not understand the issues and were not so keen to agree with the Union when it painstakingly pointed out what being opposed to segregation meant (UPIAS 1975 Circulars C15 to C20). Interestingly, Hampden Inskip, the trustee of the Cheshire Foundation, who had previously worked with Paul Hunt at *Le Court* to secure some rights for residents, now approached UPIAS for some help (UPIAS 1975: C17).

He was very concerned at the apathy of residents in the Homes. After all their efforts at *Le Court*, the main body of trustees were at last trying to encourage more resident participation, in decision making, in the various Cheshire Homes, and so Inskip set out to promote this. He approached UPIAS who, on their side, were also keen to support him. Positive approaches received from organisations, such as this, were always taken up constructively, for it was a way of pressing ahead with their arguments.

UPIAS wanted to share its ideas with others but it was not to be coerced into watering down, or compromising, its principles. In the case of the Cheshire Foundation, UPIAS said; it welcomed this early opportunity to talk to and support residents in the institutions, but there would be conditions.

Firstly, they wanted it guaranteed there would be freedom, where appropriate, to introduce residents to new ideas about how they might move back into the community with support (UPIAS 1975: C17: pp3-4). And, secondly, they would be seeking to support residents wanting to find ways of exercising more control over their lives within the Homes. These conditions raised alarm bells in the Foundation, and pushing Inskip aside, the trustees turned down the offer of UPIAS' support (UPIAS 1976 C20: pp5-8; p21: p8). They were clearly unsure how to proceed, not knowing how many of their residents might be members of this radical group, but there were clearly limits as to how far they would go to placate this new Union.

It wasn't long before major charities started to go on the defensive and antagonism developed towards UPIAS' political agenda for change. Some examples of this are to be found in the correspondence that took place between UPIAS and representatives of charities such as the Cheshire Foundation, the Disability Alliance and The Huntingdon's Chorea Research Project. Such correspondence underwent detailed exploration in the circulars and became an important means by which UPIAS members enhanced their own political consciousness and confirmed their objectives with other organisations (UPIAS December 1975 Committee Circular), (UPIAS 1975: C16: pp2-6, p15).

They, and disabled people outside the UPIAS, found the message a harsh one. People lived in institutions or accepted segregated services because there were no alternatives and here was an organisation saying all segregation should be opposed. For members of UPIAS, living in, or spending time in a segregated facility, there were contradictions to be worked through. Some people found this too disturbing and left, but others persevered.

UPIAS was charged with wanting to see the instant demolition of all institutions (UPIAS 1975 Committee Circular, Cheshire Smile 1975a, 1975b, 1975c). This was not the case. On the contrary, at that time it was more concerned than most for the well-being of residents, and it was always clear that disabled people had to make their own choices and develop their own solutions. Whilst doing what it could to promote alternatives, so people would not have to live in them, UPIAS was also very clear that residents must determine the kind of support they wanted from others. In the extract below (UPIAS 1974b: p3) the Union, makes it clear that it was neither ignoring the issue, nor abandoning residents to their fate:

The Union of the Physically Impaired regards the neglected issues of institutions as of crucial importance in the field of disability. We therefore place great emphasis on supporting the struggles of residents in existing residential institutions for better conditions, for full control over their personal affairs, and for a

democratic say in the management of their Home, Centre or Unit.

Their principle concern was that the means now had to be made available to enable people to make their choices, and resources had to be redirected towards creating real alternatives of which there were few. Once the alternatives existed the Union was fairly certain that few people would actively choose segregation. It resolved therefore to pursue this line of attack:

The Union is opposed to the building of any further segregated institutions by the state or by voluntary organisations. We believe that providing adequate services to people in their own homes is a much better use of resources. We also call urgently for the provision of non-institutional alternative housing, for example, along the lines of the Fokus scheme in Sweden, which makes genuine progress towards secure, integrated and active living for disabled people who need extensive personal help” (UPIAS 1974b: p3).

UPIAS also aroused hostility from without and within by refusing membership to non-disabled people (Heiser 1977, UPIAS 1975 C16: p22; C17: p11). In general, there was little experience of oppressed groups organising their own closed meetings, and people unused to being excluded had to reflect on why such groups found it

necessary to control access to their discussions. It wasn't only disabled people who were encountering such antagonism, and personal recollections from my involvement the 1970s of women's forums and consciousness raising groups were facing a similar response at that time (Mitchell 1971: pp56-63, Segal 2007: pp5-6: p107)

According to the postal survey of disability organisations that I carried out in 1991 (See chapter 5) it was clear that many new emerging groups in the 1970s and 1980s had non-disabled people playing a leading part in their decisions. The Barnes and Mercer 2001 survey, (2006: pp76-77) reported similar findings. Executive control by disabled people, although not entirely new, was still unusual. UPIAS made it a political issue for which it was accused of being discriminatory and segregationist (Heiser 1977). What it was doing was ensuring disabled people had full control of their own space from which to represent themselves.

For those who knew the reality of not being taken seriously, having a confidential space to discuss ideas freely, without the possibility of interference from staff, or well-meaning relatives, was welcomed. Later, when the Union was more confident, and after a lot of frank discussion, the organisation invited non-disabled ("able-bodied" as was said at the time) supporters to join as associate members (UPIAS, 1976a) It was agreed they could fully participate but would have no rights to vote or

hold office. The situation since 1975 had been muddled but clarified with a constitutional change in November 1976 (UPIAS 1976c: C20, p1) and when it was ready, it also published two editions of *Disability Challenge*, in 1981 and 1983 respectively, to publicise its ideas.

An airing of ideological differences

The next point of significance in this process of clarification came when the Union entered into formal debate with the Disability Alliance (UPIAS 1976b). Townsend had contacted UPIAS with a view to finding a way for the two organisations to co-operate, and this led to an exchange of correspondence during which attention was paid to the differences between their two approaches. Townsend proposed a meeting to discuss their differences and it was agreed.

At this meeting, in 1975, the alternatives facing disabled people became more sharply defined. Preliminary arrangements had set out some conditions so that the organisations could debate the issues on an equal footing. Having prepared itself for a formal meeting, UPIAS arrived with a statement carefully drafted, by Paul Hunt, in readiness. The Alliance, by contrast, had done no preparation, expecting the meeting to be more on the lines of a friendly exchange. Their delegates were therefore very taken aback when confronted, by the UPIAS' rigorously thought through arguments that questioned the value of the Alliance's very existence (UPIAS 1976b).

The published report of the proceedings, *Fundamental Principles of Disability*, compiled by Finkelstein (1976), has become a seminal document for the social movement ever since. In this, UPIAS clarified its own position and its criticisms of the Alliance. It argued that the Disability Alliance had, like so many other groups, failed disabled people by displaying un-thought-out spontaneity. It was argued, this did nothing to help advance understanding of the underlying causes of poverty, and therefore, they reasoned, the Alliance would not help to solve the problems facing disabled people. UPIAS took this a stage further by arguing that in concentrating on state charity, and perfecting methods for measuring degrees of inactivity, the Alliance was in effect furthering the dependency of disabled people, and was therefore adding to their problems (UPIAS, 1976b: p17).

Finkelstein's report formally presented a redefinition of disability as a social construct. By adapting the definitions from the first OPCS survey of disabled people (Harris *et al* 1971) and using the UPIAS policy statement he produced a clear definition that took the focus off the individual and put the blame for disability back into society. It offered an interpretation that was no longer personalised but made disability synonymous with social oppression:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.

To understand this, it is necessary to grasp the distinction between the physical impairment and the social situation called 'disability', of people with such an impairment. *Thus we define impairment as lacking part or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression (UPIAS, 1976b: p14) (These definitions refer to those of Amelia Harris for the OPCS but differ from them significantly. *The emphasis is added.*).*

UPIAS adopted this definition and thereafter referred to it as the social interpretation, or social definition, of disability. This concept of disability as a by-product of a socially structured relationship represented a very significant departure from the medically based definitions used before by all official bodies such as; OPCS, WHO,

and the various Parliamentary Acts legislating services for disabled people.

The significance of defining disability as socially caused

By turning the situation around, UPIAS was able to show it was no longer the individual, who should be modified, or rehabilitated, to fit into a given environment, but the environment that needed to be modified to accommodate people with impairments. With this formulation, they had the theoretical basis for a liberation movement because disability, caused by social and physical barriers, could be eliminated. The question that remained was how to achieve the changes.

What UPIAS had done was to tear away a mask of false consciousness, built up over the generations. It had started to expose the real situation, which was that disabled people had been systematically forced out of the labour market by industrialisation. This had driven them into economic dependence, which had in turn led to the creation of professionalised systems to manage their welfare and unemployment (Finkelstein 1993a: pp12-13). In practice much of the authority over the lives of disabled people had fallen into the hands of the medical establishment.

Once medicalised, disability was not only accepted as a reason for being unable to work but became associated with concepts of chronic sickness. The accompanying segregation of disabled people for special treatment, then offered a kind of resolution of a dilemma

that state welfare programmes and employers of labour had battled with for years. The dilemma being; how to manage the complication of disability in the business of managing sickness, whilst at the same time ensuring that people who could work did not become unnecessarily idle. Segregating disabled people from society became a way of managing this subgroup of long-term unemployed.

The relationship between the cause, and effect, that produced both segregation and social exclusion, had, over the years, become shrouded in mystery and blurred by the appearance of charitable concern and social paternalism. The real relationship was no longer visible to disabled people, nor to professionals or legislators. Instead it had come to be accepted that physical impairments made it impossible for many to work, live in the family home, use public transport, or take their place within the community.

Now armed with a different outlook, what would happen when disabled people started to wake up to their situation and demand their right to full control over their lives and a stake in society? How would professionals with vested interests in 'special' care facilities, view such a change in their clients' aspirations and how would legislators respond?

The social climate of that time was such that disabled people were often by-passed, ignored, patronised, and almost never taken seriously in a political

sense (Barnes and Mercer 2006: p39, Hunt 1966, Saunders 1983: p29).

Such boldness, therefore, from the UPIAS, in its criticism of the Disability Alliance and other charitable organisations, was unprecedented. It was no surprise that the contents of *Fundamental Principles of Disability* generated a great deal of anger towards this new radical Union of disabled people.

Serious attempts were made to undermine the position taken by UPIAS by trying to ridicule its breakthrough concept of the social interpretation of disability (Cheshire Smile 1975: p3, Goldsmith 1976). It had touched a nerve and the disability charities did not like the implications, but they could not afford to ignore it. The battleground drew the attention of more disabled people to the need for an alternative to the compensatory service model if they were to emancipate themselves from dependence.

Politicisation and a changing social consciousness

Within several different campaigns, it became clearer to disabled activists that the general lack of representation and consultation of disabled people was unacceptable. Over the next few years, the radical idea of disability as oppression became more acceptable and by the mid-1970s these ideas started to reach a wider audience, helped in part by a new television programme called *Link* which appeared in 1975.

It was a sign of the changing times that disability was to be given some ITV air time. Link set out to explore many issues, that had been gaining ground, and, from the outset, drew the different grass roots trends into the programme. Dominant amongst these were the incomes' approach, represented by the Disability Alliance, the social oppression approach, represented by UPIAS, and a rights approach represented by Morris Collins on behalf of "Kith and Kids", an organisation fighting for the rights of people with learning difficulties. Since 1971, it had become part of a wider grassroots lobby against the segregation of disabled people (Link, programme synopsis, 1975-1985).

During the programme's initial research period, the producer, Richard Creasey, was given introductions to people, active in the movement, by Rosalie Wilkins, who was chosen to be the new presenter. As a disabled woman with a lot of contacts in disability organisations, Rosalie was able to provide Creasey with a shortlist of people he should talk to which included Vic Finkelstein and Paul Hunt. After encountering their ideas from UPIAS, Creasey reconsidered his whole approach. Rosalie Wilkins recalled:

'He started rethinking everything. He was very excited, this really changed the programme away from the traditional sort, to one about giving control to people.' (Rosalie Wilkins [interview] 1991).

In a surviving recording of his private interview with Hunt (Creasy interview with Paul Hunt 1974 / 75), it is possible to detect this change of awareness taking effect. Creasy began the interview by trying to impress Hunt with his plans for the programme but little by little, his flow was interrupted by Hunt's searching questions. These not only challenged his assumptions about disability, and acceptance of prevailing attitudes, but also pointed out the risks of producing a TV programme that would exploit disabled people, yet again, by treating them as victims and objects for study. Creasy started to hesitate, then listen, and finally became interested in the idea of a very different approach. As Hunt put it to him:

'If disabled people could become active participants in the making of the programme instead of the objects of prescribed solutions this really would be a new departure.' (Creasy interview with Paul Hunt 1974 / 75).

From those early discussions, Creasy made the decision to involve disabled people in the making of the Link programmes and give expression to the social interpretation of disability but he needed an accessible format to put this across (Campbell and Oliver 1996: pp156-157).

This was provided when he talked with Vic Finkelstein. Together they came up with the idea of

opening the series with a serialised cartoon of “Very Crossroads”, an allegorical story about the construction of disability, written by Finkelstein (1975: p36-7). ‘LINK - ATV Sunday morning programme about disability’. This turned the world on its head by having non-disabled people made unable to manage, in an environment entirely built for a wheel-chair using population. Having moved into the specialised village they could not cope with the very low ceilings and door heights everywhere so had to be fitted with special helmets to protect their heads and special corsets to double them up to wheelchair height. Bit by bit, these disabled-able find themselves socially excluded and placed in special institutions, until they start to fight back. Using this cartoon, the programme drew attention to the many ways society had modified disabled people to fit into an unfit world rather than change the environment. It was a powerful message.

By the end of the decade, the tide was turning with more disabled people committed to a liberation struggle (Davis and Woodward 1981: pp328-329, Finkelstein 1980: pp36-37, Goldsmith 1982).

Thinking of disability as a form of oppression was no longer such an alien idea. It was easier to consider the implications in parallel with ideas coming from the other quarters such as the women’s movement. It was also more widely acknowledged that discrimination resulted in; lower pay, fewer opportunities, under employment and

general lack of representation for members of disadvantaged groups (Cornes 1984). There were many parallels for disabled people and the ideas put forward by UPIAS started to make more sense.

By the mid 1970's there was potentially more scope for disabled people to become integrated. Computer technology was developing fast and this was changing the work and physical environment (Cornes 1984: p11, Davis and Woodward 1981: p331). The future held promise. With gadgets becoming more readily available, rehabilitation developing new techniques, and the welfare service broadening its remit (Jay 1981: pp163-169), previously undreamt-of opportunities, for supported independence, and employment, were becoming more realisable (Bray and Wright eds. 1980, Greaves 1981, Topliss and Gould 1981: pp281-287).

Putting the theory into practice

The theory that segregation could be overthrown still had to be tried in practice. Towards this end, members of UPIAS took the Union's principles and started to put them to the test through local campaigns. New initiatives were developed in Derbyshire, London, Manchester, Rochdale and Scotland, where Union members provided some leadership for disabled people to set up forward looking projects in their areas.

There were two ways these initiatives developed. One approach was to encourage disabled people to set up their own alternative services over which they could

exercise some control, the other was to tackle the main service providers, and insist that disabled people had a say, in the planning of services, to promote integration.

The principal campaigns, at that stage, were; to prevent the creation of yet more institutions, promote the creation of accessible housing and support services in the community, bring about more consultation with disabled people, and give access to better information so disabled people could take control of their lives. The ending of segregated education was another issue that UPIAS worked on, alongside other organisations (Anderson 1971, Spencer: p1978, UPIAS 1975: C15: p10-13, 1977: C21: p8).

Their aim was to bring about much more control, for disabled people, within community services. As had been found within institutions, changing the power imbalance of helper-helped relationships meant disabled people having a share in the decisions within the service structures. In the community, this meant tackling the power base of the professional management of community services in the local authorities. A few examples are mentioned below to illustrate how they started to work on this.

One of the first attempts by UPIAS members to address the issue of housing and support was the Grove Road housing project in Derbyshire, mentioned in chapter 5. Once up and running, the project quickly proved, that with the right kind of support, severely

disabled people could take control of their lives. This important breakthrough, by two UPIAS members, Davis and Hines, provided the organisation with some important counter arguments to the ones that said institutions would always be necessary (Finkelstein 1993b: p38-9).

While Grove Road was in development, Ken Davis had set out to do something about the chaos of information. He, along with other disabled people in the area, realised that if they were to have choice over where and how they lived, disabled people must have access to information about what help was available. In the 1970s, this was extremely difficult to come by. Increased specialisation had generated a great deal of information but getting access to it was often limited to printed compilations held by local charities. The Central Council for the Disabled, for example, tried to spread information through its monthly bulletins, and a few magazines gave a bit out here and there, but much of the printed matter was inevitably quickly out of date.

To address this hiatus, Davis suggested that a small group of disabled residents at Cressy Fields institution, in Derbyshire, set up, and run, a local information advice service which they would operate via a telephone enquiry line. Backed by the Social Services Department, it went ahead in 1977, and became the first Disablement Information Advice Line - DIAL (Davis and Woodward 1981: pp328-331). Its success quickly led to a network of

similar DIALs around Britain and a couple of years later they formed an umbrella organisation called DIAL UK (Davis and Woodward 1981: pp329-331).

Much later, in a report of their experiences, Ken Davis and Audrey Mullender (1993) explained what an important role this service had played in the political movement of disabled people;

The service, run by disabled volunteers from a converted cloakroom at Cressy Fields, (a local residential institution) with a grant from Derbyshire County Council was a milestone in the development of the local movement. It put two important things in the hands of disabled people: resources and information. By 1980, DIAL was intimately aware of local concerns, local issues and the aspirations of local disabled people. The disabled activists involved were able to speak with authority about local problems - and had also developed clear ideas about solutions.

DIAL Derbyshire had become a base, a focal point of disability activity, and it took the gradual process of disabled people coming together which had been developing for over 20 years, an important stage further (see chapter 8).

Trying to halt the programme to build yet more segregated institutions was another pressing concern. The issue was taken up in a number of different ways, within different localities, by UPIAS' members, and this too started to have a ripple effect.

The first significant campaign began, in 1975, with a challenge to the London Borough of Ealing over their plan to build a 30-bed hostel for young disabled people. In reaching their decision, the borough's officers had neither consulted the community, nor done any research into what the best ways might be to support disabled people in the Ealing area. Representing UPIAS, Dick Leaman pursued this matter with his council by initiating a joint committee with his local disability association. Together, they set out to challenge the borough over its failure to consult disabled people about whether they wanted a hostel in Ealing (Leaman 1981, UPIAS 1975: C5: pp6-7).

After many months and angry exchanges, Ealing borough shelved the proposal (UPIAS 1976: C18: p3). In the face of opposition coming from local disabled people, which they had not expected, the councillors and officers saw little choice but to reconsider the validity of their decision.

Soon, other local authorities were experiencing similar challenges. In association with Rochdale Voluntary Action, UPIAS member, Ken Lumb, challenged his local authority for failing to consult disabled people before deciding to build a Young Disabled Unit (Finlay 1978: p3) and in Derbyshire, UPIAS members in association with the Derbyshire Coalition of Disabled People (DCDP) protested and successfully stopped plans to build an institution (Davis and Mullender 1993:

pp32-34, Northern Derbyshire (JPG) 1987). Unlike the success of challenges made by other integrationists, the YDU in Rochdale went ahead. For Lumb, a principal protestor against the unit, the ultimate insult was to be asked by an insensitive HA, if they could name the unit in memory of his brother Brian! However, another protest mounted against proposals for a local authority hostel in Rochdale was more successful and prevented it from going ahead (UPIAS 1981: C42: p5). Subjected to this new experience of determined opposition from disabled people, which they were ill equipped to answer, local authorities became more hesitant about the right course to take (Hunt 1973a, Royal College of Physicians, 1986a: p18). The Royal College of Physicians' report drew attention to the series of challenges during the 1970s that questioned the desirability of residential care, and it noted that the new YDUs had encountered criticism (Royal College of Physicians 1986b: p30).

It needs to be said here that UPIAS was not the only critical voice against segregation. There was also an increasing swell of protests against the inhumane treatment and segregation of people with learning difficulties and of people classed as mentally ill (Borsay, 2005: pp88-92). Additionally, there were an increasing number of disabled individuals who were seeking their own adapted housing and support solutions to avoid institutionalisation.

The publicised battles that had taken place in these few areas, and they had been battles, had raised implications for other authorities considering similar plans. In the circular UPIAS refers to several published reservations they had come across regarding the building of more YDUs. One for example was a DoE Circular 74 / 74 that advised on the need to avoid residential care where possible (UPIAS 1976: C20: p8) (Hunt 1973a, Jones K. 1983, Leaman 1981).

It was the beginning of a process of changing the direction that services might take. Doubt may have crept into council departments over the issue of creating special institutions to house young disabled people, but the question remained of how they were to provide care for people who had no relatives to do it for them. No other proposals for community support services were on their agendas, nor on that of any government.

The lack of alternatives to institutions, in the form of suitable housing, encouraged Lumb to work closely with Rochdale Voluntary Action to set up a housing research project to find some answers. It was the first attempt to apply the UPIAS' social definition to some formal research of a practical problem. The research set out to investigate how housing design was disabling people with physical impairments (Finlay 1978). This turned the usual research method upside down by giving its primary attention to the physical environment of the buildings as the potential cause of disability, rather than to the

impairments of individuals. It was another important break-through.

Complaint over the abysmal lack of consultation was also very much in the forefront in the campaigns around special education, in the 1970s, in which the UPIAS played a support role to other organisations taking the lead. The lack of disability awareness amongst service providers was driving disabled people to demand they were consulted in service planning initiatives (NFB / ABAPSTAS 1973, Tizard, in Anderson 1971: pp3-6, UPIAS 1975: C15: p10-13, C17: pp7-8 and 1977: C21: p8).

There were very strong reactions from blind and disabled people, in the 1970s towards both committees, established to investigate special education, when they failed to consult. In 1973, the National Federation of the Blind and Partially Sighted Teachers and Students (ABAPSTAS), took the lead when they protested about their exclusion from consultation during the Vernon Committee's investigations into education for the visually impaired. Having conducted their own wide-scale consultation exercise and established that most people with visual impairments favoured integrated education, these two organisations felt especially aggrieved that the views of their members were being ignored (NFB / ABAPSTAS 1973: pp6-7, Reid 1974, UPIAS 1975: C15: pp10-11). Two years later, in 1975, the Warnock committee prompted a similar reaction from physically

impaired people when it refused to invite any consultation from disabled people (UPIAS 1975).

When challenged, Warnock had told the Association of Disabled Professionals (ADP) that it could not invite disabled people onto it because it needed people who had a wider experience than just one handicap (UPIAS 1975: C15). In this instance it was the ADP that was leading the campaign for integrated education of physically impaired people.

Such responses were not uncommon. Too often it was assumed that disabled people were only capable of subjective judgements, the corollary being that professionals would be more objective (Goldsmith 1997: p69, Safilios-Rothschild 1981: pp5-12, UPIAS 1975: C15: p11). This line of reasoning overlooked the fact that most professionals being able-bodied, in experience terms, seriously lacked awareness of the realities of disability on a day-to-day basis. UPIAS pointed out that whilst it was traditional for doctors and other professionals to decide what was good for disabled people it (the Union) now urged disabled people to reject entirely any idea of medical or other experts having the right to tell disabled people how they were to live (UPIAS 1974b / 1976a: p4).

By this time, the theme of consultation was being pursued with increasing vigour, by a range of disability organisations. In addition to the NFB, noted above, DIG and JCMDP were pursuing all possible avenues to

influence policy makers in their campaigns for financial compensation and improvements to mobility. Whilst disabled people did not fully control these organisations, they did represent a very vocal grass roots constituency no longer willing to be ignored. The resulting wide-scale publicity for the campaigns helped to heighten public awareness and this in turn led to disability groups and some disabled individuals being approached for their advice or participation in policy discussions (DIG 1971: p13), (DIG 1977: pp11-16).

However, more normally, when it did occur, representation continued to be restricted to a few token disabled individuals (UPIAS 1977: C21: p8). This was not, as the NFB (1973: p6) and UPIAS (1976b), argued, the kind of democratic consultation they now expected of professionals planning disability services (Barnes 1996: p222). These included the Spinal Injuries Association, Joint Committee for Mobility of Disabled People, and the Disablement Income Group.

Despite the general unease about its radicalism, from the above it can be seen that by this time UPIAS was part of a growing trend in which disabled people were becoming much more vocal and assertive. But the desire for action, and impatience with theory, meant that most activists still found pressure group approaches more attractive than joining an organisation that debated everything thoroughly first and the Union's ideas, or their

significance, remained quite difficult for people to grasp (UPIAS 1974b / 1976a: p5).

Wherever possible, UPIAS entered discussions with like-minded people reaching similar conclusions. Hunt's many contacts in the wider movement, and his reputation as a progressive thinker, undoubtedly helped to give it an early authority, but it was still hard for UPIAS to reach and impress a much wider audience of disabled people. Here are just some of the groups that contacted UPIAS to express their support: The United Voice of Disabled Citizens – Port Talbot branch (C4), DDA (C7 1974) Anti-Handicap - Sweden (C8 1974), MS Action Group (C13 1974) Rehabilitation Gazette – USA (C14 1975), NFB (C21 1977), People with Disabilities Liberation Group (C22 1977), and SHARE Community (C23 1978).

As the years passed, UPIAS found itself beset with a fundamental contradiction. It knew, and believed from the start, that the task ahead was to build a grass-roots movement. It had links with the other sections, but it was finding that people shied away from joining it, or, did not want to be associated with its radical ideas or approach (Finkelstein, in Campbell and Oliver 1996: p68). For many, the organisation had the image of being too uncompromising. Difficulties arose, for instance, over UPIAS insistence that disabled people were an oppressed group, and there were arguments over this in the early discussions to agree the policy statement and constitution (UPIAS 1974 C7: p3-7, C8 pp4-11). The

differences between people's ideas, and their importance, were taken up and clarified in a document entitled *Are We Oppressed?* (1974 / 2018: with privacy redactions) which at the time was an internal analysis of contributions collected from the early UPIAS circulars (UPIAS 1974a).

For its part, the UPIAS adopted an adversarial approach because it wanted to break through and overturn a powerful opposition and it encouraged disabled people to recognise their oppression was sustained by the negative grip of a prevailing ideology that endorsed a system of exclusion (UPIAS 1974a, 1976b).

As time went on, further tensions formed within the Union and between it and people outside the organisation. The undoubted insight of the leadership, whose ideas were many steps ahead of most people, had a price. Some found the political arguments too hard-going and left: others often went through experiences of feeling unsure of themselves, unable to challenge the leadership and withdrew from the arguments. Many members were also very busy, building on the Union's ideas by setting up local projects, and it was all uphill.

Towards the end of the 1970s, a crisis came to a head within UPIAS expressed through a heated internal struggle to decide a way forward to prevent its own collapse (UPIAS 1978 C25: pp5-7, UPIAS 1978 C26, UPIAS 1979 C27, C29).

The discussions continued in consecutive issues of the circular C24 to C29 between 1978 and 1979. On one side, Hunt believed people were alienated from the union's ideas because it had not been explicit enough about the kind of social and political changes it thought were necessary. He believed the potentially emancipatory ideas, embedded within the social definition of disability, were still too rudimentary, and that the theory needed developing. He argued that the best way to achieve a more comprehensive and accessible theory, to explain the oppression of disabled people, would be through a theoretical journal. He therefore suggested transforming the Union into an organisation capable of doing this (UPIAS 1978b C24, 1979g C29).

Pursuing a different perspective, Vic Finkelstein argued that the task ahead was to apply the theory they had developed so far and build the grass-roots movement. He thought the time was right for this and argued that disabled people would gain a better political understanding of their position in society, as they struggled to change it. He believed that the development of theory would follow from this (UPIAS 1976c C20; 1979f C28).

The two leaders had presented the members of the UPIAS with alternative routes to lead disabled people forward. One was to develop a social analysis, so people had the theoretical tools and knowledge to tackle what they were up against; the other was to encourage people

to become active in building a political power base and discover what they were up against by confronting it. In so doing the need to develop a social analysis would emerge.

In the midst of this discussion, in July 1979, Paul Hunt died very unexpectedly, and with his death the polemic ended. The remaining members then agreed to concentrate on building the movement, and until UPIAS disbanded, (it was formally dissolved on 12 October 1990), that is what they did (UPIAS 1990). With this decision, they soon found a way to move things forward and it lifted them out of the crisis (see chapter 7). A resurgence of energy and sense of purpose enabled the organisation to survive for another ten years and its achievements during this time were considerable.

Debates within the liberation tendency

Another group belonging to this emancipatory trend, but working in a different way, was the Liberation Network of People with Disabilities (LNPD). It too had an important influence at the time. Founded in 1977, the LNPD, much like UPIAS, subscribed to the view that disabled people were oppressed by society and needed to take control of their lives. Unlike the Union, however, it did not spend months analysing the situation before deciding what to do. Choosing to adopt a more spontaneous direct-action style, it drew people together to respond to specific events to highlight discrimination and oppression (UPIAS 1977: C22: p3).

The LNPD put much of its emphasis on developing a better understanding of the personal experience of disability and in a similar vein to the women's movement, developed consciousness raising groups and a support network to help people find new confidence in themselves, become more assertive and develop a positive identity of their own (Mason, in Campbell and Oliver 1996: p69, Morris 1991: p181).

Drawing from the feminist movement, the LNPD rejected formal committees and office-holding structures on the grounds they were alienating (personal memory of discussions in UPIAS branch meetings). It wanted to operate as a collective and worked hard to create an organisation that offered mutual support. In this it was successful, making an important contribution to the struggles to build unity and group identity between people. In contrast to UPIAS, the LNPD attracted a larger following that showed disabled people were ready for this kind of initiative offering a safe haven to explore personal experiences with peers.

One of its most influential campaigns was over the issue of terms of reference. The LNPD opposed the term '*the disabled*' which it described as dehumanising. It argued instead for the phrase '*people with disabilities*' to be adopted on the grounds that being 'people', was the primary fact, and the 'disability' was secondary (LNPD draft policy. in: UPIAS 1981b: C41: pp6-7).

This opened a whole chapter of dispute between the two major liberation groups, which helped clarify the arguments about what disability was (UPIAS 1981c: C41: p5). The UPIAS argued that the LNPD's term of reference was wrong because it introduced a new layer of confusion to the relationship between disabled people and society, whilst UPIAS was trying to clarify it (UPIAS 1987).

Having made the distinction between impairment and disability in its policy statement, UPIAS was pointing out it was only the impairment that was a personal attribute whilst disability was imposed by society. UPIAS argued that whilst it was accurate to describe themselves as '*people with impairments*', it was not helpful to refer to themselves as '*people with disabilities*', for this destroyed the distinction and personalised disability. UPIAS argued that '*disabled people*', on the other hand, more accurately reflected their situation (Finkelstein 1987, UPIAS 1974b / 1976a).

The outcome of this polemic meant that disabled people more widely started thinking about the meaning behind the language in use. The idea that disability was caused by social factors, not biological ones, continued to change consciousness. Just after this, in the 1980s, when the new national and international councils of disabled people came into being (Davis 1993: pp287-191, Driedger 1989, Finkelstein 1993b: pp42-43), there was a readiness to take these concepts on board. The

outcome of this was that '*disabled people*', and not '*people with disabilities*' became the adopted term of reference (Campbell and Oliver 1996: pp81-104, Driedger 1989: p41, Finkelstein 1987, UPIAS 1981e: C46 and 1982: C47).

In the professional circles of disability-related services the opposite happened. There, the term: *people with disabilities*, filtered into the official language of local government, professional service literature, and the media. Professionals continued to blur the distinction between disability and impairment. This lack of clarity and the tendency to use terms of reference interchangeably is illustrated for example by the titles, and contents of the reports by Beardshaw (1988: p7) and Fiedler (1988). It meant that the tendency to ascribe both aspects to the individual remained unchallenged, and consequently, difficulties in comprehending the social concept of disability continue.

Despite their differences these two liberation groups shared some important similarities. Both defined disabled people as an oppressed group and promoted the need for disabled people to take control of their own affairs. Both also recognised the need to explore their thoughts without the presence of non-disabled people. Their primary differences were in their approach to change. The LNPD placed more emphasis on personal politics as a way of disabled people emancipating themselves from an ideology of dependence. Here

personal liberation was considered a necessary precursor to the development of a more collective approach towards changing the society (LNPD 1980, Morris 1981: p181). For UPIAS, it was the other way around. Their emphasis was on building the collective struggle for the emancipation of disabled people in general, and from involvement in this, it was believed, people would become personally liberated (UPIAS 1976b: p14).

Before leaving this section, it is important to mention another small group within this emancipatory tendency called Sisters Against Disablement (SAD). This was an offshoot of the women's movement, but also due to the lack of disability awareness within it. SAD was initiated by disabled women who were angered because women's liberation conferences were regularly organised in inaccessible venues, despite their protests (Campbell and Oliver 1996: p154). SAD drew many ideas from feminism and from the developing disability movement.

It provided a space for disabled women to explore their experiences and try to disentangle the disadvantages that arose from being women and disabled. But, as Morris pointed out, in 1991, the perspectives of disabled women still needed developing and become an integral part of disability politics (Morris 1991: p163, p179). Subsequently, studies were pursued, by disabled women, such as the important one by Gillespie-Sells, Hill and Robbins (1998) which took on the

subject of disabled women's sexuality and issues of parenting and abuse relating to this.

Liberation groups of disabled people and the women's movement found themselves grappling with some difficult contradictions. For example, those opposing institutional care were faced with how to respond to feminists arguing that women should not have to continue as unpaid carers in the family. But in the early years very few disabled women were engaged in academic research and publishing their ideas, so the perspectives on the care relationship were predominantly those of non-disabled women seeing disabled people as dependents. Morris argued it was her belief that once disabled women researched their own situation, they would view the subject somewhat differently (Morris 191: pp154-168, Morris 1993: pp40-49).

Another issue was abortion and a woman's right to choose to terminate an unwanted pregnancy, how did this sit alongside disabled people's struggle for a positive identity and the right to have fulfilling lives within mainstream society? (Hunt, 1988: p37). People, on both sides, had to work through these apparent conflicts of interest. There were no easy answers.

The charities and the liberation movement

This new spirit of defiance amongst disabled people had brought into the open the sense of grievance that many people felt towards the major disability charities. The more powerful of these were coming to be seen as

obstacles, blocking the way to disabled people gaining recognition for their own organisations.

Some of the strongest criticism was directed at the Central Council for the Disabled (CCD), or RADAR as it became in 1977 after it merged with The British Council for Rehabilitation. RADAR had become very dominant, heading up the only existing council of voluntary disability charities, many of which excluded disabled people from having a voice in their management (Barnes: p1991: p135, Borsay 2005: p53). This situation was intolerable to the emergent liberation movement and the story below illustrates some of the reasons why.

A subject that was crying out for attention was that of sexual relationships and all the taboos surrounding it (Lancaster-Gaye 1972, Shearer, 1972). In the early 1970s, working as editor of the CCD's monthly news bulletin, Rosalie Wilkins had the idea of setting up a special interest group to investigate the issues surrounding disability and sexuality. This was an aspect of personal life that was largely ignored by professionals, and relatives, and in institutions had become a highly charged issue for residents. Wilkins' thought that a discussion group of disabled people, like herself, would provide a way through the morass of sexual repression and offer some peer support (Rosalie 1991). As elsewhere, what they needed was a safe environment to explore the issues and take the discussion forward. The

SIA, for instance, set out to address this gap when it published *So you're paralysed* .. (Fallon 1975).

Similar concerns about disabled people being denied opportunities to express their sexuality and form meaningful relationships, had been surfacing in Sweden. Inger Nordqvist (1972: p8) had just produced *Life Together*, a report of a symposium on the intimate relationships of handicapped persons, arranged by the SVCR, in May 1969. Their publication took a detailed look at the prejudices and technical difficulties that disabled people could face when involved in sexual partnerships. Wilkins approached the CCD's director, Duncan Guthrie with her idea and to his credit he decided it should be pursued. But she then found her idea was not only taken up, but taken over, and without her further involvement the project became significantly altered. As she put it:

'Guthrie set up SPOD, (Sexual Problems of Disabled People), all very professional and swamped the whole thing. But that was the conflict, mine would have been a much more grass-roots disabled people's group and much more alternative' (Rosalie Wilkins [interview], 1991).

The initiative to set up SPOD produced a successful professionally run outfit whilst Wilkins proposal, for a peer support group, fell by the wayside. As an entrepreneur

Guthrie saw the potential it offered for the CCD to take a lead in promoting a new professional counselling service to support people having problems in personal relationships (Rosalie 1991).

SPOD offered disabled people a traditional response, i.e. a professional service to counsel individuals within a *medical* model of practice as was illustrated in a recorded interview between a couple of UPIAS members and a SPOD professional (UPIAS 1974. C13: pp3-7). Whilst the services it offered might have been helpful to individuals, the effect at the time was to stop an initiative that would have encouraged disabled people to take a lead to explore the issues for themselves. As a result, the space, so desperately needed to share their experiences and learn from each other, was not made available until the NLPD and SAD emerged several years later.

Contrary to the professional approach, with its tendency to medicalise the issues, Wilkins' idea offered potential for a much broader discussion around all types of barriers in the way of developing personal relationships. In common with the discussions about the social nature of disability, relationships were also about people having opportunities and some control over their lives.

Although a small event, this story demonstrates a wider tendency amongst charities to overwhelm self-help initiatives run by disabled people. As Ken Davis recalled,

it happened again in the setting up of DIAL UK (Ken Davis [interview], 1990). Welfare charities were bound up with the dependency culture of the service providers and it produced frequent contradictions between their stated intentions, to help disabled people become more independent, and their dismissive actions towards emancipatory initiatives.

Setting up conferences for professionals that were physically or financially inaccessible to disabled people, was commonplace; refusing to take disabled people seriously was habitual, and so too was the practice of charities setting themselves up in competition with disabled people's organizations. Other examples of this appear in later chapters.

For charities such as the CCD, and later, RADAR, the development of a self-help movement by disabled people, clearly posed a potential threat. They had recovered from the risk of being made redundant by the welfare state, through filling service gaps and raising funds for research, but they faced uncertainty if disabled people started to run their own affairs.

CHAPTER 7 - Becoming a social liberation movement in the 1980s

The 1980s heralded a new period of unprecedented activity from disabled people. Having progressed from the earlier spontaneous struggles to a more conscious phase, during the 1970s, they now had to sort out a political strategy to take the ideas forward.

It was necessary to build the social movement, but for large numbers of disabled people, arriving at a collective awareness about being an oppressed minority, was not going to come easily. People were not necessarily united about how to achieve their emancipation.

In due course two leading trends crystallised around the issues of independent living and services of personal support. Both trends subscribed to the social definition of disability, but they adopted significantly different strategies to achieve their objective. This is dealt with in chapter 8. Their different approaches reflected more widely held ideological divisions taking shape in the society at large.

Britain deconstructed - the political context

The surrounding political context within which disabled people were striving to become better organised was one of major change. British society was just going through a period of upheaval and massive struggle on several fronts.

Globally, and nationally, the 1980s was a period of rapid transformation. Following the discovery of micro-chip technology, a revolution was taking place in production methods, and societies everywhere were forced to adapt at a relentless pace (Castells 2000: pp52-72). Margaret Thatcher's Conservative government, determined to restore Britain's foundering economy, produced radical plans to reshape the social infrastructure and performance of capital (Hutton 1995: p2p7-32). Much that had come to be taken for granted then became targeted for major reform.

For a while it produced widespread unrest amongst the working population to the heavy attacks on their living conditions, and it prompted major industrial strikes led by the miners, and other groups of power workers. Sectional struggles also erupted between the national government and the local councils (Dearlove and Saunders 1984: pp389-390; Forrest and Murie 1988: pp200-217) and some of the impact this had on the newly forming Disabled People's Movement (DPM) is explained in chapters 8 and 9.

To briefly recall what it was like when this shake-up started in the early 1980s, one must remember the way British industry went into freefall. With the cascade of closures and bankruptcies announced in the daily news, and hundreds of thousands of workers made redundant; homelessness suddenly increased, begging, for so long more or less absent, became commonplace, and

pawnshops re-appeared. Job security, skills training, and apprenticeships, all became a thing of the past and suddenly there seemed to be no future for vast numbers of adults (Forrest and Murie, 1988: pp11-14, p169; Hannah, 1994: p345; Hutton 1995).

Over the course of the next ten years, concurrent with the steep rise in unemployment, there was a structural shake up of the public sector, including parts of the welfare state (Hutton 1995: p11, Pierson 1991). Of importance to this account, was the shift in ideology away from the idea of shared responsibility for a humane society, towards one that promoted competitiveness, the rights of the individual, entrepreneurial initiative, and the expansion of consumerism. Along with the much-flaunted importance of the individual, many of the co-operative aspects of society came under heavy attack (Hutton 1995: p13, pp27-29: pp177-178, Johnson, P. 1994: pp14-15).

In the face of severe cuts to public expenditure, the government set out to destroy common assumptions about the reasonableness of the British economy spending a proportion of the collective wealth on ensuring citizens had certain basic rights to such things as; a home, a basic standard of living, medical care and education. To win our compliance, a new culture was fostered that promoted individual freedom and personalised responsibility (Hutton 1995: pp27-29).

To win our minds over, bureaucracy was blamed; for much of the inefficiency, for stifling entrepreneurs, and for unnecessary control of people's lives, and it was not too difficult to build public support for the idea of more personal freedom and less bureaucratic restraints (Forrest and Murie 1988: p4, McChesney R. 1999: pp7-8, Pierson 1991: pp47-48).

One of the first bits of the welfare state to be tackled was council housing. Significantly, it was the mechanisms used to restructure social housing that enabled the government to establish a reconstruction model it could later apply to other parts of the welfare state.

These mechanisms involved introducing new market conditions to reduce the power of local authorities and force council departments to compete for business with the private sector. It was achieved by the double strategy of offering financial incentives to Housing Associations, to expand their role as social landlords, and giving council tenants large incentives to purchase their homes at reduced prices. A diminishing role for local councils was achieved by preventing them from building or buying more housing to replace diminishing stocks (Forrest and Murie 1988: pp1-14).

Another tactic being introduced was compulsory competitive tendering (CCT). This forced the council's direct labour services to compete with the private sector for maintenance contracts for the dwindling housing

stock, and to establish an internal market for their services (Patterson and Pinch, 2000).

The housing strategy seemingly worked well (Forrest and Murie, 1988: p7). It gave people the choice to own their home and ensured many more people had responsibility for maintaining their homes which reduced public expenditure.

Whilst it was being argued that the old council housing policy frequently failed to deliver a decent service, the accuracy of this assumption is open to some question. Forrest and Murie suggest most council tenants were not so dissatisfied (Forrest and Murie 1988: p170). Further to this there was the question of how people on low incomes were to acquire affordable and suitable homes, and that was left to the market to sort out. People might prefer to own their home, but unless they could afford to maintain it, this freedom could, and often did prove a liability (Forrest and Murie, 1988: p263). It's conceivable that this added an extra dimension to widespread fears of redundancy. For disabled people seeking social integration, only time would tell how much the housing policy could be made to work in their favour.

Local government under attack

The mid 1980s saw the national government win a major power struggle with the local councils over who decided local government income and expenditure on local services (Forrest and Murie 1988: pp200-203, Hutton 1995: p94, Kavanagh 1987: p293). To overcome

resistance from local councils a new style of management was introduced to oversee changes in local services (Dearlove and Saunders 1984: p383-390). This was much tougher than in recent years, for it had to force through the rapid changes in working practices and service arrangements that were now expected, and to cope with the unhappiness of workers and consumers when the services dwindled.

For disabled people who were seeking service improvements, the implications were twofold. Firstly, there was an increasing tendency to centralise control over local service provision and secondly there was the impact of reducing the public sector (Forrest and Murie 1988: p200, pp210-217, Hutton 1995: pp4-5, p29). Both had an impact on their negotiating capacity to bring about change.

Progressively, over successive years, local councils lost much of their control over, not just housing services and direct labour organisations, but also their freedom to grant aid to local community projects, manage; education services, community services and welfare services, and their freedom to decide priorities for local services generally (Hutton 1995: pp36-37), Kavanagh 1987). This is dealt with more in succeeding chapters.

This government made clear it would no longer protect people from undue hardship (Hutton 1995: p92, p110, p170, Pierson 1991: pp165-168). The previously prized 'welfare state', deridingly referred to as 'a nanny

state' (Pierson 1991: p166), was blamed for causing a diminished sense of personal responsibility, and one of the ways to weaken the opposition, was to target the professionals who worked for the local state. The professional autonomy of groups with status in society, such as; civil servants, social workers, and teachers, all came under attack (Gamble 1988: pp218-219, Kavanagh 1987: pp251-252). The motivation driving this strategy was threefold. It opened the door to the free market, it reduced state-run services, and achieved both without arousing too much popular complaint (Forrest and Murie 1988).

Pierson (1991: pp155-158) argues this was not entirely surprising for popular ambivalence towards the welfare state had a long history. Nevertheless, silencing opposition from powerful sections of the workforce, whilst at the same time gaining popularity for its policies was a significant coup for the government (Forrest and Murie 1988: pp6-7, Kavanagh 1987: pp248-249).

As I recall from my experience of working within the public sector, the impact left professionals feeling vulnerable and unsure how to defend themselves when faced with attempts to market their services. Having become deeply unsettled by the changes all around them, employees were often split between those who were anxious to defend public services, but didn't know how, and those who would settle for whatever benefits they could extract from the incoming arrangements. The

picture of conflict versus co-operation, in relations between staff and management, was often very confusing.

For the newly forming movement of disabled people, all this upheaval within the services meant there was potential to introduce new ideas and new ways of working with council services. The political divisions between national and local government sometimes acted in their favour, as was the case in the setting up of equalities units.

Responding to local grassroots pressures, in the mid-1980s, labour controlled councils started to establish equal opportunities policies into their council run services (Pagel 1988). They wanted to introduce fairer recruitment policies, access and disability officers, and attention to equal rights for gays and lesbians.

For local organisations of disabled people, these equality policies were an important breakthrough. It enabled them to press ahead for improvements and amongst other things it helped to expose the failures by local authorities to apply the 3% employment quota, laid down in the *1944 Disabled Person's Employment Act* (LBDRT 1988). In the London borough of Lambeth, for instance, this was taken up with unusual determination with a recruitment drive to only employ disabled people until the 3% quota was reached (LBDRT 1988). Such unprecedented action, by a council in defiant mood towards a hostile central government, was symbolic of

the polarised relations then existing between local and national governments. Actions of this kind gave unusual scope for alliances to grow between councillors and local campaigns (LBDRT 1988: p3, p12, p15, Leach 1996: pp90-95, Pagel 1988).

The development of equal opportunities units, against the political wishes of the Conservatives, added fuel to the fire of confrontation and councils that tried to introduce equality services were often viciously attacked by a hostile media (LBDRT 1988: p2, Leach 1996: pp88-95).

Their attempts to be responsive to local demands, by introducing non-discriminatory policies, were frequently labelled as “loony left”, and irresponsible. The media and political hostility towards some labour councils’ efforts to address local inequalities in the 1980s was pervasive.

These were unsettling times. For disabled people, the central attacks against equal opportunity policies and the welfare state, on the one hand, and against local bureaucracy and professional autonomy, on the other, posed a serious dilemma. Whilst there could be little dismay at seeing bad services undermined, there was considerable worry about being left without any services at all, and disabled people needed supportive local authorities if they were to make progress integrating into the local community.

People then became divided over whether to put energy into trying to change local services or whether to dispense with these professional services and set up alternative arrangements (Davis and Mullender 1993: pp37-39). By this time, disabled people were becoming much better organised, and more visible, and their demands for integration were starting to attract government interest.

Experience in the 1970s had shown that pressure group activity could be effective. Public pressure and parliamentary lobbying, by groups such as the Disablement Income Group and the Joint Committee for Mobility of the Disability had produced results (Hunt 1973d: pp99-117), Peter Large argued these organisations could claim some credit for the introduction of reforms such as the 1970s CSDP Act, the attendance allowance, mobility allowance and car tax exemption (Peter Large [interview] 1991).

However, when it came to mainstream schooling and open employment, opportunities were still extremely limited (Barnes and Mercer 2006). Disabled people needed all the support they could get to bring about reforms here. Their efforts were then substantially boosted in 1981 by the international year of disabled people during which the level of grassroots pressure dramatically changed (Barnes, Mercer and Shakespeare 1999: p11; Davis 1993b: pp285-291). New organisations that would strive for the emancipation of disabled people

were established locally, nationally and internationally, and UPIAS came to play a significant role in all areas.

Taking control of the International Year of Disabled People

By 1980, a process of realignments of activism and patchwork of pressure group activity were transforming into an identifiable social movement, and a similar process was taking place in many countries (Driedger 1989: pp11-23, UPIAS 1983a: pp1-2). In response to this changing tide of awareness the United Nations (UN) had declared the 1980s would be a decade of disabled people, starting with, an International Year of Disabled People (IYDP) in 1981 (Barnes Mercer and Shakespeare 1999: pp166-169, Campbell and Oliver, 1996: pp167, Davis 1993b: pp287-291).

Despite the intentions of the UN to put disability on the political map, the aims for this international year were set down in quite narrow terms because the promoters were still turning to traditional medical concepts to provide the way forward. To those involved in the growing discussions about the social nature of disability such a limited perspective was disappointing. Ann Shearer, a journalist that had interested herself in these debates, reflected some of this scepticism when she wrote:

The first official aim of the International Year of Disabled People in 1981 was 'helping disabled people in their physical and psychological adjustment to society'. The real question is a different one. How far is society

willing to adjust its patterns and expectations to include its members who have disabilities, and remove the handicaps that are now imposed on their inevitable limitations? (Shearer, 1981: p10).

Despite these inauspicious beginnings the IYDP proved to be historically a very significant year for it gave disabled people an opportunity to take the initiative. During that year the foundations were laid for a national and also an international body for the self-representation of disabled people and it was a definite turning point in their struggle against segregation and discrimination (Campbell and Oliver 1996, Driedger 1989, Pagel 1988).

In the process of acquiring various forms of representative democracy under their control, there came a point when disabled people could recognise a qualitative change had occurred. Prior to this time, without a political critique, there tended to be only spasmodic unity, often blighted by competition, between contending parties, for resources and influence (Campbell and Oliver 1996: p55). Through UPIAS, however, disabled people came to recognise that disability represented a form of social oppression. This became the unifying force.

Having become clearer that a restricted life was not an intrinsic fact but originated from the way society was organised and having exposed the connection between exclusion from the labour market, dependence on

charity, and the development of segregated services, it was possible to identify ways to reverse this trend. But disabled people needed to take the lead to liberate themselves from dependency (Barnes Mercer and Shakespeare 1999: pp27-31, pp76-83, Davis 1993b: pp289-290, Finkelstein 1993b: pp34 -43).

Whilst UPIAS members had seen the need to build a grass-roots movement they also realised, by 1980, that their organisation was not going to be the basis for building a mass following. This became an ongoing discussion in the UPIAS circulars between 1978 and 1988 (UPIAS 1978 C24, 25, 26, 1988 C: September). They were looking for a new formula and at one of their discussions Finkelstein (Finkelstein in: Campbell and Oliver 1996: pp68) raised the idea of forming a national council of organisations, run by disabled people, to become a proper representative base.

Building the base for self-representation: national representation

UPIAS invited all known national groups, constitutionally controlled by disabled people, of which there were about ten, to come together to create such a body. Early in 1981 a founding conference represented the first step towards establishing a council, which in due course became the British Council of Organisations of Disabled People (BCODP 1983).

About 15 years had elapsed since Nigel Harvey and Paul Hunt had first floated the idea of disabled people

having their own representative organisation (see chapter 4). The ideas they had shared in the Cheshire Smile in 1968 (Hunt 1968a) foundered, at that time, because people weren't ready or unified enough to achieve it. But, in the interim much had changed, and the appearance of the BCODP signified an important turning point.

Creating this broad-front organisation; from a range of groups with different views about disability, required skill and decisive leadership. UPIAS was formally accepted as the political vanguard (Barnes and Mercer 2006: p35, Campbell and Oliver 1996: p68, Davis 1993b: p290) and the council members elected Vic Finkelstein to chair the steering group (UPIAS 1981 C45). He provided the necessary vision to see how such a council could work and it put power into the hands of disabled people by encouraging a grassroots movement to grow (Stephen Interview 1991). With his guidance the various member groups developed a political strategy for the new council.

Local representation

Concurrent to the initiative to build national representation through the BCODP, there was a parallel trend to create representation of disabled people at the local level. The first such initiative was taken in Derbyshire where a few people, led by Ken Davis, decided to draw interested parties together to form a local coalition of organisations of disabled people (Davis and

Mullender 1993a). As well as being involved with the business of creating the national council of BCODP, they had become interested in coalitions being set up by disabled people in Canada and America (DCDPa 1981, UPIAS 1983a: p2).

The influence of UPIAS was again very much to the fore as a few of its members in Derbyshire had become well known for their initiatives to develop self-empowering projects locally, the most significant of which had been the DIAL information service and Grove Road supported integrated housing scheme (see chapter 6). The primary initiators of these service developments had been Ken and Maggie Davis (Davis 1981: pp32-36; Finkelstein 1993b: pp38-39). In both projects, encouraging disabled people to take responsibility for their own affairs had been a key principle. The next task was to take it a stage further by creating the means for disabled people to influence local service provision more generally to bring about integration (Davis and Mullender 1993a; Ken Davis and Maggie Davis [interviews] 1991).

The formation of Derbyshire's Coalition encouraged disabled people to participate in wide ranging discussions. They not only planned how to build their organisation but also entered wide ranging negotiations with statutory authorities around service issues (Davis 1985), (Davis and Mullender 1993a). Their achievements, and what they learnt there, were key for the developing movement because the coalition

demonstrated new ways of engaging and empowering disabled people in the political process. Theirs became a model for others elsewhere (see chapter 8).

International Representation

In various countries, spanning approximately the same period, parallel struggles were going on against architectural barriers and discriminatory practices, and for the means to support integration. Diane Driedger (1989: p1) records the existence of disability pressure groups in approximately 100 countries by 1981.

A key feature, of this groundswell of pressure from disabled people in different parts of the world, was the escalating criticism that professional services were failing to deliver what people wanted. It culminated in 1981, with the setting up of the Disabled People's International (Driedger 1989).

The initiative to form a Disabled People's International came about because of the dismissive way disabled delegates were treated by the professional establishment of the Rehabilitation International (RI) congress. RI congresses happened every four years and were used for sharing ideas about rehabilitation, and disability, and they had been the principal international forum on the subject since 1922 (Driedger 1989: pp29-30).

The Rehabilitation International originated as a professional medical gathering, but, as the years passed, disabled delegates attended in increasing numbers.

During the 1970s, when their number had substantially increased, disabled participants became more assertive about the inaccessible conference facilities. By the late 1970s they felt, that since the debates were on issues that had a direct impact on their lives it was essential to have disabled people's participation in all aspects of the proceedings, which should therefore be fully accessible (Driedger 1989: pp29-30).

This was brought to a head at the RI conference in Winnipeg in 1980, by a group of disabled delegates from Sweden. Bengt Linqvist formally proposed that future congresses require a fifty percent representation of disabled people's organisations on all national delegations sent to the assembly (Driedger 1989: p33) and the proposal failed to win the support of the majority of the delegates (only 250 present being disabled).

Angered by this reaction the disabled delegates abandoned the RI congress altogether and enthusiastically agreed a proposal to organise an independent disabled people's international assembly. Plans were immediately laid for a founding conference to take place in Singapore, in 1981 (Dreidger, 1989: p48).

Building the BCODP and dealing with the opposition

Back in Britain, those setting up the BCODP were aware of these international developments, and the need to send representatives from the UK, but they had to establish their own base first (Campbell and Oliver 1996: pp83-84, p92, UPIAS 1981 C40, C41, C49). This meant

tackling the hard task of building up some unity between the very different member organisations with the authority to represent disabled people nationally, and deciding on a campaign strategy for the new council.

The issues they needed to tackle were myriad and deciding priorities about how to use their limited resources presented a tremendous challenge. They were struggling to survive amidst all the practicalities of sorting out their many differences and learning to work together (Campbell and Oliver 1996: pp78-79, pp92-93, UPIAS 1983 C54, 1984 C57). It left them with limited capacity to address the many external issues pressing in upon them. Their principal task was to find ways of nurturing the development of their grass-roots movement.

Until 1983, the BCODP lacked the funding to employ any staff to do administrative tasks and so all of this had to be done on a voluntary basis. This was in stark contrast to RADAR that had just received its generous state subsidy from the Department of Health (DH) (Campbell and Oliver 1996: pp189-190, UPIAS 1984 C57).

Finding a way to obtain some proper funding presented a major hurdle. When the BCODP approached the DH for grant aid, in 1982, for instance, the delegates were told they were crazy to even think a government department would fund such an organisation as theirs (from interview with Anne Rae 2000). In 1983, however, when the BCODP reapplied, they were more successful

(Campbell and Oliver 1996: pp189-190). Having money meant they could employ an administrator and develop an office base which was essential.

Campbell and Oliver (1996) referred to these funding difficulties and to the conflict with established charities as ongoing issues for the BCODP. They put it in the following terms:

Two of the main problems that have been around since the inception of the BCODP have been its chronic lack of resources and the antipathy, not to say downright opposition, that its very presence has engendered amongst the disability establishment; that is, the traditional organisations for disabled people.

... the fact remains that the BCODP and the disability establishment are in direct competition for financial support. In terms of government section 64 funding for example, the BCODP's main competitor, RADAR, receives eight times more (Campbell and Oliver. 1996: p92).

Bradshaw, as a founder member of the BCODP recalled that progress, was slow at first, with few people, other than the UPIAS members, really appreciating the potential importance of such an organisation. It was physically difficult for many people to attend meetings and the attendance of delegates was often erratic, with member organisations sending substitute

representatives to the different meetings. Maintaining some continuity in the discussions and decisions, was therefore beset with problems (Stephen Bradshaw [interview] 1991). Bradshaw also recalled how very conscious they were, in those early days, of the fact that to be successful the BCODP had to survive the competition with, and challenge the authority of, organisations such as RADAR and the Spastics Society (Stephen Bradshaw [interview] 1991).

An early concern was about how to protect itself from being taken over by able bodied people and larger, richer, and more powerful charities. Such takeovers had happened before and had just occurred again in the formation of DIAL UK, an umbrella organisation set up to support the creation of a network of local DIALs.

In this instance it was the three most influential, information providing disability charities; RADAR, the Disability Alliance and the Disabled Living Foundation, working in tandem, and local DIALs had not put up enough opposition for fear of losing the funding and resources offered by these powerful charities (Ken Davis, [interview] 1991). A few of the more aware people had made attempts to ensure disabled people maintained overall control but they were unsuccessful. According to Ken Davis (above) this was because local groups were not interested in the political arguments at that stage, only the practicalities of getting the service up and running (Ken Davis, [interview] 1991).

After debating the control issue, in the BCODP, it was decided that criteria for council membership would be governed by disabled people having constitutional majority control of member organisations. This principle of control was a contentious one, initially, for there was no easy consensus as the illustration below shows.

'I remember the first meeting. There were those who were for and those who were against including certain groups. Some were saying "well you can't exclude the RADARs of this world, that's where all the power is, and you can't expect to get anywhere without having a system for including them".' (Bradshaw, in Campbell and Oliver, 1996: p78).

Disabled people had a long history to overcome. Part of the process was to raise awareness about why they needed to be independent of the traditional charities. In fact, when it had barely started the BCODP was confronted with a serious attempt to destabilise it by people within the establishment, who proposed to form another council of disability organisations.

It came from the Snowdon committee chaired by Lord Snowdon. This had been formed around 1978 - 1979, to enable several charities to investigate and produce some proposals to encourage integration and in 1980 had published its report *Integrating the Disabled*. With their task done and the International Year of

Disabled People generating interest, some members of this committee formulated the idea of establishing a new council to take disability matters forward in the future. Their intention was to combine all interested parties into one council body to be more effective (Campbell and Oliver 1996: p82, UPIAS 1982 C47).

If it had gone ahead, RADAR's role, as head of the existing council of voluntary organisations, would presumably have become redundant.

For the new BCODP, just getting off the ground, it presented a very serious risk to their survival, The steering group, foreseeing that many of their potential member groups would feel pressed to join a new council such as that proposed by the Snowdon Committee, rather than promote the more risky venture of the BCODP, had to work out a strategy to deal with the threat (Finkelstein, in Campbell and Oliver 1996: pp82-83, UPIAS 1985 C58).

They decided to test the integrity of the Snowdon proposal by arguing that disabled people should have majority control of any new council set up to represent their interests. If this principle could be ensured, it might be worth them exploring the potential of joining forces to form such a new council. But, when this proposal, was put to the Snowdon Committee the response was, as Finkelstein recalled, true to experience:

‘We had some telephone calls and I think Stephen (Bradshaw) must have spoken to him (Lord Snowdon) on the phone. He was just hysterical. We were trying to calm him down, saying ‘we’re not opposed to what you’re doing, we just want disabled people to control it, that’s all’. But they were adamant. Again, for me it was a surprise, because I really couldn’t understand why there was this violent opposition to disabled people controlling their own lives’ (Finkelstein, in Campbell and Oliver, 1996: p82).

It transpired that no alternative council materialised (UPIAS 1985 C58). As I recall from discussions about that time the motivation to proceed seemed to evaporate following the sudden death of a key member of Snowdon’s group. In practice RADAR continued as the existing head of a council of charities, and BCODP went on to become the council of disabled people’s organisations. Having all this going on during their first year was a significant distraction but it strengthened the arguments in favour of freedom from the control of traditional charities.

Building a base for a grass roots movement and establishing constitutional control

When the BCODP first set out to establish itself as the national representative body and decided membership should only be for national organisations

under disabled people's control, it initially had only seven member organisations but by 1985 there were 22 (UPIAS 1984 C58). Because most active disabled people belonged to one or more of these organisations, it was hoped they would be kept informed via their member organisations.

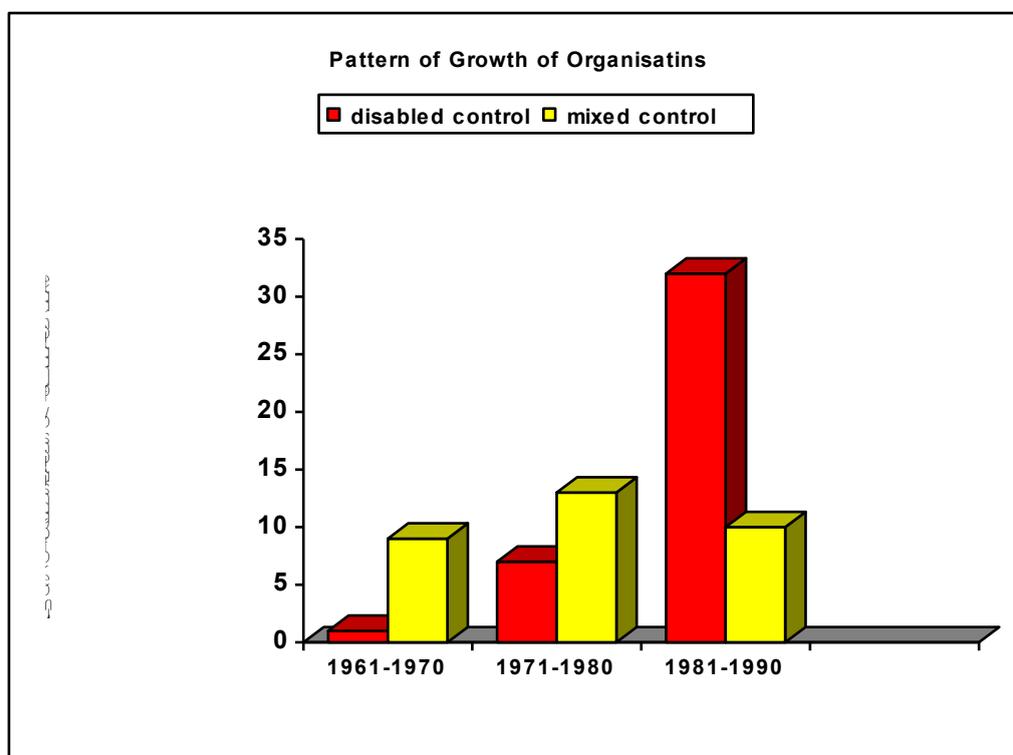
However, the situation was rapidly changing. The trend to form local representation, such as coalitions and associations controlled by disabled people, was becoming more popular (Barnes and Mercer 2006: pp76-82, Davis 1993: p285).

Excluding such organisations, from the BCODP, because they were not national organisations, was clearly not in their best interests. It became apparent that if it was to avoid becoming remote from large sections of this emerging social movement the BCODP had to find a formula to include local groups too. Constitutionally it was complicated and difficult to win everyone's agreement, so it took several years before the BCODP could extend its membership to the variety of local initiatives. When it finally opened its membership, this made an enormous difference, as Bradshaw points out:

'That was the time when it [the movement] really mushroomed, and an extensive network grew of people who knew what was going on. BCODP stimulated the development of local groups mostly by word of mouth

and the work of a few individuals in their localities' (Stephen Bradshaw [interview] 1991).

The earlier decision of the BCODP, that membership rights would only be for organisations in which disabled people had majority control, proved to be an important principle (UPIAS 1981 C46). It not only secured disabled people's control of the BCODP, but it also encouraged many local organisations to adopt the principle, so they could join the council. By the end of the 1980s, constitutions of a significant number of hitherto mixed organisations were changed to give majority control. The graph below using my survey data of organisations, illustrates this, as shown here:



Of all the organisations that returned the survey questionnaires, 70% had originally been of mixed control

when founded and 16% of these reported changing their constitutions between 1981 and 1990, to give disabled people overall control. The organisations that changed are positioned according to their constitutional status at the time of the survey in 1990.

The tide was turning. More disabled people were seeing the need to have their own organisations, and representatives with direct experience of disability engaging in negotiations and consultations with local authorities, health authorities, county councils and government departments. Bit by bit, the representational role, previously filled by traditional charities, gave way to representation from organisations controlled by disabled people. It was a change in which the BCODP had played a significant part.

Taking up the social interpretation and importance in a name

Deciding on a name for the council also became part of the politicisation of council members. The national steering group had to decide whether to refer to itself as a council “*of disabled people*” favoured by the UPIAS or as a council “*of people with disabilities*” favoured by the Liberation Network of People with Disabilities (LNPD) (UPIAS 1981 C45). It was an important terminology battle, being fought out between the two leading political liberation groups UPIAS and LNPD, (as discussed in chapter 6), and it had to be settled.

If the definitions set out by UPIAS were adopted, the council would endorse the idea that it was society that barred the way to integration and caused people to be disabled by the way it was organised. If the BCODP accepted this view it would move away from rehabilitative solutions for individuals, towards responding to the needs of disabled people in general and the priorities for the movement would be to tackle the disabling environment. The prevailing medical care and cure conceptions of disability would be challenged.

If, on the other hand, the BCODP adopted the Network's terminology of 'People with Disabilities' the difference between physical impairment and disability would remain blurred and ill defined, with the needs of the individual a primary focus. Discriminatory social attitudes would be seen as the primary obstacle which would in turn drive the BCODP to prioritise public education. By leaving the terms disability and impairment interchangeable, the medical concept (of disability) would remain largely unchallenged.

UPIAS finally won the day and so it became called the Council of Organisations of *Disabled People*. This national acceptance of the social interpretation of disability was very significant. It became, in effect, the key that unlocked and released the social movement, because, once the message went about that disability was not due to impairment, but caused by a disabling society, it was not long before people saw it as entirely

reasonable to see the causes of disability as a form of social oppression. The effect was dramatic in bringing about a change of consciousness. As more people took up the social interpretation, they became more confident and determined to do something about changing the society (Barnes and Mercer 2006: pp82-86, Oliver 1996: pp30-42).

BCODP, and its promotion of the social interpretation, represented the next important stage in the parting of the ways between disabled people and traditional service providers. There was more awareness, plus a feeling, that the time had passed when disabled people needed to be afraid of criticising the disempowering ways of professionals and their ideas (Barnes, Mercer and Shakespeare 1999: p129).

Once people rejected negative identities of disability, handed down by society, there was the possibility of creating positive images to replace them. They could now freely criticise services that tried to make them conform by adjusting to, or accepting, the so called "normal" world which was discriminatory. Over the next few years, a change of attitude became noticeable towards non-disabled supremacy. Professionals and charities alike came in for much heavier criticism, disabled people became more confident to insist on having control of their own affairs organisationally and in their personal lives. As a Director of Social Services, Jones drew attention to the big changes this demanded of them in the way the

services worked (Evans 1995: pp116-122, (Jones 1995: pp108-115).

Between the national council and the movement's grassroots, an organic relationship started developing, with the BCODP acting as a catalyst. As people struggled with the issues and became politically more involved, a shared identity grew up around the social interpretation of disability. Having this common reference point enabled many people to identify more clearly with the aims of a social liberation movement (Campbell and Oliver 1996: pp101-102, Barnes and Mercer 2006: p33, UPIAS 1983a: p3).

Anti-barrier versus compensatory objectives

Armed with this new interpretation there was not only an added thrust to the campaigns tackling the causes of social exclusion but also a drive to discover new service arrangements to end segregation and institutionalisation. Towards this end, the BCODP set up three special interest sub-groups (UPIAS 1982 C47) which were to investigate; education, housing, and personal support services (BCODP 1984a).

This anti-barrier trend contrasted with the priorities still taking up much of the time of the more traditional organisations *for* disabled people. Charities predominantly managed by non-disabled sympathisers, or ones where disabled people had no control, still tended to spend much more time on compensatory assistance or medical cures. My survey indicated they

were more often concerned with trying to alleviate poverty and isolation, and help supporting families, environmental issues were given more secondary attention.

The social interpretation goes international

In 1981, concurrent with its own early development in Britain, there was to be the inaugural conference of the Disabled People's International (DPI), as mentioned above. Although the decisions to set up the British and International Councils were independent of each other, the DPI proposal had provided added stimulus to press ahead with the formation of the BCODP, early in 1981, so that delegates could be elected to attend the inaugural congress later the same year. The result was that BCODP sent its chairperson, Vic Finkelstein, and two other steering committee members, Stephen Bradshaw and Francine White, to the Singapore congress (UPIAS 1981 C45).

As had been happening within Britain, the first international congress also had to decide how to define itself. A draft constitution was presented to the congress for debate (Dreidger, 1989: p53) in which it drew on the World Health Organisation (WHO) definitions of disability, handicap and impairment, and presented these to delegates as a framework for discussion. The WHO definitions, were, in essence, the same as those developed for the British census in 1970, by Harris et al for the OPCS (Harris, 1971), which the UPIAS had taken

apart because they focussed on the limitations of individuals in relation to a “given” environment and adopted a traditional medical view that said disability was the outcome of the physical impairment (UPIAS 1982 C47).

The BCODP delegates saw their chance to influence the political direction of the international movement by introducing it to the social interpretation of disability. Vic Finkelstein recalled to me how they had worked hard, arguing long into the night, explaining to other delegates the difference between the medical and social interpretations of disability. They needed to get across why it was, in the long run, so important for the social interpretation to be adopted by the new international.

The main responsibility for this fell upon Finkelstein, who had, after all, been the person principally responsible for originally formulating the social definition for UPIAS.

Finkelstein recalled that in the course of these discussions, the delegates from Norway and Sweden, Ann-Marit Saeboenes, and Bengt Lindqvist a long-standing delegate and critic of RI, became very interested. Together with him they presented a resolution to the DPI Congress to accept the social definition of disability. The outcome was a congress acceptance of a slightly modified version of the UPIAS definitions (discussions with Vic, 2000, Dreidger, 1989: p53, 92). This was again, very significant, for it meant the

international movement would now have its sights on an emancipatory struggle for non-dependency-creating services, rather than prioritising medical solutions.

The clarity of UPIAS ideas around the causes of disability (UPIAS 1976: p14), were not only shown to be in advance of most thinking (Siller 1980: p47) they were also timely, for there was an eagerness to accept this decoding of the disability experience. The new social conception of disability gave people all around the world the much-needed basis for arguing that societies everywhere must change so disabled people could participate (Oliver and Barnes 2012: pp20-27).

By 1982, the social interpretation was being applied in the DPI's World Programme of Action with the need for major social change clearly on their agenda;

The World Programme of Action is based on the principles of human rights, full participation, self-determination, integration into society and equalisation of opportunity, while the traditional model was based on segregation, institutionalisation, and professional control (Dreidger, 1989: p98).

Clearly, in those early days, the international movement of disabled people was strongly influenced by the British movement. Later, that was to change.

The Social Model versus the Medical Model - two ideologies clarified

Although the social interpretation was recognised as a liberating concept, it was not easy to fully grasp. It was,

for instance often difficult to accept the idea that physical impairment and disability were distinct because, in a disabling society, they always went together. Breaking through this thought barrier, so that cause and effect were more visible, was paramount.

In 1983, Mike Oliver gave the new social interpretation of disability a boost towards general acceptance by explaining it in terms that people found easier to grasp. Using the idea of models, he described the existence of two fundamentally opposite ways of looking at disability. On the one side, he identified an individual (pathological) model, in which professional practice built upon the idea of disability as a tragedy. He explained that by using this 'medical model,' professionals were trained to help individuals adjust to their disabling condition rather than challenge it (Oliver 1983: p15).

Oliver then described the UPIAS's interpretation as a 'social model' and explained how this put the onus of adjustment and adaptation onto society (Oliver 1983: p23). He then emphasised that it was not appropriate for disabled people to accept their limitations as it was important, they did not accept the world as it was.

His publication, aimed at social workers, helped to put the arguments into the public domain for discussion. It helped people to understand more clearly how the medical and social interpretations were not only different but counter to each other.

Over the course of the next ten years, the ‘social model of disability’ ceased to be a fringe idea. It entered the general fabric of vocabulary of the movement and later filtered into the vocabulary of professional groups and official documents (Oliver and Barnes 2012: pp24-27).

Referring to the ‘social’ and ‘medical’ models became a kind of shorthand to represent an overview that people either adhered to or rejected, but a lot of work still needed to be done to put the social model to the test.

Reaction of charities to BCODP

As mentioned above, far from being celebrated by traditional charities, the BCODP’s arrival on the scene tended to be seen as an unwelcome competitor. If disabled people were to represent themselves through this new organisation the national charities, would have to reconsider the legitimacy of their role.

Goldsmith drew attention to a polarisation taking place between the disabled people’s movement and the traditional ‘for disability’ charities. In his address, as winner of the 1982 Harding Award, he wrote:

‘In a climate that is fostering the fertilisation of “of” organisations we must not depreciate the worth of the “for” organisations - for example, The Royal Association for Disability and Rehabilitation, which the militant tendency would, I suspect, like to remove from the arena

...

'I am unsure that among these disparate agencies, which inevitably have conflicting interests, there can be a united cause. And I am not enthused by the performance of the BCODP, I do not buy their Marxist view of the world, which tells us that disabled people are not handicapped by their own disabilities, but by our socially oppressive capitalist culture' (Goldsmith, 1982).

Goldsmith, having characterised the new BCODP as a disturbing revolutionary tendency taking over the disabled people's movement went to the defence of the threatened charities. From being an important supporter of the more radical voice of the early movement, he had become part of the disability establishment.

A bit later, in 1986, there was another example of this polarisation at a conference set up in London by occupational therapists. It was to consider how professionals and disabled people might co-operate over future service development. It was a concerned attempt by professionals to respond to the pressure of criticism coming from the disabled people's movement.

The event drew together practicing Occupational Therapists and people from disability organisations, including members of the BCODP and in the course of the debate, it was proposed that the occupational therapists' professional association set up a joint working party with the BCODP, to take these ideas forward. The proposal was strongly objected to by the director of the

Greater London Association for the Disabled (GLAD), who argued the BCODP should not be treated as the most representative organisation above well-established membership organisations such as GLAD, or RADAR [personal memory]. For various reasons, principally time and commitment, the joint working party did not materialise.

To put this response into context, since the 1970s, GLAD had been the umbrella charity for all London's local Associations for the Disabled. But, with the trend to transform these associations into organisations of disabled people, where allegiance was transferred to the BCODP, GLAD was feeling the draught of an uncertain future.

BCODP faced many such difficulties gaining recognition as an authority on disability. Bradshaw recalled:

'With no money it was difficult to get people to take you seriously and initially not much notice was taken of us ... it was a hard fight to get over this new initiative to recognise disabled people's right to control their own lives and be involved in the politics and running of their own services.' (Bradshaw [interview] 1991).

National government response to grass roots pressure

Grassroots pressure for legislation to put an end to discrimination, was developing rapidly and in due course a vocal lobby of disability organisations, and charities,

argued that disabled people must have a legal framework with which to claim their right to services and to consultation by service providers. Many of the councils were still failing to apply the CSDP Act to deliver the welfare, or housing services, people desperately needed, leading to widespread dissatisfaction all around the country (Barnes 1991: p224, Oliver and Barnes 1998: pp88-92).

In response to these mounting pressures, the Conservatives drew up the *Disabled Persons, (Services Consultation and Representation) Act (1986)*. This legislation represented the beginning of a new phase in the government's programme to make local authorities follow central directives about the way they provided community services. The Act gave disabled people the right to have a Social Services' assessment (although the right to service provision was not so assured). It also introduced, for the first time, a requirement on local authorities to consult with organisations of disabled people, giving disabled people some rights to represent themselves.

Whilst this Act was a paltry attempt to address disabled people's lack of access to services, it did introduce into the law the concept of disabled people having some rights and a place in the consultation process. This small concession was important, but the much more comprehensive issue of discrimination had been sidestepped.

Implementation of this law faced the beleaguered and overstretched local authority services with a resources problem (Jones 1995: pp108-115). They were slow to respond and in terms of offering people assessments and better services, the 1986 Act remained largely ineffective (Barnes 1991: p137, p230, Beardshaw 1988). Little changed until after 1993 when the intentions of this Act became overtaken by the provisions of the *NHS & Community Care Act (1990)*.

The affect it had on relations between disabled people and professional services, was significant however. By raising false expectations, the national government set up a pattern that became endemic over later years. It encouraged individuals to believe they had rights to services, whilst at the same time it undermined those services by undercutting the funding. By manufacturing false hope, it fuelled frustration and antipathy towards a welfare state that didn't deliver (Finkelstein 2004b: p208, Priestly 2004: pp258-263).

For disabled people trying to change British society, this period was like being part of a see-saw of action and reaction. The efforts of their organisations were not only caught between a central government and local governments, at odds with each other, but also variously, they found themselves at odds with, or allies of, the constituent parties. Given the intense conflicts going on at the time, one might ask whether the 1986 Act was a government concession to disabled people, or a testing

ground. They were after all involved in a much longer campaign to disengage support for the welfare state and at the same time encourage a culture of individualism.

This was the time that disabled people were still forming their ideas about how to empower themselves and build up their social liberation movement. Their collective consciousness was therefore maturing just at the time that the concept of society, as a collective enterprise, was coming under heavy attack. During the first half of the eighties, whilst there was still some class solidarity, the drive to build a united struggle of their own was going with the tide. But once more general resistance to attacks upon the public services, waned, their liberation movement had to face the powerful effects of the cult of individualism.

CHAPTER 8 - Self-help as a new service paradigm

Against the backdrop of social and economic reconstruction during the Conservative party's period of government in the 1980s, referred to in chapter 7, the disabled people's movement evolved a whole new network of grassroots activity strengthened by having the BCODP (UPIAS 1981: pp1-5). This is shown in my survey results (see chapter 7) and the results of a subsequent survey by Barnes and Mercer (2006: pp76-79). Over the next decade, three dominant themes underpinned the campaigns that followed. These concerned how disabled people were to achieve their independence (discussed in this chapter); and evolving their own disability culture and campaign for civil rights, which are taken up in chapter 9.

As time went on, the ways people then responded to all these themes became manifested, predominantly, in two political wings of the movement. One set out to apply the ideas generated by the UPIAS, here referred to as the emancipatory tendency, the other, which took up ideas generated by a growing rights movement, is referred to here as the liberation tendency.

From 1981 onwards, at the time of BCODP's inception and the emergence of the various regional coalitions, by the end of 1985 coalitions had been established in Nottinghamshire, and Greater Manchester as well as Derbyshire (Davis, 1985), one of the first major concerns was about how to enable people to move out of

institutions and have a normal life. By then many were convinced that, with the right kind of housing and personal support, it was possible, even for severely disabled people to live independently of family, but this had to be demonstrated (Davis 1981: p322, UPIAS 1983: pp5-23). Starting from a point of scant availability of accessible housing (Borsay, 2005: pp172-175, Morris 1990), and almost no services to support independent living in the community (Beardshaw 1988: p45), it was crucial to devise the kind of services that would enable this integration to happen. Enabling people to have full control over their lives very soon became known as the independent living movement (DeJong 1981: pp239-247, Morgan 2014: p207, Morris 1993: pp17-28).

Taking the initiative

Independent living, what this meant and how it was to be achieved, were basic questions that needed answers. To live in your own home, find work, have a partner, get married, have children etcetera, raised innumerable questions. Many disabled people were going to need various forms of ongoing support to achieve the independence they were after and it clearly did not mean doing everything for themselves.

When trying to work out what kind of new support services were needed and what could be expected from society, it seemed there were two possible ways forward. One option was to take on the enormous task of challenging the welfare state to deliver new services in a

client-focussed way, so people could obtain the help they needed. The other option was to start afresh, and perhaps follow a model of service just emerging in the USA.

The British scene

Whilst there was much to criticise, Britain at least had a welfare state and, for those about to embark on a campaign to create a new service, this had to be taken into account (Davis and Mullender 1993: p11). The universalist principles of the welfare state which promised equality of access to public services to meet basic needs, irrespective of ability to pay, had set out to remove reliance on begging and charity during periods of unemployment or sickness. For many disabled people, and particularly for those in UPIAS, at this stage universalism was a principle to be supported (Davis and Mullender 1993, UPIAS 1974 / 76: p1).

However, disabled people, along with many others, frequently experienced the public services as alienating and inefficient. Welfare systems had become social traps forcing large numbers of disabled people into passive dependency on the family, the state and charity (Oliver 1993: p52-55). Exacerbating this dependency were the medical and welfare professionals whose understanding of disability as a human rights issue was poor and who often made things worse by discouraging people from taking risks (Oliver 1993). As UPIAS activist, Dick

Leaman, put it when proposing the creation of a CIL in Lambeth:

With 40 years of history to look back on, the collective experience of younger disabled people can be unequivocally confirmed: that the modern Welfare State has failed to meet our needs, has failed to move significantly in directions which could meet our needs and has failed to accord us any priority of provision even within its own categorisation of (according to Care in Action 1981) 'priority groups' (Leaman 1989a: p1).

To help explain this failure, Oliver (1998: p6-8), and Barnes and Mercer (2006 13-17), point to the various settlements on which the Welfare State was based. They argue that its original formulation had opened the door to discretionary interpretation. It had led to discriminatory policies, and practices, that amongst other things, produced a social security system based upon assumptions of disabled people's dependence on the family or charity. This in turn had driven policies that favoured 'special needs' provision and segregated services rather than barrier removal and integration.

This situation was driving leading disabled activists to conclude they must have an influence on future service arrangements to make them perform in a more enabling way. Dick Leaman wrote:

It is now widely recognised that the failure of professional service providers to meet the needs of physically disabled people is not simply due to lack of resources, but due to their failure to involve disabled people themselves in the planning, design and delivery of services to meet our needs, and the failure thereby to challenge, the traditional relationships between providers and recipients of 'care' (Leaman, 1989b: p3).

In Britain there needed to be a radical new approach. The question was how new services were to come about. For those who felt the welfare state, as they knew it, was beyond reform the system being pioneered over in the USA looked attractive.

The American scene

The service context in the USA was different. There, no equivalent welfare state existed, and therefore no universality principle of welfare support. The services disabled people received were broadly financed by a mixed system of private medical insurance, compensation for personal injury, private income, charity or if they met the strict eligibility criteria, they could access the state welfare programmes for the poor, funded by Medicaid and Medicare (Brock 2000: pp223-235, DeJong 1983: pp157-170, Russell 1998).

On the other hand, the US offered an extensive market of services sold as products to consumers. The system was able to boast some excellent services, such

as privately negotiated personal care, some very advanced medical care, and sophisticated technical aids which could offer high quality assistance. But, only people with the right kind of insurance could access these (Russell 1988).

Many disabled Americans, without private income remained stuck in institutions or living in extremes of hardship. Good services were often only “potentially” available to them (Russell 1989, pp74-83, pp102-108). As in Britain, the lack of comprehensive community support had driven some disabled people, in the USA, to take the initiative. From various backgrounds, including disabled Vietnam War veterans, the search was on for a way to improve control of their lives, to move from institutions, take up careers and have a life in the community (DeJong 1981: p239). After a few experiments, a new type of service organization called Centres for Independent Living (CIL) emerged. The first one was established in Berkeley, California, in 1973 (Priestley, 1999: p71).

American CILs, developed a range of support services, run *by* and *for* disabled people, with the aim of empowering people to decide for themselves and achieve their aspirations. The idea soon became a popular movement and spread from Berkeley to several other States. Out of this CIL movement, disabled people found ways to access funding, so they could employ their own personal assistants (PAs) and this was a big

breakthrough (Barnes, Mercer and Shakespeare 1999: p148).

By privately employing PAs they created a flexible service that was more responsive to their individual needs and gave them back some control of their lives. This flexibility enabled significantly impaired people to take up education and employment and get on with living alongside their non-disabled peers and the idea took off in a big way (DeJong 1981: p243), (Barnes and Mercer 2006: pp31-32). When looked at from Britain it seemed that in the US disabled people had achieved a degree of freedom that was very enviable and unsurprisingly it attracted a lot of interest.

The development of CILs and the employment of PAs were soon an integral part of a growing social movement of disabled people in the US. They too needed to tackle institutionalisation of disabled people and the social and `architectural barriers preventing integration. By the 1980s this had evolved into a significant civil rights movement (DeJong and Wenker 1983: pp4-27). It was the first, of many such movements around the world, to achieve Anti-Discrimination Legislation with *The Americans with Disabilities Act* (1990) (Oliver and Barnes 2012: pp148-149).

In the US, pursuing rights to independent living, through privately employed help, went hand in hand with developing a civil rights campaign to meet the needs of the disabled community (Bynoe, Oliver and Barnes 1991:

pp31-37, DeJong 1983). It was an approach to a liberation struggle in which people placed their trust in rights-based mechanisms, or as Russell puts it 'identity-group politics' (Russell 1998: pp230-233), to empower them as individuals to achieve independence and quality of life (Oliver and Barnes 2012: pp148-151).

Developing an independent living movement in the UK

For disabled people in the UK, it therefore appeared that there were two possible ways forward. Developing new avenues in the welfare state or following the American example (Campbell and Oliver 1996: p204, Oliver and Barnes 2012: p166).

During the next twenty years the organisations, referred to below, all played their part in setting down some of the foundations for independent living in the UK. In developing the various new service initiatives, people turned increasingly to the social model of disability to provide them with a framework. Out of this general agreement, two different strategies emerged in line with the different routes identified above.

Since the trap of dependency was principally caused by the failure of the welfare state to involve disabled people in the planning, design and delivery of services, all the pioneers of Independent Living in the UK wanted to create more involving and empowering alternatives (Oliver 1993: pp52-59).

The emancipatory tendency, led by ideas coming from the UPIAS, set out to achieve this kind of change by

entering into a partnership with the welfare state (Davis and Mullender 1993: pp18-22), The other trend, the personal liberation tendency, turned away from the professional welfare services and opted for more direct control (HCIL 1986b), (Evans 2003a: pp40-41).

In the 1980s the pioneers for independent living, in the UK, were small groups of disabled people living in Derbyshire, Hampshire and the London Borough of Greenwich independently of each other, they were all looking for ways to enable people to live outside institutions with proper support (Evans 2003a: pp41-45) (Davis and Mullender 1993), (Barnes and Oliver 2012: pp166-167).

The range of initiatives that followed then became linked by this common interest and known as the independent living strand of the movement. Once people learnt of each other's initiatives, ideas developed, and information spread rapidly through the movement as more people became linked by the BCODP. The first attempt to create an emancipatory approach to support independent living was through the efforts of people in Derbyshire; whilst in Hampshire and Greenwich people led the way towards a personal liberation tendency.

Looking back, Davis and Mullender (1993) refer to the cross-fertilization that occurred between these three pioneering groups and differences between their ideological approaches were not yet clear because of the experimentation going on (Davis and Mullender 1993:

pp37-38). Nine years later, the differences became more clearly defined when a fourth initiative appeared on the scene in the London Borough of Lambeth (Leaman 1989a). This once again took up the emancipatory approach and tried to take the ideas a bit further.

Disabled people in Greater Manchester also played a significant part in developing the early independent living politics from the perspective of the emancipatory tendency, but as their structures evolved differently from the four above (Ken Davis [interview] 1991, Kevin Hyett [interview] 1998), I shall return to this at the end of the chapter.

The way the first four developed, the service initiatives that followed, and what happened to them, is explored in some detail below.

Integrated living - an emancipatory approach

A fundamental principal of the emancipatory tendency was the idea that socialised services were the fairest way to provide help across society (Davis and Mullender 1993: pp28-p33, pp38-39, LCIL 1993, Leaman 1989a: pp2-5, 1994). With this as their starting point, it was also recognized that for disabled people to have control of their lives and become integrated they had to have a say in how resources were spent, and services were provided. To achieve this required a substantial power shift within the welfare state.

They set themselves the task of engaging with the statutory services to form a working partnership so that

new ways could be found to provide the services. This was a challenging programme. It posed a totally new way of thinking and working between, and by, resistant professional services and inexperienced disabled people.

The organisational basis for this experimental approach, first in Derbyshire, and later in the London Borough Lambeth, was to set up Coalitions of Disabled People to develop a partnership approach with the local authority. Once that had been achieved, they went on to create Centres for *Integrated* Living (CIL), from which to develop a new kind of support service for disabled people in their localities (Davis and Mullender 1993), (Leaman 1993). Both organisations adopted the term “*integrated living*” to describe what they were about. This was deliberate. It characterized what was, for them, the overall objective. They believed it was essential to pursue a holistic and integrated approach to tackle disability as a social organisational issue. Their name and methods distinguished these CILs from the others which called themselves “Centres for *Independent* Living” (Davis and Mullender 1993: p39), (Evans 2003a: p42).

BCODP’s information pack for its conference on Independent / Integrated Living, in 1984, provided the following definitions adopted by the two types of CIL:

‘Independent Living’ has been described as crystallising around the issue of independence, being a

continuous process of identifying choices and creating personal solutions. It argues that independence cannot be measured by reference to physical accomplishments but by the ability to realise individual decisions. It is not about the quantity of tasks a disabled person can do without help – but the quality of that person's life with help.

[By contrast] 'Integrated Living' has been described as the development of independent living in a social context. It crystallises around the issues of integration, extending independent living choices to include democratic control by disabled people over the design, delivery and management of the resources necessary to realise individual decisions. It sees the quality of disabled peoples' integration as being dependent on our representation in arrangements which promote our full participation in the social, economic and political mainstream (BCODP 1984a).

Both Integrated Living initiatives had their roots in the Union of the Physically Impaired Against Segregation (UPIAS). The founders; Ken, Davis, Maggie Davis and Jean Keller, for Derbyshire's CIL, and Dick Leaman in Lambeth, having been UPIAS members. They had come to see disability as a by-product of social organisation that excluded disabled people from work and full social participation (Davis and Mullender 1993: p15, LCIL 1993, UPIAS 1985).

The Coalitions and CILs, they created, were a way of putting UPIAS's ideas to the test. Only time would tell whether such organisations and the relationships they formed with the local state could be a viable way of bringing about the emancipation of disabled people.

Centres for independent living – a liberation approach

The alternative tendency, which originated in Hampshire and Greenwich, also happening around 1981 - 1982, took up the service model being promoted in the USA (Rachel Hurst [interview] 2000, Evans 2003a: p42). The principle founders of these independent living initiatives, John Evans and Rachel Hurst, respectively, did not have any direct links with the UPIAS, and in the early stages, had little or no knowledge of the ideas that the UPIAS had been developing (Campbell and Oliver 1996: p59, Evans 2003a: pp39-42, Rachel Hurst [interview] 2000). They were not, therefore, in a position to draw on the analysis that an integrated approach was fundamental to the emancipation of disabled people from a disabling and segregating society.

They did, however, hold quite similar views to those being expressed in Derbyshire about many of the failures of an oppressive welfare state, and had the same desire to enable people to exercise more control over their lives. The originators also shared the same concerns about barriers preventing people from becoming independent and wanted to find ways to tackle these locally.

In both Hampshire and Greenwich, disabled people established new service arrangements for themselves, and as they became consolidated, became known as the first Centres for *Independent Living* (CIL) to appear in the UK. Both had consciously named themselves after the American model which they took for their inspiration. An uppermost objective was that of enabling disabled people to gain direct control of some resources, so they could employ their own personal help.

A little about the background of each organisation is given below to show some of the differences and similarities in their approaches. The political backdrop was of a society in conflict because it was being overhauled by a Conservative government with an agenda to re-energise British capitalism, (chapter 7). This context was to have a bearing on the ways the new organisations, run by disabled people, operated in terms of the support they received, and how well they survived.

Coalitions and CILs: clarifying their different roles

During the 1980s, local coalitions, which were a new type of organisation in the UK, were set up by disabled people in Derbyshire (1981), Hampshire (1989/1990), Greater Manchester (1985), and Avon Coalition of Disabled People (1989), which was later renamed West of England Centre for Inclusive Living (WECIL) (Barnes and Mercer 2006: p78).

They brought together small local groups, and individuals, into one large organisation to act as a

representative base for the region. They were the means to have democratic representation for consultation, and a base to develop a more united voice when talking to local or health authorities (Mason [interview] 2000), (K. Davis [interview] 2000). The aim of coalitions generally was to promote the active participation of disabled people in securing the greatest possible independence in daily living activities, full integration into society, and general control of their lives. They set out to create a local political base from which disabled people could apply pressure for improvements to services, pull people together to campaign around specific issues, as the need arose, and set up some local support (DCDP 1990; GMCDP 1987a, 1987b; HCODP: undated, Aims and Objectives).

Because they were neither issue based, nor confined to a specific impairment or disability, they could often respond to a wide range of local concerns and, in some areas, became an important way of helping the grass-roots to grow and become more effective. The Greater Manchester Coalition of Disabled People, (GMCDP), for instance, which formed in 1985, has had a long history of very successfully drawing local disabled people into a political process whereby they have been able to develop and promote many integration initiatives in their region.

CILs were different from coalitions. They were established more specifically to develop support services to local disabled people around the idea of

independence. They set out to promote ways of enabling people to develop their skills and abilities to find suitable housing, establish their own personal support arrangements, sort out transport issues and help people to follow up their aspirations in whatever way they wanted to. The fundamental idea was that a CIL must be led by, and respond to, the requests of disabled people to provide services in a new way. It was not to confine its responses according to a set of rigid service criteria as was habitually experienced from the services of non-disabled professionals (Barnes, Mercer and Shakespeare 1999: p164, Finkelstein 1993b: pp40-42, Oliver 1990: pp120-121).

The CILs were the service wing of the local structures but were not necessarily trying to replace the services being provided by the local authority. A better description of them at this stage would be facilitators, trying to provide support, information and advice, so that people could make better use of existing resources for themselves. At times, this might mean becoming negotiators with other service-providers to highlight the absence of services, such as tackling a local housing department to provide accessible housing where none existed or engaging with local transport providers where no accessible transport existed. At other times, it could be about providing support to individuals to achieve more for themselves.

The idea of setting up coalitions and CILs spread around the UK. Some areas developed both whilst others went for either one or the other, and in some areas local associations became transformed into similar organizations but called themselves neither CILs nor Coalitions. There was no set pattern. They were evolving, and the outcome was often a combination of local conditions, and the variable skills and enthusiasms of the people taking the lead, influenced by a spread of ideas from around the country. The significant thing was that disabled people were in charge of them (Barnes and Mercer 2006: pp77-78, pp139-141).

A brief account of four pioneering CILs

In the 1980s local authorities (LAs) were still significant providers of many public welfare services, with a little help from charities (HMSO White Paper: p1989: pp17-23, pp61-62). But by the mid-1980s, many were in conflict with the central government over how much revenue they could collect, from the rates, to spend on their local services (Loughlin 1996: p88-93). The government wanted a reduction in public expenditure whilst local councils wanted to decide how to maintain their local services (Loughlin 1996: p88-93). It was an unstable political and economic period for both public services and localised sections of the disabled people's movement which were developing their own ideas for change within this confusion.

Developments in Derbyshire

Timelines:

Derbyshire Coalition of Disabled People
DCDP (1981-2000).

Derbyshire Centre for Integrated Living
DCIL (1985-2000).

then both merge into:

Derbyshire Coalition for Inclusive Living
DCIL (2000-2011).

then extends the name to:

Disability Derbyshire Coalition for Inclusive Living
DDCIL (2011-2018).

(Companies

House, Charity Commission 2019).

The *Derbyshire Coalition of Disabled People* (DCDP), formed in 1981, subsequently laid down plans for a *Derbyshire Centre for Integrated Living* (DCIL) which opened in 1985 (Davis and Mullender 1993). DCDP and DCIL then worked together to design and establish an alternative service structure (Davis and Mullender 1993) and their pioneering efforts became recognised as a key phase in the progression towards self-help within the disabled people's movement more generally.

Using the social interpretation of disability, they wanted to develop an integrated strategy in the way they

responded to the issues. It was an ambitious project and some years later it was recorded:

The Centre for Integrated Living was to be the spearhead of the way into a new future for disabled people in the county ...It was to set the pace in breaking down the barriers which prevented disabled people living a full and equal life (in: Priestley 1999: pp75-76; from INFO: The Voice of Disabled People in Derbyshire, issue 1, June 1992: p1).

A founding principle for DCDP and DCIL was that, because disability was multifaceted, they had to tackle the barriers on all fronts (Davis and Mullender 1993: p15, pp35-40, DCIL 1986). Single issue, or specialist approaches, like the Crossroads Care attendant scheme, whilst helpful were inadequate as a means to escape institutions or social isolation. A different way had to be found and it was apparent to those setting up DCDP that a new kind of helper-helped relationship was required if disabled people were to become empowered (Davis and Mullender 1993: p59; Ken Davis [interview] 2000).

Their commitment to this principle was no accident. Ken Davis, concurrently a member of UPIAS, was the driving force taking the project forward, and along with other UPIAS members, introduced a wider group of disabled people in Derbyshire to the emancipatory ideas expressed in the UPIAS (1974b, 1976a) policy statement

(Davis and Mullender 1993: p15). From the start this group set out to influence the work of professionals by initiating a power-sharing partnership between themselves and the local state (Davis and Mullender 1993).

Their actions were significant on several fronts. Firstly, they gave a lead to show how the social model could be applied to bring about visible improvements to people's lives. Secondly, they broke new ground by endeavouring to bring about some power-sharing with a LA to provide public services. Once the CIL was established the Coalition hoped it would be able to replace existing services with new arrangements under shared control (Davis and Mullender 1993, Priestley 1999).

Although it was never made explicit, Derbyshire were in practice attempting to introduce the basic principle of people's power into the socialized state sector (Davis and Mullender 1993: pp33-34, pp38-39). This would be distinctly different from the kind of power held by professional managers and bureaucrats to decide for others on behalf of the state, and much harder to achieve. To have delegated powers would mean carrying responsibility for representing a local community in their dealings with the authorities, and this required a lot of working out (Davis and Mullender 1993: pp51-54, DCDP 1990).

They had some limited success, as Priestley's (1999) study of the Derbyshire experiment showed. The local authority, whilst not seeing the potential for power-sharing with DCIL, in quite the way the Coalition hoped, was nonetheless persuaded to invest statutory resources into non-conventional forms of service development, which were then co-managed with local disabled people.

For both DCDP and the DCIL, pursuing an integrationist agenda meant also applying this to the way they worked within the organisations (Davis and Mullender 1993: p39). They emphasised that independence was not only having suitable housing and personal assistance but was also about being mobile, having the opportunities to work and enjoy leisure pursuits, have relationships and the freedom of access that others took for granted. A new service response to address all these interrelated aspects of disability was needed and they set out to create it (Davis and Mullender 1993: p40).

Some foundations for the new approach originated from the prior experiences Ken and Maggie Davis had gained from the *Grove Road* housing and support enterprise in the nearby county of Nottinghamshire (chapter 6). This had proved they could live independently of institutions with the right kind of support. Now it was a matter of taking this principle further.

Another contribution in the sequence of events had been the success of the first Disability Information Advice

Line (DIAL), also a brainchild of Ken Davis. By 1980, the people running the service had systematically analysed some 5000 enquiries from the public, and in doing so, established themselves as the most experienced and qualified group of disabled people in the county to articulate the concerns of others. This drew the attention of an officer of Derbyshire County Council when he wanted some forward-looking ideas for IYDP (Ken Davis [interview] 1991).

Working together with the Council, this group from DIAL agreed to set up an open meeting to decide how to go forward and it was from this meeting that foundations were laid for a single representative organisation of disabled people in Derbyshire (Davis and Mullender 1993: p8). It would bring together different groups and individuals, to form a democratic base from which decisions could be made. Such an organisation could then work with the council for improvements to services.

With encouragement from the county council they subsequently established the Derbyshire Coalition of Disabled People (DCDP) in 1981. It was in this setting up process they gained an important commitment from the County Council to develop a co-operative relationship (Davis, 1989).

Once up and running, the Coalition then started to test the county council's commitment to a co-operative relationship. It drafted a *Statement of Intent*, which set down how they would all promote integration throughout

the council's departments and policy directives and a considerable battle ensued. Finally, the County Council agreed to accept this statement as the basis for future service planning (DCDP and Derbyshire County Council, 1981b). Davis points out how significant this episode had been for drawing disabled people into the political process. He said:

‘To get it [the draft statement of intent] through each service committee was an awareness raising exercise itself. The establishment of the DCDP had substantially increased the level of consultation on all sorts of decision-making forums that disabled people had never been near before.’ (Ken Davis [interview] 1991).

Davis outlined some of the difficulties they had when they made their first overtures into council services with an attempt to change the traditional helper-helped relationship in the home help service.

‘Right at the beginning of the 1980s before we got funding for the CIL we held a conference and invited most of the main players and politicians. We entitled it *Help or Hindrance*. It was about the way help was provided, how it was controlled, to what extent it supported people's autonomy and control over their own lives, to what extent it took it away. It started the relationship off, in that particular area, on a very nervous footing. They found it

very difficult to cope with the idea that the kind of home help, 'home aid service', they saw as their flagship, could actually be a hindrance to disabled people's autonomy and independence. So, there were difficult concepts to deal with. At the heart of the matter was the controlling nature of the authority to the provision of the services, and an unwillingness to go any further than it was prepared to in changing that relationship. It did change that relationship to some extent, when DCIL came on stream in 1985.' (Ken Davis [interview] 2000).

What they wanted was for disabled people to have a say in the appointment of council care staff. Ken Davis explained:

'To some extent our relationship before Community Care, was to try and influence the direction in which the rates were spent. To introduce a change in the relationship between individual disabled people in need of personal assistance and the authority, to try to get people involved in interviewing of personal assistants that were then employed by the authority. A number of minor changes were made by County Council Social Services in that direction, but they were minor and it was always a tricky area between the two organisations.' (Ken Davis [interview] 2000).

The period in question, the early 1980s, was just prior to the time when local and national governments entered open conflict over rate capping made possible by the Rates Act 1984 (Loughlin 1996: p187-199). Derbyshire, as a Labour-controlled council, supported the idea of equal opportunities and was committed to the idea of providing good-quality socialised services to the local community. This meant it was inclined to be supportive to the political initiatives coming from disabled people and the DCDP project in particular (Davis and Mullender 1993: p25).

There was a wide range of issues the Coalition needed to take up with the local council, if people were to obtain general access to the community and before setting up the CIL, DCDP organized discussions with local disabled people, to decide their priorities for action in Derbyshire. From these meetings it was agreed that the most pressing service issues facing them were; information, housing, technical aids, personal assistance, transport, and access to the general environment (Davis and Mullender 1993: p40). They decided these would be the core areas they concentrated on, to which they added counselling, for it was recognized people often needed advice to help them make good use of information to reach decisions. Some years later, these seven core “areas of action” came to be called “the Seven Needs” (Davis and Mullender 1993: p40, Priestly 1999: p71). They were subsequently

adopted by many CILs around the country as a model framework for their own service provision. In 1989 HCIL increased this to eleven areas of action by adding employment, education and training, income and benefits, and advocacy (Barnes and Mercer 2006: pp47-48, p95), (Evans 2003a: p44).

In Derbyshire, trying to address these seven areas, the Coalition soon realised people needed the support of services that were not offered by the local authority, but the Coalition was not in a position to provide this.

They had become aware of ideas filtering through from America, Scandinavia and Holland, where different models of independent living were being tried out, but after critically looking into these they came up with their own scheme. This was to set up a centre for *integrated* living run by and for disabled people (Davis 1993).

Derbyshire Centre for Integrated Living

From the outset DCIL was to develop its aims, policies and service initiatives in line with the social model of disability (Davis and Mullender 1993: p15, DCDP / DCIL 1998: p2). To ensure it remained true to this philosophy, and sensitive to the views of its service-users, DCIL was made accountable to the more representative management board of the Coalition. By 1985, DCIL had acquired a building, a small staff, and opened its doors to the public.

If anyone was to think DCIL was just another variant of social services, but run by disabled people, they just

had to look at its aims. These made clear it was a fundamentally different approach. The aims stated:

‘They would promote the active participation of disabled people to ensure that the social changes they were seeking were based on their own experience’ (DCDP / DCIL, 1998).

In their aim for 'independence' they wanted to secure for disabled people the ability to make the same range of choices most people could expect, but with support where need be. In their aim for 'full social integration' they meant disabled people having the ability to take part in the mainstream of life free of prejudice, discrimination and other social and physical barriers. Their aim for disabled people to have 'full control over their lives' meant being able to make the same choices and decisions in their lives as most people would take for granted (DCDP / DCIL, 1998 Induction Booklet). As DCIL's prime purpose was to promote integration, disabled people would be supported to bring about the necessary changes to permit greater participation.

Ten years later, reflecting on their achievements, Davis felt they had been able to make a difference. He had noticed that over time the expectations of disabled people had changed substantially and the outlook of professionals within the services had also changed:

‘Even if not connected to DCDP people make greater demands for themselves ... these were helped by workers in the Social Services who now expect disabled people to have high expectations and tend to elicit certain behaviour from their clients’ (Ken Davis [interview] 1991).

The seven core areas, mentioned earlier, had provided the Derbyshire Centre for Inclusive Living (DCIL) with its basic framework for developing support along integrated lines. This was achieved by facilitating disabled people to develop local peer groups and networks and engaging people in awareness-raising discussion and activity. Sometimes it was by supporting grassroots projects, and sometimes by helping on a one to one basis.

During an interview, DDCIL’s director reflected that by employing community workers, their attempts to promote integration and participation through the formation of local groups had been reasonably effective:

‘The first access group was set up five years ago – now about 18 groups – and the effect of those groups has been a proliferation of road crossings – compared to one there are dozens - they have made post offices accessible and there are numerous examples of counselling networks locally with periodic social gatherings’ (Rob Walker [interview] 2000).

He also mentioned that having their own research workers to back up the community workers had been helpful for they were:

‘able to point out the national nature of a problem, such as in housing, which helped them (the groups) to set up what was needed locally’ (Rob Walker [interview] 2000).

Encouraging self-organisation proved effective for by supporting people to take up barrier-removal activity for themselves, they enabled such people to develop their self-confidence, and both aspects contributed to the struggle against disability. DDCIL, additionally, set out to develop its relationship with the statutory services to influence change. Engaging more disabled people in this process had also been important. As Davis noted above, it was the learning experiences people gained when working with the authorities that were invaluable.

DCIL found that when they developed a consultation process on the provision of technical aids, it was valued by the authorities as well as themselves. Together they had been able to set up a system of self-prescription that substantially improved access to the service. DCIL then developed a user group which provided useful feedback to equipment manufacturers and purchasing authorities (Rob Jackson [interview] 1991).

In developing their new approach, they drew a lot of interest from around the country. In a speech to the Glasgow Forum on Disability in 1985, Davis cited CILs in various stages of development in five regions of the UK (Davis 1985). People turned to Derbyshire for inspiration and guidance.

Over subsequent years many CILs developed. Some have survived whilst others folded.

At the time of writing DDCIL has become a dormant company and has been removed from the register of charities.

Hampshire Centre for Independent Living

Contemporaneously in the 1980s, with a different approach, the Hampshire Centre for Independent Living (HCIL) was more of a loose network of disabled people who wanted to share their own experiences of independent living to support others striving to achieve the same thing. Philip Mason, and Liz Briggs, founding members of HCIL, told the author that Hampshire CIL was run on an entirely voluntary basis and therefore not reliant on LA funding. Their objectives were to support others striving to achieve their independence from institutions (Mason and Briggs [interview] 2000).

Their focus, initially, was on; personal assistance, information and advocacy, and training in independent living skills (Mason and Briggs [interview] 2000) (Barnes Mercer and Shakespeare 1999: p149).

For them the social model was not an influence. Initially, they were not particularly aware of it and did not attempt to set up a broad-based organisation such as a coalition. Neither did they set out to change the local public services. Their interest was in finding ways to support individuals to manage their own lives and the model they turned to came from the United States.

Paradoxically, the origins of HCIL were also rooted in the struggles of the Le Court Cheshire Home. It was some years later, though, that a small group of residents, wanting to move themselves out of Le Court to live in the community set up *Project 81* to help achieve this (Evans 2003a: p40-41). They went through a tortuous process, but finally succeeded in having their financial support redirected to enable them to move out and employ their own personal assistants (Barnes and Mercer 2006: p46). A few disabled people had achieved something similar elsewhere, in the UK in the 60s, (Priestley, 1999: p201), but it was extremely rare.

The earlier efforts of Le Court's residents, for more control over their lives, was influential, and had encouraged this group to extend their control by moving out altogether. Once outside, the group provided each other with ongoing peer support over recruiting, and managing, their personal help arrangements on a day-to-day basis. Having gained this experience, they saw the potential to extend their peer support to others who wanted to try similar experiments of independent living.

In 1981, John Evans, looking for a way out of Le Court, took the opportunity to visit the Centre for Independent Living (CIL) in Berkeley, California. There he found disabled people were running their own services and promoting the idea of employing their own personal assistants (PAs). He found their scheme was enabling profoundly disabled people, like himself, to take considerable control of their lives in very significant ways and showing how empowering it could be when they ran their own services (Evans 1986, 2003b 67-68).

Returning to Britain, enthused by what he had seen, Evans set out to promote and apply the ideas with the *Project 81* group, which in turn became HCIL. This project was the first stage of moving towards private schemes under the personal control of individuals (Evans, interview 1990).

HCIL subsequently developed the idea of Self Operated Care Schemes (SOCS), which were later taken up by the developing IL movement and it published the first *PA Recruitment Manual*, (HCIL, 1986a). Their guide was extremely valuable to disabled people employing their own helpers for the first time.

Making money more widely available, to pay for personal help in the community, soon became a campaign issue, and was brought to prominence when the domestic care allowance was abolished by the 1986 Social Security Act. People had been reliant on this money to help pay for personal assistance. It galvanised

HCIL, from the Disabled Peoples Movement, to join forces with the Disablement Income Group, to press the government to release some specific funding for community care (Evans 2003a: p47, Morris 1993: p14). In 1988, their efforts resulted in the creation of the Independent Living Fund (ILF). Initially £5,000,000 were set aside by the Department of Health and Social Security to enable the experiment to proceed but by 1992 / 93, this fund was paying out £100 million to support 21,000 disabled people living in the community (Priestley 1999: p201). The demand had way outstripped official expectations. This fund was then jointly managed by Health and Social Security and DIG (Kestenbaum 1993: p37, Morris 1993: p14).

The ILF formalised the new principle (previously pioneered by the small, Project 81, group), that enabled individuals to receive state funding for personally tailored, community care schemes under their own control. As Morris noted (1993: pp13-14) this significant change laid the ground for future policy. Whilst the money still had to be channelled through a welfare organisation, such as Social Services, the principle of independent living for disabled people was accepted and from then on it became easier for others to leave, or avoid, institutional care (Morris 1993: pp13-14, pp164-165)

The process of escaping institutions and concentrating on the matter of maximum control over personal life had led HCIL members away from the

concept of the socialised services that had failed them. It was why the model from America appeared so attractive. In due course it became clear how significant this was to be for the wider movement and for society.

In 1984, also in Hampshire, the Southampton Centre for Independent Living (SCIL) was set up. The SCIL had a more formal structure by operating within a building and by 1991 had enough funds to employ some disabled people to staff it. It quickly became the major service provider of the two Hampshire CILs. HCIL then saw its role more as an advocate on behalf of the scheme in the policies and practices of Hampshire County Council. As with HCIL the general approach of SCIL was to support independent living by employing personal assistants. By 1990, in common with many other user led organisations, both HCIL and SCIL had adopted the social model of disability to inform their practice (Philip Mason and Liz Briggs [interview] 1991, SCIL 2009).

After a while, the members of these two CILs felt disabled people needed a broader, more representative base in Hampshire and they jointly set up the Hampshire Coalition of Disabled People on a similar basis to Derbyshire's, except it did not have management of either of the CILs. It was easier then to take up issues falling outside the remit of the CILs and have representation at consultation forums. The multifaceted nature of disability meant they too found the need for a

political base to respond to the wide range of issues (Philip Mason and Liz Briggs [interview] 1991).

Ian Loynes, CEO of SCIL, explained to me that in due course much of this work fell to SCIL, now renamed Spectrum CIL, and in 2012 Southampton Coalition was deemed no longer viable and disbanded (Loynes, 2014, private correspondence).

A centre for independent living in Greenwich, a variant approach

Concurrently to Hampshire's initiative, the idea of setting up a Centre for Independent Living had also taken root in the London Borough of Greenwich. Whilst it had many similar ideas to those emerging in Derbyshire, it was ideologically closer to HCIL, being predominantly influenced by the US model. A brief summary of its history is given below.

Rachel Hurst was its prime mover and she describes how separate the early initiatives were back in 1978 / 79. Wanting to do something about the extreme powerlessness she was experiencing as a disabled woman, she was on the lookout for information. She recalled:

'I looked disability up in the telephone directory. I made contact with Greenwich Association of Disabled People (GAD) which had just acquired a part time worker, not disabled, there was one disabled person on the committee who at that point in his life would do what the

other older women were telling him to do ... Every six months it had the wider membership from the day centre coming along for tea and buns.

Terrifying.

I had no experience of working in a political way at local level, but I could see this organisation had direct links with the local authority and with councillors. There was potential there' (Rachel Hurst [interview], 2000).

On becoming a committee member, Hurst soon found herself looking for other disabled allies to counter the GAD committee's plan to raise money for a respite care institution in Greenwich. The very idea appalled her. But then a television programme changed the course of events:

'I saw Rosalie's (television) film, *We Shall Not Go Away*, on Berkeley – transmitted in late 1979 to early 1980. I started reading, and information about what was happening in America started filtering through somehow' (Rachel Hurst [interview], 2000).

(Rosalie Wilkins, referred to here, was the presenter for Link; the Independent Television's (ITV) weekly disability programme of news, discussions and interviews mentioned in chapter 6.).

Like John Evans had done previously, Hurst visited the CIL in Berkeley, California, and obtained the ammunition she needed to argue her case against the institution idea. Whilst she was in the US, she learnt of the similar interest developing in Hampshire:

‘I knew nothing about UPIAS at that stage, I knew about John Evans and a little about Hampshire, but there was no way to know what was going on in the rest of the country. There was no relationship’ (Rachel Hurst [interview], 2000).

Hurst explained that she had recruited other disabled people to GAD and together they started to try and replicate what she had seen in Berkeley. Whilst Greenwich CIL was not founded on the social model principles, because this was unknown to them, once connections had been made with others in the growing movement, they started to incorporate this model into aspects of their practice. To put disabled people in control of GADCIL, (as it became), the local association had its constitution modified in 1983. Once this was done, the organisation was able to join forces with others in the BCODP and it became a leading player in the Independent Living Movement (Rachel Hurst [interview], 2000).

Adopting Derbyshire’s idea, GADCIL also drew up a statement of intent, in 1983, to obtain some commitment

from the council to promote integration and de-institutionalisation of disabled people and from there it developed new initiatives around housing, access, transport, information and personal assistance. Whilst deploying a strategy, of working with the local authority in a pragmatic way, to win improvements to the environment and services, it was sometimes able to build quite close working relationships with local authority officers. However, unlike DCDP, it did not formally seek a working partnership as a matter of principle (Rachel Hurst [interview], 2000).

As with Hampshire, GADCIL promoted the employment of PAs to support independent living (IL), and became another pioneering group in the business of gaining agreements, with statutory agencies, to channel funding direct to individuals to employ their own help. This coterminous development happening in Greenwich and Hampshire added strength to the trend that favoured the US model (Rachel Hurst [interview], 2000).

Unlike Hampshire, GADCIL did not choose to form a Coalition for it did not see the need. As an association it continued to offer both functions, of service provision and representation.

Once established, GADCIL linked up with the other CILs to develop their ideas via the BCODP (Rachel Interview 2000). From there on, the new service initiatives developing through these CILs gathered strength and popularity. What had started as separate

ventures quickly came to represent a movement of user led services promoting independent living (Barnes and Mercer 2006: pp77-82).

A centre for integrated living in Lambeth

The last CIL, to be considered here, is the one set up in the London borough of Lambeth, in 1990 / 91, with premises and paid employees most of whom were disabled (LCIL 1990). It highlights different issues because by the time this CIL came into the picture, ten years had elapsed. Rate-capping of Labour councils was well underway, and the services were having their funding squeezing, but the fundamental restructuring of the welfare sector, although imminent, had not yet begun. Disabled people in Lambeth, learning from the experiences of others, decided to follow the same course of action to organize their own user led support (Leaman 1989a).

The Lambeth group followed Derbyshire's pattern of setting up a Coalition first, in 1989 (Leaman 1989a) closely followed by a Lambeth Centre for *Integrated Living*, which the Coalition continued to manage. The difference this time was the way in which power sharing between disabled people and the Social Services was introduced.

Learning from Derbyshire, the idea of a working partnership was built into the LCIL from its conception. The principal initiators for this were Dick Leaman, an erstwhile UPIAS member, (for UPIAS had by this time

disbanded), who was leading the movement for a Lambeth Coalition, and Helen Saunders, the Principal Occupational Therapist (OT), of Lambeth Social Services. They jointly set out to negotiate an agreement with the council to hand over the running of part of the OT service, (the independent living equipment service) to the CIL (Leaman 1989b, Saunders 1989b).

The concept of joint working interested Saunders because her own service was in severe difficulties and failing to respond appropriately to provide the equipment disabled people needed. The LCIL's suggestion offered the potential to help her resolve this problem (Saunders 1989b).

For Leaman and the LCIL, working jointly with Social Services offered the possibility of much needed resources and the chance to try out a more empowering way of providing a service. The LCIL wanted to escape the tradition of prescribed solutions by professionals and introduce a concept of self-assessment with some professional advice available when needed. They wanted to foster an active relationship between service applicant and provider, instead of reinforcing passivity (LCIL, 1994, Policy document for the equipment service).

To offer people a service when it was needed required an open-door policy rather than one that rationed equipment by waiting lists. LCIL hoped that, after a period of transition, it would be entrusted with a slice of the council's budget, so it could fully run the

service (Leaman 1994, Saunders 1989b). This, if it happened, would be a significant breakthrough in changing the relationship between disabled people and professional services.

In their negotiations with council officers, for transfer of funds and responsibilities to the CIL, Leaman and Saunders confronted substantial barriers of resistance to the idea of disabled people sharing some control of public sector services. This required professionals giving up some of their power as Saunders 1989 proposal, to the council, explained:

‘Lambeth council is rightly proud of its equal opportunities policy, which underlies everything it sets out to do. In order to implement the policy in the services we provide for disabled people we must first understand what it means for them.

Disabled people cannot experience equal opportunities unless they become fully integrated members of the community. Integration must therefore be the ultimate goal of service providers and not simply independence, which can still leave disabled people isolated from the non-disabled majority.

... We do have good intentions and limited resources, but surely, we could be less possessive about our clients and more imaginative in what we offer? In order to equip disabled people with tools they need to join in the cut and thrust of life, along with everyone else, we

must learn to share our skills and knowledge and hand over some of the power we now hold. To do this, responsibly and effectively, we need to work in partnership with disabled people' (Saunders 1989a: p1).

With some hesitation the council agreed to the experiment. An occupational therapist (OT) was seconded by social services to work with LCIL to set up and run the equipment service. Reflecting back, Gitte Rinds, the appointed OT, remembered what a lonely experience it had been developing that working partnership. She found it was hard to gain the trust of the disabled people setting up the CIL but also gaining the trust of her OT colleagues from the department:

'There were disabled people working there when I arrived, and I was seen as the social services policeman arriving. They were just not talking to me. ... I felt I was feared in both camps I was seen as someone in between both camps, definitely seen as somewhere else and it took a long time.

... I was facilitating stuff happening and it did involve confrontations, in the CIL, and some fights with higher level management in social services, for funding, and for somewhere to actually provide a service ... my own profession had great hesitations they did not think it (a model of self-assessment) was possible, that people didn't know what their own needs were, or wouldn't be

able to measure up their bathroom for equipment. To them it wasn't a professional assessment' (Gitte Rinds [interview], 2000).

These were not surprising. Given the overwhelming culture of medical paternalism, a significant ideological shift had to occur before professionals would appreciate the benefits of an empowering model of service and not feel undermined by having disabled people running it. In due course, LCIL did change attitudes with some professionals recognising the benefits of shared responsibility for the service (Gitte Rinds [interview] 2000).

Like others, LCIL built up several enabling forms of support and made the centre a resource base for local disabled people. Amongst other things it included the services of a handyman to do small jobs in people's homes, money and welfare rights' advice, independent living support and training, some specific services for hearing impaired people and a leisure / toy library (LCODP 1994).

This was, until it became overtaken by other events towards the end of 1993 when public expenditure cuts, the *NHS and Community Care Act (1990)*, and the *Children Act (1989)*, started to have a big effect on the local authorities.

Between 1994 and 1996 LCIL rapidly experienced the withdrawal of goodwill and co-operation by council

officers. The local authority was in retrenchment mode having been placed under intense pressure by the government into redefining local services. Adding to their difficulties, many senior management posts changed hands, including that of Director of Social Services and Head Occupational Therapist, and with these changes LCIL lost some of its key supporters. Also, some of LCIL's key supporters, amongst the council officers, resigned their posts and were replaced by a new style of cut-and-thrust management appointed to outsource public services and introduce a market culture, forced on them by the new legislation. LCIL had not, as hoped, achieved the handover of a slice of social services' budget, for the equipment service, and in this tighter climate it lost control over the way the service was run (Gitte Rinds [interview] 2000, LCODP 1991-1997 correspondence and internal documents).

By 1995 the crunch had come for LCIL. Demand for its equipment service outstripped its ability to cope, and all requests for extra staff were refused so it found itself with no alternative but to introduce waiting lists that rationed access to the service. This meant LCIL was little more than a Social Services outpost. The whole purpose of trying to provide a more responsive and empowering service had been defeated and people lost heart.

In October 1995, the social services department took the equipment service back which meant less people came to the centre. In 1996 the local authority

then reduced the maintenance grant it gave LCIL, and other bits of the service went into decline (LCODP 1996 / 97; Ken Lumb and Kevin Hyett [interviews] 1998).

Finally, in 1999, LCIL was shut down by the council.

CIL pioneers in summary

All these CILs introduced important new ways of thinking about the helping relationship, empowering disabled people to have more control of their lives, and in time, all were trying to interpret the social model of disability. All, in their different ways, also contributed ideas that endured. In each area, they found they needed to think through how they maintained their dual roles of providing services and political representation. As the DCIL director explained:

‘One of the problems for the DCDP and the DCIL was to work out where the practical role stopped and campaigning role (assumed to lie with the Coalition) was to begin. The CIL's role on matters like transport was to be entirely practical - trying to find a way that any disabled person could move from A to B ... The overriding need was for accessible public transport, individual requests are time consuming, given the few resources the CIL has - all worker time could be absorbed in individual arrangements without any work on arrangements that could satisfy a large amount of needs’ (Rob Parker [interview], 2000).

He points out that, if CILs, the service wing of the integrated living movement, became consumed by supporting individuals they were in danger of repeating the same mistake as social services. Their priority had to be the disabling barriers in society for if these were not tackled the problems would persist.

Derbyshire, Lambeth and Hampshire all tried to get around this by creating their two-tier structures of Coalitions and CILs. Their Coalitions set out to draw local groups of disabled people together into broad representative organisations that could advocate for disabled people at local and national policy levels. CILs meanwhile were created to offer user led services to individuals and groups. In practice this distinction could be difficult to sustain, for the subsequent success of the CILs tended to make these the dominant reference points for disabled people locally and the Coalitions less relevant (Davis and Mullender 1993: p45-48). That often left it unresolved how to engage local people in ongoing political campaigning that was needed in their area.

In Derbyshire, this was addressed in part by DCIL's facilitation of local pressure groups to tackle environmental barriers and research projects that contributed data able to inform policy within local and national frameworks (Rob Parker [interview], 2000), (Ken Davis [interview] 2000).

Derbyshire found that whilst the partnership arrangement was working, they were invited into regular

meetings with councillors and officers where policy and strategy were being considered. This gave them a role in the management function of the council's services and for a period they had some influence (Ken Davis [interview] 2000). In Greenwich too, some council departments opened the door to GADCIL and co-operation was encouraged (Rachel Hurst [interview] 2000).

But once they were rate capped and government proposals for Community Care were underway, in the 1990s, these initial successes in co-operation suddenly stopped. As with the Lambeth CIL, impending changes to LA services meant councils pulled back on their resources, and very abruptly the Coalitions and CILs, being supported by LA grants, faced damaging cuts. In Derbyshire, in 1990, both parts of the organisation had to thoroughly review how they worked (Davis interview 2000, Davis and Mullender 1993: p66-70). The story of how they survived the period, post community care, is taken up in chapter 10.

GADCIL too, experienced substantial damage from the sudden withdrawal of council funding and co-operation, in the lead-up to the implementation of Community Care Act (Hurst interview 2000). HCIL suffered less, because it relied more on an informal network of voluntary support from disabled people and was therefore not so reliant on the council.

Throughout, these organisations had faced the fundamental dilemma about how to maintain themselves financially, whilst at the same time retaining their freedom to represent disabled. Relying (as most did) on grant aid from their LAs, the very structures of local power that had to be challenged, made them vulnerable.

Notwithstanding these pressures, whilst LCIL folded, the other CILs survived into the era of Community Care and went on to adapt to the new conditions. In the course of CIL development there have been two distinct periods – the time before the introduction of Community Care legislation and afterwards. The *NHS and Community Care Act (1990)* only became fully operational in 1993 which was when market principles were introduced into welfare services and this set-in motion a process of privatisation (HMSO White Paper 1989: p17-24), (Oliver and Barnes 2012: p134). After that a much more commercial environment prevailed and CILs had to compete for survival against other commercial ventures. Opportunities for power sharing with LAs, and encouragement for experimental initiatives of this kind were declining. This is explored in more depth in chapter 10.

Independent living in the social movement agenda

The CILs had opened up the idea of self-servicing organisations from which peer support, through peer counselling introduced a different kind of helper-helped relationship (DCIL 1985, DCIL 1991), Evans 2003a: p42,

Finkelstein 1990: pp37-38). The purpose was to enable people to find their own solutions by giving them a hand to achieve their goals, rather than telling them what to do. People talked in terms of creating an empowering environment within which people could develop their confidence and skills to embrace independent living (Gomme 1993: pp131-137, Brown and Ringma 1993: pp158-159). The different forms of local organization described above were in due course replicated around the country and local groups chose what suited them best. Independent living opened a range of complex issues for the movement for they were faced with how to change the helper-helped relationship, how to work with professionals and what relationship to foster with a dwindling welfare state.

Within an all-embracing Independent Living Movement, the two models became more clearly distinguishable and differently affected by the wider social forces. The UK emancipatory model, represented by the Centres for *Integrated* Living, provided the initial lead but were overtaken by a US liberation model, represented by centres for *independent* living.

The former suffered defeat once public services came under the re-organisation hammer and privatisation set in. The other CILs, in looking for a market alternative to the welfare state were swimming with the tide and were more able to win support.

Before leaving this section, I want to bring in the *Greater Manchester Coalition of Disabled People* (GMCDP), which could be seen as a hybrid development offering something between a coalition and a CIL. Over the years the GMCDP has earned itself a profile as a significant and leading centre of activity around the integration and independent living of disabled people. For; as Dorothy Whitaker put it when interviewed by Anne Rae for a video record of the history of the first ten years of the GMCDP (GMCDP 1996);

“It was able to have an influence on local authority policies because it had policies of its own; it was able to come up with solutions and answers not just criticisms.” (Whitaker, in GMCDP 1996).

In my interview with Ken Lumb and Kevin Hyett they explained that in arising from UPIAS origins GMCDP was always firmly grounded in the social model and paid a lot of attention to its grass roots work, creating projects that developed the skills disabled people needed to engage in campaigns promoting the integration agenda. To protect their freedom, to maintain this campaigning profile, they searched for alternative ways to resource their activities without becoming a charity (Ken Lumb and Kevin Hyett [interviews] 1998).

Being part of the independent living movement in the early days raises the question why GMCDP didn't form

one. In fact, this was a pragmatic decision. When the Greater Manchester [county] Council (GMC) was abolished by the Thatcher government its responsibilities transferred to the ten district councils (eight boroughs and two cities) within its area. The abolition of the GMC made it impractical for the pre-GMCDP network of small organisations to contemplate entering into service contracts with all ten LAs. The local groups in Greater Manchester therefore opted for a Coalition which was inaugurated in 1985.

Over succeeding years, in the increasingly commercial culture of service privatisation (see chapter 10), GMCDP found ways to perform many of the roles of a CIL whilst not formally calling itself one. In a similar way to other CILs it saw the importance of supporting people struggling to be independent and so established an information service and backing for a scheme around PAs (Ken Lumb and Kevin Hyett [interviews] 1998).

As elsewhere, campaigning for an accessible environment has been fundamental. Amongst its other mobility projects GMCDP played a role in the development of the accessible new tram network, worked on access to public buildings, promoted inclusive education, and provided Disability *Action* Training (DAT) to staff in LAs, HAs, and universities. Over the years it has set up a variety of training courses for local disabled people using income generated from DAT, contributed to the development of *Breakthrough UK Ltd*, two

employment support services taken out of a social services department and changed in 1997 to be run by disabled people to improve the employment of disabled people, and GMCDP established a thriving youth section of its own organisation (Ken Lumb and Kevin Hyett [interviews] 1998).

BCODP, from 1981, provided the initial forum for these initiatives to network with each other through its housing and care support sub-committee (Leaman 1983: p1; 1984). Once the BCODP's membership criteria expanded, (in 1993-94), the CILs and Coalitions had more of a direct influence, for instead of just housing, it became renamed the Independent Living sub-committee (Evans, 2003a: p48). From there on, the CILs substantially influenced the national movement by promoting their ideas. Principally these were the *Seven Needs for Action* coming from the integrationists; the Self-Operated Care Schemes, (SOCS) from the independent living model, and the self-assessment approach that came from both.

Displacing institutions - a new trend grows

During the 1980s, besides CILs, there had been various other projects set up by the voluntary sector to support people wanting to live outside institutions. One, initiated in the 1970s, by a disabled man in the London borough of Wandsworth, was a project called '*Support and Housing Assistance for Disabled People*' (SHAD). This developed several housing-with-help schemes,

including one in Lambeth (BCODP 1984c). The Spinal Injuries Association too, set up a personal assistants (PA) help scheme, offering short periods of assistance to relieve relatives (Oliver and Hasler 1985) and other voluntary organisations joined the trend. There was a personal assistance scheme initiated in the late 1970s by Community Service Volunteers (CSV); a family support scheme set up in 1979 by the Cheshire Foundation (BCODP 1984c, Beardshaw 1988: p35); and new housing with care schemes established in London and Milton Keynes by the Spastics Society (later renamed Scope). There were a few other small schemes (BCODP 1984b, Evans 2003a: p44, Fiedler 1988: pp60-62).

The tide was turning away from the assumption that institutional arrangements were necessary for disabled people needing regular personal care. But the statutory authorities were still lagging behind, as Beardshaw noted in 1988:

“A new range of living options does not appear to have emerged for disabled people in the statutory sector, and the client group as a whole remains a low priority for planners and service providers in both health and local authorities.” (Royal College of Physicians, 1986b, Fielder, 1988).

“Innovations are small scale, and tend to remain experimental, outside of the mainstream service

provision” (Leat, 1988).

“The generality of present-day local authority services have been criticised as unimaginative, relying as they do on minimal housing adaptations and inflexible care support” (Borsay 1986),

(Beardshaw, 1988: p19 is the primary source - all others in the quote are secondary sources).

Pressures to do something about this situation were building up. It was clear that disabled people from various sectors wanted more self-determination and an end to segregation, and the government needed guidance on how to respond to these pressures whilst also pursuing its agenda to reduce reliance on the welfare state. Following a damaging report on community care from the Audit Commission (1986), Sir Roy Griffiths was commissioned to go and investigate the whole issue and to come up with proposals for a new community care policy (Oliver and Barnes 1998). The *Griffith's Report* (1988) became the basis for the new *National Health Services and Community Care Act (1989)*. The Community Care Act was finally implemented in 1993 and chapter 10 explains how it then impacted on the services and on disabled people's user led organisations.

But first a look at what was happening in the wider social movement.

CHAPTER 9 - Disability culture and civil rights

Disability culture

In addition to the independent living movement was the disability arts movement. Amongst other things, this gave people new opportunities to share their experiences of the discriminatory society, through the various arts. In their account of the history of the disabled people's movement (DPM) Campbell and Oliver (1996: p111) see the significance of the arts movement in the following terms:

'Over the centuries, many individual disabled people have fought against the negative and tragic stereotypes foisted upon them by a dominant culture. One way of fighting back is personal rejection of the dominant disabling culture ... A second way of fighting back against a disabling culture is to get involved oneself in cultural production, usually through the arts. Disability arts and culture came flooding into the disability movement's agenda in the mid-1980s, providing a very important channel to promote our newly discovered identity.'

As with predominantly patriarchal and white cultures, that largely denied people a full range of self-expression about what it was to be female or Black (Greer 1979, hooks 1981: pp119-124, Segal 2007: p109), so too, the culture of able-bodied-ness denied

people the freedom to express what it was to be disabled (Finkelstein 1987, Brisenden 1988).

An explosion of activity in the arts, in the mid-1980s, had a dramatic effect in strengthening their sense of being part of a major social event and it produced the emergence of a sub-culture of difference around the experience of disability. This transformed the DPM.

The initial spark for this flowering was a controversial clash that occurred in 1985 / 86, between disabled people and the establishment, over a conference entitled '*Artability - the way ahead for arts and disabled people*'. The organisers were the Carnegie Council, which was a body set up to monitor the recommendations of the Attenborough Report on the arts and disabled people. They planned to hold this conference in Manchester in September 1986.

Unfortunately for them, they had failed to recognise the anger this would generate amongst disabled people who were no longer prepared to tolerate being told what was good for them. The spat that developed was significant for several reasons. Firstly, because it encapsulated all the characteristics of the historic relationship between establishment organisations and disabled people that was now under critical scrutiny. Secondly because it resulted in a campaign, that put power into the hands of disabled people, and thirdly, because it produced a debate within the movement about

the importance of developing their own alternative arts movement (GMCDP 1986: pp3-6).

Several months of controversy, between disabled people in Manchester, and the Carnegie Foundation, over the way the conference was being organised (Ken Lumb interview 1998), culminated in a formal rejection of *Artability*, in a policy statement, on 4 July, by the Greater Manchester Coalition of Disabled People (GMCDP), on the grounds of:

- lack of involvement of disabled people from the outset;
- use of inaccessible venues;
- the philosophy of the conference, i.e. the medical and therapeutic model used;
- its orientation towards policy-makers at the expense of disabled people (GMCDP 1986).

Later in July, Manchester City Council withdrew its funding and the event was cancelled. Ken Lumb recalled a crucial meeting that led to the demise of *Artability*:

‘We had one particular meeting with the Carnegie Foundation and the *Artability* people in Manchester and I was in my UPIAS mode and I really laced into them and Ian [Stanton] was there witnessing this and I think he was horrified. After that meeting things started to crumble, the person from London who was presenting it, started to

have doubts. It was after that meeting it was a downward path' (Ken Lumb, interviewed in 1998).

Ian Stanton, whom Lumb refers to here, was a fellow campaigner from the GMCDP, but new to the experience of witnessing a determined UPIAS member confronting the opposition. Whilst the GMCDP led the campaign it was well supported by the BCODEP, and also by the *Graeae* theatre company, the only existing professional group of disabled actors in Britain, who decided to withdraw their support from *Artability* (GMCDP 1986). The cancellation of the *Artability* conference was a significant coup for the DPM and for their radical activism. It had shown they could no longer be so easily sidelined in the planning of such events. In his evaluation of the campaign Ken Lumb (1986) wrote:

'We learned that powerful organisations who have traditionally had authority over our lives can be successfully challenged. Moreover, this challenge, which could probably not have been taken on or sustained two years ago, suggests the potential within the disabled people's movement for campaigning on national issues.

We have learnt something important about the importance of collective action and of unity amongst organisations of disabled people. Maintaining that unity was far from easy, however, in the face of actions which put individuals (those targeted by the Carnegie as

leaders of key organisations) under severe pressure to drop their opposition' (Lumb, 1986).

The organisers' response to disabled people's opposition was a very robust one. *Artability*, as Lumb explained, was to have been an opportunity to further many professional and voluntary ambitions in the field of therapeutic and recreational art provision for disabled people (Lumb, 1986) and they were unhappy with the outcome. In his evaluation Lumb raised the issue of what an alternative approach to the arts might be:

'The largely unexplored potential of Art as a means of social change was perhaps the most important issue to surface during the *Artability* controversy. Used effectively, art forms can express and communicate ideas in a powerful way. But what is crucial is that it must truly be our art that is arising from our direct experience of oppression' (Lumb, 1986).

Responding to this flowering of interest in the arts, a few UPIAS members joined forces with other disabled people to create a new forum to encourage the work of disabled artists. Their aim was; to provide a way for people to explore what was happening in the wider movement and discover its emancipatory potential.

Arising from the ashes of *Artability*, a disability arts forum day - *Our Arts Our Culture* - was held in London on

the 26 July 1986. From this, a London Disability Arts Steering Group (LDASG) was formed (Sutherland 2005, Chronology for 1976-1989, updated 2009).

In November 1986, in conjunction with Artsline, they produced the first issue of the magazine *DAIL* (Disability Arts In London). Artsline, was set up in 1980 and provided a telephone information service that offered disabled people advice on the accessibility of arts events (Sutherland 2009).

Following the work of the steering group, they formally launched London Disability Arts Forum (LDAF), in 1987. In his opening address, Vic Finkelstein, one of the founder members, asked people to consider the potential significance the arts could have for the movement. Setting out the issues being debated he said:

‘Firstly, there is a great deal of uncertainty amongst disabled people whether we do want “our own culture”. After all, we all have had the experiences of resisting being treated as different, as inferior to the rest of society. So why now, when there is much greater awareness of our desire to be fully integrated into society, do we suddenly want to go off at a tangent and start trying to promote our differences, our separate identity? Secondly, at this time, even if we do want to promote our own identity, our own culture, there has been precious little opportunity for us to develop a cultural life. Certainly, few of us would regard the endless hours that disabled

people used to spend basket weaving, under the direction of occupational therapists, in day centres, as an artistic contribution that disabled people made to the cultural life of humankind' (Finkelstein 1987: p1).

He then went on to argue that it was now essential for them to develop their distinctive cultural identity before they could participate in the multicultural world, arguing that it was now the right moment:

'to create our own public image, based upon free acceptance of our distinctive group identity. Such a cultural identity will play a vital role in helping us develop the confidence necessary for us to create the organisations, which we need, to promote the social change that we all want (Finkelstein 1987: p4). It is essential that disabled people join together in their own organisation so that there is a creative interaction between disabled people who are involved with the politics of disability and people involved in the arts. It is this interaction, which can be particularly fruitful in helping us to take the initiative in developing a new disability culture' (Finkelstein 1987: p4).

Anne Rae, another of LDAF's founding members recalled her feelings at the beginning of this project:

‘That was really incredibly exciting in the sense that disabled people started to take the politics of disability to a different medium, and the way the movement responded. I think it had an immensely emancipatory effect on the disabled people who identified with that development. The enjoyment disabled people got as audience participants was extraordinary, especially in the early days, because they had never seen disabled people lampooning through music, theatre, photography and all the things artists use to show the oppression we were suffering from, in some very tangible ways, reaching people who didn’t necessarily want to sit round committee tables to identify their own oppression. I think the disability arts movement identified oppression for people who might never have got there, from 1985 onwards’ (Anne Rae [interview], 2000).

The arts movement spawned a whole network of groups and arts initiatives around the country (Sutherland 2009), with artists presenting their ideas about disability in new ways (Hasler 1993: p282). It meant a wealth of experiences found new outlets and scope to reach new audiences, mainly of disabled people. Reaching into the general social consciousness, via mainstream opportunities for disabled artists, was still a way off. Exploring its social significance in a paper on the development of this arts movement Barnes expressed its impact in the following terms:

Disability art is potentially educative, transformative, expressive, emotionally exploratory, participative, and involving. It is a conception of cultural action that owes much to playwrights such as Berthold Brecht and educationalists like Paolo Freire because it is radical, challenging and progressive at an individual and social level (Barnes 2008: p8).

Indicative of this burgeoning creativity bubbling below the surface, had been the earlier initiatives of groups such as the *Graeae* theatre group (mentioned above), founded in 1980 by Nabil Shaban; the Covent Garden Day of Disabled Artists, in 1983, that the charity Shape organised; and the Fair Play campaign, founded in 1984, to fight for equal opportunities amongst disabled artists (Sutherland 2005).

However, it was with LDAF and DAIL offering publicity and encouragement that disability arts took off. New opportunities appeared for disabled people to develop skills as artists in many areas such as painting, sculpture, film making, photography, acting and dance (Campbell and Oliver 1996: p112). In 1988 for instance, the first Disabled Artists Day was held in Covent Garden, London, and the same year LDAF launched *Workhouse*, a regular London based disabled artists cabaret club.

Over succeeding years this cultural revolution of disability arts has amongst other things produced film

festivals and multimedia events. To name just a few in addition to the above; there was the *Moving On Festival of Arts* by disabled artists in 1987 and again in 1989, and the *Bucks Disability Arts Day* in 1988. In 1991 disabled artists were included in the *Leeds International Film Festival* and in 1995 there was the film showcase at a London-based young disabled people's performing arts festival.

Additionally, as part of the wider struggle for integration, there were various ongoing attempts being made to break through the prejudices of the mainstream media. An example of this was the demonstration organised by GMCDP outside the Granada Studios, Manchester, in 1988, against the dropping of Nabil Shaban from the cast for *Microman* (Sutherland 2009). Also occurring were various ongoing experiments to create fully integrated arts forums in which people with and without impairments, performed together; Candoco and Chickenshed were a couple of examples. Both have successfully taken their performances into mainstream theatres around Britain and abroad and participated in national and local performing arts festivals, (Chickenshed 2013; Candoco 2014).

A recent study of the web-based *Disability Arts Chronology*, shows the massive expansion in the amount going on from 1987 onwards. It also illustrates the wealth of experience that was being shared through the coming together of sub-sections within the previously divided

disability community. People with physical impairments, sensory, impairments and learning difficulties, previously often set apart by segregated care systems, now found unity as they set out to discover their true cultural identity through the arts (Sutherland 2009).

Anyone who watched the London 2012 Paralympics opening ceremony, with disabled artists engaged in aerial ballet, drama, music and sculpture, will have had a glimpse of how far the disability arts culture has advanced. Symptomatic of this journey, and a significant highlight for me, was the rousing performance of Ian Dury's infamous song, *Spasticus Autisticus*. Here was a controversial anthem of rebellion, composed for 1981, against non-disabled attitudes to disability (Resin 2008). Written in protest against the prospects of a patronising international year of disabled people and banned from the airways by the BBC for being offensive; it was now, forty years later, being performed to a global audience at the 2012 Paralympic Games in London. As the audience sang along with the band, the jubilation was apparent.

Some of the changes have been about providing opportunities for a full range of artistic expression in the performing arts, visual arts, literature film and television, as a perusal of *Disability Arts Online* chronology demonstrates (Sutherland 2009). Other activity is more explicitly concerned with drawing attention to the social oppression aspects as disability arts cabaret performer,

Claire Lewis (2007: p13) [now known as Mx Dennis Queen] explains:

‘We don’t shy away from reminding people of the things they’d like to forget. We’ll stop being angry when our people are free, which is still a long way off for most of us.

To be honest, I don’t often say I do ‘arts’ and when I do, I say activist arts... what I really do... is use some very basic capability to create propaganda which I can then occasionally inflict on groups of disabled people in the name of entertainment.’

The arts movement thus became (and has continued to be) one of many tributaries producing a change of consciousness amongst disabled people for it offers an important array of media by which to draw attention to, and fight against, discrimination. In the latter part of the decade this was given added impetus, by a new civil rights movement that emerged around 1988.

Civil rights

The take up of civil rights by disabled people was slower to catch on in Britain than in some other countries. One reason for this could be the lack of a British constitution that meant the concept of rights was not enshrined in the laws of the country, as it was in the United States, for instance. Another possible reason lay in the history of a class-conscious society, in which trade

unionism and collective bargaining were the normal mechanisms by which the working class defended itself. The existence of a welfare state providing some universal rights to access services, was another.

The disabled people's civil rights movement, in Britain, like other campaigns, built up over a period and drew on people from a variety of campaign backgrounds. The drive for civil rights legislation did not originate from the UPIAS, the BCODP or the IL movement, but came instead, from the combined influences of access campaigns, the *Joint Committee for Mobility of the Disabled* (JCMD) and interested parties within the Labour Party, through a new configuration in the *Silver Jubilee Access Committee* (SJAC). This raised the issue of discrimination in its report *Can Disabled People Go where You Go?* (1979). The arguments for some anti-discrimination legislation (ADL) were then pursued by the *Committee on Restrictions Against Disabled People* (CORAD, 1982), set up by the Labour government and chaired by long term disability campaigner, Peter Large (Barnes 1991: p7).

It wasn't until 1985 that the BCODP hesitatingly agreed to become involved. It then encouraged all its 22 member groups to join a new initiative, called *Voluntary Groups Against Segregation* (VOAS), hosted by the Spastics Society (later renamed Scope). The ostensible aim was to work towards ADL. Whilst very wary about the way VOAS had been set up, BCODP decided they were

now in a reasonable position to make it a truly anti-discrimination organisation (UPIAS 1985: C58). Some of the reasons for this delay in becoming fully involved are explained below.

The left leaning leadership of the BCODP coming from UPIAS did not initially encourage the BCODP or its Independent Living Sub-Committee to pursue the legalistic route of a civil rights campaign, because this was not seen as the way to emancipation. It was being argued that the most pressing need was to build a democratic, representative organisation in which all members, of all the organisations, had an active part in building and controlling the movement (UPIAS' report to BCODP's first AGM) (UPIAS 1983 C54).

The objective was to build a movement capable of bringing down the barriers and weakening the professional stranglehold on the services, which were essential for taking control of their lives. For some of the people providing a lead it was envisaged that part of the way ahead lay in a redistribution of power within the welfare state in the direction of the service users.

However, as we moved through the 1980s, into the 1990s, the welfare state underwent a major overhaul with the introduction of a free market of services to replace public sector provision (Hutton 1995). The impact of this on the movement is explored in chapter 10, but here it is important to note that it was at this time that the DPM's strategy became more focussed on civil rights. Changes

in society had brought in the prospect of a weakened welfare state being replaced by the market, and in tandem, the dominant ideas in the DPM also changed. The DPM took up the call for civil rights at the time when Thatcher's government was pressing ahead with a programme to deconstruct the social contract. The social contract refers here to British corporatism, in which an unofficial and uneasy agreement existed between the government and the trade union movement to accept the rules of collective bargaining to maintain stable industrial relations (Hutton 1995). This was important, because the historic establishment of collective co-operation through trade unions and public services were being forced to give way to competitive individualism, self-sufficiency and entrepreneurship, driven forward by an ideologically determined government (Hutton, 1995: pp27-29).

In the political climate of the mid 1980s, disabled people were coming to see civil rights legislation as not only necessary, but essential if they were to gain control of their lives. They were a group that might benefit from the reduction of bureaucratic control by professionals but alternatively they could significantly lose out once the society moved towards deregulation and a free market. The inevitable oscillations of the market economy and the need for Civil Rights appeared to go together. The pending collapse of the social contract, that had been a means by which governments could mediate against excessive profiteering, and provide basic services, was

driving people to seek personal protection through legalised rights. The sudden change of mood is described below:

The excessive paternalism of the welfare state, along with the absence of a strong British Civil Rights tradition, caused disabled people in Britain to be more cautious in their tactics. However, this situation changed dramatically in the late 1980s. Despite the barriers, which confront disabled people in the built environment, they have taken to the streets in increasing numbers to protest against institutional discrimination in all its forms. Since the *Rights Not Charity* march of July 1988 there have been many demonstrations and civil disobedience campaigns by disabled people and their supporters all over the country on a range of issues including inaccessible transport, an inaccessible environment, the exploitation of disabled people by television companies and charities and the poverty which accompanies impairment. To focus the public's attention on these and other injustices, disabled people are now prepared to risk public ridicule, arrest and even imprisonment (Barnes 1991: p224).

Taking direct action

Disabled people started to resort to direct action, during two street demonstrations organised by DCDP and then BCODP from 1988. The first, in Chesterfield, was against pedestrianisation of the town centre, which

it was believed would jeopardize disabled drivers' access to shops and other facilities (Davis 1993: p290), (Davis and Mullender 1993: pp60-62). There, after a long campaign from 1983 onwards, the action had involved a demonstration by many disabled people, some of whom deliberately broke a pedestrianisation order, by illegally parking their vehicles in the restricted zone, which provoked a court hearing in 1989. What had set out as a polite and peaceful demonstration, suddenly erupted into a campaign of civil disobedience led by the actions of a particularly bold individual staff member, Alan Holdsworth (Campbell and Oliver 1996: p8, Davis and Mullender 1993 p55).

It proved to be the start of a new trend, for also in 1988, when BCODP organised its *Rights Not Charity* demonstration, around 2000 disabled people congregated outside the DHSS (Department for Health and Social Security) national head office at the Elephant and Castle, London, and once again, an impromptu act led to a street sit in (Campbell & Oliver 1996). Several hours of havoc in central London's traffic gained it extensive media coverage (GMCDP 1988: pp4-10). Anne Rae recalled what it had felt like to be there:

'It was the first taste of that kind of power disabled people had experienced, apart from way back when DIG had the rally in Trafalgar Square, which people found

exhilarating and frightening. I think it was exactly the same at the day of action' (Anne Rae [interview], 2000).

After these two events, Holdsworth, the primary mover of the direct action tactics of physical obstruction and civil disobedience, joined forces with a few other like-minded people to provide some national co-ordination and leadership for people prepared to use this method to get their message across. In 1993, it culminated in the Direct Action Network (DAN), which was a loose but identifiable tendency of activists (DAN 1996). Whilst the DAN initiative was external to BCODP, many of its participants remained closely connected via their member organisations.

The name DAN was later lengthened to be the non-violent Disabled People's Direct Action Network, to make a clear distinction with journalists and others from a later, terror group in the north of Ireland which had started calling itself the Direct Action Network before disbanding as part of the peace process.

This new branch of political activism injected a new kind of energy into the movement, and with a lot of drive and a certain degree of reckless bravado, the leadership of DAN inspired people to take part. It drew public attention to their lack of rights and played an increasingly important role in the campaign for some legislation to end discrimination. During the next few years, it was DAN,

rather than the BCODP, that organized the street demonstrations (Anne Rae [interview] 2000).

Ian Stanton recalled the change when they started to demonstrate against Telethon for its patronising images of disabled people and its ethos of charity to fund things that should be available as a right. He said:

‘1990 was the first demo and 300 to 400 disabled people created havoc outside London Weekend Television. Two years later we were back with 2000 to 3000 people. People who could, threw themselves out of their wheelchairs onto the road, and the police didn’t quite know how to handle it’ (Stanton, in GMCDP 1995-96).

By the mid-1990s, DAN had become more established, and started to look around at what was going on in other countries. They soon found allies in the USA. There, drawing on the experience of a long history of civil rights movements to secure greater equality, the civil rights campaign by the American disabled people had succeeded in winning the *American’s with Disabilities Act (1990) (ADA)* (Russell 1998).

Holdsworth recalled how, when he, and others, became aware of the American’s direct-action strategy to get the law implemented, and the huge publicity it received, they realized its potential for the British movement:

‘Transport was their big thing. It wasn’t happening through ADA, so they took to the streets and started chaining themselves to buses. - About five years before we started. - Now they are doing “free our people” in America, getting people out of nursing homes, - and getting the money to follow them into the community’ (Alan Holdsworth [interview], 2000).

Adopting the same approach in Britain, disabled people started handcuffing themselves, or their wheelchairs, to buses to *draw attention* to inaccessible public transport (Hasler 1993: p283, Morris 1992: p25), and protested with sit-ins and demonstrations outside charity telethons to draw attention to the damaging effects of negative stereotyping (Morris 1992: p10).

By generally causing a public nuisance, they repeatedly drew media attention to the campaigns of the disabled people’s movement against discrimination (Hasler 1993: p283), (Oliver and Barnes 2012: p157). The GMCDP magazine cites all the various mainstream media, such as the BBC and national newspapers, that were made to take notice of the disruption caused by a lot of angry disabled people on the Rights Not Charity demonstration in 1988 (Coalition News 1988). Having this more militant flank put pressure on the BCODP to take a lead in the civil rights campaign, and in 1989 it initiated an influential research project that established

the case for anti-discrimination legislation. The research was carried out by Colin Barnes and following its publication, in 1991 (Barnes 1991), the government was pressed into tackling the need for disability anti-discrimination legislation (Oliver and Barnes 2012: p155).

In the 1990s disabled people in the UK were increasingly turning to the American disabled people's movement for their inspiration and it was a significant development. As with independent living initiatives that moved away from the idea of universal services, the development of a rights movement was moving away from collective class interests towards individual rights and consumer interests. This was significant for several reasons, not least for the increasingly dominant influence America was to have in relation to the British economy and its public services once New Labour took office in 1997. This influence could be seen in New Labour's Third Way and New Deal policy frameworks which laid some of the ground for subsequent welfare reforms (Newburn and Reiner 2007: p324, Purdy 2007: p184, Sinclair 2007: p208).

Taking up the issue of rights was not an entirely new idea, for people had been protesting their lack of rights for a long time. Within segregated institutions people had struggled for basic rights, such as to have the right to privacy or control their own medication, to marry or choose a partner, to have a say in the management of

their lives (see chapter 3). DIG's anti-poverty campaign also, was about the right to a basic income, and mobility campaigns were for the right to a means of transport (see chapter 4). There were however significant differences.

In the earlier context, the protests were more often about the failings of the welfare state and public services to treat people as equal citizens. In the latter period, the struggle for rights became more focussed around the need for antidiscrimination legislation in a society that was moving against the universality principal in favour of individuals taking more responsibility for themselves.

A campaign for anti-discrimination legislation

Oliver and Barnes (1988: p88) situate 1979 as the starting point of the UK Civil Rights' movement, with the setting up of 'The Committee on Restrictions Against Disabled People' (CORAD) by the Labour government. CORAD was established to follow up the findings of a recently published report (in 1979) by the Silver Jubilee Access Committee; *Can Disabled People Go Where You Go?* (Barnes 1991: p173).

As mentioned previously, the Chair of both the Silver Jubilee Committee, and CORAD, was Peter Large with his track record as a disability campaigner. As a leader in the Joint Committee on Mobility for the Disabled, DIG, and the Association of Disabled Professionals, he had a wide range of contacts and many years of building a close working relationship with Alf Morris MP, a long-standing Minister of the Disabled [sic] in the Labour

government. CORAD was given the task of looking into transport systems, education, employment and access to entertainment and, in 1982, reported that all the evidence pointed to the fact that the problems facing many disabled people were structural and institutional (Oliver & Barnes 1998: p88). It recommended that anti-discrimination legislation (ADL) was needed to tackle this (Oliver & Barnes 1998).

Following their report, several attempts were made to introduce anti-discrimination legislation into the UK. The first, was a bill presented in 1982 by Jack Ashley MP, which failed to get anywhere. It was shortly followed by Donald Stewart MP with his private member's bill in 1983 that failed and another attempt, by Robert Waring MP in 1983, which also failed. Later the same year, Lord Longford attempted to pursue this bill through the House of Lords, but he too was unsuccessful (Barnes 1991: p235). The government's response was:

“... it did not think there was any evidence of ‘genuine’ discrimination to warrant the establishment of a complex machine which the bill sought to provide” (reproduced in: Therapy, 8 March 1984).

The case for anti-discrimination legislation (ADL) was made by Waring again, in 1987, and other aborted attempts happened over the next few years (Barnes, 1991: p236.) The campaign for this legislation was in the

meantime, building in strength and in 1985, several voluntary organisations formed a new broad front called; the Voluntary Organisations for Anti-Discrimination Legislation (VOADL) committee. Through VOADL, the movement then set out to make a watertight case for ADL (Barnes, 1991: p7).

In 1988, the BCODP finally agreed to join this VOADL alliance to help campaign for the legislation, which was a significant change of tactic for the BCODP membership. It meant an uneasy alliance followed, between the organizations of disabled people (under the umbrella of BCODP), with the more traditional charities for disabled people, such as, RADAR (Barnes 1991: p6).

In 1989, VOADL established an advisory sub-committee, chaired by BCODP, to oversee the research project into discrimination mentioned above (from 1992 onwards this campaign became known as the *Rights Now* campaign.) With Colin Barnes appointed, and Michael Oliver to advise him, his research findings were duly published in 1991 (Barnes 1991: p7). The effect of this publication on the government's attitude was dramatic, as Barnes describes:

The production of the BCODP report on discrimination (Barnes 1991) subsequently provided the most extensive quantitative and qualitative evidence on the extent of discrimination against disabled people yet produced in the UK. Further, before the book's

publication the British government was still denying that discrimination against the disabled was a major problem. Five days after its official launch in a House of Commons debate on the tenth attempt to get ADL through parliament, the government's then minister of the disabled, Nicholas Scott MP, admitted for the first time that 'discrimination against disabled people is widespread' (Hansard 1992) (Barnes & Oliver 1998: p89).

Oliver and Barnes maintain that, by the mid-1990s, the government had to do something to address the issue for it was clear the campaign for civil rights was unstoppable (Barnes and Oliver 1998: p90).

International pressures also added fuel to the campaign. The UN World Programme for Action, concerning Disabled Persons, adopted in 1982, and the UN's 1988 update on human rights, had both put obligations on national governments to secure rights for disabled people. As ADL became introduced in various other countries, it was more difficult for the British government to ignore the facts about discrimination (Barnes and Oliver 1998: p89).

With hindsight, it can be seen how a changing economic climate created the conditions, in which rights legislation for disabled people made more sense to governments. Envisaging a future with less state provision, it made sense to stimulate changes to the

infrastructure to make society accessible to disabled people.

Taking the Parliamentary road

Once it was agreed the BCODP would throw its weight behind the other disability organisations already fighting for ADL, they entered into a major campaign that was parliamentary in focus and organized around the single issue of legislative reform (Finkelstein 1996a: pp30-36), (Finkelstein 2000: pp16-22). This had a worrying ring for those on the political left, who had witnessed the inherent weaknesses in DIG's campaigns in the 1970s (see chapter 5).

Some foresaw the danger that, too much energy directed into a parliamentary campaign would undermine ongoing efforts to build the local organisations and tackle local issues and this would damage attempts to build an emancipatory grass-roots struggle (Finkelstein 1996a: p30-36, 2007). It was inevitable that the campaign would pull on the most experienced activists, already overstretched locally, in two directions. There was the other worry that, once diverted from local, to national issues, the movement might disintegrate when the political objective was achieved, for it was these local initiatives that were the life-blood of the grass-roots movement (Davis 1999: pp45-47, Finkelstein 2007).

This produced a new set of tensions the movement had to work through. Like DIG, the parliamentary nature of the campaign needed to rely on a small group of

experts to do most of the negotiating and the grassroots to be active in demonstrating, lobbying and general campaigning, and therein lay the danger (Finkelstein 2000a 2000b, Lumb 2000: p4).

Unlike earlier campaigns, the disability movement now had its own source of experts. This new expertise came partly; from the departments of disability studies in the universities, developing a new branch of academia and research informed by the social model, and partly from a nucleus of people with skills acquired from their activities within the social movement itself. How this strong elite of experts related to the grassroots remained a question that was just as valid this time as it had been some twenty years earlier when the predominantly non-disabled experts, in DIG, left ordinary members without a meaningful role (Finkelstein 2000: pp16-22, Rae 2000: pp5-8). DIG had found that, despite its failure to obtain a proper pension for disabled people, as a right, once the Attendance Allowance had been achieved DIG's membership started to fall away.

The underlying objective for the BCODP and its member organisations was to see the social model of disability made manifest (Morgan 2014: p209 Oliver and Barnes 2012: p155). If all discrimination became outlawed disabled people could expect to become integrated into mainstream society but for this to happen comprehensively, substantial structural changes would have to take place. Work, for a start, would have to

become more flexible, and consistently available, to accommodate people with different abilities, pace, and stamina. Transport and housing would need major modification. Education methods, entertainment, communication systems, sport and leisure activities would all have to be redesigned to integrate a wider user group, and the attitudes in society towards disability would have to undergo a major shift. It was, at the same time, possible to see how such changes could benefit many sections of the community, not just those who were disabled, some of which have been highlighted by Finkelstein when he looked at implications of the social model for future service development Finkelstein 1996b, 1998. I return to this in the final chapter.

In 1994, the government finally conceded the need for legislation. After 15 years of campaigning for ADL the government introduced its own bill and, on the 8 December 1995, the *Disability Discrimination Act (1995)* (DDA) received its Royal Assent.

This legislation was undeniably a breakthrough, but as with the *CSDP Act (1970)*, also a disappointment having fallen well short of the legislation people had campaigned for. The Act, unsurprisingly, had been tailored to fit the government's own agenda with its determination to promote individualism and reduced dependence on the state (Barnes et al: p1999: p163), But, as pointed out by Oliver and Barnes, below, the Act gave scant admission to the ways society disabled

people. Rather than tackling institutional discrimination, as the campaigners had hoped for, the DDA left it largely to individuals to make the changes happen. Oliver and Barnes pointed to the difficulties people should expect when they tried to win their rights:

The Disability Discrimination Act (DDA) 1995 is weak because it is based on the traditional individualistic medical view of disability; impairment is the cause of disablement rather than the way society is organised. Hence, the idea that disabled people's legitimate requests for adjustments and change are considered somehow unrealistic and unnecessary is retained. The Act gives only limited protection from direct discrimination in employment, the provision of goods and services, and in the selling of land. Protection is limited because not all disabled people are covered by the Act, and employers and service providers are exempt if they can show that compliance would damage their business.

Most importantly, the Act is toothless because there is no enforcement mechanism whatsoever. This means that disabled individuals must challenge unfair discrimination themselves (Oliver and Barnes 1998: p90).

Whilst discrimination might now be acknowledged, applying the social model to address it had clearly not been accepted. The DDA carefully avoided state

intervention to impose major structural reform to get rid of barriers, leaving the business of tackling discrimination to individuals and their lawyers.

Given the political agenda, this was hardly surprising. The kind of legislation and enforcement mechanisms necessary to remove all discrimination and give disabled people full and equal access to secure, employment, housing and education, for instance, would not only be complex and costly (Oliver and Barnes 2012: pp150-151) but would also conflict with the Conservative's modernizing programme of deregulation, privatisation, free markets and tax cuts (Hutton 1995: pp27-28).

Following the passing of the DDA, the response from campaign groups was divided, and the uneasy alliance between the *for* and *of* disability organisations came to an end. The former, represented by the established charities such as Radar, Mind, Mencap, RNIB and the National Institute for the Deaf, all decided to put their energies into helping the government to implement the DDA (Oliver & Barnes 1998: p90) The BCODP, on the other hand, rejected this compromise and reaffirmed their commitment to seek a more comprehensive and enforceable equal rights act. In practice though, once the DDA existed, it was much harder to sustain a campaign for a better alternative, and the grass roots support fell away (Barnes et al 1999: p163) as predicted by Vic Finkelstein in 1996 (Finkelstein 1996a).

In April 2012 the Equality Act 2010 came into force and it replaced all previous discrimination law, including most of the DDA (Salmon May 2012).

Once the civil rights approach was in the ascendancy, the gap between the different independent living approaches also widened. There was a lot of correlation between the civil rights demands and the idea of having privately managed PA services. The more radical integrationists, with their socialist leanings for collectivised solutions, became marginalized when they were overtaken by the events of a rapidly changing social environment and the general thrust of the disabled people's movement taken up with the issues of individual rights and freedoms. Changes were being made to welfare legislation, and the possibility of transforming the welfare state seemed increasingly unattainable. This took the movement into its next campaign phase which was for individuals to have direct control of the money to employ their own helpers.

Making the case for direct payments

Much more questioning came from disabled people over why it was necessary for SSDs to control the resources around their personal help services (Morris 1993: p26). The idea of having money paid directly into their own accounts, to employ their own help, was a more attractive option, and by 1994, the Centres for Independent Living were leading a campaign for direct

payments (Barnes and Mercer 2006: p138, Morris 1993: p178).

The background for this had been the early pioneering projects in Hampshire and Greenwich. There, having won the argument about people employing their own help they had proved it was possible for disabled people to leave institutions to live in the community (chapter 8).

The Independent Living Fund, (chapter 8) set up in the 1980s, by the Department of Health, introduced the idea of matched funding. It created opportunities for a growing number of disabled people, but for many others the welfare departments still largely controlled the actual care arrangements. Wide dissatisfaction with the inflexibility of local authorities' home care services then led the DPM to campaign for an extension of the principle of user empowerment through direct funding (Morris 1993). They wanted to wrest control of personal care away from social services, by putting the money for personal assistants (PAs) into the hands of many more service users. There was a problem however, for under the (1948) National Assistance Act local authorities were not permitted to make payments *directly* to disabled people to pay for services (Morris 1993: p14).

By the mid-1990s, the BCODP was active in various forums promoting the application of the social model of disability in the development of social policy. Promoting support for independent living to replace institutions

remained a major theme, and in response to a general loss of faith in social services, the BCODP leadership through its Independent Living Sub-Committee pursued direct payments as the way forward for the movement (Oliver and Barnes 1998: p72, pp85 – 87, 2012: p155).

Any idea of partnerships with the LAs, pioneered in Derbyshire and Lambeth, (see chapter 8), no longer appeared to be sustainable (Ken Davis [interview] 2000) and there was considerable evidence to show that disabled people had not, as was hoped, gained a greater say in the planning and delivery of services as a result of the new legislation, the NHS Community Care Act (1990) (Oliver and Barnes 1998: p41). I shall return to this in the next chapter.

Enabling disabled people to by-pass these professionally-managed services now held more appeal.

Having BCODP use its Independent Living Committee to take the case forward with the government was significant. Jane Campbell, a leader of this campaign, explained how important it had been to them to win this principle:

‘There was this [parliamentary] bill that was in the offing and so I became completely obsessed with this because I really saw direct pay as able to dramatically change the relationship between care provider and care receiver - we went for it hammer and tongs. We thought

it was really important, and that it must go to the disabled person' (Jane Campbell [interview], 2000).

Campbell and others, interested in the idea of having the money to employ help instead of using pre-organised services, drew on personal experience. She explained why it had become so important to her personally:

'I was about to get married and I wanted to have PAs so that G--- wasn't going to become my main carer. I couldn't use home care, or the nursing services, because they all began at 9.0 am, and how was I going to get to work? So, at that time, my mother was getting me up for work. And then, after then, it was G---. We'd found a flat and moved in together and he was doing all of that' (Jane Campbell [interview], 2000).

A while later, when Campbell's husband became ill, it added urgency to their situation. It increased her personal determination to do something to ensure neither of them ended up in hospital or an institution, which was a great fear to both of them.

'I knew I had to find another way, in terms of physical support. So, you know, lots of reasons have pushed me to become quite obsessive about control of personal care.

I thought, if you can control your own body, you can control your own life, and I still believe that. I think it's all over control of our personal space that really emancipates us, or at least gives us an equal opportunity to participate' (Jane Campbell [interview], 2000).

The campaign for direct payments achieved its objective. In 1996, the *Community Care (Direct Payments) Act* was passed which made it possible for physically disabled people of working age to employ PAs if they chose to do so. Although, for a while, some eligibility restrictions remained, i.e. it did not initially include older people, children or people with either learning difficulties or mental health issues, it did nevertheless represent a significant change in the way services were organised (Woodin 2014: p250-251). Campbell's description below shows how far BCODP's leadership had distanced itself, by this time, from all defence of the welfare state:

'We were the main people that negotiated all through committee stage, through the House of Lords, and the House of Commons. Andrew Wren MP who, although he was a Tory, was streaks ahead of any other MP. In fact, we had real problems with the Labour party who saw it as a threat to municipal welfarism, and saw a lot of problems with the unions, and things like that, and of course a lot of Northern MPs were heavily lobbied by the

local authorities who wanted to keep services controlled by social services departments. They saw it as direct opposition' (Jane Campbell [interview], 2000).

It was hardly surprising that direct payments made sense to Conservative politicians busily promoting the development of a market of services in line with their Community Care plans.

Also unsurprisingly, the idea of direct payments was less well received by Labour-controlled councils that were, in many areas, still trying to resist government attempts to erode their local autonomy over service provision, as Campbell recalls in the quote above. They correctly anticipated that direct payments would help to speed up their demise and increase the privatisation of personal social services.

Developing a direct payment support service

The BCODP *Independent Living Committee*, with Campbell's encouragement, then decided the best way to promote direct payments was by transforming itself into a *National Centre for Independent Living* (NCIL) (Jane interview 2000). This placed it in a much stronger position to encourage CILs, throughout the UK, to help disabled people to obtain direct payments. The NCIL was formally established in 1997, but constitutionally, it remained a sub-committee of BCODP until 2003 when NCIL was established as an independent organisation.

The upward pressure on all the CILs, was, from then on, to provide disabled people with support to recruit and employ their own helpers. With this development, CILs became a significant service provider, responsible for devising ways of helping disabled people entering the potential minefield of becoming employers and helping them manage the financial side (Barnes and Mercer 2006: pp98-100). With the parallel rapid transfer of care services to private agencies, it was anticipated this need for support would increase.

Campbell, the first director of the NCIL, told me that in 2000 there were officially only fourteen CILs in the country run by disabled people. But the situation was changing, and with many other organisations working in similar ways, the service-providing arm of the movement was growing.

By 2005 the Prime Minister's Strategy Unit (PMSU) was recommending that:

“By 2010 each locality (defined as that area covered by a council with social services responsibilities) should have a user led organisation modelled on existing centres for independent living.” (PMSU, 2005: p76. in: Barnes & Mercer 2006: p175).

However, as Barnes and Mercer pointed out; the lack of consensus within the disabled peoples movement (DPM), about what constitutes a CIL, had left the door

open for other organisations, not necessarily controlled by disabled people, to describe themselves as CILs to secure the funding to run a support service (Barnes & Mercer 2006: p177).

Some CILs have responded by setting up their own agencies to employ a small pool of PAs for disabled people to use. Others have set up teams of support workers, or an agency, to help people with the process of recruitment, staff supervision and payroll (Barnes and Mercer 2006: pp97-100).

Despite the enthusiasm coming from the DPM's centre, the take-up of direct payments at first remained slow to catch on as was found by a national survey of CILs and similar user led organisations conducted, between 2000-04, by Barnes and Mercer with the support of the BCODP and the NCIL (Barnes and Mercer 2006: p120). During the early phase of implementation, Priestly (1999: p203) encountered individuals expressing some wariness of the responsibilities it would place on them, anticipating difficulties with recruiting suitable PAs. On the other side, there was the reluctance of many SSDs towards handing over money or responsibility to disabled people (Barnes and Mercer 2006: p96). This often, meant popularity for the scheme, was dependent on the commitment of local disability organisations.

From its inception in 1997, the NCIL, supported by a DH grant, embarked on a 3-year project to make LAs comply with the *Community Care (Direct Payments) Act*

(1996). It set out to ensure direct payments' schemes were put into place and that the means would be found to overcome professional reluctance to trust disabled people with the choice of using direct payments.

Deeply committed to the idea and convinced they were doing the best thing to liberate people from unnecessary dependence NCIL used their influence to persuade the new Labour government, to extend the principle to other user groups such as; people with learning difficulties, mental health service users, and older people.

The idea of extending direct payments to other social groups was not enthusiastically supported by the associations representing them, as Campbell recalled. They were perceived by the DPM to be traditionally backward. Referring to the initial period when the BCODP's Independent Living Committee had been leading the campaign for the legislation, she recalled:

'The IL committee would get all the papers and they would write the briefs. We needed loads and loads of disabled people to say why direct payments was going to be liberating for them and how it was going to promote disabled people's independence and possibilities in the labour market etcetera. So, we consulted through BCODP membership organisations. I personally went to Age Concern and Help the Aged because they were doing no lobbying whatsoever but that's why I think

originally, we didn't get inclusion of people over 65, because they were weak, very weak. And again, Mencap and Mind were just not there, they didn't see it as important, it wasn't on their agenda – so we went to 'People First' and they put forward a wonderful campaign. ... It was really BCODP and its organisations that got that piece of legislation through' (Jane Campbell [interview] 2000).

Once in government, the Labour party fully supported the idea of people arranging their own services. As we have subsequently witnessed, it had no plans to reverse a policy that had set in motion reductions to the welfare state and by 2001 the government had extended the eligibility criteria to include; people with learning difficulties, people with mental health needs, people over 65, carers of disabled children, and disabled 16 and 17-year olds (Department of Health, [DH]) (2006). These extensions represented a significant shift and a further nail in the coffin of the welfare state which did not necessarily bode well for the future, but for the time being the new policy still depended on the willingness of individuals to take up the offer of direct payments.

In 2007, a national survey of direct payments policy and practice found, that despite applying national performance indicators to encourage LAs to promote the use of direct payments, the take up was disappointing. They found the most positive response was from

physically disabled people – especially in the areas where there had been active support organisations such as CILs, in the early stages of the policy. The lowest take up was found to be amongst people using mental health services.

Regarding some of the detail, the survey team discovered there were marked variations in the hourly payment rates, (and criteria), for employing PAs, and that in general, wage levels had been driven lower than independent sector domiciliary care rates, sometimes below the minimum wage. The LA funding levels for support organisations was also a cause for concern for it was shown to be going down at the very time that demand for these services were increasing (Davey and others, 2007: pp111-115).

The constant pressure to drive down LA public sector provision of services, and governmental endorsement of the principle of personal budgets for people to pay directly for their services (Oliver and Barnes 2012: p168, (Woodin, 2014: p252) meant people having to fend much more for themselves.

Once people were responsible for arranging their own personal care, both direct payment users, and workers, faced the increasing prospect of becoming more isolated from others. It then became much easier for the central and local state to adjust funding levels and eligibility criteria, downwards, as welfare provision became more restrictive.

By 2012, this had become a very active issue. The *Welfare Reform Act (2012)* introduced new restrictions to the criteria for housing benefit entitlement and replaced the Disability Living Allowance (DLA) with Personal Independence Payments (PIP) (DWP March 2012). These changes meant some people lost out. Additionally, as local authorities applied tighter criteria, to manage their social care budgets, access to sufficient levels of direct payment to pay for the services became more restricted. It continues to be an important battlefield for both disabled people, and for their employed helpers, to defend their respective living standards. In 2013 the government predicted that around 600,000 people would lose their entitlement to support, under the new criteria for PIPs which started to be implemented from April 2013 (BBC News UK 8 April 2013). By April 2014 this was becoming a reality and many disabled were hard hit by loss of financial support brought about by PIPs (Russell 2014).

Things had been made worse for countless people by the chaos of a failing assessment process for the PIPs and a ministerial statement on 10 April 2014 (Hansard) announced that an independent review of PIPs would be conducted by Paul Gray.

Contract culture and marketing services

As the market for independent living support services grew in the late 1990s, CILs faced competition from commercial organisations that did not necessarily

support the essence of independent living or the principles of disabled people having control of their services. Where the objective was to win the local authority contracts to provide services, the market pressures upon them were to reduce their costs. The genuinely user-controlled CILs then faced the danger of being squeezed by the unevenly weighted market pressures (Jane Campbell [interview] 2000, Morgan 2014: pp210 -212, Hurst [interview] 2000, Oliver and Barnes 2012: pp167-168).

Later, as Finkelstein (2007: p16) succinctly pointed out, this should have come as no surprise for this is how capitalism works. I return to this subject in more detail in the next chapter. In turn it led them to conclude that, to be competitive, and still protect the principles they had fought so hard for, it was going to be necessary to professionalise and standardise their services to a nationally-set pattern (Jane Campbell [interview] 2000, Ratzka 1998). This meant CILs were inclined to introduce top-down management of their services and the earlier form of informal networks of peer support were less viable (Philip Mason [interview] 2000).

The next step was to produce a formal definition and philosophy for CILs to keep them under the control of disabled people (Hasler 2003). By early 2000, under NCILs leadership, the CILs had achieved some agreement, which said:

‘To be a CIL you have to be controlled and run by disabled people and you have to offer a service in what we call the core needs services. You have to offer information on PAs, on housing, education, employment and access, using the seven needs, that’s our model. Very loose, but as you know, many CILs concentrate in only one or two of those areas and offer a passing guidance on the others. ... “Our philosophy is that Independent Living is the emancipatory philosophy and practice, which empowers disabled people and enables them to exert influence, choice and control in every aspect of their life” (NCIL 1999). So, that’s our mission statement, from NCIL’ (Jane Campbell [interview], 2000).

This was an attempt to marry the objectives of the two types of CIL. The drive to get CILs to conform meant Centres for Independent Living must broaden their scope to incorporate local integration campaigns whilst Centres for Integrated Living must encourage the take up of direct payments. For the latter, committed to the principle of socialised services, it represented a significant defeat. The service market principle had effectively displaced the emancipatory trend based upon the universality principle that they had tried to promote during the early days. It is my view, confirmed by Finkelstein below, that the others, whilst believing their objective to be emancipatory, they were in practice bolstering the political aims of individual consumerism. Finkelstein (2007: p16) writing about

some of the inherent dangers for CILs pursuing the direct payments path as their priority, put it in the following terms:

‘We’re all the same now – “independent” competitors in the same service providers market. In short, the disability movement is no longer setting the agenda for our emancipation – instead we’ve become prisoners of a market that sets the agenda for our movement! ... This is a capitalist dream come true – every single disabled person becomes an employer, pays personal assistants for their labour, is responsible for working conditions ... etc.’ (Finkelstein 2007: p16).

By the end of the century, twenty years of campaigning for the means to live in the community had achieved big changes in many countries, and institutional care was no longer the acceptable norm. Adolf Ratzka (2003) speaking for the DPM internationally, defined what independence had come to mean:

Independent living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent living does not mean that we want to do everything for ourselves and do not need anybody, or that we want to live in isolation. Independent living means that we demand the same choices and control in our

every-day lives that our non-disabled brothers and sisters, neighbours and friends, take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and abilities, start families of our own. Just as everybody else, we need to be in charge of our lives, think and speak for ourselves. To this end we need to support and learn from each other, organise ourselves and work for political changes that lead to the legal protection of our human and civil rights.

Significant changes had taken place but the full realization of this vision of integration was still a long way off.

New professionals, new challenge

CILs now provided important new opportunities for disabled people. By promoting the employment of disabled people within the CILs either as paid staff or as volunteers they provided employment opportunities, new openings to develop skills, and a positive use of personal experience to benefit others. The CILs offered the potential of more understanding services, in touch with the people who used them, and responsive to input from their users (Barnes and Mercer 2006: p100, Davis and Mullinder 1993a pp26-27, pp42- 44).

Committed to using the social model as their basis meant aiming for integrated solutions, rather than

piecemeal ones, and empowering people rather than creating dependence. Being outside the statutory sector, they would also seem to be in a better position to innovate new and better ways of working.

To develop a new service, based on a different set of principles, CILs needed to also develop a new category of workers with a different outlook. This was uncharted territory and it opened enormous potential to the disabled people's movement to be the leaders in the field. Their frame of reference came from the collectivization of direct experience, and the experience of trying to reverse the disabling traditions of the care relationship.

No other profession existed to fill this space. Care and support services for disabled people had historically evolved from a whole range of existing professions. There had never been a proper analysis of what kind of expertise was appropriate for a community based professional, working with people to reduce disability (Hunt, J 2012). As they evolved, CILs had to find ways of training their staff to be in tune with the CIL philosophy based upon the social model of disability. In Derbyshire they used the "seven needs", referred to in chapter 8, as the basis for developing a new approach to service provision which in their words "put flesh on the social definition of disability" (Davis and Mullinder 1993a: pp42-44, p64).

Offering Disability / Distress Equality Training (DET), based upon the social model of disability, and running Training for Trainers courses, became another important area of the work for many CILs and other user-controlled organizations (Barnes and Mercer 2006: p147-152).

CILs were therefore the pioneers of a new branch of professionalism in disability services, and they faced the issues that affect all organisations providing services to others. They had to establish systems and standards to their working practices and manage demand and resources in ways that were fair and reasonable. More on this in chapter 10.

Moving into the service sector has raised many new issues for the DPM. With a long way to go to achieve a society that is integrated, and with disabled people still largely pushed to the margins, continuing to build a collective response is as important as it ever was. In the next chapter I shall look at how the 21st Century has introduced new pressures that potentially undermine the very considerable achievements the DPM has brought about, especially in the case of services organised around personal living arrangements and the use of direct payments.

From Hampshire's CIL experience, Philip Mason reflected on the outcome of their leading position in the campaign for direct payments, with some misgivings (Philip was one of the small group from *Le Court* Cheshire Home who pioneered *Project 81*, referred to in

chapter 8, to create an exit route from the institution). On the positive side he was able to say that, by the year 2000, some 600 people in Hampshire were using direct payments for their independent living, and relative to other areas, this was a phenomenal response. He acknowledged that this demonstrated their effectiveness in persuading the authorities and individual disabled people to adopt these arrangements.

From his perspective, the down side of this success had meant the end of their informal network of mutually beneficial peer support based on the sharing of experience because the scheme had become too big. His observations had led him to believe that the competitive market system had at times encouraged workers and organisations to hoard knowledge which resulted in less sharing and openness, although he stressed that in Hampshire, they had by and large managed to avoid this problem between the two CILs (Philip Mason [interview] 2000).

A more formal system had replaced it with staff funded by Social Services contracts, employed by Southampton CIL. This had left Hampshire CIL with the primary task of advocating on behalf of the scheme and negotiating around policies and practice in the County. Mason below expresses his concern that professionalisation of CIL services would raise old issues in a new form, and asks where the accountability of new generations of support workers would reside:

‘Roles are becoming professionalised. ... We have, in Hampshire, Southampton and Portsmouth, a six weekly meeting called the Direct Payments Advisory Group, and that’s where we sit down with support workers, and with Social Services officers, and talk through some of the issues, and that’s how we try to influence it.

I think that the current generation of support workers are very much steeped in the social model of disability and the disability movement. They have come out of it, it has been an integral qualification for the jobs, because we drew up the job descriptions. Why I’m dragging this issue up is because I think there will come a time, when subsequent generations may not be so steeped in all the issues. ... people growing up now who become support workers will have inherited a different tradition’.

Concerned about the already visible effects of professionalisation, in some places, he added:

‘There are disabled people in this country now who are behaving like social workers did fifteen years ago. They’ll define, and they’ll decide, and they’ll be the new professionals, these (relations) will be the new institutions they have tried to get out of. Can you believe that?’ (Philip Mason [interview] 2000).

Mason's argument is that with their first loyalty to their employers or contractors, professionals are frequently placed under pressure to determine what is proffered rather than to truly seek out what the disabled person wants to achieve. Additionally, he argues, inflexible rules can encourage support workers to see disabled people, as competitors with each other for scarce resources, rather than as people with aspirations that should be encouraged not discouraged. In his words, 'it should not be regarded as unreasonable for the disabled person to want to have 'choice and control at work, rest and play' (Philip Mason [interview] 2000).

In relation to the setting of uniform standards across the county, Mason had seen his local CILs becoming more rigid and felt they were at risk of institutionalising both the workers, and the people using their services. Explaining the processes, they now had to introduce for people using Direct Payments he said:

'We had quite big struggles in Hampshire, because people saw when the direct payments were introduced, they moved from the old SOCS (Self Operated Care Scheme), which was a much looser freer system, and moved to a more organized, structured system. It was a good thing in some ways because it ensured people were better employers.

We had letters of agreement saying, 'this is what you have to do to be a responsible employer, keep good

accounts, etc.’ People felt their old free and easy SOCS was ossifying, becoming restricting, and I’m wondering – further down the line – because support workers want instant answers such as; ‘what do I say when such and such happens’, they want a rule.

My instinct is – don’t make rules. As soon as you make rules, you’re going to find yourself trapped by them. Keep things flexible. They say, we want people in North Hants to have the same as people in the South, and that’s understandable. But ... as soon as you get structures you get systems, and you get institutionalised, that’s what I’m trying to flag up. ... I keep wondering, how do we make sure the system doesn’t become another institution’ (Philip Mason [interview] 2000).

Mason raises some interesting issues here. The service will not necessarily be better because the workers are disabled people, or because they have the right personal experience, or because they say they work to the social model. What Mason understandably wants to see is people so well grounded in their understanding of the social model they can work things out, and be consistent, without rigid protocols to guide them. His fear is reasonable - the alternative could be another form of institutionalisation but in your own home through an imbalance of power in the new helping relationship.

These are not arguments for going backwards, or against educating new generations of people to do the

work thoroughly and professionally. But they are, I believe, arguments for maintaining democratic structures, from which people can promote very different ways of working. Somehow CILs need to perpetuate an enabling culture, one that keeps the struggle for emancipation alive and keeps people alert to the fact that power and choice can never be taken for granted. This is hard in a funding environment that asks for conformity to centrally driven agendas.

Having an alternative authority structure, such as a coalition of disabled people, to which a CIL is made accountable, may be a model that needs revisiting.

CHAPTER 10 - The era of community care – creating a welfare service market

This takes us into the era of Community Care with proposals for more choice and rights for consumers. The purpose of this chapter is to take stock of what happened when the welfare services were thoroughly overhauled and consider the impact this had on the four CILs referred to earlier, and on people's lives.

Having seen how the DPM had been developing we now return to 1988, when the Conservative government passed responsibility for care back to the community. Their new strategy was to engineer a gradual erosion of the Social Services by a process of transference to a newly generated independent sector.

Legislation for change

Several new pieces of legislation contributed to the process of shifting responsibility away from the state and onto individuals and their families. The most significant for this account were; the *NHS and Community Care Act (1990)* (CCA), the *Disability Discrimination Act (1995)* (DDA), the *Carers (Recognition and Services) Act (1995)*, and the *Community Care (Direct Payments) Act (1996)*. Additionally, between 1992 – 1999, an 'Agenda for Change', introduced adjustments to Social Security and Pensions legislation through the *Welfare Reform and Pensions Act (1999)*, which, amongst other things, set out to tackle disabled people's high levels of unemployment.

This barrage of new legislation provided a multifaceted approach to reduce the welfare state and ensure disabled people became more self-financing. As the Disability Alliance (2000: p7) put it, the changes meant that: “Increasingly, government measures focused on ‘work for those who can’ rather than ‘security for those who cannot”.

The *NHS and Community Care Act (1990)* was the main vehicle for restructuring the welfare services and controlling who had access to them. The *Disability Discrimination Act (1995)* offered individuals the right to challenge discrimination and question professional decisions. The *Carers (Recognition and Services) Act (1995)* offered unpaid carers (such as relatives) the right to a Community Care assessment of their own and the *NHS and Community Care (Direct Payments) Act (1996)* made it possible for disabled people to receive money in lieu of the Community Care Services they were entitled to.

The Welfare Reform and Pensions Act (1999) came next, and it introduced capability assessments to determine who should seek employment and come off welfare benefits. Targeting disabled people along with other selected groups, it copied the New Deal policies, introduced into the US by the Clinton administration and went further. As Russell and Malhotra (2002: p220) noted:

‘The disability unemployment issue is increasingly defined in both the USA and in Britain as one of dependency which the faulty individual on welfare must overcome, not as the structural outcome of an exclusionary market.’

Drawing on an article from the *Independent* newspaper, they wrote:

“New policies to offer unemployed people jobs and training are a social democratic priority — but we also expect everyone to take up the opportunity offered”, says Blair, (Waugh and Schaefer, in Russell and Malhotra 2002: p220).

These remarks were soon followed by a notice from officials telling disabled persons to seek work or lose benefits. The *Independent* reported that ‘[s]ick and disabled people who refuse to look for work will face the withdrawal of their state benefits under a tough new government drive to slash “welfare dependency”,’ (Waugh and Schaefer, in Russell and Malhotra 2002: p220).

The community care agenda

All the Acts mentioned above, responded to calls from the grass-roots movement. They acknowledged disabled people should have more rights but also carried

strong undercurrents that were part of shaping a new society.

One of the principle reasons for introducing Community Care was to transfer social care from hospitals and institutions back to the community. Whilst it was clear there were to be new community-based services, much of the responsibility for care would return to the family as stated in the Conservative's white paper, *Growing Older*:

The increasing needs of increasing numbers of older people simply cannot be met wholly - or even predominantly - by public authorities or public finance... Whatever level of public expenditure proves practicable, and however it is distributed, the primary sources of support and care are informal and voluntary... Care *in* the community must increasingly mean care *by* the community (DHSS, 1981: p3 in Morris, 1993: p7).

The government's intentions were clear, and it wasn't just older people who they wanted to move out of institutions. In the White Paper *Caring for People. Community care in the next decade and beyond*, (HMSO 1989) the stated plan was, at long last, to close the old Victorian psychiatric hospitals and the "sub-normality" hospitals, as they were then called, for the long-term care (sic) of significant numbers of people with learning difficulties (HMSO 1989: p11). Younger physically

disabled people too, were now to be provided with better means so they could avoid institutional care (HMSO 1989: pp11-12).

For people wanting to get out of institutions, or avoid going into one, the Community Care legislation offered new hope. For organisations such as the CILs it offered an interesting opening to be part of a wider choice of service options. For relatives, straining to provide all the necessary personal help to a disabled family member, this, plus the Carers Act, offered a chink of light, for amongst its key objectives it also recognised their need for support (HMSO 1989: p5). For Social Services professionals, the new plans offered scope to be creative but their work was to change substantially with some reduction of power and job security.

Care in the community – a new service

It is not difficult to appreciate the importance people attached to this new point of departure, when we recall for how many years disabled people had spent fighting against the medicalisation of their lives and authoritarian regimes of care.

Since 1981, whether describing themselves as integrated or independent living CILs, they had all been working towards a holistic approach with their own support services. By 1993, when Community Care became operational, these groups, were concerned to have as much influence as possible on the kind of personal help to be made available through the new

funding arrangements (Morris 1993: pp175-176). For them it was a golden opportunity, to introduce a different kind of service relationship and one that would ensure people became empowered to have more control of their lives.

But for the statutory authorities it was very different, the priority there was to provide people with 'care' in the community rather than in institutions. It soon transpired that statutory concepts of care, and disabled people's idea of support, were poles apart.

To create domiciliary care where there was none, the Social Services' initial response was to transform their pre-existing domestic 'home help' services into new 'home care' services to offer people essential help with their basic personal needs, such as to get washed and dressed in the mornings, use the toilet, prepare food and go to bed at night (Morris 1993: pp156-157). One of the first disappointments, was then to see familiar institutional patterns reappearing in the community. Rigid working practices and time restraints set by distant service managers that restricted choice over when you could get up or go to bed, when you could go to the toilet or have a bath, and even, where you could purchase your food (Audit Commission 1997: pp29-34, Morris 1993: p160). It left very little scope for anything other than the basics.

Using managerialism to change the culture

Fundamental to this process, were the changes being made to the role of Social Services Departments and their professional staff. From having been the principal providers of social care, outside the health service, these departments were turned into *business management systems* with the role of commissioning services.

Pollitt argued that the introduction of a managerial culture, not only helped to transform the welfare services, but that it was an ideological tool for breaking down professional autonomy and power, in order to restrain public expenditure (Pollitt 1998: p51). It was certainly very apparent that a new language, borrowed from the industrial and commercial worlds, became the norm. Littlechild (2003) cites various social worker concerns regarding the alienating effects of the new culture of managerialism which talked more in terms of performance indicators, inputs, outputs and quality assurance measures than about the details of casework and the ethical basis of professional judgements, as had been the practice previously.

From socialised services to a privatised market – a three phase development

The Community Care Act introduced several key strategies to bring about the changeover to a market of services and these strategies worked together like a chain reaction. There was a logic of cause and effect that

bound the components of community care together and like molecular compounds, they created the new service system.

During phase one, between 1993 and 1995, change was set in motion when the conditions were created for a market of services to grow. It was as if a snowball had been set rolling into society and only time would show what its effects would be.

Significant differences soon appeared between what the legislation appeared to promote in the way of choice, flexibility and availability of better services, (White Paper 1989) and what evolved as a result of the CCA, which I shall return to.

The expectation of the government was that LAs would stimulate a competitive market of providers to achieve a cost-effective service that offered better value for money for community care (White Paper, 1989: p22). Meanwhile, the expectation of service users was that the new arrangements would provide a wider choice of services able to meet their needs in flexible and innovative ways, as inferred by the legislation (White Paper, 1989: p22). It was an open question whether it would meet these objectives.

Because the costs of community care could not be calculated in advance, expenditure was constrained by new mechanisms to determine those most in need and match this to available resources, instead of the old basis

of first come first serve (Audit Commission 1986 / 1992: pp10-14, p26).

In phase two, between 1996 and 1998, consolidation of the new arrangements was taking place. The general drift towards an independent service sector had been growing and it was leading to some decline in the number of public sector providers, but the picture of services was quite mixed. In fact, the Audit Commission found initially that progress in the direction of giving users greater choice of services met with some resistance. They reported that some of the more reluctant councils were directing their Care Managers to favour the use of in-house services before looking elsewhere.

The subsequent introduction of direct payments added a new component for this enabled service users to employ their own help and become more independent of social services with more choice and control over how and when they received help (Audit Commission 1997: p32).

With the passing of anti-discrimination and direct payments legislation, service users appeared to have more rights, more choice, and more say in decisions (Oliver and Barnes 2012: p148-150). Professionals, on the other hand were discovering the limitations of their powers to offer people more choice and more say over the services they could have, if these collided with departmental budgetary restrictions. Rationing

processes were making it difficult for them to work collaboratively with disabled people.

The rights' discourse, assisted by the new LA complaints procedures introduced by the 1989 Community Care Act (CCA) (White paper 1989: p18) became a more prominent part of the helper-helped dynamic and so disagreements about services intensified along with the confusion about who should make the decisions. As service users became more empowered to complain, professionals became more defensive and driven to assess the potential risks of complaint and litigation. Then, strongly endorsed by the New Labour government, regulations were introduced to reduce the risks of litigation (Audit Commission 2001: pp15-19, Littlechild 2003: p5).

By 1998, in phase three of the process, the control of public expenditure and service standards, were increasingly managed centrally by a newly elected Labour government (Travers 2007: p58-67, p78). The commissioning role of Social Services was consolidated, and LAs firmed up their new responsibilities to manage this process in line with the government's expectations following the CCA (Audit Commission 1996: pp17-18). It was then that changes towards service privatisation gathered momentum. This was in part driven forward by the fact that an increasing number of people had direct control of the money to purchase the help they needed

for independent living (Audit Commission 1996: pp16-19, Oliver and Barnes 2012: pp167 - 168).

A previous workforce of public employees, in secure jobs, was rapidly giving way to a workforce of non-unionised part timers. The care staff, increasingly the employees of privatised care agencies, had to survive on a mixture of short-term contracts, sessional employment, or self-employment arrangements (Glasby and Littlechild 2009: pp155-157). The study by Land and Himmelweit provides details of the impact of Community Care policies on the working conditions of home care workers (Land and Himmelweit 2010: pp31-32).

An encroaching litigious culture, as demonstrated by Mandelstam's record of legal disputes around community care, drove service managers to tighten up their regulations of working practices and risk assessments, and service users found aspects of their essential help either withheld, or prescribed for them with no room for negotiation. Within the new era of civil and human rights, disentangling the complexities, of whose rights were being infringed, and whose protected, was rapidly becoming the domain of another professional body i.e. the lawyers. Restrictive interpretations of moving and handling policies, for example, have at times been the cause of such disputes (Mandelstam 2008).

Process of change - changing the role of social services

Social services departments were encouraged to reorganise themselves, in two ways. Firstly, they had to

transform from generic to specialist social work teams and secondly, to split internally into commissioning and providing parts (Lowe 1999: p327). It's worth mentioning here that the *Seebohm* recommendations, discussed in chapter 5, incorporated into the 1970 social services legislation, had criticised the piecemeal and disruptive effect of having too many specialised sections of social work, as was current in the 1960s. The result of this critique had been to make generic social work teams the norm (Byrne and Padfield 1983: p320, Lowe, 1999: p269). The following extract from an interview with a Social Services planning officer during the initial stages of community care, points out that whilst the new legislation was not prescriptive, it did not in practice leave the LAs with many options.

'We very quickly realised the need to get a new departmental structure - the one we had wasn't able to cope with the demands of the new legislation ... There were lots of models. It's not like the NHS service where it's more of a statutory decree 'thou shalt have a purchasing authority' – it's not like that. Although I defy anyone to find a local authority that doesn't have a purchasing- provider split, it's a question of how they have done it' (Steve Peacock [interview], 1993).

It was the first time, in many cases, that disabled people had access to social workers who had to offer

them assessments and determine what personal care they needed. The social workers had responsibility for devising appropriate packages of 'care', arranging the funding for it, and in their new role as *care managers*, were also responsible for co-ordinating and monitoring the provision of services (Audit Commission 1996: p19, pp31-39), (HMSO white paper 1989: p21-22). Working directly with physically disabled adults was a new experience for many social workers. The following extract recalls how it had been before community care:

'There was never that much work on disability... when I came to this borough from Lambeth, I felt there was a tremendous dearth of services for young physically disabled people and people who had acquired disability... There was just one specialist worker in our team. I don't know how they (the team) planned anything because it was always "oh crikey we better sort out this placement", and there was the ethos "well you better wait till the specialist is in", as if generic workers couldn't make any sort of assessment, that their skills could not be helpful in that situation' (Sharon Compton [interview], 2000).

Because care in the community for physically disabled people hadn't formally existed before 1993, there was a huge gap, both conceptually and in practice. The very absence of new services made the freedom to

shop around attractive, and this began to change the relationship between the care managers and their clients. Social workers still held the purse strings and therefore much of the power, but the CCA added a twist. It obliged professionals to establish a more consultative kind of relationship with service users and disability organisations, which obscured the power imbalance, at least initially.

Back in 1993, looking for ways to introduce more consultation for planning the new services, the planning officer, quoted here, identified the tricky problem of persuading professionals to give up some of their power to people they saw as clients.

‘The legislation ought to improve the quality of life but that depends on two things, the first is resources. If there aren’t enough and one suspects there aren’t, then for a lot of people it’s going to get worse. And, secondly, it depends a lot on the Social Services attitudes changing. People have got to give up a lot more power - that’s the whole thing. If you talk to anyone who has done any work on what is really empowering disabled people, it’s about professionals giving up power’ (Steve Peacock [interview], 1993).

Creating a market of care

Whilst local authorities were reorganizing their services, a mechanism was put to work, by the government, to promote the transition from public to

private sector provision. Financial incentives called Special Transitional Grants (STGs), established through the *Local Government Finance Act, (1988)*; were offered to LAs, to help them develop their new public sector community care services, but only on condition that they used part of the money to purchase some services from the voluntary and private sectors.

The grant conditions ensured the money was used for specific purposes. Broadly, the plan was twofold; to reduce institutional care and create a market of providers. In the first year, for instance, these grants had to be spent on speeding up hospital discharges, moving people out of residential care, and developing domiciliary care services (Audit Commission 1996: p5, pp15-16).

Realising there had to be change discussions took place between the various stakeholders to try to identify what the new arrangements should be (Barnes and Mercer 2006: p25). This produced some positive results, with real attempts by professional managers to involve service users in the planning process (Steve Peacock [interview], 1993).

Building a contract culture

The local authorities still had responsibility to see that people's care needs were met, but now had to purchase some of their services from independent providers. To monitor such services, a new contractual relationship had to be created between the statutory funding authorities and the independent service

providers. This also proved a significant mechanism for change.

Previously, voluntary groups could apply for LA grants to fund local projects. Whilst some accountability was required, prior to 1992, in legal terms, local authority grants had been treated more or less as gifts, and voluntary organisations had not generally been asked to enter into legal agreements with the LA over the management of these funds (Pope 1992).

After the CCA instead of offering relatively open-ended grants to support good ideas, local authorities had to set up service level agreements (SLA) with independent providers. These service contracts acted as a double-edged tool for they encouraged local authorities to purchase services, but they also tightened control over the range of services they purchased. These SLAs then acted as a mechanism for determining which activities of the voluntary sector were to be fundable by the LA.

The new contracts encouraged the LAs to target their funding more precisely on services they had a statutory duty to make available and it encouraged them to cherry pick only the bits they wanted from independent service providers. This generally left the core costs of a voluntary provider, such as rent or administration, unsupported. They in turn, were forced to fund their own basic running costs from elsewhere.

In 1992, whilst preparing for community care, David Pope, Lambeth's then Director of Social Services

anticipated some of the inherent dangers of these new funding conditions on small groups wanting LA support for local initiatives. In his committee report (9 July 1992) he said:

‘Over the past seven years, government legislation has sought to redefine and restructure the relationship between local authorities and the voluntary sector ... underpinned by a policy which advocated “the need to create greater choice for the consumer”. ... further action in this respect has come from; the *Local Government Act 1988* which introduced compulsory competitive tendering for several services run by local authorities, the *Housing Act 1988*, the *Education Reform Act 1988*, the *Community Care Act 1989* and the *Children Act 1989*. ... all contributed to an environment that has demanded a review of the funding relationship.’ (Pope 1992).

He was drawing the committee’s attention to their new obligation to draw up SLA’s with voluntary organisations. These, he explained, were going to formally set out; terms and conditions, levels of grant, arrangements for financial accountability and constitutional standards, employment policies and practices, management policies and practices, monitoring and evaluation arrangements, clear service outcomes and performance standards, default procedures, and, detailed financial schedules. He

anticipated some of the pitfalls that would follow (Pope 1992):

The council will need to be mindful of the dangers of over-elaboration and bureaucracy in the development of any service level agreements / contracts. This will have the effect of reducing innovation, and work against new, smaller and innovative organisations, in favour of the larger funded organisations. One of the main challenges to the introduction of a contract culture is the fate of the smaller voluntary organisations. These are normally local, more issue based and significantly less established than their larger and regional counterparts ... despite redress measures over the last ten years, the larger voluntary organisations are more suitably placed to survive the contract culture (Pope 1992).

The *Association of Metropolitan Authorities* and the *National Council for Voluntary Services* made similar observations in 1990 and 1993 (Priestly 1999: p130). For CILs, and other organisations run by disabled people, SLAs immediately raised several important issues. Firstly, there was the matter of whether their LA would continue to fund their organization, or their services. Secondly, there was the issue of whether the new funding conditions would force them to provide services in ways that were contrary to their principles. Then there

were the issues of who they would have to compete with, and who would decide the criteria that went into SLAs.

During the early period differences began to show in the abilities of independent living and integrationist CILs to cope with the new climate. For those wanting to join the market it was relatively straightforward, but for those wanting to have a role in public service provision it was problematic.

From the independent living perspective, Rachel Hurst explained that whilst *Greenwich Centre for Independent Living* (GADCIL) was initially dubious about the SLAs, they soon found they could use them to their advantage:

‘We’ve benefited from SLAs, we’ve had them with agency, and with the PA (Personal Assistant) users ... we almost wrote the contract for the local authority – certainly had a very substantial hand in it. But it is a problem... When SLAs first raised their heads, at the end of the ’80s, we were very cautious because there was enormous pressure on us to do the borough’s work for them, and we said no. We would only apply for an agreement for an issue we have decided we want to do’ (Hurst [interview], 2000).

GADCIL’s decision to set up an agency of support workers to help people acquire PAs fitted reasonably well with the situation. The services people wanted were thin

on the ground. It suited their independent living agenda and also the LA to establish such a scheme, so a service contract was agreed between them.

In Hampshire, where two CILs worked together to promote the use of direct payments by disabled people (chapter 9) they too found their hand strengthened. Through the Southampton CIL with its more formal structure they were able to obtain SLAs and funding for a service of support workers to help people manage the process of employing Personal Assistants, and they found the local authority generally supportive (Philip interview 2000). But for Centres for Integrated Living, such as those in Derbyshire and Lambeth, Community Care had a constraining affect. Priestly draws attention to the DCIL experience:

DCIL's constitution had established its functions in the broadest possible terms (based on the 'seven needs'). Information provision, collective advocacy, community development work, awareness raising, research, campaigning, and barrier removal ran alongside supportive work with individual service users *... the new policy framework now required them to specify that strategy in terms of specific services that the purchasing authority could contract for_* (Priestly, 1999: p121) (Emphasis added).

The integrationists in Derbyshire then faced a difficult choice. Both their sustained efforts to run an integrated service model and desire to build a working partnership with the local authority were out of step with the national agenda. Although its previous relationship with the local authority no longer held, DCIL still wanted to influence policy and affect how the Community Care assessments were done. Davis recalled:

‘Initially DCIL was focused directly on the point of maximum control over the assessment process. The county council almost ignored the arrival of the Community Care Act, in as much that it took very little prior action and there was no real planning to get it implemented by April 1993, until more or less the year before. But, the problem then, was trying to influence the process when all the consultations that were beginning to be publicised between social services and health authorities, planning meetings, public consultations, and so on, were happening in a very short time. Whilst we made very strong representations about how disabled people should be involved, they just had no effect on what the authority intended to do. For the officers it was a golden opportunity to consolidate their controlling role. We had all sorts of misgivings of what was happening. It coincided with a period when we had come under serious funding attack, where we had to face up to some of the

hardest decisions and strongest campaigning that we'd ever engaged in' (Ken Davis [interview], 2000).

Lambeth Centre for Integrated Living (LCIL) faced the same difficulty, of sustaining a working partnership with the local authority. What had started out as a promising attempt to jointly run an equipment service, (chapter 9) was, by 1994, being squeezed out of the partnership by a local authority struggling to sustain its own statutory services. In just two years, the LCIL equipment service had demonstrated it could provide a responsive, well received, efficient service evidenced by a survey carried out by independent occupational therapists. But both success and partnership became meaningless once social services wanted to claw back control.

With community care and the introduction of direct payments, a key task for all CILs was to support disabled people through the assessments that were to decide people's fate in obtaining funding for their personal care. All the CILs were then motivated to develop a pool of support workers to help people prepare for an independent life in the community. Encouraged by NCIL they then sought to obtain local authority contracts to pay for this support and had to prove it was necessary (Barnes and Mercer 2006: p98, p150) (Interviews: Jane Campbell 2000, Philip Mason 2000, Ken Davis 2000).

Derbyshire Centre for Integrated Living (DCIL) soon discovered that, despite all its previous hard work, to bring about council agreements for integrated public services; under community care, the cash strapped LA, following rate capping, was only prepared to fund the bits of DCIL services that supported the community care agenda. To maintain their other services, such as the information service, access projects, transport campaigns, and campaigns to improve housing, etc., all essential to promote integrated living, they had to look for funding from a wide range of sources elsewhere.

Lambeth's Coalition had decided to set up a separate company to help people manage their direct payment option of employing their own personal assistants (PAs), and they called it Choices. This company was accountable to the Coalition, but it was independent of the LCIL (LCODP 1995).

By the third phase of Community Care, early in 1999, the overwhelming pressures facing small local organisations was starting to take effect and Lambeth's CIL was the first to be seriously undermined by loss of local authority funding, once the social services department resumed control of the equipment service. At that point neither LCIL nor the coalition were able to sustain themselves and so they closed (Helen Saunders [conversation with the author] 1999), (Gitte Rinds [interview] 2000).

However useful the CIL's other services might have been, they were not considered essential enough for local authority support and the more closely tailored *Choices* was, therefore, the only part to survive as I found when I visited in 2000.

Establishing a competitive market

By early 2000 a competitive environment was starting to bite all groups reliant on LA funding. GADCIL, for instance, one of the first to found a support service, almost entirely staffed by local disabled people, soon lost out to a private company operating a similar service, from outside the borough. This as it so happened was, *Choices*, another service run by disabled people with its roots in the independent living movement (Rachel Hurst [interview] 2000).

In these new market conditions CILs found themselves doubly challenged. They faced the demanding competitive conditions to win the LA contracts and the market logic of having to compete against each other for business. In due course, this was likely to lead to some degree of monopolisation.

From 2000 onwards, new government directives intensified the competition, by introducing more stringent Best Value service contracts (*Local Government Act. 1999*). These obliged LAs to compare; performance, and service costs, and measure these for best value before they could award a contract. For the CILs, struggling, on limited budgets, to run services that frequently

challenged community care assumptions, the new contracts raised two crucial questions. Who determined what was considered quality, and who decided what was of value?

Rachel Hurst argued that, in their experience under the Best Value contract culture, the importance of valuing and nurturing the services provided by disabled people through a local CIL had been neither sufficiently recognized, nor supported, by office-based contract managers with little knowledge of disability.

‘Again, it’s about relationships with local authorities and it’s a very difficult question because the people who make the decisions on who gets the contract are not the people who necessarily understand policy. The contract managers don’t understand equal opportunities policies and therefore can’t see the importance within presentations or tenders. Although not just doing it on cheapness, for they do now have to do it under “best value,” they are not sure what best value is’ (Rachel Hurst [interview] 2000).

The experience of losing their contract to *Choices* was a salutary one and raised some fundamental questions about what freedom the CILs had to determine their own agendas:

'I think we have learnt from this last tendering experience, that if we do continue on down that line then we are not going to be able to provide services in the way we would like to provide them. We are going to have to provide them in the way the local authority wants us to provide them. I think personally we probably still need to retain our identity as a flagship and not as a service provider. I think if we go down that road of tendering ... although it could be seen as a way of making money, it's a way of losing our principles. I don't think disability has got into the mainstream agenda enough yet to be able to do that. We still need to do lobbying for our principles' (Rachel Hurst [interview] 2000).

GADCIL, as it confronted the undermining pressures of the contract culture, was therefore finding it had to reassess its purpose. Significantly, the outcome of Community Care was making this long-standing activist rethink the political objective for disabled people's organisations. From pursuing the independent living and civil rights objective, both she and her organisation were possibly rediscovering the need to look again at their aims.

Competition between disabled people's organizations was one thing, but much more alarming was the fact that powerful charities, well known for their institutions, were becoming serious competitors. As Jane

Campbell (now Baroness Campbell, and original Director of NCIL) observed:

‘It’s awful, because here you get – let’s take Leonard Cheshire – a huge organisation, skilled in writing tender documents, has the money and backing to acquire premises really quickly, financial accountability that goes back years and then you’ve got the new up and coming independent living scheme, a group of disabled people desperately ferreting around for a base which they can’t afford, putting together a tender which they have very little skills to do. It’s like asking the local grocer to compete with Marks and Spencer for the same contract under the kind of contract rules that M & S know all about – it’s a game they know how to play, these small schemes are just role meat. Until local authorities can put stuff in the contracts around the importance of control and that it’s not just based on outcomes and targets and financial reliability, then I’m afraid we’ll be swamped by the Leonard Cheshire types again. It’s only been three years ... [since 1997] ... that the market has taken a grip. Suddenly these organisations have power again and the local authority can know that disabled people will not benefit from the service, but they will get a service, and they can tick their boxes under best value’ (Jane Campbell [interview], 2000).

Campbell's analogy with the supermarkets was very apt. Such organisations will diversify, like the Cheshire Foundation was already doing, to take control of an expanding range of *social care products* and push others out of their way. The Leonard Cheshire Charity for instance set up a range of care agencies, employment projects, and disability empowerment projects, which were in line with the government's agenda: *Modernising Social Services (1998)* (Mantle 2008).

There could be no guarantees now that the privatised care would prove to be cheaper, provide more choice, or offer the higher quality standards that we were led to believe would happen.

Changing the funding of community care

Obscured amongst its legislative promises to improve care in the community, was the matter of how the services were to be paid for. In practice, the legislation ingeniously set things up so that, by a process of transference, funding would fall less and less on the state, and more on individuals. It was a practical outcome that many failed to foresee.

From the outset, it was intended that three principle methods of payment would be used. The local state would continue to fund some services through local taxation, the government would channel some money through local authorities and health authorities to provide and purchase services, and private individuals would be asked to pay a contribution towards the costs. The

funding subtly shifted away from publicly provided services to privately run services and over time, a greater share of the administrative costs was financed by the private and voluntary sectors. These costs were then passed on to individuals either out of charges, set against care package funding, channelled through the local state, or directly out of privately earned income, through means testing.

During phase one of community care, the main source of funding for local authority welfare budgets came from national and local taxation supplemented by the Special Transitional Grants (STG), mentioned earlier. By phase two, a share of the costs was being financed by individuals paying charges (Baldwin and Lunt 1996), and by other parts of the economy, (such as by reduced wages and working conditions of the care staff). During phase three, charging for care became more the norm and significant numbers of people had to choose between paying for a service or going without. A number of mechanisms forced this transference to happen.

From 1993 onward some local authorities, finding they were unable to meet the costs of community care, tightened their eligibility criteria and introduced means tests. By this dual method they reduced the numbers of people who could claim their help. These methods of financial control were being introduced around 1996 / 97 (Audit Commission 1996: pp10-14). It enabled the services to manage their budgets better and started the

process of passing the costs back onto individuals. The price of care varied enormously, depending on the charging policy of the local authority where you happened to live, and this was clearly unfair (Audit Commission 1996: pp27-28). Some levied a flat rate charge, some made no charge and others developed a sliding scale according to people's financial means (Audit Commission 1996: pp26-32). So, in 2001, the DH set out to standardise the situation by offering LAs a framework for charging customers (DH LAC, 2001), and it resulted in the *Fairer Charging Policy for All (2001)*. From April 2003 all LA's had to follow the government's guidelines and criteria when charging people for personal assistance services. Charging was an important part of the strategy to reduce dependence on the welfare state. Whilst the decision rested with the LAs to decide what they did about it, the strong financial determinants meant few could resist for long.

To ensure the central economic programme remained on course, local expenditure was monitored closely by government departments. Rate capping offered one tool, to restrain levels of community taxation and expenditure, and another spur was in the conditions attached to the STGs and the SLAs. Jointly these forced local conformity to the CCA agenda.

Impact of funding pressures on voluntary organisations

During this period big changes occurred to the funding of voluntary organizations. At the end of the

1980s, even before Community Care became effective, government-imposed rate capping had hit three of the four LAs funding the CILs referred to above, and all, except Hampshire, experienced some of the backlash that flowed from this central government initiative (Hurst, GADCIL, and Davis K., DCDDP, 2000 [interviews], LCODP: 1995-97 [minutes and correspondence]).

Greenwich CIL, and the Derbyshire Coalition and CIL had substantial cuts to their funding in 1990 following rate capping and were really struggling for the next few years until they had secured other means to fund themselves. DCIL and DCDDP had their LA grants cut by as much as 50% around 1989-1990. Lambeth CIL experienced its funding cuts between 1995-1997 (LCODP: 1995-97 [minutes and correspondence]). With the public sector concentrating on their basic statutory duties and avoiding cuts to their own services, the voluntary sector often lost out.

Hurst contrasting the situation before and after the cuts recalled that in the early 1980s, GADCIL's funding had come from a variety of public sector sources. They had an urban aid grant, (this was a central government funding initiative to support deprived inner city area's), which they used to run the Dial-a-ride, a secondment from the Housing Department, some Health and Social Services funding towards their service costs, and, before direct payments came in, some income from the DH

Independent Living Fund to help disabled people who were organising their own personal assistance.

Towards the end of the 80s, following rate capping, they experienced more difficulty getting LA funding. Hurst described their subsequent transition towards becoming business orientated:

‘I was learning about what a lot of organisations were doing in Africa and realised we needed to learn some self-sufficiency. What we did was to set up a PA agency and that has kept us in a healthy position. People get funded, but we charge the local authority or health authority for managing it, so we make a profit. It was the first of its kind run by disabled people. It helped us through dire cash flow situations which all voluntary organisations were going through, certainly in those rate-capped boroughs’ (Rachel Hurst [interview] 2000).

In Derbyshire, the funding constraints placed on DCIL contributed to the pressures to move towards individualized services, as Davis reported:

‘That element of funding provided by the Act ... [the NHS and Community Care Act 1990] ... opened up a discussion which was happening in the context of our loss of funding. It also coincided with other developments, it’s fair to say, that had begun to overtake the thinking of the people in the Coalition in particular,

and also in DCIL. These were coming from the independent living movement and the arrival on the scene of a civil rights focus as a point of unity for bringing the movement together. Those two aspects in combination, had encouraged the individualism of the 1980s, and were being reflected in the development of the movement. Inevitably as new people came into the local movement they were coming out of those influences as well, so there was a process of change' (Ken Davis [interview], 2000).

Davis reference here to the combined pressures of Community Care, the Independent Living Movement, the Civil Rights' Movement, and funding cuts, is significant. For as he explained these all contributed to DCIL's decision to change course and move into direct payment support services.

To continue with its broader programme, DCIL had to seek many other funding sources to replace the lost LA support. By 2000 the picture had become very complicated as Davis said:

'Our budget for next year for example; from the county council, we still have an SLA with them. There's money from membership subscriptions, donations, sale of goods and services – quite a considerable amount, then also stuff from North Derbyshire health strategies. The city council (who used to pay them) went unitary at

the same time community care came on stream. Lottery project-based money, South Derbyshire Health and Amber Valley District Council, North East Derbyshire District Council. So many sources, some ring fenced in the sense they are project limited. It's just a totally different place from the one it was when we first set up CIL. Totally, in that funding sense alone. They all want their silly different monitoring, you need a bloody team of people just to manage the process. We only have individuals, trying to find time for it between other things' (Ken Davis [interview], 2000).

From her experiences of working for BCODP, Anne Rae observed how disabling these arrangements had become for small organisations run by disabled people. Below, she points out that when organisations give priority to employing disabled people, they face a higher than usual risk of having a proportion of staff needing time off for periods of medical treatment. Additionally, the impact on the organisation is much more significant if funding for it is strictly time limited and the work requires specific skills:

'Funding is project funding and time is restricted to two or three years for a project, even the lottery fund is time limited and for disabled people that's a really disabling way of funding any of our objectives because health issues do influence how a time related project

operates. It's crucial not just for BCODP but for local organisations too. They are all being absolutely decimated, because of this kind of funding ... Some allowance for time must always be given by them, to get more funding, to take the work on, all of which is generally on the premise that there's a research element involved, and this is another burden. Even if the organisations come up with a good idea, the conditions of funding, which go hand in hand, are usually so onerous that it is demoralizing for the organisation to take it forward' (Anne Rae [interview], 2000).

One such organisation expressing similar concerns was the Greater Manchester Coalition of Disabled People (GMCDP) which although not organised around a CIL, has played an important ongoing, campaigning role, of significance to the DPM both locally and nationally over the years.

The GMCDP, like the others had a major battle to keep financially afloat whilst maintaining its political independence to speak out. The sale of various services, including Disability Action Training, provided some income but in the main its survival has involved seeking various sources of grant aid, all with their own specific conditions to be met. This has placed a heavy burden on the organisation (from an interview with Kevin Hyett and Ken Lumb, 1998).

Being forced to operate with short-term bits of funding therefore raised several key questions for the relatively young organisations of the DPM. Firstly, there was survival, secondly, whether they could sustain an alternative service presence, and thirdly, whether they could maintain their political integrity as a campaigning force with a broad perspective.

Transferring the costs to individuals

By the second phase of the CCA, stringent funding limits for care packages were taking effect and charges were becoming more commonplace. The free domestic help service almost entirely disappeared and then it was the turn of the LA Home Care services to go into decline when they were unable to compete with cheaper care agencies (Audit Commission 1997: p32) or survive the movement away from Social Services towards using direct payments to pay for help (Audit Commission 1997: p50). Unless they met the newly restricted criteria for Independent Living Fund (ILF) money (Oliver and Barnes 1998: p86-87) many disabled people then had the unenviable choice of either using their limited income to buy help for essential aspects of daily living or they went without, or of being forced into residential care for lack of alternative options.

People over 65 were the first to be hit and many started to go without because they couldn't afford the services, or their need was not considered to be of sufficiently high priority (Gash and Roos 2012: p21).

From within a busy London social services department OT unit, working with older people, we found it was not uncommon, for instance, to find people looking for ways to avoid going to the toilet by not drinking, or taking dehydrating medication. Not getting dressed or staying longer in bed and using sheets that were rarely laundered. There were signs too of people living in squalid conditions, in housing falling into disrepair because of the lack of help or funds [personal working experience].

By the late 1990s tighter eligibility criteria for services, more means testing, and delays in making direct payments available, meant that winning LA support for independent living continued to be an ongoing campaign for individuals and for the DPM (Barnes and Mercer 2006: p95-96, 120-121, Glasby and Littlechild 2009: pp9-11, Oliver and Barnes 1998: pp86-87, Priestly 1999: pp91-92).

Welfare benefits, previously exempt from means testing, were no longer so secure, once the decision was made to permit LAs to draw on the Attendance Allowance component of the Disability Living Allowance for funding personal support (DH, Fairer Charging Policy, 2001).

Charging for services faced case workers with a different dilemma. That of how to carry out their statutory duties to provide services to people in need, who couldn't afford to pay. What could they do for people left to live in squalid conditions with inadequate or no support and

unable to cope? Community Care had few answers, and neither had their employers, other than to produce long lists of un-met needs (as I recall), in line with the auditors requirement that LAs map out the needs they had identified and what services were available (Audit Commission 1986 / 1992: p14, p34 1997: p84).

Under such circumstances, it was hardly surprising when staff hardened themselves to the deprivation. It was noticeable how the internal departmental language changed towards more emphasis on risk assessment and risk management, as professionals, and managers, became worried about potential conflict in their relationship with service users, and the need to protect against charges of negligence (Littlechild 2003).

Whilst the CCA implementations had initially ensured some flexibility to provide services in a variety of ways, and made funds available for this, by phase three, much of this flexibility was being eroded (Priestly 1999: pp102-105). It then became more difficult for disabled people to persuade their care managers that independent social activity and quality of life issues (all part of their equality of opportunity and social integration agenda) (Priestly 1999: pp104-105) should be funded by their care packages.

Developing the systems for rationing eligibility

Unlike the *1986 Disabled Persons (Services, Consultation and Representation) Act*, the CCA required Social Services to offer disabled people assessments.

The purpose was two-fold. Firstly, it gave people the right to explain what help they needed; and secondly, it enabled Social Services to decide whether they should provide or pay for a service.

The new assessments had to be consistent and offer equitable services throughout an authority and identify those most in need of state help. There was the further expectation that service applicants would have a more active role in their own assessment process (HMSO. 1989: p19-20). The procedure exposed the inherent conflict in the helper–helped relationship. However progressive sounding the rhetoric, when the question of funding arose, the conflict persisted between individual service users and budget holding professionals (Glasby and Littlechild 2009: pp135-141).

But it was not just about money anyway, it was the traditional model of “care” services that the Independent Living Movement regarded as inappropriate (Finkelstein and Stuart, 1996). Because of the ideological gulf that existed between the proponents of care, represented largely by the statutory sector and overarching Community Care legislation, and those arguing for support represented largely by the independent living movement (ILM), this was a key issue for CILs to pursue with their LAs, to try and secure a more empowering kind of service. The ILM has avoided the term care, because of its medical overtones of passivity, preferring the more dynamic concept of support that confirms citizenship

rights (Barnes and Mercer 2006: p28, 176). To do this, CILs established a new role for themselves; as agents of, or advocates for, disabled people caught up in a negotiation struggle with professionals. The aim was to ensure Community Care assessments provided disabled people with the financial and human resources they needed to follow their aspirations.

In their attempt to have an effect on the implementation of community care, Derbyshire CIL, successfully argued for a new concept to be built into the LA's service level agreements with provider organisations. This involved self-assessment and self-management (SASM, as it came to be called). Davis explained:

'SASM was our programme that we put forward to the local authority. It got discussed more widely, such as in the Social Services Inspectorate, amongst our different contacts, and within debates that developed in other channels. With the SASM line we were taking, we were trying to construct an outline that could be set in a contractual form - in a Service Level Agreement form, that recognised the social model elements of successfully living an integrated life' (Ken Davis [interview], 2000).

Whilst other CILs such as those in Coventry, Lotham and Shropshire had been pursuing a similar line, DCIL's

formulation of SASM was soon being accepted and promoted as a core principle throughout the country (Priestly 1999: p95), with a variable degree of success (Priestly 1999: p94).

The SSDs, on the other hand, were grappling with how their staff would assess people who were assessing themselves. In legislative terms, if a need was identified by a disabled person, the SSD had a duty to find some way to meet it, but, if they were to maintain control over their budgets, they had to be clear what range of help they could pay for (Glasby and Littlechild 2009: pp144-54).

Fairly quickly they faced the issue of affordability. To regain control, they started to differentiate between what they perceived as needs and wants (Glasby and Littlechild 2009: p140, 146). As I recall training their staff to then distinguish between a need and a want, social services departments went through a tortuous exercise that more or less said –

If a disabled person argued a need for something the social services couldn't fund, it would be regarded as a want, but, if both care professional and disabled person agreed a specified need, that could be met, it would be considered as a need.

A social worker talked about the confusion this caused in her professional experience:

'I think there's been tremendous weight put upon assessment, offering everybody assessment. That's what the Act says. What hasn't happened in my opinion is anybody drawing on those assessments to look at flexible services ... The problem is we have no means of asking people what they want in terms of services in a comprehensive way. People are assessed in terms of what their needs are, "what do you need" - but really what we try to do is then fit them into the service' (Sharon Compton [interview], 2000).

This dichotomy soon exposed the conflict between the different parties. Disabled individuals wanting to identify their own help in the widest possible terms to maximise their independence, the care managers trying to meet their client's needs, and the commissioners trying to limit the costs of care (Gash and Roos 2012: p35). For all concerned, the issue was; *who* determined the outcome.

Power over resources remained with the LAs who wanted to know how much *care* a disabled person needed to live in the community, when they needed it, and what it cost but when direct payments became available the struggle for flexible interpretation increased. CILs were adamant that Community Care assessments should be finding out what people wanted to achieve and interpreting need in a broad sense to encompass social

integration. It should not be restricted to a narrow band of personal care 'needs' determined by some professional (Priestly 1999: p104). Rachel Hurst from GADCIL explained why self-assessments became such an important part of the process:

'We say, what do you *want* to do? It's not what disabled people need but what their interests are, what they want. It's about empowering individuals so they can know what they want, then you get the battle. Our support workers, work with disabled people, to try to get what they want' (Rachel Hurst [interview] 2000).

Similarly, in Hampshire the CIL was trying to help disabled people maintain that choice and control:

'Self-assessment is an essential part of the process, the support worker (employed by the CIL) will help you define your needs and you will say what you want. First, we say, disabled people must define their needs. Further down the line, you say what you need irrespective of the budget, how much assistance; to get up, to walk the dog, to go to the pub to get a meal, or go to the hairdresser. You put that forward - coming from a social model of independent living. Then the care manager, it's their role to say what they can and can't do and prioritise. ... We've always argued for PA support to carry out social and domestic and personal activities. Hampshire Social

Services always recognised that it's there in their Community Care document ... being re-written now' (Philip Mason [interview], 2000).

In Derbyshire also, with an eye to the future care contracts, the CIL was trying to ensure community care wasn't reduced to a crude formula of "care":

'There was a feeling that at the end of the day it would be other players who would be developing personal assistance services in their own interest, either as profit making providers, or along some typical voluntary association managed care arrangements, without any challenge to the way the assessments were made, who had control of them and how support should be organised. We were hoping, and we to some extent secured, that there was a wider element to provision and personal support for a disabled person, in the county, than just PA itself; and that the community care assessment process itself had to be seen in the context of what people dubbed the "seven needs approach" to thinking from a social model perspective. So, we were trying to introduce that, not just for ourselves, we were trying to influence their policy as they were developing their policy documents of assessments, and their community care plan. Their framework of thinking was in those plans, we were trying to influence that, at the same time as trying to survive and being faced with the

prospect of other players coming in and eclipsing our presence' (Ken Davis [interview], 2000).

Unfortunately, as time moved on it has become more difficult for service commissioners to respond positively to the equality agenda. They have been under constant pressure to persistently narrow the baseline of what can be considered a care need for statutory support (Priestly 1999: pp104-5). It has therefore become extraordinarily difficult for CILs to maintain a broad programme of influence on the community services. As these are privatised, the battle to maintain an interpretation of independence in the broadest sense, through self-assessment, is fraught with difficulties.

Having had many years' experience of independent living, and using direct payments, Philip Mason from HCIL believed the power relationship had undergone little change:

'The community care assessment of need is supposed to be a dialogue of equals. But it isn't. The power imbalance is still totally wrong. You have no rights, no entitlements, you are there pleading your case with the care manager. That's the basics and that's not changed. There won't be any progress until that relationship has changed. The care manager can be more enlightened and better informed, but the fact is they have budgetary pressures and massive caseloads. And

it remains the case that the white middle class, probably males, do well, and those less eloquent, less well informed, continue to not get as good a deal as they should do, and we can't be satisfied with that situation' (Philip Mason [interview], 2000).

The CCA, introduced much rhetoric about joint working but the experience was disheartening, as recorded by DCIL in 1995, in its liaison group minutes, when they said:

'The involvement of disabled people's organisations in decisions about their services has declined to a lower point than at any time since 1981' (Priestly, 1999: p122).

There is little to suggest the situation has changed for the better since then within the local authorities or health services.

Monitoring the efficiency and costs of social care

Following government insistence that the services would be improved by the legislation (Travers 2007: p56), there had to be a system for monitoring the cost effectiveness of the new arrangements. This brought about possibly one of the most significant developments which was going on in the background, unseen by many.

Around 1988, LAs, along with computer software companies, started work on designing electronic information systems that would meet the new

requirements of Social Services as commissioning departments (Mike Custance [interview] 2000).

By the end of seven years, through a series of stages, computerisation of recording systems had been largely accomplished. What had also happened, in line with the wider information technology (IT) market, was a rapid process of monopolisation of the computer software programmes available to SSDs across the country (Turnbull 1986: pp17-18).

By 1988, seeing Community Care coming, LAs had realised they must install more comprehensive computer systems and initially a wide variety emerged (Glastonbury 1985: pp50-58, pp63-66). They interpreted the breadth of tasks their departments carried out, but because they were locally designed, they collected their data differently (Gould 1996: pp26-27). This was alright to start with but in due course made it impossible for government agencies to accurately compare the performance of one SSD with another. As centralised monitoring of the welfare services intensified, this became more pressing (Coates and Lawler 2000: p74).

After a series of stages in which bigger companies took on the design of systems that were purchased by several LAs (Gould 1996) it was not long before it became clear which of the SSD IT systems would have the competitive advantage. The monopolisation by then in progress was closely linked to the data bases being used to build them. By 1999 Oracle and Microsoft

dominated the field and they were providing the software to SSDs throughout the UK, (with few exceptions). They were therefore the driving force towards uniformity. Once the IT systems were under monopoly control, it significantly enhanced the capacity for centralised monitoring by government (Mike Custance [interview] 2000).

The history of government intervention to monitor community care changed substantially after 1993. Initially the government was content to see the legislation doing the job of driving local authorities to invest in IT systems to monitor their own progress. Of this earlier period the IT manager recalled:

‘Knowing some of the people involved, the impression I get is that the government believed that the commercial offerings ... were enough to make it sensible for central government not to intervene or be too prescriptive’ (Mike Custance [interview] 2000).

Monitoring the costs and effectiveness of the public sector and the independent services then went through a series of stages. First, the CCA widened the brief of the Audit Commission to inspect health and social services and then set up the Social Services Inspectorate (SSI) (Coates and Lawler 2000: p66). Up until 1998, local authority performance was monitored through annual

reports submitted to the Department of Health, detailing service outputs and overall costs, but not in much detail.

In 1998 the Labour government intensified the scrutiny. It didn't just want an overview, it wanted details about the processes, (from referral to service provision), about the costs and about the reviews being done to check individuals and their continued need for services (Coates and Lawler 2000: p76).

It meant case workers had to spend much more time recording on computers and they now had to define most of what they did by selecting from pre-determined lists of computer codes and categories, which in essence meant recording their work by a process of tick box electronic form filling. Whilst computers are enormously helpful and quicker for storing and retrieving data, this significant change also made it possible for managers and inspectorates to monitor the productivity of individual workers, teams of workers, and whole departments, in a comparative way. Un-measure-able things, such as observations that raised case worker concerns about their clients, were often put at risk of becoming hidden amongst all the statistics (Turnbull 1986).

The primary purpose of this industrial data collection was to measure the *quantity* of people processed through the system and the costs of service provision. But the *quality* of service responses, to complex situations, was far less easy to measure, and that could only be done by staff supervision and periodic inspections. In 2007, the

welfare service review; *Modernising Adult Social Care*, drew attention to the inherent limitations when using such overtly logistical regulation systems (Department of Health 2007a).

In December 1999, *Best Value* became the Labour government's paradigm for measuring the cost effectiveness of services. This provided a framework by which LAs would measure the performance of the services they contracted out, and the government would measure the performance of the LA departments. Best Value stated that service providing organisations were to be *challenged* to constantly improve, show a framework for *consulting* their users, and be *compared* against each other to determine their *competitive* value (Audit Commission 2000: pp9-10, Coates and Lawler 2000: p77, Travers 2007: pp55-56).

By using this model alongside computer monitoring, the government was in a strong position to set performance targets for LAs to adhere to. It could then compare SSDs against each other and, intervene if unhappy with the results. Similarly, the LAs were to compare independent service providers against another.

By 2000 the central government had become increasingly prescriptive of SSD activity (Coates and Lawler 2000: p77, Travers 2007: p59). From 2001 onwards LAs were judged against 50 national performance indicators that made up a new performance assessment framework and were thoroughly reviewed,

bi-annually, by the SSI (Audit Commission / SSI 2000: p11-2, 16-18). Croydon Council, Social Services Business Plan 1999-2003 provided a useful example of what they had to do. Back in 2000, the IT manager described what it looked like:

‘There’s quite a lot of movement in the market and that is responding to the joined-up government agendas. I’ve mentioned the Department of Health is becoming more prescriptive but equally what’s happening, the government as a whole is being prescriptive of how the IT should join up. So, the central IT unit, which is part of the cabinet office, is issuing a whole raft of guidelines... setting up data standards, and call service standards, security standards and confidentiality standards, it goes on and on’ (Mike Custance [interview] 2000).

He said that towards the end of the 1990s the Department of Health, Audit Commission, SSI, and the central IT unit were all putting pressure on local authorities for complex sets of statistical returns to meet different government agendas. He also mentioned that built into the universal plan for the future was the notion of personal portals, to give people access to their personal service records using a home computer. The potential of giving direct access to personal files, alongside self-assessment, tied neatly with the policy of direct payments to self-manage personal support.

Whilst using such an industrial measuring approach; improved time targets, created consistent service access criteria, and recorded throughput more efficiently, it also had the disadvantage of alienating the participants, in ways that were deeply worrying. That was because preconceived lists of human needs for one type of assistance or another were not necessarily the most appropriate recording methods for workers being sent into complex social situations, often to consider how best to help vulnerable or distressed people. In such situations, they needed sophisticated reasoning skills and the ability to think for themselves if they were to identify the best ways to respond.

When service professionals are required to only select nearest equivalents to a situation, distorted solutions result from it. As people start travelling in the direction of believing the number of people seen is more important, to their employers, than the quality of help provided, cynicism creeps in (Hough 1996: pp170-171). With less scope to talk about what disabled people want from the service, and less opportunity for workers to present their ideas, the heart starts to go out of the work and the organisation goes into decay.

Therefore, centralising the control of services, to facilitate universal standards, begs many questions about what long-term improvements are secured by it. In practice, the decision makers have become more remote. Meanwhile, the potential of more consumer

empowerment, made possible by the internet, is not universally appreciated, for apart from the cost of technical support to sort out those inevitable home computer problems, consumers also need considerable ability to wade through the plethora of information that will enable them to secure and manage their own support.

Changes to the services moved into another phase when the Labour government merged Health and Social Services by pooling their budgets to create Primary Care Trusts (PCT's) (*National Health Service Reform, and, Health Care Professions, Act 2002*). These changes were then overtaken by the Coalition government's 2012 restructuring programme for the health and welfare services. A detailed analysis of their impact on disabled people is for some future study.

CHAPTER 11 - Considerations for the future

Disabled people must go beyond ramps, with a piercing gaze that can see through the agents of oppression into those economic and undemocratic dynamics that have created inequalities. Civil rights' incrementalist history tells us, that it may not be so wise to rely on a system to generate equality, when that system's goals - increasing concentration of private and corporate ownership - are in conflict with the principles of equality (Russell 1998: p132).

Having seen, in Britain, the demand for civil rights gain predominance over the struggle for socialised provision, we might ask, as Marta Russell does, what can be achieved by concentrating on civil rights as the means to create more social equality. Further to this, we need to ask ourselves how well we understand the class interests and economic dynamics that maintain or exacerbate those inequalities (Piketty 2014: pp22-27). From the media coverage, it is very clear that people all around the world are suffering from the fallout from a globalised monopoly capitalism in crisis (Bogdanor 2007: pp173-175, Roulstone 2014: p275). As the drive for profit becomes more aggressive, expenditure on social programmes is cut back and disabled people, along with many others, lose their services (Oliver & Barnes 2012: p146, 185).

Studying the impact of US economic policy, Russell found that the *Americans with Disabilities Act (1990)* had proved a poor defence against sustained attacks on their living standards. They had suffered the double whammy of not only ranking disproportionately highly amongst the unemployed but also from having their welfare support severely reduced. She found, moreover, there was little consolation from being able to appeal against discrimination since their cases were rarely investigated.

This had meant that despite living in one of the most economically powerful countries, disabled people were not getting the benefit. Because of their inability to afford community-based support many were forced to return to institutions (Russell 1998). The direct opposite of what they had set out to achieve. In Britain many similar patterns are now emerging. Over the last thirty years, seduced by the US economic model, successive British governments have overseen the steady erosion of the welfare state whilst encouraging its replacement by private and voluntary providers. For people needing the services, this has meant becoming consumers in a new kind of market and paying an increasing share of the costs.

Having civil rights legislation can help some people gain better access to the services they want, but it does not necessarily stop the services being priced beyond the reach of many. Likewise, having civil rights, to improve our chances of employment, does not stop the erosion of

state support for those who are unable to find work or on very low wages. It is therefore important we consider the full implications of changes to our services and the limitations of civil rights to act as our defence.

We should see the cuts to our support systems as the symptoms of a breakdown of social cohesion. What we are experiencing is a re-fragmentation of our society which is taking us back to conditions not unlike those that existed before the welfare state. In the nineteenth century the laissez-faire state allowed the unfettered market economy to expand very rapidly (Hobsbawm 1968: pp226-227), and services, such as they were, emerged as largely unregulated, piecemeal responses to social needs. In the twentieth century increasing social disquiet then called for national solutions to reduce social inequality and some universal services were created (Wardley 1994: pp57-77). At different stages, the state increased its responsibility to provide services.

But, although the principle was for more social equality, in practice the services were controlled in ways that undermined any semblance of democratic decision taking. From the start, the hierarchies on which they were based, gave professionals and bureaucrats too much power whilst those using them had too little. It meant, over time, that much of the welfare state became out of touch, poor in quality, and more easily discredited. The popular disenchantment this generated opened the door to privatisation and open-ness to the theory that a mixed

economy might produce better and more efficient services (Barnes and Mercer 2006: pp27-28, pp38-49), (Piketty 2014: pp479-483).

It is therefore possible to see that we have gone through a cycle; from a period of fragmentation, to more social cohesion and back again to fragmentation. This suggests that, as the fragmented society becomes more chaotic, socialised solutions will be called for once more, to achieve more social cohesion and a fairer share of resources. At this point fresh thinking will take place about what we want in the future.

As we search for new ideas to build a more enabling society, we would do well to look back at the achievements of the disabled people's movement and consider the different strategies people followed for tackling the many barriers to integration. In terms of overarching strategies, the two most significant have been driven forward by the UK emancipatory model and the US civil rights model.

The UK emancipatory model

It is now widely recognised that the social model of disability was an important breakthrough in providing disabled people with a clearer vision of what they had to do to achieve their social emancipation. It has become integral to much of the debate around disability theorising and to practical projects and is having an increasing impact on social policy at both national and local levels (Oliver & Barnes, 2012: p24). As shown, this thinking

originated from UPIAS, a Union of People with Physical Impairments, who came together to tackle the unacceptable segregation of disabled people by a system of separate services.

In my view what is less well recognised is that the political reference point for their approach lay within British working-class movements for emancipation, uniting people around their specific 'class' interests to build a defence against oppression (It did not originate from the more individualistic and legalistic civil rights tradition that has come to the fore since). The UPIAS objective was to improve the living conditions of disabled people in general and having decided upon the political agenda that was needed they emerged as the political vanguard for a grass-roots struggle against oppression (Finkelstein 2002).

UPIAS members had set out to explain the causes of that oppression and not just respond to its effects. Once they had reached an understanding that disability was caused by the way society was organised, they recognised it called for radical and global solutions to put it right.

Having recognised the care services were keeping people in perpetual dependency, especially in the case of segregated provision, UPIAS set out to challenge their oppression through these social practices. Over time the idea took root that the best way to rid society of segregation was for disabled people to have a share of

the power to influence how public services were provided. This would enable them to promote the right kind of personal support.

In several different settings, the new dialogue developed between disabled people, professionals and local politicians, to consider how integration could be achieved. In due course experimental Coalitions and CILs took the ideas forward and became the backbone of local service reforms and an integrated living movement.

The American civil rights model

Sections of the UK movement were then influenced by the achievements of civil rights campaigns in the USA. In America too, disabled people had been following the path of earlier social traditions, but there the dominant model had been a civil-rights one following in the well-established footsteps of racial, and women's, equality movements.

Living within a culture built upon the concept of constitutional rights, the accepted route to equality was through Anti-Discrimination Legislation (ADL). This laid the framework for tackling the disabling society and the legal means to fight discrimination. Not having a welfare state, disabled people perceived the best way of accessing life in the community was by employing the aid of personal assistants (PA).

Once the UK movement decided to follow this model, the method and direction of campaigning

changed. Much more effort went into achieving ADL, to tackle the barriers, and to obtaining Direct Payments to employ PAs. With a shift towards national campaigning to influence parliament, the local focus of the DPM were overstretched. This weakened the grassroots pressure on local authority services.

Time to take stock

Now, it is time to take stock and consider what has been achieved by this strategy to achieve a better quality of life and look at what is happening to people who need the support of services. Can we say that, because of civil rights' legislation, the quality of services and employment opportunities are substantially improving for disabled people?

It is helpful here to listen to experiences from America, firstly, because they have had more time to experience the impact of ADL, and secondly, because American values have come to assume such an important influence on the British way of life. Russell, having seen the undermining effects, of cuts to welfare support, since the passing of ADL, took a critical look at the political strategy of the American movement. In her critique she noted a significant weakness had been its failure to take account of the effects of racism and class as dictators of social opportunity. She argued; this emphasis on the pursuit of civil rights had led the movement to pursue a predominantly white middle-class, and divisive agenda. Russell (1998: p131) wrote:

‘Minorities have rightly come forward to challenge the values of a disability movement that fashionably promotes civil rights at a time when “reform” to Medicaid, SSI and welfare threatens the stability of programmes that affect poor minorities.’

Achieving emancipation is therefore more complex because it involves tackling the structures of a society driven by powerful class relationships that to a large extent determine the opportunities people have, to rise above a basic existence.

Back to the roots

Whilst a social movement is made up of many groups and individuals pursuing a variety of objectives, it's important, from time to time, to question what the broad strategy should be for a movement pursuing emancipation. As a conscious political liberation tendency, the early UPIAS offered several insights that are still a useful starting point for assessing the liberating potential of the UK movement. One could describe them as ‘seven insights for emancipation’.

These insights stated that:

i) Disability was a form of social oppression caused by the many ways social organisation excluded people with impairments. It was argued that once the barriers were removed and appropriate forms of support were put in place disability could be eliminated.

ii) To become emancipated from dependency, disabled people would need to become their own agents of change. In becoming active on their *own* behalf, they would not only be more able and effective as individuals, but they would *collectively* identify the barriers and the right solutions would emerge. The vehicle for change would be their own grass-roots movement.

iii) If disabled people set aside their differences and united around the idea that they were oppressed, they would not only lose the false consciousness of assuming it was their physical impairments that caused disadvantage, but they would also find they had a sizeable voice with which to reverse their powerlessness in society.

iv) Because a disabling society was a totality, no one aspect could be dealt with affectively in isolation. The right approach had to be all encompassing, and, in the process, people would discover how to build integration into the structures of society. The kind of supportive environment that would result from this would improve life for the majority and not just for people with physical impairments.

v) A dependency creating culture was being perpetuated because of the misuse of power in the hands of service professionals. To turn a disabling culture into an enabling one, disabled people had to devise ways to control their own lives. One of the means for doing this was by creating a different type of service model.

vi) In a technologically advanced society, as people developed their aspirations, more barriers would be challenged and employment, above all, would become more accessible. This would, in turn, reduce dependency on the state and on other forms of charity and disabled people would become contributors to social wealth as well as receivers of it.

vii). To gain access to employment, and not need state charity, there needed to be some fundamental changes to the way work was organised. It was anticipated that full employment of disabled people was unlikely whilst work was primarily driven by competition and the pursuit of profit (UPIAS 1976).

Before considering whether these insights could be useful now, it is worth first looking at what happened to them once the civil rights agenda took over.

Changes through a civil rights agenda

Responding to the points one by one, it is possible to see that a subtle change took place once people became more interested in civil rights as the route to equality. For one thing, the language changed. Instead of arguing for integration, people started talking about a policy of inclusion, which is not quite the same thing. Having others include you is not the same as it being accepted that all people are *integral* members. For this to happen, the society itself and how we interact, must change to become an integrated whole.

Taking up the first insight, one can see there has been widespread acceptance that social, physical and economic barriers are responsible for causing disability, now commonly referred to as the social model. Rights legislation, as a method for tackling this, has been partially successful for significant improvements have been made to the physical environment and access to services, such as housing, transport and education. But in the process, there has been a shift of responsibility for tackling discrimination. With more emphasis placed upon the rights of individuals, it has become predominantly a personal responsibility to challenge discrimination (with or without the aid of lawyers), instead of a collective one.

Once the campaign focus was on *legislative* change, the second insight; about the need for disabled people to emancipate themselves by becoming the agents of change, became more obscured. Instead of the social movement being an organic process that engaged people more directly with issues of power and control, the campaigning turned attention to pressurising parliament. The emphasis of responsibility then shifted to politicians as the agents of change. This change meant the movement needed its own group of experts to do the negotiating whilst the grass-roots were relied upon to demonstrate their support. In the process, whilst the political skills of some people developed substantially, others risked losing opportunities to develop their

negotiating and other skills from direct involvement in more local campaigns.

It was not long before there were declining levels of grass roots support for collective forms of organisation in both national and local initiatives. By 2000, Coalition magazine was publishing a debate entitled; “Where have all the activists gone?” Here Finkelstein forcefully argued that the lack involvement in debates and decision making, at the grass roots of the movement, were directly linked to the change of direction taken by the new leadership towards a parliamentary pressure group agenda (Finkelstein 2000a).

Some parallels can be made with the earlier experiences of the Disablement Income Group (DIG). It lost its way in the early 1970s by placing too much emphasis on a small group of experts to do its parliamentary campaign work. Once DIG lost sight of the importance of not only listening to its grass-roots membership, but also developing it as a political force for change, its membership started to fall away.

The third UPIAS insight, which was to set aside differences and find a united voice, was to a large extent achieved through the civil rights campaign. It was very successful in gaining a wide coalition of support from across different sectors of disabled people and allied groups, and this worked well so long as the campaigns were building up momentum. However, once the legislation was in place, and the movement’s driving

force had gone, unity and involvement were more difficult to sustain. Campaigning then, of necessity, became more personalised, with people caught up in the stresses of employing and managing their personal support systems and fighting their own battles to have their rights respected. This left less energy, time or inclination for joint forms of action. It has faced the movement with its own fragmentation with many local groups struggling to find enough people to carry out their work.

There has been a good deal of talk, over recent years, about the demise of the DPM, some of which can be found in Coalition magazine. Through the various written debates there, attempts have been made to explain the reasons for it, such as; the change of direction towards pressure group politics with a parliamentary focus, mentioned above, which had alienated the grass-roots from meaningful involvement (Finkelstein 2000a, 2000b). That, in pursuing a rights agenda for legal safeguards, as an end, the movement had lost sight of the emancipatory social model as its basis for struggle (Finkelstein 2002, Oliver and Barnes 2006). And, that the NCIL's decision to split from BCODP in 2003 and become autonomous, was a seriously weakening event (Rae, 2003). In 2011 NCIL merged with Radar and the Disability Alliance to form Disability Rights UK (Disability Rights UK, 2012). In 2006 BCODP changed its name to the United Kingdom Disabled Peoples Council, which was disbanded in 2016.

The fourth insight was about the need to respond to the disabling society as a totality and avoid using a single-issue campaign approach to change it. Some might argue the civil rights campaign has been consistent to this principle, by trying to set some universal standards. However, it is also the case that a multifaceted strategy, developing through many strands, gave way to a single campaign approach, centrally driven with an agenda promoting anti-discrimination legislation and direct payments.

The fifth insight, about challenging a dependency culture by changing the power relationship with professionals, has been interpreted as a justification for seeking direct payments in lieu of public sector services. Here, the integrative objective to create truly universal services has given way to a preference for individually managed, privatised solutions. The emphasis has moved away from the needs of the “class” onto the needs of individuals.

Whilst the policy of direct payments has undoubtedly enabled many disabled people to develop skills around managing their own lives and have more control of their personal support and been liberating, there is the danger that the gains may be short-lived. When personalised solutions become whittled down by benefit cuts, administered by increasingly remote private companies, and there is no safety net of public services to turn to, the

future looks grim. At the very least it requires constant vigilance.

In *Coalition* magazine, Hilton (2007) drew attention to the widespread attacks made to personal support services with the introduction of FACS (Fairer Access to Care Services), and more recently to the then anticipated closure of the Independent Living Fund (Hilton 2012). Also, in *Coalition* magazine, Amath (2012) described how successive care reviews, over the last nine years, had slashed her care package from 24 hours per week to 3, and how this had changed her situation dramatically, from having help to carry out a wide range of social activity and lead a full life, in 2003, to only having the minimum to get by.

The sixth UPIAS insight, that people would take up employment once the barriers were removed, has made some headway since the 1990s. ADL and government policies, such as those that promote the employment of more disabled people, have together been responsible for putting some pressure on employers to improve their recruitment practices. Access to Work assistance via Job Centres, was initially introduced in 2003 by the New Deal policies and followed up since by a range of employment schemes targeted at disabled people (Stuart 2007: pp422-423, Roulstone 2014: p238).

However, during a period of tough austerity measures, it is also the case that various voluntary projects providing social support, including some

designed to aid people find work, reported they faced cuts to their funding (Bawden 2013, Boffey. 2012, Kane and Allen 2011).

The seventh UPIAS insight, that unemployment is largely the result of the way work is organised, has yet to be addressed. Whilst it is important to welcome social policies that improve employment opportunities, it is also necessary to be conscious that fundamental relationships between capital and labour, which is essentially competitive, profit-driven and deeply affected by global manipulations of the labour market (Taylor 2007: pp214-218). If people put too much faith in a rights culture to deliver the answers, then this underlying relationship can remain obscured.

What now?

The changes of emphasis, in the political objectives of the movement, have been subtle. Whilst disabled people, now, more widely perceive disability as a social creation, the method of resolution has changed. From the original conception that disability was a class issue, needing radical solutions, disability has become a rights issue which means it can be gradually modified. Instead of emancipation being a process that derives from engaging with the causes of oppression, it has become an issue of *legality*, for individuals to defend themselves against discrimination. Or as Lumb put it in the 1990s:

I wasn't too impressed with civil rights - they were too bound up with the system - rather than overthrowing the system (Lumb in: GMCDP 1995-1996).

We now have the Equality Act (2010) that has replaced much of the DDA. We hope for continued improvements to make the environment easier to negotiate, and for transport and other commercial services to become ever more accessible. Such improvements are very important; but there are also signs of creeping regression. Education, for instance, where huge efforts have been made to make schools inclusive, is now increasingly a competitive market place that shows signs of reverting to policies of exclusion and separate provision for children who do not fit mainstream school goals and targets. The issues surrounding how people obtain and retain employment, and survive and move around in the community, when they need some personal help or personal transport remain full of uncertainty.

Improvements to employment potential exist because anti-discrimination legislation has improved access to education and training, adapted environments, transport, and technology, all of which have helped to make work possible. But the situation remains contradictory. As jobs come and go in cyclical patterns, the improvements in the labour market remain unstable, piecemeal, and temporary. Governments may

periodically intervene to offer incentives, but these will not remove the ongoing competitive pressures, and history has frequently shown that civil rights are a limited tool to combat the pressures or discrimination (Oliver and Barnes 2012: pp129-131).

Overall, Roulston (2014: pp236-242) argues that the statistics have remained largely unchanged by government programmes to reduce disabled people's unemployment. Although, as he points out, many disabled people do work, but often in a voluntary capacity. Similarly, sex discrimination legislation, has not stopped women from being paid less than men, or from being dismissed on becoming pregnant nor from suffering sexual harassment (B. Campbell 2013). Race equality legislation has not stopped racial abuse or harassment or facing reduced employment or promotion opportunities (Finkelstein and Stuart 1996: pp174 -175, Oliver and Barnes 2012: p175, Parmar 2000: pp212-214, p217).

Given all these reasons above, the issue of striking the right balance between work and welfare support, continues to be very pertinent. Russell (1998: p82) puts it into perspective when she says:

We need to look at reality not agenda-based rhetoric. In reality there are disabled people who do work, there are disabled people who can work but are prevented from doing so for various reasons, and there

are those who cannot work. It is discrimination to deny a person who can work an opportunity to do so, but it is not 'special' treatment for people who cannot work to be guaranteed a humane standard of living – rather it is a measure of a just civilisation that they are decently provided for.

This is an increasingly pressing issue. The kind of support disabled people can receive from the state, when the government policy of 'no rights without responsibilities' is applied to get them off benefits, is now open to question (Oliver & Barnes 2012: p124).

The fragmenting effects of the market on the UK's services

Since the NHS and Community Care Act 1990 the growth in the independent service market has become well established and we can see some of the effects on care provider services. The way state, private enterprise and voluntary sector funding structures are weighted, often make it unstable. Organisations come and go according to their ability to win service contracts, charitable donations or obtain other sources of income (Berghs 2014: pp270-276, Oliver and Barnes 2012: p168). Furthermore, under these conditions there is not much scope for small organisations to engage in long-term planning or imaginative development.

Given the political direction to drive down the state's financial contribution, we must consider what will happen once most services are privatised. According to normal

patterns it is reasonable to anticipate that many small organisations will eventually be pushed out by larger ones and monopolies will appear with the support of private finance. Along with this, choice will diminish, and people will once again be driven to use services from monopoly providers. Instead of being state run monopolies these will be privately financed ones from which people will have to purchase their own personal care with or without state input (Bawden 2013, Berghs 2014).

Once privatised, such services become less accountable and less bound to address the concerns of people needing their support. The relationship is between; individuals, with little power, and management boards of corporate companies, with a lot of power, striving to maximise their profits for their shareholders. Finkelstein (March 2007) put it thus:

This is a capitalist dream come true – every single disabled person becomes an employer, pays personal assistants for their labour, is responsible for working conditions, ensures annual leave is provided, does the obligatory paper work and checks taxes etc. The only trouble is – capitalism doesn't stop here – competition means successful companies gobble up weaker groups, companies merge forming larger groups and those that fail, well they go bankrupt and disappear.

Whilst this stage has not been fully reached in Britain an increasing number of unfilled service gaps in the provision of care and support are having to be filled by individuals, family, and the voluntary sector (Berghs 2014). Having been largely reduced to commissioning organisations, LA community care departments, and increasing numbers of community NHS services, are dependent on the services that private enterprises are willing to sell. In some areas this choice may be limited to a few organisations or care agencies. From the consumers' point of view, it then becomes very difficult to challenge poor services or see them effectively dealt with. They can find themselves back in the invidious situation, for instance, of being forced to be more dependent for lack of an appropriate wheelchair (Pring 2018a) or having to get up, or go to bed, at the time an agency determines to call (Berghs 2014).

In the US, experience has already shown what can happen when disability is turned into an exploitable commodity. Below, Russell describes how corporately run residential care organisations were able to increase the institutionalisation of disabled people by discouraging Medicaid payouts to pay for personal assistant services:

The calculating corporate players have steered public policies towards institutionalisation and away from citizen-controlled community and home-based care

because institutionalised 'care' is big business (Russell 1998: p102).

Already, disabled people in the UK, face considerable state-imposed limitations to their rights to personal freedom. The charges and means-tests for personal help, constant and intrusive reviews of benefits, sudden unjustified withdrawals of social security, and lengthy and frightening ordeals of appeal tribunals, to have benefits re-instated, are all hugely distressing and deeply injurious.

People have faced cuts to their direct payments, which has reduced the help they can buy or the wages they can pay their PAs. There is no automatic provision, to reflect changes to the minimum wage, nor any specification regarding the pay scales of privately employed PA's. The trend to reduce state support for personal assistance therefore drives one oppressed group to exploit another.

The DPM slogan of '*Our Rights, Our Lives, Our Choice*' has not held off these service withdrawals. Now if people end up living in institutions, it cannot be said it is because community living is impossible, but because it has been decided, by others, that it is too expensive.

Looking ahead and re-staking a claim for cohesion

An alternative to the continuous takeover by private enterprise could be for disabled people to re-organise, and unite, with other service user groups and with

workers' organisations for some form of public services that can deliver what people now want. To date, the lack of clear vision from the political left, about how to create an alternative service structure, is one of the things that holds people back. There is clearly the need for a new service model, but it must start from a different set of assumptions, and disabled people have a wealth of experience to offer this debate.

The issues around how people are to be supported in the future, and how an integration agenda will be achieved, are important ones. We know from experience that one of the reasons public services have failed is because, whilst structurally they offered universality, their fragmentation into specialisms produced partial solutions staffed by professionals who exercised too much control, and were unable to appreciate the true impact of disability. What are now needed, are some forward-thinking responses that can tackle disability from an integrationist perspective in the broadest possible sense.

Developing a new kind of support service, means creating a new kind of enabling workforce to provide it. For workers to be enablers, rather than helpers tied down by an outdated care philosophy, they require a new outlook that is rooted in a culture derived from direct experience.

In the past, 'needs based' services have grown up in a piecemeal way as responses to service gaps in the community. Overall, these services turned to already

existing professions to provide the workforce. This has meant adjusting subsequent professional training to the changing demands of the major employers. In the field of social support, there have rarely been training initiatives that started with a clean sheet of paper seeking to find out what was wanted and the appropriate skill mix.

In the case of disability there was no nationally standardised 'professional' training specifically designed for community-based support, and the first attempt to address this gap happened when disabled people started to develop their own services from centres for integrated / independent living, but these initiatives were small scale.

If a new service is to be rooted in the social model of disability, various core principles need to be incorporated. Since active participation and empowerment are fundamental for the elimination of disability, any attempt to create non-disabling services must draw on the ideas of those who will use them. Also, since it is not only disabled people who use such services, planning them needs to draw on a wide range of experience to create the kind of relationship that can really make a difference. If such groups could join, in a new kind of partnership of experience, real possibilities for a more liberating service model might emerge (Hunt J. 2011).

Finkelstein (1999a) put forward this idea of developing a new profession of community support workers when he wrote:

[W]hilst 'community care' academic courses for practitioners in the health and social services continue to flounder in an intellectually bankrupt 'care' philosophy, developing a PAC (profession allied to the community) could bring into production a virgin field for fertilising, cultivating and reaping user *and* service provider aspirations.

In another article, exploring the potential of this idea, he said:

[T]he development of our own approaches to assistance not only requires an unpacking of the version imposed on us by people with abilities, but the creation of our own 'normal' forms of assistance. Our constructing of systematic forms of help according to our own social model of disability will generate new services and service providers - professions allied to the community (PAC's). I believe that these workers will constitute our own trade union. It is these trade unionists, truly immersed in a disability culture, who will be a vital engine for social change. They will have a crucial role in promoting the national and international criticism of the dominant health

and community care ideology that is not wanted by disabled people (Finkelstein 1999b).

Since so many knowledge disciplines, such as; architecture, disability studies – with its interdisciplinary history and incorporation of disability activism, education, health, psychology, science, social studies, technology, and many more, now interact in some way with disability, it would be invaluable to know which core values and skills are considered essential for a new brand of workers (Barnes 2014: pp19-20,: Finkelstein 2004b: pp19-23, Finkelstein and Stuart 1996: p170, Sheldon 2014: pp327-328).

In 2012 Oliver and Barnes wrote;

[M]any of the emergent movements operating in the last century have either been absorbed into government or become marginal to the political process. Regrettably, we would suggest, this has become the temporary fate of the disabled people's movement. Most significantly, there has been no coming together of the disabled people's movement and other political groups such as the lesbian and gay movement (Shakespeare, Gillespie-Sells & Davies, 1996) or perhaps more significantly the anti-capitalist movement (Horsler, 2003), for example to create more powerful alliances (Oliver and Barnes, 2012).

I would add to that by saying; UPIAS was ahead of its time when it wrote:

What all oppressed people share is a vital interest in changing society to overcome oppression, and the Union is anxious to join in common action to achieve such change (UPIAS 1976).

(Here 'the Union' refers to the Union of the Physically Impaired Against Segregation more generally referred to as UPIAS). It may not have been possible to achieve it then, but it might be in time. In recognising that a society that persistently prevents full participation is a disabling one, it should not be so difficult to see the parallels of why the struggle against disability is not only all encompassing but also a generally liberating trend. We are denied control over an increasing amount of our lives, because we live in a society that allows a declining number of individuals to manipulate vast amounts of wealth and power to serve their narrow interests (Piketty 2014). The challenge ahead must be to reverse this trend and the efforts that ordinary people make to bring about more supportive communities will be fundamental to this.

It could be that just as it has been important for disabled people to recognise the significance of institutions as the most basic expression of their social exclusion, it will be important for all oppressed people to

understand the social significance of disability. If disability is the most fundamental expression of restricted opportunity, then a society that does not disable a minority will be a society that enables the majority.

I finish with this observation and a question. The small group that made up UPIAS could not achieve all they set out for, but they made a very powerful contribution towards it by laying down some foundations. Can a re-invigorated disabled people's movement now emerge to take this legacy forward to a new stage and will they embrace their social responsibility to help change the course of history? Maybe then we could start to envisage a time when *no limits* are imposed on our potential.

Appendix 1

Union of the Physically Impaired Against Segregation - Aims and Policy Statement

Adopted on 3 December 1974

Amended on 9 August 1976

Emphasis was by underlining in the original, and here is in bold

AIMS

The Union aims to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society. These arrangements must include the necessary financial, medical, technical, educational and other help required from the State to enable us to gain the maximum possible independence in daily living activities, to achieve mobility, to undertake productive work, and to live where and how we choose with full control over our lives.

POLICY STATEMENT

DISABILITY AND SEGREGATION

Britain today has the necessary knowledge and the advanced technology to bring physically impaired people into the mainstream of life and enable us to contribute fully to society. But instead of the Country's resources being concentrated on basic human problems like ours,

they are frequently mis-spent, for example, on making sophisticated weapons of destruction, and on projects like Concorde and Centre Point. So despite the creation today of such an enormous capacity, which could help overcome disability, the way this capacity is misdirected means that many physically impaired people are still unnecessarily barred from full participation in society. We find ourselves isolated and excluded by such things as flights of steps, inadequate public and personal transport, unsuitable housing, rigid work routines in factories and offices, and a lack of up-to-date aids and equipment.

There are a few individual examples of severely impaired people being able to overcome many of these barriers by the use of sufficient resources in the right way. They prove that integration is possible. But as a group we are still often forced to put up with segregated and inferior facilities. We get sent to special schools, colleges or training centres. We are systematically channelled into segregated factories, centres, Homes, hostels and clubs. If we do manage to become mobile, it is often in antiquated tricycles or specially labelled transport. All these segregated forms of help represented progress in years past. But since the means for integration now undoubtedly exists, our confinement to segregated facilities is increasingly oppressive and dehumanising.

RECENT ADVANCES

The struggles of disabled people and their relatives and friends, together with advances in technology and medical science, have it is true resulted in larger numbers of us participating more fully in ordinary society in recent years. Some of the barriers which segregate us have been partially overcome or dismantled. So a good proportion of people with paraplegia, or those who are blind, for example, have become able to work and to lead relatively active lives which would have been hard to imagine less than 50 years ago. These developments have meant a positive shift in the attitudes of some non-disabled people as they have responded to our presence amongst them.

Such advances show that general attitudes **can** be changed for the better. They also point to our increased participation in society as the principal means for achieving further change. But they cannot blind us to what remains the basic reality of the position of disabled people as a group. This society is based on the necessity for people to compete in the labour market in order to earn a living. To the employer of labour, the physically impaired are not usually as good a buy as the non-impaired. We therefore end up at or near the bottom of this society as an oppressed group.

LOW BARGAINING-POWER

When we do succeed in getting employment, our comparatively low productivity means that we have low bargaining-power when it comes to negotiating decent treatment and facilities. Our position is similar to that of many people who are middle-aged or elderly, who have had break-downs, or are 'mentally handicapped', black, ex-prisoners, unskilled workers, etc. We are usually among the first to lose our jobs and be cast on the scrap-heap when it suits the 'needs' of the economy. If we are lucky we may be drawn in again, to do the worst paid work, when business starts to boom once more. If we are unlucky, then we could face a lifetime on the degrading, means-tested poverty line. If we are **very** unlucky we may be consigned to a soul-destroying institution.

INSTITUTIONS - THE ULTIMATE HUMAN SCRAPHEAPS

The Union of the Physically Impaired believes that the reality of our position as an oppressed group can be seen most clearly in segregated residential institutions, the ultimate human scrap-heaps of this society. Thousands of people, whose only crime is being physically impaired, are sentenced to these prisons for life - which may these days be a long one. For the vast majority there is still no alternative, no appeal, no remission of sentence for good behaviour, no escape except the escape from life itself.

The cruelty, petty humiliation, and physical and mental deprivation suffered in residential institutions, where isolation and segregation have been carried to extremes, lays bare the essentially oppressive relations of this society with its physically impaired members. As in most similar places, such as special schools, there are some staff and volunteers doing their best to help the residents. But their efforts are systematically overwhelmed by the basic function of segregated institutions, which is to look after batches of disabled people - and in the process convince them that they cannot realistically expect to participate fully in society and earn a good living. This function was generally appropriate when special residential institutions first came into being, since in the competitive conditions of the time many physically impaired people could not even survive without their help. But now it **has** become increasingly possible for severely impaired people not just to survive, but also to work and become fully integrated, the need for segregated institutions no longer exists in the way it did. They have become seriously out of step with the changed social and technological conditions of Britain today.

SUPPORT FOR RESIDENT'S STRUGGLES

The Union of the Physically Impaired regards the neglected issues of institutions as of **crucial importance** in the field of disability. We therefore place great

emphasis on supporting the struggles of residents in existing residential institutions for better conditions, for full control over their personal affairs, and for a democratic say in the management of their Home, Centre or Unit. The Union strongly opposes all attempts by the authorities to impose restrictions on visiting; to fix times for getting into and out of bed; to limit residents' freedom to come in and go out when they wish; to enforce medical and nursing opinions, or to transfer residents to other institutions against their will.

The Union sees a need for a Charter which will focus on basic rights often denied when people are dependent on others for personal needs. Disabled people living in institutions will be offered help if they wish to organise locally in defence of their rights. The Union will develop an advice and mutual-help service to assist with negotiations, formation of residents' committees etc. When asked, we will mobilise support and publicity on a national basis for those involved in particular struggles.

ALTERNATIVES NEEDED

The Union is opposed to the building of any further segregated institutions by the State or by voluntary organisations. We believe that providing adequate services to people in their own homes is a much better use of resources. We also call urgently for the provision of non-institutional alternative housing, for example, along the lines of the Fokus scheme in Sweden, which

makes genuine progress towards secure, integrated, and active living for disabled people who need extensive personal help. The Union will try to assist anyone who seeks to move out - or stay out - of an institution. But we fully respect the feelings of individuals who regard institutional life as their best solution at the present time. We understand also that some disabled people will disagree with our views on segregation, and we hope that they will organise to put forward their arguments too.

REAL CHOICE

The Union's eventual object is to achieve a situation where as physically impaired people we all have the means to **choose** where and how we wish to live. This will involve the phasing out of segregated institutions maintained by the State or charities. While any of these institutions are maintained at a huge cost, it is inconceivable that we will all receive in addition the full resources needed to provide us with a genuine opportunity to live as we choose. This point applies not just to residential homes, hospital units, hostels, villages and settlements, but also to other kinds of segregated facilities. As long as there are vastly expensive special schools, colleges and day-centres, heavily subsidised workshops and factories, and separate holiday camps and hotels, there can be no question of sufficient alternative provision being made to ensure that we all

have a real opportunity of equal participation in normal educational, work and leisure activities.

DISABLEMENT OUTSIDE INSTITUTIONS

Our Union maintains that the present existence of segregated institutions and facilities is of direct relevance even for less severely impaired people who may expect to avoid having to use them. Those of us who live outside institutions can fully understand the meaning of disability in this society only when we take account of what happens to the people who come at the bottom of our particular group. Their existence and their struggles are an essential part of the reality of disability and to ignore them is like assessing the condition of elderly people in this society without considering the existence of geriatric wards.

It is also true that the kind of prejudiced attitudes we all experience - other people being asked if we take sugar in our tea is the usual example - are related to the continued unnecessary existence of sheltered institutions. Those who patronise us are indicating that they think we are not capable of participating fully and making our own decisions. They are harking back to the time when disabled people had to be sheltered much more, and they imply that really we ought to be back in our **rightful place** - that is, a special school, club, hospital unit, Home or workshop. Physically impaired people will never be fully accepted in ordinary society

while segregated institutions continue to exist, if only because their unnecessary survival today reinforces out of date attitudes and prejudices.

MEDICAL TRADITION

Both inside and outside institutions, the traditional way of dealing with disabled people has been for doctors and other professionals to decide what is best for us. It is of course a fact that we sometimes require skilled medical help to treat our physical impairments - operations, drugs and nursing care. We may also need therapists to help restore or maintain physical function, and to advise us on aids to independence and mobility. But the imposition of medical authority, and of a medical definition of our problems of living in society, have to be resisted strongly. First and foremost we are **people**, not 'patients', 'cases', 'spastics', the 'deaf', 'the blind', 'wheelchairs' or 'the sick'. Our Union rejects entirely any idea of medical or other experts having the right to tell us how we should live, or withholding information from us, or take decisions behind our backs.

We reject also the whole idea of 'experts' and professionals holding forth on how we should accept our disabilities, or giving learned lectures about the 'psychology' of disablement. We already know what it feels like to be poor, isolated, segregated, done good to, stared at, and talked down to - far better than any non-disabled expert. We as a Union are not interested in

descriptions of how awful it is to be disabled. What we are interested in, are ways of **changing our conditions of life**, and thus **overcoming** the disabilities which are imposed on top our physical impairments by the way this society is organised to exclude us. In our view, it is only the actual impairment which we must accept; the additional and totally unnecessary problems caused by the way we are treated are essentially to be overcome and not accepted. We look forward to the day when the army of 'experts' on our social and psychological problems can find more productive work.

THE RIGHT KIND OF HELP

We know that as a small, weak, minority group, disabled people cannot achieve a fully human life by their own efforts alone. We need and welcome the help of sympathetic non-disabled people. But the basic problem we face is our exclusion from full social participation. It follows that this oppressive situation can be put right only by disabled people **actually taking a more active part** in society. The efforts of professionals and other non-disabled people are therefore really constructive only when they build on and encourage the self-help and activity of disabled people themselves. This is why our energies as a Union will be directed mainly towards discussion and common action with other disabled people. Neither we as a Union, nor non-disabled people, can solve other disabled people's problems for them.

Those problems will be correctly tackled **precisely** to the extent that we all as disabled people become involved and active in our own rehabilitation.

THE NEED FOR A UNION

Disabled people everywhere are already struggling against their isolation, segregation and other forms of oppression. Every day each of us has to face our own individual problems. And we are now increasingly getting together in groups to tackle more effectively the problems we find we have in common. This is shown by the vast growth of disability organisations in the last 25 years in Britain. Our Union takes this process of coming together a stage further. We are not restricted to one aspect of physical disability (e.g. mobility or incomes), nor to people with one medical diagnosis, nor to those in one locality. The Union exists simply to offer help to **all** physically impaired people in the fight to change the conditions of life which oppress us and to realise our full human potential.

ACTION

Various kinds of action in support of disabled people's struggles will be undertaken by the Union as resources become available. Apart from publishing pamphlets and an open Newsletter, we will mount action campaigns on various issues. We will build up information and advice services, and organise financial,

secretarial and other forms of practical assistance. For example, individuals may ask for help in fighting bureaucratic delays and efficiency, or a refusal to provide equipment, aids or other kinds of service. Other people may want assistance in tackling organisations about the provision of ramps or lifts in buildings. Residents in institutions may seek help and national publicity if they are victimised by the authorities. People in sheltered workshops or centres may ask our support in their struggles to improve their appalling rates of pay. The Union will succeed only when it helps to achieve real benefits and improved conditions for disabled people.

GUIDELINES FOR ACTION

But our actions will become more effective if we make sure that we also learn from the practical struggles which take place. So an essential part of the Union's task is to develop increasingly clear guidelines for further action. We will not do this by careful discussion about what we and other disabled people are doing, and about the real nature of the problems we face at a particular time. We need to learn from our failures and successes, and so develop arguments and a theory which have been **proved to work** - because they do actually bring about practical gains for disabled people. In this way the value of our practical experience will be multiplied many times

over, as the essential lessons learned from it are made available to other disabled people now and in the future.

TERMS OF MEMBERSHIP

Full membership of the Union is open to residents of Britain who are significantly physically impaired and who accept the Policies and Constitution. Full members are expected to take some active part in Union affairs, since the Union is firmly based on the conviction that as disabled people we can only make real progress through actively struggling for change. Members will of course have different capacities at different times, and 'active' here means at least some involvement in discussion of policy. We are sympathetic to the fact that some potential members may have problems of communication, and the Union will give encouragement and help in these circumstances. However, disabled people who feel they cannot at present contribute in this way may keep in touch by subscribing to our open Newsletter.

Able-bodied people who agree with the Union Policies and Constitution can become Associate members. Associate members may receive the internal Circular, the open Newsletter and other publications, and may take part in meetings, discussions and other events. But they are not entitled to vote on Union affairs, nor may they hold any Union office. Genuine supporters will recognise the need for us to control our own Union and so develop our powers of decision, organisation and

action. They will understand too, that since we experience daily the actual reality of disability, we are less likely than non-disabled people to be deceived about the true nature of our oppression and the radical changes necessary to overcome it.

OTHER OPPRESSED GROUPS

The particular forms which oppression takes in this society differ somewhat for each distinct oppressed group. Some, such as people who are called 'mentally handicapped', or those 'mentally ill', clearly have a great deal in common with us. Full membership of our Union is however based simply on the fact of physical impairment. This is because we believe the important thing at the moment is to clarify the facts of our situation and the problems associated with physical impairment. But it is fundamental to our approach that we will seek to work with other oppressed groups and support their struggles to achieve a decent life. What all oppressed people share is a vital interest in changing society to overcome oppression, and the Union is therefore anxious to join in common action to achieve such change.

DEMOCRATIC CONTROL

Democratic control of the Union rests with all full members, and policy is decided on a majority basis after thorough discussion in a confidential Circular or at

General Meetings. Full discussion of policy by members is necessary if we are continually to develop our action and thinking along the right lines. But once decisions have been made, members undertake not to oppose them publicly while they wish to remain in the Union. Both elements in this combination are regarded as essential for genuine progress - thorough **internal** discussion by members, together with a refusal to indulge in **public** criticism of Union policies.

Day-to-day decisions on Union affairs are in the hands of an Executive Committee, elected by, and responsible to, all full members. The Executive Committee holds the Union's funds. It arranges for the production of the internal Circular, the regular open Newsletter, and of occasional pamphlets and other publications. The Committee also speaks and acts officially for the Union on the basis of agreed policy. The overall task of the Committee within the Union is to facilitate the active participation and development of all members.

SPECIAL INTEREST GROUPS

Special-interest groups within the Union will be formed by members concerned with a particular aspect of disability. Examples may include residents' rights in institutions, incomes, employment, special education, provision of aids and equipment, housing alternatives in Britain and overseas, medical and technical research,

rehabilitation. Within the general principles of the Union these groups will work out actions and ideas based on their special interests and experiences. Reports by them on particular topics will be published in the name of the Union from time to time.

FINANCE

All registered charities receive valuable tax concessions, but they are not allowed to campaign directly for political change. We regard political involvement as essential if disabled people are ever to make real advances. So in order to protect our independence of action we are not registered with the Charity Commissioners. Nor do we intend to appeal for funds publicly in the name of the Union. We believe the time has come for an organisation in the disability field which does not depend heavily on public fund-raising. We shall be free to speak and act on the basis of Union members' views rather than those of financial supporters and noble patrons. Union expenses will be met by subscription, by donations, and by such means as the sale of literature.

OTHER DISABILITY ORGANISATIONS

The Union aims to ensure that all the organisations concerned with disability become fully democratic and responsive to the real needs and wishes of disabled people. We therefore seek a much greater say in all the

organisations which affect our lives, both by Union members as individuals and by other disabled people. Any official Union representatives appointed to Committees of other groups will promote Union policies and report back regularly to members. In addition, the Union will keep a watchful, independent eye on the policies and practice of all disability organisations. We will try not to duplicate effort, and will welcome constructive comment and help from other groups. We will ourselves offer support and co- operation whenever possible. But the Union will not hesitate to speak out freely, and act independently, when we believe the interests of disabled people require it. It will be for disabled people as a whole to judge whether or not we are correct.

Appendix 2 – Schedule of UPIAS Circulars

Circular Number	Date	Circular Number	Date
1	1972 (estimated)	21	1977 May
2	1973 (est.)	22	1977 Sept
3	1973 (est.)	23	1978 Jan
4	1973 (est.)	24	1978 Aug
5	1973 (est.)	25	1978 Sept
6	1974 (est.)	26-A	1978 Oct 1st
7	1974 (est.)	26-B	1978 Oct 3rd
8	1974 June (est.)	27	1979 Jan
9	1974 July (est.)	28	1979 Feb
10	1974 Sept	29	1979 June
11	1974 Oct	30-A	1979 June 29th
12	-	30-B	1979 July 17th
13	1974 Dec	31	1979 Sept
14	1975 Feb	32	1980 Feb
15	1975 April	33	-
16	1975 July	34	1980 March
17	1975 Oct	35	-
18	1976 Feb	36	-
19	-	37	-
20	1976 Nov	38	1980 Dec

NO LIMITS

JUDY HUNT (2019)

39	1980 Dec	58	1984 Sept
40	1981 Jan	59	1985 July
41	1981 Jan	60	1985 Sept
42	1981 Feb	"New 01" [61]	1986 June
43	1981 Mar	"New 02" [62]	1986 Nov
44	1981 June	"New 03" [63]	1986 Nov
45-A	1981 June	no number [64]	1987 July
45-B	1981 Aug	no number [65]	1987 Sept
46	1981 Oct	no number [66]	1987 Oct
47	1982 Apr	no number [67]	1987 Dec
48	1982 May	no number [68]	1988 Jan
49	1982 July	no number [69]	1988 Feb
50	1982 Aug	no number [70]	1988 Apr
51	1982 Sept	no number [71]	1988 Apr "Extra"
52	1982 Dec	no number [72]	1988 May
53	1983 Feb	no number [73]	1988 June
54	1983 May	no number [74]	1988 Aug
55	1983 July	no number [75]	1988 Sept
56	1983 Nov	no number [76]	1990 Sept
57	1984 Mar	no number [77]	1990 Nov

Adapted from: Baldwinson, 2019b, pp80-81.

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No Limits

Judy Hunt

“Every disabled person should read this book. It is the history of the emergence of the Disabled People's Movement in the UK. It was a monumental struggle against oppression and prejudice. The struggle is far from over and there is still much to do. I am disabled. I was there. I am still struggling against institutionalised oppression in the UK. This book is a record of our struggle and is here for young people to learn from, go forward and keep struggling for full equality in our society.” **Maggie Davis**

“At a time when as Judy Hunt writes: “disabled people are finding many of the gains of the 1980s and 1990s being eroded,” this book is a timely reminder of where those gains came from. Indeed it's vital to know where we've come from in order to understand the current realities we face, to work out how to make progress and to learn from the past. It is also an important book, based as it is on the experiences of someone who was there at the beginning of the struggle amongst disabled people in residential care to have control over their lives, a struggle which gave birth to the movement for independent living in the United Kingdom.” **Dr Jenny Morris**

“Without Mike Oliver, Vic Finkelstein and Paul Hunt's combined analysis of our oppression, disabled people like me would never have thrown off the chains of our passive, second-class identity to become liberated human beings with rights. We are still on our emancipatory journey and like the women's movement, and other equality struggles, our story is far from over, but goodness we have come far in 50 years!” **Baroness Campbell of Surbiton DBE**

Front cover: Valery Koroshilov