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Advocacy

The UK and American experiences

BOB SANG and JOHN O'BRIEN

Foreword by LARRY GOSTIN

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Foreword

The United Nations' Declaration on the Rights of Mentally Retarded Persons, adopted on 20 December 1971, embodies the principles of equality, integration, individualised habilitation, periodic review and natural justice. Specific articles of the declaration define rights to personal advocacy, to protection from abuse and degrading treatment, and to proper legal safeguards against any unwarranted restriction of rights. Furthermore, the United Nations' Declaration on the Rights of Disabled Persons, adopted and co-sponsored by the United Kingdom as an elaboration and refinement of those earlier principles, embraces mentally handicapped people. Article II recognises the rights of disabled people to avail themselves of qualified legal aid in order to protect person and property.

The International League of Societies for Persons with Mental Handicap has published guidelines on the implementation of the 1971 United Nations' Declaration. The League recognises advocacy as a basic support service to ensure appropriate access to needed services and facilities. It is about to publish its own declaration urging its member countries to adopt advocacy as a method of defending the rights, and securing services to meet the needs, of mentally handicapped people.

Advocacy, or positive guardianship, already exists in several countries – notably Sweden and the United States. The Swedish law on guardianship and trusteeship provides severely mentally ill and mentally handicapped people with the graded assistance of a paid and independent spokesman; the Developmentally Disabled Assistance and Bill of Rights Act requires each American state to establish an independent agency to pursue the individual rights of disabled persons – as John O'Brien's account in this book shows.

The concept of advocacy has been slow in gaining acceptance in the United Kingdom. Although it was discussed and encouraged in the Jay Report, successive governments have not made provision for it. The Advocacy Alliance was launched in 1982 by five voluntary organisations (MIND, MENCAP, One-to-One, the Spastics Society and the Leonard Cheshire Foundation) as a pioneering project during the International Year of Disabled People to create a one-to-one scheme of friendship, protection and representation for many isolated people living in long-stay mental handicap hospitals. A strong and compassionate account of the work of the Alliance is provided here by Bob Sang, its first coordinator, who examines all the barriers (both attitudinal and structural) that are placed in the way of any organisation seeking to establish such a system.

Apart from the Advocacy Alliance, some independent advice centres already operate in Britain to provide an information and advocacy service. A local Citizen's Advice Bureau established a scheme within Middlewood Hospital, Sheffield, which has been in operation since 1976. It aims 'to challenge the low status accorded to those labelled "mentally ill" by exploring ways to improve their life chances via channels of advice, information and advocacy and to work with and support other groups in the provision of services to these people'. A similar project has been established at Tooting Bec Hospital, the Springfield Legal Advice and Representation Project started in 1982 with an independent grant. Staffed by a solicitor and an adviser, the project offers a full range of legal representation. But these schemes offer something far more radical than that: they form the germ of a much-needed independent advocacy service in the United Kingdom.

An advocate is a person who effectively represents, as if they were his own, the interests of a mentally ill or mentally handicapped person who has major needs which are unmet, and likely to remain unmet, without special intervention. Advocacy is important for all such vulnerable and passive people whether in hospital, a residential establishment or the community; it is particularly vital for those who are unable to plead effectively for themselves.

The process is, therefore, one of pleading the cause and/or acting on behalf of mentally ill or mentally handicapped people, to secure the services they require and the enjoyment of their full rights. Advocates may be consumers, volunteers or professionals who act independently. As agents of people with handicaps, they owe them a duty of loyalty, confidentiality and zeal in promoting their cause. The Declaration of the International League has identified three forms of advocacy.

> *Self-advocacy* involves persons with handicaps asserting their own rights, expressing their needs and concerns and assuming the duties of citizenship to the extent of their capabilities. Self-advocates often form groups which assist members to acquire the necessary training, skills and experience to participate more fully in their communities.
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> *Legal advocacy* is a term to describe the broad range of methods and activities by which lawyers and other skilled individuals help mentally ill and mentally handicapped people to defend their rights. This can include reform or creation of new laws, as well as formal representation (eg at mental health review tribunals or supplementary benefit tribunals), and information activities to publicise the cause. Casework, negotiation, education and training, individual representation, and studying the way laws and regulations are complied with, may be involved.
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> *Lay advocacy* (also known as citizen advocacy) refers to the persuasive and supportive activities of trained, selected and coordinated people. Working on a one-to-one or group basis, they attempt to foster respect for human rights and dignity. This may involve giving voice to the individual's personal concerns and aspirations, seeing that everyday social, recreational, health and related services are provided, and other practical and emotional support. The Advocacy Alliance in Britain is organised in this way.

There is perhaps no one with as much experience in lay advocacy as John O'Brien of the Georgia Advocacy Office in the United States. The obstacles he describes will be familiar to campaigners in Britain, but the constructive means by which these have been overcome are most important for us to examine and learn from. With Wolf Wolfensberger (a pioneer in the field) Mr O'Brien has developed an effective evaluation method, and the growing British services can profit a great deal from the North American experience.

Why is advocacy needed?

The rights of mentally ill and mentally handicapped people in Great Britain have received intensive public and parliamentary attention culminating in the Mental Health Act, 1983, and the establishment of the Mental Health Act Commission. However, these changes will have little impact on informal (voluntary) patients who comprise some 90 per cent of those admitted to mental illness or mental handicap hospitals and 95 per cent of those resident there at any given time. It is possible, however, that the Commission may have some future jurisdiction over informal patients. There is at present no statutory protection against inappropriate admission to hospital of informal patients, nor are these patients entitled to a periodic review to see whether they should stay in hospital or return to the community. The assumption is that they have consented to loss of liberty and waive the right of review. However, many such patients (especially mentally handicapped people) have not exercised a positive choice to enter hospital and between one and two thirds of them are there simply because there is insufficient housing and support in the community.

Noble intentions are simply hollow verbiage if the depressed and mentally handicapped persons in the back wards of our hospitals, or forgotten in the community, are unaware of their rights or too passive or powerless to enforce them. 'Rights' are meaningless unless they help achieve a better quality of life and dignity for these people.

The term 'rights' is not used here in a limited sense. A person does not only have a right to liberty or to refuse treatment; he or she also has a right to the services other citizens receive, together with special services suited to special needs. An individual has a right to all mandatory services and a fair share of discretionary ones. These include education, health care, housing, social support and welfare benefits. Furthermore, mentally ill and mentally handicapped people are entitled to the same broad moral and social rights – respect, dignity and privacy – as the rest of us. The traditional neglect of these groups, and the gross under-resourcing of services, is partly attributable to their isolation and passivity. They have no one to speak for them.

Conclusion

It is natural for mental health professionals in hospitals and residential establishments to deny the need for advocacy. Staff who are dedicated to the treatment and care of mentally ill or mentally handicapped people feel *they* are the advocates, and probably always have been. Some social workers refer to their work in terms of 'casework advocacy' or 'child advocacy'. It is important that staff continue to assume this role, but the cornerstone of advocacy is independence of statutory authorities if conflicts of interest and loyalties are to be avoided.

The mental health services owe a debt of gratitude to the King's Fund and the Advocacy Alliance for their strong and persistent support of the concept of advocacy. Despite all our efforts to treat disadvantaged people with respect and dignity, and to ensure for them a high quality of life, we shall fail unless we touch their lives through one-to-one personal support. This is probably the most effective service we could give to some of the most vulnerable and isolated people in our society.

Larry Gostin
Founding chairman, Advocacy Alliance and
formerly legal director, MIND
General Secretary, National Council for Civil Liberties

Citizen advocacy in the United Kingdom – a first attempt

BOB SANG

Prefatory remarks

I left the Advocacy Alliance project to take up a teaching post. This paper has provided me with a much-needed opportunity to reflect on the work that I engaged in during the formative stages of the Alliance's programme.

It seems to me, as a student of social policy, that citizen advocacy is one of the most exciting developments to reach our state welfare system in recent years. If it survives successfully, then it opens up possibilities for changes which policy-makers, administrators and professionals seem unable to achieve. The exciting thing is that it can mean change 'from the bottom up'; that is, change promoted by ordinary citizens together with the residents of long-stay institutions.

My main purpose is to stimulate interest in advocacy, so that more people will feel that they should become involved. Consequently, the opinions contained in this paper are entirely my own, but the content owes a great deal to the work and ideas of former colleagues and, of course, the first citizen advocates.

1 Introduction

During the autumn of 1982 some friendships began which signified the start of a most important new form of voluntary activity in mental handicap hospitals in the United Kingdom. These relationships had developed between hospital residents and volunteer *advocates* as a result of the work of a new organisation, Advocacy Alliance[1], in collaboration with colleagues and friends working for the statutory and voluntary services. At the time I was the Alliance's full-time coordinator and I had been responsible for the preparatory work which had led to these unusual events.

The purpose of this paper is twofold: to consider some of the lessons to be learned from the implementation of this highly sensitive project; and to discuss the concept of *advocacy* in the British context and examine its value as an initiative for mentally handicapped and similarly disadvantaged people.

Advocacy occurs when a private citizen enters into a relationship with, and represents the interests of, a mentally handicapped person who needs assistance to improve his or her quality of life and obtain full rights and entitlements. By providing emotional support through friendship, spokespersonship, opportunities to learn new skills, and help in obtaining needed services, volunteers work for the benefit and growth of people who are handicapped.

Thus, advocacy implies a one-to-one relationship between two citizens which, over a period of time, should result in greater opportunities and better experiences for the individual who, by reason of restricted circumstances, has not enjoyed an integrated life in the community and the full rights of citizenship. The most important feature of advocacy is that it assumes that advocates and the people they befriend are both valued people, each with unique experiences, skills and interests to share.

Defined in this way, advocacy appears to be a positive and a controversial concept. No one disagrees that more could be done for people who live in long-stay hospitals, but many people predicted difficulties and even unacceptable effects resulting from implementation of such an idea. Others find it difficult to comprehend proposals which regard 'retarded' people as the equals of ordinary folk, entitled to the same consideration and human dignities.

The objections were, and will be, easy to predict. Advocates might stir up unnecessary disputes, or, like many well-intentioned people before them, they might actually hurt or upset those they seek to help. In addition, any new project, especially one involving outsiders sponsored by powerful voluntary organisations, can cause unnecessary work and disruption out of all proportion to the eventual benefit to small numbers of patients or clients. Another widely held point of view is that the idea is really unnecessary. Staff, relatives and existing volunteers make the best advocates and this has been so for years. They know the people and the services better than anyone and there is a tacit acceptance of their moral duty to seek improvements for those in their care.

These criticisms reflect some of the underlying problems which any advocacy scheme must confront in the UK. All those who seek to improve and change human services will recognise the various elements only too well. The point is that they acquire a particular emphasis as any attempt to develop advocacy progresses. These obstacles fall broadly within two categories: attitudes towards mentally handicapped people, and the structure of the mental handicap services with their historical reliance on institutional care.

1 Attitudes ('Handicapism')

The notion that mentally handicapped people should be regarded as having the same human rights as any other member of the community remains alien. Many professionals and a considerable section of the public do not see why a man or woman who suffers from some form of intellectual disability should be accorded the same dignities and respect as any other member of the community. Perhaps the most degrading aspect of this is the well-intentioned but suffocating paternalism which pervades many services and public attitudes.

The historical legacy, seen in the perpetuation of such labels as ‘imbecile’, ‘weak-minded’, ‘lunatic’ and ‘idiot’, remains embodied in many assumptions about the character and personality of mentally handicapped people. More recently, ‘subnormal’ and ‘retarded’ have come to dominate the catalogue of demeaning words which have a profound effect on people’s lives in a much wider community than that defined by the caring system. Mentally handicapped people themselves do not wish to be labelled at all. Sadly, we have a long way to go before we can talk, or write, about people with mental handicaps with the same lack of emphasis as when we write about people with flat feet (my particular handicap!). There are other problems, too.

The all too common confusion between mental illness and mental handicap, or ‘psychiatric’ and ‘subnormal’, is reinforced by the continued medicalisation of mental handicap services.
Misconceptions about the emotional needs and personal development of mentally handicapped people often appear to be justified by characteristics which, in fact, derive from chronic institutionalisation.
The assumption that people with intellectual disabilities have very limited potential for development; a self-fulfilling view reinforced by most of our institutional services.

2 Structure of the service

Priority Although mentally handicapped people have been accorded greater recognition in recent years, the whole service has had to start from a significantly lower ‘base-line’ within the statutory services.

Dependence on long-stay institutions Large numbers of mentally handicapped people have experienced various forms of incarceration over the centuries. Prisons, workhouses, psychiatric hospitals have all been used; and specialist establishments did not come into use until the latter part of the last century. When they did become extensively used the policy-makers apparently intended that such places should be inherently prohibitive of voluntary intervention. The principal factors to be overcome are

their geographical isolation from centres of population
the large numbers of profoundly handicapped residents
their powerfully conservative sub-cultures
the negative image they create for outsiders and the antipathy towards, and even fear of, mentally handicapped people they generate within the local community.

It is not the purpose of this paper to add to the growing number of critiques of mental handicap policy but, when examined in this context, it is clear that the objectives of an advocacy scheme can only be achieved through a persistent challenge to set ideas and established practices. Each step towards the innovation of an independent advocacy programme throws new light on the nature of the system we work within and the changes in attitudes which must be sought.

In practice, this presented Advocacy Alliance with several crucial problems that had to be overcome.

Many influential groups had to be persuaded of the need for advocacy.
The proposed scheme had to be shown to be viable within each establishment or locale.
Management and staff had to be prepared to commit resources, especially time, to the project.
And if all this was achieved, advocates had to be found and properly prepared, and a long-term commitment secured from all concerned.

Before I discuss the implementation of the project, it is essential to examine the source of justification for our efforts – the need for advocates in mental handicap hospitals.

2 Isolated and unrepresented residents in long-stay institutions

Much has been written in official and private publications about the inappropriate nature of the long-stay hospital environment – Victorian buildings, inadequate staffing, insufficient or useless facilities, out-of-date or questionable policies and practices, bad food, no privacy, and so on. Complaints, investigations, exposés, and the like have focused attention on the deficiencies of an under-resourced service. In defence of this system of care it has also been shown that new methods, better amenities, progressive innovations, exceedingly committed staff and management, have all mitigated against the damaging effects of a burdensome institutional history. While the arguments, discussions and debates have been taking place among the various interest groups, the residents have had to get on with their lives largely unaware of the concern being expressed about the conditions they experience and the future that appears to be waiting for them.

Over 40,000 mentally handicapped people live in long-stay institutions. Many could readily live elsewhere and, although efforts are being made to help them leave, it is extremely unlikely that change will take place quickly. Moreover, demographic pressure may cause an increase in hospital admissions if community-based services do not respond sufficiently to the growing numbers living with family or friends, who are finding it increasingly difficult to cope. In such circumstances it becomes depressingly easy to predict a reversion to the use of large establishments. The problem with such places, whether they are run by social services, the National Health Service, or private organisations, is that they isolate and institutionalise residents and staff. Even in cases where residents are visited regularly and the hospital or home adopts progressive policies, it is clear that this cannot compensate for their withdrawal from the wider community. For many thousands of residents of mental handicap hospitals, chronic isolation has been a persistent feature of their lives for years. Official estimates suggest that while one third of inmates never receive a visitor, many more are visited only infrequently. In other words, substantial numbers of mentally handicapped people never meet people other than their fellow residents and the staff who are paid to be there.

My own experience at St Ebba's Hospital in Epsom, and Normansfield in Teddington, was that half the residents suffer this form of social exclusion. Many had lived all their lives in care, often with no real contact with the outside community. With the best will in the world, staff cannot hope to compensate for this deprivation. Residents of institutions can never be lonely in the sense that there is always someone else there: an inescapable fact of life. But they can be extremely lonely in that there can never be anyone special in their lives who is not part of institutional life or who is not beholden in some way or another to the service system. Their individual needs and interests cannot be pursued and protected independently in these circumstances, and if there is no one to take an interest in them, how can their true wishes ever be expressed? Consider a couple of examples.

Paul is in his early twenties.[2] Unwanted at birth, he was almost immediately placed in care and within a short period of time had suffered severe brain damage as a result of lead poisoning. When I first met him he was very solitary, being unable to speak and generally very inactive. He was regarded as a problem because he was given to outbursts of violent behaviour which on occasions had caused his isolation in a secure ward, as much for his own protection as that of others. The nurse who introduced us obviously cared about Paul and could clearly see the attractive side of his personality. I subsequently spoke to several people who knew Paul and 'felt', for one reason or another, that he possessed considerable untapped potential. But no one had the time to find out and no one ever came especially to visit Paul.

Similarly, Mary had no contact with people other than her fellow inmates, staff, and the occasional volunteer. Like Paul she lived on a ward with twenty or so other people, often cared for by only two nurses. She could repeat a few words parrot-fashion, and she could show affection fleetingly. All but two weeks of her life had been spent in mental handicap hospitals and expectations were that she would be unlikely to know any other environment.

The lives of both these young people are fairly typical. They suffer from the additional handicaps of social neglect and institutionalisation, inherent in a system of residual care which relies so heavily on hospitals. The other residents whom I met had also spent much of their lives away from the community and many were growing old without much hope of change. Not that they were necessarily unhappy and poorly cared for – in some cases quite the opposite. But their experience of life was so limited, so routinised, and so lacking in choice and direction, that they were denied the opportunities for change and development which might encourage self-confidence and self-reliance.

For Paul and Mary, and five others, these circumstances changed quite significantly during the late summer and autumn of 1982. During that period they were introduced to people who were to become their advocates – except for Ian, who had known his advocate for some time, as I shall explain later – and from that time on we all began to learn about the importance and value of advocacy for such isolated people.

But it took a long time and a great deal of effort to reach that stage and it is well worth examining the background to the project and the steps it had to go through in order to achieve these small beginnings.

3 Implementing an advocacy programme in the United Kingdom – the experience of Advocacy Alliance

There have been many successful and unsuccessful advocacy schemes attempted elsewhere[3] but the first attempt in a new country inevitably produces peculiar advantages and disadvantages for the innovators. John O'Brien's paper examines one of the most effective programmes in the United States. We can learn a great deal from the experience of John and his colleagues and from their development of the principle of normalisation in this field.[4, 5] We can also draw some very useful conclusions from the early stages of the Advocacy Alliance pilot project, which is necessarily very different from the Georgia Advocacy Office. Hopefully, comparison and discussion of both schemes will encourage further attempts in the United Kingdom built on our experience and developing ideas.

Looking back to the beginning of the Advocacy Alliance's efforts, it is possible to identify three phases in the whole process which resulted in advocates befriending residents at Normansfield and St Ebba's. I shall define them simply as:

The preparatory period
Creating advocates
Consolidation

This covered a period of fully two years and each phase consisted of separate crucial steps. Advocacy cannot be promoted in a haphazard or hasty fashion. There are so many variables and uncertainties and so many people become involved, directly or indirectly, that the long-term objectives could become obscured or even lost, if an expedient approach were adopted.

The Advocacy Alliance could not have even reached the first stage of its proposal for an independent advocacy programme if there had not existed significant official support for initiatives in this field.

The 1971 White Paper, Better Services for the Mentally Handicapped, which indicated the large numbers of isolated residents, also pointed to the contribution to be made by private citizens in mitigating loneliness and to the value of individual friendships for the more severely handicapped residents.[6] The emphasis of this document was on voluntary befriending, however.

The DHSS review of services published in 1980, stated that many of these disadvantaged people needed more than friendship.

> '. . . the most important factor in safeguarding the position of vulnerable patients and ensuring that their rights are upheld is personal contact between the patient and someone whose job it is to explain the position from the patient's point of view.'[7]

This need has been highlighted by the discussions about the DHSS paper on patients' money[8] which was published at the beginning of 1981. In its response to this consultation document, MENCAP argued that if mentally handicapped people are to manage their own affairs, including welfare benefits and savings, then 'independent advocates' should be appointed to protect their interests. This need is universal within long-stay institutions for, although many patients suffer from serious afflictions, they could all find ways to improve the quality of their lives *if* someone were there to befriend and support them. It is a sad fact that many of the most profoundly handicapped residents of these hospitals are also the most isolated and the least likely to benefit from many entitlements. Also, it appears that no two establishments operate in the same way when it comes to dealing with residents' money. We discovered from talking to staff and management that many residents could be quite well off if they could gain access to their own money, whether it was in the form of savings or accrued benefits.

Clearly this remains a very difficult issue but it did seem that the problems arose from the administrative tangles which had evolved over the years. Staff often gave up after prolonged efforts to obtain funds for some special reason or another which might help a resident or residents. The result is that many millions of pounds remain unused and thousands of people could achieve considerable improvements in their quality of life if the money could be released to meet their own needs and fulfil unsatisfied expectations. This is one aspect of the total problem and there was evident enthusiasm for a project which might contribute to the solution of an apparently intractable predicament.

The issues raised in both the 1971 White Paper and the review document were given a fresh impetus by the publication in 1981 of two significant government papers: Care in action[9] and Care in the Community[10]. The former called for the 'Cinderella services' to be given a high priority and recognised the value of constructive links between the voluntary sector and statutory services when it came to dealing with individual needs.

> 'Voluntary effort is often directed towards innovative work and work at the boundaries of existing services. It can complement, enhance and extend the statutory contribution. It can bring a dimension of commitment, diversity and experiment which improves the quality of life and *encourages individual self-confidence* . . . Volunteers can provide friendship, practical assistance, and personal attention to lonely and isolated patients.'

The possibilities for more independent living are the central concern of Care in the Community, a Green Paper which calls for a shift in the context of care.

> 'Most people who need long-term care can and should be looked after in the community. *This is what most of them want for themselves* and what those responsible for their care believe to be best.'

This statement not only confirmed the importance of the wishes of hospital residents, it also suggested that a part could be played by advocates in ensuring that individual residents could have more of a say in exactly where they lived.

Members of the Advocacy Alliance saw the significance of these policy statements and were in a position to demonstrate that their objectives complemented initiatives that were being sought at a high level. However, it was also firmly stated that advocates would not be found selectively for the most able residents who, on the surface, had the best chances of spending their own money, finding a place in the community, and so on. Instead, the Alliance made it very clear that their objective was to offer mentally handicapped people, *whatever the extent of their disabilities*, friends who had access to resources *and* a training which would enable them to work together with the statutory services in order to secure changes appropriate to the residents' needs and expectations. It was on this basis that we approached the relevant authorities at the start of the first phase of the project.

The preparatory period

Step 1 Establishing viable agreements and working relationships with the relevant authorities and with management of the selected institutions

The first point to be stated, very clearly, is that it is not at all certain that advocacy schemes could ever get off the ground in the United Kingdom *except at the behest of the authorities*.

No individual living in a hospital, or a local council home, has an automatic right to the friendship and protection that advocacy offers. In fact, people whose lives are dominated by statutory instruments, no matter how humane or well-intentioned, have very few achievable rights. They are the object of rules – other people's rules – and discretionary decisions and professional judgments which rarely result from a dialogue which includes them. In parts of the United States advocacy programmes have been established with the weight of the law behind them: that is, people with mental handicaps have a publicly declared right to advocate support. Such legal authority is no panacea but it does add considerable influence to the efforts of the advocacy coordinators. Within the British welfare state those responsible for the administration and implementation of social policies have no obligation even to talk to the management of voluntary projects and external initiatives. They had to be persuaded of the need for advocacy and then to allow it to happen without setting down preconditions which would deflect its purpose or even render it meaningless.

Fortunately, from the first, the Advocacy Alliance attracted a great deal of interest at all levels within the National Health Service, especially among those with special responsibility for mental handicap services.

Inevitably there were problems and some frustrating delays as well. I shall discuss some of these later, but it is true to say that the project gained considerable impetus from the policy papers I have noted. This was enhanced by a genuine desire for change expressed by many influential people. But, at the end of the day, the key people turned out to be those responsible for local policy and the management of the chosen hospitals.

In fact, the hospitals almost chose themselves during the earliest stages. Then everyone had to step back and look at the whole package and negotiate formal arrangements.

Briefly, what happened was this. One of the constituent charities of the Alliance, One-to-One, had been involved with three hospitals for some time: Normansfield, St Ebba's, and Little High Wood in Essex. As a result of this contact, individual members of the hospitals' management had expressed an interest in the idea of advocacy, and their participation in One-to-One's projects indicated that they would be both amenable and helpful when it came to setting up the project proper. Following informal discussions and meetings with some of these interested people, including hospital administrators, senior nurses, psychologists, psychiatrists, and voluntary service organisers, the Alliance put its proposals together and raised the necessary initial funding.

The launch of Advocacy Alliance in June 1981 followed the showing of Nigel Evans' documentary Silent Minority. This film created quite a stir in the mental handicap hospital world and it caused the health authorities to look very hard at the new organisation's policies. Nigel Evans was a vice-chairman of Advocacy Alliance at that time and the promotion of the United Kingdom's first advocacy scheme was linked very closely to the needs of the deprived, and often abused, 'silent minority' of long-stay hospital residents. It is impossible to show that the fuss created by this controversial film contributed to the long delays which then occurred. Suffice it to say that among many other factors which mitigated against the early introduction of advocates was a lengthy and careful examination of the agreement proposed between the hospitals and the Alliance.

The basis of our agreement with the hospitals was an ethical code for advocates which was considered by the various levels in the administrative hierarchies. In summary, this short document emphasised the primary loyalty and duty of the advocates and, at the same time, recognised the importance of staff. Its fundamental assumption was that the human rights and dignity of the residents must be protected.

1 An advocate shall work with a resident on a one-to-one basis only for as long as the mentally handicapped person wishes this relationship to continue.

2 An advocate shall have unhindered access to the resident he has befriended.

3 An advocate shall have access to all records referring directly to the resident he has befriended.

4 An advocate shall be obliged to report, to the coordinator, any abuse or neglect of a resident which he observes, or which he is informed of by the resident he has befriended, his or her parent, or any other responsible person.

5 An advocate shall try to obtain the consent of the resident he has befriended prior to taking up an issue on the resident's behalf. (NB Severity of handicap may exclude the possibility of formal consent.)

6 An advocate shall be entitled to raise any issues concerning care, treatment, health and social services, training and education, and financial rights, which he, and the resident he has befriended, feel require attention.

7 An advocate shall treat as confidential all personal information about residents and staff that he has access to through his position within the hospital.

8 An advocate shall at all times respect the ethical code laid down by the hospital with regard to behaviour towards residents by volunteers.

9 An advocate shall not take up any issue concerning a resident against the resident's wishes.

10 An advocate shall not take the part of either side during an official dispute.

11 An advocate shall not take up any issues concerning a resident other than with the coordinator, or a member of the project team.*

12 An advocate shall not undertake any work normally performed by hospital staff.

This sounds fine – it is fine – but of course everyone can claim to have the residents' interests at heart. The key is to recognise that *conflicts of interest* may arise, focused on even the smallest issue; but that it is quite reasonable for an outsider to take up that issue within mutually agreed guidelines and procedures. Crucially, the agreement should ensure that staff at each level are given every reasonable opportunity to exercise their authority in respect of their proper responsibilities. Thus, *formally*, it is essential to obtain a mutual understanding which is appreciated from ward level through to the chairman of the district health authority. Inevitably the ethical code became modified throughout the process of achieving this understanding. For example, the idea that advocates should have 'unhindered access' was adjusted to ensure that these volunteers were not given a lease to barge into the ward. It will be interesting to see if, in the long run, the negotiated changes undermine the central objectives of the programme.

Another advantage of this document was that it provided a framework for discussing the most sensitive issues. For instance, everyone was startled by the inclusion of statement 4 which so explicitly declared an obligation to report abuse or neglect. It is my experience that volunteers and staff[11] have found it extremely difficult to deal with such problems. Volunteers often do not know where they stand and may even collude with ill-treatment by turning a blind eye when it occurs. Staff are often anxious because they feel that outsiders will not always understand their actions, for example, when restraining a disturbed patient. An uncomfortable set of taboos often surrounds this subject but we were determined to adopt a policy of clear, open discussion. There were three reasons for this.

Firstly, advocates would clearly fail as advocates if they were not able to deal with such a fundamentally important issue. Secondly, all the hospitals had proper procedures available to deal with these matters. It would not be the task of advocates to initiate these procedures, but they should ensure that residents were protected by proper implementation of existing regulations. Thirdly, we were certain that open discussion would provide a good basis for the goodwill and mutual understanding which we sought.

My experience was that once anxiety on all sides had been dispelled, this policy of openness worked well and created the basis for very constructive working relationships. However, at the best of times this can be only a temporary state of affairs, as each incident has its own peculiar ingredients and occurs in the context of changing pressures and tensions.

*Project teams, consisting of two members of the Alliance Committee, the coordinator, and three members of the hospital management, have been set up at both hospitals. Their principal task is to monitor developments and advise the coordinator.

In every institution, *informal* arrangements exist, and priorities, established out of habit, become hard to rearrange and even harder to explain to well-intentioned progressive volunteers. We have only just started to encounter the difficulties that this might raise, and they could be considerable, given the intensity of a hospital's subculture which I referred to earlier. We can only be prepared as best we can and the project coordinator has to be aware of existing tensions and attitudes towards volunteers.

The ward charge nurses, sisters and staff nurses are key people in this respect. They know the staff and residents and they often anticipate problems before they become serious issues. They tend to advocate on behalf of their staff team and in time are prepared to get on the telephone to discuss matters which directly affect the advocacy project. Their help in arranging informal discussions, and sessions designed to clear the air, is absolutely essential. They interpret the institutional environment, and cooperation between them and the coordinator is crucial for the longer term development of advocacy in any establishment.

The advocates themselves found that after a while they had worked out good arrangements with ward staff which allowed them to visit the residents freely and to discuss matters of concern without defensiveness on either side. There is an inherent danger in this and only time will reveal the outcome. I shall discuss this in the section on consolidation; but it is worth raising the question at this stage. How much is the effectiveness of advocates compromised by the need for the advocacy programme to work with hospital staff and administration?

The experience of the Advocacy Alliance project was that the preparatory period took an inordinately long time. So many important groups had to be persuaded and the problems were compounded by an unfortunate historical accident – introduction of the project coincided with National Health Service reorganisation. Two of the hospitals – Normansfield and Little High Wood – changed hands, with the consequence that new authorities and management teams had to scrutinise the proposals. Little High Wood disappeared from sight at this time, partly owing to inertia and partly because of opposition to the idea.[12] However, the management team at St Ebba's and the new district health authority responsible for Normansfield[13] continued to work towards implementation of the project.

Support for the Advocacy Alliance proposals was often sustained by committed individuals within the hospital and health services. Their contribution was invaluable and their ability to set themselves apart from professional self-interest did them great credit. Such people work in mental handicap services up and down the country and it is unlikely that advocacy could ever really get off the ground without their assistance. In addition, others working in organisations peripheral to the hospitals had a most important part to play in the first stages of the project.

Step 2 Obtaining backing from influential local groups and voluntary organisations

In every community there are small groups who lobby persistently on behalf of mentally handicapped people. The local societies for mentally handicapped children and adults in the south-west London area have gained considerable influence with the health and social services; and active individuals, who sit on the community health councils, helped to persuade health authority members of our credibility – once they had become convinced themselves. Similarly, local volunteer bureaux and Citizen's Advice Bureaux organisers helped to put us in touch with literally hundreds of groups and voluntary organisations.

In this respect, the experience and knowledge of the hospitals' voluntary services organisers is an invaluable asset. They have established a range of contacts within the local community and their access to such groups as the Rotarians, Women's Institutes, councils of voluntary service, and so on, can provide links which advocacy coordinators would otherwise find hard to make.

It is important to note that local groups are not usually a source of volunteers for an advocacy programme. Firstly, their members are usually heavily committed to their own organisation's work and cannot find the time for additional responsibility. Secondly, they tend to be involved in activities, such as fund-raising, befriending, or the provision of services, which imply a fundamentally different orientation than that required by advocacy. Their role is to complement and/or supplement existing services and in this sense they are service agencies themselves.

Thus, while they showed a keen interest in our proposals and offered moral support, they showed no desire to become directly involved.

It was hoped that existing volunteers, working within the hospitals or for local voluntary groups, would provide us with a ready source of advocates who would have the added advantage of knowing the hospital staff and residents. In fact, only two of the first advocates joined the project as a result of previous work for the voluntary service organiser.

This left us with the difficulty of finding the people who would become the United Kingdom's first advocates.

Step 3 Recruiting and selecting volunteers from the community to befriend individual residents of long-stay institutions on a one-to-one basis, and to learn to represent their interests

Without advocates, you cannot have an advocacy scheme. This is self-evident; but recruitment posed, and will always pose, considerable difficulties, especially when it comes to sustaining the momentum required to keep the programme going. Resolution of this problematic aspect of the project came down to two words: contacts and commitment. Examination of the approach adopted during the early period of the Advocacy Alliance project provides some useful insights.

The first method was to use a television appeal[14] for volunteers and identify suitable candidates from the respondents. This produced one advocate from about seventy initial replies. We also saturated an area covering a five-mile radius round the hospitals with our literature. We wrote to every relevant voluntary organisation, to local newspapers and 'free sheets'; to churches, civic officers and so on, in an attempt to achieve coverage across the whole map. The response was very low considering the input, although this was not entirely unexpected. Experience in the United States had shown that widespread publicity produced only very small numbers of recruits for advocacy programmes. But a start had to be made and it was hoped that, once a small group had been established, its members would generate their own network of contacts.

The second recruitment drive, which produced more potential recruits (seventeen compared with the original eleven) again relied on local sources. Newspapers which covered identifiable communities appeared to be the best source; but the numbers were clearly not high enough to draw significant conclusions about effective methods of recruitment.

Interestingly, the advocates themselves have found it hard to persuade friends that the commitment is worth it. One explained to me that she was regarded with a certain amount of incredulity by her peers who could not, or were not prepared to, see the point of the exercise. It seems that it is realistic to expect that most people will find the idea rather alien, even if they profess to care about what happens to other human beings who may live in less advantageous circumstances. We have also found that when the level of commitment required is explained, some of the people who responded to the recruitment drive decided to withdraw.

Not many people are prepared to say they will involve themselves with a person, as yet unknown, on a regular basis over a lengthy period of time. I have discussed this problem with the organisers of several projects which depend on one-to-one relationships between volunteers and handicapped people who live in the community. Their experience is just the same: it takes a great deal of effort to find enough recruits for small numbers of isolated people. Yet, we must emphasise the nature of the commitment required. An advocate has to be a true friend, and more than a friend. There is a deep inherent value in an advocacy relationship, but it is hard to provide strangers with the motivating insights.

This is a problem which advocacy projects must tackle if they are to become a long-term feature of our society. If there are thousands of mentally handicapped people who might benefit from advocacy, there are many, many thousands more elderly people and people with mental illnesses who are in similar circumstances.

We tried to review our strategy with help and advice from various people who had the relevant expertise. It was necessary to examine critically the *language* used and the *methods* adopted. Many voluntary organisations use words which evoke sympathy or even guilt among members of the public in order to persuade them to support the charitable purpose that is their *raison d'être*. Obviously this is not appropriate for advocacy programmes. Such evocative promotion demeans the people who are the subject of the material which is produced. For instance, posters which depict handicapped people in unhappy or degrading circumstances clearly state that 'these are unhappy, degraded people'.

This has a dual effect. Firstly, it adds to the impression that only volunteers with 'special abilities' and commitment can be involved in action or relationships with disadvantaged people. Ordinary folk are excluded from direct contact and have to make do with impersonal donations to collecting boxes. Secondly, it suggests that the relationship between the volunteers and the handicapped person is very one-sided. Handicapped persons are the passive recipients of care or benevolence. Unable to speak up for themselves, they rely on professionals and volunteers to decide what is best for them.

The overall effect of these expectations, both of volunteers and of the human capacity of people with disabilities, is to obscure the possibilities for positive change based on dialogue, mutual respect and understanding. Thus, it must be hard for members of the community to make sense of the implications of citizen advocacy. Just pose the question 'Why should anyone befriend a mentally handicapped person?', and it is clear that a new approach is demanded.

On reflection it appeared that 'friendship' allied with 'social justice' provided the best motivation for our recruits. It was demonstrably wrong that fellow citizens should live in social isolation, and the possibilities for thoroughly worthwhile, achievable change that advocacy offers should attract people with a strong sense of fairness and humanity which does not discriminate against, or patronise, people living in institutions.

The problem remains: how do you reach potential advocates or persuade others to change their orientation sufficiently to take an active interest in citizen advocacy?

The poor response from the traditional voluntary service networks and the local media might be explained by the difficulties outlined; partly by the geographical and social distancing of long-stay hospitals from the community; and partly by the need to find new methods of recruitment. To date, local newspapers and television coverage have helped to rouse interest among people who later became advocates, but such means have a limited lifetime. Word-of-mouth contact has not brought in new recruits except through the hospital voluntary service organisers. This is surprising, because experience of one-to-one advocacy in the United States indicated that this approach would provide the best source of new advocates.

I suspect that the answer is to work on building networks of support and interest within identifiable local communities.[15] Community 'networking' is a skill that is in its infancy in this country but it appears to offer the most worthwhile possibilities for citizen advocacy schemes. John O'Brien's paper illustrates the importance of well-developed local support. Although advocacy may be centrally concerned with individual relationships, those relationships cannot be isolated from other advocates and people who back the programme. It is envisaged that when difficulties arise or new lessons are learned, they are shared so that the programme as a whole can sustain, and is sustained by, the growing experience of advocates and residents alike. Clearly it would be advantageous to start this process with the recruitment of new volunteers.

An essential facility for encouraging and effecting local networks is a local office which is identified closely with advocacy in a particular area. Establishing such an office should be intrinsic to preparing the way for any citizen advocacy programme.

Step 4 Developing the role of the advocacy office

Wolfensberger draws attention to the need for an office.

> '. . . volunteer efforts of the citizen advocacy type will never play a major role unless co-ordinated and backed up by a stable administrative mechanism. This office attracts, selects, orients, guides and reinforces citizen advocates; it assesses the needs of a person for advocacy, as well as the abilities of the citizen volunteer to contribute through advocacy . . . Furthermore, advocacy offices can provide practical assistance to advocates, and mediate legal and professional services that may be needed by the advocate and his protegé. *An important point, though, is that the advocacy office does not conduct advocacy itself, but makes citizen advocacy possible and more effective.*'[16]

The long-term aim should be to set up independent, local centres which volunteers, relatives, residents of various establishments, and their friends can all turn to if an individual need for advocacy is identified or if existing relationships need support. Local offices can start the process of becoming recognised facilities within the community. This offers the possibility of extending their work into the social services area and into the private sector, where many elderly and disabled people live with virtually no contact with the mainstream of life. It is highly unlikely that a centralised organisation could achieve the necessary awareness of the local environment that citizen advocacy requires. Moreover, local offices will obviously be more responsive to individual needs and changes in conditions within the hospitals.

John O'Brien's paper illustrates the value of effective local organisation and the Citizen Advocacy Programme Evaluation (CAPE) scheme, which he has developed with his colleagues, stresses the importance of a local focus, independent of service-system facilities and funding.[17]

Until now the Advocacy Alliance has operated from a centralised office. This reflects the *modus operandi* of the constituent charities, but in time, given the necessary resources, it should be possible to develop local facilities. This would go a long way towards tackling the problems posed by the physical isolation and aggregation of the long-stay hospitals. Another possibility is closer collaboration with *non-service* community resources such as rights centres or law centres. An interesting recent development is the attempt to establish law centres or Citizens Advice Bureaux within some long-stay institutions.[18] The emphasis of such organisations on individual human and civil rights makes them much more compatible with the underlying principles of citizen advocacy than are local pressure groups or service organisations like councils of voluntary service.

Discussion of the role of the advocacy office raises many crucial issues. In common with all administrative mechanisms it offers considerable potential for development of the programme. It can also become a built-in stumbling block, an increasingly institutionalised impediment to progress, because it tends to serve the needs of the organisation, not the advocates and people with disabilities. One way of dealing with this is to open the programme up to participative management and, as *self-advocacy* by mentally handicapped people grows in this country[19], this should become much more possible. In addition, advocates themselves, with their growing experience, will have a great deal to contribute in this respect. Locally-based resources would facilitate such participation and enable local people to have direct access to advocacy. Inevitably this would aid recruitment and enhance the creditability of the scheme by providing staff with a more flexible way of working. This becomes even more significant when the project moves into the creative phase of training and supporting advocates.

Creating advocates

Step 5 Establishing a cohesive training programme
The Advocacy Alliance placed a heavy emphasis on training volunteers before introducing them to hospital residents and enabling relationships to develop. I was responsible for implementing two training programmes which sought to meet the learning objectives of citizen advocacy and to initiate the first contacts between recruits and hospital residents and staff.

Training was very intensive: thirteen weekly sessions which lasted two hours in the evening and three all-day events at the weekend. One obvious criticism is that this would put off potential recruits and unnecessarily delay direct involvement of volunteers with residents. This might be the case; but the benefits for all concerned were considerable and such a careful introduction impressed the health authorities with the seriousness of our purpose and careful preparations. This should become clear as I outline the objectives and the method adopted.

The learning objectives of the advocacy training can be stated as being:

To provide volunteers with an independent orientation by
  creating a critical awareness of systemic, medical and prejudicial models of mental handicap;
  providing an introduction to the principles of normalisation;
  identifying the relevant human and civil rights issues.

To explain the role of the advocate with particular emphasis on advocate loyalty to the resident.

To identify an individual's needs, wants and expectations from a non-service point of view.

To provide the necessary information about access to services and benefits, and the legal position of people with handicap.

To introduce volunteers to the professions and staff involved in the care of residents.

To examine alternative non-institutional methods of service provision.

To achieve these objectives the programme was divided into three identifiable components (see Appendix 1 for an outline of the content).

1. A four-week induction period designed to meet the first three learning objectives and run by trainers with a background in normalisation.
2. Five sessions, which were more informative in nature, with contributions from professionals from the hospitals and experts from the Advocacy Alliance's constituent charities. This aimed, in part, to meet the last three learning objectives.
3. Activities, including visits to the hospitals and community-based facilities. During the visits to the hospitals we helped to arrange events, including a picnic and an all-day outing, which enabled volunteers, residents and staff to get to know each other in pleasant circumstances. These informal arrangements helped the volunteers to identify with residents for whom they might wish to advocate. It was also possible to demonstrate to staff that these new people were sensitive and responsible in their attitudes and behaviour. Contact

with local services, which included two establishments where the residents had organised their own committees, introduced the advocates to self-advocacy and the alternative living arrangements which hospital residents might, in time, achieve.

Five themes cut across the training programme.

1 Attainment of the insights and orientation which would enable advocates faithfully to represent the interests of the people whom they befriended.
2 Development of communication skills and sensitivity to official reaction, especially the expectations of staff on the wards, which would enable advocates to work effectively on their friends' behalf.
3 Definition of an independent (non-service) set of criteria against which the residents' quality of life and rights could be tested.
4 Application of problem-solving skills based on knowledge of services and the legal rights of people with handicaps.
5 Development of social skills to enable the advocates to work in a difficult environment and enhance the growth of mutual support within the group. This is most desirable for the long-term success of the project. So many voluntary projects fail because of lack of attention to the group process and the internal strength it can generate.

Thus, the training programme provides the opportunity for developing skills, passing on important information, and inculcating a new orientation among the volunteers.

Training in the health and welfare field is usually identified with preparing people for service provision. The ideological underpinnings of the medical and social services are usually implied in the information that is put across in the programmes, or are sometimes overtly stressed in the introductory or concluding phases. But advocates are not service agents and the residents whom they befriend are not their 'clients'.

In short, advocates are not conventional volunteers. They are equal partners in relationships which have the purpose of achieving positive change in the quality of life and circumstances of disadvantaged people. It is essential that advocacy training programmes are seen in this context.

Finally, the three-month training period provided an opportunity to identify those recruits who would make effective advocates. Their commitment and attitude towards hospital residents was assessed and they were encouraged to evaluate their own interest and ability to meet the demands of the advocacy relationship. In effect, selection lasted for over three months, during which time staff were also encouraged to comment on the new recruits.

Responsibility for final acceptance into the project proper rested with the coordinator in consultation with project teams at the hospitals. Such safeguards ensured that everyone had full confidence in the new advocates when they came to be matched with residents.

Step 6 Identifying those residents who would benefit from the advocacy programme and matching them with advocates

As I observed, many thousands of the residents of long-stay hospitals are never visited from one year to the next and this isolation from outside contacts certainly applied to at least half of the residents of Normansfield and St Ebba's.

The need for friendship and a break from purely institutional relationships is desperate; but each individual is quite different, with his or her own personality, likes and dislikes, strengths and limitations. Paul and Mary, whom I mentioned earlier, are as unique as any member of the community.

It would have been intolerable just to draw up a list of names of suitably isolated residents and then allocate them to trained advocates without a by-your-leave. With the best will in the world, many relationships just would not work out. Imposing people on each other for the convenience of a voluntary project is obviously contradictory.

We were asked a number of obvious questions:

Should advocates work with multi-handicapped people?
What about 'disturbed' or aggressive patients?
Should a male advocate relate to a female resident and vice versa?
Should advocates and residents be of similar ages?
What happens if relationships just don't work out?
What if advocates in successful relationships have to move away?

The underlying concern for vulnerable residents was clear and these questions had to be answered.

The first point, which the Advocacy Alliance had made clear from the very start, was that in the long run every resident who was not visited should have the opportunity to have an advocate *no matter what their age or disability*. Hospitals tend to segregate the most difficult and the most profoundly disabled people in special wards because institutional common sense says that this is the best way to manage them. No advocacy programme can ignore people who are isolated in this way, more especially because they are the most likely to experience complete separation from the outside world.

However, in the early stages of the project it was decided to work on wards where the staff had willingly agreed to participate. This would allow a positive start which could be built on in time. But once the first wards had been identified it was agreed that the residents and advocates should be encouraged to choose each other in an unstructured way which avoided any form of 'social engineering'.

This process commenced during the training period when we arranged visits to the hospitals. For instance, we organised an outing which included twelve residents from two wards at St Ebba's. The people who came had previously met the volunteers at a picnic in the hospital grounds and none of them had been visited for several years. An enjoyable day out helped to break the ice, and as a result of this and subsequent activities advocates made tentative suggestions about people they felt that they identified with.

When the training programme ended, those who wished to carry on started to visit the wards on an informal basis. They got to know staff and residents better and began to build up an understanding with the individual they had related to earlier. At the end of another month we discussed the possibility of formally recognising that advocates could be associated with these individuals.

On paper this comes across as a rather tortuous process, but in practice the time went quickly and strong relationships began to form without much fuss. Staff observed these developments with interest and reported very positively on progress. Paul and Mary were soon going out with their advocates and their response to the friendship that was offered was most encouraging.

We all learned a great deal from Ian and his advocate, Lesley, who had been a friend for some time. Lesley had been a volunteer at the hospital long before the Advocacy Alliance projects started and as their friendship grew she had begun to enquire about Ian's rights. Without realising it, she had become an advocate in every sense, and she provided the other advocates with many valuable insights throughout the training programme. In return, she benefited greatly from the support of the group.

Thus, as far as possible, we tried to create conditions which enabled advocates and residents to get together and choose each other without imposing rules of selection on either side. So far this has worked out well in practice, and in one case a new development has pointed the way to new possibilities. Two recruits, a young married couple, decided to advocate in partnership for one resident. This innovation should encourage others to follow suit.

All this happened during the summer of 1982, and it then became necessary to consolidate the situation and arrange the necessary support for the new advocacy relationships.

Consolidation

Step 7 Building support for residents and advocates

If the initial steps of an advocacy programme demand careful thought and action, then the follow-through is the true test of all that has gone before. When advocates really start to operate as advocates and not as befrienders it is clear that many predictable difficulties and unforeseen problems will arise.

What pressures are advocates likely to experience?

People who live in hospitals find that the major part of their lives is shaped and controlled by the 'human service machine'. Once they become involved with advocates, their orientation towards the institution is bound to become characterised by tensions arising from contradictory forces and situations. There is no point in pretending otherwise. John O'Brien points out that the objective is to ensure that these tensions are *creative*.

Here are some examples of the sort of situation that advocates will experience.

> They will have to learn about solving problems together with a variety of people who may not always agree with the proposed approach, or even with what the problem is.
> They will surely have to learn to compensate for the pain of unresolvable situations and disappointed expectations.
> They will be under continual pressure to redefine their role, adopting one which others can more readily accept.
> They will need to share their difficulties in perplexing times.
> As each new situation creates uncertainty they will try to avoid the routine, institutionalised way of solving problems.
> They will be under persistent pressure to dominate the advocacy relationship. But, as John O'Brien points out, 'Becoming a citizen advocate does not give a person a special access to the truth about a person with a handicap'.

Advocates have already experienced these external pressures. For example, shortly after Mary had started receiving visits from her advocate, Jane, it was announced that she would be moved shortly to another ward. 'Shortly' meant in two days time. Jane pointed out that Mary was happy where she was and that there had been no discussion or time to look at alternatives. We asked if anyone had considered Mary's wishes in the matter. In fact, the question had not arisen and the move was necessitated by a change in allocation policy which had been decided at a high managerial level. We were presented with a *fait accompli* made worse by a lack of consultation which presumed no consideration whatsoever of the individual resident's needs.

When Jane realised that nothing could be done, she made arrangements to introduce Mary to the new ward before the move and subsequently supported her throughout the very unhappy time of traumatic disruption. It was very distressing on two counts. The advocate found herself caught in an unresolvable situation where she could only make the best of a decision she could not influence; and it was clear that it had never occurred to anyone with authority that Mary's wishes should be considered. Her resulting distress was interpreted as 'naughtiness' or 'disturbed behaviour', to be treated either punitively or with medication. As far as Jane was concerned, her friend was simply very unhappy and in need of strong personal support. But she did not only offer friendship during a difficult time, she also questioned the drugs that had been prescribed and tried to ensure that staff on the new ward did not treat Mary as a 'problem patient'.

This brief account illustrates just one facet of an advocate's experience. As the relationship between Mary and Jane developed, many good things happened. It became clear that Mary's command of language was much greater than anyone had realised. Away from the hospital she started to initiate conversation and identify Jane's children by name. Certainly the quality of her life improved considerably.

From this it is all too easy to assume that all resistance is external, that tensions arise through conflict with an insensitive service system. However, advocates will experience internal tension as well. These derive from a variety of sources.

Prejudice Our language and culture habituate a devaluation of people with handicaps. The stigma associated with mental 'weakness' or physical 'deformity' cannot just be shaken off and advocates must recognise that they are as likely as anyone else to have negative attitudes built in to their assumptions about hospital residents.

Lifestyle Most people who become advocates are used to a well-ordered, comfortable quality of life. Exposure to institutional deprivation can, after a time, turn people off relationships with people whose daily experience is so far removed from their own.

Withdrawal or rejection Close involvement with a very vulnerable person can provoke disruption of personal emotional calm. Such an experience can lead to personal growth as the advocate adapts or to a defensive reaction ('I'm not really suited to this after all').

Time A relationship with a person whose time is often controlled by schedules designed by others means that advocates have to plan their time to take account of hospital routines. Many people find this difficult to accept in the context of close personal relationships.

Confidence Self-confidence and confidence in the relationship will be persistently tested. For instance, when faced with authoritative professional judgments or a confusion of official regulations it is far easier for an 'outsider' to step aside and let the institutional process take over, even if it means letting the resident down. Self-confidence can be undermined by deferential attitudes to authority which are inculcated in most of us from an early age. In the face of such pressures advocates have to learn to be sure of their own feelings, self-respect and inner strength.

When the training programme ends and advocacy relationships start to develop, the work of the citizen advocacy programme is only just beginning. The advocates have to be sustained, supported and encouraged. Such a project inevitably draws a great deal of attention to itself. It exposes many hidden anxieties because it is centrally concerned with human rights and it becomes the focus of a great deal of conflict of interest. It operates in an environment where many interested groups possess the power and influence to disrupt its efforts or modify its objectives out of all recognition. The advocates themselves must try to retain their independence and commitment and at the same time seek positive change in difficult circumstances.

Thus consolidation is the most crucial phase of the project and the Advocacy Alliance has started to develop some means whereby the future of the advocacy relationships can be secured.

The advocate support group The advocates meet regularly to exchange ideas and discuss events and issues which have arisen. It is very much their group and they set their own agenda.

Further training New training needs are identified from time to time and seminars are arranged with speakers who are usually requested by the advocates.

Monitoring by the project teams Involvement of advocates in the hospitals raises questions almost daily. Project team meetings provide a forum for discussion and feedback on all sides. It is hoped that this will engender positive decisions within the service as advocates demonstrate the need for change. An open *dialogue* is essential because

> it underlines the independence of the programme and, hopefully, ensures that discontent is not allowed to simmer away under the surface.

Obviously, there is a great deal more to learn and evaluation of the project should throw up some invaluable new ideas.[20] The true test will be in the achievements of the residents and their advocates over the next two years. Indeed, we have to see if any advocacy relationships last that long.

4 Conclusion: defining advocacy in the British context

'Advocacy' in the sense that most people understand it belongs almost exclusively to the legal profession. Although the Concise Oxford Dictionary allows 'advocate' a lay definition, 'one who pleads for another', the majority remain more comfortable with the alternative, 'professional pleader in courts of justice'. When Advocacy Alliance was first established many friends and critics alike suggested that the organisation's name should be changed because it seemed inappropriate and hinted at excessive legalism. One district health authority member commented, 'They will *have* to change their name,' a view supported by most of her colleagues.

I suspect that many interested individuals were more unsettled by the direct association of the idea of 'pleading for justice' with voluntarism and the rights of residents of long-stay mental handicap hospitals, rather than with a serious concern for semantics.

It is easy to understand this early resistance to the concept of advocacy. For over twenty years the mental handicap service, and especially its institutions, has been exposed to public and private examination and fairly frequent scandals which have led to some spectacular investigations. Films like Silent Minority and expensive official inquiries, such as the one held at Normansfield, have created considerable defensiveness, a protective caution which is reflected throughout the professional and administrative hierarchies. This has nothing to do with 'covering up' or hiding the worst defects of an imperfect system; it is simple evidence of an awareness of the harm that can be done by even the best-intentioned intervention from outside.

When things go wrong, sometimes very badly wrong, it is right that they should be investigated and remedial action taken. But prolonged or dramatic criticism, no matter what the rights or wrongs of the situation, seriously affects those who have to live with it *and* go on living with it long after the spotlight has moved on to other issues in other places.[21]

These pressures also affect the voluntary groups which work in and around mental handicap hospitals, and they inevitably hurt the sensitivities of the families and friends of the residents. All this percolates through to the daily life of the residents. *Who knows how they are affected?*

Suffice it to say that although, undeniably, there have been considerable improvements in the conditions within mental handicap hospitals since the 1950s and 60s, there is no evidence to show that this is entirely the result of external agitation and dramatic exposés.

Moreover, the 'mental handicap world', like the 'child care world' or the 'disability world', consists of several well-connected communities of interest. These groups exist within the voluntary sector and the statutory health and social services and they ensure that new developments receive widespread attention and scrutiny. Long-stay institutions and the rights and future of their residents hold a special place in this sensitive environment. The endless supply of official and semi-official papers, discussion documents, and conferences, illustrates this continuing concern.

In all these circumstances it is essential that 'advocacy' be defined clearly and that the relevant people in mental handicap services and the wider community understand what an advocate is and does. Misunderstanding or misrepresentation can seriously damage a proposal in its early stages and lead to wasted effort and lost opportunities.

In the United Kingdom today advocacy exists as an idea, nurtured by a growing number of people; as an activity carried on by a small number of volunteers; and as a movement, associated, in my opinion, with the growth of self-advocacy which is being promoted within the community by mentally handicapped people themselves.[22]

John O'Brien provides us with a useful, clear definition of citizen advocacy in his paper.

> 'An ordinary citizen develops a relationship with another person who risks social exclusion or other unfair treatment because of a handicap. As the relationship develops, the advocate chooses ways to understand, respond to, and represent the other person's interests as if they were the advocate's own.'

This definition gives us a clear sense of the purpose and direction of an advocacy relationship.

In an earlier, more cumbersome definition, Wolfensberger described citizen advocacy as

> 'A mature, competent citizen volunteer representing, as if they were his own, the interests of another citizen who is impaired in his instrumental competency, or who has major expressive needs which are unmet and which are likely to remain unmet without special intervention. Viewing the interests and welfare of the impaired person as if they were his own, the mission of the advocate is to use culturally appropriate means to fulfil the instrumental and expressive needs of such a person, consistent with cultural norms and with the person's impairments and potentials.'[3]

This second definition is very useful because it introduces two important concepts: the distinction between *instrumental and expressive needs* and *the role of the advocate.* Fulfilment of *instrumental needs* ensures that people receive the goods, services and entitlements which should enable them to lead a reasonable life and achieve full citizenship. Provision of the following, or help in attaining them, illustrates the importance of meeting instrumental needs.

accommodation
welfare benefits
transport
leisure and recreation facilities
voting rights
financial management
access to shops, pubs, and so on
special medical care
dental and opthalmic care
training and education, and so on

The list is extensive and, for many people living in the community, almost taken for granted. But for most people living in hospitals, or confined in some way or other, fulfilment of such needs requires a great deal of effort on the part of someone who recognises their value and importance. One example makes the point.

Many hospital residents can visit their local pubs on occasion. However, they usually go in groups with attendant nurses to ensure that all goes well. In these circumstances they are seen as 'patients on an outing', a view that may well be highlighted by the careful way their pocket money is doled out. Thus, access to local amenities is only made available if it can be arranged and controlled in ways which meet the institution's needs. Advocacy can provide a means whereby residents can start to exercise personal choice over the use of their own money, and enjoy the everyday experiences that such choice allows.

But fulfilment of such material requirements is not everything. People need to express themselves within relationships with others. *Expressive needs* are

friendship
companionship
warmth
affection
attention
love
communication
identity, and so on

Those who live in institutions are often starved of real friendship. If they are not visited by family or friends they can only turn to staff and other residents. This situation inevitably confirms and reinforces their institutionalisation. Many people react to this circumstance of little or no choice in human relationships by withdrawing from the social round that does exist.

Citizen advocacy is concerned with identifying and meeting such basic needs. In practice this means that advocates become both friends and representatives. This synthesis of friendship and action contradicts the widely-held expectations of people who work in the hospitals and health authorities.

Voluntary work with handicapped people is usually seen as an 'either/or' activity. *Either* volunteers are befrienders, *or* they are service-providers, meeting expressive needs on the one hand, or narrowly defined instrumental needs on the other. The notion that committed volunteers could willingly develop their role extensively in both ways challenges these assumptions.

Firstly, advocates do not merely befriend individual residents within the context of the hospital world; they open up possibilities for a wide range of expressive relationships which most people experience outside in the community. Secondly, they do not see the fulfilment of instrumental needs as a service function. Their role is to ensure that service workers provide what is needed.

Thus, the role of the advocate is a complex, positive one. It implies one-to-one friendship, *plus*.

The central theme of the advocacy relationship is *advocate loyalty*. It means that the advocate's primary loyalty is to the resident and not to the advocacy programme, other residents, the institution's staff, or the service agency. Unlike other volunteers, advocates do not 'belong' to the project. Advocacy staff work to *facilitate* their advocates, not to control them. This emphasises the independent nature of citizen advocacy which is hard for people to comprehend who are used to the hierarchical, regulated organisations which are a feature of voluntary and statutory services for disadvantaged people.

Advocate loyalty implies a balanced, purposeful relationship. It means

mutual interest; it is not a one-way beneficient relationship.

equal partners; advocates do not dominate or control their friends, or dictate what is best.

direction; there is always something happening which is extending or improving the resident's experience and quality of life.

respect; advocates do not talk about residents or behave in ways which imply that they are lesser beings (for instance, they do not talk across their friends in the company of others).

All of this challenges the way most people think about people with handicaps. In practice, the advocates engage in a diverse range of activities, including

providing friendship and emotional support
providing practical help in day-to-day living
enabling social integration in the wider community
helping with financial management
pursuing statutory entitlements
assisting with access to services, leisure facilities and employment opportunities
securing necessary treatment and education
cooperating with staff on individual treatment and therapy programmes
intervening in instances of neglect or abuse

This means that advocates do not merely build a relationship with isolated persons. They have to consider a wide range of issues and, together with the residents, work towards constructive change. Inevitably they must examine a list of circumstances which may have been stagnating for years, for example

living situation (privacy, food, bedding)
personal appearance (clothing, hairstyle)
social communication (speech, leisure activities)
independence (self-reliance, lack of choice)
physical skills (occupational and social)

In order to achieve change in any of these areas advocates must achieve a set of tasks.

getting all the information
deciding what you *both* want to do
finding out where the support is
knowing about rights *and* responsibilities
building a working relationship with staff, without compromising their independence
beginning to change the way things are.[23]

The Advocacy Alliance's approach to developing the role of the advocate assumed that no one could be a successful advocate without *first* becoming a friend of the resident.

Advocacy is a difficult concept for people to accept and assimilate. In my view it offers the possibility for intervention across the whole spectrum of health and welfare services. For this reason advocacy programmes should seek *independence* from the agencies which provide for people who are dependent on some form of care.

Professionals often feel that they advocate very successfully on behalf of *their* clients. But they do so within very severe constraints imposed by their employing organisations and their professional peers. Independent advocates can challenge institutional assumptions and practices and their presence should ensure that a true dialogue can take place whenever individual residents' day-to-day needs are not met or when decisions are being taken which affect their lives.

For a host of historical, social and political reasons people who live in care are often treated as if they were less valuable than other human beings. It is the central purpose of advocacy to demonstrate that these people can and must be regarded as equal members of the community not to be demeaned or degraded in any way.

Notes and references

1 The Alliance consists of: MIND, MENCAP, The Spastics Society, Leonard Cheshire Foundation and One-to-One. (See Appendix 2).
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4 Wolfensberger, W. The principle of normalization in human services. Toronto, National Institute of Mental Retardation, 1972.
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7 Great Britain, Department of Health and Social Security. Mental handicap: progress, problems and priorities. London, DHSS, 1980.
8 Great Britain, Department of Health and Social Security. Patients' money: accumulation of balances in long stay hospitals. London, DHSS, 1981.
9 Great Britain, Department of Health and Social Security. Care in action. London, HMSO, 1981.
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12 This would be hard to prove, but a lack of enthusiasm was expressed that indicated a long and difficult passage for watered-down proposals.
13 Richmond, Twickenham and Roehampton DHA.
14 Thames Television's Help programme.
15 For recent work on this subject see Froland, C and others. Helping networks and human services. London, Sage, 1981.
16 See 4, page 200. For 'protege' read 'friend'.
17 O'Brien, J and Wolfensberger, W. Standards for citizen advocacy program evaluation. Toronto, Canadian Association for the Mentally Retarded, 1979.
18 For example, Springfield Hospital in Tooting where the Wandsworth Law Centre has established an office.
19 Williams, P and Shoultz, B. We can speak for ourselves: self-advocacy by mentally handicapped people. London, Souvenir Press, 1982.
20 An independent evaluation is based at St George's Hospital Medical School and guided by the Rowntree Trust. The researcher is Ms Robin Harris.
21 Recent disclosures from 'leaked' National Development Team reports confirm this impression. (See The Guardian, 20 July 1983).
22 See 19. It is reasonable to suggest that for many people with handicaps citizen advocacy could be a preliminary stage to self-advocacy, with the advocates helping them to learn to represent themselves.
23 I am very grateful to Michael Libby of the Leonard Cheshire Foundation for many of the ideas contained in this section.

Appendix 1

CONTENT OF THE TRAINING PROGRAMME

A *Induction and orientation*

1 People with intellectual disabilities:
The different forms of mental handicap.
The various ways it is perceived.
The experiences of mentally handicapped people, especially those in institutions.

2 Normalisation:
Discussion of the principles of normalisation and its implications for disadvantaged and impaired people.

3 The rights of mentally handicapped people:
Human rights, civil rights, legal rights and their underlying principles.

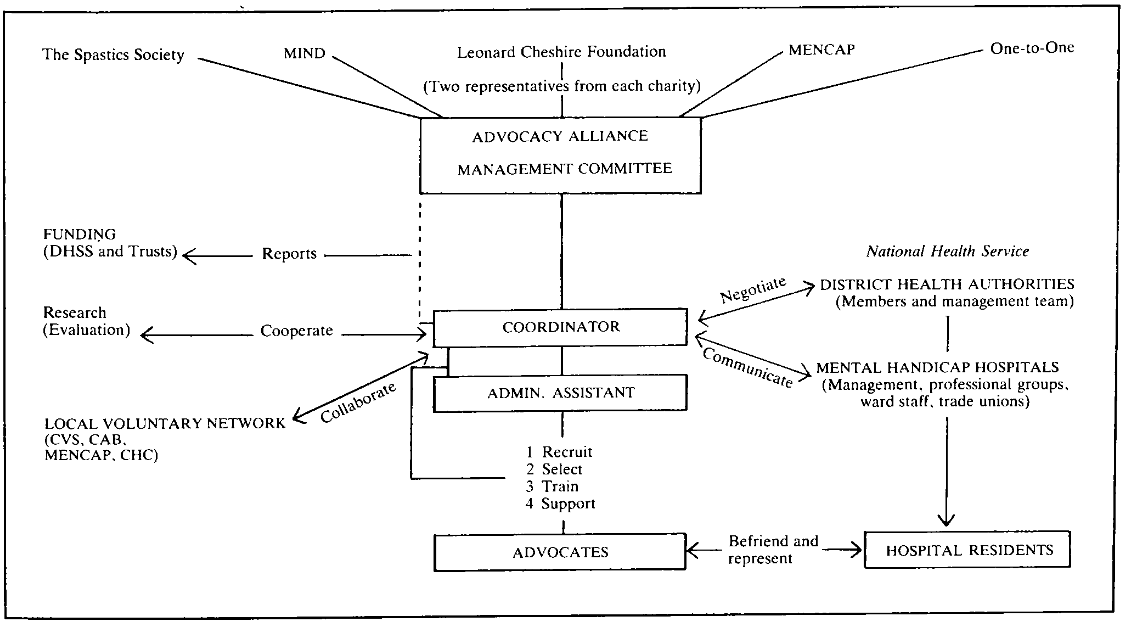
4 Citizen advocacy and residents of long-stay institutions:
Advocate loyalty and the advocate's role.
Ethical code of Advocacy Alliance.

One-day visit to the hospital to include time spent in the wards/houses and for discussion and feedback afterwards.

B *Probationary training*
5 The nursing service:
The role and responsibilities of the mental handicap nurse.
The role and responsibilities of the nursing assistants and auxiliaries.
Nursing management – lines of communication and authority.
6 The multidisciplinary approach – services within the hospital:
The psychology department.
The therapists.
Voluntary service.
Medical and psychiatric services.
7 Access to benefits and amenities:
The financial and welfare entitlements of residents.
Educational and social facilities.
Occupational training and opportunities.
8 The legal position of mentally handicapped people:
The new Mental Health Act.
Rights to representation and protection.
mental health review tribunals.
9 Care in the community:
An examination of ways in which hospitalised people may be enabled to live in the community.
Support in the community (CVS, CAB, LASSDs).
Visits to a variety of community-based facilities.
10 Appraisal and evaluation:
Participation in discussion and feedback by trainees, teachers and members of Advocacy Alliance.

The second and third all-day visits to the hospital will be arranged as appropriate.

Appendix 2



Building creative tension

The development of a citizen advocacy programme for people with mental handicaps

JOHN O'BRIEN

In this text, 'services' or 'human services' can be taken as the equivalent, in a UK context, of the wide range of services provided by health and local authorities and voluntary bodies, including health, education, social services, housing and others.

'Service workers' includes people at any level working in any or all of these fields.

Introduction

'Beware thinking of systems so perfect that nobody will have to be good.'
– Gandhi

How does one measure social progress? If the increasing investment of public resources, the development of new services and methods of assistance, the entry of growing numbers of professionals into 'caring' careers, and public statements of rights and entitlements are valid criteria, the past twenty years have witnessed a transformation in policy and potential for people with special needs. But the daily experience of many people shows the transformation to be incomplete in practice. Large numbers still live in institutions; much 'deinstitutionalisation' has been a matter of swapping larger older institutions for smaller newer ones; many people still do not receive technically competent assistance; and rights to services and protections are hard to enforce.

The gulf between promise and common practice is sobering, but it need not be cause for cynicism or defeatism. It can motivate constructive action on the part of ordinary citizens and the professionals who serve their communities.

Citizen advocacy is one channel for constructive action. An ordinary citizen develops a relationship with another person who risks social exclusion or other unfair treatment because of a handicap. As the relationship develops, the advocate chooses ways to understand, respond to, and represent the other person's interests as if they were the advocate's own. Their relationship is arranged and supported by a citizen advocacy office which operates independently from service providing agencies. Such relationships build creative tension around the service experience of particular people. Resolution of the tension introduced by citizen advocacy relationships can lead to changes in understanding and reorganisation of action on behalf of people with handicaps. Some of these changes will be within service programmes; others will touch the life of the wider community.

This paper describes the role of the Georgia Advocacy Office, as I see it – how it sets about planning and implementing methods of representing the interests of individual Georgians with special needs. (For a brief description of the Georgia Advocacy Office (GAO), see Box 1.) Citizen advocacy is the key factor in GAO's protection and advocacy strategy.

Some of the details of GAO's operation are specifically American in legal and social context. But many of the decisions and principles which shape the growth of GAO are, I believe, relevant to developed countries with a substantial investment in organised health and social services.

Box 1

A BRIEF DESCRIPTION OF GAO

The Georgia Advocacy Office serves the south-eastern state of Georgia, which has a population of about five and a half million people. A little more than a third of the state's population lives in the Atlanta area. The state covers 48,000 square miles.

GAO is a private, non-profit agency which was planned by a state-wide network of concerned citizens during 1976 and began operating in 1977. It is designated by Georgia's governor as the state's protection and advocacy system, in voluntary compliance with the federal Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94-103, II: 113). Official designation makes GAO eligible for federal funds but does not confer any special powers or sanctions. Volunteers and staff working on behalf of people with developmental special needs have access to the same administrative and legal recourses as any other citizen.

In 1982, GAO's working budget was approximately $387,000, of which $172,000 was provided by the federal Department of Health and Human Services. Federal law does not require states to share in the funding of protection and advocacy systems, and GAO enjoys an exceptional level of legislative support in comparison with designated agencies in other states.

GAO has as its headquarters a state office. The staff includes an executive director, a staff attorney, two staff advocates, a state citizen advocacy coordinator, an office manager, and an administrative assistant. The staff advocates and the staff attorney deal with a wide variety of requests for assistance from people with special needs, and their families, throughout the state. Their role is a supportive one: to help people with special problems and handicaps, as well as their families and other concerned citizens, to cope with problem situations in a manner that respects the handicapped persons' rights, interests and human dignity. GAO itself has not made use of the courts. When it appears that a lawyer could help, the staff attorney can help a client to find one. The staff attorney also acts as a link with lawyers representing people with special needs.

The citizen advocacy coordinator supervises the running of six local citizen advocacy offices, each of which is staffed by a local coordinator and an administrative assistant. These local offices, which are funded by the state legislature, are the heart of GAO's strategy for advocacy.

Local office staff do not themselves represent people. They match people with special needs, who require person-to-person relationships, with citizen volunteers who undertake to respond to them as people and be their allies in improving their situation in life. Some of these relationships are relatively brief and focused on a particular situation. A growing number have lasted for more than three years, and some people say they regard their relationships as for life. GAO staff are at hand to support the relationships they initiate, and may provide citizen advocates with help in identifying options for constructive action.

Each local office is supported by an advisory board of local citizens and a group of advocate associates. Associates include lawyers, local politicians, and experts from the 'caring' professions who volunteer their skills and knowledge to assist advocates.

Local offices also train people to form a clearer understanding of the difficulties faced by people with handicaps and encourage citizens to expect high standards from their community health and social services.

The six local offices were opened, one at a time, between 1977 and 1981. By January 1982, well over 600 relationships had been established by local offices and more than 300 relationships are currently active. Over 2500 citizens have attended training programmes.

All of the American states and territories have chosen to participate in the federal programme which requires a protection and advocacy system; but they vary substantially in the way they organise and operate the system. Most states rely much more heavily on staff attorneys and staff advocates than does GAO. Georgia, Wisconsin and Vermont have made citizen advocacy a basic component of their approach. GAO is, however, unique in the amount of resources it invests in citizen advocacy.

Design principle 1

Develop an agency that can learn. State assumptions clearly and test them against experience.

Standing up for people with handicaps is nothing new. Concerned people, especially parents, have long experience as advocates. A publicly funded, independent agency mandated to protect, and advocate for, the individual rights of everyone in the state with special disabilities, *is* something new. At the time GAO was planned there were many opinions about how best to 'do advocacy' but no functional models that met the criteria specified in the law which stimulated its creation. Then, as now, there was no research to inform the debate. In the absence of a validated method, GAO planners decided to invest in an organisation designed for learning.

Like any organised way to help, an advocacy programme is formed by a set of assumptions about

the nature of the community in which it operates
the nature of the service system to which it is related
the situation and most important needs of the people it will (potentially) serve
the most effective strategies for making necessary changes.

These assumptions may be openly discussed and agreed upon, or may remain implicit in the operation of an advocacy programme. In either case they influence the way in which a programme deals with problems and manages constraints. Clearly stated assumptions can guide management decisions and can be tested against accumulating experience.

GAO has committed a substantial amount of resources to clarifying and testing its assumptions. Wolf Wolfensberger – an expert in advocacy, voluntary association dynamics, and human service design and evaluation – was commissioned to review the available literature and provide the planners with a description of a comprehensive advocacy and protection system[1]. More than 500 people with many different viewpoints were consulted in the planning process. Board and staff members periodically set aside time to reflect on and revise the assumptions, strategies, and tactics expressed in the original plan. Regular surveys of consumer satisfaction, and annual evaluation and consultation with outside experts, provide a wide spectrum of views on the quality of GAO's activities and the usefulness of its assumptions. Regular contact with representatives of other advocacy organisations invites comment and criticism. This effort does not necessarily make our assumptions correct; it does make many of them explicit.

Implications

Modest expectations are justified. Any contemporary advocacy agency lacks resources proportional to the task. In 1982 Georgia will spend $50 operating the smallest of its seven institutions for each dollar in GAO's total budget. Moreover, there is no sure-fire approach to advocacy. The temptation must be avoided to promise oneself, and others, that the programme will deal effectively with the problems of everyone in need. So, do not promise to get it perfect the first time. Build a constituency for a learning, changing organisation.

Pick an overall advocacy strategy, define it as clearly as possible and commit yourself to developing it. (GAO's approach to citizen advocacy is operationally specified in CAPE: Citizen advocacy program evaluation standards.[2])

State the limits and disadvantages of the strategy clearly and publicly. Plan to stick with the basic strategy at least until the agency has learned to implement it. This means absorbing development costs, involving some disadvantage to people with handicaps. One very likely price to pay for clear focus and acknowledgment of limits is strong criticism and opposition from others who prefer another advocacy strategy.

Grow slowly, in a piecemeal fashion, rather than trying to implement a big system all at once. Phased growth allows for repair of design errors and gives later beginners the advantage of learning from earlier starters.

If large sums of money are offered on condition of rapid growth, resist.

Invest in organisational learning: consultation, external evaluation, board and staff training, and board and staff reflection and planning time.

Budget to allow reserve funds to repair errors or develop new opportunities. Resist the understandable pressure to spend every available bit of money on 'doing advocacy'. Spending without reserve staves off (self) criticism for 'sitting on money while people suffer violation of their rights'. But it rapidly causes a programme to outrun its resources and fall into the panic of over-commitment, leading to deeper and more justified disappointment.

Design principle 2

Respond to reality in the community in order to shape the best possible response to people with handicaps.

The way advocacy programme designers and operators view natural communities and ordinary citizens will make a major difference to their choice of advocacy strategies.

The accepting community

Some advocacy programmes act as if they believe that natural communities are essentially accepting towards people with special needs. They conceive the advocacy problem as one of getting good information across to the public, usually through the mass media or educational programmes for community groups. Once people are informed they have the means at hand to respond positively, out of natural benevolence. Discrimination against people with handicaps is individual, exceptional, and unintentional. The rest of us can and will stop discriminating if we are simply told how our behaviour adversely affects people with handicaps. An informed person who persists in negative behaviour towards a person with a handicap places himself at odds with his community. He can usually be called to order by an appeal to the community at large. Very rarely, an advocate may have recourse to the courts to deal with an unusually recalcitrant person. When this happens, the court will represent the positive element in the community and intervene to protect the handicapped person.

The rejecting community

At the other extreme are advocacy programmes which appear to regard natural communities as essentially rejecting of people with special needs. The problem is to create a protected environment and special provision for people that nobody really wants. Ordinary people will, at best, be indifferent; often they will be cruel. Guilt may motivate some to say that they would like to act positively towards people with handicaps but, faced with them, they will react negatively. In the long run, the only people who can be trusted are those who are insulated against common rejection patterns by a special role: that of a professional service worker, a handicapped person with the same handicap, the devoted parent of a person with a handicap, or an (aspiring) saint. If conditions inside a special programme become abusive, the solution lies in increasing the amount of money available and providing more effective insulation by further 'professionalising' those involved. The advocate's role is to get people with handicaps into special programmes and places. Once they are there, the advocate supports the programme organisers by helping clients adjust to the realities of their status as rejected people, and lobbying decision-makers for additional funds. Advocates have no business interfering with professional prerogatives, especially clinical judgments about what is best for people. Indeed, if advocates undermine the status accorded to the community's caretakers, the people who depend upon them will suffer.

The community with potential for transformation

We see an ambiguous situation in Georgia's communities. There is clear evidence of rejection. Segregation on the basis of handicap is the general, and generally unquestioned, rule within the organised services. Large numbers of people have no alternative but to live in public and private institutions. One can read a depressing collection of press clippings in which people proclaim support for group residences in general, 'but not in my neighbourhood.' But there are equally clear examples of community acceptance. A small but growing number of professionals all over the state have won community support when they have organised services encouraging the participation of people with handicaps in ordinary living, learning, and work places. The state's leaders have declared a policy of alternatives to institutionalisation, supported by legal and (partly) budgetary decisions. After one upper-middle class neighbourhood demonstrated public opposition to a home for three men with special needs, several similar neighbourhoods welcomed the home. Our communities have potential, therefore, for both acceptance and rejection. People with handicaps substantial enough to need very special accommodation evoke an ambivalent response from their fellow citizens.

Discrimination on the basis of handicap is woven into the fabric of community life. People with significant handicaps are very likely to occupy a devalued social role, which exposes them to risk of social exclusion and unfair treatment. Discrimination is masked and justified by such common myths as 'they really don't experience situations as the rest of us do', or 'nothing can be done for people like this', or 'people who need help should be grateful for what they get', or 'people like this are happiest living with their own kind'.

A community can take affirmative action to include people with handicaps and encourage them to assume positive roles, but it will not always be simple. Change will require more than good intent. Some community members may be disadvantaged by changes and there will often be conflicts of interests. While the courts may provide a forum to deal with some of these conflicts, many situations appear beyond their ability to resolve.

Georgia communities can draw on a tradition of community action to change unjust conditions and deal with unfair circumstances. But people with special needs are usually cut off from this tradition and most of their fellow citizens have no person-to-person contact with them. When contact does occur, it is generally with a faceless group seen to need pity or charity. ('Help with the handicapped. Donate your spare change.')

Most people think: 'Those people are well taken care of. We pay taxes and make donations to provide special centres and homes for them. They don't need anything else from us.'

The growth of professional services leaves many citizens confused about how to go about influencing this vital sector of their community. In providing for ever-increasing numbers of people, today's complex, bureaucratised services have outgrown citizen control. This imbalance strains the very meaning of citizenship. Ordinary people who want to change things have to organise and invent new ways of influencing services.

GAO assumes that there are significant numbers of ordinary citizens who are variously motivated to become personally involved with people with handicaps and to work to protect their interests. Over a period, a pattern of relationships which gradually weaves itself into the fabric of the natural community will be a force for transformation. Such relationships do happen spontaneously, but many more are likely if the community has resources dedicated to their initiation and support. These

Implications

relationships can be important for people with special needs; they are also important in forming more just and more competent communities. Think of an advocacy office as a catalyst, a source of energy. Think of it as linking ordinary citizens with people who are handicapped, so that they may act together on behalf of people who are handicapped. This is different in concept and practice from running a volunteer bureau to supply a low-cost supplement to the professional, statutory service workforce.

Measure success in terms of the varied networks of ordinary citizens linked together by the office; the extent to which these networks come to include people with handicaps in their everyday life; and the extent to which the situation of people with disabilities becomes the occasion for action and learning within them. Expect these fundamental changes to take time. Growth will be organic and slow at first.

Situate advocacy offices so that networks of ordinary people can easily relate to them. State-wide is too wide; so are regional offices based on the human service system's map; and so is one office for a large metropolitan area. What is just right is hard to say, but when networks of ordinary people cannot relate to an office, most supporters will be professionals and volunteers already involved.

Convene a local group whose members have wide personal contacts throughout the community. Count on this group to identify and support people they know who could become advocates. To broaden the programme's reach, avoid recruiting too many people already involved with human services.

Hire staff with community roots and expect them to pick out and support advocates within their own familiar environments, for example through churches, civic organisations, neighbourhood clubs, pubs and so on. If resources allow more than one member of staff, hire people whose contacts are complementary rather than overlapping. This is as important for people who do ancillary and clerical work as for 'professional' staff.

Arrange and support personal relationships with a wide range of people. Include people of different ages, abilities and circumstances. People volunteer to a person, not an agency or a problem. Cultivate the expectation that an advocate will learn to know the other person by working to understand, and change, that person's situation. Also that, as the relationship grows, the person will become more and more a part of the everyday life of the advocate and of the advocate's social group.

Position the advocacy office as a support to citizen networks rather than as one more human service or as a place to go if one has problems with human services.

Responsibility for action rests with citizen volunteers who, as a group, will become more effective with experience in dealing with the problems created by human service agencies.

Avoid competing directly with service agencies for funding.

Don't depend on services to pinpoint the people with whom citizen advocates will form relationships by seeking referrals through official channels. Develop a strategy for identifying and making contacts with a wide range of people with handicaps in a variety of social settings. To begin with, liaison with service workers will help, but as the number and variety of relationships grow, people who form relationships will pick out others who need them.

Matching is a person-to-person process. Rely on expanding personal contacts to recognise potential advocates, rather than 'marketing' people with handicaps as a group in need through mass media appeals for a group of volunteers.

When planning, accept the fact that citizen advocacy is unlikely to cover all of the people with handicaps who need personal representation. Because a citizen advocacy network grows slowly, this shortfall will be most acute in the first year of an office's operation. Supporters and staff should avoid promising, or expecting, too much.

First phase funding should not depend on the number of relationships formed or problems successfully solved.

Design principle 3

Bear in mind the realities of the existing service system in order to improve the quality of life for each person with a handicap matched by the programme.

A question of perspective and focus

Most of the people who call on GAO need special support if they are to develop. At present, society allocates resources in such a way that providing support is the designated responsibility of one or another organised statutory service. The past generation of political advocacy for people with handicaps has promoted a policy of replacing care with service: what families cannot do, services should. Many people with handicaps rely on organised services for such life defining functions as a place in which to live, work and learn. Beyond this, the real nature of services is a matter of perspective.

Many staff and advocates look at the service system as a whole from the point of view of service providers. They point with justified pride to a record of steady progress. More services than ever are available and, compared with the past, quality is good and getting (slowly) better. Better services will continue to evolve through a political coalition of professionals and organised consumer advocates. If progress lags, litigation on behalf of deprived classes can help. Many people who seek change from this perspective define their work as 'systems advocacy'.

GAO looks at the service system as it affects the experience of particular people. It looks at their natural support and their home communities. Our mental perspective at GAO is formed by a studied commitment to the principle of normalisation[3,4]. From this point of view, there are more services than ever, but many people still do not get what they (or those intimately concerned about them) believe they need. Their development is retarded if we do not make allowance for their (often) horrific past. Efforts to change the system as a whole from the top down continue to yield important gains, but are necessarily out of phase with the immediate needs of many people. More fundamentally, service (what organisations do for people) is no substitute for care (what people do for one another). Indeed, growing public investment in service may have the reverse effect of driving out care by weakening the structure of voluntary action by citizens.

Georgia has a number of active 'systems advocacy' organisations, some with an enviable history of success in influencing legislation. GAO chooses and maintains what it believes is a complementary focus, working with a relatively small number of people to create change in their relationship with their community and its service system.

Different ways of thinking

Advocates can start by seeing things from the service point of view, or from the point of view of those who rely on services. Either way, the advocate is likely to encounter people who regard the service system as if it were a perfectible machine. It is important for those who plan and implement advocacy programmes to consider the consequences of this way of thinking and to shape alternative metaphors.

The perfect(ible) service machine

Many American human service administrators like to think of their work as the assembly, operation, and maintenance of a complicated set of machines. Here is a caricature of this way of thinking.

An alliance of rational planners and specialist lobbyists in federal and state capitals provides brain and muscle to blueprint and implement an increasingly comprehensive array of service programmes based on progressive principles. Computerised 'needs assessment' surveys identify gaps in service. The planning and budgeting process converts these into programme 'slots', 'seats', or 'beds'. An ever-increasing army of laws and regulations divides the work between the various service agencies; coordination is achieved by joint committees. Major coordination problems are solved by reorganising the bureaucratic machine to achieve more rational integration.

Interdisciplinary teams produce individual service plans based on objective client assessment. Case managers introduce clients to service 'packages' through which they will be able to reach independence.

From time to time the service machine malfunctions. Incorrect application of eligibility criteria causes denial of service. Human or machine error causes a benefit cheque to go astray. Failure to heed good individual programme planning procedure leads to misclassification or inappropriate placement. Breakdown of management control at the programme level results in staff abusing clients in violation of written policy. These accidents present well-structured problems which are solved through a variety of administrative appeal procedures. Error is proven; responsibility is established. Redress follows according to regulation. Those who cannot represent themselves effectively have agency-paid internal advocates and ombudspersons to assist them.

From this point of view, personal advocacy is one more component of a comprehensive system of services. Advocates solve routine problems by applying defined rules. Advocacy serves as a stabiliser by providing feedback to those who operate the system. If change is required, managers will make it through established channels. Managers have the big picture required to make balanced decisions; advocates feed information about system performance discrepancies into managers' big picture files.

The limits of effective advocacy are the limits of the service system. When the system is unable to provide what a person needs for good reason, the advocate's role is to help the person adjust to the realities of the situation. Good reasons mostly have to do with resource shortages beyond the control of the managers. 'Fred can't have an electric wheelchair because the severely retarded are low priority for the few chairs available'. 'We can't design a mealtime programme for Alice because we are unable to recruit occupational therapists out here'. 'The authorities won't raise enough money to develop community homes for people like George'.

A herd of clumsy dinosaurs

The service system GAO has to deal with seems more like a herd of clumsy dinosaurs than an almost perfect machine. It dwarfs the many people who depend on it for housing, jobs, education, recreation, and health care. At times it inadvertently squashes smaller creatures. It has a significant impact on its environment because it consumes great quantities of resources and moulds society's response to its vulnerable members. It is not noted for its subtlety of response to small differences or for its ease in steering. And it faces a crisis of adaption to change, against which its bulk and power may insulate until too late.

Many dinosaur tales are swapped when advocates gather. Here are three, to illustrate the setting in which GAO works.

One of Georgia's dinosaurs is its Department of Mental Health and Mental Retardation (DMH/MR). Since 1972 DMH/MR has had legislative mandate to provide all Georgians with community alternatives to institutionalisation. In 1982, the Mental Retardation Division of this beast consumed about $75,718,000, allocating $8.50 to institutionalisation for every dollar spent on community programmes. 3,500 people still have to live in institutions, though the department itself has recently identified 600 as currently ready to move into other types of accommodation. Throughout the state, only 300 people are supported in community residences. In short, everyone talks about a continuum of service; but hardly anyone flows through it. All the laws, plans and coordinating council minutes make cold comfort to those still waiting for a decent place to live.

The herd moves slowly even under the goad of law. In 1976, federal law said that each school district was responsible for providing a free and appropriate public education for all children, no matter what the nature or severity of their handicap. In 1981 there were still 600 school-age children included with adults in DMH/MR programmes because of an inter-agency coordination agreement ruled illegal in 1979. The use of fiscal sanctions, provided in law for recalcitrant education agencies, has never even been threatened. Passing progressive laws is not sufficient to ensure a good place to learn for everyone.

Many dinosaurs seem to have a learning disability. Georgia's Vocational Rehabilitation Agency heralded the implementation of a comprehensive appeal system – an unparalleled opportunity to identify and solve problems. In its first year of operation, a grand total of five appeals was processed; the agency was right, the client wrong one hundred per cent of the time. People and advocates who rely on the rehabilitation agency for employment training find the maze of forms, procedures and deadlines which protect their rights so confusing that they do not know how to complain.

Implications

Concentrate on changing the personal experience of a variety of individuals who rely on the service system by involving a variety of people one-to-one in their situations. This offers many options for solving problems, reframing situations to allow creative action, or, if other measures fail, compensating somewhat for the pain of unresolvable situations.

If you manage to approach people's problems from many angles expect some adverse reaction from service managers – especially those who think of their work in mechanical terms. An advocacy strategy that demands more varied responses from staff in a programme may seem to them inconsistent, unpredictable and uncomfortable. Workers may press the advocacy office to define itself more clearly – that is, to specify limits on what advocates may do. This should be an ongoing source of tension and negotiation between the programme and the service system.

Advocates and people with handicaps will need ongoing support in a cyclic process of social learning. They will have to cope with the contradictions in services, as experienced by people with handicaps. This can lead to expanded awareness of the needs of the person for whom the advocate is concerned, and of the realities of a heavily-serviced society. Heightened consciousness reframes situations and inspires renewed action by citizens. Action transforms situations, usually in unpredictable ways. The social learning cycle is renewed as action reveals new possibilities and contradictions.

Advocacy based on a social learning cycle includes routine problem solving, but goes beyond it. The social learning cycle changes the terms of the problem and reveals new options. It also calls for an ongoing relationship to contain the uncertainty it releases.

The social learning cycle is interrupted if an advocate takes a narrow view of the situation. Thus, the programme will have to support advocates and people with handicaps as they clarify the situations in which they are involved.

The most common way to simplify contradictions is to blame the victim. Things that seem wrong are explained away by claiming that the person's handicap justifies the abnormal situation: 'Retarded people don't mind living six people to a bedroom'.

It seems reasonable, but is frequently unhelpful, for advocates to assume that those who provide services know best. 'This seems unreasonable to me, but if qualified staff are doing it, it must be right'. Effective advocates are good at raising questions that challenge the usual perspectives and flatten hierarchies.

Advocates and people with handicaps gain support from others concerned with similar situations. The advocacy office may bring people together to explore themes like: 'Improving living arrangements' and 'Better schooling', or provide training sessions, or put people in touch with professionals who volunteer their skills as advocate associates.

Discovering new possibilities

No relationship can be described solely in terms of discrete activities and accomplishments. Within these limits, the following summarises some examples of action by citizen advocates.

Some citizen advocates simply – and importantly – provide a relationship with a person with a handicap. Some citizen advocates represent, or work with, the person for whom they are concerned to solve routine problems through routine bureaucratic means. Some citizen advocates adopt a role defined by the service system, for instance as trustee for a person's funds, or monitor of an individual programme planning process. Some citizen advocates seek legal definition of their relationship as adoptive parent or guardian. But no matter how a citizen advocate sees his role, there is a good chance that he will experience creative tension from time to time.

Becoming a citizen advocate does not give a person special access to the truth about a person with a handicap. It does provide a special perspective and platform for action: a citizen advocate only relates to one person, and can look at things from that person's point of view. Service workers spend almost all their time working with a person as one of a group. Even individual programme planning coordinators experience a person as a case-load. But a citizen advocate has many ways of spending time with the person he is concerned about: within the rules, he can take a person home, on a trip, or to a new place. Official staff are nearly always limited by routine.

A citizen advocate can take time and decide how much responsibility to take for a person with a handicap. As a volunteer the advocate can choose to accept formal responsibility for a person, bring the person back to the programme if time is short or problems become unmanageable, or even choose to terminate the relationship with the minimal cost to the advocate. Professional staff have a different accountability. They are more likely to be punished for failing to prevent a problem than rewarded for taking a risk. They may even be held responsible for what a citizen advocate does with a person.

Many citizen advocates lack the socialisation experience that shapes service workers' perceptions of a person with a handicap. They often lack information about a person's history and the official 'prognosis' for his growth. This naivety might lead a citizen advocate to over-estimate a person, but it can also be the basis for new expectations and experiences.

The different perspective a citizen advocate brings can form the basis for constructive action if others involved can negotiate through creative tension. Creative tensions spring from a new sense of potential; they are experienced by the person and his widening social circle – the citizen advocate and the support network, service workers and their organisations, family, and often other ordinary citizens – and their resolution evokes new learning through action.

Most citizen advocates lack expert knowledge of human services; thus, their new expectations often emerge from unique personal knowledge. With support to identify with the person's interests, getting to know a person with a handicap will probably lead to a new appreciation of that person's situation. This appreciation develops along two lines.

The citizen advocate gets a feeling for the person's undeveloped potential. He may decide that the person could communicate better, be more mobile, learn more functional skills, be more productive, or relate to a greater number of ordinary settings and ordinary people. He may see a person currently engaged in 'work activities' as a job holder or a person living in a residential centre as a potential friend, neighbour or member of the family.

The citizen advocate believes that what others accept as part of a person's situation is unacceptable. He may conclude that there is nothing inherent in a person's handicap that justifies poor food, insufficient choice of clothing, overcrowded living quarters, work without pay, denial of necessary services, inactivity, or being moved from place to place without being consulted.

These perceptions become the basis for action. At first, this seems to the citizen advocate a straightforward task of clear communication. Others need to be informed and, once informed, they will either help change things or offer better ideas to work on. But many straightforward tasks become convoluted because of the resistance the citizen advocate encounters. Resistance comes from outside – the 'dynamic conservatism' of service organisations – and from within, coming to terms with his own confusion and conflicts.

Box 2

EXAMPLES OF CITIZEN ADVOCACY ACTION

A citizen advocate who has known a man with mental retardation for more than five years recently concluded that the adult training centre was under-estimating his ability and failing to provide relevant training. The advocate informed himself about personalised vocational services, used his business contacts to find the man a job, and found help to teach the person to get to, and perform, his job competently. Despite staff scepticism that the man is 'too low-functioning to be employed', he has worked successfully for over a year, earns a minimum wage, and provides health insurance for himself and his elderly mother.

A citizen advocate met a ten-year-old boy who had been institutionalised for most of his life because of mental retardation and severe behavioural problems. The citizen advocate visited regularly and put pressure on staff to pay more attention to the boy. His grooming and speech improved and behavioural problems decreased. Far from satisfying the citizen advocate, these successes led him to decide that institutionalisation was inherently destructive. After personal struggle and working through a complicated tangle of procedures, he became the boy's adoptive father and offered him a home.

Over a year ago a citizen advocate became involved with a man who had been placed by the authorities in a 'board and care' home, in poor conditions. The advocate was initially appointed to manage the person's funds, as he was judged incapable of doing this for himself. As their relationship has developed, the advocate has helped the person find part-time work and move into much better accommodation. A dentist by profession, the advocate has also performed necessary dental work which the service system had neglected.*

A citizen advocate has known and represented a child with mental retardation since 1978. When they met, the child was living in an institution. She felt he could live with a foster family. As the months passed, the citizen advocate knew that she would have

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*Most Americans rely on themselves, or on private insurance plans to meet their medical expenses. The examples just quoted show that the poor rely on a confused, limited patchwork of benefits.

to act if this was to happen, so she wrote letters, made telephone calls, and attended meetings persistently until he moved in with the foster family with whom he has lived since late 1979.

Another advocate has known a woman with mental and physical handicaps since 1979. The citizen advocate decided that an electric wheelchair would improve her mobility and her options. When she was told that the service system would not provide an appropriate chair, the citizen advocate raised funds through local civic organisations and bought it.

Another person, known to a citizen advocate for over a year, is a woman with mental retardation who lives in a private nursing home. The woman's sister, her legal guardian, has instructed the staff that she is forbidden to leave the building. The citizen advocate, who lives nearby, has observed the sister's rule and visits regularly, frequently bringing her other friends. The citizen advocate has decided that she now has a strong enough relationship to begin to negotiate new rules.

A citizen advocate met a young man of 18 with cerebral palsy who was living in a home for unmarried mothers, his fifteenth 'placement'. While pressing the services to find him somewhere more suitable to live, the citizen advocate came to know the young man and decided to invite him to share his home. They enjoy the arrangement and say they intend to live together 'long-term'.

A citizen advocate decided to buy batteries for a man with mental retardation living in a nursing home, so that the man can now listen to his portable radio.

A fifteen-year-old, who had lived in an institution for most of her life, was visited every week by the citizen advocate. Through family and other community contacts, the advocate developed a support network. This allowed the family to bring their daughter home.

A married couple met a young woman who had lived all her life with her elderly mother before her recent placement in a local group home. The young woman had led a very sheltered life and missed many of the ordinary experiences of growing up. The citizen advocates involve her in a wide variety of everyday activities: cooking meals, shopping, attending movies and concerts, and just visiting.

Meeting resistance

Resistance from 'outside'

Sometimes a citizen advocate's sense of potential communicates itself easily to others. They come together to make the necessary changes and learn the implications of the new concept. For instance, adult training centre staff were certain that George could never be employed. George's citizen advocate felt that he could be. Institution staff were convinced that it was unrealistic to find Ken a foster home; his citizen advocate decided that one should be found. The 'board and care' home manager was sure that no one who did not benefit financially would bother with Tom's financial situation; his citizen advocate was willing to try.

But not all service workers are ready and able to cooperate with a citizen advocate's notion of what might be. Service workers who do not want to engage a creative tension control important resources which they can use to neutralise a citizen advocate's concern. Public faith in professionalised service is a very important resource, which can be used at little cost and often with powerful effect. 'We appreciate your interest. But we experts can explain why what you want is not really in the person's best interests.'

Most citizen advocates want to be seen as reasonable, well-mannered people. But even when a request for change is respectfully made, that request often challenges everyday assumptions and practices. Service workers may therefore interpret a citizen advocate's statements as 'aggressive', 'unconstructive', and 'confrontational'.

Red tape is always a reality; even under the best conditions, it can discourage a determined advocate. At worst, red tape can snarl up an effort to change things, and sap a citizen advocate's strength.

Service organisations are complex hierarchies and there can always be somebody 'up there' or 'down there' who will not cooperate.

Service programmes are responsible for many people, not just the person for whom the citizen advocate is concerned. It may be that investing in a change to benefit one person will disadvantage others, at least in the short run. Even when creative effort could improve things for everyone in a programme, service workers can react to a demand for change by appealing to the citizen advocate's sense of fairness. 'If we pay special attention to *your* request, the other people we serve won't get what they deserve.'

Staff who are cooperative can share their skills and lend their resources to solve the inevitable problems involved in change. Those who simply remain passive, and let problems develop, can almost guarantee that negative prophecies will be fulfilled.

Some citizen advocates are vulnerable in other ways. A college faculty member was told by her profession of complaints of 'unprofessional conduct' arising from her efforts to represent a handicapped person's interests as she saw them.

Many programmes control access to a person who is handicapped. If other means fail, a citizen advocate can be 'cut off'. This obstruction can be subtle, as when schedules are adjusted so that a person is 'unfortunately in speech therapy' when the advocate arrives. It can be more overt, as when a citizen advocate is barred from seeing a person 'because he is upset when the citizen advocate brings him back.' There have even been threats of arrest for trespass. Each of these controls has some legitimacy, and most service workers feel justified in using them instead of more open, time-consuming ways to deal with disagreement which might produce changes. Since many citizen advocates often feel insecure, they frequently withdraw for a time to reconsider their position when service workers under-value their perspectives on a person's situation.

Resistance from 'inside'

Not all resistance is external. Creative tension is experienced by the citizen advocate as well. The advocate, too, has grown up in a culture that devalues people with handicaps and is as likely to confront prejudice within himself as among service workers or uninvolved fellow citizens.

Beyond prejudiced attitudes, involvement with people who have substantial handicaps raises powerful issues which are unresolved for most of us. Many of us live most of our lives out of contact with sustained suffering, real physical and emotional dependency, violence, and mortality. A citizen advocacy relationship can disorganise personal defences. Disorganisation may lead to personal growth or to withdrawal through rejecting the relationship ('I'm not strong enough or good enough to relate to her', or 'He really isn't worth my time', or 'I don't know what happened, I just got busy with other things and we drifted out of contact'). Disorganisation can also be avoided by denying a person's disability and its implications for others ('He really isn't handicapped at all'). Getting a proper sense of a real person with a handicap without retreat into denial of potential, or denial of inability, is difficult for most of us[5].

Any relationship takes time and care. A relationship with a person who relies on a time-controlling service programme is often additionally complicated by the need to accommodate unusual schedules and rules. Involvement with most people who have handicaps means involvement with people who have professional status, and substantial power over handicapped people's lives. It is challenging to establish a constructive relationship with people in authority who can assist or frustrate a citizen advocate's plans. A citizen advocate may find himself reacting to authority with submission, unquestioning dependency for guidance, or rejection out of hand. Some citizen advocates fear that taking positive action may lead those in authority to cut off the advocate's contact or even punish the handicapped person. Sorting out situations like this is more difficult when authority relationships are confused.

Then again, citizen advocates often face complex bureaucratic problems. They may find themselves struggling to make sense of confusing and contradictory regulations and procedures. As one citizen advocate said, 'I used to think my income tax forms were threatening until I got involved with Jane'. In many situations, it is hard for a citizen advocate to decide when to stop. If a particular problem isn't resolved at one level, a citizen advocate faces a choice. For instance, if ward-level staff turn down a request or fail to follow it through, will the citizen advocate take the matter up with people further up the hierarchy? If this is unsatisfactory, will the citizen advocate initiate a formal complaint or appeal? If mediation fails, will the citizen advocate go to court? When should a citizen advocate involve advocate associates or an attorney?

Where is compromise possible and when does compromise become a sellout of a person's rights and dignity?

Once one problem is resolved will a citizen advocate declare victory and take a well earned rest, or look for a new problem?

Many people with handicaps have limited ability to state their own preferences and desires. Sometimes this is because of inability to communicate effectively. Often, and more ambiguously, it stems from lack of experience of real alternatives. It can be hard for a citizen advocate to be confident that he is working for the best interests of a person who depends on him to interpret his or her wishes, or say what is best.

A growing number of citizen advocates conclude that the service system cannot meet a person's basic needs for a home and an occupation. This creates a new challenge – defining the limits of personal responsibility. Some citizen advocates, as we have seen, respond by going outside the system and sharing their own home or using their network of relationships to find a person a job. This creates new uncertainty. How long can this arrangement last? If it falls apart, who will pick up the pieces and what will be the consequences for the person with a handicap? Do I as a citizen advocate have a personal network which will support my commitment? Can I rely on the service system for support?

Citizen advocates who decide to do for a person with a handicap what might reasonably be expected of the service system may face a dilemma. 'If I find her a job or pay for her medical care or buy her basic clothing, I'm taking away a source of pressure to improve services. But if I don't, it looks like the service system will delay matters forever'.

None of these sources of tension is simply removed once and for all. There cannot be a citizen advocate's manual of answers. With the support of allies who listen, clarify, and respond to requests for joint action, each citizen advocate works out personal responses in the context of a unique relationship.

Constructive action

Action by citizen advocates reorganises the situation surrounding a person with a handicap. This reorganisation may not lead directly to the expected result. A citizen advocate who sets out to get a person referred to a group home ends up sharing his own home. It may not even lead to a solution. A citizen advocate may decide that he can do no more – and no less – than spend time with a person who acts violently and actively rejects the demands of structured contact.

People with mental retardation in a community which supports citizen advocacy relationships can expect a variety of responses to their situation. Those who are part of a citizen advocacy relationship should experience

- personal concern for their individual experience, which can lead others to notice, and pay more attention to, their uniqueness;
- respectful interaction – and often genuine affection – which can change other people's evaluation of them;
- individual experience of new places and people in company with someone who knows the way;
- positive contacts with a broader network of people which can provide support and an increased sense of personal security;
- active help in defining their personal interests and concerns, and representation to help solve problems in a way which will serve their interests;
- monitoring of the programmes handicapped persons rely on;
- (occasionally) direct care in the form of a job, a home and family life.

Not every relationship provides all of these benefits. And because citizen advocates are not service workers, benefits cannot be planned, managed and charted. The effects of citizen advocacy can best be measured in terms of the stories of citizen action generated by groups of advocates.[6]

Citizen advocacy is one way in which ordinary people, and people who rely on service programmes because of mental retardation, can work together to explore the meaning of citizenship. Not all the lessons of citizen advocacy action are easy. Not all of the stories have happy endings. But every person who becomes involved and acts can grow and promote growth.

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