

AN ORDINARY LIFE AND TREATMENT UNDER SECURITY FOR PEOPLE WITH MENTAL HANDICAP

Proceedings of a workshop organised at the King's Fund Centre - 23rd May, 1989

Edited by Anne Leonard

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The King's Fund Centre for Health Services Development, which dates from 1963, is in purpose-built premises in Camden Town. Its aim is to support innovations in the NHS and related organisations, to learn from them, and to encourage the use of good new ideas and practices. The centre also provides conference facilities and a library service for those interested in health care.

The Community Living Development Team is part of the King's Fund Centre, with a particular interest in the development of high quality services for people with long-term disabilities, including people with learning difficulties, physical disabilities, and people with mental health problems. In common with other groups within the Centre, the team's approach to service development is to support innovations in service organisations, to learn from them and to encourage the use of good ideas and practice. The team works at many levels but is particularly concerned to work with services, user groups and voluntary organisations at the <code>local</code> level to promote good practice. Along with other parts of the King's Fund organisation we are also concerned with policy issues and with the large-scale management of change.

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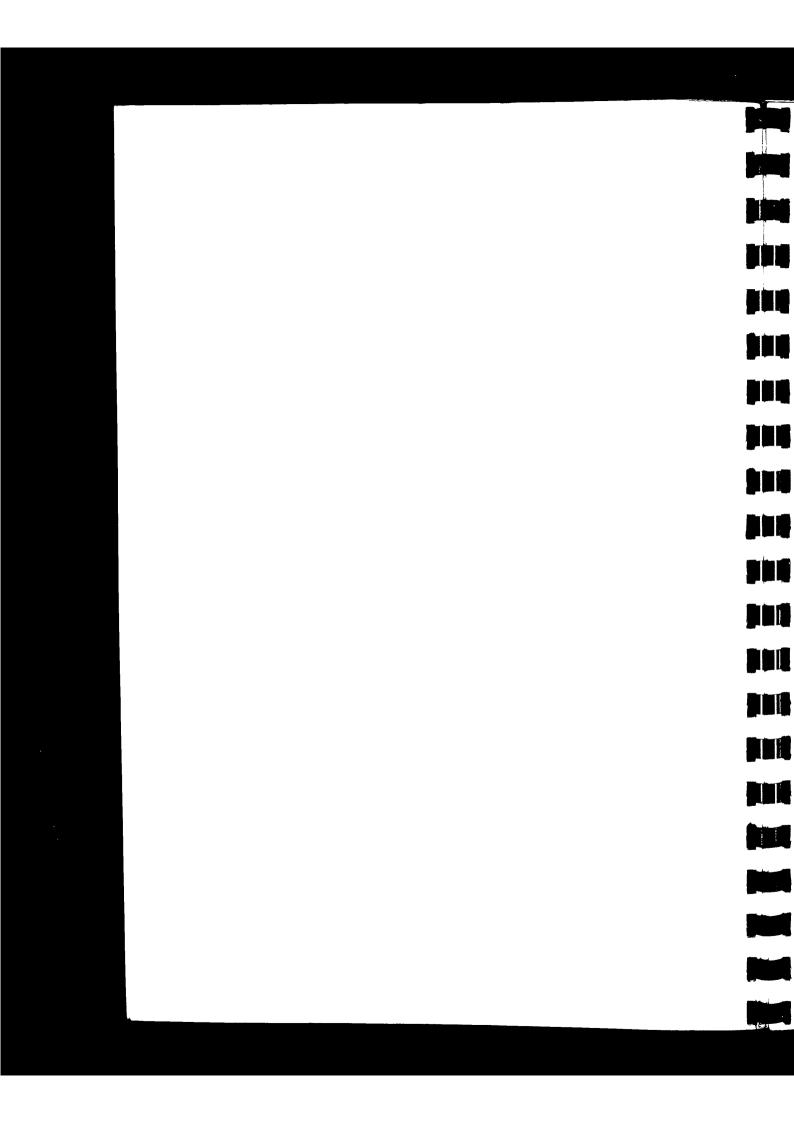
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INTRODUCTION

The workshop An Ordinary Life and Treatment under Security was held at the King's Fund Centre on May 23rd, 1989. It was the latest in a series of such events organised as part of the King's Fund Ordinary Life initiative for people with learning disabilities* (KF Project Paper No. 24, 1982: An Ordinary Life - comprehensive locally-based residential services for mentally handicaped people). The papers that were presented at the workshop form the backbone of this report. In addition, the main issues that emerged in the course of the day's debates and discussions are highlighted alongside the conclusions and recommendations for future policy development.

Within the Ordinary Life initiative, Challenging Behaviour has provided an important focus of attention, leading to the publication in 1987 of the discussion paper Facing the Challenge (KF Project Paper No.74, 1987: Facing the Challenge - an ordinary life for peole with learning difficulties and challenging behaviour). However, it was recognised that the implications of the Ordinary Life perspective has so far been overlooked for a significant group of people, namely those people with learning disabilities who are held in secure units. Secure custody may have come about for the people in question as a result of having been identified by the courts as 'offenders', or for other reasons, such as their being considered 'a danger' to themselves or others. This workshop sought to make good the omission by gathering together key people from a variety of appropriate backgrounds to begin to tackle the issues, taking the principles underpinning the Ordinary Life initiative as the starting point for the day's deliberation.

Four main issues were identified for exploration in the agenda for the day:

the values underlying the **Ordinary Life** initiative and how they can be incorporated into any emerging strategy;

the concept of **security**, including an examination of whose security and safety is at issue and the implications for services;

the concept of dangerousness, its definition, assessment, and the necessary responses to it;

the problem of where responsibility should lie, how accountability can be guaranteed and individual and societal needs negotiated equitably.

The contributions which follow take up these themes.

In a background paper, Rita Lewis outlined the historical context of current service provision where people with learning disabilities may be held in secure settings which are not always appropriate, and do not meet the needs of all of the individuals living in them.

^{*} In much of this publication we use the term "people with learning difficulties" in place of the more common "people with mental handicap". Service users, for example members of the People First organisation, have said that they would prefer not to be labelled at all, but that if this is necessary "people with learning difficulties" is preferred.

Diana Dickens made a contribution to the discussion of current provision, focusing on the concrete outcomes of policy development in Rampton and Moss Side Special Hospitals, acknowledging both the strengths and weaknesses of these settings and identifying individual needs that these services leave unmet. The vision of a spectrum of services permitting a more sensitive and appropriate response to the full range of individual requirements found an echo in Dr. Mary Myers' account of an initiative that is successfully implementing the Ordinary Life philosophy for seven people previously recipients of less than ideal services. The results of the work Mary Myers described included not only improved quality of life for the people in question, but dramatic reduction of their challenging behaviour, as a result of improved understanding of the patterns of disturbances and their sources. These results came about through the intensive observation made possible when people live in very small groups, with a suitable number and quality of staff who are appropriately trained both in the Ordinary Life philosophy behind the service and the functional analysis of behaviour.

David Carson's paper identified the underlying ethical and legal issues and problems in the present state of affairs for people with learning difficulties, indicating ways in which their individual rights could be better safeguarded.

Dr.Tony Holland discussed the complexity of the service response required to meet individual needs, with special emphasis on staffing and training implications, a theme that recurred throughout all the speakers' contributions and the discussions that ensued.

Edited versions of the contributions from Rita Lewis, Diana Dickens and Mary Myers comprise the first three chapters of this report. Following these, summaries of individual case studies presented to the conference and of the subsequent group discussions make up the second section of the report. The contributions from David Carson and Tony Holland provide the next two chapters, before a brief summary of the plenary discussion which is followed by the conclusion.

SECTION I: TAKING STOCK

CHAPTER 1: THE DEVELOPMENT OF POLICY

Rita Lewis

This chapter sets out to identify the main issues in the formulation and development of policy regarding secure services for people with a mental handicap. It reviews the recommendations of the Glancy(1) and Butler(2) reports and identifies some of the problems encountered in their implementation. The chapter goes on to consider the specific needs of people with mental handicap who require treatment under security, and the relevance of the Regional Secure Unit model for that purpose. Some other services and possible needs for varying levels of security are suggested, and possible models for the future are offered.

- (1) DHSS: Report of the Working Party on security in Psychiatric Hospital. 1974.
- (2) DHSS & Home Office: Report of the committee on mentally abnormal offenders. HMSO 1975.

Background To The Policy on Regional Secure Units

The movement towards 'care in the community' was established in the Report of the Royal Commission of 1954-57 which advocated informal status for psychiatric patients and the reduction of compulsory admissions. The resulting 'open door' policy freed many patients from restraint and led to changes in staff attitudes from a previous custodial orientation towards increasing opposition to locked facilities. The subsequent evolution of services led to what has been described as 'a yawning gap' between the maximum security of special hospitals, and mainstream psychiatric services, neither of which met the needs of people with learning disabilities requiring treatment in secure settings.

The tolerance both of staff in hospitals and of the general public became strained and as a result many people with mental illness were sent to special hospitals and prisons, rather than receiving appropriate care in the National Health Service. Alternatively, people were placed in hospitals in locked wards with inadequately trained staff and with staffing levels insufficient to provide the therapy and supervision they required. Several official inquiries into conditions in psychiatric hospitals, set up in response to a series of public scandals, reported on the low priority given to locked wards, leading to poor care standards. These reports, and those on overcrowding in the prison and special hospital services, in conjunction with concerns about specific instances of public safety risks, led to demand for a thorough review of the need for security and specialist forensic services.

A Ministry of Health working party report of 1961 identified the need for some hospitals to provide secure facilities and for Regional Hospital Boards to provide secure assessment and diagnostic . Only two such services were provided and these did not last long. By the 1970's the difficulty in placing people requiring treatment under conditions of security was exacerbated by the trend towards providing psychiatric services within District General Hospitals, and by the reduction and closure of large scale mental handicap and psychiatric hospitals.

The Glancy And Butler Reports

The Department of Health and Social Security responded to the pressures to review the unsatisfactory state of security in National Health Service hospitals by setting up a working party to look into the existing guidance for these services and to consider present and future needs. Dr Glancy produced the final report in 1974, after comments had been received from hospital services and the Butler Committee, which was sitting at the same time.

The working party accepted the need for revised guidance to take account of the service changes that had occurred and that were planned for the future. It was not considered necessary to provide detailed guidance on how the need for security should be interpreted in practice in the service context, on the assumption that this was generally understood by people responsible for services. As in 1961, the Department accepted that such provision was essential in the National Health Service as part of a comprehensive plan. Thus, Health Authorities, under the guidance of the Regional Health Authority, were to plan and provide secure facilities in hospitals or in the community.

According to National Health Service calculations, there was an estimated need for 1000 beds for people who were either mentally ill or who had learning difficulties with disruptive behaviour. This included those with personality disorders and multiple handicaps. Recognising the broad category of patients likely to need such services, the working party specifically excluded elderly wanderers, people in acute phases of illness and people with severe mental handicap with destructive and/or over active behaviour. The working party suggested that any unit built should be capable of providing services with varying degrees of security for both men and women, for many types and categories of patients, and that security should be less than that provided in special hospitals, but essentially physical (rather than pharmacological). It was recommended that staffing levels should be such as to provide active therapy, education and occupation. The optimum unit size suggested was 50-100 beds, with units located close to other services. Lengths of stay were unspecified.

The Committee on Mentally Abnormal Offenders set up in 1972 and chaired by Lord Butler, considered what changes were necessary in the powers, procedures and facilities available for the appropriate treatment in prison, hospital or community, of offenders with mental disorder or abnormality and for their discharge. It also considered wider aspects of the law in relation to mentally abnormal offenders. The 1974 Interim Report of the Committee was produced as a matter of urgency, to appear simultaneously with the Glancy report since the lack of appropriate secure units was identified as crucial in the inappropriate placement both of offenders and non-offenders requiring psychiatric treatment.

Butler identified four main difficulties impeding the proper placement of people requiring secure services:-

- Overcrowding in the special hospitals. This had worsened in the decade prior to the report.
- ii) Difficulties for the courts in placing offenders in psychiatric services. Prison placements were often the only available facility.

- iii) Difficulties for the special hospitals in transferring patients to less secure services.
- iv) Lack of co-operation between the prison and National Health services and joint medical training and consultancy.

The Butler report supported the conclusions of the Glancy report on the need for regional secure units, with scope for variation in the models adopted.

The Butler Model

Regional secure units would provide a hospital base for the development of forensic services which would also cater for non-offenders by providing assessments and suggesting or negotiating future placements in appropriate services. The length of stay would be shorter term (usually not exceeding 2 years) These services would be placed in the community and linked with Courts and other forensic facilities and services. The major criteria for the location of treatment was proximity to the home and community from which the patient had come. Taking account of the hospital and forensic services, the Butler committee estimated a need for 2000 beds initially, to be provided in units of between 50-100 beds with supporting services, or 200 beds if unsupported. Staffing was to be of high quality and levels: 1 to 1 nurse/patient ratios were suggested. Research and close academic links were considered crucial to the development of professional knowledge in this area. Particular reference was made to the possibility of admitting people to the units who were not of immediate danger to the public.

Unlike the Glancy report, Butler identified the need for money to provide the buildings and staff for these services.

Progress In Implementing These Reports

The final Butler report was extremely critical of the lack of progress in implementing the Regional Secure Unit policy. They considered that Regional Health Authorities were both unwilling to plan the services and to give the high priority felt necessary for planning interim and permanent units.

There were other reasons for the delay of the start of the programme locally. The Department of Health and Social Security did not clarify what funding was to be provided for the Units. Initially only the capital was agreed. A formula for revenue funding was not produced until 1975. This was unfortunate, as many authorities were aware that, to provide the service according to the model prescribed, per capita costs would be in the range of £25-30,000 annually, a commitment that could not be suddenly made. Shortages of the staff necessary to provide the service, the slow development of the specialism of forensic psychiatry, and the lack of clear pay guidelines especially for nursing, compounded the problems. The latter gave rise to problems of industrial relations.

Whilst it is possible to argue that the lack of a specific model of service and facilities allowed flexibility of response, it also caused considerable delay in planning and agreeing the type of service. The confusion within the National Health Service, expressing itself in staff concern about the outcomes of local proposals, undermined public confidence. In many cases, public opposition led to delays. There were other factors which caused hold-ups, such as the re-organisation of Social Service Departments and a reluctance to commit social work time to planning. The National Health Service itself was going through the disruption of re-organisation, and public expenditure was contracting as a result of the oil crisis.

Conceptually, there was confusion about the meaning of 'dangerousness' in relation to mentally abnormal offenders, the types of patients to be treated in the units and the 'treatability' of psychopaths. Some eminent people, such as Dr Peter Scott, found difficulty in accepting the National Health Service rather than the prison service as the appropriate location for Regional Secure Units. The need for a local service 'champion' was evident and many other factors influenced the speed of policy implementation.

The Regional Secure Unit policy is now reaching the end of the first stage of implementation, as most Regional Health Authorities have at least one permanent unit completed or nearly so. However, with the exception of two Regions, the Regional Secure Unit policy has been focused on mental illness services. These services may or may not include people with a mild mental handicap in combination with other mental disorders.

Secure Services For People With A Mental Handicap

The summary of the Regional Secure Unit policy shows clearly the lack of specific consideration of the needs for secure services or people with a mental handicap.

The 1980 Review of progress since the 1971 White Paper, Better Services for the Mentally Handicapped, reports that much effort has gone into planning for hospital closures, relocation into the community, and the development of comprehensive services. The National Development Team has emphasised the need to develop a range of secure services, for a variety of people who have proved challenging to manage, including some people who have offended, or who might do so should they be given the opportunity. The second and third National Development Team Reports suggested specific semi-secure specialist units of between 10-12 places per 1 million population for people with severe mental handicap and a similar number of beds for mildly handicapped people. The fourth Report in 1984 drew attention to the very slow progress in implementing these recommendations.

It was envisaged that these services would be provided sub-regionally. The delay in implementation has left adolescents and adults with mental handicap in a similar situation to that of many people with mental illness identified in the Butler and Glancy reports. That is, they find themselves in special hospitals even when that level of security is not required, or in the prison service, or in locked wards in mental handicap or mental illness hospitals, or in private sector services. A common factor in the ad hoc solution to the problem of providing secure services, is the often vast distances that separate them from home and and relatives, and their isolation from local services. There are some specialist services in the National Health Service which tend to become supra-Regional services as a result of the pressure of demand.

In 1981, the Royal College of Psychiatrists produced a paper on the Future of Special Hospitals which drew attention to the problems of transfer delays for special hospital patients. These are exacerbated in the case of people with a mental handicap as a result of the paucity of secure services available in the Regions. A 1987 inter-departmental working party of Home Office and Department of Health and Social Security officials drew attention to the poor state of information on the numbers of mentally disordered people in the penal system. The Social Services Select Committee of the House of Commons (The Short Report) also identified problems. The Government response promised action on the Prison Medical Service.

The Mental Health Commission's Biennial Reports of 1985 and 1987 also expressed concern about the inadequacy of planning for secure services. People with a mental handicap who are detainable under the 1983 Mental Health Act, often require secure facilities for their appropriate treatment. In the course of the Commission's visits in England and Wales, it has become increasingly aware of the need for a range of secure services which would prevent detention under maximum security where it is not appropriate, and in particular would provide services for people leaving special hospitals.

There is ample evidence of a significant problem in relation to the need for secure services for people with a mental handicap. The question remains as to where attention should now be directed.

Future Services For people With A Mental Handicap Requiring Security

It is incumbent on the Department of Health and on local Health Authorities, to ensure that appropriate facilities and services are provided to meet the needs of the population served. A plan of action to meet these needs might be expected to proceed through the following steps:

- Identify the needs for the service.
- Break these needs down to geographic and service requirements.
- Plan relevant services accordingly.

One of the major problems, however, is identifying the type of secure services needed, since the necessary information is dispersed and must be compiled from a variety of sources.

One approach can be found in the Regional Secure Unit model which two Regions have modified for people with mental handicap and which other Regions consider to provide an appropriate service for people with mental handicap and with an additional psychiatric condition.

The Regional Secure Unit provides a range of specialist assessments and treatments and usually has good links with forensic and community services and the special hospitals. For people seen to be a potential public safety risk, the Home Office often insists on the level of security provided by Regional Secure Units. Similarly, the Courts need the same reassurance. However, it is often very difficult to place a patient from psychiatric services in a Regional Secure Unit for specialist advice. The funding arrangements for such units may make the option of adapting the model for people with a mental handicap particularly attractive. Research links may offer particular advantages. However, disadvantages include the possibility of 'silting up' with patients, unless adequate services are available to transfer clients either to other National Health services or to community placements. Where an existing Regional Secure Unit is mainly for mentally ill people, the number of people with mental handicap for whom the service is appropriate is likely to be very small.

Nevertheless, the Regional Secure Unit model may provide one approach for mentally handicapped people who require security in their treatment.

Some Regions, either themselves or in conjunction with Districts, have developed specialist assessment and treatment units, e.g. South West Thames, South East Thames and the Northern Regions. Such services may fail if inadequate attention is paid to the need for very clear policies for admission, treatment and discharge. The service models are many and varied and perhaps there is considerable advantage in this variety. Each Region and District can assess and provide for the needs identified. It is likely that the volume of service will be relatively small, and such services will not usually be sustainable on a District basis.

Supra-District and Regional specialist secure services may provide a greater range of services to meet more varied needs.

Whatever supra-Districts services are planned, the key to successful services for people with a mental handicap requiring security will be the development of a comprehensive range of services at District level, in conjunction with relevant authorities and agencies. Without such

services the options will be limited and the ability to meet the needs of individuals difficult. In 1980, the Royal College of Psychiatrists' advice on secure services for psychiatric patients identified the need for a comprehensive approach to ensure that services are integrated and a range of choice is available. The context in which services are provided is changing, and alternatives to hospital provision are essential. The services may remain in the National Health Service, but the nature of facilities will inevitably change.

The challenge for the future is therefore to provide secure services to meet the needs of individuals within a context in which services are integrated with the community in the 'Ordinary Life' model.

This chapter has attempted to tackle a very large issue in a few pages, and therefore could not be comprehensive. However, it is hoped that it provides sufficient background information to stimulate thought about this very difficult service problem. The main lesson to be learned is that a 'best buy' solution is unlikely: the need to maintain flexibility within and between services is paramount.

CHAPTER 2: PRESENT PROVISION, ISSUES AND PROBLEMS

Diana Dickens

Introduction

Like all other members of society, people with mental handicap may exhibit maladaptive behaviour patterns which are so dangerous that the general public needs a degree of protection from them. At a simple level, protection can be achieved by purely custodial means. This, however, totally disregards the needs of the person concerned. An attempt to balance the requirements of security against those of treatment has always been a fundamental problem in carring for people with severely challenging behaviours and in trying to establish a programme of care that will meet both requirements.

Whilst at one extreme the use of locks is essential in view of the severity of some behaviour, at the other extreme 'security' need only imply very careful observation with no physical containment whatsoever. In an ideal situation all levels of security from one extreme to the other should be freely available, and in forms suited to meet the needs of each individual. It should also be a fundamental principle that no person at any time should be contained in a greater level of security than is appropriate to his other needs. Unfortunately, this is not an ideal world. The following discussion addresses some of the weaknesses and strengths of current provision.

Special Hospitals

The most secure provision for people with mental handicap is that provided by Rampton and Moss Side Special Hospitals. The purpose of these hospitals is to treat, in conditions of special security, patients with mental disorder who have demonstrated that their behaviour is very dangerous to others. Although the levels of perimeter security vary slightly (Moss Side has no perimeter fence) other security measures are fairly similar. The aim of these hospitals is that, given the constraints of security, the patient shall be treated in a manner which is consistent with the best in modern practice in the care of people with mental handicap. The end product of such treatment is that the patient should be sufficiently well, mentally, and in social and educational capabilities, to be integrated back into the community. Depending on the original problem that the patient presented, this rehabilitation may be directly back into the community or alternatively via a service operating a lesser degree of security, such as one of the Regional Secure Units.

From the treatment point of view the strengths of the Special Hospitals include very high levels of trained nursing staff, reasonable levels of staff in other disciplines and in addition a tradition that all patients, unless severely disturbed, receive daytime occupation of some description. This occupation aims to be as constructive as possible and from early in the patient's stay in hospital is directed towards the ultimate goal of rehabilitation into less secure surroundings.

Both Moss Side and Rampton are fairly old and provide spacious accommodation on an extensive site. Most patients have their own rooms and within the perimeter have a considerable area in which they can move. There are also very good facilities such as gymnasium, swimming pool, shop, etc, and patients are taken on outside visits accompanied by staff whenever possible. Both hospitals offer good rehabilitation facilities

in terms of patients' education and rehabilitation units, one of which, for example, has a training flat where patients can learn domestic skills and budgeting. Another at Moss Side is integrated. High staff ratios provide ample opportunity for nursing staff to spend time interacting with patients and this interaction is also a vital part of the treatment and rehabilitation process.

There are, however, considerable disadvantages, the main one being that because of perimeter security and the relative isolation, particularly of Rampton, there is little opportunity for contact in an informal way with the outside world. The need to escort patients means that even on rehabilitation outings where there is only a small number of patients it is difficult for them to experience full interaction with the ordinary community.

Many of the patients within a Special Hospital system need to be there on grounds of dangerousness and for these patients in general the setting is an appropriate one. However, the average length of stay for a patient with Mental Handicap is about 12 years. It is absolutely vital during this time that residents do not lose touch with the outside world, and this is perhaps one of the hardest things to ensure. There is also a substantial group of individuals who do not require to be in the Special Hospitals because they do not need the high level of physical security. However, their challenging behaviour may be of such a nature that the high staffing levels provided by the hospitals are essential to cope with these demanding problems.

The large size of the hospitals may give rise to all the problems of institutionalisation. On the other hand, there may be a certain advantage in the availability of spacious grounds and other facilities for a group of patients who would not be able to use these facilities in the community by reason of their high security risk.

At the moment there are considerable numbers of patients on Special Hospital transfer lists for whom it has been agreed that Special Hospital care is no longer appropriate but who are not accepted by other services. This lack of provision means that many patients are deprived of relative freedom through no fault of their own.

Regional Secure Units

At a lower level of security are the Regional Secure Units or semi-secure units. In general these units (all placed in the grounds of large mental handicap hospitals) provide security which can be more flexibly applied. It is debatable whether these facilities benefit or lose by being connected to such hospitals. At one level it is advantageous to patients because it is possible for them to move freely around the hospital in a flexible manner (where considered appropriate), but on the other hand this association might constitute a barrier to free movement in and out of the local community. The merit of these units is that being more locally (albeit Regionally) based, patients' contact with relatives is more easily maintained than it is in Special Hospitals with their national catchment area.

Bearing in mind that people with mild handicap do not seem to be provided for by Regional Secure units, it could be argued that developments of units such as these for people with mental handicap at a Regional level should be mandatory. If this development were to take place then many patients presently housed in Special Hospitals, far away from their families, could be brought back closer to them. Such units, like Special Hospitals, have high staff/patient ratios and an excellent input of other professional services (probably at a higher level than that of the Special Hospitals). Again, treatment and rehabilitation are high in priority in the management in such units. It is also important that any facility set up on a Regional or sub-Regional basis should offer a service which supports carers. In this way not only may admissions be avoided by good support and preventative work but rehabilitation and reintegration into the community would be aided.

Local Provision

Attachment to local hospitals makes the rehabilitation of the patient within the main hospital more likely, thereby making the person more ready for community placements. One of the basic problems in the rehabilitation of people with mental handicap who have been placed in any level of security, is the anxiety about their dangerousness which is produced in accepting agencies. Therefore, one of the fundamental tasks of rehabilitation from any secure setting into the community should be the demonstration that the patient has ceased to be a danger. At present the inability to do this is in many cases a serious hindrance to an individual's return to full community care. For example, many local hospitals are not prepared to accept Special Hospital patients with the challenges which they present, perhaps because within the totally secure environment it is impossible to demonstrate the absence of risk.

In order to achieve this it could be argued that hostel-type accommodation might usefully be set up under the aegis of the parent hospital. For example, Rampton is involved in conjunction with "Turning Point" in the running of a hostel in an ordinary residential area of Nottingham which takes patients with mild mental handicap into conditions of no security, other than observation, and reintegrates them into the community. This type of hostel arrangement (a small group of not more than eight residents with fully trained and experienced staff in as near a domestic setting as possible) presents considerable advantages. Firstly, when run in conjunction with the parent hospital it ensures continuity of care and appreciation of problems which a patient might present and, secondly, exchange between the hospital and hostel is very easy. For example, a patient may be moved quickly should difficulties

Options for the future

Unfortunately, the present system of secure services is such that realistically it is impossible to start afresh. Any future plans will have to evolve gradually. It is debatable whether many of the people with mental handicap in Special Hospitals require the existing level of security, which is designed to withstand the determined effort to abscond, an attempt which is unlikely in their case. If it were possible to start afresh in the design of secure facilities for people with mental handicap, one possible model is of a national maximum security unit to contain the (probably small) number of patients who actually required that degree of security.

At the next level it would seem vital that there should be a secure or semi-secure provision in each Region for cases which require some security. One of the problems which would arise then is that certain patients may need this level of security for some years, requiring a fairly large unit in each Region, yet obviously otherwise the smaller the unit the more advantageous this is likely to be. It could make sense to provide much smaller 'units' on a sub-Regional level, with the advantage of maintaining even closer local links. However, a disadvantage would be that this group of patients require highly specialised services which might be better rationalised on a Regional basis. Another consideration is that of space. It is generally agreed that many people exhibiting challenging behaviour need plenty of space. If their living space is too confined, the degree of disturbance may increase, very often because of the nature of the mental disorder which underlies such behaviour.

Unfortunately, the provision of living space and grounds is expensive and realistically it may be more cost effective to provide this in larger facilities.

As long as mental handicap hospitals continue to exist they may have a place in the treatment of this type of patient, but once the level of security is less than that of a secure or semi-secure unit, there seems little reason why residential provision should not be made in the community. It remains essential that reasonable staffing levels are maintained and the process of treatment and rehabilitation continued. There is also a need to consider patients with severe handicap who present very challenging behaviour, where it is quite clear that care either at Special Hospital level or Secure Unit level is inappropriate in terms of security. This group requires high ratios of experienced staff. It is also necessary to create a physical environment that will withstand some of the destructive propensities of the group. There is no reason why this should not be provided in spacious domestic-type accommodation which is suitably adapted.

In conclusion, It should be remembered that the basic problems of people who require treatment in secure conditions may be very long term. It is therefore particularly important that they should all be cared for under circumstances where it is possible to provide a very good quality of life, as well as the best and most appropriate treatment, in conjunction with a level of security which is kept to the minimum necessary.

CHAPTER 3; NEW APPROACHES

Mary Myers

Introduction

The main intention of the workshop was to explore how people with challenging behaviour can be responded to in such a way as to promote their best chances of an ordinary life while ensuring that no harm should arise to anyone else in the process. The individuals themselves should be the starting point for any such deliberations; it was therefore appropriate that Mary Myers began her presentation by portraying in outline the seven people with whom she has been working closely over the past few years. Subsequently, she described the efforts that have been made to provide appropriate homes and services for them, and the initial outcomes of these efforts.

The following brief biographies of seven people from a large city describe a situation where their problems had been prominent and under debate by service providers for six and more years. The degree of learning difficulties ranged from severe to mild; their verbal skills from nil to near average; their challenging behaviours included repeated grave assaults, major self injury, sexual assaults, fire setting and repeated window smashing. All 7 had very long histories, all had been detained patients, several had been under Hospital Orders via a Crown Court, and 3 had been in Special Hospitals, and 4 had spent time in private psychiatric hospitals. Efforts have continued to improve understanding of the needs of these 7 people. In retrospect it was clear from case notes that systems had tried inadequately to meet their needs, and failed. This usually meant nothing more than providing medication, often used more in hope than in science. In some instances the individuals were not understood but simply contained in the secure environment, their needs ignored.

The Biographies

Angus, aged 40, had mild learning difficulties, early temporal lobe epilepsy and in adolescence he did not cope at work where he had received a great deal of teasing. He was under parental pressure to achieve skills which he was not able to meet. He became increasingly preoccupied, aggressive and destructive. Over 15 years he was repeatedly admitted to a total of 8 various hostels and hospitals, plus police stations and prisons. His parents were terrified of him. He was finally sent for several years to a private hospital from his last stay in prison.

Craig, aged 32, had mild learning difficulties and early temporal lobe epilepsy. He experienced family pressures of another kind. He was treated as a continuing child and at the same time criticised for failure to achieve. He spent a few years in a very deprived, male institution. He was aggressive, unpredictable, menacing, uttered bizarre talk, was highly destructive and often withdrawn. He was sent to a private hospital after assaulting a member of the public.

Joyce, aged 50, had been severely autistic from early childhood and had spent the rest of her life in institutions, including 30 years in a special hospital. She has no speech, extremely limited interactional skills and had displayed serious self-injurious and other problematical behaviours over the decades. She was transferred from a Special Hospital 2 years previously.

<u>Michael</u>, aged 29, has been described in detail in the King's Fund document Facing the Challenge. He was admitted to a private hospital after an outburst when he threatened a stranger in the street with a bread knife. He was sent to hospital by the Court, and a year later he was transferred to a privately run hostel which had tried to address his long standing emotional needs and lack of interpersonal skills, with some success.

<u>Desmond</u>, aged 45, was a man with a long history of hyperactivity and disturbed behaviour. He was discharged abruptly from a Special Hospital some 5 years previously, and spent intervals in each of several hostels and prisons. Despite many attempts to provide him with choice and some autonomy and support, he lived very impulsively and helped himself to property and sex wherever it could be seized. He also has a recurrent hypomanic disorder, and his overactivity and irritability compound his problems.

<u>Daniel</u>, aged 26, had been severely autistic from a very early age and spent most of his life in hospitals. He experienced a very deprived childhood. He had no speech and his social interactions had been mostly hostile and dangerous for many years. Daniel had physically injured many people. He had dislocated a policeman's shoulder, bitten off ears, and had been only just prevented from inflicting a lethal head injury. All staff were extremely wary of him.

Simon, aged 26, had mild learning difficulties, experienced an appalling childhood and was taken into care early on. His behaviour included 'pranks' with serious implications. He had lit fires in childhood and adolescence and was sent to a residential school far from home. He responded well to psychotherapy in that setting but then was charged with stealing a car and other property, which led to his Court appearance, prison on remand and, eventually, admission to a private hospital. During a stressful period there he lit fires again; but the policy on that ward was to discourage the discussion of personal problems. Simon was then transferred to a Special Hospital for 18 months, and was currently on extended leave.

An Account Of Progress In One District

Over the preceding 6 years much hard work was necessary to refine the skills required for this group of clients. The needs which were presented by all 7 of them had defeated the system at the time that they were sent away or detained.

It is now possible to make the simple statement that we <u>had to apply security because we had not understood the client.</u> Where our understanding and knowledge of the individuals increased, staff have seen the dangerous behaviours reduced by various means, and the levels of security have become less important.

For 5 years an individual planning process which makes assessment client-centred and positive was developed. This encompassed the 'getting to know you' exercise. More recently, the service aimed also to acquire skills in the functional analysis of behaviour. The individual planning process incorporated the principles of An Ordinary Life, the aims of the Five Accomplishments (presence and participation in the community, relationships with people in the community, dignity and choice) and the positive values associated with them. These are now fairly widely understood bases of good practice.

Functional analysis, however, is less well understood. It is qualitatively different from assessments which focus on problem behaviour solely as if that resided within the individual. Firstly, a good functional analysis looks at the behaviour in context, at antecedents and consequences, at reinforcement history and at preferences. Secondly, the possible communication function of the behaviour is examined. From a comprehensive functional analysis a strategy can be developed that precludes, prevents and redirects problematic behaviours. It also enables systematic instruction in more effective ways of behaving and communicating.

From a combination of individual planning (completed for all 7 clients) and functional analysis (in progress for 3 clients) it has been possible to identify many hitherto unrecognised or ignored factors in the lives of clients which provoke or maintain dangerous and destructive behaviours.

Angus was sent to prison and hospital to protect the public. It was only after he was provided with a small personal environment that it was recognised that his first need was to be relieved of the pressures to perform and conform, which came from his family and the various hostels he had lived in. He responds well to gentle and courteous interactions and requests. He needed to be offered more effective ways of withstanding life's pressures. He did not need the major tranquillizers which had caused his tardive dyskinesia (involuntary facial and hand movements).

Craig was also sent away to protect the public from his aggression . . and destructiveness. We did not understand the nature of his frightening outbursts, nor did the private hospital where he spent 4 years. After 2 weeks in a very small, personal environment (where he did much damage) there were such good observations and recordings available that a diagnosis of a sub-clinical form of epilepsy was suggested. Anticonvulsant medication appeared to have reduced the outbursts and left him able to talk more coherently about himself, his poor self-image and his family difficulties. After even early days, the small, intimate environment enabled us to learn more in a few weeks than anybody did in 15 years before.

Joyce had spent a largely quiet, if boring, 2 years since her transfer from a special hospital. Then she needed major surgery for non-invasive cancer. She appeared to recover fast, but then became desperately self-injurious and distraught, as apparently she had done on occasions in the past. Improved observation and recordings, coupled with the individual planning approach, pointed to a manic episode. Medication targetted at that produced results very rapidly.

Michael needed to gain in self-esteem, which in turn can depend on competence. He acquired self-care and social skills which he needed, but remained emotionally very vulnerable. Nevertheless, he continued to make progress in the small hostel where he has been living.

Desmond is a person whose needs are still only partly understood. Treatment of his hypomania has helped, but the remaining need is to help him to internalise a sense of responsibility towards others.

Daniel has remained a frightening enigma. It has not yet been possible to create a small and consistent environment in which to maintain detailed observations, and in which to start to understand his tremendous hostility. We do not know or understand his needs yet, and we must maintain vigilance and security until we do.

Simon, too, is a person about whose needs we are still hypothesising. Although his personal care skills have been the best of the seven clients, his view of life has remained unrealistic and he has little or no trust in adults whom he tests out with risky pranks and lies. We need to build trust and replace devious behaviour with open adult conduct; always assessing how big a risk we can take.

CONCLUSION

By reducing the environments to very small ones, and especially by improving our skills in behavioural analysis, in recordings, in neuro-psychiatry and pharmacology, it has been possible to begin to identify and meet some clients' needs more accurately. However, in most of the members of this sample of clients there has seemed to be an element of vengefulness in their challenging behaviour. This is hardly surprising given their appalling life experiences and deprivation. How then is it possible to help them to grow in trust and self-esteem and establish meaningful relationships within the boundaries of externally applied controls?

Two small units have been set up. These are 2 houses, each accommodating 2 men, in the care of a team of staff prepared in the way already outlined. At the time of the workshop, the two months during which this project had been operating had enabled much to be learned about the four residents. In particular, a familiarity and understanding grew, so the anxieties about and emphasis on security diminished. By responding sensitively to accurately assessed needs, problem behaviour diminished.

The District had to devise these new arrangements because two men had to be transferred into a private hospital in the absence of any alternative. The costs for the arrangement had escalated to £100,000 annually, which provided a service where the two men were merely being contained, without any improvement to their quality of life or expectations.

Out of a sense of the wastefulness both of men's lives and of resources a new individualised approach was devised which, while actually costing no more, offered considerable benefits. These are only beginning to be fully appreciated.

SECTION II: FOCUSING ON INDIVIDUALS

CHAPTER 4: LIFE STORIES

Much of the workshop was spent in small groups, considering in detail the needs of a particular person whose life story and problems had been outlined for that purpose. Four of these individual stories (altered so as to protect identities) are recounted here, so that what might otherwise be a generalised and abstract discussion will be illuminated with a clearer sense of the way policy affects people. The individual biographies are followed by an account of the group discussion on each, with some of the possibilities and recommendations that were suggested.

William Oxbury

William, 22 years old, was born in Coventry to Catholic parents. His father worked in the army. When 2 years old William was noted to have poor eye contact and lack of communication skills. William was subsequently referred to a psychiatrist in Birmingham. He was said then to be "severely retarded".

An admission to hospital at age 3 led William's mother to remove him after a week due to his heavy sedation and apparent isolation. Later, William briefly attended a normal school. However, this lasted only a few days because of William's screaming on separation from parents, headbanging and ritual attachment to objects.

The family then moved to Northern England and William attended an infants school briefly before being transferred to a special school, where he stayed until about 9 years old. This was a fairly stable period.

William described himself as having had one friend at that special school. When asked what he and his best friend most liked to do, he said they used to like breaking things.

At 9 years William was transferred to another school as a result of difficult behaviour (his 'friend', he says, went too). One year later, William was still unsettled and was sent to a school for' maladjusted' pupils in the South West of England. Five years later (14 years old) he was moved to a school nearer home but bullying from peers led his mother to move William yet again. This time he went to a school for autistic youngsters. William described himself as having been happy at the autistic school and he was subsequently placed in a semi-independent hostel within the school.

When in the hostel (aged 18), William gradually became very difficult to manage. He became increasingly agitated, had mood swings, was aggressive towards his peers, talked obsessively about religion, and worried about little girls staring at him. Medication was not helpful and, after an attack on another boy, William was moved to a less independent hostel.

At 19 years of age, at his parent's request, William returned to live at home. Initially this went reasonably well but 6 months later, after repeatedly complaining that the family cat was staring at him, William stabbed the cat with a carving knife. At about the same time, William had shown very disturbed behaviour in the Social Education Centre, smashing windows, being verbally abusive, and exposing himself.

As an urgent necessity, William was removed from home and settled into a nearby hostel for adults with learning disability. One year later he became unmanageable, threatening a resident with a knife, masturbating in public, and seeming to be obsessed with a desire to harm children. Two years later, while still at the same hostel, William was arrested for taking and driving away cars on several occasions. repeatedly absconded from his hostel and eventually was admitted to a private psychiatric hospital in the West Country. In the hospital he again settled relatively well at first but then appeared to make little progress, being teased and bullied by peers, being noted for high distractability, poor motivation, aimless pacing and inappropriate social behaviour. Before a year had passed he had stolen knives from the dining room, threatened to stab staff members and was aggressive to fellow patients. He constantly talked about absconding and often referred to suicide (he did cut his wrists on one occasion). Finally, he jumped through a window, went off to the nearby village, stole a car and drove for 14 miles before being arrested. He was subsequently sent (on Section 37 of the Mental Health Act) to a locked private psychiatric hospital.

There William's behaviour was similar and staff became increasingly worried about his odd behaviour towards the few children he would see. William appeared obsessed with them and would stare at them fixedly. social worker from his District of origin subsequently referred him to a Special Unit for assessment of his sexual interests. The Unit reported, after several months, that William certainly had a clear sexual interest in children, used children in his masturbatory fantasies and became agitated in the presence of children. He also reported a number of times when he had been called a child molester by staff and other clients in some of the previous institutions where he had lived. He did not consider himself a child molester, since he had never assaulted a child (though he had occasionally sat his neighbour's children, for example, on his lap and wanted to kiss them). He was aware that a sexual interest in children was 'not normal' and very much wanted to have a girl friend and get married. He knew that sexual activity with children was against the law.

This Special Unit subsequently offered William treatment for his sexual problem and over a period of a year attempted to alter his sexual interests by means of orgasmic reconditioning, sex education, and covert sensitisation. The first two techniques appeared to alter William's interests slightly, but not to a lasting extent. With respect to the third procedure, having consented to begin treatment, William decided that he no longer wished to participate in the treatment, because it made his feelings seem 'bad'.

During his time at the Special Unit, William went through a period where he was clearly extremely agitated, pacing up and down the ward, unable to settle, picking his fingers, and stuttering much more quickly than normal. Careful data collection around this time, using momentary time sampling throughout the day, indicated that William almost certainly had a mood disorder and this, together with his history of periods of depression with periods of uninhibited behaviour, suggested that treatment for a mood disorder might be helpful. William subsequently began on lithium therapy. The diagnosis of mood disorder and the treatment appears to have dampened down William's mood swings to the extent that he can now control his own behaviour to a large degree.

However, his self-control still slips occasionally, particularly when he is anxious. For example, he recently discussed his sexual interests in a very loud voice in public, when he was feeling extremely upset and agitated for other reasons.

Questions

- What are William's psychiatric, psychological and every day care needs?
- Can William live an ordinary (or near-ordinary) life in the community? If so, how could this be achieved and with what level of staffing and what other clients (if any)?
- Will William be a danger to children and/or adults in the community? What safeguards do you think you would need (if any)?

Jason Kenworthy

Jason Kenworthy, aged 28, is a man with mild mental handicap - Klinefelter's syndrome. (Klinefelter's syndrome is a chromosomal abnormality consisting of an additional X chromosome to the normal XY configuration for males. It is known to be associated with reduced sexual potency and increased aggressive conduct.) Jason's birth was at full term and apparently normal. There are two elder brothers in Jason's family.

Jason's early life was unremarkable, although there may have been some difficulties because of the way he modelled himself on his father. Mr. Kenworthy senior is a man with pronounced opinions who tends to become angry when things do not go the way that he would like. There is a history of conflict between father and mother, although to our knowledge, Jason was not physically abused more than most as a child.

In his teens, Jason became interested in war films and the martial arts. He came into contact with the law following theft from a sports shop and was put on probation for this at the age of 17. Three years later he was apprehended when trying to use his father's credit card and was put on probation for a further two years. A little over one year after this Jason threatened a police officer and was transferred to a mental handicap hospital as a condition of his Probation Order for appropriate treatment for his condition.

Jason did not keep the terms of his probation and worked only spasmodically in the hospital. A condition of his probation was that he should be within the hospital during the evening but he did not keep to this. Shortly after the expiry of his Probation Order he assaulted a gentleman in the street when he asked him for money and he would not give this to him. Jason ran off during this assault when the man started yelling but was apprehended shortly afterwards. He said at the time that he wished that he had killed him so that he could get all his money. As a result of this assault and his subsequent comments, Jason was placed on a Section 37 (41) by the Court. This Section only allows release or easement in the conditions of care imposed on the approval of the Home Office.

Jason has remained for the past 4 years in a well-supervised, locked, semi-secure unit. Although he did well at first, showing much more restraint than many of the people living in the unit when exposed to stress, his behaviour has become more unacceptable over the past 2 years. His main problems identified by the clinical team include:

- (i) His attacks (often sadistic) on vulnerable people when unobserved. There is a sexual element to these assaults. Associated with this tendency Jason is inclined to respond to any form of threat from anybody else by further physical attack. For instance, when a resident with severe mental handicap nipped him recently, Jason punched the resident in the face, causing severe damage to his nose.
- (ii) His complete lack of insight into his condition and his total denial of events that have occurred if he believes that nobody has witnessed these. There is strong evidence that he has made at least three assaults on patients within the grounds, from the comments of the victims themselves. However, Jason completely denies that these events ever took place. He becomes impassioned when protesting his innocence and then gets angry, threatening the consultant and all concerned with solicitors and legal proceedings.
- (iii) His overcompensation for perceived difficulties: for example, he weight-trains although he is quite a slight person.
- (iv) His intermittent letter writing to authority figures expressing bizarre ideas. These appear to be precipitated by his fantasies.

It is extremely difficult to treat Jason. He does not acknowledge that he has a problem and therefore it is not easy to engage him in productive discussion about the events that have brought him into hospital. As his aggressive behaviours are infrequent, physical assault only occurring on four or five occasions a year, it is difficult to treat this behaviourally. He appears to obtain perverse delight from injuring others although he does not recognise this within himself.

It is possible that Jason's behaviour has deteriorated because he sees no exit from the hospital. Because of the aggressive episodes described, the Home Office will not allow Jason to have unescorted time either within or outwith the hospital grounds. Jason is therefore likely to remain within a hospital setting for many years.

Questions

- 1. What are Jason's psychological, psychiatric and daily care needs?
- 2. How could Jason be helped towards as near as possible an ordinary life in a community?

David Stainforth

David Stainforth, 19 years of age, was born in Manchester, the youngest of three children. His father died several years ago following a sudden stroke, his mother works full time in Liverpool.

His mother reports that her pregnancy with him was uneventful but that he was an unexpected breech delivery at home. There were major difficulties at the time of his birth. He spent six weeks cared for in an incubator and for a time was not expected to live. He was noted to have major difficulties feeding because of a generalised stiffness and he developed fits very early in life. His family were advised that he was likely to be severely handicapped.

Despite many difficulties, the family were able to look after him at home and his development, contrary to expectation, was not unduly delayed. He smiled at 10 weeks, and was sitting up at one year and walking at 17 months. He was using phrases by three years. He was, however, described as being over-active throughout the day and he had to attend a 'special opportunities class' at the local primary school. He was described as lacking in normal childhood play but liked one-to-one attention.

From approximately 5 years of age his mother describes numerous behavioural difficulties which resulted in his transfer to a number of different schools. These problems usually took the form of serious aggressive behaviour and throwing food.

Over many years he was admitted to a number of specialist health service and educational establishments. All his placements broke down because of a deterioration in his behaviour, usually violence directed towards other residents and members of the staff.

The family report that there were periods of time when he was very much more settled and his behaviour was under control. During that time he demonstrated that he had acquired adequate living skills, although he always needed some prompting with general self care. There were periods in his life when he would become obsessed with certain objects, eg the washing machine.

In his early childhood he suffered from a number of physical problems including epilepsy and was admitted to hospital with pneumonia. His admissions to general hospitals were complicated by his behaviour and there are reports of him running around the ward hitting other children and throwing things. Over several years he has been prescribed a number of different neuroleptic and sedative medications as well as receiving specific treatment for his epilepsy.

At age 13, during an admission to a specialist children's unit, it was demonstrated that a strict behavioural programme resulted in an improvement in his behaviour but there was a deterioration within a period of months.

At age 16 years, at the family's request, he was seen by a neurosurgeon for advice about whether neurosurgery (amygdalotomy) would help his aggressive behaviour. The family were advised against this.

Following a deterioration in his behaviour he was admitted to a special unit for adults with learning disabilities and challenging behaviour. Since being at that Unit his behaviour has proved a major management problem. He has been very aggressive towards staff and other residents, for example, rushing out of his room for no apparent reason in order to hit people. He has thrown food, broken crockery and been verbally very threatening. More recently he has frequently urinated on the floor of his room and has been soiling himself.

Following admission, his medication, which had been started when his behaviour had started to deteriorate, was again stopped and he developed a serious movement disorder. There was no evidence that he was suffering from a psychotic illness and following treatment with anti-cholinergic medication his movement disorder improved. Because of a further deterioration in neuroleptic frequency and severity of his behaviour he has had to be confined to his room, coming out at specific times when staff can control his aggression. Detailed observation suggests that he is more inclined to hit when in particular situations but no adequate explanation has been found to account for the variety of challenging behaviour he presents. At present no specific treatment or management strategy has improved the frequency and severity of this behaviour.

Questions

- 1. What more can be done to help David control his behaviour? Should such behaviour necessarily be seen to have a function?
- 2. If his behaviour does not improve, what sort of facility might be established so that he can live locally with some acceptable quality of life? If this is to be achieved, what level of staffing might be needed?
- 3. What sort of support and training would have to be given to staff who would be expected to look after him?

Janine Cavendish

Janine Cavendish is a 33-year-old woman from a family with two younger brothers and two elder sisters. Her father was repeatedly in prison - on one occasion for 3 years and there was some violence within the family. Family life for Janine as a child appears to have been fairly chaotic, but with considerable affection from both her mother and her father. She attended an ESN(M) School where she was described as solitary with violent outbursts. She truanted on a number of occasions.

At age 6 her mother died, 4 weeks after being knocked unconscious in a road traffic accident. Janine was taken into care but was separated from her siblings and appears to perceive this as because she was naughty.

At age 9 she returned to live with her father, who sexually abused her. He used physical force to achieve this on occasions when she resisted. Yet in other respects he cared for her, and Janine's feelings towards her father remain very ambivalent. During her late teens, Janine bore a son.

Her son was made a Ward of Court and fostered locally. She subsequently discovered that her son had been sexually abused by the brother of the foster mother. He has subsequently been with further foster placements which have broken down.

When Janine was aged 16 her eldest sister, who had spent some time away from the family, killed herself following an overdose. Janine reports that following this she commenced self-injury with overdose and the insertion of foreign bodies. Two further children have both been taken into care at birth and subsequently adopted.

Shortly after her sister's death she was implicated in burglary. spent 2 years in an Adolescent Unit where she was involved in fights with staff, and at least one incident of fire setting. She later spent some time in Borstal, 18 months in prison, and at the age of 25 she was detained in a Regional Secure Unit, being discharged nearly 2 years later after apparently little change. She then made threats to kill a child, for which she was subsequently detained in Rampton Hospital for 6 years. Before her discharge there had been four unsuccessful periods of trial leave. One of these was at a hostel attached to Rampton Hospital where she was described as unmotivated. She related that she did not get on with the other Rampton patients at the hostel. The other trials of leave were at a mental handicap hospital where her disrupted behaviour led to both staff and other patients feeling unable to manage her, and a psychiatric hospital where it was stated that her mental handicap meant she could not be treated.

Following her discharge by a Mental Health Review Tribunal, she stayed at a hostel for approximately a month before moving to a council flat. In the flat, she was reported to be very lonely but was commented to have little idea how to deal with this problem and seemed unable to make the effort to go out and meet people. Her only contact was with social workers.

A further threat to kill a child one month after moving into her own flat, led to treatment in a psychiatric hospital on a Probation Order. She took her own discharge, which led to admission to the Special Unit on a Hospital Order (Section 37 of the Mental Health Act).

Her strengths include a considerable degree of insight, a strong concern for others more vulnerable than herself, a powerful fluctuating motivation to change, and a quiet, generous sense of humour.

Her own account of her difficulties, when admitted, included: feelings of wanting to hurt babies and children; a habit of temper: self-inflicting injuries and inserting foreign bodies; verbal or physical attacks on those who try and get close to her; dislike of being on her own and inability to cope in the community. Behind these problems, her thoughts of harming children appear linked to her bitterness at the loss of her child. Her self-injury appears to be a self-punitive response. She has overriding feelings that she is worthless, and believes that she is to blame for the problems in her life, including the sexual abuse to which she was subjected. She shows a great ambivalence towards those who offer help, exhibiting alternatively rational discussion and vitriolic hostility toward those who try to help her. She is diagnosed as having Borderline Personality Disorder: her dependency needs are enormous but she constantly attempts to cope with difficulties by attempts to be independent and by responding to others with anger.

Since admission to the Unit, the frequency of her physical attacks on staff has diminished almost to zero. She has twice attacked other patients. On one of these occasions she lost her temper and tried to hit a patient with whom she is friendly. She subsequently inserted staples into her arms. On the other occasion she made an apparent attempt to strangle a very disturbed patient who had repeatedly tried to pinch her on her breasts. She has twice run away from escort staff when annoyed, but on neither occasion attempted to leave the hospital. She injured her hand breaking a window after a visit from her surviving sister, with whom she had had little contact for many years.

Her current treatment aims to provide Janine with a valued role caring for elderly people attending a 'day centre' within the hospital, an educational stimulus through escorted outings to pursue particular 'projects', and an experience of stability through supportive relationships with one consistent group of staff over a period of several years. A cognitive approach to her beliefs has been put aside because of her unwillingness to proceed with this. The main focus of treatment is psychotherapeutic work jointly with male and female therapists, with support for the therapists through a specialist in psychotherapy.

Questions

- What are Janine's psychological, psychiatric and daily care needs?
- 2. How soon could Janine live a near ordinary life in the community, considering her great but fluctuating and ambivalent needs for dependence?
- 3. How could this be achieved, and what safeguards would be needed?

Issues from the discussion

William

Discussion identified William's major assets as his ability to confide and discuss his problems (demonstrating some sense of confidence, both in himself and others) and his straightforwardness: he does not lie, since he does not understand deception.

The main threat he poses is verbal: he has not actually carried out violence against people (except towards himself in the suicide attempt described). His knowledge that he is a 'major success' in the eyes of the staff where he is now living has helped to make his stay there happier for him and everyone dealing with him. He himself recognises that his interest in children is problematic; he longs to be 'normal' and have a successful relationship with a woman. In general, he relates to women rather better than to men, showing acute sensitivity to facial expression.

A summary of William's needs included: help with his mood disorder, to reduce the suddenness and severity of his mood swings; counselling and monitoring to modify his continuing psychological problems; help in establishing normalised rhythms and patterns of life; provision of opportunities for occupation, activities and interests; above all, the opportunity for social interaction and friendship. The assets he obviously has need to be developed.

The discussion identified that any living arrangement would need to provide him with stable relationships with staff, whose shared consensual approach should be low-key and supervisory, rather than directive. He would need to have the opportunity to establish friendships with other residents and people in the wider community. Risk counselling and careful sex education might help him over some of his present difficulties.

A valuable strategy for William would be the provision of an advocate, who could strengthen and improve links with his family, including coping with the negative side of that relationship.

The consensus among the group was that all of William's needs could be met in a small unit in the community. Good staffing levels and adequate staff preparation would ensure the required degree of control and supervision, along with appropriate support. Staff training and preparation would need to include detailed knowledge of William's story and problems, the development of a consensual approach to this situation and care, and familiarity and skill, with appropriate responses, both pharmacological and interactional, to his difficulties. There would need to be more than one member of staff on duty at all times, as a 'safety' guarantee. This would be compatible with his need for meaningful relationships, and the opportunity to extend his social competence by living with other people.

The possibility of opposition from neighbours to the setting up of any such unit was considered to be negotiable, in the light of the fact that William has never, in fact, assaulted anyone. An important feature of his new environment should be clear and explicit definitions of what is permissible and what is unacceptable.

The specific recipe was for a large ordinary house with a garden (as he has a need for space to move around in), which William could share with up to 3 other people, preferably older women. Approximately 10 staff (to include sleeping-in arrangements) should provide a mix of age, sex and background. Ideally, the house might be part of a network of 3 or 4 such units, to provide wide interaction opportunities and flexible and adequate staff support. Estimated costs would thus be around £80,000 per unit. (i.e., £20,000 per resident). The cost of William's present care was £53,000 annually.

Jason

The discussion initially sought to clarify some general issues and themes, before going on to analyse Jason's specific needs and possible responses to them. First, the continuing, as well as the reciprocal, interactive nature of the assessment process was recognised. Expectations of 'client' and 'professional' both need to be recognised, as both parties have the ability to learn and respond.

Second, the importance of the physical environment was stressed, recognising the need that some people have for extra space, or private space, for instance to avoid a fear of being confined.

Third, the need for risk-taking to be negotiated through careful assessment and management was highlighted. This might require the provision of appropriate supervision when danger is suspected, rather than total insulation from risks.

Fourth, strategies should include devising plans to help people weather such routine life crises as illness, or job loss, so that episodes of disruptive behaviour are avoided, and distress limited. Self-esteem may be built by ensuring that good role models are available.

Turning to the specific example of Jason, several psychological needs were identified: someone to talk to privately, help in modifying his excessive suggestibility, and help to improve his ability to cope with stress, and especially to cope with threats. The narrow range of his opportunities for satisfaction could be extended, particularly in regard to his sexuality, and his interest in the martial arts.

His life plan might include strategies for crisis management: such as coping with unemployment or having to deal with the police. A crucial development would be to supply him with a positive role model. His current non-problematic interests should be exploited to develop his capacity for making relationships. The possibility of finding a job should also be explored, as his existing skills make him employable, and can be built upon.

However, the restriction order in force at present (Section 37/41) clearly impedes progress in several areas. There would therefore be a need for a strategy to be devised to negotiate with the Home Office an appropriate and positive future for him. An attempt could be made to explain what is being attempted, and to agree attainable targets about his legal and social situation. There was agreement that his needs were psychological rather than psychiatric.

David

Discussion of David's situation focused first on the need for thorough assessment in several environments, so that fuller knowledge about him could lead to better understanding of the causes of disruptive or aggressive behaviour. In this context, a functional analysis of the individual's communication was recommended as a valuable approach to assessment, both on a day-to-day basis and for the longer term understanding of the person in question. Such an assessment process would have resource implications, since it will be lengthy and staff-intensive to make observations in a diversity of settings as a general rule.

Limited access to a variety of settings may also make full assessment impossible, and ways round this are needed: without some means of checking actual behaviour in realistic circumstances where 'temptation' might arise, they can neither be confirmed nor denied. In this context the distinction between security needs deriving from public safety requirements and those of individuals was emphasised. Security was viewed as best provided through staffing arrangements, which also allow individual clients' personal needs to be met at the same time.

David's individual situation thus became the means of identifying some general needs: for resources, adequate staffing levels, and staff training and support; consistency of management; better community resources to enable preventive measures to be implemented sufficiently early; better ways of facilitating client choice. measures early; means of facilitating client choice.

Janine

The group's reflections about Janine's needs began with extended consideration of how far it might be necessary to await a process of maturation, to help Janine achieve self-control. This discussion highlighted the importance of working in other ways in the meantime, particularly in ways which might help accelerate this process of maturation. Non-judgemental respect from staff was seen as a cornerstone in this process. Hence, in helping an individual so prone to anger and rejecting behaviour as Janine, there appears a great need to help staff understand and cope with the ambivalent feelings she can generate in others.

It was acknowledged that there were many difficulties in setting targets for progress to less secure conditions, given her ambivalence about her own independence, and her great need for dependence on others. This indicated the importance nevertheless of progressing by very small steps to conditions of less security in a controlled way, whilst planning her after-care well in advance of her discharge in order to avoid a breakdown at that point.

The complexities of such a caring and treatment strategy emphasised the importance of a systematic approach to treatment, so as to evaluate the effectiveness of each component of treatment, and in order to be able to prioritise clearly what aspects of her problems to address at a particular point in time. The problems of relying on staff assessment may need to be recognised. Assigning priority to needs is the ineluctable outcome of the practical impossibility of meeting them all.

Should they then be prioritised in relation to the likelihood of the success of any intervention, or the centrality of a particular need, or cost implications, or practicability, or wider moral values?

The issue of 'treatability' bedevilled the group's discussion of Janine's situation. Several underlying issues emerged: in assessing Janine's needs, whose views are to be given most weight? Should it be a consensus of opinion? What part should her own self-assessment play? It was felt that some of the most significant insights and understanding are likely to emerge from giving full attention to her own story as she recounts it, while backing this up by checking accuracy wherever possible.

The wider issues emerging from this discussion included the importance of careful testing of the effectiveness of each approach, Thus efforts to bring about improvements should be sustained and persistent, not abandoned in the face of what might seem to be failure at some stage, perhaps because the gaps between levels of service provision are too wide. Carefully graded stages of transition are needed, so that services are more sensitive to the wide variety of client need and phases of change.

SECTION III: FACING THE DILEMMA

CHAPTER 5: PROFESSIONALS AND NON-PROFESSIONALS' RESPONSES

David Carson

The dangerous behaviour of people with mental handicaps causes many problems for professionals who respond to it, for the general public and for the people concerned. Many of these problems arise out of

- (i) problems of definition (for example, of 'danger');
- (ii) the creation and communication of accurate information
 (such as about 'risk');
- (iii) the absence of a clear legal structure to legitimise responses (such as defining when individuals may be transferred to a secure hospital or regime); and
- (iv) the absence of clear goals, philosophies and standards for professionals who direct services, (such as whether clients should be regarded as responsible for their conduct).

PROBLEMS OF DEFINITION AND LEGITIMATION

In the absence of clear justifications for interfering with clients' civil liberties, there will be public confusion and suspicion about what professionals are doing and are seeking to do, how and why. Insofar as clients' civil liberties are or appear to be infringed, or not taken seriously, the public will be encouraged to think of clients' rights as unimportant. We need justifications for intervening in such dramatic ways.

What behaviour constitutes 'dangerous'? Which responses constitute 'security'? We have relatively clear definitions of criminal behaviour. If a court adjudges that a crime has been committed, then moral opprobrium and legal action are justified. But criminal court proceedings are not, currently, a pre-requisite for treating a person in a secure setting. On the other hand, substantial proportions of people in our prisons, which are secure settings, are said to have mental disorders or learning difficulties. Yet they tend not to be thought of as the people with whom this workshop is concerned or as people receiving 'treatment'. The Mental Health Act, 1983 can also legitimate detention, security and imposed treatment. But still, there will be a large number of people who receive treatment in secure conditions outside of a clear authorising structure.

Security need not take the form of physical restraints or limits. It could be said to include restrictions on activities, such as prohibiting unaccompanied trips or use of certain equipment. It could include drug-induced inhibitions. It can lead to restricted activities such as limited sexual experiences and restrictions on experiencing the power that comes with the ownership and exchange of property. It can occur by administrative transfer between hospitals of different levels of security, by transfer within units or by changes in staffing.

The events leading to treatment within secure conditions can also vary considerably from unpredictable violent attacks with implements, to inability or difficulty in working with a client in an open community setting which might include only threats of violence or simply jostling. The need for security might be due to a deficit in the range of service responses available in a particular place rather than the behaviour of an individual.

Requiring proof based on an explicit test of dangerousness, before admitting a client to a programme of treatment in secure conditions, may be opposed as inflexible and contrary to clients' interests. Nevertheless it would appear an essential first step towards protecting clients' legal rights, ensuring service accountability, sorting out the confusions in service philosophies, creating a 'contract for resources' and enhancing the public reputation of professional carers.

Equality Under The Law

It has been argued elsewhere ['Prosecuting people with mental handicaps' Criminal Law Review (1989)] that people with mental handicaps ought to be 'prosecuted' for their alleged criminal behaviour. That argument stressed the importance of avoiding the reinforcement of criminal behaviour by ignoring it, until it becomes too serious. Adults should not be treated as children and therefore incapable of crime. Rather, the dignity of individuals should be upheld by recognising their personal responsibility for their behaviour. The argument also criticises current professional procedures whereby incidents are investigated, adjudicated upon, punishment administered (e.g., through changes in treatment, or ordering compensation payments) and official records maintained, without representation for the accused, or even a hearing that approximates to judicial standards. The client has no means of defence against or mitigation of the charges, by counter-claiming against the poor quality of services or treatment provided.

It was not suggested that the police or courts should be involved on every occasion, but rather that 'gate-keeping' procedures should be improved: that is the system by which decisions are made as to the appropriateness of prosecuting. An independent but accountable tribunal could decide whether the client's acts were prima facie criminal and determine the appropriate response.

Given the breadth of the criminal law, there should be no objection to insisting that no person is treated in any circumstances of security without proof of responsibility for a criminal act. Clients who lack the necessary mental capacity for certain serious offences, because they have not been taught the consequences of certain behaviour, will nevertheless often be liable for a more general offence such as occasioning actual bodily harm.

Of course it does not follow that treatment within secure conditions is an appropriate response just because a client has committed a crime. But it should be a pre-requisite. Pleas in mitigation should be considered. Clients who are violent in response to provocation, or through boredom with unimaginative services, should be able to avoid being 'punished' or treated in an inappropriate manner. They should be able to avoid gaining a reputation that might never leave them, even if the criminal law would not provide them with a formal defence. (Provocation, for example, is only a legal defence to murder).

Treatment In Secure Conditions

It is suggested that treatment in secure conditions should only occur after proof of criminal behaviour. We should no longer just speak of dangerous behaviour, unless, as a minimum, the conditions for detention under the Mental Health Act, 1983 are satisfied and the client is actually detained. This is, currently, a decision for psychiatrists and social workers to make and thus beyond the remit of any tribunal that 'gate-keeps' responses to clients' crimes. However if, as is suggested, this tribunal includes members of the Health Authority concerned (to ensure that they know of conditions in their services and that they are accountable for the authority's response) they can use their independent powers and duties, under the Mental Health Act, 1983, to review the continued detention of clients who have not been proved guilty of a crime and/or have not threatened to commit a crime. It is more honest to subject clients to legal detention than to achieve the same ends by other means, such as by relying upon clients being unaware of, or too anxious to exercise, their rights. Whilst detention is a pre-requisite to imposed treatment it can also provide peer review as it involves the Mental Health Act Commission in monitoring.

Unfortunately these proposals would not cover the transfer of clients between authorities, such as to a secure hospital, or to the private sector. They are liable to perpetuate situations where people can be detained, as a result of their behaviour, for periods far in excess of those for which they could be imprisoned. This is justified, by both professionals and members of the public, on the basis that such confinement is treatment and not punishment, irrespective of how it is perceived by the clients. The justification ought perhaps to be that the right to detain and treat people in secure conditions can only be balanced by a duty to provide effective treatment for the perceived problem.

Duty To Offer Contract For Services

We should perhaps think in terms of a contractual duty to provide adequate services. The principle is enshrined in declarations of human rights; certain rights can only be withheld for a particular purpose and/or with adequate compensation. Those receiving clients for treatment within secure settings could be legally obliged to produce results or, at least, to offer specific treatments. The Griffiths' Report on community care offers a model. After assessment of the service that the client needs, a contract could be offered to any reputable agency willing to undertake to achieve the goals. Contracts could contain penalty clauses for failure to provide services to the standards promised or to achieve specified results within a specified period. Unfortunately the Griffiths' proposals are not as consumer orientated as they could be since they limit the involvement of clients in particularising their needs, in choosing services, in specifying standards and having rights of appeal. The clients being considered here could be enabled and encouraged to have representatives or advocates. The use of such 'contracts' would help ensure that clients are not just detained but are provided with services that have, as a primary goal, the removal of the need for a secure setting for further treatment and services.

Risking Ending Detention

There remains the issue of when detention should end because any danger or risk to others has passed or been reduced to an acceptable level. Here professional and public attitudes are confused and are often regarded as opposed. Whilst there is broad disapproval of preventative detention, many members of the public would appear to be happy to see people with mental disorders, and people with mental handicaps with whom they are associated, detained for prolonged periods rather than be exposed to a risk from them. Given the daily dangers and statistical predictability of, for example, road injuries and recidivism, these attitudes may be regarded as irrational. Those involved with clients can find themselves torn between responding to this public fear and wishing to allow clients greater freedom and responsibility.

The confusion about danger and risks largely arises from the tendency to reify risk and locate it in clients rather than in services. It may be convenient to think of a client posing a certain degree of risk or danger but that, quite simply, must always be in a particular context. If the context for an individual's propensity to violence can be removed, then the risk is reduced or removed. The assessment of the risk that a client poses must take into account the extent to which services can adequately respond.

It is suggested that the risk a client is perceived as constituting to others should be analysed in terms of the services and steps that need to be taken until it can be said that he or she poses no significant risk. These can then be ordered into a chronological sequence, the critical features can be isolated and alternative strategies identified. For example it might be decided, amongst many other items, that a client needs to know how to approach people in an appropriate manner and needs a particularly kind of accommodation. (This analysis would help to identify conditions to be included in the contract for services and results suggested above). If all the proposed services are provided, the risk must, if the analysis is correct, be nullified or be treated as unimportant. Working back through the path, assessments of risk can be made which progressively get larger. Without skills training it is one level of risk and without appropriate accommodation it is greater.

Accountability For Risk-Taking

In this way it is possible to monitor the extent to which the risk is being successfully tackled. In this way it is clear which resources are necessary and it becomes possible to see whether clients are being treated in conditions of security because of a service deficit rather than anything 'in' the client. Value judgements may still be necessary and trial risks taken, for example to discover whether the client can manage money. The analytical approach will have highlighted many possible problems, which, if acted upon, will make the trial risk safer. But the approach can be supplemented with risk-taking policies ['Risk-taking Policies' (1988) Journal of Social Welfare Law 328] which encourage the individual assessment of the likelihood of each perceived benefit and harm that can arise from taking a decision. These policies, which could be endorsed by authorities, care teams and professional bodies, can take into account a valuation or weighting of the importance of withdrawing security, and all the attendant invasions of and restrictions upon civil and personal liberties.

Instead of risk being treated as a vague, amorphous threat, it can suggest strategies for the delivery of services that enable clients to regain their freedom as soon as possible. Instead of blame being directed at professionals for both not taking enough risks, and taking too many, they should be able to point to the extent to which any limits in resources are confounding their work. The generalised fears of the public can be allayed with more specific assessments. Certainly risk analysis and assessments would be open to peer and judicial review but, it is submitted, a clear strategy and assessment will convince more effectively than a general statement mystified as a professional judgement.

CHAPTER 6: WHAT KINDS OF SERVICE?: THE RESPONSE OF THE AGENCIES.

Tony Holland

The provision of different services to meet the psychiatric, psychological and social needs of people with a learning disability who also present challenging behaviour must complement each other. Concentrating purely on the social and ignoring specific psychological or psychiatric needs can result in the breakdown of the community service for the individual, leading to crisis. Equally, a failure to appreciate and give priority to the social and individual needs, too easily results in the person continuing to live in an inappropriate environment with a poor quality of life.

The question therefore should be: what are the individual's needs? rather than: what kinds of services should be provided?, since services should be formulated in response to need, rather than pre-defining what provision is made available.

People who present challenging behaviour have a right to expect that appropriate skills and services will be available so that the reasons for the behaviour can be understood and help offered. If behaviour results in a conviction on a criminal charge, they also have the right to expect that if specific psychiatric or psychological help is needed then the services will be there to meet these needs.

The psychiatric/psychological needs of this very diverse group of people described as having learning disabilities and challenging behaviours is immensely varied. The causes of the problems and thus the solutions may be either straightforward or very complex, and in many cases are likely to be due to interactions between biologically determined factors, learned behaviour and many environmental determinants. It is important to keep in mind that social and psychological needs can not be divorced. Services designed to meet these needs must therefore be robust and diverse, should not rigidly adhere to specific theories as to the cause of these problems but be able to apply a constructive and critical approach to each problem.

Concern of service providers must constantly shift between individual diagnosis, and preoccupation with setting-up viable services in response to discerned need. Since the causes of challenging behaviour are so diverse, solutions must be equally so, drawing on any help that can be found to be effective. This eclectic outlook is willing to adopt and adapt any approach that works.

As for the priority of the issue of security, there is no evidence that most people with learning disabilities and very challenging behaviour need to be kept in secure conditions, since they do not usually seek to escape, and rarely present a danger to the public if they did. Living situations with adequate staffing levels provide a more appropriate solution to the problem, since secure units perpetuate the individual's isolation, prevent putting theories and speculations about conditions to the test, and do not meet the needs of those seeking help informally.

In addition to good staff-resident ratios, staff need to be well-trained. Training will normally need to include a major element on violence management, which might help to reduce risks and the likelihood of failure with some aggressive people. The setting up of an attractive career structure might also help this sector to compete in a shrinking labour market.

Ideally, a range of services would offer clients a variety of options from which to choose, with obvious benefits. For those rare cases where an individual needs a secure setting, Regional Secure Units provide an answer, enabling experimentation with approaches and techniques to be carried out by concentrating a range of services on one site. The resulting scale of such provision may make Regional support indispensable. By contrast, of major concern at present are the signs that for people who combine mental illness, learning disabilities and challenging behaviour, the private sector is fast becoming the main option for long-stay provision, whilst community services continue to be inadequate.

The policy developed within the Health Districts of the South East Thames Regional Health Authority is that the psychiatric and psychological needs of this group of people should be able to be met by the carers with additional support from different disciplines based within the community teams and with access to other established services. The Districts may seek additional support from three Regional initiatives. These include the Special Development Team for those with severe learning disabilities and challenging behaviour, the Mental Impairment Evaluation and Treatment Service (M.I.E.T.S.), for those with mild learning disabilities and challenging behaviours, and the Sensory Impairment adviser for those with hearing and visual impairments. Thus, in this Region a combination of local, district and regional services has been designed so as to meet the different requirements of a group of people who will vary in their abilities as well as the type of challenge they present; as with other Districts throughout the country there is also access (at a cost) to an increasing number of private facilities, as well as to the Special Hospitals.

CHAPTER 7: THE OPEN FORUM - A SUMMARY

The overall view was that more questions had been raised than answered, but that this process had productively suggested ways forward. The case histories had usefully opened up ways of thinking, so that participants had found much to agree about when people were the focus of attention rather than abstract issues.

Resources

Resource constraints had been perceived as an underlying and intractable difficulty in extending and developing services.

However, it was remarked that the large amounts of money used to send people to be cared for at a distance could be used more cost-effectively in developing better local services so that people need not be moved. What is needed is to be able to 'link money to people'. An important skill resource in the staff of hospitals subject to closure could be used more effectively in the community than is presently happening.

The commercial cost of private care could be adopted as a basic standard for care costs in other settings.

Training

Awareness of the resource implications of appropriate training, and the staff-intensive nature of community care, raised questions of how to plan and deliver training, the need for professional career structures for carers and the question of sustaining their motivation and morale. Case histories such as had been used in the workshop could provide a valuable component of training programmes.

The management of training should be a focus for concern, answering such questions as what do we mean by good staff, what forms of training work best, how can staff be supported in dealing with stress. The lack of training in managing violence, or dealing with problems that tend to evoke a complex emotional response (e.g. child sexual abuse) were noted, even within agencies such as the Probation Service.

The law

In addition to those already raised, legal issues included the position in law regarding the inadequacy of services - who is held legally responsible? While there seem to have been no tests of legislation, Local Authorities and public bodies are not legally bound except where they act 'outrageously'. The law provides no leverage at present to ensure adequate services. If the people under discussion are refused care because of lack of resources, the only option remaining is to put them in prison. On the other hand there is a danger that if service providers offer to cope they will be expected to without extra help.

Research

Research has a useful role to play in helping to refine certain concepts and achieve greater accuracy in understanding issues, e.g. the problem of dangerousness. However, research to identify danger and carry out random testing of strategies underway is impracticable and, more importantly, irrelevant, since it perpetuates the mistake of seeing 'risk in people'. The question of whether a condition is untreatable is more properly a question of 'not yet knowing' how to treat this person. the identifying of individual needs is of no less importance than the problem of resources, and a good deal more complex. A great deal of descriptive research is necessary before the process of making precise prescriptions can be undertaken confidently.

CONCLUSION

As we expected, this workshop raised more questions than it answered. A number of vitally important issues were drawn out both in the presentations and the discussions. Some of the key themes to emerge from the day were:-

- * Quality of life How can we enable people with seriously challenging behaviours to enjoy reasonable quality of life? For many people it seems as if their perceived lack of value and lack of self-esteem adds to their problems and make solutions even harder to find.
- * Treatment How can we provide people with effective 'treatment' for their problems? This raises issues of the planning and monitoring of services. All too often we 'blame the victim' for ineffective services.
- * Crises How can we support people in times of crisis? Many of the services we discussed were little able to anticipate crises and work out effective ways of dealing with them.
- * Safeguards How can we provide effective safeguards for the people treated under conditions of security, who are often extremely vulnerable to abuse from themselves and others? How can this be done in a way which also provides safeguards to society.
- * Financial resources How can we attract financial and other resources to provide high quality services to individuals? People with seriously challenging behaviours are often unpopular causes and money is often allocated for 'units' of service provision, rather than to fund individual care and treatment programmes.
- * Staff How can we recruit, train and support high calibre staff with the skills and other characteristics to work effectively with this group?
- * Individual plans How can we plan and co-ordinate services around individuals?
- * Models What do 'good' services look like? How can we learn from examples of good practice and disseminate this learning?
- * Prevention What can be done to ensure that people never get so damaged that they develop seriously challenging behaviours? What can be done to improve services in the early years so that problems are resolved quickly and effectively?
- * The law What are the implications for the law and those who operate it? Are changes needed which will afford better protection both to the people who come into contact with the courts and the penal system as well as to the public at large?

The meeting came up with no easy answers. However, it was clear that these issues are not often discussed and that there is scope for further discussion and mutual understanding. There was a surprising amount of agreement between participants about what the main issues are, and this seemed to be helped by discussion centred around real life issues relating to individuals.

It is also apparent that a great deal of useful experience is being gained about ways of planning and implementing effective services around individuals. There is a need to find ways of more effectively disseminating the lesson arising from this experience. Finally, it was agreed that more research is needed in this area so that effective approaches to individuals and the services implications of these can be discovered.

The day included representatives from the Department of Health, the National Development Team for People with Mental Handicap and the King's Fund, as well as planners, managers and practitioners. We hope that it will have stimulated all these groups to look further into the questions raised above and to work together to find solutions.

APPENDIX I

King Edward's Hospital Fund For London

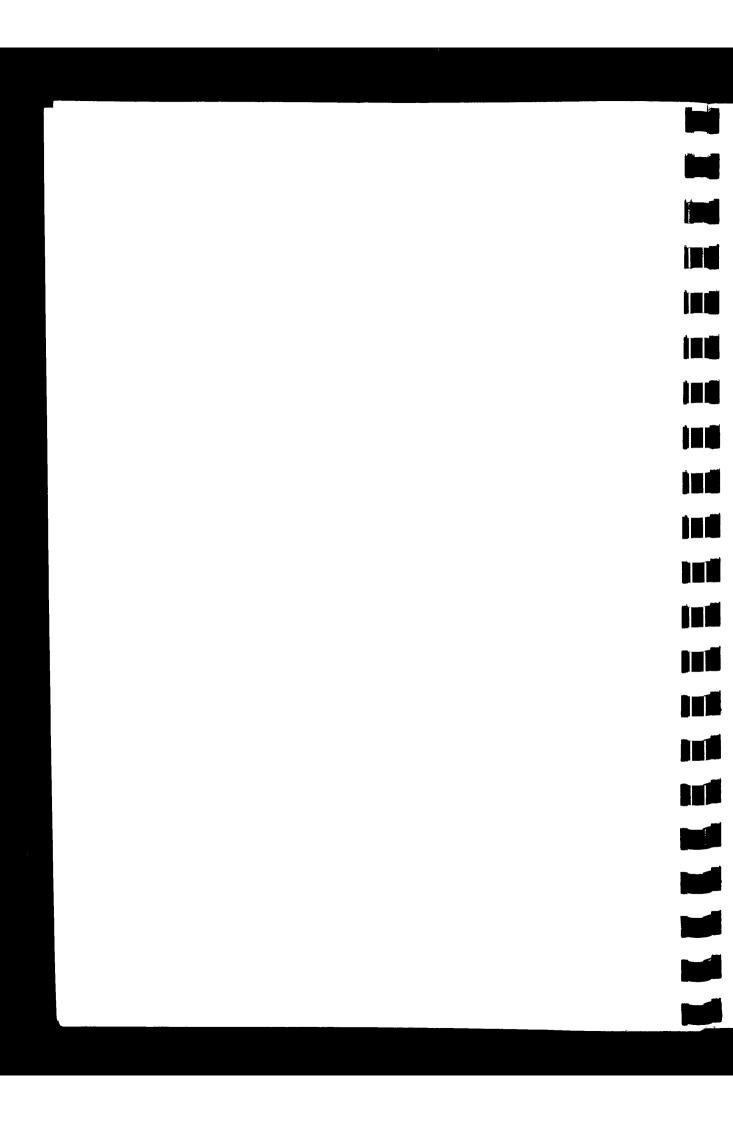
King's Fund Centre

126 Albert Street London NW1 7NF

AN ORDINARY LIFE AND TREATMENT UNDER SECURITY FOR PEOPLE WITH MENTAL HANDICAP

WORKSHOP: 23RD. MAY, 1989

9.30 а.ш.	Arrival and Coffee	
9.45 a.m.	Welcome and Introductory presentation	Dr Oliver Russell
10.00 - 10.30 a.m.	Presentation A (10 mins + discussion) The clients - what kinds of needs?	Dr Mary Myers Psychiatrist
10.30 - 11.30 a.m.	Group Work I Identifying individual needs	
11.30 - 12.30 p.m.	Presentations B, C & D (10 mins each + di Professionals and non-professionals responses	scussion) Mr David Carson Senior Lecturer in Law
	Problems with present provision - Special, Regional and local hospitals	Dr Diana Dickens Psychiatrist
	What kinds of services?	Dr Anthony Holland Psychiatrist
12.30 - 1.30 p.m.	LUNCH	
1.30 - 2.30 p.m.	Group Work II Identifying a service response	
2.30 - 3.45 p.m.	Plenary session, covering: * Report back from groups on issues and problems * General discussion * Ways forward - information and dissemination	
3.45 p.m.	TEA and CLOSE	
NOTE:	All presenters will have written papers which will be circulated beforehand to all participants.	
NOTE:	Group work will be based on real case stories. Each group will include a scribe and rapporteur. Groups will feedback to the plenary session only major issues, problems or conclusions, to introduce the discussion.	



King's Fund Centre

126 Albert Street London NW1 7NF

AN ORDINARY LIFE AND TREATMENT UNDER SECURITY FOR PEOPLE WITH MENTAL $\underline{ \text{HANDICAP} }$

WORKSHOP 23RD MAY, 1989

LIST OF PARTICIPANTS

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