UPIAS Theme: Researching The Researchers

Settling Accounts with the Parasite People

- a critique of '*A Life Apart*' by EJ Miller and GV Gwynne -

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Two Perspectives

> "Britain today has the necessary knowledge and the advanced technology to bring physically impaired people into the mainstream of life and enable us to contribute fully to society."

These are the opening words of our Policy Statement published in 1975.

In a later section we contrast this exciting potential for integration with the grim reality of the conditions which characteristically exist in segregated residential institutions for disabled people. We go on to say at the best efforts of staff in such places,

> "are systematically overwhelmed by the basic function of segregated institutions, which is to lock after batches of physically impaired people - and in the process convince them that they cannot realistically expect to participate fully in society and earn a good living. This function was generally appropriate when special residential institutions first came into being, since in the competitive conditions of the time many physically impaired people could not

> even survive without their help. But now... the need for segregated institutions no longer exists in the way it did. They have become seriously out of step with the changed social and technological conditions of Britain today.”

This Union assessment has been confirmed in the years since our Policy Statement was first published. On the one hand, further evidence has accumulated of the cruelty and deprivation which institutional life involves (1). On the other hand there has been the rapid development of micro-processors and other technological aids with tremendous potential, both for solving specific problems associated with impairment, and accelerating the need for the reorganisation of society along lines which make

> “employment and full social participation,... accessible to all people, including those with physical impairments”(2).

There are also the continuing achievements of particular experiments which move towards more integrated living arrangements, involving personal help from the community, such as the Grove Road project (see page 32 [in this volume]). Instead of physically impaired people having to adapt to a hostile environment, the means now exist to create a physical and social environment that takes account of the needs of people with physical impairments.

The conclusion which follows from this assessment is that segregated institutions are essentially oppressive under modern conditions, and they should therefore be phased out and replaced by secure, integrated living arrangements in which severely impaired people would be able to participate fully in society. Looking at our situation from the position of an oppressed group, we in the Union are enabled to view reality objectively, recognising the potential that has now been made possible and by contrast the oppressive conditions of life that we are forced to put up with. The important thing is that our approach maintains a scientific analysis of our situation, which examines segregated institutions objectively within the context of modern social developments, is both necessary and possible, This positive perspective ‘is in sharp contrast to the pervading view of the vast majority of politicians, civil servants, managers and “experts” connected with our lives.

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

There have been a number of publications in recent years which attempt, amongst other things, to reconcile physically impaired people and our friends to the continuing existence of segregated institutions. Examples of those are the Warnock committee report on special education; the Snowdon committee report on integration(!); and the long introduction to Selwyn Goldsmith’s book *Designing for the Disabled*. But probably the most influential publication so far has been *A Life Apart* by Eric Miller and Geraldina Gwynne of the Tavistock Institute of Human Relations. First published in 1972, their book was reprinted as a paperback in 1974 and adopted as one of only four set books for the Open University course “The Handicapped Person in the Community”. (4). *A Life Apart* is also widely used on training courses for social work and health work students. Yet, as far as I can ascertain, the only critique of the book which has appeared anywhere is one I wrote for the magazine of the Cheshire Homes in 1973.

(5). Despite the strong criticism my review contained, it is clear now that I failed to tackle adequately the essential issues raised by Miller and Gwynne's work, and this article is intended to remedy that omission.

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

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

‘Detached’ and out of touch

Miller and Gwynne agonise a lot in *A Life Apart* about their “problem” of personal involvement as researchers. They see involvement entirely as a source of *stress* for themselves (and anyone else having contact with residents), and making it difficult for them to acquire a balanced and unbiased outlook as social scientists. They say, for example, “To respond to the emotional needs of the inmate, the staff member most experience an emotional involvement in the relationship; yet the greater the involvement the greater the stress” (6). As I shall later show, it is highly significant that they see involvement, for them and for staff, essentially as a *problem* in this way, and strive so hard themselves to take all possible precautions against it, so as to “acquire and maintain a balanced outlook” (7) or “regain some detachment” (8). For this purpose they underwent personal psychoanalysis; “relied heavily on the intervention of an uninvolved colleague to restore some semblance of balance” (9); and made sure they worked concurrently on other projects.

The authors paint a graphic picture of the stress and strain on them in visiting the institutions and talking to residents, and of profound oscillation of feeling they underwent - one day overwhelmed by “pity for the plight of the disabled”, and the next day seeing “the staff as victims of the insistent, selfish demands of cripples who ill-deserved the money and care that were being so generously lavished upon them” (10). Miller and Gwynne were, however, consoled by the fact that the only people “concerned with the disabled population” who were not struggling with a similar ambivalence were those who were “captured by a permanent bias”(11). This strange phrase, in the light of other references to staff being “captured” by residents, can only be interpreted as meaning people who support the struggles of residents for greater autonomy.

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

Their bias is embodied in the terms of reference of the Miller and Gwynne study. The terms of reference which they themselves proposed and which the Ministry of Health accepted, were in general terms, “to identify more precisely what was involved in providing residential care for incurables, and to discover possible ways through which appropriate changes could be brought about” (12).

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

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

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

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

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

By pleading a lack of scientific status to their work, Miller and Gwynne avoid completely the awkward problem of its objective evaluation. An obvious point to make is that, even for the remotest scientific credibility, “external criteria” are still needed to determine whether the “practitioner” has actually enlarged his own theory and extended his competence, unless his personal feelings on this are the only test which would be about as scientific as magic. Miller and Gwynne's formulation also abandons any attempt to establish criteria by which to determine the truth in the new theories *before* they have been tested in practice – it is of course precisely beforehand that it is vital to know whether a particular theory is likely to be of use. Even in their own terms, Miller and Gwynne reduce science to a set of subjective theories that cannot be verified or evaluated. Their denial of the possibility of objectivity should be seen for what it is – a complete betrayal, not only of science as it should be, but also of physically impaired people whose needs they claim to have special expertise in investigating.

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

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

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

Throughout the rest of the book, and especially in the chapter significantly entitled, *Social and Psychological Consequences of Disability*, again and again the authors describe the social and psychological disadvantages imposed on us as though they were natural *consequences* of our impairments (what they call our physical disabilities). Their view of our psychological state is summed up on page 72 as “infirmity has psychological – even psychopathalogical – consequences which are often insidious and even irreversible”. On the social “consequences” we are told for example on page 53 that the inability to achieve quite ordinary goals “arises out of the physical disability itself”. Similarly Miller and Gwynne go on to say that the cripple has to contend, amongst other things, with the physical, emotional and financial dependency “that the disability imposes on his relations with others”. Is it not extraordinary that supposedly balanced and unbiased social scientists can consistently be confused like this by an obvious fact, such as for example that physical impairment and low income characteristically go together in our society, into making the ridiculously naive assumption that the impairment *causes* the low income? This is about as sensible as assuming that women’s bodies cause their low income and financial dependency in a particular society, or that black people’s bodies cause them to be in characteristically in low paid employment. The social disabilities of oppressed groups are not a consequence of their own physical attributes, but of forms of social organisation which discriminate against them. It is in fact these that create, maintain and justify the discrimination forms of organisation who in reality are the main cause of our social disabilities or death sentences.

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

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

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

It is commonly believed that commitment to the cause of an oppressed group means that ‘reality’ will be ignored or distorted, and therefore that the best scientist is the one who tries to be least involved and most detached. Nothing could be further from the truth, as *A Life Apart* illustrates. It is precisely those who try to take a detached view of oppression who *cannot be objective*. This emerges very clearly in relation to the notion of “parasitism”. Miller and Gwynne make various references to residents as parasites, and throughout see us as essentially feeding off society not only economically but emotionally as well. However, an objective examination of the situation shows that it is not people who are segregated and demand the chance of employment who are the true parasites. The real parasites are those like Miller and Gwynne who grow fat by feeding on other’s miseries. On pages 18-19 they come out with the blatant admission that they see the institutions issue as “socially important” and “technically interesting” and as promising “both a theoretical and practical pay-off”.

Parasites in search of extending their influence

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

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

Throughout the pages of *A Life Apart* we can see how the authors’ bias towards “technically interesting” work with a “theoretical and practical pay-off” conditions all their investigation, methods and findings. The first paragraph of the Preface tells how they received from the Ministry of Health (now part of the Department of Health and Social Security) not only financial support but also advice, interest and encouragement throughout the project. Miller and Gwynne were so grateful for their help that they voluntarily submitted a draft of their book to the department officials for comments and suggestions. It is no surprise to find that Miller and Gwynne were later commissioned by the DHSS to do research into the problems of geriatric hospital wards, and that Miller was later to be seen leading a series of “action research” projects into *health care systems* of a similar type to that undertaken as part of this project.

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

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

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

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

Miller and Gwynne are in no doubt that basically these problems, like those of the residents, stem from the residents’ (or clients’) irreversibly defective bodies, and therefore essentially have to be accepted and lived with. However, with Miller and Gwynne’s expert help the situation may be improved slightly by making various minor organisational changes, and especially by conceiving theories “ to recruit staff and train them to operate more successfully”. On recruitment, Miller and Gwynne suggest the development of a new kind of profession specifically to care for cripples both inside and outside institutions: the suggestion is essentially a matter of redefining “professional boundaries” and creating a profession which makes cripples its sole concern (17). Another suggestion is to use as heads of institutions mature and balanced professionals on short term loan from other fields, such as the prison service or industry, or to appoint retired businessmen, ex-service officers and ex-colonial officials. Psychiatrists and clergymen are also thought necessary as back up resources to help heads of Homes to deal with particularly awkward problems amongst residents.

Training for control

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

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

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

Conclusion (by Judy Hunt assisted by Dick Leaman)

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

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

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

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

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

Judy Hunt.

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(11) p. 8.
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APPENDIX

QUESTIONNAIRE

by Paul Hunt

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

Confidentiality

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

1. Name
2. Age
3. Occupation
4. Previous occupations
5. Parents’ (or other Guardians ‘) occupations
6. Type of school(s) attended (e.g. comprehensive, public)
7. Places of further / higher education, and subjects covered

8. Qualifications obtained

9. Any experience relevant to present project

10. Salary from employment

11. If student, grant per annum

12. If student, estimated first salary when qualified

13. Other income - please give sources

14. Estimated top salary in career path

15. Do you have any physical impairments - if so please specify?

16. How did you first become involved with disabled people?

17. Why do you think you chose the kind of work that brings you into contact with disabled people as a group?

18. Good verbal communication is impossible without agreed definitions of at least the most important terms. Throughout this questionnaire *impairment* is taken to mean the lack of part or all of a limb, or a defect in a limb, organ or mechanism of the body; this includes brain damage, disease or deficiency, but not "mental illness" as it is usually called. *Disability* is the disadvantage or restriction of activity caused by e contemporary social organisation which taken little or no account cf people who have physical impairments, and thereby excludes them from participation in the mainstream of social activities.

Please comment, and if you disagree with the definitions say why and suggest alternatives.

19. What will happen to the information gathered by you (e.g. published. pigeon-holed, marked by examiner)?

20. Who will have access to the information – who is it *for*?

21. Who is paying the expenses?

22. Are you being paid a fee for the work (in addition to salary or grant) – if so, how much ?

23. What are the exact terms of reference you are working to ?

24. Please say how you think the project will help disabled people as a whole.

25. It is well known that the basic ideas which people *already* have when they draft questionnaires often very largely determine both the answers they get and the subsequent selection of material for use. In phrasing your questions, what was the main thing you had in mind to find out – what idea was uppermost to your mind ?

26. It is of the utmost importance that disabled people learn to distinguish between those workers on their behalf whose fundamental principles are correct, and those whose principles are incorrect. Correct principles are based on a recognition that society has now developed the technological capacity and other means to integrate physically impaired people into the mainstream of life (that is, into employment and other related areas of life such as education, transport and housing). It follows that the time is ripe for the elimination of disability, i.e. for full integration, and our struggles should all be directed towards this end. Commitment to this basic principle, and to others which flow from it such as the absolute necessity for the mass of disabled people to become active in tackling their own problems, is essential for professionals and others who seek to help us. Only with such a positive commitment to integration can workers on our behalf help to eliminate disability. Those who take the opposing view will instead create and entrench disability, and should be struggled against.

Please comment on these statements.

27. Recently a researcher sent a Questionnaire to members of hospital management committees, and some of them were indignant at being asked for personal information. Yet researchers, social workers, etc, frequently ask personal questions of physically impaired people, and everyone concerned seems to take this for granted as a natural situation, and does

not expect the roles to be reversed. The first group is characteristically active, dominant, and confident of their right to ask questions of the second group , which by contrast is characteristically passive, submissive, and careful not to question their questioners in return.

In your view, why does this situation exist? And do you agree that it is itself part of what is meant by disability as defined above, and as such should be struggled against?

28. How do you feel about receiving this Questionnaire?

29. Have you any suggestions for improvements to future versions of this Questionnaire?

(retyped digitally, 2018)