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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

KING'S FUND CENTRE

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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:

'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.'

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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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