MEETING

THE CHALLENGE

Some UK
perspectives on
community services
for people with
learning
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and
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Edited by
David Allen
Roger Banks
and
Susan Staite

KING'S
FUND
CENTRE

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DAVID ALLEN

ROGER BANKS

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SUSAN STAITE

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The King's Fund Centre is a health services development agency which promotes improvements in health and social care. We do this by working with people in health services, in social services, in voluntary agencies, and with the users of their services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences and publications. Our aim is to ensure that good developments in health and social care are widely taken up.

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David Allen
Roger Banks
Susan Staite

FOREWORD

We have come to expect that the King's Fund Centre's 'ordinary life' publications will combine vision with the art of the possible. This one does not disappoint. It is timely in view of the particular emphasis that Stephen Dorrell, Minister of Health, has recently placed in his important recent policy speech on the need to improve services to people with learning disabilities who have behaviour that we and they find difficult and disturbing.

All the contributions courageously adopt approaches that move away from the 'safe' but often maladaptive service strategies of the past. These typically involved moving the 'problem' along, grouping together people with similar problems, and developing living and day time arrangements that were very separate. Instead efforts are made to use ordinary settings, to keep people in touch with family and friends and most importantly to seek to understand the functions of particular behaviours.

However, it is also evident that there is no attempt to deny or minimise the complexity of individuals' needs and how difficult it can be to make effective service responses. The excellent concluding overview makes the point that what is needed is an integration of values, good organisational structure and capacity, together with skilled systematic therapeutic interventions based on a good understanding of each person. Another important theme is the use of non-aversive approaches, and the teaching of alternative behaviours and coping strategies.

There is a long way to go. Far too few people currently have access to such sensitive, flexible and individualised approaches. While the achievements reported here for particular individuals are very impressive, we know we could do better. The modesty of the claims of success and the authors' willingness to learn from their mistakes, plan actively for crises and evaluate and review their own performances bode well for the future.

I hope the publication will provide encouragement to the relatives and the practitioners who offer person-to-person support. But I also hope it will stimulate those who are in senior positions within public agencies to create more favourable policy contexts, review the effectiveness of current services, and manage resources in a more creative and cost-effective manner.

Derek Thomas
Director
National Development Team
July 1991

CONTRIBUTORS

David Allen	Service Manager	Challenging Behaviour Service, Cardiff
Roger Banks	Lecturer in Psychiatry and Mental Handicap	University of Sheffield
Ivan Burchess	Co-ordinator	Intensive Support Team, Kidderminster
Alick Bush	Psychologist	Mental Handicap Services, Sheffield
Brian Cooper	Manager	Special Projects Team, Sunderland
Janet Dearn	Support Specialist	Intensive Support Team, Kidderminster
Tony Doyle	Clinical Nurse Specialist	Challenging Behaviour Service, Cardiff
Mark Feinmann	Psychologist	Liverpool Health Authority
Heather Hughes	Lecturer	University of Kent, Canterbury
Cliff Hawkins	Lecturer	Institute of Psychiatry, London
Donna Heath	Support Specialist	Intensive Support Team, Kidderminster
Jan Hill-Tout	Psychologist	Challenging Behaviour Service, Cardiff
Denise Johnson	Psychologist	Sunderland Health Authority
Joan Maughan	Project Co-ordinator	The Children's Society, East Suffolk
Peter McGill	Senior Lecturer	University of Kent, Canterbury
Mary Myers	Consultant Psychiatrist	Mental Handicap Services, Sheffield
Susan Staite	Psychologist	Hortham Hospital, Bristol
Jean Walker	Support Specialist	Intensive Support Team, Kidderminster
Mark Williams	Day Services Leader	South East Cardiff CMHT

Other people who contributed to the work through comment, support and information are:

Roger Blunden	Director	Community Living Development Team, King's Fund Centre
Geraldine Holt	Consultant Psychiatrist	Greenwich Health Authority
John Lewis	Principal Officer	Suffolk Social Services
Joan Rush	Senior Project Officer	Community Living Development Team, King's Fund Centre
Derek Thomas	Director	National Development Team

CHAPTER 1

INTRODUCTION

Roger Blunden

This publication forms part of the 'ordinary life' series produced by the King's Fund Centre. In the last few years the Centre has been particularly concerned with the development of services for people with learning difficulties who pose a particular challenge to service providers. In 1987 we produced *Facing the Challenge*[1] which was a first attempt to explore the issues involved in providing high-quality community services to support people with challenging behaviour. There can be particular challenges in providing services based on the belief that all people have the right to 'an ordinary life' in the community, on the basis of respect for individuals, and the need for carefully planned and implemented systems of community support.

Facing the Challenge presented a series of ideas for service development, but at the time it was written, there were hardly any services in Britain which were putting these ideas into practice. However, there was considerable interest in developing new initiatives and an information exchange published three years later identified some fifty examples of people attempting to set up services based on the 'ordinary life' model for people with challenging behaviour[2]. Others, though, were more sceptical: 'The philosophy is all very well, but show us where it's working in practice' was a common response.

This volume is an attempt to meet the demand for accounts of practical examples of services for people with challenging behaviour based on the 'ordinary life' model. Each has set out to provide individualised community-based services for people who are usually considered the most 'difficult' to help, and who are traditionally excluded from services or placed in restrictive, institutionalised environments.

It must be made clear from the outset that none of the services described here claims to have 'got it right'; each is able to identify its difficulties and limitations. None should be regarded as a 'template' or exact recipe for other services. However, a start has been made, and there are useful lessons to be learned from the experiences described here. We would also like to stress that the examples presented here are not the only ones in existence. There are many other examples of good practice throughout Britain and we would encourage you to seek them out.

Many of the services described here are small scale developments which have survived very precariously in an increasingly cost-conscious and business-oriented world. For some people at certain points in their lives, service costs may be high, but we believe these can be justified by the benefits to the individual concerned when compared with cheaper (or, even in some cases, equally expensive) options. The services were often set up with short-term 'soft' funding and their futures are uncertain. Sometimes an evaluation was planned, but often a funding review was scheduled before the evaluation was completed.

One function of this publication is to document the progress made and to draw out some of the lessons learned. Another is to demonstrate to those who are sceptical that it is indeed possible to set up and run 'ordinary life' style services for this client group. At the time of writing, it is rumoured that an anticipated policy statement from the Department of Health will pull back from a firm commitment to community-based services based on individual needs. We hope that the examples presented here will help counter the argument that such services are not feasible or are too expensive.

Finally, it must be made clear that the service principles outlined here are not uniquely concerned with services for people with challenging behaviour. While most contain elements of intensive work with individuals, often involving specialist expertise, their basic principles and their practices are relevant to all community-based services for people with learning difficulties or other long-term disabilities. In particular, each of the services described places considerable emphasis on enhancing the competence of mainstream services and of the community to meet the challenge presented by people who sometimes exhibit difficult behaviours.

We illustrate the work of the services with descriptions of their involvement with one or more users. In all cases, the names quoted are fictitious.

CHAPTER 2

HOUSING

One of the fundamental principles of an ordinary life states that 'Mentally handicapped people have a right and a need to live like others in the community'. In this chapter we provide two examples of services addressing this need. The Sheffield development is an example of a health service response to an urgent demand for locally-based residential facilities, to meet the needs of individuals who had previously been contained in secure environments or excluded from local health service accommodation. By contrast, the South East Thames Special Development Team illustrates a regional initiative, providing advice, and practical and financial assistance in developing residential services within ordinary housing.

THE BERNERS ROAD PROJECT, SHEFFIELD

Roger Banks, Mary Myers and Alick Bush

ORIGINS

In 1986 the Mental Handicap Unit of Sheffield Health Authority set up a working party to develop service plans for those individuals who presented serious challenges to services. While a general model for the development of community services for people with mental handicaps had been laid down in the 1981 Sheffield Strategic Plan, more detailed planning was clearly required for this group. Increasing demands were being made on existing services to provide for people with challenging behaviours, and this trend could reliably be expected to continue given the overall change in service patterns that was taking place.

The working party included practitioners who had a particular interest in developing services for individuals with challenging behaviours and who shared a common philosophy of community care based on respect for the individual and the use of non-aversive interventions. One of three clear service deficiencies identified was the absence of appropriate local, residential accommodation (the others being advice and practical support to carers, and day services). Particular concern was expressed about two groups: people residing in private hospitals outside the district (changes in local funding arrangements scheduled for April 1987 meant that their situations had to be reviewed); and a small group being cared for in the special hospitals. An options appraisal within the working party's report suggested that more individualised community-based models of care could be set up for these clients with no greater financial outlay than placement in private hospitals. At the time, three people were being contained in private facilities at a cost of almost £150,000 per year.

The existence of vacant health authority accommodation in the form of two adjacent, detached houses suitable for the needs of four identified individuals provided an opportunity to test out an alternative residential model. The project was funded solely by the health authority, partly with monies which would otherwise have been used to appoint a consultant psychiatrist in mental handicap.

DESCRIPTION OF SERVICE

The Berners Road project was set up in March 1989 to meet the needs of four specific individuals: two came from a private hospital, one from a special hospital, and one had been excluded from a health authority hostel. Three were detained under the Mental Health Act at the time of their transfer to the service.

The properties are on a street of ordinary local authority housing, adjacent to an NHS hostel and were originally intended as staff accommodation. Despite being technically an inpatient facility, every effort is made to ensure that the properties are, first and foremost, people's homes. The decision to link the properties was pragmatic: single houses would have been unworkable from the point of view of staff cover, managerial support and funding implications. They were also the only small-scale environments available at that time.

The basic staffing consists of a charge nurse, four staff nurses, six home support workers and two day support workers. At the outset, a senior nurse was included within the staffing structure of the service but this was found to be unhelpful and unnecessary and a senior nurse from the general service for people with learning difficulties now contributes in an advisory and support role. There is a project support team consisting of the service manager, senior nurse, charge nurse, administrator, a social worker representative and the consultant psychiatrist.

KEY APPROACHES

The institutional settings where people had been living had provided them with few opportunities to develop appropriate living skills and, to a large extent, their inappropriate behaviours had been maintained by their living environments. While those settings were with some exceptions seen as being effective in controlling behaviours, they were largely ineffective in terms of producing lasting behavioural change.

All four clients had difficulty interacting with the community so, rather than continuing to segregate them, it was felt that they should be part of the community with opportunities to learn new and appropriate behaviours. Safety for the community would be provided by adequate levels of appropriately trained staff. The aim was that staffing levels would be reduced as people's behaviour changed over time, which contrasted with the more traditional model of changing people's residence at intervals (for example, from secure unit to hospital ward to hostel to group home) as their behaviour changed. The traditional model requires people to develop new behaviours within each setting, few of which are going to be useful to the person when they are living with less supervision in the community.

The organisation of the service is determined chiefly by the strengths and needs of the clients as identified via individual planning. Only a small number of staff are directly involved with each client in an effort to foster a sense of responsibility for and commitment to them.

The general therapeutic approaches involve the use of individualised, non-aversive, behavioural techniques that aim to treat the client with respect and dignity. The starting point for each individual is an understanding that their challenging behaviour serves some function for them, and that there may be more adaptive ways of communicating the same need. A detailed functional analysis always precedes an individualised, long-term, positive plan that aims to provide each person with new behaviours incompatible with their challenging behaviour. Some of the more traditional behaviour modification approaches (time out, response cost, and so on) are avoided. Most of these methods had failed these clients in the past, focusing as they do on the elimination of behaviour rather than development of adaptive skills and involving punitive or aversive elements. For three people, chemotherapy is also an essential and facilitative part of their treatment.

In view of the sometimes unpredictable and potentially serious nature of the clients' behaviours, it is essential not only to pre-empt and hopefully prevent difficulties, but also to provide a rapid, effective and co-ordinated response when crises do occur. Following unhelpful responses from the on-call systems from the general service for people with learning difficulties, it was felt necessary to establish an on-call rota of senior staff involved in the Berners Road service and this is presently provided on a voluntary basis via a radio pager.

Colin's story provides an illustration of life at Berners Road.

> Colin is 31 years old. His early childhood appeared quite normal until the age of three when he is thought to have had an epileptic fit. On starting normal schooling he would run home at playtimes and eventually was transferred to a school for children with learning difficulties. At the age of 14 he moved to a training centre. Around this time he began to exhibit severe temper tantrums and for two years was seen by a child psychiatrist who excluded a diagnosis of schizophrenia.
>
> At the age of 19 he was referred to a consultant in mental handicap having become destructive and verbally aggressive over a number of months. Once, during the night, he had destroyed the family television set and on another occasion, when denied a new shirt, had taken his father's new one and flushed it down the toilet. He spent a great deal of time fighting with his younger brother. His mother, who has mild learning difficulties herself, tended to protect Colin and, while maintaining that he was 'not a baby', continued to treat him as such. She would project the blame for Colin's behaviour on to her husband and deny the reality of his situation by believing him to be normal 'underneath'. Colin was described at this time as having a mild learning difficulty.
>
> Colin was admitted temporarily to a hospital for people with learning difficulties but after a short time his mother took him home. A year later he was referred again. He was becoming increasingly difficult to manage; unwilling to get up in the morning, throwing objects out of windows, breaking items or tearing them up, getting in and out of bed and singing during the night, and hitting out at strangers in the street. He was therefore readmitted to hospital under the Mental Health Act where he remained until its closure in 1977 when he was transferred to another hospital.
>
> Colin's new ward contained a number of individuals with highly aggressive behaviour and this milieu seemed to suppress much of his own difficult behaviour. But on closure of this ward and his transfer to another, the behaviour problems re-emerged. In 1985 he was described as a loner, unable to work in groups. He would try to go to bed at inappropriate times, damage other residents' property and tear up photographs of them. He also had a long history of unpredictable aggression and would frighten people with his stares. His mood was one of anger and resentment and he was having fantasies about killing children and adolescents. During one month in 1985 there were 17 incidents of physical violence to residents and staff and some serious incidents involving members of the public. In view of the inability to contain him and the need for a

secure placement, which was not available within the district or region, Colin was admitted to a private hospital out of the region.

Throughout his time in the private hospital the same patterns of behaviour continued with unpredictable violence and destruction of property and clothing. At times he would readily co-operate with ward routine and staff interventions, but at others his mood could change almost instantaneously from one of quiet relaxation to anger and violence. Various medication regimes were tried but with no apparent effect; behavioural interventions were similarly ineffectual and he continued to be detained under the Mental Health Act. His parents visited regularly and always expressed their wish to see him living back in Sheffield. However, Colin was transferred to a ward for long-stay patients, where the aim was merely to contain people, with no view to skills development or any future move into the community.

In March 1989, after very detailed assessments and visits from clinicians and staff in Sheffield to get to know Colin, he was transferred to one of the houses at Berners Road together with another person from Sheffield who had been at the same hospital.

In the first few months, incidents of destructive behaviour continued with some frequency though with significant changes in quality. There were no incidents of aggression towards people, and whereas he had regularly torn up his clothing, given a free choice of clothes readily available in his wardrobe, the frequency of this particular behaviour diminished considerably. Colin had also often broken toilets while in hospital but this has never occurred since his return to Sheffield. He continued to be quite threatening in his manner and his moods changed rapidly and unpredictably.

Highly detailed observation and recording of Colin's behaviour has allowed certain triggers to be identified more clearly enabling episodes of challenging behaviour to be pre-empted and diffused.

Over time, increased understanding of Colin and the formation of good working relationships and friendships with selected staff has allowed a greater degree of communication and a much more realistic approach; people now negotiate directly with him on the acceptable limits of his behaviour.

Colin isolates himself much less in his bedroom and takes part in many household tasks. He also has considerably more contact with the community with regular shopping trips and walks, and recently has made two trips to seaside resorts, his first for very many years.

Although on first impressions Colin was felt to be the most challenging client to work with, he has proved in many ways to be the most rewarding. The most significant factor in the reduction of episodes of challenging behaviour seems to lie in the quality of a few but strong interpersonal relationships that he has forged with some staff members. These have allowed an insight into a man with intellectual abilities that in the past have been negated, a strong sense of humour and considerable understanding of the way in which his behaviour has affected others and how various life events have moulded him; his insights into his own experiences often providing invaluable assistance to staff and clinicians in understanding the lives of clients who challenge us. Those with whom he has the closest relationships are quick to express considerable respect and affection and feel that there is a great depth of honesty and sincerity in their friendship with Colin.

MANAGEMENT AND SUPPORT

Each member of staff participates in an induction course at the beginning of their employment. Additional training days are scheduled every six weeks and staff also have access to and are encouraged to attend appropriate courses, meetings and conferences. A staff support group is held regularly.

The houses were established as a separate unit within the mental handicap service, a clinical psychologist (Alick Bush) initially taking the role of service manager and being directly accountable to the unit general manager. Specialist inputs (for example, consultant psychiatrist, GP cover, nurse manager support, administrator, and paramedical services such as OT) are provided on a sessional basis from professionals working in the mental handicap service. The nursing staff complement, however, is administered purely within the Berners Road service and does not involve other mental handicap unit nursing staff.

EVALUATION

Project workers consider that all the clients using the service have made substantial gains, though one person has had to be moved back to a private hospital due to an increase in fire-setting activity. Two people have progressed to the extent that they can now consider moving on.

The service is currently being evaluated more formally along the following dimensions: quality of the environment, nature and frequency of challenging behaviour, skills, quality of life, clients' opinions, changes in mental state, and service costs.

PROGRESS, PROBLEMS AND PRIORITIES

The obstacles that the project had to overcome in its development phase were many and varied. They included concern over the level of expenditure, ability to recruit staff of adequate quality, and persisting fears/myths/legends from individuals' previous residence in Sheffield. On a general organisational level, there was some suspicion and resentment of a facility and staff perceived as 'elite', and uncertainty on the part of the Mental Health Act Commission due to their lack of previous experience of similar establishments. Finally, the parents of one individual identified for the scheme were very resistant to the idea of the project.

It has now become apparent that the siting of the two houses is unsatisfactory: the neighbourhood is 'difficult' and has been rather unaccepting of the project, and the proximity to the health authority hostel for people with learning difficulties was particularly unhelpful in creating too high a profile in the neighbourhood. Another problem has been the forced adoption of hospital procedures incompatible with ordinary living (for example, centralised laundry, health and safety at work regulations for kitchens, fire alarms, and so on) although some of these have been modified after negotiation.

An alternative site for the service is currently being sought which would aim to include a number of other houses within the vicinity, providing a similar service to other clients while being able to share resources (for example qualified nurse cover, training costs, and so on) and thus decreasing per capita costs (which at 1989 prices were in the region of £50.000). This new development may also include a similar service model with a limited number of places for acute assessment and management of psychiatric or behavioural disturbance. Future models will also recognise that residential places need not be 'for life' because, while this assumption was made at the start of the project, people using the scheme have challenged this notion by the gains they have made.

Having sleeping-in night staff has proved something of a double-edged sword; while it enables the clients to have one group of staff for a 24-hour period, and thus a greater consistency, working in such long stretches presents certain difficulties; communication at the handover between shifts, for example, is difficult and if staff have a disturbed night then it is less easy to work effectively the next day. Staff also have varying levels of skill in defusing behavioural problems and encouraging clients to maintain a normal sleeping pattern, so there may be occasions when clients are awake for considerable periods during the night. This makes the staffing budget difficult to control due to the unpredictable level of overtime pay.

The issue of staff support and staff stress and burnout was not addressed at the outset and is now becoming a significant problem. Shift patterns and staffing levels have never permitted frequent staff group meetings with resulting factions and isolation. Having to integrate two staff groups has also caused problems; staff who were providing care for one person prior to the establishment of the current service have always found it difficult to merge with newly appointed, qualified staff.

As mentioned above, one person has had to leave the scheme because of an increase in fire-setting. This place remained vacant for ten months while negotiations and planning were carried out to accept a client from a special hospital.

The establishment of a programme of acceptable and client-determined day activities remains a problem, partly due to the personalities and particular difficulties of the people themselves, but also due to entrenched traditional attitudes to nursing roles and client activities. None of the established employment/education facilities within the city was felt to be appropriate for any of the clients and daily living activities are therefore provided via two day support workers. This has met with limited success. One client managed to obtain full-time, paid employment, initially trained and supported by a job trainer from the Intowork service (see Chapter 4), and latterly with fortnightly support visits from one of the home support workers.

The Berners Road service stands alone as a one-off development. With the benefit of hindsight it would have been better if the residential facility had been established as back-up to a community support team. Presently it does not fit into established patterns of service within the health or local authorities; it does not have a clear context and is thus handicapped as a result. This issue will be addressed in the review of the Sheffield Strategic Plan.

THE SPECIAL DEVELOPMENT TEAM, SOUTH EAST THAMES

Peter McGill, Cliff Hawkins and Heather Hughes

ORIGINS

By 1985 the replacement of long-stay hospitals by community services was already well advanced in the South East Thames Region. One of the two large hospitals was scheduled to close and numbers were reducing in the other, a process which has been aided by the Regional Health Authority's (RHA) early development of a funding policy allowing the transfer of resources from long-stay hospitals to residents' 'home' districts. As in most other places, those moving out of hospital tended to be less handicapped clients and plans for those who display challenging behaviour were governed by the the existing regional special needs policy[3] which proposed the development of sub-regional units for these and other clients who presented particularly special needs.

However, such plans were seen as increasingly out of step with the more innovative developments for others with learning difficulties. The ideas promulgated in *An Ordinary Life*[4] had been greeted enthusiastically by local professionals and the RHA had supported their desire to develop services on this model. In particular, the appointment of a regional co-ordinator of staff training in 1983 had been a significant development. This co-ordinator had organised a course for district professionals and managers on the development of staffed housing (described and evaluated in Mansell[5]) and South East Thames had developed more staffed housing projects than any other region.

The time was right, therefore, for the acceptance of relatively radical proposals for those groups of clients yet to be included in new developments. A review of the special needs policy proposed that instead of sub-regional units, a special development team (SDT) should be set up to provide expert assistance to district health authorities seeking to establish local services for people with severe learning difficulties and severely challenging behaviour. The proposal was accepted by regional and district officers, the support of the regional nursing officer being particularly crucial to its success.

DESCRIPTION OF THE SERVICE

The Special Development Team was initially established as a five-year project (December 1985 to December 1990). Regional funding was provided for the recruitment of a team leader and five team members based at the University of Kent Staff were appointed on the basis of their experience and ability to do the job and, while no attempt was made to appoint a multidisciplinary team as such, the team has included individuals with backgrounds in clinical psychology, social work, nursing, teaching and service management.

The SDT's remit was to help develop services for clients within the region who had severe or profound learning difficulties and who presented severely challenging behaviour, defined as 'behaviour of such an intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities'[7]. The clients selected were to be those perceived as presenting the greatest challenge to the development of community services. Formally the team's aims were defined as:

- the provision of practical assistance to local health, educational and social services in the design and implementation of individualised model services for people with a severe learning difficulty and challenging behaviours
- the provision of advice and information on a consultative basis to local services within the SETRHA area regarding the development of services for this client group.

In addition to its staffing resources, the team was able to help local agencies access regional pump-priming monies to support the development of community services for this client group. An amount equivalent to £45,000 per client (1990 prices) was available, in addition to any existing dowry, to help with the initial revenue costs of the services. From 1986 the RHA also made capital available and many of the later projects used this to help purchase property.

Briefly, the team's mode of operation was to help local agencies identify the individuals that they most needed help with, to work with representatives of those agencies to help develop individual service plans for the clients and then, subject to acceptance of the plans, to work with the agencies to develop and support new services.

Clients were accepted on to the team's caseload on the basis of their level of ability and the severity of the challenge presented by their behaviour. Some clients were judged to be too able and the referring agency was directed to the regionally supported initiative for clients with mild learning difficulties - the Mental Impairment Evaluation and Treatment Service (MIETS). Some referrals were judged to not display severely challenging behaviour and, in such cases, regional policy was that local agencies should make their own arrangements for such individuals without external assistance.

By the end of 1990 the team had been significantly involved with more than 30 clients and new services had been developed for 16 of these.

KEY APPROACHES

The SDT's role has been to act as consultant and to advise and support local agencies – district health authorities, social services departments, housing associations, and so on – as they develop and manage services. Accordingly it is useful to consider both the key elements of this particular process of consultation and the key elements of the services which have been set up.

The following appear to have been key elements in the consulting process:

- *the development of clear written contracts between the SDT and the referring agency:* such contracts have reduced the possibilities of misunderstanding and their development has often proved a very helpful way of clarifying with managers of the agency the nature of the task involved in developing and supporting such a service;

- *the involvement of all interested parties in individual service planning:* as far as possible planning teams have included senior agency managers (with access to and responsibility for the allocation of resources), representatives of the agency currently providing a service, and the client and family or their representatives. As well as modelling a process of open planning with good levels of consumer involvement this has been seen as crucial to the acquisition and maintenance of a clear mandate for the service.

In setting up and maintaining services for individuals the following factors seem to have been particularly important:

- *individualism:* each service is designed around the perceived needs of the individual client[8], although service design has, of course, been informed by other matters such as an 'ordinary life' philosophy, resource constraints, and so on. While there are, therefore, many common features in the design of services (for example use of ordinary houses or flats) there are also many individually tailored features. This process of individual design has enabled the service to take account of important characteristics of the individual which may influence the success or failure of the service. The features considered here have included the number and kind of other people with whom the person should live, the nature of the physical environment, and the number and kind of staff;

- *a structured, organised approach:* projects have been encouraged to use detailed, often meticulous, approaches to planning and organising the service.[9] Starting from a process of individual programme planning, systematic strategies have been devised to help involve the client in the activities generated in the process of everyday living. This has been seen as of considerable value in its own right as well as providing activities to which the client can be redirected in the event of challenging behaviour. Attempts to involve clients in activity ('demands') have often acted as the trigger for the occurrence of challenging behaviour. It has been very important, therefore, to ensure that staff are prepared for and skilled in handling such behaviour in a way that minimises the degree to which it interferes with client participation in activity;

- *staff training:* the innovative and difficult nature of the services developed has made it particularly important to arrange good staff training. Staff teams have usually received a two-week induction prior to the new service opening as well as subsequent on-the-job training. This on-the-job training has proved vital to successful implementation of approaches to engaging clients and managing their behaviour;

- *high staffing levels:* the 'safety nets' of seclusion rooms and staff from other wards have not generally been available to the staff of these services. Consequently, high staffing levels have been necessary to ensure thatany particularly difficult incidents can be managed without danger to clients, staff or members of the public. The staffing ratios are not usually any greater, however, than in other services for comparable clients;

- *avoiding congregating people with challenging behaviour:* as far as possible, services have deliberately sought not to have co-tenants who display challenging behaviour because of the problems associated with the development of such 'special' units[10];

- *a clear and agreed operational policy:* developed to cover as many eventualities as possible and updated as required.[11]

Sue Thompson was one of the clients referred to the SDT. Her story is as follows.

Sue was born in 1954 in the south of England. The birth was, according to Sue's mother, difficult and prolonged. Medical records from Sue's infancy have not been traced but it appears that her early development was rather slow but otherwise normal. Her mother reports that Sue's abnormal development began at the age of three, shortly after a bout of pneumonia, when Sue lost the little speech that she had attained, and her development seemed to cease in all respects other than physical growth.

Her mother reports that Sue's behaviour gradually became socially inappropriate: she began tearing clothes and soft furnishings, and showed little interest in other people. Sue's parents consulted numerous specialists, hoping for a definitive explanation of what was wrong with her, and were eventually told that she was 'autistic'. They did not feel, however, that they had been given an adequate explanation of what this actually meant. By the time she was six, Sue had grown to the point where her parents were unable to continue to meet the challenge presented by her tendency to destroy furniture. She was therefore admitted to the children's section of a large NHS mental handicap hospital within the South East Thames Region.

Sue spent the next 27 years in this hospital. By 1987 most of the residents had moved out as the hospital was scheduled for closure by the end of 1988, but Sue was still there and many were pessimistic about her chances succeeding in a community service. The district health authority (DHA) that was due to take responsibility for providing a service for Sue therefore referred her to the SDT.

The SDT and the DHA started preliminary planning of an individualised service for Sue. In late 1987, Sue's parents asked if she could be resettled in their local area, as they had moved house since Sue's original admission to hospital. By late 1988 their local DHA had agreed to take responsibility for resettling her, and the planning process recommenced with the SDT.

This was too late, however, to allow Sue to move directly into her new house. The hospital that had been her home for so long closed in late 1988, and Sue was moved, via a small hospital and a large hostel, to the region's other large mental handicap hospital.

During early 1989, the SDT spent time observing and interacting with Sue, interviewing staff and examining records, and by late 1989 an individual service plan (ISP) was presented to the DHA. The ISP outlined the behaviours that Sue currently exhibited that would be likely to severely challenge a future service: 'these (behaviours) include assault of others (pulling hair, pinching and scratching), manual evacuation and smearing of faeces, removing and tearing her clothes, eating inappropriate objects (for example, torn clothing) throwing objects and stealing food. These behaviours occur on at least a daily basis if she has the opportunity. Aggression occurs regularly and persistently whenever she is approached. She currently spends the majority of her day sitting or lying under a blanket in the corner of the ward. The combination of faecal smearing and aggression on others approaching has led to her being avoided by staff unless it is absolutely necessary to approach her. In general she is a very challenging young woman who will respond with unpleasant aggression (faeces smeared in the victim's hair) if approached.

While this was a formidable picture, the plan proposed staffing and other arrangements that would allow Sue to live in an ordinary four-bedroomed house with three other people. The DHA accepted the plan and started preparing for the type of service that the SDT had recommended. By November 1989 a suitable house had been identified and, shortly afterwards, the first staff (team leader and deputy) took up post.

During early 1990 the DHA renovated, decorated and furnished the house, identified three co-tenants with mild learning difficulties for Sue and, by March 1990, had recruited a complete establishment of eight whole time equivalent support workers. The DHA and the SDT jointly organised and ran two weeks of induction training for the support workers and Sue and her co-tenants moved into their new house in July 1990. Sue was now aged 35 and had been in various institutions since the age of six.

Due to its own staffing problems the SDT had little input to Sue's new service during its first three weeks. The team leader and his staff had deliberately not provided much structure for Sue during this time, in the expectation that a relaxed regime would help her to settle in.

By the end of the first month it seemed that more structure was necessary, primarily to enable inexperienced support workers to follow clear guidelines regarding how they should help Sue to take part in normal everyday activities, while minimising her challenging behaviours. Sue had been participating to a very limited extent in everyday activities, apparently because the lack of structure meant that support workers were having to think 'on their feet' of activities to present to Sue, as well as how to present hospital activities. Sue was spending significant amounts of time pulling support workers around the house (sometimes with an obvious objective such as a biscuit, but sometimes apparently aimlessly), and staff were having to guard against her pulling their hair.

The SDT was by this time able to provide more input, and helped the service to significantly increase the amount of structure in Sue's (and the staff's) life. Sue was now provided with a balanced day's activities, comprising 'work' outside the house (initially consisting of tasks such as learning to tolerate the presence of other people while shopping), leisure (such as listening to music) and the housework tasks created by everyday living. Systems of opportunity planning, shift planning and recording of Sue's participation in everyday activities were put in place to ensure that the service could check on how it was doing.

The increased structure within the service quickly resulted in Sue becoming much more active and independent in everyday living. At the time of writing (six months after the service's opening) Sue has, for example, progressed from being completely fed by staff to feeding herself with minimal physical prompting, from throwing any crockery within range to performing some food preparation and clearing tasks completely unaided, and from being unable to tolerate the presence of the public to going shopping with only one member of staff accompanying her.

Sue is no longer pulling staff around the house unless she has a specific request (in which case she has now learned to either point to what she wants or to get it herself). Hair pulling is no longer a challenge, and the service is able to deal with any socially unacceptable behaviour (such as plate throwing). It is becoming clear that the biggest barrier to Sue rapidly increasing her independence further is a lack of technical teaching skills within the service. The next task for the SDT is to ensure that the service's staff are fully competent in such areas as task analysis, functional analysis, and fading of prompts.

Sue has always been a person of many strengths and these are now clearly noticeable. She appears to be enjoying life and is beginning to communicate dissatisfaction and satisfaction in socially acceptable ways. She makes choices about what to wear, participates in household activities, likes walking on the beach and going on trains. She is gradually participating in more and more out of house activities and generally coping well with them.

For the SDT, the biggest lesson from Sue's service is that structure is very important, both for giving staff the confidence and ability to work consistently, and, crucially, for giving clients a sense of their environment as both predictable and controllable.

MANAGEMENT AND SUPPORT

The services set up in conjunction with the SDT are managed by the responsible local agency, usually the DHA. While they therefore fit in to existing management structures, the SDT has endeavoured to encourage the development of additional structures to protect the services from threat. This has usually taken the form of setting up a project co-ordinating group chaired by someone other than the home leader's line manager (for example, the principal psychologist) and involving senior managers, client/family and SDT members as well as the staff and managers delivering the service. This group has usually met on a monthly basis, perhaps reducing to quarterly as time goes on.

While other management and support arrangements ultimately depend on what is provided by the responsible agency, the SDT has encouraged the use of regular staff meetings and individual supervision and has often sought to build in staff training time to the initial staffing establishment.

The support provided to the agency by the SDT is initially often very intensive. In the months before and immediately after the setting up of the service one team member may be working on an almost full-time basis with the service's staff, being involved in commissioning and staff training activities and then, perhaps most crucially, in working out 'on the ground' how to provide a good service to the individual client and how to overcome the many difficulties which inevitably arise. This period of work usually culminates in a report on the service to the agency at the end of the first six months. As well as being a description of what has happened, the report seeks to evaluate the success of the development to date and make recommendations to the agency concerning improvements.

The support provided by the SDT gradually reduces and becomes less direct, with advice and consultation being offered through the management and support structures which have been set up - project co-ordination group, individual planning meetings, staff meetings, and so on. While the amount of support provided to individual projects has varied considerably, the aim has been to reduce involvement to the point where complete withdrawal can occur after 18 months.

EVALUATION AND MONITORING

The services set up in conjunction with the SDT have been the subject of a formal evaluation study funded by SETRHA. The full results of this study are forthcoming but preliminary publications[12] indicate that significantly better outcomes have been obtained than in the clients' former services or in services set up for similar clients. SDT clients have shown higher levels of engagement in everyday activity, have had more contact from staff and have shown reductions in stereotyped behaviour. However, there have been no significant changes in the frequency of their more severely challenging behaviours.

A number of approaches have been taken to internal monitoring. In some projects, management information systems have been developed which involve the regular collection of data relating to service quality, the data being presented to and reviewed by the project co-ordinating group. The SDT's six-monthly reports on service performance constitute another source of information. Agencies have been encouraged, sometimes explicitly in the operational policy, to use and/or develop their own quality assurance processes, and quality action groups have developed around some of the projects.

A number of structures monitor the SDT's work. As the team is a regional initiative, the team leader attends and reports to the Regional Mental Handicap Steering Group, an RHA-organised group of unit general managers or their representatives. As part of the Centre for Applied Psychology of Social Care, University of Kent, the SDT has included annual objectives in the Centre's work programme and these have been approved and monitored by the RHA.

Internally, weekly team meetings have been the main focus for planning and monitoring work with a system of individual performance appraisal recently put in place.

PROGRESS, PROBLEMS AND PRIORITIES

Much has been achieved in the last five years:

- individual service plans have been developed for 31 people in 14 of the region's 15 districts. As a result of these plans, individualised services have been set up for 16 people in seven districts. Of these services, one was a temporary day service, one broke down some weeks after it opened, in two the individuals have been temporarily placed in hospital, one person is living in an interim service, and one person died of natural causes nine months after the placement was established. The remaining ten people have been maintained in community-based residential services for periods from six months to over three years. Of the remaining plans, work is currently underway to establish services for a further five individuals but the other ten plans seem unlikely to be implemented for a variety of reasons, including lack of money, lack of local competence to sustain the service, and disagreement about the most appropriate model of care for the individual concerned;

- the services set up are, on average, producing significantly better outcomes for the individuals than the institutional services that they replaced[12];

- consultancy has been provided to a number of districts and social services departments, both in respect of individuals displaying challenging behaviour and in respect of broader issues concerning the planning and organisation of services;

- attitudes within the SETRHA area towards the development of individualised community-based services have significantly changed in the last five years. While, at first, doubt about its viability was frequently expressed, it is now generally accepted that it is possible to develop and maintain such services. Opposition to their development now centres on their relative cost-effectiveness, or occasionally on their viability with the handful of people whose behaviour is potentially very dangerous to staff or others. There seems little doubt that the services set up have contributed to this change of attitude and there is clear evidence of a few districts being confident enough to proceed more or less on their own;

- the establishment and achievements of the team have had a significant influence at national level, partly as a result of the efforts made since 1985 to disseminate information through publications and presentations. A large number of peripatetic teams have been established throughout the UK, many apparently at least partly based on the SDT model.

While these are significant successes, there have been many problems along the way and, therefore, also many limitations to what has been achieved.

- there is little doubt that most of the services which have been successfully set up and maintained 'could do better'. There is considerable scope for improving the quality of implementation so that better outcomes for individuals are achieved. This limitation is not generally related to a lack of resources but, rather, to a lack of skill and knowledge (and, sometimes, will) among both direct service providers and the managers and professionals who support them;

- the original plan was that the team would spend limited periods of time supporting new services after they had been set up. This would allow 'throughput' so that the team could go on to develop more services. Interestingly the silting-up effect characteristic of 'special' units is now manifesting itself in the team's work. It is difficult to withdraw our support from existing placements without significant concerns about their safety. Consequently, it is becoming increasingly difficult to take on new development work. There are a number of reasons for this state of affairs including generally high staff turnover in the services developed (though not necessarily much higher than in some community services for people without challenging behaviour) and, in some districts, the lack of an adequate professional and managerial infrastructure to support the services once the team has withdrawn. We should assume that these services will always need significant amounts of professional and managerial support - the issue is where it comes from rather than whether or not it is needed;

- the team has not succeeded in working with all districts (in the region). In most cases this reflects attitudinal and philosophical differences about the most appropriate services for this client group. The team has not generally been prepared to work in services which congregate people with challenging behaviour, although on a number of occasions compromises have been agreed with districts concerning the grouping of two or three people with challenging behaviour with two or three others. As a result, the support and pump-priming monies available through the team have been distributed unevenly across districts - although this is consistent with the original regional intention to support certain kinds of innovative service development;

- the team has not generally succeeded in developing the confidence and/or competence of most districts to the point where they can become self-sufficient in respect of this client group. Thus, large numbers of people with challenging behaviour are in out-of-district placements, some of them very expensive, with little prospect of imminent return to a local service;

- it is becoming increasingly clear that the 'problem of challenging behaviour for services cannot be solved by developing a relatively small, finite number of individualised services or even by providing a special unit or out-of-district placements for a similarly finite number. We are still left with the prospect of more challenging behaviour being created by mainstream services which lack the skill and knowledge to effectively prevent its development.

The work of the SDT over the last five years has demonstrated that it is possible to develop and maintain - at least in the short term - individualised community-based services for people with severe learning difficulties and challenging behaviours. It is clear, however, that such services are very vulnerable to deterioration in quality and in terms of their very existence.

The RHA has now provided funding for an additional five years to continue and extend the work described above. At the time of writing, the second five years' work is just beginning and priorities are currently being determined. The three major priorities at the moment would appear to be:

- consolidation of existing achievements, by helping to maintain and improve the quality of those services which have been set up, and describing the process of individualised service development in a way that will be useful to others setting about the same task;

- extension of the model in further service development work, focusing on the needs of clients already in community residential services for individualised day and support services. It may also be important to seek to extend the model to the development of individualised housing services for clients with particularly difficult problems or unusual circumstances;

- generalisation of achievements through the provision of training and consultancy to local agencies to help them develop their competence to prevent and detect challenging behaviour, support people locally, and manage crises effectively.

In drawing abstract conclusions about the success or failure of an innovation of this kind, and in attempting to identify general issues, it is easy to lose sight of the concrete, specific outcomes for individuals. Some photographs were taken recently of Sue Thompson, some seven months after she had moved into her new home. They show her walking on the beach, loading the washing machine, drinking tea in a cafe, pouring milk on her cereal, and participating in many other ordinary, everyday activities. She is fully dressed and looks healthy - previously thin and almost emaciated, she has put on two-and-a-half stone since coming out of hospital. When asked to comment on the changes her father wrote: 'if it is possible, with only nine months love, and house care, to see such improvement in health and behaviour, then I have only one question - why did it take 27 years of torment in an institution to achieve this?' Of course, it did take more than love and care. It took the persistence and determination of senior officers (such as the regional nursing officer) in the face of comments to the effect that Sue was the type of person who would never be able to live outside hospital. It took the willingness of service planners to make the necessary leap into the dark to imagine the sort of lifestyle that Sue might have. It took the determination and skill of direct care workers and their managers to actually implement that vision. And it took the skill and knowledge of those supporting the service to solve the inevitable problems that arose. It happened, however, and provides an example that should not, indeed must not, be ignored. People with severe learning difficulties and the most seriously challenging behaviour can live in ordinary houses and can have lifestyles that bear no comparison to that found in institutional settings. In many ways this is a conclusion which no longer needs to be justified or 'proved'. It needs, instead, to be acted upon.

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CHAPTER 3

COMMUNITY SUPPORT TEAMS

Many recent initiatives in the field of challenging behaviour have centred on the development of peripatetic community teams. Here we focus on three support services that provide a wide perspective on the establishment, practice and problems of such teams. The Bristol and Kidderminster services are both jointly funded by health and social services, though with slightly differing therapeutic approaches. Kidderminster has a specific focus on assessment of and detailed intervention strategies for challenging behaviours; Bristol has a more eclectic approach that incorporates elements of family work, counselling and psychotherapeutic techniques. The client stories illustrate how these different approaches were employed with similar challenges.

The Suffolk team is an example of a joint venture between social services and the Children's Society. The team works specifically with children and young people and their families and raises some of the issues encountered in working largely outside of statutory agencies.

THE FAMILY SUPPORT TEAM, SUFFOLK

Joan Maughan

ORIGINS

Several important local factors led to the establishment of Suffolk's Family Support Team: it had been recognised that challenging behaviour was often a very significant factor in precipitating breakdown in families of children with learning difficulties, resulting in high levels of use of residentially-based respite care and out-of-county school placements; another small group of children were 'on the edge' of services which were unable to meet their needs – at best their behaviour was being contained, an approach which was costly both in financial and quality-of-life terms; finally, the decision to close a large residential unit would also have substantial 'knock-on' effects in demands for respite and residential care.

Suffolk Social Services had recognised these and other deficiencies in their existing service provision, and initiated discussions with local health, education and voluntary agencies to examine alternative possible models. The eventual outcome was a partnership between social services and the Children's Society with a commitment to develop higher quality, more individualised and flexible services for children with severe learning difficulties – a commitment which was shared and supported by the Director of Social Services, the Principal Policy Officer (Social Services) for services for children with severe learning difficulties, and the Eastern Region Management Team of the Children's Society.

The Family Support Team is one joint-funded component of this partnership between the local authority and the Children's Society (the others being a six-place respite care facility and a flexicare budget).

DESCRIPTION OF SERVICE

The Team, consisting of a co-ordinator and three supportworkers, commenced operations in May 1989. A community support team, it works intensively with children and young people who have severe learning difficulties or multiple disabilities, with their families and with other relevant carers. Referrals may come from any agency, including self-referrals via the co-ordinator. Team members usually work with families, but have also provided a service to individuals living in long-term residential care. The service does not commence new work with clients who are over 19 years of age.

As well as providing practical support (by way of equipment, time, assistance, escort duties, and so on), the workers design and help implement behavioural programmes. Their aim is to work with the family in helping them bring about behavioural change, rather than removing this responsibility from them. The focus of the work centres on making a personal commitment to a client and establishing a relationship with him or her.

The service is available for as long as it takes to change or substantially reduce challenging behaviour. A service agreement is drawn up with the individual, the family, and with other other interested parties, and this is reviewed regularly.

The team also has access to the flexicare budget (£30,000 a year). This is available to meet any identified need that cannot be financed by other means, and would include such items as staff time, equipment, assisting parents, holidays for individuals or families, helping parents to have some space while a family support programme is developed, or transport. The running costs of the team itself are £60,000 a year. The project co-ordinator's salary is additional to this, and is included within the project's overall administrative costs of £42,500.

KEY APPROACHES

The workers aim to create consistency across a child's different environments. Assessments are made over a very intensive 'getting to know you' period across relevant settings in order to help establish where inputs are needed (that is, family/school/short-term care/relatives). Areas assessed include personal skills, interpersonal relationships, family information, environmental factors, physical profile, medication, and so on. Detailed assessments of the nature of the challenging behaviours are also carried out. Families have access to all information that is collected in order to foster a relationship of trust and commitment.

Broad intervention targets are then agreed, starting with 'easier to achieve' changes first so that the family can develop a sense of success and confidence. Intervention programmes are devised as a group exercise, providing an opportunity for both group guidance and group learning. Psychology input from a clinical psychologist working with the health authority is now given on a sessional basis. Further consultative support may be bought in from outside as necessary.

Here is one account of the Team's work:

> Peter and Paul are two brothers with Angelman's syndrome. Aged 12 and 10 years they have displayed many of the difficult behaviours associated with this condition. Both boys are extremely active and have major problems of epilepsy. Despite intervention from a number of sources over the years, including health authority and social services staff, no real impact had been achieved in changing particularly difficult behaviour. As the boys grew older and stronger, life for the family became increasingly difficult.
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> Work started in the family around two main areas. Mealtimes were particularly difficult, being totally disrupted from start to finish. Both boys also had a history of 'dismantling' their bedrooms, getting up at all hours, upturning beds and pulling clothes out of cupboards. This had resulted in beds being bolted to the floor and the rooms being emptied of almost every moveable object.
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> Both parents were very demoralised, lacked confidence in dealing with the boys, and were increasingly forced to 'manage' the behaviour rather than change it (for example, eating meals as and when they could; one parent spending half the night up and down to one or both of the boys). By the time the Team became involved, they were depressed and worn out by the increasing demands of their children's behaviour. Their feelings of anxiety had been further exacerbated by the reactions of a neighbour who had become abusive about the boys, suggesting that they should be 'locked up'.
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> An initial assessment was undertaken which involved spending time with the boys at home, in school, during leisure activities, and within a respite care service provided by the project. A picture emerged of the boys' individual strengths, weaknesses, responsiveness and the trigger points to 'out of control' behaviour.
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> The Team's intervention started with mealtimes in order to build up the parent's confidence in their own ability to achieve success. Up until this point, the parents had been removing either Peter or Paul from the table and taking them up to their rooms for a period of five minutes. It had become an ineffective strategy and six or seven trips upstairs often occurred during the course of one meal. Prior to a new plan being implemented, a member of the Support Team worked with the children for two evenings, both to give the parents a rest and to establish a new set of expectations at mealtimes. Components of the programme included the boys helping prepare the table for the meal, all the items required during the meal being 'to hand' to avoid unnecessary getting up, minimum interaction when disruptive behaviour occurred, brief non-exclusionary time out, and positive reinforcement for appropriate behaviours. This was followed by an intensive period of support to the parents while they carried through the programme. This covered every mealtime for a five-day period. The same pattern was established in school and at their respite care facility. Within three weeks the family was sharing meals with no disruption, and the parents were so enthused by their success that work started fairly promptly on the bedroom situation.
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> Some initial work was done with the boys on valuing their environment, focusing around picturebook work, drawing pictures of the rooms and developing a sense of ownership. In conjunction with the parents, a plan was put together to redecorate and furnish the rooms. The boys were involved at all stages in the preparation of their rooms and their moving back into them was made into something of an 'event'. While this work was going on, a new pre-bedtime routine was also established which incorporated putting away clothes and toys used during the day's activities. This was introduced by the family with intensive support from the worker, and also carried out within the respite care service.
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> The programme finished 14 months ago and the boys continue to use and value their bedrooms appropriately. They both sleep well, which has made a vast difference to the parents. Both have endearing personalities with a great sense of fun and mischief. Because of this they have attracted

a huge commitment from staff working with them and this has, no doubt, contributed to maintaining and increasing skills. They both enjoy a range of outdoor play, including bicycling, climbing frames, and swings. Peter, the eldest, enjoys helping with domestic tasks and will help lay the table, clear away and wash up. He will attempt self-help skills although he needs considerable assistance to complete them. Paul, the youngest, is imaginative in his play and particularly enjoys rough and tumble, sing-along games related to activities, and is becoming more able to settle into structured play. Both boys are developing a more appropriate sense of humour and will play 'tricks' and respond appropriately to humorous situations. They have a strong sense of brotherhood and are mutually defensive of one another.

The family recently attended a three-day conference on Angelman's syndrome where they stayed in a hotel with an evening babysitting service, something they would not have contemplated before the Team's intervention. The boys' mother has gained so much confidence that she now does voluntary work at a local special school. Both parents feel they have learned a more positive approach to difficult behaviour and will now ring the Support Team worker to check out a programme they have developed themselves if a problem starts to emerge.

MANAGEMENT AND SUPPORT

The three team workers are accountable to the co-ordinator. The assistant regional director of the Children's Society is responsible for the overall well-being of the project. There is also formal support from Suffolk Social Services through their principal policy officer. Informal networks of support are available through good contacts with key 'decision makers' in many other organisations – for example head teachers, educational officers for special needs, Mencap, United Response, community paediatricians and hospital paediatricians.

The project was originally linked with a steering group involved with the overall development of the child services, but as this no longer exists, there are plans to establish a new steering group to include representatives from parents, educational bodies, social services, the health authority and, wherever possible, clients. The project is structurally linked via the co-ordinator into local planning groups in Suffolk Social Services, divisional client planning groups, and other working groups within social services.

Regular opportunities are provided for appraisal of work and progress, and the team meets frequently to discuss referrals, treatment plans or problems. The psychologist provides eight hours a week of consultancy and advisory services. Staff complete an annual appraisal which gives opportunities for defining training needs, personal development and support to achieve personal goals. Each team member receives monthly individual supervision and new assessments for intervention are discussed at team meetings to enable a free flow of ideas.

A full basic training course was provided for staff between November 1989 and February 1990 and regular opportunities are also provided to attend local and national courses, seminars, and workshops.

EVALUATION

Funding has been secured for a comprehensive research and evaluation project which will compare the service's strategies for intervention with other forms of response to challenging behaviour. The three-year research programme started in January 1991.

To date, all targeted behaviours except two have been successfully helped, 'success' being defined by the family agreeing that the problem has been resolved. The two behaviour problems that did not respond related to sleep patterns and seem to centre around families being unable to face taking on the process of change at that time. Many parents have wanted to keep in contact and to feel that there is ongoing support. This can be maintained by telephone, although the team would not want to expand this too greatly while at the same time recognising it as an important issue.

PROGRESS, PROBLEMS AND PRIORITIES

Project staff feel that this service has been fortunate to receive the commitment of key people locally and an ongoing promise of financial support. Without these, things could have gone very wrong.

Difficulties surrounded the development of a project against a background of closure of another facility and trying to sell a vision before it was a reality. Parents were being asked to give credence to a service that did not actually exist in comparison with a bricks-and-mortar service that was being dismantled. There were also anxieties about heading into an area that felt like uncharted territory.

The availability of permanent funding has been a key factor in promoting development and a sense of future and commitment. There is also a commitment to local decision making and accountability, to 'being good stewards of resources and credibility'. The concept of the flexicare budget caused considerable anxiety to managers and planners and there were practical problems adapting existing systems to cope with it. In fact, it has been a tremendous asset and is currently being considered for use within other areas in social services and in the Children's Society.

Although in some respects it would have been helpful to have had contact with others developing similar services, there was also a wish not to be bound by established modes of practice and to develop plans with an open and flexible mind. It has, in fact, been very helpful to have been outside statutory agencies since not having to adhere to established bureaucracy gives a freshness and informality.

There are considerable differences in working in a residential situation that does not involve a family and, compared with family members, it has proved difficult to secure the commitment of paid staff. There is also considerably less flexibility within the organisational structures. The team hopes to produce a training and consultancy package for organisations, but has reservations about the ability of organisations to implement new ideas and to generalise from specific interventions.

There are no plans to change or expand the service at present. Aims for the future centre on continuing to develop the present work and on learning and developing new skills.

THE SUPPORT TEAM FOR PEOPLE WITH CHALLENGING BEHAVIOUR
SOUTHMEAD HEALTH AUTHORITY, BRISTOL

Susan Staite

ORIGINS

Once families and community services felt they could no longer cope, admission to mental handicap hospital used to be the only option for people with learning difficulties and challenging behaviour in the Bristol area. In this process, links with families had more risk of breaking, engagement in everyday life in the community tended to cease, and the 'solution' of the hospital environment itself often exacerbated the original difficulties. While there was also some access to respite services in hostels or homes, this was infrequently used as staff in these facilities felt ill-equipped and resourced to deal with serious difficulties. Community mental handicap teams had been operating in the area since 1985, but in a crisis they too were unable to provide adequate support to help people 'keep going' in their day-to-day lives. Since 1987, support services have been developed to tackle these challenges within community settings. The new approaches came about through a combination of several factors.

1. There was a growing awareness of alternative ways of providing services from some individuals' involvement in contributing to the writing of the King's Fund Centre document *Facing the Challenge*.

2. Managers and planners in Southmead were willing to include new ideas in their plans to develop a community service for people with learning difficulties.

3. A number of people with learning difficulties themselves challenged the system to think creatively about how to provide for their needs differently.

DESCRIPTION OF THE SERVICE

The Support Team comprises skilled staff of varying levels of experience who can work in any service or community setting to support people with challenging behaviour and those who live and work with them. Only people in community settings are supported; services are not provided to hospital clients or to anyone without a learning difficulty. There is no cut-off point in terms of ability level.

Assistance is provided to any agencies requiring help, but particularly to social services day centres, education and respite services, and also to families. Guidance and expert advice is provided by an 'extended' team, comprising a psychologist, clinical manager, psychiatrist, and social services manager. Co-ordination is through a team leader who is managed within the learning difficulty services in Southmead.

Referrals are made to the Team when a CMHT feels unable to meet the scale of need presented by a client with challenging behaviour. However, the CMHT continues to hold responsibility for the client; it is not part of the Support Team's brief to take over this function. Once agreed, inputs are then provided in conjunction with existing CMHT services. All referrals to the team are made via a CMHT meeting and completion of a detailed referral form to ensure good co-ordination of services and mutual awareness. Two key workers are allocated to each client. A weekly review of all work takes place, and input is adjusted according to need and is available for as long as is deemed necessary.

KEY APPROACHES

1. A clear value base. Goals are to help individuals to achieve the values of 'an ordinary life' and the five accomplishments of competence, dignity, choice, a range of relationships and community presence.[13]

2. A 'person-centred' approach, assessing all aspects of functioning, including behavioural, physical, cognitive and emotional needs.

3. Carefully planned input, linking in with IPPs already established for the person and including all key individuals in the person's life.

4. Careful, ongoing assessment.

5. Formulation of the function of the challenging behaviour.

6. The use of non-aversive procedures only.

7. Varied therapeutic inputs are used including skill building, counselling, relaxation training, providing new activities and experiences, cognitive therapy, aromatherapy and massage, confidence building, assertiveness and working with families.

8. Support with an emphasis identifying the most effective way of supporting the person and those around them.

Mary's story illustrates some of the pressures which led to the creation of the Team and its response to her situation once it was established.

> Mary, now aged 26 used to live at home with her parents and had an extremely close relationship with her mother. For many years Mary relied on her parents to interpret her efforts to communicate to people, as she found it hard to make herself understood. She was sensitive, and also found it hard to deal with the many fears she had in her life, such as sickness and dying. She was particularly worried that her mother might die. She found it hard to leave her and go to her day centre in the mornings and didn't like being separated at all. She would ask continual questions of people to try to reassure herself, always looking for the one answer she wanted. This caused great strain on everyone around her. Things needed to be a certain way in her life, and if they were not, her anxiety would reach great peaks and she would kick, scream, shout abuse, bite people and run away from the centre.
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> She did not really have much of a life on her own as she never wanted to leave home and would react in an extreme fashion to the suggestion of doing so, becoming anxious, clinging and aggressive. The pressure on her family was massive; her parents were very stressed and tired. Sometimes Mary was admitted to the local mental handicap hospital to give her parents some rest, but although this helped to relieve the pressure, she hated the experience and it was often used as a threat – 'If you don't behave you will go to the hospital'.
>
> The high pressure points in the week were the mornings when tussles would develop trying to encourage Mary to go to the centre. The weekends could be difficult as well, and the situation could sometimes escalate into violence when the only option open to the family was to call in the

police who (in turn) would suggest Mary went to the local mental handicap hospital. Mary would react badly to this and the whole situation would escalate even further.

To break through these difficulties, the local health authority agreed that the community nurse, who was putting time into supporting the family, would increase the time she spent working with them. She started to visit the family every morning to help Mary leave the house and go to the centre. She responded well to this approach and agreed to go with her. The deadlock in the mornings was broken and pressure eased slightly.

However, the strain in the training centre was intense. Mary needed a great deal of individual attention and staff ratios were not sufficiently high to allow this to happen. When she asked her questions, people would become very frustrated and some would confront her. She was very hard for the staff to deal with, under the pressure of busy jobs, and staff were under such strain there was a danger she could have been excluded from the centre.

The CMHT and training centre staff decided that using the IPP system they would take the time to look at her particular needs and strengths that could be met and built on. She was neat, precise, and methodical and liked gardening and animals. Other settings were considered for her to spend her time in. She started going to the city farm to help out and begun a horticulture course. They were so impressed by her skill, they wanted her to sit a City and Guilds course! She also discovered she was very good at ironing. This led to her developing an ironing business one morning a week where people would pay her to do their ironing for them. She started to attend adult literacy classes and her reading skills developed. She was also very creative and artistic, and worked on collages with the local occupational therapy department which were much prized.

By this time people had started to understand her far more when she talked to them. She started to learn to express herself by saying the way she felt, rather than just exploding. She was taught to relax to bring her anxieties down, and was found a friend, through a local befriending scheme. This relationship proved to be extremely successful and she started leaving her family to go out shopping, to visit her friend's home, and to go to parties together. She was starting to be respected and valued more and was becoming more independent and, for some of the time at least, calmer.

Back at home the family received regular support and counselling from the CMHT's community nurse and psychologist. The family knew that they could telephone the CMHT for help, although this service didn't operate at weekends and evenings. Her parents wanted to keep Mary at home and while recent developments were improving things, it was at a high cost. The family was exhausted and the local CMHT was finding the input huge. As well as the daily morning visits, there was also the time spent taking Mary to activities, counselling her parents, and responding in times of crisis.

This and other situations happening simultaneously emphasised the need for a service that could support the local CMHT in providing all these things. Staff were needed who could work flexibly and move between settings, helping where needed. They would have to be able to cover times of crisis as well as supporting on a routine basis. They also needed to be people skilled in working with people with challenging behaviour. Southmead Health Authority responded by setting up a support team which consisted of five people, headed by a team leader, and linking in to the three local CMHTs. The Support Team started to help by identifying Mary's present needs and providing input in a practical way by helping with the daily visits and transport arrangements and responding to crises. Luckily this was all in place before Mary's mother actually became ill with cancer. This was Mary's worst fear. As her mother became increasingly ill, Mary was becoming more and more agitated, saying she wanted to 'go with' her mother when she died and finding it hard to understand why she could not. The CMHT and Support Team helped Mary move to a local hospital (not the one she was scared of) when her mother was admitted to the general hospital. Unfortunately the planned 'base' for the Support Team which could provide the facility of short to medium stays had not been provided (and still has not!).

The Support Team enabled her to keep up all her regular activities. They helped Mary to come through her mother's death and the funeral and then to start to recover and develop a life of her own. Avon Social Services also helped at this point by providing an additional one-to-one, full-time support worker for six months. This was in response to a recognition that the situation was sufficiently crucial that intensive input needed to be provided by social services to supplement the Support Team's input. The extra help was to ease the burden of the many journeys needed to keep Mary's life in the community intact now she was in hospital, and to provide the intensive help she would need to develop skills to enable her to move into a house in the community. The worker helped her to develop independence skills (for example, shopping, using buses, and getting about in her local community). With the help of hospital staff she learned to cook, look after herself and wash her clothes. She was then helped to move into a staffed house close to her father and sister, as was her wish. She shares it with other people with a learning difficulty; staff inputs are geared to encouraging each individual to live as independently as possible. She is there now. She visits home regularly and goes on holiday with her father. She sees her sister and her friend and is making friends in her home as well. She has just started to work one morning a week as a nursing assistant in an elderly person's home. She is still visited by the CMHT and Support Team but is no longer seen as a challenge. By meeting her needs, she has been able to take up her place as an individual in her local community.

MANAGEMENT AND SUPPORT

The project is staffed and managed by the NHS in Southmead Learning Difficulty Services. There is also input to the Support Team's management team from Avon Social Services.

All staff receive training on extended 30 or 40 day block release courses on challenging behaviour which run in Bristol. 'Understanding and working with challenging behaviour' is an English National Board of Nursing 30-day course for post-qualified staff or staff in managerial positions[14]. A 40-day course organised by the Workers Education Assocation[15] is open to all comers with accreditation from Bristol Polytechnic. Both have been developed and organised around the Facing the Challenge document and aim to help staff use these principles in their work settings.

A two-week induction course is provided for all new staff and regular team building days are run for the entire team by an outside agency. To gain experience, staff are enabled to work in other settings (for example, the mental health unit). A service training programme for staff is also available.

Support needs for staff and technical assistance are provided though weekly team meetings and there is a constant ongoing emphasis on mutual support.

EVALUATION

The Support Team is part of the South West Region's evaluation strategy for challenging behaviour services. Dimensions of challenging behaviour, quality of life, carers' attitudes, care-staff stress and satisfaction with the service are evaluated using standard methods to allow cross-district comparisons in the region.

The ongoing work is monitored through IPPs and care work strategies and the development of a modified personal questionnaire approach which is on individualised assessment to monitor progress on a weekly basis.

PROGRESS, PROBLEMS, PRIORITIES

Over the last year the team has had to fight hard to stay in existence. It was established at a level of four team members with a team leader. The extended team members were already working in the services for people with learning difficulties, and retain responsibilities within components providing inputs to the team.

The initial plan was to expand the team to ten to allow them to cover a base which could provide short stays for people. The staffing was increased to eight in autumn 1989 to start to allow this to happen. Christmas 1990 saw a time of great financial crisis in Southmead and cuts in the service affected many areas including the Support Team, reducing it back to five and then further to three. However, the outcry from parents and others at the loss and potential further reduction of the service influenced managers and the team has now stabilised. There is a new appreciation of the value of its work. Plans are under way to increase the team's numbers again in April 1991 and again in October of that year. At one time it was envisaged that there might be three such teams in Southmead but it is unclear at present whether further teams will be set up.

It is also still uncertain whether a base will be provided for the team. Similarly, the development of a house which could be staffed by the team members to provide short-term to medium stays for people with challenging behaviour has not been possible to date.

In a recent survey of consumer views by users of the Support Team, people clearly valued the team's work. Some suggested a way forward for Southmead could be to have higher staffing in the team, and closer links between health and social services in the management, staffing and development of the team. This, plus bringing together the two aspects of support work described in this chapter, and the provision of a home for respite for emergencies, would seem to be important next steps for the service to consider.

Both the Support Team and support workers have shown how important the idea of supporting people in their local communities is, both as a concept and as a practical philosophy.

INTENSIVE SUPPORT TEAM, KIDDERMINSTER

Ivan Burchess, Jean Walker, Janet Dearn and Donna Heath

ORIGINS

Service planners in Kidderminster accepted some time ago that additional support would be needed by local services if people with severely challenging behaviours were to be maintained in community settings. What was less clear was the form this support should take. A number of different models were proposed ranging from a large region-wide specialist service to a locally based 'flying squad' working with clients in crisis.

The solution eventually chosen was that of a peripatetic behavioural support team. The Director of Community and Resettlement Services had learnt of a community-based support service operating in Los Angeles[16] and decided to send a member of the psychology department to train within this programme who was then given the responsibility for establishing a similar service within the Kidderminster District Health Authority.

With the support of local service managers, funding of £150,000 spread over three years was obtained through the joint (health and social services) funding programme.

DESCRIPTION OF SERVICE

The Intensive Support Team (IST) was established in March 1990 to provide additional support to existing local services for adults and children with learning difficulties and severe challenging behaviour. The IST consists of five members: a co-ordinator, assistant co-ordinator and three support specialists. It works across agencies including health services, social services, education and independent services, largely in the community but with some support to the district's two hospitals.

The service has an open referral policy but in order to avoid pre-empting other professionals from making an input and to maintain good relationships with colleagues, community referrals are first approved by the relevant CMHT and hospital referrals are initially screened by the appropriate psychologist. Referrals passed on to the IST after this process are then checked by the IST to ensure they meet agreed referral criteria and, subsequently, are prioritised by the IST Steering Group.

KEY APPROACHES

The IST provides the following services:

- a comprehensive assessment and analysis of referred problem behaviours (including home and occupation, life events, health, intervention history, resource issues and functional analysis);
- detailed and specific intervention strategies to overcome and manage challenging behaviour;
- practical support in implementing and monitoring of intervention strategies.

Underlying the work of the IST is the recognition that most referrals will require considerable practical assistance if interventions are to be successful. For this reason the IST is organised to provide intensive direct 'hands on' work with its clients over prolonged periods of several months if necessary, and at times when intervention is most needed.

Fundamental to the work of the IST is a commitment to a number of principles: the team places great importance on ensuring its work at least reinforces, but preferably increases, clients' access to ordinary life opportunities; and the IST does not use intervention strategies which could be considered to infringe upon clients' dignity (interventions are, therefore, non-aversive).

Jane's story illustrates the nature of the IST's work:

> Jane is 22 years old and lives at home with her mother and father. She has been described as having a severe mental handicap, epilepsy and microcephaly. Her speech is unclear and she often shouts as if to compensate for this.
>
> Jane has a long history of unco-operative behaviour and aggression, primarily directed at her mother. These difficulties first became apparent to services when Jane was around 11 years old. Although Jane enjoyed herself at school, when the school bus arrived to collect her she often would kick out, resisting attempts to encourage her on to the bus. These situations were managed at the time by 'manhandling' her on to the coach. Once on board, her aggression soon stopped, but as Jane became older and bigger, more force was required to 'encourage' her on to the bus and sometimes as many as three adults would be needed. By the time Jane was 15 'manhandling' her on to the bus had become so distressing for Jane and dangerous for those 'persuading' her, it was no longer viable and, consequently, Jane rarely attended school. However, Jane's difficult behaviour was not restricted to leaving home. She often ignored her mother's requests and would become aggressive – shouting, hitting and kicking out, sometimes with considerable force. Predicting when Jane was likely to be aggressive was difficult, although it more often occurred when the family had visitors or when Jane's mother was preparing to leave home.
>
> Between the ages of 15 and 19 Jane rarely left home and then only when accompanied by her mother or father. Invariably these trips were only a few hundred yards and because Jane would often refuse to walk back home her parents would have to take a wheelchair.
>
> When Jane reached adulthood attempts to introduce her to day services met with only short-term success. Previous placements had broken down and, by the time that the IST became involved, the quality of life for Jane and her family was severely impaired. Jane and her mother rarely left the house. Jane had little structure to her life; she spent her days watching television and lying on the settee, sometimes spending the whole day in her night clothes. The various professionals involved were concerned about morale within the family. Jane's aggression had increased in both frequency and severity. Jane's mother was invariably badly scratched and bruised and appeared – and reported being – 'worn down'. Understandably because interventions had broken down in the past, Jane's parents were sceptical as to whether further interventions would be any more successful.
>
> Following its detailed assessment of Jane's situation, the IST hypothesised that Jane's behaviour was related to her early experiences of being 'coaxed' on to the school bus, the unintentional reinforcement of her behaviour by removal of demands, and her limited opportunities to spend time away from her mother. The intervention plan devised focused upon enabling Jane to leave home and attend a day service without becoming anxious or aggressive. Key elements of the intervention included:
>
> - a 'graded exposure' programme which involved exposing Jane to increasingly longer periods away from her mother and home, and gradually longer periods at the day service;
> - developing Jane's repertoire of skills related to leaving home which involved getting dressed and preparing a handbag to take to work;
> - a reinforcement programme for attending the day service;
> - use of a pictorial timetable to remind Jane when she was to attend the day service and the activities planned for that day;

- the use of a variety of reactive strategies in the event that Jane presented difficult behaviour during the implementation of any of the above programmes.

All the above interventions were initiated by the IST. Six weeks after starting intervention Jane was attending the day service three full days a week. At this point, two staff from the day service took it in turns to join a support specialist in escorting Jane. This provided an opportunity for the support specialist to demonstrate the intervention and, subsequently, observe and provide feedback to the day service staff in carrying it out. After three weeks, the day service staff were confident using the intervention and took over responsibility for taking Jane to the centre. At this stage the IST's role essentially became one of monitoring and supporting the interventions. In addition, training was provided by the IST specifically in implementing the reactive strategies, since limited opportunities to manage Jane's aggression had occurred during the 'handover' period. This training involved a seminar describing the strategies, their underlying rationale and a role-play demonstration.

During the seven months the IST were directly involved in implementing and monitoring the intervention, Jane regularly attended the day service, the only exception being two days when she had flu. Data collected and the observations of the Team would suggest Jane found leaving home increasingly easier. The frequency of her aggressive behaviour when asked to leave home reduced over the period of intervention, although it did not extinguish. In the first seven weeks of intervention there were nine incidents of aggression compared with five in the last seven weeks. Furthermore, as the intervention progressed, the duration of Jane's aggressive outbursts gradually became shorter. On every occasion when Jane actually left home and got in the car to attend the day service she appeared happy, relaxed and looking forward to visiting the centre. Importantly, those responsible for escorting Jane knew they could cope without impinging upon Jane's dignity should she become aggressive.

Although the frequency and severity of Jane's aggression reduced during this period, it often took her up to 30 minutes to leave home with her escort. The reinforcement programme for attending the day service was therefore adapted, with Jane being rewarded for successive approximations towards being ready to leave home immediately her escort arrived. This revised plan was effective to some extent, although the length of time it took Jane to leave home continued to vary, ranging from 14 minutes to less than a minute.

In addition to securing Jane's attendance at the day service and significantly reducing the likelihood of her becoming distressed when asked to leave home, the intervention appears to have contributed to other important outcomes. Prior to and throughout the intervention Jane continued to be aggressive towards her mother at times other than leaving home. However, although no formal data collection procedures were used, Jane's mother has reported that such incidents now occur less often.

At home Jane frequently practises skills she has learned at the day centre. In the past the extent to which Jane engaged in leisure or domestic activities was extremely limited; she now enjoys activities at home such as cooking and general housework. Jane's social and self-help skills have also developed. She appears more comfortable when meeting new people at home: she will smile and say 'Hello' and attempt conversations whereas, in the past, she often objected strongly to visitors. She has also formed close and significant relationships with several of the workers with whom she has come in contact. At home, she more frequently and openly displays affection for her parents and her pet dog. Her sense of humour has also become apparent, and she clearly enjoys participating in 'pranks'.

The intervention provided Jane with a variety of experiences away from home, not only through attending the day service and excursions from there; her weekly reward has provided Jane with visits to friends, restaurants, hairdressers and parks. Furthermore, because of Jane's confidence in leaving home, she ventures out more with her parents and often without the need for a wheelchair. The intervention appears to have had important 'pay offs' in the quality of life for Jane's parents too. Jane's mother now knows her daughter will reliably attend a day service and is, therefore, guaranteed 'respite' three days a week. Jane's mother is also now able to leave home in the evening without fear of provoking aggressive behaviour from Jane.

MANAGEMENT AND SUPPORT

The IST is largely independent of other services but has links, via its steering group and through informal channels, with other local services and teams. All team members are accountable to the co-ordinator who, in turn, reports to the Director of Community Services. The IST is supported by a multidisciplinary steering group which meets monthly to support and monitor the work of the IST.

All team members complete the team's competency-based training – a self-instructional learning package designed to teach the necessary skills to work effectively with the team's clients. It consists of 17 modules combining written and field experience, and competency is demonstrated by team members completing written tasks, role-plays and field-based assignments. The topics include: normalisation, ethical issues, non-aversive approaches, ecological manipulations, direct treatment strategies, methods of evaluation and assessment and intervention reports.

In addition to the competency-based training, team members attend weekly seminars covering work-related issues such as analogue assessment, didactic teaching, and use of video equipment. These seminars are supplemented by attendance on courses organised locally and nationally and visits to and from other specialist services for people with challenging behaviour.

Staff development and support issues are primarily addressed by weekly IST meetings and utilisation of the health authority's individual performance review system.

EVALUATION

All interventions with clients are systematically monitored and evaluated, including the collection of follow-up data after the IST has stopped working with the client and his/her carers. The IST is committed to carrying out an annual evaluation of its work and functioning and presenting this to its steering group and other service managers. The IST was also subject to an external appraisal shortly after its establishment. This focused upon the organisation, management and training within the team and reached very positive conclusions about the service.

PROGRESS, PROBLEMS AND PRIORITIES

The main difficulty to date has been the recruitment of competent and experienced behavioural consultants and this has led the IST to make a temporary appointment from the USA. Predictably, the team has sometimes experienced difficulties in maintaining good relationships with other service workers. The reasons for these difficulties include differences in values and a reluctance on the part of referers to provide continued support after the IST has stopped working with a client.

Since the project is in the early stages of development, its impact on other services is difficult to estimate. However, considerable interest has been shown by other services in utilising ideas initiated or pursued by the IST. These include: the use of an 'ad hoc common pay spine' which the IST uses as a means of remunerating competent service workers who may not have professional qualifications, and the competency-based training system. The service is currently extending its professional networks both nationally and internationally.

Important future goals for the IST obviously include securing continued funding for the project while exploring ways of expanding both the number of clients served and the range of services offered by the team.

CHAPTER 4

OCCUPATION AND EMPLOYMENT

It is in the area of daytime activities that individuals are often most vulnerable. Existing day services are frequently too poorly staffed and inflexible to meet the many and complex needs of clients labelled as challenging. The South Glamorgan community-based day service in effect turns the tables, using high staffing ratios to support clients in the use of ordinary community facilities. Building on the techniques and ideals of systematic instruction, the Sheffield Intowork service aims to support people into ordinary employment. It explores difficulties encountered in this process as a further aid to understanding and intervening with specific behavioural challenges.

COMMUNITY-BASED DAY SERVICES, SOUTH GLAMORGAN

David Allen and Mark Williams

ORIGINS

The most important single factor enabling this service to develop was the launch of the All Wales Strategy in 1983. Under this initiative, a network of CMHTs was established in South Glamorgan, an enhanced and more widespread commitment to individual planning developed, and more flexible and substantial financial support made available.

The specific trigger was the 'rediscovery' of a number of people who had been excluded from existing day services. CMHTs in two areas had identified similar service development needs. Two client groups were highlighted for whom there were clear deficiencies in day service provision. The first group were people excluded from services in their childhood because of their challenging behaviour, who were now young adults, some of whom had received no support for two decades leaving them virtually confined within their own homes. The second were school leavers with multiple handicaps for whom no service existed (local special care facilities being limited and already over-subscribed), for whom the prospect of having to remain at home was looming large; some of these school leavers also had behavioural challenges.

As no ready-made service response was available to meet these needs a new service had to be planned from scratch. While individual needs obviously varied, the basic service elements necessary to provide them with high quality day services were similar (high support levels, age appropriate activities in community settings, and so on). A proposal for a service designed to cater for both sets of clients was therefore put together. The CMHTs established a joint steering group in order to develop detailed service proposals and the resulting partnership, between CMHT members and the parents of some of the clients concerned, created a substantial body of support for the project.

DESCRIPTION OF THE SERVICE

The day service, which operates in two areas of South Glamorgan, was initially set up as a demonstration project, although its funding is long term.

To ensure that the service reached those people for whom it was intended, the following eligibility criteria were agreed: the person requires at least one-to-one staffing support; has profound learning difficulties together with multiple handicaps and/or challenging behaviour; is resident within the catchment areas of the CMHTs in which the services are based; and is unable to access other day services within his or her area. All these factors are necessary, but are not independently sufficient conditions for acceptance into the service. The central aim is to provide a flexible and reliable day service for people whose severity of learning difficulty and/or challenging behaviour discriminates against their placement in other established or developing services. The day service is designed according to individual need with the long-term goal of enabling each person to gain access to a wider range of services. In short, the service aims to act as a gateway to the use of normal community facilities.

The main resource in each area is two permanent staff teams of three people, operating from the CMHT patches concerned; the teams have access to additional funding which allows them to augment the service by hiring extra support workers as required. Although the two services share the same basic objectives and principles, they have evolved in slightly different ways which take account of the differences in people served and the considerable geographical variation in the areas covered (one service is based in a major city, and serves an area covering approximately one quarter of that city; the other is based in a large town, but serves three towns and a large rural area).

The principal operational difference is that in the town/rural area, because of the greater geographical area involved, the service is run from an administrative base which also provides the location for a limited number of service sessions; more recently, this base has also been used as a general resource centre for other groups of people with learning difficulties. In the second area, although there is an administrative base, the service itself is provided on a totally peripatetic basis using community facilities available to the general public. Close links were maintained by the two separate services initially, but they currently function more or less independently. Further details of the service are available in Allen et al[17].

At the time that the project was formally evaluated (1988-89) 11 people were using the service. Forty-five per cent of those people accepted into the service by that stage had challenging behaviours, the most common of which were (in order of frequency): self-injury, damage to the environment, overactivity, and physical aggression. At the present time, a total of 15 clients receive the service.

People with challenging behaviours who have less severe learning difficulties are not accepted into the service, although separate provision for this group has now been started in one of the CMHT areas.

KEY APPROACHES

The service teams would not claim to use any particular single therapeutic or management approach. The day service plan is a key ingredient, as is the one-to-one (or higher) staffing levels. Almost purely through experience, staff have become highly skilled at judging the rate and complexity of demands that people can cope with. They seek to offer a wide variety of experiences to their clients, and planning is to a large extent determined by the results of this 'opportunity sampling'. Above all, the service has an unequivocal commitment to sticking with people through 'thick and thin'.

Richard Palmer was one of the people whose 'rediscovery' by the community services prompted the development of the service described here. He was also one of the people whose stories were included in *Facing the Challenge* (pages 17-18) and the following passage summarises what has happened to Richard in the years since then:

> Five years have passed since Richard was referred to the Community Mental Handicap Team and there have been major changes in his life. They are mostly positive changes, but in achieving them, Richard, his parents and the people who have worked with him have experienced some desperately difficult times.
>
> First, Richard's parents were persuaded that he would benefit from admission to the local hospital for people with learning difficulties for a behavioural and medical assessment. Richard was prescribed medication to act as a mood leveller and, when he returned home, his parents saw a change in him that they described as a 'miracle'. He was markedly calmer, which was indicated by the fact that they could take him out for a walk – whereas previously he would only go out on his tricycle. And, while in hospital, they had taught him to sit at a table and eat his meals; in the past this had proved impossible.
>
> Two support workers were now recruited and a twice-weekly programme of activities was set up for Richard, mostly using facilities within the hospital grounds. Richard's parents were overjoyed to see him quite contentedly walk out of the front door and into a car with the workers. But at the hospital it was quickly discovered that this was only the beginning.
>
> Richard obviously had a fear of entering buildings other than his own house, and although a lot of effort was made to interest him in a range of activities – swimming, art, music – Richard often spent much of the time showing his disapproval and would indicate this by banging his head, tipping furniture, or removing his trousers. There were times when he would relax and begin to enjoy himself, but this happened inconsistently and the only times he was consistently content were when he travelled by car or went for a long walk. After several months, sessions were set up in community settings but Richard was not particularly happy being 'indoors'.
>
> Despite these difficulties, considerable progress was made overall, and the work that was done with Richard in some ways acted as a model for the new service. When it began operating in 1987 he was one of the first people to be accepted on to its books. Luckily the three people who began operating the service had worked with Richard at some point during the previous 12 months, and began by taking him back to some of his favourite walking spots so as to re-establish their relationships with him in a relaxed setting. They then began indoor sessions using local community centres, on the basis that Richard needed to learn to accept being indoors, otherwise he would be restricting himself.
>
> Things ran smoothly for a period with Richard actually accepting the situation. But, once again, there came a point where he decided he had had enough and set about avoiding being indoors on most occasions. It became a real battle to even get Richard through the door of a building: at this

stage the team felt that the situation was becoming very negative and so for the next six months three afternoons a week were spent pursuing something he did like doing – walking. This did not necessarily meet some of the principles of the service but, at the time, it did seem to be the only way to meet Richard's needs.

Several months later Richard went through an extremely difficult patch. He spent a lot of time in a very distressed and confused state: he would drag his worker to the door to go out, yet be upset at the same time. While out he would go from one extreme to the other – deliriously happy to very upset – in an instant. He would grab people, pull his trousers down, and was not even happy to return home. At home, his parents found it increasingly difficult to cope, and when he was very distressed he was given a variety of medication (which could have only added to his confused state of mind, although this obviously was not the intention).

Eventually things reached breaking point, and the only option for Richard was to be readmitted to hospital, shortly after which he returned home. The difficulties resurfaced and increased, however, and finally he went back into hospital for a three-month assessment. His system was cleared of all medication, apart from that needed to control his epilepsy, and it was agreed that the day service would temporarily stop. His parents accepted that he needed to live at the hospital until a more suitable solution was found.

When the day service did get involved again, they found that Richard was 'different' – apart from looking different (he had lost weight) he behaved differently, being much calmer. This may have been due to the lack of drugs and/or to living in a situation where the attention was not always on him, and the pressure he may have felt previously was reduced. Whatever the reason, the day service decided it was worth planning for situations they had never tried before such as having lunch at a table, using public transport and going swimming at a leisure centre. They also arranged to meet much more frequently and to plan in much more detail than before.

The following extracts are from Richard's service diary around this period:

'Everybody was, and still is, amazed at how Richard has coped. The first time we had a picnic at a table we were expecting Richard to stay sitting very briefly, if at all. He sat with us quite happily for half an hour! Could this be the same man who six months ago would only sit down in a car?

'The first time we took him to a leisure centre for swimming, we anticipated problems going through the door. Richard walked in with no fuss, got changed and followed us into the water – he wasn't happy, but he was accepting. We have had our problems, but we have learnt to make small adjustments to the way we work with Richard, always planning meticulously, and minimising any unforeseen difficulties.

'Presently Richard spends a long weekend at home and four nights in the hospital. His day service is four full days. He goes swimming at the leisure centre twice a week, spends an afternoon in a health club, goes horseriding, enjoys going window shopping in town and eats lunch in local pubs or cafes every day.

'A recent highlight of his achievements was when Richard, together with all the people who have worked with him over the years and his parents, met in a pub for a Christmas lunch – the first time his parents had seen him in a public place eating lunch; it was very emotional for them. Richard sat for over an hour, accepting every pint that came his way, enjoying himself.'

While the day service has clearly not been the only important factor in Richard's progress, its contribution has been substantial. In particular, it has stuck with him during particularly difficult times – times when most services would have withdrawn their support. Richard still gets upset and still has 'off' days or weeks – just like the rest of us. Life is definitely full of ups and downs and, during the last five years, Richard and his parents have had their fair share; but it seems to have been worth it. Now there are plans for Richard to have his own self-contained flat within the next two years.

Richard is very resilient and, despite the difficulties described, has coped well with the various changes that have happened in his life in recent years. His tremendous personal determination has undoubtedly provided inspiration for his services during some critical periods of high stress.

He also has a mischievous sense of humour, and this has helped him establish a number of relationships which have survived some extraordinarily difficult times.

* * *

MANAGEMENT AND SUPPORT

The service is run by the Social Services Department. Although reflecting the principles of the All Wales Strategy, its original planning and subsequent management support were and are multi-agency and multi-professional. Although there are no direct links with other day services located within the patches served, the projects are directly managed by the day service manager who has overall responsibility for all day services within that area. This person in turn is managed by the relevant CMHT co-ordinator. The service staff also participate in training days which are held for all day service staff working in their particular CMHT patch.

Each service team has its own management support group, whose membership varies in each area, but includes a parent of a service user in each case. The main functions of the groups are to set and review six monthly objectives for each service, provide support for the day service leaders, and participate in service evaluations.

Staff receive a basic induction which covers essential topics such as the management of epilepsy, lifting techniques, what to do in an emergency, administration of petty cash budgets, and so on. Inservice training days are held on a six-monthly basis, in addition to which staff are sent on relevant courses. Each member of staff also has a monthly supervision session.

EVALUATION AND MONITORING

As in any dispersed scheme, monitoring of the service received by individual users is difficult. For the most part, the two-day service leaders are dependent on their staff being honest and reliable about their work. The performance of individual staff is appraised by the day service leader spending occasional sessions working alongside day service workers, but other demands on the leader's time make such opportunities limited.

A formal evaluation of the service was carried out just over 18 months ago[18] which compared the services received by people in the new project with those of a group of clients attending a special care unit who were of a similar age, sex, and level of disability. The services were compared on the basis of the level of community presence, the quality of activities on offer (nature, variety, and age-appropriateness), and the person's levels of engagement in these activities. These were all significantly superior in the new service. At 1989 prices, the cost of a full-time placement in the service was found to be approximately £12,000 per year (compared with £4,500 in special care).

Informal evaluation is also regarded as an important component of monitoring. For example, one management support group spent two days accompanying clients on sessions, attending team meetings, and examining written and video materials, and it is planned to repeat this exercise on an annual basis.

PROGRESS, PROBLEMS AND PRIORITIES

The major obstacle to establishing the service was intense competition for limited funding with a large number of other equally deserving projects. Pen portraits of the unacceptable living conditions of some potential service users which were presented with the application undoubtedly helped in this respect. Some members of the county planning group were also dubious about the proposed nature of the scheme; there was an understandable concern as to whether people who had been excluded from 'standard' services for people with learning difficulties could be substantially provided for by (using) normal community facilities.

A number of important issues have arisen since the service became operational. Having the community, rather than a building, as a base has raised a number of points. Its obvious advantage is that community presence and integration are to a large extent 'built-in'. A disadvantage is that the service is inherently more fragile. Staff sickness, for example, has a greater impact in a service of this type than within more conventional models such as adult training centres. In an adult training centre, for instance, one staff member going sick would not prevent any clients from attending the service, although it may impact on what they did while they were there. With the new service, staff sickness may lead to the session for the day being cancelled if a relief worker with experience of working with the client(s) concerned was not available.

The impact of the scheme on local service development is difficult to measure. It had been envisaged that if the project were successful, it would need to be replicated within other parts of the county. This has not happened to date, although the service for more able people with challenging behaviour mentioned above was based on the same basic format.

A major concern for the future is whether the service should be provided 'for life'. It was originally intended that once individualised services had been established, responsibility for supporting and managing these situations would be transferred to the main day service provision within the area in question. In practice this has been difficult to achieve, primarily because there is concern that this would result in a decline in the quality of these individual services and because the financial mechanisms to enable such transfers to take place do not exist. There are therefore no plans at present to substantially change the service in any way, although it needs to expand and this may necessitate some modification in its structure.

PROJECT INTOWORK, SHEFFIELD

Mark Feinmann

ORIGINS

Project Intowork was developed primarily because of the failures associated with a segregated employment service for people with challenging behaviour which had been set up in 1985 to provide employment opportunities for a number of people who had traditionally received no day care. The service, which has been documented elsewhere[19], met with considerable initial success in that the eight people who attended on a full-time basis learned a number of positive vocationally-related skills. This 'positive programming' led to a major decrease in the challenges presented by individuals and a high level of motivation by staff to work with the people who had previously been poorly served.

However, after initial successes the service gradually deteriorated because it offered no choice in terms of work opportunities or environmental stimulation. Staff were unable to fade their input, and therefore independent functioning could not increase beyond a prescribed level. The project ended up with people re-challenging the service because of the failure in flexibility and responsivity by the service providers.

DESCRIPTION OF THE SERVICE

The Intowork project was set up as a more valued and responsive alternative to the above service. Based on the work of Marc Gold[20], and adapting the systematic instruction techniques that are enshrined in the supported employment models of service provision, direct one-to-one support to individuals was provided in natural environments (that is, real jobs). Four job trainers were appointed, together with a job finder whose specific responsibility was to work for two and a half days a week with eight people described as having challenging behaviours. The intention of the service was to find a part-time job for each of the eight people and provide one-to-one support for that individual in a job of his or her choice.

The service began with a careful holistic assessment of each individual, resulting in the production of a vocational profile of their job requirements. Once a clear understanding of the job preferences of the individual was ascertained, job finders carefully looked for a job environment that matched that individual's needs, followed by further assessment of the workplace and a careful match between this and the individual. The specific role of the support worker was to bridge the discrepancy that was perceived to exist between the competencies of the individual and the demands of the workplace. The job trainer, who had a detailed knowledge of systematic instruction techniques, trained the individual on a daily basis in the skills required for the job and faded support as required. This process of supported employment is well documented[21]. On the commencement of the project, all the individuals using the service were described as having challenging behaviour, all lived in long-stay hospitals where opportunities for day activities were extremely limited, and their futures were seen as relatively bleak.

KEY APPROACHES

The essential success of the scheme lay in the job trainers teaching constructional activities that were developed as valued alternatives to the challenges the individual presented. This fundamental 'positive' programming of functionally equivalent or related behaviours produced major changes in the lives of individuals. More importantly, the myriad range of opportunities available in an ordinary workplace allowed the individual to develop and grow in ways that had not been possible in the segregated service. However, in addition to the basic skills teaching approach, staff also needed to be aware of the importance of avoiding antecedents in the workplace that might increase challenging behaviour. Similarly, they had to identify triggers that would decrease challenging behaviour. This sensitivity to environmental cues (noise, people, activities, food, coffee, and so on) became a key management response, and the success of the placement often depended on the flexibility of the workplace in allowing the 'manipulation' of these antecedents.

While job trainers needed training and functional analysis skills, respect for the relationship that they developed between themselves and their clients was even more important. It was essential that they saw learning and teaching as a joint venture, rather than something imposed on the employee by the job trainers. Job trainers needed to realise that they learned as much from teaching as the clients did from being taught – the notion of equitable interaction was vital. Job trainers also needed to take time to listen to what clients were saying to them. Rather than imposing their own pace, they needed to take the development of skills and competence at the rate the client wanted. Imposing a set of demands prescribed by others was not successful, and when this occurred a placement would usually fall apart.

Job trainers were required to adopt a trial-and-error approach for the individuals that they supported. For example, it became clear that one of the individuals served preferred informal and humorous workplaces rather than formal and controlled ones. This was discovered by the job trainer providing him with the opportunity to sample a number of environments, and listening to what he felt about different settings.

A third central requirement of job trainers was their ability to develop careful and responsive relationships between the employee and other people in the workplace. This building of relationships often contributed as much to success and long-term placement as any building of competencies. Just as in any other workplace, when people were liked and respected for the individual they were, rather than their label or their history, give and take was established which made the difference between success and failure. It was the project's experience that people could do some quite extraordinary things before they lost their jobs.

Simon's story provides an illustration of Intowork in operation:

> Simon, who is 25 years old, comes from an emotionally disturbed and impoverished background. His mother suffered from frequent episodes of mental illness and alternated between complete detachment and a rather smothering over-involvement with her two sons. The boys were often left in the care of a grandfather who sometimes lived rough and who also suffered from a mental illness.
>
> When Simon was three his mother committed suicide. In subsequent years, he and his brother started to display many difficult behaviours, the most significant and persistent of which were theft and the lighting of fires. This fire-lighting seems to have begun as a result of natural childhood curiosity and experimentation, but later became a means of expressing frustration or distress when Simon felt out of control or unable to deal with difficult emotions.
>
> Simon and his brother spent a considerable time in various children's homes or hostels and then with a foster mother. As a result of continuing behaviour problems and law-breaking, however, Simon was placed in an adolescent unit in the South of England. Over the years his behaviour gradually improved and he came to acquire many independent living skills. Estimates of his intelligence around this time described him as having mild learning difficulties.
>
> In his early 20s, Simon again became involved in episodes of antisocial behaviour, including stealing and joy-riding, and eventually a court ordered his detention in a private hospital.
>
> Initially, Simon was compliant with the rigid, behavioural regime of the hospital and worked his way up through the hierarchy of increasing responsibility to the point where he was working towards discharge to the community. Unfortunately there was little, if any, opportunity for Simon to discuss and work through the considerable anxiety and emotional disturbance that he increasingly felt as more responsibility was given to him. He began to set small fires as a way of indicating his distress, and was thus placed back at the bottom of the behavioural hierarchy with the removal of all 'privileges'. It was at this time that he began to be assessed by workers from Sheffield services as a preliminary to moving to a community-based house for individuals with challenging behaviours (described in Chapter 2). Unfortunately, plans had also been set in

motion for his transfer to a special hospital which went ahead despite the plans being made for his return to Sheffield.

A considerable amount of work had to be done on the issue of his 'dangerousness' before Simon's eventual transfer to the Sheffield placement. In evaluating Simon's needs, it was clear that addressing the issue of day activities would be very difficult. His abilities, combined with a need to test out those around him to the limit and his low tolerance of change, meant that traditional day placements for individuals with learning difficulties were totally inappropriate.

The Intowork project provided an opportunity to support Simon on a one-to-one basis into employment that matched his level of ability. It was seen by him as a valued adult role, and allowed for a flexible provision of support and training which could be withdrawn as his competence increased and his perceived dangerousness decreased.

Within a week of his arrival in Sheffield, there were two fires on the same night in the staffed housing where Simon was living. In the absence of any concrete evidence as to who was responsible, and as Simon could not have been responsible for both fires, the decision was made to continue with his placement in Sheffield. A job was set up for Simon at a large bakery and a job trainer began accompanying him to and from work and training him daily in the workplace. Shortly after he had begun it was apparent that Simon's abilities were greater than had been anticipated and he was 'promoted' to a more difficult task which he also grasped quite quickly. He began to travel to and from work on his own, and the amount of input required from the job trainer was gradually reduced as he began to form supportive relationships with his work colleagues. At home and at work, however, Simon began an increasingly frequent pattern of tampering with and destruction of electrical apparatus such as switches, plugs, timers, fuses; settings on machines at work would also often be adjusted. Simon was never witnessed to have been responsible for any of these incidents but they were a repetition of lifelong patterns of behaviour when he was anxious or unhappy. Within the home he was developing the opportunities to discuss his problems with a member of staff. At work his employers, using the job trainer as a source of advice and liaison between Simon's various carers, were quite willing to tackle the problems in a non-threatening and tolerant manner. Simon was seen as a valued and able member of the workforce; he was extremely proud of his job and at one point was so successful that he was earning more than his job trainer.

Unfortunately, a number of separate events then coincided, some of which were foreseeable, others not. The job trainer obtained a post in another city and, although he was by now only providing once-weekly or telephone support to Simon, he was unable to be replaced and a home-support worker had to step in to take his place. At the same time, Simon was coming under increasing pressure from his family and from staff who were having to deal with continued, frustrating behaviours in the home. Three small fires in wastebins at his workplace occurred within the space of one week. Though his employers were desperate to try to find ways of continuing his employment, it was eventually agreed that the risks were too great both at work and at home and a decision was taken to move him to a private secure hospital. Simon had, predictably, pushed and tested the system to its limits.

Perhaps the major lesson of this story is not in Simon's failure, but in the failure and inability to carry on individualising the support that was required for him. Supporting people with challenging behaviour in work places is not an easy task. It requires enormous commitment and dedication both from those who support the individual and employers.

Despite the stresses and fears of working with Simon, it is significant that staff and others still feel a strong wish to be able to continue to find ways of working with him in the future. Although emotionally handicapped in many ways, certain aspects of his relationship with a few staff members were valued greatly by them. He shows many skills and an ability for sustained attention and diligence to tasks that if enabled provide a strong basis on which people can help him build. More recently, Simon has indicated a wish to begin to confront more openly and honestly, the difficult times in his past and an understanding for how and why some aspects of his behaviour are viewed by others as unacceptable. He keeps us up to date with his life through letters which, while often sad or despairing, also show considerable humour, affection and concern from his friends in Sheffield.

MANAGEMENT AND SUPPORT

The service is run by the health authority's psychology department and occupational therapy department on a project basis for all. Staff meet together on a weekly basis during which behavioural and other interventions are discussed.

PROGRESS, PROBLEMS AND PRIORITIES

The Intowork project was initially set up to provide employment services for people who had challenging behaviours. As the service developed there was an increasing demand for other people who had learning difficulties to use the service. Problems also occurred in that the support requirements for people who are challenging were found to be intense and increasingly long term. Finding job placements for individuals which sensitively and accurately relate to their individual needs was also problematic. Job trainers who worked with individuals who were challenging found that their success was long term and, most importantly, those individuals who were motivated to maintain and develop the service left to take other appointments elsewhere.

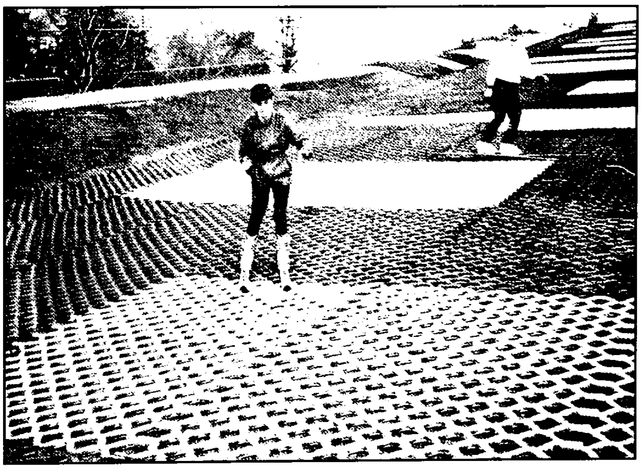
The project clearly demonstrated that people who have challenging behaviour could be found jobs. Employers who are prepared to work with people who have both severe learning difficulties and very high levels of challenging behaviour do exist. Individuals are able to learn the competencies required to do a job, and they can hold down jobs and be paid well to do this. Job trainers can work alongside people and train people in the appropriate competencies, services can be flexible and responsive to ensure that all involved are supported to make sure the service works.

In retrospect, it was a mistake to set up a service which specifically tried to find employment opportunities for people who were challenging. It would have been more appropriate to have set up an employment service which met the needs of all people with disabilities, and then found ways of supporting people who were challenging into that service. Trying to set up a service for people with challenging behaviour and a service for employment simultaneously proved too much for both individuals and the providers. In the end, demands become excessive and the kind of pressures which led to the breakdowns experienced by Simon occurred. Supporting people with challenging behaviour is a long-term requirement and requires continued flexibility and responsivity.

People with challenging behaviours are best served during the day in the same place as the majority of us receive our support – that is, in jobs that we like doing, get paid for and maybe move on from. The experience of the first project showed that segregated and congregated settings were inappropriate as the place in which to do this. Real jobs offer the opportunity that so many people with challenging behaviours have been missing for so long.

CHAPTER 5

MULTI-COMPONENT SERVICES



It is clear that services for individuals with challenging behaviours which are too narrow or have too specific a target for intervention run the risk of increasing the isolation of their clients and of precipitating failure in areas outside their influence. The two multi-component services described in this chapter attempt to provide an integrated, 'holistic' approach that addresses the needs of individuals in all aspects of their daily lives. The Special Projects Team in Sunderland works across many agencies, complementing and supporting the activities of existing service structures. The account of the Challenging Behaviour Service in South Glamorgan places a greater emphasis on the issues and problems in prospective planning and advisory work and in the establishment of common aims and co-ordination of the various service components.

THE SPECIAL PROJECTS TEAM, SUNDERLAND

Denise Johnson and Brian Cooper

ORIGINS

Historically, all specialist NHS provision for adults with a learning difficulty in Sunderland was provided from a long-stay hospital in another district 25 miles away. In 1985, plans for new, more local comprehensive services were being introduced. The local authority had already developed provision for day and residential care, but wished to continue using the NHS to provide for people whose behaviour challenged their existing services.

A categorisation system originally intended for resettlement planning purposes was used to pinpoint individuals requiring additional resources to meet their needs and three groups of people were identified as needing specialist (NHS) facilities:

1. school leavers deemed 'unsuitable' for future ATC places;

2. people whose needs or preferences could not be met by existing services; and

3. people whose needs were so complex that it was felt they could not be met by regular service providers.

Several key factors influenced the creation of the Special Projects Team in response to these identified needs. The absence of any local long-stay beds provided the opportunity for a fresh start using the innovative approaches cited in *Facing the Challenge* and elsewhere. Support for such an approach from senior NHS and local authority managers, service users and specialist professionals like CMHT members, was crucial. There was also a willingness and an ability to share the available skills of clinical psychology and nursing, and an opportunity to recruit new staff rather than 'convert' existing personnel.

DESCRIPTION OF THE SERVICE

The project is based on a team of skilled domiciliary workers who are supported by a six-place alternative day service, a domiciliary/respite support service, and a five-place, long-stay house. The service began in October 1988, incorporating the alternative day service which had been operating since January of that year.

Although the project is staffed and managed by the NHS, it works across other agencies (particularly the local authority) and serves any person with a learning difficulty who, in the opinion of the team, has needs which challenge local services and who requires a level and type of intervention beyond the scope of the local CMHT support.

Users gain access to the service by initial referral through their local CMHT, who conduct an initial assessment of need. The SPT staff are used as an extension of this process and are often called upon to implement structured interventions.

The service works flexibly around the needs of the people referred and aims to help them develop quality lifestyles which remove their need to challenge[22]. By complementing and expanding the work of local CMHTs, it seeks to extend specialist skills to the existing service system. Specific client needs are identified through detailed individual planning and the development of workable solutions compatible with community living.

The service excludes people whose primary problems are mental health related rather than learning difficulty based, except where assistance is provided as part of a shared package.It also excludes people who currently require a secure environment subject to Mental Health Act controls. However, no referral is actually excluded without at least an initial investigation and team consideration of resource availability.

There is no specified time limit for services, some clients have been with the service since it started, and each person once allocated to a team worker, is subject to regular review where objectives are set, resources allocated, or the case referred back to the CMHT. It is anticipated that future users will need support for an average of 12 to 18 months, but sometimes longer. When clients leave the service, the intention is that they will have a range of new and existing options. People who have not yet left the service are in some cases awaiting new resources.

KEY APPROACHES

Key features of the SPT's work include:

- careful initial and ongoing staff training which emphasises systematic behavioural record-keeping (stressing the importance of functional analysis), the use of recognised assessment methods that emphasise individuality (for example 'getting to know you', Bereweeke skill teaching system) and the use of behavioural management techniques;

- provision of a wide choice of age-appropriate, individual, integrated community activities (leisure, further education, supported work);

- careful investigation of any physical states (for example epilepsy) that may be implicated in the person's behaviour;

- individual face-to-face therapeutic counselling with clients by psychology, nursing, and occupational therapy staff;

- continuous application of measures of staff performance using a novel, participative system based on the 'five accomplishments';

- an individual plan for each client in which they participate as fully as possible;

- a quality assurance system;

- an awareness of clients' emotional needs, including provision of individual therapy when required (most clients have had seriously upsetting and psychologically damaging experiences in the past and after a while begin to reveal these to staff). The importance of staff support is recognised, as the more staff learn of a client's feelings, the greater their own need for therapeutic support.

The project's work is illustrated by the stories of Peter Thompson and Annette Williams.

> Peter is 21 years old, tall and fair. He had attended a well-staffed day centre in Sunderland since leaving school two years before. Although Peter appeared to enjoy the day centre, he often behaved in ways which were harmful to others. Some days he hit anyone who came near him and he often hit staff who tried to discourage him from practising rituals like flushing the toilets many times – even when others were using them. Peter weighed 15 stone and some other clients were frail and vulnerable. So staff reluctantly excluded him, the manager describing him as 'very dangerous'.
>
> At home, Peter's elderly parents had adapted the household to revolve around him, although they were unable to take him out because they could not control him. A cassette player was broken at least once a week because Peter would not be separated from it even when in the bath, and there were times when they felt that they had to take it from him. He frequently broke TV sets by throwing things at the screen.
>
> Peter sometimes stayed at a local hostel for a few days, where staff said, 'When Peter is there the tension rises in other residents. He is disruptive and has broken tape recorders and TV sets belonging to others'. As a result, he was then sent to a local NHS unit where staff had this to say: 'Peter is violent and will not be allowed to return here. He broke a TV set, putting himself at risk'.
>
> If this had happened two years earlier his exclusion from day and respite services would have meant that Peter's parents could not look after him at home. The only alternative would have been a long-stay hospital 25 miles away where he might have been admitted to a treatment ward along with his labels of 'violent' and 'dangerous'. Luckily Peter's exclusion came at a time when

the local NHS service was granted an experimental funding of £23,000 a year to set up alternative day care for two people barred from the usual services because of 'challenging behaviour'.

The alternative day service was designed to meet the individual's needs, so Peter's behaviour was carefully analysed by staff who got to know him well and who worked with his parents. Detailed records were kept. He was given opportunities to try new activities and encouraged to have a more responsible attitude to others. Unlike Peter's parents and the staff at the day centre these staff were able to insist on certain things (like only flushing the toilet once, and only when he had used it) because this was seen as the main focus of their day.

Within a number of weeks, there was a marked reduction in the number of times Peter hit people. As Peter's epilepsy was thought to be implicated in his occasionally unpredictable behaviour, he was referred to a consultant neurologist for treatment. (Previous records had not been able to show the difference between days when his behaviour was not under control, and the rest of the time when it was.)

Eight months after commencement of the individually-based day activities, Peter was taking part in outdoor activities, such as swimming, absailing, and canoeing. He had slimmed to eleven and a half stone and would take part in group activities without hitting people. He was able to travel frequently on a crowded bus and eat in pubs and cafes. At home, Peter's parents no longer had to buy a succession of TVs and tape recorders. He would take a library book to bed and leave his tape recorder in a drawer.

Although no direct work had been done with Peter at home, according to Peter's father, the new way of working appeared to have 'made him easier to live with – he seems to understand and respond to what we say to him, even though he still can't speak to us'. A significant landmark around this time was an invitation for the whole family to go out to tea – the first time this had happened for many years.

Almost two years on, Peter is still receiving alternative day services from the Special Projects Team. He attends a local college one day a week, and divides the rest of his time between supported employment and leisure activities in the community. He has a variety of hobbies, from carpet bowling to skiing, and has not hit anyone for months. He has a great love of music, especially classical music, and is learning to play the organ. Peter is also a member of the public library, and particularly enjoys books on nature. During the day, he has a number of preferred activities which include acting as delivery man, washing up and cleaning cars (as a paid job).

He has resumed regular stays at the NHS unit where he was previously excluded, and these are accomplished with minimal extra support. Peter and his family are moving towards the day when he will leave home permanently, but this will depend on money being available for staffing a house or flat. At present it is difficult to foresee how this can be obtained.

* * *

Annette Williams is 21 and has lived in a local mental handicap hostel since she was a child. When the time came for her to leave school, the staff there referred her to the Special Projects Team for alternative day services, saying that no ordinary day centre could possibly cope with her behaviour which was said to include 'running through plate glass windows', injuring herself and others, and damaging property.

Annette has now been receiving an individually-based day service for two years during which time none of the earlier behaviour has been seen. However, it has occurred at the hostel in the evenings. SPT staff were invited to make some changes in the routine at the hostel and were able to offer some practical assistance. Annette has decided that she wants to leave the hostel and live in a flat with support. Sceptics among the hostel staff are being rapidly persuaded by her enthusiasm for domestic activity and have agreed that she can move to a flat within the hostel – a solution which was previously thought to be beyond Annette's level of ability.

During the day Annette has a variety of activities including supported employment in a craft workshop and a drama course at the local college. She is now able to initiate conversation and ask questions, and has learned to tell trusted people when she feels upset or angry. Annette likes clothes and shopping, and particularly enjoys eating out and holidays abroad. Dry skiing is included among her hobbies, as are holidays abroad! Annette can be extremely helpful to others and is very loyal to those who treat her with dignity. She attends a local women's centre without an escort and is busy planning her future with enthusiasm.

In Annette's case the main contributions of the alternative service have been listening, getting to know her and being prepared to elicit and support her point of view.

MANAGEMENT AND SUPPORT

Support is provided to individual team members through a system of supervision and facilitation and regular support meetings are held where staff are able to share their feelings within a closed group. Above team level, support is provided by a general manager responsible for a geographical health care sector, though the team has a district-wide role.

All staff are given a structured induction/training programme, regular training workshops are held and some staff have also attended external workshops covering a variety of skill areas. A continuing inservice training programme exists which covers much of the team's work. A structured individual staff development process which will shape individual career profiles and form the basis of an effective training plan is also being developed.

EVALUATION AND MONITORING

The project employs a wide-ranging set of monitoring procedures. Each client served has a record kept by staff (and, where possible, themselves) of new skills, achievements and positive behaviour, photographs and video of progress, and reductions/changes in problem behaviour. Both individually tailored records and published checklists are used. All service users have an adaptive behaviour checklist filled in at initial referral and every six months thereafter. As an additional control, members of staff have filled these in for their own behaviour.

The alternative day service has developed its own quality monitoring system[23] which ensures that social and other opportunities are consistently available. A one-year study of the quality of life of five residents occupying a house taken over the SPT from the local authority is being carried out using three available published measures.

Finally, the first of a proposed series of questionnaires designed to elicit views of referrers and users has been sent to CMHT members. Data is being processed and fed back to respondents and management.

All the above work has been carried out using clinical psychologists' time to instigate and facilitate evaluation, and with the full co-operation of SPT staff (whose initial training emphasised the crucial importance of evaluation and record-keeping).

PROGRESS, PROBLEMS AND PRIORITIES

In order to establish the service, funders and other service providers had to be convinced about the merits of an alternative approach. From a local management perspective, problems which in the past had been dealt with by the long-stay hospital would now remain at local level. While for many service users this was a welcome change, it was regarded with some suspicion by those existing service providers with unsatisfactory staff-user ratios. The idea of moving away from a familiar (and, for some, popular) 'bricks and mortar' containment model also raised anxieties. On the financial side, joint finance arrangements had to be negotiated, and a local and regional commitment obtained to development of alternative services in the long term.

Plans are currently being made to increase the team's funding over the next few years. At present the service is unable to meet the needs of some users who require various kinds of residential accommodation (as in Peter's case). It also needs funding for individual packages of care. Currently the service is helping people who urgently need alternative living arrangements, but who are trapped in unrealistic situations (for example, in hospital or living at home with elderly/stressed families) despite evidence of cost-effective alternatives. A parallel expansion is required within the day services.

An options appraisal to clarify the service's future role within the wider system is planned for the near future.

A business plan is also in preparation,and it is hoped to be able to extend the service to other districts, and to the voluntary and private sector.

The SPT is encouraging other agencies to develop realistic alternatives for service users and with this in mind is seeking to strengthen its lines of communication inside and outside the organisation. Improved access to planning at a wider level would help to influence service needs by fostering 'user friendly' environments which minimise the need for users to challenge with their behaviour.

CHALLENGING BEHAVIOUR SERVICE, SOUTH GLAMORGAN

Jan Hill-Tout, Tony Doyle and David Allen

ORIGINS

If people with learning difficulties who present behavioural challenges are to live ordinary lives, comprehensive community-based networks and resources will be needed to support them. Introducing 'special' services in the absence of these essential foundations is likely to prove ineffectual. Rather than facilitating integration, they only serve to reinforce the isolation often experienced by people who display difficult behaviour.

An infrastructure of community-based services has been gradually developing in South Glamorgan over the last six or seven years. While there is now a solid base from which individual needs can be met, it has also become apparent that for some people this infrastructure is insufficient. These are people who continue to be excluded from day services and staffed houses, and for whom hospital admission or readmission is often sought as a last resort.

In 1988, the South Glamorgan Joint Management Board requested that a detailed programme of service development for people with challenging behaviours be drawn up. The planning process for the Challenging Behaviour Service (CBS) was underpinned by a key objective of the South Glamorgan strategic plan – to prevent inappropriate admissions to institutions, regardless of the challenge made to services. The need to develop a community service was also highlighted by an impending phased reduction in local hospital provision. It was agreed that the main function of such a service should be to support rather than supplant local services in the task of meeting the needs of people with behavioural challenges. Acknowledgement was also made that no single profession or service component holds the monopoly of skills in this area.

A clinical psychologist had already been appointed to work in this area, and the task of convening a working party to plan the new service was delegated to her. It soon became clear that, in spite of the county's official aims, there were various unofficial agendas which needed to be dealt with. There were at least three schools of thought about how to proceed. First, some people working within the community-based services felt that if they could be given the additional money that a specialist service would cost, they could do the job themselves. Secondly, there were others working within community services who wanted a specialist service to remove difficult clients, 'deal' with them, and bring them back when they were 'better'. Lastly, there was a strong professional lobby, particularly among the nursing staff, who felt that they had the experience and expertise in working with this client group and that they should therefore make the major contribution to any such service. This diversity of opinion was reflected as far as possible within the membership of the working party to try to ensure that there was some ownership of the resulting plan by all key stakeholders. Membership of the group consisted of the clinical psychologist, a consultant psychiatrist, and the assistant director of nursing (health authority), a CMHT co-ordinator and development officer (local authority), a representative of local voluntary agencies, and a member of the Parent's Federation.

The working party had a series of meetings over a number of months, considered documents produced by other services, discussed local issues and also bought in an external facilitator for half a day in an attempt to get some perspective on the data to hand. One of the first tasks assigned to each member of the working party was to contribute a description of one or two people they knew who presented challenges to services. The group then discussed what would be needed to support such a person. This highlighted the incredible diversity of need which existed within this small client group, and illustrated the fact that a multi-component service would be required to help meet their needs. It also helped to ensure that the group stuck to its task of producing a needs-led service plan.

DESCRIPTION OF SERVICE

The service plan was accepted by the Joint Management Board and subsequently funded via the All Wales Strategy. A second multi-agency working group was then established to work out in detail how the service would operate in practice. The service, which became fully operational in 1990, has four major components:

Specialist Advisers: a principal clinical psychologist and a clinical nurse specialist work full time with the CBS, and psychiatrists (who work on a geographical patch basis) are available as required. Additional professional expertise may also be brought in on a sessional basis when needed. The specialist advisers work primarily through staff and therefore invest a good deal of time in staff development work. This is mainly with carers of clients using the CBS but also, as a more general preventive measure, to other staff teams requesting basic training.

Additional Support Team: advice alone is often not enough. Implementing effective interventions in many service and domestic settings often proves difficult. While it may be possible to identify potentially helpful strategies, putting these into operation may be problematic because of insufficient carer time or, more commonly, insufficient carer support. The Additional Support Team was established to meet this need by being available to undertake 'hands on' work in any setting. The team's role is to help people change their approach by modelling appropriate attitudes, skills and responses. To date, the four team members have had to react to several crises but, as time progresses and the client group is more clearly defined, they are increasingly able to work in a preventive fashion. They keep in touch with clients and carers by working monthly shifts in relevant service settings and in this way can identify new or recurring problems at an early stage and take the necessary steps to try to avoid them developing into major crises.

The AST is employed by the NHS but does not come from any particular professional background, specific skill and expertise being regarded as more important than any particular training. Clinical direction of the AST is provided by the clinical psychologist.

Additional Support Money: it was acknowledged that in some circumstances it is additional rather than specialist support for an existing service which is needed. For example, helping to ease someone through a major life change, or during a period of acute disturbance when more people are needed to implement an already agreed intervention procedure. The CBS therefore has a short-term, ring-fenced budget which can be accessed whenever a community-based service needs to buy in this extra support. Long-term money is also available for special housing and day services for individuals whose service needs are such that they go beyond the level of resources usually available. This provision also enables the CBS to test out the service models for people who have presented long-term challenges to services.

Rowan House: Rowan House is a purpose-built, six-bed unit in the grounds of a large institution. Its role, when commissioned in 1988, was to admit and treat people who presented challenges. However, the unit rapidly began to experience many of the difficulties associated with facilities of this type[24, 25] and, in the light of current service developments, its role has had to change. Instead of being seen as a place where difficult behaviours would be 'cured' prior to the person returning to their original environment, the unit is now attempting to provide more of a back-up role for work undertaken within people's existing environments. It is anticipated that it will provide planned respite admissions for clients who cannot access ordinary respite facilities, and emergency admissions as part of a contingency arrangement in an agreed management plan. Rowan also provides a venue for assessment investigations which may be difficult to carry out within a person's normal setting (for example, drug reviews and 24-hour EEGs).

Referrals to the CBS are made (by telephone or letter) to a senior member of the service who then visits the referring agent and completes a screening form, which is then discussed by a multi-agency access panel. This screening form includes a check to ensure that other possible means of helping the person have been tried prior to the referral having been made (for example, referral to a CMHT psychologist). The service does not work with people under 16 as the county has a separate service for children with learning difficulties and challenging behaviour.

Referrals are made to the service, and not to any of its constituent parts, But once a client has been accepted, the CBS will negotiate with referring agents to put together a package of support which best meets the needs of the person concerned. This may include one or more of the four service components. A contract is negotiated making it absolutely clear what the CBS has undertaken to provide and what the continuing responsibilities of community-based services are. This helps to secure clear ownership of CBS involvement by the community-based service and the maximum opportunities for skill sharing.

KEY APPROACHES

Upon acceptance of a referral, detailed assessment and intervention then takes place at two levels. At a service level, an organisational assessment is carried out through discussions with key service providers which helps to ensure that there is some agreement of assets and deficiencies in the referring service. Areas covered include: uniformity of service aim; effectiveness of service structure and decision-making; communication; management process; and human resource capabilities. These discussions would reveal whether staff differed in their perception of the service objectives, if decision-making was confused, whether communication frequently broke down and if specific staff training was needed. Having identified any gaps, co-operative action can then be taken to fill them.

At the individual level, the four key approaches outlined by LaVigna and colleagues are used:[26].

- ecological assessment and intervention to determine and modify specific triggers in a person's environment;
- positive programming to help the person develop skills which they might find useful in controlling their difficult behaviour, thus enhancing their opportunities for community integration and participation;
- direct treatment (behavioural, psychotherapuetic, pharmacological, and so on) for any specific difficulty;
- reactive strategies to enable carers to cope with outbursts as quickly and effectively as possible.

The AST also compiles a management profile for each client every six months. This involves interviewing key care staff and recording the details of day-to-day management, individual idiosyncracies, and so on. In this way, when a member of staff leaves they do not take this information with them, and when relief staff are used they have reliable access to important data.

The CBS has recently been working with Jo Stephens and her service providers. Jo has severe learning difficulties, communication problems and a very assertive nature. The work that CBS did with Jo illustrates the approaches outlined above.

> Jo is in her late 20s. She is small, dark haired and very pretty. She is also very strong.
>
> Jo had lived in a small institution for about eight years and moved to an ordinary house when the institution closed. Much of the time, she was very pleasant to be with and had quite a mischievous sense of humour. At other times, though, she would have severe temper tantrums and a time-out room had been established for her which was said to have been effective in 'controlling' her behaviour.
>
> After the move to an ordinary house, Jo's behaviour worsened and proved difficult for staff to manage in more confined surroundings and without access to a time-out room. Her behaviours included grabbing people, hitting and punching them, and pulling them to the floor; a member of staff's ribs had been broken and, after only six weeks in the house, Jo's exclusion was a very real possibility. In the absence of any other alternatives, this would have meant hospitalisation.
>
> The CBS accepted a referral from Jo's carers and, as an immediate move, CBS staff worked a limited number of shifts at the house to help assess and stabilise the situation. The organisational assessment identified conflicting feelings within the staff group: they wanted to help Jo, but were also concerned for the other clients in the house. Staffing levels were also clearly inappropriate at certain times of the day, and some clarification was needed about the role of the senior care worker. Finally, assessment revealed that different staff had different conceptual models for dealing with behavioural challenges – ranging from being very firm to being very comforting. These issues were worked through with the staff team and senior management and agreement reached on remedial action. Feelings about excluding Jo from the house were openly discussed and a final negotiated settlement was reached whereby staff agreed to suffer short-term conflict in order to achieve long-term change for Jo, on condition that they were given adequate support, resources and training.

At an individual level, the hands-on staff came together with the CBS to identify key triggers associated with Jo's behaviour. These were not immediately obvious, but discussions facilitated by the CBS helped staff to look at what was happening and to see the causes. Teaching staff to look at incidents in terms of their triggers and consequences was most helpful here. It enabled them to explain and hence understand Jo's behaviour and therefore be in a position to do something about it. For Jo the triggers included sudden noises, lack of sleep, noisy meal times, too many people and, most significantly, unclear and inconsistent staff approaches. Once the staff could see what was happening the solutions were relatively simple. When staff were being inconsistent, for example, this was highlighted by the group, and very clear boundaries were agreed and their implementation monitored. The main focus for positive programming where Jo was concerned involved strategies for improving her communication skills, since staff identified this as her greatest need. Staff agreed that they should listen more to what Jo was trying to say and also introduce some symbolic systems (in this case Makaton) to aid communication.

Direct treatment did not feature in the intervention, but reactive strategies did. There was a very real need to protect staff and other residents during aggressive outbursts and a non-painful method of minimal restraint was designed and implemented. This was used in preference to medication, and was a crucial factor in enabling staff to cope with Jo in the short term while longer-term strategies were given a chance to work. In the intervening four months the use of restraint has dropped to zero. Staff are much more confident and can now spot situations and defuse them before they blow up. Jo is also getting much better at asking for what she wants in more usual ways. A number of more qualitative changes have also occurred in Jo's life. She has taken on board responsibility for a number of jobs in and around the house and is very proud of this responsibility. She goes out far more, and is gradually expanding her range of social and leisure activities.

A member of the AST has now been assigned to Jo and works a shift in the house every three to four weeks. The psychologist attends their staff meetings monthly and visits the house monthly to read and graph up behavioural records.

MANAGEMENT AND SUPPORT

To try to ensure that all components of the CBS work together, a manager was appointed for the whole service. His role involves agreeing and implementing common aims and practices between the different components, administration of the service budgets, and the supervision of service staff. AST members are directly accountable to the manager, while staff from different professional backgrounds such as the clinical nurse specialist are managed with co-management agreements.[27]

Multi-agency support for the service is reflected in its access panel where, in addition to the service manager, psychologist and clinical nurse specialist, a consultant psychiatrist, a CMHT co-ordinator, and a voluntary services representative are involved. As well being accountable to NHS managers, the service reports to the Joint Management Board on a six-monthly basis.

EVALUATION

The service is being evaluated by the Mental Handicap in Wales Applied Research Unit in a study which involves producing more detailed descriptions of what characteristics lead to clients being regarded as a challenge to services, and measuring the impact of the service in terms of client behaviour and improved quality of life outcomes. Assessing the impact on client behaviour is not easy; most of the service's clients do not get referred, get treated, and get better. On the whole they have longstanding unmet needs that take years to meet. Acute treatment models therefore have little or no validity.

The service itself is currently in the process of conducting a cost-benefit analysis of the work of the Additional Support Team. Initial data suggest that its input is considerably cheaper than hospital admission while, at the same time, producing more constructive outcomes both for the people concerned and their carers. Working in this way is not easy, however, and skilled personnel are required to undertake it. Four residential schemes will be established over the next two years, the costs of which compare favourably with those of private care facilities (which are likely to offer the only real alternative for accommodating the people concerned once the local hospital facility is no longer available). While the costs may be comparable, the proposed new services will offer far greater potential for meeting the needs of the people involved than private hospital placement.

PROGRESS, PROBLEMS AND PRIORITIES

Two main concerns affected the CBS during the initial planning and development phase: first, the above mentioned need to devote time to exploring differing perceptions of what type of service was required; and, second, combining some pre-existing service components (Rowan House, the psychology post) with new service elements (the Additional Support Team, ring-fenced budgets). So far, it seems to have been possible to address both these issues to the general satisfaction of all parties. However, this is a process rather than a finite piece of work and further development needs to take place in this area.

The success of all services of this kind ultimately depends on other agencies and staff being able to utilise the support which is on offer. Experience to date suggests that often what needs to be done to help people referred to the CBS is fairly easy to find out, but enabling services to deliver what is required is a little harder. Building effective working relationships with these services is therefore an ongoing task. It is hoped that the sucesses to date will be 'contagious' within community-based services. But it is already clear that different parts of the service within the county do not seem to be learning from each others' mistakes – they seem to have to make them themselves first! The dissemination of these experiences throughout the community dissemination of these experiences throughout the community service is a major responsibility and one which so far the CBS has not addressed adequately.

During the first full year of operation, three potentially problematic trends have emerged in referral patterns to the service. First, in the absence of adequate clinical psychology inputs to the local CMHTs, there has been a tendency to refer people with less severe behavioural difficulties to the service and, although a limited amount of preventive work is undertaken with those individuals whose behaviour has the capacity for becoming more difficult if help is not provided, most referrals of this type are not accepted. Second, the same service deficit is making it difficult to hand back full responsibility for supporting successful interventions to local services, thus increasing the risk of the service silting up. Third, the service tends to receive frequent referrals for more able clients whose primary problems seem to be psychiatric rather than behavioural. Where the CBS feels that it has something to offer such clients, inputs are provided as part of a joint package of care with the psychiatric sector. But the main motive behind such referrals is often the reluctance of the general psychiatric services to work with such clients.

The fact that services for people with learning difficulties in Wales currently have access to increased financial resources is clearly also an important factor in precipitating such referrals. For people with more severe learning difficulties who display challenging behaviour and have an identified superimposed psychiatric disorder, a limited number of creative packages of care have been produced. These have involved making use of beds within the psychiatric ward of a large general hospital earmarked for use by people with learning difficulties. As an integral component of care plans, potential admission to these beds is negotiated as part of a set of contingencies which may need to be brought into play should a deterioration in a person's psychiatric state occur.

The basic service model appears to have most of the components required to achieve the service objectives, one main deficit being respite care. Respite can be provided within a client's own home via use of the additional support monies. But despite the development of good links with some of the short-stay facilities within the county, the only real option for out-of-home respite for many people remains the hospital. This function will have to be reprovided within a community setting as the hospital service continues to shrink.

CHAPTER 6

OVERVIEW

KEY INGREDIENTS OF EFFECTIVE SERVICES

The projects described here have all developed innovative ways of working with people with learning difficulties and challenging behaviours. While each scheme is different, some common themes seem to have contributed to this success and these are discussed under the following headings:

*Shared value base

*Organisational issues

*Therapeutic approaches

The project descriptions also present an honest picture of the difficulties. We also discuss these.

SHARED VALUE BASE

The projects are all based on the same core values set out in *An Ordinary Life* and reiterated in *Facing the Challenge*. Clear commitments were made to providing services in ways which recognise that people with challenging behaviour have an equal value, that they have a right and a need to live and participate fully in their local community, and that services are planned around individuals.

Several schemes had also adopted O'Brien's 'five accomplishments'[13] – a practical application of the 'ordinary life' values.

- Community Presence: people with learning difficulties have the right to live and spend their time in the community rather than in residential, day or leisure facilities which segregate them from other members of society.
- Relationships: living in the community is not enough. People with learning difficulties also need help and encouragement to mix with other non-disabled people in their daily lives.
- Choice: people with learning difficulties often have limited power to make choices and safeguard their own interests. A high-quality service will give priority to enhancing the choices available to people and protecting their human rights generally.
- Competence: in order for people with learning difficulties to live a full and rewarding life in their local community, many will require help to learn more skills and to have access to a wider range of activities.
- Respect: people with learning difficulties often have an undeservedly bad reputation and are regarded as second class citizens. Services can play an important part in helping people enjoy the same status as other valued members of society.

Applying these values to people whose behaviour poses major challenges to services is not easy, but all the services discussed here were striving to do so.

ORGANISATIONAL ISSUES

Local factors

Changes in service provision (for example, availability of hospital beds, funding arrangements, reduction in short-term care facilities) often provided 'windows' of opportunity for developing the type of services described here. Each project was based on an assessment of local conditions and the need for change in local services. An increasing focus on individually-planned service development had frequently revealed unmet needs and created a shared dissatisfaction with existing services. Service plans were therefore a response to local requirements.

Getting going

In most examples, the impetus for planning new services came from a small group of people acting as 'change agents' – individuals who were able to 'exploit' the above conditions. This echoes the Audit Commission's report, *Making a Reality of Community Care*[28], which noted that 'Probably the most important factor common to all the successful community care initiatives ... was the presence of people with vision, determination and stamina who had pushed development along. It was always possible to trace initiatives back to one or two people who would not take no for an answer.'

Getting support

Local 'champions of change' may be an important catalyst for service development, but developing a larger 'critical mass' of support is equally important. People leading the planning for new services had usually enlisted the help of key individuals and in several schemes, formal or informal, collaboration had developed between statutory and/or voluntary agencies. A strong, broadly-based lobby of support may be crucial in securing funding.

Planners – particularly non-clinicians – may have little or no experience of this kind of work. Making proposals more personal, by including brief 'pen portraits' of potential clients, their lives and the challenges they present as used by people planning the South Glamorgan day service described in Chapter 4 and Sheffield Health Authority's working party of 1988[29], gives a more lucid, practical and lifelike feel to the issues.

Although local plans can sometimes be approved relatively easily, in many areas, securing a regional commitment to a clear and acceptable long-term view of the future of services to people with challenging behaviour has been important. However, regional commitment remains unclear in many places.

Owning responsibility

Various agencies have been reluctant to accept responsibility for meeting the needs of individuals with challenging behaviour. The 'problem' has often been handed over by sending individuals to out-of-area agencies – special and private hospitals, prisons or sense units. All the schemes described here are committed to meeting the needs of individuals with challenging behaviour within their own area and continuing to try to provide for them as long as it is appropriate and possible for them to do so.

Innovation and flexibility

Moves to establish community-based services for individuals with challenging behaviours tend to provoke fear or uncertainty – a resistance to leaving behind established and familiar models of service delivery.

Clients' past histories and the mythologies which have built up around them increase the anxieties of planners, staff, carers, relatives and, not least, clients themselves. Moving away from the traditional practices of containment and risk-avoidance in managing challenging behaviour, towards models that promote community presence and participation can feel risky, challenging!

In *Facing the Challenge* the rationale for the use of the term 'challenging behaviour' was clearly laid out:

'... such behaviours represent challenges to services rather than problems that individuals with learning difficulties in some way carry round with them. If services could rise to the 'challenge' of dealing with these behaviours they would cease to be 'problems'. The term challenging behaviour places the focus of discussion on services rather than on the individuals showing the behaviours.'

All the schemes demonstrated a willingness to look beyond models based on containment. There is a clear shift away from the historical emphasis on 'special' buildings and a focus is on skilled staff working alongside people with challenging behaviour in their homes, jobs or day activities, and leisure time. Greater flexibility in funding, allowing for greater creativity in service development may be a key element here.

A number of models have emerged in response to, and based on largely identified individual needs. In keeping with this philosophy, models can also be flexible, changing in accordance with the changing needs of the individual. An excellent example of this is provided by work with Mary from the Bristol-Avon services.

Relationships with other services

Once schemes had become operational, clear links were established with other relevant agencies (for example, CMHTs) likely to have a major impact on the success of the projects. Considerable care was often taken to involve other services in screening referrals – an approach which can help reduce the feelings of threat or exclusiveness which the creation of a specialist service can generate.

Including representatives of referring agencies in management support groups can also reinforce feelings of ownership in jointly planned developments. (This in turn will help protect the scheme should it come under threat of closure at a later date.)

Individualisation

In all the projects, individual planning provided the underlying structure for identifying service and therapeutic goals for people. Clients' progress can be regularly monitored by looking at people's strengths, needs and goals in a systematic, structured way. As such, they form a natural vehicle to enable goals relating to challenging behaviour to be worked on and reviewed.

Securing funding

This is often the biggest initial obstacle to be overcome. Pressure to meet the needs of challenging individuals is not always matched by a readiness to make adequate resources available. Agencies which are willing to spend large sums of money on private out-of-district arrangements are often unwilling to invest similar sums in developing the competence of their own services. Although services to people with challenging behaviour will all be expensive, the relative costs of the alternative models of care (for example, special or private hospitals or secure units or community care/day services) are unlikely to be very different. The difference lies in what these services are likely to accomplish for their users (that is, containment or development).

Heightened national awareness and a developing body of expertise, combined with tighter control of increasingly scarce resources, had led many areas to establish 'pilot schemes' or projects, making creative use of existing resources. For example: the use of redundant staff accommodation; the creation of self-financing business ventures; outdoor pursuits. In many areas, specialist advice is also obtained from existing services such as psychiatry or social work using staff on a sessional or peripatetic basis.

In order to create an adequate budget, revenue may need to be drawn from a number of sources, but it is essential to identify separate budget headings for the service rather than simply relying on budgetary slack or underspending elsewhere in the agency. This is particularly relevant to health authorities as they start to establish contracts between purchaser and provider with their various units, with specialist services being bought and sold between districts and regions.

Difficulties can arise when an individual requires resources from different agencies - for example, day services or paramedical expertise for someone in a residential service. The degree to which professional bodies accept responsibility for addressing the needs of people with challenging behaviours varies considerably. In light of the impending changes within the health and local authorities, the management of challenging behaviours is likely to be seen as one of the core responsibilities of the health service. As this publication has demonstrated, however, effective models of service delivery require considerable inter-agency collaboration and, therefore, a collective ownership of the problem and a willingness on the part of these agencies to fund adequate and varied resources.

Staffing

A team approach was implicit or explicit in all the developments, with professional and 'hands-on' staff from many backgrounds working in a wide range of settings. This demonstrates that no one professional group holds a monopoly on the skills required to provide effective services to people with challenging behaviour.

Staff training has a high profile in several projects, with training schemes using a combination of elements which include operating within the chosen value bases; accurate behavioural recording; assessing and empathising; counselling; understanding normalisation principles; and carrying out positive behavioural interventions. In some instances, training is linked to pay-related competence levels for staff. Training is carried out either through inservice training or established courses (for example, WEA and ENB in Avon).

Management and support

Projects had a variety of management and administration structures ranging from the creation of separate management units to the use of existing systems. In some cases, administrative or clinical expertise is delivered on a peripatetic basis. The common factor, however, is a clear focus on responsibility, ensuring that services are not isolated from effective managerial and professional support – a problem cited by Emerson and colleagues[26] in their evaluation of community services.

Monitoring and evaluation

All the services described here are clearly goal-directed, both at the service and individual planning level; staff support and review mechanisms also appear clear and positive. Most projects have a strong commitment to monitoring their effectiveness through an 'action research' approach. In addition, several projects are or have been formally evaluated.

In a comparison document to this publication, Emerson and colleagues[31] offer a guide to evaluating services for people with learning difficulties and challenging behaviour. As they point out, without sound evaluative data, decisions about initial or future funding for innovative services will often be made for political or administrative reasons. Emerson and his colleagues specify three areas on which an evaluation should concentrate, and suggests a number of key questions for each of these.

1. Process of service delivery
    - Who are the people served?
    - What service actually gets delivered?
    - What does the service cost?
    - How is the service managed?
2. User outcomes
    - Is there a reduction in the severity of users' challenging behaviour?
    - Are there important changes in the users' quality of life?
3. Service outcomes
    - Does the service lead to fewer people being excluded from local services?
    - What is the impact of the service upon people with learning difficulties with whom the user lives or works?
    - What impact does the service have upon carers?
    - What is the impact of the service upon opinions in the local county?

Several of the service evaluations mentioned above are considering these issues, although the main focus is on service and user outcomes.

All service models for people with learning difficulties and challenging behaviour should be evaluated. At present, though, only the more innovative services of the type described here seem to be subject to close scrutiny; the effectiveness of more traditional institutional 'solutions' is apparently taken for granted.

THERAPEUTIC APPROACHES

Assessment

Individualised assessment is viewed as essential. A range of approaches is employed which includes both behavioural recording and systematic assessment measures using standard plans and approaches (for example, adaptive behaviour scales and functional analysis) as well as the 'softer', more subjective, methods (for example the 'getting to know you' assessment[32] which try to understand what life might be like 'standing in the client's shoes.'

In line with the interactional definition of challenging behaviour, the South Glamorgan Challenging Behaviour Service also places considerable emphasis on conducting assessments of the organisational environments in which clients live and work.

Combining opportunity with technology

Effective services for people with challenging behaviours will have several components – a place to live, meaningful activities during the day, a range of social activities, and so on. Support of this kind is fundamental to ensuring a good quality of life but, on its own, will often have a minimal impact on behaviour. Many people with challenging behaviour also require specific help, focusing on their particular needs.

Combining technology with values

Most of the services described here use a structured behavioural approach as part of their work, having moved away from approaches where the sole aim is to reduce problem behaviour. Behavioural change is now seen as one of a broad range of desirable outcomes leading to a fulfilled life.

Many of the services use the values and principles described above to underpin their therapeutic work with clients. Far from being incompatible, as is sometimes suggested, a strong value base and effective therapeutic methods (for example, a behavioural approach) are both necessary components of effective services for people with challenging behaviours. Emerson and McGill[33] provide a useful discussion of the relationship between normalisation and behavioural approaches.

'In many respects applied behaviour analysis represents a technology bereft of any inherent value base in deciding upon goal selection and procedural acceptability...'Social role valorization (i.e. normalisation) on the other hand represents a conceptual framework bereft of specific implementative technology to effect individual behaviour change.'

Positive methods

Historically, services have tended to 'control' challenging behaviour, whether by restraint, medication, or psychological methods. However, services based on respect for the individual focuses much more on understanding the person and valuing them while working out what needs they have and how these might be met. This also leads us to question what message the person might be communicating about their needs through their challenging behaviour. The approach then becomes one of understanding, teaching, empathising, valuing, enabling and supporting rather than controlling, restricting or detaining – a shift which is evident in the services described here.

The moral, technical, ethical and legal issues raised by the use of punitive or aversive methods are extremely emotive. Whole books have been devoted to their discussion (for example, Guess et al[34], Repp and Singh[35]) and no attempt will therefore be made to review these issues here. Suffice to say that these methods do not, by their very nature, value and respect the person and none of the schemes discussed here use therapeutic methods based on punitive techniques.

Broad base of interventions

The schemes generally favour what might loosely be called a person-centred approach, combining aspects of the behavioural approach such as goal-setting and programming with counselling-related approaches – the ability to emphasise, support and recognise the integrity of the individual. This is highlighted, for example, in the work of the Sunderland project where accurate behavioural recording and intensive structured programmes are used alongside one-to-one counselling.

COMMON PROBLEMS

Organisational resistance

Schemes which service clients in their usual environment (rather than creating a separate facility) meet with resistance often from staff or carers who not only find the challenging behaviours unacceptable but do not believe they have a role to play in managing these problems. Sensitive educative and supportive work is required to help staff to understand that they can play a keen role in the person's network, and to ensure that they have ready access to clear lines of support or emergency assistance should the need arise.

Funding

Time-limited or project-based funding that is cobbled together on an *ad hoc* basis is clearly in jeopardy in the current financial climate. For the future of a service to be secure, its funding basis must be secure. Clearly identified budgets with a budget-holder should be established, but creativity and flexibility in management should be safeguarded. The Suffolk and South Glamorgan schemes are examples of flexible and innovative budgetary allocations; clear limits and accountability for spending are combined with the opportunity to use resources in a creative and responsive manner, though in one case there was considerable initial anxiety.

Unmet needs

One or two schemes mention problems arising from a lack of resources in other parts of the service system and this may preclude necessary developments in day service or residential support. However, when necessary resources are available, there remain a number of individuals for whom the challenge is difficult to meet. It would be unwise to make generalisations from such limited numbers but, not surprisingly, these people are likely to be those who display low frequency, but highly dangerous behaviours such as fire-setting, severe physical violence or inappropriate sexual behaviours.

These behaviours need not present an impossible challenge to services but added weight does need to be given to clear and detailed planning, swift and effective emergency back-up, the establishment of possible fall-back positions, and staff support.

People with dual diagnosis

Many people who display challenging behaviour will also have been diagnosed as suffering from psychiatric disorder. Good psychiatric support is therefore likely to be an important component of effective care plans for some individuals.

Responsibility for providing a service to such clients is often unclear, particularly in relation to those with more mild learning difficulties. With the exception of South East Thames RHA, where the Mental Impairment Evaluation and Treatment Service (MIETS) unit was created to serve this group, no clear policies appear to exist for such clients. Those that fall between the 'two stools' of mental health and mental handicap services often suffer as a result. For those with more severe learning difficulties, differential diagnosis of mental illness is difficult and contributes to the inadequate support often received.

Significant staff training in the causes, presentation and management of mental illness is needed. However, many staff and clinicians find it difficult to assimilate a model of mental illness into models of behavioural disturbance and of learning difficulties. Tension often exists between professionals who are seen to support a medical model and those who, for example, promote the understanding of behaviour disturbance as aberrant or maladaptive communication. While differing approaches to diagnosis and management are of great value in achieving a holistic understanding of the needs of clients, dogma is not. It is essential, therefore, that professionals integrate their views into a coherent management plan that is understood by, and has the support of, all staff and carers.

Where individuals are detained under the Mental Health Act, this may affect the type of service that can be provided. 'Patients' are generally required to be resident in hospital beds – unless subject to guardianship orders where place of residence and access to treatment and follow-up may be otherwise specified. Qualified nursing staff may also be needed to implement the requirements of the Act, thus significantly increasing staffing costs, as in the example of the Sheffield residential service. In forensic cases, certain requirements can be imposed by the courts or the Home Office, which although aimed at reducing the risks of re-offending and 'dangerousness', and thus potentially helpful, can often be at variance with the approach to care developed by the schemes illustrated here.

'Silting up'

Several schemes mentioned a lack of 'throughput'. while it had been anticipated that individual change could be achieved with relatively limited interventions, it had become clear that long-term support was often required. This is not really surprising given the long standing nature of many challenging behaviours. As the Special Development Team states the issue then is who should provide this support. The majority of specialist services described here aim to increase the competence of community services to support people with challenging behaviour. It is too early to assess the likely outcome of this objective, but it is clear that effective long-term support of people with challenging behaviour requires a solid infrastructure of basic community supports.

REPLICATION

The schemes described here are essentially demonstration projects, often fairly small-scale initiatives seeking to show what can be achieved in community services for people with challenging behaviour. One of the main aims of this publication has been to share their strengths and weaknesses more widely. However, this chapter is not intended to provide a complete recipe for successful innovations elsewhere.

Generalising from results of specifically funded programmes carried out by teams of highly motivated innovators to a model that can be replicated more extensively can be problematic[36]. Attempts at replication will inevitably lack both the necessary resources and pioneer spirit of the original work. Patton[37] suggests that it is often the very 'smallness' of demonstration projects which is the key to their success and if this is the case they will, by definition, be incapable of replication on a larger scale.

Attempts to replicate demonstration services may also sometimes fail to produce high quality results because of an over-emphasis on replication of structural, rather than functional, programme components; too much time is spent trying to copy the exact shape of the service and not enough on copying what it actually does.

Demonstration projects are usually based on an analysis of prevailing conditions and resources in the geographical area in which they are to be developed and replications also need to be tailored to match local resource patterns if they are to be effective.

CHAPTER 7

MEETING THE CHALLENGE

In the four years since *Facing the Challenge* appeared, substantial progress has been made in developing community services for people with learning difficulties and challenging behaviour. In a relatively short space of time, we have moved from essentially theoretical discussions about possible 'ordinary life' service models to reviewing a number of actual services in operation.

A considerable amount of new knowledge has already been gained from setting up these services, both in terms of their essential ingredients and their likely problems. While constituting a powerful illustration of what can be achieved, these 'warts and all' accounts also demonstrate the commitment required to translate good ideas into good practice.

Those areas starting to consider services for people with challenging behaviour will find the services described here offer a rich source of ideas. We hope that they will provide an additional impetus to people already going through the processes of service planning and development. We also hope that the reporting of these schemes will help 'bridge the gap' as we await the publication of their evaluations.

The increasing number of hospital closure programmes is leading many more areas to consider possible service options for people with challenging behaviour. So the question is not whether or not to invest money in this group of people – a 'do nothing' option does not really exist. Once large institutions close, some alternative form of provision must be made available and the only real choice is what type of service to provide.

By referring people on to 'specialist' services which remove the 'problem', services may become increasingly less tolerant of difficult behaviour. In the long run, this option may prove more expensive, and inadvertently contribute to the retention of current institutions or even encourage the development of new ones.

It is important that innovative services generate local support for their ideas. One way of doing this is through contact with other similar schemes around the country. It can sometimes be helpful to show information on what is being done elsewhere, to arrange a presentation, or to send key people on a visit. However, most new schemes have very little time to spend seeing visitors or giving presentations.

The projects described here only represent a sample of the schemes which have been established in the United Kingdom. The information exchange document[2] (available from the King's Fund Centre) lists many more existing or planned initiatives. Readers may also be able to identify useful contacts.

While an impressive start has been made, we still have a long way to go. *Meeting the Challenge* represents an early stage in an ongoing development process. Its value is that it illustrates what can be achieved in an area where many felt 'ordinary life' principles could not apply.

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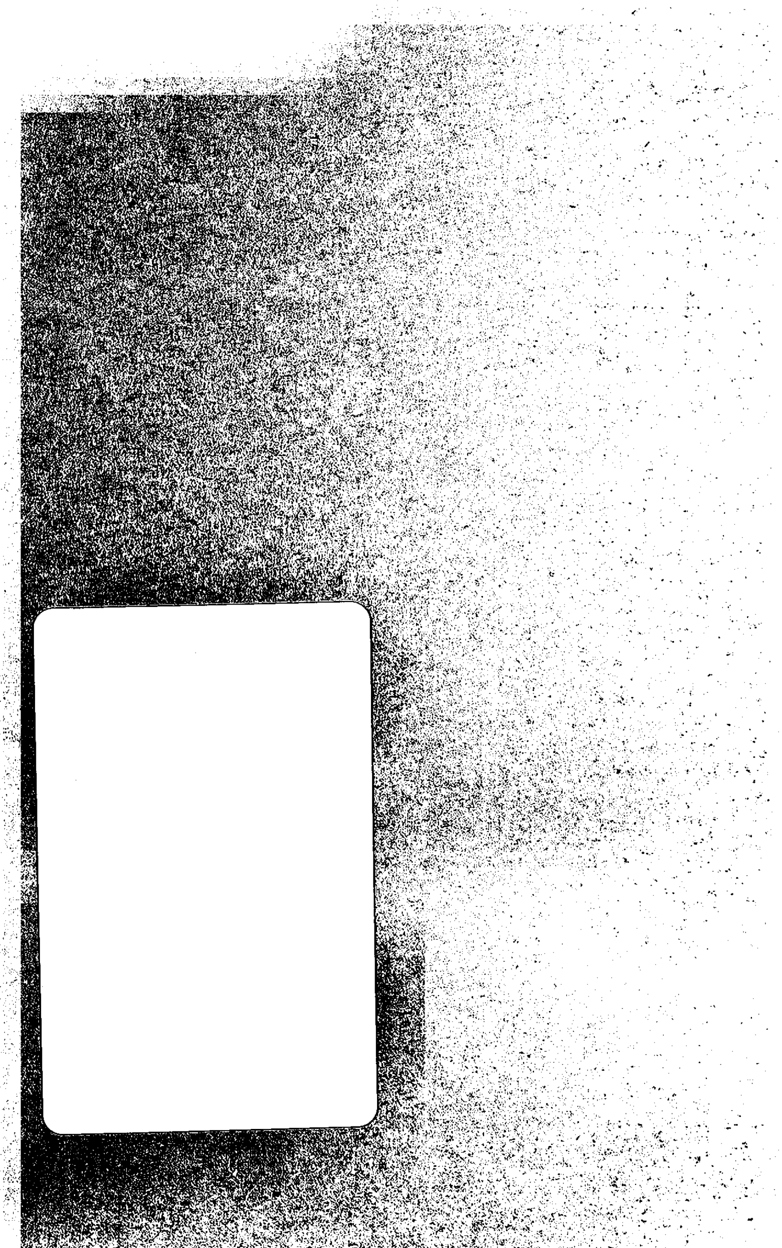

MEETING THE CHALLENGE

Some UK perspectives on community services for people with learning difficulties and challenging behaviour

Edited by David Allen, Roger Banks and Susan Staite

This document is the latest in the 'An Ordinary Life' series, produced by the King's Fund Centre. It follows on from *Facing The Challenge* and *Evaluating The Challenge*, and gives practical examples of services around the country for people with challenging behaviour. As well as describing the services it looks at the key issues of:

- management and support, including funding
- evaluation and monitoring
- progress, problems and priorities

To quote Derek Thomas, Director, National Development Team:

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