

May  
1981

UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION

# DISABILITY CHALLENGE

NUMBER  
1

REGATION : ISOLATION : OPPRESSION : INSTITUTIONS  
 PATRONAGE : SHELTERED WORK : SPECIAL SCHOOLS : INST  
 ISOLATION : INSTITUTIONS : SPECIAL SCHOOLS : OPP  
 SHELTERED WORK : SEGREGATION : INSTITUTIONS : PA  
 SPECIAL SCHOOLS : PATRONAGE : ISOLATION : SEGR  
 INSTITUTIONS : SEGREGATION : SHELTERED WORK  
 SCHOOLS : SHELTERED WORK : OPPRESSION : PATRON  
 ATION : PATRONAGE : SEGREGATION : SHELTERED  
 OPPRESSION : SPECIAL SCHOOLS :  
 SCHOOLS : ISOLATION : OPPRESSION  
 SCHOOLS : SHELTERED WORK : OPPRESSION  
 SHELTERED WORK : SEGREGATION : ISOLATION : INST  
 INSTITUTIONS : SEGREGATION : SHELTERED  
 ISOLATION : INSTITUTIONS : SHELTERED  
 PATRONAGE : ISOLATION : SPECIAL  
 IN : PATRONAGE : OPPRESSION : SHELTERED  
 OPPRESSION : SPECIAL SCHOOLS :  
 SEGREGATION : ISOLATION :  
 SCHOOLS : SHELTERED WORK : OPPRESSION  
 ATION : PATRONAGE : SEGREGATION  
 INSTITUTIONS : ISOLATION :  
 SHELTERED WORK : PATRONAGE  
 PATRONAGE : INSTITUTIONS : OPPRESSION  
 ISOLATION : SPECIAL SCHOOLS :  
 INSTITUTIONS : SEGREGATION : PATRONAGE  
 PATRONAGE : OPPRESSION : ISOLATION : SHELTERED  
 SHELTERED WORK : ISOLATION : SHELTERED  
 PATRONAGE : SEGREGATION : SHELTERED WORK : SPECIAL SCHOOLS : PATRONAGE : ISOLATION : PAT  
 SCHOOLS : SHELTERED WORK : OPPRESSION : PATRONAGE : SEGREGATION : INSTITUTIONS : ISOLATION : SHELTE  
 OPPRESSION : SEGREGATION : SPECIAL SCHOOLS : SHELTERED WORK : SPECIAL SCHOOLS : OPPRESSION : IN  
 PATRONAGE : SHELTERED WORK : OPPRESSION : ISOLATION : SEGREGATION : ISOLATION : INSTITUTIONS

***The Union aims to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society . . . . .***  
 . . . . .

UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION

Flat 2, St Giles Court, Dane Road, Ealing, London W.13.

C O N T E N T S

|   |    |
|---|----|
| Editorial .....   | 2  |
| Obituary: Paul Hunt .....   | 8  |
| 1. Reflections on the death of hope. Harry Emery .....  | 10 |
| 2. The Union of the Physically Impaired fighting<br>against segregation. Dick Leaman.....   | 17 |
| 3. A question of choice. James Thorpe.....  | 27 |
| 4. Tenants eye view. Ken Davis.....   | 32 |
| 5. Settling accounts with the parasite people: a<br>critique of 'A Life Apart' by E.J. Miller and<br>G.V. Gwynne. Paul Hunt ..... | 37 |
| 6. Paul Hunt: an appreciation by some Union members.....  | 51 |
| Appendix: UPIAS Aims, Policy Statement and Constitution   |    |

## **EDITORIAL**

### **Great Expectations**

During the late 1960's and early '70s 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 (CSDPA) of 1970. With this legislation, expectations were raised to yet 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 CSDPA won greater advances for professionals 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.

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. A 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.

### **The "Expert", Administrative Option**

The differences between the two tendencies are profound. This has been made crystal clear in the record of the Union's struggle against the Disability Alliance. In the Union's analysis' (Fundamental Principles of Disability', published by UPIAS, 1976) the Disability Alliance, by promoting a narrow, "incomes" solution to our problems, has done little more than promote the interests of its "expert" leadership. This elite inevitably becomes more and more "expert" in economics - leaving the members more and more isolated, and in increasing ignorance of the issues being fought on their behalf.

This approach can be characterised as essentially an "administrative" one, and the Disability Alliance is a particularly clear example of this. Highly qualified and professional, the leadership use the Disability Alliance to carve out for themselves a permanent future on our backs. The organisational "umbrella" structure of the Alliance gives them a supposed "authority", but spares those with most to gain the burden of direct participation with their disabled membership.

Their efforts to gain credibility, however, drive them to make progressive sounding, plausible statements: but, in the final analysis, they really only see the problem of disability as one of mere individual bad luck. It is little more than an unfortunate quirk of our society that an individual physically impaired person is impoverished. The solution is essentially simple - more money to be administered by specially qualified personnel on behalf of the State. The utter bankruptcy of the "expert" view that

"authority" is the principal ingredient for successfully pushing the narrow incomes solution is starkly revealed in their own recent publication. Since the Disability Alliance was created, "Disabled people have been singled out for particularly savage cutbacks in public expenditure" (The Guardian, 12th May, 1980, on 'A Very High Priority' from the Disability Alliance). This conclusively shows that, despite all their acquired "authority", these "experts" are treated with even greater contempt by the Government and was DIG. So much for the "administrative" option.

### **The Collective, Organised Option**

The Union on the other hand, though reacting to the same circumstances as the Disability Alliance, had no vested interest in diverting attention behind a mask of "fury" from the real issues facing disabled people and from the real, social struggle that we must undertake together if we are to achieve lasting changes. At this crucial time it was left to the Union to build a different approach - not one based on spontaneous, unconsidered activity. We recognised that our struggle had to be based on a clear analysis of the situation we were in. Unlike the Disability Alliance, with its leadership of social scientists bent on acquiring the authority to "educate" the Government and public about disability whilst studiously avoiding any serious analysis of our problems, we recognised the need to take on this pressing task in the emerging Union of the Physically Impaired.

It was a long and difficult struggle. Some people in the early stages wished to involve the new group in immediate spontaneous actions. Nevertheless, it came to be generally agreed that physically impaired people had ample opportunity to continue our various activities, while at the same time we engaged in the struggle to understand our situation more accurately. At an early stage, an Interim Committee was created to produce internal, confidential Circulars and to draft Aims, Policies and a Constitution for the organisation. A conference was held in October 1974, and following a postal vote of participants not able to attend, the Union was inaugurated on the basis of these finally agreed documents on 3rd December, 1974. Slightly amended on 9th August, 1976, when able-bodied Associate Members were allowed greater participation, these papers are reproduced in full as an Appendix to this publication.

These documents are the result of the Union's efforts to define our problems our way, out of our own collective experience of disability. They recognise that, in the end, there is no real choice for us but to lead the struggle ourselves as a collective, social force. There is no security in any narrow approach for State Charity handouts. Such approaches merely serve to make us even more dependent on able-bodied people, teaching us with a vengeance the lesson that what able-bodied people can give they can just as easily take away. The latest cutbacks in public expenditure serve an educational purpose unequalled by all the Disability Alliance's pamphlets put together - and show that a collective, organised struggle is the only real option.

### **Defining the Problem**

In our collective struggle to understand the truth underlying our impoverished social situation we were led - through the pooling of experience and

through discussion arising from it - to recognise two clear features. First, we are members of a distinct group with our own particular physical characteristics (physical impairment) and second, that society singles this out for a special form of discrimination (disability). This perspective differs radically from the "expert" medical or social scientific view, that disability arises out of the individual and his or her physical impairment. Our analysis leads us to declare that it is the way our society is organised that disables us.

The Union's definitions, then, are:-

"Impairment : lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body: and

Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression".

(Fundamental Principles of Disability, p.14)

This clear and principled recognition of the social origins of disability enables us to see through and resist the many false explanations and tendencies which can and do divert our struggle. For instance, it follows from this view that poverty does not arise because of the physical inability to work and earn a living - but because we are prevented from working by the way work is organised in this society. It is not because of our bodies that we are immobile - but because of the way that the means of mobility is organised that we cannot move. It is not because of our bodies that we live in unsuitable housing - but it is because of the way that our society organises its housing provision that we get stuck in badly designed dwellings. It is not because of our bodies that we get carted off into segregated residential institutions - but because of the way help is organised. It is not because of our bodies that we are segregated into special schools - but because of the way education is organised. It is not because we are physically impaired that we are rejected by society - but because of the way social relationships are organised that we are placed beyond friendships, marriages and public life. Disability is not something we possess, but something our society possesses.

The Union's unambiguous position forms the basis of all our policies and activities, and similarly the basis of our challenge to those involved in disability struggle. The clear explanation of our situation not only enables us to identify the true source of our sufferings, but also helps us to draw together our diverse struggles for a better life by facing directly and consciously the challenge of an oppressive society which singles out particular groups of people for particular forms of discrimination. Because the discrimination levelled at our particular group (disability) is one of many forms of social oppression, it follows that the first lesson that we (physically impaired people and our supporters) must learn - if we seriously intend to oppose oppression - is that ours is essentially a social and not an individual struggle. This struggle of necessity requires the active and leading participation of the oppressed group. Others speaking on our behalf, typically the so-called "expert" or charity spokesperson, can only perpetuate the oppressive social relationship that is disability.

## **Avoiding Diversions**

Although it is just about impossible today to meet anyone in any organisation who would not agree that our social organisation has something to do with the restrictions we face, it is equally true that the clear-cut relationship between physical impairment and disability is usually confused in one way or another. One specious diversion is the idea that "We are all disabled in some way", or that disability is the result of "labelling" and the way people talk about us. Both confusions imply that disability is something possessed by the individual, thus diverting us from seeing the concrete ways in which society disables us and from distinguishing the oppressors from the oppressed. The cause of our problems is seen as lying within the psychology of the individual, thus making the oppressive society safe from criticism.

There are those who hold the view that they do possess disabilities - but only as an incidental appendage to their real selves. With this view, it is insisted that we are people first and only secondly do we possess a "disability". This serves as a meaningless, comfortable generalisation behind which we can hide from unpleasant truths - and even believe that it helps us gain confidence. In fact, however, it merely bows to the able-bodied idea that we possess two aspects: our human-ness and our not-quite-so-acceptable disability. Again, the cause of our problems is held to lie in the way we think about ourselves, which may lead to the view that the concrete barriers set up in the able-bodied world are actually internal barriers in our minds. Some people then conclude that what we face is internal oppression, i.e. we are our own oppressors! Our real oppressors could not wish for a more congenial interpretation - or for one that left them more secure from attack.

We do not organise because we are people first, nor because we are physically impaired. We organise because of the way society disables physically impaired people, because this must be resisted and overcome. The Union unashamedly identifies itself as an organisation of physically impaired people, and encourages its members to seek pride in ourselves, in all aspects of what we are. It is the Union's social definition of disability which has enabled us to cut out much of the nonsense, the shame and the confusion from our minds. It has raised the floodgates for a river of discontent to sweep all our oppression before us, and with it to sweep all the flotsam and jetsam of "expertise", "professionalism" and "authority", which have fouled our minds for so long, into the sewers of history.

## **Disability Challenged**

From its beginning the Union always intended to produce a regular, open publication. Before we could set about this task, however, we had to clear away many problems and clarify issues through discussion, if we were not to go the way of all other "disability" organisations. There was a price to be paid for this: many early members left, feeling there was too much talk and not enough action. But for those of us who remained and participated, the active struggles which we undertook in other areas of our daily lives became increasingly identified with the policies of the Union. Now, more and more struggles are being carried out under the banner of the Union.

This first issue of 'Disability Challenge', therefore, is built on a very carefully laid foundation. It contains articles by several members - but its

pages are open to contributions from able and disabled people, whether Union members or not. This will ensure that future issues can become an important forum for clarifying matters amongst ourselves. All letters and articles sent to the Union will be considered for publication. Accepted articles, whether from Union members or otherwise, represent the views of the authors and, in order to promote free expression of ideas, the Union accepts no responsibility for their contents. When anonymity is desired (particularly for contributors living in institutions, who often have to pretend that they are in full agreement with everything said by doctors, wardens, matrons, nurses, etc) pseudonyms may be used. Union documents will also be published from time to time, i.e. documents which represent the agreed position of the Union on particular issues. In this edition of 'Disability Challenge', this Editorial, the Obituary for Paul Hunt, and the Union's Aims, Policy and Constitution are all agreed Union documents.

### **Against Segregation**

It will be the task of 'Disability Challenge' to channel the river of discontent against all the able-bodied created falsehoods, myths and distortions of our struggle for emancipation. They will no longer be able to claim credit for our welfare with the same historical impunity that they have enjoyed up to now.

We have already mentioned the vital contribution Paul Hunt made to the creation of the Union: but it is worth noting that, while Paul was making his positive contribution to the long-term struggle against oppression, the "official" world of "disability" remained largely in ignorance about the really significant stirrings among disabled people going on under their noses. Thus, while they ignore the contributions of physically impaired people like Paul, they involve themselves in orgies of sycophantic praise for people like the late Sir Ludwig Guttman.

Whatever the merits of Ludwig Guttman's work in saving the lives of spinally injured people, it is well known that he was vain, incredibly arrogant, and an oppressive tyrant towards independently minded physically impaired people. He was not hesitant in banning us from facilities he controlled when his views clashed with ours and, of course, he gained notoriety for systematically channelling physically impaired people into segregated sports. In all this, he not only held us back in the development of our independence, but he positively struggled against us. The contrast between his contribution and that of Paul Hunt to our struggles could not be greater.

It has always been the Union's view that understanding what happens in institutions, why they were built and how they are run, is of fundamental importance to our struggle to overcome disability. In our view, it is institutional living which characterises the reality of our lives. Those of us who are not actually imprisoned within such walls carry them with us wherever we go in this society.

Because we view institutionalisation as characterising disability, we have given discussion about this a priority, and our first edition of 'Disability Challenge' is devoted to this form of oppression. We therefore open our new campaign against the disablement of physically impaired people with an attack against segregated residential institutions and, as we begin raising the floodgates, we look forward to the future - a world where physically impaired people are truly people first, and last.



## **OBITUARY: Paul Hunt**

Paul Hunt, a founder member of the Union of the Physically Impaired Against Segregation, died on 12th July, 1979, at the age of 42. Paul's sudden death has not only been a great personal loss to his family, to the members of the Union, and to his many other friends, but it is also a significant loss to all physically impaired people who struggle to improve their conditions of life by integration into the mainstream of society. In his life and work, Paul consistently fought against all forms of oppressive relations, and he devoted a major part of his efforts to improving the conditions of life of physically impaired people. To our organised struggles he made a contribution that was characteristically dynamic, determined, selfless and courageous in its content and practice.

This powerful and radical contribution to organised struggle, made consistently throughout his life, placed Paul in a position of leadership over the past two decades. From the work that he did, he came to hold an unshakable conviction that full integration for physically impaired people into normal housing, employment, education, mobility, etc, had become socially and technologically possible, and was therefore a realistic goal for which physically impaired people had actively to strive. The strength of his views, and of his principled approach to the issue of 'disability', became well known to those of us who were active in the growing movement of physically impaired people against our disablement by forms of social organisation which needlessly exclude us from normal participation and consign us to 'special' segregated facilities.

Paul himself suffered a degenerative physical impairment from early childhood. His formal education was curtailed when, at the age of 13, he became chairbound and was forced to go and live in hospital. In 1956, at the age of 18, he got himself moved from a chronic sick ward to Le Court Cheshire Home in Hampshire. He spent 14 years at Le Court, and throughout that time took a leading part in many struggles to improve conditions for physically impaired people. The 'Cheshire Smile', a journal that is distributed internationally throughout the Homes, bears witness to Paul's regular and outspoken contributions promoting progressive changes in the Cheshire Homes. Paul also edited and contributed to 'Stigma', a book of essays by physically impaired people. He vigorously promoted the introduction of Fokus, the Swedish integrated housing and work scheme, into this country; he had published a number of articles on different aspects of the needs of physically impaired people, and he was an active member of the Disablement Income Group from its inception up until the foundation of UPIAS around 1974.

Paul believed fundamentally in the principle that people should have control over their own lives and that, in contemporary society, this control should not be denied to anyone, including those who need particular kinds of technological or personal help because of physical impairments. At Le Court, despite any fears of intimidation, Paul was over a considerable period of time a trusted leader and outspoken participant in the eventually successful struggles of residents for representation on controlling committees and for a much greater voice in running their own Home and their own affairs.

In 1970, Paul married and left Le Court to live in the community and work as a computer programmer. His wife, Judy, shared Paul's convictions, and with her support, his dedication to the cause of full integration never wavered, but if anything became even more urgent when other demands were made on his time and severely limited energies. He never forgot the struggles of physically impaired people who remained segregated and isolated in institutions of all kinds, and the focus of his work was consistently to encourage and support those who are most oppressed by their exclusion from normal society.

For some twenty years then, Paul Hunt was at the forefront of our struggle. He consistently opposed the intimidation of physically impaired people by established authorities and noble patrons, etc., who control our lives and claim to speak with our voice. He strove always, and often at personal cost, for the concrete application of the lessons he learnt in struggle, and the principles that he developed, for the benefit of the mass of physically impaired people. His natural hatred of oppression and its attendant suffering, for example, led him to an increasingly conscious struggle toward its root causes in our particular society. He also came to understand the fundamental need for the mass of physically impaired people to unite and organise ourselves to put forward our own agreed views as a group and in support of each other. To that end, Paul was determined that we should have an independent and democratic organisation of our own which could campaign against all segregated facilities and institutions, and give support to such struggles as furthered this aim. It was through Paul's initiative in 1973 that the organisation which eventually became known as UPIAS was formed; and in the six years of struggle that remained to him, Paul's strength, humanity, experience and abilities made a major contribution to the organisational and ideological character of the Union, as well as being a profound influence and source of strength for all of us with whom he joined in struggle.

No brief obituary can pay full tribute to the contribution Paul Hunt has made to the organised struggle of physically impaired people in the United Kingdom. Such a tribute can only come when a complete and honest history is written about our struggles for emancipation. Such a history will be free from misplaced praise for patronage and so-called experts who claim to act in our interest. It will look to the struggles of physically impaired people themselves, and in this light Paul Hunt will certainly be recognised as the figure of leading significance in his time.

To Paul's wife, Judy, and to their son, Patrick, we offer our deepest sympathy.

As members of UPIAS, we pledge that Paul's death will allow no respite to our oppressors, and with confidence we assert that others will come forward to join us in developing the struggle which Paul Hunt did so much to advance, that is, the struggle of physically impaired people for emancipation and the elimination of our disabilities.

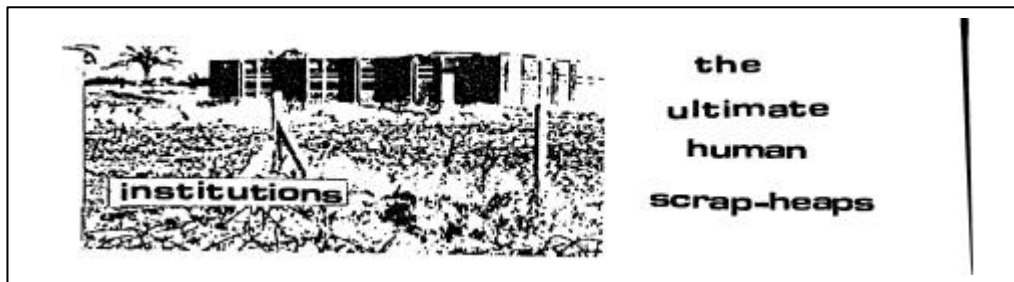
Union of the Physically Impaired  
January, 1980.

# REFLECTIONS ON THE DEATH OF HARRY EMERY OF HOPE

Working together with my fellow Union members in clarifying the issues which affect us, and developing policy has been very rewarding. I have resigned myself to accept that the changes we seek will not come quickly: for instance I still live in a segregated residential institution. The rewards so far have come out of participation; out of contact and co-operation; and out of our analysis of the forces which work to oppress people who happen to be physically impaired.

Working with others holds difficulties for me. My education as a child was almost non-existent and I have problems in communicating. This contribution has itself been produced with help from a fellow Union member. Being labelled spastic leads to many other problems of course. But like anyone else, I need a roof over my head and I need help. Twice in my adult life so far, I have been forced to accept other peoples' ideas about what was best for me in terms of accommodation and care.

The first time, my parents sent me to the local workhouse for a fortnight's break, and I didn't escape until thirteen years later, when I met my wife. We had four good years together in a Council prefab. It was a struggle to survive - but at least we lived in an ordinary dwelling, in an ordinary street, in a normal community setting. We were like other people.



After my wife's death, I met a social worker with another version of the Final Solution. He said the new institution was A Showplace. It had a pretty name and lots of regulation social spaces joined up by a clean wall to wall carpet. It was, to translate, the Workhouse tarted up. The County Council invited the Minister for Talking about Integration to come up from a place called London to open it and, quite appropriately, all the Elected Members present had Multiple Orgasms as The Plaque was unveiled.

**"Happily more and more people are coming to see that it is undesirable to institutionalise even severely disabled people, that their needs must increasingly be met in the community....."**

**MINISTER FOR THE DISABLED, SUNNINGDALE 1976**

Then they all went off home never to be seen again, and that's where this story begins.

There were at least two bright sparks in the New Workhouse. One was an inmate, the other the Warden. While most of the other inmates were busy developing superficial relationships and becoming happily institutionalised, these two were planning Big Things.

Almost nine months to the day the first inmate was incarcerated, the idea of the Residents Committee was born. The Bright Inmate got himself elected as Spokesman and immediately started making trouble. His trouble was that he thought that institutions could be organised in such a way that they didn't institutionalise people. He was filled with enthusiasm and High Hope.

The Warden too was enthusiastic. But he suffered from horizontal management disease which caused him much trouble. His problem was that he thought that the Chief/Indian aspirations in staff could be ironed out flat such that they operated as equal co-members of a caring team. As Homo Horizontalis-in-Chief, the Warden saw himself as popping up briefly from time to time to do Necessary Things. He was filled with Hope and Conflict at least in equal measure.

Against this background, there was an inmate proposal that the Residents Committee should be restyled as the "Association of Residents and Friends" - and a Constitution was drafted accordingly. After two Open Meetings of inmates and staff, a number of amendments were incorporated and a final version adopted. All in all, it was quite a democratic affair. It was sent up to the Appropriate Department of the County Council for perusal, and a meeting was arranged shortly afterwards to discuss why the County could not approve.

I remember that meeting and subsequent events very well. The bureaucrat who descended to explain the County's position had the grand title of "Residential Homes Advisor" and he clearly wasn't very used to having direct contact with those whom he was well paid to oppress. Revealingly, he opened the contest with a counter-punch, saying that County's view had already been made known to inmates through Normal Channels and invited responses from the residents towards that view.

Bright inmate rose to the occasion as spokesman for residents and parried with an historical overview. He outlined the growth of the Association from the first few informal meetings with the Warden which culminated in the desire of residents to organise themselves such that they could have some opportunity to influence decisions affecting their lives, as well as taking an active interest in their social life.

I wondered whether it was wrong of me to envy the fluency of Bright Inmate's opening. He went on to describe how inmates had volunteered to form an Interim Committee and how that Committee had elected him as Spokesman and to take on the job of drafting a Constitution based on the Interim Committee's discussions. You could see the pattern now: the guard of logic held well up with Democratic Principle poised for a knock-out in the first round.

He described how the draft Constitution had been discussed point by point at two subsequent Open Meetings, how revisions had been made to it, and how it had been adopted unanimously by residents on such and such a date. Nominations for the appropriate number of Committee

Members had been received, an election held, and the Committee formed in accordance with and on the basis of the Constitution. He asserted that the formation of the Association of Residents and Friends had been as democratic as it was possible to devise: he paused, as if waiting for someone to declare the occasion No Contest.

No one spoke. Unabashed, Bright Inmate continued the assault. He explained that the Constitution had been drafted to cement the basis of an organisation within which inmates could take an active, participative role. Activity, he said, and the opportunity to take responsible decisions about matters affecting residents lives, was essential for their well-being. It was essential, if the insidious effects of institutional life were to be offset. He pointed out with some authority, since he hadn't always been inside - that responsible participation in life was the norm for individuals outside of institutions and the exception for those within. Going on, he said it was crucial to have the Constitution accepted and wholeheartedly supported by everyone concerned, if apathy, submissiveness, lack of interest in matters not immediate or personal and any other effects of institutionalisation one might care to think of were to be obviated.

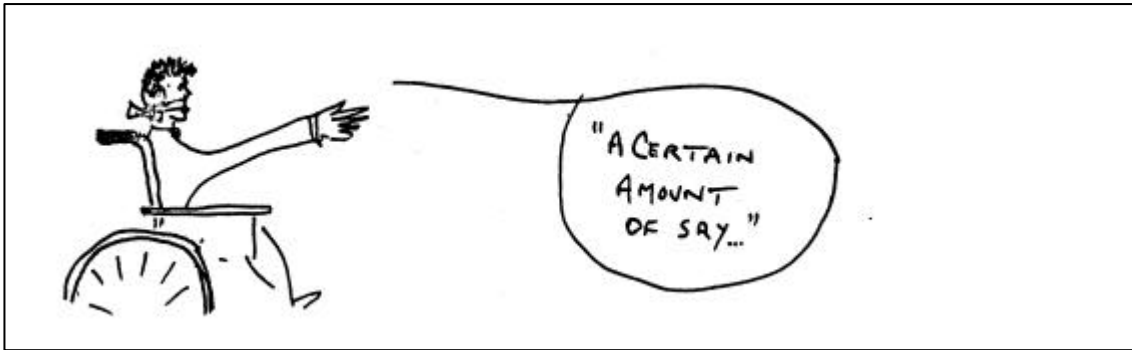
Again, silence. Slightly abashed, Bright Inmate proceeded, diminuendo. In setting out to organise an association of residents and friends, he said, the Constitution provided for the removal of the distinction between disabled inmates on the one hand and able-bodied friends on the other - providing for interaction and participation together.

The Latter-Day Overseer interjected with a very straight Right, claiming that the Constitution did make a distinction between residents and friends, since the latter could not vote. Elected Members would have been proud of their employee's performance: they had been elected to Rule; they thought they had decided the issue of the New Workhouse; it was their Department's responsibility to run it; their employee was defending their perceived Right to Rule. As a diversionary tactic, it wasn't particularly outstanding. But it stood out.

Bright inmate retorted that the point did not constitute a notable distinction, merely took account of the fact that the people who could vote were the people who actually lived in the institution. It simply ensured that decisions were taken by the people who had to live by them. There was a difference, he explained patiently, inasmuch as inmates by definition lived inside the institution whilst friends would live outside it - this was a difference which had to be recognised and protected. But on the key issue of interaction and participation, the distinction between the traditionally passive recipients of care and attention, the inmates, and some wearisome outside group of active Do-Gooders, would on paper be removed.

The Overseer demolished this by pointing out the Obvious with all the studied indifference of someone who observes that Big Toes hurt when continuously stubbed against stones. All people, he observed, had a lot of decisions taken for them by others. I felt I should have been significantly enlightened. In his opinion, he went on, such an Association was not practicable and inmates would defeat

Their own purpose to join together with friends. If inmates wanted a certain amount of say - which was a possibility - we could form



a separate Committee of Residents. A League of Friends might then form as a separate organisation on the outside, in a supportive position. This was the normal form of organisation in a situation such as this, and a combined association would not work. He was getting testy.

It was clear that Overseer had no sense of Occasion. Obviously he was aware that he was caught up in a situation which required him to assert and maintain Control. But he was only barely tolerant: it was a matter to be got out of the way with as little delay as bureaucratic decorum would allow. I thought it a shame that the symbolic nature of the confrontation escaped him: here, in microcosm, was the Great Showdown - the Oppressed locked in struggle with the Oppressor.

Bright Inmate said that he was all too aware that Overseer was describing the traditional form of organisation, but it was not what the inmates wanted. Groups such as a League of Friends, he pointed out, frequently followed their own interests rather than those of the people they had chosen to support. The Constitution was designed to ensure that any decisions taken conformed to the real wishes of inmates. Even so, it did not totally exclude 'Friends' from decision taking - and referred to some obscure Clause which allowed the formation of sub-committees including a proportion of non-inmates. Nor, said Bright Inmate with a flourish, did it exclude the possibility of 'Friends' influencing inmates and affecting the outcome of voting - at least four meetings each year had to be Open Meetings, and they could be called at any time.

The difference between them was quite enormous. Bright Inmate was serious, sincere, full of conviction: he was Part and Parcel of what was happening, and not a bit detached. Overseer replied mechanically: it was not possible to function in this way: the normal form of organisation was as he had already described. Full stop.

When Bright Inmate responded to the insult by enquiring whether the Department was afraid of outside influence being brought to bear, I thought that he was going to concentrate more directly on the great issue of Who Controls. Certainly, Overseer now came close to Life. This was not the case, he said, just that the proposed Association was not practical. If he was a member of a League of Friends and,

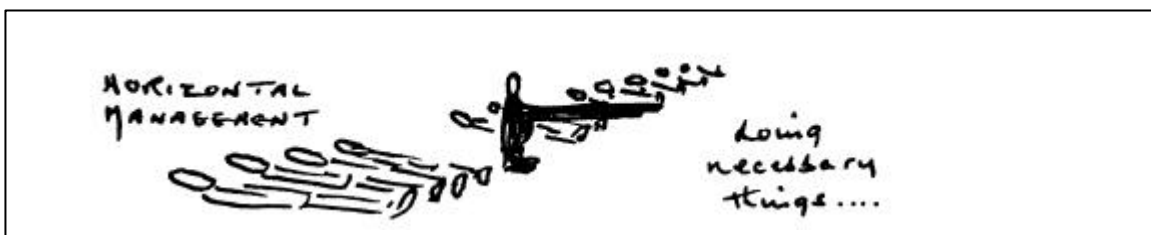
having worked to raise money only to find that he could have no say or vote as to how it was to be used - it was not the sort of Association he would join. This brought the predictable retort from Bright Inmate to the effect that, in such circumstances, Overseer was not the kind of member the Association would find congenial.

Having manoeuvred an opening, Overseer tried a sharp Put-Down by objecting to the discussion becoming personal, saying he would not accept it. Bright Inmate adroitly reminded the Overseer that it was he who had first raised the issue on a personal level, and requested that the proceedings continue on a more objective basis. As far as membership was concerned, individuals could decide for themselves whether or not they wanted to apply to join. Copies of the Constitution were freely available, so people could fully inform themselves before deciding. The Constitution made it plain that only inmates could vote on internal matters, though friends could have some control through sub-committees on external matters.

The road from this point on was now strictly downhill. In time-honoured Top Bureaucratic fashion, Overseer began studiously to ignore any points proffered by Bright Inmate - simply making comment or raising questions on subjects as remote from the central issue of Control as possible. He twice led Not-so-Bright Inmate on to answer points already well-covered and when the aforesaid Inmate reacted by saying that Overseer was merely saying that the Association would not work without offering an explanation of why it wouldn't work, Overseer retorted that there was little point going over the whole matter again. It was better to have one committee inside, and a League of Friends outside.

The meeting then degenerated into a General Babble. Hearteningly, some inmates insisted that residents should have the opportunity to make decisions, to which Overseer eventually replied that if residents thought they were always correct there was nothing for him to discuss. At that, Bright Inmate woke up again to say that there was no more likelihood of inmates being always correct as anyone else. Everyone made mistakes, and inasmuch as the Constitution was designed to give inmates an opportunity to make decisions, including wrong decisions, it was through this process that people learned, gained experience and confidence. He would probably have had more effect had he pushed his wheelchair full tilt into the nearest wall.

The Horizontal Management then began to pop up and show their real colours. The Deputy Warden said that if a separate League of Friends was formed, residents could probably sit on their Committee and influence their decisions. When Bright Inmate responded to that by saying that it was better for people to do things together on an equal footing, Matron reared up to say that having a separate League of Friends didn't mean that Decisions couldn't be taken together with residents. Warden said that the Constitution (which he had collaborated in drafting) was loaded against the able-bodied - and that decision taking in a County Council Home must be limited because of local authority set-up.



The Old Lags began to stir, sensing the close of the meeting was drawing near. Overseer gave a practical example of why decision making must necessarily be limited, with Bright Inmate protesting that no responsible person would wish to take a decision about how to repair the leaking roof on an institution without first consulting an expert on leaking roofs. Ignoring this Overseer went on to point out that the question of money had to be considered: Social Services Committee sliced the cake - but it was open to residents to try and influence them if they could. Our Inmate noted we would best be in a position to do this if we had a strong and united association of residents with outside friends. Overseer signalled the close, by remarking that we were now back to Square One.

Warden at this point demonstrated Mock Solidarity with inmates by asking whether they wished the Overseer to go back to County Offices and discuss the matter further with his colleagues in the light of what had been said. A vote was taken, confirming this, and Overseer melted away.

It's hard to believe that five years have gone by since all this happened. As you would expect, the New Workhouse is sunk in apathy, so much so that the Department found it necessary to persuade their Committee to provide the money to employ a Special Person to counter-act Apathy. Incredibly, they agreed, so we now are treated to the daily spectacle of one frustrated Occupational Therapist cajoling apathetic inmates to become Healthily Independent. The remainder of the not so horizontal caring team continue to beaver away as before, pulling trousers on and off and wiping bottoms and so on, generally encouraging dependent behaviour. But I digress.

The end game was dirty. One month later Warden announced an Open Meeting with Overseer present. It just so happened that Bright Inmate was away. The rest of the inmates tried, but they were not really up to all the manoeuvres. Not that it wasn't without its lighter moments: after a smooth performance by Overseer backed by Warden, a vote was called for on the proposal that the residents should have a House Committee separate from a League of Friends. The vote was 4 for, 12 against and 2 abstentions. Warden suggested that the vote represented a misunderstanding and should be re-cast. The proposal was rephrased accordingly and the voting went 13 for with 4 against.





The next to go was the Warden: after all, horizontal ideas about management hardly fit into vertical hierarchies. Having removed all disturbing influences, this institution settled down to its basic function. Our Union defines this in its Policy Statement as being a system designed to "Look after batches of disabled people - and in the process convince them that they cannot realistically expect to participate fully in society" (1)

I would say that this process began, externally, long before inmates here proposed their unacceptable Association. No one can fully escape the influences of his or her own times, and all of us have grown up in a country littered with segregated Homes. It is part of the great British institutional tradition. It is not surprising that the social thinkers who have clawed their way to the top of the Health and Social Services hierarchies still salivate institutional solutions for peoples dependency needs. As we say in the Union Policy document: "Both inside and outside institutions, the traditional way of dealing with disabled people has been for doctors and other professionals to decide what is best for us". (2) No wonder our elected representatives - when confronted by the persuasive reports of the professionals - "decide" in committee to use our money to imprison us. It is here that the alienation we suffer is systemised and justified. It is enshrined in our so-called democracy.

Although our Union accepts that there was a time when institutions played a part in the lives of people who happened to be physically impaired, our view is that "they have become seriously out of step with the changed social and technological conditions of Britain today." (3). Nevertheless, the New Workhouse is here and I'm in it. And the crushing of the inmates attempt to participate actively in their lives by our local bureaucracy was, internally, the beginning of the end for residents. Apathy reigns supreme: slick local bureaucrats now point at the apathy and bewail how difficult it is to get residents to do anything!

I have little doubt that the sense of powerlessness we all feel, comes over with this account. In conclusion I can only refer, with some frustration, to our Union's Policy Statement: "The efforts of professionals and other able-bodied people are ... really constructive only when they build on and encourage the self-help and activity of disabled people themselves." (4)

## references

- (1) Union of the Physically Impaired, Policy Statement, p.2.
  - (2) Ibid, p.3.
  - (3) Ibid, p.2.
  - (4) Ibid, p.3.
-

# IMPAIRED - FIGHTING AGAINST SEGREGATION

DICK  
LEAMAN

## CONSULTATION ON AN IMPORTANT ISSUE - THE SHORT ANSWER

"The Union is opposed to the building of any further segregated institutions... We believe that providing adequate services to people in their own house is a much better use of resources. We also call urgently for the provision of non-institutional alternative housing for example, along the lines of the Fokus scheme in Sweden, which makes genuine progress towards secure, integrated, and active living for disabled people who need extensive personal help".

(UPIAS: Policy Statement)

In March 1975, the Ealing Association for the Disabled decided to make the topic for one of its annual open meetings the issue of housing for disabled people. At the meeting a short film was shown which promoted an integrated housing scheme being operated in Denmark. This scheme, by providing the right kind of facilities and personal help arrangements, enabled severely physically impaired people to live active and independent lives outside of institutions and within the normal community. The film emphasised that the success of this housing scheme had notably been achieved by its encouragement of the active participation of physically impaired people in their own rehabilitation, and by their close involvement in decisions regarding the planning and development of the scheme which was intended to meet their special needs.

One of the invited guest speakers at this EAD meeting was Paul Hunt from the Union of the Physically Impaired Against Segregation. The showing of this exciting film to an audience largely made up of disabled people and their friends and relatives helped Paul to promote in a positive and concrete way the Union's Aim: "to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society ... and to live where and how we choose with full control over our lives".

However, when the meeting was opened to discussion from the floor, and this theme was taken up by disabled people with local knowledge, it soon emerged from questions to the Local Authority representatives on the panel that the Social Services Department in Ealing at that time already had well-advanced plans for building a 30-bed residential Hostel for the younger physically handicapped people of the Borough.

The obvious question arose as to what consultation there had been with disabled people on this local issue, and how had those whose lives would be affected been involved and been allowed to participate in the decisions about what kind of facility should be provided for them. The answers from the authorities were slightly embarrassed and very confused. The particular need for the Hostel, they said, had been "proved" a long time ago. Nobody at the meeting was responsible for the

decision, but, they argued, there was no such facility at present in the Borough, the Social Services had a long waiting list of

applications for residential care, they were having to pay to keep some people in Homes outside the Borough, and the Hostel should be seen as part of a policy of providing a "range" of services to meet the needs of the disabled.

The short answer was clearly that there had been no consultation whatsoever, and that none of the people who were most likely to end up living their lives in this proposed segregated institution had been presented with any real choices about the kinds of alternative housing and personal help arrangements that could be made for them.

## WHAT SHOULD CONSULTATION MEAN

### A SLIGHTLY LONGER ANSWER

"Neither we as a Union, nor able-bodied people, can solve other disabled people's problems for them. Those problems will be correctly tackled precisely to the extent that we all as disabled people become involved and active in our own rehabilitation"

(UPIAS: Policy Statement)

Following this meeting, and with the possibility of a continuing involvement in the Ealing Hostel issue through having a member (myself) on the EAD Committee, the Union proposed further action. In accordance with our policy of offering support and co-operation with other disability groups wherever possible, we proposed that a small joint sub-committee be set up by the EAD and ourselves. This was agreed, and a small group of London based Union members quickly met to discuss drawing up clear terms of reference to propose to this committee. The purpose of this was to ensure that our activities were fully in line with agreed Union policy, and also to establish a firm basis on which to work with the EAD, whose commitments as an organisation were not the same as ours and whose individual members would not necessarily agree with all aspects of our Union policy.

It was agreed with EAD that the fundamental point at issue was our shared conviction that disabled people should actively participate in the decisions which affected their lives so closely. Our joint struggle, therefore, had to be to press for and achieve a meaningful process of consultation with the disabled people of Ealing on the issue of whether they themselves really wanted the kind of help represented by a residential Hostel, or whether they would prefer the allocation for the huge resources involved to go into providing such alternative arrangements as could enable them to live independently, or with their family or friends, within the community.

that the correct decision was towards increased integration and normal social participation for disabled people. A Hostel could, and no doubt would, be filled from the ranks of those who, without the right kind of help, would be unable to live as normal members of the community. But we ourselves were sure that the decision to build yet another segregated institution was grossly out of tune with modern developments and reflected only bankrupt ideas of housing and care facilities, insofar as it attempted at all to represent the real interest of disabled people as a whole.

Consultation, the principle of disabled people's active participation in society, required fundamentally that they be enabled to take part in these kinds of decisions and therefore that they take part also in open discussion beforehand of all the issues involved and of the various differing points of view, such as the view of the people who would decide to build an institution, but including also our view that more integrated alternatives offered a better solution. In order to be responsibly involved in that decision, disabled people should have all the information that could be made available, and should be freely allowed to express their own views in the context of open discussion about that information. As organisations struggling to represent the real interest of disabled people, it was primarily our joint responsibility with the EAD to make the achievement of such a consultative process the basis of our involvement in the issue and of our dealings with the Local Authority.

After the brief discussion about the proposed Hostel at the EAD meeting, and after the initial attempts of our joint sub-committee to publicise and follow up the issues it raised, we received a quick response from the Social Services Department. The Director wrote to the Organising Secretary of the EAD (a member of our committee) with a ready recognition that "There has been a lot of misunderstanding about the home for the younger physically handicapped people and I regret very much not having involved you in consultation earlier". This seemed a promising start and, as some urgent action was necessary before building work on the Hostel began and consultation about it became purely academic our joint committee accepted an invitation to meet with Councilors and Council officers at the Town Hall to discuss the Hostel plan and possible alternatives to it. At this meeting we presented our view, supported by evidence, that the further institutionalisation of disabled people was an unnecessary and harmful misdirection of resources. We referred to other schemes which were well established abroad whereby suitably designed and equipped housing units were integrated into ordinary housing developments and a 24-hour personal help service, on call from these units, was organised to serve the site. There were the issues, we said, about which there needed to be consultation with disabled people.

We met with two main reactions from the Council officers. In the first place they persistently sought to defend the present Hostel scheme, although they were very vague and confused about the people for whom it was intended and about how they themselves had established that such a scheme was the best answer to the living problems of the Borough's disabled people. They argued that the Hostel was a part of this "range" of provision and that it was necessary to enable disabled people to have the choice of living in that way. The Director of Social Services claimed that it would be "just as wrong for me to tell handicapped people that they must live in the community as for me to tell other handicapped people.. they must live in a residential home".

our integrated housing alternative to the Hostel: but, to our surprise the Social Services officers (Director and Assistant Director) continually asked us for details of the need in the Borough for such a scheme. They, with all their resources and expertise, and despite all the work they might have done in "proving" the need for residential care, obviously had no idea about this. We again put forward the pressing need for consultation with as many of the Borough's disabled people as possible, and for the open discussion with them of all the information that could be made available on these issues.

The question of full consultation was hardly taken up by the Authorities at all, but was rather left hanging in the air as a meaningless adjunct to the business of decision making. Meanwhile, we were appalled by the lack of real research knowledge of the so-called "experts" on the needs of disabled people, and by their clearly unprincipled decision to allocate some £300,000 of capital resources to an institutional solution to the problems. We put in writing to the Director of Social Services a number of specific questions about the groups of people for whom the Hostel was planned. The answers to these questions, about which our meeting had left us confused, seemed to us to be basic essential knowledge required before any sensible decision could have been made about making provisions to meet real needs. Our letter elicited a totally different response from the Director. He adamantly refused to attempt answers to the questions, or to discuss with us further the need for the Hostel. When, some time later, he had to defend this position to the Borough's MPs, there emerged a much clearer interpretation of what we had initially taken as an encouraging response to the question of consultation. We had been given a chance to express our views at the meeting we had attended, this Director wrote to the MPs: the decision to go ahead with the Hostel had subsequently been confirmed in Council, and he had seen no point in continuing to discuss the issue with us as we had fixed views about the provision of alternative facilities.

So much for our attempt to establish the need for real consultation with disabled people! Clearly the Director's "regret" had been that he had not gone through the token forms of consultation, i.e. with the paid secretary of the grant-aided EAD, so as to draw off possible opposition to Council plans and to avoid this particular embarrassment of being challenged on the issue by a community group. Fortunately, the then Secretary of the EAD stood firm with our committee's agreed position and there was no question of her being used, as others might have been, to be drawn into "responsible" consultation over the heads of the people whom our group was consistently saying should be enabled to express their views.

Thus the slightly longer answer to the question of what real consultation should mean demonstrated a fundamental difference of position between the local Authority and ourselves. As the Union's Policy Statement concludes: "It will be for disabled people as a whole to judge whether or not we are correct".

## AN UNEASY CO-OPERATION

"I think you are pushing an open door"  
(Asst. Director, Ealing Social Services)

After the small amount of encouragement we had received, especially from the polite interest that had been shown in the possibility of integrated alternatives to institutions, and from a willingness amongst Councillors on the Housing Committee to have designed and built units for such a scheme, our committee put a lot of effort into developing this idea and into gaining for it the political will to make it a reality within the Borough.

Nevertheless, we remained very clear in our view that consultation did not mean a tiny group of activists campaigning for their own ideas, discussing their own views about disabled people with the Local Authority, and being drawn into compliance with official decisions when looking at the problems from their "responsible" point of view. We therefore maintained our sharp concentration on the issue of consultation. Our activities involved contacting the Borough's three MPs, the DHSS with its Minister for the Disabled, the DOE with its special Housing Directorate, sympathetic members of the local Council, and other groups of disabled people - all in an attempt to open this issue to more public scrutiny. The outdated ideas of the Social Services Department in their planning for disabled people had been matched by an equally outdated and bureaucratic notion of consultation which these other bodies could not openly support, however much they may privately have preferred the topic to have been left unraised. In a society where some forms of consumer representation and democratic participation have been generally won in principle so as to be standard expectations, neither the Social Services ignoring of the issue, nor their interpretation of it as discussing with a tiny unrepresentative group, could be sustained as a reasonable position.

Under mounting pressure, the Director of Social Services claimed that consultation was now going ahead with disabled people who were being kept in residential Homes outside the Borough, to see if they would wish to return by means of the proposed Hostel. This seemed rather odd, as these people's need to return had been put forward as one of the main justifications for the planning of the Hostel. The Director also told one MP that he had offered to enable the EAD to be involved in consultation in that, if we provided him with a letter together with envelopes and stamps, he would send it on to the several thousand handicapped people registered with his Department. This was an offer which he certainly had not made clear to our group, but which we quickly calculated would have cost something well over £500. Nevertheless, we took up the offer positively as it appeared to give some chance of contacting a substantial number of disabled people, both those already in residential care, and others who were still managing within the community. We then approached the Director of Social Services again in order to proceed with this, and to see which relevant groups of handicapped people could be identified from the Department's records for initial circularisation.

There followed an extraordinary saga of correspondence and discussion about how, and with what purpose, this initial consultation could be carried out. We were told by the Social Services in November, 1975, that most of the groups we had asked about could be readily

identified, but that there were some difficulties. The Department's records were then in the process of being transferred to a new system, but when this was completed in the New Year, the Director told us, we could go ahead with "some sounding of the views" of handicapped people. In January, 1977, over a year later, we were still being told that the records were not yet transferred; and in July of that year we were told that two months would be required to set up the survey.

At no time during this two year period did the Social Services Department say that they were unwilling for there to be consultation with disabled people; nor, after the Director's initial attempt to treat the matter as closed, did they say that they would not co-operate. The assistant Director told us in October, 1976, when he detected a note of doubt in one of our references to the issue, that in pressing for consultation "I think you are pushing on an open door". The fact remained that, despite all our efforts and despite our concentration on this issue in everything that we did, we were quite unable to get through this "open door".

### **THE IMPORTANCE OF CONSULTATION - WHOSE PROBLEM IS TO BE SOLVED**

"Our Union rejects entirely any idea of medical or other experts having the right to tell us how we should live, or with-hold information from us, or take decisions behind our backs".

(UPIAS Policy Statement)

Through these protracted discussions we had with the Social Services officers, the idea of our co-operating in consultation developed from our just being enabled to mail a letter, to being a joint exercise between ourselves and the Department which could provide specific information that could be used in planning. This exercise became the drawing up of a postal survey or questionnaire. We agreed to take part in it, provided only that we could also agree with the Department on an accompanying letter to go with the questionnaire. This was to give some information about our joint sub-committee, explaining our involvement in the issue; it was to mention the new housing scheme with a 24-hour help service which was now scheduled for development in the Borough; and it was to enable the disabled people receiving the questionnaire to contact us further if they so wished.

However, with the views that we held on the meaning of consultation, and with the difficulty that we had experienced in getting the Local Authority's practice in line with this, we had concluded that it was no accident that the bureaucrats and social workers who were insisting on building still more out-of-date institutions were the same people who could find no initiative for proper consultation, and responded to the idea only with complication and delay. It seemed to us that the

Social Services Department, with their attitudes to the problems, would include in the document only certain kinds of question. Their solutions to the living problems of disabled people were the wrong ones, and the implementation of a full process of consultation would make this clear. The importance of full consultation is that it brings into the discussion and into the process of decision making the very people who do have the correct solutions, i.e. the people who actually experience the problems. When disabled people are not consulted about solutions to their own problems, all that becomes clear is that those real problems present themselves quite differently to people who do not actually experience them. For example, a disabled person's problem that he or she is finding it impossible to carry on living in their present home in the existing conditions there, might in terms of solutions present itself as a totally different problem to, say, a Supplementary Benefit officer, a Director of Social Services or a Council official with responsibility for Residential Accommodation.

This explains why the Social Services officers and Councillors with whom we dealt not only did nothing to advance a consultation process, but maintained an apparent indifference to the issue. It could not really, they seemed to think, provide any help to them in their difficulties. As the Director once put it; you can ask people questions, but "their answers as to what they feel they need are not necessarily going to be the right answer for them. We might have medical advice to the contrary, and so on...". The Assistant Director echoed this position, and for him establishing the need of disabled people was "a professional matter"; but he still professed to think that there was some value in consulting about "what they think they want, and what they feel is going to meet their needs". Some time later, when the power of the Councillors in the political field had pushed the officers into the apparent acceptance of a new housing scheme with a 24-hour support service, this same Assistant Director was telling us that he was "not prepared to circulate those people who, in my opinion, are unsuitable for housing provisions", and he was off discussing with officers of the Health Authority and their Planning Team "the kind of care that may be provided". At that time, his Director had come to the position of writing to us about ascertaining "the particular needs of individuals by distribution of a questionnaire".

## **A CONSULTATION QUESTIONNAIRE - WHO ASKS THE QUESTIONS**

"The Union's eventual object is to achieve a situation where as physically impaired people we all have the means to choose where and how we wish to live. This will involve the phasing out of segregated institutions maintained by the State or charities".

(UPIAS: Policy Statement)

This total confusion of the officers about the importance and possibilities of consultation made it absolutely essential for us to understand and overcome the difficulties of how people really can be enabled to express their needs, and we also had to understand independently



of the local Authority what helpful function such tools as a postal questionnaire (the standard equipment of professionals who want to make decisions about our lives) can have in this. The Director, for example, was not entirely wrong when he said that people's answers to questions about their needs might not be "the right answer for them". But what his Department and, say, the Union of the Physically Impaired might think to be the right answer for them could be two very different things.

The collection and interpretation of information, then, is not a simple process. It involves assumptions about the social relationship between the researcher and the researched, and it also particularly involves the difference of interest between the two parties when they represent two quite different social groups. These factors will inevitably produce bias in a questionnaire, and so the fundamental issues become - which bias should the questionnaire have, or crucially, who determines what questions are asked.

This point was made very early on in our detailed discussion with the Authority about a draft questionnaire. Originally their indifference to the subject had indicated that they did not mind who drafted the document, and our small group proceeded to put a good deal of work into doing this. However, as soon as we circulated our draft for discussion, the Assistant Director of social Services immediately expressed his view that it was "too one-sided in that it virtually leads the respondent into accepting purpose built accommodation with a 24-hour service on call without posing any alternatives". Of course our questionnaire would reflect that bias. It reflected our position that this was the best kind of provision that could realistically be made, and that it was the correct provision to make in the interest of disabled people as a whole. There was no reason why our questionnaire should reflect the interest of those who want to segregate and institutionalise disabled people, any more than it would reflect the interest of others who might want to exterminate us altogether.

It was agreed at yet another meeting that the Social Services own Planning Officer (questionnaire expert) would work further with us on producing another draft which we could then take back to the group of officials now involved for comment and/or approval.

This Planning Officer brought with him to our first meeting a specimen questionnaire, based on so-called 'functional assessment', which he claimed was in standard use, avoided bias, and might be suitably adapted to provide specific information for planning. We immediately had to point out a strong bias which already existed in this whole approach. After quite long discussion with the officer, we all came to agree that proper consultation for planning has to involve discussion and exchange of information, and no questionnaire in itself can fulfil that requirement, precisely because it is a vehicle only for gathering information. The questionnaire could not be seen as a survey on which need could be assessed and objective planning decisions made; it was rather a means of gaining some information which could be of use in planning, and it should be seen as a "step on the road to consultation". The officer himself introduced this last phrase into the letter which he also agreed should accompany the questionnaire.

When we went on to look in detail at the sample questionnaire the officer had brought, we found that all the questions which sought to probe and measure the physical abilities of the individual, also contained a powerful bias in that they failed to recognise that the activities about which they asked were all basically social activities, i.e. they take place within a socially organised, man-made environment. The focus of the questions was entirely on the individual physically impaired person, and the social environment itself was assumed and unexamined. One actual question might serve to illustrate the point: - under a section headed 'Moving Around at Home', it read, "Do you have difficulty with stairs?". What is ostensibly behind the question is an intention to discover the ability of the respondent to move inside a building from one level to another. The assumption is that in our society this is done by using stairs, and whether or not the individual can use stairs determined their ability at this function. The fact that a lift, an escalator or a ramp could replace the stairs and enable the physically impaired person to perform this function is not considered. In fact, every question becomes meaningless if one assumes the availability of the appropriate aid or arrangement to meet the need of the impaired individual. It becomes clear that this 'functional assessment' gives no objective measurement of ability to perform social tasks, but rather measures only the divergence of the physically impaired person from the norm in a given (fixed) social environment.

Our group's original draft questionnaire had been criticised for offering disabled people the chance to choose such an integrated housing and help scheme as was then being positively planned in the Borough. The 'functional assessment' questionnaire with which the Planning Officer began, on the other hand, offered disabled people no options about how they would like to be helped to live. It contained long sections on personal details about the individual and the nature of their impairments, but it did not examine their physical environment nor the existing help arrangements in which they were having to try and cope with these social activities; it did not suggest any options for different arrangements, other kinds of help, alternative facilities or improved or more suitable equipment.

Clearly there was a very strong bias here in the questions that were being put to disabled people. We discussed this in considerable detail with the Planning Officer until we were in close agreement. Then we worked hard with him to develop a different questionnaire which was to be explicitly an initial step towards consultation, and which would not contain this bias against the real interest of disabled people in possible changes and in the application of resources that could solve their particular problems and enable them to be fully participating members of society.

## **HOW TO ENSURE REAL CONSULTATION - BUILDING THE STRENGTH TO FORCE THE DOOR**

"Disabled people everywhere are already struggling against their isolation, segregation and other forms of oppression... The Union exists simply to offer help to all physically impaired people in the fight to change the conditions of life which oppress us and to realise our full human potential".

(UPIAS: Policy Statement)

As our promising work with the Planning Officer drew to its conclusion, and we were virtually ready to take the new draft that was agreed with him back to the whole group of officials that was now involved, the "open door" to consultation was unexpectedly and resoundingly slammed in our face.

We learned that while we had been working with their officer as agreed, the Social Services Department had drawn up, without any contact with us, another questionnaire, and was actually in the process of using this within the Borough. We were appalled at this unilateral action and at the Department's betrayal of our co-operative exercise in consultation. We contacted the Planning Officer with whom we had worked so hard and with whom we thought we had come so far in agreement; but his only reaction was to try and convince us that this other questionnaire was based on our latest drafts and was an application of the views we had agreed on consultation. By this time we had seen a copy of it and we know that it was not. The whole format of the questionnaire was changed by its being no longer a postal questionnaire but one that was being "administered" by a visiting researcher from the Planning Department who had had no part in our discussions. Also this questionnaire reverted to the basic pre-conceptions of the kind of 'functional assessment' which the Authority's own expert had had to agree with us contained a fundamental bias that needed to be redressed for it to have validity as a consultative document. There was no accompanying letter with the questionnaire, and no indication that any of the information that had been in ours and which we had agreed was essential was being imparted to disabled people.

As regards any genuine process of consultation, this Local Authority gesture of form-filling was utterly meaningless, and our joint sub-committee dissociated itself from it. In one way, after some three difficult years of struggle on this issue we were back to the beginning, and the whole fight for consultation with disabled people required to be taken up afresh outside of the Town Hall and in the community. On the other hand, even though we were still a small group, our participation in the struggle for genuine consultation had been far from meaningless.

The central bearing of this issue on real decisions which directly affected the lives of disabled people had become very clear, The Local Authority in Ealing might or might not build a residential Hostel, and they might or might not develop a non-institutional alternative scheme, but whatever their decisions were they would certainly not be based on any expert knowledge of the real needs of disabled people, and their decisions could no longer make any pretence of representing our real interest. In the course of our struggle as a whole, these facts became clear in a number of different ways, but in no way clearer than over the struggle for full consultation.

What had at first appeared to be an oversight on the part of the Authority, and then a matter of mere indifference and low priority to them, had proved in the end to be a most significant and fundamental issue on which they in fact had a fixed determination, i.e. not to consult. As our focus on the issue became clearer, and the meaning of genuine consultation a more alarming threat to the interest

of the Authorities, this determination asserted itself with all the power of an intractable bureaucracy to wear down and outlast the best efforts of a small group of people within the community.

It is important to draw critical lessons from our group's experience, so that when the issue of consultation is again taken up, as it will be in Ealing and with other Authorities who have power over our lives, it will be with greater strength and with better understanding of the requirements of our success.

The main lesson, perhaps, is that the work and the struggle cannot be left to a few people on the behalf of the many. The first requirement is for the involvement of all disabled people in the struggle for participation in decision making and control over our own lives. The second requirement is for organisation of our resources and efforts, so that we can work and develop our abilities together, and bring an overall solidarity to the many individual struggles that we have to undertake. An example of this would be the support that was given to our group in Ealing by the Union of the Physically Impaired. Advice, help and active co-operation were given to us by members. Those living within easy reach in London carried the main burden; but all members were involved in our work through the Union's Internal Circular, and through this we received a feedback of views and practical help, such as that from the Nottingham based group who sent a donation to help with the expense of our work.

The right to full consultation is not going to be won without hard struggle. Struggle demands unity, organisation and active participation. These are principles upon which UPIAS is founded, and we call upon all physically impaired people and our friends to join us in the struggle to make our voice heard wherever decisions are taken that affect our lives by those who claim to have expertise in knowing what is best for us, but yet resist any real attempt to involve us in the decisions they make on our behalf.

## A QUESTION OF CHOICE

**JAMES  
THORPE**

We in the Union have always been clear about our feelings towards the existence of segregated residential Homes. We regard our struggle for the replacement of these facilities as an important part of our struggle for emancipation:

"The Union aims to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society. These arrangements must include the necessary financial, medical, technical, educational, and other help required from the State to enable us to gain maximum possible independence in daily living activities, to achieve mobility, to undertake productive work and to live where and how we choose with full control over our lives" (1).

"But how", we are often asked, "can we campaign to close down segregated residential institutions for physically impaired people, and so remove This choice from their lives, and at the same time say we are struggling to increase choice?"

Real and spontaneous choices.

When we take a closer look at these institutions we will see that they were set up by people who were quite unable to think creatively about alternatives for disabled people faced by a lack of accommodation choices in the community. It is a symptom of an oppressive society that it offers no real choice for severely physically impaired people to live independently in the community. This poses the problem, for those who wish to help us, either to struggle with us to create such increased choices in the community, or to accept these lack of choices and remove us from society. The creators of residential institutions spontaneously chose not to struggle to change the oppressive society but rather to remove us from society. A grudging admission of this has now been made by one apologist for these Homes:

"In fact, it can be suggested that the original early type of Cheshire accommodation offered, in practice, the reverse of integration in society. It could even be described as being 'Segregation form Society'" (2) page 6.

From the above it would appear that the existence of segregated residential Homes depends and builds upon a lack of choice in society. Let us look at this more closely. When able-bodied segregationists indulge themselves in their periodic gatherings to pat themselves on the back and give "do-gooding" awards to one another they give us some insight into their attitudes about our oppression. No segregationist has received more of these able-bodied awards than Leonard Cheshire, the father of the more liberal "Cheshire" Homes, and on these occasions they never tire of telling us how the first Home was started:

After the second World War Cheshire had been involved in a failed adventure to set up a co-operative community scheme for ex-servicemen. "In May 1948, while winding up this project and disposing of a large empty house, Le Court in Hampshire, he was told that one of the ex-members of the settlement, a 75-year old man, was dying of cancer and had nowhere to go. After trying unsuccessfully to find accommodation for the man, Leonard Cheshire took him into the house and nursed him until he died. Then others came....." (3) page 15.

It is clear that the first inmate of the Le Court Cheshire Home lacked choices in the community. Cheshire tried "unsuccessfully to find accommodation for the man" who "had nowhere to go". When Cheshire was faced with this real lack of accommodation he did not use his much acclaimed talents to struggle for increased choices in the community but spontaneously accepted the dictates of an oppressive society. He set up an institution which left the lack of accommodation alternatives in the community for physically impaired people absolutely unchanged. Far from offering an increase in accommodation choices for disabled people in the community the building of segregated residential accommodation serves to keep the choices in the community permanently limited.

Either one joins with disabled people in trying to change the real world so that "we all have the means to choose where and how we wish to live" (4) in the community or one joins the oppressors by devising means of avoiding the creation of real community alternatives. Facing a real lack of accommodation choices for physically impaired people, one might have thought, would be "significant enough" for this problem to become "an

urgent reason for re-examining fundamental issues" (5) page 12. However, just as the people who created the Disability Alliance studiously avoided analysing the way society disables physically impaired people (just when such an analysis was most needed) and "adopted 'spontaneity' as its basic method for reacting to the problems we face" (5) page 12, so too Cheshire makes a virtue of ignorance:

"If I were asked what I look upon as the most important element or feature of the way the Foundation came into being and subsequently developed, I think I would answer, its spontaneity. ... We have so far never planned our growth, never tried to decide where the next home ought to be opened ..." (6) page 4.

It is no accident that those who are insensitive to the oppressive nature of our society should be so much in harmony in campaigning around isolated issues, such as "benefits" and "accommodation", and in defending their "spontaneous" efforts in these areas. Able-bodied helpers (precisely because they do not suffer the social oppression of disability) have to choose between real community alternatives or they will spontaneously defend able-bodied chauvinism and see our problems as unconnected to their society.

Are able-bodied spontaneous choices real choices for physically impaired people?

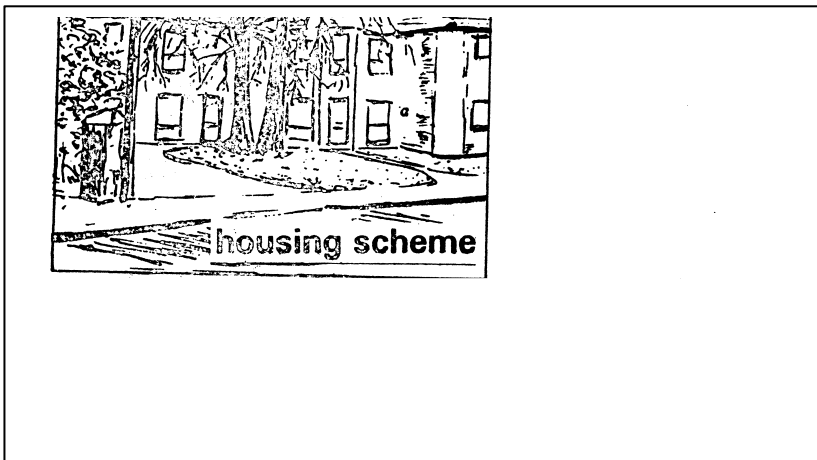
Some might agree that removing physically impaired people from society and placing them in segregated residential accommodation means an acceptance of limited choices in the community. But at the time, they argue, the segregated residential Home "was the only alternative to life in a total institution" (7) page 7. While there are now new developments which might enable a physically impaired person to remain in his or her home, the argument goes, at that time Cheshire Homes, for example, were a great step forward. The telling point is that this type of defence of past spontaneous mistakes has to be repeated again even when referring to later Cheshire Foundation residential provision:

The Cheshire Estate was built in co-operation with the Greater London Council in 1964 at Tulse Hill in London for physically impaired people and their families. "I am sorry to say that this particular experiment has been widely criticised as producing a ghetto; a separate nucleus of handicapped living. We could not help being rather resentful of this criticism because, although nowadays it is, admittedly, not the most acceptable way of integrating people into society, it was a great step forward at its time". (2) page 7.

It is the destiny if those who do not consciously examine the social cause of our disability to make the same type of mistakes over and over again. Thus it is hardly surprising that the Cheshire Foundation, like the Disability Alliance, should find itself being forced to excuse its past. We can be certain to hear more of these "resentful" excuses until the Foundation and the Alliance are disbanded as the spontaneous mistakes of able-bodied chauvinists and segregationists.

Another line of argument is that, while in general, segregated residential Homes may serve to limit the provision of increased choices in the community, these Homes do increase the choices of certain individuals;

- (3) JONES, D. (1974) "Press release on 'Variety clubs humanitarian award for 1974'". Cheshire Smile (Spring 1975) vol. 21 (1).
- (4) UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION (1974) "Policy Statement"
- (5) UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION (1976) "The Union of the Physically Impaired Against Segregation and the Disability Alliance discuss Fundamental Principles of Disability".
- (6) CHESHIRE, L. (1973) "25th Anniversary". Cheshire Smile (Autumn 1973) Vol. 19 (3).
- (7) INSKIP, J.H. (1978) "The Leonard Cheshire Foundation". GLAD News (July 1978) Vol. 3 (3).
- (8) CHESHIRE, L. (1978/9) "Address: 1979 Annual Conference of the Foundation". Cheshire Smile (Winter 1978/9) Vol. 21 (12).
- (9) BRATTGARD, S-O. (1972) "Social and psychological aspects of the situation of the disabled". Twelfth World Congress of Rehabilitation International, Sydney, Australia. (Aug/Sep.1972) Vol. 1, Proceedings Preview.
- (10) GANNON, R. (1977) "Le Court - Cheshire Home". Magic Carpet (Summer 1977) Vol. XXIX (3).



the  
**UPIAS**  
 connection  
 KEN DAVIS

A SCHEME OF SIX FLATS - THREE GROUND FLOOR SPECIALLY DESIGNED WITH DISABLED PEOPLE TOGETHER WITH THREE FLATS FOR "SUPPORTING FAMILIES" ABOVE. THE SCHEME WAS DESIGNED BY ANTHONY PEARSON OF THE WYVERN PARTNERSHIP FOR RAGLAN HOUSING ASSOCIATION TO AN IDEA SUPPLIED BY DISABLED PEOPLE.

## Origin

The seed idea came from physically impaired people whose aim was to find a way to live 'normal' lives integrated into the community. They wanted to get to grips with the dilemma facing many significantly physically impaired people whose only alternative to the family frying pan is the institutional fire. Each had direct personal experience of both situations. Deprived of a real choice, they joined with other disabled people to form the Union of the Physically Impaired, to struggle against segregation and for all arrangements necessary for us to participate full in society.

At the time, the disabled initiators were reacting against conditions in the Sir Ludwig Guttman Hostel, a particularly oppressive institution situated in the grounds of Stoke Mandeville Hospital.

"...the reality of our position as an oppressed group can be seen most clearly in segregated residential institutions, the ultimate human scrap-heaps of this society. Thousands of people, whose only crime is being physically impaired, are sentenced to these prisons for life - which may these days be a long one. For the vast majority, there is still no alternative, no appeal, no remission of sentence for good behaviour, no escape except the escape from life itself..." (1)

Conditions in the Guttman institution at that time were so bad, that a few inmates had systematically stored the means of an early escape from life should their isolation and oppression become more than they could bear. The only acceptable 'escape' of course should have been out into the community, into properly designed housing units coupled with a secure, flexible system of personal support - such as that provided by the Fokus Society in Sweden. It will be no surprise to those who have first-hand knowledge of institutions to hear that the initiators suffered active hostility and discouragement from the authorities, as they tried to develop their ideas on a community based alternative to enforced batch living.

## Concept

Outside the vested interests of the institutional tradition, the initiators received more encouraging and positive responses. This was particularly so in the case of the Director of Raglan Housing Association (then Inskip St Giles Housing Association) who not only accepted the viability of the seed idea, but also fully agreed with the proposition that disabled people should exercise full control over their own lives. It was a fortunate and fruitful relationship which eventually led to the commissioning of the scheme of six flats at Grove Road, Sutton in Ashfield.

The basic idea underlying the project was subsequently written into the Tenancy Agreement as follows:-

"The concept of the scheme is that ground-floor units shall be occupied by disabled persons and the first-floor units shall be occupied by non-disabled persons. Occupants of the first-floor units will accept a "supporting family" role in respect of the ground-floor occupants. It is not expected that this should be on a specific one/one basis but that all participants in the scheme should accept a co-operative basis of giving/receiving assistance...." (2)



### Basic principles

The prospective disabled tenants wanted actively to participate as fully as was practicable with as many parties to the project as were willing to do so. There was a high degree of co-operation, particularly with the Architect. It says much for the progressive outlook of the people concerned. From the point of view of the initiators, active participation was a crucial point of principle, a principle developed within the Union for specific, clear reasons:-

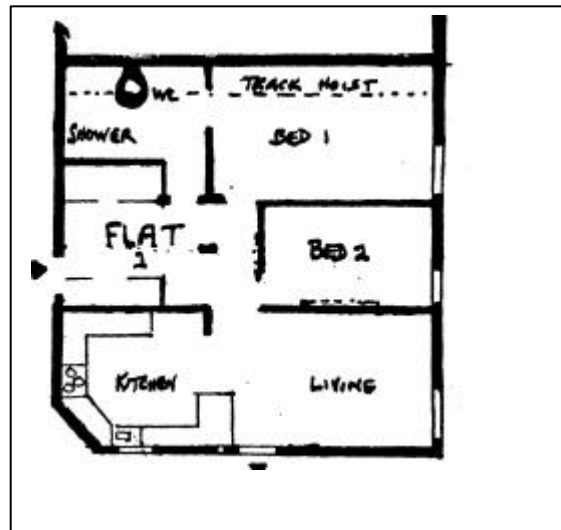
"...as a small, weak minority group, disabled people cannot achieve a fully human life by their own efforts alone. We need and welcome the help of sympathetic able-bodied people. But the basic problem we face is our exclusion from full social participation. It follows that this oppressive situation can be put right only by disabled people actually taking a more active part in society. The efforts of professionals and other able-bodied people are therefore really constructive only when they build on and encourage the self-help and activity of disabled people themselves..." (3)

The identification of prospective tenants in advance of the development; taking as a starting point the definition by disabled people of their own problems, out of their own experience; and the active participation of disabled people in the reality they were trying to transform, placed the Grove Road project out in front of most contemporary developments in this field.

In putting principles into practice, three basic elements interact to produce the basis for a high level of independent daily living for the physically impaired tenants. The first is good basic design; the second, the right aids and equipment; the third a secure, flexible system of personal help.

### Good basic design

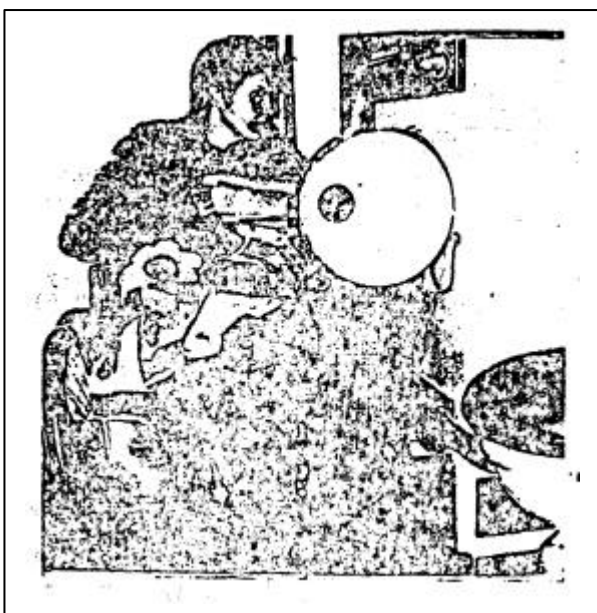
Detailed design features are too numerous to convey in this type of article. Fundamental is the relationship between the main bedroom and the bathroom, which provides for an efficient combination of functions using the track hoist. Also important is the corner work-station in the kitchen, which makes it easy to use both the sink and the hob unit without having to propel the wheelchair.



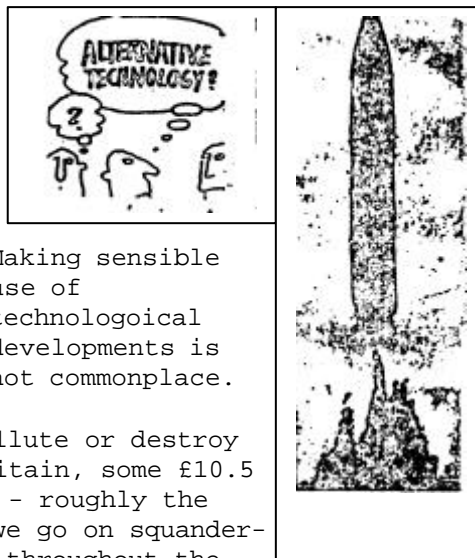
The active participation of disabled people on design details is not simply a one-way benefit. The architect notes:-

"...contact with the real client (the user) as well as the actual client (the Housing Association) is of the greatest assistance in solving problems which are so often, through absence of the real client, left to the architect to work out in unsure isolation..." (4)

### The right aids and equipment



Getting the basic design right can be essential to the most efficient provision of aids and equipment necessary for individual independence, eg, the track hoist. Providing aids in participation with users, is the sure way of tailoring technology to meet human needs.



Making sensible use of technological developments is not commonplace.

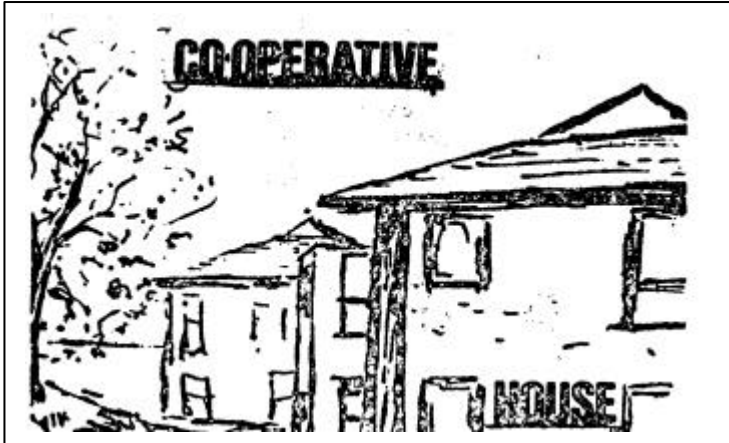
Too often such developments are used to pollute or destroy human life rather than enhance it. In Britain, some £10.5 millions a year are spent on the arms race - roughly the same amount we spend on education. While we go on squandering such enormous sums, millions of people throughout the world are dying from hunger or in poverty - whilst closer to home, physically impaired people are being denied the opportunity to overcome disability. For us, isolation and exclusion from society are the rule.

"Britain today has the necessary knowledge and the advanced technology to bring physically impaired people into the mainstream of life and enable us to contribute fully to society. But instead of the Country's resources being concentrated on basic human problems like ours, they are frequently mis-spent, for example, on making sophisticated weapons of destruction..." (5)

### The support system

Active participation with the architect and others on getting the basic design right and in choosing the right aids and equipment has enabled the handicapped tenants to maximise independence, and their own capacity for self-help is their first line of support.

The support they need from others comes first from available statutory sources, supplemented by help from the three "supporting families" on the first-floor. Also involved on an ad hoc basis are neighbours and friends living close by, local voluntary help and occasional assistance from relatives. The combination of support designed to 'spread the load' is co-ordinated by the disabled tenants, is paid for out of their Attendance Allowances, and successfully meets their immediate needs.



"Full inter-tenant co-operation is pre-requisite to the smooth running and long-term stability of the scheme ..." (6)

### Co-operation

Although not a housing co-op in its own right, tenants participate in areas of management through their democratically constituted association, in agreement with the Housing Association. Other functions include initial aspects of tenant selection, the organisation of - and payment for - the support system, and the Tenants Group also operates as a medium for mutual education of individual and group needs.

### Social relationships

Physically impaired people trapped and isolated within families or in oppressive State or voluntary Homes, recognise the power of such institutions to prevent self-determination and full social participation. The system of relationships devised in the Grove Road Scheme offers an insight into the way individuals can organise themselves and others to overcome aspects of oppressive familial and State relations. It cannot demolish structural capitalism, which systematically isolates, divides - and then plasters over any issues which threaten to expose the relationship between our fragmented ills. But inasmuch as physically impaired people are part of the State, we can all engage in the struggle to change relationships from within - as well as organising from 'without'.

"PROBLEMS WILL BE CORRECTLY TACKLED PRECISELY TO THE EXTENT THAT WE ALL AS DISABLED PEOPLE BECOME ACTIVE AND INVOLVED IN OUR OWN REHABILITATION".

### The Scheme in practice

Three handicapped tenants, previously incarcerated in segregated institutions for a combined 25 years, are now active members of their local community. Their participation with the progressive agencies involved will result in substantial savings for the State.

### References

- (1) UPIAS, Policy Statement, p.2. para 6.
- (2) 28 - 38 Grove road, Tenancy Agreement, Raglan Housing Association.
- (3) UPIAS, Policy Statement, p.5. para 16.
- (4) Design for Special Needs (No.16), CEH, May - August 1978, p.10.
- (5) UPIAS, Policy Statement, p.1, para 1.
- (6) 28 - 38 Grove Road, ATV Link Series leaflet, 1978, p.4.
- (7) UPIAS, Policy Statement, p.5, para 16.

# SETTLING ACCOUNTS WITH THE PARASITE PEOPLE:

A Critique of 'A LIFE APART'  
By E.J. Miller and G.V. Gwynne

By  
Paul  
Hunt

two perspectives

"Britain today has the necessary knowledge and the advanced technology to bring physically impaired people into the main-stream of life and enable us to contribute fully to society". These are the opening words of our Policy Statement published in 1975. In a later section we contrast this exciting potential for integration with the grim reality of the conditions which characteristically exist in segregated residential institutions for disabled people. We go on to say that the best efforts of staff in such places "are systematically overwhelmed by the basic function of segregated institutions, which is to look after batches of physically impaired people - and in the process convince them that they cannot realistically expect to participate fully in society and earn a good living. This function was generally appropriate when special residential institutions first came into being, since in the competitive conditions of the time many physically impaired people could not even survive without their help. But now ... the need for segregated institutions no longer exists in the way it did. They have become seriously out of step with the changed social and technological conditions of Britain today".

This Union assessment has been confirmed in the years since our Policy Statement was first published, On the one hand, further evidence has accumulated of the cruelty and deprivation which institutional life involves (1). On the other hand there has been the rapid development of micro-processors and other technological aids with tremendous potential, both for solving specific problems associated with impairment, and accelerating the need for the re-organisation of society along lines which make "employment and full social participation ... accessible to all people, including those with physical impairments". (2) There are also the continuing achievements of particular experiments which move towards more integrated living arrangements, involving personal help from the community, such as the Grove Road project (see page 32). Instead of physically impaired people having to adapt to an hostile environment ... the means now exist to create a physical and social environment that takes account of the needs of people with physical impairments.

The conclusion which follows from this assessment is that segregated residential institutions are essentially oppressive under modern conditions, and that they should therefore be passed out and replaced by secure, integrated living arrangements in which severely impaired people would be able to participate fully in society. Looking at our situation from the position of an oppressed group, we in the Union are enabled to view reality objectively, recognising the potential that has now been made possible and by contrast the oppressive conditions of life that we are forced to put up with. The important thing is that our approach maintains a scientific analysis of our situation, which examines segregated institutions objectively within the context of modern social

developments, is both necessary and possible. This positive perspective is in sharp contrast to the pervading view of the vast majority of politicians, civil servants, managers and "experts" connected with our lives. Blinkered by their vested interest in the continuation of the traditional segregating practices and institutions which disable us, they hold the view that severe impairment often makes "residential care" a regrettable necessity when there is no supportive family available - and similarly that integrated employment and education are just not possible for many of us because of our problems. As the gap widens between this out of date view of theirs, and the reality that it is they who are the main problem now that the means to integration are at hand, increasingly they have to find new ways of controlling or diverting the struggles which arise in different forms in connection with segregated institutions. One of the most important means of plugging this credibility gap is the development of increasingly sophisticated "explanations" to convince everyone concerned that some segregation will always be necessary, given the enormous problems posed by our defective bodies and/or minds, shortage of funds, public attitudes and so on. This is the underlying message even of those politicians who sometimes appear to be all in favour of integration. (3).

There have been a number of publications in recent years which attempt, amongst other things, to reconcile physically impaired people and our friends to the continuing existence of segregated institutions. Examples of these are the Warnock committee report on special education; the Snowdon committee report on integration (!); and the long introduction to Selwyn Goldsmith's book Designing for the Disabled. But probably the most influential publication so far has been A Life Apart by Eric Miller and Gerldine Gwynne of the Tavistock Institute of Human Relations. First published in 1972, their book was reprinted as a paperback in 1974 and adopted as one of only four set books for the Open University course "The Handicapped Person in the Community". (4). A Life Apart is also widely used on training courses for social work and health work students. Yet, as far as I can ascertain, the only critique of the book which has appeared anywhere is one I wrote for the magazine of the Cheshire Homes in 1973. (5). Despite the strong criticism my review contained, it is clear now that I failed to tackle adequately the essential issues raised by Miller and Gwynne's work, and this article is intended to remedy that omission.

Miller and Gwynne's involvement with segregated residential institutions first started in 1962 at the request of several residents, of whom I was then one, at the Le Court Cheshire Home in Hampshire. We were at the time struggling for representation on management to extend the range of control over our lives and prevent the reinstatement of infringements of our individual liberty as expressed in such freedoms as, to choose our own bedtimes, drink alcohol if we chose, freedom for the sexes to relate without interference, freedom to leave the building without having to notify the authorities, etc. All of these had been hard-won extensions of control over personal life. We had thought, naively, that "experts" on "group dynamics" like Miller and Gwynne would be likely to support (and promote elsewhere) our struggle to build a community life in which residents took a really active part and shared in decision making. As is still the case today in every institution where the same struggle for participation continues, we needed every bit of help we could get. Resulting from our request, in 1966 Miller and Gwynne were financed by the then Ministry of Health to do a part-time pilot study lasting three years. During this period they visited 22 institutions; did in-depth interviewing of people in 5 of them; carried out some "action-research" at the

Le Court Home; and held some discussion groups in London for the administrators of various Homes and Units.

Long before publication of their research findings in A Life Apart in 1972, it was clear that we, the residents, had been conned. It was clear to us that Miller and Gwynne were definitely not on our side. They were not really on the side of the staff either. And they were not even much use to the management and administrators. They were in fact basically on their own side, that is the side of supposedly "detached", "balanced", "unbiased" social scientists, concerned above all with presenting themselves to the powers-that-be as indispensable in training "practitioners" to manage the problem of disabled people in institutions. Thus the fundamental relationship between them and the residents was that of exploiters and exploited.

### **'detached' and out of touch**

Miller and Gwynne agonise a lot in A Life Apart about their "problem" of personal involvement as researchers. They see involvement entirely as a source of stress for themselves (and anyone else having contact with residents), and making it difficult for them to acquire a balanced and unbiased outlook as social scientists. They say, for example, "To respond to the emotional needs of the inmate, the staff member must experience an emotional involvement in the relationship; yet the greater the involvement the greater the stress". (6). As I shall later show, it is highly significant that they see involvement, for them and for staff, essentially as a problem in this way, and strive so hard themselves to take all possible precautions against it, so as to "acquire and maintain a balanced outlook" (7) or "regain some detachment". (8). For this purpose they underwent personal psychoanalysis; "relied heavily on the intervention of an uninvolved colleague to restore some semblance of balance" (9); and made sure they worked concurrently on other projects. The authors paint a graphic picture of the stress and strain on them of visiting the institutions and talking to residents, and of the profound oscillations of feeling they underwent - one day overwhelmed by "pity for the plight of the disabled", and the next day seeing "the staff as victims of the insistent, selfish demands of cripples who ill-deserved the money and care that were being so generously lavished upon them". (10). Miller and Gwynne were, however, consoled by the fact that the only people "concerned with the disabled population" who were not struggling with a similar ambivalence were those who were "captured by a permanent bias". (11). This strange phrase, in the light of other references to staff being "captured" by residents, can only be interpreted as meaning people who support the struggles of residents for greater autonomy.

What Miller and Gwynne completely fail to recognise is that their "profound oscillations of feeling" are caused primarily by the fact that they themselves are profoundly biased and committed against the residents' interests from the start of their research. I shall try to demonstrate this bias against us and how as a result of it Miller and Gwynne have conducted a project totally lacking in scientific objectivity, in spite of calling themselves "scientists". This bias is evident in their whole conception of the issues, and therefore in their chosen research methods, and in all their analyses, conclusions and recommendations.

Their bias is embodied in the terms of reference of the Miller and Gwynne study. The terms of reference which they themselves proposed and which the Ministry of Health accepted, were in general terms, "to identify

more precisely what was involved in providing residential care for incurables, and to discover possible ways through which appropriate changes could be brought about". (12).

Miller and Gwynne's interpretation of these vague guidelines is given in the words "to understand and try to tackle the problems of operating these institutions" (emphasis added), consistent with this, they claim to have shown that "it is possible both to arrive at more effective concepts of residential care and to recruit staff and train them to operate more successfully". (13).

A Life Apart only mentions modern developments in technology and to home care facilities to proclaim their essential irrelevance to the matter in hand. There is no mention whatsoever of the Fokus housing, care and employment schemes in Europe, nor of the countless other exciting developments throughout the world in which the most severely impaired people are increasing their participation in society. Such developments prove conclusively that segregated institutions are no longer necessary, and can be replaced by much better arrangements. It follows that the basic processes at work in existing institutions can only be properly understood in the light of this key development. And above all it follows that the social oppression of residents in segregated institutions is realistically to be struggled against and eliminated.

Throughout their research, however, Miller and Gwynne restrict themselves to a narrow, blinkered approach to the issue, i.e. to try to make the institutions work a little better. They recognise the institutions in question are oppressive, and say that entering them amounts to social death: similarly, they call institutional life a "living death" and say that "institutions have inherent pathogenic characteristics" and so on. (14). But they want to make them work a little better.

Miller and Gwynne, the "balanced" "scientists", in restricting themselves to this narrow blinkered approach to the question of segregated institutions, are at no stage prepared to look seriously, i.e. objectively, scientifically, at the situation of physically impaired people in our society to discover whether these oppressive "social death sentences" in pathogenic (i.e. disease producing) institutions are something which must be passively accepted as inevitable, or are something which is unnecessary today and should therefore be actively struggled against.

Rather than approach this question in a scientific way, Miller and Gwynne prefer to plead that, because social science is relatively medieval, the results of their research (unlike the physical sciences) have no scientific status. The results, they say, cannot be objectively verified, and therefore their principal criterion in developing their ideas about institutions is not whether they are 'true' but whether the practitioner (the person for whom the theories are designed) can make use of their new approach to enlarge his own theory of the situation he is in and extend his competence.

By pleading a lack of scientific status to their work, Miller and Gwynne avoid completely the awkward problem of its objective evaluation. An obvious point to make is that, even for the remotest scientific credibility, "external criteria" are still needed to determine whether the "practitioner" has actually enlarged his own theory and extended his competence, unless his personal feelings on this are the only test which would be about as scientific as magic. Miller and Gwynne's formulation also

abandons any attempt to establish criteria by which to determine the truth in the new theories before they have been tested in practice - it is of course precisely beforehand that it is vital to know whether a particular theory is likely to be of use. Even in their own terms, Miller and Gwynne reduce science to a set of subjective theories that can not be verified nor evaluated. Their denial of the possibility of objectivity should be seen for what it is - a complete betrayal, not only of science as it should be, but also of physically impaired people whose needs they claim to have special expertise in investigating.

It is their bias against the residents and their betrayal of our interests that lead Miller and Gwynne to conduct a project totally lacking scientific validity. Their lame excuses about the medieval nature of their science merely erect a smokescreen around their basic error, i.e. that they nowhere question the fundamental nature of their relationship as researchers with residents. The true nature of the relationship they in fact adopt is clearly revealed when we identify the 'practitioner' mentioned above for whom their theories are developed. If it were the enlarged theories and competence of residents which were to be the end product of Miller and Gwynne's work and the criteria for judging the truth of Miller and Gwynne's theory, then at least the general orientation would have been the correct one. But throughout the book it is made abundantly clear the 'practitioners' are the administering staff in institutions. It is their knowledge and competence which is to be increased, while the main objects of this process do not feature except precisely as objects about whose existence someone else is to be given greater knowledge and competence. It is abundantly clear that Miller and Gwynne's bias is not in favour of increasing the residents' control over their own lives.

Avoiding any explicit examination of the cause of the residents' "social death sentence". Miller and Gwynne have in fact adopted from the start the old medical view that it is "caused" by the severely crippled bodies of the inmates. This unexplained fundamental assumption runs right through A Life Apart and its acceptance is essential for their book to have even the appearance of being coherent and rational.

As early as page 4 and on page 14 they argue that, although some of the disadvantages of institutions can be mitigated, "there remains the underlying problem of irreversibility". What is irreversible in Miller and Gwynne's view is not just the impairments of residents but also the psychological and social consequences of these impairments. Clearly Miller and Gwynne maintain that the root cause of the whole problem is in our defective bodies and not in the social death sentence unnecessarily passed on us.

Throughout the rest of the book, and especially in the chapter significantly entitled Social and Psychological consequences of Disability, again and again the authors describe the social and psychological disadvantages imposed on us as though they were natural consequences of our impairments (what they call our physical disabilities). Their view of our psychological state is summed up on page 72 as: "infirmity has psychological - even psychopathological - consequences which are often insidious and even irreversible". On the social "consequences", we are told for example on page 53 that the inability to achieve quite ordinary goals "arises out of the physical disability itself". Similarly, Miller and Gwynne go on to say that the cripple has to contend, amongst other things, with the physical, emotional and financial dependency "that the disability imposes on his relations with others". Is it not extraordinary that supposedly



balanced and unbiased social scientists can consistently be confused like this by an obvious fact, such as for example that physical impairment and low income characteristically go together in our society, into making the ridiculously naive assumption that the impairment causes the low income? This is about as sensible as assuming that women's bodies cause their low income and financial dependency in a particular society, or that black people's bodies cause them to be characteristically in low paid employment. The social disabilities of oppressed groups are not a consequence of their own physical attributes, but of forms of social organisation which discriminate against them. It is in fact those who create, maintain and justify the discriminatory forms of organisation who in reality are the main cause of our social disabilities or death sentences.

The half concealed assumption that our severe impairments actually cause our social problems is essential for Miller and Gwynne's attempt to justify their concentrating on the task of reconciling us to the inevitability of our social death, and for legitimizing their research into how the sentence may most humanely be carried out. Miller and Gwynne say they think that in institutions the "essential task to be carried out is to help the inmates to make their transition from social death to physical death" (15); and their whole research was from the start geared to assisting the staff in carrying out this task more efficiently. I do not dispute that the task as they define it is the one which is assigned to institutions in this society. But to recognise this as a present reality is not at all the same thing as accepting it as the only way things can be. As we already know, the means to overturn the death sentence and restore residents to active social life have now been available. In these circumstances, to try to reconcile residents to their "irreversible" fate is fundamentally oppressive. There is no essential difference between Miller and Gwynne's behaviour in relation to segregated institutions for people with physical impairments and the behaviour of social scientists who advise, say, on concentration camps for a racial minority, and who do not see the necessity to help the inmates to struggle for their freedom, but just limit themselves to comparing one camp with another, telling the inmates it is unrealistic to think of escape, and making recommendations for training the authorities to run the camps more efficiently.

Whatever their pretensions to giving a balanced, detached, unbiased view, the fact is that Miller and Gwynne are extremely biased against the interests of physically impaired people, and operate as agents of our oppression. Faced with any socially oppressed group, social scientists have a choice of only two alternatives; either a firm commitment to serve the interests of the oppressed group to end their oppression, or a commitment to serve the interests of the oppressors to continue their oppressive practices (which last they also do by serving their own interests). There can be no middle way.

In the first instance a scientific approach remains possible, i.e. objective reality can be looked at, and science can be placed at the service of the oppressed group to help them free themselves. In the latter instance a scientific approach is not possible, objective reality cannot be examined straight but can only be distorted. This latter approach may be obscured by talk of balance, of the medieval nature of science, and heart searching, etc, as practiced by Miller and Gwynne in A Life Apart.

It is commonly believed that commitment to the cause of an oppressed group means that 'reality' will be ignored or distorted, and therefore that the best scientist is the one who tries to be least involved and most

detached. Nothing could be further from the truth, as A Life Apart illustrates. It is precisely those who try to take a detached view of oppression who cannot be objective. This emerges very clearly in relation to the notion of "parasitism". Miller and Gwynne make various references to residents as parasites, and throughout see us as essential feeding off society not only economically but emotionally as well. However, an objective examination of the situation shows that it is not people who are segregated and demand the chance of employment who are the true parasites. The real parasites are those like Miller and Gwynne who grow fat by feeding on other people's miseries. On pages 18-19 they come out with the blatant admission that they see the institutions issue as "socially important" and "technically interesting" and as promising "both a theoretical and practical pay-off".

## **parasites in search of extending their influence**

It is of course necessary for Miller and Gwynne to see the institutions issue as "socially important" and "technically interesting" to justify their claim to have an indispensably important role themselves. And it is in defence of this real parasitical interest of theirs, that would provide them with "theoretical and practical pay-offs", that they cannot face and explain objective reality, since to do this would mean recognising and abandoning their own parasitism, and that of all their fellow social scientists who approach such issues in a similar way (Erving Goffman, for example, of whom Miller and Gwynne think so highly).

On the other hand, social scientists who consciously abandon their own particular interests to serve the interests of oppressed people are freed to undertake the most careful and genuinely "disinterested" enquiry into objective reality. Oppressed groups have nothing to lose, and everything to gain, from the most precise and thorough understanding of the situation we are struggling to change. To change our oppressive reality we cannot afford to leave out of account any significant factor in the situation: to do so necessarily means defeat and the continuation of the segregation which allows parasites like Miller and Gwynne to grow fat on our problems. Whether they are from amongst the ranks of physically impaired people ourselves, or from amongst others who seek to help our struggle forward, social scientists committed to ending our oppressive situation are the only ones who can look straight at reality - not those who are mainly on the lookout for technically interesting theoretical and practical pay-offs. A scientific approach must look at a part in relation to the whole, or institutions in relation to the society in which they exist. It must look at social forces as in a state of movement and development, not as being static; and therefore it must look at institutions in the context of a changing society. It must also look at the struggles of people for change in relation to the material and social changes that have taken place in the society, not as mere reactions to irreversible natural causes.

Throughout the pages of A Life Apart we can see how the authors' bias towards, "technically interesting" work with a "theoretical and practical pay-off" conditions all their investigation, methods and findings. The first paragraph of the Preface tells how they received from the Ministry of health (now part of the department of Health and Social Security) not only financial support but also advice, interest and encouragement throughout the project. Miller and Gwynne were so grateful for their help that they voluntarily submitted a draft of their book to the department

officials for comments and suggestions. It is no surprise to find that Miller and Gwynne were later commissioned by the DHSS to do research into the problems of geriatric hospital wards, and that Miller was later to be seen leading a series of "action research" projects into health care systems of a similar type to that undertaken as part of this project.

One of the book's recommendations which highlights the interest being served by A Life Apart is for training courses for senior staff of institutions along the lines of some by the Tavistock Institution and Tavistock Clinic. Whether or not this recommendation ever bore fruit, at least one other form of educational or training pay-off did result. As has been noted, A Life Apart became one of only four set books for the Open University course 'The Handicapped Person in the Community', which started in 1975, and for which Dr Miller was employed as an external consultant. Miller and Gwynne's "balanced" view of disability, their failure to break with the old medical model (which sees our social disadvantages as caused by our impairments), and their overriding message that staff must be found or trained to reconcile us to the continuation of our disadvantages, evidently rang the right bells for those constructing the course.

The aim of the course is given as "To enable students to improve their professional and social skills in order to assist handicapped people to achieve maximum autonomy " (Unit 1, page 5, emphasis added). A detailed analysis of the OU course is highly desirable, but it is not necessary in order to judge which part of its declared aim predominates throughout: it is sufficient to note here the uncritical use of A Life Apart as a key text, and the use of Miller as a course consultant who was asked to write study unit 10 on 'Problems and Demands of Face to Face Work with People'. Clearly Miller's unit is aimed at the anxiety many professionals experience increasingly as they go about their work, whether in institutions or not. There is no doubt about the existence of this anxiety: the vital question is, what is causing it, and therefore how should it be resolved? On these matters, the position taken in Miller's OU study unit is basically identical to that in A Life Apart, i.e. that the cause lies in irreversible physical characteristics of clients, and therefore cannot be resolved but only alleviated.

As I hope I have shown, Miller's orientation (and by association the OU's) is clearly not towards "assisting handicapped people to achieve maximum autonomy" as we would understand it. Rather, he totally betrayed the struggle of the handicapped people who looked to him for help in achieving this aim, and turned his efforts towards assisting the 'practitioners' - the administering staff, the "professionals" - to operate oppressive institutions more successfully.

The main training task that results from their analysis in A Life Apart cannot, therefore, be to help staff solve the problems that are at the root of their anxiety, i.e. to struggle to eliminate the need to operate an oppressive social death sentence by working towards alternatives, but rather to alleviate the anxiety experienced by staff in order to reconcile them to 'reality' (as defined by the authors), and so in their turn reconcile residents and others to the same 'reality'. One suggestion they put forward as a means of taking the burden of responsibility off the shoulders of the staff operating these social death sentences, is to prescribe a death pill to residents entering institutions for them to administer to themselves when they think the time is right.

Miller and Gwynne are in no doubt that basically these problems, like

those of the residents, stem from the residents' (or clients') irreversibly defective bodies, and therefore essentially have to be accepted and lived with. However, with Miller and Gwynne's expert help the situation may be improved slightly by making various minor organisational changes, and especially by conceiving theories "to recruit staff and train them to operate more successfully". On recruitment, Miller and Gwynne suggest the development of a new kind of profession specifically to care for cripples both inside and outside institutions: the suggestion is essentially a matter of redefining "professional boundaries" and creating a profession which makes cripples its sole concern. (17). Another suggestion is to use as heads of institutions mature and balanced professionals on short term loan from other fields, such as the prison service or industry, or to appoint retired businessmen, ex-service officers and ex-colonial officials. Psychiatrists and clergymen are also thought necessary as back up resources to help heads of Homes to deal with particularly awkward problems amongst residents.

## **training for control**

However, what is required above all is that senior staff should receive the Tavistock kind of training. One type of "training" they advocate would be specifically aimed at helping heads of institutions to tease out the nature and implications of their task, and to find more effective ways of carrying it out. (18). What is to be "teased out", of course, is that their central task is to help residents accept the irreversibility and inevitability of their social death sentence. There are many oppressive implications of accepting this definition of the task, and one of them is revealed in Miller and Gwynne's description of the other type of training they recommend. This is intended for people in leadership positions in all kinds of different organisations, and it is designed to "concentrate attention on the unconscious elements at work in group processes". (19). By "unconscious elements" Miller and Gwynne mean the babyhood and other previous experiences which may influence the ways people behave in groups. Such unconscious mechanisms as denial of reality, splitting, collusion, scapegoating and projection are to be looked for in any situation - especially one where inmates' "infantile dependency tends to mobilise extreme and infantile strategies". (20). But professionals themselves are not altogether immune from this process either, and part of what helps them to become "mature" and "balanced" like Miller and Gwynne is to be trained also to look inward at their own motivations, and backward at their own experiences as infants. This is one of the standard psychiatric methods of helping people to come to terms with intolerable situations, rather than seeking fundamental change in the situation itself. Acute anxiety and depression are commonly "treated" not just by physical assaults on people's minds (drugs, ECT), but by concentrating attention inwards onto their own and other people's mental processes, as though they were the root of the problem. Where the training of professionals for work is concerned, especially in the case of social workers and psychiatrists, their anxieties are increasingly being treated in a similar way. By "concentrating on the unconscious processes at work", professionals are helped to become "detached" and "balanced", which helps them to intervene more effectively to control explosive situations and reconcile clients or patients to intolerable reality. This way of dealing with professional workers' anxiety succeeds only at the price of detaching them from clients: when this process gets too far, we than see the extraordinary sight of professionals ending up having to be taught how

to relate to clients as though they were fellow human beings!

Miller and Gwynne's own "detached" position, which they seek so hard to propagate through training schemes that focus on unconscious elements, is revealed very clearly when they comment on examples of naked oppression. Significantly they say that any stories of oppressive behaviour by staff they were told be residents are only "alleged", "hearsay", etc: but there were a few things they witnessed themselves which they had to accept as real. They refer to a ward consultant whom they witnessed strip a patient intent only to display her deformed legs; a unit where inmates were not allowed to eat between meals, and many had their drinking and toilet arrangements rigidly controlled; a nurse who was dismissed for having an attachment to a patient; a consultant who referred to electric wheelchairs as "expensive toys". When writing about these sorts of things in a section sub-headed 'Institutional Defences against Anxiety; Miller and Gwynne say, "some of the things we say appalled us and although we have struggled to understand how they have come about, it is difficult to write about them without exasperation". What should be noted here is that, because they see these "appalling situations" primarily as expressions of the staff's unconscious need to 'erect institutional defences' against the anxiety produced by the inmates' deformed bodies, they actually try so hard to write about them without exasperation. "Understanding" such appalling things from this "detached" professional point of view tells us little about the possible motivations of some staff, but a great deal about the "detached" position which Miller and Gwynne seek so hard to propagate.

The function of concentrating on the unconscious elements in a situation is revealed very clearly. It is to emphasis the need for professionals like Miller and Gwynne who can help to train staff to continue to cope with the intolerable task of being the executors of the oppression of physically impaired people, and through this training alleviate the anxiety the staff experience in carrying out this role.

## **Conclusion (by Judy Hunt assisted by Dick Leaman)**

Paul has shown us that A Life Apart demonstrates how the fundamental bias of these so-called social scientists, Miller and Gwynne, is against the interests of physically impaired people. The real function of their study, and of their book, has been to serve their own professional interests as parasites, making a living for themselves out of the problems of an oppressed group.

The criticism contained in Paul's article makes it clear that, when faced with professionals making recommendations on how the physically impaired should live their lives, we need to find out what interest is being represented by those recommendations, i.e. who would benefit as a result of their implementation.

One means of finding this out is to reverse the normal situation in which others ask the questions about us, to a situation in which it is we who ask the questions, and we who thereby become informed about them. In other words, we now need to research the researchers.

One method of gathering such information might be for us to face them with our own questionnaire, and Paul produced a draft of such a question-

work student. Before he died, Paul indicated that he intended to publish the questionnaire as an appendix to his article, but he also expressed certain reservations on its usefulness. The validity of questionnaires in general as a means of gathering relevant information is open to question and needs to be carefully examined. The draft questionnaire published here is in no way intended to pre-empt that examination. It is put forward as no more than an example of how physically impaired people might develop, when faced by the questions of other researchers, a positive third alternative to either passive co-operation or inactive non-co-operation. Obviously it would need to be developed and strengthened if it were to have validity for general application in acquiring information. But equally obvious are the advantages that it seeks to gain for the disabled user, by giving them some objective information about the material interest of the would-be researcher, and some subjective information of that person's own commitment in facing the reality of oppression. Any information the questionnaire can give would need careful interpretation, and it is at best a rudimentary tool to the development of which physically impaired people need to give careful consideration. But it is appended here basically as a concrete example of how we can change the relationship that is normally imposed on us by researchers - and, instead of remaining the passive respondents to prying questions, become active participants in the relationship by acquiring knowledge that will be of use to us in our struggles against all forms of segregation and for emancipation.

With the help of R. Leaman I have prepared this article for publication from a draft by Paul Hunt. I have had to write in a few amendments, reorganise some of the material for ease of understanding, and write a conclusion. I can only hope that the end result is true in content to that which Paul was himself aiming at.

Judy Hunt.

## references

- (1) Maureen Oswin - Holes in the Welfare Net.  
Bedford Square Press (National Council of Social Services).
- (2) Fundamental Principles of Disability, p.15  
The Union of the Physically Impaired and the Disability Alliance  
Discussion document.
- (3) Alf Morris - A Personal Message, 4th September, 1974  
Cheshire Smile, Autumn 1974, Vol. 2 No. 3 p.4.
- (4) The Handicapped Person in the Community  
Open University Block 3. Part 1. Units 9-10.
- (5) Paul Hunt - Parasite People  
Cheshire Smile, Autumn 1972, Vol. 18 No. 3. P.15.

Page references from A Life Apart - E.J. Miller and G.V. Gwynne.  
Tavistock Publications and Lippincott. 1972.

- (7) p.23.
- (8) p.6
- (9) p.8.
- (10) p.7.
- (11) p.8.
- (12) p.21.
- (13) p.72, 15.
- (14) p.226, 9, 223, 196.
- (15) p.89.
- (16) p.89.
- (17) p.226.
- (18) p.216.
- (19) p.216.
- (20) p.121.
- (21) p.125.

## appendix

### QUESTIONNAIRE

Disabled people increasingly find they are asked by researchers, reporters, film makers, etc, for personal information and opinions on disability. Until recently, my automatic response when approached with such requests was to co-operate willingly. However, it now seems to me that it is necessary to look much more closely at the kind of questions being asked, the assumptions on which they are based, and the purpose to which the information will be put. The fundamental question which we ourselves need to ask on such occasions is this: will our co-operation advance or retard the interests of disabled people as a whole? The following questions are therefore designed to help me make up my mind about whether or not I should accede to your request for information and assistance.

Confidentiality. The normal rules of confidentiality will be observed with regard to any information or opinions you give. If its use with other information for publication is ever envisaged, every care will be taken to ensure that there is no possibility of identifying you as an individual.

1. Name
2. Age
3. Occupation
4. Previous occupations
5. Parents' (or other Guardians') occupations
6. Type of school(s) attended (e.g. comprehensive, public)
7. Places of further/higher education, and subjects covered
8. Qualifications obtained
9. Any experience relevant to present project
10. Salary from employment
11. If student, grant per annum

12. If student, estimated first salary when qualified

13. Other income - please give sources
14. Estimated top salary in career path
15. Do you have any physical impairments - if so please specify?
16. How did you first become involved with disabled people?
17. Why do you think you chose the kind of work that brings you into contact with disabled people as a group?
18. Good verbal communication is impossible without agreed definitions of at least the most important terms. Throughout this questionnaire impairment is taken to mean the lack of part or all of a limb, or a defect in a limb, organ or mechanism of the body; this includes brain damage, disease or deficiency, but not "mental illness" as it is usually called. Disability is the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments, and thereby excludes them from participation in the mainstream of social activities.  
Please comment, and if you disagree with the definitions say why and suggest alternatives.
19. What will happen to the information gained by you (e.g. published, pigeon-hole, marked by examiner)?
20. Who will have access to the information - who is it for?
21. Who is paying the expenses?
22. Are you being paid a fee for the work (in addition to salary or grant) - if so, how much?
23. What are the exact terms of reference you are working to?
24. Please say how you think the project will help disabled people as a whole.
25. It is well known that the basic ideas which people already have when they draft questionnaires will often very largely determine both the answers they get and the subsequent selection of material for use. In phrasing your questions, what was the main thing you had in mind to find out - what idea was uppermost in your mind?
26. It is of the utmost importance that disabled people learn to distinguish between those workers on their behalf whose fundamental principles are correct, and those whose principles are incorrect. Correct principles are based on a recognition that society has now developed the technological capacity and other means to integrate physically impaired people into the mainstream of life (that is, into employment and other related areas of life such as education, transport and housing). It follows that the time is ripe for the elimination of disability, i.e. for full integration, and our struggles should all be directed towards this end. Commitment to this basic principle, and to others which flow from it such as the absolute necessity for the



mass of disabled people to become active in tackling their own problems, is essential for professionals and others who seek to help us. Only with such a positive commitment to integration can workers on our behalf help to eliminate disability. Those who take the opposing view will instead create and entrench disability, and should be struggled against.

Please comment on these statements.

27. Recently a researcher sent a Questionnaire to members of hospital management committees, and some of them were indignant at being asked for personal information. Yet researchers, social workers, etc, frequently ask personal questions of physically impaired people, and everyone concerned seems to take this for granted as a natural situation, and does not expect the roles to be reversed. The first group is characteristically active, dominant, and confident of their right to ask questions of the second group, which by contrast is characteristically passive, submissive, and careful not to question their questioners in return.  
In your view, why does this situation exist? And do you agree that it is itself part of what is meant by disability as defined above, and as such should be struggled against?
28. How do you feel about receiving this questionnaire?
29. Have you any suggestions for improvements to any future versions of this Questionnaire?

# PAUL HUNT:

## An Appreciation

### BY SOME UPIAS MEMBERS

Paul Hunt died on 12h July, 1979. With his death, the Union of the Physically Impaired Against Segregation lost one of its founder members, and many other members who know Paul lost a most valued personal friend.

Physically impaired people in general, and in particular we who worked closely with Paul, can only suffer with sadness the loss of his further leadership because there is nothing we can do to change that. What we can struggle to change are the conditions under which people have to live their lives. That is what Paul did unceasingly. For some twenty years he was a leading participant in the struggle of physically impaired people for a better life, and in that time he made a great personal contribution to taking that struggle forward into a new direction with increasingly clear foundations on which to advance it further. The sustaining message of this new direction is a realistic aspiration to full participating membership in a society which does not have to segregate and exclude people because their bodies are impaired. The significance and influence of this work are most clearly contained in the Aims and Policy Statement of UPIAS, and the legacy that Paul has left us is perhaps best seen in the strength of the contribution that he was able to make to these documents and to their application and development.

Whether or not those of us who continue in the struggle are able to carry these developments forward, they are nevertheless a concrete advance in the struggle of physically impaired people. By his own hard struggle for a decent life, by his work, and with the help of his friends, Paul has contributed immensely to the crucial phase of our struggle in which we, physically impaired people as a group, have to bring clearly into consciousness the real social nature of our disabilities. The development of UPIAS has a great historical significance in this struggle, in that it has focused the attention of physically impaired people onto the technological means which our society has now undeniably developed to integrate us into the mainstream of life, by allowing our full participation in productive work, education, housing, mobility, and all the normal functions which characterise people's belonging to the society in which they live. The fully realised fact of this technological capability for the first time roots the possibility of full integration in firm reality, rather than in any idealistic, futuristic wish-fulfillment. Nevertheless, with this clear realisation we are immediately forced to face the paradoxical reality - the truth and experience that is known to every ordinary physically impaired person - that the developed means of society are not generally applied to this end. Rather, we still find ourselves systematically excluded from every normal area of social activity, with, if we met the applicable criteria, 'special' provision sometimes being made for us, as the available resources allow in the economic conditions of the time.

We can all share in some degree an awareness of this contradiction which we experience in our daily lives: and it was in struggling towards a working through of its significance that Paul initiated in 1973 what later became known as the Union of the Physically Impaired Against Segregation. There followed a period of intense discussion and work by a small group of physically impaired people whom Paul had brought into contact. The result of this was that, in the early stages of its develop-

ment and in the six years of struggle that remained to Paul, the Union made a major break from other established disability organisations by the clarity of its position and the principled stand of its published Aims and Policy Statement. In applying its clear material basis to the development of our organised struggle, the Union has been able to redefine 'disability', not as an intrinsic characteristic of certain individuals, but rather as the exclusion from full participation in society that is caused by a contemporary social organisation which takes little or no account of people who have physical impairments.

This raising of consciousness creates for us the potential to unite as an oppressed group within society on the basis of our common experience of oppression which we share with many other social groups. We unite by looking no longer inwards at our differences from able-bodied people, and thereby appealing to those with power over our lives for greater charity towards us, but rather by looking outwards to make the first analyses from our own point of view of the ways in which and the reasons why our present society segregates us as a particular group from normal participation. Instead of being the passive "patients" of so-called "experts" who control our lives, we have to become the active opponents of an oppressive system, and we have to represent for ourselves our own real interest in radical social change.

The shift of perspective is a major one, and its first significance is to take the full burden of struggle and responsibility onto physically impaired people ourselves. For the first time, our individual struggles can be united on an objective (outward looking) basis, and they can be integrated with the struggles of the majority of people whose conditions of life are also being decided for them by those who have power to dominate. Our particular struggle can now become conscious of its real strength, and for the first time the possibility of ultimate victory is opened up for us, if we can find the responsibility, the strength and the determination to carry it through for ourselves. In that sense, with Paul's contribution and with the formation and development of UPIAS, the struggle of physically impaired people for full integration has come of age and reached a maturity which, whatever future we are able to make for the Union, is now at the disposal of physically impaired people as a whole, and cannot be ignored either by those who really wish to help us or by those who stand in opposition to our full integration.

It is no intention of this article to suggest that the achievements mentioned here are Paul's work alone, nor that they were reached by him working in isolation from other physically impaired people. Central to the Union's Policy is the insistence on joint activity and the absolute necessity for physically impaired people to become involved - in whatever way we can and with whatever help we need - in our own struggle, and particularly in the processes of decision-making which affect our lives. This principle informed all of Paul's work in "disability": and his struggles were never for us but with us to achieve a better life for all.

It is a crucial distinction. In the face of such ability and qualities of leadership as Paul developed, there is a temptation for us - physically impaired people as a group - to follow passively the guidance of others or to leave our struggle in their hands, confident that they will contend with the accredited "experts" better than we can in establishing our best interests. At the same time, the people who now hold power in "disability" continually proffer respectability and inducements to our ablest leaders to draw them over to their own ground of compromise

and what is "reasonable" for us. The Union's first principle of active participation is totally opposed to both of these tendencies.

Paul, perhaps, came to realise the importance of this principle most directly in the long and difficult struggle at Le Court Cheshire Home, where, with his powerful participation, residents achieved for themselves more representation on controlling committees, establishment of rights, and control over their own affairs than in any comparable institution. The special responsibility of leadership always to bring the struggle back to the group concerned, and to avoid making decisions and compromises with authorities above our heads or on our behalf, had very clear meaning in that situation. The point is not that Paul never made any mistakes in this respect, but rather that his own struggles clearly demonstrate that the principle of active participation by physically impaired people is something which it has to be actively striven to apply at all levels of our group's overall struggle. It is a principle which, despite the difficulties and apparent advantages of compromise, he always tried to let guide his work and activity, because he understood better than most of us that real advances could never be made in any other way.

Often people who talk in praise of Paul, and quite often those who do not, mention his integrity and this refusal to compromise on basic principles. They are undeniably qualities he possessed, but what it is necessary to add here to the mere praise of them is an understanding that they were developed and used as an essential element in the work of finding and beginning to build the new direction of struggle for physically impaired people as a whole.

Active participation in struggle by physically impaired people at all levels is a basic necessity, without which our Aims of full integration are unobtainable. If our struggle is to be effective, we must each apply that principle at every turn: and we must criticise both those who do not and ourselves when we fail. If we are to become this active group working for our own emancipation, then we must unite to organise and work together. In order for such a various group of people with different experiences and attitudes to unite, there must be a common objective understanding of our real position in society as a group. Throughout the Policy and activity of UPIAS is the uncompromising determination to establish that clarity of understanding as a basis for united struggle. For the first time, the work has been started by the only possible means to success, that is, the prior establishment of an objective method which relates our position as a group directly to the reality of our daily social experience. Characterised by openness and full democratic participation, this method is part of a wide struggle towards Truth, which recognises the conflicting social interests involved in the processes of historical development, and unashamedly strives to represent the real interest of physically impaired people in that struggle. One example of the strength of this approach is seen in the publication of the Union's meeting with Disability Alliance. There, despite the sophistication of so-called "disability experts", the Union's insistence on fundamental principles enables us to clarify the real interests involved, and to take the struggle of physically impaired people one step forward by seeing what is reasonable from our own point of view, and by exposing the confusion that is the hallmark of those who would perpetuate our oppression. Real integrity and the uncompromising quest for truth are our weapons in the developing struggle which we need have no fear of using.

It may seem that for an obituary we have said very little about Paul's life and his qualities, and too much about UPIAS and what it stands for. We would say that every word that is written here is about Paul Hunt, and that we would hope that what is written concentrates on the things that Paul would have wanted to be said.



**UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION**