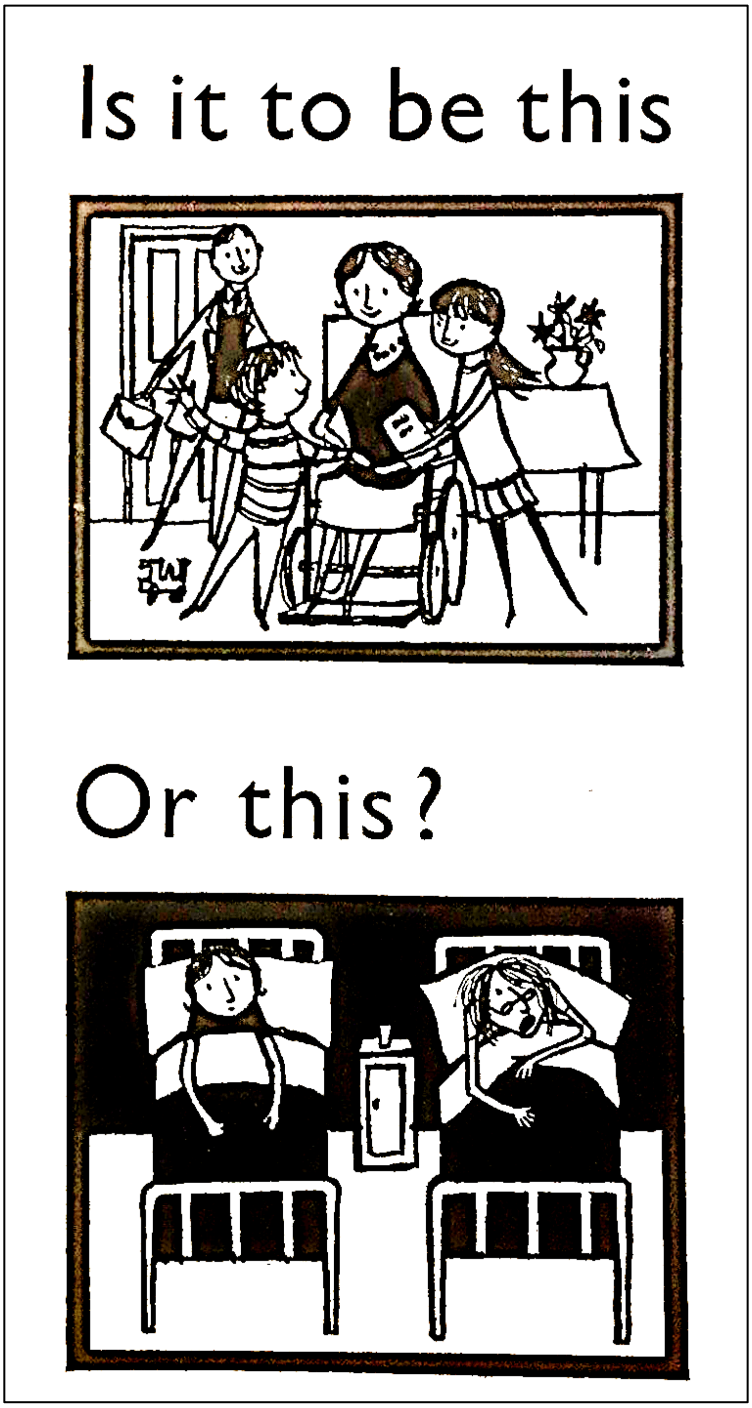
Bloody Angry

Social Care campaigning by Disabled People in 1960s Britain



The National Campaign for the Young Chronic Sick
1964 – 1974

Tony Baldwinson

3rd edition

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Social Care campaigning by Disabled People in 1960s Britain,

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From the front panel of NCYCS Newsletter #1,
credited to Miss Eccles-Williams, 1965.

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Summary

> “The Campaign is conducted ***by*** the Young Chronic Sick [disabled people], not only ***for*** them.”
>
> “NCYCS is … of working people, and is dedicated to securing political ends through the mobilisation of the Labour and Co-operative Movement … not as a charity.” [1]

Social care has perhaps never been as strong a political topic in the UK as it is currently. People are weary of broken promises - “we will fix social care” as said in Downing Street by different Prime Ministers year after year.

In 1965 a small group of disabled people and their allies – all being political activists – created a policy calling for a new radical form of social care, with their idea of the job role of **personal assistants**.

Unanimously approved at the 1965 party conference, this policy committed the Labour Party to support the emergence of a new type of support for disabled people – known at the time as **medical home helps**.

This campaign for independent living became the National Campaign for the Young Chronic Sick. A small but very influential political campaign, it continued until 1974. They concluded their work by campaigning against the under-resourced implementation by central and local government of a new 1970 law giving disabled people some partial rights to services at home for their independent living.

The title of this research comes from “**Why we are bloody angry**” in the fourth newsletter published by the National Campaign for the Young Chronic Sick in 1967, after the hostility NCYCS faced at the time from Ministers in the Labour government when trying to get these policies implemented, leading to new legal rights in 1970.

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[1] NCYCS Newsletter 1970 (emphasis in original);
and NCYCS constitution.

Lost for over 50 years, this research has begun to uncover those bloody angry voices again, to tell the story of their struggle, warts and all, for new generations of disabled people, academics and activists to explore, recognise and appreciate.

In a reflective interview included at the end of the book he co-wrote with Jane Campbell in 1996, Mike Oliver traces the birth of the Disabled People's Movement in Britain to the early campaigns of groups like NCYCS as follows.

> "Mike Oliver [speaking] – 'What the book has made very clear for me is what was first, **the rise of the movement in Britain was organised around struggles to get out of residential care** with the development of groups such as UPIAS. Second, it was organised around the relative deprivation of disabled people at a time when society, was getting richer. This is vitally, important to understand. The 1960s was the age of affluence, but the gap between disabled people and the rest of the population widened significantly and disabled people decided that this was no longer acceptable. I think that those are the two most important aspects, if you are talking about cause and effect, and these are the two main reasons why the movement emerged as it did.'"
>
> (Campbell and Oliver, 1996, p183; emphasis added)

With Paul Hunt writing to NCYCS in 1966 it is possible to link NCYCS to UPIAS six years later. (Appendix 14)

For a quick summary of the results of the campaigning by disabled people in the 1960s and early 1970s, see Appendix 48 written by Ann Shearer in 1973.

* * *

Summary, Easy Read

A long time ago, in 1965, a small group of disabled people and their friends worked together to make things better for lots of other disabled people. They thought of a new way to help disabled people live at home and be more independent. They wanted to have personal assistants to help them.

This idea was liked by many people and it became part of the Labour Party's plans. This group, known as the National Campaign for the Young Chronic Sick, worked very hard to make these changes happen. They kept working until 1974.

They were upset because the government didn't give enough support to make their plans work well. They fought for new laws in 1970 to help disabled people get more help at home.

This story was almost forgotten, but now researchers are finding it again. They want to share this story with new generations of disabled people, students, and people who want to make changes.

There was also a book written by Mike Oliver and Jane Campbell in 1996. They said that the work to help disabled people with independent living started because they wanted to live outside of special homes. This was because they felt left out and society was getting better but they were not.

This story shows how important it is for people to work together and support each other to make life better.

Abbreviations

AMR	Action Medical Research - charity
CCD	Central Council for the Disabled
CIL	Centre for Independent Living
CLP	Constituency Labour Party
CPAG	Child Poverty Action Group
CSDPA	Chronically Sick and Disabled Persons Act 1970
DDA	Disabled Drivers Association
DHSS	Department of Health and Social Security
DIAL	Disability Information & Advice Line
DIG	Disablement Income Group
FPAI	Former Public Assistance Institution (ex-workhouse)
GMCDP	Greater Manchester Coalition of Disabled People
JCMD	Joint Committee on Mobility for the Disabled
LP	Labour Party
NCYCS	National Campaign for the Young Chronic Sick (1965-1970)
NCCSD	National Campaign for the Chronic Sick and Disabled (1970-1974)
NEC	National Executive Committee
NFRCD	National Fund for Research into Crippling Diseases
NSAC	National Society for Autistic Children
PA	Personal Assistant
POSSUM	Patient Operated Selector Mechanism
PPS	Private Parliamentary Secretary
WS	Women’s Section - of a local Labour Party
YCS	Young Chronic Sick
YDU	Young Disabled Unit – a residential building within a hospital
YS	Youth Section - of a local Labour Party

Introduction and context

Advisory Note: Some of the language used to describe disabled people around the 1960s is now inappropriate or offensive. Any disabilist terms in the source material are reproduced for historical accuracy to hopefully help other researchers.

In terms of health and social care, it is well researched that the British current health service was established in the 1940s, but less appreciated that important developments in British current social care policy (as well as incomes and payments for disabled people) can be traced back to the 1960s.

Specifically, it has not been well known by historians or policy researchers that it was campaigning disabled people and their allies who helped shape the British modern social care system with new alternatives to residential institutions and commercial and charity homes.

This research uses surviving fragments of the work of the National Campaign for the Young Chronic Sick (‘National Campaign’ and NCYCS here for short) to explore and promote an overlooked but important aspect of social policy and human rights.

In the 1960s the Disablement Incomes Group was far bigger and much better known than NCYCS. Influential people like Duncan Guthrie had far greater contacts than NCYCS. Groups like the Responauts were bold and pioneering in self-help, for example with disabled people using a respirator and living at home.

But I suggest that this research shows that NCYCS were leading the **campaigning** for disabled people’s independent living generally – and especially with their new ideas for ‘medical home helps’ and for assistive equipment – today’s PAs and smart homes.

Big institutions can write their own history. Unfunded and unstaffed radical campaigns rely on the work of researchers to give other histories a fair hearing. The National Campaign was deliberately never a registered charity or similar organisation, instead it remained a political structure within the Chelsea Constituency Labour Party (as was) in central London despite its national remit.

Some collections of papers from the National Campaign have been found in archives, including papers held in the collections of individual politicians such as Alf Morris and David Owen; both MPs at the time and later members of the House of Lords. More recently some NCYCS papers have been found in the Labour History Archive in Manchester.

On 29 September 1965 the founders of what would soon become the National Campaign changed Labour Party policy at its national annual conference in Blackpool. The full text is here in the appendices. This policy includes the invention of ‘medical home helps’, personal assistants as they are known today.

And shortly after this, with the recruitment of Pamela La Fane in 1966, a self-taught disabled writer and journalist, the National Campaign quickly gains significant national press and television coverage. I believe the National Campaign also prompted the creation of a national working party to study and report on the issue of disabled people’s independent living.

By having both a policy and a media agenda, the National Campaign had a profound influence in the second half of the 1960s, culminating in their direct political influence in the new provisions for independent living in the Chronically Sick and Disabled Persons Act 1970.

Independent Living, USA

It is important to note that some of these developments in the UK pre-date some similar ones in America, contrary to some assumptions.

In California, the pioneering Berkeley Center for Independent Living (CIL) was established in March 1972. Ten years earlier in 1962 Ed Roberts was the first disabled student to live on campus at Berkeley, near San Francisco, in what he insisted had to be renamed the Cowell Residence, formerly the Cowell Medical Centre. Then sometime between 1966 (when two other disabled students moved in alongside Ed Roberts) and 1969 (by which time there were 12 disabled students as residents) the **Cowell Residence Program** had become established, being the precursor to Berkeley CIL.

Also in 1966, a six-hour drive away at the University of California in Los Angeles, was a 22 year old disabled student who had just arrived from Germany – Adolf Ratzker. Writing later about the development of PAs in Sweden, he recalled from his younger days in the USA:

> “I was the one who hired, trained, scheduled, supervised, paid and motivated fellow students who helped me with personal needs, household chores, and other tasks. Without any role models, it took [me] several years of trial and error, mistakes and small successes before I felt reasonably in control of my assistance situation. The money for my assistants’ salaries, through an unbureaucratic ad hoc solution, came from the government of the State of Bavaria.” (Ratzka, 2012, paragraph 13)

The collection of papers from the working life of Alf Morris, now held in the library archive at the London School of Economics (LSE), includes some letters from people in the USA in the 1960s asking him various points, and some thanking him for meetings they had while visiting London, so it is reasonable to think there would have been some sharing of ideas between the UK and USA, both ways, on disabled people, rights, social care and independent living.

50th Anniversary in 2020, Manchester

The new British law in 1970 was heavily influenced by the NCYCS. The Chronically Sick and Disabled Persons Act moved the legal responsibility for supporting disabled people away from hospitals and over to the recently-expanded social services departments of councils. The promoter of this new law was Alf Morris, supported by campaigning disabled people.

Prior to the Covid pandemic restrictions a number of events had been planned to take place in Manchester in 2020 to celebrate the 50th anniversary of changes that Alf Morris made for disabled people, informed by his own family life experience of disability and his political friendships.

The local connection was that Alf Morris was the Member of Parliament for Wythenshawe, a neighbourhood in south Manchester. Instead, because of these restrictions some alternative events took place online.

L to R: Michele Scattergood (GMCDP), Alf Morris MP, Keith Bradley MP, Lorraine Gradwell (GMCDP), Tony Lloyd MP, Cllr Martin Pagel.(c.1994)

This book is connected to those celebrations and had its first edition as a shorter research paper published in June 2020. It started as an attempt to add and extend the political context of Alf Morris' work. It sought to explore the campaigning for social change that disabled people and allies were organising in the 1960s leading up to and radically shaping his 1970 landmark Act of Parliament.

In a paper reflecting on Alf Morris' CSDPA for this anniversary, Jameel Hampton in the Disability & Society journal noted that,

> "By the end of the [1960s] decade, both major parties, the media and the public were aware that the welfare state settlement had neglected disabled people. … There was also political pressure exerted by the Disablement Income Group **and other groups** for and of disabled people (Oliver, 1986)."
>
> (Hampton, 2020, p831-832, emphasis added)

This research on the National Campaign seeks to explain with newly-found records where some of that pressure from disabled people and their allies came from, not least via their efforts in the Labour Party, The Guardian newspaper and using BBC television channels.

And in particular, this research seeks to raise the previously neglected profile of the National Campaign for the Young Chronic Sick, which was led by disabled people and allies campaigning to escape from hospitals and to gain their own independent living in the 1960s.

Discussions on disabled people’s campaigns in the 1960s tend to focus particularly on DIG (the Disablement Income Group), and sometimes on charities too, reasonably so because DIG had a high media profile at the time and a more substantial membership list than had NCYCS, and practically because DIG produced extensive press coverage including strong photographs. This research isn’t to detract anything from the campaigning by DIG and others in the 1960s, only to add a further dimension by focusing on independent living.

Gaps in the literature

It is truly invidious to have to choose an example in the current literature to show where this gap exists, so I hope the authors will accept the intended compliment of my choosing the best as the example - Understanding Disability Policy, by Alan Roulstone (who kindly supervised the early years of my MPhil) and Simon Prideaux (2012).

Looking at the 1960s and the section headed, 'Imperatives to deinstitutionalisation', the focus for the 1960s is the landmark 'water towers speech' by the Conservative Minister for Health in 1961 which marked a change in government policy if not law on the use of two categories of long-stay institutions: for learning disabled people, and for people labelled (usually many years previously) as having mental health difficulties (Roulstone and Prideaux, 2012, p42-43).

In terms of community care (independent living) for a third category, that is, disabled people known then as the young chronic sick living in hospitals full-time, the historic emphasis is placed on the Health Services and Public Health Act 1968 which -

> "followed the spirit of community care in proposing home help services to avert entry into expensive long-term institutional contexts (Blakemore, 2003, p205). In reality, it took more than 10 years for the Act's objectives to permeate local authorities whose default approach remained that of supporting disabled people in

> residential homes and long-stay hospitals (Tinker, 1983)." (Roulstone and Prideaux, 2012, p43).

So from 1961 we go directly to 1968, a gap this research aims to explore and to amplify the voices it finds inside that gap. As an example of this gap consider this extract:

> "the pervasive interpretation of community care understood it to include residential homes, staffed community (half-way) houses, sheltered housing, and so on. One contemporary concern involved in such a half-baked interpretation of community was that some groups were to experience simply a shift in the context of institutional provision. For example, Young Disabled Units (YDUs) were established to cater for this group in response to the **outrage** that young disabled people with complex health needs were hitherto being housed in geriatric wards. The response from the Royal College of Physicians (1986) was for YDUs to cater for this age group, without acknowledging that this was simply shifting the institutional context of largely medical care in a way that made independence and choice virtually impossible (Brisenden, 1986). This, then, represented a slow evolution from large-scale institutional provision" (Roulstone and Prideaux, 2012, p44; emphasis added).

But that “outrage” can be traced back nationally to 1946, and locally to 1935, as shown in this research. What happened in the 1960s that was different and caused the change in policy was the start of a sustained period of political and media **campaigning** by disabled people and allies.

Neither this “outrage” nor this campaigning against the use of geriatric wards as a housing solution for disabled people are included in other social policy textbooks to the best of my knowledge. Mostly the “outrage” isn’t picked up until references to Paul Hunt in 1973 when he wrote his article saying that disabled people did not want more YDUs (Appendix 46 here).

So a totally accurate - but incomplete - common narrative has emerged that the independent living designs and practices that were co-produced with disabled people's choices only emerged in the 1970s and 1980s. Perhaps the nuance to add is: yes, but this is insufficient. There were earlier national campaigns and politically-engaged policy initiatives by disabled people at least a decade earlier.

Obviously any academic texts that cover British disability policy developments in all their aspects, and usually limited to around 200 pages, have to be selective and brief. However some texts seem to connect the policy of creating YDUs either directly back to the water towers speech, or to doctors responding to an "outrage".

To be fair, this agreed narrative is found elsewhere too. For example,

> "Public criticism of large-scale institutions reached a peak in the 1960s and 1970s, fanned by a series of scandals in long-stay 'mental handicap' and 'psychiatric' hospitals (Martin, 1985). ... The Seebohm Report (1968) argued for a major reorganisation of local authority social services, and echoed the claims of many disabled people that they were forced into [these] institutions because of the lack of alternative community support services, and the difficulties experienced by their reliance on family and friends as 'carers' (Carter, 1981). Such concerns attracted Parliamentary attention, which led to the Chronically Sick and Disabled Persons (CSDP) Bill introduced by Alf Morris after he came first in the Private Member's ballot in 1969." (Barnes and Mercer 2006 p17).

Perhaps a reasonable explanation for why this this gap in the literature is now apparent is the sophisticated digitisation in recent years of some key journals of record in terms of British social policy. For this research this digitisation has been particularly important with respect to Hansard (the journal of record for the British Parliament) and to The Guardian newspaper for its letters page and for some seminal social policy articles. A further useful change would be if digital access for researchers was also applied to historic social documentary programmes held by ITV and BBC while respecting the intellectual property (IP) rights.

The first occurrence of the name of the National Campaign for the Young Chronic Sick was found for this research within the speeches of Alf Morris as an MP in the House of Commons. This group was thus noted as having been a significant and overlooked influence in his forming of the Chronically Sick and Disabled Persons Act 1970 in the literature, as I concluded in the first edition of the findings of this research. Having found their name, what followed were the more analogue methods of archive inspections, although digital catalogues where they exist can be of some help in this process.

Hopefully this new research helps to explain a campaign by disabled people that fills a gap in the standard community care and independent living narrative.

A source book

This book has over 60 appendices and extracts from archived records as well as references to published works. This is deliberate, hopefully by placing these materials in the public domain it might be a useful resource for other researchers and commentators on disabled people’s independent living – community care as it was called then.

The social model

This research is based within the social model of disability. If this is a new idea to you, there are useful resources online provided by a number of disabled people's organisations, DPOs, for example:

https://gmcdp.com/beliefs-values-aims/social-model

In short, the social model of disability says that "the problem" faced by disabled people is not because of some impairment or aspect of the body, but rather is caused by society's refusal to include disabled people’s needs alongside the needs of non-disabled people.

The social model of disability was first written about academically by Mike Oliver (1983) and this idea built on the idea of the "social interpretation" of disability developed in the 1970s (UPIAS, 1976; J. Hunt, 2019). This in turn built on discussions about "social handicap" for example in Morris and Butler (1972, p9-10) where Morris reports on this phrase being discussed in the 1960s.

For a good summary with strong academic references and analysis, see the chapter written by Colin Barnes in The Disability Reader (1998).

Was the NCYCS a DPO?

The short answer is almost certainly not. The phrase DPO - a disabled people’s organisation - is used to describe an organisation that is controlled by disabled people, usually because that control is written into their constitution or rule book.

There is a copy of a six-page constitution for NCYCS in the LHA records. It has been amended by hand to reflect the name change in 1970 to

NCCSD after the Alf Morris Bill became law. Only the name is changed, everything else continued as before.

The document is undated, but it probably was originally agreed in 1964 or 1965 because the Labour Party probably would not agree to the organisation working within it without the certainty of a written constitution. For example, within the constitution it states, “The Chelsea Labour Party shall be in a special relationship to NCYCS. As founding organisation, it shall have the right to be a corporate Sponsor, and to appoint delegates who may be elected to any position or office in NCYCS.”

Individual members are not required to be members of the Labour or Co-operative parties, but its Aims and Purposes section included:

> “(d) by these and other means to stimulate knowledge and interest within the Labour Party and the Trade Union and Co-operative movements, with the objective of securing political advances”.

Labour Party

Finally, a comment about the Labour Party aspect of this research, though strictly speaking it is as much about the Co-operative Party too.

When I have been discussing this ‘project’ with researchers and activists, I've sometimes noticed a sudden chill when I mention the Labour Party dimension. One response was "able-bodied do-gooders".

Just to be clear, I'm not here to write a recruitment leaflet for the Labour Party, nor an airbrushed history. As I said at the start, this account is warts and all.

I guess my comment is that, in effect, there isn't one unified Labour Party (and the same is true for any large party). It's been a place of tension between different political philosophies since its creation. It was the same when I researched one of my relatives, Fred Hammill, who had been a trade union leader (he organised the first London-wide bus strike, for shorter hours on the same pay) and one of the 28 founder members of the Independent Labour Party, founders who first tried to get elected to the Parliament in 1895. Fred’s attempt at being elected was in Newcastle; unfortunately he lost and died six years later aged 45 years from pneumonia (Baldwinson 2016). He was a ‘radical’ and the 'moderates' laid into him, though he usually gave as good as he got. Was ever thus.

So, please try to put your reflexes about the Labour Party on hold for a while, and hopefully I've managed to convey some of those same internal policy tensions and nuances from the 1960s in this account.

Remember, when the NCYCS said, "we are bloody angry" it was with their **own** Labour government. You don’t have to agree with their choice of party politics to appreciate that they were being political to their bones.

* * *

In summary, and looking at the following table, from 1962 to 1967 the number of working-age disabled people living full-time on a hospital ward **probably fell nationally by at least 52% in five years** - dropping from a sample of 170 institutions with 8900, to 4200 disabled people across all England and Wales. It was an average of 930 fewer disabled people living in hospital each year, with some achieving their independence and with some maybe only getting as far as a Young Disabled Unit.

This research is about the disabled activists and allies involved in campaigning to make this structural change happen.

Surveys and studies 1935 - 1971

Note: Some surveys and studies lasted for more than one year.

Dates	People and Organisations	Summaries
1935	Marjorie Warren	714 disabled people (Warren, 1943)
1951	SMA	Est. 5000 to 12 000 disabled people
1956	Ann Whitaker	314 people (Whitaker, 1959a)
1961	Joseph Sheldon	Building conditions (Sheldon, 1961)
1962	Peter Townsend	8,873 disabled people in 170 institutions (Townsend, 1962)
1963	Oxford RHB	Regional Health Board
1964	Droller and Paley	79 disabled people (Droller & Paley, 1964)
1964	(via NCYCS)	In Northampton (Appendix 10)
1965	-	Recommended by Waine & Guthrie
1966	Lambeth	London Borough Council
1967	Tower Hamlets	201 disabled people, (Skinner, 1969)
1967	Peter Townsend	211 disabled people (Sainsbury, 1970)
1967	NHS survey	4,223 YCS living in hospitals, 50% in geriatric wards, England & Wales
1967	Rankine & Weir	Unpublished, flawed.
1968	Ministry of Health / DHSS	Survey of disabled people in the general population (becomes DHSS in Nov 1968)
1970s	Ealing	District Council
1970s	Harlow (proposed)	District Council
1971	MacLennan	Greater Glasgow area, published in 1973.
1971	DHSS	Reports of the 1968 survey (Harris, 1971; Buckle, 1971)

Section 1 – Initiatives from 1935 to 1964

Who were the young chronic sick campaigners?

Up to the 1980s many thousands of disabled people in Britain were incarcerated for life in hospitals, and were being warehoused in wards for elderly sick people, only there because their family care had collapsed or never existed.

They had no say about how they lived and with only pocket money for an income. From the age of 16 years disabled children were taken out of the children's ward and for the rest of their life they were kept in bed for most or all of the day for staff convenience, living on a geriatric ward of mostly unwell elderly people.

> **Young** - this meant that the disabled person was younger than 65 years of age for a man, 60 for a woman.
>
> **Chronic** - this meant that the hospital had nothing to offer in terms of treatment other than personal care such as manual help with washing, using the toilet, eating and getting dressed.
>
> **Sick** - most YCS disabled people were actually in good health. The label of ‘sick’ was used because the medical model was the only way in which most hospital staff and most politicians could understand the lives of disabled people.

However, some disabled people living in these appalling conditions had better ideas:

Paul Hunt was a YCS disabled person, living on hospital wards from the age of 14 years old after he broke a leg while playing and could no longer be provided for by his parents, until he was aged 19 which was when he got himself out.

He later spoke of the oppressive and miserable nature of this institutional life and the effects it had on his mental health. He said that one evening in 1955 he watched a BBC programme on the hospital television about a Leonard Cheshire charity home for disabled people called Le Court (pronounced - Lee Court) (Appendix 4). He was immediately and absolutely determined to escape the hospital to live there, so he lobbied hard for over many months for his release, and he finally achieved it in 1956.

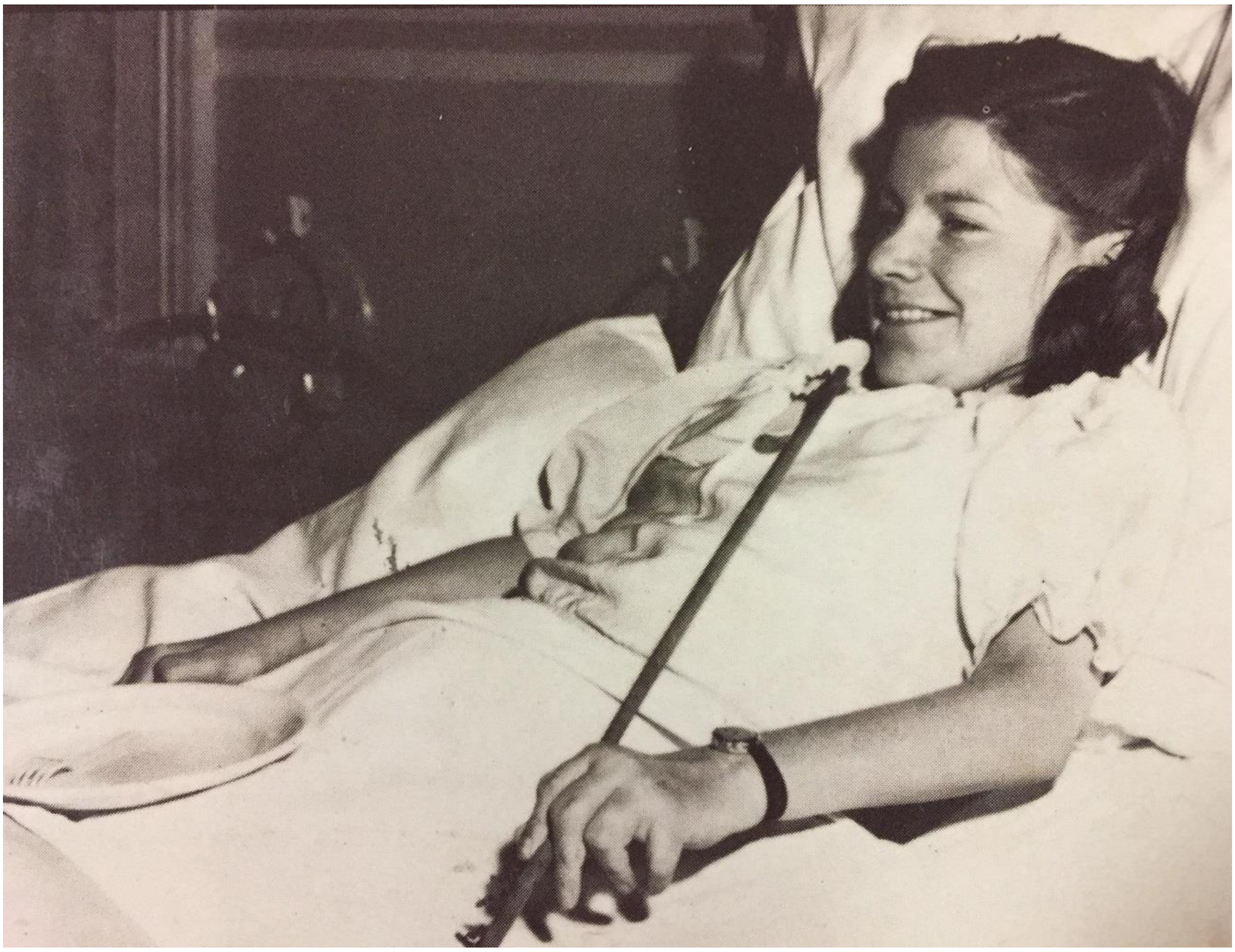
He wrote about this time in the ‘Social Services’ journal in 1973 (Appendix 46). In 1970, and married to his partner Judy, he moved from Le Court into an independent flat in London. Their papers are archived in the Judy and Paul Hunt Collection at the Disabled People’s Archive in Manchester.

Paul Hunt, from the book he edited and contributed to in 1966

Pamela La Fane was a YCS disabled person, living in hospitals for over 20 years before reading a letter from the National Campaign for the Young Chronic Sick (Appendix 13), eventually gaining a flat of her own, writing in The Guardian (Appendices 17, 27) and appearing on national TV programmes (Appendix 24) and writing her autobiography (La Fane 1981).

In 1940 aged about 13 years, she had begun her hospital 'career' in Oxford, mostly in children's wards but at times in adult wards when beds were full. Aged 16 years in 1943 and no longer a child, she was moved to a ward for adults, this time in another hospital in London, the ward being for geriatrics. When she arrived on the ward, another patient confided to her, "**the first ten years are the worst**" (La Fane, 1981, p59).

A short bio of Pamela La Fane is given in Appendix 51.



Pamela La Fane, with her improvised spoon for eating, 1960s

Maggie Davis was a YCS disabled person. The story of her and Ken Davis is of a complicated and institutionally abusive 10-year journey from hospital to independent living in the Midlands region of England in what became known as their **Grove Road** project and later setting up the first Coalition of Disabled People, is told in her book (Davis and Davis 2019).

Maggie Davis at home, and the Grove Road housing project

Margaret Wymer and **Jack Wymer** were two disabled people in the east of England who created their own independent living package from scratch, later writing their book to share their learning with others (Wymer and Wymer 1980).

Margaret Wymer and Jack Wymer

Jack was one of six children, and he and a sister were disabled children. His father had died in the 1939-45 war. Their book tells of his time in hospital, and how it started. Jack had been in hospital for three years when Margaret first met him at a social club for young disabled people in Norwich.

> "Although his mother had married again many years later, with all the will in the world she could scarcely cope with two handicapped children, and four other daughters as well. There were no hoists or gadgetry in those days, and the money was very short. Therefore, she had to steel herself to the fact that she had little chance in her already overburdened existence to give Jack anything like a normal life.

> At the age of nineteen, Jack left a special boarding school for disabled boys, and his grandparents, rallying around in the true family way, cared for him for almost a year. Their pre-fabricated bungalow was quite convenient for his invalid chair, and his step-father and uncle helped grandfather on a rota system with the local ambulance-men in looking after his needs. ...
>
> [They had been told he only had six months to live.] In fact, eleven months had passed at the [bungalow] when Granny reluctantly informed Jack he would be going into hospital.
>
> "Just for a month, to give us a little rest."
> "I felt terrible," admitted Jack, "but I could hardly be annoyed, could I? Sitting in that big ward full of old men on the first day, I could smell the mixture of disinfectant and stale urine. I kept asking myself, 'Is this really me?' I kept repeating, 'I am Jack Wymer' over and over again in my mind, because I couldn't believe it was happening to me."
>
> The family visited him regularly, and after five weeks, Jack began to ask when he was going to come home again. The question was evaded several times before his mother finally had to break the news.
>
> "I hope you won't mind, but Nanny can't have you back again."
>
> The words were stunning. ... ”
>
> (Wymer and Wymer 1980 p19-20) see also (Shearer, 1982)

Joan Dawe was a YCS disabled woman in London who was admired by Maggie Davis as a pioneer and role model for disabled women, especially those desperately trying to gain their independence in the 1960s and 1970s (Davis and Davis, 2019, p29). Ann Shearer wrote a detailed account of her life and achievements (Shearer, 1982, pp49-61).

Born in 1935 Joan was originally from Kenya where, aged 20, she injured her spine while diving from a boat and became paralysed. Having moved to England for treatment she became active in the paraplegic games, and disability sports were reportedly an important part of Joan’s life, along with her membership as a founder of the Spinal Injuries Association (SIA).

After a difficult time moving around between her separated parents and many hospitals and care homes including Stoke Mandeville, Joan moved to the Leonard Cheshire care home in Dulwich, south London, where she married a resident and a few years later they divorced.

Single again aged 36, she finally got a flat of her own in 1971 with the St Giles housing association in Balham, south London.

As she later told a local journalist, she had been ‘one of the first extensively paralysed people in Britain to hold down a full-time job and

Joan and Robin Dawe 1979 (press photo publicising a TV programme) live on her own, she had left the institutional atmosphere of a Home and set up her own flat, travelling to work every day by car.' (press cutting, c.1979).

After breaking a leg and needing more assistance she moved to a John Grooms sheltered housing scheme in north London. She continued working, now as a receptionist at the King's Fund Centre, where the SIA had its first office.

It was at Stoke Mandeville hospital in 1972 where she met Robin, another wheelchair user, and they married in 1976. Joan was said to be easily recognised for her use of bright green eye shadow. Sometime after getting married and living apart by necessity, they found an affordable bungalow in Chinnor, a small village 10 miles from Stoke Mandeville, and fund-raised to have it adapted.

One story which Maggie Davis remembered from the 1970s was that Joan Dawe had said to her that she only married her first husband because together they would become eligible for an adapted Mini car.

Joan and Robin were both described as pioneers of the do-it-yourself approach to independent living by using as many 'gadgets' as possible, even if it took half an hour each to put on a pair of trousers. The Le Court film unit was making short documentaries to inform disabled people about the range of gadgets that can assist with independent living – what today would be called 'smart homes' (Baldwinson, 2019a).

They were filmed for a television documentary on independent living made by Associated Television (ATV) and broadcast in February 1979. Some press articles and photographs recently surfaced when the itemised contents of a cuttings archive of an unnamed local newspaper were put online for sale by a USA company.

Joan was reportedly later a counsellor for the Chiltern branch of the Spinal Injuries Association, SIA.

It is fair to say that it was a stubborn-minded decision by Joan and Robin to see independent living as meaning they could **never** use personal assistants, though they admitted relying on friends and neighbours at times. Their self-acknowledged struggle to do everything for themselves caused debate and concern with other campaigning disabled people for the message it was giving, even though they were liked as close friends. Some disabled friends also worried that their approach had been sadly life-shortening.

Dorothy Dickson (disabled) and Marsh Dickson (non-disabled) were members of the Co-operative Party and were active in the Chelsea Constituency Labour Party (CLP) in the 1960s. They were motivated by their personal circumstances and their political beliefs to campaign for disabled people more generally to gain services that support independent living. Some specifics we do know about them are:

1. Marsh Dickson had been advised to give up his paid work to be the only carer for his disabled wife Dorothy Dickson;
2. They were both fearful that Dorothy Dickson as a disabled person would have to spend the rest of her life in a hospital bed living on a geriatric ward if Marsh Dickson was to die before her; and
3. They were having discussions about social care from 1964 with other Labour Party members, including David Owen MP who lived nearby on a river boat and was also working as a hospital doctor.

Unfortunately little is currently known on Dorothy Dickson. She was reported as visiting the Labour Party Annual Conference on three occasions and becoming well known by delegates. These times might have been those conferences that were held in Brighton (alternate years with Blackpool) - being easier to travel to from London for a wheelchair user.

It was reported that she and Marsh Dickson lived together for 24 years before they were married. Both of them had been previously married and Marsh Dickson’s divorce was only finalised a month before they married in 1973. Dorothy had changed her surname by deed poll many years earlier, and they referred to themselves as ‘Mr & Mrs Dickson’. Dorothy died in 1975 aged around 66 years.

Disabled women leading as activists

In the absence of finding a membership book for the National Campaign, the list of names of disabled people identified in this research as pioneers for their own independent living or as the disabled members of the National Campaign must ultimately be seen as an arbitrary list that has been re-assembled from archives and books. But because of this, is it an arbitrary accident that so many of the disabled people here are women? I think not.

The first observation to make here is that the work of many of these pioneering and campaigning disabled women is only known today because they wrote their own life stories in books. They weren’t the chairs of important committees in the professions, in parliament or in government; a traditional way for their words to be noted down and preserved for future generations. For example, sadly we know little about Dorothy Dickson as a person even though she made a strong impression on many delegates at a minimum of three Labour Party conferences.

The second observation is that, without kidding ourselves that everything now is sorted, the social expectations on women, disabled and non-disabled, at the time were very different to those on men. For example, a disabled man at home was far more likely to receive support from the statutory Home Help service than a disabled woman would. Men were not expected to know about shopping, cooking or cleaning; a single man would be expected to live with parents or as a lodger or in some type of institution where these aspects of life - in the absence of a dutiful wife - would be provided for him. A woman was expected to fend for herself using whatever contacts she had with other women, with young single women away from home being expected to flat-share with others like herself, rehearsing their coping roles.

Consider the following extracts from a PhD thesis by a doctor written in that era. It was based on his survey in 1971 of ‘young chronic sick’ disabled people in the Greater Glasgow area, being 96 disabled people (50 female and 46 male) living at home and 101 living in various hospitals. (MacLennan, 1973)

> “A wife looking after a disabled husband rarely experienced much disruption in her domestic arrangements. Though she often had financial problems she was often able to continue in the single role of housekeeper.

> If the wife was the patient, the situation was much more difficult. This was due to the fact that her husband usually attempted to combine the duties of breadwinner, housekeeper and nurse. Inevitably this imposed a considerable strain on him. It often affected his wage earning capacity." (MacLennan, 1973, p107)

Where do we even start with that? It seems that not experiencing 'much disruption in her domestic arrangements' was an older way of saying the current phrase, of telling her to suck it up.

This focussing of home help services away from married disabled women is confirmed in this extract:

> "Most single men and women requiring these [home help] services were provided with them. If [disabled] men were married, home helps were rarely required. The two husbands requiring them, had wives who went out to work. Married disabled women and their relatives were in a less fortunate position. Many of them required a home help but only two were provided with such a person. … Men usually received help from someone living within the household. Women relied more heavily on outside sources. … If the [disabled] subject was married the principal helper usually was the spouse. Single people more often had the support of a mother or sister. They also received a lot of support from neighbours and more distant female relatives." (MacLennan, 1973, p57-58)

We also need to overlay these unequal social expectations and statutory service patterns with the sexism of designed-in income inequalities in the benefits system, whereby a disabled married woman would be paid only the fraction of the benefits due to disabled man, and we get a sense of how hard it was for many disabled women to achieve their independence - no wonder they wrote books about it, a debt we owe them to learn from.

Women as default carers

There is also the position of non-disabled women as the default unpaid carers to be considered. For example, consider this following extract both with and without the additional words, and its social assumptions.

> "During the course of the survey it became apparent that relatives [women] played a major part in maintaining disabled people in the community. More detailed assessment of the hospital population confirmed this impression. Many people, in this group, either had

> no home to go to, or had no one to look after them. The high proportion of single as opposed to married subjects receiving hospital care was another striking demonstration of the importance of relatives [women].
>
> The care of single disabled people usually followed a characteristic pattern. Those people, in their youth, were supported by parents [mothers]. Eventually their parents died or became disabled themselves. At this stage, it often became necessary to admit the young chronic sick patient to hospital.
>
> Some disabled people were more fortunate in that they were taken into the home of siblings [sisters]. This solution was often unsatisfactory, however. There rarely were the same bonds of duty [social pressures] between siblings as there were between husband and wife or parent and child. The situation was even more unstable when the sibling [sister] was married. Here there was a division of loyalty between spouse or children, and the disabled sibling. The patient usually came off second best in such a conflict." (MacLennan, 1973, p127-128)

Similarly there were strong leadership roles taken by disabled women within the Disablement Income Group (DIG) in its early years. (J. Morris, 1991, 1994)

Typical geriatric wards in the 20th century

When the NCYCS campaign started the NHS was just 16 years old, and it is worth taking a moment here to look at what geriatric wards were typically like up to the early 1960s, and in some cases into the 1980s.

Workhouses started to be built in the late 1600s (seventeenth century) with many being built in the 1700s (eighteenth century), so that by the 1770s decade there were around 2,000 workhouses in operation with a total of around 90,000 inmates (Turner 2012).

At the start of the NHS in 1948 it inherited an estate with many basic and dilapidated 'hospitals' which were over 200 years old, and one was 800 years old. This inherited estate included many wards still being used inside former workhouses some of which were languishing in the neglected corners of many hospital sites. Some of these former workhouse buildings were renamed as ‘infirmaries’ to be more acceptable to local communities who lived in fear of having to go to the workhouse, as was intended. There was also a legacy estate of charitable or ‘voluntary’ basic hospital buildings. In the NHS jargon of the 1950s and 1960s these workhouse buildings which were still in use were known as FPAIs – Former Public Assistance Institutions.

These dilapidated buildings had continued from Victorian times through to the 1960s (and later) to receive and warehouse mostly elderly ill people. For example, papers in the Socialist Health Association archive in the Hull History Centre report that in 1939 (pre NHS) the government had to make a hasty survey of all the hospitals across Britain at the time to see which ones would be suitable to receive the casualties of air raids in the coming war, and which were just warehouses. The survey findings shocked some people because, "it was found that there was a large amount of unrelieved sickness." (A. Davis, 1951)

And new backwaters were being created within the NHS, albeit with good intentions. For example, Dr DS Wilson wrote this in 1978 about some earlier work in Cumbria, North West England:

> “With the development of the concept of district general hospitals, some new hospitals were built, thus releasing older hospitals to be available for long-term [chronic] care. … [One doctor] had the foresight to use the old Whitehaven Hospital for long-term illness, and Workington Infirmary has since taken on the same role. … [The] Medical Officer of Health for Cumberland, had instituted a hostel of 20 beds for the younger physically handicapped in Maryport, for those disabled not requiring nursing care.” (Wilson, 1978, p448)

Health care for elderly people was also a backwater professionally: seen as a place for ‘second-rate doctors, third-rate nurses, and fourth-rate patients’ as the ‘canteen culture’ of some medical schools had it.

And things were not getting better. In the NHS at the time 14% of the beds were for elderly people, but they only received 6% of the capital programme for refurbishments and new buildings. It was estimated that this low level of spending meant every new building for elderly people would have to last for 200 years. Hospital spending for young chronic sick people – disabled people – was mostly wrapped up in their budgets for services for elderly people.

1935, Warren

There were a few exceptional pioneers, with perhaps the best known being Dr Marjory Warren (1897-1960). In 1935 she was working at West Middlesex hospital when it incorporated the nearby Poor Law Infirmary and her workload grew overnight by 714 chronically ill elderly patients. She examined each patient and started rehabilitation and discharge arrangements, helping almost 500 elderly people get better and go home. At the time her work was criticised as being "cruel" for expecting elderly people to be helped to get out of bed and dressed if possible during the day.

Writing later in 1943 about her previous work, Dr Marjory Warren stated,

> “I will make one or two cursory remarks on the care of these younger patients. First, I think that they should be nursed and treated with ample accommodation in small units, and separate from elderly patients. Secondly, there should be adequate opportunities for medical research into the chronic conditions affecting the young and those in the prime of life. Lastly, no pains should be spared in affording these patients all the possible amenities by which their cramped and restricted lives may be made pleasanter, seeing that many of them live for several years.” (Warren 1943 p822-823)

In her comprehensive book on the history of disabled people, Anne Borsay considers the work of Warren to be “patronising” (Borsay, 2005, p62), and that:

> “Elderly people in hospital were prepared for community living not because home care was more appropriate to their situation, but to release beds for acute patients.” (Borsay, 2005, p64),

However this rather denies people their own agency in the matter, and rather ignores the fact that there were no acute wards or beds in these institutions, it was totally about lifelong or chronic wards and beds. To be fair, it did become about saving money in the 1960s as we’ll see later.

1946, Mackenzie

Basil Mackenzie was a physician. While working, in 1942 he inherited his father's seat in the House of Lords becoming Lord Amulree, though he continued to spend his working hours as a doctor. Four years after becoming a Lord he made his first speech, which was during the debates on the creation of the NHS, and he spoke on the long-term neglect of many elderly and younger disabled people.

Two particular examples stand out from his speech (see Appendix 1), as follows:

> "There is one particular tale that I was told by a friend of mine who was a doctor. About fifteen years ago he went into practice in the country, and one of the places where he visited was the local Poor Law infirmary. He was there for about a year and then moved to somewhere else. **About fifteen years passed** and he went back to the same part of the country on some other work. He called at the infirmary, where he was pleased to find that the same master and the same matron were there as well as several of the nurses. What really horrified him, however, was to find that a large number of the same patients who had been there when he had seen them fifteen years before were still in the infirmary. They had never left the building." (Amulree 1946; emphasis added)

and

> "A new doctor was appointed to one of them Public Assistance infirmaries [ex-workhouses]. He went there and was inquiring what was wrong with the various patients when he came to one woman who looked youngish and seemed quite well. He said:
>
> 'Why is that person in bed?'
>
> and the nurse replied:
>
> 'I do not really know. I have been here five years and she has been in bed all the time.' " (Amulree 1946)

Following this speech he became one of the founding members in 1947 of what is now known as the British Geriatric Society, along with Marjory Warren, Joseph Sheldon and other founders.

1951, Socialist Medical Association

From well before the start of the NHS the number of disabled people classed as YCS living in hospitals, and especially in their "long-stay annexes" was unknown to the authorities. The Socialist Medical Association (SMA) devised a questionnaire in 1951 to try and get better data, though it has to be noted that their main concern in doing this was about poor health care for elderly people living with chronic health conditions. Based on figures in the SMA report quoted below (SMA 1951), the estimates of YCS disabled people living in hospitals was anywhere between 5,000 and 12,000 such disabled people.

> "One of the biggest problems is the number of patients who are occupying 'chronic' beds for social and not medical reasons, ie because they cannot be looked after in their own homes or in old peoples' homes run by voluntary associations or local authorities." (A. Davis, 1951)

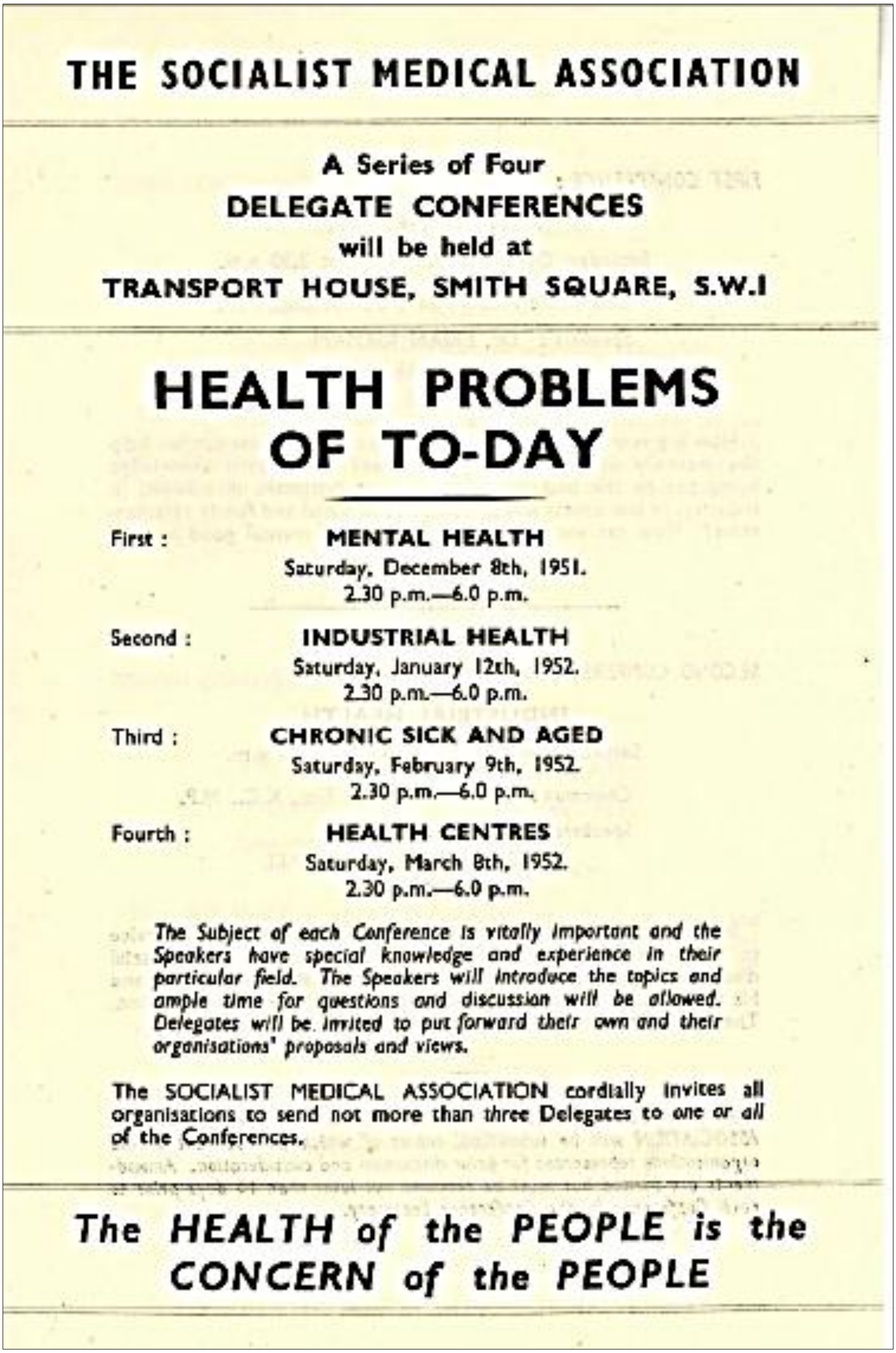
The SMA identified four pressing issues and organised a series of delegate conferences to cover these issues:

- mental health
- industrial health
- chronic sick and aged
- [the new idea of multi-GP] health centres.

In advertising ahead of the third of these conferences, held on 9 February 1952 in London, the SMA leaflet states:

> “The urgent needs of the chronic and long-term sick and of the aged constitute the most serious challenge to the existing health and social services of this country. How much longer do we intent to tolerate the present state of affairs? Whose is the responsibility?" (SMA leaflet, 1951, SMA Collection, Hull)

The West London branch of the SMA organised a similar conference earlier on 3 December 1951, and Somerville Hastings MP spoke at both conferences.



THE SOCIALIST MEDICAL ASSOCIATION

A Series of Four
DELEGATE CONFERENCES
will be held at
TRANSPORT HOUSE, SMITH SQUARE, S.W.1

HEALTH PROBLEMS OF TO-DAY

First : **MENTAL HEALTH**
Saturday, December 8th, 1951.
2.30 p.m.—6.0 p.m.

Second : **INDUSTRIAL HEALTH**
Saturday, January 12th, 1952.
2.30 p.m.—6.0 p.m.

Third : **CHRONIC SICK AND AGED**
Saturday, February 9th, 1952.
2.30 p.m.—6.0 p.m.

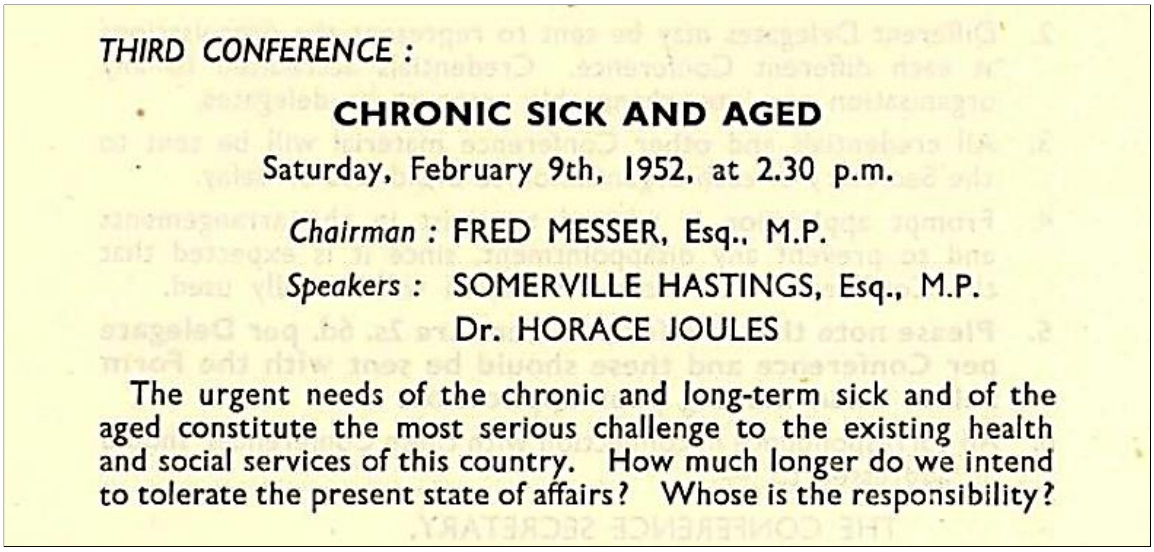
Fourth : **HEALTH CENTRES**
Saturday, March 8th, 1952.
2.30 p.m.—6.0 p.m.

The Subject of each Conference is vitally important and the Speakers have special knowledge and experience in their particular field. The Speakers will introduce the topics and ample time for questions and discussion will be allowed. Delegates will be invited to put forward their own and their organisations' proposals and views.

The SOCIALIST MEDICAL ASSOCIATION cordially invites all organisations to send not more than *three* Delegates to *one or all* of the Conferences.

The HEALTH of the PEOPLE is the CONCERN of the PEOPLE

SMA Leaflet 1951, front cover, (SHA Collection), note third conference.



THIRD CONFERENCE :

CHRONIC SICK AND AGED

Saturday, February 9th, 1952, at 2.30 p.m.

Chairman : FRED MESSER, Esq., M.P.
Speakers : SOMERVILLE HASTINGS, Esq., M.P.
Dr. HORACE JOULES

The urgent needs of the chronic and long-term sick and of the aged constitute the most serious challenge to the existing health and social services of this country. How much longer do we intend to tolerate the present state of affairs? Whose is the responsibility?

SMA Leaflet 1951, extract from inside pages (SHA Collection)

The terminology starts to change with the creation of the NHS. In November 1948 the SMA Bulletin number 103 starts with the headline, "The Care of the Chronic Sick" which is taken to cover all ages from childhood to old age.

By 1952 a letter from the SMA Chronic Sick and Aged Sub-Committee Secretary to SMA branches, June 1952, starts:

> "The [SMA] Central Council has indicated that ... branches ... should now plan and organise ... conferences and campaigns on the serious problem of the Chronic Sick and of the Aged. **This is essentially a dual problem but difficult to sub-divide.**"
>
> (SHA archived collection) (emphasis added)

And by 1953 Geoffrey Cheshire writing a letter to The Guardian uses the phrase, "young chronic sick" as a distinctive group of non-elderly disabled people. (Appendix 3)

1956, Whitaker

Another systematic approach was taken by Ann Whitaker in her survey in 1956 and 1957. She was a hospital almoner, an early type of hospital social worker, and her survey was funded by the Nuffield Foundation. (J. Hunt, 2019, p21)

Her survey covered 314 young chronic sick people aged 15-55 years and living in 57 institutions. In summary, her main finding was that **not one** of these 314 disabled people needed a doctor (Whitaker, 1959b; Appendix 6 here).

A key passage in Ann Whitaker's summary of her full report is as follows:

> "Many explained that they wanted something different from hospital life. Two wards especially for the young chronic sick were visited. Patients there who had previously been in wards for old people were so delighted with the change that they had no complaints; those who had never been with the old were restless at having to be in hospital at all and longed for a more normal routine and for more activity and opportunity to share in the every day life of the world about them." (Whitaker, 1959b, p4)

The reference to "wards especially for the young chronic sick" is the design model for the later young disabled units (YDUs) often still located in hospital grounds. But it is clear from this report that while some disabled people were "so delighted" to be released from geriatric wards, other disabled people who had somehow avoided this oppressive experience simply desired to live independently in the community.

In summary she found:

- 314 such disabled people were living in 57 institutions,
- 0 (**not one person**) needed a doctor for their daily care,
- 191 were under the care of nurses, but a doctor working with her assessed that only 83 actually needed nurses to provide that care,
- 89 needed assistance during the night,
- 157 were not needing medical treatment of any kind,
- 86 were on drugs only,
- 58 would benefit from physiotherapy, and
- 136 would benefit being regular wheelchair users, because having their own wheelchairs would greatly help in their mobility and independence.

Adapted from: (Whitaker 1959b) as in Appendix 6.

Looking in more detail at the 83 disabled people judged to need **nursing** care, this related mostly to needing assistance with lifting and moving in bed, pressure sores, female incontinence, catheters and colostomies.

Other tasks such as assistance with washing, dressing, using toilets, could all be provided by **hospital attendants**, who did not need medical training.

On the issue of whether the assistance provided should be done by nurses or by attendants, Ann Whitaker notes that, "the help needed is of the most repetitive kind." (Whitaker 1959b) as in Appendix 6.

1961, Sheldon

In the footsteps of Marjory Warren and Ann Whitaker was Dr Joseph Sheldon who produced a damning report on the conditions in geriatric wards in Birmingham – “Geriatric Services in Birmingham Regional Hospital Board, 1961” – which caused a national scandal.

Perhaps astutely in terms of popular publicity, his report included an appendix of photographs he had taken. One picture showed the piles of bed pans that had to be stored in a bath, with the same washroom being used to both wash out the bed pans and to clean crockery for the patients’ food.

Buildings had many floors but no lifts, with patients carried up and down narrow stairs. Beds were crammed in, placed only 11cm side by side, and with very little space at the foot of each bed which meant two nurses with trolleys could not pass each other on a ward.

A mortuary was found to share its rooms with a piggery.

Two years after his report the British Medical Association (BMA) recommended that geriatric departments be created across the country and resourced as a new specialism. Perhaps the key finding of Joseph Sheldon, echoing Marjory Warren and Ann Whitaker, was that half of the people in these "chronically ill" wards didn't need to be there at all - it was just "human warehousing". (Whitaker, 1959b)

1961, NHS Community Care

The emerging policy of community care in the early 1960s can maybe best be tracked to a book of four essays by Ervin Goffman, published in 1961 with some of his ideas first written and shared in 1957.

A key concept he created was that psychiatric hospitals are ‘total institutions’ - an idea he developed to explain how the Nazi concentration camps in the second world war managed to function and control their inmates. As can be imagined, he caused controversy when he identified the same methods of inmate control at work in American psychiatric hospitals in the 1950s. Nevertheless his analysis caused a substantial policy shift in policy regarding institutions, even if shifting their practices would take many years more.

The ‘water towers speech’

In the UK the key moment of this change in policy is the so-called ‘water towers’ speech given by the Minister of Health in 1961 to the annual conference of the National Association for Mental Health (Mind). He said about the psychiatric so-called hospitals or asylums:

> “There they stand, isolated, majestic, imperious, brooded over by the gigantic water-tower and chimney combined, rising unmistakable and daunting out of the countryside – the asylums which our forefathers built with such immense solidity to express the notions of their day. Do not for a moment underestimate their powers of resistance to our assault”

This speech fed into the 10-year plan, published as Health and Welfare - The Development of Community Care in 1963, also known as the ‘blue book’, for psychiatric hospitals. This community care plan built on the Hospital Plan of 1962 which was for the new type of ‘general hospitals’ with 600-800 beds to exist in each district of the UK.

However, a key difficulty with discussing the ‘water towers’ speech was that the Minister of Health at the time was Enoch Powell MP, who later in 1968 became notorious for his ‘rivers of blood’ racist hate speech in Birmingham by appealing to the extreme right.

A later analysis of this community care policy, covering the decades of successive Labour and Conservative governments, concluded that its failure was rooted in the lack of ring-fenced funding for health authorities and the competition they faced with other hospitals’ funding demands. A second shortcoming was that the new ‘general hospitals’ usually had no provision for people with distressing mental health needs turning up at the doors. (Timmins, 1996)

1962, Townsend

In 1962 Peter Townsend published a major work of over 500 pages on the appallingly poor state of care support for elderly people in the UK, The Last Refuge. He is especially critical that more than half of all elderly people living in hospital or council institutional Homes in 1960 were still located in former workhouse buildings.

> "In the social history of Britain there have been, as Beatrice Webb once said, few objects which have attracted such universal hatred and hostility as the old workhouses. After 1948 they were going to

> be abolished. Yet in 1960 they were still the mainstay of local authority residential services for the handicapped and aged." (Townsend 1962 p63)

Although he was investigating poor provision for elderly people, about 10% of the residents he surveyed were non-elderly disabled people - the young chronic sick - and that they were more likely to be living in an old workhouse than an elderly person. In detail, he found 8,873 non-elderly disabled people living in such institutions, 5,166 of them (58%) in old workhouses, compared with 31.0% of all residents. (Townend 1962 p43, adapted from Table 6).

These old workhouses had been officially renamed within the NHS as Former Public Assistance Institutions (FPAIs) but everyone knew what they truly were.

One commentator reportedly said that Townsend's survey work which included his and his small team of volunteers visits to around 170 institutions and then writing his major publication was such a major project that it was comparable in its detail and scope to a Royal Commission. Today we would probably say his work was as extensive as holding a Public Inquiry. (Anon, 1963; cited in Walker, 2009).

In concluding his investigation, Townsend made some policy suggestions.

> "the long-term objective of public policy should be to remove the need for communal Homes of the kind that exist today. This would mean
>
> (1) creating a large supply of sheltered and specially designed housing for the handicapped and aged;
>
> (2) building up a strong local authority family help service to meet the domestic, environmental and social needs of sick and infirm persons living in their own homes;
>
> (3) rapidly developing the preventative and after-care health services available in the community, partly by extending [GP] group practice;
>
> (4) transferring to hospital management committees, under the general direction of regional hospital boards, the responsibility for administering or supervising (a) institutions catering for incapacitated and chronically sick old persons who for the time

> being cannot be given adequate nursing and medical care in their own homes, and (b) short-stay Homes for infirm and handicapped persons recovering from illness or more active persons requiring temporary accommodation; and
>
> (5) rapidly reducing the number of communal Homes.”
>
> (Townsend 1962 p393-394)

These are worth considering for the similarities with the policy positions of NCYCS and later of Alf Morris MP. Later in his book Peter Townsend expands on what should be involved in the second recommendation above, for “building up a strong local authority family help service”:

> "a comprehensive local family help service should be created. Its primary responsibilities should be:
>
> (1) [to visit, inform and assess elderly people].
>
> (2) To plan and manage local 'sheltered' housing schemes for the handicapped and aged.
>
> (3) In co-operation with housing departments [to repair and improve homes and to provide home equipment to support independent living].
>
> (4) To provide regular home services: domestic help, shopping, laundry, meals, night attendance and occupational therapy.
>
> (5) To provide facilities for [clubs and holidays].
>
> (6) To visit persons living in institutions to investigate personal and social problems and arrange alternative accommodation when requested and when practical." (Townsend 1962 p411-412)

These ambitious and challenging proposals were in a context of political neglect.

> "No serious attempt has been made by the Labour or Conservative Governments since the war to collect the necessary information or to review developments in policy. ... Apart from some fleeting references [in two reports] ... no government committee or commission has examined since the war the problem of the care of the aged." (Townsend 1962 p394)

Townend was a constant ally of campaigning disabled people throughout the 1960s and 1970s, as shown here in his public vilification by a

Minister (Appendix 29) as well as his supportive writings in the national press. He later had some disagreements with UPIAS (Beesley, 2022).

His seminal work from 1962 was revisited by researchers in 2010, a publication he assisted the authors with by answering enquiries about his original research details. (Johnson and others, 2010)

1962, NHS Hospital Plan

Although this was mostly concerned with poor care standards and dilapidated buildings used of elderly people, the NHS's

> "1962 Hospital Plan inaugurated slow improvement by abolishing the distinction between acute and chronic hospitals. ... [however] ... Only in the 1970s did hospital-based geriatric units arrive in all health authorities in England and Wales, albeit 'often still in outdated buildings and understaffed.' " (Borsay, 2005, p63; quoting Flinn, 1976).

As noted above, this was followed by the Health and Welfare - The Development of Community Care in 1963, also known as the ‘blue book’, for psychiatric hospitals.

1964, Droller and Paley

A survey was made in Leeds in 1964, but this time it was looking at the independent living needs of disabled people living in the community.

Two consultants (senior doctors) Hugo Droller and Ronald Paley, interviewed 79 disabled people living in the Leeds area. The majority were receiving personal care from family members. The summary findings were that local authority registration systems needed to be improved, and that better links to education, training and employment services were needed. It has to be noted that some of their conclusions are problematic and ‘of their time’, such as their using school exam qualifications as a proxy for “intelligence”. (Droller and Paley, 1964)

1964, Guthrie

Duncan Guthrie chaired a working party to investigate the issues of and needed improvements for disabled people wanting to live independently. This working party is the focus of Section 3 later in this book. In their report they summarise Guthrie’s “approaching” the relevant government ministers in 1964 for better home nursing services or an attendance allowance instead. (Guthrie and others, 1968, para. 8)

The same report summarises similar lobbying by the Aberdeen Association of Social Service in 1961, and the Scottish Council of Social Service in 1964 and 1965. (paras. 9-10)

The Scottish Council of Social Service was given a reply by Miss Herbison, the Minister of Pensions and National Insurance, “that the position of long-term and substantially disabled persons would be considered in the course of a review of the Social Services which was taking place.” (para. 11)

As was later summarised in a feature-length newspaper article by Nicholas Timmins in 1996:

> “The policy [of community care] was first enunciated by Derek Walker-Smith, a Conservative health minister, in 1959 as part of the changing attitude towards the mentally ill which led to mounting criticism of traditional asylums and the liberalising 1959 Mental Health Act. New drugs, which allowed effective treatment and symptom suppression, made it possible to imagine that care in the community might work. To that was added a political push delivered by Enoch Powell in his famous "water towers" speech [in 1961] …
>
> [So] the beds in the traditional asylums closed, and at virtually the rate Powell predicted. What did not close, until the late 1980s, was the hospitals themselves. Instead they ran on, the numbers in them depleting and their costs per patient rising, as health authorities struggled to find the cash to create the new services. …
>
> [But] much of that cash was diverted by health authorities for other uses.” (Timmins, 1996).

‘Contracted beds’ in charity Homes

It's now hard to find any discernible response after 1946 by the new NHS to the concerns raised by Basil Mackenzie (Lord Amulree) and others about the neglect of young chronic sick people - disabled people - spending their lives in long-stay wards in its many old workhouses. But perhaps the main policy development was in the growth of 'Homes'. These were institutions run by charities and perhaps the most well-known would be those of the Spastics Society (now, Scope) and the Leonard Cheshire Foundation with its Cheshire Homes.

Initially these Homes were funded by a mixture of charity fundraising, and money from the new NHS where a placement of a disabled person who would otherwise be living in hospital could being paid for as a ‘contracted bed’.

This contracting is perhaps an ancestor of the current NHS system of personal health budgets – PHBs.

Later, this contracting arrangement was extended so that local authorities (council social services) could also pay for social care residential places for disabled people if they had a family connection to the area.

Typically each Home had a staff team headed by a Manager and a Matron, confirming the medical culture of each Home even if few or no medically-trained people actually worked there. Many of these Homes were in former stately homes in the countryside which had fallen into disrepair with the social class changes in Britain after the First World War.

In terms of the wider history of the Disabled People's Movement in Britain there is the pivotal role of the residents of one of the Cheshire Homes in Hampshire, called Le Court. (J. Hunt 2019). A useful piece of writing would be to draw all the Le Court influences into a political narrative. It was pronounced as "Lee Court".

In a letter in 1953 to The Observer newspaper, Leonard Cheshire's father Geoffrey takes exception to the paper's recent reference in a news item to residents at Le Court as being "unwanted". Instead he uses the phrase "young chronic sick" and sees the Homes as an alternative to "life-long inactivity in the senile wards of our hospitals". (Cheshire, 1953; see Appendix 3 for full text). However, from this and other writings such as La Fane (1981) we can see that phases such as "the unwanted" and "the incurables" were in common circulation; indeed, some of the older hospitals had "The Incurables" formally in their name - for example up to 1988 in Putney, London.

* * *

This outline of the living conditions for many disabled as well as elderly people at the time is to give some sense of the daily living conditions of Paul Hunt, of Pamela La Fane, and of the other disabled activists at the time who fought hard against their segregation, a fragile history that appears to be mainly found now in a few autobiographies. Their life was just expected to be an existence of staying in a bed usually on a dilapidated geriatric ward.

MPs raising issues with government

Somerville Hastings MP

In 1956 the Conservative government's Minister of Health was asked by a Labour backbench MP, Somerville Hastings, about the policy of regional health boards in keeping disabled people living in hospitals on geriatric wards regardless of their age, and why special units were not build instead? The answer was that hospitals were easier for relatives to visit. In asking the question he uses the phrase, "young chronic sick", (Appendix 5) as did Geoffrey Cheshire earlier in 1953 (Appendix 3).

As background, Somerville Hastings was a Labour MP from 1923 to 1959, and he had been a doctor and a surgeon in the Medical Corps during the First World War. It was said that the idea of an NHS was created in his home while he was chatting with socialist friends. In 1934 he presented the motion to the Labour Party conference that proposed the creation of the NHS. He was the founder and first President of the Socialist Medical Association (later, the Socialist Health Association).

David Owen MP

We know now that there were discussions from the early 1960s between MPs and Marsh Dickson, including backbencher David Owen who lived nearby on a river boat. He had been working as a junior hospital doctor, and by 1966 when he was an MP he still worked part-time on research.

This 1960s discussions timeline is confirmed by correspondence with Lord Owen, as follows:

> “[On] the National Campaign for the Young Chronic Sick. I knew its chairman, Marsh Dickson, because if my memory serves me right we were both members of the Chelsea Labour Party when I lived on a houseboat off Cheyne Walk from 1960-64. He was the power behind the Campaign. I think it was a few years later that Alf [Morris] took up the cause. Also Jack Ashley [did].
>
> I was due to present a Private Members’ Bill* to the House of Commons [which would have set up a Disablement Income Commission, but] when I was appointed Minister for the Navy in July 1968 [and therefore I could not raise a Private Members Bill]

> I passed the Bill on to Jack Ashley to present in the Commons and [on 16 July 1968] it was his first speech after having [become profoundly] deaf due to a viral infection.
>
> I was there to listen to him and Alf almost lay on the bench in front of Jack putting his index finger and thumb up in the air moving apart to indicate to Jack whether to be louder or quieter. It was quite a performance from both of them."
>
> (Owen, personal email, 27 April 2020)
>
> * To see the Government's open hostility to this Bill see the published letter in Appendix 22.

The papers in the archived papers of the David Owen Collection include an undated first sheet of a written submission he apparently made about the position of YCS disabled people. He submitted this in his medical capacity as Dr David Owen, Department of Neurology, St Thomas's Hospital, London (Appendix 52). He says there, "Geriatric care has made undoubted progress but for young people to live the remainder of their life in an environment of old and often senile patients is totally unacceptable."

David Owen was interested in these issues around independent living, along with his colleague Alf Morris. David Owen was based at St Thomas' hospital on the southern bank of the Thames, facing the Houses of Parliament. His specialism was in neurology, and he was in contact with the work of the Lane Fox Unit there. He followed with interest their pioneering work in post-polio treatments and the ground-breaking work of the **Responauts** in achieving independent living outside of the hospital - mostly by having ventilators fitted to their powered wheelchairs by volunteer engineers.

This group had a quarterly magazine, The Responaut, from December 1963 to around 1988, edited by Doris Page (her pen-name was Ann Armstrong), herself a disabled woman and respirator user.

In terms of pioneering independent living, the following related press comment is of interest:

> "During the last Labour Government [1966-1970], there was some concerns about a group of people suffering from respiratory polio living out their time in an annex of St Thomas's Hospital, even though each of them could have lived outside if they had the funds. So, as an experiment, each of them got the cost of their hospital

> bed to spend as they would, and very satisfactory it turned out to be. One, for instance, is in a residential home of her choice: another found a flat, a job, a residential helper and a part-time chauffeur and has been living thus ever since." (Ann Shearer, Housing to fit the handicapped, The Guardian, 26 June 1973).

Alf Morris MP

Marsh Dickson might have first met Alf Morris when he was invited by Dickson to speak at a Constituency Labour Party meeting. Some details have been provided, as follows:

> "Marsh Dickson, founder of the National Campaign for the Young Chronic Sick, had prompted Alf to put parliamentary questions about the need for legislation or ministerial action to tackle the plight of young people locked away in the geriatric wards of hospitals. This was one of the issues in which Alf was also very much involved 'off the Order Paper' in detailed correspondence with Richard Crossman [Secretary of State for Health].
>
> (Kinrade 2007 p154)

and

> "Also influential was Marsh Dickson, who had a strong personal experience of disability. For years he had looked after his severely disabled wife [Dorothy Dickson] who but for him could not possibly have lived in the community. As a member of the Labour Party and President of the National Campaign for the Young Chronic Sick, he worked to draw public attention to the plight of young people with long-term illnesses and disabilities who were then routinely consigned to geriatric wards and old-people's homes. Alf, who had spoken at one of Marsh's constituency meetings, was able to include a clause in his [CSDP] Bill requiring local authorities to advise the Secretary of State of the numbers of people under the age of 65 cared for in premises accommodating people over that age." (Kinrade 2007 p159-160)

Arthur Blenkinsop MP

In 1965 Arthur Blenkinsop MP asked a series of questions to Government Ministers on the numbers of disabled people living in YCS conditions in Britain (Appendix 8).

David Winnick MP

David Winnick asked questions in Parliament in 1967 and has very kindly responded to this research to say he has no particular recollections to add, being over half a century ago.

Trades Union Congress

In his book which examines the role of DIG in detail, Jameel Hampton (2016) also mentions the interest taken by the Trades Union Congress (TUC) annual congresses from 1965 to 1971 in supporting the campaigns for rights by disabled people. To some extent the TUC faced a difficulty because people who were injured at work were privileged and qualified for extra benefit payments when compared with the disabled people who didn't acquire an impairment at work, nor in the war. However, the TUC supported people who were called the "civilian disabled" even though they were mostly not their members. The influence of the Labour Party might have been a factor here and it merits further research. (Hampton, 2016, pp83, 101, 146)

Section 2 – NCYCS in 1964 and 1965

Made in Chelsea, 1964

Marsh Dickson explained the origins of the NCYCS in his introduction to a 1971 booklet which transcribed two of Alf Morris' speeches, the main speech he possibly gave at a meeting at the Labour Party conference in the autumn of 1970. As Marsh Dickson wrote:

> "Alf Morris' Chronically Sick and Disabled Persons Act 1970 had its beginning in the grass roots of the Labour and Co-operative Parties. Work on it began in 1964, when in the Chelsea Labour Party we set up a committee to deal with the problems of the Chronic Sick and Disabled. It started as do so many campaigns because, having just been told that my wife [Dorothy Dickson] would never walk again and could only get worse, as a socialist I brought the whole problem to my own CLP. It was a problem that did not just affect me but so many others worse off than I was. We set up a committee of the Chelsea Labour Party which was to grow into the National Campaign for the Young Chronic Sick ... After much research the Party put the following resolution to the 1965 Party Conference which was very ably presented by Dorothy Young: … [see Appendix B for the full text of the motion] and which became Labour Party policy.
>
> Doris Rewers took up the same theme, equally successfully, at the [Co-operative Party] Women's Guild Conference [see Appendix A for the full text of the motion]. Each year's resolution added to the original until they touched many of the points covered in Alf's Bill."

(Morris and Dickson, 1971, p1)

From its early meetings the group appears to have adopted the Ministry of Health's definition of a YCS disabled person, one which excluded Deaf people, visually impaired and blind people, learning disabled people, and people in psychiatric institutions. They also adopted the current medical terminologies. It would be some years before NCYCS had a policy of independent living for all disabled people, and in this respect the Disablement Income Group (DIG) was more pan-impairment in their early days.

The politics of their campaigning

The annual reports of the Co-operative Women's Guild (CWG) include the resolutions passed but not the names of the speakers nor their speeches. From the records there was an evolving set of resolutions which started with - calling for more hospital places for YCS people nearer to where their parents live (1965); then the removal of YCS people from geriatric wards in favour of YDUs (1968); and then calling for accessibility in all new public and "semi-public" buildings, and calling on branches to support the Alf Morris Bill (1970). (CWG 1965, 1968, 1970) (Appendices A, E, G)

It is noteworthy that the CWG Congress in 1965 was held in May, whereas the Labour Party Conference was later, in the autumn. It seems plausible to think that the success achieved by the women members of the **Co-op Party** like Doris Rewers gave the new YCS committee within the Chelsea Labour Party the impetus to push forward into the autumn to try to change **Labour Party** policy nationally as well, to be the campaign’s second success in 1965. The details are later in this section.

If so, then the discussions within the National Campaign during the spring and summer of 1965 must have been quite intense, including doing more research by getting questions asked in the House of Commons (Appendix 5), in order to explain the shift in position between the CWG resolution in the spring (Appendix A) and the more complex and wide-reaching Labour Party resolution in the autumn (Appendix B). And in particular the creation of ‘medical home helps’ or PAs.

And although Paul Hunt is writing in the spring of 1965 about the need for more rights and democracy in charity-run institutional Homes for YCS disabled people (P. Hunt, 1965; Appendix 7), there is no evident connection between him and the National Campaign until an introductory letter the following year (P. Hunt,1966b; Appendix 14).

Of course, there was more happening in the campaigning by disabled people in Britain in the 1960s than was covered by the range of NCYCS resolutions to successive Co-operative Women’s Guild and Labour Party conferences, but equally the NCYCS was in the grass roots vanguard within the Labour and Co-operative parties.

Political differences with DIG

The Disablement Income Group (DIG) was formally created in May 1965 following a letter in The Guardian from two disabled women, Megan du Boisson and Berit Moore on 22 March 1965.

From the beginning DIG was focussed on campaigning for a national disability income, and for it to be paid equally to disabled men and disabled women and regardless of how their impairment had been caused. The disability benefits at the time were highly discriminatory. The following story was used at the time by NCYCS members when giving their campaign speeches, and may well have been a common example used in DIG speeches too:

> "For example, if a man falls from a ladder at work and permanently injures his spine, he will, if lucky, be covered by industrial injuries and the new invalidity and attendance payments. But if the same man has the same injury while picking fruit in his garden, his entitlement financially is much lower. If his wife should climb the ladder and receive the same injury, she would be entitled to even less, or indeed, nothing at all. Is this social justice? Is this to each according to his need?" (speech by Gray, 1969; Appendix F)

The Disablement Income Group (DIG) first met with ministers in 1965 soon after it was formed, lobbying government for a National Disability Income, but came away disappointed with half-promises. (Hampton, 2016)

This focus on benefits set DIG against NCYCS, because the National Campaign insisted that it was better state services that were required to meet the independent living needs of disabled people. This tension is shown in the report from the Guthrie working party on independent living, in which DIG was a member and NCYCS was not. The report concluded that extending home help services for disabled people was “not the answer”. (Guthrie and others, 1968, para 12(3)). This difference could be glossed over by saying that DIG was referring to ‘standard’ home helps whereas NCYCS was referring to ‘medical’ home helps. But the rift was real, and based on political differences.

From the outset DIG aimed to be non-party political, and it had three presidents, one from each of the major UK parties; by contrast NCYCS was only for Labour and Co-operative Party members and organisations.

As we’ll see in the NCYCS fourth newsletter of they saw themselves as more working class and DIG as a more middle class campaign. In many ways this core disagreement would continue into the 1990s, dividing the disabled people’s movement into money-first (at worst seen as individualist) and services-first (at worst seen as paternalist). An example of this long-lasting difference was the bitter spin-out of NCIL (National Centre for Independent Living) from BCODP (British Council of Organisations of Disabled People). (J. Hunt, 2019)

DIG and NCYCS, similarities and differences

	NCYCS	**DIG**
Created	1964	March - May 1965
Party politics	Yes: Labour and Co-op	No: three presidents (Conservative, Labour, Liberal as-was)
Campaign Focus	Rights to Services	Rights to Income
Membership	Tens of people, 146 CLPs	Thousands, ‘many’ local branches
Internal Communication	Newsletter, roughly one a year	Newsletter, monthly
Decline in 1970s	Illness of key individuals, new legal rights for disabled people achieved	Over-reliance on professionals, start of Attendance Allowance
Successor organisations	None, became lost from historical records	Disability Alliance

Sources: This research, and (Millward, 2015, p284), (Hampton, 2016).

A bit beyond this research, but it could be argued that this tension was resolved after the mid-1990s, if we accept that NCYCS was essentially aligned with ‘Old Labour’ policies and DIG was more towards ‘New Labour’ policies plus some of the centrists in the pre-austerity Conservative and Liberal Democrat parties.

Non-disabled allies within NCYCS

Although there were some disabled people who were self-organising their release from hospitals to live independently, with some notable individuals described in Section 1 earlier, it must be noted that at least half of the NCYCS members were non-disabled people. There are not many surviving details of their interests and work, but some details about the following individuals have been found in various archives.

Judith Kazantzis

Judith Kazantzis was the NCYCS member who wrote to The Guardian in November 1965 as the group's main spokesperson shortly after their victory at the Labour Party conference. (Kazantzis, 1965; Appendix 12).

In later life she was an internationally acclaimed writer, poet and artist, always with a political edge.

> “During the 1970s she worked for the first Women's Liberation Workshop in London, becoming a member of the Women’s Literature Collective, reviewed poetry for Spare Rib and other journals, and taught writing via the Inner London Education Authority.” (M. Roberts, 2018)

Her feminist beliefs and activism were a good fit with NCYCS policies of paying carers, predominantly women, for their unpaid work in the home, compensating for their loss of earnings, at a time when married women were often referred to as 'housewives'. By recognising the cost of caring it helped make possible the creation of new paid job roles as personal assistants. Attendance Allowances to carers were first paid in 1970.

Writing over 20 years later, Jenny Morris is still having to challenge the views of some non-disabled feminists that all community care is wrong because it risks placing the burden on women to provide unpaid care in the family home. Jenny Morris argues for an intersectional expression of solidarity, which Judith Kazantzis as a non-disabled feminist in the 1960s was clearly putting into practice. As a reminder about the tensions being expressed for some decades afterwards, Jenny Morris noted:

> “Non-disabled feminists would serve us better by joining with us in defending the current government limitations on the ILF [Independent Living Fund] rather than assuming that the only way to mount an attack on women's caring role within the family is to consign us to residential care. Disabled people would join with non-

> disabled feminists in rejecting the way that 'community care' too often means ‘family care'. But we would assert our own political demand - a demand for the right to live within the community in a non-disabling environment with the kind of personal assistance that we would choose. In doing this, we are not only pursuing the human rights of disabled and older people but also launching an attack on the form that caring currently takes. Such a strategy should therefore also be clearly supported by all feminists who wish to undermine women's dependency within the family.”
>
> (J. Morris, 1991, p168)

Alec and Judith Kazantzis

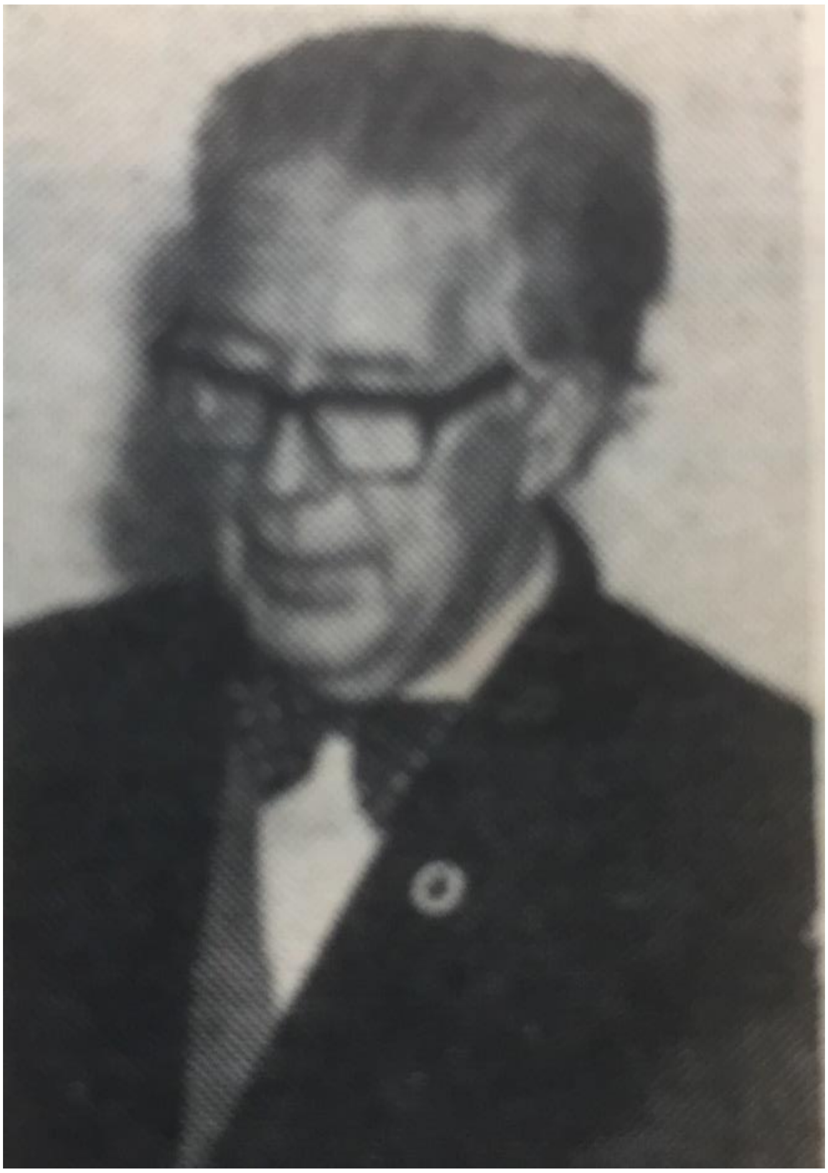
It should also be noted that NCYCS spent most of its small advertising budget on ads in Labour Woman, and noted that NCYCS made a particular point of taking policy motions to the movement's annual women's conferences, both of the Labour and of the Co-operative Parties. For example, in 1967 it is the National Conference of Labour Women which submits a motion about young chronic sick / disabled people to the national Labour Party Conference.

Also from Appendix 53 and limited surviving records, we can see that probably half of the members known to date were women, including women being in leadership positions within the executive committee.

Alec Kazantzis

Alec Kazantzis was a member of NCYCS and became the national secretary in the 1970s. He was a barrister in maritime law and he had ambitions to be elected as a Labour MP. He stood in two elections, neither successful. He was elected as a councillor for Camden Council, 1962-65, and for the Greater London Council (GLC) 1970-78.

Marsh Dickson



Marsh Dickson identified as an ally and a family carer. Although he was the instigator of NCYCS in 1964 and the most active member in the 1960s until his health started to decline in the early 1970s, little has been found that speaks of him and his life.

In 1971 he was the vice-chairman of the Kensington and Chelsea Borough Co-operative Party.

“He was the power behind the Campaign” said David Owen (personal email, 27 April 2020). Possibly the best explanation of his motives is in his interview in the Tribune newspaper in early 1970 (Appendix 38).

Marsh Dickson was a founder member of the Chelsea Community Health Council, a statutory consultative body. He had fought as an officer in Burma in the Infantry, then as a Kings Messenger. He died in 1995 aged around 73 years.

Mike Gerrard

Mike Gerrard was a long-term member of the Anti-Apartheid Movement (AAM) executive committee in the 1960s and 1970s. The AAM archive at the Bodlean Library, Oxford University and online includes an audio interview with Mike Gerrard in 2000 where he mentions the NCYCS while mostly talking about the AAM. He recalls at the time the criticism he and others faced for supporting the armed struggle of Black people against a state that had shot school children for protesting their rights, a difficult aspect of being an anti-racist that is maybe less known now but speaks of his determination.

YCS lobbying and Labour MPs

An unsigned typed 7-page paper in the Alf Morris Collection at the LSE Library, headed “Synopsis: Chronically Sick & Disabled Persons’ Bill” starts with a timeline, the first part of it being:

> “Background:
>
> 1944/48: major basic legislative provision.
>
> 1956: Report of the Piercy Committee (Rehabilitation)
>
> 1956/59: No record of a major debate on the problems of disablement or chronic sickness; scant attention from party election manifestos or policy statements (more in Conservative than Labour publications); where their needs are considered, thought of as a ‘cash needs’ group rather than a ‘service needs’ group, and major attention given to this aspect of their benefit programmes in legislation and official reports –
>
> 1965: Report of the McCorquodale Committee (assessment for cash benefits for disability).”

Against this political background of no major debates nor manifesto commitments involving the national Labour Party in particular, we nevertheless can find traces of local debates and discussions, definitely in London and very likely in Scotland too.

These local policy discussions about disabled people and independent living in the community might have started in London in the mid-1950s and in Scotland in the early 1960s. From the details contained in the Guthrie Working Party Report (1968) there had been reported attempts to improve the position of YCS disabled people, including by the Aberdeen Association of Social Service in 1961, and by the Committee on the Welfare of the Disabled, a committee of the Scottish Social Services Council (SSSC), in 1964 and again in 1965. (Guthrie and others 1968 p8-12)

This period in Scotland merits further research, and may well have informed the policy demands of the NCYCS which started in London. The Aberdeen Association of Social Service has been known as VSA (Voluntary Service Aberdeen) since 1973.

Policy innovation in new idea of PAs

The political discussions and groundwork with MPs described earlier was informed by the surveys done in institutions by people such as Sheldon, Warren and Whitaker, in the community by Droller and Paley, and in the speeches of Mackenzie. The Chelsea Labour Party had created mostly on Marsh Dickson’s initiative a Young Chronic Sick Campaign committee in 1964, a grassroots response from its own members. They set to work, researching, getting questions raised in Parliament and debating the issue locally, and then very quickly, nationally.

These political discussions and groundwork led up to the first debates at the national policy-making conferences of the Co-operative Women’s Guild Annual Congress (May 1965, Cleethorpes) and then the Labour Party Annual Conference (September 1965, Blackpool).

The first motion was:

Resolution on Hospital Accommodation for the Chronic Sick

> “This Congress is of the opinion that more Hospital accommodation should be reserved for the chronically sick

> patients, and asks that Hospital Authorities cease to transfer such patients to Hospitals and Nursing Homes outside of their home town. Great hardship is imposed on elderly parents visiting such patients.” (see Appendix A)

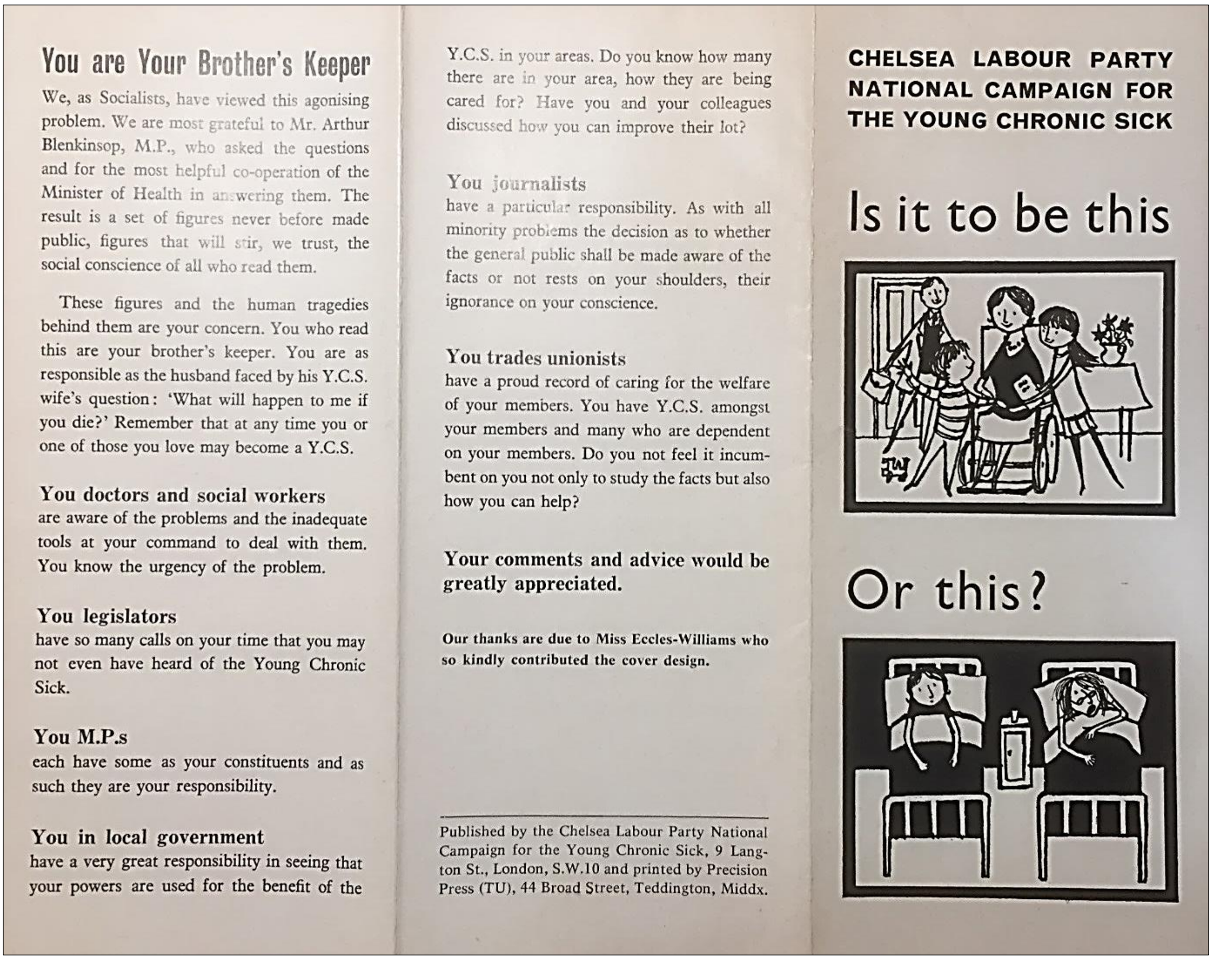
Four months later this policy has been substantially extended into four policy proposals, the above motion becoming part (d) in the Labour Party policy motion below. The debate in May probably led to intense talks.

The Labour Party conference agenda included the following motion by Chelsea Labour Party on the intolerable position of YCS disabled people, which was debated on 29 September 1965. In reply, this motion was supported by Jennie Lee MP for the Labour Party’s National Executive Committee (NEC) and the vote by conference delegates was unanimously in favour. (see Appendix B)

Labour Party Conference, Motion 93, Blackpool 1965

> “This Conference urges the Government to remedy the plight of the young chronic sick by:
>
> a) enrolling and training special medical home helps;
>
> b) making mandatory and extending services provided by local authorities;
>
> c) paying relatives undertaking the care of the patient at home;
>
> d) establishing more Young Chronic Sick units near patients' homes and abolishing the present practice of confining the young chronic sick in geriatric wards with the senile.”

There were two speeches made to the conference delegates in support of this motion, as reproduced here in full in Appendix B. Perhaps the most striking element of this motion was the call for "medical home helps", now known as **personal assistants**, and often abbreviated as PAs.



You are Your Brother's Keeper

We, as Socialists, have viewed this agonising problem. We are most grateful to Mr. Arthur Blenkinsop, M.P., who asked the questions and for the most helpful co-operation of the Minister of Health in answering them. The result is a set of figures never before made public, figures that will stir, we trust, the social conscience of all who read them.

These figures and the human tragedies behind them are your concern. You who read this are your brother's keeper. You are as responsible as the husband faced by his Y.C.S. wife's question: 'What will happen to me if you die?' Remember that at any time you or one of those you love may become a Y.C.S.

You doctors and social workers
are aware of the problems and the inadequate tools at your command to deal with them. You know the urgency of the problem.

You legislators
have so many calls on your time that you may not even have heard of the Young Chronic Sick.

You M.P.s
each have some as your constituents and as such they are your responsibility.

You in local government
have a very great responsibility in seeing that your powers are used for the benefit of the Y.C.S. in your areas. Do you know how many there are in your area, how they are being cared for? Have you and your colleagues discussed how you can improve their lot?

You journalists
have a particular responsibility. As with all minority problems the decision as to whether the general public shall be made aware of the facts or not rests on your shoulders, their ignorance on your conscience.

You trades unionists
have a proud record of caring for the welfare of your members. You have Y.C.S. amongst your members and many who are dependent on your members. Do you not feel it incumbent on you not only to study the facts but also how you can help?

Your comments and advice would be greatly appreciated.

Our thanks are due to Miss Eccles-Williams who so kindly contributed the cover design.

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CHELSEA LABOUR PARTY
NATIONAL CAMPAIGN FOR
THE YOUNG CHRONIC SICK

Is it to be this

Or this?

NCYCS Newsletter 1, c.1965, (full text in Appendix 10)

As an example of how difficult it was for disabled members to participate in this annual political conference, Dorothy Dickson could not afford to attend the conference with her husband because of the discriminatory high rail fares for wheelchair users. The price for both of them would be four times that for a non-disabled person, being £46 in 1965 for a disabled passenger and non-disabled companion; the equivalent return rail fare for two people from London to Blackpool of £900 at 2021 prices.

Becoming a national campaign

The first entry in the accounts book of the NCYCS is dated as May 1965 and at this stage the group is being called "**The Chelsea CLP YCS Campaign**" in that book.

Some months later between November 1965 and March 1966 the name was changed – to become national, not Chelsea any more. The estimated date for this change to a national name is based on two letters published in The Guardian from campaign members, one with the old name, the next with the new one (Appendices 12, 13).

Despite the new national name the group remained under the wing of Chelsea CLP rather than becoming an independently registered organisation.

Following the launch of the newly-named NCYCS it published its first newsletter (Appendix 10). There is a strong sense of energy, determination and optimism in this newsletter.

Because NCYCS was not a registered charity nor a non-profit company there are few official records of the organisation outside of the Hansard record of speeches in Parliament, a few notes in political memoirs and papers in various archives where political people have left collections of their papers. Although Marsh Dickson wrote to Alf Morris in April 1969 (Appendix 31) saying the NCYCS is about to become a “truly” national organisation, this was still to be as a political organisation within the Labour and Co-operative parties.

However, this reorganisation was soon put ‘on hold’. An unexpected and golden opportunity came just a few months later in November 1969, where NCYCS could assist Alf Morris’s private members bill. This opportunity created much urgent new work for NCYCS which stopped any longer term re-organisation plans.

Section 3 – NCYCS and the Guthrie Working Party, 1965 to 1968

A national working party on independent living was created by a charity in late 1965. It started less than a month after the National Campaign had gained the Labour Party’s full support for the NCYCS policy position at the party’s annual conference.

The open meeting

This working party started with an open meeting which was held in London at Church House, Westminster, on 25 October 1965. The meeting was very probably prompted by the positive Labour Party conference vote on 29 September 1965, and the working party was “to consider the problem of enabling certain YCS [disabled people] to live at home instead of in hospital”.

Nor would it have been a coincidence that the morning after this meeting that two articles by Nesta Roberts appeared in The Guardian under the general title, 'Life for the chronically sick' (1965, and Appendix 11 here).

The first article tells the stories of three disabled women and a disabled man - Miss Forbes, Freda, Mrs Foster, and Mr Fleming - all living for years in hospital long-stay wards. The second article is a discussion on current policies and their shortcomings.

A detailed account of the 25 October 1965 meeting was published the following summer in the journal, Cheshire Smile (vol 12 number 2). The speakers included:

- Sir George Haynes, chair
- Lord Harding and Duncan Guthrie, co-hosts
- Marsh Dickson, Chelsea Labour Party Chronic Sick Committee
- Megan du Boisson, Disablement Incomes Group
- Mrs Stacey and Mr D Powell, British Polio Fellowship
- Mr Bentley and Mr Bowstead, Edinburgh Committee for the Coordination of Services for the Disabled

- Mr A C Waine, Multiple Sclerosis Society
- Miss Warburton
- John Astor MP

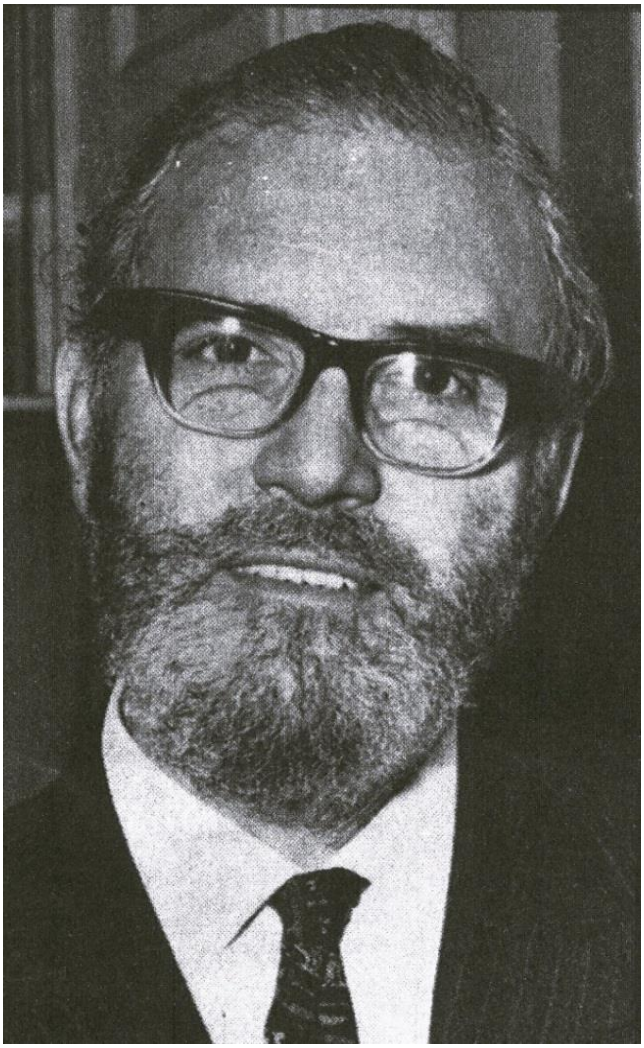
The contributions included favourable comments by Duncan Guthrie on his visit "several years ago" to a housing scheme in Copenhagen called, Hans Knudsenplatz, with 170 apartments where "the majority" had extra space inside for wheelchair users and 14 apartments had further facilities for "severely disabled" people. He noted that the scheme was designed so that disabled and non-disabled people could live together. Duncan Guthrie is reported to have said, "We should remember that we are helping nobody if we segregate people, because of their disability, from the rest of society, all we would be doing would be setting up ghettos for the disabled. What we must do is integrate them, so that they can live with their families, next door to their [non-disabled] neighbours." (Cheshire Smile, summer 1966, p13).

It was formally voted "this Meeting set up a Working Party to prepare a statement based on Today's Meeting, so that a meeting could be sought with the appropriate Minister or Ministers." (Cheshire Smile, summer 1966, p14).

Letters in the papers

The following letter was agreed by the meeting:

> Dear Sir,
>
> **Independent Living for the Disabled**
>
> A Working Party, whose members represent national organisations concerned with the disabled, has been set up to examine the problem of enabling severely disabled patients to leave hospital when there is no longer a medical reason for them to remain in hospital. Anyone who would like his or her views brought to the attention of the Working Party is invited to write to me, as secretary, at: The National Fund for Research into Poliomyelitis & Other Crippling Diseases, Vincent House, Vincent Square, London SW1.
>
> Duncan Guthrie



Duncan Guthrie

In November 1965 the general secretary of the Multiple Sclerosis Society (MSS) had a letter published in The Guardian supporting the new working party, the articles by Nesta Roberts, and the letter by Judith Kazantzis. The MSS letter included:

"my society is vitally interested in the future welfare of this section of the population, and some three months ago appointed a special committee to examine all aspects of the problem. An interim recommendation of this committee is that a survey be carried out to ascertain their needs." (Waine, The Guardian, 6 November 1965)

Cool feelings, probably

The National Campaign publicly welcomed the creation of this charity-led working party, even if privately they might have seen it as something like an opportunist jump into their policy initiative. We know from comments made by Marsh Dickson six years later in the Tribune political newspaper (Dickson, 1971) that he didn’t like charities at all. Nevertheless, Marsh Dickson was included as one of the main speakers at the inaugural meeting of the working party.

So it seems reasonable to think that the feelings between them might not have been especially warm. The National Campaign was **not** a member of the working party, probably not invited because it was a Labour Party organisation and the working party founders wanted it to be a non-party endeavour.

Marsh Dickson later also provided them with oral evidence, and Paul Hunt is reported as having provided them with written evidence (Guthrie and others, 1968, Appendix 1). Unfortunately no archive papers of this working party have yet been found.

Working party membership

The membership of the working party was mostly people who represent various national disability charities, and included Megan du Boisson from DIG and two hospital consultants (senior doctors).

In detail, the membership of the Working Party consisted of fourteen people representing:

a) National Fund for Research into Crippling Diseases
b) Scottish Council of Social Science (3 people)
c) Disablement Income Group (DIG)
d) British Rheumatism and Arthritis Association
e) Central Council for the Disabled
f) British Polio Fellowship
g) Multiple Sclerosis Society of GB and Northern Ireland,
h) and two hospital consultants, one working, one retired.

The Chair of the Working Party was Duncan Guthrie, who was later described as “a non-party socialist” and as being very closely involved with Alf Morris in the work around getting the Chronically Sick and Disabled Persons Bill drafted and steered through Parliament (Duncan Guthrie obituary, The Independent, 20 October 1994).

Disappointments

Half-way through their deliberations, a delegation from the working party met with ministers in November 1966. A good summary of that disappointing meeting is given towards the end of their Appendix 2 of the working party report, copied here in Appendix 16.

> “In conclusion the Minister emphasised that the Government were very conscious of what needed to be done for chronically sick and severely disabled people, but that improvements in this, as in other directions where help was needed, depended very much on the rate at which the country's economy could grow.” (Guthrie and others, 1968)

Assistive technologies – from gadgets to Possums

In 1966 the NHS agreed that the POSSUM (patient operated selector mechanism) system could be provided to disabled people by an NHS prescription for a medical device – provided it was agreed by a senior doctor, usually a hospital consultant. But it wasn't easy to get this prescription - three years after the general introduction into the NHS of POSSUMs, Marsh Dickson wrote to Alf Morris to say that in the borough of Kensington and Chelsea he knew of only three disabled people who had been given a POSSUM to improve their independence in the home, and these three people were "all of middle class background with access to information", he said. (Dickson, 1969d; Appendix 34)

So, in 1967 the third newsletter of NCYCS (Appendix 23) was longer than the first two newsletters, and in particular included two articles on the new POSSUM. This was a new and highly touch-sensitive control device which allowed many disabled people for the first time to control and use items like telephones, intercoms, typewriters, dictaphones, televisions, radios, heating controls, and to turn book pages. Today's tech for 'smart homes' is a direct descendent from these devices.

In the 1960s the devices that a disabled person might use to help them with tasks around the home were commonly known as 'gadgets'. The Disabled People's Archive in Manchester has minutes of annual meetings in 1960 and 1961 of a voluntary group called **Independence Unlimited**, which consisted of non-disabled volunteers who worked with residents at the Leonard Cheshire Le Court charity Home to make these ad-hoc devices. One example was an electric door opener made using a recycled turntable motor from an old record player.

A group of disabled filmmakers (known as the **Le Court Film Unit**) created three documentaries concerning these types of 'gadgets' to promote their usefulness to other disabled people:

- No Limit, 1964,
- Challenge, 1965, and
- Words without Hands, 1969. (Baldwinson 2019a)

Possibly in order to promote the POSSUM system more widely to doctors, the British Medical Association (BMA) produced its own paper, "Aids to the Disabled" (1969).

This information was no doubt useful to Alf Morris in his drafting of the CSDPA which closed down the failing NHS prescription-based route and instead making the provision of assistive technology a responsibility of local authorities. The need for adapted telephones in particular was made explicit as an entitlement in the new law.

Recommendations in their report

In July 1968, two and a half years after being founded, the Guthrie working party published its findings as a report, “At Home or in Hospital?” Its cover is pictured on the next page.

NCYCS must have wondered about the timing of this publication, with its launch following just a few weeks on from Pamela La Fane featuring in three TV programmes on BBC 1 (Appendix 24); plus knowing that the Working Party was convened less than a month after their victory at the Labour Party conference in 1965.

Nevertheless, NCYCS appears to have accepted it with good grace, and maybe more.

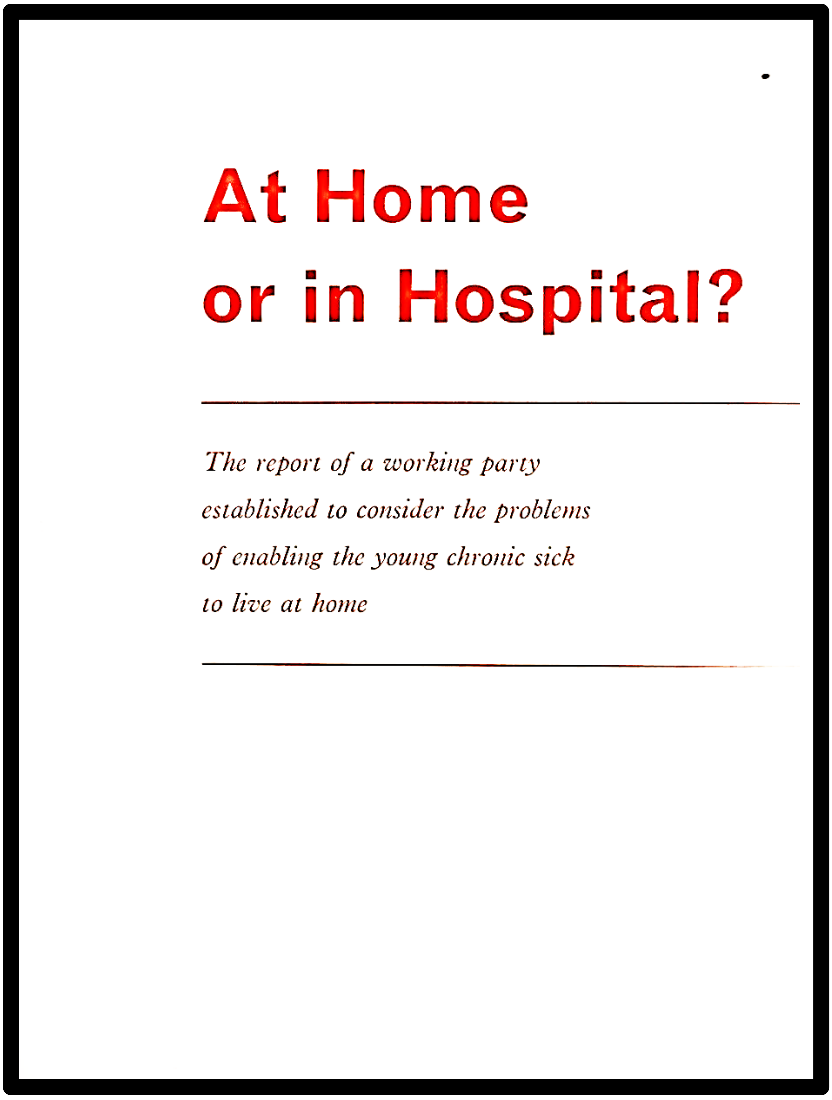
In summary, the report’s recommendations were:

(a) Chronic sickness and substantial and permanent disablement must be recognised as creating a financial need which is not met by existing legislation.

(b) More information is essential regarding the numbers of chronic sick and substantially and permanently disabled persons who are in need of services and financial assistance.

(c) There should be reliable information regarding individuals in need of a service. This is not available from the registers which local authorities are required to maintain under Section 29(4)(g) of the National Assistance Act 1948.

(d) Domiciliary nursing services should be strengthened by other types of ancillary staff. More should be done in the way of providing physiotherapy and occupational therapy.



At Home
or in Hospital?

The report of a working party
established to consider the problems
of enabling the young chronic sick
to live at home

The Working Party report, front cover,
32 pages (Guthrie and others, 1968).

(e) Need for purpose-built family accommodation.

(f) Need for purpose-built institutions and schools.

(g) Need for adequate assessment.

(h) Need for more day centres.

(i) Need for better liaison between the three branches of the health service.

(j) Better publicity regarding services available for disabled persons in different localities.

(k) Need for holiday arrangements for disabled persons and more information about what facilities are available.

Adapted from: (Guthrie and others 1968 p23-24)

David Owen has archived his papers in the Special Collections section of the Library at the University of Liverpool, where he was the University Chancellor. His collection includes the printed report written by the Guthrie working party. A digital copy has been made available for research.

The following news item was printed in a Sunday newspaper the day before the launch of the report.

‘Disabled should live at home’

More aid to help the chronic sick and physically disabled live at home rather - than in hospitals or institutions is urged in a report out tomorrow.

A 14-man working party, after two years study of the question, call for more home nursing services, adequate financial assistance, and suitably constructed houses for the sick. Their report, At Home or in Hospital? says the extent of disability should be the deciding factor in assessing financial needs.

Commenting on the report, Mr Duncan Guthrie, director of the National Fund for Research into Crippling Diseases, who was chairman of the working party, said it was intolerable that people severely disabled from other causes than war injury or industrial accident should be the ‘cinderellas’, receiving allowances often below subsistence living.

‘It is outrageous,’ he said, ‘that the Government should play the part of Baron Stoneybroke only when dealing with those who are disabled from birth or by disease or by accident outside the place of work. The disabled are becoming very angry at this injustice.'

The working party say that chronic sickness and permanent disablement must be recognised as creating a financial need not met by existing legislation. More information is essential regarding the numbers involved.

They call for more day centres, better health service liaison, better publicity of services available, and holidays for the disabled.

The Observer, 14 July 1968

The publishers of the report were the National Fund for Research in Crippling Diseases, NFRCD. They changed its name over the years and are currently known as Action Medical Research, AMR, which focuses on disease prevention for babies and children. From enquiries without responses, AMR unfortunately appear not to have an extensive collection of NFRCD papers.

Support in parts of Parliament

In the week before the Guthrie working party report was published, a full twenty-two years after his maiden speech on the matter in 1946, and seventeen years after his book in 1951 on poor geriatric services for elderly people, Lord Amulree (Basil Mackenzie) spoke again in a debate in the House of Lords, speaking against the continuing practice of confining 'young chronic sick' disabled people to a life spent on geriatric wards. He referred to the three recent BBC 1 TV programmes featuring Pamela La Fane.

> He added a further example, "that of a young man in the Royal Air Force, who suffered a severe injury in a car accident. He was a young man of 24; he had made a fair recovery but ... he is being moved around from one geriatric ward to another". (Amulree, 1968).
>
> He added, "The first time I addressed your Lordships was in October 1946 and I then referred to the fact that people have been kept in these long-stay hospitals for far longer than they need - 10, 15, 20 years. I am now addressing your Lordships again, in July 1968, and I am afraid that I have to say exactly the same thing now as I said in October 1946." (Amulree, 1968).

However, the government's response to the findings of the report was to kick it into the political long grass. They announced a **Social Survey** that would include chronically sick and disabled people, to report back to government two years later, in 1970 (Hansard, 4 December 1968) – and which was eventually published in 1971 (Butler, 1971; Harris, 1971). The suspicion of NCYCS was that this delay was to take it to around the time of the next general election when, it was probably hoped by Ministers, any unfinished laws or un-kept promises can be quietly dropped.

The Seven Needs of Independent Living, 1984

It is worth considering how this working party list of eleven recommendations from 1968 compares with the one created by a disabled people's organisation about 15 years later and known as the 'seven needs of independent living'. The following table shows the fit and the gaps between the two lists.

Seven Needs of Independent Living (K. Davis, 1990)	**Report of the Working Party (Guthrie and others, 1968)**
1. Information	(b) (c) (j)
2. Counselling / Peer Support	-
3. Housing	(e)
4. Equipment	(g)
5. Personal Assistants (PAs)	(d)
6. Transport	-
7. Accessible Environment	(f) (h) (k)
Income	(a)
Services	(i)

In particular we can see that the working party did not identify the importance of peer support. They did consider mobility but only in terms of accessible cars and not public transport as well, and no transport recommendations resulted.

In 1990 Ken Davis wrote a paper called, The emergence of the "seven needs". It was a teaching and research resource for the Open University. In this paper he described how the 'seven needs of independent living' that had emerged from the Derbyshire Coalition of Disabled People (DCDP) and their efforts between 1981 and 1984 in creating the Derbyshire Centre for Integrated Living (DCIL).

The 'seven needs' grew organically from papers and debates based on the experience of disabled people in the mid-1970s in creating and running the pioneering Grove Road project, and alongside that the first

Disability Information and Advice Line (DIAL). (Ken Davis, 1990; in (Davis and Davis, 2019, p102-112)

Other organisations have subsequently created their own longer lists of the needs for independent living, one from Spectrum CIL being ‘12 Basic Rights’. A feature sometimes overlooked is that the ‘seven needs’ were seen by DCIL as **a sequential list**.

> “From the Grove Road experience, it had emerged … [that] the three key elements of housing of good basic design, appropriate technical [equipment], and a flexible system of personal assistance, were tightly inter-related. … it was housing design that facilitated the efficient use of certain technical aids [equipment]; and those two elements in combination had a dramatic effect on the amount of personal assistance needed to make the whole scheme work. The logic of this process was then extended to other key elements” so that we deliberately organised the list in sequence, from those three at the centre and expanding out to the seven needs. (K. Davis, 1990, paras 5.4, 5.5)

Looking at the issues of incomes versus services, Vic Finkelstein later commented that in his view these were only properly addressed when UPIAS established its policy position in 1974, and amended in 1976. In that UPIAS was the first organisation to “attempt to avoid ‘piecemeal’ solutions to our oppressive segregation.” (Finkelstein, 2004, p10)

This is also the paper of the event where he notably declared that, “*Independent living is a lie*.” (Finkelstein, 2004, p14, emphasis in original), on the basis that all humans are social beings and we all live mutually inter-dependent lives. This was part of his wider view of creating progressive alliances with non-disabled professional staff – or PAC – Profession Allied to the Community. (Finkelstein, 2004, p22)

Section 4 – NCYCS from 1966 to 1969

We've seen that the National Campaign very probably only wanted to have an arms-length involvement with the Guthrie working party. Even so, there must have been some comment when the charity-led working party started less than a month after the success of the National Campaign in changing Labour Party policy.

And when the working party got the brush off from government ministers in November 1966 (Appendix 16) we can speculate that it wasn't a coincidence that the National Campaign responded just a month later with a strong press campaign in The Guardian, a campaign that caused comment in Parliament and led on to three BBC TV programmes on independent living.

The National Campaign don't hold back politically either - the fourth newsletter, timed to fit the 1967 Labour Party annual conference, has the headline, "We are bloody angry". This followed the July 1967 national demonstration and rally in London of disabled people, organised by DIG, a rally they repeated in July 1968.

Even the British Medical Journal eventually comes out in support of the principle if not the campaign by name (BMJ, 1969; Appendix 28).

Clearly the lucky win by Alf Morris in late 1969 of first place in the ballot for a private members bill fell straight into their lap at just the right time. But the National Campaign hadn't wasted its time in the years beforehand, and arguably the press and political profile they had built up were instrumental in helping Alf Morris push his Bill through Parliament against the wishes of some ministers and senior civil servants.

The following table summarises the policy motions proposed by NCYCS from 1965 to 1972, and shows some of their emerging thinking and changes in their positions over these years. These policy changes are discussed below in this section.

NCYCS Motions to Annual Political Conferences		
Year	**Co-operative Women's Guild (CWG) – Spring**	**Labour Party – Autumn**
1965	Disabled people in hospitals nearer to parental homes, and not in geriatric wards (**Appendix** A)	As in CWG motion, plus: - medical home helps, PAs - mandatory council services - allowances for relatives (B)
1966	-	Mandatory council statistics, help at home, accessible housing (Submitted but not debated.) (C)
1967	-	Three resolutions on: geriatric wards, surveys, and national standards for local services (D)
1968	No disabled people in geriatric wards, more YDUs, better home services (E)	-
1969	-	Physical and financial entitlements to be mandatory across the country (F)
1970	Accessible public spaces and buildings (G)	-
1971	-	Full implementation of the CSDPA and councils to ignore the AMC circular (H)
1972	-	Full closure of institutions and community care, better research, a National Disability Income (I)

Letters in brackets refer to Appendices.

Pamela La Fane joins the NCYCS

Although no definitive membership list has been found for the National Campaign a start has been made here (Appendix 53) and the literature found to date suggests about four named individuals were involved as office holders including a president and a treasurer, plus some roles such as lawyer for which two names are possible. The modest finances of NCYCS, discussed below, reflect the small size, even the fragility, of the campaigning group. However, fairly early on there is one key recruit, Pamela La Fane. At the time of joining in 1966 she was a YCS disabled woman who had been living in hospital since 1940, from childood.

In March 1966 Marsh Dickson had a letter published in the New Statesman, a left-leaning political weekly journal (Appendix 13). This letter was seen by Pamela La Fane while living in hospital. Against the opposition from ward staff, she had already managed to teach herself to write as a journalist by getting learning materials and textbooks donated. She responded to Marsh Dickson's letter and became involved in the National Campaign and she soon became their media lead person in newspapers (Appendix 17) and in three television programmes (Appendix 24). (La Fane, 1981)

Writing was her only way of making a little money and to draw attention to her campaigning to be released from a lifetime in hospital. In harsh realities such as this, the policies and practices of independent living were being invented by disabled people.

Within a few months of joining she used her writing skills to produce a leaflet which, she said, so impressed the rest of the NCYCS committee that they decided to offer it as an exclusive article to The Guardian newspaper, and it was accepted for publication. (La Fane, 1981, p131) (Appendix 17)

Although the issue of independent living had been given some press coverage already, for example by Nesta Roberts in The Guardian in October 1965 (Appendix 11), it was the article the following year by Pamela La Fane in the same paper that caught the public's imagination. Pamela La Fane wrote first-hand from her lived experience, and it struck a chord. At the end of 1966 her newspaper article becomes the first media high point for the National Campaign, and it attracted substantial amounts of public and political comment. (Appendix 17 for the text and the newspaper article is pictured below).

Growing up geriatric

by Michele Gilbert

AT the age of 16, in 1943, I entered a geriatric ward. There was nowhere else for me, it seemed. An acute attack of rheumatoid arthritis had left me completely incapacitated and in need of permanent care. As there was no one at home to give this the authorities had no alternative. So for 23 years the geriatric ward of the Chronic Hospital has been home to me.

During my first night in hospital I was awakened at 3 a.m. for a wash. I thought I must still be dreaming, but as I peered round the darkened ward I could discern that others were receiving similar treatment. I felt like a character in a Dickens novel, and in the days that followed I came to realise more and more that the social evils which aroused Dickens had not all been left behind in the darkness of the nineteenth century.

There were 26 patients in the ward, not all elderly. It was decorated in the usual institutional dark brown and green, relieved occasionally by dingy cream. Down the centre stood a long oak cabinet and this was the principal object of the nurses' loving care. Every afternoon, regardless of staff shortages or patients' immediate needs, that cabinet was polished for at least half an hour. When it was mirror-bright it was covered with a clean sheet (sometimes there was a patient who would have been glad of that clean sheet), and under the sheet, for extra protection, was a red blanket.

I witnessed the daily ritual from my bed. I had been put there on arrival and was told that as I couldn't walk (in actual fact I could) or do anything for myself 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. My crime, and that of hundreds like me, was that of being a "young chronic."

After the early wash came the early breakfast—at 6 a.m. This was simply dumped on the locker and there it remained till someone had time to feed it to the helpless patient. Many a time I have fallen asleep while waiting and been rudely awakened by someone anxious to shovel in the congealed bacon and stone-cold tea as rapidly as possible and be done with the job.

It wasn't long before I was in trouble with the authorities because I wanted something to occupy my perfectly normal mind. They suggested I might, as I was so anxious, make an iron holder. I could get a piece of canvas and some wool from the woman who came to the hospital once a week. (She wasn't really an occupational therapist.) It amazed them when I made it clear that even this was not enough to satisfy me. I wanted books! And writing materials! I was cluttering up my locker and making the ward look untidy. I even had books on the window sill. What did I want them for? I could read only one book at a time, couldn't I? Didn't I realise I was in hospital?

Yes, I realised that. All too well. I realised that this bed and locker were my home and would be for the next fifty years or more. I wanted to take correspondence courses, to learn. This meant more books, as well as papers. On one occasion an irate sister confiscated everything I needed for my studies and locked them away in a cupboard. It was only my doctor's intervention that got them back for me. When after several years I at last managed to get a typewriter, the comment was: "And where do you think you are going to keep *that*?"

One day in 1949, just after the coming of the National Health Service, a group of doctors came round, examining everyone and making notes. We learned that our old Chronic Hospital was to be integrated into a regional hospital group with the local general hospital as the nerve centre. Dared we hope? The first and most important change that affected me was that I was ordered out of bed. "Whatever do they want to start getting you up for?" grumbled the nurses, as they bundled me into the wheelchair I'd had as a twenty-first birthday present and which had hardly been used. "You've been happy in bed all these years." Fancy. I'd never known that my feelings "all those years" were what is known as "happiness." Did it never occur to them that we could be human enough to feel despair and frustration at the barrenness of our existence?

Then those visiting doctors, appalled to discover how long I had been kept inactive in bed, wanted me to have treatment, and ordered that the newest methods should be tried in my case. "A waste of money," grumbled the nurses, and every excuse was brought up for not getting me out of bed, for not giving me that treatment that had been ordered. I had to fight for it, and if I did get it I was deposited back in bed immediately afterwards—the naughty child who must be punished for tiresome behaviour. One day a doctor came round and asked me if I *wanted* to go back to bed so early. After that, my time "up" was extended. For a long time the ward sister wouldn't speak civilly to me because I had dared to say that I didn't really want to go back to bed at two o'clock in the afternoon.

With the reorganisation of the hospital, which began in 1953, the young patients were split up and I found myself more and more in the company of old people. If they are not too senile and beyond being companionable, they tend to be very jealous of the extra attention I must have. Instead of being thankful that they can do things for themselves they can be heard complaining to their visitors: "She always has the nurses fussing round her: she's a cripple, been here for years. I suppose that's why. They don't do it for me." So the choice is between senile, rambling, incoherent companions and alert, sensible, but jealous ones.

But this is where we came in. I sit here, the elderly women around me. Many of the evils of the past have been eliminated. I can now go out whenever someone wants to take me, and the staff get me ready. Visiting times are relaxed from twice a week to twice a day (again, if anyone wants to come). There are more facilities for some kind of mental life. An enlightened matron has provided a cupboard for my things, as well as shutting her eyes to all visible "junk," realising that this is my "home."

But we are still regimented and ruled by the clock, so that never for a moment do we forget we are "lifers." The slightest deviation from routine seems to set the machinery wrong and panic reigns. Members of the staff are continually bewailing the fact that it's nothing like the old days now. Thank goodness it is not. I have revived painful memories that I would rather forget. But so long as there are young people normal in their minds and feelings, lying imprisoned in crippled bodies, in geriatric wards, helpless and hopeless, one must remember, so that the general public are not allowed to forget.

Throughout England and Wales there are
230 contractual beds for the young chronic sick
432 beds in young chronic sick units.

There are in geriatric wards
140 patients between the ages of 16 and 35
920 patients between the ages of 36 and 50
2,069 patients between the ages of 51 and 60.

From The Guardian to the BBC

Sometime in the spring of 1967 the National Campaign was contacted by Richard Thomas, a television producer at the BBC, who asked to meet Pamela La Fane. As she explains:

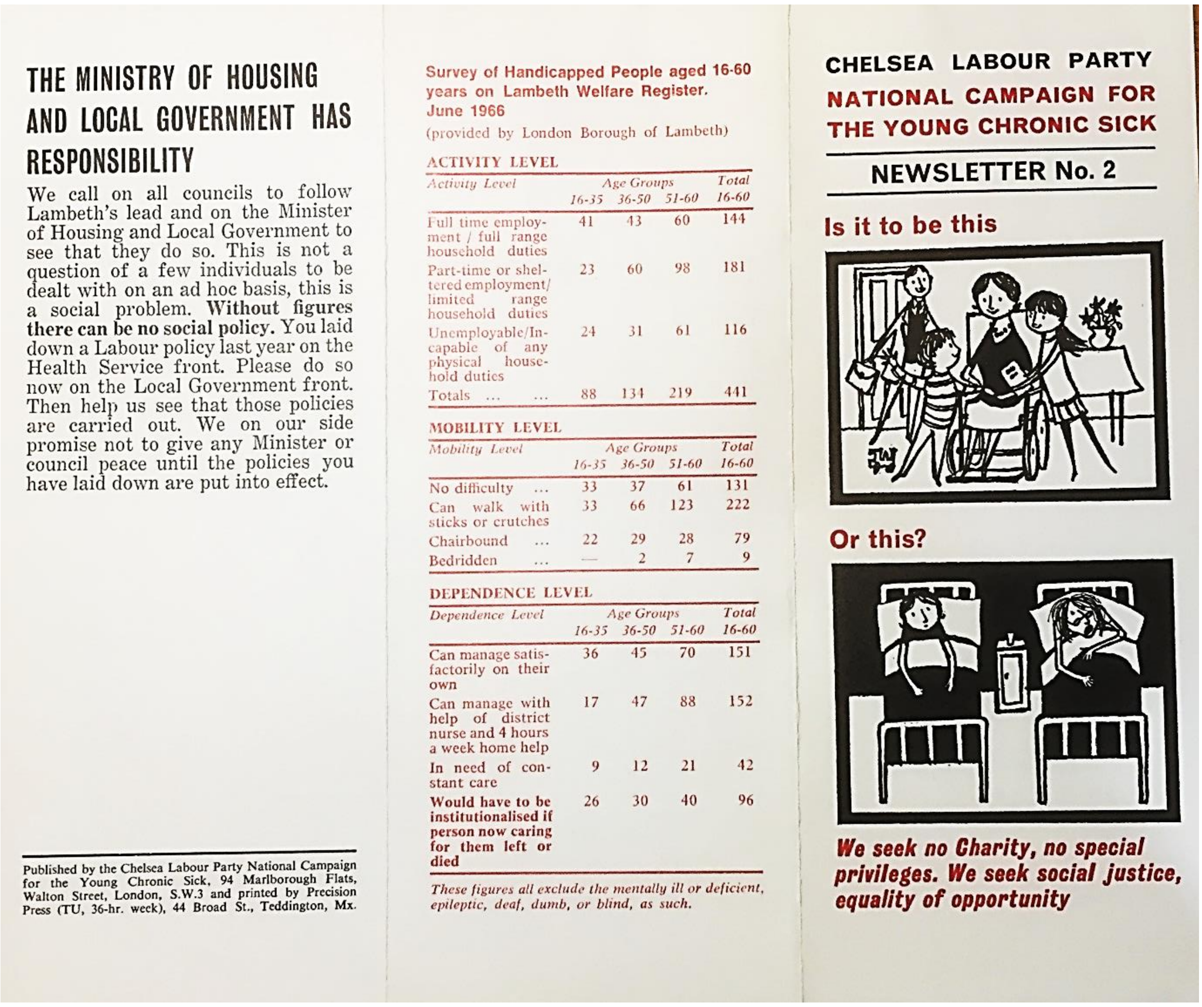
> The young man in an open neck purple shirt sitting beside my bed wasn’t a bit how I imagined a BBC Television producer to be. I had rather expected someone older, dressed like a city gent and formal in manner. But Richard, as he introduced himself, was quite the opposite. He talked enthusiastically, with a faint Welsh accent and the fear I’d had of being overawed by someone from television soon went.
>
> “You’ve heard of ‘Man Alive’?” he asked. I said I had. “Well, as you know the programme deals with matters we feel should be made public. So when we saw your article [in The Guardian and] we felt here was a subject for us to tackle. We have found,” Richard outlined his plans, “a couple of other young disabled people in a similar situation to yourself and we’d like to do a ten minute piece on each of you.”
>
> …
>
> Tuesday arrived. Surrounded by bright lights and with the interviewer seated beside me, Richard rushed about giving last minute instructions. Then the clapper board snapped down Take One. Then his question was put to me. And I began to tell the world what it had been like to grow up in a geriatric hospital, I don’t know how long the interview lasted. But it was much more than ten minutes.
>
> “Marvellous, marvellous!” shouted Richard, excitedly, when it was at last over. “There’s enough material there for a programme all to yourself.” And so it was decided to film a day in my life.
>
> (La Fane, 1981, p135)

The programme was broadcast by BBC 2 on Wednesday 2 August 1967 at 8.35pm, lasting half an hour. It was called “The Life Sentence”.

The following year the BBC broadcast a further three programmes featuring Pamela La Fane, this time on the BBC 1 channel, in three consecutive weeks in June 1968. This mini-series followed her attempts to improve her mobility and to live independently, and included the early days in her new flat.

Her last known contact with the BBC was on 14 September 1981 when her interview on the Woman's Hour programme about her new autobiography was broadcast by BBC Radio 4.

See Appendix 24 for details of all these broadcasts.



THE MINISTRY OF HOUSING AND LOCAL GOVERNMENT HAS RESPONSIBILITY

We call on all councils to follow Lambeth's lead and on the Minister of Housing and Local Government to see that they do so. This is not a question of a few individuals to be dealt with on an ad hoc basis, this is a social problem. **Without figures there can be no social policy.** You laid down a Labour policy last year on the Health Service front. Please do so now on the Local Government front. Then help us see that those policies are carried out. We on our side promise not to give any Minister or council peace until the policies you have laid down are put into effect.

Published by the Chelsea Labour Party National Campaign for the Young Chronic Sick, 94 Marlborough Flats, Walton Street, London, S.W.3 and printed by Precision Press (TU, 36-hr. week), 44 Broad St., Teddington, Mx.

Survey of Handicapped People aged 16-60 years on Lambeth Welfare Register. June 1966

(provided by London Borough of Lambeth)

ACTIVITY LEVEL

Activity Level	*Age Groups*			*Total*
	16-35	*36-50*	*51-60*	*16-60*
Full time employment / full range household duties	41	43	60	144
Part-time or sheltered employment/ limited range household duties	23	60	98	181
Unemployable/Incapable of any physical household duties	24	31	61	116
Totals	88	134	219	441

MOBILITY LEVEL

Mobility Level	*Age Groups*			*Total*
	16-35	*36-50*	*51-60*	*16-60*
No difficulty ...	33	37	61	131
Can walk with sticks or crutches	33	66	123	222
Chairbound ...	22	29	28	79
Bedridden ...	—	2	7	9

DEPENDENCE LEVEL

Dependence Level	*Age Groups*			*Total*
	16-35	*36-50*	*51-60*	*16-60*
Can manage satisfactorily on their own	36	45	70	151
Can manage with help of district nurse and 4 hours a week home help	17	47	88	152
In need of constant care	9	12	21	42
Would have to be institutionalised if person now caring for them left or died	26	30	40	96

These figures all exclude the mentally ill or deficient, epileptic, deaf, dumb, or blind, as such.

CHELSEA LABOUR PARTY

NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK

NEWSLETTER No. 2

Is it to be this

Or this?

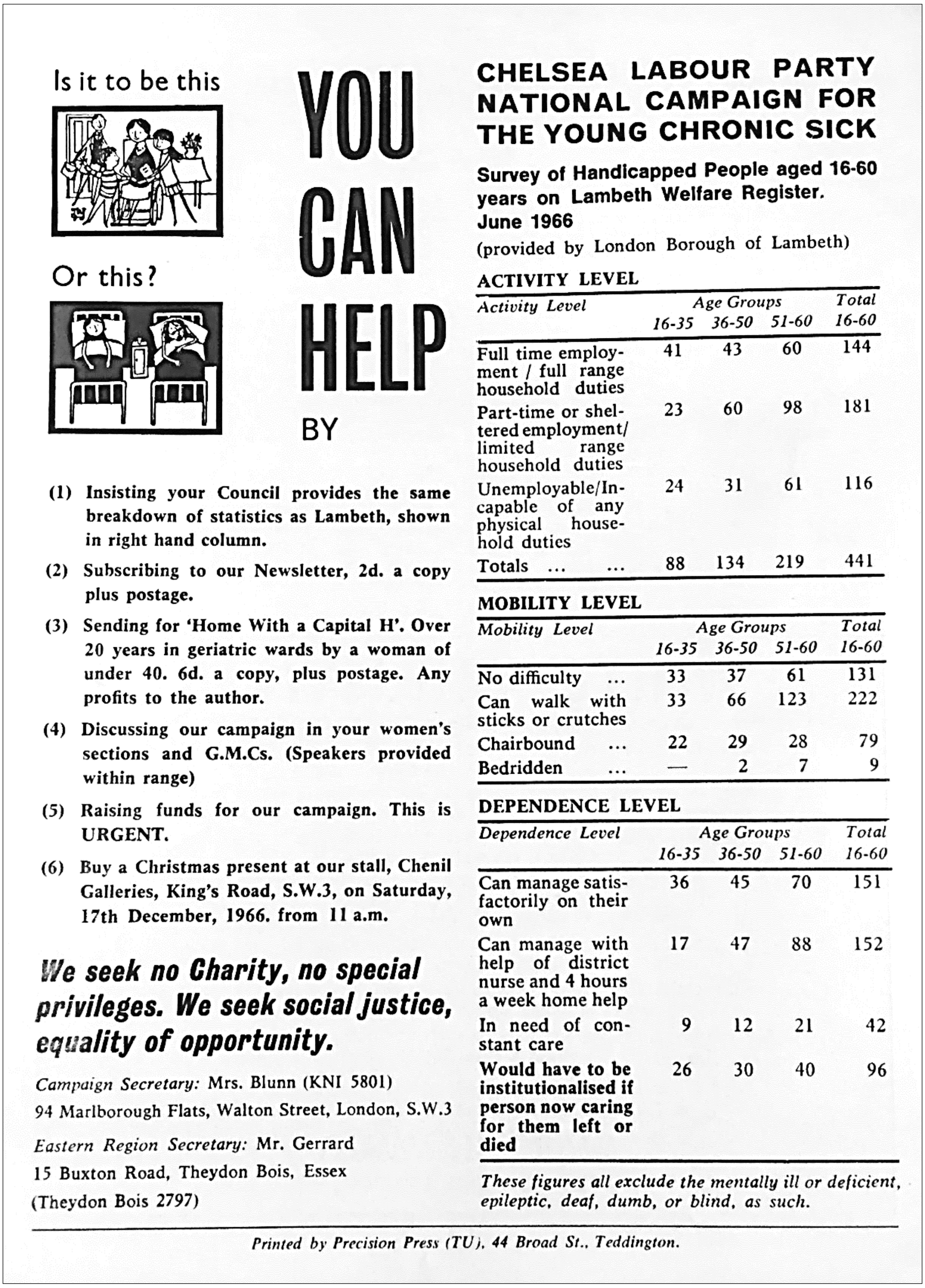
We seek no Charity, no special privileges. We seek social justice, equality of opportunity

NCYCS Newsletter number 2, autumn 1966 (see Appendix 15 for text)

NCYCS and local government

It is worth noting that in the 1960s the idea of a single 'social services' department was a novelty – local authorities instead had a separate children's service, welfare service, and also a health service that included district nurses, health visitors and home helps. Each service had its own committee, staff, workload, policies and lists of clients. This fragmented structure – silos in modern terms – was beginning to change to become client-centred rather than service-centred.

One of the arguments between local and health authorities was on the control of the District Nurses service, which eventually was taken away from local authorities and given to health authorities.



Is it to be this

Or this?

YOU CAN HELP

BY

(1) **Insisting your Council provides the same breakdown of statistics as Lambeth, shown in right hand column.**

(2) **Subscribing to our Newsletter, 2d. a copy plus postage.**

(3) **Sending for 'Home With a Capital H'. Over 20 years in geriatric wards by a woman of under 40. 6d. a copy, plus postage. Any profits to the author.**

(4) **Discussing our campaign in your women's sections and G.M.Cs. (Speakers provided within range)**

(5) **Raising funds for our campaign. This is URGENT.**

(6) **Buy a Christmas present at our stall, Chenil Galleries, King's Road, S.W.3, on Saturday, 17th December, 1966. from 11 a.m.**

We seek no Charity, no special privileges. We seek social justice, equality of opportunity.

Campaign Secretary: Mrs. Blunn (KNI 5801)
94 Marlborough Flats, Walton Street, London, S.W.3

Eastern Region Secretary: Mr. Gerrard
15 Buxton Road, Theydon Bois, Essex
(Theydon Bois 2797)

CHELSEA LABOUR PARTY NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK

Survey of Handicapped People aged 16-60 years on Lambeth Welfare Register.
June 1966
(provided by London Borough of Lambeth)

ACTIVITY LEVEL

Activity Level	*Age Groups*			*Total*
	16-35	*36-50*	*51-60*	*16-60*
Full time employment / full range household duties	41	43	60	144
Part-time or sheltered employment/ limited range household duties	23	60	98	181
Unemployable/Incapable of any physical household duties	24	31	61	116
Totals	88	134	219	441

MOBILITY LEVEL

Mobility Level	*Age Groups*			*Total*
	16-35	*36-50*	*51-60*	*16-60*
No difficulty ...	33	37	61	131
Can walk with sticks or crutches	33	66	123	222
Chairbound ...	22	29	28	79
Bedridden ...	—	2	7	9

DEPENDENCE LEVEL

Dependence Level	*Age Groups*			*Total*
	16-35	*36-50*	*51-60*	*16-60*
Can manage satisfactorily on their own	36	45	70	151
Can manage with help of district nurse and 4 hours a week home help	17	47	88	152
In need of constant care	9	12	21	42
Would have to be institutionalised if person now caring for them left or died	26	30	40	96

These figures all exclude the mentally ill or deficient, epileptic, deaf, dumb, or blind, as such.

Printed by Precision Press (TU), 44 Broad St., Teddington.

Labour Woman, ad on back cover, December 1966
(original has a dark blue background)

Having succeeded in creating a new national policy in 1965, and having started to produce newsletters and to recruit members, the National Campaign turned its attention the following year to look at the changes needed in local government and the new types of social services departments that were being discussed by politicians and practitioners.

So, at the 1966 Labour Party conference the Chelsea CLP proposes a further motion, this time calling on local authorities to recognise the needs of disabled people for independent living, to mirror their successful motion the previous year on health authorities.

The policy priorities of the National Campaign appear to have changed subtly in the months since their success at the Blackpool conference the previous year. By focussing now on local authorities they clearly have to avoid medical criteria, so the phrase “help in the home other than ‘home helps’” is used without the word ‘medical’ to distance personal assistants from being controlled by health authorities, but instead the campaign was trying to expand the remit of local authorities.

This policy shift is in keeping with wider policy discussions and reviews in the 1960s on the growing role of social series departments. For more details on the context, see the Kilbrandon Report, 1964 (for Scotland) and the Seebohm Report, 1968 (for England and Wales).

The Curse of Permissive Powers

However, it seems fair to summarise here that non-elderly disabled people’s needs were not being included in these political discussions on creating new all-embracing social services departments. For example, in the substantial debate in the House of Lords on the Seebohm Report (Hansard, 29 January 1969) there is not one mention of disabled people nor of chronically sick or ill people, other than about elderly persons.

This massive gap in policy thinking within government and within political and academic circles kept the National Campaign with much work to do, and feeds directly in the CSDPA when Alf Morris thoroughly shakes up social services in terms of ‘young’ disabled people’s needs.

This gap in policy thinking also meant that local authorities had almost no obligations to meet disabled people’s needs. As shown in 1966 in NCYCS Newsletter 2 (Appendix 15) the focus of the campaign is for local government provision for disabled people’s needs in the community to shift from being based on weak ‘permissive powers’ to becoming strong, mandatory powers or obligations.

In this newsletter the National Campaign calls it “the curse of permissive powers” and notes how usually this means that charities are expected to fill the gaps in provision.

The motion that NCYCS put forward for the 1966 Labour Party annual conference was not selected for the agenda. So it wasn’t debated, but a delegate from Chelsea CLP, Pat Sears, was allowed to speak on the topic within the wider debate on social security. Her speech and the proposed motion are shown in Appendix C.

She starts her speech by complaining that nothing has been done by the authorities to help disabled people in the year following the landmark 1965 policy motion. She asks all the local authority councillors attending conference to make independent living a priority for their councils, to create local registers of disabled people and to start collecting statistics of the unmet needs. She admits that when she had been a county councillor she had been unaware of these issues and has felt ashamed about that. She finishes by saying that disabled people “do not want charity, they want hope, they want faith in the Labour Movement, and above all they want justice from you, Comrades, every one of you from the Ministers down to our people who go out and knock [on doors] for the local councillors.” (Labour Party annual report 1966, p177).

NCYCS and its changing policy on residual roles for institutions

Although the call by NCYCS for medical home helps (personal assistants) in 1965 was a key change in policy for the Labour Party, and in wider social care policy thinking, we cannot avoid the conditional nature of this demand - that in their view some disabled people should remain living in institutions.

The conference speech in 1965 by Leslie Massey was clear:

> “The young chronic sick can be divided into three categories:
> [a] those who on medical grounds must be institutionalised - and I make no bones about using this unpleasant word, it has an unpleasant meaning;
> [b] a much larger group who under present conditions have to be institutionalised because the problems such as incontinence are too much for the families to cope with, because they have

to be left alone between visits of home helps and district nurses whilst their spouse, parent or child earns the family living and also because of the unrelieved strain on those caring for them when it just becomes intolerable; and of course,

[c] there are those who are being cared for in their own homes.…" (Full text in Appendix B)

We see the same thinking the following year in the NCYCS motion put again via Chelsea CLP to the Labour Party annual conference in Brighton – calling for the "chronically ill … not to be institutionalised unless this is medically inevitable."

On a parallel track, Paul Hunt had written earlier in 1965 in The Guardian about the minimal rights of disabled people who are living in homes run by charities, sometimes under contract to health and local authorities and sometimes independently funded (P. Hunt, 1965; Appendix 7). At this point he isn't yet questioning the existence of these segregated institutions, but he is beginning to question the rights of disabled people within them. He had already concluded, though, that payments should be made directly to disabled people and not to their relatives; in advance of the NCYCS position as the time.

However, something changes within the National Campaign because in her long speech on behalf of NCYCS in 1969 to that year's Labour Party conference, Mary Gray no longer calls for some categories of disabled people to remain being held in institutions; nor is this former NCYCS policy referred to by the speakers that followed her in that debate.

In the absence of anything more positive being found, maybe the best that can be said here is that the earlier calls for institutions to remain for certain groups of disabled people have been 'quietly dropped'. This quietness might have been because the policy had become an embarrassment not to be spoken about, or it might have been because of an unresolved policy difference that remained within the campaign's members.

This silence appears to have continued through to 1971. For example, keeping some disabled people in institutions isn't referred to as a NCYCS policy objective in the motions and speeches in 1971, although by this time the focus is very much on the hostile and reactionary implementation of the recent Chronically Sick and Disabled Persons Act 1970 and how it was being enacted (or not) by many local authorities.

Finally, by 1972 we see an explicit reversal of the 1965-to-1968 policy statements that had seen institutions as remaining acceptable for the needs of some disabled people. The following motion was a 'composite' meaning that it included wording from other similar motions to save time, and it was moved by Neil Kearney, a delegate from Chelsea CLP, ‘the home' of NCYCS:

> "This Conference considers the problems of the physically and mentally handicapped, and those of the aged, as major areas of concern for the next Labour government, which must endeavour to bring those two groups fully into the community, and end their present almost complete isolation. …” (full text in Appendix I).

It took until 1972 with the start of UPIAS for this position to be challenged (J. Hunt 2019) (Baldwinson 2019b), by which time NCYCS was also against all segregated provision but it was also in terminal decline as an organisation.

But the same eventual policy alignment cannot be said in terms of the NCYCS policy position on payments to enable independent living, where other organisations continued to take a more progressive view.

The following extract from Pamela la Fane’s book gives a case study on what was involved in trying gain independence with a visit to Mary Marlborough Lodge in Oxford in July 1967:

> A week later the Medical Social Worker called in. “Oh, Pamela,” she spoke in an offhand way, “I thought you might like to know that an application was sent a few days ago to that place in Oxford you wanted to go to.”
>
> My heart missed a beat.
>
> “And you’ve been accepted.” I could not contain a broad smile. “Of course,” she went on casually, “it’ll be a few weeks before you go.” “That’s all right,” my manner was as casual as hers. “I can wait.”
>
> …
>
> The ambulance stopped outside a new building, a little apart from the hospital. Tubs overflowing with fuchsias, geraniums and petunias stood at the entrance. “This is it,” announced the driver. “Looks like a hotel.”
>
> I thought so, too, as I was pushed through a bright, flower bedecked foyer to my bedroom, a large spacious room containing two beds. The walls were a pale yellow, and pretty floral curtains hung at the windows. There was modern teak furniture and several

bowls of flowers on the windowsills. To my institution-accustomed eyes it seemed luxurious.

“Doctor will see you in the morning,” Sister told me. “But if you’re not too tired after your journey, perhaps you’d like someone to show you around.” There was no mention of bedtime!

When the doctor, a middle aged, homely looking woman, came in the next morning and sat down, I immediately felt at ease.

“Now Pamela, I believe it all started here in Oxford?”

“Yes. In 1940.”

“Tell me about it.” She listened attentively, occasionally writing something down or making a comment.

“… and then I was sent back to London in 1943.”

“And you’ve been in that place ever since?”

“Yes.”

“Christ!” she spat out the expletive. “We’ve got to get you out!”

Later that morning I attended a conference, a gathering of doctors, physiotherapist, social worker and technical officer, to discuss ways of making my dream of escape possible. “We haven’t designed a chair yet that would stand you up,” said the technical officer, on hearing that this was what I wanted. “But by having an electrically powered wheelchair, you would be independently mobile.” (I had noticed several of the patients whizzing around the centre in such chairs.) When I mentioned that in hospital I had two nurses to lift me in and out of bed, the occupational therapist interrupted, “That’ll be my problem, to work out something easier.” It was suggested that Kathleen be brought in one day to know what was happening, and the social worker said she’d be contacting the necessary people for the extra help we’d need. It seemed that everything had been thought of. “There’s no reason why you can’t live at home,” was the general confident opinion of everyone at the conference.

The first thing to be dealt with was the electrically powered wheelchair. It was to be made specifically to enable me to have the maximum independence. The control box from where the chair was operated was to be attached to the left arm, and the two six-volt batteries would be fixed on a tray underneath the chair. I felt disappointed when the technician said it would be six to nine months before it would be ready. “It is made at a factory in Wales,” he explained, “and we keep them pretty busy with special orders.”

Next the occupational therapist took me along to the specially equipped flat, which was used for trying out the problems that one could encounter at home. She took me into the bedroom. There

> suspended from the ceiling above the bed, was a contraption of hooks and ropes attached to rails in the ceiling. “This is what most people use to get themselves in and out of bed,” she told me. “I want to see if you can manage it.”
>
> The girl wrapped my body and legs in wide canvass slings, which she then fastened to a hook. By pulling on the ropes I slowly came up from the chair until I was airborne. “I feel like a cargo of freight going into the hold of a ship,” I joked, trying not to sound as terrified as I felt as I swung about in mid air.
>
> When she began to jerk the rope I moved sideways until my body was over the bed. She then released her hold on the rope, and I gradually came to rest, with a sigh of relief, on the bed.
>
> “It’s quite simple,” pronounced the occupational therapist, “but of course, you do need to be able to use your hands fairly well.” (La Fane, 1981, p137-138).

The firm in Wales making electric wheelchairs was probably Zimmer Orthopaedics in Bridgend, south Wales. (Cyphus, 2021, p13)

NCYCS and its changing policy on payments

In terms of benefits and incomes it is possible to see different paths emerging in the various campaigns by disabled people and allies at this time, maybe from around 1966 and evidently by 1968.

For the Guthrie Working Party and for the Disablement Income Group (DIG) the focus of their campaigns and representations to government Ministers was focused of the appallingly low and sexist discriminatory benefits paid to disabled people. For example, depending on the cause of a disabled person's impairment they could receive anything between £20.60 a week and £8.35 a week, with disabled married women - "housewives" - almost always getting the lower amount (Guthrie and others 1968).

However, for the National Campaign the focus was very much about getting disabled people out of languishing (or rotting) in hospital geriatric long-stay wards. This wasn't always about independent and unsegregated living, and included their advocating for the expansion of more special hospital-based Young Disabled Units (YDUs) throughout the country.

The fourth newsletter of NCYCS is revealing in terms of their differences with DIG and the campaign for a National Disability Income. They use the passive wording “it has been said” rather than the active wording “we say”, but it is clear that NCYCS sees itself as more working class and DIG as more middle class, as the box below shows in detail.

It has been said that a disablement income would favour the better off disabled. What do you think about this?

Unless adequate provision for help in the home has been made I think this is true. I understand that private help is very expensive and the more people are trying to get that help obviously the more expensive it will become. The State provides nurses in hospital, why not help in the home? It's their responsibility. A disablement income would be a great help to deal with the extra expenses all chronically ill have apart from the basic needs of help in the home.

What do you think of Labour Party policy on the Young Chronic Sick?

It has more to commend it than any other. It would make it possible for me to live at home without depending on charity. Above all it would stop anyone having to spend 24 years as I have done up to now in a geriatric ward.

What does the National Campaign for the Young Chronic Sick mean to you?

It means home, the home I hope to have. It means a group of people who really care what happens to me and others like me. It means hope for me and for all the other Young Chronic Sick.

Pamela La Fane, in NCYCS Newsletter No. 4, 1967, p6.

On a less divisive front, the National Campaign also starts to heavily promote the use of technology in the home to assist in independent living for disabled people, and in particular the new POSSUM controls. This heavy promotion includes long sections of speeches given to Labour Party conferences delegates, almost educational lectures.

In terms of income payments though, there were strong debates between the supporters of different campaigns. For example, on the point of extra income for disabled people, the National Campaign in its early years was of the opinion that it should be paid to the family, not directly to the disabled person. Paul Hunt writes to Marsh Dickson in June 1966 strongly supporting the idea of "medical home helps" but also strongly taking them to task for not supporting payments to disabled people directly (Appendix 14).

It is worth remembering that Paul Hunt had written in The Guardian the previous year about the benefits of living in a charity Home for 40 disabled residents, (P. Hunt, 1965; Appendix 7), though by 1966 he was taking a more radical approach to independent living. (P. Hunt, 1996b; Appendix 14, paragraph 2).

Looking at these differences between DIG and NCYCS from the current Disabled People’s Movement viewpoint, both approaches appear flawed. The incomes-only approach presumed that disabled people, just by being given more money, would be able to buy their way into independent living. And while the National Campaign was clearer that segregation and oppressive ‘care’ environments were a problem, the need to get disabled people out of hospital wards for geriatric people made them view any alternative as a positive move, even to hospital based Young Disabled Units (YDUs). Neither of these approaches started with having independent and desegregated living as the core policy objective.

However, by the time the report of the Guthrie Working Party is published in July 1968 NCYCS has moved towards the DIG position of payments directly to disabled people.

And by 1969 the tone of the policy positions held by NCYCS had changed considerably. On 3 October 1969 Mary Gray from Wycombe CLP was the main speaker to the conference delegates on the NCYCS policy motion that year, which stated:

> "This Conference call on the Government to ensure that the chronically ill and disabled are made aware of all their entitlements both financial and physical, and to make mandatory on local authorities those powers to help the chronically ill and disabled,

> which are presently permissive, ensuring the necessary funds to make this possible. This Conference further calls on the Government to abolish all distinctions between different categories of the chronically ill and disabled with regard to entitlements."

In the main this resolution, or motion, was about the different levels of income benefits paid to disabled people which depending on their gender, and on how they acquired their impairment. Mary Gray gave a summary of this inequality in benefits entitlements as the ‘falling off a ladder’ example in her conference speech in 1969 (Appendix F).

This reflects the campaign demands of the Disablement Income Group, DIG, which NCYCS had aligned itself to. However, this motion also extended the non-discrimination principle to "physical" as well as financial entitlements, so they combined NCYCS’s position with DIG’s but also extended it beyond benefits alone.

Accessible housing

The Guthrie working party report considers three general issues around disabled people's independent living: the two issues above of (1) higher incomes and of (2) stopping using hospital wards for a lifetime of social care; and brings in (3) the issue of the need for housing that is adapted to the needs of disabled people. (Guthrie and others, 1968).

On the third issue, the role for assistive technologies within the home **might** have been included in their understanding of adapted housing, but it is not said so explicitly.

Government inaction, national demonstrations, and bitter lessons

The first three newsletters of the National Campaign, from 1965 with the new policy having just been agreed and through to early 1967, all give a sense of optimism, purpose and progress. But by the time of the Labour Party conference in the autumn of 1967 the mood has definitely soured. The front page of the fourth newsletter, produced as a "conference special" (Appendix 25) has "**Why we are bloody angry**" printed in bold red type at the front cover.

30 July 1967, DIG March and Rally at Trafalgar Square, front of march

So the fourth newsletter is very different in tone. It refers to the large protest march and rally held by disabled people in Trafalgar Square on 30 July 1967, and this protest probably marked a turning point for the National Campaign, where fruitless delegations to meet with ministers were finally accepted as having been useless.

The fourth newsletter is highly critical of Government ministers and of their “inaction” by ignoring the Party policy agreed two years ago and in continuing to "allow civil servants to get away with it".

30 July 1967, DIG March and Rally at Trafalgar Square, length of march

30 July 1967, DIG March and Rally at Trafalgar Square (speakers)

The notes of the Guthrie Working Party meeting with Government in November 1966 (Appendix 16) had a wide circulation including being reprinted in full in the Guthrie Working Party report. The government’s dismal conclusion, "that improvements ... depended very much on the rate at which the country's economy could grow", was taken as a callous insult in the NCYCS fourth newsletter.

30 July 1967, DIG March and Rally at Trafalgar Square (crowd scene)

CHELSEA LABOUR PARTY
NATIONAL CAMPAIGN FOR
THE YOUNG CHRONIC SICK

NEWSLETTER No. 4
CONFERENCE SPECIAL 1967

Is it to be this

Or this?

We seek no Charity, no special privileges. We seek social justice, equality of opportunity

Why we are Bloody Angry

Next year a further rally in Trafalgar Square on Sunday 14 July 1968 didn't achieve the same prominent coverage in the national press as in the previous year, but it was reported as a news item in the August 1968 edition of the journal, Occupational Therapy as follows:

"Disabled rally in Trafalgar Square [1968]

Three hundred people in wheelchairs, with helpers and supporters, attended a rally of the Disablement Income Group in Trafalgar Square …. Mrs. Megan du Boisson, director of the Group, said that Britain alone of the major West European countries did not provide for the civilian disabled. Mrs. du Boisson read out a petition addressed to Mrs. Judith Hart, Minister for Social Security, who was present, asking for the case for a national disability income to be put urgently to the Prime Minister and the Chancellor.

Mrs. Hart said that the housewife was outside the scope of the national insurance scheme because she had not paid contributions. When she was disabled and could not look after home and children it was reflected throughout the family.

After the rally Professor Peter Townsend, Professor of Sociology at Essex University, said that in 1964 the Government had announced a long-term review of social security for the disabled. Little progress had been made. The Ministers of Health and Social Security could not recommend action for the disabled because they had still to find out how many there were." (OT, 1968, p12)

The same hostile tone from 1967 can be seen two years later in the exchange of letters in The Guardian in 1969 (Appendices 29, 30), with phrases from a Minister such as, "the disabled cannot sensibly be looked at in isolation from other groups."

The Minister also attacks Professor Peter Townsend in this letter, criticising an activist academic who was taking a high-profile interest in the poverty in Britain and the social policies that could be used to reduce it, including working with disabled people's campaigns.

Information in the NCYCS accounts book

The original handwritten financial accounts book of the National Campaign is held within the Labour History Archive held at the People's History Museum in Manchester in their NCYCS Collection. The book consists of roughly 80 pages of itemised income and expenditure from 1965 to 1973 and the book gives a good insight into the operational details of the campaign.

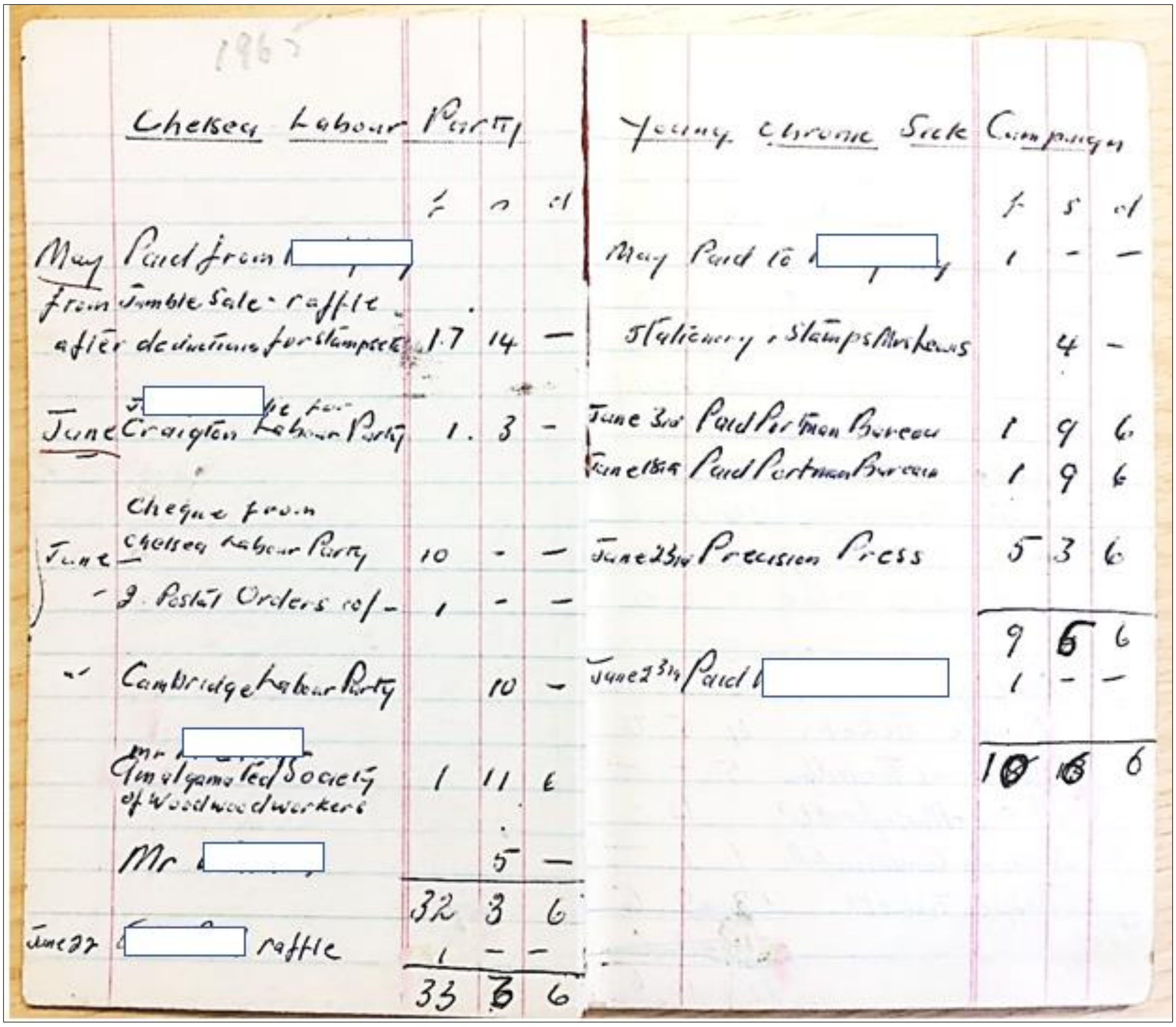
For example, affiliation payments were received from 146 local Labour Party and Co-operative Party organisations across Britain, as listed in Appendix 55. The Labour Party doesn't organise in the north of Ireland. There were very few affiliations from disabled people's organisations - the Sunderland branch of the Disabled Drivers Association being a notable exception.

Between 1967 and 1969 there were around nine advertisements paid for, as listed in Appendix 56. The first six were in 1967 and these were in a monthly journal, Labour Woman, which ran from 1911 to 1971.

The first entry in the accounts was in May 1965 for income of £17 14s 0d (£17.70p) fundraised from running a jumble sale and a raffle. The last entry is on 27 December 1973 is for postage of 6s (30p).

There are a number of payments made to the "Portman Bureau" which seems to have had offices in Sloane Street, London SW1, and specialised in providing professional photographers to weddings and press events. Assuming that was the purpose of the payments, so far no surviving photographs have been found.

A payment of £10 10s 0d (£10.50p) - known at the time as 'ten guineas' - was received from the BBC on 7 July 1967, most likely as the fee for Pamela La Fane appearing in the BBC2 programme in the Man Alive series, broadcast on 2 August 1967, with details in Appendix 24.



1965

Chelsea Labour Party

		£	s	d
May	Paid from [redacted]			
From	Jumble Sale - raffle after deductions for stamps etc	17	14	—
June	[redacted] for Craigton Labour Party	1	3	-
June	Cheque from Chelsea Labour Party	10	-	—
	2 Postal Orders 10/-	1	-	—
	Cambridge Labour Party		10	-
	Mr [redacted] Amalgamated Society of Woodworkers	1	11	6
	Mr [redacted]		5	—
		32	3	6
June 27	[redacted] raffle	1	—	—
		33	3	6

Young Chronic Sick Campaign

		£	s	d
May	Paid to [redacted]	1	-	—
	Stationery & Stamps Mrs Lewis		4	-
June 3rd	Paid Portman Bureau	1	9	6
June 18th	Paid Portman Bureau	1	9	6
June 23rd	Precision Press	5	3	6
		9	6	6
June 23rd	Paid [redacted]	1	-	—
		10	6	6

Image of the first pages of the accounts book
of the National Campaign (redacted names).

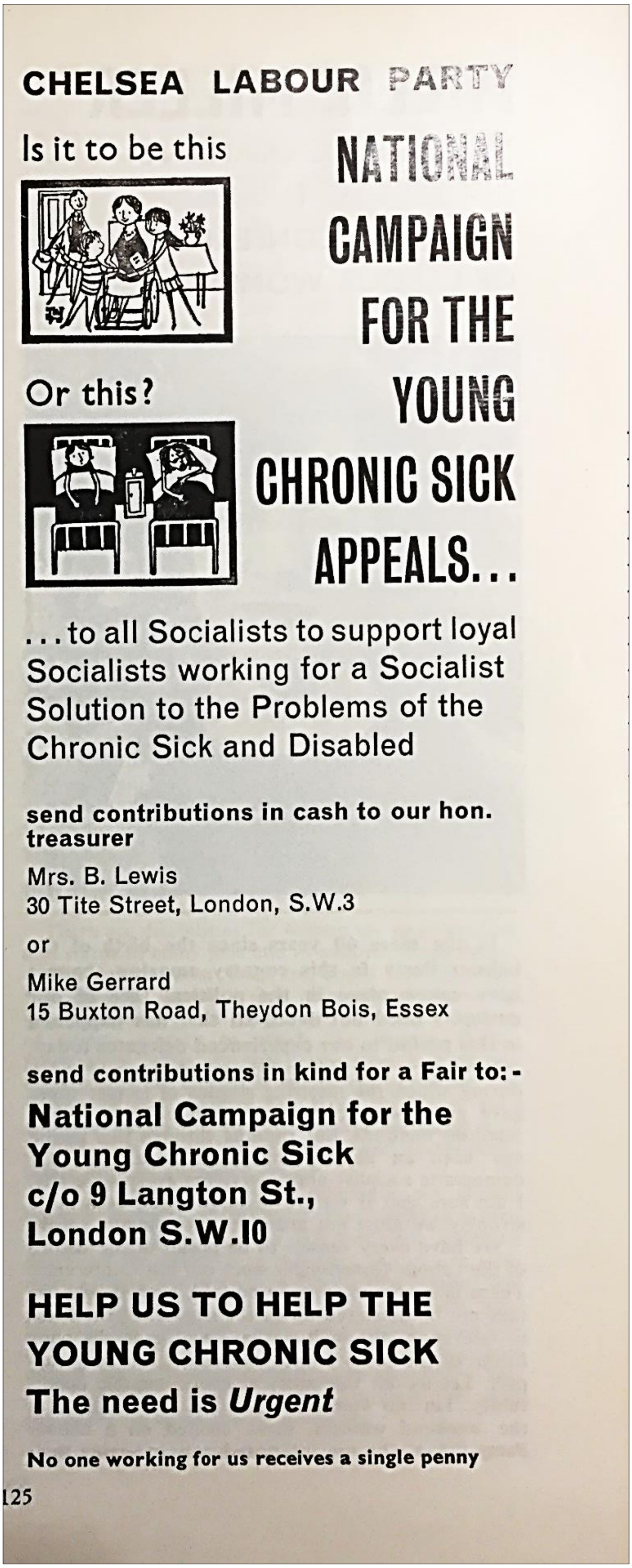
The National Campaign also appears to have employed Margaret Robertson, reported to be also working as Pamela La Fane’s PA, on modest wages, possibly part-time, for secretarial duties. These wages payments were made between November 1969 and December 1970, probably to coincide with the increased workload they had in supporting Alf Morris MP with his private members bill being pushed through its Parliamentary stages. Previously the honorary (unpaid) secretary was bought a typewriter costing £21 10s 0d (£21.50p) in September 1966.

A large number of the regular campaign's payments were made to printing companies, and without a definitive list of publications there is the possibility of one or more publications yet to be found. An alternative explanation is that these payments are for reprints of material which had run out of stock.

The ad pictured here is from the July 1967 edition of Labour Woman. The call for funds here is very clear.

There is a similar appeal for funds a few months later at the back of the fourth NCYCS Newsletter, a “Conference Special 1967”, which included the text of an open letter signed by 18 MPs – “We need cash to fight for YCS”.

This ‘open letter’ included an ambitious fundraising target of £2,000. From the accounts book it is clear this wasn’t achieved, not even £200 was raised. A possible beneficial outcome was that the appeal increased the number of paid subscriptions from Constituency Labour Parties (CLPs).



CHELSEA LABOUR PARTY

Is it to be this

Or this?

NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK APPEALS...

...to all Socialists to support loyal Socialists working for a Socialist Solution to the Problems of the Chronic Sick and Disabled

send contributions in cash to our hon. treasurer

Mrs. B. Lewis
30 Tite Street, London, S.W.3

or

Mike Gerrard
15 Buxton Road, Theydon Bois, Essex

send contributions in kind for a Fair to:-

National Campaign for the
Young Chronic Sick
c/o 9 Langton St.,
London S.W.10

HELP US TO HELP THE YOUNG CHRONIC SICK

The need is *Urgent*

No one working for us receives a single penny

125

Political summary

1965

We’ve seen that the National Campaign very probably only wanted to have an arms-length involvement with the Guthrie working party. There must have been some comment when the charity-led working party started in late 1965, less than a month after the success of the National Campaign in changing Labour Party policy.

1966

And when the Guthrie working party got the brush off from government ministers in November 1966 (Appendix 16) we can speculate that it wasn’t a coincidence that the National Campaign responded just a month later with a strong press campaign in The Guardian, a campaign that caused comment in Parliament and led on to four BBC TV programmes on independent living in the coming two years.

1967

The National Campaign don’t hold back politically either - the fourth newsletter, timed to fit the 1967 Labour Party annual conference, has the headline, “We are bloody angry”. This followed the national demonstration and rally in London of disabled people in July 1967, organised by DIG.

1968

One could forgive NCYCS if they started to feel a bit upstaged again by the Guthrie working party. In the month following the broadcast of three programmes on independent living with NCYCS on BBC 1, the Guthrie working party hold their event to launch their report findings with coverage in Parliament and in the media. Alternatively, it could have been a welcome and well-coordinated approach to synchronise public attention by both organisations – political and charitable. The records found so far don’t say one way or the other.

1969

Little did NCYCS know, but all their months and years of detailed lobbying and battling with officials and politicians was about the pay big dividends when the golden opportunity of a new law arrived. It was pure luck, but they were very well prepared and so they made the most of it.

Section 5 – The Chronically Sick and Disabled Persons Act 1970

Alf Morris wins first place for a private members bill

By chance Alf Morris won the first place in the ballot for private members bills in November 1969, ahead of around 250 other backbench MPs. It is called a ballot, but really it is a just a lottery draw, like having the names of a handful of lucky MPs pulled out of a hat.

He was taking part in an official visit to India at the time, and it was his brother Charles Morris, also an MP, who put Alf Morris' name into the lottery. Reportedly Alf Morris wrote the key parts of the bill on blank sheets in his address book while travelling back to Britain by ship.

He had quickly decided not to 'adopt' any of the substantial number of Bills sent to him by a wide range of lobby groups, and instead he worked on writing his own Bill based on his family experiences, and his political ideas and discussions on meeting the needs of disabled people. He had also been working for years behind the scenes, working "off the order paper" as they say in parliament, to try to improve the lives of many disabled people by casework and lobbying Ministers.

Early resistance

And although it was not planned for in advance, it was a very helpful for him that the National Campaign, with others, could quickly provide him with extra information for his political road map, showing him where many or all of the obstacles to change for independent living for disabled people were to be found.

When he took his early ideas for a private members bill to a meeting with the Secretary of State for Health, Richard Crossman, he faced again the same ministerial hostility he had found previously and that the National

Campaign had found in 1967. Writing two years after the CSDPA had become law, Alf Morris described in detail the outright hostility of the Department of Health, the Secretary of State and the junior ministers to his ideas (Morris and Butler, 1972).

The National Campaign were keen to give Alf Morris all the help they could, and they had been in discussions with him for many years previously, where he agreed to be an official sponsor in Parliament for the National Campaign in April 1969, six months before he won his position in the ballot for a private members bill (Appendix 31). The relationship between Alf Morris and the National Campaign became stronger as he struggled against his own Government's departments.

Armed with the NCYCS 'road map' of political obstacles, Alf Morris could write his new law in ways to work around those barriers to progress in social care. For example, many of the new powers and responsibilities were deliberately given to local government. Only a residual role was given to health authorities – the new law mostly required them to **stop** doing their harmful practices such as having non-elderly disabled people living for the rest of their life on geriatric wards.

In a leader (an opinion article) in The Guardian newspaper, it started as follows:

> "If Mr Alfred Morris's private member's Bill to improve the lot of the chronic sick had not got beyond its first reading it would have been worth the trouble of its sponsors. The problems of this particular minority have not received the attention they deserve. As in so many cases the principle of "out of sight, out of mind" seems to operate. One of the most distressing facts to emerge as a result of the work of those supporting the Bill is that thousands of young people have to spend their lives in hospital geriatric wards. There is evidence that the psychological distress which this can cause actually exacerbates the patient's condition. If the Bill sponsored by Mr Morris becomes law chronically sick young people could only be admitted for more than three months to geriatric wards with the authority of the Secretary of State for Social Services and the knowledge of Parliament. ..." (The Guardian, 16 December 1969)

A letter in response to this Leader article was published from a senior doctor in geriatric medicine fully supporting the position and emphasising that in his experience no disabled people wanted to remain in long-stay hospital wards. (The Guardian, 1969, December 29; Appendix 36).

The Chronically Sick and Disabled Persons Bill 1969-70

For detailed accounts of the mammoth political task faced by Alf Morris as a backbencher who had to build a coalition of support with and against his own party’s government there are other books, and especially the one that Alf Morris co-wrote with Arthur Butler (1972) and also the analysis of Judy Hunt (2019) terms of the wider coalition of disabled people’s campaigns which both encoraged and challenged him.

Some of the written lobbying that Alf Morris received from various charities **for** disabled people clearly started with their own priorities. For example, in the Alf Morris Collection at the LSE Library there are papers from national charities which set out their priorities for his Bill, the first two priorities being to give more tax relief to charities, and only later on are there items of direct concern to disabled people. This was naïve and counter-productive: they should have known that a Bill of this kind cannot change taxation law, and it set them at odds with the loose coalition of disabled people’s campaigns that were supporting the Bill.

And that coalition was mobilised. For example in Appendix 35 we can see four backbench Labour MPs and the NCYCS writing a public letter in December 1969 to disabled people and their allies such as family members. The MPs are asking for more support and case studies to be used politically in the committee negotiations on the new proposed law.

The key points to note in terms of the CSDPA are that it placed new duties on social services departments in councils, though some were optional or written with many compromise exemptions.

In terms of the policy agenda of NCYCS, based on their initial policy motion in 1965, the scorecard would read, in summary terms:

1) personal assistants / medical home helps - no
2) new and mandatory services from councils - partial
3) an income for carers - no
4) more YDUs and no use of geriatric wards - partial.

As Judy Hunt points out when considering the work of Paul Hunt and his 1973 paper (Appendix 46), she notes that a –

> “great disappointment was the absence of any recommendations to encourage the development of personal assistance services to avoid institutionalisation.” (J. Hunt, 2019, p63).

Where did that great disappointment come from?

In Alf Morris' initial negotiations in 1969 with Ministers in the Labour government, they had not wanted the CSDPA to tie their hands, and therefore they would only accept new duties that were either optional or fairly weak. Politically, it is very likely that Alf Morris would have also lost support from his allies in the Conservative parliamentary party if he had pressed for stronger powers. As it was, he faced substantial negotiations and consequential redrafts of many of the clauses during the committee stage of getting the bill though parliament.

As Peter Townsend commented later in the press:

> “It is gradually being recognised, however, that the Act is not very effective in practice. As a whip for recalcitrant authorities, the Act is not very useful mainly because of weaknesses in three key areas: the registration of handicapped people, the discretion it leaves with local authorities in providing services and the all-important issue of money. When these defects are spelled out they show the need for a more broadly-based attack upon the problems caused by physical and mental handicaps.” (Townsend and Jaehnig, 1973; Appendix 47)

Perhaps the most useful frame to use to look at the detailed redrafting of the clauses is: Alf Morris and some backbench MPs from both parties plus some campaigns **of** disabled people - versus - a united front of both the political parties' front benches plus certain charities **for** disabled people.

However, within the Parliamentary Labour Party the high drama and energy used in getting the CSDPA its Royal Assent, and thus becoming a law, on the very last day possible before the general election was seen as a victory, as a great success against all the odds and with a nail-biting finish.

An unsigned paper in the Alf Morris Collection at the LSE Library, headed “Synopsis: Chronically Sick & Disabled Persons’ Bill” concludes with the following paragraph:

> “Reasons for success against the odds? – the following are most frequently put forward by those with whom we have discussed the Bill:
>
> 1) The friendship between Peart and Morris.
>
> 2) The bipartisan nature of the legislation and lack of opposition in strength from either front bench.
>
> 3) Morris’ tenacity and determination not to be put off his original intention;
>
> 4) The decision by DHSS to make it part of their package for the session and their willingness to make the best of a bad job when [their] Superannuation Bill was clearly lost;
>
> (5) The unbeatable nature of the cause: it would have been politically disastrous to have opposed a proposal of this character.”

Peart was Thomas “Fred” Peart, a Labour MP who at the time was also the Leader of the House of Commons, a role with a lot of control on the timetabling of debates and other formal work done by MPs.

There is a convention in Parliament that private members bills from backbench MPs should not commit the government to spending extra money, such as a new welfare benefit or a tax relief. In the early meetings Alf Morris held with Treasury ministers this convention was put by them to him forcefully.

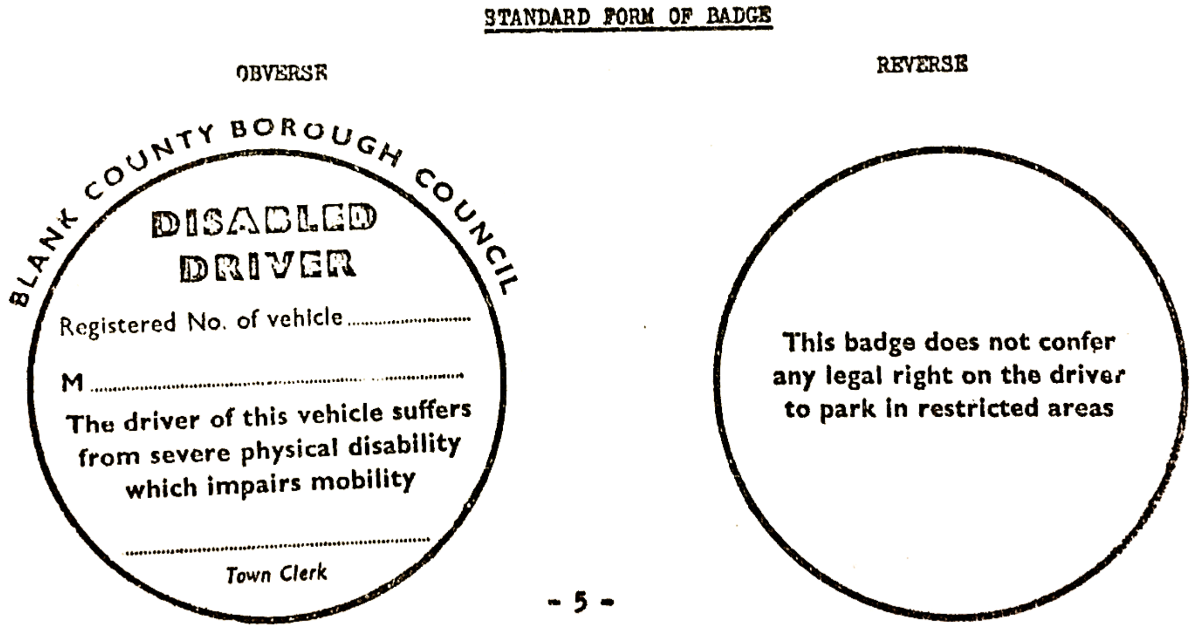
The work of Fred Peart MP was essential to the success of the CSDPA because he intervened and persuaded the Treasury to allow both the House of Commons and the House of Lords to agree to what is called a money resolution in favour of the CSDPA, busting open the convention.

On 22 April 2012, The Independent newspaper published Jack Ashley’s obituary written by Tam Dalyall. This included Jack Ashley’s role in the CSDPA:

> “As Richard Crossman’s PPS at the time, I knew better than anyone else the huge pressure that Crossman and officials at the Department of Health put on Morris to accept a more innocuous bill. The exception was the Chief Medical Officer, the formidable Sir George Godber, who had increasing sympathy with what Morris was trying to achieve. He told me that any support in putting spine into those sympathetic to Morris’s Bill would be welcome. I know at first hand the critical importance of Ashley and [Conservative MP

> co-chair John] Astor’s All-Party [Disablement] Group [created in July 1969] in sustaining the indefatigable Morris in sticking to what he had proposed rather than giving in, as most other backbench MPs would have done.”

The following table is also in summary terms, and shows the main aspects of the CSDPA and which campaigns were specifically lobbying and for which aspects. The table is adapted from J. Hunt (2019 p62-65) and from archived papers referenced here.



STANDARD FORM OF BADGE

OBVERSE

BLANK COUNTY BOROUGH COUNCIL

DISABLED DRIVER

Registered No. of vehicle ....

M ....

The driver of this vehicle suffers from severe physical disability which impairs mobility

....

Town Clerk

REVERSE

This badge does not confer any legal right on the driver to park in restricted areas

- 5 -

“Standard Form of Badge” for Orange Badges (for parking, later became Blue Badges), Alf Morris Collection, LSE Library.

New duties in CSDPA	Lobby by
1. to create a register of disabled residents living in their area by council social services,	CCD NCYCS
2. to provide assistance within the home for disabled people, including adapted telephones, radios and TVs, and to provide access adaptations to houses and flats,	CCD NCYCS
3. to make all public buildings accessible unless unreasonable, including all education settings,	JCMD
4. to provide accessible public toilets,	JCMD
5. to provide accessible travel to work and adapted vehicles for disabled people,	JCMD inc DDA
6. to provide parking permits for disabled people (Orange Badges, later being Blue Badges),	JCMD inc DDA
7. to support new provision for young disabled people seeking work,	CPAG DIG
8. to provide educational support for children with autism or dyslexia,	CPAG NSAC
9. to provide recreational opportunities for disabled people, including holidays,	NCYCS
10. to publicise their services with tailored advice,	(all)
11. to create national annual reports on research into independent living.	CCD NCYCS
12. to instruct hospitals to stop placing non-elderly disabled people in geriatric wards.	NCYCS

Credit given by Alf Morris to the NCYCS

Each time Alf Morris MP stood up in the House of Commons to make a speech asking for support for his Bill to become law, he was careful to pay tribute to the people and organisations who had informed and helped him. This included his appreciation to the Disablement Income Group, DIG, as well as to the National Campaign.

For example, at the third reading stage of the Bill in the House of Commons on 20 March 1970 he paid tribute, not for the first time, to:

> “the National Campaign for the Young Chronic Sick, to its officers and to the help they have given from the outset in helping the Bill”.

Probably his most important and wide-ranging speech was earlier, at the second reading of the Bill in the House of Commons on 5 December 1969. Even allowing for a few interventions and questions from other MPs, the speech given by Alf Morris was four hours long and is 30,000 words in Hansard. He said:

> “We must also pay tribute to the Disablement Income Group, the National Campaign for the Young Chronic Sick and, perhaps I might add, the Chelsea Labour Party, which has done so much in this regard and shown that the Labour Party in that area has a soul in this matter, as it has in so many others.”

Roy Jenkins MP

Speaking to ask a long question during Alf Morris’ speech, Roy Jenkins MP said the following about one of his constituents in Birmingham, who we now know to be Pamela La Fane:

> “I should like to make three short points. First, a constituent of mine wrote an article in the Guardian, in December 1966, which drew a great deal of public attention to this problem. I think that the consideration in particular of the young chronic sick and the growth of public concern dated from about that time.
>
> That article performed a very considerable service. My constituent who wrote it had been in a geriatric ward for a considerable time — in fact, since the age of 16. At the end of the article, she said:

> > ‘I have revived painful memories that I would rather forget. But so long as there are young people normal in their minds and feelings lying imprisoned in crippled bodies, in geriatric wards, helpless and hopeless, one must remember so that the general public are not allowed to forget.’
>
> That is an important statement and I am glad to be able to say that owing very largely, I think, to the efforts of the National Campaign for the Young Chronic Sick, my constituent is now in her own home in my constituency. She says, indeed:
>
> > ‘Thanks to the work done on my behalf by the Campaign for the Young Chronic Sick I have left the geriatric hospital behind me and am now living in my own home.’
>
> The reason that my constituent is now in that happier position was due to chance reading of an article in the New Statesman by Mr. Marsh Dickson.”

At the time Roy Jenkins was the Chancellor of the Exchequer in a Labour government, and his constituency was Stechford in east Birmingham. It seems that Pamela La Fane had moved to Birmingham from Wandsworth sometime in the late 1960s.

Finally here, there is a further public credit given to the National Campaign for the Young Chronic Sick in the letter by four Labour MPs, published in The Guardian on 19 December 1969 (Appendix 35).

Perhaps the best way to appreciate the significance of the CSDPA is that, though it had been watered down by government ministers and others in parliament, nevertheless it was a world-first in the idea of general legal rights for disabled people and not just medical care.

After years of campaigning the glass for some was now half-full.

Section 6 – NCYCS / NCCSD and the 1970s

> "The Act has never been quite the charter for the future of the disabled that has been claimed." (P. Hunt, 1973b, p108)

The passing of the CSDPA was an act of high political drama right up to the last moment before becoming law.

The National Campaign committee must have been elated but also exhausted, and then being Labour Party members for them it was straight into canvassing for the 1970 general election.

Labour lost that election which meant that the first four years of the CSDPA were implemented by a Conservative government. We learn later that Marsh Dickson was needing to substantially reduce his involvement due to his health problems. The National Campaign was also overdrawn at the bank and owed money to its suppliers. From their elation concerning their enabling role in the new law, within weeks the National Campaign as an organisation was fully on the back foot.

Councils drag their feet

Within months of the CSDPA becoming law the backlash had started. Many local authorities started to look for loopholes and similar tricks to avoid having to implement the law as intended. Alf Morris and the National Campaign had to switch their campaigning strategy to meet these reactionary forces.

In the spring of 1971, a year after the new law came into effect, Alf Morris spoke in Manchester at an event called, 'New Horizons for the Disabled.' The text of his speech was included as a postscript to a publication of another speech, 'Needs Before Means', the main part of the document, that was probably given to a fringe meeting at the first Labour Party annual conference after his law was enacted (Morris and Dickson, 1971). The speech included as a post-script is shown in Appendix 40.

In this 1971 speech, ‘New Horizons for the Disabled’ given in Manchester Alf Morris refers to a document that has come into his possession, which advises councils on suggested ways to deprive disabled people of their rights under the new law. For example, the semi-official document tells local authorities of **six different ways of avoiding providing disabled people** with an adapted telephone or television. It had already been reported in the press that Birmingham City Council planned to issue disabled people with whistles instead of telephones, cheaper to issue if disabled residents needed to try to summon help in an emergency.

Similarly, when Alf Morris comes to write his book with his account of his mammoth efforts to get the private members bill passed into law, written with Arthur Butler, he doesn't dwell too long on the process and people. Instead the focus is on the begrudged and reactionary attitudes shown by some local authorities to making any improvements in their poor and uneven services for disabled people. A common phrase that Alf Morris is using at this time of that councils are 'dragging their feet' and so the book is called from the point of view of some disabled people, No Feet to Drag. (Morris and Butler 1972)

After this book was published, 68 people and organisations signed a letter to the Prime Minister, Edward Heath calling on the Conservative government to provide more public spending including funding to councils to provide better for disabled people. Their letter and his reply were published in The Guardian (2 May 1973) as part of a wider feature titled, Enabling the Disabled. The Prime Minister’s letter included the following:

> "... Turning to local personal social services, forecast expenditure for 1973/74 represents a growth in real terms of 21 per cent in real terms over actual spending in 1971-2. And within that total it is estimated that there will be a growth of spending on services specifically for the physically handicapped of 50 per cent in real terms over the two year period. This is not to deny that the base on which this development is taking place was a small one."

(Heath, 2 May 1973)

Some academics were beginning to see fault lines in both the Labour and the Conservative party approaches, and this debate is aired in the national press. Writing the same day in response to this exchange of letters, Professor Peter Townsend and Walter Jaehnig made their detailed comments including the following:

> "A rational and comprehensive system of allowances and a coordinated programme of occupational and community services have yet to be worked out." and also,
>
> "It is gradually being recognised, however, that the [CSDPA] is not very effective in practice ... [with] weaknesses in three areas: the registration of handicapped people, the discretion it leaves with local authorities in providing services and the all-important issue of money" given by central government to councils.
>
> (Townsend and Jaehnig, 1973, May 2; Appendix 47)

The NCCSD encouraged as many local Constituency Labour Parties (CLPs) to organise their own local surveys of the needs of disabled constituents, especially in areas where the local council was ‘dragging it feet’ including Ipswich, Ealing, and Harlow in collaboration with the local Council for Voluntary Services (CVS).

Growth in hospitals and YDUs

So, if many councils were dragging their feet in a context of this 50% growth in public spending over two years, and after inflation too, where was all this money going to?

Well, by contrast with the constricted spending for the needs of disabled people's needs by councils, the spending by health authorities is growing at an incredible rate. Within six months of being elected, the new Conservative government had a programme in place to build lots of new YDUs - Young Disabled Units - in hospital grounds as an alternative to using geriatric wards. In the 1970 the announced funds are £3 million; and by 1972 the figure is £5 million.

> "Sir Keith [Joseph, the Secretary of State for Health and Social Services], has set aside an extra £3 millions over the next four years for special units for the young chronic sick, many of whom were at present being cared for in geriatric wards. In answer to a question from Mrs Shirley Williams [MP], he said he was not claiming that all the group would at once be removed from general

> hospital and geriatric wards but he did see the situation improving." (The Guardian, 1970, November 12).
>
> (Extract from: More money for 'neglected sectors' of NHS, News item, The Guardian, 12 November 1970).

The political comment on the ground from a Labour-controlled area concerning the generosity of the government was quite complimentary.

> "Announcing the Department of Health's allocation for 1971/2 to the Manchester Regional Hospital Board ... [the] chairman of the finance committee, said that the inflationary allowance was the highest the board had ever received. ... The Government's comparatively sudden generosity to the board is part of a national effort by the Government to ensure that hospital boards will be able to improve their services in spite of inflation. The Manchester board has been asked to pay special attention to mentally handicapped patients, accident and emergency services, the younger chronic sick, and alcoholics."
>
> (Extract from: £85m for hospital services, The Guardian, 24 February 1971).

Nationally, Sir Keith Joseph had announced an additional £5 millions:

> "to enable the young chronic sick to be accommodated separately from elderly long-stay patients. Hospital boards are now bidding for their share of this. Annual grants and reports on the research into new equipment for the disabled are made by the Department of Health and Social Security."
>
> (Extract from: Leg-up Lags, a book review of, No Feet to Drag, Alf Morris and Arthur Butler, (1972), in The Guardian, 4 September 1972).

So, just at the moment that the new duties were given to local authorities by the CSDPA, the Conservative government was sending much of the new money to health authority boards, “the highest the board had ever received”. The solution it seems was to be medical, not social.

A medical model

A teaching professor once told me that a lot of students would complain that there were lots of books and articles on the social model of disability, but there was nothing equivalent in the uni library to explain the medical model. Of course, the answer was that the medical model is so pervasive and powerful that it doesn’t need to explain itself, it ‘just is’. The rules that are unwritten are often the most powerful, setting the culture.

So, perhaps as a light-hearted antidote to make a serious point, we might think about the following scientific formula as a tangible example of the medical model which you can find in the library. In all seriousness, this model by two doctors claims to tell NHS managers how many disabled people will need a hospital bed, and for how long. As a formula it is, of course, totally ‘Horlicks’ but its importance is instead as a sign of just how powerful the medical model remains even within social care.

$$\mathbf{P}(t) = \frac{e^{-\frac{t}{b}}}{b} \quad t \geqslant 0$$

Formula in: Williams and Lambourne, 1973.

To the careful reader, the medical authors’ assumptions can be deduced from the following commentary:

> "The most severely physically handicapped represent only a small proportion of the total who are ... disabled ... but their degree of dependency often makes it necessary to care for them in institutions". (Williams and Lambourne 1973 p129)

Marlborough Lodge, Oxford

If there was just one medical institution that stood out against the trend to reinforce the medical model it was the Mary Marlborough Lodge (MML) in Oxford, with its own identity into the 1990s and later incorporated into the NHS Nuffield Orthopaedic Centre (OX3 7HE).

Basically, there were two hurdles a disabled person had to overcome before they were ‘allowed’ to move out from living in a hospital. First was an assessment at MML; the second was to find or create an accessible flat or bungalow. The first-hand account earlier by Pamela La Fane of

her visit to MML for an assessment gives a sense of their progressive culture and working methods, as did Margaret and Jack Wymer.
(Wymer and Wymer, 1980; Davis and Davis, 2019, p42).

The Lodge was essentially one of the earliest British centres of expertise in independent living, and getting an appointment to visit there was gold dust for many disabled people seeking their independence. It is listed in the Historic England database as a heritage building of national importance.

Delivery of accessible housing grows slowly

Perhaps the slowest aspect of independent living to improve within the 1960s in terms of delivery was that of accessible housing.

There had been a single landmark - in 1963 - when Selwyn Goldsmith published his first edition of ‘Designing for the Disabled’, with some later editions known as ‘Universal Design’. He was an architect who became a wheelchair user as an adult when he caught the polio virus and became impaired. He would continue to be a ‘leading light’ in the accessible housing field, but some campaigners thought he was too close to government and too ready to compromise and wait for improvements. He was inspired to write the first edition of his guide after meeting Duncan Guthrie and two others. (Richards, 2011)

So in the 1960s there was little progress - basically there was ‘Designing for the Disabled’ and there was the Mary Marlborough Lodge in Oxford. Getting access to an assessment and then to adapted housing were ad-hoc and only leant about by word of mouth.

In response, disabled people’s campaigns turned to the media to highlight the issue, and comparisons with some other parts of Europe started to be made. It was not uncommon for people to have to visit Scandinavian countries to find working examples of accessible housing and independent living. Some of these ‘schemes’ created mixed feelings in disabled people in Britain - seeing them as maybe not quite as medical as YDUs but still a form of social segregation - villages apart from mainstream living, still something “special”. But again, glass half full, a learning opportunity for British disabled people and better than many ‘schemes’ in Britain in terms of pre-planned accessible housing.

The table below lists some of the Scandinavian housing schemes that were publicised and visited.

References to continental European accessible housing

Housing project name	**Referred to by -**
Hans Knudsenplatz, Copenhagen, **Denmark**	Duncan Guthrie (1965) impressed, having visited “many years” earlier.
Het Dorp (The Village), The **Netherlands** (Opened 1962, telethon funded)	Paul Hunt (Feb 1972, The Guardian), not in favour, preferring “small groups” of flats, in response to David Cohen. World in Action - Granada ITV - 10 April 1972; visited by Rosalie Wilkins, summarising with mixed feelings. Ann Shearer, The Guardian, 26 June 1973, not in favour.
Collectivehaus, **Denmark**	Maggie & Ken Davis, visited in 1970s
Fokus, **Sweden** (Started 1964)	Maggie & Ken Davis, visited in 1970s Case study at CEH seminar, 1973 (Paul Hunt, Social Services journal, 24 March). Ann Shearer, The Guardian, 26 June 1973, in favour, better than Het Dorp.

There were a few micro-size specialist housing association, for example the Inskip St Giles which helped in the construction of the Grove Road independent living project. (Davis and Davis, 2019). There was also the Habinteg housing association, an offshoot of the Spastics Society (now, Scope) which at the time of writing managed around 3000 accessible properties.

The typical British approach up to the 1970s was to find a ground floor flat or bungalow and then rebuild it internally with new rooms, new kitchen and bathroom fittings, wider doorways, ramps and so on. This was ad-hoc, expensive, and took up to a year to complete each time.

Slowly in the 1970s the volume of accessible housing started to rise, albeit often still in special ‘schemes’ rather than being integrated within the general housing stock. An example of this growth is from a book review:

> "Further progress is marked by an increase in the number of councils who are submitting housing schemes for the disabled: 24 in 1970: 130 in March [1972]."
>
> (Extract from: Leg-up Lags, a book review of, No Feet to Drag, Alf Morris and Arthur Butler, (1972), in The Guardian, 4 September 1972).

But the growth in health authority budgets in the early 1970s meant that many new YDUs were also being built.

A few years after the CSDPA had time to establish itself, radical disabled campaigners such as Paul Hunt (the key founder of UPIAS, the Union of the Physically Impaired Against Segregation) were voicing their doubts and criticisms, especially about the newly expanded forms of segregated hospital YDUs. By March 1973 Alf Morris supported these criticisms being made by disabled people. (P. Hunt, 1973a; Appendix 46)

At this point it seems that campaigning to influence the Government for independent living was focused on challenging their policy unit called the Centre on Environment for the Handicapped, CEH. (Appendix 48)

From personal memory, Ian Stanton, working at the Greater Manchester Coalition of Disabled People and its magazine editor, later parodied this policy unit as: “CEH - Cementing the Exclusion of the Handicapped”.

Jean Symons (1974) concluded that 'so far as chronic sick units are concerned, in their present concept no more should be designed'. (cited in Nichols, 1978, p445), and this from the King’s Fund:

> “When the disabled themselves are consulted it becomes clear that their main desire is to have the opportunity to choose their own home. The majority want to live in a street, near shops, churches, pubs and people. They want a single or a double room, they want to be surrounded by their own things, to mix as they want and to have freedom of choice of their daily living activities.” – source: King’s Fund, report: (Kings Fund, 1975; cited in Nichols, 1978).

It is worth noting that Nichols, writing these accounts in 1978, was working at the Mary Marlborough Lodge in Oxford, and his other points of reference include The New Poor (1973) a book part-written by Paul Hunt.

Becoming the NCCSD, then closing

> "The Campaign subsists entirely on the moral support and financial backing of the Labour Movement without which it cannot continue its work. Apart from proposing development in Labour Party Policy by Conference decisions over the last eight years, and playing a material role in the support of Alf Morris' Bill, it is now working to secure full and wider implementation of provision for the sick and disabled than the Bill foresaw, and to give it proper Government and Party backing in line with the sentiments expressed at Blackpool last October."
>
> (1973, 10 January, extract from correspondence, Mike Gerrard to London Co-operative Society Political Committee, held at LHA)

It is fair to say that during the six-month period from December 1969 to May 1970, the NCYCS had thrown everything they had into the ring to support Alf Morris. And they also had thrown in a few things they didn't have, going overdrawn at the bank without permission and building up debts with printing firms who were pumping out their leaflets.

The NCYCS also employed Pamela La Fane's PA during 1970 with some extra hours to do clerical work for them during this intense period. This arrangement ended in 1971 when the PA had to return to Australia because her visa expired.

These debts were not attended to during 1971. The political focus of the National Campaign was on trying to force local authorities to implement the CSDPA to the maximum extent, at a time when the Conservative central government was issuing guidance on how to minimise its implementation, and when even more restrictive semi-official plans were in circulation.

National Campaign for the Chronic Sick and Disabled

With the success of the passing of the CSDPA in 1970 it seems that the phrase of "young chronic sick" was finally becoming old fashioned; a reminder of the old practices the new law was set out to change.

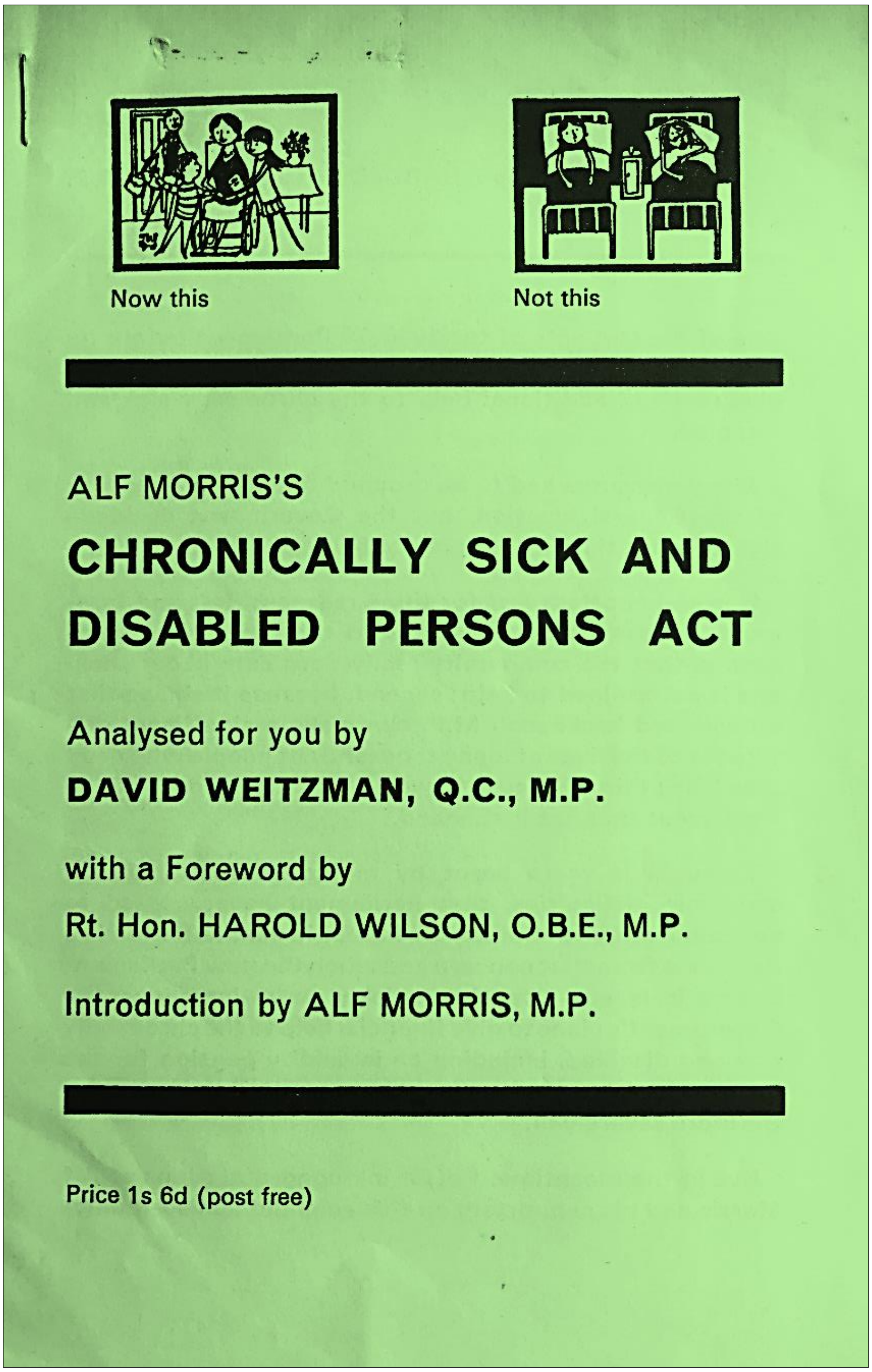
So, as a consequence of helping create this change in policy, the NCYCS changed its name to become the National Campaign of the Chronic Sick and Disabled, the NCCSD. This seems to have happened sometime between May 1970 (Appendix 37) and summer 1971 (Appendices 39, 40).

In 1971 the new name was confirmed in a speech at the Labour Party’s annual autumn conference. Graham Towers started his speech with these opening remarks:

> “The movement, which started with a committee in the Chelsea Labour Party, went on to become the National Campaign for the Chronic Sick and Disabled and culminated with the passage of Alf Morris’s Chronic (sic) Sick and Disabled Persons Act, represents a great triumph and it is a credit to the power of a private Member in Parliament”. (Graham Towers, Chelsea CLP, Labour Party Conference Report 1971, p291).

Mike Gerrard was the Eastern regional secretary of the NCYCS, a position he took after moving with his wife Heather out of London in the 1960s to live near Harlow in Essex. Whether they were living in the Chelsea CLP constituency at the time isn't known. In Essex he was a locally elected councillor and was the Prospective Parliamentary Candidate in a general election, possibly in 1974.

In the political archives Mike Gerrard is generally better known for having been a long-standing member of the national executive committee of the Anti-Apartheid Movement from the early 1960s, and he described a high point in a later interview (Transcript, AAM archive, 2000) when he chaired an AAM large rally ("a meeting" in his modest words) in Trafalgar Square.



Now this

Not this

ALF MORRIS'S

CHRONICALLY SICK AND DISABLED PERSONS ACT

Analysed for you by

DAVID WEITZMAN, Q.C., M.P.

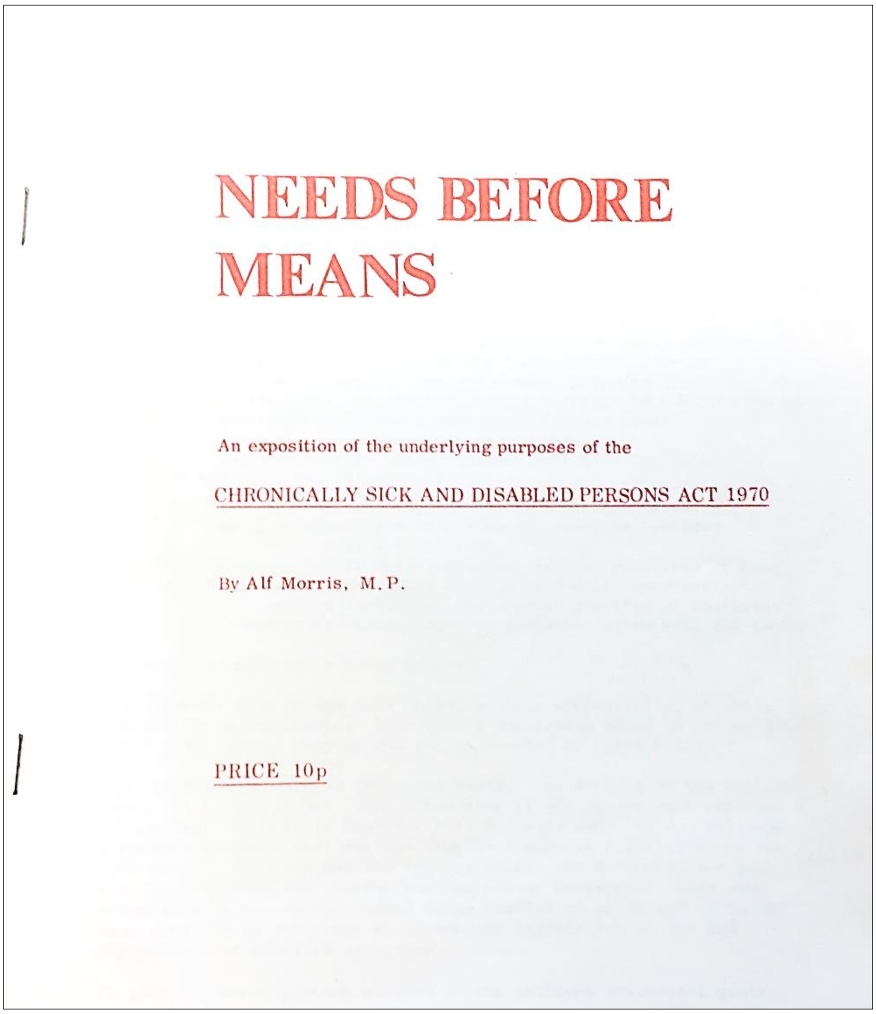
with a Foreword by

Rt. Hon. HAROLD WILSON, O.B.E., M.P.

Introduction by ALF MORRIS, M.P.

Price 1s 6d (post free)

The Labour History Archive (LHA) in Manchester contains a box of catalogued files from the NCYCS / NCCSD, almost all from 1970 to 1974. Most of these papers are copies of correspondence from Mike Gerrard, and as he explains at one point, he has effectively taken on the administration of the National Campaign after Marsh Dickson had become increasingly impaired with spinal issues.



NEEDS BEFORE MEANS

An exposition of the underlying purposes of the

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By Alf Morris, M.P.

PRICE 10p

Looking at the accounts book of the National Campaign for this period, particularly intriguing is the entry for "booklet sales" dated 20 April 1972, and this might relate to the booklet, Needs Before Means (Morris and Dickson 1971) published by the Co-operative Union for the Co-operative party; or possibly the booklet about the CSDPA published by NCYCS / NCCSD and written by David Weitzman QC MP as a lawyer (Weitzman, 1970; Morris and Dickson 1971 p9).

There are also entries in the accounts where some of the committee members are loaning the campaign their own funds in order to pay a bill on time, notably in 1972.

From these papers held at the LHA it can be seen that by 1972 the National Campaign has decided informally to wind up. Even so, they still went the annual Labour Party conference that autumn and got involved for the last time in changing policy as part of composite 42 (a motion composited from various similar proposals). (Appendix I)

L-R: Mike Gerrard, Marsh Dickson, Ben Hazelwood (a local head teacher), David Sharp (Council Chairman, Harlow Council)
Credit: Harlow Gazette, 12 January 1973.

The need to raise some funds to pay off the debts was now fully appreciated, and Mike Gerrard gained the approvals of the FA (Football Association) and the local council, giving him a gambling licence to run a fundraising lottery based on picking which team will win the FA Cup Final in 1973. He had the lottery tickets printed (he had to pay the printers in cash) and they were posted to CLPs around Britain.

The fundraising was a mixed success - as a project it lost funds, costing £91 more than it raised, but it helped attract £131 in new subscriptions that year so there was a net surplus. But not enough to cover all the debts, so Mike Gerrard then wrote to the head office of the Co-operative Party asking for funds. They declined, but suggested instead that they would publish an appeal in their next edition of Co-operative News dated 31 August 1973. This worked well, and by 28 November 1973 this appeal had generated £124, enough to clear the debts.

At the end of 1973 the campaign has a small surplus - £9.34p.

A difference towards the end of the accounts book is that these pages have a formality not found in the earlier pages for the earlier years. This new formality includes having a balance sheet for the year and coloured pen ticks and comments typically made during a formal financial audit, which was probably a requirement of a formal closure process under

Labour and Co-operative party rules. All was in order, and now more methodical.

Around 11 March 1974 Alf Morris is announced as the world's first government minister for disabled people in the newly elected Labour government. Mike Gerrard had written to the prime minister Harold Wilson on 9 March 1974 suggesting the widest remit possible for Alf Morris, with Wilson's thanks in return dated 20 March 1974.

Not by coincidence, on 16 March 1974 the executive committee of the campaign meets for the last time and winds up the organisation with a cash surplus of £9.39p. They issue a "Terminal Newsletter" dated April 1974. (Appendix 49)

The now-named NCCSD had always been small by comparison with campaigns such as DIG, and so it closed in 1974 predominantly for internal reasons. UPIAS was now a rising campaign, more radical, and strictly under the control of disabled people.

But even if NCCSD had been able to continue and thrive it would have found itself being openly criticised by a new generation of disabled campaigners for being too focussed on parliament and not enough on the disabled people’s movement. For example, Vic Finkelstein said this later about similar campaigns:

> “we had very firmly shifted the focus of our activities from parliamentary pressure group politics, so favoured by the Disablement Income Group (DIG) and the Disability Alliance (DA), onto grass roots work within the disabled community” (Finkelstein, 1996a)

Finkelstein also criticised these parliamentary campaigns for, as he saw it, squandering the opportunities given with their large numbers of supporters instead of mobilising them for the needs of the movement.

> “In November 1972 the Disablement Income Group handed the Labour MP Jack Ashley a petition signed by 258,404 people demanding a ‘disability’ pension as of **right** for all disabled people. Within a few years of this impressive achievement this leading organisation of disabled people played no further role in the development of our movement. DIG had allowed its single-issue campaign for legislation to become its top priority and paid the price for neglecting its grass roots membership.” (Finkelstein, 1996b) (emphasis in original)

To be fair, not everyone who signs a petition will be willing to give up their spare time and skills for many years ahead for the movement.

But the point remains, that NCYCS / NCCSD by its nature was more of a 1960s campaign model, and it passed to others in the 1970s to start new campaigns which were less top-down and less concerned with influencing parliament and political parties.

Curiously by the 1990s the pendulum had swung back again, with the lobbying of parliament and political parties by disabled people’s organisations for new legal rights to protect disabled people against unfair discrimination. And the tensions between the top-down (Rights Now, etc) and the grass roots (DAN, etc) emerged again.

Legacy, but funding dries up

The first tragedy of the CSDPA was that the increase in funding coincided with a new Conservative government, so much of the new money went on building shiny new YDUs for health authorities across the country.

The CSDPA had created large changes in policy and provision with more powers and duties being given to local authorities and their new social services departments. But while the Act had been taken away powers from hospitals to support independent living, it had been alongside an increase in hospital funding.

The second tragedy as that on the later return of a Labour Government (1974-1979) there was soon a profound setback to implementing the CSDPA when Anthony Crosland in 1975 as a minister makes a key speech to tell local authorities that spending cuts were coming. His words became the headline, "**the party's over**". (speech made at Manchester Town Hall, 9 May 1975).

June Maelzer

June was a wheelchair user living in Manchester after having graduated with a psychology degree from the University of Manchester in the early 1970s. She was interviewed by Gita Conn for The Guardian, mostly about her struggles to find a job as a social worker, and in this article she explained her parallel struggles to live independently.

> " 'No one's ever told them to bugger off and keep their homes,' she said with a touch of pride as she described her protracted struggles

> with officialdom to assert her right to live in a flat of her own. Before beginning her studies in Manchester, she was offered a place in 'this lovely home' and, when she campaigned for a place of her own, was told that it could only be considered once she had found a suitable flat and someone to help her. 'The whole thing was a vicious circle. Obviously I couldn't get a flat or hire an au pair until I had the money - and they wouldn't give me the money until I had found them. The circle could not be broken.
>
> One day I thought, "Sod the lot of them" and I went out and got a flat and finally got a loan from the bank which I paid back when my grant came through.'
>
> A breakdown in domestic arrangements forced June into a home for her final year. Between au pairs, student friends had looked after her on a three-day rota basis, an arrangement that that in spite of the good intentions, simply couldn't work satisfactorily for long. Much to her delight, she is back now in her flat in of her own in Chorlton near Manchester." (Conn 1973)

Shortly after this interview was published Paul Hunt wrote a letter to June Maelzer dated 17 March 1973. He enclosed a copy of the first Circular of UPIAS, the Union of the Physically Impaired Against Segregation, saying,

> "I have been meaning to write to you since reading your Guardian interview ... [and] I should be very interested to have your responses to our [UPIAS] proposals - particularly in view of your determination not to be put away in a home. ... However, what made me finally get down to writing was seeing that you are to give the final paper in a forthcoming Spastics Society Oxford Conference on integration." (P. Hunt, 1973, Judy and Paul Hunt Collection)

June Maelzer managed to continue to live independently in a flat in Manchester into the 1980s. Her ad-hoc use of PAs was a mixture of young people from the Community Service Volunteers (CSV) organisation, mostly living-in, and payments from the social services department of Manchester City Council (MCC) sent to her via the Irwell Valley Housing Association (IVHA), based in Salford.

At the time local authorities were forbidden by law from making direct payments to disabled people for their independent living costs such as the wages of PAs. However, housing associations were not limited by law in the same way, so MCC and IVHA put together a 'housing scheme' which was in effect just about June Maelzer. MCC could fund a housing scheme and IVHA could fund a disabled person. Peter Norman was the director of IVHA at the time and he was fully engaged and supportive of the arrangement, including attending meetings of the Greater Manchester Housing and Disability Group which was one of the feeder groups into the creation of the Greater Manchester Coalition of Disabled People.

From personal discussions with the then-director of social services in Manchester, June Maelzer apparently inadvertently caused a change in the financial regulations for all local authorities in England. Probably sometimes in the early 1990s she moved home from Manchester to live in the south west of England. The problem was to ensure the continuity of payments for the wages of her PAs. MCC proposed to continue to pay her for up to six months to give time for the social services department in her new area to get a replacement arrangement up and running. But the county treasurer who was in charge of all the funds in the 'new' council objected to the idea of paying June Maelzer for her PAs' wages. So there was a bit of a stand-off, but she still had allies in Manchester including working for MCC, so they arranged for national guidance to be issued to all council to the effect that such direct payments, properly assessed, were a legitimate expense for any council.

1980s

The core of this research is 1964 to 1974, however some press articles and professional recollection from the 1980s show – despite disabled people’s campaigns such as *Project 81* and *Grove Road* – just how slow or even absent was the progress being made by statutory services to create independent living opportunities for disabled people – community care as it was known then.

Some examples follow.

The Young Victims who are Trapped for Life

Nicola Barry

The provision of care for the young chronic sick in Scotland falls a long way short of what it should be. Nicola Barry reports that good intentions abound but delay in taking action prolongs suffering.

... Eddie lives in Cowglen Hospital in Glasgow with 50 other physically handicapped people. ... their daily routine is limited to getting up, having meals and sitting around. They have few possessions, usually neither family nor friends - certainly no real relationships to speak of. Every minute of their lives is planned. Days, months, years pass by and there they sit, slumped forward in wheelchairs, imprisoned in a kind of morgue for the living. ...

About 1,000 young disabled adults live in hospitals in Scotland because adequate community facilities do not exist elsewhere for them. A Scottish Office report on the young physically disabled, produced in 1987 and still unpublished, has come into the hands of Observer Scotland. ...

[In Glasgow] as many as 100 of the 200 in-patients could have moved out of the young chronic sick units. ...

The Observer, 12 March 1989

The following is a first-hand account from
a social worker in the north of England:

"In 1983 I got a job at a newly built residential home. It had been built with joint funding from the Health and Social Services. I was working as a residential social worker and had specific responsibility for one of five units. We were approached to take a woman in her 50s who'd had a severe stroke. Initially we all said no that it wasn't appropriate for a woman her age to be in a home for elderly people. We then discovered she was living in a long stay geriatric ward. We decided that the unit would therefore be for people over the age of 50.

Sadly even in the 1980s we were still finding a number of people in their 50s and early 60s who had found themselves stuck on long stay geriatric wards.

It worries me even today that whilst young disabled people may no longer be on long stay geriatric wards they are often still institutionalised in nursing homes."

(source: private email, 1 February 2022)

Pamela La Fane, around 1980

Criticisms and Conclusions

One of the frequent criticisms of the CSDP Act made in the early 21st century is that it legislated for "non-enforceable" rights. But this rather misses the point.

The CSDP Bill was ‘watered down’ as its various drafts worked their way through Parliament. For example, an early draft proposal concerning YCS disabled people was that Parliament would have to vote each time if the authorities planned to keep any named disabled person on a hospital geriatric ward for more than three months. The rights were given to Parliament, not to the disabled person.

The whole premise as the time, as clearly shown by the National Campaign for the YCS, was the political strategy and belief that change was led by **the party**. The ruling party would then instruct parliament. And in turn parliament would instruct the government. And the government would instruct the health authorities and local authorities via their respective ministries.

Some might call this a Leninist approach, and patriarchal too, a top-down view of political change, where the party has dominance over all. The idea of individual disabled people having to enforce their own rights would be seen as clearly non-collective, unsocialist and individualistic, maybe these days what would be described as neoliberal. But working top-down was a reasonable position to take - only 18 years earlier this same approach had **created** the NHS in Britain, so why shouldn't it also work to **reform** the NHS when instructed by a group of disabled people and allies?

The fact that ministers in the Labour government in the 1960s consistently and openly refused to listen both to parliament and to the party on the needs of disabled people was a bitter lesson for the National Campaign for the YCS.

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The dysfunctional relationship between health and social care systems and delivery is not new. It was already identified by DIG and by the Guthrie Working Party, where health authorities and local authorities were called on to work closer together (Guthrie and others, 1968, p31-32). Institutional initiatives followed in later years, such as Joint Finance, which was a shared budget which both types of authority could influence but neither had absolute control. But perhaps this research shows as a stark example that institutional changes will not work if the pre-existing culture remains untouched. For examples, for some years now GPs and hospitals are both theoretically managed within the same authority and budget, but to assume that has resolves the tensions between community-based and hospital-based health care would be unwise.

The inability of the National Campaign nor DIG nor later campaigns by disabled people, to change the underlying culture of tension, sometimes dysfunction and at worst contempt, between health and social care is maybe an ask too big to make of a 1960s unstaffed and unfunded campaign by disabled people and their allies. But equally it was an objective they set for themselves, so it is fair to measure how far they succeeded with it, or not.

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The terminology used within the National Campaign publications uncritically repeats the descriptions of disabled people which today would be judged as inappropriate and in some cases highly offensive. The terms were used without comment, so we cannot be sure whether it was a passive act of uncritically using the health sector terms of the time, or an active act of speaking their language back at them - speaking to the enemy in their own language, as it were.

But harder to process and understand is the division of disabled people at the start of the campaign into those worthy of independent living, and those "who on medical grounds must be institutionalised." (Appendices B, C). This includes learning disabled people and people with mental health experiences such as extreme distress. There is no explicit sense of pan-impairment solidarity from NCYCS until 1972. Although the first coalition of disabled people in Britain isn't created until 16 years later; or UPIAS from 1972 if you can accept it as being pan-impairment in its values, there were other campaigns in the 1960s for the desegregation of learning disabled people and of people in mental health confined in long-term institutions.

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Although it is a major development with the invention of the new role of medical home helps / personal assistants, these are firmly seen both by the National Campaign and by DIG as only being employed by the state, and under control of the professional governing bodies in matters such as training and supervision (Appendices 10 and 26). The idea of disabled people employing their own PAs while using state funds seems to be unthinkable at the time. One conclusion that can be argued from this research is that, while the NCYCS was campaigning for independent living, its contribution was a policy to create the **medical model of PAs**; and that it was only later in the 1980s that the **social model of PAs** and explicit autonomy came into being. Nevertheless, as a development in social care policy and delivery, it remains a highly significant milestone on that road to independent living.

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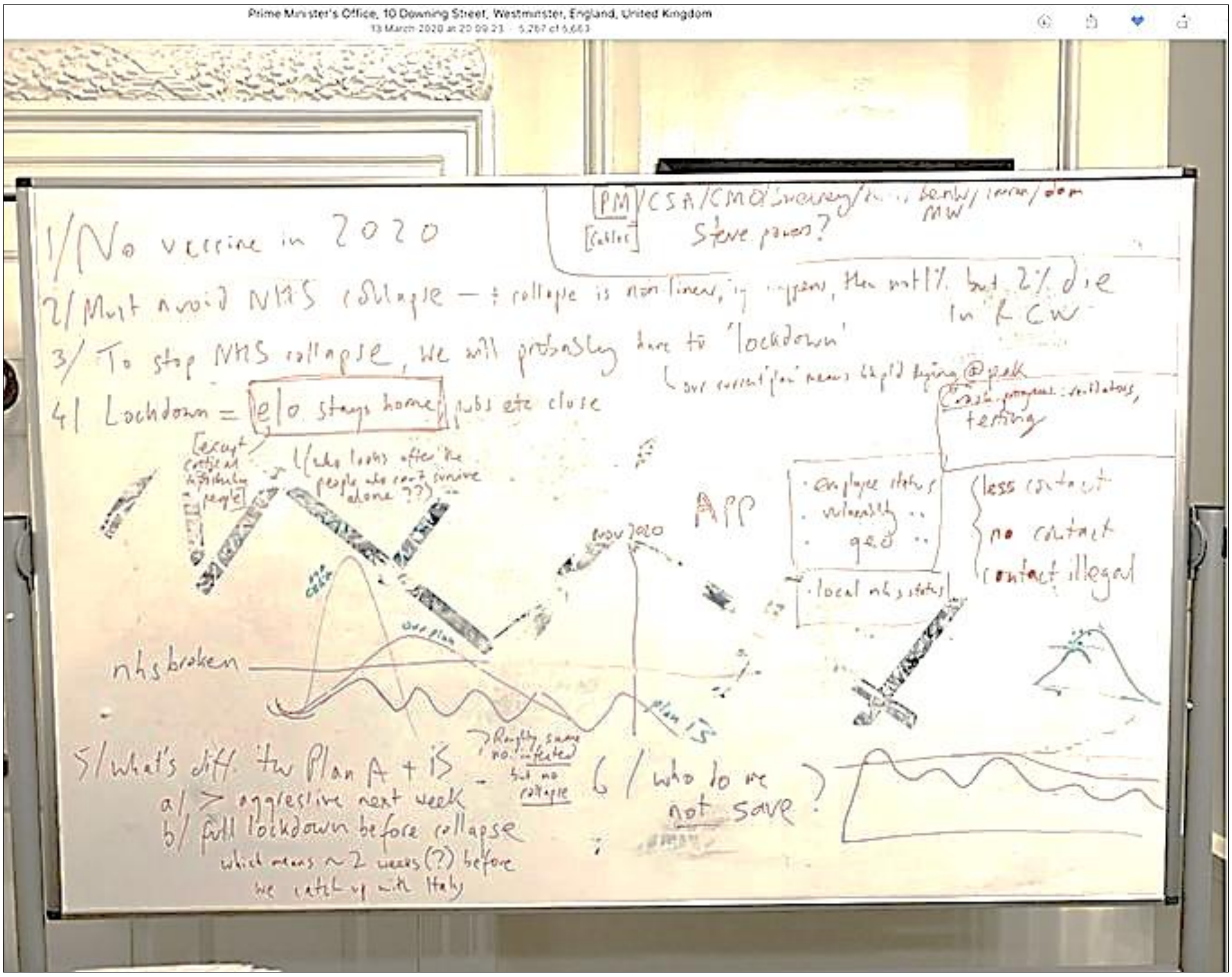

Prime Minister’s Office, Downing Street, 13 March 2020
(Twitter 2020, and Covid Public Inquiry 2023)

2020s

In my view, perhaps the most timely conclusion from this 1960s research for the 2020s is to recognise **the durability of a streak of cold indifference** running through the heart of Westminster and Whitehall to the intolerable livings conditions of many disabled people in Britain.

The overused feel-good publicity from the 2012 Paralympics in London doesn't reduce the extra hardships and deaths faced by working age disabled people in the 2010-onward years of austerity. The 57,550 calculated excess deaths caused by the first four years of the politics of austerity barely registered a public comment and certainly attracted no shame nor apologies. (Martin and others, 2021).

Similarly there has been no reckoning for the many thousands of excess deaths of disabled people caused by the political and organisational mismanagement of the Covid pandemic, with (at the time of writing) the Public Inquiry starting to take public evidence. So far we know:

> "Between 24 January and 20 November 2020 in England, the risk of death involving the coronavirus (COVID-19) was 3.1 times greater for more-disabled men and 1.9 times greater for less-disabled men, compared with non-disabled men; among women, the risk of death was 3.5 times greater for more-disabled women and 2.0 times greater for less-disabled women, compared with non-disabled women."   (ONS, 11 Feb 2021)
>
> "more-disabled" and "less-disabled" relates to the flawed definitions currently used in the UK Census.
>
> and
>
> "The death rate for people aged 18 to 34 with learning disabilities was 30 times higher than the rate in the same age group without disabilities, researchers found." (Public Health England, 2020) – https://www.gov.uk/government/news/people-with-learning-disabilities-had-higher-death-rate-from-covid-19

The role of 'supported housing' in increasing the rate of covid infections and deaths of learning disabled people is still to be fully understood, with a question of what better outcomes might have happened if independent living principles had been more widely applied before 2020.

Truly, if we do not learn from our political past then we are condemned to repeat it

“Who do we not save?”

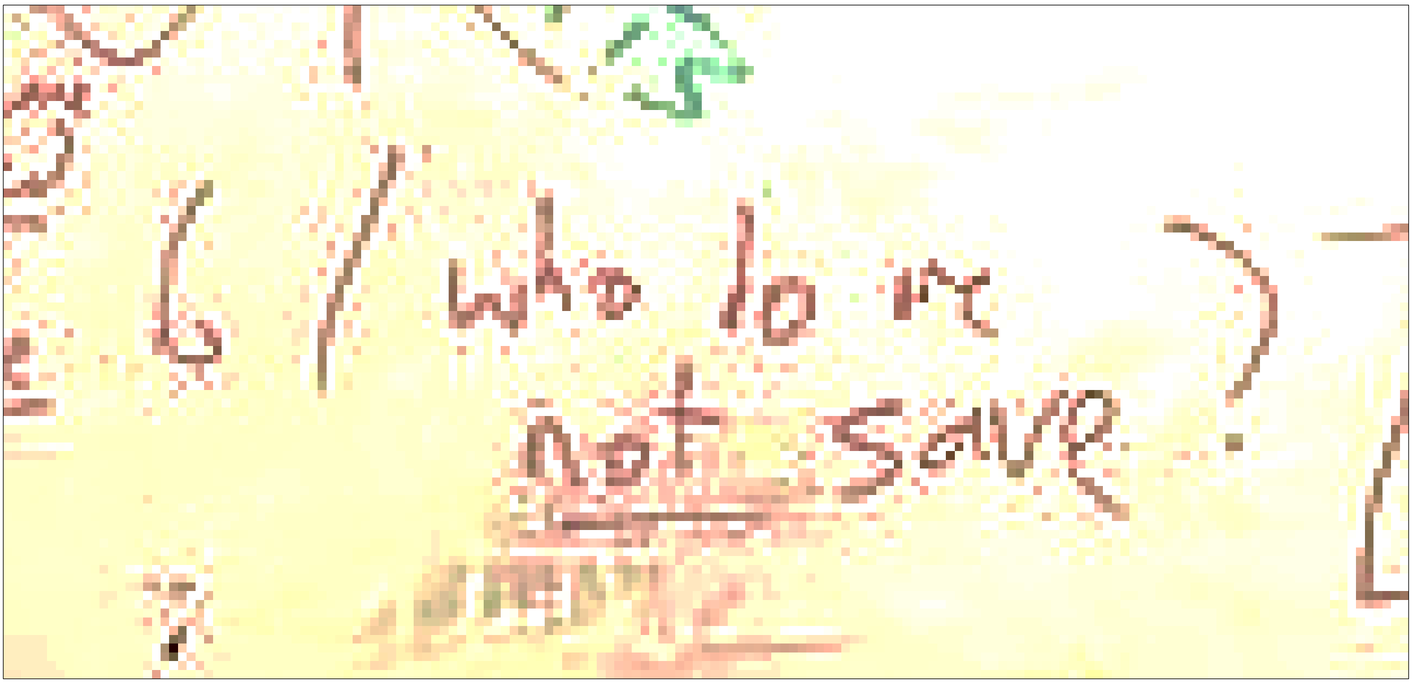

Image extract: Prime Minister’s Office, Downing Street, 13 March 2020
(Twitter 2020, and Covid Public Inquiry 2023)

* * * * *

Further research

There are a number of substantial books on the histories of disabled people in Britain, including the works of Judy Hunt, Anne Borsay, Jane Campbell, Colin Barnes and Mike Oliver. Their research has been of substantial assistance in this work on the NCYCS; however it must be noted for completeness that none of these 'canonical' works mention the NCYCS. (Full disclosure: I copy-edited and published the book, No Limits by Judy Hunt.)

I think it is worth speculating on why the NCYCS has 'slipped under the radar' of research to date, if only to try to fill in some of the gaps next time.

I think some major factors that might help in understanding this gap might be:

(1) NCYCS was in its legal essence a committee within the Labour Party. Somehow this places it in the province of political studies, potentially obscured from the view of disability studies. A phrase that jumped off the page for me in this regard was recorded by Judy Hunt, which I see also as being a comment on the role of political parties as seen by some campaigners:

> “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.” (J. Hunt 2019, p62, emphasis added)

(2) In campaigning and social policy, it can be a mistake for organisations to only see politicians as objects without agency, as people to be lobbied, in that they are empty of their own ideas and motivations. For want of a better phrase, the ‘feedback loop' from politicians back into social campaigns isn't always understood. The low esteem that the general public holds of its politicians maybe inhibits us in challenging this gap in thinking.

(3) History isn't only written by the victors, it is also shaped by what can be found in the literature from earlier times. The fact that NCYCS was hardly documented at the time has made it much harder now for researchers doing a literature survey to discover its existence and take its work into account. The purpose of providing so many

appendices to this research is an attempt to help improve the findability of the National Campaign for academic studies.

(4) In terms of the history of independent living campaigns, the resources of the big charities that were running residential institutions, "Homes", appear to have given them a louder voice. Thus much research focuses on Cheshire Homes and on the Spastics Society (as was, now Scope). To be fair, in historical accounts of the 1970s there are references to other initiatives in independent living such as the Crossroads scheme and the Grove Road project, and for the 1980s the growth of Centres for Independent Living (CILs) and initiatives such as Project 81. But accounts of independent living campaigns in the 1960s currently focus on residential institutions, income benefits, and adapted motor vehicles. The various direct escapes achieved by disabled people from hospital wards to live independently in the community don't currently get a profile as political acts of defiance. None of this is to detract from the excellent developmental work done in the 1950s and 1960s, especially by residents at Le Court; this is just to add more campaigning details alongside it.

(5) Some histories seem to rely too much on what the law says should be happening, and maybe a bit too little on the lived experiences recorded at the time. In particular, most formal histories of disabled people tell us that workhouses ended with the birth of the welfare state in the 1940s. But really, just because some Act of Parliament says so? Well, yes. The writings here are in disabled people's own words on what many geriatric wards were like to live in, and tell us about their lived experiences with the continued use of these workhouse buildings and their cultures, albeit with a new NHS sign on the front door. Surely at least some workhouses must be thought of as, in effect, still existing in the 1960s if not later, no matter what the law said.

I offer these points with humility and trepidation, but I do think that these considerations need to be part of the reflective approach by which research self-corrects and progresses.

* * *

This is a history of NCYCS. For me it suggests that a comprehensive history of independent living campaigns and practices in the UK needs to be investigated in detail and preserved too.

Acknowledgements

This 3rd edition

This research continues to grow.

In the second edition I said “it feels there is still more to find out” and this feeling proved right. With this third edition comes new details of four years (1970-74) of the campaign. Thanks must go to Simon Sheppard and Darren Treadwell at the Labour History Archive and Study Centre of the People’s History Museum in Manchester for finding a wealth of material, building on the papers in other archives in London, Liverpool, Hull and elsewhere.

2nd edition, 2021

> Title: We Are Bloody Angry: The National Campaign for the Young Chronic Sick (1965 – 1970) (ISBN 978 191 314 8140)

Despite this continuing research which has substantially expanded the 2020 publication for Alf Morris’ anniversary, it feels there is still more to find out about the National Campaign for the Young Chronic Sick and about the role of the Chelsea Labour Party in these campaigns.

I am especially indebted to Indy Bhullar at the London School of Economics who very kindly pointed me towards the additional NCYCS newsletters in the Alf Morris Collection held there; and to Luke Beesley who very kindly made extensive comments on a draft copy. All the mistakes remain my own.

This research is ongoing, and new contacts and suggestions are very welcome.

1st edition, 2020

Title: Alf Morris MP and the campaigning by disabled people that led to the 1970 CSDPA (ISBN 978 191 314 8119)

I am indebted to Maggie Davis for our many conversations, and especially in this research for her recollections of Joan Dawe, Pamela La Fane, Margaret Wymer and Jack Wymer, all disabled people fighting to create their own independent living in the 1960s with minimal legal rights and incomes. Maggie Davis, and Ken Davis, were younger disabled people learning from these older campaigners.

All but Joan Dawe wrote books about their struggles, and these have been the essential bedrock in this research. Other disabled people were also writing in the 1960s, notably Paul Hunt with Stigma, 1966, which he edited; and the numerous disability magazines such as Responaut, Magic Carpet, and Cheshire Smile, which while not being radical they provided a means for isolated disabled people to share ideas and connections. There was a fantastic amount of interest in “gadgets”, home-made devices to help disabled people live independently.

We know from Pamela La Fane that NCYCS had a committee, and that she, Marsh Dickson and probably Dorothy Dickson were members. And we know NCYCS had close links to the Chelsea Labour Party.

TB

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Note: The contributors to Cheshire Smile journal, and Guthrie and others for the Working Party report, are attributed here as the **authors**; the Leonard Cheshire Foundation and the National Fund for Research into Crippling Disease respectively are their **publishers**, but are not the authors in my view. TB

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Files held in the Alf Morris Collection, LSE Library

Archives and their collections

Hull

Socialist Health Association Collection
Hull History Centre, Hull University

Liverpool

David Owen Collection
Special Collections, Library, University of Liverpool

London

Alf Morris Collection
Special Collections, Library, London School of Economics
(Especially in box – “Morris 1 / 24 / 2”)

Co-operative Women’s Guild Collection
Bishopsgate Institute, Archives and Library Special Collections

National Newspapers
British Library (and online)

Manchester

Judy Hunt and Paul Hunt Collection
Disabled People’s Archive, Archives+, Central Library
https://disabledpeoplesarchive.com/

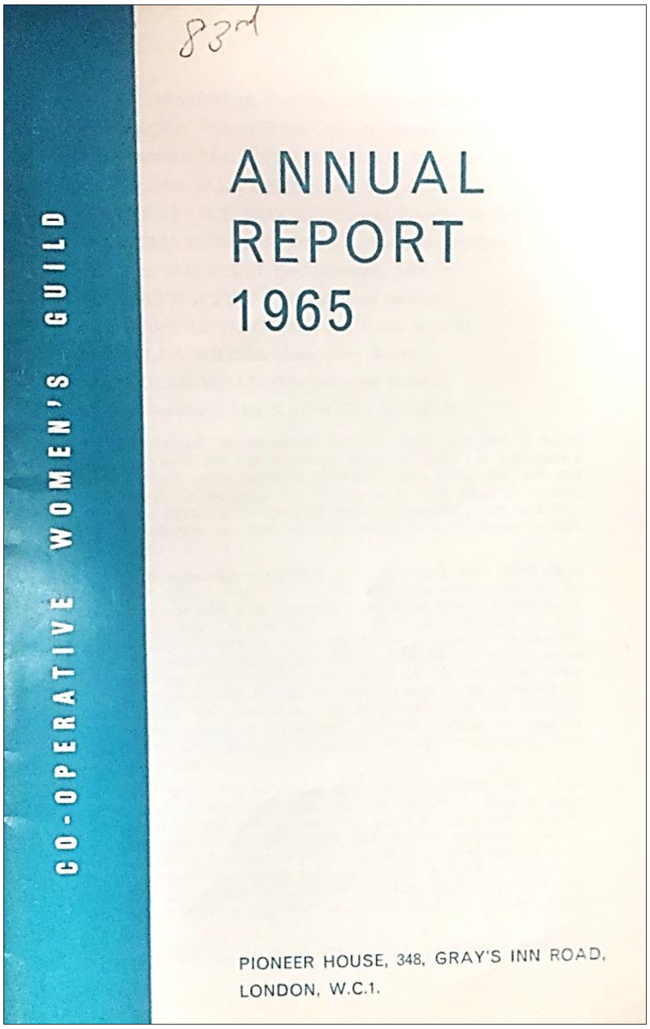
NCYCS Collections, & **Labour Party** Annual Reports,
Labour History Archive (LHA) and Study Centre
People’s History Museum

Oxford

Anti-Apartheid Movement Archive
Bodleian Library, University of Oxford (and online)

APPENDICES

A - Co-operative Women's Guild, Annual Report, 1965



83rd

CO-OPERATIVE WOMEN'S GUILD

ANNUAL
REPORT
1965

PIONEER HOUSE, 348, GRAY'S INN ROAD,
LONDON, W.C.1.

Congress held in Cleethorpes, May 1965

Resolution:
Hospital Accommodation for the Chronic Sick

"This Congress is of the opinion that more Hospital accommodation should be reserved for the chronically sick patients, and asks that Hospital Authorities cease to transfer such patients to Hospitals and Nursing Homes outside of their home town. Great hardship is imposed on elderly parents visiting such patients."

Annual Report: Disabled Housewives

The Congress resolution calling for pensions for disabled housewives was followed up with the Government. In addition support was given to the Disablement Income Group.

B - Labour Party Conference, 29 September 1965

Labour Party Conference Motion 93, Blackpool 1965

> This Conference urges the Government to remedy the plight of the young chronic sick by:
>
> a) enrolling and training special medical home helps;
>
> b) making mandatory and extending services provided by local authorities;
>
> c) paying relatives undertaking the care of the patient at home;
>
> d) establishing more Young Chronic Sick units near patients' homes and abolishing the present practice of confining the young chronic sick in geriatric wards with the senile.

Passed unanimously.

Mrs. Dorothy Young (Chelsea C.L.P.) moved resolution No. 93:

I am very conscious of the great responsibility which is mine to speak on behalf of the young chronic sick. The young chronic sick includes youngsters suffering from Duchenne dystrophy who will probably die by the time they are 20; multiple sclerosis patients struck down sometimes at a very early age to become utterly dependent on others; there are those, more often in middle age, so crippled by rheumatoid arthritis they can no longer manage on their own; there are polio victims, victims of accidents and many others.

Voluntary societies do their best to alleviate the suffering under present conditions. Our attitude as Socialists is necessarily quite different. Our job is to see that these conditions are changed so that these unfortunate people shall lead the fullest possible lives.

The home is the basis of human society and human happiness. This is particularly so for the chronically ill whose one consolation is the love and affection and comfort that only their own homes can provide. I could talk for a long time of the harrowing experiences I have had in seeing the young chronic sick in geriatric wards with the senile as their companions.

I have been to homes for the chronic sick and seen for myself the struggle they have to provide adequate equipment and always the same story of the long waiting lists because families are unable to cope for lack of funds and lack of trained medical help.

To realise the horrors of the many geriatric wards they must be seen to be believed I have seen them myself: the look of utter hopelessness on the faces of the aged packed like sardines in a tin, except it is a ward with two long rows of beds with barely space for a chair between the beds. In these wards our young chronic sick spend not only days, weeks, but years of their lifetime. I have seen young chronic sick patients that have been in geriatric wards for more than 20 years.

The brochure which the Chelsea Labour Party has produced and given to you today will give you facts and figures which must convince you that our young chronic sick are sadly neglected. I am quite sure a Labour Government—a Socialist Government—with the support and encouragement of the people will give to our young chronic sick a sense of being wanted and a sense of security. If we cannot restore their health the least we can do is to brighten their lives to the best of our ability.

It is most significant that as the age groups rise the number in geriatric wards rise sharply. This is partly due to the cumulative effect. Can you imagine what it would be like for a son of yours to enter a geriatric ward in his late teens surrounded by the aged. The years go by for him until finally losing all hope he either dies of unhappiness or in self-defence withdraws from life into empty existence.

Then there are the multiple sclerosis patients: for instance, the young woman with small children because of the lack of the right facilities would not be able to cope at home. Unless the husband is really well off he cannot afford the something like £15 a week which it costs to have trained adequate help while he earns the family living. Then, of course, she loses the loving environment of her own home and she is forced into an institution with long hours of emptiness between visits and only too often she loses the home she has built and the children—

> **The Chairman:** I am awfully sorry, you have had more than one minute over your time already. I see you have a lot still to deliver, but if you wind it up very quickly we shall be obliged.

Mrs. Young: All right. Should our young chronic sick be considered as equal citizens and be enabled to live as full a life as possible or should they be put away where they cannot disturb us with their uncomfortable reminder of the reality of disease and suffering? Can I remind you, it could be someone we love or maybe ourselves? I ask you in the names of our humanity and all that our Party stands for to vote for this resolution.

Mr. Leslie Massey: (Kensington South C.L.P.)

[Speaking to second the motion]

The young chronic sick can be divided into three categories: those who on medical grounds must be institutionalised - and I make no bones about using this unpleasant word, it has an unpleasant meaning; a much larger group who under present conditions have to be institutionalised because the problems such as incontinence are too much for the families to cope with, because they have to be left alone between visits of home helps and district nurses whilst their spouse, parent or child earns the family living and also because of the unrelieved strain on those caring for them when it just becomes intolerable; and of course, there are those who are being cared for in their own homes.

The purpose of this motion is to keep the patient in his or her home for as long as possible until it is absolutely necessary on medical grounds for the patient to go into an institution.

Now how can we keep them in their homes? I think there are four basic ways in which this can be done. First of all, there is the provision of a special medical home help who could care for the patient and home whilst the husband or wife or parent or child earns the family living. Present-day home helps have not the training or time to carry out these duties and district nurses (already overworked) have a purely nursing function. Such personnel must be at home in the family environment and a short period of training in a hospital in wards where young chronic sick are admitted would be necessary. They would further be ideally suited to train and relieve relatives caring for patients and proportional charges according to family income could be made for this service.

There is also a lack of a mobile physiotherapy service which often results in patients having to leave their homes for an institution earlier than necessary. We would ask the Government to investigate the present deployment of available physiotherapists and give a pledge that as soon as possible the provision of a mobile physiotherapy service shall be available physiotherapists and give a pledge that as soon as possible the provision of a mobile physiotherapy service shall become part of the National Health Service.

The next point we would put is that payment of the relative or friend caring for the patient should be investigated. This is to the advantage of the National Health Service in the freeing of hospital beds and to the patient and to the family and a great advantage of this scheme would be the consequential decrease in the number of special medical home helps required.

Finally, a periodic admission to a suitable convalescent home or young chronic sick unit to allow the family a regular holiday. This is done in certain places but should become general practice.

Now what do we want for the state where the patient has to be institutionalised? We want more young chronic sick units to be established to abolish the confinement of young chronic sick patients to wards with the senile and the dying. There are some patients in London who have lived in such wards for more than 30 years and I think this is quite disgraceful. Throughout England and Wales there are only 664 beds in young chronic sick units or such special institutions and we think this should be increased. The Regional Hospital Boards in East Anglia, Manchester and Liverpool make no special provision whatsoever for the young chronic sick. In consequence 140 patients between the ages of 16 and 35 lie in geriatric wards; 920 patients between 36 and 50 lie in these wards; and well over 2,000 between 51 and 60 lie in these wards.

Now we are very grateful to Mr. Arthur Blenkinsop [MP] for getting these figures. All the figures that we base our requirements on have been gleaned from Hansard and these figures were got from Parliamentary questions.

I would also like finally to say to those members of this Conference who serve in any capacity in welfare or health committees that they should really look into this situation in their own local districts and if you can give us the support today to try and press the Government to do something on a national scale and if you can look at your own situation back at home we shall be indeed very grateful.

C - Labour Party Conference 1966

Labour Party Conference, Motion 141, Brighton 1966

“This Conference urges the Minister of Housing and Local Government:

(a) To require local authorities to provide statistics of registered and unregistered young chronic sick in their jurisdiction according to the age grouping used by the Minister of Health as a distinct section of their disablement register;

(b) to make mandatory the provision of day centres and adequate help in the home other than 'home helps' to ensure that the chronically ill shall not be institutionalised unless this is medically inevitable;

(c) to make mandatory on local authorities the provision of adequate housing based on the statistics in section (a) above.”

This motion was not debated, but the following speech was heard:

Mrs. P. Sears (Chelsea C.L.P.):

Comrade Chairman, Comrades, I was very pleased to hear the last speaker talking about a register for old-age pensioners for local authorities. We are asking for a register of the disabled and the chronic sick; we have asked for this in our resolution which is not going to be called and so I have come up here to tell you what has happened to our Resolution of last year. This was passed by Conference and nothing has been done, it was passed by the Labour Women's Conference and nothing has been done, and this is partly because we do not have the figures and people do not understand what the problem is.

I hope you have all had this leaflet which I have been passing round. On the back of it you will see what an enlightened council can do; they have found out the figures and having found out the figures they have done something. They have put forward their programme for disabled people's houses five years (sic). This is the sort of thing we want done, and it will not be done until councils know what is happening.

We are told that the Minister of Housing and Local Government is going to give extra money to councils; I would ask Tony Greenwood, if he gives this money, to make sure their permissive powers – the way they can help disabled people – are no longer permissive but mandatory. This is what we are asking for, and I would ask all of you here to go back home to your constituencies and do something about it.

Many of you are councillors, I have spoken to some of you, but how many of you know what the problem is in your area? I was a county councillor and, quite frankly, I did not know about this when I was. I am ashamed to admit it, but admit it I do. I hope you will admit it and go back home and do something about it.

We want all of you to help, we have heard on the television, "What use is Conference? Can Conference influence the Labour Government?” Well, Conference can certainly influence your local government on this, because a great many of you are representatives on your local government. Local government elections are coming along, these poor people fall between two stools; part of their work is under the National Health, part of it is under local government. That part of it that is under local government, I want all of you to help in doing something about. This is Help the Disabled Week, you may have seen the charities are organising things. These people do not want charity, they want hope, they want faith in the Labour Movement, and above all they want justice from you, Comrades, every one of you from the Ministers down to our people who go out and knock up for the local councillors. Thank you. (Applause.)

D - Labour Party Conferences 1967

Conference Resolutions

Please mandate your delegates to vote on the following resolutions.

NATIONAL CONFERENCE OF LABOUR WOMEN

56 This Conference is deeply concerned at the plight of the Young Chronic Sick who are often accommodated in geriatric wards and urges the provision of adequate accommodation for the aged to relieve this situation.

Norwich Labour Party

LONDON LABOUR PARTY CONFERENCE

53 This Conference urges the Government to require, and all Labour Groups in the London area to press for, the publication and break-down of statistics of the chronically sick and disabled between the ages of 16-60 as done by the Borough of Lambeth, in order that action shall be taken at local government level with-out which the chronic sick have little hope of attaining the equality and social justice to which they are entitled.

South Kensington Labour Party

EASTERN REGION LABOUR PARTY CONFERENCE

22 This Regional Conference notes with regret the wide variation in treatment facilities for Young Chronic Sick patients within the Regional Hospital Board Areas in the Eastern Region and in calling upon all County, Borough, and District Councils and all Hospital Authorities to work unremittingly towards an equalised high standard of Home and Institutionalised Care, it urges also Parliamentary representation to seek a firm policy directive from the Minister in pursuance of this information.

Epping Labour Party

E - Co-operative Women’s Guild, Annual Report, 1968

Congress held in Southend, 1968

Resolution: Care for the Young Chronic Sick

“This Congress urges that:

(a) No young chronic sick patients shall be admitted to geriatric wards.

(b) When institutionalisation is inevitable for such people it shall be in Young Sick Units.

(c) New adequate services and payments shall be introduced to enable young chronic sick patients and chronically disabled persons to live in the environment to which they are entitled – in their own home.”

F - Labour Party Conference 1969

Labour Party Conference 1969, Brighton, Resolution 285:

On 3 October 1969 Mary Gray from Wycombe CLP was the main speaker to the conference delegates on the NCYCS policy motion that year, which stated:

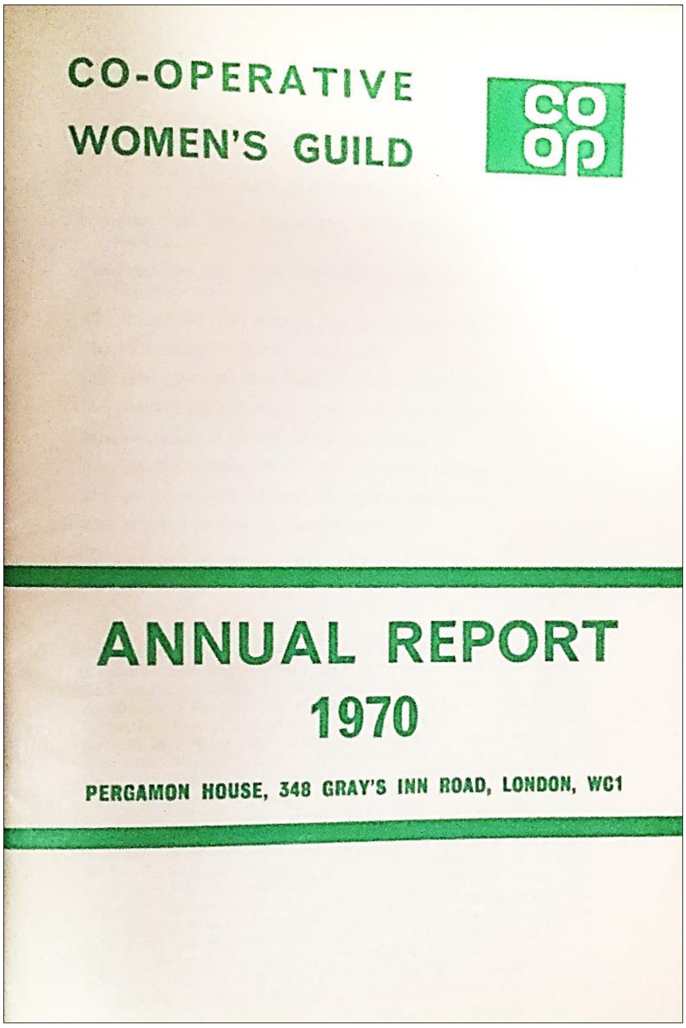
> **Resolution 285:** "This Conference call on the Government to ensure that the chronically ill and disabled are made aware of all their entitlements both financial and physical, and to make mandatory on local authorities those powers to help the chronically ill and disabled, which are presently permissive, ensuring the necessary funds to make this possible. This Conference further calls on the Government to abolish all distinctions between different categories of the chronically ill and disabled with regard to entitlements."

In the main this resolution, or motion, was about the different levels of income benefits paid to disabled people which depending on their gender, and on how they acquired their impairment. Mary Gray gave the following summary in her speech:

> "For example, if a man falls from a ladder at work and permanently injures his spine, he will, if lucky, be covered by industrial injuries and the new invalidity and attendance payments. But if the same man has the same injury while picking fruit in his garden, his entitlement financially is much lower. If his wife should climb the ladder and receive the same injury, she would be entitled to even less, or indeed, nothing at all. Is this social justice? Is this to each according to his need?"

G - Co-operative Women's Guild, Annual Report, 1970

Congress held in Scarborough, 1970



CO-OPERATIVE
WOMEN'S GUILD

ANNUAL REPORT
1970

PERGAMON HOUSE, 348 GRAY'S INN ROAD, LONDON, WC1

Resolution: Physically Handicapped

"This Congress believes that facilities for the mobile physically disabled in public and semi-public places are inadequate and unnecessarily restrict such persons in living a life to the extent of which they are capable.

We accordingly call upon the Government Departments concerned with planning and local planning authorities to refuse planning approval for public buildings and other places open to the mobile physically disabled, commensurate with their numbers within the community, when such facilities are not provided.

It further calls upon the Guild to actively campaign for the provision of facilities for the mobile physically handicapped."

Annual Report: Help for the Disabled

In connection with the Bill presented by Mr Alfred Morris MP, an appeal for help for the Young Chronic Sick was circulated and Branches are urged to follow up the matter.

H - Labour Party Conference 1971

Labour Party Conference 1971, Brighton, Resolution 285:

> "This Conference calls on the Parliamentary Labour Party and the National Executive Committee to press for full implementation by local authorities including ILEA [Inner London Education Authority] of the Chronically Sick and Disabled Persons Act, of May, 1970 taking special note that the intention of Section 1, is to identify all the chronically sick and disabled in local authorities areas; also that the Association of Municipal Corporations circular completely and deliberately misrepresents the intentions of Section 2 (h) in an attempt to exclude the majority of those entitled to a telephone under the Act." (Resolution carried.)

This motion was proposed by Betty Shuttlewood, Sudbury & Woodbridge CLP, and seconded by Graham Towers, Chelsea CLP.

These two speakers talked delegates through the main provisions of the Act, emphasising the need to make all its powers mandatory instead of some being only permissive, and the need for delegates to take these issues back to their councils for local funding from the rates (pre Council Tax) and implementation in the face of hostility from the Conservative national government.

Graham Towers was especially scathing about a circular [a briefing note] that had been recently produced by the Association of Municipal Corporations with the title, The Provision of Telephones for Disabled People. He said:

> “the criteria it lays down are vicious in the extreme … so vicious … that ninety per cent of the chronically sick people would be barred from receiving their rightful benefits. This local authorities circular has no basis is law [and] must be ignored.” (Graham Towers, Chelsea CLP, page 291, Conference Report).

I - Labour Party Conference 1972

Labour Party Conference 1972, Blackpool, Composite 42:

"This Conference considers the problems of the physically and mentally handicapped, and those of the aged, as major areas of concern for the next Labour government, which must endeavour to bring those two groups fully into the community, and end their present almost complete isolation.

Accordingly, it demands that the next Labour government establish two departments under separate junior ministers to deal with the old and the handicapped with those powers to co-ordinate the activities of all other ministries in those fields. Furthermore it demands that the National Executive Committee immediately begin work along the following lines:

- (i) That the research department at national and local level keep itself informed of the way in which local authorities are implementing the Chronically Sick and Disabled Persons Act, and other relevant legislation and help co-ordinate the work of the Labour groups at a regional and national level.
- (ii) That regional committees set up groups composed of socialist specialists in the problem of the physically and mentally handicapped to consider and recommend to local authorities and national government the best ways of bringing the handicapped into their rightful place in the community.

Conference calls on the National Executive Committee to include in its next election programme a declaration that the next Labour Government will:

- (a) Introduce a broadly based national disability income for the blind and other disabled persons;
- (b) finance all aspects of the Chronically Sick and Disabled Persons Act from the national purse and this can be met by part of the proceeds of the nationalisation of financial institutions and the private pension schemes, by arms cuts and wealth tax and by increased National Insurance contribution from employers."

1 – Lord Amulree, House of Lords speech, 8 October 1946

Basil Mackenzie

Second Reading, NHS Bill

My Lords, this is the first time I have had the pleasure of addressing your Lordships and I hope I may claim that indulgence which is always afforded to speakers in that position. The first thing I am very pleased to see in this Bill, and I think it will be a great improvement in the service, is the clause dealing with the provision of regional hospital services.

…

The second point I want to make is in regard to the large body of the sick who I think will benefit enormously from the transfer of the municipal hospitals to the central authority. I am now referring to that sad and melancholy collection of patients who are usually classed together under the general term "chronic sick." It is very hard to say what the number of those patients will be, but, so far as I can make out, in 1944 there were about 60,000 for the whole country, of which about 6,000 were in London. I do not think there was anywhere near enough treatment for them, because one has frequently heard tragic tales of people suffering from one of the chronic incurable diseases who could not get treatment at any hospital at all. There has been a tendency to say that these people are old and not much can be done for them before they die. That again is not at all true, because if you take the total figures of the chronic sick you will find that at least 30 per cent. are under 65 and ten per cent. are under 45. So you have a very mixed lot who are at present treated in some of the smaller institutions in conditions which are really deplorable and almost Dickensian. No attempt has been made to classify them. You get young people in the same wards as [learning disabled people] and [elderly] people suffering from senile dementia, and all kinds of people are jumbled together with no attempt to treat them and they have no examination before they go in.

There is generally one doctor on the staff who comes in occasionally, but the patients are never given the benefit of an examination by anybody of consultant or specialist standing and therefore no attempt can be made to treat them or to remedy their condition properly. It was thought that their condition might improve when the Local Government Act of 1929 was passed, under which it was possible to transfer the Poor Law infirmaries, where the bulk of these people are housed, from the Public Assistance Committee to a committee of the local authorities. But that did not quite work out as expected, because once that transfer took place, as it did in a good number of towns with progressive authorities, the medical attendants who were appointed to the staff of the new hospital tried to turn the place into a general hospital, with the result that the conditions of the chronic invalids was not made very much more comfortable. That is quite understandable, because other cases are much more interesting and one feels that one is doing much more good if one is treating a number of patients for a very short-term disease.

The real trouble about these people is that once they went in there they were admitted for life and there was very little or no chance at all of their ever seeing the world again. There is one particular tale that I was told by a friend of mine who was a doctor. About fifteen years ago he went into practice in the country, and one of the places where he visited was the local Poor Law infirmary. He was there for about a year and then moved to somewhere else. About fifteen years passed and he went back to the same part of the country on some other work. He called at the infirmary, where he was pleased to find that the same master and the same matron were there as well as several of the nurses. What really horrified him, however, was to find that a large number of the same patients who had been there when he had seen them fifteen years before were still in the infirmary. They had never left the building. There is another story which I was told. It did not happen to me personally. A new doctor was appointed to one of them Public Assistance infirmaries. He went there and was inquiring what was wrong with the various patients when he came to one woman who looked youngish and seemed quite well. He said: "Why is that person in bed?" and the nurse replied: "I do not really know. I have been here five years and she has been in bed all the time." Those two stories are typical of the general attitude of a large number of people in this country.

For a very long time nobody thought there was very much you could do about it; there was a kind of defeatist attitude that there they were and there they lay. However, fairly recently one or two doctors have been put in charge of the chronic sick wards at these institutions, and because they were interested in seeing what they could do for the people there it has been found that a remarkable change can take place if a proper approach is made. There is one big institution which I know not far from London where they have got an extremely good medical officer in charge of the chronic sick wards. She has been there now for about fifteen years. When I went down to see her the other day she told me that about 60 per cent. of the patients who came into the chronic sick ward were discharged and went into their own homes, or if they could not go to their own homes they went to various hostels for old people, or somewhere like that. I asked her "Can that be done by anybody or is there something special or expensive about it?" She said "No; you have merely got to realize that these patients are sick, and that it you have got a person who is sick the first thing you have to do is to make him better and get him up out of bed and walking about."

I do hope when we get this Bill passed and the hospitals are taken over, that the chronic sick wards will become part of the big acute sick wards. I do not think it will be possible to do it physically, because they are generally separated and in different parts of the town, but that does not seem to me to be of any great importance. It should be possible for the chronic sick to get the same medical attention from the same staff which the acute sick get who go to the voluntary hospitals. I think that no persons should be admitted to a chronic sick ward without first passing through an acute sick ward of a general hospital where they can be seen by a consultant and specialist, a line of treatment can be worked out for them, and they can continue to be seen by these doctors during the rest of their stay. It will probably be the case, then they have been seen, that they will have to be put into two categories, because I think there will be those who can be cured as well as those who are going to be chronic invalids and will probably stay in bed for the rest of their lives.

It is very important that accommodation should be prepared for them where they can stay for six months, nine months or whatever it is. If you have these rather unattractive old buildings, something can be done to make them more cheerful and more comfortable for the people who have to spend the rest of their days or long periods in them. A tremendous amount can be done with colourful curtains, flowers and counterpanes. If you go into the normal Public Assistance infirmary you will find it is a most depressing place. The walls are usually painted brown and the lights are wrong; as you lay in bed you have lights shining in your eyes all the time. Simple things like those I have suggested will make a tremendous difference to those places, and also to the nurses and the patients. I hope that will be one of the directions in which progress will be made when this Bill comes in.

Arising out of that, there is another thing on which I should like to touch briefly. Although I have said a certain number of these chronically sick people are comparatively young, the bulk of them, naturally, are elderly. You will get into a very difficult position if you try to separate your elderly people into those who are healthy and those who are sick, having the sick under one authority and the healthy under another. Both, I think, should come under the medical authorities. When people grow old, there is a very narrow borderline between sickness and health, and there has got to be a simple, easy flow to and from the hospital, if they want to go in for a few days and come back again to their homes. That is a thing which can be done very simply and easily. It has been done. I have just paid a visit to some of the Public Assistance buildings in France, and there the central authority takes charge of all people who want any kind of institutional treatment, whether they are sick or healthy. A certain number of voluntary bodies in this country founded homes for old people, and they all began with the idea that they were not going to have any sick people in them; they were going to be purely for healthy old people. In two of them which I came across quite recently that just did not work, and I think they have realized that if you are going to have a collection of old people living together you must have some kind of sick ward. If you try to organize any kind of institution for old people and there is a sick ward there, you are going to get a recurrence of the old Poor Law infirmary, which is a thing we have been trying to get rid of for a long time.

2 - Audrey Davis, Interim Report, Socialist Medical Association, Chronic Sick and Aged, 1951

Socialist Medical Association [1],
86 Rochester Row, SW1

Chronic Sick and Aged Sub-Committee

Interim Report

PAST

Boards of Guardians, under the Poor Law Amendment Act of 1834, were enabled to build workhouses and, in time, were forced to build Infirmary blocks for the sick who were either transferred from the Homes or from another hospital or from their own homes. All “destitute” had right of admission through the Relieving Officer – “destitute” used in the broad sense, not necessarily financial.

Appearance:

Built in the 19th Century – stone stairs with metal banisters, high narrow treads. Walls of unplastered brick painted in two shades of green or brown. Sanitary arrangements very inadequate. Day rooms unattractive and so crowded as to make life a misery for the “inmates”.

Medical Aspect:

Clean bedding, plentiful but uninspiring meals. Standards of nursing sometimes surprisingly high, although usually only senior staff were trained nurses. Large institutions had Medical Superintendent and one or two assistant medical officers. Smaller institutions often staffed by overworked general practitioner and a matron. Wards contained ill-assorted groups ranging from young adults or children to senile dements. A few institutions had improved and resembled general hospitals.

When these hospitals were surveyed at outbreak of war in 1939 (to find which of them were able to take air-raid casualties) it was found that there was a large amount of unrelieved sickness. Excellent results were, however, being obtained in one or two large municipal hospitals, notably West Middlesex [2] at Isleworth where “chronic” sick were classified and treated.

PRESENT

Since 1949 care of chronic sick has been responsibility of Regional Hospital Boards and Boards of Governors of Teaching Hospitals (under National Health Act). The major local authorities have been responsible (under National Assistance Act) for those who are unable to live normal lives. There is no statutory liaison between these two authorities and it is not always easy to decide who is responsible for infirm persons who are neither well nor ill.

National Assistance Act established 300 area officers. The officers will call on the old people if required to do so, but the present service has replaced one existing before where there were 1,500 Relieving Officers operating a 24-hour service.

There are 50-60,000 beds for chronic sick patients in the country (80/90% occupied by patients of 60/65 and over). 5,000 beds are empty owing to shortage of nursing staff. Problem is therefore primarily one of getting these empty beds into use rather than the provision of more new beds.

Children are now not normally nursed in old peoples’ wards.

One of the greatest problems is the number of patients who are occupying “chronic” beds for social and not for medical reasons, ie because they cannot be looked after in their own homes or in old peoples’ homes run by voluntary associations or local authorities. With proper medical treatment, including occupational therapy and physiotherapy, many of these patients, even those who have been bedfast for a considerable period, can be restored to reasonable health. The problem still remains, however, of their disposal when they are fit.

FUTURE

Suggestions made in Lord Amulree’s book: [3]

1. In chronic wards and in the old Infirmaries the senile dements should be separated from the others and nursed in a separate ward.

2. Wards should be brightened up by painting in bright colours, dividing up into smaller units, possibly by the use of cubicles, and the use of

pictures on the walls and curtains at the windows. This action would have beneficial effect on the health and certainly on the mental condition of the patients.

3. Occupational therapy and physiotherapy to help patients’ mental condition and to get as many of them as possible fit for a normal life and thus cut down the average length of stay in the chronic wards. It is important that these old people should feel of use and it is recommended that they should be able to earn money by sale of articles made during occupational therapy.

4. Chronic sick patients who will continue to need hospital treatment should be nursed in "long-stay" annexes.

5. Home Hospital Service - Minister of Health promised that no domiciliary service would be introduced but one or two British hospitals are operating such a service. Patient remains under care of general practitioner but under supervision of medical officer from hospital who makes an initial visit to the patient at the request of the GP. Many ailments such as foot ailments could be satisfactorily, and much more cheaply, treated in the patient's home.

6. Provision of more homes for patients who are sufficiently restored to health not: to need to stay longer in a hospital bed but too infirm for Homes run by local authorities or voluntary bodies. People in these homes should remain under medical supervision of the hospital and there should be a "two-way traffic" between home and hospital.

December 1951 Audrey M Davis

Notes

1. SMA changed its name to Socialist Health Association in 1981.
2. “West Middlesex” refers to the work of Dr Marjory Warren.
3. Lord Amulree’s book is, Adding Years to Life (1951).

3 - Geoffrey Cheshire, letter to The Observer, 28 June 1953

‘The Unwanted’

Sir,

As Group-Captain [Leonard] Cheshire's father, may I ask you to clarify two points arising from last Sunday's reference to the Cheshire Foundation Home for the Sick, Le Court, Hants, which might otherwise mislead your readers?

First, it exists for the benefit of those young chronic sick and permanently disabled who, not having homes of their own to cope with them, would otherwise have to face more or less life-long inactivity in the senile wards of our hospitals; it is only in this sense that the patients at Le Court could be regarded as "unwanted", since the Foundation is not a last refuge for the dying or the social outcasts.

Secondly, although the generous benefaction of the Carnegie Trust, when completed next year, will enable those at Le Court to move from their present very dilapidated mansion into a fine new building, there is as yet no financial provision for furniture, equipment or endowment. Le Court still needs generous aid if it is to fulfil its unique pioneering task in this vital field of social medicine.

Yours faithfully,

Professor [Geoffrey] Cheshire,

Liss.

4 - BBC TV programme, 27 Sept 1955

BBC TV, Tuesday 27 September 1955, 19:30

From the Radio Times: (i) a programme listing and (ii) a feature article:

(i) Title: Founded on Failure

Seven years ago in a derelict mansion a dispirited man sat contemplating the failure of his ideals and hopes. To that house came a former aircraftsman, dying and in need of a home. The relief of this man’s need, and that of others like him became from that moment a driving force in the life of Group Captain Leonard Cheshire VC, DSO, DFC.

In this outside broadcast he revisits the first of the eight homes he has so far founded, and introduces some of his friends – the incurable and disabled people who are now ‘at home’.

From Le Court, Liss, Hampshire.

Subject: Group Captain Leonard Cheshire
Interviewer: Raymond Baxter
Producer: Derek Burrell-Davis

(ii) Peace-time Mission of a Bomber ‘Ace’

by Andrew Boyle

On Tuesday [27 Sept 1955, 7:30pm] television cameras will go to Le Court, in Hampshire, where seven years ago Group-Captain Leonard Cheshire discovered his vocation - ‘to relieve the sufferings of the unwanted, chronic sick.’ The background to this story of a successful venture in practical idealism is sketched here by ANDREW BOYLE, whose biography of Cheshire, ‘No Passing Glory,’ will be published next month.

Viewers looking for ‘sermons in stone’ may be disappointed when the television go to Le Court on Tuesday. The big house which seven years ago became the first Home for the chronic sick founded by Group Captain Leonard Cheshire, v.c., is no longer a landmark in the gently undulating countryside around the Hampshire village of Liss. Stone by stone, the demolition men have pulled it down until only the rubble and the scarred bare ground show where it stood. Even in its heyday, however, when Le Court was the country seat of a shipping magnate half a century ago, the house would hardly have ranked as a historic monument. Architecturally, it was undistinguished except in the wooded distance. Its tall chimneys and angular grey mass, seen from the main road to Alton, latterly gave an illusion of solid Victorian comfort which slowly dwindled as one climbed the steep rutted drive towards the rather prosaic, dilapidated reality.

Cheshire bought the house cheap from an aunt by marriage in 1946, during a critical period of his ill-starred venture to establish self-sufficient colonies for unsettled [homeless] ex-servicemen. This short-lived project in social idealism virtually collapsed while he was recuperating from illness in Canada. He was recalled in late 1947 to face crippling debts of nearly £20,000, which he defrayed largely by selling the 300-acre estate surrounding the house. Le Court itself he kept. With the small group of colonists who remained, he still hoped somehow to make a living - either by turning the place into a country hotel or letting it out in flats. Providence decreed otherwise.

In April, 1948, Cheshire returned from a short holiday to discover that one of his former colonists, an elderly, self-effacing man called Arthur Dykes, was dying in Petersfield hospital of incurable cancer. Dykes had no relatives or friends able to care for him at home; the hospital, lacking space and facilities for incurables, could not guarantee to keep him, nor yet to tell him his true condition until provision had been made for him. As Le Court was Dykes's last known address, Cheshire was confronted with an extremely difficult dilemma. He resolved it with characteristic courage - by undertaking to tend the cancer victim himself, learning the rudiments of nursing as he went along.

The patient's last four months of life at Le Court marked the birth of Cheshire's vocation as a man pledged to relieve the suffering of the unwanted, chronic sick. But those four months meant far more in terms of his spiritual development. The drama of the sick room, of Dykes's death, of Cheshire's conversion to Roman Catholicism, and of Le Court's more gradual conversion into a real home where discarded wrecks regained their self-respect as human beings has been told before, invariably in edifying, oversimplified accounts that ignored the extraordinary complexity of Cheshire’s own character. Usually depicted as a man already half way towards eccentricity or sanctity, he was then - as he is now - one of the most fascinating yet unpredictable men of his generation. The few who were closely involved with him in the establishment of the original Home know that Cheshire is a man who combines a gloriously wild trust in Providence and an elaborate form of selflessness with an uncanny flair for making things happen at his own pace. The strangely inspiring story of Le Court’s growth is inseparable from his own. Indeed, the return of Arthur Dykes was a far more decisive turning point in the career of this ‘ace’ bomber pilot than, for example, his final wartime mission to Nagasaki (beloved of the legend-makers). Whereas the sight of atomic destruction left him elated and unmoved, the plight of Dykes and the experience of tending him fundamentally changed Cheshire’s outlook.

The house where all this happened has disappeared. So have many of the early patients and staff. But if the demolition men have done their work well, the spirit of Le Court lives on in Cheshire’s six other Homes (founded since) as well as the new, functional, red-brick building - about 200 yards away across the lawn - which now replaces the old. In 1952 the UK Carnegie Trust gave a grant of over £65,000 to rebuild Le Court - and late last year the patients and staff moved in, bringing the old ideals with them.

5 - Questions in the House of Commons, 1956

Young Chronic Sick

6 February 1956 (Hansard, vol 548)

Mr. Hastings [Backbench MP, Labour]

> - asked the Minister of Health in how many of the hospitals under his charge there are special units for relatively young patients who are suffering from chronic illnesses from which they are not likely to recover; and whether he will point out to regional boards the value of such units.

Mr. Turton [Minister of Health, Conservative]

> Regional boards have not been asked generally to set up units of this kind because it has seemed better for a young chronic sick patient to be in a hospital near his home, where he can be regularly visited. I understand, however, that in ten hospitals it has been found possible to try special arrangements for groups of the young chronic sick.

Mr. Hastings

> Does the right hon. gentleman appreciate the condition of young people with chronic rheumatoid arthritis, etc., who spend perhaps twenty or thirty years of their lives in a chronic sick ward where there are old people who are dying at intervals, and from which no one ever goes out alive?

Mr. Turton

> I appreciate that very much. That is why we try to keep the young chronic sick together in wards; but I think it is important to make every opportunity for the young chronic sick to be near their homes, so that they can be visited by their relatives.

6 - Ann Whitaker, Studying the Problem, 1959

Studying the Problem

by Ann Whitaker, in Cheshire Smile, Autumn 1959 (vol 5 no 3, p3-6)

> [She is] A hospital almoner, author of a recent report on the care of the young and middle-aged chronic sick, [and she] provides us [in the article below] with a summary of her report, [which is called:].
>
> > “The Disabled Young and Middle-Aged (15-55 years) in Chronic Sick Wards, Local Authority Accommodation and Homes in one of the Metropolitan Regions of the Health Service. The report of a survey sponsored by the Nuffield Foundation.” 1959

This study was made in 1956-57 by a hospital almoner with the medical advice of a consultant in physical medicine. It sought to discover how many of the disabled 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.

The entire hospital region was not covered but 314 cases were included and 57 establishments visited. We hope that these figures dispel once and for all the view that this category of sufferer is too small for its needs to be especially catered for.

The most important findings were that no one (including those in hospital wards) needed a resident doctor, that 157 were not on treatment of any kind and that a further 86 were on drugs only. The consultant advising (who made a clinical examination of patients) rarely thought that further investigations or specific treatments for a patient's condition were necessary; on the other hand 58 needed expert medical help in making a better adaptation to their disability and in achieving a greater measure of personal independence (re-education in walking, more efficient wheel chairs, or a study of individual problems related to independence).

At the time of the enquiry 191 of these patients were under the care of fully trained nurses and were mainly in hospital beds. The doctor judged, however, that only 83 of these really needed the care of a trained nurse. These 83 were those who were helpless and unable to move in bed, or who (among the women) had a special problem of urinary incontinence, those with pressure sores, catheters and colostomies. The other patients being looked after by trained nurses could well have been cared for by much less skilled attendants as their care amounted to assistance in lifting, in dressing and in the bathroom and lavatory. The need for really expert nursing for those who do need a nurse's care has, however, to be emphasised and for these most severely disabled there can be no possibility of a fuller and more normal life except against a background of expert nursing. In every case, whether a nurse or an attendant is concerned, the help needed is of the most repetitive kind. The enquiry revealed that nearly half the patients needed help involving lifting and that 89 needed attention at night. 136 were chair-borne (sic), 125 “ambulant”, while only 54 could climb stairs.

Most patients needing an indoor wheel-chair had one but when a patient had come to need a chair after permanent admission to hospital he was often given the use of any chair available on the ward, whether it was really adapted to his needs or not. Sometimes this led to his being unnecessarily dependent and restricted in movement and real hardship occurred when, transferred to another hospital or home, he had to leave the chair behind. Enquiry revealed that the supply of self-propelled and motor-chairs to those capable of managing them was haphazard, although to have one often worked a wonderful change in the disabled person's life. Sometimes a doctor, at others a nurse, or a physiotherapist, or the patient had the idea. Once so equipped patients felt that they could escape from the narrow and artificial life in the ward to a more normal life outside and some preferred to be out of doors in their chairs however unsuitable the weather, only returning when strictly necessary.

The craving for activity and for a more normal existence was very marked among the people interviewed. Patients whose mental and emotional powers were not impaired, or only slightly impaired, by illness were entirely out of place in the old people's wards and homes. Distress was not, on the other hand, related to age, the most vigorous mentally, whether at the top or bottom of the age group, being usually the most out of place. The sense that there was nothing else for them, that they were entirely cut off from the outside world and destined to remain so, boredom, unhappiness at constant association with the very old, the deaf and the senile — these were freely and repeatedly expressed. Many explained that they wanted something different from hospital life. Two wards especially for the young chronic sick were visited. Patients there who had previously been in wards for old people were so delighted with the change that they had no complaints; those who had never been with the old were restless at having to be in a hospital at all and longed for a more normal routine and for more activity and opportunity to share in the everyday life of the world about them.

The report recommended that the mentally alert young and middle-aged disabled should be accommodated in what, for want of a better word, it called "residential centres". These were to be administered by the regional hospital board but disabled people who would normally be the responsibility of local authority welfare departments were also to be received there. In this way patients would not have to leave an establishment in which they had, perhaps, been cared for for many years, when their disability increased. Centres should be used flexibly according to the individual needs of those admitted to them; some would need short stays at regular intervals to give a rest to those nursing them at home, others might need a much longer spell, with the object of helping them to go back, in more favourable circumstances, to life outside; others again would need to use the centre as a permanent home. The aims of the centres should be to provide opportunity for living as normal, as active and as interesting a life as possible for each disabled person, and to study the medical and social needs of each one. Unobtrusive but expert nursing and attendant care would be indispensable in the background. Centres should, where possible, be altogether separate from a hospital and situated in suburbs or small towns so that the disabled could mix as freely as possible with the rest of the community. Age limits for admission should be flexible and those coming should be disabled people anxious to make the best use of the facilities available.

7 - Paul Hunt, Patients or People? article in The Guardian, 10 March 1965

"The young chronic sick" is a rather unpleasant official term for people with severe, incurable, and often progressive physical disabilities. It indicates those who are paralysed and handicapped either through accident or by diseases such as rheumatoid arthritis, multiple sclerosis, cerebral palsy, muscular dystrophy, and poliomyelitis.

In Britain there are probably several thousand people like this who need, at present anyway, some kind of institutional care. Mostly they want help with dressing, bathing, toilet, maybe feeding, and do not have the sort of home background where this assistance can be given.

These people do not require the skilled services of a hospital - except in acute illness, like anyone else. Yet a proportion of them have to enter the chronic wards of over-crowded hospitals, among those who are aged, probably senile and dying.

Even where there in a special unit set aside within a hospital, this usually means living in one large ward, bereft of all privacy. When lucky enough to be got up for the day they are put back to bed in the afternoon, mostly just for administrative convenience. They may need a doctor's permit to go out, and visiting hours are infrequent. A little occupational therapy is probably the only outlet for the abilities left them.

Perhaps the worst thing is being so completely in the hands of the staff. Those who work in chronic wards are doing an unpleasant job, poorly paid and in depressing and often primitive conditions. Many of them do not abuse the tremendous power they have over their patients, but unfortunately others do. Dependent as they are, the chronic sick are scarcely in an ideal position to complain with effect.

Anybody can put up with conditions like this for a while. But as a permanent prospect for someone with years ahead of him, they become intolerable - except that until recently there was no alternative to toleration. In the last few years voluntary organisations such as the Cheshire Foundation and the Spastics Society have made at least a dent in the problem. Their answer has been to set up community homes throughout the country, each of which caters for perhaps forty residents, both men and women, and is independent of the hospital system. Some county [social services] authorities have now followed suit.

In these small homes people are helped with daily living activities in a far more congenial atmosphere. Usually there is a large measure of personal freedom, unrestricted visiting, frequent outings, and the opportunity for many kinds of work and social activities.

However, this enlightened approach has been so successful in some of the homes that the residents are beginning to ask for more. In spite of the immense improvement in conditions and everyone's good intentions, they feel that something essential is still missing. In one important respect these new homes have simply imitated the hospital system. They are all run either by central trustees or local committees of voluntary people, or a combination of both. These self-perpetuating bodies decide matters of policy, make the rules, and appoint senior staff. So, as in a hospital, the "patient" is on the receiving end of all formal power and authority.

Yet really this kind of set-up is inappropriate to the special purpose of residential homes. They exist to provide a setting in which severely disabled people can lead the fullest possible lives. For an adult one normal maturing element is the founding of a home where he has an automatic share in the decisions which create and build it up. Of course it is impracticable to give everyone in a community home a similar informal say in its affairs. But some sort of analogous participation in decision-making appears to be indispensable.

In every community there is a "political" sector, an area of official authority and power. A share in this for the residents seems just a logical extension of the attempt to provide them with a substitute home. Their involvement in day-to-day administration and work in the home, while desirable, cannot really be legislated for, since it depends on such factors as the general health, mobility, strength and intelligence of those in a particular home. So the main suggestion is that the residents should elect representatives from amongst themselves to serve on the various governing committees, together with the present able-bodied members.

The advantages of some such development seem obvious. There should be an improvement in communications all round, with an added sense of responsibility percolating to even the most severely handicapped people. The residents' ability to influence decisions at the highest level would help to give them the sense of security which is so vital as a basis for personal growth. And the blurring of clear and rigid lines of authority, though it might cause initial problems, ought to prove a healthy thing for everyone in the homes.

These stirrings in a few homes for disabled people should naturally be of interest to those who are concerned with the dangers - and the potential - inherent in all kinds of institutional living. But there are wider issues involved. Not least of these is the whole question of the relation of society to its disabled, sick, aged, helpless members. Should they be considered as equal citizens and enabled to live as full a life as possible? Or should they be put away where they can't disturb us with their uncomfortable reminder of disease and death, and their implicit query as to what gives a person his value?

8 - Written questions, House of Commons, May to August 1965

24 May and 21 June 1965

Arthur Blenkinsop MP asked written questions seeking regional data for disabled people living in “contractual beds” paid for by the NHS, and beds in Young Chronic Sick Units.

2 August 1965

Mr. Blenkinsop

asked the Minister of Health

(1) what are the numbers of young chronic sick on long-stay in general wards, in young chronic sick units, and in contractual beds, respectively, in the age groups 16 to 35, 36 to 50, and 51 to 60;

(2) how many young chronic sick are on waiting lists for geriatric wards, long-stay in general wards, young chronic sick units, and contractual beds, respectively for each Regional Hospital Board;

(3) how many young chronic sick are on waiting lists for geriatric wards, long-stay in general wards, young chronic sick units, and contractual beds, respectively, in the age groups 16 to 35, 36 to 50, and 51 to 60;

(4) what are the numbers of young chronic sick in geriatric wards and long-stay in general wards, respectively, for each Regional Hospital Board.

(continued)

Mr. K. Robinson

The numbers of young chronic sick in geriatric wards on 31st May, 1965 were:

	Age Groups		
Hospital Region[*]	**16–35**	**36–50**	**51–60**
Newcastle	10	73	136
Leeds	4	58	171
Sheffield	14	97	187
East Anglian	6	40	80
North West Metropolitan	3	28	81
North East Metropolitan	3	36	103
South East Metropolitan	7	53	122
South West Metropolitan	3	37	80
Wessex	10	43	84
Oxford	4	22	72
South Western	3	37	76
Birmingham	46	228	407
Manchester	16	114	306
Liverpool	6	20	51
Wales	5	34	113
	140	920	2,069

[*] including Teaching Hospitals

I regret the other information requested is not available centrally.

[Making a total for England & Wales of 3,129 people]

9 - NCYCS Constitution, extracts

From an undated document in the NCYCS collection
at the PHM archive, as typed:

2. Aims and Purposes:

The aims and purposes of NCYCS will be:

(a) to secure publicity for the situation of the Young Chronic Sick and Disabled in the country at any time, hus bringing it to the attention of the Government and the people as a whole.

(b) to take direct action in furtherance of 2(a) above with medical, social and political authorities both local and national, and with the press, radio and television, and other organs of communication.

(c) to collect information regarding all aspects of provision made for the Young Chronic Sick and Disabled either as individuals or collectively in one or any location throughout the country, and to utilise it in furtherance of 2(a) and 2(b) above.

(d) by these and other means to stimulate knowledge and interest within the Labour Party and the Trade Union and Co-operative movements, with the objective of securing political advances in the statutory provision made for the care and financial support of the Young Chronic Sick and Disabled and their dependents and families.

(e) to draw attention to individual cases of financial or social hardship, and to undertake any appropriate form of activity which may alleviate it.

(f) to use any legal method to further the aims and objectives set out above.

3. Composition

NCYCS shall be composed of its Sponsors, an Executive Committee, Local Groups, and individual and corporate members.

4. Sponsors

...

The Chelsea Labour Party shall be in a special relationship to the NCYCS. As founder organisation, it shall have the right to be a corporate sponsor, and to appoint delegates who may be elected to any position or office in NCYCS.

...

13. General

In all the foregoing, it shall be understood that NCYCS is an organisation of working people, and is dedicated to securing political ends through the mobilisation of the Labour and Co-operative Movement in this country. NCYCS is itself constituted as a democratic political movement and not as a charity.

10 - NCYCS newsletter 1, post-conference 1965

CHELSEA LABOUR PARTY

NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK

NEWSLETTER

Who are the Young Chronic Sick

Many chronic sick patients are almost totally dependent on others.

Bedridden or chairbound, they either have to be helped even to move in bed. If they lie motionless for more than a few hours they can develop severe bedsores. Control of the bladder and bowel is often lost or is too uncertain and they often need help to wash, to go to the lavatory, to dress, and even to eat.

The Ministry of Health gives as a definition of the Young Chronic Sick - those between the ages of 16 - 60 but excludes the blind, deaf, dumb [non-verbal], epileptic, and mentally defective as such.

…

CHELSEA LABOUR PARTY
NATIONAL CAMPAIGN FOR
THE YOUNG CHRONIC SICK

Is it to be this

Or this?

A report on the Young Chronic Sick in Northampton County and Borough shows that **34% of those in hospital could be returned home if adequate help was available.**

The Young Chronic Sick can be divided into four categories -

(1) Those who on medical grounds must be institutionalised.

(2) A much larger group who **under present conditions** have to be institutionalised because:

- (a) problems such as incontinence are too much for their families to cope with;
- (b) they cannot be left alone between the visits of home-helps and district nurses while their spouse, parent or child earns the family living;
- (c) the unrelieved strain on those caring for them becomes unbearable;
- (d) although they have a home they have lost the person caring for them owing to death or desertion.

(3) Those being cared for in their own homes.

(4) Those in hospitals with handicaps who are able to care for themselves and look after their homes [if assisted by services].

Some facts and figures

Throughout England and Wales -

only 230 Contractual beds for the Young Chronic Sick

Only 434 beds in Young Chronic Sick Units.

The Regional Hospital Boards in East Anglia, Manchester and Liverpool make no special provision for the YCS - yet all Regional Hospital Boards have been asked to group Young Chronic Sick patients in special units where this is practical.

In consequence 140 patients between the ages of 16 - 35 lie in geriatric wards; 920 patients between the ages of 36 - 50 lie in geriatric wards; 2,069 patients between the ages of 51 - 60 lie in geriatric wards. The Birmingham figures are an utter disgrace.

Ignorance breeds neglect -

We don't even know -

how many Young Chronic Sick there are
what diseases are most frequent
how many are lying in general wards
how many are on waiting lists
or the length of the waiting lists.

What these figures show

1. The number of Young Chronic Sick in geriatric wards is nearly five times as great as those in wards suited to the needs of the Young Chronic Sick.
2. The steep rise with increasing age in the number of Young Chronic Sick in geriatric wards is due to -
    - (a) the cumulative effect of the younger age groups, meaning that some patients have been in geriatric wards for as much as 30 years.
    - (b) Certain chronic diseases have an average incidence of onset between 20 - 30 years of age and chronic disability between 30 - 50 years.
    - (c) Present lack of facilities for caring for the Y.C.S. in the home makes the care of these patients progressively difficult. It means that those who have for years been lovingly cared for are pitched into geriatric wards on the death of their loved ones.

The Y.C.S. at Home

In theory councils should know the number of Y.C.S. in their area. In practice they do not, as many patients are not registered as disabled persons. This accounts for the lowness of the figures often produced and the consequent tendency to act only in individual cases on an ad hoc basis. It militates against a planned approach and a policy that will help to lessen the appalling conditions revealed in this brochure which led Jennie Lee to protest, when replying to the health debate at Blackpool [1965 LP Conference], at the dreadful ratio of Y.C.S. patients in geriatric wards.

At Whose Mercy

The most severely affected Y.C.S. are amongst the most helpless members of the community. There are those who, by superlative strength of character, are able to rise above their disabilities, but the majority can only too easily fall prey to exploitation, even, at times, by relatives. This is why we reject, as panaceas, such solutions as allowances in lieu of assistance and pensions. Such solutions absolve the State of all further responsibility. Our solution would not only be far more economical but would also provide a far greater safeguard for the individual patient. Services do not depreciate, pensions, alas do.

STILL MORE Y.C.S. IN GERIATRIC WARDS?

All authorities including Regional Health Boards, are agreed that the right place for many Y.C.S. at present in geriatric wards is in their own homes, but that lack of proper facilities, especially help in the home, is the basic problem. The home help service was never designed to meet the needs of the more severely disabled Y.C.S. In many areas it is desperately under-manned. Both quantity and quality vary greatly in different local government areas.

Under present conditions the number of Y.C.S. in geriatric wards is likely to increase.

Aims of the Resolution

1. **Above all to keep the family together by:**

(a) Provision of special Medical Home Helps who would care for the patient and home while the husband, wife, parent or child earns the family income. Present day 'home helps' have not the training or time to carry out the duties of district nurses, already [required only] to have a purely nursing function. [Such medical home helps] must be at home in the hours of a carer's employment. In private practice £15 a week is a minimum salary so they must [obviously] be well paid and a short period of training in a hospital, in wards where Y.C.S. patients are admitted for investigation would be necessary. They would further be ideally suited to train and relieve relatives. Proportional charges according to family income could be made.

(b) **Lack of a mobile physiotherapy service** often results in patients having to leave their homes for an institution earlier than necessary. We ask the government to investigate the present deployment of available physiotherapists and give a pledge that as soon as possible the provision of a mobile physiotherapy service shall become part of the NHS.

(c) **Payment of a relative of friend caring for the patient.** This is so obviously to the advantage of the State in the freeing of hospital beds and to the patient and family that it is amazing that it is not already done except in the inadequate and unrealistic payment of a member of the family as a 'home help' in exceptional circumstances. Payment must be realistic remembering that the person concerned has given up his or her employment to carry out this duty. A great advantage of this scheme would be the consequent decrease in the number of special Medical Home Helps required.

(d) **Periodic admission to a suitable convalescence home or Y.C.S. unit** to allow the family a regular holiday. This is done in certain places but should become general practice.

2. When institution [sic] is inevitable

(a) Establishing more Y.C.S. units to abolish the cruel confinement of Y.C.S. patients to wards with the senile.

(b) Co-ordinating carefully the siting of Y.C.S. units and contractual beds in order to avoid overlapping and make visiting far easier.

A Note for Administrators

When seeking administrative solutions it is only too easy to think of the Y.C.S. as figures. Before taking administrative action certain facts must be faced honestly.

1. **To institutionalise, in however good conditions, is to deprive the individual of his or her most cherished consolation; the love and comfort that only one's own home can provide.** It means, for instance, that a woman who has built up her home and is bringing up her young family will, if she must leave her home, lose everything she has; her children and often her husband.
2. We are prepared, as a community, to go to considerable expense to ensure that children are found foster homes instead of institutions. We are prepared to pay foster parents to care for them in their own homes. We make allowances to parents for their children. We go to great lengths and expense to keep people out of prisons and other

institutions. Is there a valid reason why the same should not be done for the Y.C.S.?

3. **The basic principle on which the NHS was founded is that the individual shall not be deprived of the most beneficial treatment by reason of his or her financial status.** Today, unless the family income is above a certain level, the Y.C.S. patient is very likely to be forced to become institutionalised. This is a negation of the basic principle of the National Health Service.
4. When institutionalisation is inevitable, where and how shall the patient be institutionalised? Too often it is in chronic geriatric wards, too often far away from any likely visitors. Would any one of you accept this for the wife or husband you love, or your child, possibly still in his or her teens?

You are Your Brother's Keeper

We, as Socialists, have viewed this agonising problem. We are most grateful to Mr. Arthur Blenkinsop, M.P., who asked the questions and for the most helpful co-operation of the Minister of Health in answering them. The result is a set of figures never before made public, figures that will stir, we trust, the social conscience of all who read them.

These figures and the human tragedies behind them are your concern. You who read this are your brother's keeper. You are as responsible as the husband faced by his Y.C.S. wife's question: 'What will happen to me if you die?' Remember that at any time you or one of those you love may become a Y.C.S.

You doctors and social workers

are aware of the problems and the inadequate tools at your command to deal with them. You know the urgency of the problem.

You legislators

have so many calls on your time that you may not even have heard of the Young Chronic Sick.

You M.P.s

each have some as your constituents and as such they are your responsibility.

You in local government

have a very great responsibility in seeing that your powers are used for the benefit of the Y.C.S. in your areas. Do you know how many there are in your area, how they are being cared for? Have you and your colleagues discussed how you can improve their lot?

You journalists

have a particular responsibility. As with all minority problems the decision as to whether the general public shall be made aware of the facts or not rests on your shoulders, their ignorance on your conscience.

You trades unionists

have a proud record of caring for the welfare of your members. You have Y.C.S. amongst your members and many who are dependent on your members. Do you not feel it incumbent on you not only to study the facts but also how you can help?

Your comments and advice would be greatly appreciated.

Our thanks are due to Miss Eccles-Williams who so kindly contributed the cover design.

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11 - Nesta Roberts, Life for the chronically sick, two articles in The Guardian, 26 Oct 1965

Part 1 - The Talk was about Who had Died and Who Was Likely to Die

Miss Forbes was 25 and teaching at a girls' high school when she developed arthritis. It is an off and on sort of disease, and she managed to keep going in her own job and a variety of others, with more and more pain and longer and more frequent intervals in hospital for ten or twelve years before she became totally housebound. Seven years after that they tried rehabilitation, but she could not quite make it.

"So, when was 43 I spent six months in what a friend of mine called 'an extremely depressing depository for very old ladies," writes Miss Forbes. It was the local chronic hospital. I was in the 'young' ward. There were nine patients. The average age of all, including myself, was over 70. My neighbour had Parkinson's disease. You could not carry on a conversation with her as, half the time, she did not seem to hear you. Opposite was a good humoured old lady of 80 plus. She had been reading the same novel for three or four months, but when people asked her what it was about she would say: 1 don't know-I've only just begun.'

"Most of the dayroom was taken up by a large table where meals were served. The patients sat against the walls on either side of it. All but two of them did nothing; they were too handicapped, or past it. The two active ones knitted and gossiped. The main topic was the people in the 'old' ward next door-who had just died and who was likely to die in the foreseeable future."

Freda had six months in a chronic ward, too, only she was 16, not 43, and she had been in hospital since she was six. She remembers that many people were kind to her there, but she remembers also a number of things that frightened her. "I saw people with their minds wandering," she wrote, and at least two or three people died each week." (The figures here may have an element of adolescent exaggeration.)

Freda and Miss Forbes were lucky. They were moved from their respective geriatric wards to a small unit for the young chronic sick where the world came into the ward and the residents of the ward, even if it had to be by ambulance, were taken out into the world. Mrs Foster, who is 28 and paralysed from the waist down, Is in the corner bed of a large geriatric ward. Her neighbour is stone deaf and very old. She is going to be in one hospital bed or another for the rest of her life.

Mr Fleming is still in a London teaching hospital. He is in his forties, married, with two children. Until this last hospital admission his wife had looked after him at home, with the help of overburdened, but marvellously willing district nurses. Now she has got to the end of her tether, so he will have to stay in hospital. Mr Fleming knows that "hospital" is likely to mean the geriatric ward, and he feels, says the almoner sees with painful acuteness the situation of both himself and his wife, as if he has been thrown on the rubbish heap.

Both Mrs Foster and Mr Fleming may be lucky too, but the mathematics are against it. The waiting period for small units for the young chronic sick is up to five years, and five years is a long time when you have a degenerative disease. The total number of young chronic sick beds in England and Wales is 664, of which 434 are In young chronic sick units and the balance are contractual beds-that is, beds provided by private agencies and " rented " by the regional hospital boards. The total number of patients between 16 and 60 who are now in geriatric wards is 3,129, of whom 140 are under 35 (figures from Hansard, May 31).

The number of patients on waiting Lists for young chronic beds is not known, for, like university candidates, patients in search of a bed, or almoners acting for them, normally apply to several places and there is no central clearing house. The number in general wards is not known. The number of those being cared for at home is not known. The number of those in hospital who need not be there if there were anyone to care for them at home is not precisely known, but a survey made by Oxford Regional Hospital Board in 1963 showed that 34 per cent of those in hospital in Northamptonshire County and Borough could have gone home If adequate who help had been available.

Part 2 - Happiness or Misery are not Measurable in Cold Statistics

This may be the place to say that while the Disablement's Income Group's campaign for allowances which would enable the chronic sick to arrange their own home care deserves success, and while there is much to be said for setting up a category of "home medical attendants" akin to Holland's "maternity home helps," to provide such care, it would be unrealistic to suppose that those measures would cut the young chronic sick hospital population by one third. They would help, chiefly, by enabling relatives to stay at home to care for the invalid, but there is an absolute shortage of recruits for all of the social service (in the widest sense) jobs, and it is unlikely that a home medical attendant service would be the exception.

We are back, then, with the hospitals, suitable and unsuitable, where the young chronic sick spend five years, or ten or fifteen years, or a lifespan which may be a good deal longer. It is not always realised that most of these "young" chronics (sic) are between 40 and 60 years old, still less that mentally alert patients of 60 or 65 are as unhappy and out of place among the senile as they would have been at half that age. The geriatric ward which housed Miss Forbes was obviously not a particularly good one, even for geriatric patients. A London unit with 370 geriatric beds equally obviously is. The interest and expertise of the doctor in charge are reflected through every department of the staff. Younger patients are separated from the senile, there is occupation for them, physiotherapy is available for those that need it, the medical social worker helps both patients and relatives with their problems.

With it all, the doctor in charge is the first to point out how poor a place it is for the 70 young chronic sick - nearly 19 per cent of the total - whom it cares for. The list of the things which he and his colleagues want for them starts with ground-floor rooms so that beds and wheelchairs can be pushed out into the garden, and a regular follow-up, including weekly visits from a neurologist by the hospitals from which they were transferred. ("Consultants should not be allowed to lose sight of their failures," says this consultant geriatrician rather tartly, quite apart from the consideration that chronics should not be overlooked when new treatments are evolved.)

The rest can summed up as anything and everything that will give a chance "not only to exist but to live a fuller life" to men and women for whom the degree of happiness or misery involved are "not measurable in cold statistics." For this is much more than a clinical problem. It is a non-stop battle to preserve the personality of those who have to submit to the small daily indignities which severe handicap imposes. A look at two or three units for the young chronic sick shows how much that "everything" can cover. One is a Cheshire Home for 21 residents and occasional holiday guests, limited to those with stabilised conditions, which means that, however grave the disability, nobody is getting worse. The small size means that rules and regulations can be cut almost to vanishing point, the fact that both men and women are admitted gives the atmosphere an immediate lift (there is a dreadful emotional impoverishment about single sex units whichever the sex - it is like being limited always to singing the melody only and so miss the richness of part-songs.)

Quite early on, this community decided they were bored with the more arty-tarty kind of occupational therapy and started their own workroom. The present projects include a typing agency that holds its own in the commercial market. Local Friends of the home range from the school girls who come in to cook and serve Sunday dinner to the men and women at the transport depot who have raised the money to buy and adapt a bus for the residents and provide drivers for outings but the role of the residents is not to sit back and be befriended. They are healthily aggressive, teeming with critical and constructive suggestions, involved in life to a striking degree. For more than two years they have been raising funds for the Cheshire Home in Tangier, which cares for disabled children.

Almost more remarkable is the achievement of two other small units in the neighbourhood, for here there is no selection of patients. They are at all stages of ailments that come under the heading "chronic sick", the blind and the bedridden and incontinent as well as the relatively mobile and capable. Both units too, are within the NHS which has encouraged rather than tolerated the survival of the ethos of the medical mission by which they were started. Here, apart from a good occupational therapy unit, and visits from the travelling shop and library and from the hairdresser, the patients have discussion groups, play readings, and a singing class amongst themselves and are closely linked with local churches and youth groups. One wall of the ward which is the home of the really young is plastered with photographs of pop stars - Adam Faith came to see them not long since and left an imperishable memory.

Even the most helpless, with the aid of adapted cars and coaches and the use of every possible gadget, are taken on trips to the seaside, to the cinema, to concerts, or on visits to the homes of friends. The generous staffing ratio - 20, plus matron and assistant matron, for 28 patients at one of the homes - is a judicious blend of senior and experienced nurses (who, for the residents, are the very pillars of the house) and young auxiliaries, mostly from abroad, who bring youth and life and welcome diversion besides very real kindness.

The comments of the patients are revealing. "There is more going on here - there was nothing to do in the old people's ward." "It is more homely. In the chronic sick ward we felt like numbers." "The nurses here are more intimate and friendly." (No slight here on the geriatric nurses - it is simply that those in the small unit have more time for friendship.)

The running costs of these two last homes are not above average for their group though what they offer their patients is life compared to death in life. How, in face of that, can the presence of 3,129 patients in geriatric wards be justified? The answer is that it cannot, but it is all too easily explained. In the total sum, upwards of 3.000 patients is a small problem, and small problems tend to be nobody's responsibility. The Ministry encourages but does not enjoin boards to set up such units. Regional boards are concerned with capital programmes governed for the most part by individual management committees. For the average individual management committee the problem of a very small number of young chronic sick is a minor one, and stays fairly well down the list of needs.

Society might, of course, press their case. But our welfare society is still fairly primitive in the consideration it gives to the less rewarding subjects of care. It takes a very high degree of civilisation indeed to see that the chronic sick, with the long-term mental patients and the dying, are properly looked after.

12 - Judith Kazantzis, letter to The Guardian, 1 November 1965

Help for the young chronic sick

Sir,

I'd like to congratulate Nesta Roberts on her article (October 26) on the young chronic sick.

This year's Labour Party Conference unanimously accepted Chelsea Labour Party's resolution that medical home helps be established for the chronic sick so as to release relatives to work; that relatives be paid to look after their chronic sick at home; that the mobile physiotherapy service be extended accordingly; that there should be better provision of young chronic sick units.

We are glad that Nesta Roberts drew on the figures, hitherto unknown, that our campaign dug out of the Ministry of Health last session. We hope that groups like ours will eventually be able to make a considerable dent in the worst of these figures, with the help, one hopes, of a humanitarian Labour Government.

Yours sincerely,

(Mrs) Judith Kazantzis

Chelsea Labour Party,
Young Chronic Sick Campaign,
9 Langton Street, London SW10.

13 - Marsh Dickson, letter to the New Statesman, 18 March 1966

The Young Chronic Sick

Sir,

May I draw your attention to Mr Heath’s speech in the House of Commons in which he said: ‘*The chronic sick could have a special benefit of one pound a week after the first six months, to deal with their particular problems*’ (Hansard, 23 February)?

For sheer audacity this takes some beating. There are over 3,000 young chronic sick in geriatric wards in England and Wales. Unless conditions are changed, there are more than 3,000 living at home who will be going into geriatric wards. £1 a week cannot prevent a single one of these cases from entering a geriatric ward to spend anything from five to 40 years amid the aged and often the senile. I cannot see the young chronic sick patient or the very worried relative who is giving up everything to care for the patient touching his cap in gratitude for this magnificent charity handout.

M. Dickson

Chairman
National Campaign for the Young Chronic Sick

14 - Paul Hunt, letter to Marsh Dickson, 22 June 1966

Le Court, Liss, Hants.

The Chairman, Chelsea Labour Party,
9 Langton Street, London S.W.10

June 22nd, 1966

Dear Sir,

A friend recently sent me your brochure and memorandum about the ‘young chronic sick’. As I am officially classed in this category myself, I am very interested in your campaign and would like to respond to your invitation to comment on your proposals.

Firstly, I am delighted that you have taken up this urgent issue, and wholeheartedly endorse most of what you say. If what follows is mainly criticism I hope you will take it as in a way the best compliment I can pay you.

(1) The suggested medical home help service is an excellent idea, as is the plan to pay allowances for relatives and friends caring for the disabled at home. However I disagree strongly with your suggestion that allowances should be paid to the relative or friend. I consider it absolutely essential that an adequate pension and allowances (linked to the cost of living so that they don't depreciate) should be paid direct to the disabled person himself. Other arrangements could be made when there is evidence of mental confusion or of misuse of the money. You seem to have in mind only the case of the disabled person with a loving partner whose one concern is his well-being. But surely this is the exceptional case. Usually, even where there are relatives willing to help, relationships are complex and difficult, and the tendency of the able-bodied helpers is to forget that the disabled person is still an adult and should be responsible for his own decisions as far as possible. Physical dependence tends to have so many unfortunate social consequences that it is vital the person should not be economically dependent too. The effort to become, or remain, an independent-minded and responsible individual is great enough without an added handicap. Much the same thing applies to institutions like the one I am

in here; it would be an enormous (if subtle) help if the state fees for my maintenance were paid to me first, and only then to the administration.

(2) I think the provision of young chronic sick units within hospitals is certainly a step forward, but it is important to bear in mind that this is not the ultimate ideal. In my experience the assumption is still made far too easily that people need hospital care at a certain stage in their deterioration. I believe that in the vast majority of cases the care necessary could be provided outside hospital, right up until the time of death. Usually this could best be done by the provision of blocks of flats, a proportion of which are designed and set aside for the disabled either living alone or with relatives. There could be a nursing wing for those who needed skilled help. There is a fine scheme like this operating in Copenhagen, and one of its best features is that two-thirds of the flats are let to the non-disabled, thus helping to integrate the disabled into ordinary society.

(3) I think it is very important that the holiday centres you mention should have high standards of personal care and freedom, with single rooms available. Apart from anything else, this is necessary in order to persuade the disabled people and their families to make full use of such facilities.

(4) With reference to your interesting statistics about the young chronic sick (what an unpleasant term that is) in hospital, you may be interested to know that in the Cheshire Foundation Homes there are only about thirty R.H.B. [Regional Health Board] contractual beds out of a total of roughly 1,000. Yet the Homes are catering almost entirely for Y.C.S. people.

I hope some of my points will be of use to you. You might also be interested to read a book of essays I have edited which is to be published in September. Twelve of us have written about our situation as people with physical handicaps, and some of this is relevant to your memorandum and brochure. The book is called Stigma: The Experience of Disability, and is being published by Geoffrey Chapman Ltd. Professor Peter Townsend has written a Foreword, and there is an Appendix on Social Security in Disablement done by a social worker.

Yours sincerely, Paul Hunt

15 - NCYCS newsletter 2, autumn 1966

CHELSEA LABOUR PARTY

NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK

NEWSLETTER No. 2

We seek no Charity, no special privileges. We seek social justice, equality of opportunity

RAILWAY TRAVEL

You have had your holidays - as of right because men and women of our movement have fought for that right over the years.

This year chronically ill people have been deprived of that right by British Railways due to the Tory Act of 1962. It now costs a seriously chronically ill patient and an escort four times as much as it does you to travel by rail. Incredible but true. Even more incredible our own socialist Ministers have up to now, done nothing about it. Passing the buck does not help.

CHELSEA LABOUR PARTY

NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK

NEWSLETTER No. 2

Is it to be this

Or this?

We seek no Charity, no special privileges. We seek social justice, equality of opportunity

CONFERENCE RESOLUTIONS

Last year at Blackpool you passed unanimously the Chelsea Labour Party resolution on improving social justice for the chronically ill on the Ministry of Health front. As the responsibilities for the care of the chronically ill are divided between the Ministries of Health and Local Government, the Chelsea CLP resolution this year - 141 - deals with local government.

THE CURSE OF PERMISSIVE POWERS

At present the chronically ill are at the mercy of the social conscience of the local authorities. Many local authorities would prefer to hand this problem over to the charitable societies rather than face their social responsibilities.

As socialists we regard making our unfortunate brothers and sisters dependent on charity an insult.

THE Y.C.S. LIVING AT HOME

Last year we gave you the appalling figures for the chronically ill in geriatric wards. This year, thanks to the co-operation of the London Borough of Lambeth we can give you a very rough estimate of those living at home who are registered with local authorities and the actual figures for Lambeth. It is only by getting such figures that we can hope for real action by local authorities.

How many of you councillors know the actual situation in your own councils and consequently demand action? Please look at the Lambeth figures.

We estimate that in England and Wales there are over 500,000 registered chronically ill living at home of whom some 125,000 will be institutionalised if the person at present caring for them dies or can no longer, under present circumstances, take the strain.

It is wrong that the future of the chronically ill should he at the mercy of ignorance or indifference. We call for your support for the Chelsea Labour Party resolution.

THIS IS WHAT DOES HAPPEN

Here is the story of what can happen to an institutionalised chronically ill patient.

> Y--, struck down by Polio becomes institutionalised but determined to make the best of her position learns to type, contributes to magazine and on all sides draws praise for her efforts. But gradually her environment closes in on her. She is unable to break through the barrier of understanding, overworked, over- wrought staff. Years pass. Lacking the encouragement of those in authority around her, determination degenerates to despair, cheerfulness to bitterness and she calls out to all who will listen for the scraps of sympathy that may fall from charity's tables.

It is a tragic story that should never have had to be told if, as a society, we faced our responsibilities at both local and national level.

THE MINISTRY OF HOUSING AND LOCAL GOVERNMENT HAS RESPONSIBILITY

We call on all councils to follow Lambeth's lead and on the Minister of Housing and Local Government to see that they do so. This is not a question of a few individuals to be dealt with on an ad hoc basis, this is a social problem. **Without figures there can be no social policy.** You laid down a Labour policy last year on the Health Service front. Please do so now on the Local Government front. Then help us see that those policies are carried out. We on our side promise not to give any Minister or council peace until the policies you have laid down are put into effect.

Survey of Handicapped People aged 16 – 60 years on
Lambeth Welfare Register, June 1966

(provided by London Borough of Lambeth)

ACTIVITY LEVEL

Activity level	Age groups			Total
	16-35	36-50	51-60	16-60
Full time employment / full range household duties	41	43	60	144
Part-time or sheltered employment / limited range household duties	23	60	98	181
Unemployable / incapable of any physical household duties	24	31	61	116
Totals	88	134	219	441

MOBILITY LEVEL

Mobility level	Age groups			Total
	16-35	36-50	51-60	16-60
No difficulty	33	37	61	131
Can walk with sticks or crutches	33	66	123	222
Chairbound	22	29	28	79
Bedridden	0	2	7	9

DEPENDENCE LEVEL

Dependence level	Age groups			Total
	16-35	36-50	51-60	16-60
Can manage satisfactorily on their own	36	45	70	151
Can manage with help of district nurse and 4 hours a week home help	17	47	88	152
In need of constant care	9	12	21	42
Would have to be institutionalised if person now caring for them left or died	26	30	40	96

These figures all exclude the mentally ill or deficient [learning difficulties], epileptic, deaf, dumb [non-verbal], or blind, as such.

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16 – Guthrie working party, meeting with government, 22 Nov 1966

Note of a deputation to the Minister of Social Security from
The [Guthrie] Working Party to Consider the Problems of Enabling the
Young Chronic Sick to Live at Home, on 22nd November 1966
in the Minister's room at 10 John Adam Street, London, W.C.2.

Present Minister
Mr. Norman Pentland) Joint Parliamentary Secretaries
Mr. Harold Davies) Joint Parliamentary Secretaries
Mr. R.S. Swift
Miss N. Hellon
Mr. N.M. Hale
Mr. J.H. Ward
Mr. R.G. Wendt

Mr. Duncan Guthrie
Mr. J. Bowstead
Mrs. M. du Boisson
Mrs. L. Stacey
Dr. D. McAlpine
Mr. A.C. Waine

1. Mr Guthrie introduced the members of the deputation and explained that the Working Party had been set up in October 1965 to consider the problem of enabling young chronic sick and disabled people to live at home instead of in hospital. The age groups concerned were 16 – 65 for men and 16 – 60 for women. On the question of cash benefits, the Working Party's general view was that cash provision for the "civilian" disabled should be comparable to the benefits provided for the industrially and war disabled.

They had three proposals which they wished to put before the minister -

(i) the immediate provision of an adequate disability pension related solely to the degree of incapacity (and irrespective of the cause of the disability);

(ii) in addition, in severe cases, a supplementary allowance as may be necessary for such purposes as constant attendance and other requirements;

(iii) the inclusion in the above proposals of the disabled wife and mother who, prior to her disability, was working fulltime in her own home.

2. Members of the deputation made the following further points -

(i) Mr. Bowstead, said that long-term disability created a different financial need from short-term sickness and referred in particular to the need for officials of the new Supplementary Benefits Commission to be able to make the fullest possible use of their discretionary powers so as to give adequate help for the financial needs of the disabled. He emphasised that it was not the cause of the disability which mattered but the extent of it and that this was a matter for medical assessment. He also suggested a relaxation of the rule under which sickness benefit is curtailed after a relatively short period in hospital. Here again there was unfair differentiation between those who benefit under the Industrial Injuries Act and other severely disabled people.

(ii) Mr. Waine asked whether the provisions of the Ministry of Social Security Act in relation to discretionary additions represented any improvement on the national assistance scheme.

(iii) Mrs. Stacey said that "subsistence" benefits alone were inadequate for the disabled who had special financial needs in addition to normal subsistence requirements.

(iv) Mrs. du Boisson referred to the position of the disabled housewife, who did not usually qualify for benefits in her own right, and to the consequent financial burden on the family, especially where the husband had to give up work to look after his wife. She also suggested that some relaxation should be made in the rule that a disabled man could not receive any increase of sickness benefit for his wife if she earned more than £2 10s 0d [£2.50] a week.

3. In reply, the Minister made the following points –

(i) The Government were very conscious of the financial needs of disabled people, and of the difficulties which could arise where a housewife was herself disabled or working and caring for a disabled husband. All these matters were being considered in connection with their review of the social services. It would, however, be wrong to give the impression that any immediate changes could be made. There were a number of competing claims on the resources which could be made available for expenditure in the social services field. A problem receiving urgent attention, which linked to some extent with the considerations raised by the Working Party, was that of poor families in general. The Government were however also studying the problems raised by all the various groups of disabled people, including housewives, and the question of a "constant attendance" allowance was one of the matters under consideration. The earnings rule for dependent wives was another of the matters which would be looked at in the course of the review.

(ii) The provisions of the Ministry of Social Security Act, which would come into effect on 28th November, were designed to benefit in particular those with a long-term need, including the chronically sick and disabled. The special addition to the basic rates of 9s. [45p] a week, which would be payable to old people and also to long-term sick and disabled people, was in replacement of the various discretionary additions which had been payable under the national assistance scheme for small special expenses up to that amount, and would avoid the need for detailed enquiries into such expenses in the future. Where however, as would often be the case with more seriously disabled people, the 9s. addition was insufficient to cover the extra expenditure involved in consequence of the disablement, e.g. for domestic assistance, extra heating and special diet, the new Supplementary Benefits Commission would make full use of its discretionary powers to provide further additional amounts to cover the excess. In this way the Commission would be able to channel extra help to where it was most needed. The Ministry of Social Security Act was the first step forward in improving the financial provision for long-term sick and disabled people, and would help the hardest hit financially of them. It was however too early to say what further steps might be possible as a result of the review of the social services.

(iii) In conclusion the Minister emphasised that the Government were very conscious of what needed to be done for chronically sick and severely disabled people, but that improvements in this, as in other directions where help was needed, depended very much on the rate at which the country's economy could grow.

4. Mr. Guthrie thanked the Minister for receiving the deputation. It was agreed that a note of the meeting should be made available to the Working Party.

17 - Pamela La Fane [as Michele Gilbert], Growing up Geriatric, article in The Guardian, 23 December 1966

[Pamela La Fane used the **pen-name** Michele Gilbert for this article to avoid possible reprisals from staff in her hospital accommodation – TB]

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At the age of 16, in 1943, I entered a geriatric ward. There was nowhere else for me, it seemed. An acute attack of rheumatoid arthritis had left me completely incapacitated and in need of permanent care. As there was no one at home to give this the authorities had no alternative. So for 23 years the geriatric ward of the Chronic Hospital has been home to me.

During my first night in hospital I was awakened at 3am for a wash. I thought I must still be dreaming, but as I peered round the darkened ward I could discern that others were receiving similar treatment. I felt like a character in a Dickens novel, and in the days that followed I came to realise more and more that the social evils which aroused Dickens had not all been left behind in the darkness of the nineteenth century.

There were 26 patients in the ward, not all elderly. It was decorated in the usual institutional dark brown and green, relieved occasionally by dingy cream. Down the centre stood a long oak cabinet and this was the principal object of the nurses' loving care. Every afternoon, regardless of staff shortages of patients' immediate needs, that cabinet was polished for at least half an hour. When it was mirror-bright it was covered with a clean sheet (sometimes there was a patient who would have been glad of that clean sheet), and under the sheet, for extra protection, was a red blanket.

I witnessed the daily ritual from my bed. I had been put there on arrival and was told that as I couldn't walk (in actual fact I could) or do anything for myself 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 the punishment of criminals. My crime, and that of hundreds like me, was that of being a "young chronic."

After the early wash came the early breakfast - at 6am. This was simply dumped on the locker and there it remained till someone had time to feed it to the helpless patient. Many a time I have fallen asleep while waiting and been rudely awakened by someone anxious to shovel in the congealed bacon and stone-cold tea as rapidly as possible and be done with the job.

It wasn't long before I was in trouble with the authorities because I wanted something to occupy my perfectly normal mind. They suggested I might, as I was so anxious, make an iron holder. I could get a piece of canvass and some wool from the woman who came to the hospital once a week. (She wasn't really an occupational therapist.) It amazed them when I made it clear that even this was not enough to satisfy me. I wanted books! And writing materials! I was cluttering up my locker and making the ward look untidy. I even had books on the window sill. What did I want them for? I could read only one book at a time, couldn't I? Didn't I realise I was in a hospital?

Yes, I realised that. All too well. I realised that this bed and locker were my home and would be for the next 50 years or more. I wanted to take correspondence courses, to learn. This meant more books, as well as papers. On one occasion an irate sister confiscated everything I needed for my studies and locked them in a cupboard. It was only my doctor's intervention that got them back for me. When after several years I at last managed to get a typewriter, the comment was: "And where do you think you are going to keep **that**?"

One day in 1949, just after the coming of the National Health Service, a group of doctors came round, examining everyone and making notes. We learned that our old Chronic Hospital was to be integrated into a regional hospital group with the local general hospital as the nerve centre. Dared we hope? The first and most important change that affected me was that I was ordered out of bed. "Whatever do they want to start getting you up for?" grumbled the nurses, as they bundled me into the wheelchair I'd had as a twenty-first birthday present and which had hardly been used. "You've been happy in bed all these years." Fancy. I'd never known that my feelings "all these years" were what is known as "happiness." Did it never occur to them that we could be human enough to feel despair and frustration at the barrenness of our existence?

Then those visiting doctors, appalled to discover how long I had been inactive in bed, wanted me to have treatment, and ordered that the newest methods should be tried in my case. “A waste of money,” grumbled the nurses, and every excuse was brought up for not getting me out of bed, for not giving me that treatment that had been ordered. I had to fight for it, and if I did get it I was deposited back in bed immediately afterwards - the naughty child who must be punished for some tiresome behaviour. One day a doctor came round and asked me if I **wanted** to go back to bed so early. After that, my time “up” was extended. For a long time the ward sister would not speak civilly to me because I had dared to say that I didn’t really want to go back to bed at two o’clock in the afternoon.

With the reorganisation of the hospital, which began in 1953, the young patients were split up and I found myself more and more in the company of old people. If they are not too senile and beyond being companionable, they tend to be very jealous of the extra attention I must have. Instead of being thankful that they can do things for themselves they can be heard complaining to their visitors: “She always has the nurses fussing round her; she’s a cripple, been here for years. I suppose that’s why. They don’t do it for me.” So the choice is between senile, rambling, incoherent companions and alert, sensible, but jealous ones.

But this is where we came in. I sit here, the elderly women around me. Many of the evils of the past have been eliminated. I can now go out whenever someone wants to take me, and the staff get me ready. Visiting times are relaxed from twice a week to twice a day (again, if anyone wants to come). There are more facilities for some kind of mental life. An enlightened matron has provided a cupboard for my things, as well as shutting her eyes to all the visible “junk,” realising that this is my “home.”

But we are still regimented and ruled by the clock, so that never for a moment do we forget that we are “lifers.” The slightest deviation from routine seems to set the machinery wrong and panic reigns. Members of the staff are continually bewailing the fact that it’s nothing like the old days now. Thank goodness it is not. I have revived painful memories that I would rather forget. But so long as there are young people normal in their minds and feelings, lying imprisoned in crippled bodies, in geriatric wards, helpless and hopeless, one must remember, so that the general public are not allowed to forget.

Text box:

Throughout England and Wales there are:

230 contractual beds for the young chronic sick

432 beds in young chronic sick units.

There are in geriatric wards:

140 patients between the ages of 16 and 35

920 patients between the ages of 36 and 50

2,069 patients between the ages of 51 and 60.

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18 – AC Waine, letter to The Guardian, 2 January 1967

An alternative to growing-up geriatric

Sir,

Your article "Growing-up Geriatric" (December 23) will excite a lot of comment - as no doubt was intended. A lot has been done since those dark, dismal days about which your correspondent writes so tellingly.

The fact is that many young chronic sick have to face years of incarceration in a geriatric ward because there are no alternatives available to them. Surely it is time that public opinion asserted itself and made alternatives available? What are they?

First, there is a need for adequate financial provision to enable cases who do not need constant medical care and nursing attention (and thus, hospitalisation) to remain in their own homes and with their families. Consider the case of the disabled wife or mother who, prior to her disability, was working full time in her home. No financial benefits, sickness or disability allowances were available to her.

Then, in severe cases, supplementary allowances may be necessary for such purposes as constant attendance and other requirements.

Such cases could also be catered for by the provision of more purpose-built residential accommodation alongside a day hospital or day-care centre.

Together with other organisations, my society is deeply aware of the shortcomings in the Welfare State where the chronically sick are concerned. For this reason, articles such as "Growing-up geriatric" are welcome and valuable as they bring to light shortcomings which, lamentably, are not generally known. Thank you for publishing it.

Yours faithfully,

A. C. Waine

General Secretary
The Multiple Sclerosis Society
London W8.

19 - Megan Du Boisson, letter to The Guardian, 2 January 1967

Sir,

There is no doubt that, in accordance with the expressed intentions of members of the medical profession, the Ministry of Health, the Ministry of Social Security, and other bodies concerned with the long-term sick and disabled, any patient who could do should be enabled to live outside the confines of a hospital. Hospital beds are costly, precious, and designed for the **cure** of patients or for the nursing of the elderly and those in the terminal stages of their disease.

If Michele Gilbert had the means, and was offered the full services of her local authority, her tragic experience of growing up geriatric need never had happened. With the enlightened local authority, properly supported from funds from Central Government, and with a suitable income which recognised the degree of her dependency, Michele Gilbert could today choose whether she wished to continue to live in the care of an institution or to live in the community. Society does not offer her this choice.

It is the work of the Disablement Income Group to ensure that such tragedies do not occur wherever they are preventable, by working for a National Disability Income. The story of Michele Gilbert makes us more determined than ever to continue to represent to members of Parliament the appalling plight of our chronic sick. Alas, Michele Gilbert is one of a growing company. We shall make private approaches to Miss Gilbert and we hope your readers who are interested in our work will write to us.

Yours sincerely,

(Mrs) Megan Du Boisson

Hon. Secretary
Disablement Income Group
Rellen House, Busbridge Lane, Godalming.

20 - Marsh Dickson, letter to The Guardian, 6 January 1967

Sir,

Some of your readers may feel that the conditions mentioned in Michele Gilbert’s article “Growing up geriatric” must be exceptional.

In the experience of many of the people we have come in contact with this is not so and in some cases the improvements she mentions have hardly begun to materialise.

As we have pointed out to the Minister of Health and his colleagues, unless proper services and financial assistance are provided to keep the majority of these cases at home, where it is generally agreed they should be, this dreadful state of affairs will continue.

Organisations such as ours, started by the Chelsea Labour Party, DIG and others can batter at Ministry doors, but in the long run it is the pressure of an awakened social conscience that rebels at the present treatment of the Michele Gilberts, and the growing number of potential Michele Gilberts, that will achieve positive action. It is up to all of us.

Yours faithfully,

[Marsh] Dickson,

Campaign Chairman
National Campaign for the Young Chronic Sick
93 [sic] Marlborough Flats
Walton Street
London SW3.

21 - Pamela La Fane [as Michele Gilbert], letter to The Guardian, 10 January 1967

Growing up geriatric

Sir,

I should like, through your columns, to express my appreciation for all the interest shown to my article "Growing Up Geriatric," published in your paper on December 23.

Every letter will be answered personally, but as this may take some time I should like them to have this general acknowledgement of my heartfelt appreciation. Yours etc,

(Miss) Michele Gilbert
c/o The National Campaign for the Young Chronic Sick
94 Marlborough Flats
London SW3.

22 – Stan Newens MP, Letter to The Guardian, 23 January 1967

The young sick

Sir,

I hope the publication of Michele Gilbert's letter does not mean a conclusion of correspondence in your columns on the young chronic sick, because to my mind this is an important subject which should form an essential part of the comprehensive review of the social services begun by Douglas Houghton.

Since this point has not featured in correspondence, it may interest a number of your readers to know that the Labour Party has a policy for the young chronic sick laid down at the 1965 Conference in Blackpool, where a resolution from Chelsea Labour Party was adopted, calling on the Minister of Health to (a) enrol and train medical home-helps; (b) extend and make mandatory local authority services; [(c)] pay relatives for care for care in the home; (d) establish young chronic sick units in local hospitals with a specific purpose of making growing up geriatric a condition of the past.

Of course an Annual Conference resolution does not commit the Government in any way, but it does mean that Ministers, as members of the Labour Party, have no reason not to be aware of, and give attention to, this tragic situation.

Stan Newens [MP]

House of Commons.

23 - NCYCS newsletter 3, spring 1967

CHELSEA LABOUR PARTY

NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK

NEWSLETTER No. 3

We seek no Charity, no special privileges. We seek social justice, equality of opportunity

Price Sixpence

EDITORIAL

ONE STEP FORWARD

Since Newsletter No. 2 there has been one important advance in provision for the Young Chronic Sick — POSSUM — Patient Operated Selector Mechanism controls for the severely disabled. These electronic aids developed under a research grant from the Polio Research Fund at Stoke Mandeville by a research group under Reg Maling are now available on prescription by a consultant on the National Health Service.

CHELSEA LABOUR PARTY
NATIONAL CAMPAIGN FOR
THE YOUNG CHRONIC SICK

NEWSLETTER No. 3

Is it to be this

Or this?

We seek no Charity, no special privileges. We seek social justice, equality of opportunity

PRICE SIXPENCE

Our solicitor, a polio victim who runs his whole practice with the use of only one thumb, thanks to POSSUM, tells you about it in this issue. We add a note on its possibilities for the progressive diseases such as Multiple Sclerosis. What do you know about this? What does your Council know about it? What does your Regional Hospital Board know about it? For further information a self-addressed stamped envelope, please.

HOUSE OF COMMONS

It is with no sense of complacency that we bring to your notice Question and Answers in the House. We are pleased that they have been raised, grateful that our efforts have been praised. Above all, we are grateful to the M.P.s who have asked the questions, however unsatisfactory some of the answers are. Lack of information at both National and Local Government level is still the greatest barrier to action, and to the discussion at local government level on which action so much depends. More about this later in this Newsletter.

CONFERENCE RESOLUTIONS

The Young Chronic Sick are not to be forgotten at Conferences this year. See further on the resolutions at the Women's Conference, the Eastern Region Conference and the London Party Conference. We are the party of Conscience or we are nothing. Ours is the only party that consistently raises the problems of the Young Chronic Sick at our conferences. It is up to all of us to make sure that resolutions are transferred to statute book and action in the council chamber.

WHAT PRICE HOLIDAYS?

The scandal of Railway charges for the Young Chronic Sick continues. St. Beeching still lords it over social justice and pious buck passing swings its malodorous censors. The Young Chronic Sick are far too unimportant for even junior ministers of the Ministry of Transport to bother to meet us to discuss the problem. But don't think we have given up. Until the Young Chronic Sick get social justice we'll never give up.

IT DEPENDS ON YOU, MINISTERS

We are grateful to Robinson and Snow for their genuine interest in the Young Chronic Sick but are they prepared to be sufficiently forceful to ensure that NO Young Chronic Sick shall be condemned to geriatric wards, that the necessary action is taken to allow the Young Chronic Sick to remain at home and that the public has access to all available information in adequate form, not only at national, but also at local level? Please, please have the guts to require instead of asking.

POSSUM and a single thumb

POSSUM has thrown not only the necessities of doing and selecting, but also daily important right of rejecting. The exercise of the will arising out of this is the key to the vicious circle, whether for the productive, or the unproductive.

BODY

To say that it would be as hard for the paralysed person to imagine life without POSSUM, as for the able-bodied person to imagine himself paralysed, is an inadequate, but possibly accurate attempt to indicate the value of its limitless applications to the disabled person. To all disabled it provides domestic independence, and control of the environment from heat and light, to entertainment, be it radio, television or model trains; to communications -- the most vital sphere of all to the disabled, by the use of the telephone, or the intercom system. Its application in the field of rendering the disabled productive is even more startling; while its potential is limitless, and already reaches into the field of industry, the mere application of the telephone, typewriter and dictaphone make a potential tax-payer out of the man who cannot move a muscle.

AND MIND

On the other side of the picture, it serves what may be yet a more valuable end; who, but the totally paralysed, can conceive the horrifying effects of the environment in which they are placed, upon the mind, the will and the spirit; the sheer vulnerability, the gradual subjugation, especially of the institutionalised, to the will of others to whom they are nothing but an added demand upon their time and physical resources, the slow loss of self-respect, and ultimately the so-called 'secondary paralysis' that is, the a deadening of the anaesthetising of the will and desires which subconsciously occur as a result of the reluctance to make — and often the sheer impossibility of satisfying — the persistent requests commensurate with one's needs. Even with the most kind natured and tolerant of helpers, this environment can have a stultifying and repressive result. The wrong circumstances -- the snubs, impatience, or downright heedlessness of institutional staff, or indifferent assistance, can create a vicious circle of negativeness in which the end result can only be the degeneration of the will to the state of a vegetable.

Into this limbo, POSSUM has thrown not only the basic necessities of doing and selecting, but also the vitally important right of rejecting. The exercise of the will arising out of this is the key to the vicious circle, whether for the productive, or the unproductive.

REALITY RESTORED

The practical effect of POSSUM is, in short, that the proposition can now be made that no mentally healthy person need be unproductive, however great the degree of his physical disability, barring only of course, actual illness and pain. To project the disabled into the living hurly-burly of everyday life by being given the means to escape from wallowing in the sickly sweet comfort of nothingness to feeling the hard edges of life's realities, to have the opportunity to be on equal terms with one's fellow men in the use of one's mind, and to make this the means of restoring one's earning power to almost normal, must surely be the ultimate, but most improbable hope of any totally disabled person. That POSSUM has developed this phantasy into a reality is a breakthrough in these realms of a consequence which has not yet received anything like the recognition it deserves.

ENDS WITHOUT MEANS

POSSUM has at least been recognised, however, albeit grudgingly and inadequately. It could not be ignored. What is ignored now, by the sterile consciences in Whitehall, is that these fantastic potentials can never be developed, without a full and realistic recognition of the need of those who are in the position to benefit from the advantages of POSSUM, of adequate practical help and financial provision to enable them to carry the enormous additional financial burden thrown upon them by their need for constant attendance and assistance in the actual process of living. The one is complementary to the other; but the absurd situation now exists that this tremendous discovery can only be used by a comparative few not because of its intrinsic cost (which is extremely low for what it is and does) — but because of the short-sightedness of those who cannot realise that it would save the State large sums of money to make adequate provision of financial and practical help to the potential users of POSSUM of an order of a mere fraction of the cost to the State of them being kept in hospital; to enable them so gladly to vacate their sorely needed hospital beds and once again, even if after a necessary period of rehabilitation, to set themselves up again as useful working members of Society.

LET THEM NOT ROT

It has often been found that the disabled have a particularly high power of concentration which enables them to do jobs, especially in the scientific and electronic field. which cannot be tackled by others; not only the average intelligences therefore, are being thrown to waste, but even these exceptional talents lie rotting in geriatric wards — those supremely expensive breakers' yards of our civilisation.

POSSUM in progressive diseases

AIDS such as POSSUM and the coupled G.P.O. telephone loudspeaker have enormously widened the scope of activity of the patient. With these aids a wife who could not dial or call for help can now do her shopping over the 'phone, speak to whomever she wants, switch on the TV or radio programme of her choice, regulate the heating, turn over the pages of the book she could not handle, or manipulate the talking book. She can recognise the caller at the door and let him in. She can type the letter she can no longer write by hand. She can discuss her children's problems with their teachers. She can call for help in an emergency. All this without the minute to minute dependence on another human being, however loving, however loved. Love thrives on giving not on dependence. We who love our increasingly dependent partners do not seek any easy way out, we know that the more independent we can make them the deeper our relationship will be, and the more fruitful, not only for ourselves but for our families and for the community.

As together husband and wife face the increasing disability of the partner they can face the future more serenely and securely. These aids should be brought into use before total incapacity sets in so that the shock, both physical and emotional, of increasing disability, be reduced as much as possible and does not vitiate their implementation.

Of course such aids do not obviate the need for the services for which the Labour Party in its policy stands. They are not a 'lavabo' [Latin: a handwashing bowl] for the Pontius Pilates of officialdom. But they have a vital role to play if only the blind will see.

HANSARD

30th JANUARY, 1967

DR. OWEN asked the Minister of Health (1) what evidence he has that there has been any reduction in the number of patients classified as young chronic sick living in geriatric wards during 1966; and what further reduction he expects to occur in 1967; (2) what evidence he has of an increase in the number of beds provided in special young chronic sick units during 1966; and whether any further increase can be expected in 1967.

MR. K. ROBINSON: Up-to-date information about the young chronic sick in hospital will be obtained in the course of a survey which is in preparation. When the results of this survey are available, I will write to my hon. Friend.

6th FEBRUARY, 1967

MR. ALFRED MORRIS asked the Minister of Health what progress is being made towards establishing more young chronic sick units near patients' homes and abolishing the present practice of confining the young chronic sick in geriatric wards with the senile; and if he will make a statement.

MR. SNOW: I would refer my hon. Friend to my right hon. Friend's reply to my hon. Friend the Member for Plymouth Sutton (Dr. David Owen) on 30th January.

MR. ALFRED MORRIS asked the Minister of Health what consideration has been given to enrolling and training special medical home helps to reduce the numbers of the young chronic sick who are confined in geriatric wards; and if he will make a statement.

MR. SNOW: It appears to me that my hon. Friend's objects can best be met by the development of home nursing services, particularly through the increased use of ancillary staff for less skilled work; and local authorities have been asked to review their staffing with this in mind.

MR. MORRIS: May I inform my hon. Friend (Hon. Members: `No'.)—is my hon. Friend aware that it is considered by many people to be a crime that any young chronic sick should be in a geriatric ward? Will he state what is being done in the near future to encourage local authorities to take much more action than they are taking at present?

MR. SNOW: This was done in March 1966. Local authorities were asked to review their internal arrangements for co-ordinating the services for handicapped children and school leavers and to take into account the chronic sick aspect of it. We are carrying out this survey. We are fully conscious of the serious nature of the problem.

13th FEBRUARY, 1967

MR. WINNICK asked the Minister of Health how many chronic sick patients under 60 years of age have been taken out of geriatric wards in hospitals and placed in more suitable accommodation in the last 18 months.

MR. SNOW: I regret that this information is not available.

MR. WINNICK: Is my hon. Friend aware that there is a great deal of public concern about this whole matter? Has he been in touch with the Chelsea Labour Party which is organising a first class campaign on this issue? Has my hon. Friend's attention been drawn to a recent article in ‘The Guardian' written by a former patient, which again has caused a great deal of comment?

MR. SNOW: I am in touch with the Chelsea Labour Party on this matter. In my view, the Chelsea Labour Party has carried out a very good service indeed in drawing public attention to this matter. A pilot survey by my right hon. Friend on the question of younger chronic sick in hospital is in the process of being organised.

***

DR. DAVID OWEN asked the Minister of Health if he will instruct regional hospital boards to provide a service for relatives and friends of the bedridden chronic sick so that for a period of weeks once or twice a year they can be admitted to hospital to allow a rest and holiday for the people who undertake their care at home.

MR. K. ROBINSON: Hospital authorities already provide this service wherever possible.

DR. OWEN: Is the Minister aware that this service is provided at only a few centres, that where it is provided it is possibly the greatest single factor in keeping patients at home and that an extension of this service would be greatly appreciated?

MR. ROBINSON: I agree with the second part of my hon. Friend's supplementary, but not with the first because my information is that hospital authorities in general are fully aware of the value of the short-term admission of patients who are normally cared for at home. My hon. Friend will be interested to learn that there are arrangements for such short-term admissions in the Plymouth area.

BRIEF COMMENT

The answers will satisfy few people. It is scandalous that statistics are not readily available to provide clear cut answers to David Owen's questions or those of Alf. Morris and David Winnick. The answer to Morris's question on medical home helps is equally disturbing. Those on the receiving end will have some bitter things to say about this, knowing as they do how inadequate local authority provision is and how its lack fills geriatric beds. When will the Minister start to require instead of asking local authorities to act, and face the bill which will save him hospital costs?

David Owen appears better informed than the Minister about the short term admission of Young Chronic Sick to allow rest periods for the family. We know of cases where this can only be done in geriatric wards, not a suitable environment. It takes great courage to face a geriatric ward while the family is away on holiday.

Fighting for the facts

The appalling lack of figures about the Young Chronic Sick is the greatest single stumbling block to all progress. How can there be the necessary discussion unless we know what figures local councils and the ministries have available?

LOCAL GOVERNMENT

The only relevant figures available are those that can be extracted from the welfare registers. These, of course, are not complete. But they are the only figures on which they can, at present, act. If the Minister requires a breakdown such as the Lambeth breakdown of figures uniformly throughout the country, then we can:

1. compare figures for councils throughout the country;
2. have some idea, however incomplete, of the extent of the problem in our own areas;
3. have some sort of check on the work of our councils concerning the Young Chronic Sick;
4. compare them with such surveys in depth as the Ministry carries out. The ratio of registered cases of different categories to normal incidence based on Ministry research can be of vital importance in assessing the work of the council;
5. make the public in the area aware of the extent of the problem locally. Local figures are newsworthy.

MINISTERIAL LEVEL

Ministers naturally need to know two things. National incidence which can be calculated on a properly conducted survey and what is in fact being done locally, how adequate local statistics and activities are. If there is a great disparity between normal incidence and welfare register records, why is this so and what are the councils doing about it?

To refuse to demand figures because they are inevitably incomplete is like refusing to look at a landscape because you have no binoculars.

CORRESPONDENCE

Our Hon. Secretary spends some four hours a day at the typewriter. It would be invidious to quote from all the letters we receive from so many parts of the country. While the cases brought to our notice are heart breaking, the appreciation of what we are trying to do and above all the confirmation that Labour Party policy is viewed by those at the receiving end as the one hope for the Young Chronic Sick and those relatives who are struggling to keep them at home against all the odds is a tremendous encouragement to us. So let us once again quote Labour Party policy adopted at Blackpool in 1965.

LABOUR PARTY POLICY … [full 1965 text - see Appendix B]

MICHELE GILBERT

Many of you will have read either 'Home with a Capital H' or as it appeared in the 'Guardian' `Growing up geriatric'. We are doing our best to bring to an end her 24 years in geriatric wards since she was 16. It is not easy, but we don't ever give up. We are also fighting for social justice for others. Whilst our main effort must remain on the political fight at national and local level we can never ignore individual cases.

CASH

We need it urgently. Our treasurer is raising her eyebrows at the cost of producing this Newsletter. Please put them back in place for her by sending us some cash.

Conference Resolutions

Please mandate year delegates to vote on the following resolutions.

NATIONAL CONFERENCE OF LABOUR WOMEN [May 1967]

56 This Conference is deeply concerned at the plight of the Young Chronic Sick who are often accommodated in geriatric wards and urges the provision of adequate accommodation for the aged to relieve this situation.

Norwich Labour Party

LONDON LABOUR PARTY CONFERENCE [13 May 1967]

53 This Conference urges the Government to require, and all Labour Groups in the London area to press for, the publication and break-down of statistics of the chronically sick and disabled between the ages of 16-60 as done by the Borough of Lambeth, in order that action shall be taken at local government level with-out which the chronic sick have little hope of attaining the equality and social justice to which they are entitled.

South Kensington Labour Party

EASTERN REGION LABOUR PARTY CONFERENCE

22 This Regional Conference notes with regret the wide variation in treatment facilities for Young Chronic Sick patients within the Regional Hospital Board Areas in the Eastern Region and in calling upon all County, Borough, and District Councils and all Hospital Authorities to work unremittingly towards an equalised high standard of Home and

Institutionalised Care, it urges also Parliamentary representation to seek a firm policy directive from the Minister in pursuance of this information.

Epping Labour Party

Published by the Chelsea Labour Party National Campaign for the
Young Chronic Sick, 94 Marlborough Flats, Walton Street, London,
S.W.3 and printed by Precision Press (TU, 36-hr. week), 44 Broad St.,
Teddington, Mx.

24 - BBC TV programmes, 1967 and 1968

SUMMARY: **1967 – BBC 2**

1968 – BBC 1, three programmes

(and)

1981 – BBC Radio 4

1967 - BBC 2 television, Wednesday 2 August, 20:35, 30 minutes

Radio Times listing

Man Alive: The Life Sentence: 1: Pamela

A weekly programme which focuses on people and the situations which shape their lives.

In 1943, when the war was at its height, a pretty girl of sixteen, crippled with rheumatoid arthritis, was admitted to a geriatric hospital in South London - a place only for old people. Today, twenty-four years later, she is still there, living in a hospital surrounded by the old and the dying. Pamela needs little medical attention, she is bright and intelligent. But Pamela has an official national health label: Young Chronic Sick. This two-part enquiry looks at conditions both inside and outside hospital for people like her - and there are at least three thousand like Pamela, sentenced to spend the rest of their lives in geriatric hospitals.

(See page 31, issue 2281, Radio Times, 27 July 1967)

Contributors -

Director: Richard Thomas; Editors: Desmond Wilcox, Bill Morton.

Reporters: Angela Huth, Jeremy James, John Percival, Trevor Philpott, Desmond Wilcox.

1968 – BBC 1 television, Thursdays 6, 13, and 20 June

A Life of Her Own

From a newspaper TV guide:

Campaigning for the young chronic sick

[This is] … a three-part series under the ‘At a time like this’ umbrella.

Concerns Pamela la Fane, prone solid with rheumatoid arthritis in a side ward of a geriatric hospital in South London since she was 16. She’s now 40. The worst of it is, she’s not “ill” and she’s remarkably intelligent and buoyant on her own behalf.

The first programme is scenes from hospital life. Painful viewing. Man Alive editor Desmond Wilcox first became interested over a year ago, when he read a piece she wrote in The Guardian. Since then, producer Richard Thomas has followed her case regularly. Murmured remarks about “intrusion”‘ get the short answer that Man Alive subjects invariably ring up afterwards to say they now feel much better. If they complain at all, it’s cosmetically: “You photographed me when my tie wasn’t straight.” Wilcox: “We not only find the stories, but cure the cases.”

In the second programme, on 13 June, viewers will see how Miss Fane [sic] campaigned to try to improve her circumstances and, on 20 June, whether or not she succeeded. “These programmes have been constructed as a series of cliff-hangers,” says Wilcox, “and I don’t see why one shouldn’t.” Valid new protest, or journalistic outrage?

The Observer, 2 June 1968, TV guide, page 22

Research Note: The TV production team for the Man Alive series made these three programmes for transmission on BBC1, having first met with Pamela La Fane in making their 1967 programme on BBC2, which was the usual channel for Man Alive programmes.

AT A TIME LIKE THIS - A LIFE OF HER OWN

Programme 1: It All Seems such a Waste

6 June 1968, BBC1 TV, 22:50 hours

BBC catalogue listing

Film about Pamela La Fane who is forty and has spent the last 25 years in a geriatric hospital, suffering from rheumatoid arthritis.

Reference: LGF5361E

Radio Times listing

In 1943, when the war was at its height, a pretty girl of sixteen, crippled with rheumatoid arthritis, was admitted to a geriatric hospital. Today, twenty-five years later, Pamela La Fane is still there, living in a hospital surrounded by the old and the dying. Everyone agrees that she ought not to be there, that there should be some other way of caring for her and the 3000 young chronic sick like her. This three-part enquiry looks not only at Pamela's life in hospital but her struggle to find a new life outside.

[Programme 1 was first broadcast on 2 Aug 1967, on BBC 2]

Programme 2: It's Marvellous to be Mobile

13 June 1968, BBC1 TV, 22:50 hours

Pamela La Fane has been crippled since she was sixteen.

Reference: LGF5367T

Radio Times listing

For twenty-five years Pamela La Fane, crippled with rheumatoid arthritis, has lived in a geriatric hospital. For the 3000 young chronic sick like her there are few alternatives. For years she has dreamed of being able to live a more independent life, free from the routine and discipline of hospital. During the last year she has paid three visits to Mary Marlborough Lodge, a Rehabilitation Centre at Oxford, where she hopes she may be helped to overcome the obstacles that stand in the way of getting 'a flat of her own.'

Programme 3: Beyond These Four Walls

20 June 1968, BBC1 TV, 22:50 hours

The third of three programmes about Pamela La Fane who has spent 25 years in a geriatric hospital suffering from rheumatoid arthritis. This week Pamela sets about finding a flat & companion in her quest for independence. Jeremy James reports.

Reference: LGF5369H

Radio Times listing

Finding and moving into a flat of one's own is a problem for anyone. For severely disabled Pamela La Fane, who has spent twenty-five years in a geriatric hospital, the problem is not only to find the flat; to be equipped with mechanical aids; but to find a companion. In this, the last of a three-part enquiry into the problems of Pamela, one of the 3000 young chronic sick in this country, we examine this stage of her quest for independence.

Series credits (for all episodes)

Contributors:

Subject: Pamela La Fane
Reporter: Jeremy James
Producer: Richard Thomas
Editor: Desmond Wilcox
Editor: Bill Morton

BBC Radio 4, Woman’s Hour, Monday 14 September 1981

Listing: “Pamela La Fane, an arthritic patient, talks to Barbara Myers about her 30 years in hospital.” [Probably to launch her book.]

Sources: BBC Listings.

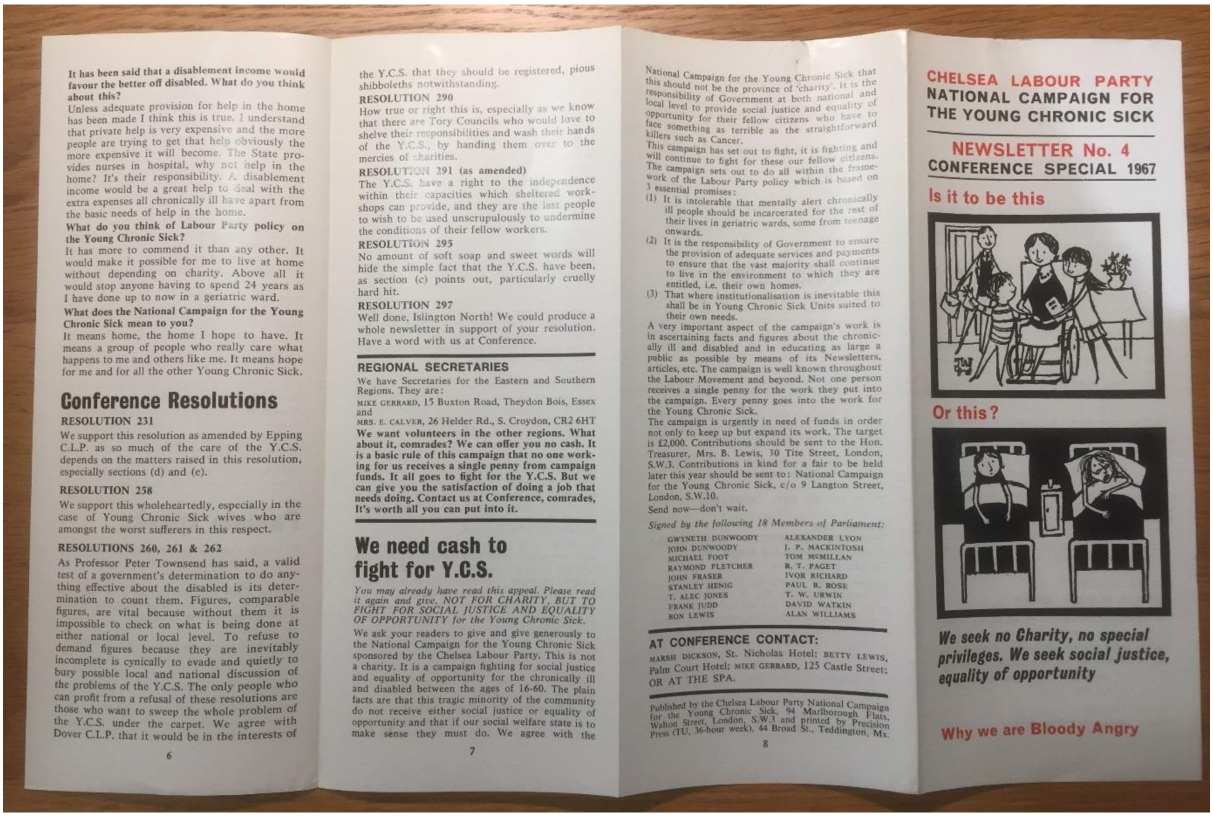
25 - NCYCS newsletter 4, autumn 1967

CHELSEA LABOUR PARTY

NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK

NEWSLETTER No. 4

CONFERENCE SPECIAL 1967



It has been said that a disablement income would favour the better off disabled. What do you think about this?

Unless adequate provision for help in the home has been made I think this is true. I understand that private help is very expensive and the more people are trying to get that help obviously the more expensive it will become. The State provides nurses in hospital, why not help in the home? It's their responsibility. A disablement income would be a great help to deal with the extra expenses all chronically ill have apart from the basic needs of help in the home.

What do you think of Labour Party policy on the Young Chronic Sick?

It has more to commend it than any other. It would make it possible for me to live at home without depending on charity. Above all it would stop anyone having to spend 24 years as I have done up to now in a geriatric ward.

What does the National Campaign for the Young Chronic Sick mean to you?

It means home, the home I hope to have. It means a group of people who really care what happens to me and others like me. It means hope for me and for all the other Young Chronic Sick.

Conference Resolutions

RESOLUTION 231

We support this resolution as amended by Epping C.L.P. as so much of the care of the Y.C.S. depends on the matters raised in this resolution, especially sections (d) and (e).

RESOLUTION 258

We support this wholeheartedly, especially in the case of Young Chronic Sick wives who are amongst the worst sufferers in this respect.

RESOLUTIONS 260, 261 & 262

As Professor Peter Townsend has said, a valid test of a government's determination to do anything effective about the disabled is its determination to count them. Figures, comparable figures, are vital because without them it is impossible to check on what is being done at either national or local level. To refuse to demand figures because they are inevitably incomplete is cynically to evade and quietly to bury possible local and national discussion of the problems of the Y.C.S. The only people who can profit from a refusal of these resolutions are those who want to sweep the whole problem of the Y.C.S. under the carpet. We agree with Dover C.L.P. that it would be in the interests of the Y.C.S. that they should be registered, pious shibboleths notwithstanding.

RESOLUTION 290

How true or right this is, especially as we know that there are Tory Councils who would love to shelve their responsibilities and wash their hands of the Y.C.S., by handing them over to the mercies of charities.

RESOLUTION 291 (as amended)

The Y.C.S. have a right to the independence within their capacities which sheltered workshops can provide, and they are the last people to wish to be used unscrupulously to undermine the conditions of their fellow workers.

RESOLUTION 295

No amount of soft soap and sweet words will hide the simple fact that the Y.C.S. have been, as section (c) points out, particularly cruelly hard hit.

RESOLUTION 297

Well done, Islington North! We could produce a whole newsletter in support of your resolution. Have a word with us at Conference.

REGIONAL SECRETARIES

We have Secretaries for the Eastern and Southern Regions. They are:

MIKE GERRARD, 15 Buxton Road, Theydon Bois, Essex
and
MRS. E. CALVER, 26 Helder Rd., S. Croydon, CR2 6HT

We want volunteers in the other regions. What about it, comrades? We can offer you no cash. It is a basic rule of this campaign that no one working for us receives a single penny from campaign funds. It all goes to fight for the Y.C.S. But we can give you the satisfaction of doing a job that needs doing. Contact us at Conference, comrades, It's worth all you can put into it.

We need cash to fight for Y.C.S.

You may already have read this appeal. Please read it again and give. NOT FOR CHARITY, BUT TO FIGHT FOR SOCIAL JUSTICE AND EQUALITY OF OPPORTUNITY for the Young Chronic Sick.

We ask your readers to give and give generously to the National Campaign for the Young Chronic Sick sponsored by the Chelsea Labour Party. This is not a charity. It is a campaign fighting for social justice and equality of opportunity for the chronically ill and disabled between the ages of 16-60. The plain facts are that this tragic minority of the community do not receive either social justice or equality of opportunity and that if our social welfare state is to make sense they must do. We agree with the National Campaign for the Young Chronic Sick that this should not be the province of 'charity'. It is the responsibility of Government at both national and local level to provide social justice and equality of opportunity for their fellow citizens who have to face something as terrible as the straightforward killers such as Cancer.

This campaign has set out to fight, it is fighting and will continue to fight for these our fellow citizens. The campaign sets out to do all within the framework of the Labour Party policy which is based on 3 essential promises:

(1) It is intolerable that mentally alert chronically ill people should be incarcerated for the rest of their lives in geriatric wards, some from teenage onwards.

(2) It is the responsibility of Government to ensure the provision of adequate services and payments to ensure that the vast majority shall continue to live in the environment to which they are entitled, i.e. their own homes.

(3) That where institutionalisation is inevitable this shall be in Young Chronic Sick Units suited to their own needs.

A very important aspect of the campaign's work is in ascertaining facts and figures about the chronically ill and disabled and in educating as large a public as possible by means of its Newsletters, articles, etc. The campaign is well known throughout the Labour Movement and beyond. Not one person receives a single penny for the work they put into the campaign. Every penny goes into the work for the Young Chronic Sick.

The campaign is urgently in need of funds in order not only to keep up but expand its work. The target is £2,000. Contributions should be sent to the Hon. Treasurer, Mrs. B. Lewis, 30 Tite Street, London, S.W.3. Contributions in kind for a fair to be held later this year should be sent to: National Campaign for the Young Chronic Sick, c/o 9 Langton Street, London, S.W.10.

Send now—don't wait.

Signed by the following 18 Members of Parliament:

GWYNETH DUNWOODY
JOHN DUNWOODY
MICHAEL FOOT
RAYMOND FLETCHER
JOHN FRASER
STANLEY HENIG
T. ALEC JONES
FRANK JUDD
RON LEWIS
ALEXANDER LYON
J. P. MACKINTOSH
TOM MCMILLAN
R. T. PAGET
IVOR RICHARD
PAUL B. ROSE
T. W. URWIN
DAVID WATKIN
ALAN WILLIAMS

AT CONFERENCE CONTACT:

MARSH DICKSON, St. Nicholas Hotel; BETTY LEWIS, Palm Court Hotel; MIKE GERRARD, 125 Castle Street; OR AT THE SPA.

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CHELSEA LABOUR PARTY
NATIONAL CAMPAIGN FOR
THE YOUNG CHRONIC SICK
NEWSLETTER No. 4
CONFERENCE SPECIAL 1967

Is it to be this

Or this?

We seek no Charity, no special privileges. We seek social justice, equality of opportunity

Why we are Bloody Angry

We seek no Charity, no special privileges. We seek social justice, equality of opportunity

Why we are Bloody Angry

DEAR DELEGATES,

We are bloody angry …

… that government inaction should have driven so many wheel-chaired patients to protest in desperation in Trafalgar Square;

… that two years after our party laid down party policy on the chronic sick at Blackpool the civil servants who draft ministerial letters still try to pretend that it does not exist and when faced with its contents either deliberately misrepresent it or evade the issues involved; (our Chairman will gladly prove this to any delegate at Conference)

… that Ministers allow the civil servants to get away with it;

... that after three years of socialist government people like Pamela La Fane (see interview on pages 5 and 6), who is by no means an exception, still moulder in geriatric wards;

… that the only hope for such people is still not social justice but charity which is the last thing that any self-respecting Young Chronic Sick human being wants to us as socialists it is intolerable;

… that the severely disabled Young Chronic Sick are now third-class citizens on British Rail; (it would have cost our Chairman and his wife £46 return to come to Conference from London by rail second class)

.. . that a Junior Minister of the Ministry of Transport found the Young Chronic Sick too unimportant to meet us or even to write to us personally—or was it that he had not got the guts to meet fellow socialists on this issue

… that Ministries still evade their moral responsibilities by hiding behind the petticoats of 'permissive powers'.

AS SOCIALISTS

WE ARE BLOODY ANGRY

As bloody angry socialists we intend to continue to fight for the policy you democratically decided on, for social justice and equality of opportunity not as shibboleths but as realities in everyday life in the home, in their own homes, or in Young Chronic Sick Units.

Yours fraternally, THE CAMPAIGN COMMITTEE

Pamela La Fane

In 'Home with a Capital H' you knew her as `Young Chronic'. In 'Growing Up Geriatric' you knew her as Michele Gilbert. Pseudonyms were essential to protect her. But now some of you have seen her as she is in the Man Alive programme —`Life Sentence' — Pamela.

We will repeat nothing more about this wonderful woman, but let quotes from the programme speak for her and also the interview she gave for publication in this newsletter.

We will only add that we are fighting to make it possible for her to live her own life in her own flat and that Wandsworth are doing all they can to help.

It is up to you to see that never again shall a Y.C.S. suffer as she has been made to suffer over 24 years.

IT IS UP TO YOU, COMRADES.

Quotes from

THE LIFE SENTENCE — Part 1 — PAMELA

Shown Wednesday, 2nd August, [1967] on BBC 2 'Man Alive'

Jeremy James: Six o'clock in the morning, the beginning of another day in the geriatric hospital, a place where the old are sent to die, a place where sometimes the young have to live. Pamela La Fane is forty. She's been in this hospital for twenty-four years. She was first brought here when she was sixteen, crippled by Rheumatoid Arthritis. She was put in wards with senile and dying people and for the first eight years wasn't allowed out of bed. She's spent a lifetime surrounded by the very old, a lifetime that started even before the National Health Service came in. In this country we now have good health service but it isn't perfect and it is in the areas of imperfection that people like Pamela can be found. There are at least three thousand others like Pamela. To be woken at 6 a.m. in order to be washed and have your teeth cleaned may seem inhuman and unnecessary, it's at least better than it used to be.

James: How do you feel about those twenty-four years?

Pamela: Um. I don't feel, I don't feel bitter but I feel very frustrated, I feel it's been a waste, I feel that perhaps with a different environment I might have been able to do something more useful with my life, particularly I wanted to create in a field of writing and I feel that it's been such a waste.

I think it's just that I'm angry at my environment. I'm not angry at my physical disability. It's so often been the lack of mental stimuli. I've so often wanted somebody to be able to talk to, share my interests and I had so little encouragement when I first came here. I just had two books on the locker and they were confiscated. It was the fact that I wasn't allowed to use my mind I think, that makes me more angry than anything.

James: Do you think that in fact in hospitals like this where you do have people like Miss La Fane that there ought to be some sort of special provisions where you have rooms with ramps and French windows and so on which would make it easier for them to get around by themselves?

Doctor: Yes, I do feel very strongly about this and I think most Physicians who specialise in Geriatrics feel this very strongly too that this is one of the deficiencies of the National Health Service that they have not provided special units for the young chronic sick.

James: Well, for instance when you're going out with somebody, when they wheel you out of the hospital gates do you feel as if you're being released or when you're wheeled back in again do you feel that you're coming home?

Pamela: No, I don't feel as if I'm coming home, I feel rather like a snake that sheds its skin. You know, you sort of feel a different person. When I come inside the gates again I feel that I'm sort of reverting to somebody that isn't quite me. It certainly isn't a feeling of coming home.

James: Do you really think that people like Pam ought to be in hospital?

Physiotherapist: No I don't. I think it's very bad that they're institutionalised and hospitalised for so many years. I think the company that she's having to keep and the fact that she's up here and people are totally unsuitable as companions and old people are just not suitable for her intellectual level and physical level as well.

James: Where do you think you ought to be?

Pamela: Well, I think I should be somewhere where there are more young people and where there's a social life, where one hasn't got to run, or conform to the hospital routine which is all very well for sick people but when you don't happen to be sick it's very gruelling to have to conform.

James: So where would you like to be?

Pamela: If I could be in my own flat with sufficient gadgets to help me to be independent and also to share the flat with a friend so that I could be completely away from institutional environment.

James: Do you think this is a feasible possibility that you might finish up in a flat of your own?

Pamela: Well, there is a possibility that it will come to pass and so it's given me quite an incentive to think about the future now, whereas before it was just a blank wall with nothing ahead.

James: What, in fact, is demoralising about them? (the old and the senile)

Pamela: Well, I think I find it demoralising only to look at them and I can see my own situation and I think that I'm just going on the road to ending up as they are. I know it happens to all of us in the end but one doesn't like to be brought so forcibly aware of it when one is still young enough to consider I'm young.

Pamela speaks

Do you feel you have a right as a citizen of this country to live in a home of your own?

Yes, I do.

Do you think that the necessary services and facilities for you to live at home should be provided by the State or by charities?

By the State.

What is your attitude to receiving charity?

It is humiliating. It puts me at the mercy of somebody else's condescension. It is too selective. The charity choses to whom it will give or not give and they can take it away again so that one feels insecure. I don't want charity, I want to be able to live in my own home and, as far as possible, earn my own living.

It has been said that a disablement income would favour the better off disabled. What do you think about this?

Unless adequate provision for help in the home has been made I think this is true. I understand that private help is very expensive and the more people are trying to get that help obviously the more expensive it will become. The State provides nurses in hospital, why not help in the home? It's their responsibility. A disablement income would be a great help to deal with the extra expenses all chronically ill have apart from the basic needs of help in the home.

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Send now — don't wait.

Signed by the following 18 Members of Parliament:

Alexander Lyon
J. P. Mackintosh
R. T. Paget
Paul B. Rose
David Watkin
Gwyneth Dunwoody
Michael Foot
John Fraser
T. Alec Jones
Ron Lewis
Tom McMillan
Ivor Richard
T. W. Urwin
Alan Williams
John Dunwoody
Raymond Fletcher
Stanley Henig
Frank Judd

AT CONFERENCE CONTACT:

MARSH DICKSON, St. Nicholas Hotel, [Scarborough];
BETTY LEWIS, Palm Court Hotel;
MIKE GERRARD, 125 Castle Street; OR AT THE SPA.

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26 - Megan Du Boisson, Thoughts on Developing a Nurses’ Aide Service, 15 July 1968

(in the) Working Party Report by Guthrie and others, 1968

APPENDIX 3

THOUGHTS ON DEVELOPING A NURSES' AIDE SERVICE

Submitted by Mrs. Megan du Boisson on behalf of the Disablement Income Group (DIG).

That some augmentation of the present admirable District Nursing Service is essential to the need of the community is almost unquestioned, especially in view of:

(1) the social desirability of nursing chronic sick patients at home, when only custodial care can be offered in a hospital or institution;

(2) the shortage and expense of hospital beds. How this augmentation is to come about is a matter for thought and discussion by all concerned with the subject.

These Notes are intended as a basis for the first two stages in the progression towards enlightened action to meet the need.

Tentative thoughts

1. Recruitment should be from a body of women and men of suitable educational standard, health, personal and family circumstances.
2. Training be of a length and type approved by the Queen's Institute of District Nurses, realising that in-training is likely to be impossible.
3. A minimum number of hours of part-time service should be acceptable.
4. The scheme should be administered by the local authority who administers the district nursing service: (it is envisaged that special funds from central government should assist the local authority to

develop this service, in view of the saving of hospital costs if patients are suitably and sufficiently nursed at home.)

5. The Nurses Aide (or similar title), should be trained:
    - i. to carry out the nursing tasks thought to be appropriate for delegation by the Queen's Institute;
    - ii. to observe the family situation as a whole and report to the District Nurse if she sees tensions developing, alterations to the home which would assist mobility of the patient, or other difficulties;
    - iii. teach the patient's family how best to care for him/her. This category of training should be one which, like that of the Red Cross and St. John's Ambulance activities, is regarded with pride by those engaged in the work.
6. Training given by the Red Cross and St. John's should be fully utilised. (The battle today is with the neglect of the long-term sick at home, not less than in the emergency field.)

Positive thoughts

1. These recruits should be paid.
2. The need for nursing of the type mentioned above is growing, owing to the number of persons who are now kept alive by medical science but in a state of severe, and often increasing, disability.
3. The desirable continuity of service by the individual nurse to the patient, in so far as this is possible.
4. The absolute responsibility of the District Nurse or Health Visitor for her patient and the subordination of a Nurses' Aide to the direction of the District Nurse.
5. Under the new group practices of GPs now developing, it is envisaged there will be:
    - i. a team providing ancillary services (eg medical social work, occupational therapy, physiotherapy, etc) which would be more or less loosely attached to the practice;

    - ii. an attachment of nurses to these practices and, therefore, a greater demand by the GP upon the services of the nurses;

    - (a) There will undoubtedly be a great need for a nurse of very high calibre (eventual nursing degree?) to lead the team.
    - (b) SRNs and / or SENs to attend in general to the acute cases and those requiring the skilled nursing deemed by the Queen's Institute to be properly provided by the fully trained nurse.
    - (c) Nursing of the chronic sick, the elderly, and other categories requiring less skilled but continuous care, of a rather more routine nature; this is the category in which it is envisaged that the **Nurses' Aide** will be the most involved.
    - (d) The occasional attendant such as the bath attendant.
- iii. The Home Help service run with a view to having two categories:
    - (a) a corps of women (or men) available for emergencies:
    - (b) a regular body of men or women who are employed in the homes of long-term cases.

(DIG supports the local authority who feels that attendance upon the **person** of the sick and disabled individual is not properly provided by the Home Help Service and such work should not be asked of them in addition to the very heavy responsibilities they already undertake in the home, caring for the family, doing the washing, cooking, cleaning, etc.)

To sum up:

It will readily be seen that one of the greatest disadvantages (to the patient) of the present tripartite structure of the health service will begin to be overcome: the GP and Local Authority and even perhaps the hospital, will have some point of liaison and at this point the patient will be made aware of the services available.

All these will be of little use unless he can be assured of regular nursing in his home as and when it is needed. There are not enough fully trained nurses to continue even to maintain the present nursing provision. Unless we are to return to the Sarah Gamp [an incompetent nurse from Charles Dicken’s novel Martin Chuzzlewit] days, some acceptable form of training, limited in scope but carrying the status now associated with nursing in Great Britain, must be devised.

27 - Pamela La Fane, Goodbye to Geriatrics, article in The Guardian, 15 July 1968

> "At the age of 16, in 1943, I entered a geriatric ward. There was nowhere else for me, it seemed. An acute attack of rheumatoid arthritis had left me completely incapacitated, and in need, of permanent care. As there was no one at house to give this, the authorities had no option ..." - that was the way Pamela la Fane began her original articles which she wrote under a pseudonym.

Today, I am leaving the geriatric hospital that has been my “home” for 25 years – since I was 16 years old – to start a life of my own. Leaving behind the restrictions of institutional life, the sounds of noisy old people, and the distressing sights of senility and awareness of death that have been with me for so long.

In December, 1966, my article “Growing Up Geriatric” appeared in these columns. It was an account of my life spent in the only environment I had known since I was 16, which I had been asked to do by the chairman of the National Campaign for the Young Chronic Sick, an organisation concerned with the sort of things I wrote about, I doubt whether anybody at that time realised what would be the outcome of that article. I certainly had no idea that 18 months later I would be writing this sequel, with its happy ending!

The article brought a tremendous response, and many people became interested in my future – to the extent that I was asked through the campaign “If you had a suitable companion and accommodation, would you consider leaving the hospital?” I didn’t need any second asking.

To achieve this, to me, miraculous event, there were three main problems. To increase my physical independence; to find the right sort of companion; and to get somewhere to live. I felt the first problem could be overcome by my going to a rehabilitation centre at Oxford, where even the most disabled person could be helped in some way. An earlier application to go there had been turned but I was luckier the second time. So, a year ago, I paid my first visit to the Mary Marlborough Lodge to be assessed. It was like going into a different world I revelled in the spaciousness and freedom from hospital routine, and the stimulating company of younger people. But the real purpose of the visit was to see if I could be made more independent, and here there were two very important breakthroughs.

By using a small device I could get myself in and out of bed, almost unaided; and an electric powered wheelchair was ordered for me. This would give me mobility which would certainly increase my independence. We discussed the possibilities of my sharing a fiat with another disabled friend, and as the centre had its own flat it was suggested that my friend and I had a trial there to see how we coped and what problems there would be. So I returned later in the year with my disabled companion to see how it worked. It soon became apparent to me that was asking too much of another disabled person. I had been under the impression that we would have the daily services of auxiliary help from the local welfare department. As this was not in fact going to be available, I sadly bad to abandon the idea of living out of hospital with anybody other than an able-bodied person.

Someone suggested that I advertise for a companion, so I returned to the geriatric hospital to do this and to wait for my electric [wheel] chair. My advertisements brought little response, and I began to doubt whether this was the answer to finding a companion. I was on the verge of giving up when the National Campaign for the Young Chronic Sick took over the advertising on a larger scale than I could.

Simultaneously, I received a small remuneration from the local council as well as the free accommodation, and news came through that I was to return to Oxford to collect my long-awaited wheelchair. The seven months I had waited were worth it. For the first time in 25 years I just had to press a switch and I was mobile.

It opened up such possibilities I would no longer have to sit to by my bedside all day, nor have to wait for someone with the time to take me out into the hospital grounds when the sun shone. Even In bad weather there was the third floor of the hospital corridor to drive up and down — at the end of it there was a window opening out to a view of treetops and roofs. It was like having a new pair of legs.

I returned to hospital to learn from the Campaign that replies to their advertisement brought hope of a suitable companions. And, right enough, I met a young woman, who was just the sort of person I was looking for. She was very emphatic that she had no nursing experience but as I pointed out, I wasn’t ill. I didn't need a nurse, but a companion, who could help to do the things I couldn't do for myself, like washing and dressing.

I had been assured that as soon as I had a companion the council would find a flat. A ground floor flat on a nearby estate been vacant and offered us. It was not entirely suitable for someone in a wheelchair, so they knocked down a wall to make easy access into one room, and widened the doors for my chair to go through easily; they made a ramp instead of steps so that I could go in and out of the flat on my own. I shall never forget the day we went to see the fiat for the first time - there was dust flying everywhere as the workmen went about the necessary structural alterations, but to me, it was a better sight than the most stately home! Nor shall I forget the thrill on being told, "This is going to be your bedroom" after 25 years of communal living, I was to have my own room! Where I could enjoy privacy.

Now all is ready for us to move in. The dream which I never imagined would happen has. There will be problems to be sorted out and adjustments to be made in my new way of life. For the first time for many years, I shall be making my decisions, instead of them being made for me by the general routine. I’ve been told “life outside is very hard." Our financial situation will not permit us to live in the grand manner, but with the Social Security benefits and financial help from a couple of charities, we won't be worse off than a lot of people.

During the past 18 months there were some bad moments but the encouragement, moral support and untiring efforts from many people and organised sources have brought them to an end. I know they share my happiness for what I leave behind today in exchange for my freedom.

28 - The Young Chronic Sick, Leading Article, British Medical Journal, 18 January 1969

The young chronic sick, *Br Med* J 1969;1:134.

The recent announcement (1) of an alliance between two voluntary organizations, the Central Council for the Disabled and the National Fund for Research into Crippling Diseases, under the general direction of Mr. Duncan Guthrie, follows hard on three publications (2-4) about the young chronic sick which have appeared during the last few months. These signs of growing interest in a particularly difficult group of patients are welcome.

The first of the new publications (2) reports a day conference held at the Royal College of Surgeons under the auspices of the National Fund in November 1967. The second (3) is the report of a working party established by the National Fund to consider the problems of enabling young chronic sick people to live at home. The third (4) is a memorandum endorsed by the Ministry of Health's Standing Advisory Medical Committee and addressed to hospital boards and management committees. Taken together the three documents highlight the many difficulties of terminology, classification, age range, and incidence to be considered. Each category of handicap covers (and may obscure) a range of different kinds and different degrees of handicap. Probably the most useful classification is according to the individual's functional capacity and welfare needs. From this viewpoint disabled people may be divided into three groups: those requiring hospital care; those who can stay in the community but cannot lead an independent life and therefore need accommodation in special hostels or other sheltered environment; and those who can live at home if they are given various kinds of help.

The working party was set up in October 1965 after an open meeting convened by Mr. Duncan Guthrie gathering together people with practical knowledge of the field. Its fourteen members consisted of appointed representatives of national voluntary organizations and individuals with relevant professional skill. There was general agreement that the proper place for the chronic sick, and particularly the younger ones, was with their families and among able-bodied neighbours, but in discussion it became clear that there was much ignorance and confusion about the complex problems involved and urgent need to collate the information available.

The working party decided to cover the age range 16-60 for women, and 16-65 for men - that is, between school leaving age and entitlement to retirement pension. Terms of reference were restricted to the physically handicapped, excluding those whose primary condition was mental disorder, blindness, or deafness. The inadequacy of financial provisions, the unevenness of home help services, and the ever-present housing difficulties were already well known, but in the course of its inquiries the working party came vividly to realize the need for improved comprehensive medical assessment and regular periodic reassessment, for uniformity of social provisions, and for better paramedical services and improved mechanical aids. In June 1966 it submitted to the Ministry of Social Security an urgent memorandum recommending that disability pensions should be related to degree of incapacity, irrespective of the cause of disability; the payment of supplementary allowances when needed; and equality of financial assistance, with special reference to certain classes of disabled housewives, for whom there was no provision under existing regulations.

Later the working party extended its inquiries by looking into the problem of the young chronic sick already in institutions with a view to considering the sort of residential accommodation which should be provided for those who could not remain at home. It was mainly concerned with resolving two conflicting questions: Are disabled patients' interests better served by grouping them according to physical capacity, intelligence, and social background in a purpose-built well-equipped homely unit, which might be far from home and family? Or are they happier in a less well equipped hospital or institution nearer home? The general opinion was that at least those patients under 35 years, with the prospect of many years of residential life before them, should be accommodated in the former type of unit. The working party also decided that medical assessment should preferably be carried out in one hospital and coordinated by one consultant. Liaison between the three main branches of the Health Service was found not to be so close as it should be, and not only the patients but many of their family doctors were unaware of the services available. The working party also considered that the provision of nursing aides working under the supervision of trained nurses, or in some cases the enlistment of responsible neighbours as permanent home helps, would fulfil a real need.

The Ministry of Health Memorandum (4) gives the figures of a census carried out in April 1967 showing that 4,223 chronic sick between the age of 15 and 59 were in non-psychiatric hospitals. Of these, 502 were under 35, of whom 101 were in special units for young chronic sick, 74 in geriatric or chronic-sick wards, 271 in other wards, and 56 accommodated by contractual arrangements. A number of them were in temporary residence to give relief to their families. The Ministry found that most of the regional hospital boards made what was called special provision for the younger chronic sick by concentrating them into certain wards or certain hospitals, but some boards considered it more suitable to place the patient in any sort of ward which was near his home. Though the patients were adequately nursed in these units, they undoubtedly lacked enough provision for occupation, hobbies, intellectual interests, and the sort of stable personal relationship which they would have been having at home. The recommendations made in the Ministry's memorandum reflect how carefully and sympathetically the other two reports have been studied. The Ministry gives its official blessing to purpose-built units accommodating not fewer than 25 patients, which is the smallest group for which appropriate provisions can be made, and not more than 50, since larger units tend to acquire too institutional an atmosphere. And it makes a number of recommendations that will be helpful to those charged with care of the young chronic sick. A covering letter notes that the Minister intends to call for reports on progress in about 2 years' time. If these recommendations can be carried out, the welfare of the young chronic sick should be greatly improved and the confusion at present existing alleviated if not finally resolved.

(1) Brit. Med. J., 1968, 3, 563.

(2) Proceedings of a Symposium on the Disabled Young Adult, ed. W. H. Bradley. National Fund for Research into Crippling Diseases, Vincent House, Vincent Square, London S.W.1 (2 guineas net plus 1s. 10d. postage).

(3) At Home or in Hospital? National Fund for Research into Crippling Diseases (5s. net).

(4) National Health Service: Care of Younger Chronic Sick Patients in Hospital. Ministry of Health, H.M. (1968) 41.

29 - Steven Swingler, letter to The Guardian, 12 February 1969

Proper care for the disabled

Sir,

I read with some surprise the letter from Professor Peter Townsend. The professor suggests that my department lacks both information and advice about the disabled and their needs, and that the Disablement Commission envisaged in the Private Members Bill now before the House will remedy these defects.

I am afraid that the professor has not read the Bill very carefully. The Commission of six which it proposes would be responsible for reviewing pensions and benefits payable to disabled people and for recommending changes. This is essentially a Government responsibility, not only because of the potentially large expenditure involved, but also because of implications for other social security benefits – the disabled cannot sensibly be looked at in isolation from other groups.

As for expert advice, we are always ready to listen to it, as the Secretary of State and I made it clear to the DIG deputation which recently came to see us. But we already have a wide range of advisory committees and it is not really very sensible to think that the whole span of expert advice now available to us could be obtained from a small body of six men. I feel sure Professor Townsend would not consider it an advance if all the university faculties at Essex were amalgamated into a single faculty of general knowledge.

I agree with the professor on the need for comprehensive social security and welfare provisions for the disabled – I would add “and for the whole community," because the disabled are not a homogeneous group. This is precisely what we expect to achieve with our new combined Department of Health and Social Security.

Yours sincerely,

Stephen Swingler, [MP, Minister for Social Services]

Department of Health and Social Security,
10 John Adam Street, London WC2.

30 - Marsh Dickson, letter to The Guardian, 14 February 1969

Credit where due

Sir,

Stephen Swingler in his letter on the proper care for the disabled, while making some valid points has overlooked others (“Guardian,” February 12).

This is the only Government that has ever set out to discover the facts about the chronically ill and disabled in the community and it is only reasonable to allow it time to digest the facts it unearths. It was certainly prodded into action by the National Campaign for the Young Chronic Sick and DIG, but it is entitled to the credit for acting.

Swingler must face the disrepute in which his civil servants are often held by the chronic sick and disabled. Some of the letters sent by the old Ministry of Health were so completely out of touch with the realities of the recipient patients’ lives as to make them despair.

The problem of priorities, especially in the case of those in the lower income groups: social security and welfare is as much a problem of services as of pensions, and in many cases the services are more important. Constant attendance will often be more important than a constant attendant allowance which may not meet the needs.

The most crying need is that integrated health and welfare departments at both local and national level, should have as the civil servant heads officers with long and varied experience as professional social workers in the field, men who would vastly improve the communications between the patient and the authorities and who could advise their political masters with a genuine understanding of the problems involved.

Yours faithfully,

Marsh Dickson,

Chairman, National Campaign for the Young Chronic Sick,
1 Sutherland House, Marloes Road, [London] W8.

31 - Marsh Dickson, letter to Alf Morris, 19 April 1969

National Campaign for the Young Chronic Sick
98, Eaton Place,
London, S.W.1.

19th April 1969

A. Morris, Esq., M.P.,
The House of Commons,
London, S.W.1.

Dear Mr. Morris,

After four years under the wing of the Chelsea Labour Party, the National Campaign for the Young Chronic Sick is now becoming a truly national organisation. With support from the Labour movement in many different parts of the country, we are reorganising ourselves to use this energy to help improve the life of the chronically ill wherever they may be. We remain completely a socialist campaign, seeking recognition of their plight and trying to build a better future for them by political means, through the Movement, the Party and the Government.

In the past you have responded to our appeals for support, and we would now like to invite you to become a sponsor of the campaign. This need not involve you in any work additional to the heavy load you at present carry; since although we hope
that some of our sponsors will advise us on Parliamentary campaigns and lead delegations from time to time, we recognise the pressures put upon M.P.s and ask no more than your pledged Parliamentary backing. If you feel you can spare the time to act periodically as a consultant to us, we shall naturally be very pleased indeed.

Copies of our campaign newsletters to date are enclosed. Sponsors will automatically receive the more regular newsletters we hope to put out in future, and with a major recruiting drive about to take place, we are confident of drawing in new ideas and talents to increase our general effectiveness. If you give us your support, please also commend the campaign to your fellow Members and Constituency Party - the broader the base of our work, the better the chances for a new deal for the Young Chronic Sick.

Hoping to hear favourably from you,

Yours fraternally,

Marsh Dickson
President

32 - Marsh Dickson, letter to The Guardian, 19 May 1969

Sir,

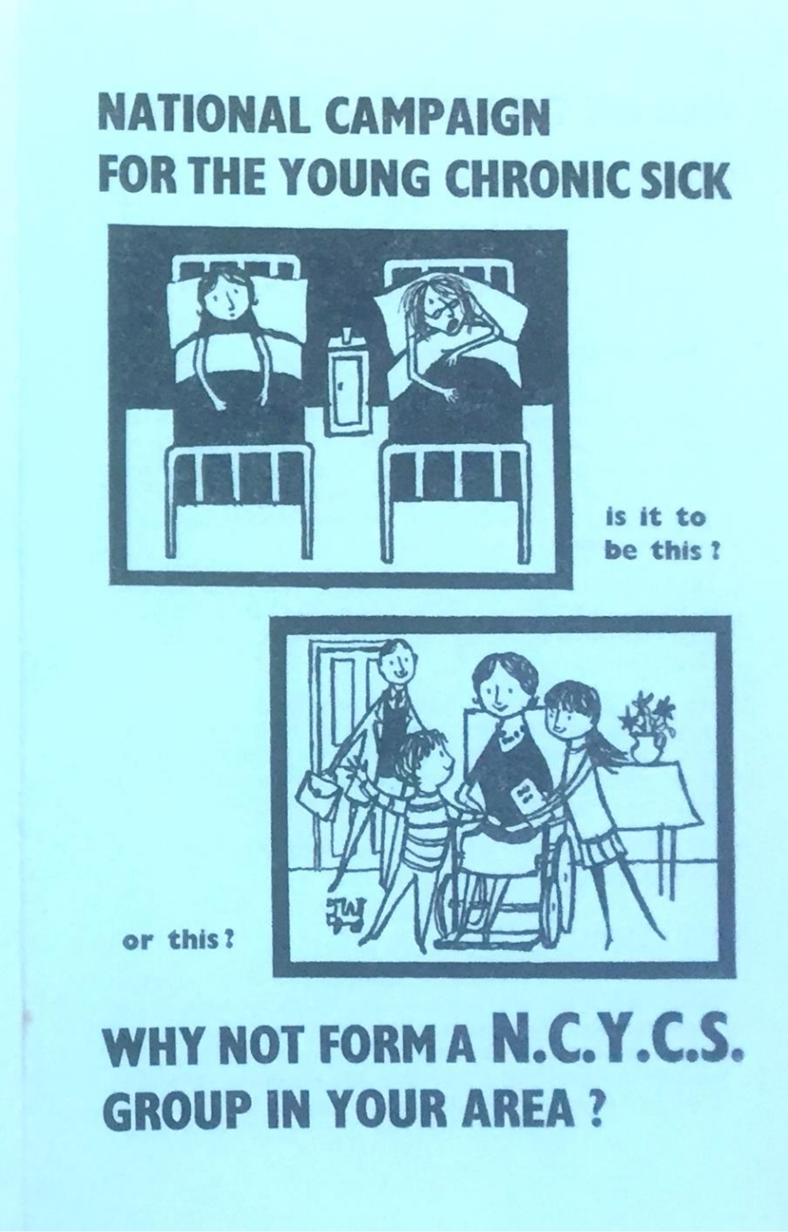
We are now told that those in need of National Health services should pay for the necessary expansion of comprehensive schools. Robbing Peter to pay Paul has not, and never has had, anything to do with the maxim that Socialist advance is a problem of social priorities.

This latest manoeuvre appears to be a cynical exercise in the tactics of dividing your enemies, in this case those who, as loyal members of the Labour Party, call on the Government to carry out its pledges to the nation and to the Labour Party on behalf of those in need of the health services and the children in need of equality of opportunity in education. The price of one mile of motorway is no justification for this very smelly double talk.

Yours faithfully,

Marsh Dickson
President
National Campaign for [the] Young Chronic Sick
98 Eton Place
London S[W]1.

33 - NCYCS membership drive pamphlet, summer 1969



NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK

WHY NOT FORM A N.C.Y.C.S. GROUP IN YOUR AREA?

WHO ARE THE YOUNG CHRONIC SICK?

The Young Chronic Sick (Y.C.S.) are aged between 16 and 60, and suffering in the main from progressive diseases like Multiple Sclerosis, Rheumatoid Arthritis, etc. They may be able to work and look after themselves. Most of them are chair or bed-bound. They may be found in their homes, in hospitals or in institutions.

Ask yourself these questions:

1 Are there any Y.C.S. in your area who are kept in the geriatric wards of local hospitals? Are there Y.C.S. in specialised units who could be at home? How many Y.C.S. are in danger of being taken from home and put into institutions? What steps are the Local Authorities taking to prevent this? What type of accommodation does the local Authority provide for Y.C.S.? Have you seen it? Is it suitable?

2 How many friends or relations are paid by your Local Authority as home-helps? How much do they receive? Do the Y.C.S. in your area know what they are entitled to? Do you? Do your Councillors? Do your G.P.s?

3 Do your hospitals have a liberal visiting policy? Can relatives and friends call at any time? Are there restrictions both on time and number? Are your Y.C.S. imprisoned in hospitals? Are they given full opportunities for reading, creative work, etc., or are they given only the crudest occupational therapy?

4 What are you? What is the Labour Movement in your area doing about it?

Now try these:

1 What are the most pressing problems in your area? Industrial injuries and diseases? Over-crowding? Concentration of sick and convalescent people due to the healthy air or mild weather? Sparse population and difficult communications? Lack of suitably designed and equipped public buildings? Theatres? Cinemas? Restaurants? Public conveniences?

2 How would these affect the Y.C.S.? What do you think should be done? Put yourself in a wheelchair and figure it out.

From your wheelchair, consider this:

1 How many chair or bed-bound patients in your area have battery-operated seat-pads, or ripple mattresses to prevent discomfort in the chair and bedsores in the bed? They are entitled to them.

2 How many have a 'Possum' or equivalent aid to broader horizons and greater independence? How many can control electronically a typewriter, a telephone, a television set? How many on the other hand are forced to do without or to put up continually with what other people want, without a choice of their own?

WHAT ARE YOU, AND THE LABOUR MOVEMENT LOCALLY DOING ABOUT IT?

How to form a N.C.Y.C.S. group

Use your own Ward, Party, Women's Section, Y.S. group, Co-operative or Trade Union Branch, or your G.M.C. Raise the questions there. Make your Comrades understand why action is needed.

Choose a suitable administrative area for operation. For example, a Borough or a continuous Urban area; a Rural district or a Hospital Management Committee area. Select whatever area you think most suitable.

Make contact with all C.L.P.s and Labour, Trade Union and Co-operative organisations in that area for support. Seek the sponsorship of Labour M.P.s and well-known Councillors and personalities in the area you have chosen.

Remember N.C.Y.C.S. is made up of members of the Labour Movement, motivated by socialist philosophy. Make sure all officers you appoint are members of the Labour Party. Your primary object is political.

Do not attempt to undertake what local or central Government should do. Only ensure that they are doing their job. For your part you can make enquiries, conduct surveys, ask questions to see how well they are doing it.

Wherever they are not, use Labour Councillors, M.P.s, the local and national Press and radio to expose their failures. Seek publicity for your effort, both to educate the people around you to the problems of Y.C.S. and to demonstrate that your local Labour Party really cares.

When you tackle a problem, whether or not you solve it, keep in touch with us so that we can co-ordinate your efforts and those of other comrades in different areas. This can put greater pressure on central and local Government than isolated assaults.

The Members of the Group

Try to include among your members people whose special skills can best help disabled comrades :

people who live in the same house as chronically sick or disabled ;

local Councillors, members of Regional Hospital Boards, social workers, etc. ;

ordinary Labour Party members who will not permit themselves to be hoodwinked by local or national clap-trap and bureaucracy ;

and make sure you have a good Secretary, an enthusiastic organiser, a Press-Officer with a flair for publicity.

Fund raising

You will need money, if only to pay your postal expenses. The mote you raise, the more you can do. Raise money in any way you can-for yourselves, and for the central funds of N.C.Y.C.S.

Get as many wards, local Parties, etc., as possible to affiliate. Half of any money you receive from local affiliations may be retained as a working fund. In national draws, you may keep 6d. for every book of draw tickets sold. It all helps.

One last thought

What does it mean to a woman that she can no longer make herself up, or do her own hair? That she can no longer adjust her frock, or keep comfortable in her enforced sitting position. That she cannot even take her children on her knee?

What does it mean to a man that he can no longer do odd little jobs around the house? That he cannot even go through the motions of caring for and protecting his wife and children?

What does it mean to anyone to spend lonely hours in a chair or a bed with no one to talk to?

You can help make these peoples' lives more worthwhile; not in a spirit of condescension or charity, but as a good neighbour and a fellow-fighter. The Labour Movement is rich in these.

THE NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK

Sponsored by

Norman Atkinson, MP; Edward Bishop, MP, Cllr. Mrs. Marjorie Clark; Mrs. Freda Corbet, MP; Raymond Fletcher, MP; Will Griffiths, MP; Frank Judd, MP; Dr. David Kerr, MP ; Miss Joan Lestor, MP ; Arthur Lewis, MP; Alfred Morris, MP ; Albert Murray, MP , Stan Newens, MP ; Laurie Pavitt, MP; Ivor Richard, MP , Roy Roebuck, MP; David Winnick, MP and the Chelsea Labour Party

THE EIGHT OBJECTIVES OF N.C.Y.C.S.

NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK

1 Treatment at home wherever possible, and never in a geriatric unit.

2 Payment to a relative or friend for home care.

3 Provision and training of medical home helps.

4 A specialised YCS unit in every hospital group.

5 Compulsory registration by Local Authorities.

6 Provision of the means of transportation, recreation and holidays.

7 Integration and development of Town Hall, Hospital and Government services, on a mandatory basis.

8 Adequate income for the special needs of the disabled.

Published by N.C.Y.C.S., 15 Buxton Riod, Thevdon Bois, Essex.

Printed by Precision Press, 3 Easton Street, High Wycombe, Bucks.

The calculated date of this undated leaflet is, summer 1969. This calculated date is based on five factors:

(1) the postal address being used,

(2) the lack of a mention of the Alf Morris private members bill (suggesting pre-November 1969),

(3) that the leaflet was not included in a letter sent to Alf Morris (suggesting post-April 1969),

(4) that the campaign team usually produced a printed newsletter or leaflet for the Labour Party conference held around September each year, and

(5) the speech given by Mary Gray at the Labour Party conference, 1969, which included, “take back to your local authorities and trade union branches the green leaflets that are on your chairs this morning”. p348 Labour Party Conference Report 1971.

34 - Marsh Dickson, memo to Alf Morris, 3 December 1969

Memorandum
To: Mr A. Morris, M.P., House of Commons
From: Mr M. Dickson
Date: 3rd December 1969

Re: Information, and the case generally of [name redacted]

M- suffers from advanced Multiple Sclerosis and is unable to read, write, feed [themselves], stand, and [their] vision is very much impaired. [They have] available aids such as POSSUM, Ripple Mattress and battery operated Ripple Cushion for [their] chair.

In the case of the POSSUM, I knew that [they were] entitled to this and asked [their] GP to arrange a visit to the Consultant at the Middlesex [hospital]. The Middlesex themselves did not realise the entitlement and, in fact, were most discouraging, saying that people with [their] disease, to the best of their knowledge, were not entitled. Fortunately, I knew this not to be true and [they] fought on, eventually gaining the support of the Consultant and obtaining the POSSUM.

One of the great problems is, of course, bedsores. … Again, when [they] discovered about the Ripple Mattress and Ripple Cushion [the] GP got on to the Local Authority who then proceeded to obtain [these for them]. It is interesting that the Social Workers concerned had never heard of a battery operated Ripple Cushion.

It will be seen from the above that M- was **not** informed either by the hospital or the Local Authority about any of these important aids.

In the Boroughs of Kensington and Chelsea there are three POSSUMs. In not one single case has the information about POSSUMs come from either the hospital or the Local Authority. In the first case, this was understandable as far as the Local Authority was concerned but in the case of the hospital, as they had full knowledge of these, there seems to have been a slip-up in information. I understand that this is because they do not consider it their duty to bring these to the notice of patients. Why?

It is interesting that the three POSSUM users are all of middle-class background with access to information from campaigns or voluntary organisations. M– knew of these aids through the National Campaign for the Young Chronic Sick. How many people in North Kensington need these things? How are they to get to know about them - especially those who, because of lack of education and background have no way of finding out for themselves?

35 - Labour MPs, letter to The Guardian, 19 December 1969

Sir,

Mr. Alfred Morris's Chronically Sick and Disabled Persons Bill is at present under discussion in Committee in the House of Commons. This measure, which won acclaim from both sides of the House during the debate on the second reading was rightly described as Charter for the chronically ill, and promises to be the most significant advance in social provision for the long-term sick and disabled ever made in this country.

Among its provisions are clauses which prevent the chronically sick being housed in geriatric hospital units; require local health authorities to inform them of their entitlements, and to provide certain basic services including access to public buildings, and provide for training and consultative functions in the planning of further legislation. It is important to all who care for the chronically ill that such humane and socially responsible Bill should become law.

In commending the Bill to you and your readership, we make an appeal to the public to lend it their support. The role of the public lies in providing the supporting evidence, and we ask that if your readers know of any case of hardship caused to person or family through lack of information; through inadequate Local Authority or medical services, or as result of accommodation in geriatric units, they send details to

> The Secretary, National Campaign for the Young Chronic Sick,
> 11 Domelton House, Iron Mill Road, London SW18.

Assistance of this kind will be invaluable and warmly appreciated.

Yours faithfully

> Lewis Carter Jones
> John Golding
> Jack Ashley
> Laurence Pavitt [omitted in some early editions]

House of Commons

Also reprinted in Cheshire Smile, Spring 1970

36 – Consultant doctor, letter to The Guardian, 29 December 1969

The chronic sick

Sir,

Your leading article ("Guardian," December 16) and subsequent letter by four members of Parliament on December 19 suggesting that young chronic sick patients should spend a maximum period of three months in a geriatric unit is a sad reflection on the Health Service. Experience among geriatric physicians show that the young chronic sick are uniformly unhappy in geriatric wards irrespective of whether the geriatric department is good, bad, or indifferent.

Surely our own hospital is not unique in its progressive view that the young chronic sick, although a serious and urgent problem, is not within the domain of geriatric medicine, which itself has serious and urgent problems to deal with.

Yours faithfully,

James Andrews

Consultant Physician to the Geriatric Service
West Middlesex Group.

37 - NCYCS newsletter, January 1970

NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK

NEW YEAR NEWSLETTER 1970

FLASHBACK TO BRIGHTON

The Campaign made the biggest impression so far on the 1969 Annual Conference. A Campaign meeting; constant contact with delegates, and seat by seat distribution of our leaflet set the scene. The health debate put the seal on it with an excellent speech front the Delegate for Wycombe, who moved our resolution, and its acceptance in full by the N.E.C. A just reward for the work done in 1969 and a token of the Campaign's wide support within the Labour Party.

IAN MIKARDO'S SPEECH

Benefits must go where need is greatest - permissive powers are not good enough - exclusive definitions are destructive. Just what NCYCS has been saying for four years. We believe in a humane and comprehensive health and welfare service. Nobody needs it more than the Chronic Sick. And the N.E.C. fully agrees.

NATIONAL CAMPAIGN
FOR THE
YOUNG CHRONIC SICK

Is it to be this

Or this

NEW YEAR
NEWSLETTER
1970

CONFERENCE MEETING

Laurie Pavitt M.P., and Mike Gerrard, campaign chairman, spoke on the NCYCS platform, setting out clearly the present condition of the chronically ill. Dorothy Dickson, Pamela La Fane and Diana Staples lent charm and point to the occasion, giving those present the chance to discuss life at home and in geriatric hospitals, and demonstrating that the Campaign is conducted **by** the Young Chronic Sick, not only **for** them. The audience displayed a keen, intelligent and compassionate interest, and the meeting was very useful in establishing a close relationship with new friends, and in setting the mood for the later debate.

THE DEBATE ITSELF

The Young Chronic Sick resolutions were taken as part of the Health Service debate, and attracted as many speakers as the main health motion. Moving, for Wycombe C.L.P., Mary Gray made use of the Conference leaflet, drawing delegates' attention to the necessity of local watch-dog and corrective action. Stressing the need for informed attack, she selected specific entitlements of the chronically ill, and called on all present to pledge themselves to ensure that these entitlements are obtained, wherever the need arises. A most popular speaker was the delegate from Easington, his own life story one of triumph over chronic disability, who supported this appeal. With speeches of this calibre and point, the result was never in doubt.

TEXT OF OUR RESOLUTIONS (NOW LABOUR PARTY POLICY)

"This Conference calls upon the Government to ensure that the chronically ill and disabled are made aware of all their entitlements both financial and physical, and to make mandatory on local authorities those powers to help the chronically ill and disabled, which are presently permissive, ensuring the necessary funds to make this possible. Conference further calls upon the Government to abolish all distinctions between different categories of the chronically ill and disabled with regard to entitlements."
Moved by WYCOMBE C.L.P.

"This Conference urges the Government to take urgent steps to provide suitable hospital accommodation for the young chronic sick, and so bring to an end the practice of accommodating them in geriatric hospitals.”

Moved by SUDBURY AND WOODBRIDGE, C.L.P.

THE EIGHT OBJECTIVES AND THEIR ADOPTION

1. Treatment at home wherever possible, and never in a geriatric unit.
   Labour Party Conference 1965 & 1969
2. Payment to a relative or friend for home care.
   Labour Party Conference 1965
3. Provision and training of medical home helps.
   Labour Party Conference 1965
4. A specialised YCS unit in every hospital group.
   Labour Party Conference 1965
5. Compulsory registration by Local Authorities.
   Labour Party Conference 1967
6. Provision of the means of transportation, recreation and holidays.
   Labour Party Conference 1967
7. Integration and development of Town Hall, Hospital and Government services, on a mandatory basis.
   Labour Party Conference 1967
8. Adequate income for the special needs of the disabled.
   Labour Party Conference 1967.

So what has happened to them? Now read on ...

AND FORWARD TO WESTMINSTER

The impetus gained at Brighton has been carried over into this session of Parliament with Alf Morris' Private Member's Bill for the Chronically Sick and Disabled. This valuable and comprehensive measure, embracing most of the eight objectives, has passed its Second Reading and is now being studied by a Select Committee. A special newsletter***** will be devoted to this Bill and will come out later in the year. For the present, readers are urged to persuade their M.P. to support the Bill, and to get in touch with Alf Morris at the House of Commons if they have any information, case histories, etc., which will help to push the Bill through.

*** as yet not found – TB**

THE ENTITLEMENTS OF THE YOUNG CHRONIC SICK

Many supporters of the Campaign will want to know exactly what are the entitlements of the Young Chronic Sick under present Health and Welfare legislation: what rights are prescriptive and which permissive. As a guide to local action, we make the following comments:

A. Benefits and allowances.

These are all in the melting pot of current legislation. Figures supplied today will be out of date almost before printing. The most disgraceful current anomaly is that a woman rearing young children at home is not regarded as being employed, and therefore not entitled to any social security benefits, if she becomes chronically ill. There are also vast discrepancies between the benefits available to the chronically ill and those injured or disabled as a result of military service, or through industrial accidents. The military disabled come first, and the ordinary civilian chronically sick last.

B. Services.

Home nursing and home-help are a right. Home-helps in particular are badly paid and in short supply. Most local authorities provide very inadequate home-help services. Recreational transport, sheltered workshops and purpose-built toilet facilities in shopping and recreational areas are services which good authorities (very few of them) provide. All authorities are empowered to do so, and the Chronically Sick and Disabled Persons Bill proposes to make such provision mandatory.

C. Equipment.

Patients who fulfil the medical requirements are entitles to wheelchairs (with battery-operated ripple pads), special types of bed, hoists, and ripple mattresses in the home. They are entitled to POSSUM, to disabled persons' vehicles, and to the domestic alterations (including garage building) necessary for their installation. None of this equipment is supplied obligatorily, and because the great majority of those entitled do not know what they can apply for, they are in no position to profit by the wide powers granted to medical and local authorities.

THE CHRONICALLY SICK AND DISABLED PERSONS BILL SEEKS TO CORRECT THE POSITION BY EXTENDING THE AREA OF MANDATORY LOCAL AUTHORITY PROVISION, AND BY REQUIRING THE AUTHORITIES CONCERNED TO INFORM THE CHRONIC SICK OF THEIR ENTITLEMENTS, BOTH STATUTORY AND PERMISSIVE.

NCYCS AND HIGHER EDUCATION

The question of opportunities in higher education for the Young Chronic Sick was raised with us by Ken Wright of N. Lewisham; himself a disabled student. The Campaign has up to now concerned itself with the chronic sick in the home, the factory, the hospital and the institution. It believes the question raised to be an important one and proposes to tackle it in the coming months as a research project. The N.U.S. have agreed to collaborate in this work. The Campaign warmly welcomes the intention of the Open University to give special consideration to people who by disablement or chronic illness would otherwise find it hard to study at University level. This policy has received insufficient publicity.

INTO THE SEVENTIES

We start the new decade with a clear and precise commitment. Our responsibility is not only to help in the passage of the Chronically Sick and Disabled Persons' Bill, but to create the climate of feeling which makes its nationwide implementation an immediate imperative. We must use Parliament, the Press, Radio and Television nationally and locally to make an impact on the Medical and Local Government Authorities and to impress the need for change on administrators at all levels, and on the public at large. Our sponsors will do the work in Parliament, and lead the way in Trade Unions. It is up to us, Labour Party, Trade Union and Co-Operative members to wake up the country and produce that overwhelming response. This is why the Campaign is asking for affiliation and financial support among Labour Parties, T.U. and Co-Operative Branches; this is why it will publish news and information letters as the year goes on. Return information—case histories, instances of anomalies, injustices or maladministration—will be most valuable, and the Campaign will be happy to give advice on how to cope with, or counter, such circumstances. If 1970 is to be the year of advancement for the cause of the Chronic Sick, we all must help each other, and them, to make it so.

Support the NATIONAL CAMPAIGN FOR THE YOUNG CHRONIC SICK
Secretary: Margaret Robertson
11 Domelton House, Iron Mill Road, LONDON SW18.

Annual Affiliation fees:

Constituency, Borough and Central Labour Parties; T.U. and Co-Operative Branches -	£2. 0. 0.	
Local and Ward Labour Parties, Y.S. Branches, and Women's Sections -	£1. 0. 0.	
Individual Members -	10s. 0d.	[50p]

Sponsored by
Jack Ashley, MP ; Norman Atkinson, MP ; Joan Baker; Edward Bishop, MP; Cllr. Mrs. Marjorie Clark; Jim Conway (AEF); Mrs. Freda Corbet, MP; George Doughty (DATA); Fred Evans, MP; Andrew Faulds, MP; Raymond Fletcher, MP; John Golding, MP; Will Griffiths, MP; Eric Heller, MP; Lord Jacques; Clive Jenkins (ASTMS); Hugh Jenkins, MP; Jack Jones (TGWU); Frank Judd, MP; Herbert Kemp; Mrs. Anne Kerr, MP; Dr. David Kerr, MP; John Lee, MP; Miss Joan Lestor, MP; Arthur Lewis, MP; Alfred Morris, MP; Albert Murray, MP; Stan Newens, MP; Chris Norwood, MP; Terence Parry (FBU); Laurie Pavia, MP; Ivor Richard, MP; Sir William Richardson; Roy Roebuck, MP; Hugh Scanlon; David Winnick, MP; and the Chelsea Labour Party.

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38 - Marsh Dickson, article in Tribune, 2 January 1970

Personally Speaking

At this moment when Alf Morris's Private Members' Bill, "The Chronically Ill and Disabled Persons Bill" has reached committee stage, it is an ideal opportunity to look at a unique form of socialism in action, the National Campaign for the Young Chronic Sick.

Many times we have been asked why we do not join up with the Disablement Income Group, why we do not widen our appeal to all parties, why we do not register as a charity. The answer has always been, and I trust always will be, because we are socialists looking at the problems of the chronically ill and disabled through socialist eyes and seeking answers based on our socialist philosophy.

It might have been financially worthwhile to be registered as a charity if our aims [had] been those of the charities in the field of the disabled. But they are not. We are concerned with safeguarding and advancing the rights of the chronically ill and disabled exactly as any trade union looks after the rights of its members and seeing that the appropriate authorities are kept up to scratch. We do not ask for charity but social justice, a term that is apt to make most charities wince.

Where we to join up with "non-political" (whatever that means) charities, we would forfeit the right to speak to you as fellow socialists in terms of socialist answers to one of our most difficult social problems.

Steadily, against the odds, we have persevered through the constituency parties via Labour Party conferences to argue the case for this unfortunate minority. It has not been easy and it won't be easy, just as it won't be easy to get Alf Morris's Bill on the statute book. It represents five years of hard grind on our part, five years of resolutions endorsed by you at Labour Party conferences. Now it needs the support which only you in the constituencies, you in your trade unions, you in your Co-op parties and guilds can provide to ensure its passage.

It is not just a matter of passing resolutions, important as these are, but of giving Alf Morris the ammunition he needs: case histories of chronically ill still in geriatric accommodation; instances of the lack of information given to the chronically ill and disabled about their entitlements; the hardships of disabled drivers, details of the lack of facilities such as ramps, of public lavatories that are free for use of all members of the public in legal theory but not in legal practice, etc.

Alf Morris's Bill includes: registration of the chronically sick and disabled; mandatory duty to inform patients of their entitlements; no patients to be kept in geriatric accommodation without the specific authority of the Minister; improvements in provision of vehicles for patients; mandatory provisions for providing access to public buildings, toilets, etc.; mandatory housing provision; prevention of surcharging the disabled and chronically ill for necessary telephone equipment; special provision for the deaf, hard of hearing and deaf-blind; and representation on advisory committees.

A Government Bill of the same complexity as Alf Morris's Bill would have 100 civil servants working on it. As a private Member, Alf Morris does not have these facilities. We are happy to act as a channel of information. So if you write to is, we will file and process the information and then pass it on to him.

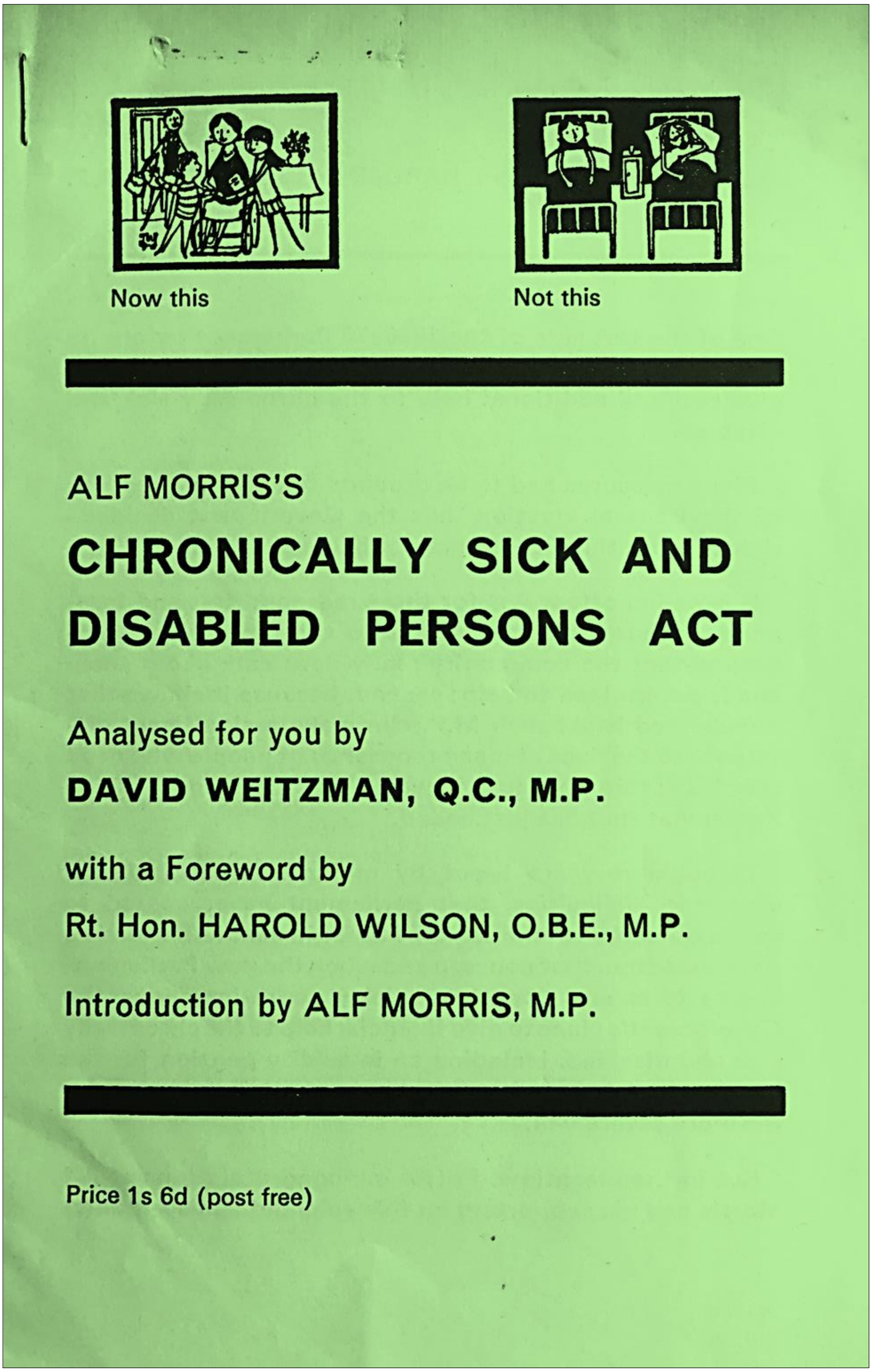
Please send copies of resolutions of support, details of individual cases etc., to the National Campaign for the Young Chronic Sick, 11 Domelton House, Iron Mill Road, London SW18 (Telephone. 874 4615).

Please comrades, don't just read this and say what a good idea it is; get down to it and help.

MARSH DICKSON

President, National Campaign for the Young Chronic Sick

39 - CSDPA Booklet by David Weitzman, May 1970



Now this

Not this

ALF MORRIS'S

CHRONICALLY SICK AND DISABLED PERSONS ACT

Analysed for you by

DAVID WEITZMAN, Q.C., M.P.

with a Foreword by

Rt. Hon. HAROLD WILSON, O.B.E., M.P.

Introduction by ALF MORRIS, M.P.

Price 1s 6d (post free)

Text follows:

Alf Morris's

Chronically Sick and Disabled Persons Act

Analysed for you by

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with a Foreword by

Rt Hon Harold Wilson OBE MP

Introduction by Alf Morris MP

Price 1s 6d (post free)

Foreword by the Rt Hon Harold Wilson OBE MP

One of the last acts of the 1966-70 Parliament before its dissolution was to pass Alf Morris's new Bill to give real and additional help to the chronically sick and disabled.

Many measures had to be dropped temporarily because of the General Election, but the Government decided - rightly - that this Bill should not be delayed.

It is an important Act for three reasons: first and foremost, because it demonstrates to the physically handicapped that the community really does care about them and is determined to help: second, because it shows that a determined backbench MP can make a significant difference to the lives of many thousands of people who need that help: third, because it symbolises the purpose of the Parliament that has just ended.

Throughout years beset by major international and economic difficulties, that Parliament never ceased to concern itself with the cause of those in need. Alf Morris's Act flows from that concern and when the new

Parliament begins it is our intention quickly to re-introduce the Government's plans to give financial help to the chronically long-term sick and a constant attendance allowance for the more severely ill.

But in the meantime, I offer my congratulations to Alf Morris and his supporters on this splendid achievement.

Introduction by Alf Morris MP

Sponsor of the Chronically Sick and Disabled Persons Act

It was good fortune in the Private Members' ballot that gave me the opportunity to legislate for the long-term sick and disabled. I had no ready-made Bill - only a fixed intention to increase the welfare, improve the status and enhance the dignity of severely handicapped people. Drafting the Bill immediately brought me into close fellowship with some very fine colleagues in the National Campaign for the Young Chronic Sick. Marsh Dickson and Mike Gerrard were a constant source of help and encouragement. The Bill also excited the active support of other organisations working for disabled people, of many of my parliamentary colleagues and of several Ministers and their officials.

As I said in the House of Commons (5th December 1969) when moving the Second Reading of the Bill, my own approach to disablement favours a society where there is genuine compassion for the long-term sick and disabled; where understanding is unostentatious and sincere; where needs come before means; where if years cannot be added to the lives of the chronically sick, at least life can be added to their years; where the mobility of disabled people is restricted only by the bounds of technical progress and discovery; where the handicapped have a fundamental right to participate in industry and society according to their ability; where socially preventable distress is unknown; and where no man has cause to be ill at ease because of disability.

It is in this context that the provisions and purpose of the new Act can best be understood.

Alf Morris

Member of Parliament for Manchester, Wythenshawe

[**Introduction**]

This leaflet is your guide to the Chronically Sick and Disabled Persons Act of 1970.

It is meant for Councillors, Trade Union Branch Secretaries, Doctors, Social Workers, District Nurses, Civil Servants, Patients and their families and friends. In fact all those who have to deal with the Chronically Sick and Disabled. David Weitzman has put it into language we can all understand.

This Bill is based on Labour Party and Co-operative Party policies laid down at the Blackpool Conference in 1965, and expanded yearly since then. We of this campaign are proud of the part we have played in formulating those policies and that it was one of our Sponsors, Alf Morris, Labour Party and Co-operative Party member for Wythenshawe, who so ably, as a Private Member, piloted this Act through the House of Commons. We are grateful to Lord Longford for doing the same in the House of Lords. This was an extremely complicated Bill involving ten different Ministries. No wonder this Act has been called the Private Member's Bill of the Year! Only a Labour Government would have given it the help and support that were essential to its passage, and a special vote of thanks must go to John Dunwoody, Reg Freeson, Lady Serota, Lord Kennet, and Lord Hughes. The Government too, must be thanked for the unique step it took in tabling an open-ended money resolution to this Private Member's Bill which makes possible the public expenditure which the Act involves. We are grateful to DIG for their support and to others who have helped add to the basic structure of the Bill. It is far from perfect, but it is a sound basis for further progress and a magnificent achievement if you at local level make it work. Of Socialism in action it was born. Socialism in action can make it a landmark not only in our Movement, but throughout the world if you make full use of it.

Marsh Dickson, President

Mike Gerrard, Chairman

Margaret Robertson, Secretary

...

Provisions in respect of persons under 65

[Section 17]

A geriatric ward in a hospital is a ward dealing with the health of old people and it is naturally felt that young patients confined to hospital for long periods should not spend their time solely in such wards. There have been cases of young people spending years in such conditions. [Section 17] seeks to remedy this state of affairs. It enacts that the best endeavours shall be made to see that, **no chronically sick of disabled person in hospital for long term care or because his condition precludes him residing elsewhere without assistance which is not available,** shall be cared for as an in-patient, in any part of a hospital, normally used for the care of persons aged 65 or more or suffering from the effects of premature ageing, unless he himself is such a person.

Information as to such persons shall be supplied to the Secretary of State and an annual report made to Parliament.

...

Printed and Published [29 May 1970].

40 - Speech by Alf Morris MP, Manchester, Spring 1971

Speech printed as a postscript in: Needs Before Means (Morris and Dickson 1971 p16-18).

(emphasis in original)

Postscript

Mr Alfred Morris MP, Opposition Front Bench Spokesman on the Social Services with special responsibility for the disabled speaking on “New Horizons for the Disabled” at the Norwest Co-operative Society Hall, Downing Street, Manchester M1, at a Conference held in the Spring of 1971, said:

“I have just learned of a most disturbing and shocking manoeuvre by which certain local authorities plan to deprive even some of the most severely disabled people of the new deal intended by the Chronically Sick and Disabled Persons Act 1970.

A document which has come into my hands prompts me to warn these authorities to stop tampering with the law.

Under Section 2 of the Act, there are provisions allowing for the supply to telephones, TV and other benefits to disabled people living at home.

But the plan I have seen would make it virtually impossible for any disabled person to receive these benefits. With regard to telephones and TV, this plan lays down:

1. The handicapped person must be unable to leave the house, even in normal weather.
2. It must be proved that he is at risk when living alone if left unaccompanied.
3. There must be no member of the patient’s family or friend within reach of the house.
4. The disabled person must be physically and mentally capable of using the instrument.

5. He must be unable to afford to pay reasonable costs himself and it must be **unreasonable to ask relatives to do so**.
6. He must be able to indicate that at least one person is willing to be in touch on the ‘phone to avoid total isolation (doctors may not be included in this) and there must be a definite need for the handicapped person to get in touch with a doctor quickly.

These criteria bear no relation whatever to Parliament’s intention of enacting Section 2 of my Bill. They are a hard-faced and cynical blueprint for diluting and evading the purpose of the law. Mr and Mrs Bumble would have had qualms about some of the criteria.

Under 5 above, even all the relatives of the severely disabled person would have to be means-tested. If the home-bound person is unable to nominate anyone to keep in touch, 6 [above] seems to accept ‘total isolation’ as tolerable and the authors of the plan appear unaware of the system for emergency calls. Nor is there any mention of the provision in the Act for helping the disabled person to obtain ‘any special equipment necessary to enable him to use a telephone.’

As the Minister has been reminded in Parliament in recent days, the leaders of organisations working among the disabled are angered by the dragging of feet in county and town halls no less than in Whitehall.

Far from being premature, the new Act is now seen to have been long overdue. By any test of priorities, its provisions are wholly admissible and must be fully implemented in the localities.

Quite apart from telephones and TV, the Act gave the go-ahead for many other forms of help to the severely disabled. They include:

- practical help in the home.
- the provision of, or assistance in obtaining, radio, library or similar recreational facilities in the home.
- the provision of lectures, games, outings or other recreational facilities outside the home or assistance in taking advantage of educational facilities.
- travel to and from services provided outside the home.
- the provision of assistance in arranging for the carrying out of any works of adaptation in the home of the provision of any additional facilities to secure the disabled person’s greater safety, comfort or convenience.

- the facilitating of holidays, whether at holiday homes or otherwise, and whether provided under arrangements made by the local authority or otherwise.
- the provision of meals whether in the home or elsewhere.
- special housing schemes for the disabled.
- access to public and social buildings.
- improving residential accommodation for the younger disabled.
- an extended chiropody service.
- improved mobility for certain categories of disabled person.
- public provision for the special educational needs of deaf-blind, autistic, dyslexic and other groups of disabled children.

The bad local authorities are not **saving** public money by failing to provide this new charter of services for the disabled. In fact, they are **wasting** public money. For the severely handicapped person who is not helped to live in his or her own home often has to be hospitalised at very much higher cost to public funds.

That is why the Minister should now tell the black sheep in county and town halls to get a move on in fulfilling all their responsibilities under the Act.

It would be wise to tell them also that the alternative to getting on is getting out. For local authority leaders who neither share nor even understand the philosophy of the new Act will very soon have to make way for those who do.”

41 - Ann Shearer, A Case for Care, article in The Guardian, 12 March 1971

Dorothy and Fred Fisher will not have to separate and go into a home after all. Instead, the Royal Borough of Kensington and Chelsea has finally agreed to make the adaptations to their council flat which it has said in the past were impossible and which should now, at last, make life tolerable for the heavily disabled couple.

Mr Fisher has muscular dystrophy and has not been able to work for 20 years; just standing up from a chair is now a major effort for him. If he falls, he must wait to be lifted and his wife is not the best person to help him, for she has one leg amputated below the knee and suffers from diabetes and arthritis. Both of them have wheelchairs, but in all the years they have been in the flat they have not been able to use either of them or walking frames because the doorways are too narrow. So Mrs Fisher gets about on her stump and her one good knee, whether she is doing the housework or dragging the coal in from the outside.

The coal is important, for Mr Fisher must have heat, and the living room fire can eat up over £3 of the £10.25p a week that the Fishers have had to live on. The bedroom is so cold that they have had to move their bed into the small living-room.

Tolerable

Mrs Fisher has always known that crawling about would get her down in the long run, and the point of their long struggle to achieve a tolerable life is [one] that many other people have known too. The Kensington welfare department has known, and if it had been inclined to forget, it had letters dating back to 1968 from Guy's Hospital pressing that the Fishers should be rehoused. The welfare office of a charity has known, and Mrs Fisher herself made sure that three popular newspapers, David Frost, and Harold Wilson, when Prime Minister, knew too. She started her own campaign for rehousing in 1966.

Yet not one of the social agencies involved with the case though, for instance, of querying the level of supplementary benefit the Fishers were getting, even though she is meant to have a special diet and their grave disabilities should surely put them above the minimum entitlement. It turned out, in fact, that they had been under-assessed by 30p a week for some years, and they are now getting the extra.

When I wrote about the Fishers last December, Kensington had provided, over the years, sporadic home help and meals on wheels, both discontinued at Mrs Fisher's request and not re-offered. Practical aids amounted to two pieces of rail in the bathroom, a charging point for a powered car, and a piece of rail and sloping kerb outside the house. "If adaptations were needed," Kensington said then, "we should have provided them already." Yet it was only when the **National Campaign for the Young Chronic Sick** and Mr Bruce Douglas Mann, the Fishers' MP, joined the battle and a local newspaper gave the case some publicity, that the possibility of widening the doorways of the flat was first considered.

Worse

Since then, the possibility of rehousing has again been gone into. The Fishers got wind of the GLC [council] flat, but it turned out to be already allocated, and nothing a local neighbourhood group did by way of protest squatting could alter that. Kensington's only offer had already been made in 1967, and was worse, the Fishers thought, than the flat they were in.

The housing committee then considered adaptations to the present flat, but decided that they were impossible, as the ramp Mr Fisher needed to get outside safely would constitute a barrier to other pedestrians. (And, after all, adaptations would have been made already if needed.) Finally, however, at the end of last month, the council decided that adaptations were possible after all. The doors will be widened, a cheap and effective form of heating is being looked for, and a new entrance will be knocked into the flat so that Mr Fisher can get about.

The Fishers are delighted. Mrs Fisher can go into hospital today knowing that work will at least have started by the time she comes out and that a period in a home, if necessary, will be only a prelude to going back to her own converted flat.

(emphasis added)

42 - Paul Hunt, letter to The Guardian, 6 February 1972

Sir,

David Cohen has been seduced by the obvious charms of Het Dorp, the Dutch village for the handicapped. He should have treated some of the public relations claims made for the venture with a little more scepticism. He might have noted, for example, that to enter and remain in Het Dorp it is necessary to belong to an elite minority of the severely disabled - that is, you have to be young, not *too* severely handicapped, and have no mental impairment.

But there is a more fundamental point to be made. Perhaps we all secretly wish that the severely disabled would go away somewhere together and be happy, leaving us with the important business of leading normal lives. Large ghettos such as Het Dorp, however imaginatively designed and run, are surely more a result of this feeling than of the actual needs of the handicapped themselves.

It is true that a number of heavily disabled people either cannot or do not wish to rely on relatives for constant help, and yet they find that hospital is quite inappropriate as a permanent environment. In Britain at present the only alternative may be an equally unsuitable residential hostel or home, probably isolated in the country, and certainly beset by the intractable problems of institutional living.

What is needed, I believe, is not a big final solution such as Het Dorp, but small groups of flatlets incorporated in housing schemes throughout the country. Perhaps half a dozen severely disabled people could thus live out in the community, each as a private householder in his own home, but sharing some facilities and with daily care provided.

Such a scheme would not in itself solve the difficulty of participation in society, but also make it a lot harder for society to ignore the awkward fact of disability.

Paul Hunt.

43 - Ann Shearer, Doing Our Thing, article in The Guardian, 18 September 1972

> Ann Shearer analyses society’s ambivalent attitude to the mentally handicapped: the wish to improve their life while denying them a voice in the way they want to live

There must have been more talk of reform in our services than at any time since the turn of the century. But nowhere among all the conferences and debates have the consumers been asked their views on the way they would like for the future.

This is a fairly draconian way to treat any group of people – as planners of services, for others who need help are at last beginning to discover. It is, perhaps even more frightening for this particular administrative bunch because, of all people, they are most likely to need at least some of the services we offer not just for the odd difficult year but for the whole of their lives.

Earlier this summer, Campaign for the Mentally Handicapped * tried to start redressing the balance by holding a conference for mentally handicapped people — the first one ever in this country, though Sweden has done it over some years. It wasn't an ambitious attempt by normal, conference standards— less than forty people came to the weekend of discussions. But the report, published today should go some way towards shattering our stereotypes and offer some sharp lessons on how in our; best intentioned planning we can trample the people we are trying to help.

Twenty two of the delegates to the conference were stamped as mentally handicapped by the institutions they lived in, the schools they had been to or the work centres they attended. They fell well within the top to medium range of people we choose to label this way. Some had additional handicaps: two were physically disabled, one fairly dead, another almost blind, while several were epileptic and one needed help to wash and dress.

But they knew—and are you surprised — what they wanted. If they couldn't live at home (as about a third of them, did and others wished they could), they nearly all wanted to live in their own room in an ordinary house, with a few chosen friends. They wanted staff who would befriend them and guide them through the intricacies of daily life. They wanted the chance to work and earn a decent wage, and to spend their free time as they chose. Most of all, perhaps, they wanted to feel that they had some part in running their own lives, that their views accounted for something, that their future didn't belong to someone else.

More Freedom

It doesn't seem much to ask. Their aspirations are no more than most of us take for granted in our daily living. Yet what account does our planning take of them? All the hospital delegates, who bet ween them clocked up something like 150 years residence, wanted to leave for greater freedom. But for many people like this, we're told, it would be "cruelty" to send them out from the only security they know. They are not priority people for local authority hostels.

And when these hostels are built, as we are assured they will be, how will they fit with what these delegates would like? Many of them said they thought six or seven friends the ideal number to live with, yet. Councils are now planning purpose built hostels for up to 25 people, with all the appalling frustrations of group living that this must bring. Already the most basic choices re being taken from the people who are going to have to live with the decisions.

It won’t be a new experience for people like these delegates to have to fit into other people's plans for them. We recognise, we say, the deadening effect that institutional living can have on people. We guard against it in our efforts to foster as much independence and' fulfilment as we can. Yet some of the descriptions of life as it is still lived — and in community hostels as well as the hospitals — should make us wonder again at the extra handicap we are creating for these people and others like them.

They may have, for instance, no choice or participation in the decoration of the place that is, after all, their home. One man would have liked, he said, a pink wallpaper with pretty flowers on it in his bedroom, but what he got was plain white gloss. Only in one hostel did the delegates choose their own schemes and help decorate. Delegates from hospital had no chance to learn to cook, or sometimes even to make a cup of tea, although some would have liked the chance. Again, only one hostel encouraged residents to make their own food. In another, one delegate had specifically asked if she could help with the housework, to feel she was making some contribution to the life of the place, but she was told not to be difficult.

Most residents lived, in short, by what other people told them to do. Although foremost of the hospital residents life had improved enormously from what they remembered, there were still passes to be signed for if they wanted to go out, still no chances to go to the pub. Only in one of the hostels were there no rules at all about coming in in the evening and getting up at weekends.

Some delegates spoke highly of their staff. More found them unapproachable, inconsistent in their demands, unwilling to discuss even the most important aspects of the future.

In one hospital, the relationship between resident and staff was clear. “If the staff ask, you've got to give answer to it. If you don't do as you're told, you'll get your punishment." This came from a woman of about 30, whose punishment was being sent to bed. In one hostel, as a delegate said gloomily, “You got to do as they say."

Staff only

Nearly all the delegates found, at the very least, a lack of sensitivity from staff. This was, in one case, promising to help find a job and then appearing to do nothing about it. And, in another case, finding a job in a slaughterhouse which the delegate could only stick for a fortnight, because no one had thought to explain to him that it meant killing cattle.

One delegate had specifically asked if there could be joint staff resident meetings at her hostel. She was told that meetings were for staff only. At the very least, you would have thought, institutions like this could start joint discussion groups on the way the place is run.

For most delegates, work brought no greater independence. In hospital, some helped look" after the most handicapped residents — work they had not chosen, did not enjoy, but knew they had to do because they were told to. For some, it could mean up to 55 hours a week, yet they earned less than »£2, because higher pay would mean they bad to start contributing to their keep: No one% had been offered the choice of earning more and helping to pay their own way. Few had even discussed it.

People in local authority centres are hit by a similar earnings rule. On man got £1 a week doing a printing job for the council. These delegates, and the hospital ones too, were amazed to find but that people from one hostel got £20 a week in open employment.

We say we want to' help mentally handicapped people to become as independent as possible, to enjoy as far as they can the normal fulfilments of life. But if there was one refrain running through; the whole of the conference, it was that at every turn we contrive to do the opposite.

We deny them participation, consultation, the most basic respect we would expect for ourselves. We deny them the elementary tool on which choice and independence is based by keeping them in a handout society, pacified by pocket money.

These are just some of the things this group of people thought about the way we treat them. They were not angry about it: they were very diffident, at least before they had had this small experience of being treated as we treat each other.

They all wanted another conference. Some offered a, contribution towards it out of their pocket money. And it wasn't just because for two days in their lives no one had told them what to do next, where to sit at meals, what time to come out of the pub or go to bed. It wasn't even that, for some, it was the first time they had held a paint brush, been on a boat, heard a concert. For some at least, the important thing was that for the first time in their lives people were listening to and learning from what they had to say. It's time, they thought, that other people did too.

* "Our Life." Campaign for the Mentally Handicapped,
96 Portland Place, London W1. 50p.

44 - Paul Hunt, letter to The Guardian, 20 September 1972

Sir,

Ann Shearer's account of the CMH conference **of** and not **on** the so-called mentally handicapped, challenges our patronising assumptions about such people. It also has important implications for anyone who genuinely wants to help other disadvantaged groups. For instance, practically every sentence in her article could apply with equal force to the severely physically handicapped, many of whom also find themselves in isolated and unsuitable institutions, where their views are ignored and they are subject to authoritarian and often cruel regimes.

I am proposing the formation of a consumer group to put forward nationally the views of actual and potential residents of these successors to the workhouse. We hope in particular to formulate and publicise plans for alternative types of care. I should be glad to hear from anyone who is interested to join or support this project.

Yours faithfully,

Paul Hunt

(emphasis in original)

Notes:

1. This is the letter which lead to the creation of UPIAS – the Union of the Physically Impaired Against Segregation.

2. The CMH conference was in the summer of 1972 by the Campaign for the Mentally Handicapped, where of 40 delegates 22 were Learning Disabled people who had discussed their institutional regimes, their rights and needs for independent living. (Appendix 43)

45 - NCCSD Newsletter, December 1972

December Newsletter 1972

MARSH DICKSON, President and leading light of this Campaign since its inception has not been seen around so much this year. Active in the Press and on TV, Marsh and his wife Dorothy used to be a familiar feature of Annual Conference, which is the less pleasurable for not seeing them these days. Unhappily, they are a classic example of what this Campaign is all about. In the last twelve months Dorothy's disease has continued to progress, and Marsh's back trouble has become worse, making the two of them less mobile. They are still in good heart, and campaigning continuously for the Sick and Disabled. They are very happy to send fraternal Christmas greetings to all members and supporters of NCCSD, in which they are joined by the other Officers and activists.

COMPOSITE RESOLUTION 42 at the Labour Party Conference this year was carried convincingly in spite of reservations expressed by Barbara Castle, replying to the debate. The resolution had two purposes: (a) to being special responsibility for the Sick and Disabled into Government machinery, setting Ministers over it, and (b) to involve the Labour Party officially in the work being done by this and similar Campaigns. This Resolution, moved once again by Chelsea CLP, is part of the policy of NCCSD, and is a great opportunity for a political party to identify itself officially and directly with work for the underprivileged. Representations for early action on it were made immediately after the Conference, and are to be submitted to the NEC by Ron Hayward, the General Secretary. We hope to be accorded a voice on the Working Party on the Disabled to be set up shortly by the Labour Party.

ACTS OP PARLIAMENT like the Industrial Relations Act and the Housing Finance Act are extremely difficult to get round, as anyone who is sympathetic to Trade Unions or to Tenants will realise. By a curious contrast, the Government itself has wriggled round the Chronically Sick and Disabled Persons Act through ministerial circulars which have taken all the force out of the Identification Section. We have heard of the case of one local Authority (not a Health Authority) which wished to spend money on a complete survey of the Disabled in its area. This Council has been denied permission to spend the money by the DHSS, which has pointed out that since a sample survey in the County has been performed, in its view there is no need to find out exactly who is in need in any particular town.

If that were not enough, the Government has the knack of giving away with one hand and taking back with the other in any legislation supposed to be for the benefit of the disadvantaged. The difficulties, frustrations and miseries of the Constant Attendance Allowance and its effect on Supplementary Benefit Entitlements are now well known; a new element of "give and take" has been introduced by the Disabled Drivers' Act of 1972. A case has been drawn to our attention demonstrating that anyone who benefits under this Act will lose their right to borrow a replacement vehicle from the local authority when their own is out of commission for servicing or any other reason. Anyone familiar with the difficulties of the Disabled driver will bitterly oppose the short-sighted limitations of this Act. NCCSD is asking all its members and supporters, including Trade Union and Parliamentary sponsors to act to have this myopic provision taken out.

THE FOOTBALL SEASON gives pleasure to a large section of the population, including the Disabled who can get into grounds to watch their favourite teams or who can enjoy it through "Match of the Day" and other TV presentations. By kind permission of the FA, we have been able to bring the Football Season into our Draw this year, which will be a sweepstake on the result of the FA Cup. All teams qualifying for the third round will go into our Draw. The eventual winners will have to wait for their prizes but will have double the pleasure and tension of succeeding rounds until the results are known. Some books of tickets are enclosed with this newsletter. Please help us to continue campaigning by trying to sell them among your friends, in your office, Branch or Local Party. The return date for counterfoils and money is the 30th December, and you will be able to sell during the run up to Christmas, which we hope will not be a bad time. When sales are completed, please remember to send back counterfoils and money to the Promoter at 35, Hawkenbury, Harlow, Essex.

EVERY GOOD WISH for Christmas and the New Year.

46 - Paul Hunt, Young Chronic Sick Don’t Want ‘Units’, 24 March 1973

Reprinted from ‘Social Services’ periodical, Vol 2, issue 12.

Radical criticisms of current Regional Hospital Board [RHB] plans for young chronic sick units, put forward by the severely disabled themselves, have been sent by Alf Morris MP to Sir Keith Joseph [Minister for Health and Social Security] for his personal consideration. It was following Alf Morris’s Chronically Sick and Disabled Persons Act, which drew attention to the plight of younger disabled people living in geriatric wards, that Sir Keith Joseph allocated £5 million for providing 1,800 places in alternative accommodation.

But at a recent seminar held at the Centre on Environment for the Handicapped, a group of the severely disabled confronted doctors, architects and administrators from eight regional hospital boards. They objected to the whole concept of the proposed units as being segregated, institutional, and medically dominated, and they maintained that except in acute illness (like anyone else) their needs were essentially social and **not** medical.

They were forced to live in hospitals only for lack of alternative care, finance and accommodation. This was demonstrated, they argued, by the fact that even people who were completely paralysed and dependent on a respirator for breathing could live purposeful lives at home when they had the right financial and social support.

It emerged from the seminar that there had been no previous consultation with the ‘young chronic sick’, and none of them were represented on the committees planning the new hospital units - although the Alf Morris Act specifically says that the disabled should be members of committees which concern their affairs.

None of the doctors at the seminar put forward convincing reasons why the severely disabled need permanent hospital care, and several were quite clear that the only reason for admission at present was the breakdown of social support. It was equally clear that, although the hospital board administrators pleaded they were only working to a political brief, there had in fact been no directive to provide hospital units for the severely disabled as opposed to experimenting with other kinds of accommodation.

The seminar was told that the present RHB plans were backward-looking and prison-like in conception, and would inevitably create all the well-known institutional characteristics in their inmates. What the severely disabled urgently needed instead was a new domiciliary care service to provide help in their own homes with such daily living activities as dressing, washing, lavatory and feeding. In Sweden each disabled person had the right to up to four hours a day of this sort of help at home. In addition, the Swedish Fokus Society now had schemes which provided 24-hour care for the most severely disabled, who lived in groups of 12-15 flats integrated into ordinary housing blocks.

At another seminar in the current series being held by the Centre on Environment for the Handicapped, Professor O S Brattgard of the Fokus Society gave details of how their housing and care schemes operate, and announced that the Swedish government had just agreed to underwrite the whole of the Society’s future plans to rescue more younger disabled people from institutions. Professor Brattgard said that 85 per cent of the Society’s tenants used wheelchairs, over 50 per cent needed dressing and undressing, 20 per cent required feeding, and 33 per cent needed help during the night. Some had to have as much as eight hours assistance a day. Yet there were no restrictions, and tenants enjoyed full rights as ordinary citizens. They were represented on all Fokus Society committees, and they shared communal facilities in their block of flats with the non-disabled tenants.

Professor Brattgard said that within two years of moving in, a high proportion of previously institutionalised or isolated tenants were married or co-habiting; 39 per cent went out to work; and 27 per cent were at university or other educational establishment. 74 per cent were going out somewhere each day. Yet, Professor Brattgard said, the cost per tenant for full care was only half the cost of a hospital bed and two-thirds that of a place in a nursing home.

With facts like these before us, is it too much to ask that the real needs and wishes of the disabled here in Britain should be taken into account before retrograde, institutional schemes to house them are implemented? Sir Keith’s reply to Alf Morris is awaited by one group of the severely disabled with something more than academic interest.

47 - Peter Townsend & Walter Jaehnig, Enabling the Disabled, The Guardian (extract), 2 May 1973

Less than three years ago a Bill sponsored by a Labour backbencher, Alfred Morris, was being championed as the “civilised and compassionate charter" for which disabled people had waited so long. The Chronically Sick and Disabled Persons Act promised much: local authorities would have a duty to provide a broad range of services to people with severe handicaps, easing their welfare, housing, education and transport problems, and enriching their lives through the provision of such aids as telephones, radios televisions, books and meals. More important, it seemed to give authorities the responsibility to seek out disabled people and offer them assistance, rather than require them to come to the town hall, hat in hand, asking for help.

It is gradually being recognised, however, that the Act is not very effective in practice. As a whip for recalcitrant authorities, the Act is not very useful mainly because of weaknesses in three key areas: the registration of handicapped people, the discretion it leaves with local authorities in providing services and the all-important issue of money. When these defects are spelled out they show the need for a more broadly-based attack upon the problems caused by physical and mental handicaps.

Most confused is the registration issue. Since 1948 local health and welfare departments have been required to keep registers specifically of blind or partially-sighted people, but only for general classes of disabled persons who apply for assistance.

In fact, authorities have tended to keep a number of registers corresponding to different categories of handicap, and these were rarely up-dated. More important, persons requesting assistance did not have to register to obtain help; the Government survey of 1968-69 found that while 40 per cent of handicapped persons were using services available to them, only 12 per cent were actually on local authority registers.

Morris aimed to make registration compulsory, by making it a local responsibility to seek out and identify handicapped people. This element of his Bill was scrapped in committee however, and the Act as approved by Parliament required only that authorities inform themselves of the numbers of disabled people in their areas, and of the need for making provision for their handicaps.

Moreover, instructions from the Department of Health and Social Security assured local authorities that while 100 per cent identification of chronically sick and disabled people was to be the ultimate goal, this was not expected at the present time Given this latitude, authorities have responded to the Act in many different ways — and only a slim minority have tried to identify and register persons eligible for assistance.

Equally confused is the amount of discretion left to authorities by the Act. Morris and other members of the disability lobby argue that the Act requires authorities to make a wide range of services available. It does, but for the most part these services were already covered by Section 29 of the National Assistance Act 1948.

The Act makes this provision mandatory, but leaves two enormous areas of discretion with local authorities: first, in getting in contact with the disabled person — and social services departments are exhibiting a remarkable range of diligence in carrying out this task — and second, in establishing that a particular service is actually needed by the disabled person.

“Need" invariably is defined by authorities in accordance with the resources available: in scarcity situations, with a large number of handicapped people eligible for a low level of provision, a strict criteria of need is used to eliminate all but the most desperate cases.

And herein lies the third shortcoming of the Act. It did not carry the necessary financial backing to assist authorities in expanding provision (and could not because it was only a Private Members' Bill). To help finance an overall expansion of local social services, the Government has increased the rate support grant by 12 per cent in each of the past two years.

This is clearly insufficient, even if there was a guarantee that authorities would use the extra funds for the disabled, as opposed to filling potholes or holding down the rates. And there is no such guarantee. A special form of finance, such as support for five years or the re-introduction of a percentage grant, is needed.

The ambiguity surrounding this legislation and the lack of commitment on the part of the Government have led therefore to charges that some authorities are not complying with the law. In fact, vast disparities exist between the quality of services available to disabled people from one authority to the next. These existed before passage of the Act, and one of its consequences appears to be a widening of the gap between progressive and recalcitrant authorities: the good get better, the bad get worse.

Figures published by the Institute of Municipal Treasurers and Accountants — and supplied by local authorities themselves — show, for example, that last year some authorities spent four and five times more on services for the physically handicapped than neighbouring boroughs (per 1,000 population); Rochdale's £815.21 is nearly six times as great as Stockport's £16.75 [sic]; Lewisham’s £1,226.13 per 1,000 physically handicapped people is nearly five times greater than Harrow's £269.60.

The evidence is that over the past three or four years, the difference between authorities has widened; Braford's expenditure has more than doubled since 1969-70, whilst Stockport's has remained the same, even after account is made for inflation in this period.

Serious questions have been raised over the validity of these figures, however. Accounting principles apparently are not similar in all authorities, some did not include expenditure on social work for example. The figures also do not include costs of housing adaptations or projects.

If these differences do not exist; the Government should publish figures to show that where a disabled person lives does not make a difference in the support he receives from his local authority. If these disparities do exist the Government should take urgent and remedial action, if necessary through legislation to ensure uniform and equitable levels of social support.

But overall, what is needed is a stronger commitment from the Government in constructing a comprehensive policy covering not only local authority support services, but employment, rehabilitation and training. Primary importance should be placed upon employment, to assist as many disabled people as possible to be self-supporting and independent. A full range of programmes is needed, requiring more ambitious attempts from the Department of Employment and Productivity in integrating handicapped people into the country's occupational structure, to a range of sheltered workshops and home-work programmes run by local authorities. Finally, this policy should address itself not only to physically handicapped people, but also to the more intractable problems implied by chronic sickness, mental handicap and psychiatric disorders — conditions often left out of discussions of disablement.

48 - Ann Shearer, Housing to fit the handicapped, article in The Guardian, 26 June 1973

> The Prime Minister will open the Habinteg Housing Association’s first scheme for the disabled at Haringey tomorrow. **Ann Shearer** discusses looking after the disabled in and out of the community.

The Habinteg housing scheme is offering physically disabled people their best chance in this country so far to live in the kind of housing they need, with the help that makes it possible, and still be part of the immediate community.

The Habinteg Housing Association is an independent offshoot of the Spastics Society, but caters for people with any sort of physical disability, whether single or married, with children or without. The first scheme, at Haringey offers 17 homes for disabled people among its total of 58; the size of other schemes will vary between 100 in Milton Keynes and 10 in a Kent village.

The Habinteg philosophy goes further than others in special housing. It isn't enough, it reckons, to plonk down a "special" block of housing for disabled people in an ordinary estate and call it "integrated.” This marks the inhabitants out as "special" from the start and so, society being what it often is, liable to find that their only friends are each other. No one yet knows the ideal mix, but Habinteg is at the moment providing about a quarter of its homes in any one scheme for disabled people. Because they are often single, this will work out at around a tenth of the scheme's whole population.

They will be able to summon a "community assistant" when they need help. They will also be able to make their way around the rest of the scheme when they want to. For, unless it is all accessible to them, Habinteg thinks integration is going to remain a pretty empty idea. The other tenants come off the local authority's housing list, chosen by the association. So far few disabled people have turned down the chance - though one person did because even a scheme as carefully "unspecial" as this one seemed too different from the normal for him.

Rents will run between £7 and £14 week all round, for housing for between one and seven people. This sort of flexibility should offer, for instance, the chance for an elderly mot her to go on lit inn with her middle aged disabled son even when she is herself beyond coping with his physical needs. It should offer families the chance of staying together when one parent becomes disabled, and give single disabled people their chance of independence. It has already meant that three spastic couples have been able to get married. For all such people too often at the moment the only alternative is an institution, with all the end to normal social expectations that this must bring.

Community care is something we talk about for severely physically dis abled people no ICSS than for the elderly, or people recovering from mental illnesses, or people who are mentally handicapped — one of the blanket Good Things of social provision over the last decade. The institutional provision for all these groups, and for others categorised as "single homeless" is seen as a poor second best to living independently. The physically disabled can’t complain, either, that we discriminate against them by letting the practicalities of their situation override our theories. We are forever sending old people into residential care because it's simpler than providing the sheltered housing that could allow them to keep their dignity, just as we are forever advising that mentally handicapped people should go into hospitals for lack of an alternative in the community.

Grotesque example

Nevertheless, some of the present official plans for severely physically disabled people provide a grotesque example of the gap between what we say and what we do. It is for severely disabled people that we have "younger chronic sick units" in our hospitals.

This is not a happy way to designate a group of human beings; it is also misleading. Their inhabitants are not generally young, for most people come to these places in middle age, when families are no longer able to cope at home. They are not chronically sick, as someone who needs kidney dialysis could be said to be. Mostly, they are not “sick" any more often than the rest of the population, but happen to be suffering from a series of diseases which bring physical disablement that is likely to get worse rather than better.

The Government has been urging an increase of younger chronic sick units on its hospital boards since 1968, when a survey found that half the

4,200 or so severely disabled people being catered for by the NHS were in geriatric wards, even though they had not reached the great divide of their 65th birthday. Seventy-four of them, indeed, were under 34. Another 1,300 were in general hospital wards, and only 500 in special units with others of their kind.

A couple of years later, the Chronically Sick and Disabled Persons Act made a special point of saying that younger disabled people should not live in geriatric wards. And so the Department of Health released £5 millions for a crash building programme to get them out. By 1975 another 1,800 beds are promised in special younger chronic sick units, and hospital architects are now drawing up the plans. "The aim," as the original Government memorandum on the subject said, "should be to provide as relaxed and permissive an atmosphere as possible within a hospital setting."

At Ashurst, in Hampshire, the Wessex Regional Hospital Board has had its pilot unit open now for something over four years. It is in the grounds of a geriatric hospital, with which it shares staff, and to some extent occupational therapists, who come in during the afternoon for basket making and other diversions. There can be no doubt at all that this is a hospital, from the polished lino (carpet in the waiting-room only), to the four-bedded wards where some of its inhabitants are still in bed at 11 in the morning, because they are said to be more comfortable that way. It is very clean, very bright, and very clinical. There is, as one disabled visitor noticed, a very large bedpan steriliser and a very small dayroom. And this is where 16 people will live out their days, unless the housing situation outside improves or they go away to a general hospital to die. An able bodied person would recoil from calling such an environment home. So do the "younger chronic sick" themselves. The difference is that for most people the prospect is hypothetical.

At a recent seminar in London, run by Centre on Environment for the Handicapped, a group of the disabled made their reaction to such places perfectly clear. Paul Hunt, who has had his share of hospital living and is now married and living in an ordinary fiat, said flatly that to talk of design for such places was irrelevant, for their whole concept was 20 years out of date. "I do not think," he said, "that anyone can seriously imagine that if they were given a genuine choice, the disabled would actually choose to go into a younger chronic sick unit. But it seems to be quite clear that there has never been any intention of offering us a choice. So many thousands of people, whose only crime is that they are disabled, are being sentenced without trial to imprisonment for life. These are harsh words: but anyone who has lived in a chronic sick ward will know that the analogy with prisons is not simply a figure of speech."

Not one of the other disabled people at the seminar disagreed with him, and the regional architects and staff, and the men from the Department of Health, were duly flummoxed. It was bad enough to be confronted by consumer representatives. "But they never leave their units, do they?" asked one perplexed delegate on being told who the consumers were going to be. But such determined and logical opposition, from a group who indeed had never once been consulted about their own preferences in the matter, was virtually impossible to resist.

The point about the particular disabled people who took part in this seminar is that, although none of them at this precise time live in a younger chronic sick unit, each and every one of them is a candidate for a place if their personal fortunes should change. And this to many people is the central fallacy about having such units at all. "Younger chronic sick" people are not medically defined in any sense of that word. The definition comes when they move into the unit and it is a purely social one. Most people become candidates for hospital care because they have become ill; these people become candidates for the specialist hospital simply because their previous social arrangements have broken down.

The situation is not peculiar to people with this particular label. In the same way, some mentally handicapped people become overnight candidates for hospital places not because their handicap has suddenly worsened, but because a parent has died; some elderly people end up in back wards of psychiatric hospitals not because they have a mental illness or confusion, but because they cannot find the help they need to go on living outside.

Dividing line

For every one person in hospital in each of these categories, there is another, equally or more disabled living at home. The dividing line is not illness, nor degree of disability, but the degree of choice they are offered. Half the people living in the Ashurst unit could go home tomorrow If they could be sure of proper help, according to Dr Douglas Lilley, who runs the place; one woman is kept in the unit by six steps between her and her fiat He confirms that some of the people who come into the unit for short stays to give their family a break are in fact more disabled than some of the permanent residents.

All these things are known, and behind each academic study that con firms them are people eking out their lives. Yet the Government puts £5 millions into a crash programme for younger chronic sick units which potential inhabitants contemplate with pain and despair.

At the CEH seminar, some people argued that these places are necessary because they provide the sort of skilled nursing that some severely disabled people need. But are they really vital, if families are caring for people as, if not more, handicapped? The care they get in such places can actually be inferior to what families can provide; one delegate told of the disabled son of a 78-year-old mother who never got bedsores except when he came into a specialist unit to give her a break, Even if disabled people do not live at their own home, there is no need for them to go into hospital. Local authority homes cater for exactly the same range of disability as hospital units, with only a few trained nurses on the staff. Le Court, the first and best-known Cheshire Home, spells this out even more clearly; it has people sponsored by both local authorities and hospital boards, and the two groups are indistinguishable in degree of disability.

Some people support such units for people in the last stages of their disease. Dr Lilley, at least, maintains that younger chronic sick units should not cater for anyone who is unconscious, as that is a job for the skills of a general hospital. Dying in hospital, in any event, is not something that everyone would choose; there can be dignity in death in a caravan, and there is dignity in death, so we were told, at Le Court.

Others argue for younger chronic sick units to cater specifically for people whose physical disability brings them psychiatrically definable mental distress. But at Ashurst, at least, local psychiatrists are not anxious to expend much therapeutic energy on the inhabitants, and, as the disabled delegates at the seminar said, a change of social environment and relationships works wonders on the psyche.

Needs obscured

In the end, there was no defence. The units were going up because there was £5 millions in the kitty, and people were going to live in them because the units were there. Better, argued their defenders, than living in a geriatric ward. And so it probably will be. But what measure of success is there in this administrative compromise?

The compromise is important to nail because it has bedevilled so much of our planning for so many people who need social help in their living arrangements. As long as these people end up under the wing of the NHS — whether in younger chronic sick units, psychiatric hospitals or geriatric wards —the real nature of their need is going to be obscured. Medicine, geared as it is to "cure," can do nothing to reverse their condition. It can treat occasional acute illnesses, as with any member of society; what it cannot do is "cure" degenerative disease or mental handicap. The very term "chronic sick," as applied to any of the groups who bear it, means that medical knowledge, in its present state, has failed them.

It seems peculiar, then, to hand the severely disabled over at this point to the very people who, admit, as they stick on the label, that they cannot cope. Peculiar in theoretical terms, that is; entirely comprehensible as a moue to get local authorities off the hook of their own responsibility for people's social needs, to shift care on the rates to care from central coffers. As long as the NHS facilities are there, they will be used; and as long as they are there, they will from time to time be abused.

This is not just a political debating point. It matters very much to the people who have to live with the result. Life in a general hospital is not, as one of the disabled delegates to the CEH seminar pointed out, the cheeriest prospect if what you want above all is to share as far as you can in the life of the local — and non sick — community. (Living in a geriatric hospital is even worse; the Ashurst site ought never, it seems agreed, to have been chosen.)

As important as relationships with the outside world are those within the residential community. There seems no doubt that the traditions and hierarchies of the hospital service are not, and cannot be, the best foundation for what is in effect home. Any kind of residential establishment for severely disabled people is bound not to be an easy place to live and work in; rejection by the outside world without hope of improvement in their condition is what, after all, sent most sf the inhabitants there in the first place. Eric Miller and Geraldine Gwynne recently turned a Tavistock eye on the nature of institutions of this kind in their book "A Life Apart," and concluded that the first task of such places was to cater for the period between the social and physical death of the residents; not comfortable for the outsider, perhaps, but acceptable to realistic inhabitants.

Nevertheless, there are ways and means of dealing with this hiatus, and the hospital way is not the one the residents appreciate. "A Life Apart" identified two solutions: the warehousing and the horticultural. The first emphasises the prolonging of physical existence and the dependent side of the residents' lives this is found mainly in hospital units, where medical diagnosis concentrates on what people cannot do and nurses are geared to caring for people who cannot, by their very presence in the unit, care for themselves. The second emphasises not what residents cannot do, but what they can, concentrating on personal growth and fulfilment, and is found mainly outside the hospital setting.

Put baldly like this, the thesis sounds too neat to be useful, and indeed its authority modify its outlines and the division between hospital and other types of care as they go along. But it remains uncanny how far the outlines jump to life in a couple of visits. The research was actually suggested by a group of residents at Le Court, and to compare life there with the Ashurst unit is to get an idea of the differences between warehousing and horticulture.

The first thing that hits you at Le Court is the activity. There is a constant coming and going of battery operated wheelchairs, huddling around in corridors to make every space a social one. It is untidy and noisy and everyone seems to be doing, which makes a sharp contrast to a morning in bed or watching the television at Ashurst. Miller and Gwynne reckon that the staff attitudes to the use of battery powered wheelchairs is one of the best indicators of the temper of the place. These, and other gadgets, can either be offered to give each resident maxi mum independence, or can be left in a corner, perhaps because the staff feel their own job more clearly defined if they are doing things for people. At Ashurst it's hard, they say, to get the nurses to use what's there to make their job lighter.

There are other differences that follow the thesis. At Ashurst, such work as there is is organised by the occupational therapists: at Le Court, the residents run their own workshop. At Ashurst, the staff tend to stand at the end of someone's bed and talk about his condition over his head, even though his disability has nothing to do with either deafness or daftness. At Le Court the staff not only don't wear uniforms but apologise when they have to weave their way between you and a wheelchair and generally treat the residents as equals.

Running the show

At Ashurst, there is no doubt about who is in charge and who dependent. At Le Court — though not without hassle — the residents have got themselves full voting places on the management committee, have a say in who is hired as staff and who not, and run the social life of the place. The one looks after people, because that is what nurses are trained to do — particularly, perhaps, those who vend much of their time in the geriatric hospital across the way. The other helps people as far as possible to run their own show. The difference is enormous.

This is not to say that the staff who run hospital units are wicked or wrong. It is just that they are geared to a completely different set of needs from those of people who aren't ill but happen to need a certain amount of physical help. The sad thing is that residents can start to fulfil their side of the contract, and become either suitable cases for warehousing or suitable plants for horticulture.

One resident of Le Court, for instance, reckons that the people in the wing for the supposedly "sicker" group, although in fact indistinguishable from those on the other side, actually behave sicker because they are encouraged to by the high concentration of staff and atmosphere there. It's not surprising that they should, just as it's not surprising that elderly people deteriorate in special homes for the mentally infirm, or that mentally handicapped people behave more handicapped in hospital than they do if they are able to leave it. You would have to be a tough character to withstand the expectation of the society around you, particularly when independence can be labelled "troublemaking" and you haven't the option to wheel yourself out.

So is the answer for severely disabled people more horticultural homes? There are some 50 new local authority homes on the stocks just now, as the Department of Health points out when it defends its younger chronic sick units as part of a grander strategy for the disabled. But there is, of course, absolutely no guarantees that one local authority home will be any better or richer for the people living there than another hospital unit indeed it could be worse in its quality of life. Habinteg, and the few other schemes that exist, hope to show that institutional living need not be necessary at all for many severely disabled people. Exactly the same distinctions as apply to younger chronic sick units in relation to local homes, apply to local homes in relation to sheltered housing. Which, after all, would any of us choose of the three?

Other Europeans have gone about solving the housing shortage for severely disabled people in different ways. At one end of the scale is the Dutch experiment, Het Dorp, which a decade or so ago was reckoned about the most advanced provision for this group of people in the world. This is a special village where around 400 severely disabled people have every opportunity and encouragement to make the most independent life they can. Every architectural device has been used to simplify their living, and each can summon the assistance he needs to his own and individual apartment.

Glossing over facts

To build a Het Dorp is to recognise that all this talk of integration and participation in community life is bound to be an unrealistic attempt to gloss over the hard fact that physically disabled people are disabled, are not able to share in many of the activities common to the people around them and can only bring themselves frustration if they try. This kind of place will appeal to those who agree with these arguments, just as those who want to protect mentally handicapped people from the rigours of life In our urban communities will be attracted by the "villages" that have been our main form of provision for them for 100 years, whether we call these "colonies" or "hospitals." The essence of such communities is that they are segregated from the main streams of life as it is lived outside; at Het Dorp, the village hall, petrol station and supermarket were meant to be used by the surrounding community as a ploy for integration — they are not.

Physically disabled people are now a lot less enthusiastic about the Het Dorp solution than they were — though in a situation of real choice, there could be some who would opt for it. The point is to establish a choice rather than impose one particular solution or another, and we are a very long way indeed from choice.

Sweden has gone about provision for several disabled people very differently and its Fokus housing is now the Inspiration behind Habinteg and others edging towards community solutions. Since 1964, Fokus has built some 300 flats for disabled people, scattered through normal housing blocks all over the country. Staff are available at any time the residents want help, with housewives paid to come in at the "peak" morning, evening and lunchtime hours.

When Fokus started, it was told by the professionals working in the field that it was impossible to cater for people so disabled in ordinary domestic surroundings. Over three quarters of its tenants are now in wheelchairs, nearly a quarter need help with eating, a third need turning and help during eve / night to go to the lavatory, some get their only independence through the near-miraculous response of electronic gadgets to their breathing. The professionals have had to pipe down.

Fokus is meticulous in relating research on disability and capability to what it provides for its tenants. All the fittings of its flats, for instance, are entirely flexible for height and position and it tests individual tenants' reactions to them for a year before making their positions final. As one measure of what Fokus means to its tenants, over a third of them are now either married or living together — before they came here, the proportion was under 10 per cent. Only a quarter of the population a housebound; the rest either work or are completing their studies. Before they lived here, a third were in their family home, and the rest in nursing homes and other Institutions.

Fokus started as a voluntary body. Now it has been taken over, together with its philosophy, by the state. The aim is to have a block of its flats in every town in the country. Professor S.O. Brattgart, its president himself responsible for much of the research into living solutions for disabled people at the University of Gothenburg, reckons that Sweden needs 2,000 Fokus flats if everyone who wants one is to get the chance. The institutional solution is completely rejected.

Fokus, as Professor Brattgard says, is not an architectural solution, it is a philosophy built on two very sensible assumptions, that the only people who know how the disabled want to live are disabled people themselves, and that the State has an obligation to do all it can to meet these demands. This is a very long way from the present British situation; when the disabled people at the CEH seminar tackled the men from the Department of Health about why they had not been consulted on younger chronic sick units, they got nothing more than the vaguest of assurances that they were perfectly free to drop in and see them any time for a chat. In view of the wheelchairs, this was, it's fair to say, amended to being perfectly free to drop the Department a line. But there was nothing at all in the way of concrete suggestions to join future working parties.

In Britain, some disabled people are beginning to work out their own solutions. If Fokus shows that even extremely disabled people can live in a way that respects their independence and offer them the opportunity to run their own lives as they want to. Margaret and Jack Wymer show that with enough determination you can play the system to go rather further than that. Both wheelchair-bound, they got married, and began working out what they needed; as they say, if they had waited for the provision to make it possible, they would never have got started at all. They got a council fiat from Norwich — which is a progressive council, in its approach to disabled people — and with "special allowances" from social security, now find, hire and train part-time housewife staff to give them the 22 hours of physical help that they need in a week. It works — though not without anxiety about their helpers turning up and the arrangement has now been going on for three years. If they lived in Sweden, they would be guaranteed as of right four 'tours' help a day as well as a disability income.

Individual experiments like this knock right on the head the argument that severely physically disabled people can't be offered dispersed — that is, normal — housing because they need too much physical help to be catered for separately. Many, in fact, need around two and a half hours a day, and it shouldn't be beyond the wit of our social agencies to provide this outside a local authority home or hospital ward. Very slowly, the message is beginning to creep through to the official planners. Selwyn Goldsmith, an architect who knows more than any other in Britain about designing for disabled people, is now working part time with the sociological research branch of the Department of the Environment. His unit is trying to find local authorities who will build, say, six flats for disabled people into normal housing provision and work with social service departments to get the help the tenants need to cope with independent living.

The local authorities haven't been picked yet, but the experiment, though by now not new in its broad outlines, will be an important chink in official policy. One of the things that hold up experiment in community care for disabled groups — particularly when their members are single people — is the gap between local authority housing and social service departments. As things go at the moment, Housing builds houses for people and Social Services build homes for the disabled, and very different the two ways of life offered can turn out to be. Until housing authorities are obliged to turn over a proportion of their ordinary stock to, the people who need sheltered housing, the gap is bound to subsist; even though the right to a house may turn out to be the right to jostle on the waiting list, its surely an overdue principle to be established.

While the Department of the Environment experiments, the Department of Health could do worse than remember one or two items from its own history. During the last Labour Government, there was some concern about a group of people suffering from respiratory polio living out their time in an annex of St Thomas's Hospital, even though each of them could have lived outside if they had had the funds. So, as an experiment, each of them got the cost of their hospital bed to spend as they would, and very satisfactory it has turned out to be. One for instance, is in a residential home of her choice: another found a flat, a job, a resident helper and a part-time chauffeur and has been living thus ever since.

Positive power

Hospital boards don't even have to go that far. There is positive power in the White Paper on mental handicap, for instance, for them to provide domestic housing as an alternative to wards, in residential areas instead of on hospital sites. Admittedly, the signs so far aren't hopeful; for a start, only two boards have taken up the option in any large way and one of these has been doing it for some years, while the other is a Government experiment. Admittedly too, hospital board architects have a rather different idea of what constitutes a small domestic house from almost anyone else in Britain. Admittedly yet again, if the people who are to live in these houses are able to sustain this kind of life, they should be free of the atmosphere of the Health Service.

Yet in our present tangled situation, where local authorities appear to be so crushed with work that they have little time, money or inclination for new ventures, while the hospitals seem to have both cash and the ability to do something about it, the principle of extending Health Service provision could be seized on rather more energetically. If the reorganisation of our Health Service to unite hospital and community care more closely is to mean anything at all to the consumer, it is surely essential that experiments In community living aren't left entirely to social service departments.

Just think, as one disabled person said wistfully, what others like him could do with the £40 or so a week that it will cost to keep someone in a younger chronic sick unit. Just think too of using that £5 millions to acquire housing which could then be handed over to the local authority to support. This is not to say that some severely disabled people may not either need or choose residential alternatives to supported life in the open community. The sadness is that the residential provision is coming first and isn't at the moment an alternative to anything. When Paul Hunt and his colleagues dubbed younger chronic sick units a sentence to life imprisonment they weren't joking.

49 - NCCSD Terminal Newsletter, April 1974

NATIONAL CAMPAIGN FOR THE CHRONIC SICK AND DISABLED

11 Domelton House, Iron Mill Road, London, S.W.18

Sponsored by:

Leading Members of Parliament and Trade Unionists; prominent members of the Labour Party, the T.U. and Co-operative movements; and the Chelsea Labour Party.

Harlow Branch: 35 Hawkenbury, Harlow, Essex.

TERMINAL NEWSLETTER – APRIL 1974

During the last three difficult years we have been less in evidence than previously, yet we have continued to campaign on principles and advise on individual cases wherever we could.

We know that the Labour Movement has remained aware of our objectives, and no better proof could be found than the Government's appointment of Alfred Morris MP as Minister with special responsibility for the Disabled. We wrote to Mr Wilson the same day, congratulating him and urging him to give Alf Morris the widest possible brief.

Now that Government has taken on the responsibility, and recognising the crucial shortage of manpower and money which has limited our campaigning ability, we have decided to wind the campaign up, with some sense of pride in achievement. We know that at least partly as a result of our efforts, the Disabled of this country now face a more hopeful future than ever before.

Our thanks are due specially to Alf Morris for his unique contribution to this, and to the practical help he has given the campaign in time of need. We also want to thank you, our supporters over the years. Whether as sponsors, members, associates or in whatever capacity, we should have accomplished less without you, and we gladly acknowledge our debt. These thanks are extended to our printers The Precision Press for their remarkable patience, and to the Co-operative Party and its branches throughout the country, without those assistance we should never have remained solvent.

A copy of the final balance sheet is attached. We are grateful to our auditors, Glyn Harris and John Houghton of Harlow for their thorough and good humoured examination of the accounts. These are available for inspection at the Harlow address above at any time until 30th June 1974.

MARSH DICKSON	President
MIKE GERRARD	Chairman
ALEC KAZANTZIS	Secretary

50 - UPIAS, Disability Challenge, May 1981

EXTRACT:

“**Editorial**

Great Expectations

During the late 1960s and early 1970s there was a significant upsurge in the level of agitated discussion and activity amongst physically impaired people. It was a period of change and growing awareness. The creation by advanced technology of an obvious potential for a fuller life, the exciting developments in integrated living arrangements abroad, and a rising militancy among some groups - here and overseas - all contributed to this climate of agitation and high expectations.

It was a period when more and more of us were openly identifying ourselves as disabled people and demanding change. Left behind over the post-war years of growing prosperity, many physically impaired people and our families were living in relative poverty and unnecessary hardship. In a spontaneous reaction, the Disablement Income Group (DIG) was formed to demand much greater financial help from the State. DIG had massive support amongst physically impaired people and our friends. With its formation agitation was increased and hopes were raised high.

It was a time of changing social attitudes towards disabled people, and this was given limited expression in the passing of the Chronically Sick and Disabled Persons Act (CPDSA) of 1970. With this legislation, expectations were raised to get higher levels.

Greater frustrations

Even as the momentum of agitated expectations gathered strength, it was becoming apparent that hopes had been raised which could not be met by the struggles in hand. DIG had become established, but its spontaneous appeals for State help bore little fruit. The CPDSA won greater advances for professional and specialist services than for physically impaired people themselves. The truth was that the collective will of disabled people lacked cohesion and clear direction: we were unable to win in practice even those few, limited rights which had been achieved on paper.

These frustrated expectations raised increasing doubts about the nature of our struggles. Criticisms were being made about the way our organisations were being run - for whose benefit our energies were being expended. It started to become clear, as some of us had warned at the time, that "charters" such as the CSDPA did not herald a new age for disabled people. Rather did it mark the end of an era in which physically impaired people could naively continue to believe that able-bodied people would solve our problems for us.

In the early 1970s, the frustrations openly broke out within DIG. Members demanded to know whose interests were being served by the various national "disability income" proposals put forward by DIG's "leadership", and why the grassroots membership was not involved in the preparations of such proposals. Critics claimed that members at large were being used purely for fund raising purposes. Dissenting views were forcefully expressed about why little headway had been made towards the goal of a national disability income.

Opposing tendencies

After the storm broke, two distinct and opposing tendencies emerged. On the one hand there were people who clung to the elitist, expert, administrative approach of solving our problems for us. On the other, there were those who advocated a collective, organised struggle by physically impaired people for full social participation."

Within DIG, the first tendency maintained that the main reason why a national disability income had been pushed aside by successive Governments was because the proposals which had been presented lacked detail and economic viability, and therefore begged greater expertise. Those who took this position, who were "united in fury" at our plight (on our behalf) sought our formal backing and the authority to speak for us. Given this, it was held that they could work out a better proposal, and educate, pressure and negotiate with the Government in our name. The "experts" holding to this tendency went on from DIG to form the Disability Alliance.

The second tendency was represented in a letter published in The Guardian on 20th September, 1972, in which Paul Hunt spoke with the voice of those disabled people who were dissatisfied with our exclusion from serious participation in our own organised struggles for a better life. Paul called for a "consumers" organisation, and for the coming together of all physically impaired people in a united struggle on all the issues that we faced. He was fundamentally opposed to the creation of an organisation around any single issue ... considerable number of disabled people wrote to Paul. He replied to each of these people, and what started as a personal correspondence became a confidential Circular amongst a group of physically impaired people, several of whom went on to form UPIAS.

UPIAS (Union of the Physically Impaired Against Segregation), Disability Challenge, No 1, 1981, p2-3.

51 - Pamela La Fane, a short bio

Tony Baldwinson

Born in southern England in 1927, Pamela La Fane developed rheumatoid arthritis from 1936 at the age of nine years. Her mother and grandmother both worked in the theatre and home was mostly in temporary digs and flats.

By 1940 aged about 13 years, she had begun her hospital 'career' in Oxford, mostly in children's wards but at times in adult wards when beds were full. Aged 16 years in 1943 and no longer a child, she was moved to another hospital, this time in London, for geriatrics. When she arrived on the ward, another patient confided to her, "**the first ten years are the worst**" (La Fane, 1981, p59).

Later, aged 20 years she managed to get a free subscription for a freelance journalism postal course, and slowly managed to get paid small amounts for her published articles. She soon acquired a typewriter.

With the start of the NHS and social security payments, long-stay patients also were given an income for the first time, 12 pence a week (two shillings and sixpence). Hospital nursing staff began to be qualified. Before the NHS, only the ward sisters were trained and qualified (La Fane, 1981, p84). The rest of the staff were untrained and called nursing "assistants" and all the "walking patients" were expected to do all sorts of jobs including feeding other patients, and cleaning.

In one of Pamela La Fane's articles – "Some Ideas on How to be Independent" – she wrote about the 'gadgets' she had devised to feed herself, to put her lipstick on, and so on. She wrote later in her book:

> " 'You dark horse,' my physiotherapist greeted me some time later, 'you didn't tell me you'd sent an article to our magazine.' I didn't tell her that I'd been paid £2 for it either!" (La Fane, 1981, p95)

The years pass by: various operations, various hospitals, and the occasional day trip out by a volunteer visitor. The medical system expected her to stay for life. She asked about alternatives. A council welfare officer told her, "the only places that look after the young chronic sick and disabled are the Cheshire Homes. And most of them are out in the country."

In March 1966 Pamela La Fane noticed a letter in the New Statesman magazine, written by Marsh Dickson, a non-disabled man married to a disabled woman. The couple had been told he would have to give up his job and care for her at home, or she would have to go to the local geriatric hospital. He gave up his job, but feared what might happen to her if he too became disabled. He became the founding president of National Campaign for the Young Chronic Sick, a lobby group for independent living.

Marsh Dickson persuaded Pamela La Fane to write a publicity leaflet for the campaign, but when the committee read it they offered it as an article to the Guardian newspaper, and it was published on 23 December 1966. The pen name Michele Gilbert was used to avoid any reprisals. She only told two junior members of the hospital staff, both allies of hers.

It also led to a benefactor. There was a retired company director who ran a charity “which gives financial help to enable disabled people to live at home. And she wants to help you to live out of hospital,” she was told by the campaign people. (La Fane, 1981, p133)

Pamela La Fane continued to push for independence, seeking out one of the first electric wheelchairs (made in Wales), and pushing the hospital and council authorities for a flat that could be adapted to her needs.

In the summer of 1968 she finally left hospital to live in a flat, along with a volunteer helper who would receive rent-free housing plus a small allowance. Later, this was modified to be a rota of two volunteers (La Fane, 1981, p156).

For the purposes of television she may have been filmed within the flat during early June 1968, as if already living there, for the programmes made by the BBC and broadcast that month.

She had a new POSM (patient operated selector mechanism, “POSSUM”) system installed in her flat with its remote controls for household items such as opening curtains, switching on lights, which she updated in the 1970s to extend the devices she could control.

(Adapted from Davis and Davis, 2019, p37–38)

52 - David Owen, note, undated

Dr David Owen, Dept of Neurology, St Thomas’s Hospital, London

It is difficult to explain the extraordinary lack of provision in this country for the young chronic sick without invoking some form of psychological block. It is as if the element of acute personal anxiety felt when forced to contemplate the possibility of chronic incapacity can from its very penetration blunt rather than stimulate; so that concern for action can subconsciously or consciously be supressed into passive acceptance. The N.H.S. has an overall shortage of beds for young chronic sick patients, either through contractual arrangements with privately run nursing homes or in special units. Local Authorities show immense variation both in the extent and standard of the services available to patients living at home so that in some areas a patient is forced to leave home as a direct result of the provision of an inadequate service. In consequence it is left too often to individuals to declare their concern when faced with the harrowing entity of chronic illness in young people their attempts frequently against great difficulties deserve the utmost praise but all too often the standard of care is hampered by the necessity for financial stringency, staff shortage and lack of modern buildings and equipment.

Many doctors and particularly neurologists who tend to see the majority of young chronically disabled patients have been all too aware for years of this distressing situation. Knowingly they have had to place young chronic sick patients in geriatric wards for lack of any other facilities, they have been forced to watch powerless the mental and physical breakdown of a husband or wife gallantly struggling against impossible difficulties because of their determination to keep their partner at home rather than to commit them to a geriatric ward. Geriatric care has made undoubted progress but for young people to live for the remainder of their life in an environment of old and often senile patients is totally unacceptable. Chronic illness at any age is an intolerable misery but when the patient is still young there are the superadded anxieties that threaten a family unit in early ——— [archived copy ends here]

[a partial record, missing pages]

53 - Names of 27 people involved

Name	**Position in NCYCS**	**Labour / Co-op Party**
Mrs L E Blunn	**Secretary**	
Mr Blunn		
Glenys Bowes		
Mrs E Calver	Southern Regional Secretary	
Dorothy Dickson		Chelsea CLP
Marsh Dickson	**President**	Chelsea CLP
Mike Gerrard	**Chairman** & Eastern Region Secretary,	Harlow CLP
Mary Gray		Wycombe CLP
Alec Kazantzis	**Secretary, Lawyer**	Chelsea CLP
Judith Kazantzis		Chelsea CLP
Neil Kearney		Chelsea CLP
Donald King		Sudbury & Woodbridge CLP
Pamela La Fane (1)		
Betty Lewis	**Treasurer**	
Leslie Massey		Kensington South CLP
Moses Pattison		Cllr, Easington CLP
John R Poston		Chesham
Mr W G Price		Uxbridge CLP
Doris Rewers		
Margaret Robertson (2)		
Pat Sears		Cllr
Betty Shuttleworth		
Diana Staples		
Graham Towers		Chelsea CLP
James Whelan		Darlington CLP
Terry Wilson		CLP Chair
Dorothy Young		Chelsea CLP

(1) pen name was Michele Gilbert in 1966

(2) paid wages for admin work in 1970

54 - Addresses used by the campaign

1964 Chelsea CLP
9 Langton Street
London SW10 0JL

1966 Flat 94 Marlborough House
61 Walton Street
London SW3 2JY

1967 15 Buxton Rd
Thevdon Bois, Epping
Essex CM16 7HD

26 Helder St
South Croydon
Greater London CR2 6HT

1969 1 Sutherland House,
Marloes Road, Kensington
London W8 5LG

98 Eaton Place
London SW1X 8LW

1970 (Flat) 11 Domelton House
Iron Mill Road
London SW18 2AF

35 Hawkenbury
Harlow
Essex CM19 4HY

55 - Subscriptions from 146 local Labour and Co-op Parties

Acton Central Ward LP
Adlington & District LP
Ashdon CLP
Ayrshire Regional Council Co-op
Backdene District CLP
Bangor LP WS
Basingstoke LP
Bath Co-op
Bath LP
Batley & Morley CLP
Beverley LP
Bexhill CLP
Bidsford CLP
Billingsley CLP
Birkenhead & District Co-op
Blaby CLP
Blackpool North CLP
Bollon End CLP
Borstall LP WS
Brentford Chiswick LP
Brentwood CLP
Brierly Hill CLP
Brighouse LP
Brighton & Hove Fabian
Brightside Sheffield LP
Bristol West CLP
Buckingham CLP
Bury St Edmunds CLP
Cambridge LP
Cardiff Co-op
Cardiff West CLP
Carlton-in-Lindwick CLP
Chelmsford CLP
Chelmsford Co-op
Chelsea CLP
Chepstow Co-op
Chesham & Amersham CLP
Chichester LP
Chiqwell & Ongar CLP
Colchester CLP
Craigton LP
Croydon North East LP
Darlington LP
Dudley West LP
Ealing South Central Ward LP
Ealing South LP
Earlstown & District LP
East Chelsea Ward LP
East Dumbarton CLP
East Fife & Kirkcaldy Co-op
East Flintshire LP
East Lancs LP

Bromley CLP
Eastleigh LP
Elland LP WS
Epping LP
Exeter LP WS
Fakenham LP
Falkirk & District Co-op
Farnworth CLP
Faversham CLP
Folkestone East LP
Fulborough CLP
Glasgow & District Co-op
Gosport & Fareham LP
Grays Ward LP
Great Baddow LP
Greater Northern Co-op
Greenwich CLP
Haringey LP
Harlow CLP
Hatfield Welwyn LP
Hemsworth Urban LP
Hoddesden LP WS
Hornchurch CLP
Horsham CLP
Huddersfield Co-op
Huyton LP YS
Jarrow & Hepburn Co-op
Kensington & Chelsea LP
Kidderminster CLP
Leicestershire Co-op
Leyton LP
East Scotland Co-op
London Co-op
Luton Co-op
Manchester Area Co-op
Manchester LP
Maryhill Co-op
Merton & Morton LP
Morecombe Voluntary Party Co-op
Nazeing LP
Newark CLP
Newbury CLP
Newcastle CLP
Newcastle-under-Lyne CLP
Newport CLP
North Lewisham LP
Northamptonshire LP
Nottingham City LP
Oldham Co-op
Ormskirk CLP
Otley LP
Paisley CLP
Paisley Co-op
Perivale Ward LP
Peterborough CLP
Portsea Co-op
Preston South CLP
Prideford & District CLP
Puckeridge LP
Reigate CLP WS
Renfrew Co-op
Rhonda LP

Liverpool Co-op

Runcorn CLP
Saffron Walden CLP
Sheffield Co-op
South Bucks CLP
South Wales Regional Co-op
South West Norfolk LP
St Albans Co-op
St Cuthberths Co-op
Stoke-on-Trent LP
Swansea LP
Taunton Somerset LP
Theydon Bois LP
Tonypandy LP WS
Torbay Co-op
Twickenham LP
Waltham Abbey LP
Walton & Weybridge CLP
Wandsworth Central LP
Wandsworth CLP
Wanstead-Woodford CLP
Ware LP
Weedhidge Mellin CLP
West & Midlothian Co-op
West Derby CLP
West Lewisham LP
Wolverhampton North East LP
Worsley LP WS

Rhondda Co-op

Yarmouth CLP
Yeovil LP
York LP

CLP – Constituency LP
LP – Labour Party
WS – Women’s Section
YS – Youth Section

56 - Advertisements etc by NCYCS

Date	Description	Amount	Decimal
21-Jan-1967	Labour Woman (December)	£8 11s 0d	£ 8.55
14-Feb-1967	Labour Woman (January)	£8 11s 0d	£ 8.55
5-May-1967	Labour Woman (May)	£17 2s 0d	£ 17.10
3-Jul-1967	Labour Woman	£8 11s 0d	£ 8.55
1-Sep-1967	Labour Woman	£8 11s 0d	£ 8.55
31-Oct-1967	Labour Woman	£17 10s 0d	£ 17.50
17-Jan-1968	Tribune [a LP journal]	7s 4d	£ 0.37
11-Mar-1968	Evening Standard [London], advertising	£10 10s 0d	£ 10.50
11-Mar-1968	Evening News [London], advertising	£9 0s 0d	£ 9.00
26-May-1968	The Observer, advertising	£8 5s 0d	£ 8.25
15-Oct-1968	Tribune [donation?]	£10 0s 0d	£ 10.00
19-May-1969	Tribune [donation?]	£10 0s 0d	£ 10.00
24-Jun-1969	“Advertising”	£18 0s 0d	£ 18.00
24-Jul-1969	Tribune [donation?]	£20 0s 0d	£ 20.00

57 - Personal Assistance: Notes on the Historic., Maggie Davis, 1993

(reprinted in Davis and Davis, 2019, p113-117)

Many of the ideas which currently cluster together under the banner of independent living have been part and parcel of the struggles and aspirations of individual disabled people, probably as long as disabled people have dreamed of freedom and independence. A central element of independent living is personal assistance and, in particular, having direct access to the cash which gives freedom to hire and fire assistants who carry out duties determined by and under the control of the disabled person him or herself.

It is sometimes overlooked that, in the same way that the British disabled peoples movement has a long history of growth – since at least the 1890s – so too has the development of ideas around the notion of independent living and personal assistance. Certainly in Britain, as elsewhere in the world, these ideas came out of the experiences of many early pioneers, whose struggles were more directed to living independently than to independent living.

Unlike the United States, in post-war (1939-1945) Britain, disabled peoples aspirations of living independently have had to be fought for on at least two fronts. There was in both cases of course the shared struggle for practical resources and attitudinal support in the community. However in Britain, as in some other countries, disabled people have had in addition to overcome the obstructions, anomalies and vested interests of a well-established welfare state.

These welfare barriers to independent living can be traced back in the British Poor Laws to well before the famous, “43rd Elizabeth of 1601,” (legislation) and this in itself indicates how deep rooted the vested interests in welfare really are. These Poor Laws were always associated with the practice of giving what was called outdoor relief which, as an idea, can be imagined as a precursor to direct payments. However, this system and the bill attached to it through the poor rates, eventually came under strong attack. The new Poor Law of 1834 attempted to put paid to it altogether, by replacing it via the harsh corrective regime of the workhouse.

Victorian society may have extolled the virtues of hard work, thriftiness and sturdy independence – but was clearly not interested in doing anything about the proliferation of social barriers which prevented disabled peoples participation in the same value system. Instead, it reinforced the picture of workhouses and institutions as the proper place for people who couldn’t support themselves. Coupled with public hostility to vagrancy and mendacity, this climate stifled the kind of social developments which could have supported disabled peoples independence and participation.

The proliferating number of Charities took the same values on board. For example, John Grooms may espouse independent living today, but it started in the 1860s as John Grooms Crippleage and Flower Girls Mission. Later, the increasing role of the state adopted the same values and assumptions. After World War II, as part of the modern welfare state, the 1948 National Assistance Act was supposed to replace the Poor Law but Section 29 merely introduced a new wave of institutions.

Against this background, tough-minded individualism was the only choice for disabled people who had no family or who wished to live independently of family. The multitude of barriers and disincentives that existed, however, made living independently a more realistic description of what actually happened in the lives of these pioneers, than the notion of independent living. The difference can be summed up by the necessity on the part of those individuals involved to perform the maximum number of tasks without help rather than the maximisation of choices with assistance.

1960s

Clearly, at this point in time, the name of the game was survival -for many, survival on a knife edge, where a mistake could land you straight back in the institution. New thinking and a fresh use of resources was badly needed. A change in the prevailing climate came with the questioning by disabled people of the role of institutions. One of the most significant challenges came during the 1960s, with the struggle to liberalise the Le Court Cheshire Home in Hampshire led by **Paul Hunt**. This influence lay in the background of moves in the 1970s by residents of Le Court to set up **Project 81** and, a few years later, the Hampshire Centre for Independent Living (HCIL, now known as **Spectrum**). Other struggles to reform institutions also took place at the Ludwig Guttman Hostel at Stoke Mandeville, at the Pearce House YDU in Essex and at Cressy Fields Part Three institution in Derbyshire.

There were many graphic examples of disabled people's struggles to live independently. I can personally recall being encouraged by people like **Pamela La Fane, Joan Dawe, Yvonne and John Hall, Jack and Margaret Wymer** and others who escaped the all-embracing clutches of a variety of state run or charitable institutions. Together with many more courageous, tenacious and inspiring individuals they helped change the prevailing climate of ideas so that now, disabled people see themselves differently.

1970s

It was the efforts of such people which led, in the late 1960s and throughout the 1970s, to significant shifts of attitudes in both the state and in the charities. However, some developments, for example, that involved the **Responauts** from St Thomas Hospital, London, were so successful that future progress was halted. In that case, people using respirators, hiring their own help at home with special DHSS money made it clear that existing welfare provision and institutions were inappropriate. To develop this kind of policy more widely could obviously have had serious repercussions for the disability industry.

These developments linked up with news of the Swedish Fokus housing schemes, Danish Collectivhaus and the Het Dorp development in Holland. Events in Berkeley, California and across America (see **John Evans**' writings) began to influence developments in the United Kingdom. The charities in particular began to protect their own controlling influences in disability affairs by adjusting and adapting to the changes that disabled people had set in motion.

For example, the Spastics Society tried a version of the Fokus system at Neath Hill in Milton Keynes; the Habinteg Housing Association started building houses with limited support services; the Leonard Cheshire

Foundation set up flats with some personal assistance services at Tulse Hill and started their home care service; and the Crossroads Care Attendant schemes came about on the initiative of a disabled person called **Noel Crane**.

At the same time disabled people began to look for a more structured approach, one built much more closely on the direct experience and under the control of disabled people themselves. In 1972 **Delia Dudgeon** organised a well-attended conference in London for disabled people with a view to stimulating well-designed housing for disabled people seeking to live independently of their families. In the mid-1970s **Brian Lewis** was proposing a commune as an alternative to institutions and set up a housing cooperative to bring about better community based housing for disabled people.

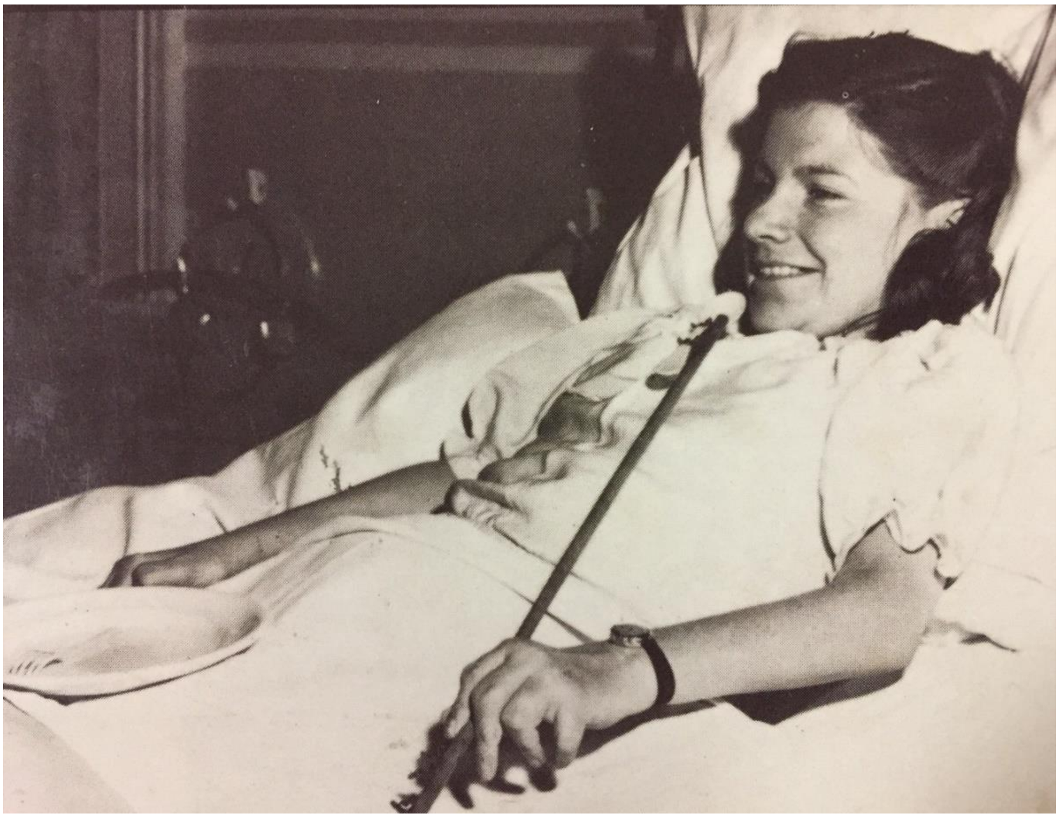
About the same time, with my partner **Ken Davis**, the Grove Road scheme was set up as yet another approach to securing more choice and control in disabled people's lives. This was a collective approach to meeting a number of identified needs including information, peer counselling and support, good housing design, appropriate technical aids as well as personal assistance. Similar schemes followed in Edinburgh, Rochdale and Gillingham.

Sheltered Housing for the Disabled (SHAD) in Wandsworth with **Stephen Burton** looked at the use of voluntary helpers in the community and the scheme at 22 Main Street, Newton, Derbyshire, was another collective approach to hiring and organising personal assistance. Each of these initiatives helped to reinforce the notion that disabled people could and should live in the community rather than in an institution, and that the resources should be available to permit this development.

1980s

During the 1980s the expansion of the disabled people's movement stimulated a further growth of ideas, backed by the collective strength of its members. The sheer necessity for people to live independently began to be replaced as new opportunities for funding personal assistance were conceded, such as the use of flexible budgets by local authorities and, more significantly by the Independent Living Fund (ILF). The latter gave a boost to those promoting the kind of individualistic approach to personal assistance pioneered by the American Independent Living Movement and favoured by HCIL.

Groups such as the Derbyshire Coalition of Disabled People (DCDP), whilst supporting the drive for a more committed approach on the part of the Government for direct payments - particularly since the ILF came under threat - sees this approach as being just one element in a spectrum of arrangements which offer a wide range of disabled people more choice and control in the availability of personal assistance. Through the Derbyshire Centre for Integrated Living (DCIL) it has also worked to set the need for personal assistance squarely within the context of other essential needs. In this way, it tries to ensure that the personal assistance issue is not used as a political device simply to replace care with cash -and as a means to conveniently dodge the wider social responsibility to remove the many other social barriers which prevent disabled people as a group to secure equal rights and opportunities.



Pamela La Fane, with her adapted spoon for eating, 1960s

Pamela La Fane, around 1980

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