

**NUMBER**

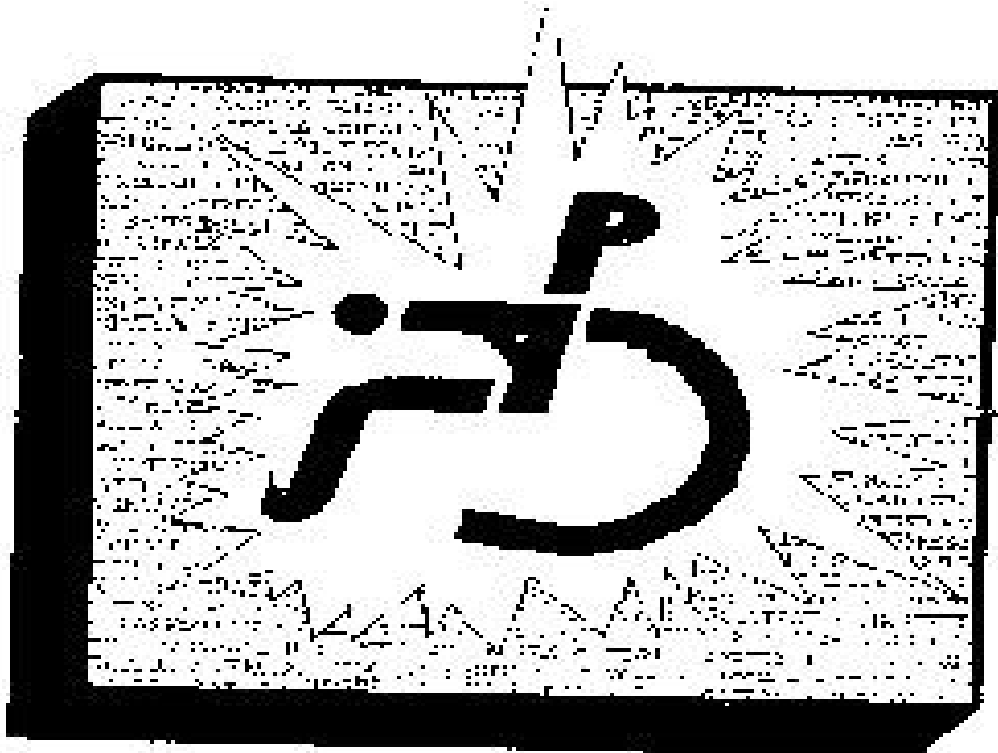
**DISABILITY**  
DECEMBER

**2**

**CHALLENGE**  
1983

**UNION OF THE PHYSICALLY IMPAIRED AGAINST  
SEGREGATION**

**THE UNION AIMS TO HAVE ALL SEGREGATED FACILITIES  
FOR PHYSICALLY IMPAIRED PEOPLE REPLACED BY  
ARRANGMENTS FOR US TO PARTICIPATE FULLY IN  
SOCIETY.....**



FLAT 2 ST GILES COURT DANE ROAD LONDON W.13

## On the Move in the 80's

### IYDP Antics

Predictably 1981 – the IYDP – deepened that already entrenched conditions which perpetuate the social oppression of physically impaired people. The year was ushered in by non-disabled people on our behalf and passed into history to fanfares orchestrated by the same elites. This simple fact sums up the nature of our problems and their solutions. Disabled people could have been consulted about the appropriateness of such an International Occasion: disabled people themselves could have considered the consequences. The resources and machinery for discharging such a simple obligation existed within and through the United Nations but they were not employed. Being passed over in this way is, of course, something disabled people have become resigned to. The minor flurry which preceded the change of designation of the year from for to of Disabled People proves the rule. The ‘does he take sugar’ sickness is endemic: it can be diagnosed as readily in the behaviour of our most august international organisation as it can interpersonally in the High Street.

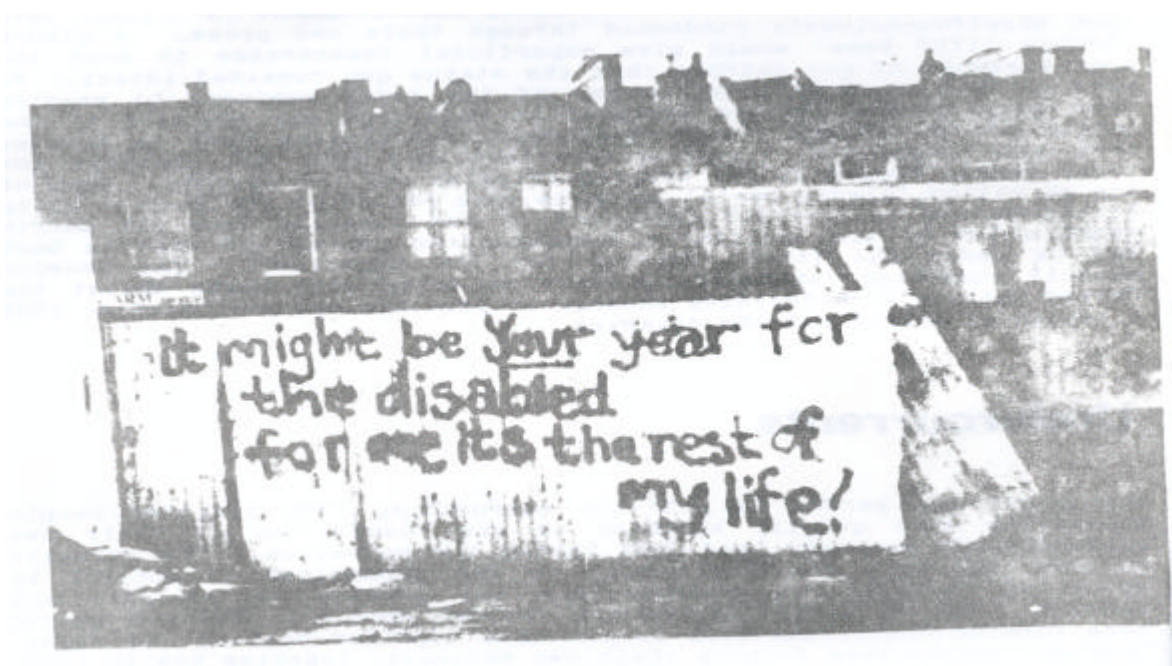
The spontaneous antics of the disability establishment in Britain have been unselfconsciously condemned through their own press. A glance through ‘IYDP News’ would give superficial reassurance to even the most paranoid of our patrons that the status quo remained intact. We read of our nobility crawling out of the royal woodwork to preside over soggy garden parties designed to reinforce our position at the bottom of the social pile. Craftwork competitions were in greater than ever abundance. Arch-segregationalists like Mr. Cheshire got their medals topped up for keeping cripples off the streets. Some of the so-called ‘clever one’s’ among us were patted on the head at civic functions and self-styled champions of the disabled like Alf Morris spent a lot of time selling a comprehensive package of what is best for us under the label ‘Charter for the Eighties’. The Snowdon Council assembled dutifully to carry on doing good works whilst the United Nations were deciding whether to proclaim the period up to 1992 a decade of action for the disabled.

## Undercurrents

Throughout the period of activity surrounding IYDP disabled people themselves were quietly building on the foundations of their own self-help and activity laid down during the seventies. The struggle by more and more disabled people to rid themselves of control by so-called experts and professionals was growing in strength and numbers. In the United States and Canada, mobility impaired people were forming Coalitions with people with impaired hearing and sight. Disabled people were forging their own movement, learning how to fight their own political battles, use the media, and the machinery of power. They were learning how to struggle, to sacrifice and win their own victories. The occupation of State Department premises in Washington by the American Coalition of Citizens with Disabilities (ACCD) and the subsequent governmental climb-down over welfare rights was a milestone. Alongside such political activity, disabled people in the States were designing and delivering practical services from Independent Living Centres under their own control.

The effects of this movement were felt inside the World Congress of Rehabilitation International (RI) at Winnipeg in June 1980. This international gathering of professional experts, whose tentacles reach into influence and control vast resources of potential good to disabled people, confirmed the nature of their relationship to use in unmistakable terms. They decisively threw out a motion for sharing control within their own organisation with the disabled people and in the process spelled out that our true role: we remain the passive recipients of whatever they choose to consider best for us.

The fact that the Canadian Coalition of Provincial Organisations of the Handicapped (COPOH) organised a response from disabled delegates to the RI Congress, which has led to the formation of the Disabled People's International (DPI) is now well known in disability politics. The need now to consolidate and build our movement is crystal clear. Wherever disabled people attempt to gain control over our own lives the effects are the same: whether it is in a village Club Committee, in local government or Rehabilitation International – AB rule OK.



## Feeling our own strength

At home in Britain, disabled people have successfully continued to organise their own movement. During IYDP there was much quiet but persistent activity; it received little publicity, no accolades, no distribution of knighthood. At the local level, groups of disabled people organised round particular issues – such as Project 81 and their goal of breaking the grip of the Leonard Cheshire Foundation, or the Norwich attempt to set up a Centre for Independent Living. In Derbyshire the drive to organise the disabled peoples' movement was more embracing, with the formation of the Derbyshire Coalition of Disabled People (DCDP).

At the national level, our Union was actively involved in bringing together national organisations of disabled people and the subsequent formation of the British Council of Organisations of Disabled People (BCODP). This – by far the most significant and potentially far-reaching event of the International or any other year in the disability calendar in Britain – was duly noted by the establishment. Non-representative organisations like RADAR and the Spastics Society soon began to take predictable steps to protect their vested interests in keeping us in our place at the bottom of the

pile. When the three disabled BCODP representatives set off for the DPI Work Congress in Singapore for instance, they found a Spastics Society delegate attempting to gain credibility for his organisation at our first international gathering. More subtle attempts to undermine the development of the disabled peoples' movement can be expected as time goes on.

One sign of the growing confidence among disabled people in Britain in their own movement has been the forging of organisational links with other oppressed groups. Disabled women in our own Union, as well as Sisters Against Disability (SAD) are exploring their position as women overcoming disability. In a similar way, people who are both disabled and homosexual confront the interlinked aspects of their oppression through organisations such as Gemma. More recently, disabled people have demonstrated their solidarity with the oppression of people who are black through Disabled People against Apartheid (DPAA).

## Reading the signs

Other sorts of signs indicate the present position of the disabled peoples' movement in Britain today. The media, in particular magazine programmes' such as ATV's Link, have so far tiptoed carefully through the evidence our movement leaves in its wake. Given the tight grip of establishment disability on the media, it is hardly surprising that the movement only gets scraps from the table – a programme here, an interview there – sufficient to maintain the status quo.

Yet it is significant that ATV's researchers are keeping a closer than usual eye on developments; attending a recent national CIL meeting, the Derbyshire Coalition's AGM and other contracts. The problem for the media, since they can now no longer ignore us, is how can they best neutralise the social and political implications of our activities and absorb us into the status quo. All disabled people in the movement need to recognise and learn from such signs.

The situation is very similar with other commentators and reporters who feed and grow fat on our oppression. Typically, the more active we become in our own cause, the more likely we are to become hosts for their parasitic activities. Authors like Campling and Shearer are cases in point; they approach disabled people and request their co-operation as subjects in their

latest literary endeavour, get us to write up our experiences (i.e. suffer and do all the work). Then they set our efforts in whatever context they choose, publish and wait for the social and financial rake-off. In this way we tend unwittingly to collude in maintaining the oppressive social relations which are disability. As always, the problem for us is one of gaining control and preventing our situation in a self-determined context.

Other variations on the same theme have consisted of moves by the disability establishments to use disabled people to do their dirty work for them. It is reported that RADAR's disabled representative to a recent European conference repeatedly undermined the position of the BCODP representative there. The tactics employed ranged from filibustering as a means of dominating exchanges; using RADAR's long list of affiliates as an attempt to demonstrate representative status; claiming to speak with authority in the name of the United Kingdom's disabled people; and imputing a "left" (fringe, extreme, etc) status of BCODP as an attempt to isolate and possibly discredit their representatives contribution. It would clearly be irresponsible to suggest that organisations of disabled people such as BCODP should adopt any similar tactics in response. Nevertheless, it poses a problem for the disabled people's movement, when disabled people themselves are willing to be used as tools to perpetuate the dominance of those who have everything to gain from maintaining the oppression of physically impaired people.

## Our Challenge for the 80's

In the union, we are fully aware of the long-term nature of the struggle to overcome disability. Power resides in a formidable network of statutory and voluntary institutions and agencies who have convinced themselves as well as many disabled people that they are rightly vested with control and we are properly the passive recipients of their decisions. The organisational machinery set in motion by the United Nations to implement their International Year inevitably reinforced the very attitudes and practices they set out to try and change for us. But it also stimulated a reaction centrally important to the struggle to overcome the oppression of physically impaired people. It gave impetus to the process of 'coming together' which had been developing for over a decade in Britain. Inadvertently, the United Nations Organisation lent support by default to the only way their keynote theme

‘full participation and equality’ could be achieved in practice; through the active and direct involvement of disabled people in the process.

The challenge for disabled people as we continue into the eighties, is to maintain and consolidate our movement. The time has come for those able-bodied people who dominate and control our lives to stand aside. The days of their dominance and control our lives to stand aside. The days of their dominance are already numbered; it is up to disabled people themselves to clear up the mess they have created. The task is formidable – their institutional legacy alone amounts to little less than a social crisis. The enormous financial and other resources which are now bound up in incredibly expensive and totally unnecessary institutional care – have led to the social deprivation of disabled people, their families and friends on a scale which defies the imagination.

The time is also here for disabled people themselves to resist colluding with or unwittingly maintaining the oppressive social relations which are the source of disability. To find one’s self in the employ of oppressive employers is nothing unusual or particularly confined to the disability establishment. But the identification of disabled people in this position can only be with the disabled people’s movement towards emancipation, self-determination and social integration. To use the oppressed as willing instruments of oppression is the well tried technique of oppressors in all spheres of life. The struggle for social and political awareness through our own raw experience of disability is, however, a collective responsibility and our Union will continue to work constructively within the movement with all those prepared to take up the challenge.

THE LINK

**Between**

HOUSING & HELP

If you are severely physically impaired and need the help of another human being to survive you have all the potential for incarceration in institutional care. We live in a society which is built on the assumption that the family is the right and proper source of help. Institutions operate as a social defence mechanism to protect this general assumption. Inevitably, in a society which provides minimal family support services, the stress on families operating as sole carers leads inexorably to breakdown and the incarceration of the person who is physically impaired.

It may seem unusual to commence an article about housing for physically impaired people with a statement about care. But the fact is that the more severe the impairment, the greater the likelihood of dependence on other people and the less likely that housing per se will satisfy the conditions for social integration. Housing however well designed, however well equipped with gadgetry, will never meet the needs of dependent physically impaired people. Housing and help are inexorably linked and must be consistently perceived in this way if physically impaired people are ever to achieve a secure base for full participation in our society.

### No choice

In my case, following an accident which led to my own physical impairment, the question of family breakdown under the stress of caring for my needs did not actually arise. One parent was dead and the other too frail to cope with my needs. Then as now there was no adequate domiciliary support services. Apart from the Community Nurses, help provided by the Local Authority was purely discretionary, since my accident was before the CSDP Act. Indeed, before my accident I was working as a nurse and never challenged the situation. I assumed, like most do, that our social welfare

provision was sufficiently all-embracing and that if people did end up in institutions by virtue of their age, mental or physical condition, then surely this was the right and proper place for them.

The only time I ever encountered the suggestion that the way we did things was not the perfect model was while nursing in the Lebanon, where dependent family members were contained within the extended family rather than in more formal social solutions. By and large my attitudes were those of the average professional in health and social welfare; those physically impaired people I encountered were seen as cases based on the medical model.

My awakening began in a real sense when I found myself on the other side of the fence. I found myself on the observing end of the very same attitudes and perceptions I had found myself. I can't say that I liked it.

However, having survived the acute stage of my paralysis in hospital, further rude awakenings were in store. There were no houses for people like me, no flexible system of domiciliary supports comprehensive enough for someone as physically impaired as me. Since my family could not cope I was swept neatly into the nearest institution. It was there that I really began to wake up to the oppressive social relations existing between our society and its impaired members.

Institutions were places people like me died in. The longer I lived there the more I realised I was one of society's social outcasts thrown onto the ultimate human scrap heaps. I resented the devaluing and dehumanising regime. It was impossible for me to accept this form of accommodation and care as being an acceptable substitute for housing and help in the community. Society had incarcerated me because they thought – and still do – that institutions were the right places for people like me. For me the natural place was out there in society playing an active part as I always had done in the community. We are social beings – it is offensive and wrong to remove us from society and treat us as subhuman.

## UPIAS

The way back was long and tedious. I had begun to see along with many other physically impaired people that we needed to come together, get organised and develop unity of purpose.

When Paul Hunt publicly suggested that we should come together in this way it was a lifeline for me. The Union of the Physically Impaired Against Segregation was formed and as it developed many things about my situation came clear to me. I could see that I and my fellow inmates were victims of other people's prescribed solutions to our problem. What we needed was that physically impaired people should define their own problems and their solutions out of their own direct experience of disability.

We needed to get back into society with real control over our lives. Of course we need help, but I could see that existing service providers (among whose number I had so recently been) must become a resource to be drawn on by those in need of help. This would mean a radical change: the professionals prescription of stock solutions to our need for help had to be replaced. But the idea of service providers actually lending themselves as a resource under the direction of their so called patients or clients is still a long way off.

## An Alternative

The solution to my immediate housing/help needs had to be struggled for in advance of these required changes. When I met my husband-to-be we set about devising our own alternative to institutions and the principles on which it ought best to be founded. That we were able to achieve what we wanted says a lot for the individuals with whom we worked along the way.

Our answer was a small development of housing units, some of which were designed with the architect to meet the specific needs of potential tenants identified in advance. Other units were to be let to non disabled tenants who were willing to supplement the help available from local domiciliary services in meeting our need for support. This quasi-collective solution was developed out of our own perception of our needs – and as a reaction against the institutional reality forced on us by other people.

## Grove Road

The Grove Road scheme in Sutton-in-Ashfield has subsequently offered a pointer to other people seeking an alternative to institutions. The approach is simple enough; it rests on the premise that physically impaired people should be fully participating citizens integral with their local community. It shows that there is nothing particularly special required except a willingness on the part of the service providers to work with us in designing and developing 'independent living' arrangements. It suggests first, that the basic design of a house should be evolved out of the dialogue between architect and disabled person. Second, that aids to independent living should be provided with the housing to reduce artificial dependency on human resources, so that no one source bears the sole burden of care.

Statutory sources of domiciliary help can have a valuable underpinning and stabilising effect providing that they are responsive to the requirements of the disabled person concerned. But it is essential that support systems are socialised further than this, drawing on the resources available out of normal neighbourhood relations. This has the effect of removing from the family the burden of being the sole carer and increases the needs of the disabled person and the needs of the carer. We hope that Shelter's involvement into the housing needs of the physically impaired person will take as their starting point those people whose requirements for help usually place them at the bottom of the pile – in institutions.

Maggie Hines

# UPIAS Support

for

**Ann & Bob Mason**

For legal reasons most of the names of people and places in this article have either been changed or their identification obscured.

I first met Ann and Bob Mason in the autumn of 1979 when I went with a group from my local Community Health Council (CHC) on an official visit to Byron House, a Young Disabled Unit (YDU) situated in the grounds of a large hospital in the north of England.<sup>1</sup> I had purposefully arrived early for this visit to ensure that I would be able to chat to some residents free from official intimidation. My conversation with Ann and Bob at this stage was very brief, but it was long enough for them to make it clear that their situation was particularly desperate. I suggested that the Union might be able to help them, and they were very keen that I should return to Byron House within a few days to discuss this further. What follows is an account of the Union's support for Ann and Bob, which spanned a three and a half month period from late 1979 to early 1980.

## Marriage – Cause for Scandal

Ann and Bob had been in Byron House for about a fortnight ostensibly to be assessed for their capacity to live independently in a flat. Their permanent 'home' was 'Daisynook', a hostel administered by a local authority Social Services Department. To put it mildly they found life at Daisynook unbearable and were determined to get out. The solution suggested by their social workers was an assessment lasting six weeks which, if they passed, would then qualify them for a bungalow or flat. There was a catch, however. Their social workers also informed them that suitable housing may take up to three years to become available, and in the meantime they would have to return to Daisynook, and this they were not prepared to do – and with good reason.

---

<sup>1</sup> My involvement with the CHC in this visit was part of a long-running campaign carried out by a group of disabled people against the proposed building of a YDU in our locality. The intention was to persuade the CHC to disassociate themselves from the oppression of disabled people by opposing the proposal.

Things began to get really bad for Ann and Bob at Daisynook in the latter part of 1978 when they made it known they intended to marry in the summer of 1979. It was obvious that the warden wasn't going to have any such nonsense when he commented that, "It would ruin the whole atmosphere of Daisynook if they got married". And he further implied that if they continued with their plans then one of them might be moved to another hostel. These threats didn't work, so more weighty methods of coercion were brought into play. A series of meetings took place. The first two meetings were attended by Ann and Bob, their parents, respective social workers, two residential care officers, the warden and deputy of Daisynook. The purpose of these meetings was clearly to crush or at least delay the marriage plans. They received no encouragement whatsoever, rather they had to defend their decision to marry through what amounted to two lengthy cross examinations. (It hardly needs saying that few couples in our society who are aged 30 plus have to submit themselves to this sort of procedure before marrying).

The next two meetings were at once, both more subtle and more crude. In what were obviously 'divide and rule' tactics the warden interviewed Ann and Bob separately. At which he informed Bob that Ann was 'man-mad' and selfish, whilst Ann was told that Bob might well die from a heart attack if they had sexual intercourse for example.

By this time they were thoroughly sick of the pressures, and furthermore they realised that as time went on there was a distinct possibility of them being split-up, with other tactics having failed. So they decided to marry sooner than they had planned. In what was akin to a 'cloak and dagger' exercise which necessitated the collusion of the Registrar and Daisynook's handyman (the person they most trusted there) – they married secretly in early 1979. Needless to say when word of their marriage got round at Daisynook there were no celebrations, rather the already firmly institutionalised processes of neglect of residents were stepped-up for Ann and Bob to the extent that on the day of their honeymoon they were more or less left to fend for themselves. It was three months after they had married that they were able to share a room together. Even then their double bed was a hastily constructed affair consisting of two single beds knocked together which had a tendency to slide apart when they attempted to meet in the middle.

## Prisoners of Welfare

The more 'normal' pattern of oppression of Daisynook will have a familiar ring to those who have experience of residential institutions. In addition to living in the midst of the monotonous grind of timetabled routines that occur day in day out, and are arranged essentially to meet the needs of staff, there is, interwoven with this, incredible insecurity and humiliation that occurs when the unscheduled but regular needs of residents require a response. It wasn't unusual, for example, for residents to be left in the bath for long periods without attention. It could also take up to two hours to get assistance to visit the lavatory. And once on the loo there was no certainty that residents would get off within the next two hours. It was hardly surprising therefore to hear that some multiply impaired residents occasionally used the lounge floor to evacuate themselves. Ann's solution to the loo problem was to collaborate with her father in redesigning her wheelchair so that it would also function as a commode which could be used independently. The official response to this was that it was unhygienic and she should stop using it. (Interestingly, the DHSS have recently copied this same design). Moreover, a particularly nasty preoccupation amongst some members of staff concerned the inconvenience caused to them during Ann's (and presumably other female residents) menstruation period. Ann says that constant pressure was placed on her to have a hysterectomy.

Complaining about such abuses and humiliations wasn't a solution either. For example, those residents unable to dress themselves were often left, following a morning or afternoon bath, in their robes for the rest of the day. Ann complained about this, but in return she was harassed for some time by certain members of staff. Constant references to the untidiness of her room was one line of counter-attack. The next complaint was made directly to a member of staff by Ann about the way she was being spoken to. For this she was belted across the face and told she was insolent. This time, to avoid recriminations, Ann's parents made the complaint and even though it travelled further up the social services hierarchy the staff member concerned only received a reprimand. Ann and Bob were, however, 'sent to Coventry' for some time. Significantly, this incident was the only occasion on which outside help was sought at this time. Ann's father contacted a local councillor who, unfortunately turned out to be a close friend of the warden.

In the midst of all this the major concern of the warden was with knowing 'what it feels like' to be disabled. But instead of observing what was going on around him, his method was to walk around the hostel for days on end using a tripod, or trying to write with a pen stuck in his 'imitation' of a contorted hand. These then are some of the depressing details which formed the basis of our involvement.

## Organising to Confront the Carers

A little over a week had passed since my second meeting with Ann and Bob (during which time a Union colleague and I had been making enquiries about suitable housing) when I was asked to support them at a meeting initiated by the social services department to discuss their reasons for not wanting to return to Daisynook. Ann and Bob also agreed to my suggestion that we have legal representation at the meeting; past experience suggested that this could be crucial, particularly in handling the allegations against Daisynook which Ann and Bob were intending to make.

There was a formidable gathering of authority at this meeting. Representing the Social Services Department was their Principle Residential and Day Care Officer plus the warden of Daisynook ostensibly representing Ann and Bob were three social workers (of which one was in the process of resigning her post). From the health authority was an occupational therapist and social worker, both of whom were based at Byron House. The rest of the meeting was made up by Ann and Bob, Ann's parents, a representative from the Law Centre and myself from the Union. In retrospect I feel this meeting was essentially intended to persuade Ann and Bob to return to Daisynook with, no doubt, certain assurances that their grievances would be looked into. However, the meeting took a somewhat different course.

For Ann and Bob to have both Union and legal representatives at the meeting came as something of a shock to the 'carers'. Noticeably uncomfortable throughout were the social workers who seemed to view our intervention as interference. As one of them commented to Ann following the meeting, "I don't know why you are placing trust in those two". The Principle Officer acted as the chairmen of the meeting, and from the outset attempted to create a jovial atmosphere. Having prepared the ground in this fashion he then suggested that as the meeting was public it wasn't the place to make accusations against anyone.

Rather he requested that we concentrate on making constructive suggestions that would help Ann and Bob with their problem. Wisely, Ann's reaction to this 'battering-up' was to state quite firmly that she and Bob had no intention of returning to Daisynook, and then promptly asked John Wilson from the Law Centre to read out their statement which listed serious allegations against Daisynook.

Following this we emphasised the point that the contents of this statement made it quite clear that Ann and Bob couldn't, under any circumstances, return to Daisynook. This was only partially accepted by the Principle Officer who said, "Of course they couldn't return whilst these allegations are being investigated". The allegations brought forth three types of response from the 'carers'. Whilst the majority maintained a stoney-faced silence, Bob's social worker got quite aggressive with Ann and attempted to 'pick-holes' in some details of their statement. The warden on the other hand was trying to suggest that he wasn't on duty at the time when most of the incidents mentioned in the allegations had occurred.

## Divided they Fall

The next shock for the Social Services group came when the occupational therapist, in her only contribution to the meeting, made a short statement to the effect that Ann and Bob had passed their assessment and could live independently provided that they had a suitably adapted flat or bungalow, and the provision of a hoist that would enable Ann to get in and out of bed. This information was also received with a stunned silence. What had initially been a meeting to sort out the problems of Ann and Bob had now revealed that the problems actually belonged to the local authority.

It was revealed that the Social Services Department had just implemented a policy, as part of cuts in expenditure, of not placing anyone in hostels outside of the authority, and they only had the one hostel specifically for physically handicapped people, i.e. Daisynook. In addition, Ann and Bob's social workers hadn't made any approaches to housing authorities or housing associations to see if suitable accommodation was available. They did mention 'putting their names on the housing waiting list' but their major concern was to identify a suitable hostel, run by a voluntary organisation, in

the locality. Our suggestion that suitable housing should be looked for as a matter of urgency was regarded as being naïve. Throughout all of this one



can only guess at the intention of the social workers involved. But I suspect that Ann and Bob were sent on the assessment primarily to 'cool them off', so that the 'nasty' feelings they had towards Daisynook would diminish. Only in the unlikely event that they passed the assessment (in fact Bob's social worker admitted to me that he was very surprised they had passed) would they then involve themselves with the housing problem, that is, when they had an 'official prescription' to act.

Moreover, there was little love lost between the Social Services Department and the health authority – they regarded each other with the utmost suspicion.

It seems that the Social Services had used Byron House as a ‘dumping ground’ for those disabled clients who were no longer able to maintain their struggle for independence in the face of inadequate housing, and the lack of human and technological support from the Social Services. To counter this the health authority had tightened up on the admissions policy of Bryon House, so that most ‘patients’ are given a specific time period for their stay. The exception to this rule applied only to those who are not expected to leave (at least alive), who are designated as being ‘hopeless cases’; and not informing them of their length of stay is supposed to be a humanitarian gesture.<sup>2</sup> So as far as Ann and Bob were concerned they had only another two weeks left at Byron House.

## A Near Disaster

This is where our support for Ann and Bob crumbled and nearly proved to be disastrous. Firstly, John Wilson was supposed to return to Byron House soon after the meeting to make some additions and corrections to the statement made by Ann and Bob before typing it up and forwarding it to the Director of Social Services. He was also supposed to get statements from two other people in Byron House who had been residents at Daisynook in the past and received similar treatment to Ann and Bob. However, John had what appeared to be serious emotional problems and he just disappeared for some time. Secondly, I was involved in a family crisis which took me away from home for a few days. This meant that they had no outside support during a period when they were concerned (with good reason) that they might simply be dispatched back to Daisynook. Adding further to their distress was a series of fruitless telephone calls to the Law Centre. Ann has a speech impairment which the centre was unable to cope with, and although she spoke to a number of people on consecutive days she was told, somewhat insensitively, to ring again when John Wilson might be in. (At

---

<sup>2</sup> Like a number of other YDU’s Bryon House tried to give the impression that they are concentrating their efforts on rehabilitation, yet during the two and a half years, the unit had been operating, ten patients had died, whilst others had been given a ‘life sentence’ without being informed of the fact.

this time Bob was lacking in self-confidence and had problems with conversation, so Ann made all the telephone calls).

When I re-established contact with Ann and Bob it was to learn that they had been informed they were being moved to a hostel in the Midlands (about ninety miles away). They had been given just four days notice of this move. It appears that Ann's social worker and the Sister in Charge at Byron House had visited the hostel (owned by a voluntary organisation), decided it would be suitable for them, then promptly started to make arrangements for their move. They were told that their first three weeks at the hostel would be a trial period for both parties (of course there was no need to tell Ann and Bob where they would be going if they didn't like the hostel). Then, if everything was satisfactory they could enter on an assessment for three months which apparently tested their suitability for a flat in the grounds of the hostel. For all of this they were expected to be very grateful. It was obvious that something had to be done very quickly now.

## Wheels into Motion

A Union colleague had already made contact with a large housing association and learned that a flat might be available at one of their schemes in a neighbouring country. This scheme was some fifty miles away but we had already established with Ann and Bob that they were prepared to move some distance providing the accommodation was right. So we arranged transport for the visit on the following day. We also arranged to call in on two other Union members, Ken and Maggie Davis at Grove Road, in Sutton-in-Ashfield, so that Ann and Bob could experience at first hand the possibilities for independent living when good design, technology and human assistance are combined in a creative way. (See Disability Challenge No. 1).

This was a good day. The visit to Ken and Maggie wasn't only of practical value it also boosted our spirits. Ann and Bob were now more determined than ever to escape from residential care. At the housing scheme there was a two bedroomed flat available which was spacious and reasonably well designed. Ann and Bob had no doubts about wanting the flat but certain conditions had to be met. The Association wanted written confirmation of the results of their assessment at Byron House – this was relatively straight forward. But Ann and Bob had a further assessment to pass. The tenancy

for the first eight weeks would be on a trial basis, during which they would be assessed for their ability to cope. On what criteria the assessment was based wasn't clear, but it appeared to be widely known that the number of times you rang the bell (situated in the flat) for help was crucial; so persistent 'bell-pushers' would soon be out! The reverse seemed to occur however; that is, tenants being terrified of ringing for help in case they got a 'black mark'. In the event that Ann and Bob failed the assessment the Association required, in writing, an assurance from a statutory agency that accommodation would be provided for them. Needless to say the statutory agency was the local authority Social Services Department which administered Daisynook.

## Nothing to Lose

The way Ann and Bob viewed these conditions was that throughout their lives they had been through one assessment after another, so what difference did this one make? Moreover, they felt they had little option but to agree to return to Daisynook, although they had no intention of doing so. If need be, Ann was prepared to sleep in her wheelchair until they had acquired an appropriate hoist.

What was of immediate concern to Ann and Bob however was that nobody would believe that they had been offered a flat when they returned to Byron House. After meeting with their social workers I think they had every reason to be worried. To get around this Ann asked the manager of the housing scheme to put the offer in writing. This done, it was still worrying to them having only one copy of a document which was the most important bit of paper they had held in their life, thus the thought of having to pass it on to one of their 'official carers' and possibly losing control of events was a sickening thought. We solved this by making a dozen photocopies on the way back to Byron House.

## Bureaucracy

What we now had to do was to ensure that the arrangement of their move to the hostel was cancelled, and to try to get their stay at Byron House extended beyond the coming weekend. The following day there was another mass gathering of authority at Byron House to discuss their future. We were not able to have Union representation at such short notice, and the Law Centre (who had arranged for another member of staff to replace John Wilson) were not able to be present either. Rather than do nothing, however, we decided to ring a number of the officials involved giving them our point of view, whilst at the same time letting them know that their actions were being observed. The outcome was that the hostel proposal was scrapped and their stay at Byron House was extended by one week. However, by the time the Social Services had got round to forwarding the necessary correspondence to the housing association (which they required in order to secure the trial tenancy) there was just three days left for Ann and Bob to make arrangements for their move. And there was still one more meeting to get through before these arrangements could be set in motion.

## Who are the Carers

This meeting, which turned out to be something of a farce, was called to ensure that satisfactory arrangements had been made for Ann and Bob when they left Byron House when, of course, they had hardly been time to make any arrangements. At this Ann wasn't prepared to take any chances by openly stating problems, rather she decided to tell a few lies. One, which took me by surprise, was that John Lloyd (a Union colleague) was organising a neighbourhood support scheme for them until the necessary equipment, in particular the hoist, was acquired. The point about this is that the health administrator and social worker didn't even ask who John Lloyd was! In fact it became increasingly obvious that the health authority and Social Services couldn't get rid of Ann and Bob soon enough; and probably also wanted to get lawyers and Union representatives off their backs.

The main problem now was financial. During their stay at Byron House neither Ann nor Bob had received one penny of their £3.99 weekly pittance. In addition Bob discovered that the furniture he thought had been placed in storage by his sister had, in fact, been sold. So Ann took a taxi to the DHSS

and got a grant towards the purchase of a bed, bedding and a table. Fortunately, the flat was already equipped with a fridge and cooker. Another Union member was sorting through other aspects of income entitlement, in particular the need to get their entitlement to attendance allowance quickly reinstated in case human assistance had to be paid for once they were in the flat. This left Ann's parents one clear day in which to travel over to the flat, purchase the furniture and get the electricity switched on etc.

## Assessment made a Nonsense

Amazingly, nothing else went wrong before their move to the flat on the following day. Ann's parents stayed with them for the first few days until they had got organised which was just as well because the district nurse which Ann's social worker was supposed to have made arrangements for, didn't turn up.

The nonsense of the housing associations eight week assessment policy also became apparent. For Ann to achieve the necessary independence she required a hoist to enable her to transfer from her wheelchair into the bed and vice versa. Yet her new local authority social service department shelved their application until the assessment period was completed. After this they refused to provide a hoist on the grounds that Ann and Bob had been 'imported' into the district, and their needs must come behind those of 'genuinely local' disabled people. So for a time Ann had to make do with early nights in bed with the district nurse calling in. This changed when Ann struck up a friendship with the Community Assistant who offered to help Ann in her free time.

The assessment created further difficulties. Ann's parents, who are retired, showed some reluctance in purchasing on their behalf, a carpet sweeper and washing machine until their tenancy was secure. However, in December the tenancy agreement finally came through, thus ending weeks of doubts and worry. As far as the hoist was concerned they had eventually to buy it themselves, with the help of a donation from a charity. And then Ann's parents sold their home and moved to live nearby so that they could provide the help which wasn't available from statutory sources.

At the time Ann and Bob were very happy and revelling in their newly acquired independence. But Daisynook was (and still is) a recurring nightmare, and they are only too well aware that their places will have been quickly filled.

## Post Script

### Additional Information and some Clarification

1. In the weeks that followed the local authority solicitor, after an interview with Ann and Bob, investigated the allegations against Daisynook. From correspondence between the local authority and the Law Centre, whilst none of the allegations were denied, the actual changes made at Daisynook were minimal.
2. The present living arrangements of Ann and Bob are very insecure, particularly now that Bob has very little sight left. With the statutory services not being prepared to provide the kind of help they require this means that they are now heavily dependent on each other, and on the help provided by Ann's parents. Living with the constant stress of this is bad enough, but they also live with the fear of the system breaking down through illness, for example. If a breakdown does occur they also know that the statutory services will then move rapidly into 'top gear' to put one or both of them into a residential institution.
3. We have learned some crucial lessons from struggles such as this one. Most urgent was the need to work for non-institutional forms of housing and round-the-clock support systems. In addition to their obvious practical value as alternative forms of accommodation they also serve as political weapons, exposing in a concrete way many of the myths used to legitimate residential institutions. Moreover, we have learned that it wasn't enough to simply demand the provision of alternative forms of housing and support arrangements whilst leaving the planning to others. The active involvement of disabled people in this process, from the conception of a scheme to its completion, and possibly beyond, is absolutely vital. But we need to discuss and develop strategies for securing the maximum control over this process.

4. As the approach to this article was largely descriptive there is a danger that it could lead to some misunderstanding about the function and nature of residential institutions. The impression might have been given, for example, that institutions are oppressive because ‘nasty’ or ‘incompetent’ people manage them.

From such an impression the solution for oppressive residential institutions would be fairly obvious, that is, to ensure they are managed by ‘nice’ and ‘competent’ people. What needs to be made clear then is that whilst residential institutions will obviously differ according to who controls them, this shouldn’t detract us from the fact that they are, in themselves, fundamentally oppressive. They are fundamentally oppressive because of their social purpose which is to facilitate the incarceration of certain social groups who are defined as being social ‘problems’. Incarceration is, therefore, a socially determined practice which involves extreme forms of segregation, dependency, regulation and control. It also involves the construction of elaborate myths (odd mixtures of ‘stone-age’ beliefs and pseudo-science) which attempt to make residential institutions appear ‘natural’, ‘inevitable’ and even ‘beneficial’ for us. Consequently the existence of residential institutions, their mode of organisation and function won’t be understood simply by reference to individual motivation, i.e. ‘goodies’ and ‘baddies’. Rather, what is required is an understanding of why a particular society, at a particular point in time, maintains, develops and justifies particular forms of incarceration. To think that residential institutions wouldn’t be oppressive if nice and well intentioned people are in charge of them is as ridiculous as believing that the system of apartheid in South Africa could be maintained yet become non-oppressive by changing the personnel which controls that system.

5. Another misleading impression which the article may have given is that the forms of control which physically impaired people are subjected to in residential institutions can occur within certain types of environment, e.g. hostel, hospital unit or large country house. Whilst environmental factors must influence the kind of control which can be exerted over us there is, nevertheless, ample evidence to show that methods of control are being modified and transferred into housing schemes by traditional segregationist organisations such as the Leonard Cheshire Foundation and the Spastics Society. (I) Some of

the most visible practices being employed by these organisations in housing schemes which serve to ensure the dependency of physically impaired people are, for example, through tenancy selection and assessment procedures, then writing up of the tenancy agreements, the organisation of 'care', the regulation of the tenant's income, and through the use of technology with a built-in dependency.

In one sense it's hardly surprising that these organisations are moving into housing projects. With high costs of residential institutions, a diminishing clientele, increasing attacks on their segregationist policies, and the rise of the Independent Living Movement, it must have registered within these organisations that the writing was on the wall for their traditional methods of operation. So their move into housing and 'care support' is crucial for their survival. For if there is one thing these organisations can't allow it's for us to become independent of them, they would simply go out of business! In another, much deeper sense, the whole structure of these organisations, their historical development and present methods of operation is based on a belief in our dependency and the 'naturalness' of our exclusion from 'normal' society. The words and actions of the leading exponents of our oppression, who have built-up these organisations, have never sought to understand or challenge the special cause of our dependency and exclusion. Rather they have concerned themselves with the justification and resolution of what is their mission in life; to 'care' for 'lesser beings', the 'socially inadequate' and 'incompetent', the 'poor cripples' of this world.

But what is particularly significant about this latest phase in the development of these organisations is that they are now pinching our ideas and words and attempting to absorb them within their own view of disability. So that in a recent edition of 'Responaut' (Summer 1982) we have the nauseating spectacle of Leonard Cheshire explaining how the Foundation is 'feeling its way' in providing alternative ways of living and integration within the community and so on. There wasn't even the slightest hint in this article of the true source of these ideas, i.e. disabled people. Nor was there any awareness that alternative ways of living have been struggled for by disabled people as an alternative to the misery and humiliation caused by segregated residential institutions such as those run by the Cheshire Foundation.

This raises the question of how are these segregationist, dependency creating and parasitic organisations explaining and justifying apparently radical changes of direction. How do they gloss over the major contradictions

which arise when integration, creating dependency and supposedly encouraging practicing independent living, 'caring' for us and seemingly working with us (e.g. as with Project 81')?

As far as the Cheshire Foundation are concerned there is no intention to phase out the residential institutions, rather institutions and the alternatives are seen to be ..... being both provided as a direct response to 'our needs', 'our preferences' and 'our wishes' ('Responaut', Summer 1982, p.9). This is of course the familiar practice of 'victim blaming' in which the responsibility for any contradictions arising out of their actions is thrown back at us. But more than this, these arguments are plainly mischievous and daft when these charities have consistently taken an authoritarian position in interpreting our needs and preferences for us, and in doing so have consistently failed to understand these needs and preferences, with devastating results. We were for example initially forced to accept their solution of segregated residential institutions for our housing support problem. And the subsequent growth of the vast network of these 'dumping grounds' has served to obscure and hold back the development of real solutions to our needs. (For more detailed criticism of the kind of arguments presented by Leonard Cheshire in 'Responaut', see Disability Challenge, No. 1). As for these organisations seemingly working with groups of disabled people, this is only likely to occur with those few who they judge to be 'exceptional', the 'competent', 'intelligent', and 'highly motivated minority'. But the propaganda value of these occasional exercises in forging 'shame partnerships' with disabled people could be immense in giving them a 'progressive' appearance, and in deflecting attention away from their main work of segregating disabled people.

We must, therefore, draw on these lessons of the past to know that these charities are now up to when they start to talk about alternative ways of living for disabled people. They are 'feeling their way' in establishing new forms of control over our lives in housing. It's no accident for example that one fundamental demand to emerge from the struggles of disabled people that these charities are not talking about, is that we should have full control over our lives. this is one part of our vocabulary which they could not possibly absorb, and one which we must confront them with at every opportunity.

.....**Keith Jones**

# Moving Out of an Institution

..... Chris Law

As a contribution to the discussion on non-segregated housing for disabled people, I wonder if my own experiences will be of interest.

I was born in 1972 with spina bifida, and have never been able to walk or stand, I am also incontinent. For the first 41 years of my life I was looked after by my parents, attending a normal local council school until I was 12. Our house was not suitable for anyone in a wheelchair, I could not reach a lavatory, bathroom or even the kitchen sink after I got too heavy to be carried easily. Thus I was very heavily dependent on my parents.

In '63 my father became ill and could no longer lift me, and as my mother got older a move became imperative. A Cheshire Home where I had already been several times on holiday, seemed the only possibility, and I went there in '68.

After a while there, I was fitted with a catheter and learned to use a sliding board to get between bed and chair. I also became mentally more self-confident, and came to realise that given suitable accommodation I could live on my own, with some outside help.

The difficulties were great however. I had no money to buy a house or flat, nor did I know of any organisation who would help. (The Cheshire Foundation had no interest in anything outside Residential Homes at that time). The only possibility seemed a Local Authority.

Therefore in 1972 I began writing to my local council, with absolutely no result. I continued to pester Councillors and others, but met with a blank wall. Not only did they believe I couldn't live alone, they thought I was crazy to try, when I was safe at the home. Many people at the home including the Executive management Committee and residents wrote on my behalf. While on holiday at home, I had an interview with the Housing Manager, together with the Head of Social Services, but still made no progress, though I learned later that the latter was interested.

One of the things against me was that I had never done any cooking or housework so someone suggested that I go to Mary Marlborough Lodge, Oxford, to get an independent assessment of my capacities in that direction. The report was quite good, but partly owing to misunderstanding, not really satisfactory, and again I was turned down by the Council. Thanks to the Warden at the Cheshire Home, I went again to Mary Marlborough Lodge and this time the report was good.

I was told afterwards that there was still a lot of doubt and argument still among the Councilors and officials, but finally my great ambition came about. In the summer of '76 I got a message to say I had been allocated a house, and one never-to-be-forgotten day, August 23rd. 1976 I moved into my small bungalow where I still live. It had taken over four years to get there.

But my difficulties were not yet over. I was on a six months 'trial' and if at any time the District Nurse or Social Worker thought I wasn't coping I could have been sent straight back to the home. The house was not properly adapted for someone in a wheelchair, the only adjustment before I came was lowering the kitchen sink. I couldn't balance on the toilet and had to use a bed-pan. I was allotted three hours home help, and was reluctant to ask for more, in case it was constructed against my fitness to manage. I worked hard and long trying to keep the house clean and neat, terrified all the time that an adverse report would send me back to an institution for good.

However, I survived these six months and gradually things have been done to make life easier. The last were done last year nearly five years after I moved in. The cramped bathroom was extended, a little conservatory built to store and charge my electric chairs and the kitchen altered. I now have six home help hours a week, and I manage. There are still problems, but I have never regretted my efforts to live a more normal, independent life.

# News from West Germany

*upias member*

## on integrated housing & support services

.... A Group has been formed here in Munich and we are carrying out a Care Attendant and Support Service for the integration of impaired or handicapped people. The name of the organisation, translated into English, means Assistance for the Promotion of Integration – V.I.F.

The association was formed and registered in 1978, and has now about 70 members. About 15 of them are physically handicapped. We have not sought a mass membership because we feel it is more important to have members with firm and decisive views about integration. Our constitution says we want to promote the integration of handicapped people and other social groups who are the objects of discrimination. In fact these other groups have up to now not been a relevant part of our work, but nevertheless we think this formulation in our constitution makes clear that there is no special note about the handicapped besides discrimination and oppression, which are in fact shared by other social groups and constitute a central theme of capitalist societies.

Our main goal was to build up this care attendant or support service, which was to enable handicapped people to live on their own, in their own flats, to learn, to study, and to work as independently as possible, which means outside of huge ghettos, school's, sheltered workshops etc. Although this practical goal has certainly some important political implications and preconditions, I must confess that our theoretical base, in terms of political principles about disabled conditions, were not so sophisticated as in the case of the U.P.I.A.S. Another reason for this was, as the membership shows, we started off more as an organisation for handicapped than of handicapped people.

## Practical work of V I F

Within the city area of Munich, V.I.F. now has about 45 helpers working with handicapped people, at home, in regular schools, (normally only private ones) at universities or in their jobs. 35 of these helpers are young men doing their Civil Social Service, an alternative to military service, and 10 young women doing their so called Voluntary School Year, which is some sort of female alternative to the compulsory service for young men. These helpers receive a short training period at the beginning of their service. After that they go into their practical work. Handicapped attendees and attendants get into contact before the practical work begins in order to get an idea if they can get along with each other. Handicapped attendees are involved in the short training curriculum for attendants and play an important role in directing the concrete work of these non-professional helpers.

Attendees have various kinds of impairments; physical, visual, mental, as we do not want to exclude certain groups. The degree of impairment varies greatly, but the bulk of the attendees can be described as severely handicapped e.g. with paralysis of all four limbs with additional problems in some cases (responants or speech impairments). Family status and age of attendees varies greatly as well. There are young children in their families who are cared for in order to accustom them to helpers from outside, and in order to free parents and families partly from the continuous stress of caring for their family members. There are also old people, normally those with considerable impairments, as these sort of people are not usually cared for by other community care services in Germany.

Somewhat simplified, I might say that other community based care attendant and home help services in Germany care only for acutely ill and old people and in some cases for the families, for instance, if a mother is in hospital for a short period. Possibilities of these community based organisations are limited as to the intensity of care (for instance, 40 hours and more a week, up to around-the-clock care) and as to duration of care (not longer than 3 months). It is evident that these limited possibilities of community based care services are not very suitable for the care of severely handicapped people, especially if these live alone. So V.I.F. is up to now one of the very

few organisations to arrange intensive care (in terms of time) for in principle, unlimited duration.

## Financing the Scheme

Financing such a service as ours is very difficult in Germany, because Insurance and Social Security regulations tend to prefer segregated forms of special care. Social subsidies or long term home help or care are limited to the poorest part of the population. However, the bulk of the people are not poor enough to get Social Assistance Subsidies, and not rich enough to pay for themselves. We have tried to ease this problem by making our service dependent on public grants. In this way it was possible to keep the cost of the service to a maximum of 5 D Marks an hour. The real cost of an hour's care would be about 11 D Marks, and the difference, as I said, covered by public grants. But we are not sure yet how long these grants will be given. One very important task of our four regularly employed people (3 social workers and one administrator) is to ensure good public relations in order to keep the thing going.

## Lessons from Fokus

I am interested in the 'Fokus' scheme as we are also thinking on these terms, because we have found out that building up only support services without caring about suitable flats grouped together but in a reasonably small area (without any ghetto effect!) is not good, in three ways; 1st... It is so difficult to get suitable flats in Munich that an organised help to find them is very useful. 2nd.... If attendees are scattered over the whole city there are reasonable problems in organising the service to meet their individual needs and rights of attended and attendants. 3rd... The scattering of attendees over large areas is not very economical, because attendants have to travel a lot of the time and have to stay with the attendees a considerable time (during which there are no helpful activities to be done) just because it would not pay to go away and come back.

## Independent living

Through closer investigations into the Fokus scheme which we carried out with handicapped friends in Sweden during summer 1981 we did learn however that the Fokus scheme has severe drawbacks especially in the eyes

of handicapped people who are strongly orientated towards the concept of independent living. The Fokus scheme implies that there be an organisation that keeps helpers or attendants readily available in case of acute or long term needs of handicapped people. It's by this principle that handicapped people do not only depend on practical help in everyday life but they do additionally depend on some sort of service organisation.

In our further thinking and through closer contact with the American Independent Living Movement we develop the idea that it is better not to have an organisation that has helpers readily available and being employed by that organisation but rather have an organisation that gives advice and refers helpers to handicapped people. The direct contact and direct relationship of employment should then develop between the handicapped consumer and his helper.

The work of the organisation could then be described as some sort of solidarity, personal and professional back-up, and political or publicity lobby organised and run predominantly by handicapped people themselves.

## Living, learning, working in the community

We were affirmed of this view by international participants in a conference which we organised in Spring 1982 here in Munich.

The title of the conference was 'Living, Learning, Working in the Community – community based help and care services for independent living'.

There were about 350 participants handicapped and non-handicapped from 10 nations including the U.S.A., Canada, the U.K., Denmark, Sweden, Holland, Italy, Austria, Switzerland and Germany.

In confronting the well organised systems of community based help and care for handicapped people in Scandinavia with the not so well developed system in the United States we found out that autonomy or independence of handicapped people can be even threatened by a system which is too well

organised. We feel it is extremely important that autonomy or independence is the first principal guiding whatever form of organisation or private help needed by handicapped people. As a matter of fact we would nowadays be very cautious to establish a service which employs a considerable number of helpers, as this could tend to become some sort of community based institution.

# Disabled People Against Apartheid

“Africans want a just share in the whole of South Africa. They want security and a stake in society .... We also want equal political rights because without them our disabilities will be permanent”.

From Nelson Mandela’s closing speech at his trial in 1963.

The South African apartheid system which discriminates against its black population forces its black majority to live under harsh conditions. They cannot choose where they live but are dumped out in gigantic institutions called Bantustans. Equal opportunities to work and wages are made impossible. Schooling for black children is totally inadequate and therefore only a few blacks ever reach the academic qualifications that the whites are brought up to. The apartheid system creates barriers which prevent black people from securing a stake in society. With its high rate of industrial injuries plus its appalling health care facilities for black people, the apartheid system creates physical impairment at an alarming rate. The black people of South Africa are singled out for discrimination because of their single characteristic difference; the colour of their skins. To be black in South Africa is to be disabled.

People who have some form of impaired body (such as blindness, deafness or paralysis) can readily identify with the restrictions placed upon the black people of South Africa. For us the apartheid system has a familiar ring. We have separate schools, often of a low educational standard. Job opportunities are therefore limited for various reasons such as lack of qualifications, offices and factories being inaccessible and limited access to public transport. Physically impaired people are still dumped in institutions. We are also discriminated against because of a single characteristic different; our physical impairment. The be physically impaired is to be disabled.

In this context it comes as no surprise to us to find South Africa heavily involved in disability support. The white controllers of South Africa have found staunch friends amongst the able-bodied controllers of British

disabled sport. They play on people's sympathy for disabled people and use us in their efforts to build sporting links with the rest of the world. On the one hand the apartheid system creates disability on a massive scale and on the other hand the defenders of apartheid conjure up sympathy for these black people and use them to argue for breaking the Gleneagles Agreement.

## Background of DPAA

Over the past few years the International Stoke Mandeville Games Federation (ISMGF) have repeatedly invited a disproportionately mixed team from South Africa to play at the International Games at Stoke Mandeville. Despite protests they are continuing to break the sporting boycott on South Africa. They openly flout United Nations policy and break the Gleneagles Agreement which Great Britain is pledged to uphold. In fact the sporting boycott has made South Africa make minor alternations to its racist laws in a weak attempt to defuse international criticism of apartheid. This clearly indicates that the sporting boycott should be upheld until such time as the apartheid system itself is eradicated. The ISMGF's position is offering apartheid credibility in allowing South Africa to participate in international sport so adding further to the plight of black able-bodied and physically impaired people in South Africa.

If we take a closer look at the ISMGF set up we can find many similarities in their behaviour towards critics of apartheid. South Africa deals in a heavy handed way with opposition to its racist laws. Similarly the ISMGF is guilty of this. First lets see what gains the ISMGF receives from being active in disability.

In the conventional view of disability with its emphasis on personal misfortune, it is seen as very commendable to 'help the disabled', those poor unfortunates. In fact prizes are given out for doing so. This area is a rich stomping ground for collecting OBE's and CBE's and any other sort of B's you care to think of. This medal of course brings a certain amount of importance and influence to the receiver. These same people are the supporters of racism in this most vile form. They collect baubles in the name of helping disabled people, with one hand, and with the other shake the hand of apartheid.

The very atmosphere around Stoke Mandeville reeks with dominance and authority. If you should ever stroll around the grounds of the sports stadium, giving out leaflets against apartheid, you will smell this odour, mixed up with paternalism. One afternoon two supporters were wheeling around the grounds giving some information about apartheid to the athletes that were around. A man dressed in a smart blazer and looking every inch like a Stoke official walked up to them and asked if they were competitors. When the reply was no, he said "well get out. I have worked here for 20 years and I love these people." One would assume that this man only loved physically impaired people as long as they did not criticise the ISMGF's position in collaborating with apartheid. It seems that they want physically impaired people to be uninformed of the issues involved, not to protest if they do know the facts and in that way stay 'lovable' people.

In 1979 we saw how the ISMGF reacted to one of their athletes, Maggie Jones, a table-tennis player who gave out leaflets at Stoke, highlighting the appalling health care facilities that are provided to black disabled people. Maggie was immediately banned by the ISMGF and could no longer play sport in England. This action would be unheard of in able-bodied sport. The ISMGF gave the same type of reaction to Maggie's protest as the South African government gives. Punishment is dealt in an attempt to silence criticism.

Despite the ISMGF's attempts to silence Maggie Jones, supporters of anti-apartheid rallied around, joining in the protest that Maggie had started. The same year that the ISMGF ended Maggie's sporting career, marked the first demonstration at the International Games. Maggie was prepared to go to court over the ban, when the ISMGF heard this they quickly reinstated her. Time will tell whether they will ever pick her for future games again.

By 1981 plans were well under way for the second demonstration. This year's demonstration was being organised by the Anti-Apartheid Movement with support from the disabled organisations. During the build up to the campaign, one of Stoke's top swimmers, Bernard Leach, withdrew in protest of ISMGF's collaboration with racism. This action added further to the success of the campaign as the slogan 'Don't play with apartheid' was being carried by yet another athlete. This year the number of demonstrators increased on the previous years. At one stage during the demo, the South African team made a brief appearance and tried to argue with us that the apartheid system was not so bad. However their arguments did not convince

the demonstrators and only reinforced that the team is sent over to act as ambassadors for apartheid. Their arguments did not fool the anti-apartheid supporters, nor did it convince the other team members, many of whom came out to talk to us and expressed their concern at the breaking of the Gleneagles Agreement.

## Forming DPAA

In an atmosphere of united protest, disabled people were becoming more aware of the need to work in a more organised way to increase the pressure on the ISMGF in order to get them to comply with the Gleneagles Agreement. After the 1981 demonstration disabled people formed an organisation called Disabled People Against Apartheid (DPAA).

DPAA consists of co-ordinators who liaise with individual supporters and organisations. Jointly they work towards the main aim of DPAA which is to support the struggles of black disabled people South Africa against all forms of discrimination imposed by the apartheid system. One of its priorities is, of course, increasing pressure on the ISMGF to comply with the British Government's wish to support the Gleneagles Agreement and not to show contempt for this pledge by inviting a South African team to compete in disability sport.

Over the past year DPAA has coped with many difficulties that are involved when physically impaired people need to organise. Transport to and from meetings, demonstrating, leafleting events have all brought added problems. We repeatedly have to battle with our own segregation and lack of mobility, as well as adverse press reporting. All these problems have to be coped with as well as coping with the stubborn attitude of the ISMGF. Despite these added problems DPAA has been very successful. The organisation has many supporters, individuals as well as organisations, both able-bodied and disabled people. This year's demonstration, for instance was organised jointly between DPAA and the Anti Apartheid Movement (AAM). The South African Non Racial Olympic Committee, (SANROC) has given us a lot of assistance through their international contacts. Further support has come from Trade Unions, the Aylesbury Labour Party and National organisations controlled by disabled people.

Supporters of DPAA have passed resolutions through their organisations calling for the banning of the South African team from international games.

At this year's demonstration more disabled people turned up than ever before. Inside the sports village there was a very different picture. The number of competitors was down from 800 to 400. Many countries have pulled out of the games and they can no longer be called international. In 1918 Jamaica withdrew and the following countries have withdrawn their support in 1982, Canada, Kenya, Philippines, Sudan, Equador, India, Malaysia and Bangladesh. This undoubtedly shows the success of the three year old campaign. The once well attended international games have dwindled to hardly surpassing the attendance of that of the national games. The ISMGF have lost credibility for collaborating; with world opinion of physically impaired people increasing in their condemnation, they will lose.

#### Police Harassment

This year's demonstration had barely started when the police began to harass us. People were just beginning to arrive when the police told the physically impaired people in wheelchairs that they could not hand out leaflets and would have to stay on the grass verge out of the way. The people concerned were very cross about this. We had previously informed the police that disabled people were going to be demonstrating and the police did not raise an objection at the time. On the day it was a different story, they told wheelchair demonstrators that they were causing an obstruction and must go on to a grass verge nearby. This meant that we could not demonstrate. We repeatedly told the police that this was a disabled people's demonstration, but they just insisted that we move away. Their argument being that we had "helpers" with us who could hand out the leaflets and demonstrate for us! The police were referring to our able-bodied supporters. When the police failed to see the reasons why our able-bodied supporters could not demonstrate instead of us, we asked all able-bodied people to leave the demonstration. This they did, and a line of physically impaired people in wheelchairs faced a line of policemen. We were then able to negotiate with the police. Half the wheelchair users stayed leafleting and half went onto the grass verge.

Here we have a situation whereby the police are attempting to reinforce society's traditional view of disabled people. They see us as passive recipients; that we should be put out of the way to keep society tidy and

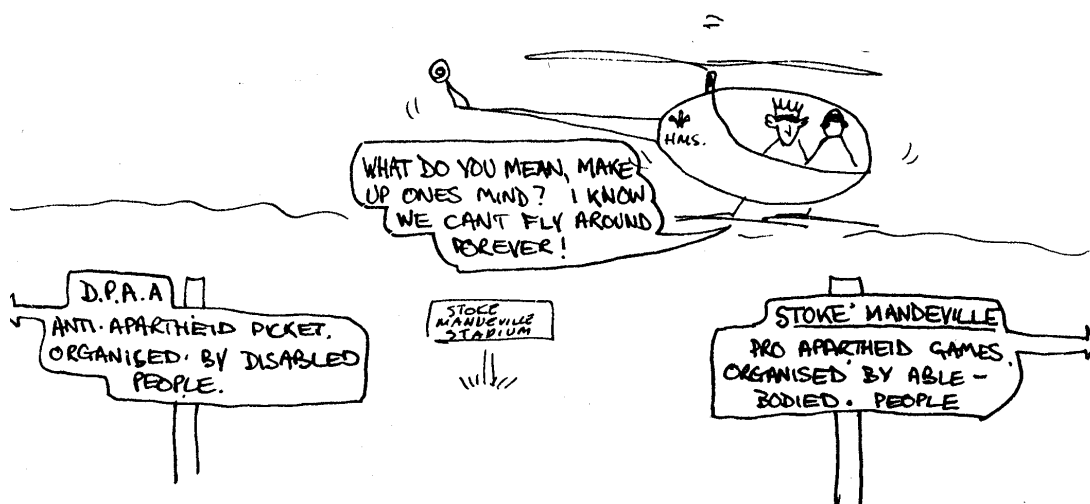
orderly. Most of all attempts are made to deny us a political view. The South African government tries to hold down its apartheid resisters, the ISMGF tries to gag its athletes, and our police try to stop disabled people demonstrating on the question of apartheid. What they have most in common is that they are all becoming unsuccessful.

Not surprisingly DPAA has received a mixed reception from the press. Although last year's demonstration received more press coverage in the national newspapers, many daily papers reinforced a traditional view of disability in their reporting. None of the popular nationals put their reports on the sports page. The better quality papers gave only adequate coverage, but others took a very paternalistic slant by pushing the view that it was a shame to stop poor disabled people from playing games. The Express distorted to such an extent that their reporting gave an untrue picture. They referred to 'Wheelchair Heroes', i.e. the South African team (Daily Express, 27/08/81., Colin Pratt). They gave a slant to their article which implied that able bodied demonstrators were being unkind to disabled people. They failed to mention the fact that many demonstrators were themselves disabled. This type of reporting tries to deny disabled people the right to have a political view. These reports continually attack our supporters. Last year they attacked AAM and SANROC, and this year they attacked the Aylesbury Labour Party who gave us support in organising transport. The Express again distorted the facts, saying that the Aylesbury Labour Party were transporting in disabled people in their attempts to disrupt a disabled sports meeting (Daily Express, 19/07/82., Colin Pratt). The Aylesbury Labour Party were responding to our request for support in getting to our demonstration. Not an easy task when the public transport system excludes us from access to use it. It is very noticeable that these attacks are aimed at DPAA's supporters. They do not attempt to attack us directly. How can they, when the resistance is coming from disabled people? Instead they portray us as poor disabled people who are being used. In sharp contrast the left wing newspapers have given us good press coverage.

In general this year's press coverage, although more limited, was clearer and more accurate than previous year's. DPAA had taken the decision that disabled demonstrators would talk to the press direct. This probably went a long way to ensuring that reporters got their facts right, and would reinforce disabled people's desire to be politically aware.

## Prince Charles

Apart from the police harassment, demonstrators were also upset to find that the ISMGF had invited His Royal Highness Prince Charles, to open the games. DPAA has since written a letter of protest to His Highness, explaining that disabled people both here and abroad are angry that an invitation to South Africa is still being extended in disability sport. Disabled people are well aware that South Africa's apartheid system itself causes disablement of the black population due to its blatant inequality of health care facilities.



28

We also pointed out to Prince Charles that we have had an assurance from the present Government that it seeks to fulfill the obligations of the Gleneagles Agreement, and the ISMGF do not receive grant aid because of the participation of South Africa. We stressed our surprise that in the light of this he decided to attend, as his appearance at such events could be misinterpreted as collaboration and support with apartheid.

As Prince Charles is the royal patron of the British Paraplegics' Sports Society, we have asked him to seek an assurance from ISMGF to comply with the Gleneagles Agreement and ensure that this has been achieved before attending future Games at Stoke Mandeville. As heir to the head of

the Commonwealth, we are confident that Prince Charles would not wish to upset the Commonwealth countries nor add to the distress of disabled people who are dissatisfied with the present situation. Therefore we are expecting a favourable response to our request.

So far the whole campaign has been a great success. Each year the demonstration has grown. Couple with countries' withdrawing in such large numbers, it will gather momentum and grow in strength. Next year DPAA hopes to draw more physically impaired people to Stoke. If more countries withdraw, who will be left playing with apartheid?

Anyone who would like more information and to assist please contact Brenda Robbins, Central Co-ordinator, Disabled People Against Apartheid, c/o 89 Charlotte Street, London W1P 2DQ.
---

# The Outsiders Club

..... Di Beck

Physically impaired people experience systematic segregation and isolation because they are denied full participation in the mainstream of social activity. I see as a predictable product of this the development of facilities such as the Outsiders Club, which describes itself as a social and contact club for socially isolated people, especially those who are physically handicapped. I have criticisms to make of the Outsiders Club, (which will from now on be referred to as the O.C.) for the way it actually furthers the oppression of physically impaired people rather than creating a situation in which people can overcome their isolation. The O.C. has a clear objective that is to gratify people's desire for sex and also their desire to form loving relationships. It is my contention that because the former is such a strong prevailing influence that it works against the latter.

..... the spy

The club was set up by Tuppy Owens and some of her friends. Owens gives herself the respectability of professionalism by being termed a 'sexologist'. As a founder member she gives the club a lot of its publicity and gains publicity in return. She is the authoress of publications such as 'The Sex Maniac's Diary' and 'The Male Chauvinist Pig's Diary'. She is occasionally written about in the more pornographic Sunday press. She has also written a book which is subtitled 'A Guide to Feminine Psychology' – 'Take me I'm Yours'. This is on the recommended reading list for members of the O.C. and is one of only four books they have taped for the blind. It has been described most aptly by a UPIAS member as a manual of rape. It is indeed one of the most hideous pieces of writing I have ever come across. In it Owens sets herself up as an authority on the female psyche and describes it in such a way as to leave no doubt that her understanding is about equivalent to that of the type of less agreeable ancient who left his baby daughters on a mountainside for the wolves. This book is aimed at a male readership and to quote from the foreword is 'for all nervous, anxious and doubtful men (and who is not) she serves the purpose of the *spy* by revealing the weakness in the enemies defences' (emphasis added). It is difficult to know where to start in giving examples from this book, but if we

look at Chapter she says ‘Women do give you a hard time and I’m sorry’. Ms. Owens sees a need to make apologies for the fact that women do not necessarily want to gratify any man who approaches them. The basic thesis of the book is that women are fundamentally too stupid to know what they want. Consequently when they say no, they mean yes and would it not be better if they just said yes straight away and saved the man a lot of anguish. In Chapter 2 she suggests, ‘Few girls are actually on the look out for sex’, she advises the man to show just enough caring to inspire confidence sufficiently for her to sleep with him. She is actively encouraging men to deceive women and yet earlier in the chapter she says she believes in love, romance, permanent relationships. However, her attitude towards permanent relationships is ‘the main difference between who you’ll marry and who you’ll screw is that people marry for status and screw for lust’. How does she think trusting relationships can be achieved while she maintains that men are perfectly within their rights to lie to women and want them for nothing more than their bodies. The way women are supposed to distinguish between the lying lech and the man who wants an honest relationship, predictably is of no concern to Ms. Owens. Neither is there ever any suggestion that it would not be impossible that it would not be impossible for us to change the whole way in which society is organised in terms of oppressive one-to-one relationships. The status quo into which disabled people do not fit is never challenged by the O.C.

## Manual for Rape

### A Manual for Rape

Later on in the book she writes on techniques for getting a woman who does not seem willing to participate in the full sexual act to succumb. She advises

copious touching and then ‘turn her over and ram it in. Whilst she can’t see you she won’t fight too hard’. Tuppy has decided ‘this is the sort of rape a girl enjoys’. I think I have probably quoted sufficiently to convey the general flavour of this book which is incontrovertibly oppressive to women. It does everything possible to perpetuate the images of the feather-brained passive woman willing to serve the dominating egocentric man. This latter, incidentally, not one which is generally compatible with physical impairment. By giving it such importance she does nothing to change the

social scene from which a physically impaired man may find himself rejected.

Tuppy Owen's attitude to physical impairment is hardly progressive, because she sees people primarily as sexual objects rather than as sexual people. She says if you've got a really repulsive body don't take your date to the swimming pool, where she'll see it and get put off. If you've got six fingers on each hand don't leave the sixth poking out of your five fingered glove – try a strip club; most of the guys in there are ugly *too* (my emphasis).

Physical impairment is thought of as repulsive and something to be hidden or disguised when out to conquer your girl. In tune with this the O.C.'s policy is to try and match up people who can compensate for each others' inadequacies. This is an interesting euphemism. It means for example the matching of a blind person with someone who is considered very unsightly. It is a firm indication of the manipulative, reactionary, oppressive tendency of the O.C. organisation.

A recent advertisement in the 'Scottish Council on Disability' newsletter in the 'Wanted' section serves to demonstrate further the sexist stance of the O.C.

#### WANTED/FOR SALE

##### WANTED

Ladies to help co-ordinate the Scottish Network of the Outsiders Club which is a social and contact club for socially isolated people, especially those who are physically handicapped.

This poses the very obvious question – why ladies and not gents as well? It says a lot about the nature of the club.

## Oppressive behaviour

The mood of the O.C. is then influenced by an arch misogynist and the effects of this are made fairly apparent at the O.C. gatherings. On one occasion a stripper was employed at an O.C. function. It is hard to think of ways in which the female Outsiders would benefit from this entertainment,

the men in the club do then behave in an oppressive manner, choosing to entertain themselves with this spectacle and linking their relief from social and sexual isolation with active participation in such abuse.

A UPIAS member has been present at an unofficial gathering which consisted very largely of O.C. members. One of those occasions a physically impaired woman was taken out of the room on three separate occasions by the different men and made use of. One could argue that she was perfectly in control of the situation and that it was entirely her own choice. I think, however, this would be to oversimplify, given the prevailing ideas in the club that sex is the primary objective and that the role of a woman is to gratify men's sexual urges – pressures were being put upon her, which would make resistance very difficult. I see here the logical role that women have to play in a club orientated towards men who are encouraged to regard them as sex objects. The women have to prostitute themselves as a substitute for the relationships they sought to alleviate their social isolation. here they do not even get paid, but can be used for free.

On another occasion Tuppy Owens, draped across a sofa was being fondled by three men simultaneously, one of whom was married to a physically impaired woman he had met at the O.C. She was sitting watching this spectacle. It can hardly have boosted her morale. Tuppy Owens would not have been in this situation at all if she really cared about the relationships of two of her members. At the same gathering a physically impaired woman was talking to a man in a wheelchair when Tuppy Owens went by with a brush of her hips against him and a come-on look.

These incidents demonstrate in her orientation towards men that she does not care about the feelings of physically impaired women and is quite prepared to put them down and compete with them while also using them.

It is deplorable that this woman is achieving credibility and respect from the establishment. This is probably partly because she has created a convenient dumping ground for the emotionally and sexually stranded. An article about herself and the O.C. has appeared in the journal 'Therapy'. Of course the content of the article does not include any suggestion that society is at fault for creating these isolated people. Society simply applauds any token gesture of a solution.

It must be made plain that I do understand that a lot of the work of the O.C. is done by the active membership trying to be mutually supportive. A lot of this is done on an individual basis teaching people ways of fitting into the environment. This sort of assistance can realistically be of little use as it is the environment which excludes physically impaired individuals. It is not their personal problem but the problem of an oppressed group. However, it is important that the social needs of the physically impaired are not ignored, but that they are met through another structure. A structure which is not oppressive to women and not oppressive to the disabled. A reactionary group such as the O.C. can only do long-term damage to the cause of physically impaired people. It is a development on the disability scene against which we must put up a struggle.

# THEATRE WORKSHOP

PRESENTS

FESTIVAL FRINGE  
NEW PRODUCTION



"COMMITTED AND  
POWERFUL" - SCOTSMAN

## THE YEAR OF THE CABBAGE

Tom Lannon, author of stage-play "The Year of The Cabbage", discusses his approach to radical theatre drama.

"The Year of the Cabbage" was first performed by Edinburgh Theatre Workshop in March-April 1982 in a four-week tour of Scotland, and at the 1982 Edinburgh International Festival. The play was published in book form in Autumn 1982 by the Scottish Society of Playwrights, 37 Otago Street, Glasgow.

When trying to make sense of such a complex business as social change, it is sometimes tempting, but always very reckless, to ascribe monocausal status to the contributions of particular people, processes and events. In the light of a kaleidoscope of causal factors, it is safe to say only that social change is the outcome of a helluva lot of diverse pressures at a helluva lot of pressure-points usually over a helluva long time. As the "disability" realm of discourse is no exception to this general rule, we will explore in this short article some of the ways in which one particular theatre production, a fast-moving black comedy called "The Year of The Cabbage", has set out to show how in many ways disability is the result of social, political, and economic factors, rather than personal "failure". Beyond a shadow of doubt, disability is a particular type of negative discrimination against people who

happen to have impairments. A spirit of healthy skepticism, however, is virtually essential as soon as we start to consider what impact, if any, a single stage production might have on conventional wisdoms.

## Tailism

The big danger for any creative and radically experimental writer is the danger of indulging in tailism. In his recent book “A Good Night Out”, John McGrath of the 7.84 Theatre Company in Scotland defined tailism as ... “.. trailing along behind the tastes of the working classes, debased as they are by capitalism” instead of presenting “.. an oppositional form of theatre which points forward in the direction of a future”.

The temptation to indulge in tailism arises from the need to attract and hold an audience at all, the need to guard against being so far ahead of the audience that contact, and therefore positive impact, is lost. So the problem is not one of preaching to the converted, but rather how best to reach the unconverted. “The Year of The Cabbage” tries to overcome this problem of tailism by using a double dialectic. In other words, there is opposition built into the play in both its form and its content. The first half of the story is all very believable. With simplistic naturalism, a workman called Jimmy falls from a roof, breaks his back, goes into hospital, is confined to a wheelchair, loses fair-weather friends and fiancée, and undergoes a “typical”, real and credible experience. So far, so conventional, and the audience can easily identify with all that’s going on. But the dry realism imposes severe limits on a critical and progressive angle – it chokes the possibility of challenging the spectators, and we are in danger of falling in with yet another ritualistic endorsement of the status quo.

## Collective struggle

If I had chosen to operate the entire play within this overwhelmingly naturalistic style, I would have been forced back onto metaphors in order to extend the significance of any message I wanted to project, and the result would have been an inevitable imprecision about the meaning of that message. Instead of a sense of collective struggle against disabling attitudes and practices within the social environment, the impression would have been

given of Jimmy as an isolated individual whose predicament is put across as a personal failing.

## The campaign

After the interval, though, the set changes for the second half of the play from a hospital ward to the workshop of an industrial rehabilitation unit, and at the same time the stylistic emphasis switches from the plain and factual to the more colourful slant of pure fantasy and the counter-factual. Jimmy meets his fellow-inmates, one of whom is in a wheelchair, one is deaf, and one is blind, and he is introduced to the possibility of an adversary standpoint of the victims vis-à-vis the well-heeled, “expert”, able-bodied professionals who run the place. The ambiguity of the term “cabbage” is revealed when Jimmy joins his companions in a Campaign Against Bureau-Babble and Grievous Exploitation. An atmosphere of free-wheeling anarchy is built up in a series of scenes which include jazzy song-and-dance, the bugging of a case-conference, and a wheelchair society complete with normless darkness and melancholy hypothetical music. The tension culminates in a siege when, after a bellyful of authoritarian benevolence, the victims demand, with menaces, a Bill of Rights for people with impairments, and the abolition of exhibitionist charity.

By setting the progressive elements of the play in this kind of context, the story can shake off the shackles of uncritical realism and make explicitly points about the oppression of disabled people without awkwardness, and without the turn-off effect that is so often the understandable response to social protests, however valid these protests might be, which are presented or perceived to be presented, only in the monotonous form of a humourless gripe.

In addition to the stylistic devices within the play itself, there are other ways of getting minds on the move. The physical layout of venues, for instance. It was decided to do away with the traditional stage/audience relationship and instead go for an “open theatre” production in which the hospital trolleys, wheelchairs, and the rehabilitation unit workshop were set up on the floors of the venues, so that the audiences had to clamber into the hall via the “stage”, and leave by the same route, infected with tactile confirmation of the whole experience. Also, many of the venues on the Scottish touring production of the play included discussion sessions directly after the

performance. The mass media, too, at local and national levels, have been generous in their coverage of the show.

## A balance

Live theatre, then, is an excellent vehicle for ventilating the victim's version of reality. The question of whether and to what extent it can make any impact towards social change, however, remains stubbornly imponderable. This is why it is so vital to balance polemics with entertainment value. The paying public rightly expects, at the very least, a good night's entertainment. The crucial thing, therefore, is that even if all the heavy moral points don't get through to all of the people all of the time, there should still be something else there to generate an evening of escapism which is therapeutic for as many people as possible, even if some of the ideas presented are almost, but not quite capable of being immediately applied.