Challenging Behaviour in People with Learning Disabilities

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1997
For my parents and for Dyfi, Caitlin, Abigail

& Madelaine
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PERSONAL STUDY PLAN

Name: David Gerwyn Allen

Date: 16th October 1996

Date of registration: 2nd October, 1996

Registration Number: 3608433

OVERALL OBJECTIVE

- To produce an integrated portfolio which investigates aspects of challenging behaviour in people with learning disabilities.

CLINICAL DOSSIER

Aims:

- To demonstrate professional competence
- To enhance professional competence by critical reflection on practice

Proposed content:
A reflective and empirical review of my professional practice since 1989, focusing on my role in developing, managing, and directing a new community service for people with learning disabilities and challenging behaviour. The review will make reference to interventions at the client, systems, and organisational level. It will be presented in three main sections concerned with the psychologist's role in shaping service structures, clinical approaches, and clinical outcomes. The service climate and policy framework within which the service evolved will also be described. Reference will be made throughout to empirical evaluations of the service conducted both by the psychologist and by independent researchers.

ACADEMIC DOSSIER

Aims:

- To enhance my personal knowledge of two specialist areas of clinical psychology
- To improve skills in the critical evaluation of the relationship between theory & practice
Proposed Content:

Two 4,500 reviews will be produced on the following topics:

- The nature, treatment & management of physical aggression in people with learning disabilities.

Physical aggression is one of the most challenging forms of problem behaviour in people with learning difficulties. Historically, very little attention has been paid to this type of behaviour in this client group. More recently, a limited number of studies have looked at specific areas of interest regarding this topic, but no comprehensive reviews are currently available which cover epidemiology, reactive management, and psychological treatment. The present critical review will cover all three areas, and also relate research findings on aggression in persons with learning disabilities to comparable work on other client groups. The review will aim to produce a synthesis of good practice points from the available literature.

- Carers' understanding & responses towards challenging behaviour in people with learning disabilities.

Recent years have seen researchers attempting to gain a greater understanding of how natural and paid carers construe challenging behaviour in children and adults with learning disabilities. Several investigative strands are evident. These include essentially
qualitative research on the impact of caring for a person with challenging behaviour in family settings, research exploring the formal and informal models of challenging behaviour utilised by various groups of paid carers, and studies involving responses to general and specific stresses (e.g. the consequences of assault). The review will analyse the available literature from each of these areas and look at the implications for training and supporting carers working with this client group.

RESEARCH DOSSIER

Aim:

- To increase research competence

Study 1: Survival in the community: The prediction of placement outcome for mentally ill and mentally handicapped clients in local authority community residential facilities

Originally submitted for the British Psychological Society Diploma in Clinical Psychology and included here as per the regulations for the degree of PsychD.
Study 2:

- Success and Failure in Community Placements for People with Learning Disabilities and Challenging Behaviour: an analysis of key variables

Research Supervisors:

Dr. Eithne Buchanan-Barrow and Dr. Glynis Laws

Background & Relevance:

Previous research has shown a clear, positive relationship between the presence of challenging behaviour and the risk of institutionalisation and re-institutionalisation for people with learning disabilities (see Emerson, 1995). Much of this research was, however, carried out at a time when both the availability and sophistication of behavioural support to people living in the community was limited. In the last decade, there has been a significant growth in this area, and there is an increasing body of research to show that the provision of positive behavioural support can have beneficial outcomes for even the most severe forms of challenging behaviour in a variety of community settings.
Locally, specialist community support services have been available for over six years and have been shown to be effective both in clinical and cost-benefit terms. Despite the availability of these services, a small number of individuals continue to suffer placement breakdown and continue to be admitted to long-stay institutional care.

It is unclear at present what factors determine the successful maintenance of community placements, but it is apparent that the mere presence of challenging behaviour itself, as suggested by the early research, is not a sufficient condition for placement breakdown. Recent work on the determinants of high quality outcomes in community residential services for people with learning disability in general (Emerson & Hatton, 1996) suggests that three factors (the availability of appropriate resources, the internal organisation, and the quality of leadership) are important. It is therefore possible that these factors have as much influence on community placement success or failure as the nature and severity of an individual's challenging behaviour.

The present study will examine both the personal and service setting characteristics of people with learning disability and challenging behaviour successfully and unsuccessfully supported in community settings in an effort to produce a more sophisticated analysis of factors relevant to placement maintenance and breakdown.
Methodology:

i. Design

A natural group comparison design will be employed to study potential differences between groups of people with learning disability & challenging behaviour successfully maintained in community settings and those suffering placement breakdown.

ii. Subjects

The groups will be self-selecting and defined as follows:

**Maintained Group**: People who have received intensive input from a specialist challenging behaviour community support team over a six year period and who have remained in their community placement during this time.

**Breakdown Group**: People from within the same geographical patch covered by the specialist support team who have experienced permanent exclusion from their original place of residence followed by a stay of six months or more in an institutional setting within the same six year time frame.
iii. Data

Three forms of data will be collected on each individual:

a. Personal characteristics

Data on the behavioural, psychiatric & adaptive characteristics of both groups are available via the following measures: The Psychopathology Instrument for Mentally Retarded Adults, the Aberrant Behaviour Checklist, the Disability rating Scale and the Adaptive Behaviour Scale (part 1). All these scales are proven research instruments.

b. Resources, internal organisation & management features of service settings.

Data will be collected retrospectively on the service settings of both groups (the ongoing service setting for the maintained group and the pre-institutional service setting for the breakdown group). This will involve a novel research tool devised for the study and based on the key service areas hypothesised to be of importance by Emerson & Hatton (1996) and constructed with reference to the literature on organisational psychology.
c. Nature of support services received

Data will be abstracted from case files on the volume and nature of specialist support services available to both groups.

iv. Data Analysis

Mann Whitney U tests will be utilised to analyse differences between the independent groups. More sophisticated statistical techniques may be employed if the data are sufficiently robust; expert advice will be sought on this point.
Clinical Dossier
1. INTRODUCTION

This dossier will provide a description of my clinical practice in the field of learning disabilities between the years 1989-1997. It will focus on my role in developing a specialist service for adults displaying severely challenging behaviours (such as physical aggression, destructiveness and self-injury) within the former county of South Glamorgan. The dossier is in five major sections. The first section outlines the major setting conditions which influenced this project; these are considered at a national policy level, a local policy level, and at a personal level. The second section defines the service development task, and the third section outlines how the task requirements were met both in structural and functional terms. A brief synopsis of outcomes from the project will then be provided before a concluding section describes the personal and organisational lessons learnt.

2. SETTING CONDITIONS

2.1 GENERAL

I entered the profession of clinical psychology at a time when an increasingly accelerated programme of hospital closure was starting to take effect. From the 1970s onwards, an all inclusive model of community care for all people with learning disabilities had been strongly espoused by influential independent bodies such as the King's Fund Centre (1980) and the Campaign for Mentally Handicapped People (Tyne,
1981). Despite more equivocal official policy statements (DHSS, 1971; 1989) and seemingly endless reorganisations within both health and social care services, large scale changes in provision became increasingly evident during the 1980s (Mansell & Ericsson, 1996).

As a general rule, earlier efforts at resettling people with learning disabilities from long-stay institutions had focused on those individuals who were more able and who presented with less complex support needs. This 'creaming off' process served to increase the percentage of highly dependent residents within residual hospital populations, thus making the completion of the deinstitutionalisation process a more complex task.

As will be described in detail in the research dossier, the presence of severe challenging behaviours places an individual with learning disabilities at high risk of institutional admission and re-admission. Many of the individuals within this residual group could thus be expected to present with such behaviours. To achieve successful hospital closure, an alternative infrastructure of community support would therefore need to be developed which allowed for such individuals to be successfully resettled, and which prevented their readmission to hospital and the admission of new long-stay residents.

In the mid-1980s, traditional thinking on alternatives to hospital care focused largely on the development of smaller scale treatment units, or on new 'home like' residential services developed on existing hospital campuses. While such units attracted
considerable criticism (Vischer, 1982; Keene & James, 1986; Newman & Emerson, 1991; Emerson, Beasley, Offord & Mansell, 1992), few examples of alternative community based models were in evidence at this time.

2.2 LOCAL DEVELOPMENTS

Although the All Wales Strategy (1983) had provided a broad template for the development of community services for people with learning disabilities in Wales over a ten year period, it had failed to provide any guidance on the future of the long-stay hospitals. This was rectified by a Welsh Office circular entitled 'The Changing Role of Specialist Mental Handicap Hospitals in Wales' (Welsh Office, 1995) which required relevant agencies to formulate plans for the replacement of the 'social care' elements of their current services, and to plan for the reprovision of any specialist health care functions such as psychiatric in-patient services.

The local response to the circular within South Glamorgan outlined an initially modest resettlement programme for Ely Hospital, together with the provision of a range of facility-based community services to support adults with challenging behaviours and people experiencing social crises (such as the illness or death of a key carer). The latter were felt necessary because the earlier formation of a network of patch-based community support teams (an amalgam of health, social service and voluntary sector staff which will be described in more detail in section 2.3) had proved insufficient to stem the flow of both short and long-term hospital admissions of people in these
groups. The plans for both the adult challenging behaviour service and the emergency intervention service were subsequently re-drawn and, instead of being based on residential facilities, were re-fashioned into more flexible community models. The service for people with challenging behaviour was planned to come on line in 1990 and, when the position of service manager became available in late 1989, I decided to apply and was subsequently offered the post.

2.3 KEY PERSONAL INFLUENCES

2.3.1 General Introduction

Within this section, I will seek to outline some of the key influences which shaped my approach to the task of developing the community based challenging behaviour service.

My work experience prior to undertaking clinical training was almost exclusively with people with learning disabilities. Most of this experience was gained within an institution which some years earlier had gained considerable national notoriety following a Parliamentary inquiry into allegations of ill-treatment (Martin, 1984). Although substantial environmental improvements had been made to the institution in the interim, and many of the 'old guard' staff had left, the standards of care were such that one could be left in no doubt that there had to be a better way of caring for people with learning disabilities than that offered by long-stay hospitals.
Despite the exposure to other client groups which I subsequently gained during clinical training, this early experience was sufficient to convince me that this was the client group with whom I wished to specialise. Immediately after qualifying as a clinical psychologist, I therefore spent four years, first as a basic grade and then as a senior psychologist, in a newly established community support team for people with learning disabilities in South Glamorgan. Although community team models have been criticised within the profession (Allen, 1987; Ancio & Kirkpatrick, 1990; Watson, 1990), this period provided an invaluable insight into the complexities of developing community services, and into the strengths and pitfalls of multi-disciplinary working. The former included chances for the improved co-ordination of multi-professional inputs, skill sharing, and single points of access for consumers; the latter concerned the potential for the excessive role-blurring and subsequent de-skilling of team members through an over-emphasis on generic team tasks, problems in exerting management control over professionals who each have separate professional lines of accountability, and the over-democratisation of teams resulting in poor decision making processes. This experience was reinforced during a further two year period which I then spent in a principal post as part of a four-person team charged with developing the resettlement programme for Ely Hospital.

The work in both posts was extremely varied, but the majority of people on my individual clinical caseload were individuals who presented with varying degrees of difficult behaviour. While the window of opportunity offered by the All Wales
Strategy had enabled some extremely creative service responses to be made to the needs of specific individuals, these responses were sporadic, and it was readily apparent that, on their own, the existing community services were not capable of maintaining all challenging clients within the community. As mentioned earlier, this proved to be the case as admissions to Ely remained largely unaffected by the presence of the new community services.

With hindsight, this was perhaps not surprising. At the time there was little local experience of managing severe challenging behaviours outside of hospital, and the historical tradition was to bar entry to community services for people with special behavioural needs, or to exclude them once such needs first became apparent.

There were probably five key critical experiences which shaped my personal views and approaches at this time. These were: personal experience gained in developing services (especially services for individuals with complex needs), being involved in a national ‘policy shaping’ initiative for people with learning disabilities and challenging behaviour, gaining direct experience of a non-aversive approach to working with challenging behaviour, having an opportunity to research the effectiveness of a traditional model of providing care to people who challenge, and, finally, the opportunity to study for a Masters degree in learning disabilities. Each of these areas will be discussed in turn.
2.3.1 Service Development

While in the community support team, I had gained some experience of developing specialist day services for people with complex needs (profound learning disabilities and additional physical disabilities, sensory deficits, or challenging behaviour). Traditionally, services for this diverse group have been provided within special care units attached to adult training or social education centres. A local shortage in the availability of places within such units, together with a general dissatisfaction with the quality of the support which they provided, prompted us to develop an entirely new service for people in this group who were currently without any form of day time support (Allen, Gillard, Watkins & Norman, 1989; Allen & Williams, 1991). Its most unusual feature, in view of the severity of disability of its users, was that the service was entirely community based.

By the creative use of high-levels of flexible staffing and the use of naturalistic community opportunities for activity within locations and educational establishments available to the general public, the service was able to demonstrate significantly superior outcomes for its users as compared to a matched control group attending a special care unit within a local adult training centre (Allen, 1990). These included higher rates of participation in age appropriate activities, higher rates of community-based activities, greater individualisation of planning goals, and considerably more comprehensive menus of activity.
My involvement with this project was a formative experience in that it involved designing a service from first principles, advocating on behalf of the potential service users, bidding for funds, designing staff specifications and appointing staff, supporting the running of the project once it became operational, and evaluating its impact. While the service produced extremely positive outcomes - a visiting delegation from the Welsh Office felt that the service came closer to meeting the aspirations of the Strategy than any other that they had visited in the Principality - it also taught me some important lessons about the frailty of community services (concerning, for example, the heightened impact of staff sickness on a non-building based service) and the extent to which they were dependent on key individuals for their results. These lessons were to prove extremely useful when developing the community challenging behaviour service.

2.3.2 Policy Development

In late 1985, I was fortunate enough to become involved in a King's Fund Centre working party which was set up with the aim of producing some good practice guidelines for the development of community services for people with severely challenging behaviours. The group involved, either directly or indirectly, most of the leading clinicians, academics, and service providers working in this area at the time. I therefore had the benefit of being exposed to the latest thinking in this field, and of being heavily involved in the preparation of the working party's recommendations.
The resulting project paper, 'Facing the Challenge' (Blunden & Allen, 1987), was extensively cited and, despite being superseded by the Mansell Report (Department of Health, 1993), it probably remains one of the key U.K. references in this area. The report's adoption of the term 'challenging behaviour' and of the definition proposed by the Special Development Team at the University of Kent (Emerson, Barret, Bell, Cummings, McCool, Toogood, & Mansell, 1987) undoubtedly helped promote the widespread use of the term throughout the United Kingdom.

Because of the absence of effective community models at this time, the advice and guidance offered in the document was to a large extent theoretical. It nevertheless provided a clear template for how community services for this group should develop and operate. Amongst its many recommendations, three were probably paramount. These were that:

- Services for people with learning disabilities and challenging behaviour should be values led and that they should aspire to the same quality of life standards which applied to all people

- That intervention approaches should be 'constructional' (that is, they should be based on determining behavioural function and helping individuals develop positive alternatives to their challenging behaviour)
That the development of specialist peripatetic support teams to support challenging individuals within natural community settings should be the service option of choice.

As mentioned in Section 2.1, there was very much a vacuum in existence with regard to developing community services for this group, and one of the undoubted reasons for the success of this report was that it helped fill that vacuum.

2.3.3 Positive Behavioural Support

The third key influence concerned the development of the constructional approaches referred to above. At the end of the 1980s, the acrimonious debate about the use of punitive behavioural procedures was gaining momentum (Repp & Singh, 1990), and an embryonic movement for the use of non-aversive approaches to behaviour change had begun to emerge.

At the forefront of this movement was Gary LaVigna and his colleagues from the Institute for Applied Behaviour Analysis in Los Angeles. LaVigna's model (LaVigna & Donnellan, 1986; Donnellan, LaVigna, Negri-Shoultz, & Fassbender, 1988) rejected the use of all aversive behavioural approaches, was explicitly based on the functional analysis of behaviour, and contained the following four components:
• Ecological change strategies - short-term behavioural control strategies which involved the removal or elimination of identified environmental triggers for challenging behaviour

• Positive Programming - longer-term skill teaching interventions designed to teach individuals skills which were functionally equivalent or functionally similar to their challenging behaviours (and which thus could produce the same outcomes for the person without their having to resort to behaving in challenging ways)

• Focused interventions - strategies focused directly on challenging behaviours which could be used to achieve more rapid control (such as the differential reinforcement of alternative or incompatible behaviours)

• Reactive strategies - strategies to be employed by carers should challenging behaviours occur in order to regain behavioural control.

The model in many ways represented a re-packaging of traditional antecedent and reinforcement based behavioural change strategies; these were updated, and presented in a values-led format which met the demands of a speciality which had been heavily influenced by the philosophy of normalisation in all its various guises.

Via my connections with the King's Fund, I was able to negotiate for LaVigna to run a workshop on his approach in Cardiff on his first visit to the U.K. in 1988. I was
therefore able to gain first hand experience of a therapeutic model which seemed to embody all the requirements for technical support outlined by the King's Fund group. This transatlantic influence was hugely important, as the historical failure of behavioural technology to take root within the U.K. again meant that there were few national examples of good practice which could be studied.

2.3.4 Research into Service Design

The fourth influence was a research project conducted by a clinical psychology trainee whom I supervised. The study was an evaluation of the impact of a special residential treatment unit which had been opened on the Ely campus in 1988. Its results confirmed in practice many of the hypothesised problems with such facilities (Hoefkens & Allen, 1990), most notably the tendency for behavioural recovery to occur upon discharge as a consequence of a failure to consider the contingencies in operation in the person's normal setting, the inability to discharge residents upon the completion of treatment, and the ability to provide help to only a small proportion of those in need of intervention at any one time (all of which are discussed in more detail within the research dossier). It was therefore apparent that a service model of this type would be unlikely to meet the support requirements for challenging individuals within the county.
2.3.5 Personal Development

The final influence was a more general one. Between 1987-1989, I studied on a part-time basis for the Degree of Master of Arts in the Applied Psychology of Learning Disabilities at the University of Kent. This course was designed specifically for senior managers and planners working in learning disability services, and covered topics such as the management of organisational change, service design, case management, and learning disability policy.

As well as placing me in close contact with key personnel involved in the Special Development Team project (essentially a specialist resettlement project for people with severe challenging behaviours, and one of the few 'new wave' services to be actually up and running at this time), this experience helped me gain a deeper understanding of organisational aspects of delivering services to this client group. The latter were largely derived from detailed case analyses of innovative services in learning disabilities (such as the Wessex scheme, the closure of the Pennhurst institution in the U.S.A, and NIMROD). These analyses involved an assessment of key factors influencing organisational change, their influence on service design, and the relationship between aims, design and outcomes.
2.4 Section Summary

Through a variety of means, I was therefore able to gain some experience of service development for people with challenging behaviour, some insight into more strategic service development issues, and a grounding in the best contemporary approaches to behavioural intervention. I therefore felt that I was reasonably placed to develop the new service.

3. THE SERVICE TASK

Detailed planning for the challenging behaviour service was achieved via a multi-agency working group which contained representatives from the key stakeholders in the local delivery of the All Wales Strategy (social services, health services, and the voluntary sector). This broad based approach to planning helped ensure that there was a commitment to the development of the service throughout the county which would not have been the case had the project been an exclusively health-led initiative.

The main conclusions of the planning group's report were that:

- The new challenging behaviour service should be community based

- Its central aim should be to help avoid the inappropriate admission of people with challenging behaviour to institutional care. This would be achieved by
providing high levels of support within the environments in which problems were occurring.

- The service would act as a secondary source of support to the community teams which, in turn, would retain primary responsibility for the provision of front-line services.

- The service should consist of a small team of 'therapeutic consultants', a peripatetic 'satellite' team, and a series of ring-fenced, flexible service budgets which could be used to facilitate the development of individualised services.

- The special residential treatment unit at Ely Hospital (described in 2.3.4 above) should also continue to serve this client group although it would remain outside of the management structure of the service.

- Access to the service should be via a multi-agency panel who would screen each referral and assess the likely level of provision required to meet identified needs.

At the time, a non-building based service model was viewed as being fairly radical, and the project was therefore funded only for a three year trial period. If it could prove its clinical effectiveness and demonstrate cost-benefits within this period, then substantive funding would be made available.
Both the specification for the service and the job description for the manager were somewhat vague. The former dealt far more with service structure (what the service should look like) rather than service function (what it should actually do). As originally conceived, the post was a general management job. It was open to people from any relevant background, and not conceived as a position for a psychologist. However, I felt that my personal background enabled me to develop the core role and to alter its focus from general management to clinical management (that is, management which was driven by the desire to develop clinically effective procedures, and not simply concerned with the overseeing of resources and their distribution). In this sense, the lack of clarity regarding roles and expectations was an advantage in that it allowed me to develop the model in a fashion which was in keeping with my previous experience and to focus on the service's functional aspects. The fact that I carried a clinical caseload also helped ensure that my management decisions were based on experience of delivering the service in practice.

As the service had a three year time frame to demonstrate its worth, I was on a similar contract. There was therefore a powerful incentive to get things moving very quickly. In the next section, I will describe how I developed the role in terms of establishing the basic service structure and its clinical model.
4. PROCESSES AND OUTCOMES

This section will consider the structural and functional development of the service in turn.

4.1 STRUCTURAL SERVICE DEVELOPMENT

The major components of the Intensive Support Service (as the project became known) were in place and operational within seven months of my taking up post. The following synopsis briefly describes the role of each component:

- **Specialist Advisors**

  I chose this title in preference to the somewhat grander term of 'therapeutic consultants' contained in the initial proposals. The staff concerned were a clinical nurse specialist and clinical psychologist who, along with myself, carried senior case responsibility for all individuals supported by the service. The advisors worked essentially via other staff using a triadic model (Tharp & Wetzel, 1969), but also provided individual and group therapy as required.
- **Additional Support Team**

  This 'satellite team' of initially four staff were available to work directly alongside carers supporting challenging individuals. Their brief was to provide practical help to these enable carers to translate interventions into practice. Along with the specialist advisors, they were also extensively involved in delivering staff training.

- **Additional Support Budgets**

  The service operated a variety of flexible budgets which could be deployed on a short-term basis (for example, to provide additional staffing in services at times of crises or to buy in therapy skills which were not available within the team) or in the medium to longer-term (for example, providing funding for day service or residential schemes).

  As stated earlier, the service would operate at a tertiary care level, providing additional support to community teams whenever they felt that they were unable to meet the need of challenging individuals on their caseload. Referrals to the service could only be made through the teams and, while the service assumed clinical responsibility for individuals accepted onto its caseload, case management responsibility remained with the community support team at all times in order to encourage a continued feeling of ownership.
The model was obviously heavily influenced by the King's Fund paper (notably with regard to its emphasis on the peripatetic team model and the use positive behavioural approaches) and also, from my personal perspective, by the earlier writings of psychologists who had argued convincingly that the profession could only maximise its impact and meet the need for psychological support by training non-psychologists to deliver psychological skills (Tharp & Wetzel, 1969; Hawks, 1971). A central aim of the service was therefore to develop the competence of front-line carers in order to increase their capacity to manage severely challenging behaviours. This had major implications for the person specifications drawn up for staff working in the service (the people selected would be required to display a wide variety of skills - such as being good at direct client work, carer training, behavioural assessment, and so on), and for the management of the environments in which the service would work (in that part of the service's role would involve helping these environments develop the capacity to implement potentially complex interventions). The difficulties surrounding this model of working are discussed in the second review within the academic dossier.

As stated above, it was not proposed within the original project design that the pre-existing special residential unit should be under my control. I argued, successfully, that it should on the basis that the effective co-ordination of the work of the unit and the new community service could only be achieved if they were both managed via a single individual. This would allow for a consistent therapeutic style to be developed across community and institutional settings, help ensure that admissions were for bona fide reasons (that is, they were to address identified health gain targets and not simply
to cover deficiencies in social care services), and that discharges were well-planned and appropriately supported both by the community support team and Intensive Support Service staff. Its role was also re-defined in order to take account of the criticisms of behavioural units described above. The unit was now viewed as providing a 'safety net' for the work undertaken within the community (and not as a major centre for behavioural intervention as had been originally intended). The final configuration of the service was therefore as shown in the following chart:

**Figure 1. Organisational Structure of the Intensive Support Service**

![Organisational Structure Diagram]

Effective co-management contracts (Ovretveit, 1986) were negotiated for the clinical psychologist and clinical nurse specialist working in the service; these specified that their professional management remained in the hands of their existing line managers.
while their operational management was under my control. Although they had been full partners in drawing up the service plan which specified that their inputs into the service should be managed by the service manager, in practice local psychiatrists viewed the prospect of ceding any management authority to a psychologist as an anathema. Co-management contracts were therefore not agreed regarding medical input although, after some initial teething troubles, very good working relationships were generally established and psychiatric inputs were agreed on a case-by-case basis.

Recruitment to the Additional Support Team posts was initially very hard, as there were few staff available who could meet the multiple requirements of the job (that is, being very skilled at 'hands on' work with clients and staff, being effective teachers who could use a variety of teaching modalities, being good at group work, and reliable 'team players'). Over the years, as we have worked with more and more carers, we have now built our own pool of staff who could do this work, and regularly suffer from an embarrassment of riches on the rare occasions that a post becomes available (rates of turnover within the service being generally very low). By 1997, the service employed almost fifty staff and operated a total budget of over £800,000. On average, forty-five clients are on the case load at any one time.

As the service's flexible budgets would mostly be spent supporting social care situations, I negotiated that the monies concerned should remain in the social services budget for the sake of administrative ease (the local authority having already developed mechanisms for the operation of such budgets). This created the somewhat
unusual situation of having an NHS manager act as budget-holder for a social services budget. This situation worked extremely well, and the fact that it was possible in the first instance bears testimony to the excellent inter-agency relationships which existed at that time.

The multi-agency access panel (which assessed the appropriateness of each referral to the service) was politically invaluable in the early days as it allowed the agencies who had invested time in the service design to have a continued stake in how it operated in practice, and also helped ensure that primary responsibility for supporting challenging individuals remained with the front-line community services.

Initial calculations of likely service need were based on epidemiological data. While this was helpful in the short-term, it is a generally an unreliable means of assessing local need as it is well recognised that significant variations in prevalence rates may be evident between different localities. As the service became more established, it was possible to plan on the basis of actual client need; plans for the future development of the service have therefore been constructed on the basis of identifying all clients who have received input from the service to date, those who will require input during resettlement, those children with chronic behavioural difficulties who will require support once they reach adulthood, and those people from the locality who are currently inappropriately placed outside of the county and who need to be brought back home.
4.2 FUNCTIONAL SERVICE DEVELOPMENT (CLINICAL APPROACHES)

I determined very early on that the LaVigna positive behavioural model would provide the therapeutic framework for the service. As well as providing the clear assessment and intervention guidelines which are essential when working with highly complex behavioural challenges, the model was attractive in that its broad base allowed for a wide diversity of potential environmental, psychiatric, cognitive, and neurological factors to be taken into account. It offered a clear systems approach which attempted to include in the assessment process the full range of intra-personal and environmental variables which might be implicated in a person's challenging behaviour (Clements, 1992; McGill, 1993). Despite its unashamedly behavioural structure, it was therefore appealing to the range of professionals whose skills would be required if clients referred to the service were to receive comprehensive assessments and interventions.

My aim was to provide unity and coherence across the service via the adoption of the best available therapeutic model. Staff working in the service itself were therefore required to complete a self-instructional training system based on LaVigna's work as a condition of their probationary periods. This required staff to read materials and complete self-test exercises, carry out practical assignments (for example, completing a functional analysis on a service client), and then, at the end of each major unit, running a seminar for more junior staff on the material contained in the unit. The service model was therefore taught in detail in induction, and then reinforced via individual client care.
plans and in monthly clinical supervision, thus providing a solid clinical base for the service.

The weakness in the model was in the area of reactive management, where there seemed to be very little readily available information on how to physically manage serious episodes of aggression, destructiveness and self-injury. Given that, as is discussed in the first academic review, physical aggression is often the major reason why people with learning disabilities and challenging behaviour are referred for specialist support, this was a major concern. This lead to the service developing its own approach in this area (Doyle, Dunn, Allen & Hadley, 1996). The major focus of the training model was preventative, in that carers were taught the importance of creating service climates which reduced the likelihood of aggressive behaviour in the first instance. Other topics included recognising the early stages of aggression, defusion and distraction techniques, self-protective physical techniques, and a non-aggressive, non-painful method of minimal restraint. The success of this approach was such that it has subsequently been adopted by a wide range of agencies for people with learning disabilities from across the United Kingdom.

Under my direction, the clinical team developed the concept of behavioural support profiles for the clients referred to the service. We were only too acutely aware of the lack of impact that training direct care staff in general behavioural principles could have, and our training was therefore delivered on an almost entirely individualised basis. The profiles were essentially individual instruction manuals based on LaVigna's
approach which gave staff detailed information on exactly how to work with individuals in their care, and training was in each case profile-lead. The term 'support profile' was also chosen in preference to 'behavioural programme' in an effort to avoid the negative connotations which the latter had attracted. The emphasis in each profile was very much on proactive, preventative approaches, but each profile also contained emergency management plans for responding to out of control behaviour.

In the next section, I will provide some outline details on the results of research into the service's clinical effectiveness.

5. CLINICAL OUTCOMES

Given the general absence of supporting research data for new models of community services for people with challenging behaviour, evaluating the impact of the service was particularly important. Listed below is a brief summary of studies published to date:

- Lowe, Felce & Blackman (1996) reported that the service was effective in bringing about changes in reported levels of challenging behaviour, mental health problems, adaptive skills and levels of programmed activity. A second specialist service from another locality studied by these authors failed to achieve any significant clinical impact for its users. It was felt that major differences in how the two services were managed, employed different therapeutic models, monitored
and assessed outcomes, and selected their staff may have accounted for these differences in clinical effectiveness.

- Allen & Lowe (1995) showed that the costs of community intervention for the service compared favourably with the costs of more traditional institutional solutions.

- Allen & Kerr (1994) found that there was a significant overlap in clinical need between two theoretically distinct groups of clients described as challenging behaviour and dual diagnoses (of learning disability and mental health problems) and made recommendations for a unified multi-disciplinary approach to assessment and intervention.

- A further publication from the King's Fund (Allen, Banks & Staite, 1991) highlighted the experience of the service and other U.K. initiatives.

- Allen, MacDonald, Dunn & Doyle (1997) showed how the introduction of training in preventing and managing aggressive behaviour lead to a reduction in the rates of use of restraint and emergency medication, and in staff and client injuries within the residential treatment unit.
Allen (in press) reported on the impact of the service in reducing short and long-stay admissions to institutional care but that it had not proved possible to entirely eradicate the latter.

The study presented within the research dossier examines this last point, and may therefore be viewed as a further contribution to the portfolio of research which has been developed on the service.

In addition to the external evaluation of the service conducted by Lowe et al (1996), the progress of the service was subject to independent scrutiny by a multi-agency team led by the social services department, part of which involved a separate audit of cost-benefit. The overwhelmingly positive results of these various evaluations resulted in the service being granted substantive funding in 1992.

6. CONCLUSIONS & REFLECTIONS

The Intensive Support Service has undoubtedly been a successful project. In addition to being reflected in research results, this is supported by formal and informal feedback from local agencies which clearly value the support which it offers. The service has also endured over a seven and a half year period, something which is in itself no mean feat given the hostile climate in which many such services operate.
From my personal perspective, one of the central contentions of this reflective analysis is that the combination of clinical experience and the opportunity to manage a service were critical to the outcomes obtained. I will examine this assertion in this concluding section. I will also consider things which could have been done differently, and outline future service plans.

5.1 The Interface between Clinical Psychology and Management

The first point to note is that taking up a senior management post makes one fully appreciate how badly we prepare staff for management in our services. This situation has been summed up very well by LaVigna and colleagues:

'In the human services field ...we are promoted to our supervisory, managerial, and administrative positions not so much because of our abilities to produce results in this managerial sense, but because of what we know and because we have excelled in our different disciplines...We have been neither trained nor prepared for the essential role of management'.

(LaVigna, Willis, Shaull, Abedi & Sweitzer, 1994, p.2)

I certainly had not been prepared for the 'essential role of management'. As significant numbers of psychologists moved into general management posts in the late 1980s, the profession certainly became increasingly aware of the need to prepare staff for high
level management. However, the kind of grounding in management skills offered by, for example, the Division of Clinical Psychology's White Hart Management Course, is available only to a few. It is hard to say how it would have affected my approach to the job had I received such training, but I am sure that somehow it would.

Despite this lack of specific preparation, the task which I was given was essentially concerned with complex organisational change, and it has been clearly recognised that clinical psychology training, in theory at least, provides us with many skills which are relevant to this task. According to Brunning, Cole & Huffington (1990) these skills include insights into group work, team building, supporting staff at times of change, and assisting in the development of new organisational structures.

Management for me provided both the opportunity and authority to quickly put into practice what might otherwise only have been achieved through protracted negotiation (and quite probably not even then). I feel that my background as a clinical psychologist was critical to the development of service, perhaps most notably in the development of its coherent therapeutic model and in the development of a novel approach to the management of aggressive behaviour. The service would undoubtedly would have looked and functioned very differently had it been, for example, psychiatrist or nurse lead. Management in this clinical context also offered the opportunity to develop, via the feedback loop which was created between clinical practice and academic research, the 'scientist-practitioner' model to which
psychologists were encouraged to aspire to in the late 1970s (Davidson, 1977) and which still has great validity and relevance.

5.2 Unfinished Business

There are four areas in which, with hindsight, a greater or a different investment of time might have produced better results:

- Although there is no substantial empirical support for the long-term effectiveness of early intervention for challenging behaviour, it would seem logical that the greatest investment of time should be spent on trying to prevent the development of chronic behavioural difficulties through pro-active intervention with children and adolescents. This is not the case in Cardiff at present, there being a far greater investment in adult services. There is a separate specialist support service for children and, while there are strong links between the adults and the child service, these have yet to develop into an effective clinical partnership.

- While the standard of behavioural practice within the service is high and continues to improve, it could be better. The service is extremely competent at devising ecological and reactive interventions, but is less competent at implementing constructional programmes of skill development (such as functional
communication training) and at contingency management approaches (such as differential reinforcement).

- The individualised approach to clinical intervention has been an undoubted success, and is in keeping with the highest contemporary standards. We have, however, perhaps failed to take on a more strategic role in providing more general training in challenging behaviour for community service providers.

- Although the service has demonstrated that its clinical interventions are cost-beneficial, we have recent evidence that our influence over our health commissioning team is weak. Despite repeated proclamations about their desire to purchase cost-effective services for this client group, in practice they appear to be interested only in cost, and at present seem to be very keen to invest substantial sums of money in independent sector services of dubious quality. They appear to have developed what the Mansell report (1993) described as a 'remover' approach to purchasing services. Although all existing components of the Intensive Support Service will continue to be funded, plans for a small number of dedicated community residential schemes run by the service which had initially been supported by the commissioners now seem unlikely to reach fruition.

5.3 Future Directions

The service's immediate task for the future is to assist in the completion of the closure of Ely Hospital. Only ninety-nine people now remain in this institution which was once
'home' to over six hundred and fifty. This task will be completed within the next eighteen months, and the service has a central role to play in achieving an effective closure.

The service will continue to support many of these individuals for long periods following their resettlement, but the completion of this phase of the programme will free up valuable staff resources for other activities. High on the agenda is the development of a series of short courses and diploma courses in challenging behaviour designed for front-line staff and middle managers in community services. These will help to address both the internal and external training concerns raised above. The courses will be run under the auspices of the Welsh Centre for Learning Disabilities, which is an amalgam of clinical and academic staff based on the North American University Affiliated Programme model (Eberly, Eklund & Simon, 1986). Planned further development of the service as a training and consultancy agency is therefore well underway.

Whether it is possible to influence the further development of children's services, and of specialist residential services for adults against the ever shifting sands of health and social care policy, remains to be seen. If it is not, then we run the risk of being witness to the development of new smaller scale, but functionally identical, services to those which we are currently seeking to replace.
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Academic Dossier
The Nature, Treatment and Management of Physical Aggression in People with Learning Disabilities

1. Introduction

Aggression is generally regarded as one of the most perplexing and stressful forms of challenging behaviour shown by people with learning disabilities (Burke, Burke & Forehand, 1987; Dura, Mulick & Myers, 1988; Tutton, Wynne-Willson & Piachaud, 1990). It can act as a major barrier to community placement, is frequently cited as a reason for placement breakdown, and increases the risk of failure in competitive employment (Gardner & Moffat, 1990). Aggression may also result in increased service costs as a result of high staff sickness and turnover rates, increased support & supervision costs, and potential compensatory payments to injured staff (Sigafoos, Elkins, Kerr & Attwood, 1994). Not surprisingly, aggression tends to be the most common form of challenging behaviour referred to specialist behavioural support teams and treatment units (Maguire & Piersel, 1992). The present review will examine the prevalence, causation, treatment and management of this form of challenging behaviour.

2. Epidemiology

As with any epidemiological research, comparisons between studies are made difficult because of variations in the form of prevalence investigated and also because of
variations in the operational definitions of key concepts. Thus, some available studies have concentrated entirely on inter-personal assault, while others have also included both verbal aggression and destruction of objects in their definition of 'aggression'. Hence, differences in terminology can in themselves explain apparent differences in reported rates of aggressive behaviours. Prevalence may also vary according to the level of behavioural severity required to qualify for inclusion in a study sample (e.g., aggression which causes no injury versus aggression which results in tissue damage), the age profile of the sample (e.g. children versus adults), and the location of the study (e.g. institutional versus community based) (Borthwick-Duffy, 1994).

Despite these difficulties, it is nevertheless possible to abstract some key overall findings from the literature:

- The prevalence rate for aggressive behaviour in this client group appears to vary between 2-20% depending on the sampling procedures adopted (Quine, 1986; Harris & Russell, 1989; Sigafoos et al, 1994; Borthwick-Duffy, 1994)

- Higher rates will generally be found in males (Quine, 1986; Harris & Russell, 1989; Borthwick-Duffy, 1994; Davidson, Cain, Sloane-Reeves, Speybroeck, Segel, Gutkin, Quijano, Kramer, Porter, Shoham & Goldstein, 1994)

- Higher rates will be found in institutional settings than in the community (Eyman & Call, 1977, Harris & Russell, 1989; Borthwick-Duffy, 1994)
Rates tend to increase with increasing severity of disability (Borthwick-Duffy, 1994; Davidson et al, 1994.)

Although aggression may start early in life, rates tend to peak around late adolescence (presumably as the individuals concerned attain adult size and strength) (Koller, Richardson, Katz & McClaren, 1983; Harris & Russell, 1993; Davidson et al, 1994).

Aggression tends to co-exist with other forms of challenging behaviour (Emerson, Cummings, Barrett, Hughes, McCool & Toogood, 1988; Harris & Russell, 1989; Borthwick-Duffy, 1994; Sigafoos et al, 1994) and is also associated with the presence of mental health problems (Borthwick-Duffy, 1994)

Aggression tends to remain stable over time (Raynes & Sumpton, 1985; Lowe & Felce, 1995; Kiernan & Alborz, 1996)

Much aggression appears to be episodic (i.e. it is of comparatively low frequency), but is potentially of high intensity (Harris & Russell, 1989; Sigafoos et al, 1994)

In general, there appears to be a clear correlation between ratings of frequency and severity (Harris & Russell, 1989; Lowe & Felce, 1995); that is, aggression
that occurs frequently is likely to be rated as posing more severe management problems.

- Whilst most incidents of aggression seem to involve single punches, slaps & kicks, weapons may be used by between 17-29% of individuals who present with aggressive behaviours (Emerson et al, 1988; Harris & Russell, 1989; Sigafoos et al, 1994). The use of weapons in this population may not therefore appear to be as low as has sometimes been claimed (see, for example, McDonnell & Sturmey, 1993a). No information is generally available in the literature on the types of weapons used; this is a potentially serious omission as there are obviously significant differences in the risks posed by, for example, a small household object being thrown in anger and the malicious use of a knife.

In the absence of any universal measurement criteria, clinicians and researchers are required to piece together a picture of the problems presented by persons with learning disabilities who are aggressive on the basis of the above studies. Although huge individual variations will exist, the research suggests that a typical individual within this group is therefore likely to be male, to present with long-term problems of aggression which peak in the late teens, to be at risk of institutionalisation, to present with fairly low frequency (but possibly high intensity aggression), to present with multiple challenging behaviours, and to attack others primarily using kicks, slaps, and punches.
3. Aetiology

3.1 Motivational Differences in Aggression

A number of authors have attempted to differentiate between various forms of aggressive behaviour. Moyer (1987), for example, describes four types of aggression; instrumental aggression (which is goal directed, incentive led, and typically associated with low arousal), irritable aggression (which arises out of frustration and is associated with anger), sexual aggression (which is associated with sexual arousal), and fear-induced aggression (which essentially relates to the fight-flight scenario). Other writers (e.g., Berkowitz, 1993; Breakwell, 1997) have been content to distinguish between two principal forms of aggressive behaviour - instrumental and emotional aggression. Instrumental aggression, as described by Moyer, is essentially a means to an end, the act of aggression being secondary to attaining a specific objective. In contrast, it is the urge to hurt another which is the primary feature of emotional aggression. The latter is typically impulsive, and is most likely to occur when a person is highly aroused and has reduced self-control.

3.2 Theoretical Models for Aggression

Numerous general models of aggressive behaviour exist (Mulick, Hamer, & Dura, 1991; Peters, McMahon & Quinsey, 1992). Bowie (1996), for example, describes no
less than 21 such theories ranging from the intra-personal to the systems level. Breakwell (1997) has summarised the three most commonly cited theories:

- **Instinct Theory**

  This states that the need to be aggressive is common to all individuals as it is innate, biologically determined, and serves the function of helping to ensure the survival of a species. Thus, the need to be aggressive is comparable to the need to eat, drink, sleep and reproduce. Within the human species, individuals will differ only in terms of how they act out their aggressive behaviour; for some, this may be via contact sports, while for others it may be via domestic violence.

- **Socio-cultural Learning Theory**

  Unlike the instinct theory, the learning theory model does not suggest that aggression is an inevitable feature of the human condition. Instead, it proposes that aggression may be acquired through a process of instrumental learning (in which aggressive responses will be shaped and reinforced as a consequence of the outcomes which they achieve for the individual) or observational learning (in which the aggressive behaviour of others is modelled or copied).
- Aversive Stimulation Theory

This is based on the premise that aggression constitutes a powerful mechanism through which the heightened physiological arousal known to be generated by aversive events can be decreased. There is clear evidence, as will be outlined further in section 3.3.2, that a number of aversive conditions (for example, the infliction of pain, the presence of noise, crowding, and heat) are reliably associated with aggression, and that aggressive behaviour may serve to terminate such aversive events. The possibility of aggression occurring under these conditions is increased by the presence of certain stimuli (for example, potential weapons). Dollard, Doob, Miller, Mowrer & Sears (1939), cited in Berkowitz (1993), proposed a frustration-aggression hypothesis for aggression, claiming that this behaviour occurs when individuals are unable to reach their goals, or do not receive rewards which they perceive are due to them. The frustration-aggression theory can be viewed as a specific form of the aversive stimulation hypothesis.

As Breakwell (1997) observes, while all the above theories make some contribution to our understanding of aggression, their common flaw is that they promote uni-dimensional explanations of aggression which appear to have little relevance to incidents which occur in real life. The development of a more comprehensive understanding of aggressive behaviour therefore requires the adoption of an interactional perspective which more fully takes into account potential multiple
influences on an aggressive episode. This concept will be developed within the remainder of this section.

3.3 Aggression and learning disabilities

There is no reason to presuppose that the basic mechanisms governing aggressive behaviour in people with learning disabilities are any different from those which are relevant in the general population. The presence of a learning disability may, however, introduce additional risk factors which increase the probability of aggression. These factors can be viewed as setting conditions for aggression, and may be related both to individual characteristics and to characteristics of the environments in which people with learning disabilities are typically supported.

Gardner & Moffat (1990) describe a specific multi-component 'biopsychosocial' model for the causation of aggression in people with learning disabilities which, although being essentially behavioural in nature, adopts a clear interactional stance which allows a wide range of causal factors to be taken into account. The model helps identify potential risk factors relevant to this population, and also describes processes through which aggression may be strengthened and maintained or weakened and reduced.

Each component stage of this model will now be considered in turn and illustrated with reference to both the general literature on aggression and to specific research with people who have learning disabilities.
3.3.1 Individual Setting Conditions

As outlined above, some studies have shown that the prevalence of aggression increases with the severity of learning disability, a factor that has been interpreted as evidence of a causal association with neurological damage. Evidence from research on animal models has also shown that lesions within or the stimulation of certain areas of the brain (such as the septum or hypothalamus) can induce aggression, and this body of research, together with evidence from studies on human subjects who displayed aggression subsequent to acquired neurological damage, has been cited as further evidence for organic causation (McCleary & More, 1965; Davison & Neale, 1974). More recently, the use of sophisticated neuro-imaging techniques such as SPECT (Single Photon Emission Computerised Tomography) has also suggested that there may be more subtle differences in neurological functioning between aggressive and non-aggressive individuals (Amen, Stubblefield, Carmichael & Thisted, 1996). Well established relationships also exist within the general literature between aggression and the abuse of alcohol and other drugs, vitamin deficiencies, infections, tumours, and oxygen deficiency, all of which may impact on the functioning of the neocortex and the limbic system (Blumenreich & Lewis, 1993).

It is not difficult to construct a list of behavioural sequelae (such as reduced attention span, poor impulse control, impaired memory, etc.) to the neurological damage inherent in learning disability that may predispose towards this form of behaviour. Within the learning disability literature, there is specific evidence that aggressive
behaviour may fluctuate over long periods of time in discrete cycles and the suggestion that underlying neurological mechanisms may be implicated in these cycles (Lewis, Silva & Silva, 1995), that aggression may be associated with abnormal electroencephalographic rhythms (Chaney, Forbes & Levy, 1989), and that aggression may also linked with disturbances in the dopamine systems (Marazziti, Palego, Silverstri, Presta, Balestini, & Conti, 1996).

Other physiological factors which have been investigated with regard to their role in precipitating aggression in people with learning disabilities include epilepsy (Creaby, Warner, Jamil & Jawad, 1993), acute or chronic pain, allergies, hormonal disorders (Gourash, 1986), pre-menstrual tension and disruption in the menstrual cycle (O'Dwyer, Holmes & Friedman, 1995; Carr, Reeve & Magito-McLaughlin, 1996). While all these factors are equally relevant to the general population, the risk of such medical conditions remaining undetected and untreated is heightened in persons with learning disabilities (Welsh Health Planning Forum, 1992), and the risk of them remaining as unrecognised factors in aggression is therefore increased.

Super-imposed psychiatric problems present similar diagnostic challenges, and it has been empirically demonstrated that psychiatric disorder is likely to be under-diagnosed in this population (Reiss, Levitan, & Szyszko, 1982). Research has however shown a consistent relationship between aggression and schizophrenia in the general population (Harris & Rice, 1992; Turns & Blumenreich, 1993), and between depression and aggression in both the general population (Berkowitz, 1993) and in people with
learning disabilities (Reiss & Rojahn, 1993). Other broader psychological states (such as poor self-esteem) and reactions to life events (physical and sexual abuse, bereavement, and service transitions) may also play important roles as setting events within this population (Royal College of Psychiatrists, 1995).

People with learning disabilities also display a variety of skill deficits which may increase the probability of aggression. General skills deficits which may be relevant include limitations in communication skills, social skills and general independent functioning. Other far more specific skill deficits may also exist. For example, Walz & Benson (1996) provided some experimental data illustrating differences in the ability of aggressive and non-aggressive subjects with mild-borderline learning disabilities to discriminate between facial expressions of emotion. Aggressive subjects mislabelled both 'angry' and 'sad' expressions significantly more than controls, and were more likely to apply the label 'anger' when they were unsure of an emotion, thus suggesting a negative emotional bias for ambiguous expressions. Davidson et al (1994) found that individuals who were destructive towards property but not people were more likely to be functioning at a higher cognitive level, possibly suggesting that higher functioning individuals may make use of their verbal and cognitive skills to limit their aggression. This should not be surprising if, as has been argued by a number of authors (Berkowitz, 1993; Black, Cullen & Novaco, 1997), cognitive mediation plays an important role in determining whether or not aversive stimuli actually generate aggression.
3.3.2 Environmental Setting Conditions

As Gardner & Moffat (1990) indicate, it is rare in clinical practice to find isolated conditions under which aggression can be reliably predicted to occur. It is unlikely, for example, that the presence of any of the single individual characteristics described above would constitute a sufficient condition for aggression. It is far more probable that a complex combination of stimuli set the scene for the occurrence of aggressive behaviour, and that aggression is typically the product of an interaction between both internal and external provocations. The latter may include the presence of a number of environmental 'pollutants' such as excessive heat, noise, and overcrowding, together with other service related factors such as high turnover rates of younger age clients, inexperienced staff with poor and/or inappropriate interactional styles, a lack of structured activity, the presence of aggressive models, and the intermittent reinforcement of aggressive behaviour, all of which have been identified in the literature as being environmental risk factors associated with aggressive behaviour within institutional settings in general (Harris & Rice, 1992; Blumreich & Lewis, 1993).

While personal and environmental conditions may set the occasion for aggression to occur, its actual onset may be precipitated by far more discrete events. Thus, there are examples from the general psychiatric literature of aggression being triggered by nursing staff denying patients' requests (Palmstierna, Huitfeldt & Wistedt, 1991), general staff: patient exchanges (Colenda & Hamer, 1991), and a variety of aversive
interactions from staff including approach or physical contact, frustration, activity demands, and negative verbal statements (Whittington & Wykes, 1996).

In the learning disability literature, aggression has similarly been shown to be functionally related to the occurrence of aversive social contacts (Carr, Newsom & Binkoff, 1980; Horner, Sprague, Day, Sprague, O'Brien, & Heathfield, 1991; Carr, Taylor & Robinson, 1991). Carr, Reeve & Magito-McLaughlin (1996), for example, describe a single case study which demonstrated that rates of aggressive behaviour were highest at times when the person concerned was presented with demands from carers (in the form of domestic chores) during her menses. As well as illustrating the role of aversive social events as a specific trigger for aggression, this study therefore also demonstrated an interactional relationship between specific environmental triggers and personal setting events.

3.3.4 Maintaining Variables

In Gardner & Moffat's (1990) model, aggression that has been precipitated by individual and environmental factors and events will be maintained or decreased depending upon the responses which it generates. Thus, aggressive behaviour may be maintained and strengthened through positive reinforcement (e.g., by gaining access to preferred activities) or negative reinforcement (e.g., the reduction of aversive carer interactions). This corresponds with the 'social learning' and the 'aversive stimulation' model of aggression described above. Aggressive behaviour may be weakened and
reduced via extinction (the termination of previously available reinforcing consequences), positive punishment (e.g. via over-correction, electric shock) or negative punishment (e.g. via time-out or response cost).

4. Interventions for Aggressive Behaviour

A number of authors (LaVigna & Donnellan, 1986; Horner, Dunlap, Koegel, Carr, Sailor, Anderson, Albin, & O'Neill, 1990; Gardner & Moffat, 1990; Carr, Robinson & Palumbo, 1990) have made the distinction between the treatment and the management of challenging behaviours in people with learning difficulties.

Treatment aims to produce behavioural change which endures over time and generalises across relevant settings. It is likely to involve the modification of provocative environmental stimuli via ecological change, the introduction of new coping strategies to help the person manage both internal and external precipitants of aggression, and the development of adaptive responses that will serve to replace the aggressive actions.

Management approaches, in contrast, focus on safe responding to aggressive behaviour when it occurs. Emergency or reactive management plans are not concerned with behaviour change, but simply with the safe and efficient management of out of control behaviours which represent a physical threat to the safety of the client and/or others. Treatment and management approaches will be examined in turn.
4.1 Treatment Interventions

Two main methods of intervention will be considered here, those based on behavioural models and those involving medication. At present, these are indisputably the most frequently used interventions for aggressive behaviour within this population.

Historically, there has been a clear bias against the use of psychotherapy with this population which has been largely founded upon the belief that people with learning disabilities lack the intellectual ability to make use of 'talking therapies' (Alford & Locke, 1984; Hurley, 1989). This view has been attacked both from a 'rights' perspective (Lovett, 1985), on the basis of the fact that psychotherapy need not always be dependent on verbal strategies (Beal, 1984), and because the goals of therapy can be adjusted according to the population served (Matson, 1984). Cognitive approaches with people who have learning disabilities have been subject to considerable interest of late, and it is entirely appropriate that they should be considered for use with a population whose primary defining characteristic is cognitive impairment. Despite a recent expansion in interest in both these approaches (Nuffield, 1986; Stavrakaki & Klein, 1986; Sinason, 1992; Beal & Warden, 1996; Kroese, Dagnan & Loumidis, 1997), they are still developing, and therefore not yet subject to the same degree of empirical scrutiny that has been applied to behavioural and pharmacological interventions. Although they represent potentially positive additions to the range of therapeutic options available, they will therefore not be considered within the scope of this review.
4.1.1 Behavioural Treatment

The bulk of clinical and research interest in terms of interventions for aggressive behaviour in persons with learning disabilities has undoubtedly been invested in behavioural approaches. A wealth of literature exists on this topic, and a number of extensive reviews are available which consider interventions for aggression either as a main or as a subsidiary topic (Matson & Gorman-Smith, 1986; Guess, Helmstetter, Turnbull & Knowlton, 1987; Lennox, Mitlenberger, Sprengler & Erfanian, 1988; Carr, Robinson, Taylor & Carlson, 1990; Scotti, Evans & Walker, 1991; Whitaker, 1993; Scotti, Ujcich, Weigle, Holland, & Kirk, 1996; Didden, Duker & Korzilius, 1997).

Several points emerge from these reviews:

- There is clear evidence that behavioural techniques can be effective in changing aggressive behaviours

- Intervention effectiveness is likely to be enhanced by using a combination of behavioural procedures

- The available reviews are, naturally, very technique focused, and typically offer conclusions about the superiority of one approach over another (e.g. facial screening versus over-correction). A cautionary note is required in interpreting such conclusions in that the analyses of the effectiveness of some techniques are
based on a very small number of studies and subjects. Between-treatment comparisons may therefore be misleading.

- Central to the discussion on techniques has been the often acrimonious debate on the use of aversive versus non-aversive approaches (Repp & Singh, 1990). This is of particular importance as regards aggression, in that more severe behaviours appear to attract the use of more intrusive interventions (Scotti et al, 1991). Viewed overall, there is no really compelling evidence for the superiority of treatment outcomes of one approach over the other. This being the case, a criterion of social acceptability, rather than clinical effectiveness, should perhaps be used to determine which approaches are to be encouraged and supported. On this measure, non-aversive positive behavioural approaches would almost certainly be the techniques of choice (Kazdin, 1980; Taranowski, Rasnake, Mulick & Kelly, 1989; Miltenberger, Lennox & Erfanian, 1989; Bihm, Sigelman & Westbrook, 1997).

- In reality, it may be argued that the efficacy of individual approaches is to some extent spurious in that the 'best' technique for any given client is an individualised functional analysis which generates an individualised intervention option (Danforth & Drabman, 1989; Carr, Robinson & Palumbo, 1990).

- Following on from the previous point, it is a source of serious concern to note that many interventions for challenging behaviour which appear in the literature
are not based on functional analysis (Carr et al, 1990; Scotti et al, 1991), although some recent evidence suggests an improvement in this trend (Scotti et al, 1996).

- Even when functional analyses are performed, there does not always appear to be a logical link between the results of the analysis and the selection of the intervention option (Scotti et al, 1996).

- Reviewers have analysed the effectiveness of individual techniques by behavioural topography or class whereas, according to applied behaviour analysis, an assessment by behavioural function would be more meaningful. This criticism has, however, to be viewed against the typical failure to report functional analyses referred to above.

- Both Guess et al (1987) and Carr et al (1990) point to other deficiencies in the behavioural research literature in terms of the lack of reporting of the maintenance of intervention effects over time, the generalisation of change to non-targeted behaviours, and the occurrence of positive (e.g. gains in adaptive behaviour, changes in quality of life) side effects and negative (e.g. elicited aggression) side effects. Additional technical deficiencies in studies applying differential reinforcement procedures have been described by O'Brien & Repp (1990).
A major overall concern is the frequent failure to report concurrent medication usage (Poling, Grossett, Karas, and Breuning, 1985); one famous single-case study (Linscheid & Landau, 1993; Meyer & Berkman, 1993) has provided a graphic illustration of the potential importance of such data.

Whitaker (1993) draws attention to two important areas where demonstrations of intervention effectiveness are lacking. These are where the aggression is of a fairly low frequency and where aggression occurs in family settings, the bulk of the literature being concerned with staffed environments (in Scotti et al's (1991) review, for example, only 8% of published studies involved parents implementing interventions versus 61% which involved direct care workers). Both factors are likely to be of considerable clinical significance in that many aggressive behaviours may, as stated above, occur at a comparatively low frequency, and also because this behaviour will often emerge at an early age and therefore is highly likely to occur, initially at least, largely within family settings.

Behavioural rate has been the primary measure of change to the comparative exclusion of measures of intensity and duration. Intensity measures (e.g. the force of a hit) are of particular clinical and practical significance, but the fact that their measurement will inevitably involve a degree of subjectivity is one likely explanation for its under-reporting.
The bias in the literature is very much in favour of behavioural techniques which involve the manipulation of environmental variables and behavioural contingencies by carers. Comparatively little attention to date has focused on potentially promising self-control procedures such as anger management (Benson, Rice & Miranti, 1986; Black, Cullen & Novaco, 1997).

4.1.2 Medication

Numerous studies have shown that individuals with learning disabilities who display aggressive behaviour are likely to receive psychotropic medication (Tu & Smith, 1983; Harper & Wadsworth, 1993; Linaker, 1984; Kiernan, Reeves & Alborz, 1995; Fleming, Caine, Ahmed & Smith, 1996). Neuroleptics (anti-psychotics) appear to be the most commonly used compounds (Aman & Singh, 1991; Poling, Gadow & Cleary, 1991), although there is also a body of research on anxiolytics (anti-anxiety drugs) (Calamari, McNally, Benson & Babington, 1990; Ratey, Sovner, Mikkelsen, & Chmielinski, 1989; Ratey, Sovner, Parks & Rogetine, 1991), Lithium (a 'mood stabiliser') (Dale, 1980; Craft, Ismail, Krisnamurti, Mathews et al, 1987; Spreat, Behar, Renesi & Miazza, 1989) and anti-hypertensives (Schall & Hackenburg, 1994).

Qureshi (1994) found that 53% of people with learning disabilities who displayed aggressive behaviour were receiving drugs to control this behaviour; only 20% were reported to be receiving any form of behavioural intervention. Similarly, Harris & Russell (1989) found that 55% of people whose aggression was reported to present
extreme management difficulties received drug treatment for their behaviour, whereas
only 17% were in receipt of behavioural interventions. These findings parallel those of

Taken at face value, these results would seem to suggest that medication clearly
represents a more effective form of treatment for aggression than the behavioural
procedures described above. However, Lennox et al (1988) found medication to be
the least effective intervention for aggression in terms of percentage change from
baseline as compared to a variety of behavioural interventions, and questioned its
continued use for behaviour problems in general in the absence of empirical evidence
for clinical effectiveness. These results were echoed by Didden et al (1997). Aman &
Singh (1991) have also observed that, despite prescribing practices which favour
neuroleptics for the control of aggression and other challenging behaviours, there are
few well-controlled studies from which clear conclusions can be drawn. Lappiere &
Reesal's (1986) review of the drug literature also concluded that there were no
specific drug treatments for aggression in learning disabilities, and evidence also exists
to show that aggression may in fact be induced by certain medications (Sovner &
Hurley, 1986).

Despite the availability of a number of theoretical models which could provide a solid
underpinning for prescribing medication for behavioural difficulties (Thompson, Egli,
Symons and Delaney, 1994; Emerson, 1995), it is clear that most medication for
challenging behaviour is prescribed on the basis of topography rather than neurological
function (Schaal & Hackenburg, 1994). It is equally apparent that, rather than being prescribed for any specific therapeutic effect, medication is typically applied as a general behavioural suppressant.

Sobsey (1989) has made the point that when evaluating the potential benefits of medication, clinicians must distinguish between the benefits for the client and the benefits for the carers; he points out that there are no legal or ethical rationales for prescribing on the basis of the latter. The same argument could, of course, apply to behavioural techniques, as it is sometimes questionable as to whose needs are being served with the application of procedures such as time-out or response cost.

One possible explanation for the bias towards the use of medication over behavioural approaches in clinical practice may be that the former require considerably less investment of carer time and effort than the latter. As with behavioural interventions, it is therefore vital that drug studies demonstrate significant changes in quality of life as well as changes in behaviour (Poling & LeSage, 1995), particularly in view of the fact that psychotropic use is associated with a range of harmful side effects (Aman & Singh, 1991) which have been described as varying between 'annoying and distressing to permanently debilitating' (Schall & Hackenburg, 1994, p. 124).

While there is evidence for the effectiveness of various forms of medication for short-term behavioural reduction, the best use of drugs would appear to be in the creation of a 'window of opportunity' for the introduction of behavioural methods
(Schalock, Foley, Toulouse & Stark, 1985; Sovner & Hurley, 1986; Lapierre & Reesal, 1986; Gardner & Moffat, 1990; Schaal & Hackenberg, 1994; Thompson et al, 1994). This point will be considered further in the concluding section of this review.

4.2 Reactive Management

Irrespective of whether behavioural or pharmacological interventions are employed, the complete elimination of aggressive behaviour is an unlikely outcome. Carers of aggressive individuals, even those who have been the subject of successful therapeutic regimes, will therefore periodically be faced with out of control behaviours from which both they and the client may need to be protected. Failure to adequately prepare carers to cope with such behaviours may, as already stated, inflate service costs and could also result in prosecutions under Health and Safety legislation (Health & Safety Executive, 1994). Procedures for responding to aggression and other forms of challenging behaviour have been collectively described as 'reactive management strategies' (LaVigna, Willis & Donnellan, 1989).

Reactive management strategies are not treatments, and are therefore not concerned with changing behaviour, but only with the safe and efficient management of out of control behaviours. At their least intrusive level, they may consist of strategies to defuse potentially aggressive incidents via verbal, non-verbal and distraction techniques. At their most intrusive, they may involve self-defence techniques (often referred to as 'breakaways'), emergency physical restraint (as opposed to the planned
use of restraint as an aversive consequence in a behavioural intervention), emergency medication, and seclusion (Harvey & Schepers, 1977; Willis & LaVigna, 1985; Mason, 1996; Harris, 1996).

There is evidence that planned reactive strategies are, not surprisingly, less risky than unplanned reactive strategies (Spreat, Lipinski, Hill & Halpin, 1986; Hill & Spreat, 1987), that staff can be effectively trained in these procedures (van den Pol, Reid & Fuqua, 1983; McDonnell, 1997), and that such training can have a variety of positive outcomes which include reduced rates of assaultive behaviour, lower levels of injury to staff and clients, and reduced frequency of use of emergency medication (Infantino & Musingo, 1985; Mortimer, 1995; Allen, McDonald, Dunn & Doyle, 1997).

The most prevalent form of training in this area within the United Kingdom is 'Control & Restraint' (recently renamed, rather euphemistically, as 'Care & Responsibility'). It consists of a set of procedures originally developed within the prison service and subsequently passed down into the general psychiatric and learning disability services via the special hospitals (Special Hospitals Service Authority, 1992). The methods used in this system reflect its origins, and are dependent for their effectiveness on inflicting a degree of pain on the person being restrained etc. in order to achieve compliance. Control & Restraint techniques are undoubtedly effective; however, as the Royal College of Psychiatrists (1995) have observed:
'There must be grave concern that the widespread and deliberate use of pain, whether actual or threatened, has become part of the management of patients without consideration as to the moral and ethical issues involved. There is no evidence in the literature that the use of pain in Control and Restraint has been examined to determine its relevance. Its role becomes particularly problematic and hazardous where the patient's perception of pain is altered (as might occur with learning disability, autism or various psychiatric states).'

Royal College of Psychiatrists (1995, p.6)

The method has also been criticised in its application to persons with learning disabilities (Doyle, Dunn, Allen & Hadley, 1996) on the grounds that its techniques do not match the typical assault pattern shown in this group, that it is likely to be unacceptable within community settings (an increasingly important consideration with the drive to accommodate more challenging individuals in non-institutional settings), and that it is impractical to implement within the staffing ratios in many services. The same authors also question the wisdom of teaching aggressive techniques to staff working with clients who are known to be at greater risk of carer abuse (Rusch, Hall & Griffin, 1986; Marchetti & McCartney, 1990), with behaviours which are likely to produce strong emotional responses from carers (Bromley & Emerson, 1995), and within environments which have a history of supporting abusive practices (Martin, 1984). In addition, if effective methods which were not dependent upon pain for managing the aggressive behaviour of people with learning disabilities could be
demonstrated, pain-compliance methods could be viewed as illegal in that they would fail to comply with the principle of minimum force and, in the absence of consent, could technically be regarded as assault.

Several alternative approaches which do not inflict pain, and which meet the joint requirements of effectiveness and acceptability (McDonnell & Sturmey, 1993a; McDonnell, Sturmey & Dearden, 1993) are in fact now available. The training procedures described by a variety of authors (Dempster, Tucker, Warnick, Fogarty & Attwood, undated; New York State Office of Mental Retardation & Developmental Disabilities, 1988; McDonnell, Dearden & Richens, 1991a, b, c; Doyle, Dunn, Allen & Hadley, 1996; Cornick, Holt & Bromley, 1996), whilst having different origins and emphases, contain many common principles including a major focus on preventative approaches, the use of a gradient of techniques which are tailored to the severity of the behavioural incident, and strict rules to govern the prescription and monitoring of technique use. Recently, guidelines have been produced which aim to enable organisations to construct their own reactive management policies which meet these good practice points (Harris, Allen, Cornick, Jefferson & Mills, 1996). Extensive guidance is also available on the legal issues which surround the use of reactive procedures with children who have learning disabilities and challenging behaviour (Lyon, 1994).

Despite the importance of this area, there is some evidence to indicate that significant numbers of carers receive no training of this sort. Harris & Russell (1989), for
example, found that under 40% of carers of clients rated as posing extreme
management problems had received training in restraint despite the fact that over half
their clients had been restrained at least once in a four week period. Similarly, Allen
& Hill-Tout (1995) found that few staff supporting people with challenging behaviour
in day services received training in restraint techniques and were often left to determine
physical intervention methods for themselves.

5. Conclusions

Although estimates of prevalence vary, aggressive behaviour clearly represents a
significant management problem in working with people who have learning
disabilities. An extensive literature exists regarding this form of challenging behaviour,
the bulk of which is concerned with epidemiology and treatment to the relative
exclusion of reactive behavioural management. As a number of observations regarding
the epidemiological research have already been made in the text, this discussion will
concern itself primarily with treatment and management aspects.

A major criticism of the treatment literature is that only rarely does the sophistication
of published interventions match the likely subtlety of causal factors for aggression
described above. All too often, reported interventions focus on the manipulation of
single variables which, although they may constitute necessary conditions for the
generation of aggression, are unlikely to act as sufficient conditions for its occurrence.
Fortunately, it is becoming increasingly recognised that simple, single-element
interventions are unlikely to prove effective for aggression and other forms of challenging behaviour (Horner et al, 1990; Meyer & Berkman, 1993; Scotti et al, 1996).

A significant body of research exists to support the clinical effectiveness of behavioural interventions for aggression in this client group. Although there is considerably less empirical support for the use of medication, it is the use of psychotropic drugs which tends to dominate in clinical practice. Given the growing body of evidence that challenging behaviours such as aggression may be both environmentally and neurologically motivated, optimum interventions are likely to need to combine both chemical and behavioural elements (Thompson et al, 1994).

As with behavioural intervention, medication prescribing must be functional, with decisions about which medications to employ being taken on the basis of empirical research on specific drug actions, and following a behavioural and neurochemical analysis of behavioural function. Most drug trials report a percentage of clients whose behaviour fails to respond to chemical intervention. Just as with environmentally motivated behaviours, this may be because the behaviour of the non-responding individuals is driven by different neurochemical functions. Current prescribing of medication for behavioural difficulties often resembles a poorly-monitored stab in the dark, and a specific research task is therefore to identify variables which predict treatment outcome (Thompson et al, 1994).
It is already possible to piece together theoretical accounts of how dual drug-behavioural interventions might work. Schaal & Hackenburg (1994), for example, cite evidence from research on animal models which suggests that neuroleptics may act specifically to reduce the behavioural avoidance of aversive events. This being the case, neuroleptic medication may have beneficial short-term effects for a person whose high intensity physical aggression had been shown to be functionally related to the presentation of demands from carers. The prescription of an anti-psychotic could be paired with behavioural strategies such as ecological changes which lowered the rate and degree of complexity of demands in the short-term, functional communication training which taught the person more socially appropriate methods of terminating demands which they perceived to be aversive, instruction in self-control strategies for use when aversive demands were presented, and the gradual reintroduction of more aversive (but socially valid) demands via a process of desensitisation. How such combined pharmacological-behavioural interventions might work in practice needs to be a clear focus of future research activity.

The apparent failure to build behavioural interventions upon functional analyses within the currently available research literature is a particular worry. It might reasonably be pre-supposed that published interventions would provide something of a 'gold-standard'. If this is the case, then it is worrying to contemplate that routine clinical practice might not even attain the unsatisfactory standards of the published studies. As a number of good practice guidelines now exist for behavioural interventions (Horner, Dunlap, Koegel, Carr, Sailor, Anderson, Albin & O'Neill, 1990) and for the reporting...
of such interventions within scientific journals (Scotti et al, 1991; Meyer & Evans, 1993), such low standards are both unacceptable and unethical in that they clearly compromise clients' rights to effective intervention.

A final major concern regarding the intervention literature is the failure to report data which support the social validity of treatments. Emerson (1995) argues that interventions need to demonstrate social validity on the basis of showing that they are addressing a socially significant problem, that they are undertaken in such a way as is acceptable to the main stakeholders involved, and that they result in socially important outcomes or effects. Whilst behavioural studies are showing a gradual improvement in this respect, social validity data have been almost totally absent from drug studies (Poling & LeSage, 1995). A particularly important point to note regarding the social validity of behavioural or pharmacological interventions is that, given the often inappropriate and dysfunctional environments within which many persons with learning disabilities are forced to live, their expressions of anger and aggression may be viewed as a legitimate response to unacceptable conditions. This being so, interventions must focus on modifying these conditions as well as on modifying reactions to them in order to achieve ethical stringency. In this sense, improving quality of life is a treatment intervention as well as a treatment objective (Scotti et al, 1996).

As reported in the text, the safe management of aggressive behaviour is a key concern for services but, despite the availability of a number of ethically sound approaches, there is scant evidence to indicate that carers are receiving training in this area. This is
a major omission, and recommendations for safe management need to be viewed as an essential component within intervention packages. While further research is required to identify optimum techniques for client and carer safety, this needs to be combined with initiatives to raise services' awareness of the importance of this area. The latter will almost certainly be driven more by legal requirements than by scientific study. As with intervention approaches, the demonstration of social validity is a critical requirement for reactive strategies (McDonnell & Sturmey, 1993 b).

In summary, aggressive behaviours in persons with learning disabilities pose major challenges for services as well as for the individuals concerned themselves. While there is a considerable research literature available, present research initiatives tend to follow unilateral therapeutic strands, and an integration of current approaches will be required before really effective help can be offered for this serious problem. As Thompson et al (1994) observe, a failure to achieve such a synthesis is likely to continue to result in direct and indirect service costs which are truly staggering.
References


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Carers' understanding of and responses to challenging behaviour in persons with learning disabilities
Carers' understanding of and responses to challenging behaviour in persons with learning disabilities

1. Introduction

The importance of utilising a client's regular carers as agents of behavioural change was recognised early on in the history of applied behaviour analysis. As far back as 1959, Ayllon & Michael described training psychiatric nurses as 'behavioural engineers' in order to help them shape the behaviour of people with psychotic disorders or with learning disabilities. A decade later, Tharp & Wetzel's (1969) classic text, 'Behaviour Modification in the Natural Environment' observed how the drive towards the creation of specialists in mental health services ignored some of the greatest resources available, namely:

'...the client's natural relationships, with their extraordinary potential for generating behaviour change; and talented sub-professionals, with their energy and enthusiasm.'

(Tharp & Wetzel, 1969, p.2)

Tharp & Wetzel asserted that, as applied behaviour analysis was concerned with the relationship between people and their environments, the obvious locus for interventions was the person's natural environment rather than some contrived artificial
setting, such as clinics or psychological laboratories. The latter were seen as being inappropriately founded upon the medical model, and rejected for their failure to take into account natural contingencies. As an alternative, a triadic model of intervention in natural environments was described in which behavioural consultants worked to influence and shape the behaviour of mediators who, in turn, influenced and shaped the behaviour of target individuals. Consultants were defined as 'anyone with the knowledge', mediators as 'anyone with the reinforcers', and the targets as 'anyone with the problems'. Consultant skills could be 'given away' to individuals in close daily contact with individuals displaying behaviours of concern, thus making good use of scarce professional resources by delivering treatment interventions via persons who had natural relationships with target clients in naturalistic settings. The latter included family members and formal carers, as well as other professionals. In more recent times, this desire to disseminate behavioural principles to carers in the 'front line' has been reflected in the appearance of a variety of 'cook book' behavioural guidelines aimed at parents and other direct carers (e.g. Carr, 1980).

Although Tharp & Wetzel recognised and discussed various individual and organisational 'resistances' which may impede the implementation of the triadic model, it is only within the last two decades that the complexity of establishing interventions within natural environments has been fully realised. It has become readily apparent that, while intervention in the natural settings with natural carers may represent the optimum conditions for behavioural change, achieving adequate implementation under
these conditions may be hugely problematic (Woods & Cullen, 1983; Emerson & Emerson, 1987; Praill & Baldwin, 1988).

This review will consider potential reasons for these difficulties, and will separately analyse issues surrounding interventions with natural carers (parents and families) and with paid carers (institutional staff or community service staff) supporting people with learning disabilities and challenging behaviour. These groups were selected because a substantial but separate literature is available for both; although other groups of care givers (for example, teachers) are also important potential agents of behavioural change for this client group, the literature concerning their role is generally less well developed, and they will not therefore be considered in any detail within the present paper. It was also felt appropriate to consider the natural and paid carers independently as it might be expected that the variables influencing behavioural intervention with blood relatives who have 24 hour a day care responsibility would be different from those influencing contracted, '8 hour' carers.

For both groups, the potential importance of carers' beliefs about the causation of challenging behaviours, their emotional and behavioural responses to them, and general factors concerned with providing training in behavioural interventions will be discussed in an effort to gain a clearer understanding of the multiple influences on treatment success.
2. Natural Carers

The potential power of interventions within family settings has been repeatedly demonstrated in the literature (Moreland, Schewbel, Beck & Wells, 1982; Budd & Fabry, 1986). Dunlap, Robbins & Darrow (1994) found that parents viewed contingency management approaches to be the most successful interventions available to them. Despite these findings, published demonstrations of behavioural interventions in family settings tend to be far outnumbered by those conducted in staffed environments (Scotti, Evans, Meyer & Walker, 1991; Whitaker, 1993).

2.1 Beliefs about and understanding of challenging behaviour

Attribution theory is based on the premise that thoughts govern behaviour (Weiner, 1988); if this is the case, the way in which people view challenging behaviour is likely to be a good indicator as to how they will respond to such behaviour. As much of the published literature tends to focus on observable behaviour, the role of 'internal events', which are likely to set the scene for effective or ineffective interventions, remains comparatively unexplored. This is particularly true for family members.

Orford's (1987) review of the literature on families coping with problem behaviour, cited in Qureshi (1993), identified four factors associated with unsuccessful intervention outcomes. These were attributing the person's behaviour to personality traits (e.g. laziness, stubbornness), viewing the behaviour as being under the control of
the person, regarding the behaviour as being deliberately designed to provoke others, and blaming oneself for the behaviours by attributing them to historical and personal factors.

While it would appear that such views would need to be explored and questioned as a necessary pre-condition for the development of successful intervention strategies, this may prove to be far from easy as this process will involve challenging fundamental belief systems and basic coping mechanisms. Qureshi (1993), for example, found that the belief that challenging behaviour was not a deliberate act on the part of the young person was quite widely held amongst parents, and that professional advice was sometimes rejected because it appeared to go against this belief and was, therefore, counter-intuitive from the parents' perspective. Turnbull & Ruef (1996) also found that parents wanted professionals to stop blaming their relative or themselves for the challenging behaviour. Qureshi (1990) states that literature from other specialisms (e.g. care of the elderly) has shown that the belief that people are not responsible for their behaviour (e.g. as a consequence of a diagnosis of dementia) may play an important role in helping carers come to terms with this behaviour. Such beliefs are likely to have a major bearing on treatment effectiveness, and professionals working within a behavioural framework therefore need to take great care in explaining basic concepts to parents.

As Hastings & Remington (1994b) have observed, carer behaviour may be 'rule governed', or shaped by verbal descriptions of contingencies normally learned through
direct experience. Rules may be externally determined (e.g. via cultural or group norms) or self-generated. In either case, rule-governed behaviours tend to be inflexible, a factor which can prove extremely problematic if carer responses towards challenging behaviours are evidently counter-therapeutic.

Some studies have indicated that parents may not in fact have a model for many behavioural incidents. Kiernan & Alborz (1996) found that 46.9% of parents said that they could hardly ever or only sometimes explain the challenging behaviour of their relative. Parents interviewed by Turnbull & Ruef (1996) also expressed frustration at the fact that neither they nor professionals working with their relatives had a clear understanding of the factors involved in precipitating and maintaining behaviours of concern. They recognised, however, that factors such as an inability to communicate needs, to tolerate changes in routine, to manage transitions, and to make choices could all be implicated in challenging behaviours; this is an important finding, as such factors are likely to feature strongly in intervention plans.

2.2 Emotional responses

In the absence of any clear theoretical model of why people behave in a challenging way, it is perhaps more likely that carer responses to provocative behaviours will be driven by emotional factors. An association between the presence of child behaviour problems and increased family stress and discord is well established in the literature, although the interpretation of the causal direction of this association is complex.
(Quine, 1986). Links have also been found between parental stress and the presence of specific conditions which are associated with the presence of learning disabilities and specific forms of challenging behaviour (Sarimski, 1997).

Dunlap & Fox (1996) state that parents who have been told that their child has a learning disability are at risk of feelings of isolation, loneliness and depression. While this may be partly be a consequence of a bereavement reaction for the 'loss' of a normal child, Dunlap & Fox also suggest that such feelings may arise because of difficulties in finding other family members or friends who can relate to this experience. As indicated above, such negative emotions are likely to be further exacerbated if a child also has challenging behaviour:

"You don't know what it's like to have a child nobody wants. When Donald goes to school, I always try to make myself invisible in the play ground. I feel the other parents will be pointing fingers at me all the time - there's the mother of the child that nobody wants. It's just me and Donald and it's very lonely."

(Mental Health Foundation, 1997, p.8)

Families will obviously show wide variations in their capacity to cope with a child who has learning disabilities and challenging behaviour. Sloper & Moss (1993) found that the parents of children with Down's Syndrome who displayed comparable challenging
behaviours did not always rate these behaviours as posing the same degree of management problems. Earlier research had shown that such coping differences were related to the quality of the mother-child relationship and the mother's ability to view the child positively despite its difficulties. For mothers, the key factors relating to their appraisal of problems included the child's level of developmental disability and excitable behaviour together with increased maternal age; it was hypothesised that the latter may have been an indication of lower coping capacity and tolerance amongst older mothers. For fathers, child distractibility and maternal dissatisfaction were key. Poor maternal child adjustment was associated with increased behavioural difficulties at two year follow-up and vice versa. Maternal acceptance of the child was also likely to deteriorate over time when the child showed disturbed, socially intrusive behaviours (i.e. those most usually recognised as classical challenging behaviours).

Turnbull & Ruef (1996) discovered that families often lived in the constant fear that difficult or dangerous behaviours could occur at any time, even if the behaviour in question was actually of extremely low frequency; they expressed particular concerns about the potentially negative consequences for their relative (e.g. institutionalisation) should the behaviours occur. They also worried about the reactions of others, stating that professionals often tended to live in 'crisis mode', and to express concerns about behaviours which the person had never actually displayed. Additional anxieties focused on behaviours such as inappropriate or odd vocalisations, and stereotypic or other unusual body movements which could cause significant embarrassment or annoyance in public. Qureshi (1990) found that 76% of parents of individuals with challenging
behaviour expressed worries about the potential embarrassment caused by these behaviours. Baxter (1989) also found that the potential stigma arising from behavioural difficulties was significantly associated with parental stress.

Dunlap & Fox (1996) suggest three possible sources of social support for families which may help reduce emotional distress: formal counselling from professionals, informal support from other parents with learning disabled children, and support groups for siblings of children with learning disabilities. A common theme in the literature is that parents value sympathetic and non-judgemental listening, and that it is critical that professionals do not adopt strategies which appear to blame parents for their children's behaviour (Mental Health Foundation, 1997). It must also be recognised that socio-emotional support for families needs to be long-term, commencing with 'breaking the news', and continuing through to the time that the person reaches adulthood and is ready to leave the family home and beyond.

2.3 Behavioural responses

Although there is a significant literature concerning interactions between parents and learning disabled children, there appears to be a lack of published papers which have looked at parents behavioural responses to challenging behaviour per se. It may be hypothesised though that emotional responses (e.g. embarrassment, fear) are highly likely to lead to behavioural responses (e.g. capitulation) which may result in the rapid termination of challenging behaviour in the short-term, but which could theoretically
reinforce the behaviour of both parties in the long-term. Thus, emotional responses may set the scene for the unintentional strengthening of inappropriate behaviours. The validity of this assumption will be examined later.

Taylor & Carr (1994) describe a series of studies which, although they involve undergraduate and graduate teachers and psychologists and not natural carers, clearly demonstrate the reciprocal nature of the social relationship between the behaviour of children with challenging behaviours and the behaviour of adult carers. Their results showed, for example, that adults responded differentially to children with and without challenging behaviours (by, for example, reducing the number and nature of their demands), that adults attended differentially to children with behaviours that served different functions, that child behaviour typically prompted adults to produce access to reinforcement, and that such effects were durable, powerful, and immediate. These results demonstrate that contingencies do not operate in one direction only, and highlight a need for a more sophisticated approach to intervention planning.

2.4 Training for and interventions with families

Sloper & Moss's (1993) findings on the association between the presence of socially-intrusive challenging behaviours and deteriorating maternal acceptance over time clearly points to a need for early intervention. Wacker, Berg & Northup (1991) have also suggested that early intervention is desirable because challenging behaviours could potentially become more complex over time as they come to serve multiple
functions, and will therefore be more complex to treat. Furthermore, Dunlap & Fox (1996) propose that early intervention is pragmatic because it is 'socially normative' (in that it is not unusual for parents to seek outside assistance regarding their child's development), and that it is easier to intervene with the challenging behaviour of children rather than adults because of the obvious differences in size and strength. It is clear though that early intervention may not always be effective even under the most favourable conditions (Wacker, Peck, Derby, Berg & Harding, 1996), that maternal stress may impact on child progress within early intervention schemes (Robbins, Dunlap & Plienis, 1991), and that such interventions may in themselves act as an additional stressor for parents (Brinker, Seifer & Sameroff, 1994).

Sloper & Turner (1993) found that interventions were more likely to be successful when they focused on the problem behaviour, helped families interpret their child's behaviour in a more positive way, and helped maintain positive parent-child interactions. One factor which discriminated between successful and unsuccessful family intervention was inadequate housing, and it was suggested that socio-economic factors may exert additional stresses which militate against parental ability to implement interventions.

Other indirect factors may have a similar impact. Turnbull & Ruef (1996), for example, found that the need to sustain parental energy levels was vital. Two sources of support were identified by parents. The first was time away from their relative via respite care services. This was critical to families who felt that they often had no 'down time' as a
consequence of being 'on duty' 24 hours a day. Qureshi (1993) found that 70% of the parents of young adults with challenging behaviour living at home indicated that they would like more respite care, even though half felt that the respite care which was available was not of a satisfactory quality. Even when respite was provided, parents reported being asked to take their children home mid-stay as the respite services felt that they could not cope with them, to remain on the end of the phone 'just in case', or to take their relative home during each day of a stay because no day services were available. Under such circumstances, it is questionable whether the term 'respite' can be used in any meaningful sense.

The second source of support identified by families studied by Turnbull & Ruef (1996) was generated by religious faith or the optimism of professionals and others. Somewhat conflicting results were however reported by Dunlap et al (1994) who found that parents rated teachers, family members and published material the most helpful, and doctors, psychologists, friends, social workers, and the church the least helpful. Qureshi (1990) found that 26% of parents received no advice from professionals, 61% received none that was helpful, and only 13% received helpful advice. Kiernan & Alborz's (1996) five year follow-up of the same parents recorded similar results, 88% of parents reporting that they had received no professional help regarding behavioural management during this period.

Qureshi found that even when advice was provided, the behavioural support on offer was often inadequate. Much of the advice on behavioural management given to
parents appeared to be only distantly related to applied behaviour analysis and was
generally not based on any kind of meaningful assessment of behavioural function.
Advice was frequently felt not to be useful either because it was impractical to
implement, or, as suggested earlier, because its assessment of causes varied from the
views of the family. The first point is graphically illustrated by the following account:

"Most of the advice which we had from the Unit has been to ignore what she does,
even the throwing and the tantrums, they even did a video at the Unit and asked
me to watch it when she was having all the behaviours -crying, throwing
things- how they coped with it and they wouldn't even look her in the eye. She got
no eye contact, which we can't do at home. They never even uttered a word. (Did
you find that advice useful for your situation here?) No I didn't. No. You couldn't
really because there was nothing there (at the Unit) that she could get hold of. She
was doing it in her room. And there was hardly anything in the room. Where as
here I mean she was throwing tins of soup and jars of pickle or something: milk
bottles - I mean I could get rid of the milk bottles, I had plastic bottles in the
end...when she's thrown eggs on the floor and somebody came to the door or
whatever I could walk over them and not comment on it I could leave it there for
three hours...that I could do. And even the milk - running down the walls- I wasn't
you know that bothered.

But I couldn't, not with the violence and the you know the chairs-the dining
chairs."
You'd have to duck or you'd have to - if it hit you or whatever - you'd have to react.'

(Qureshi, 1993, p.104-5)

As Whitaker (1993) states, techniques such as differential reinforcement (which are cornerstones of the positive behavioural approach; see, for example, LaVigna, Willis & Donnellan, 1989), are complex to implement and require an investment of time which may be beyond the personal resources of most families. Koegel, Koegel, Kellegrew & Mullen (1996) suggest that it is intervention procedures which require one-to-one input and dedicated training time which add to family stress, and which are therefore likely to encourage poor compliance. Simpler procedures, which can be incorporated easily into daily routines, are therefore advocated. Taylor & Carr (1994) also concluded that intervention implementation is likely to be enhanced when procedures pose minimal risks to the target child (a factor which perhaps suggests the use of positive rather than aversive behavioural procedures) and do not disrupt the target environment. Similarly, while it has been demonstrated that parents can be trained to be effective data gatherers (Wilkinson, Parrish & Wilson, 1994), the development of 'user friendly' recording systems (Meyer & Janney, 1989) is likely to improve utilisation.
Neef (1995) suggests that social scientists need to ensure that interventions take the
ecology of a situation fully into account, and that interventions are compatible with
conditions so identified. This view is mirrored by the conclusion of Engel & Power's
(1989) extensive review of family training methods. They advocate a systems approach
to family training that is 'ecologically sensitive', and which takes into account, for
example, overall family needs, an understanding of what help a family would like (and
how they feel this should be provided), the involvement of relevant others in the
programme, and the provision of detailed plans for treatment and generalisation. This
concept is developed more fully by Albin, Lucyshyn, Horner & Flannery (1996) who
stress the need for intervention plans to demonstrate a 'goodness of fit' with the
characteristics of its intended mediators and their operating environments. An
intervention plan which has a good contextual fit is characterised by the fact that it is
responsive to the values base and objectives of the mediators, builds upon their
experience, skills and knowledge, and, as suggested by Taylor & Carr (1994) and
Koegel et al (1996) above, is compatible with the environment's typical routines and
activities. Implicit in this model is a team approach which includes families as partners
rather than simply as recipients. Much could be learned in this respect from the general
literature on family interventions for non-learning disabled children (Webster-Stratton
& Herbert, 1994).

In Turnbull & Ruef's (1996) study, families indicated that they wanted a
multi-component support package which combined, for their relatives, a
comprehensive emphasis on structured household routines, enhanced communication
skills for their relatives, and increased choice making, together with reduced stress for themselves (both via stress management strategies and improved support services). It is interesting to note that this is entirely consistent with contemporary views on best practice in positive behavioural support (Horner et al. 1990). Singer, Irvin, Irvine, Hawkins and Cooley (1989) demonstrated some experimental support for the notion that such intensive, multi-element packages (in this case, stress management and parenting skills training, support groups and additional community-based respite care) can produce superior outcomes in terms of parental anxiety and depression as compared to more basic interventions (respite care and case management). Dunlap & Fox (1996) have suggested that comprehensive family support systems are likely to include information services (regarding general and specific disabilities, statutory rights, available services etc.), education and training (concerning child development, parenting skills, positive behavioural support etc.), case management (via brokerage, individual planning etc.), respite care, and socio-emotional support (as described in 2.2).

In the Qureshi (1990) study, the 13% of families who felt that they had received helpful advice seemed to form this view because the professionals concerned came to the family home, modelled the implementation of the techniques for the parents, and demonstrated that they could be successful. The peripatetic intensive support team model which has become prominent in recent years, and which is based on providing carers with practical help in environments in which problems are occurring, testing out and role modelling interventions, and then supporting carers to implement these
interventions, would appear to meet these requirements extremely well (Allen & Felce, in press). For some families though, it is also possible that a clinic based model of intervention (such as that described by Wacker, Steege, Northup, Reimers, Berg & Sasso, 1990) may be more appropriate than home-based programmes.

Irrespective of the intervention location, it is important that those providing behavioural support possess a broad range of skills. McGimsey, Greene, & Lutzker (1995), for example, demonstrated that a knowledge of behavioural techniques was an insufficient condition for parent training, and that effective training only occurred once consultation skills had also been taught to instructors. This obviously has significant implications, as most training for professionals in this field tends to be technique-led.

3. Formal/ Paid Carers

3.1 Beliefs about and understanding of challenging behaviour

Sigafoos, Elkins, Kerr & Attwood (1994) found that formal care staff often used fairly vague explanations (such as 'boredom' or 'frustration') for client challenging behaviour, and frequently offered multiple explanations for single behaviours. Staff surveyed by Harris & Russell (1989a) felt confident that they could usually offer an explanation for approximately 50% of incidents.
Hastings, Remington & Hopper (1995) found that both experienced and inexperienced staff tended to assign causations for challenging behaviour which were essentially consistent with contemporary behavioural theories, but that experienced staff were more likely to cite themes that were prominent in the literature (e.g. regarding the communicative function of challenging behaviour) and also to identify potential biological causes. Their analyses of potential functions also varied according to the topography of the behaviour (e.g. stereotypic behaviour commonly being regarded as being self-stimulatory). The inexperienced group tended to offer more explanations based on internal emotional states and antecedent environmental factors. The authors suggest that one possible reason for lack of success in programme implementation could be a mis-match between the views of staff and the principles of the intervention. Rasnake, Martin, Tarnowski & Mulick (1993) found no relationship between staff experience and the acceptability of behavioural interventions.

Oliver, Hall, Hales & Head (1996) used a structured questionnaire to test the understanding of self-injurious behaviour amongst four groups of carers, those in direct contact with self-injurious individuals, a group of hospital staff who were in contact with people with learning disabilities but who were not necessarily self-injurious, staff working at a special behaviour unit for children with learning disabilities, and behaviourally trained staff with qualifications in nursing and psychology. The direct contact group performed significantly more poorly than all the other groups overall and were significantly less likely to select correct behavioural explanations for example behaviours. They were also more likely to choose responses
that would be likely to reinforce self-injury, and to attribute behaviours to internal emotional responses. The behaviourally trained and behavioural unit staff fared significantly better than the hospital staff and contact groups. Furthermore, there were high and significant correlations between the tendency to select correct behavioural explanations for behaviours and the tendency not to select reinforcing responses for self-injury. Conversely, the tendency to make internal causal attributions were correlated strongly with the likelihood of selecting reinforcing responses. Translating these results into practice would mean that those in closest contact with self-injurious clients would be the staff most likely to engage in reinforcing consequences.

Furthermore, if those responsible for implementing techniques have a poor knowledge of those techniques, the chances of successful implementation are likely to be reduced and a dependence on outside experts fostered.

Bromley & Emerson (1995) found that 41% of carers from a variety of services attributed the challenging behaviours of specific clients to their internal state or mood, 26% to past or current environment, 24% to self-stimulation, 23% to communication, and 17% to attention seeking. Thus, factors over which staff could exert some control (e.g. communication) were very much in the minority, whereas those over which they had no influence (internal, general environmental) were more dominant. This could lead staff to feel that there is nothing that they can do to influence such behaviours, a state which Seligman has described as 'learned helplessness' (Seligman, 1975); the impact of any attempts at intervention via care staff under such
circumstances would obviously be greatly reduced as a consequence of low motivation.

Cottle, Kuipers, Murphy & Oakes (1995) focused specifically on attributions regarding violent incidents amongst staff on three hospital wards. Staff rarely blamed themselves for incidents, but instead attributed violent episodes to factors internal to the client, external to themselves, and as uncontrollable by themselves. One month post-incident, staff were more likely to attribute incidents to internal client factors. In a related study, Hastings (1995) found that staff felt that 74% of challenging behaviours were intentional. This is in clear contrast to research by Whittingham & Wykes (1996) which found that almost 90% of assaultive incidents in a psychiatric hospital were precipitated by staff initiated aversive interactions (e.g. demands, physical contact etc.)

3.2 Emotional responses

As with family carers, the emotional responses of staff may set the scene for the rapid termination of challenging behaviour and its subsequent avoidance. Hatton, Brown, Caine & Emerson (1995) found that violent client behaviour was a clear precipitant of staff stress. Bromley & Emerson (1995) asked individual staff members what percentage of their full staff team would feel certain emotional reactions to various challenging behaviours. Anger, annoyance and disgust, and despair, sadness and fear were found to form two inter-correlated clusters. For aggression, results suggested
that 41% of staff responses would be annoyance, 24% anger, and 19% fear; for self-injury, the results were sadness, 38%, despair 32%, anger 15%, and disgust 15%. Harris, Cook & Upton (1996) found similar responses amongst teachers of children with learning disabilities and challenging behaviour.

Hastings (1995) reported that such emotional reactions may diminish over time as staff habituate to client behaviours. In Bromley & Emerson's study, however, the wearing nature of challenging behaviour over time was identified as the most significant cause of carer stress (reported by 75% of all carers). Lack of effective intervention strategies for the behaviour, its unpredictability, and carers' inability to understand why the behaviour occurred were all significantly greater sources of stress than injuries to the person or others, or concerns about the physical strength of the client. Other sources of stress related to deficiencies in resources and staff skills and systems problems, such as lack of communication between staff.

Cottle et al (1995) found that anxiety levels increased by statistically significant levels following violent incidents, and returned to baseline within a month, although major individual differences were observed in this respect. Over 56% of staff made critical or hostile comments about the client concerned following the incident; this figure rose to over 66% after a month.

Although challenging behaviour acts as a clear stressor for staff, Lyall, Holland & Collins (1995) found very high rates of tolerance for offending behaviours. They found
that in only 6.6% of services would staff consider reporting minor assault to the police and in 23.3% would they report minor damage. Sexual assault or exposure would be reported in 23.3% of services, 26.7% would report theft, and 40% would report major assaults requiring medical attention. In 9.9% of services, staff indicated that they would be reluctant to report the rape of a staff member, co-client, or member of the public. In services where offences had actually occurred, however, there was generally a lower tolerance level. Anecdotal evidence suggested that staff responses were motivated by concerns about the negative consequences for clients should they report incidents or by beliefs that reporting incidents would be construed as a personal failure.

3.3 Behavioural responses

Hastings & Remington (1994 a, b) cite a variety of studies which demonstrate that staff typically have very low rates of engagement with learning disabled clients, but that a disproportionate amount of this attention is directed towards individuals with challenging behaviour. A number of studies have attempted to assess the nature of these interactions (Sandow, 1975; Maurice & Trudel, 1982; Hill & Bruininks, 1984; Intagliata, Rink & Calkins, 1986; Wilson, Reed & Bartak, 1995; Bromley & Emerson, 1995; Hastings, 1996). In general, these studies indicate a significant dependence on verbal strategies (giving attention, reprimands, coaxing) but with more intrusive responses (restraint, seclusion etc.) being used with more severe behaviours. Data from direct observational studies conflict with staff's own accounts of their responses to challenging behaviour. The former suggest that they are not likely to respond to
behavioural incidents, whereas self-report studies suggest that they are more likely to respond than not (Hastings & Remington, 1994a).

The overall theme in the literature is that immediate staff responses are typically unhelpful in that, while they may bring about short-term reductions in challenging behaviour, they are likely to be positively reinforcing for clients and negatively reinforcing for staff, and will therefore strengthen the behaviour of both parties in the long-term via differential and/or intermittent reinforcement schedules. Thus, Wilson et al (1995), in a study of staff responses to challenging behaviour in community living schemes, concluded that:

'**the aim of the staff was to immediately stop the behaviour, with no apparent consideration for the long-term consequences on the frequency and intensity of the target behaviour**'

(Wilson, Reed & Bartak, 1995, p. 137)

Hastings (1996) found that many immediate responses likely to be employed by staff involved the removal of social contact, and suggested that such actions are likely to be counter-therapeutic in many instances. This would only be the case, however, if the function of a particular behaviour was to escape from an aversive social situation; it would not be so if the function was gaining social attention (in which case, social withdrawal would act as a punisher). Whether or not a social or any other response
acts as a reinforcer will also depend upon its availability at times other than when the behaviour is displayed. Thus, if the only means via which carer attention can be obtained is to engage in self-injury, then the contingent provision of attention may act as a powerful reinforcer. However, if attention is provided at high rates and not contingent upon self-injury, then the possibility that it will reinforce self-injury is considerably reduced.

Criticisms such as those expressed by Wilson et al above may in turn be criticised as being naive. A duty of care (Dimond, 1990) will prevent staff from ignoring serious behaviours such as self-injury and aggression. It is also totally unrealistic, for example, to expect carers such as one described in the earlier quote from Qureshi (1993) to sit by and see their home gradually destroyed while they wait for 'ignoring' to take effect. As well as providing longer-term interventions aimed at behaviour change, intervention plans must therefore also include recommendations for short-term control via ecological change (the removal or modification of precipitating events) and reactive strategies (responses to out of control behaviours which minimise any possible reinforcing qualities) (LaVigna, Willis & Donnellan, 1989). In the absence of these components, it would appear that the chances of carers persisting with longer-term change strategies would invariably be limited. Indeed, it may be unreasonable to expect otherwise.

The staff in Hastings' (1996) study described immediate responses to challenging behaviour which may have been inappropriate in that they were potentially reinforcing,
but they also described longer-term interventions which were behaviourally appropriate, thus lending some support to the notion that it is in the area of reactive management that more work needs to be done. Although Hastings (1995) showed that staff were more likely to have received training in reactive approaches than proactive approaches, this has not been supported by other research (Harris & Russell, 1989b; Allen & Hill-Tout, 1995).

3.4 Training for staff

Hastings & Remington (1994b) have commented that the principles of applied behaviour analysis are not generally applied to staff behaviours. There is however a vast literature on the effectiveness of training techniques and organisational strategies for shaping staff behaviour (Reid & Schepis, 1986; Anderson, 1987; Reid, Parsons & Green, 1989). The general consensus at present is that simply training direct care staff is an ineffective strategy for change (Clements, 1993). Such training needs to take place within the context of a supportive management system and one that provides staff with clear models in terms of first line managers who will act as 'practice leaders' (McGill & Bliss, 1993; Mansell, Hughes & McGill, 1994). This has been demonstrated experimentally by Shore, Iwata, Vollmer, Lerman & Zarcone (1995), who found that the most effective procedure for getting staff to implement behavioural strategies with a group of clients displaying self-injurious, aggressive and disruptive behaviours was to train their supervisors in the approaches. A very thorough in-service training package, which the authors stress was significantly more intensive than most training usually
available to staff, had earlier failed to produce significant results. Peer training may also merit some investigation as informal workplace cultures undoubtedly exert a powerful influence on staff behaviour (Hastings & Remington, 1994b; Hastings, 1995). The value of more wide scale ecological or 'whole environment' interventions which focus on a wider array of organisational variables (e.g. selection procedures, quality assurance systems etc.) has also been described and demonstrated (Landesman-Dwyer & Knowles, 1987; Mansell et al, 1994; Hastings, Remington & Hatton, 1995; Harris et al, 1996).

Much of the literature in this area points to the fact that very little time is invested in proactive work which may prevent the occurrence of challenging behaviour. Rates of client engagement in constructive activity and staff assistance in services, for example, are known to be often extremely low (e.g. Felce, Lowe & Blackman, 1995), and it is highly likely that such conditions may set the scene for challenging behaviour to occur. Training for direct care staff needs to acknowledge that intervention needs to be both proactive and long-term if clinically significant gains are to be made (Carr, Robinson & Palumbo 1990).

In addition to training staff in specific techniques of intervention, support must be provided which acknowledges and deals with the strong emotions generated by challenging behaviours. This could be done both proactively, in terms of teaching carers stress management techniques which could be employed both routinely and at times of high arousal, and reactively, in terms of providing counselling and support in
the aftermath of severe behavioural incidents (Robb, 1995; Doyle, Dunn, Allen & Hadley, 1996). This is an extremely important but under-researched area. Failure to provide care staff with this kind of help may be an important precipitant of further behavioural incidents (Cottle et al, 1995; Whittington & Wykes, 1996) and could be implicated in the abuse of persons with challenging behaviour (Rusch, Hall & Griffin, 1986; Marchetti & McCartney, 1990).

5. General Conclusions & Implications

A number of points emerge from this review. Differences might be expected in the responses of natural and paid carers to challenging behaviours, and this is partly supported by the existing literature. These behaviours clearly provoke strong emotional responses in both groups, although embarrassment may be the more common emotion in the former and feelings of anger, frustration and annoyance may be more prevalent in the latter. Although both groups feel that they can explain about 50% of challenging behaviours, the nature of their attributions tend to vary. Parents appear to be reluctant to assign responsibility for challenging behaviour to their children, but staff are more likely to blame factors within the person, and less likely to acknowledge their own role in precipitating difficult incidents. Caution needs to be adopted regarding these conclusions, however, as they are based on a small number of studies and may simply reflect methodological differences. There is clearer evidence
that the presence of challenging behaviour is a stressor for both groups, the common feature being the fact that the frequently unremitting nature of these behaviours serves to grind carers down.

It is apparent that there has generally been less research carried out in this area with families than with paid carers. This may be partly because families of children with challenging behaviour are hard to access in that they may be disconnected from services (Turnbull & Ruef, 1996), or because services may be reluctant to expose them to the additional stress of participating in research projects (Qureshi, 1993). Our understanding of parental interpretations of and responses to challenging behaviour is therefore more limited; this is unfortunate because, although evidence for the long-term effectiveness of early intervention for severe behaviour problems is generally lacking (the work of Lovaas (Lovaas & Smith, 1994) being the obvious exception), logic would suggest that it would be easier to intervene with challenging behaviours of recent origin than with ones that had been established in a person's repertoire for many years.

While there is therefore a clear need for additional research on parental beliefs which parallels that undertaken with paid carers, there is an equivalent need for research on professionals attitudes to and assumptions about carers, a comparatively neglected but hugely important influence on intervention effectiveness (Donnellan & Mirenda, 1984).
For interventions to be effective, it is apparent that a broader range of approaches is indicated than has been adopted historically. Clearly, much more time and attention needs to be given to how carers construe the behaviours of those individuals in their care. A lack of congruity between the models employed by therapists and carers may explain much of the apparent reluctance to implement interventions reported in clinical practice. Attention also needs to be given to the understandably strong emotional reactions which challenging behaviours provoke. The use of cognitive-behavioural approaches with carers offers one possible means of making the link between beliefs and behaviour, and of establishing a platform for intervention which moves beyond simple contingency management (Kushlick, Trower & Dagnan, 1997). Stress reduction techniques to help carers cope with daily pressures can also be effective with both groups (Singer, Irvin & Hawkins, 1988; Todis & Singer, 1991; Rose, 1997).

Behavioural intervention procedures focused on the challenging behaviours themselves need to be based on best practice, and not on vague approximations to applied behaviour analysis. It would seem particularly important, as Taylor & Carr (1994) suggest in their work on social reciprocity, that functional analyses be extended beyond their traditional focus to include an assessment of the impact of the person with challenging behaviour on their environment (and not simply vice versa). Finally, interventions need to be multi-component, and to include both proactive behaviour change strategies and reactive behaviour management plans.

There are a number of additional implications for therapeutic intervention. Firstly, it is of major concern that so few families receive the kind of professional help which they
and their children so clearly deserve. It is of equal, if not greater concern, that when such help is provided, it is frequently viewed as being not particularly beneficial. Both issues are to some extent concerned with resources and service design.

The shortage in the availability of skilled professionals in this field can be partly addressed by the better use of the triadic model. Specialist support teams would seem to offer particular promise in that they are designed to give parents and other carers the kind of practical 'hands on' support which the literature suggests that they clearly value. It is important though that team members have an effective grounding in consultation skills as well as positive behavioural support techniques.

The adoption of a model which provides carers with practical assistance to develop effective behavioural interventions would also deal with another major criticism of current approaches. This is clinicians' over-reliance on verbal instruction to tutor carers in intervention techniques. As a developmental strategy, this is naive both in its conception and its execution. Very few carers are likely to achieve successful implementation on the basis of simply being told what to do. A more realistic approach is suggested by LaVigna, Willis, Shaull, Abedi & Sweitzer (1994) who advocate taking carers through a three stage skills acquisition process. Having first had the intervention modelled by behavioural specialists, carers then first achieve competence at describing the intervention (oral competence), then at role playing the intervention (analogue competence), and finally in terms of implementing the intervention under real life conditions (in vivo competence).
Perhaps the most critical point from this review is that interventions need to take into account the general ecology in which they are to take place if they are to be maximally effective and be able to demonstrate 'goodness of fit'. One recent assessment tool for challenging behaviour actually includes a mediator analysis amongst its contents (Willis, LaVigna & Donnellan, 1993) which could help enhance contextual fit.

Similarly, Albin et al (1996) provide an interview protocol and a checklist to aid in this process.

Almost three decades after Tharp & Wetzel (1969) advocated the use of natural carers as vehicles for behavioural change, it must be concluded that their potential has yet to be fully realised. A clearer understanding of the full complexity of the systems which Tharp & Wetzel described has, however, begun to develop. These systems involve cognitive and emotional aspects as well as behavioural components, and all these components need to be addressed if the full benefits of behavioural interventions are to be obtained.
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STUDY ONE:

Survival in the community: The prediction of placement outcome for mentally ill and mentally handicapped clients in local authority community residential facilities.

Survival in the Community: The Prediction of Placement Outcome for Mentally Ill and Mentally Handicapped Clients in Local Authority Community Residential Facilities

D.G. Allen

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ABSTRACT

108 residents from 13 Local Authority group homes and hostels were followed-up approximately two years after they had been assessed on a 52-item behaviour rating scale. Both mentally ill and mentally handicapped individuals were included in the sample, together with a small number of 'unclassified' subjects. The placement status of each resident at follow-up was recorded, together with any temporary re-admissions to hospital which had occurred in the two-year period since the initial assessments. It was found that a large majority of residents had 'survived' in the community with very few instances of temporary rehospitalisation, and that a substantial minority (almost 20%) of residents had achieved greater independence. Multiple regression analyses were used to identify possible personal, environmental and demographic characteristics associated with temporary rehospitalisation and movement to more independent or dependent living settings. When the sample was studied as a whole, temporary rehospitalisation was found to be associated with antisocial behaviour problems, neurotic tendencies and levels of sociability and activity, but no relationship was observed between any of the predictor variables and movement between residential units. When the mentally ill and mentally handicapped residents were studied separately, it proved possible to predict both rehospitalisation and residential movement for the former, but not for the latter. It was suggested that the scale may have some predictive validity for identifying 'at risk' individuals who might need additional support in order to remain in their community placements.
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One of the assumptions on which the philosophy of community care is based is that the majority of residents in both mental handicap and psychiatric hospitals could live successfully in the community given adequate support. The re-admission rates for these groups of patients, however, suggest that many individuals experience great difficulty in making this adjustment. McCrver & Craig (1974), in their review of studies on the community placement of mentally handicapped individuals conducted between the years 1948-68, found that the mean success rate (i.e., the number of residents remaining in the community) was 69%; this figure was derived from 44 studies with a follow-up time of between a few weeks and 20 years. Anthony, Cohen & Vitalo (1973), in a similar review of the research on placement outcome of psychiatric patients, found that at 5-10 year follow-up, only 25-30% had not been admitted at least once; this result was based on six studies conducted between 1964 and 1970.

Despite these somewhat depressing figures, there has been some recent evidence from the work of Leff et al (1982) that appropriate interventions with families of schizophrenic patients can significantly reduce relapse rates. Jacobsan & Schwartz (1983) have suggested a number of possible strategies, including the establishment of crisis stabilisation teams to augment existing care staff and a greater emphasis on counselling, which could serve to produce a similar reduction in re-admission rates for the mentally handicapped.

Being able to identify which individuals are likely to experience problems in adapting to life in the community would enable this additional support to be provided for 'at risk' individuals before a crisis point was reached and rehospitalisation became necessary. With
the growth in emphasis on community care in recent years, there has
been an increasing body of research devoted to identifying predictors
of successful and unsuccessful community placement. For the
mentally handicapped, predictors of successful placement have been
found to include levels of personal maintenance skills, communication
skills and degree of community integration (Schalock, Harper &
Carver, 1981); work skills and appropriate social behaviour
(Schalock, Harper & Omung, 1981); chronological age at release from
institution (McCarver & Craig, 1974); and time spent with parents
prior to institutionalisation (Jackson & Butler, 1963). The most
common predictor of re-institutionalisation seems to be the
presence of behaviour problems, and of anti-social tendencies in
particular (Landesman-Dwyer, 1981; Intagliata & Miller, 1982).

Work on predicting community placement outcome for de-
institutionalised psychiatric patients is generally less extensive
than that on the mentally handicapped. The best predictor of
rehospitalisation has consistently been found to be the previous
number of hospital admissions (Anthoney, Cohen & Vitalo, 1978),
although emotional climate within a patient's family, length of
hospital stay, and administrative policies concerning re-admission
have also been cited as being of importance (Bachrach, 1982).
Diagnosis has generally not been found to be related to placement
outcome.

More recent investigations have drawn attention to the need to
study the moderating influence of the environment on a client's
individual characteristics. Landesman-Dwyer (1981) and Miller &
Intagliata (1981) have emphasised the importance of both types of
variables in determining the successful placement outcome of mentally handicapped individuals. In the latter study, for example, individuals who exceeded the tolerance level for disruptive behaviour in both family care homes (private family homes caring for up to 3 mentally handicapped clients) and group homes (run by non-profit making agencies and catering for up to 10 individuals) were more likely to be re-admitted; the tolerance level for maladaptive behaviour was, however, considerably higher in the group homes. This meant that behaviour which led to rehospitalisation in one setting would be tolerated in the other; thus rehospitalisation was as much a function of the attitudes of the carers in the two environments as it was of the behaviour of the clients. The research into the social reactivity of schizophrenic and depressed patients (e.g., Vaughn & Leff, 1976) suggests that a similar interaction of individual and environmental factors may determine the outcome of community placements for certain psychiatric groups.

While the research outlined above has produced some consistent and useful findings, it can be criticised on several accounts. Lack of homogeneity of the research samples and community care facilities makes comparisons between the different studies difficult, and probably explains the variation in their results. Defining what constitutes a successful placement is in itself contentious (McCarver & Craig, 1974; Crawford et al, 1979; Landesman-Dwyer, 1981; Bachrach, 1982). The use of recidivism in isolation has been questioned because it fails to consider quantitative measures of community adaption. While this criticism is undoubtedly valid, as Anthony et al (1978) point out, recidivism is a standardised measure of placement outcome, has con-
siderable face validity, has traditionally served as a standard for programme planning and development and provides a data link with previous studies. On an individual level, rehospitalisation is also an extremely important outcome variable in that it may have serious effects on the motivation and confidence of both the client and his carers.

A more serious criticism is that the majority of studies look at the placement status of the client group at only one point in time. As Intagliata & Miller (1982) have stated, this means that those individuals who are hospitalised at the time the study is conducted are, in effect, assumed to be permanent community placement failures. These authors' own research certainly questions this assumption as far as the mentally handicapped are concerned. They found that almost 25% of their sample of 477 de-institutionalised subjects living in the community at the time of follow-up had been returned to hospital since discharge, with 12% having had two or more re-admissions.

By concentrating on a re-admission vs. non-re-admission outcome variable and by examining placement status at only one sampling point, the research has failed to investigate factors which may be prognostic of longer term community adjustment. If community care is to become the norm, then it will be important to identify factors associated with further movement along the continuum of community integration. Those individuals who adapt particularly well will, ideally, move away from hostels or group homes to more independent living settings. 'Problem' clients may benefit from the type of additional support
services described earlier, temporary rehospitalisation, as Intaglia and Miller (1982) have found, or a move to an establishment with higher staffing levels, more able to tolerate their difficult behaviour. Being able to predict which residents fall into these various categories could be helpful both in planning services, and in identifying those individuals likely to need extra support in order to remain in their residential setting or to move to a more independent one.

In what seems to be the only published paper on this particular aspect of predicting placement outcome, Schalock, Harper and Carver (1981) found that, for mentally handicapped clients, sensorimotor/work skills, appropriate socio-emotional behaviour, sex of the client and family support were associated with movement to more independent residential settings, while progress through a training programme was linked with measured intelligence and visual processing, language and psychomotor skills, education prior to community placement, institutional size and family involvement.

The present investigation is a follow-up study of residents in Local Authority group homes and hostels, originally surveyed by Allen and Hall (1981). Both mentally ill and mentally handicapped individuals were included in the group of 108 subjects, together with a small group of 'unclassified' residents. Each resident was followed-up two years after his/her initial assessment. The current placement status of each subject was recorded, together with the number of temporary rehospitalisations within the group and the degree of movement that had occurred between residential settings. A series of multiple regression analyses were performed in order to try and ascertain
whether the original data identified characteristics of the residents and of their environments which were associated with rehospitalisation and movement towards more independent living settings. Residents were also reassessed using the rating scale from the original survey in order to evaluate the consistency of their scores over time.

METHOD

(a) The Original Survey

The original data on the residents in the present study was collected between November 1979 and March 1980. A Mental Health Services Department requested some assistance in assessing the abilities and disabilities of residents in its 13 hostels and group homes. Staffing changes within the Department had brought to light the fact that very little information was available on these individuals. This meant, for example, that staff could not decide whether residents were currently in the most appropriate type of accommodation, and which homes and hostels were most suitable for new clients entering the service.

Only one of the residential units was purpose built. This was a large hostel which catered for 30 long-stay and 5 short-stay residents; only the long-stays were included in the survey. All the remaining residents were cared for in ordinary housing; the number of residents catered for in each of these houses varied between 4 and 11.

As both mentally ill and mentally handicapped clients were catered for within the same residential establishment, the prospective assessment package had to cover the potential disabilities of both these groups.
The scale eventually used was based on that originally devised by Kushlick et al (1973) (The "Wessex" Behaviour Rating System), incorporating some modifications suggested by Udall & Corbett (1976). As this scale was designed to assess the behavioural characteristics of the mentally handicapped, additional items were added to cover behaviours likely to be displayed by residents with a history of mental illness.

The final scale therefore consisted of a 13-item background information section and a 52-item resident assessment form. The background information sheet covered data such as age, diagnosis, total time in residential care and previous place of residence; this was completed wherever possible by reference to social service records. When this information was not available from case files, the data were obtained from care staff. The resident assessment form included 45 behaviour ratings; these were divided into five subscales, details of which are given below:

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Format</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>Three 5-point items assessing the content, intelligibility and compre-</td>
</tr>
<tr>
<td></td>
<td>hension of speech.</td>
</tr>
<tr>
<td>Incapacities</td>
<td>Sixteen 3-point items assessing the frequency of various problems (e.g.,</td>
</tr>
<tr>
<td></td>
<td>incontinence) or degree of lack of skill (e.g., self-help skills such as</td>
</tr>
<tr>
<td></td>
<td>washing and dressing).</td>
</tr>
</tbody>
</table>
Subscale                                      Format
Adaption to Environment                     Seven 3-point items assessing degree of participation in community and residential activities (e.g., participation in household jobs, sociability, degree of independence).

Behaviour Problems                          Thirteen 3-point items assessing the frequency of occurrence of problems (e.g., physical aggression, inappropriate sexual behaviour, self-injurious behaviour).

Psychiatric Symptoms                        Six 3-point items assessing the severity of specific symptoms (e.g., generalised anxiety, depression, mania).

The scale also included seven items relating to the use of various support services, attendance at places of occupation, physical handicaps and preferred social activities. The ratings were completed by the person who knew each resident best; this could be a member of the care staff, a non-resident housekeeper, or a member of the social services team. In two of the group homes there was no staff member available with a sufficiently detailed knowledge of the residents' behaviour, so the scales were completed with the assistance of a former member of the social services department.

Several procedures designed to enhance the reliability of the assessments were carried out. The purpose of the assessment was explained to each rater, who was then asked to complete a form on
a selected resident in the presence of the author. If there were any points which the rater did not fully understand, these could then be explained to him/her before further assessments were conducted. To ensure that each resident was assessed on the basis of his/her current behaviour, the raters were asked to base their completion of the form on the resident's behaviour over the 3-4 days prior to the assessment. Each rater also received some written notes regarding the completion of the scales.

Brief descriptive statistics derived from the original survey data are given in Section (a) of the results. The complete rating scale, the background information sheet and rater's guide are included in Appendix I. A published paper (Allen & Hall, 1981) giving further details of the survey forms Appendix II, while a statement of the author's role in the original work is given in Appendix III.

(b) The Follow-up Survey

All the residents assessed in the original survey were included in a follow-up study which was conducted between February and August, 1982. The first part of this study involved an examination of social service and hospital records in order to establish the current placement status of each resident and whether or not he/she had been re-admitted to hospital on any occasion during the two years since the initial assessment.

On the basis of this information, each resident was then classified as either having remained in his original place of residence, having moved to a more independent setting (e.g., from a group home to a flat), or having moved to a more dependent setting (e.g., from a group home to
staffed hostel, from a hostel to hospital etc.). Hospital re-admissions were coded in terms of frequency. These two variables - movement within residential settings and hospital re-admission - formed the dependent measures in the study. The main aim of the investigation was to examine whether it was possible to predict, on the basis of the data collected in 1979-80, which residents were likely to move along the continuum of community integration and which residents were likely to require temporary rehospitalisation.

In order to try and account for possible environmental influences on placement outcome, additional data were also collected regarding the general characteristics of each client's residential environment at the time of the initial study. This was coded in terms of three variables, one relating to the size of the residential unit, one to the level of staffing, and a third to the type of facilities provided at the unit. Residential unit size was based on the number of clients the unit catered for, and was rated on a 4-point scale. Staffing level was coded on a 3-point scale, ranging from minimal staff input (i.e., social worker pays occasional visits to monitor budgets, bills etc., residents do own cleaning and cooking), part-time support (i.e., housekeeper comes each day to do shopping and prepare meals), to maximum support (i.e., staffed hostel, care staff on premises 24 hours a day). A care facility type score was derived based on the criteria described by Butler & Bjaanes (1977). These authors classified community care environments into one of three categories. 'Custodial' environments are those in which there is a lack of planned activities and little emphasis on normalisation; such environments may lead to deterioration amongst their residents.
'Therapeutic' environments provide a more active programme of skill training and social integration. 'Maintaining' environments are those in which little change takes place in the ability of the residents. The authors claim that those environments can be differentiated on the basis of the following criterion measures:

<table>
<thead>
<tr>
<th>Criterion Measure</th>
<th>Therapeutic</th>
<th>Maintaining</th>
<th>Custodial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Habilitative Programmes</td>
<td>+</td>
<td>+-</td>
<td>-</td>
</tr>
<tr>
<td>Community Integration</td>
<td>+</td>
<td>+-</td>
<td>-</td>
</tr>
<tr>
<td>Recreational Activities</td>
<td>+</td>
<td>+-</td>
<td>-</td>
</tr>
<tr>
<td>Sheltered Workshop Participation</td>
<td>+</td>
<td>+-</td>
<td>-</td>
</tr>
<tr>
<td>Social Participation in Chores</td>
<td>+</td>
<td>+-</td>
<td>-</td>
</tr>
<tr>
<td>Active Caretaker Involvement in Care</td>
<td>+</td>
<td>+-</td>
<td>-</td>
</tr>
<tr>
<td>Daily Activity Routine</td>
<td>+</td>
<td>+-</td>
<td>-</td>
</tr>
</tbody>
</table>

(+ = facility available, - = facility not available)
(from Butler & Bjaanes, 1977).

As part of the following study, the author rated the presence or absence of each of the above facilities in each group home/hostel on a 3-point scale. The rating was carried out on the basis of information provided by the social services department and following discussions with the social workers responsible for the supervision of the unit. A score of 1 indicated that the facility was a well-established feature of the residential unit. A score of 2 indicated that the facility was available, but not provided as a matter of routine, and a score of 3 indicated that the facility was not available.
This yielded a unit facility score of 7-21. This variable, together with those relating to unit size and staffing levels, were added to an existing computer file containing the original survey data.

The second part of the study was essentially a replication of the original survey. As many residents as possible were re-assessed using the 52-item resident assessment form; this enabled the stability or otherwise of their scores over time to be examined. Wherever possible, the rater who assessed the resident initially was asked to complete the new assessment. A sample of 20 residents were each assessed by two different raters in order to obtain a measure of inter-rater reliability for the 45-behavioural items on the scale. A further sample of 23 residents had their follow-up assessment scores on the 45-behaviour items of the survey instrument compared to their most recent scores on an assessment scale at a psychiatric day hospital in order to obtain a crude measure of concurrent validity. The day hospital scale was completed on each client by nursing and occupational therapy staff approximately every six months. The scale had been devised with the help of a psychologist working within the hospital and consisted of 22-items rated on 10-point linear scales; behaviours covered in the scale included incontinence, physical violence, stealing, picking up rubbish, managing money and using public transport. A copy of the day hospital scale is included in Appendix IV.

(c) Analyses

As a preliminary to conducting the main analyses, a principal component analysis of the 45 behaviour items in the resident assessment form was performed. This was because the subscales which made up the
fora were not based on any empirical data, and could not therefore be used with any confidence in analysing the predictive validity of the scale.

A number of factors were derived from this analysis; the residents' computed scores on these factors, together with the demographic data on the residents and the information relating to environmental characteristics, were then used in the predictive analysis. A series of multiple regressions were performed in order to examine possible relationships between these variables and the two outcome variables of movement between residential settings and number of hospital re-admissions. Multiple regression was used in order to obtain a measure of the overall dependence of the outcome variables on the predictor variables. All multivariate statistics used in the study were performed using the Statistical Package for the Social Sciences (Nie et al, 1975).

Inter-rater reliability of the scale data was analysed using the weighted Kappa statistic (Hall, 1974). The Spearman Rank Correlation coefficient was used to examine the concurrent validity of the scale and the stability of the residents scores over the two-year follow-up period.

RESULTS
(a) Descriptive Statistics from the Original Survey

The sample consisted of 40 males and 68 females. While a formal diagnosis was available from medical records for 83 residents,
'informal' diagnoses were also obtained on the basis of information contained in social service records (e.g., on allowance and benefit claims, transfer documents, reports from institution of origin etc.). In the analysis of the data, informal diagnosis was used to split the sample as this resulted in fewer missing cases. For residents where it was possible to obtain both formal and informal diagnoses, the agreement between these was 96.6%. Because of the lack of information available in the social services records, there were a number of residents for whom it was not possible to obtain either a formal or informal diagnosis; these residents were placed in an 'unclassified' category.

The mentally handicapped group were slightly younger overall than the mentally ill. The former had an age range of 17-69 years and a mean age of 46.5 years (s.d. = 14.7), whereas the latter had an age range of 30-37 years with a mean of 39 years (s.d. = 10.4). The majority of the sample overall (53%) had come to the hostel/group home from a psychiatric or subnormality hospital. 15% had been transferred from another hostel. 23% of the mentally handicapped group had lived previously with their parents. The mean length of time spent living in the current residential unit was 5 years 8 months for the group overall with a range of between 4 months and 16 years 7 months.

The score range and mean score for the mentally ill and mentally handicapped on the original five subscales are given overleaf:
TABLE 1: Score Range and Mean Scores of Mentally Ill (n = 45) and Mentally Handicapped (n = 52) on Original Subscales

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Possible Range</th>
<th>Actual Range</th>
<th>Mean</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>3-15</td>
<td>MI 3-14</td>
<td>4.09</td>
<td>2.30</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MH 3-13</td>
<td>5.46</td>
<td>2.17</td>
</tr>
<tr>
<td>Incapacities</td>
<td>16-48</td>
<td>MI 16-32</td>
<td>18.29</td>
<td>3.18</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MH 16-34</td>
<td>20.59</td>
<td>3.94</td>
</tr>
<tr>
<td>Adaptation to</td>
<td>7-21</td>
<td>MI 7-19</td>
<td>11.51</td>
<td>3.42</td>
</tr>
<tr>
<td>Environment</td>
<td></td>
<td>MH 7-18</td>
<td>11.01</td>
<td>2.79</td>
</tr>
<tr>
<td>Behaviour Problems</td>
<td>13-39</td>
<td>MI 13-27</td>
<td>15.47</td>
<td>3.35</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MH 13-24</td>
<td>16.53</td>
<td>3.40</td>
</tr>
<tr>
<td>Psychiatric Symptoms</td>
<td>6-18</td>
<td>MI 6-13</td>
<td>7.89</td>
<td>1.62</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MH 6-11</td>
<td>6.76</td>
<td>1.23</td>
</tr>
</tbody>
</table>

While both groups of residents produced quite a wide range of scores on each subscale, scores generally were low, indicating relatively low levels of disability in the majority of residents. Overall, the two groups were very similar both in the type and frequency of problems they displayed. There were clear differences in some areas, however. Approximately 60% of the mentally handicapped residents had problems on each of the three items in the communication subscale as opposed to 20-29% of the mentally ill group. 70% of the mentally handicapped had some difficulty in using money compared to 20% of the mentally ill. Only 52% of the mentally handicapped made some use of public transport compared to 80% of the mentally ill, and the former needed much more supervision generally (33 vs. 6.6%).
(b) **Factorial Analysis**

The principal components analysis of the 45 behaviour ratings for the 108 subjects in the original survey yielded 12 factors. 7 of these were significant according to the criterion described by Kaiser (Childs, 1970); this states that only factors having eigenvalues greater than one can be considered as common factors.

The significance of each factor loading was determined using the Burt-Banks formula (Childs, op. cit.). This allows for the gradual intrusion of unique variance into later factors by adjusting the significance level; it also takes into account the number of variables and the sample size. Individual items were allocated to factors on which they had their highest factor loading. Details of the seven significant factors are given in Table 2.

Factor I seems to be made up of items relating to community skills and degree of independence. Factor II is made up primarily of items from the Behaviour Problems subscale, and might best be termed 'Antisocial Behaviour'. The third factor taps both 'personal maintenance' skills and some additional behaviour problems; while the behaviour problems in Factor II were largely directed towards others, however, several of the behaviour problems in Factor III are self-directed. Factor IV is mostly made up of items relating to incontinence and Factor V contains the language items. The sixth factor appears to tap two types of behaviour, sociability and activity. Finally, Factor VII consists of items from the Psychiatric Symptoms subscale relating to neurotic tendencies. Together, these seven factors accounted for 85.1% of the total item variance.
<table>
<thead>
<tr>
<th>Factor</th>
<th>Loading (sig. level .01)</th>
<th>Eigen Value</th>
<th>Cumulative Variance</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independence</td>
<td>.8968</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Road Safety</td>
<td>.8908</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use of Public Transport</td>
<td>.8528</td>
<td>7.567</td>
<td>27.1</td>
</tr>
<tr>
<td>Money Sense</td>
<td>.7056</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Awareness of Danger</td>
<td>.6091</td>
<td></td>
<td></td>
</tr>
<tr>
<td>II</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verbally Aggressive</td>
<td>.7597</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disturbs other Residents</td>
<td>.7496</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attention seeking</td>
<td>.7150</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domineering with other residents</td>
<td>.7032</td>
<td>5.123</td>
<td>45.4</td>
</tr>
<tr>
<td>Emotional lability</td>
<td>.5875</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resistance to change</td>
<td>.4791</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physically aggressive</td>
<td>.4555</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mania</td>
<td>.3973</td>
<td></td>
<td></td>
</tr>
<tr>
<td>III</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeds self</td>
<td>.9502</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self injury</td>
<td>.9502</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dressing</td>
<td>.6035</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Washes Self</td>
<td>.5304</td>
<td>3.244</td>
<td>57.1</td>
</tr>
<tr>
<td>Destructive tendencies</td>
<td>.4177</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hallucinations</td>
<td>.4073</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self stimulatory behaviour</td>
<td>.3739</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
TABLE 2 cont:

<table>
<thead>
<tr>
<th>Factor</th>
<th>Loading (sig. level .01)</th>
<th>Eigen Value</th>
<th>Cumulative % Variance</th>
</tr>
</thead>
<tbody>
<tr>
<td>IV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wets (night)</td>
<td>.7293</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wets (day)</td>
<td>.7982</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Soils (day)</td>
<td>.6848</td>
<td>2.463</td>
<td>65.9</td>
</tr>
<tr>
<td>Confusion</td>
<td>.5179</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Soils (night)</td>
<td>.4910</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supervision taking medication</td>
<td>.2938</td>
<td></td>
<td></td>
</tr>
<tr>
<td>V</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intelligibility of speech</td>
<td>.8489</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Content of speech</td>
<td>.7872</td>
<td>2.217</td>
<td>73.8</td>
</tr>
<tr>
<td>Comprehension</td>
<td>.7743</td>
<td></td>
<td></td>
</tr>
<tr>
<td>VI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activity level</td>
<td>.7473</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sociability with residents</td>
<td>.6887</td>
<td>1.893</td>
<td>80.4</td>
</tr>
<tr>
<td>Organisation of activities</td>
<td>.6663</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sociability with staff</td>
<td>.5617</td>
<td></td>
<td></td>
</tr>
<tr>
<td>VII</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>.7073</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>.6158</td>
<td>1.296</td>
<td>85.1</td>
</tr>
<tr>
<td>Hypochondria</td>
<td>.4303</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phobias</td>
<td>.4090</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
While the analysis produced logically attractive factors, the results need to be treated with some caution. As Everitt (1975) has stated, the minimum subject : variable ratio necessary to be able to perform multivariate statistics with confidence needs to be in the region of 5:1; in the present study this ratio was just over 2:1, so the stability and independence of the factors produced could not be regarded as conclusively established. In an attempt to validate the factors, two random samples were generated from the total sample of 108 with a view to subjecting these samples to further principle component analysis. This would have enabled some measure of the stability of the factors to be obtained. The resulting reduction in sample size produced statistical complications which meant, however, that further analyses were not viable.

In spite of these qualifications, the new factors were adjudged to have greater validity than the original subscales. Each resident's total score on each of the seven factors was therefore computed and the new variables so derived added to the computer file.

(c) Rating Scale Reliability and Validity

i) Inter-rater Reliability

The most common methods of assessing reliability are deriving a correlation between total scores of subjects, calculating percentage agreement between raters, or applying the Chi-squared test. As Hall (1974) has pointed out, these methods make a number of assumptions about the data which may not be justified. It is assumed, for example, that scores are normally distributed, that
total scores are meaningful, chance agreement is negligible and that the mean scores of each rater are similar. Each of the assumptions is questionable where rating scale data are concerned. The weighted kappa statistic described by Hall (op. cit.) but originally derived by Cohen (1968) takes into account these limitations, and of chance agreement and relative level of disagreement between raters in particular. Weighted kappa can have a value ranging for +1 (indicating perfect positive agreement) through to 0 (chance agreement) to -1 (perfect negative agreement); it is therefore interpreted like a correlation coefficient.

In the present study, 20 residents were assessed by two different raters. The agreement between these two raters, as indicated by weighted kappa, on each of the seven factors derived from the principal components analysis is shown in Table 3.

**TABLE 3: Weighted Kappa Values of Scale Factors (n = 20)**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Weighted Kappa</th>
</tr>
</thead>
<tbody>
<tr>
<td>I (Community skills/independence)</td>
<td>.482</td>
</tr>
<tr>
<td>II (Antisocial behaviour)</td>
<td>.654</td>
</tr>
<tr>
<td>III (Personal maintenance skills/problem behaviours)</td>
<td>.593 -</td>
</tr>
<tr>
<td>IV (Incontinence)</td>
<td>.541</td>
</tr>
<tr>
<td>V (Language)</td>
<td>.031</td>
</tr>
<tr>
<td>VI (Sociability/activity)</td>
<td>.546</td>
</tr>
<tr>
<td>VII (Neurotic 'symptoms')</td>
<td>.654</td>
</tr>
</tbody>
</table>

The results of this analysis indicate that the inter-rater reliability of the scale is at best modest. The weighted kappa value for the language factor indicates that agreement on this
factor was no better than on a chance basis. On the remaining six factors, the value of weighted Kappa ranged between .48 and .65. The most reliable factors were those relating to antisocial behaviour (Factor II), neurotic 'symptoms' (Factor VII) and personal maintenance skills (Factor III).

ii) Test-retest reliability

It proved possible to reassess 96 of the original 108 residents on the 52-item assessment form; the shortfall was largely accounted for by deaths, moves to other agencies and moves to other geographical areas. Of those who were reassessed, 64 (66.7%) were re-rated by those care staff who had completed the initial assessment. The correlation between residents' initial and follow-up scores on each of the seven factors produced by the principal components analysis was determined using the Spearman Rank Correlation Coefficient; the significance of rs was calculated using the t statistic. The results are given in the following table.

<table>
<thead>
<tr>
<th>Factor</th>
<th>rs</th>
<th>t</th>
<th>Sig. level (for 2-tailed test)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I (Community skills/independence)</td>
<td>0.22</td>
<td>2.13</td>
<td>.05</td>
</tr>
<tr>
<td>II (Antisocial behaviour)</td>
<td>0.55</td>
<td>5.32</td>
<td>.001</td>
</tr>
<tr>
<td>III (Personal maintenance skills/ problem behaviours)</td>
<td>0.44</td>
<td>4.26</td>
<td>.001</td>
</tr>
<tr>
<td>IV (Incontinence)</td>
<td>0.43</td>
<td>4.16</td>
<td>.001</td>
</tr>
<tr>
<td>V (Language)</td>
<td>0.05</td>
<td>0.49</td>
<td>not significant</td>
</tr>
<tr>
<td>VI (Sociability/activity)</td>
<td>0.65</td>
<td>6.28</td>
<td>.001</td>
</tr>
<tr>
<td>VII (Neurotic 'symptoms')</td>
<td>0.21</td>
<td>2.04</td>
<td>.05</td>
</tr>
</tbody>
</table>
These results indicate that, with the exception of the language factor, there was a significant correlation between residents' initial and follow-up scores on each factor. For Factors I and VII, this correlation was significant at the 0.05 level and for Factors II, III, IV and VI at the 0.01 level. This suggests that there was not a great deal of change in residents' scores over the two-year follow-up period. Again, this statement needs to be qualified in that these correlations are between scores on groups of items; while the total scores on the various factors may have been very similar at each assessment, within each factor there may have been some variation. The non-significant correlation between the two scores on the language factor (Factor V) probably reflects its low inter-rater reliability rather than significant changes in the residents.

iii. Concurrent Validity

This analysis was based on a sample of 23 mentally ill residents who attended a local psychiatric day hospital. The correlation between the residents' follow-up scores on the 52-item survey scale and their most recent assessment on the 22-item day hospital scale was again analysed using the Spearman Rank correlation coefficient, the significance of rs being determined by the t statistic.

When subjects' total scores on the 52- and 22-item scales were compared, rs was found to be 0.436 which was significant at the .05 level for a two-tailed test.
In view of the different lengths of the two scales and, therefore, the different range of behaviours covered therein, a further analysis was carried out which involved comparing the subjects' scores on the 15 items of behaviour which were common to each scale (these items are listed in Appendix IV). In this second analysis, r was found to be 0.738 which was significant at the .001 level for a two-tailed test.

The results indicate a significant positive correlation between residents' scores on the two scales, suggesting that the survey scale had some degree of concurrent validity. This conclusion can only be stated in very tentative terms because no measures of reliability or validity were available for the day hospital scale, and it is possible that this scale itself had low reliability and validity. In spite of these shortcomings, however, this comparison does clearly suggest that the two sets of ratings have a broad degree of agreement.

(d) Placement Status and Frequency of Temporary Hospital Re-admissions at 2-Year Follow-up

Changes in the placement status of the 58 residents in the original survey are given in Table 5.
### Table 5: Placement Status of Residents at 2-year Follow-up

<table>
<thead>
<tr>
<th>Category</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Remained in original residential setting</td>
<td>66</td>
</tr>
</tbody>
</table>

#### Administrative Moves

- Moved to another hostel within the county | 14|
- Moved to another Authority/agency          | 2|

#### Other Moves

- Hostel $\rightarrow$ Flat                  | 19|
- Hostel $\rightarrow$ Hospital              | 2|
- Hostel $\rightarrow$ Part III accommodation| 2|
- Deceased                                    | 3|
These results indicated that of the 105 residents who were still alive at the time of the follow-up study, 66 (64%) had remained in their original place of residence. 39 residents had moved to a new residential setting. 14 of the residents in the latter group had been moved from one hostel to another similar one in order to create one residential unit catering exclusively for the mentally ill and another for the mentally handicapped; it will be recalled that, previously, the general policy of the social services department was that both groups of residents were catered for under one roof. A further two residents were now cared for by another agency or Authority. The movement of these 16 residents had come about through purely administrative decisions, and had involved no change in levels of independence and dependence for the residents. For the remainder of the analysis, this group of 16 were therefore considered to have remained in a residential setting equivalent to that which they were in at the time of initial study.

This left a group of 23 residents who could be considered to have had moves not due to administrative changes. 19 residents had moved from hostels or group homes to flats (both council and privately owned); 4 pairs of residents were sharing flats, but the remaining 11 residents had moved independently. This group were classified as having moved to more independent settings in that they had less supervision and were more responsible for their domestic arrangements than in their previous accommodation. Two residents had gone back into hospital; it was generally accepted by both Local Authority and Health Service staff that these would probably be permanent re-admissions. Two older residents had left the hostels for the care of an old people’s home.
Together, these four residents were considered to have moved to more dependent settings. The summary results on the outcome variable of residential movement are given in the following table:

**TABLE 6: Summary of Moves/Non-moves (n = 105)**

<table>
<thead>
<tr>
<th>Moved to more independent residential setting</th>
<th>Moved to more dependent residential setting</th>
<th>Remained in original/ equivalent residential setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>19</td>
<td>4</td>
<td>82</td>
</tr>
</tbody>
</table>

An analysis of movement within residential setting by diagnosis is given in Table 7. Twice as many mentally handicapped as mentally ill individuals moved to more independent living settings, but otherwise there was little difference between the groups.

**TABLE 7: Analysis of Movement by Diagnosis (n = 105)**

<table>
<thead>
<tr>
<th>DIAGNOSIS</th>
<th>Mentally Ill</th>
<th>Mentally Handicapped</th>
<th>Unclassified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moved to more independent settings</td>
<td>6</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>Remained in original/ equivalent setting</td>
<td>37</td>
<td>37</td>
<td>8</td>
</tr>
<tr>
<td>Moved to more dependent setting</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

The number of temporary hospital re-admissions during the two-year follow-up period is given in Table 8. Five re-admissions had occurred in the mentally ill group, as opposed to one in the mentally handicapped group and one in the unclassified group. Six of these
residents had been re-admitted on one occasion, and one resident on two occasions. The first re-admission in the group occurred just over five months after the initial survey was conducted. The duration of the re-admissions was generally between a few days and two weeks.

**TABLE 8: Frequency of Temporary Hospital Re-admission by Diagnosis (n = 105)**

<table>
<thead>
<tr>
<th>Number of Re-admissions</th>
<th>Mentally Ill</th>
<th>Mentally Handicapped</th>
<th>Unclassified</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>38</td>
<td>59</td>
<td>10</td>
</tr>
<tr>
<td>1</td>
<td>4</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

To summarise, the follow-up data indicated that approximately 20% of the residents had moved residence for other than purely administrative reasons, but only a very small number (less than 7%) had undergone temporary rehospitalisation. The latter finding is interesting in that it demonstrates that the majority of residents had 'survived' in the community without the support of occasional hospital stays, while the degree of movement between residential settings was perhaps surprisingly large given the relatively short follow-up period.

(e) **Multiple Regression Analyses**

Prior to performing the multiple regression analyses, cross-tabulations of the residents' original scores on the seven factors, the environmental variables and demographic data against the two outcome variables were obtained in order to identify possible
TABLE 9: Cross-Tabulations of Prediction Variables by Outcome Variables

<table>
<thead>
<tr>
<th>Predictor Variable</th>
<th>Outcome Variable</th>
<th>n</th>
<th>$\chi^2$</th>
<th>df</th>
<th>Sig. level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor VI Score (Sociability/Activity)</td>
<td>Movement between residential settings</td>
<td>108</td>
<td>34.85</td>
<td>21</td>
<td>.0293</td>
</tr>
<tr>
<td>Factor II Score (Antisocial Behaviour)</td>
<td>Temporary Hospital re-admission</td>
<td>108</td>
<td>32.11</td>
<td>14</td>
<td>.0039</td>
</tr>
<tr>
<td>Factor VI Score (Sociability/Activity)</td>
<td>Temporary Hospital re-admission</td>
<td>108</td>
<td>18.99</td>
<td>7</td>
<td>.0082</td>
</tr>
<tr>
<td>Factor VII Score (Neurotic 'Symptoms:')</td>
<td>Temporary Hospital re-admission</td>
<td>108</td>
<td>22.68</td>
<td>5</td>
<td>.004</td>
</tr>
<tr>
<td>Number of Previous Hospital Admissions</td>
<td>Temporary Hospital re-admission (Mentally Ill Residents only)</td>
<td>43</td>
<td>20.06</td>
<td>11</td>
<td>.0445</td>
</tr>
</tbody>
</table>
significant relationships. The significant cross-tabulations are recorded in Table 9. Residents' scores on the factor related to sociability and activity appeared to be associated with movement between residential units, while hospital re-admission was linked with sociability and activity, neurotic symptoms, antisocial behaviour and number of previous hospital admissions. No significant relationships were therefore observed between the outcome variables and the environmental or demographic variables, other than between re-admission and previous number of admissions (which was significant in the mentally ill group only).

These relationships were then subjected to further analyses using the S.P.S.S. subprogramme REGRESSION. Cases with missing data were eliminated using the default option which employs listwise deletion of data. While sample size is often greatly reduced using this method, it is preferable on statistical grounds to the alternative of pairwise deletion of data which may produce computational inaccuracies and statistical anomalies (Nie et al., 1975). Analyses were performed initially on the whole sample of 108 residents, and then on the groups of mentally ill and mentally handicapped individuals separately. Detailed statistics are provided in Appendix V, but the key findings are given in Tables 10 and 11.

The inter-correlations between the predictor variables are given in Table 1 of Appendix V. All the inter-correlations were low, and therefore there were no problems of multicollinearity (a situation where the inter-correlations between some, or all, of the dependent variables are high, placing restrictions on both the analysis and interpretation of the relative contribution of each variable).
TABLE 10: Significant Regressions for Whole Sample (n = 108)

<table>
<thead>
<tr>
<th>Predictor Variables</th>
<th>Outcome Variable</th>
<th>Multiple R</th>
<th>$R^2$</th>
<th>Standard Error</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor II (Anti-social Behaviour)</td>
<td>Temporary Hospital Admission</td>
<td>.43</td>
<td>.18</td>
<td>.23</td>
<td>7.72*&lt;sup&gt;2&lt;/sup&gt; (df 3, 104)</td>
</tr>
<tr>
<td>Factor VI (Sociability/Activity)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factor VII (Neurotic Symptoms)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* sig. .01 level
The only regression which was significant for the whole sample was that of rehospitalisation on Factors II (Antisocial Behaviour), VI (Sociability/Activity) and VII (Neurotic 'Symptoms'). The sign of the regression coefficient (R) indicates the direction of the relationship between the predictor and outcome variables. The coefficient of determination (R²), which is the proportion of the variance explained by the variables in the regression equation, reflects the overall accuracy of the prediction. The standard error of estimate for the regression equation indicates the prediction accuracy in absolute units. Thus, for the whole sample, 18% of the variance on the variable of temporary rehospitalisation is accounted for by the variables Factors II, VI and VII operating jointly. The standard error of estimate is .23, indicating that, on average, predicted scores on the rehospitalisation variable (which is measured in absolute frequency) will deviate by .23 scaled units from the actual score. The overall F value of 7.72 indicates that the observed linear association is statistically significant at the .01 level.

Table 11 shows the significant regressions for the mentally ill group. In a bivariate regression, Factor VI accounts for 18% of the variance on the outcome variable of movement between residential settings. Factors II, VI and VII, together with number of previous hospital admissions, account for 46% of the variance on temporary rehospitalisation. By consulting Table 3 in Appendix V, it can be seen that residents' scores on Factors II and VII account for the bulk of the variance in the regression equation with Factor VI scores and the number of previous hospital admissions making only a minimal contribution. Both regressions are positive and significant at the .05 level.
<table>
<thead>
<tr>
<th>Predictor Variables</th>
<th>Outcome Variables</th>
<th>Multiple R</th>
<th>R²</th>
<th>Standard Error</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor VI (Sociability/Activity)</td>
<td>Movement between residential settings</td>
<td>.43</td>
<td>.18</td>
<td>.47</td>
<td>4.68* (dF 1,21)</td>
</tr>
<tr>
<td>Factor II (Antisocial Behaviour)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Factor VI (Sociability/Activity)</td>
<td>Temporary Hospital Re-admission</td>
<td>.68</td>
<td>.46</td>
<td>.34</td>
<td>3.77* (dF 4,18)</td>
</tr>
<tr>
<td>Factor VII (Neurotic &quot;Symptoms&quot;)</td>
<td>Number of Previous Admissions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Sig at .05 level
Table 11 shows the significant regressions for the mentally ill group. In a bivariate regression, Factor VI accounts for 18% of the variance on the outcome variable of movement between residential settings. Factors II, VI and VII, together with number of previous hospital admissions, account for 46% of the variance on temporary rehospitalisation. By consulting Table 3 in Appendix V, it can be seen that residents' scores on Factors II and VII account for the bulk of the variance in the regression equation, with Factor VI scores and the number of previous hospital admissions making only a minimal contribution. Both regressions are positive and significant at the .05 level.

No significant regressions were obtained for the group of mentally handicapped residents when analysed separately.

Individual's expected scores on the outcome variables may be computed on the basis of their scores on the predictor variables by applying the formula:-

\[ Y = A + B_1X_1 + B_2X_2 \ldots \ldots B_kX_k \]

where

- \( Y \) = estimated value of outcome variable
- \( A \) = intercept (constant)
- \( B_i \) = regression coefficients
- \( X \) = value of predictor variables

While the quality of the data in the present study does not really merit further analysis of this sort, to illustrate this procedure and to test the accuracy of the predicted scores, these were calculated for the group of 45 mentally ill residents on the two outcome variables.

* This analysis was performed on a UNI Spectrum Computer.
The residents' predicted and actual scores are given in Tables 1 and 2 in Appendix VI, but summary findings are given in Tables 12 and 13.

Adopting a cut-off point of 0.6 on the temporary hospital re-admission variable (i.e., score > 0.6 indicates resident likely to be rehospitalised) results in 42 correct predictions (4 re-admitted, 38 not re-admitted), two false-positives (i.e., resident's predicted score indicated re-admission, but resident remained in community), and one false-negative (i.e., resident's predicted score did not indicate re-admission, but rehospitalisation did in fact occur).

<table>
<thead>
<tr>
<th></th>
<th>Cut off point = 0.6</th>
<th>Cut off point = 0.4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Re-admitted</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Correctly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Classified</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not re-admitted</td>
<td>38</td>
<td>37</td>
</tr>
<tr>
<td>False Positives</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>False Negatives</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

Adopting a cut-off point of 0.4 produced 42 correct classifications (5 re-admitted, 37 not re-admitted), three false positives and no false negatives. False negatives are generally considered to be more serious than false-positives; in this instance, a false-negative would mean that a resident potentially at risk of being rehospitalised would not be identified as such. In the present analysis, selecting the lower
cut off point of 0.4 would seem appropriate because this successfully identified all the residents who were in fact rehospitalised and, at the same time, produced no false-negatives.

**TABLE 13: Prediction Accuracy for Mentally Ill Group on Outcome Variable of Movement between Residential Settings**

<table>
<thead>
<tr>
<th>Cut-off points</th>
<th>Correctly classified</th>
<th>False-Positives</th>
<th>False-Negatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;2</td>
<td>13</td>
<td>30</td>
<td>2</td>
</tr>
</tbody>
</table>

Prediction accuracy was much lower on the outcome variable of movement between residential settings (see Table 13): particularly noticeable is the large number of false-positives. Adopting a cut-off point of less than 2 to indicate movement to a more dependent setting and greater than 2 to indicate movement to a more dependent setting produced only 13 correct classifications, 30 false-positives and 2 false-negatives. The explanation for this is that, whereas the predictor variables in the re-admission regression equation accounted for 46% of the variance, Factor VI scores account for only 16% of the variance on the residential movement variable. Similarly, while the regression of hospital re-admission on Factors II, VI and VII was significant for the whole sample, predicted scores derived from this regression would be generally far less accurate than those computed from the regression for the mentally ill group, as the latter accounts for a far greater percentage of the variance.

**Summary:** When the whole sample of residents are considered together, it is possible to predict their likelihood of temporary rehospitalisation
on the basis of their scores or factors II, VI and VII. It is not possible to identify which clients were likely to move to new residential settings. When the group is split by diagnosis, it is possible to identify variables associated with both rehospitalisation and movement between residential units for the mentally ill, but not for the mentally handicapped. Degree of prediction accuracy is variable, but most accurate when predicting rehospitalisation amongst the mentally ill group.

**DISCUSSION**

This report describes a follow-up study of mentally ill and mentally handicapped residents in local authority community care facilities two years after the residents had initially been studied in a survey designed to assess their behavioural characteristics. At follow-up, it was discovered that only a very small number of residents had undergone temporary rehospitalisation in the period since the original study, but approximately 20% had moved to more independent living settings. A series of multiple regression analyses were performed in order to try to identify factors associated with rehospitalisation and movement between residential units. It was proposed that being able to predict 'at risk' individuals would potentially enable additional support to be provided for these clients in order to maximise their chances of succeeding in community placements. The results showed that, despite the inclusion of variables relating to environmental and demographic characteristics, the only predictors which were identified were those relating to the individual behaviour ratings. Temporary rehospitalisation, in agreement with much of the previous work in this field, was
found to be associated with antisocial behaviour problems, but also with the presence of neurotic tendencies and levels of sociability and activity; this relationship was found in the sample overall, but predictive accuracy was far greater when the mentally ill group was considered separately. It was not possible to predict rehospitalisation for the mentally handicapped when they were analysed as a separate group. Predicting movement between residential units did prove possible, but with low accuracy and, again, only in the group of mentally ill clients; this was also associated with residents' sociability and activity. This difference between the groups was particularly interesting given that twice as many mentally handicapped as mentally ill residents moved to more independent settings.

The fact that when the group was split by diagnosis predictors were only identified for the mentally ill group may indicate that individual characteristics are of prime importance in determining placement outcome for this client group, but that for the mentally handicapped environmental variables play a far greater role. Diagnosis in this instance could be regarded as a 'moderator' variable (Ghiselli, 1956; 1963). Psychometric studies (e.g., Hobert & Dunnette, 1967) have shown that it is possible to differentiate between those individuals for whom a test or other measure is a good predictor and those for whom it is a poor one. The theory behind this is that errors of measurement and prediction are not of the same magnitude for all individuals but that there are systematic individual variations in error and in the importance of a given characteristic in determining a particular outcome. The factors which differentiate individuals in terms of their predictability are termed moderator variables. Thus in
the present study, diagnosis could be considered as a moderator
because outcome prediction was possible for one sub-sample (the
mentally ill), but non-existent for another (the mentally handicapped).

The fact that environmental characteristics did not prove
important in determining outcome may, in part, have reflected a lack
of sophistication in the environmental measures used. These were
largely based on physical characteristics (e.g., the number of
residents within each residential unit) which in studies on the
mentally handicapped have been found to be relatively unimportant in
determining outcome (e.g., Miller & Intagliata, 1981); it is
conceivable that using a more detailed measure of environmental climate,
such as that developed by Moos (1974), would have produced different
results. The Hospital & Hostel Practices Profile (Tykeson, 1982) would
also seem worthy of consideration in this respect.

An important omission from the present study is that, while it
has been demonstrated that it is possible to predict outcome to a
statistically significant level, the incremental validity of these
predictions over more simple ratings (e.g., care staffs' opinion of
those residents likely to be rehospitalised or to move from the
hostel) was not investigated. In retrospect, staffs' predictions of
each resident's placement outcome should have been obtained at the time
that the reassessments were conducted. This would have enabled a
prospective study to be carried out where, for example, at the end of
a further two years, the relative accuracy of the staffs' predictions
and the predictions based on the rating scale data could be examined.
The fact that the first re-admission to hospital did not occur until
over 5 months after the initial assessment does suggest, however, that
the scale data does have some capacity to predict future occurrences,
and is not merely identifying imminent events.

While the amount of variance explained by the predictor variables
was not particularly large (18-46%), this is again consistent with
previous research (Hull & Thompson, 1980; Schalock, Harper & Carver,
1981; Schalock, Harper & Genung, 1980). The amount of unexplained
variance may reflect the fact that both individual and environmental
factors are just some of the factors which come into play in the
decision-making process which ultimately determines whether a resident
is rehospitalised or moves from a hostel to a flat etc. The perceptions
and beliefs of staff such as social workers are also likely to be
important, as is the prevailing economic climate. Polivka et al (1979),
for example, found that movements to less restrictive settings increased
and movement to more restrictive settings decreased as financial support
became more available. Vitello, Althore & Cadwell (1983) in a systematic
examination of the placement decision process regarding de-institutionalised
mentally handicapped individuals, did find that demographic and
behavioural factors varied significantly with placement recommendations,
but it could be that the importance of these variables in decision-
making varies according to economic and other factors.

As already mentioned in the text, the significant correlations
between the residents' test and retest scores needs to be viewed with
some caution as the statistics were based on scores on groups of items.
This caution is necessary because, while an individual's score on a
particular factor may be very similar on initial assessment and at
follow-up, within those total scores there may have been some variation
in individual item scores which would go undetected in this form of
analysis. Nevertheless, studies which have looked at social and
behavioural changes in both the mentally ill (Pryce, 1977) and the
mentally handicapped (Hemming et al., 1981; Martindale & Kilby, 1982;
Cohen et al., 1977) on moving to a new residential environment have
found that most change occurs, both in terms of improved social
functioning and increased behaviour problems, in the first few months
following the move. As the majority of residents in the current study
had already been in their current placements for longer than a few
months at the time of the initial survey, it might therefore be
expected that there would be little change between the initial and
follow-up scores. The fact that there were no statistically signifi-
cant changes does not, of course, rule out the possibility that there
were some clinically significant changes. In a hostel where perhaps
staff are just coping with a particular resident's difficult behaviour,
a one-point change on a behaviour problem score (e.g., from 'sometimes'
physically aggressive to 'often' physically aggressive) may be highly
significant in terms of that resident remaining in the hostel.

Mention also needs to be made of the use of multivariate statistics
in the present study. As Keane & Fahy (1982) state in relation to the
use of such analyses 'these methods make assumptions about the nature
and distribution of data which can seldom be completely justified in
clinical and social psychiatric investigations'. This certainly applies
to multiple regression, which requires the use of data on at least an
interval scale; whether rating scale data can be considered to be such
is highly dubious and this necessitates further caution in drawing
conclusions from the results in the present study. The further diffi-
culties of sample size in relation to the number of variables in factor analysis have already been discussed elsewhere.

The moderate levels of inter-rater reliability cast further doubt on the predictive validity of the scale data but at least the factors identified as being associated with placement outcome were amongst the most reliable of the seven produced by the principal components analysis. Inter-rater reliability measures from the present study seem fairly consistent with those reported for the Wessex Behaviour Rating Scale (Jay et al., 1982; Palmer & Jenkins, 1982) on which the survey scale was based.

Despite these doubts regarding the present research, the results would seem to be sufficiently encouraging to merit further studies. Future research would ideally involve a demonstration of incremental validity, more sophisticated independent and dependent measures, a greater number of subjects and a longer follow-up period. It would also be desirable to weed out unreliable individual items from the rating scale in order to enhance its overall reliability. Perhaps, more importantly, it would be necessary to repeat the study on groups of individuals in community care settings other than those provided by local authorities. As the Professional Affairs Board of the British Psychological Society noted in its response to the consultative document 'Care in the Community' (P.A.B., 1982), the type of facilities associated with local authorities are only one manifestation of community care. It cannot be assumed therefore that the results from the present study can be generalised to residents in other settings.
Finally, some comments need to be made on the overall utility of this type of research. Until some degree of incremental validity has been demonstrated, no real conclusions can be drawn regarding whether or not predictive studies are worthwhile and cost-effective. Their utility also rests, however, on whether or not, having identified 'at risk' individuals, support can be provided which reduces their chance of rehospitalisation. If such support is not available, or not effective, then the whole exercise is limited in its practical value.

Several authors have pointed out (e.g., Hawks, 1975; de Silva & Fallik, 1976) that the majority of the mentally ill and mentally handicapped have always been cared for in the community. In view of this, perhaps the main task of research is as Hawks (op. cit.) has suggested, that is, to consider what factors enable certain families to successfully care for their handicapped members and how can these factors be facilitated in others. The current emphasis on community care is, however, as much a political exercise as it is an attempt to improve services for certain client groups; as such, it is an enterprise which cannot afford to fail. Whereas it has taken many years to gain public and financial support for community care projects, support for such projects might be withdrawn very quickly if high rates of failure are observed. There are indications (Wertheimer, 1934) that the backlash has already begun in the United States. Any research which may help in insuring against failure would therefore seem worthy of encouragement.
RE FE RE NCE S


REFERENCES cont:


REFERENCES cont:


REFERENCES cont:


FRYCE, I.G. (1977) The effects of social changes in chronic schizophrenia: a study of forty patients transferred from hospital to residential home. Psychological Medicine, 7, 127-139.


Appendix 1: Rating Scale, Background Information Sheet and Rater's Guide
RESIDENTS ASSESSMENT FORM

NAME: .................................................. D.O.B. ......................

ADDRESS: ..................................................

..................................................

..................................................

Please ring the appropriate number for each item.

COMMUNICATION

1. Use of Speech
   (Actual content of speech, ignoring poor articulation)

   Advanced speech, relates to matters outside his everyday world 1

   Simple conversation, short linked sentences 2

   Spontaneous disconnected phrases e.g., "want dinner" "want to go out". 3

   Few words e.g., uses names only, repeats words said by others etc. 4

   No recognisable words 5

2. Intelligibility

   Normal pronunciation and delivery 1

   Can be easily understood but has some mis-pronunciation or impediment (e.g., stammer) 2

   Understood by people who know him/her well but not by strangers 3

   Very difficult to understand even by those who know him/her well 4

   Impossible to understand except perhaps for an occasional word 5

   cont....
3. **Comprehension**

- Understands *ordinary conversation*
- Understands *simple conversation* with everyday content
- Can understand several instructions in one sentence
- Understands simple, one-sentence instructions
- Understands virtually nothing

### INCAPACITIES

<table>
<thead>
<tr>
<th></th>
<th>1</th>
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<th>3</th>
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<tbody>
<tr>
<td>4. Wetting at night:</td>
<td>Never</td>
<td>Occasionally</td>
<td>Frequently</td>
</tr>
<tr>
<td>5. Soiling at night:</td>
<td>Never</td>
<td>Occasionally</td>
<td>Frequently</td>
</tr>
<tr>
<td>6. Wetting in the day:</td>
<td>Never</td>
<td>Occasionally</td>
<td>Frequently</td>
</tr>
<tr>
<td>7. Soiling in the day:</td>
<td>Never</td>
<td>Occasionally</td>
<td>Frequently</td>
</tr>
<tr>
<td>8. Mobility:</td>
<td>Walks unaided</td>
<td>Walks with help</td>
<td>Cannot walk</td>
</tr>
<tr>
<td>10. Washing self:</td>
<td>No help needed</td>
<td>Some help needed</td>
<td>Maximum help needed</td>
</tr>
</tbody>
</table>
11. Dressing:  
- No help needed: 1  
- Some help needed: 2  
- Maximum help needed: 3  

12. Vision (with glasses if worn):  
- Normal: 1  
- Impaired: 2  
- Blind: 3  

13. Hearing (with aid if worn):  
- Normal: 1  
- Impaired: 2  
- Totally deaf: 3  

14. Money sense  
- Understands money values: 1  
- Some understanding: 2  
- No understanding: 3  

15. Road sense:  
- Goes out on streets unaccompanied: 1  
- Appreciates traffic dangers but does not go out unaccompanied: 2  
- Does not appreciate traffic dangers: 3  

16. Awareness of danger  
- Has full awareness of danger: 1  
- Aware of more obvious sources of danger (e.g., open fires, sharp implements etc): 2  
- Has no awareness of danger: 3  

17. Use of Public Transport  
- Makes frequent and varied use of buses etc: 1  
- Sometimes makes short bus journeys: 2  
- Never uses public transport: 3  

18. Confusion (unable to find way around, loses possessions etc)  
- Never confused: 1  
- Sometimes mildly confused: 2  
- Almost always confused: 3
19. **Medication**
When drugs are prescribed he/she:
- Takes medication unaided 1
- Needs supervision to take medication 2
- Resists taking medication 3

### ADAPTATION TO ENVIRONMENT

20. **Independence and Supervision**
- Can go out on trip alone (e.g., to shop, town centre etc) 1
- Can go out in immediate vicinity of hostel/home (e.g., about house and garden) 2
- Always needs supervision 3

21. **Activity**
- Always likes to be occupied 1
- Likes to be occupied some of the time 2
- Happy to sit around doing nothing all day 3

22. **Organization of Activities**
- No help needed 1
- Some help needed 2
- Maximum help needed 3

23. **Participation in household jobs**
- (Cooking, washing-up, laundry etc.)
  - Willing, does things on own initiative at times 1
  - Willing if pushed 2
  - Never willing 3

24. **Resistance to change**
- None, quite happily goes along with new ideas 1
- Sometimes hesitant with new suggestions made 2
- Marked resistance, will not accept the slightest change in routine 3

25. **Sociability with staff**
- Establishes a good relationship 1
- Has some difficulty in establishing a good relationship 2
- Has a great deal of difficulty in establishing a good relationship 3
26. **Sociability with other residents**
   - Establishes a good relationship
   - Has some difficulty establishing a good relationship
   - Has a great deal of difficulty in establishing a good relationship

**BEHAVIOURAL PROBLEMS**

<p>| | | | |</p>
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<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>27. Physically aggressive</td>
<td>Never</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Often</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>28. Verbally aggressive</td>
<td>Never</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Often</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>29. Stealing</td>
<td>Never</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Often</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>30. Attention-seeking</td>
<td>Never</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Often</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>31. Self-stimulating behaviour (rocking, hand-clapping etc.)</td>
<td>Never</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Often</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>32. Self-injurious behaviour (biting, head-banging etc.)</td>
<td>Never</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Often</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>33. Destructive Behaviour (damages clothing, furniture etc.)</td>
<td>Never</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Often</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>34. Inappropriate Sexual Behaviour</td>
<td>Never</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Often</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>35. Wandering away</td>
<td>Never</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Often</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>
36. Abuse of alcohol/other drugs

- Never 1
- Sometimes 2
- Often 3

37. Domineering with others

- Never 1
- Sometimes 2
- Often 3

38. Disturbing other residents

- Never 1
- Sometimes 2
- Often 3

39. Emotionally labile (easily and quickly shifts from one emotion to another).

- Never 1
- Sometimes 2
- Often 3

**PSYCHIATRIC SYMPTOMS**

40. Generalised anxiety (anxious or frightened without apparent reason)

- None 1
- Some 2
- Marked 3

41. Depression (long periods of unexplained or undue unhappiness)

- None 1
- Some 2
- Marked 2

42. Mania (long periods of unexplained excitement of elation)

- None 1
- Some 2
- Marked 3

43. Hypochondriasis (pre-occupied with own health or body)

- None 1
- Some 2
- Marked 3

44. Phobias (undue fears of harmless things)

- None 1
- Some 2
- Marked 3

45. Hallucinations, delusions (e.g., talking to or hearing imaginary voices)

- None 1
- Some 2
- Marked 3
OCCUPATION

46. Principal Occupation during the day
   Has full-time job ......................................................... 1
   Has part-time job .......................................................... 2
   Attends training centre, sheltered workshop ....................... 3
   Attends industrial therapy unit, occupational therapy unit, day hospital etc. ......................................................................................................................... 4
   Helps out in hostel/home .................................................. 5
   None ............................................................................... 6
   Other (specify) ............................................................... ..............................

47. Frequency of attendance at above
   Daily .............................................................................. 1
   Three times a week ........................................................... 2
   Twice a week ..................................................................... 3
   Once a week ...................................................................... 4
   Other (specify) ............................................................... ..............................

48. Other activities
   Specify other activities e.g., visits to the cinema, social clubs etc., which the resident engages in:

       ......................................................................................
       ......................................................................................
       ......................................................................................

GENERAL

49. Stability of behaviour
   How changeable is the resident's behaviour?

   Stays about the same ......................................................... 1
   Some mild fluctuation ......................................................... 2
   Very erratic ........................................................................ 3

50. Does the resident have any physical condition which is an additional handicap? If so, please specify:

       ......................................................................................
       ......................................................................................
       ......................................................................................
51. Does the resident suffer from epileptic fits? If so, please specify their severity and frequency:

..........................................................................................................................
..........................................................................................................................
..........................................................................................................................

52. Degree of Psychiatric support given

Has the resident had contact with any of the following during the last 3 months? If so, please tick the relevant box.

- General Practitioner
- Psychiatrist
- Domiciliary Nurse
- Social Worker
- Day Hospital
- Industrial Therapy Unit
- Occupational Therapy Unit
- Hospital Ward

Rater by: ................................. Date: .................................
Position: .................................
NAME: 
ADDRESS: 

1. Age: 
2. Sex: 
3. Marital Status: 
4. How long living here: 
5. Total time in residential care: 
6. Where living before admission here: 
7. Previous jobs held: 
8. Length of unemployment before admission here: 
9. Country of origin: 
10. Staff Diagnosis: 
11. Formal Diagnosis: 
12. Time since first contact with psychiatric services: 
13. Legal status: 

H3/PS/3/II
18.2.80.
How to Rate

1. There are a few items on the form which require a written answer but, for the majority of items (Items 1-45), you should simply circle the number of the answer most appropriate to the resident concerned. Thus, for example, for a resident who is heavily dependent on staff to help him dress, Item 11 would be completed as follows:

   11. Dressing
       No help needed 1
       Some help needed 2
       Maximum help needed 3

Most of the items (Items 4-45) offer you three choices; the exceptions to this rule are the three items on communication at the beginning of the scale, in which you have five choices.

2. At the end of the form fill in your name, your position in the hostel e.g., warden, houseparent etc., or your relationship to the resident and the date on which you filled in the form.

3. Finally, check that you have completed all the items and that you have given only one answer for each item.

Who should rate?

The best person to complete the form is the one who has the greatest opportunity to observe the resident being rated. It is not necessary that the rater should have known the resident for a long period of time but it is best to avoid using people as raters when they have known the resident only a few weeks.

When to rate

There is no set time over which to carry out the rating but a good method of doing it is to decide a few days in advance which residents you are going to rate. By the time you fill in the forms you will then have had several days over which you will have been able to pay particular attention to the behaviour of the residents concerned and thus make sure that you have a correct impression of them.

Points for your guidance

In rating certain items, it may be helpful to bear in mind the following:

Incontinence Ratings: On the items relating to incontinence (4-7) score:

(1) if the resident is never incontinent.
(2) if the resident is incontinent less than once a week.
(3) if the resident is incontinent more than once a week.
Behavioural Problems

On the items relating to behavioural problems (27-39) score:

1. If the behaviour never occurs or if it last occurred so long ago that it is difficult to remember.

2. If the behaviour occurs but presents no problem (or only a minor problem) of management at the time.

3. If the behaviour has occurred in the past month and continues to constitute a major problem of management.

Further Guidance

If you need any further guidance on the assessment form, please contact:

David Allen
Psychology Department,
Hospital.

(Tel: ...%
Appendix II: Published Paper Summarizing Criminal Survey Research
the rights of the claimant, although it is argued that claimants are no better off as a result of the legislation. But, according to Ruth Lister, the major impact on CPAG’s court work will stem from the announcement of a new appeals procedure from supplementary benefit appeals tribunals.

For the first time, claimants dissatisfied with the result of a supplementary benefit tribunal ruling will be able to appeal to the new court, which, under the new commission, would be expected to hear the appeal within six months. This would then be published, effectively forming precedents. Before, claimants could only appeal on a point of law to a High Court and Ruth Lister forecast that the new procedure would reduce CPAG’s court work.

MIND is confident that the new Mental Health Act — expected any time now — will heed many of the rights issues it has raised, as well as incorporating the results of its European Court victories. “The 1959 Mental Health Act put the balance of total discretion on the side of the hospitals. The new Act, we hope, will attempt to redress that balance, but to what extent, we shall have to see,” said Larry Gostin. He believed that more advocacy work would be needed, both before mental health review tribunals and in the courts, over the next 20 years, to ensure that any gains made in the new Act would be firmly registered. The association intends to monitor changes in mental health law by publishing in the New Year a mental health legal bulletin, similar to the social welfare legal bulletin published by LAG.

In housing, the Homeless Persons Act is still on the statute books despite the vociferous opposition of the local authority associations. The voluntary sector must be an achievement in itself. The present housing crisis has meant that groups like Shelter have been forced to fight a rearguard action. But it is probably no coincidence that Neil McIntosh predicted that the growth area in the charity’s legal work would be in providing lay representation in eviction cases in the county courts, where legal aid is not available.

In child care, Rachael Hodgkin believed that the greatest effect of increased representation of parents in care proceedings had been to make local authorities much more careful about taking children into care. “They [the social workers] will usually take advice from the authority’s legal department first, because they know they will be challenged and cross examined in court,” she said.

The Children’s Legal Centre, for which she works was founded two years ago, the most lasting achievement of the International Year of the Child. Then the rights of the child were judged the most important issue of the year. It will not be surprising if the disability legal centre gets off the ground this year — the International Year of Disabled People — for the very same reason.

FOR MANY YEARS there has been a steady movement of people away from continued care in hospitals for the mentally ill and mentally handicapped. This is not a simple drift away from long-term hospital care, however, since at the same time the number of acute admissions and out-patient attendances is growing, and the alternative types of day and residential care are increasing in range, if not greatly in numbers.

Ryan (“Residential care for the mentally disabled”, in Wing, J K, and Olsen, R, Community care for the mentally disabled, Oxford University Press, 1979), and Udall and Corbett (“Non-hospital residential care for adults with mental retardation”, in Wing, J K, and Olsen, R, op.cit, 1979), have reviewed the pattern of non-hospital care for the mentally ill and mentally handicapped respectively, indicating the range of group home, hostel, lodging, and boarding-out schemes which exist.

Despite the energy of many local and national voluntary groups in providing accommodation, the majority of places are provided by statutory authorities. For example 95 per cent of day places for the mentally ill are provided by either area health authorities or by social services departments (Edwards, C, and Carter, J, “Day services and the mentally ill”, in Olsen, R, op.cit, 1979), although the voluntary sector makes a greater contribution to residential care (Barter, J, “Role of the voluntary sector in the provision of accommodation and other facilities for mentally ill and mentally handicapped people”, in Olsen, R, The care of the mentally disordered, BASW, 1979).

The pattern of provision from area to area varies in every conceivable way, including relative number of places provided, degree of supervision, whether accommodation is purpose built or adapted, and the type of client accommodated. There is accordingly a wide variation in the average age, degree and nature of handicap, range of remaining social and domestic skills, and the main problems of management within an individual establishment. Planning the principles of care for any one such place, and the associated management procedures and staff training procedures, depends on an accurate knowledge of the residents in the particular setting.

There are a number of procedures available to assess residents of group homes and hostels. Measures have been developed to assess the behaviour of the chronic mentally ill in hostels (Ryan, P, and Wing, J K, “Patterns of resident care”, in Olsen, R, op.cit, 1979), and the mentally handicapped in large surveys (Kushlick, A, et al, “A method of rating behaviour characteristics for use in large scale surveys of mental handicap”, Psychological Medicine, No. 3, 1973). In general, assessment procedures for the mentally ill and handicapped have been developed separately, although the adaptive behaviour scale (ABS), designed for use with the mentally handicapped, has also been used with the chronic mentally ill (Sylph, JA, et al, “Social disability in chronic psychiatric patients”, America Journal of Psychiatry No. 134, 1977).

Apart from assessing the residents, may be equally useful to assess the setting or the hostel practices, and measures have been developed to measure these (Hewett, S, et al, “Living without the mental hospitals”, Journal of Social Policy, No 4, 1975). Apart from the need to assess clients and setting directly, some form of assessment is also needed to evaluate the...
way in which services are provided (Walton, R., "Management of the residential care system", Social Work Today, October 2, 1979).

The present study resulted from a wish to assess all the residents of the hostels and group homes administered by a South Glamorgan social services department. An administrative change within the department had revealed that relatively little was known about the residents, so it was uncertain whether the current residents were in the most appropriate type of accommodation. It was unclear which homes or hostels were the most suitable for new referrals and what goals and guidance should be offered by supervising residential and field social workers.

A relatively unusual aspect of the provision of the department was that no attempt had been made to separate accommodation for the mentally ill and handicapped, so that both categories of residents were living in the same establishment. The distinction between these two categories is made on the type of service managing the patients before admission, or the diagnostic label used. It does not imply that residents called "mentally ill" were currently displaying symptoms, or that residents called "mentally handicapped" had ever been formally assessed as such.

An appropriate assessment measure needed to be relatively short and relatively easy to understand by direct care staff and even housekeepers, with no professional training. Udall and Corbett ("A home to go to: Residential care for adults with mental retardation in South London", Institute of Psychiatry Report, London, 1976), carried out a similar survey of mentally handicapped residents in South London, using a modification of the checklist devised by Kushlick and his colleagues. They suggested further modifications to the checklist, and these were incorporated into the final version used in this study.

The assessment instrument was in two parts:

- A 13-item background information sheet, covering age, diagnosis, etc., filled in wherever possible by reference to records. In cases where written records were not available, information was obtained from staff;
- a 52-item resident assessment form, completed by the person who knew each resident. This was usually a member of the hostel staff, a non-resident housekeeper or member of an area team. In two group homes there was no-one with adequate knowledge of the residents, so the form was completed with the co-operation of a retired former officer of the department.

The form consisted of the following sub-scales, (the indicated score range for each sub-scale increases with greater severity of the problem):

- **Communication**: Three 3-point items, assessing quality of speech, use and comprehension.
- **Incapacities**: Sixteen 3-point items, assessing frequency of various problems (e.g. incontinence) or degree of lack of skill.
- **Adaptation to environment**: Seven 3-point items, assessing degree of participation in community and residential activities.
- **Behavioural problems**: Thirteen 3-point items, assessing frequency of occurrence of problems (e.g. self-injurious behaviour).
- **Psychiatric symptoms**: Six 3-point items, assessing severity of specific "symptoms".

Seven other items relating to attendance at places of occupation, nature of physical handicaps, and amount of other support were included. It took several months to complete this form for the 108 residents of the departments accommodation. The form was previously circulated to relevant staff, and it was discussed with them before use. It is helpful if the person introducing the scale has some familiarity with the problems of this type of assessment, in particular the problems of inter-rater reliability (Hall, JN, "Psychological assessment" in Wong, JK, and Morris, B, "Handbook of psychiatric rehabilitation practice", OUP, pages 17-28). It was impossible to obtain information on some items for some residents — up to 35 per cent of residents fell into a "not known" category for some items.

There were major differences between the two categories of residents on the background data section. The mentally ill (MI) were 59-years-old on average, while the mentally handicapped (MH) residents were 46-and-a-half years old. This difference is accounted for by the absence of any MI residents aged under 30, and by the presence of seven MI residents aged over 70. There was no available age for three residents. The male:female ratio was 1:1.26 for MH residents and 1:2.21, 43 MI and 22 MI residents were single.

The average length of stay in each unit was over three years longer for the MI residents than for the MH residents, but the respective total time in care of the Department was 90.6 months and 73.7 months; this information was missing for 31 residents. Most residents (58) had lived in another hostel or in hospital immediately before moving to their present accommodation: 12 MI residents had been admitted from living with their parents, but only one MI resident. Records of previous employment were available for 39 residents, and were not relevant for 33 residents (mostly MH residents who had never worked). Of the remaining 36 residents, only two had held jobs other than unskilled.

The resident assessment form indicated clearly some differences between the two categories of residents. While about 60 per cent of the MH residents had problems on each of the communication items, only 20 to 30 per cent of the MI residents had communication problems. For some incapacities there were marked differences between the groups, the most extreme example being that 70 per cent of the MH residents had problems with money sense, but only 20 per cent of MI residents. MH residents were worse on four incapacity items, and better on one incapacity item (confusion), but there was no real difference on the other 11 items, including incontinence. Forty-four per cent of the MI residents were self reported or depressed compared with two per cent of MH residents, and for symptoms of generalised anxiety the respective proportions were 31 per cent and four per cent.

However, the most striking feature of the results was the relative similarity of the two groups. There was no great difference between the groups in the relative levels of adaptation to the environment, or of behaviour problems. Overall, the average scores on all scales were low, indicating relatively low levels of disability as indicated by specific items.

Only 13 residents held a full-time job, most were occupied during the day at an
OT or IT department (37) or at a training centre (24). Apart from this place of attendance, the main source of support for the residents was the GP. In the three months before data was collected 35 residents had seen their doctor: 23 had seen a social worker, and 11 a psychiatrist. Nineteen residents had a major physical handicap, equally divided between MI and MH residents, and one resident had two major handicaps. Only seven residents were epileptic.

The information from a survey of this type can be used in several ways. For the whole group, the relative levels of various specific disabilities, for example, can be ranked to identify priorities for some form of support or guidance from either paid staff or voluntary helpers. Table 1 shows the seven most frequently recorded disabilities. Helping residents to understand and use money thus emerges as a main problem in its own right, but improvement in this area could also contribute to better use of transport. There is a gap after the first five problems, so that the greatest number of residents would be helped by developing some sort of programme to attack these rather than trying to change too many problems which are not relatively common.

Given a range of types of accommodation, residents can be allocated to the accommodation most suitable for them. For the 18 per cent of residents who were wet at night it would be helpful to put them in a room near a toilet. For new residents it may be possible to place them where they will be with similar people. It may also be possible to introduce a training programme aimed at reducing levels of incontinence. It is necessary sometimes to move residents within the available accommodation, often because of increasing age or disability. While wholesale shuffling of residents is not desirable, a limited amount of planned movement can help to ensure that the resulting vacancy is in the place will most benefit the incoming resident.

The staff in hostels and homes of this type can change rapidly and the proportion of staff who have any sort of training may be very low. An assessment of this type can provide some sort of guidelines to new staff and ensure that any in-service training is rooted in the realities of the clients' problems. It was most encouraging to see the very real interest taken in the assessment by all levels of staff, especially by many wholly untrained staff quite unused to this sort of procedure.

Another use of this sort of assessment is to ease the problems of transfer between hospital and hostel. As noted already, a hospital was the most frequent place from which residents came. There can be major disagreements between hospital and hostel staff on the suitability of a particular patient for discharge, and recollection of previous episodes of discharged patients having to return to hospital may leave bad memories in the minds of staff. If the receiving hostel can give its criteria relatively clearly, and if the hospital uses some form of assessment at least analogous to a schedule of this sort, at least some common and agreed information available on which a decision can be based.

At the same time it is important that results of the schedule are not used to set up crude cut-off scores which might form the sole basis of decisions on transfer. During the period of this study the assessment system at the local psychiatric hospital had been improving (Pryce, KT and Hall, JN, "Up-to-date records of long stay patients", British Journal of Psychiatry, page 398 Vol. 137, 1980) and this contributed in part to a better system of joint assessment of potential hostel residents. Careful collection of data in this way can also lead to better planning of both types and size of further non-hospital accommodation.

A simple assessment form of this type has been shown to be practical, in terms of its use by direct-care staff who do not have any specific training in this type of assessment. It has been of benefit to both departments in helping both the direct-care and the senior staff identify priorities for clients and staff. The form is now being used by several other people involved in residential care services, and thus appears to have some general appeal. Although the mentally handicapped and mentally ill residents differed in a number of personal characteristics, the difference between them in terms of handicaps and problems was less marked than expected, and certainly indicates that the need to provide residential provision for the two groups separate may need careful justification.
Appendix III: Statement of Author's Role in Original Research
The original survey was conducted while the author was working as a psychological technician in what was then the Area Department of Clinical Psychology, South Glamorgan. The survey rating scale was devised in collaboration with the author's supervisor at the time, Dr. John Hall, and the paper enclosed in Appendix III was also a joint effort. The author had sole responsibility for the collection of the data and the analysis of the results using the S.P.S.S. computer programme. The data collection took place over several months and involved visiting each residential unit to explain the scale and instruct care staff in its use, checking the completed scales and then feeding back the results to groups of hostel staff. The author also did a search of the files in the Area Social Work Department in order to complete the 'Background Information' sheets.
Appendix IV: Copy of Day Hospital Scale and List of Items Common to Day Hospital and Survey Scales
<table>
<thead>
<tr>
<th>Item Number in Day Hospital Scale</th>
<th>Behaviour Description</th>
<th>Item Number in Survey Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Incontinence</td>
<td>4-7</td>
</tr>
<tr>
<td>2</td>
<td>Physical violence</td>
<td>27</td>
</tr>
<tr>
<td>3</td>
<td>Destructive Behaviour</td>
<td>33</td>
</tr>
<tr>
<td>4</td>
<td>Self-injurious Behaviour</td>
<td>32</td>
</tr>
<tr>
<td>5</td>
<td>Inappropriate Sexual Behaviour</td>
<td>34</td>
</tr>
<tr>
<td>6</td>
<td>Stealing</td>
<td>29</td>
</tr>
<tr>
<td>8</td>
<td>Verbal Aggression</td>
<td>28</td>
</tr>
<tr>
<td>11</td>
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<td>Prompting/Organisation of Activities</td>
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<td>21</td>
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</table>

* For behaviours which were covered by more than one scale item, an average score was calculated for use in the concurrent validity analysis.
This form should be completed at the end of a working month in time for the assessment meeting if one is scheduled.

This form is in two parts:
- **Part 1** is concerned with the patient's difficult or embarrassing behaviour
- **Part 2** is concerned with the patient's general social and Day Hospital behaviour

You will indicate your answers to the questions in different ways in the two sections. Please read the instructions for answering each part.

### Part 1: Deviant Behaviour

**Instructions**

The questions in the following checklist are all concerned with particular types of deviant or embarrassing behaviour. Tick the box alongside the particular behaviour you know occurred. If the behaviour has not happened do not mark the item in any way. Take account of any reports of incontinence etc., which happened when you were not with the patient during the period. If you wish to add further comments about these or any other unacceptable behaviour, you may do so on the last page of this form.

Before you begin, remember to consider the patient's behaviour only over the last month.

1. Was the patient incontinent of urine or faeces?
   - [ ]

2. Was the patient physically violent to any other person?
   - [ ]

3. Did the patient break or damage anything deliberately?
   - [ ]

4. Did the patient hurt or mutilate him/herself?
   - [ ]

5. Was the patient sexually offensive in any way? (sexual behaviour in a public place or unwelcome attentions towards others)
   - [ ]

6. Did the patient steal anything?
   - [ ]

7. Was the patient seen picking up rubbish or cigarette ends?
   - [ ]

8. Did the patient shout or swear at others inappropriately?
   - [ ]

9. Did the patient talk or laugh to him/herself?
   - [ ]
Number of days per week expected to attendTEGRAN .............................................
Number of hours per day .................................................................

PART 2. General Behaviour

Instructions

These thirteen questions are all concerned with the general Day Hospital behaviour of the patient. Each question is followed by a line. Next to each line are three statements. The statements range from the worst possible standard of behaviour at the left, to the standard of behaviour expected from 'normal' people at the right. You answer each question by putting a mark through the line at the point which best shows how the patient has been during the last month. You may make your mark at any point on the line.

Before you begin remember to:

1. Use the standard of ordinary life outside the hospital.
2. Only consider the patient's behaviour over the last month.
3. Make your rating by putting a mark through the line.

10. How well did the patient get on with others on the unit?

<table>
<thead>
<tr>
<th>Very poor relationship with other patients. Solitary and withdrawn</th>
<th>Got on with some patients</th>
<th>Got on well with other patients</th>
</tr>
</thead>
</table>

11. How active was the patient

<table>
<thead>
<tr>
<th>Sat or lay most of the time in one place, without moving</th>
<th>Periods of inactivity, but (and speed) of otherwise moved activity reasonably normally</th>
</tr>
</thead>
</table>

12. How much did the patient speak

<table>
<thead>
<tr>
<th>Mute or occasional sounds</th>
<th>Spoke in short sentences as talkative as normal only person</th>
</tr>
</thead>
</table>

13. How much did the patient initiate conversation?

| Patient never started off a conversation himself. | Occasionally started a conversation with nurses and patients. |
14. How sensible was the patient's speech

- Nonsense speech
- Impossible to make sense of what was said.
- Spoke sensibly and to the point.

15. How clearly did the patient speak? But if mute, tick this box

- Speech unclear
- Impossible to make out what was being said
- Speech partly unclear but could be mainly understood
- Speech was clear and easily heard or understood

16. How well did the patient manage money

- Unable to count
- Small amounts of money, no understanding of value
- Spent some money on simple purchases
- Budgeted money over the week

17. Did the patient use public transport or other facilities

- Never used public transport or public shopping facilities
- Made short bus trips
- Used public shop for sweets, cigarettes
- Made varied use of buses, cafes, etc., depending on cash available

18. How much prompting or help did the patient need to do things for him/herself?

- Cared for self and did things only if constantly supervised or tasks had to be done by the staff
- Patient did things with some prompting
- Did things without being told. Made all own arrangements

19. How acceptable was the patient's appearance in terms of personal hygiene and dress?

- Face, hands, hair and clothing looked dirty and unkept
- Fairly clean and tidy
- Appearance clean, neat and tidy at all times
- Appearance poor in one or two aspects
20. How regular and punctual was the patient in attending Day Hospital?

<table>
<thead>
<tr>
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<th>Punctuality and attendance not very reliable</th>
<th>Attended regularly and punctually on set days</th>
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<tbody>
<tr>
<td></td>
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</tbody>
</table>

21. How much reassurance or attention did patient seek from staff?

Tick box if not known.

- [ ]

Overall Rating

22. How good was the patient's general behaviour?

- Taking everything into account, very poor socially and at doing things for himself/herself.
- Several problems are present which affect the patient's ability to live without support of Day Hospital.
- Taking everything into account as good socially and at looking after self, as needed to live without support of Day Hospital.

- Constantly tried to get reassurance/attention from staff.
- Sometimes quite demanding of reassurance/attention.
- Sought reassurance from staff in an appropriate manner.
In answering the questions so far you have only considered the patient's behaviour during the last week. On the whole, was the patient's behaviour during that week:

- [ ] better than usual
- [ ] about the same as usual
- [ ] worse than usual

Please add any comments that you wish to make about the patient's behaviour:

Name of Person doing rating ____________________________

Position ____________________________ Date ____________

For use by Psychologist/Information Co-ordinating Centre

<table>
<thead>
<tr>
<th>Deviant Behaviour</th>
<th>Total</th>
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<th>Lowest</th>
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Appendix V: Summary Statistics from Regression Equations
TABLE 1: Intercorrelations of Predictor Variables

(a) Whole Sample

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<th>Factor VI</th>
<th>Factor VII</th>
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(b) Mentally Ill Residents

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<th>Factor VII</th>
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<td>0.4178</td>
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### TABLE 2: Summary Statistics for Regression of Hospital Re-admission on Factors II, VI and VII (whole sample n = 108)

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<th>F</th>
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<tbody>
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<td>Multiple R</td>
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### VARIABLES IN EQUATION

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TABLE 3: Summary Statistics for Regression of Hospital Re-admission on Factors II, VI, VII and No. of Previous Hospital Admissions (Mentally Ill Group n = 23)

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### VARIABLES IN EQUATION

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### TABLE 4: Summary Statistics for Regression of Residential Moves on Factor VI (Mentally Ill Group n = 23)

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**VARIABLE IN EQUATION**

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STUDY TWO:

Success and failure in community placements for people with learning disabilities and challenging behaviour: An analysis of key variables
SUCCESS AND FAILURE IN COMMUNITY PLACEMENTS FOR PEOPLE WITH LEARNING DISABILITIES AND CHALLENGING BEHAVIOUR: AN ANALYSIS OF KEY VARIABLES

ABSTRACT

Previous research has clearly demonstrated that people with learning disabilities and challenging behaviour are at increased risk of admission and re-admission to long-term institutional care. Research has also suggested that service variables may moderate this process and also impact on the effectiveness of clinical interventions for challenging behaviour in community settings. The present study used a natural group comparison design to study differences in the individual and service characteristics of two groups of people with learning disability and challenging behaviour, one of which was successfully maintained in the community and one which experienced placement breakdown. Few behavioural or psychiatric differences were observed, although the breakdown group were significantly more able. People in the breakdown group were significantly more likely to come from service settings which were rated as having less than optimal resource utilisation and internal organisation. Carers in the breakdown group were also significantly less likely to have received training in emergency management techniques. Implications for future research and clinical practice are discussed.
CHAPTER 1. LITERATURE REVIEW

1.1 INTRODUCTION

For many years now it has been policy to try to reduce our dependency on long-stay hospitals for people with learning disabilities by developing a range of alternative support services within the community. This research project concerns itself with the sub-group of people with learning disabilities who indisputably represent the greatest challenge to the concept of institution-free services - those people who display severe behavioural problems such as physical aggression, self-injury, and destructiveness. For reasons that will shortly be explained, these behaviours have come to be described as 'challenging behaviours'.

Despite improvements in both the quantity and quality of community support services available to people in this group, some individuals with challenging behaviours continue to be admitted to long-term institutional care. The logical consequence of this situation is that it may not prove possible to close all existing institutional provision or, alternatively, that institutions will come to be re-invented and re-provided by the National Health Service or the private sector within the new 'markets' created by recent care reforms.

The present study aims to examine the factors which determine whether or not challenging individuals can be successfully supported in the community. Factors relating both to the persons with challenging behaviour themselves and to the service settings in which they are supported will be investigated, and key themes and lessons for service commissioners and providers will be described.

In Chapter 1, key terms for the study will be defined before a review of the literature is presented. The review is divided into three main sections covering the epidemiology of challenging behaviour, the association between challenging behaviour and institutionalisation, and the provision of community support services for people with
challenging behaviour. The context within which the research was conducted will then be described before an overall outline of the theses is presented at the conclusion of the chapter.

1.2 DEFINITIONS

There are two technical terms which will be used throughout this study which require definition at the outset. The terms are 'learning disability' and 'challenging behaviour'.

The American Psychiatric Association (1987) defines learning disability as:

- significantly sub-average intellectual functioning accompanied by
- significant deficits or impairments in adaptive functioning with
- an onset before the age of 18 years

Each of these three criteria will be discussed briefly in turn. 'Significantly sub-average intellectual functioning' refers to an Intelligence Quotient (I.Q.) of 70 or below on an individually administered intelligence test with proven psychometric properties (e.g. the Wechsler Intelligence Scales for Children or Adults) A score of 70 is an arbitrary cut off point which, on the most commonly used intelligence tests, represents a score of two standard deviations below a mean of 100. 'Adaptive functioning' refers to a person's effectiveness in performing the skills required for everyday living; these include communication skills, social skills, personal care skills, academic skills, and domestic skills. A wide variety of assessment scales exist to measure adaptive behaviour (e.g. Adaptive Behaviour Scale, Nihira, Foster, Shellhaas & Leland 1975; Pathways to Independence, Jeffree & Cheseldine, 1982). These scales vary considerably in their standardisation, intended usage, and general quality, and the assessment of 'significant deficits or impairments' in this area invariably requires a degree of clinical judgement. 'Onset before the age of 18' makes it clear that learning disabilities first become apparent during the developmental period; 18 is chosen because it is generally accepted in Western society that adult roles and responsibilities
are assumed at this age. This cut off point may be employed, for example, to distinguish between a person aged 19 who fulfils the requirements of the definition because of neurological damage acquired through oxygen deprivation at birth, and a 19 year old with previously normal intelligence who develops significant cognitive impairments consequent upon suffering neurological trauma in a road accident. Although there will be similarities in the clinical picture presented by these two individuals, there are also likely to be important differences in their requirements for both health and social care.

A key point to note in the definition of learning disability is that all three criteria must be met for the classification to be made. It is quite possible, for example, for a person to score consistently below the I.Q. point of 70 over the lifespan, and yet to be more than capable of caring for themselves on a day-to-day basis; in this situation, the I.Q. and developmental period conditions would be met, but the adaptive functioning criterion would not. The term learning disability was adopted by the Department of Health in 1991 and will be used throughout this report except when reference is made to historical documents which may use descriptions such as 'mental handicap', 'mental retardation' or 'learning difficulties'; these terms can be regarded as synonymous however.

The second key term requiring definition is 'challenging behaviour'. The term was coined initially by the North American body, the Association for Persons with Severe Handicaps (TASH), and achieved widespread use within the United Kingdom following the publication of the influential King's Fund Project Paper 'Facing the Challenge' (Blunden & Allen, 1987). 'Challenging behaviour' was introduced as an alternative to terms such as 'problem behaviour', 'aberrant behaviour' and 'disruptive behaviour'. The behaviours concerned include physical aggression to others, self-injury, destruction of the environment, stereotypies (typically, high-rate, repeated body movements such as rocking or finger flapping), severe non-compliance, pica (the ingestion of inedible objects), and hard to tolerate personal habits (e.g. smearing faeces
and saliva, inappropriate sexual behaviour etc.). The aim in describing these behaviours as 'challenging' is to try to emphasise the fact that:

'.such behaviours represent challenges to services rather than problems which individuals with learning difficulties in some way carry around 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 the discussion on services rather than on the individuals showing the behaviours.'

(Blunden & Allen, 1987, p.14)

This definition therefore stresses the point that challenging behaviours are a result of an interaction between individual and environmental factors.

Several more specific definitions of challenging behaviour are available, three of which will be discussed here. Emerson (1995) has recently revised the definition originally provided by the Special Development Team at the University of Kent (Emerson, Barrett, Bell, Cummings, McCool, Toogood & Mansell, 1987) to read as follows:

'culturally abnormal behaviour (s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities'.

(Emerson, 1995, p.4)

This definition has a number of key elements. First, it states that whether or not a behaviour is viewed as challenging is to some extent culturally determined, and acknowledges the fact that there are, for example, behaviours such as smoking and drinking alcohol which, while clearly placing the 'physical safety of the person in
jeopardy', would not be viewed as culturally abnormal. Second, the definition recognises that the characteristics of a behaviour (i.e. its frequency, intensity and duration) are as important in determining its severity as is its topography (i.e. what the behaviour looks like). Third, there is the suggestion of 'dangerousness', in that the behaviour represents a threat to the person performing it or others, or exclusion, in that the behaviour may prevent the person from accessing normal life opportunities.

While Zarkowska & Clements' (1996) definition overlaps to some extent with that provided by Emerson (1995), it also introduces additional considerations. They suggest that behaviour may be viewed as challenging if:

- Its nature or severity is inappropriate given the person's age or stage of development
- It is dangerous
- It constitutes a barrier to the person learning new skills
- It causes significant stress and impairs the quality of life of those who live or work with the person
- It is contrary to social norms.

Dockrell, Gaskell & Rehman (1992), in their evaluation of the Mental Impairment Evaluation & Treatment Service at the Bethlem Royal Hospital, adopted a different definition in their analysis of the challenging behaviours of clients referred to the unit. Dissatisfied with the Emerson definition, they distinguished between 'Problem Behaviours' and 'Dangerous Behaviours'. The former typically occurred quite frequently, but in general posed few management problems for carers; verbal abuse, pestering, defecating/smearing, throwing objects, and exposing oneself were cited as examples of problem behaviours. 'Dangerous behaviours' were generally less frequent, posed major management problems when they occurred, and often fell within the purview of the Criminal Justice System; typical examples included serious physical assault, arson, sexual abuse, and attempted suicide. Dockrell and colleagues viewed the latter as being truly challenging behaviours, and expressed the view that while
many local services were able to cope with problem behaviours, few such services had the experience to cope with dangerous behaviours.

In summary, challenging behaviours are those which challenge and test the competence and capacity of services to support people with learning disabilities. They are defined by the fact that they are culturally atypical, pose a threat to the safety and well-being of the person displaying the behaviour and/ or their carers, and serve to further handicap the person in that they inhibit personal development or access to normal life opportunities.

1.3 The epidemiology of challenging behaviour in people with learning disabilities

It is generally accepted that challenging behaviours are more common in people with learning disabilities than in the general population, and numerous studies have sought to measure the prevalence of these behaviours amongst this client group. As previously described in the academic dossier, comparisons between epidemiological studies are often problematic due to variations in the type of prevalence being studied (e.g. true prevalence versus administrative prevalence), the definitions of challenging behaviour adopted, and the research tools employed.

Some researchers have focused on single forms of challenging behaviour (e.g. Pica - Danford & Huber, 1982; Self-injury - Oliver, Murphy & Corbett 1987; Physical aggression - Harris & Russell, 1989; Sigafoos, Elkins, Kerr & Attwood, 1994), while others have attempted to produce epidemiological data for a range of topographies. Three examples of the latter type of study will be considered briefly.

Kushlick & Cox (1973) undertook one of the first attempts to collect systematic behavioural data on a total population. Included in their sample were all children and adults with learning disabilities living in the Wessex region of England in the late 1960s. As part of a general prevalence study, data were collected on challenging
behaviours using the Degree of Dependency Scale (Kushlick, Blunden & Cox, 1973). The survey suggested that 10 children and 20 adults with learning disability per 100,000 general population could be expected to display some form of challenging behaviour.

Qureshi, Alborz & Kiernan (1990) studied the prevalence of challenging behaviour in children, adolescents and adults in the geographical region covered by the North Western Regional Health Authority in England. Their results indicated that 4.6 individuals per 10,000 general population showed some form of difficult behaviour, a subset of whom (1.9 per 10,000) met a definition of severe challenging behaviour. This corresponds to around 5.7% of people with a learning disability.

Borthwick-Duffy (1994) studied the prevalence of three principal types of challenging behaviour (physical aggression, self-injury and destructiveness) in a very large sample of people with learning disabilities supported by the Californian Department of Developmental Disabilities. Fifteen per cent of the sample were found to display serious levels of at least one of these behaviours.

Emerson (1995) has summarised some of the other key findings regarding the epidemiology of challenging behaviour. These include the fact that challenging behaviours tend to:

- endure over time (i.e. they are chronic rather than acute in nature)
- to present in multiple forms within single individuals
- be generally more common in males
- increase in prevalence with age during childhood, peak between the age of 15-34, and then decline
- become more prevalent as the degree of learning disability increases
- show some association with specific syndromes (e.g. de Lange, Lesch-Nyhan, Prader-Willi Syndrome)
• be more prevalent in people suffering from secondary disabilities (e.g. communication difficulties, visual or hearing impairments, mental health problems)

1.4 Challenging behaviour and institutionalisation

Several decades of research have demonstrated that the presence of challenging behaviour in people with learning disabilities is positively associated with admission or readmission to institutional care. Four main types of study are in evidence:

1. Studies assessing the characteristics of new admissions to institutional care

2. Studies comparing the behavioural characteristics of institutionalised subjects with those of community subjects

3. Studies which have followed up groups of people with learning disabilities discharged from institutions into the community, and then analysed the behavioural features of those subjects remaining in the community and those experiencing institutional readmission.

4. Studies which have employed the same methodology as those in Type III, but which have also investigated environmental conditions associated with readmission.

Each of these research areas will be examined in turn.
1.4.1 Studies analysing individual characteristics correlated with initial admission to institutional care

Studies in this category have sought to identify new admissions to institutions and to provide behavioural descriptions of the individuals concerned in order to try to identify key factors leading to hospital care.

Early studies in this area were reviewed by McCarver & Craig (1974) and indicated a clear trend for admission to institutional care to be associated with high rates of pre-admission challenging behaviour. These authors concluded that:

'...it appears that most retardates (sic) are institutionalised either because they exhibit behaviour which the community will not tolerate, their families are unable to properly care for them, or community facilities are not adequate.'


Black, Cohn, Smull & Crites (1985) studied the demographic and family characteristics of individuals referred for institutional admission in a defined geographical area in a single calendar year. Sixty-seven per cent displayed at least one form of challenging behaviour, and 53% displayed two or more. Property destruction was the most common behavioural category cited. The presence of behavioural problems was not associated with any other client characteristics or family stress levels.

Khan, Cumella, Krishnan, Iqbal, Corbett & Clarke (1993) surveyed new long stay patients at a hospital for people with learning disabilities. 'New long stay' was defined as a stay in excess of one year but less than five years, and individual characteristics were assessed using the Disability Assessment Schedule (Holmes, Shah, & Wing, 1982). The majority of residents (74%) were assessed as having a mild or moderate learning disability, 71% were male, and the majority were physically mobile and able. Eighty-four per cent were rated as having a severe behavioural management problem
or a behaviour which would potentially present a severe management problem in a community setting, 39% received medication to control behaviour disorders, and 29% had a 'dual diagnosis' of learning disability and superimposed psychiatric disorder.

Khrisnan, Upadhyay & Londhe (1993) studied new long stay admissions to separate institutions located in rural and urban areas; the definition of long stay was the same as in the Khan et al study. While the presence of behavioural problems was the most common reason for admission in the urban setting, social care factors were the most prevalent cause in the rural location. The presence of behaviour problems was the principal reason for continued inpatient care in both groups however.

Studies within this group may be criticised in that, while they show that people admitted to institutional care display high rates of challenging behaviour, they do not prove that these rates are higher than amongst learning disabled people living in the community. This weakness is addressed by studies in the next three sections.

1.4.2 Comparative studies of institutionalised and community subjects

Studies in this category have employed a variety of measures to assess potential differences in the demographic and behavioural characteristics of people living in institutions and in community settings. Any observed differences between the groups are then viewed as potential reasons for their different placement status.

Two large-scale North American studies of this type are in evidence. Eyman & Call (1977) studied 6,870 people receiving a range of institutional or community support services in California, Colorado & Nevada. With the exception of young severely disabled individuals, who showed a low prevalence of challenging behaviour in all placement settings, institutionalised subjects showed far higher rates of challenging behaviour. In general, the presence of challenging behaviour was positively correlated with increasing severity of learning disability. Borthwick, Meyers & Eyman (1981) studied a sample of over 6,000 persons with learning disabilities living in a wide range
of care settings in three North American States. Institutions were found to have a far higher prevalence of behaviour problems than board and care homes, family care homes or natural family homes.

Jawad, Krishnan, Sansom & Butler (1993) looked at subjects admitted to a new hospital for people with learning disabilities in England over its first three years of operation and compared the characteristics of those resettled into the community with those remaining in care during the study period. Physical aggression was significantly more common in the hospital group, but no other behavioural differences were apparent.

A general interpretational problem with studies of this type is that while institutional placement is associated with higher rates of challenging behaviour, it is conceivable that institutional placement in itself is a sufficient condition for the development of such behaviours given the generally negative conditions which prevail within such settings (Goffman, 1961; Oswin, 1978) It is therefore possible that challenging behaviours in the institutional samples developed as a consequence of admission, rather than being a reason for admission. Data from Eyman, Borthwick & Miller (1981) suggest that this is probably not the case however. These authors studied 426 subjects referred for services in California at their initial point of screening and at two year follow up. A shortened version of the Adaptive Behaviour Scale (Nihira et al, 1974) was used to assess the personal characteristics of the sample at these two points. At follow up, 214 individuals had been placed in institutional care and 212 had been placed in a variety of community services. The institutionalised subjects showed higher rates of challenging behaviour but, regardless of whether subjects were institutionalised or not, challenging behaviour remained extremely consistent between the initial assessment and follow up, leading the authors to conclude that the notion that institutions produced challenging behaviour could not be supported by the results. Interestingly, in the institutionalised sample, challenging behaviour was more prevalent amongst those more able clients.
1.4.3 Studies analysing individual characteristics correlated with readmission to institutional care following resettlement

The research under this heading is generally more sophisticated in terms of its experimental design and has attempted to identify personal factors which differentiate between the successful and unsuccessful placement into the community of previously institutionalised subjects.

Jacobsen & Schwartz (1983) looked at three large cohorts of people with learning disabilities. The first, consisting of 2,742 subjects, were resident in group homes and had no perceived risk to their continued placement in these establishments; the second (491 subjects) were considered to be at risk of placement failure; and the third (3,092) were in institutional care at the time of the study but deemed suitable for deinstitutionalisation. The study looked at four categories of challenging behaviour: 'cognitive' problems associated with selective neurological deficits or psychosis (delusions, perserveration, hallucinations), 'affective' problems associated with psychiatric impairment or interpersonal difficulties (extreme mood swings etc.), 'major' violent or anti-social acts (physical assault, destructiveness, inappropriate sexual behaviour and self-injury), and 'other' behaviours frequently associated with developmentally disabled populations (pica, stereotypy, hyperactivity etc.) The results indicated that cognitive and affective behaviours were more common amongst the group home residents at risk of placement failure, while major and 'other' behaviours were more common in the institutional group. More able subjects were at greater risk of placement failure than their more disabled peers. The authors concluded that the group homes were less tolerant and less capable of managing chronic individual traits (as evidenced by the affective problems) than they were of more episodic problems. Although the research did not study environmental variables, it was suggested that service system, rather than individual client characteristics, presented the greatest obstacles to continued community placement. This conclusion relates mainly to the finding that the at risk group had a far greater volume of unmet service needs (e.g. for mental health and behavioural support services) than the stable group.
An obvious weakness in the Jacobson & Schwartz study was that it considered potential, rather than actual, placement failure. The clients deemed at risk may or may not have gone on to experience placement breakdown, and therefore no firm conclusions can be drawn from the results. The remaining studies in this section have analysed characteristics of people who were actually readmitted to institutional care following community placement failure.

Windle, Stewart & Brown (1961) studied the failure of people with learning disability placed on three kinds of leave (vocational, home and family) from institutional care. Forty per cent of vocational leave failures, 65% of home leave failures, and 32% of family leave failures were associated with behavioural problems; no clear definition of the different types of leave was provided. Moen, Bogen & Aanes (1975) compared the behavioural profiles of 72 people successfully placed and 13 people unsuccessfully placed from institutional care into the community. The most common reasons for placement failure were physical aggression (62%), inappropriate personal habits (54%), hyperactivity (39%), medical problems (31%), and inappropriate sexual behaviour (8%); these categories were not mutually exclusive. Gollay (1977), cited in Crawford, Aiello & Thompson (1979), found that institutional returnees scored higher on all challenging behaviours as measured by Part II of the Adaptive Behaviour Scale (Nihira et al, 1974) than individuals who continued in community placements.

Sutter, Mayeda, Call, Yanagi, & Yee (1980) looked at 77 subjects placed into community services over a three year period. Seventeen subjects were re-institutionalised. The latter group contained more males and were generally far more able than the successful group, thus echoing the findings of Eyman et al (1981) and Jacobsen & Schwartz (1983) reported above. The unsuccessful group also displayed a significantly greater frequency of behavioural difficulties such as physical aggression and absconding from care.

Schalock, Harper & Carver (1981) conducted a five year follow-up of 69 people with learning disabilities placed into independent housing. Twenty per cent experienced
placement failure, and this was found to be associated with bizarre and inappropriate social behaviour, inadequate nutrition, or problems in maintaining the home setting. Schalock & Lilley (1986) similarly found that socio-emotional functioning was clearly related to the successful placement of 85 subjects into independent housing and community employment.

Hemming (1982) studied 51 subjects transferred from institutional care to new small units built in hospital grounds. During the course of the study, 11 people were returned to institutional care. No significant differences were found between those remaining in their placement and those re-institutionalised in terms of age, sex, I.Q, or years in institutional care. The study found that the best predictor of re-institutionalisation was a combined index consisting of institution staff's pre-placement prediction of likely placement success and the presence of anti-psychotic medication. The study also measured behaviour disturbance via incident record books maintained by the new unit staff; these were used to produce an average weekly disturbance score for each subject. Higher disturbance scores were associated with a significantly greater likelihood of re-institutionalisation and also with greater levels of disability.

An association with anti-psychotic medication was also found by Harder, Kalachnik, Jensen & Feltz (1987) who discovered that unsuccessful community placements were linked with higher rates of physical aggression in more mildly and moderately disabled individuals who were prescribed anti-psychotics for their problem behaviour. Heal, Sigelman & Switzky's (1978) major review of the literature concluded that the presence of challenging behaviour was the most reliable personal predictor of placement failure.

While studies in both this and the previous category clearly show that a high percentage of institutionalised subjects have challenging behaviours and that the rates of these behaviours generally exceed those shown in community settings, they do not indicate whether individuals with similar behavioural profiles have been maintained in community services. That is, from the data it is not clear whether the presence of
challenging behaviour is either a sufficient or necessary condition for readmission. This issue is considered by the next set of studies.

1.4.4 Studies analysing individual and environmental characteristics correlated with readmission to institutional care following resettlement

Almost without exception, the above studies have focused on the characteristics of individuals with learning disabilities and their role in precipitating institutional careers. The studies in this section are much fewer in number, and have attempted to identify both relevant personal and environmental conditions.

While there is a substantial body of research exploring the general impact of environmental conditions on the development and progress of people with learning disabilities in community and institutional settings (see reviews by Haney, 1988, for example), only two published studies have specifically considered the impact of both individual and service setting characteristics on community placement success for people with challenging behaviour.

Willer & Intagliata (1981) followed up 338 individuals between two and four years after placement in foster care or group homes in an effort to identify predictors of successful placement. Questionnaires were completed by each individual's principal care provider and multiple regression analyses performed on five outcome measures of community adjustment, these being self-care, community living skills, use of community resources, social support, and behaviour control (defined as an absence of challenging behaviour). Some measures had pre-scores taken prior to community placement and others were completed retrospectively. Independent variables included individual client characteristics (e.g. age, sex, pre-placement behaviour etc.), care provider characteristics (e.g. age, sex, education, and mental health), and social environment characteristics (e.g. location, number of co-residents, and social care practices).
Pre-placement measures were highly predictive of challenging behaviour, and this relationship was particularly pronounced for more able individuals in group homes. Older residents were less likely to display behavioural problems. Environmental characteristics also appeared to be able to moderate the impact of challenging behaviour. Foster care homes which encouraged residents to express feelings and frustrations, and which encouraged residents to form cohesive, mutually supportive relationships were more successful in achieving behaviour control. Similar results were obtained for the group homes, but group home settings which restricted resident autonomy also experienced fewer management problems. Pre-placement behaviour accounted for over 20% of the variance in both settings and environmental factors just under 11%.

Schalock, Harper & Genung (1981) studied 166 people placed into community care services over a nine year period. Sixteen per cent of the sample were readmitted either to learning disability or mental health institutions during this time. Appropriate socio-emotional behaviour was found to be a predictor of placement success, while the presence of challenging behaviour was the reason for readmission for all failed placements. Differences were apparent between those readmitted to the learning disability and mental health facilities. The former tended to suffer breakdown fairly rapidly after community placement (half were readmitted within 4 months) and typically experienced problems associated with destructiveness, stealing and incontinence; the latter tended to be readmitted some 5-6 years after their initial placement and tended to show problems of temper tantrums, bizarre behaviour and abusiveness. Readmission to both types of facility was greater for smaller scale community programmes, and it was hypothesised that such programmes may offer less specialist support services for hard to manage clients.

In addition to the 26 subjects with behavioural difficulties who were reinsitutionalised, the study identified 23 subjects with similar behaviours who were maintained in their placements. The study showed that the maintained group showed a number of key
features which may have explained the differential results. They tended to display their challenging behaviours within their formal care settings (i.e. residential and day care) rather than in public places, they had been institutionalised for shorter periods prior to community placement (and hence, the authors speculate, may have been more amenable to therapeutic intervention), each one had access to an advocate, the majority received local mental health support services, they were supported by committed staff groups, and a greater proportion were female.

One important point regarding both the studies by Willer & Intagliata and Schalock et al is that they were conducted at a time when people with the most severe challenging behaviours would probably not have been viewed as good candidates for resettlement; the extent to which they were represented in the study samples is therefore unknown.

1.4.5 Conclusions

The data from the four different types of study described above provide unequivocal evidence that the presence of challenging behaviour is a major risk factor in terms of admission to institutional care for people with learning disabilities. Although the vast majority of studies have concentrated on the personal behavioural and psychiatric characteristics of their subjects, two studies have suggested that whether or not a person with challenging behaviour is institutionalised may be partly a function of their personal characteristics and partly a function of the support services which they receive.

1.5 Challenging behaviour and community care

This section builds on the information presented so far. It briefly reviews the evolution of current thinking regarding best practice in the delivery of specialist services to people with challenging behaviour and then examines the available outcome research on different service models.
1.5.1 The nature of specialist support for people with challenging behaviour

The bulk of the research described above was conducted at a time when community support services for people with learning disabilities and challenging behaviour were extremely limited in terms of their scope, sophistication and general availability. This situation has changed over the last fifteen years as the trend towards the closure of institutions has gathered pace (Emerson & Hatton, 1994), and the need to make available alternative forms of support for people with challenging behaviour has been increasingly recognised.

Within the United Kingdom, a succession of policy statements initially placed the focus for the development of specialist support for this group fairly firmly within institutional frameworks (DHSS, 1984; Social Services Committee, 1985; DHS, 1989). Special residential behavioural treatment units on hospital sites or in community locations were often seen as the preferred model, the idea being that having received expert assessment and treatment, admitted clients could then be successfully returned to their environments of origin and effective treatment programmes maintained therein. However, research from both the United Kingdom and North America revealed limitations of this approach (Keene & James, 1986; Fidura, Lindsey & Walker, 1987; Hoefkens & Allen, 1990; Newman & Emerson, 1991; Dockrell et al, 1992). Specific criticisms were that:

- Assessments conducted in such units would not, by definition, be able to assess possible causal or maintaining factors which existed within a person's normal environment

- Treatment effects achieved within units were found not to generalise to other environments

- Units often 'silted up' with clients whom community services were reluctant to accept back into their care
• Units offered poor coverage in that they could only provide a service to as many people as there were beds

• Referring people to units did little or nothing to improve the competence of staff in mainstream services to work with challenging behaviour (and hence reduce the dependency on institutional care)

• Units appeared to represent a poorer option in cost-benefit terms.

The creation of peripatetic community behavioural support teams was seen as a possible solution to these problems, and the development of such teams has perhaps been the most significant initiative in this field within the last decade. This model of intervention was promoted in the U.K. within the King's Fund publication 'Facing the Challenge' (Blunden & Allen, 1987) and in North America via the national Research & Training Centre (R.T.C.) programme on Community Referenced, Non-Aversive Behaviour Management (Anderson, Russo, Dunlap & Albin, 1996). The main benefits claimed for this model were that:

• By delivering 'on site' services in the environments in which the challenging behaviours were being displayed, a more comprehensive assessment could be conducted.

• Generalisation problems would also be avoided by providing treatment within the normal environment.

• As the person's normal carers would be the vehicles via which interventions were delivered, their competence and skills relating to challenging behaviour would increase, thus making the need for institutional admission less likely.

• Greater coverage would be possible (although silting up may still occur).
Greater cost-benefit could be achieved as this service would not be building based.

Many of these points had in fact been recognised much earlier in the triadic intervention model described by Tharp & Wetzel (1970), but the King's Fund and R.T.C initiatives represented the first high profile attempts to encourage their use with people with challenging behaviours in community settings.

At the time that the King's Fund paper appeared, the alleged superiority of delivering specialist behavioural support via such teams remained almost entirely hypothetical, but a number of empirical evaluations of peripatetic support teams are now available which have helped to examine the model more critically.

The earliest published paper is by Donnellan, La Vigna, Zambito & Thvedt (1985) and describes the impact of a time-limited intensive support team on sixteen subjects aged between 3 and 56 years living in community placements in the Los Angeles area. Fifteen subjects showed improvements in levels of challenging behaviour from baseline, 10 showed increases in the amounts of positive social interaction between the subject and carers, and the majority of carers gave very positive satisfaction ratings for the intervention. The positive gains for most subjects were maintained at follow up, and the costs of the intervention compared very favourably with the cost of admission to state institutional facilities.

Scorer, Cale, Wilkinson, Pollock & Hargan (1993) reported on the results of a six-month specialist support team pilot project, and found that positive behavioural change was evident in 5 out of the 6 cases studied following intervention. In addition to designing individualised client focused interventions, the team was often required to make additional recommendations for restructuring the organisational systems of referring agencies in order to enhance the effectiveness of client-focused interventions. Where it proved possible to influence organisational variables, rapid progress was
made, but in other situations organisational resistance led to problems and reduced intervention effectiveness.

Allen & Lowe (1994) provided an initial analysis of the outcomes and costs associated with a specialist support team operating in a locality which also had a special residential behaviour unit. They described three detailed single-case studies which demonstrated positive behavioural changes both at intervention and follow-up. The costs of the interventions were significantly less than admission to institutional care. A more in-depth analysis of this team was provided by Lowe, Felce & Blackman (1996) as part of a larger study which compared the effectiveness of two support teams from different geographical localities. Subjects receiving input from the two services were initially analysed as a single sample, and their progress compared to a control group of people with challenging behaviour not referred for specialist input. Only minor differences were observed between the experimental group and the controls, and evidence for any treatment effects was extremely weak. However, when the two specialist support teams were analysed separately, one service was found to have statistically significant changes in reported levels of challenging behaviour, mental health problems, adaptive skills, and the amounts of scheduled activity. No significant changes were recorded for the second service on these variables; neither service produced statistically significant changes in observed behavioural difficulties, carer stress or carer morale. Carers using both services reported high rates of satisfaction. Differences in the organisation and staffing of the two services were hypothesised to be potentially key variables explaining the variation in results.

A key theme to emerge from this study was the generally poor programmatic environments (most notably in relation to low levels of client engagement in constructive activities and even lower rates of staff: client contact) in which the services delivered their interventions, and the likely impact of these settings on intervention effectiveness. Staff from the two specialist services were interviewed in order to identify factors which, in their view, helped or hindered their work. Commonly cited 'helpful' characteristics included receptive and committed staff,
adequate resources, and high levels of co-operation with recommended plans. 'Unhelpful' characteristics included poor leadership, the provision of inaccurate information by care staff, basic problems in physical settings and staffing, and poor communication.

Mansell, Hughes & McGill (1994) described a project to reduce rates of placement breakdown in a large community service providing housing for people with learning disabilities. Critical factors identified in one case which resulted in readmission to institutional care included the employing organisation operating a general recruitment procedure which failed to inform relevant staff that they would be required to support challenging individuals; a concentration on training staff in values rather than in effective working practices; a care model which resulted in a 'minding' ethos rather than one which sought to involve clients fully in the activities of everyday life; management's failure to listen to and correctly interpret care staff's views; and the organisation's agreeing to allow the senior care worker to take a month's leave at exactly the same time that support from staff from a special assessment unit (where the client had been placed prior to resettlement) were withdrawn.

Colond & Wieseler (1995) measured the impact on institutional admissions of a community service team which provided a menu of support services including on-site behavioural assessment, behavioural management, carer training, programme evaluation and follow-up consultancy. Without any changes in institutional admission policies, a 53% reduction in admissions was observed in the 9 months following the introduction of the service as compared to the 9 months prior to the team's development. Risk of admission for clients on a waiting list for services was three times greater than for individuals receiving team input. Unfortunately, no other information was provided regarding differences between the maintained and readmitted groups. Satisfaction ratings for the service were very high, and the authors claim that the presence of the team resulted in cost savings via the avoidance of institutional admission, but no data are provided to support this statement.
Davidson, Cain, Sloane-Reeves, Giesow, Quijano, Van Heyningen & Shoham (1995) describe a crisis intervention service for people with challenging behaviour and dual diagnoses operating in Monroe County, New York. The team operated as part of a network of support services for people in crisis, and included amongst its functions staff training and development, in-home counselling for carers of at risk clients, and follow-up support following admissions to acute psychiatric services. Shoham-Vardi, Davidson, Cain, Sloane-Reeves, Giesow, Quijano & Houser (1996) compared 98 clients re-referred to this service following crisis intervention support with 131 who were not referred over a five year period. Differential predictors of re-referral were found for subjects aged under and over 30 years old; for the former, the presence of self-injurious behaviour and residence outside of the family home predicted re-referral, whereas for the latter, the presence of aggression was the only predictor. The authors did not study carers capacity to deliver interventions, but concluded that this could also play an important role in determining recidivism and argue that further study of this area was required.

There has been a sizeable investment in specialist teams both within the United Kingdom in the decade (Hill-Tout, Allen & Doyle, 1991; Toogood, 1994; Bering, Tupman & Jacques, 1994; Emerson, Forrest, Cambridge & Mansell 1996) and the United States (Maguire & Piersel, 1992) and, while it is apparent that they are capable of supporting extremely challenging individuals in community settings and reducing institutional admissions, it is not clear as yet that they can completely eradicate such admissions. Some individuals still fall through the community care net, and it seems that the reason for such failures may be as much to do with problems in service systems as with the problems displayed by individuals per se. As Mansell, McGill & Emerson (1994) observe:

'In a sense...challenging behaviour represents a special vulnerability to weaknesses of, or problems in, the management of the care environment'

(Mansell, McGill, & Emerson, 1994, p.70).
1.5.2 Conclusions

Studies in this section have suggested that the success or failure of community based interventions for people with learning disabilities and challenging behaviour is dependent on organisational variables as well as the characteristics of the people being supported. In the main, however, the evidence for the importance of these organisational variables has been based more on anecdotal accounts rather than empirically derived measures.

1.6 THE CONTEXT FOR THE CURRENT RESEARCH

In this section, the local context within which the research was conducted will be described. This description will relate to the national context concerning the development of specialist services for people with challenging behaviour described above. An analysis of the impact of the development of specialist support services on admissions to institutional care will also be provided.

1.6.1 The development of specialist support services for people with learning disabilities and challenging behaviour within South Glamorgan

The former county of South Glamorgan has a population of approximately 400,000 people. For many years, the highest profile service for persons with learning disabilities in the locality was Ely Hospital. Originally a poor law institution founded in 1862 which then became a hospital under the NHS Act of 1946, the hospital achieved national notoriety in the late 1960s due to concerns over its standards of care. These concerns were of such magnitude that an independent inquiry was held; the subsequent report of the inquiry (NHS, 1969) became a landmark document in the development of services for people with learning disabilities in the United Kingdom. It was to be the first in a succession of scandals that followed throughout the next decade (Martin, 1984). The inquiry also had a major role in prompting the appearance of another key document, the White Paper 'Better Services for the Mentally Handicapped' (DHSS,
1971), which appeared a year later and which effectively sowed the seeds of the community services which are seen today.

At its peak, in the late 1960s, Ely's total long-stay population reached almost 600. This figure had declined to 99 by July 1997, and a 'fast track' resettlement programme was in place which will result in the hospital's closure by 1998.

In the 1970s, only rudimentary community services existed in the form of three adult training centres, a 25 bed hostel modelled on the service provision developed in the Wessex region in the 1960s, and a small number of residential places within smaller scale hostels of around 12-15 places. The NIMROD project (Lowe & de Paiva, 1991) began in 1981, and piloted the development of a comprehensive community service (incorporating residential, community and specialist support components) in one locality in the City of Cardiff containing approximately 15% of the County population. The residential service included a number of individuals rated by carers as having severely challenging behaviours (Felce & Lowe, 1993).

With the advent of the All Wales Strategy for the Development of Services for Mentally Handicapped People (Welsh Office, 1983), a wider network of community services developed in the shape of five geographically based multi-disciplinary, multi-agency support teams. This mirrored a national expansion in community support teams across Wales at the time (McGrath & Humphreys, 1988). By the mid-1980s, the attention of the All Wales Strategy switched to a consideration of the future of the remaining long-stay institutions in the Principality, and in 1987, a resettlement programme was commenced for the hospital with the eventual aim being its closure. Early on in this programme, it was recognised that closing the hospital would be dependent on two parallel processes - resettling the existing residents and preventing the admission of new long-stay residents who would be added to the resettlement queue and potentially prevent closure. It was also recognised that the development of community support teams had proved insufficient for the latter task to be achieved.
Three new service initiatives were therefore put in place in order to provide an enhanced community service to people likely to be at risk of admission. The latter essentially fell into two groups, the first being people experiencing social care crises through the sudden illness or death of a carer, and second, those people with challenging behaviour and/or a dual diagnosis of learning disability and mental health problems whom community services found difficult to support. Providing effective community services for the latter group was particularly important, as increasing numbers of people with complex needs of this type would be being cared for in the community as the hospital closed.

For social care crises, an Emergency Intervention Service was established; this consisted of a number of project workers who controlled a budget which enabled them to provide individualised responses to crises and which could involve the provision of respite support in the person's own home or elsewhere as appropriate.

For behavioural and psychiatric crises, two new services were developed. The first was an Intensive Support Service which operated on a non-aversive behavioural model (La Vigna, Willis, & Donnellan, 1989) and which included specialist advisors (psychologists and a clinical nurse specialist), a peripatetic support team, ring-fenced budgets for individualised service development, and an acute admission in-patient unit on the Ely Hospital campus. In addition to devising pro-active behaviour change strategies, the service trained carers in reactive management procedures (such as defusion techniques, self-defensive breakaway techniques, and minimal physical restraint). Both the admission unit (Hoefkens & Allen, 1990) and the community service (Allen & Lowe, 1994; Lowe, Felce & Blackman, 1986) have been subject to empirical evaluation as described above. The latter studies clearly demonstrated that very challenging individuals could be successfully supported in community settings.

The second service development in this area concerned enhanced provision for people with learning disabilities and more acute psychiatric or neurological needs. This involved a greater investment in community psychiatry, and, in particular, the
establishment of a series of weekly outpatient clinics at a local general hospital. Over four hundred clinic consultations a year were provided by this service by 1995.

1.6.2 Patterns of admission to Ely Hospital 1975-1995

Allen (in press) studied the admission patterns to Ely Hospital over the two decades from 1975 to 1995. Admission data were examined in three time phases of baseline (prior to the introduction of community support teams in 1983), following the introduction of community support teams (1983-1990), and after the creation of the specialist support services described above (1990-1995). Short-term and long-term admissions were considered separately, and variations in admission trends to the hospital between phases were examined using the Mann-Whitney U test. The pattern of short-term admissions is shown in Figure 1.1.

**Figure 1.1**: Short-Term Admissions (1975-1995)
Figure 1.2: New Long-Stay Admissions (1975-1995)

There was no significant change in the rate of short-term admissions prior to and following the development of community support teams (the mean rates of annual admission being 142.5 and 124.71 respectively), but the reduction in admission rates following the introduction of the specialist services (mean = 30.67) was significant at the p <0.005 level.

The rates of new long-stay admissions (defined as stays in excess of 6 months) are shown in Figure 1.2. The mean number of annual admissions of this type was 15 in the pre-development phase, 9 in the community support team phase, and 3.5 in the specialist service phase.

The difference between the baseline and community support team phase, and between the community support team phase were both significant at the p <0.005 and p <0.05 levels respectively.
Consideration needs to be given to alternative explanations of the results other than the service developments described. The admission of children to the hospital stopped in approximately 1976, and does not appear to be associated with a change in either short or long-term admissions. The changes in reported admission patterns could not be explained as a function of decreased bed availability at the hospital. Admissions in 1995 showed an almost 90% reduction on the rate in 1985, but the overall bed complement reduced by only 46.3% during the same period. Furthermore, in the 5 year period between 1990-1995, the number of vacant beds decreased by only 36.5%. It was also conceivable that admission to hospital could have been replaced by admission to services other than those described, most notably to private facilities within or outside the catchment area. The private sector was in fact virtually non-existent within the county, but a number of large-scale private institutions had been created outside of, but geographically proximate to, South Glamorgan within the last few years of the study. It proved impossible to track admissions to such facilities over the full course of the study, but only four admissions to adult out of county services took place between 1989-1995, thus suggesting that increased admissions to alternative facilities was an unlikely explanation for the results obtained.

The area in which the study was conducted was generally well resourced, and it was therefore of concern that, despite the development of a range of general and specialist community support services for people with learning disabilities, and evidence that the specialist support team was effective in achieving change in community clients, a small but significant number of people continued to be admitted to long-stay institutional care.

1.7 OUTLINE OF THESIS

The literature review presented above combines two strands of research activity. It has examined studies into the characteristics of people with learning disabilities admitted into institutional care and studies into the effectiveness of providing therapeutic intervention for the same group in community settings. The first group of studies has
shown that people admitted to institutional care are likely to show high rates of challenging behaviour, that institutional populations show higher rates of challenging behaviour than community samples, and that challenging behaviour will be the main reason for re-admission to institutional care following resettlement into the community. A smaller number of studies have suggested that service setting characteristics may interact with personal behavioural characteristics to produce placement breakdown. Service characteristics which have been identified as being important include:

- The size of the service (small services potentially being less able to support challenging individuals)
- Whether or not adequate specialist support is provided (e.g. in terms of mental health services)
- Whether clients have access to an advocate
- Whether residential services encourage residents to express feelings and provide each other with mutual support
- The degree of restrictiveness of the residential setting
- The setting in which challenging behaviours occurred

The second group of studies have also suggested that organisational variables may influence the effectiveness of interventions for challenging behaviour within community settings. It has been reported that:

- Some features of service settings (e.g. low engagement and staff:resident contact) clearly militate against effective interventions being introduced
• Recommendations may need to be made for restructuring the organisation of referring agencies if interventions are to be optimally effective

• Training received by staff may not be appropriate for work with this group

• Placement breakdown may be hastened by poor inter and intra-organisational communication

• Ineffective deployment of resources may also contribute to placement breakdown

With one or two notable exceptions, these suggestions are based on anecdotal post-hoc analyses rather than on any empirical endeavours to measure differences in functioning between service settings which may contribute to outcome variance.

It is therefore unclear at present which factors determine the successful maintenance of community placements, but it is likely that the mere presence of challenging behaviour itself, as suggested by the early research, is not a sufficient condition for placement breakdown.

This being the case, it is important to try and identify those individual and environmental independent variables which impact on the dependent variable of institutional admission. As stated earlier, failing to do so will result in a continuing trend of hospital admission for a minority of people with learning disabilities and challenging behaviour, resulting in the need to maintain a level of institutional provision for such individuals or the creation of new institutional settings.

The present study will examine both the personal and service setting characteristics of those groups of people with learning disability and challenging behaviour who were successfully and unsuccessfully supported in community settings within South Glamorgan in an effort to produce a more sophisticated analysis of factors relevant to
placement maintenance and breakdown. Data will be collected on each subject relating to their level of functioning, psychiatric status, and challenging behaviours. In addition, a wide variety of environmental variables will be studied. These include measures of service support and internal management and organisation. Bivariate nonparametric statistics will be employed to identify key variables which discriminate between maintained community status and institutional admission.
CHAPTER 2. RESEARCH DESIGN AND METHOD

2.1 Introduction

This chapter is divided into two main sections which cover the hypotheses to be investigated in the study and the experimental design employed.

2.2 Experimental Hypothesis

Based on the review of the literature presented in chapter 1, two experimental hypotheses were generated in relation to placement outcome for people with learning disabilities and challenging behaviour in community services. These were as follows:

- **Hypothesis 1.** That people with challenging behaviour experiencing placement breakdown and subsequent admission to long-stay institutional care would display higher levels of behavioural and psychiatric disturbance than other challenging individuals maintained in the community.

- **Hypothesis 2.** That people with challenging behaviour experiencing placement breakdown and subsequent admission to long-stay institutional care would come from service settings which were deficient in terms of their internal organisation and the levels of support which they provided.

2.3 Method:

The method is presented in three subsections dealing with the study design, subjects, and research measures. The last sub-section includes an account of the construction of a novel measure of organisational functioning designed for the present study.
2.3.1. Design

A natural group comparison design was employed to study potential differences between two groups of people with learning disability & challenging behaviour, one of which experienced placement breakdown, and one of which was successfully maintained in community services.

The study was conducted in the County of South Glamorgan and adopted a six year (1991-1996) research window. Given that both groups were from the same geographical locality, able to access the same range of specialist support services, and subject to the same policies regarding admission to institutional care, it would be reasonable to assume that differences in their respective outcomes (i.e. admission to long-stay institutional care vs. remaining in the community) would be a function of differences in the behavioural characteristics of the individuals concerned and/or differences in their immediate care services.

2.3.2 Subjects

The groups were self-selecting and defined as follows:

- **Breakdown Group**: People with challenging behaviour who experienced placement breakdown which was defined as permanent exclusion from their community placement followed by a stay of 12 months or more in an institutional setting.

- **Maintained Group**: People with challenging behaviour who received medium to long-term support from the Intensive Support Service over the 6 year study period and who remained in their community placement during this time.

The breakdown group (n=14) consisted of the total population who met the definition of placement breakdown described above by being admitted to either Ely Hospital or
to out of county, private psychiatric facilities on a long-stay basis over the 6 year study period.

Individuals in this group would typically first have been admitted to institutional care on a short-term emergency basis following behavioural crises; very often, community services would make the case that they could not receive them back into their residential placements as these were now felt to be inappropriate to their needs. The people concerned would then have little or no alternative other than to remain in institutional care while efforts were made to locate alternative accommodation and support services which could cope with their behaviour. As a consequence of the resource difficulties faced by most community services, this process was always protracted and frequently fruitless. After a period of time, the individuals would be re-designated as long stay residents and efforts to find alternative accommodation would subsequently wane.

The maintained group consisted of subjects who had all been in receipt of clinical services from the Intensive Support Service (I.S.S.) for a minimum period of one year during the 6 year study period. Some individuals were referred from community settings at a time when they were deemed to be at risk of placement failure. Others were resettled from Ely Hospital with the full support of the I.S.S. after being positively identified in a screening exercise to identify those hospital residents who showed severely challenging behaviours; all these individuals had been resident in Ely for between 5 and 30 years prior to their resettlement. Individuals in the latter group were only included in the study group if they had been successfully placed in the community for a minimum period of 12 months at the time that the study was conducted. Collectively these subjects were viewed as an appropriate 'control' group for the breakdown group as they all showed severely challenging behaviour and, on the basis of the studies reviewed in Chapter 1, were also at high risk of placement breakdown either at the point of referral or following resettlement.
The I.S.S. offered three levels of intervention:

I. **Brief consultation**: usually single, one off consultations for assessment purposes.

II. **Fixed term inputs**: time-limited interventions, usually carried out in conjunction with psychologists from community support teams, designed to prevent further deterioration in a client with less severe challenging behaviours.

III. **Intensive, long-term support**: open ended support to individuals displaying chronic challenging behaviours which are likely to pose major management problems to community services in the long-term.

Seventy-four people were accepted onto the community caseload of the Service in the study period. The maintained group (n=33) were self-selecting in that they all received level III input and, accordingly, had detailed information available about their personal and service characteristics; all subjects receiving support at this level were included in the study and a 100% sample of clients receiving level III input was therefore achieved. The group represented a 45% sample of subjects supported by the Service overall.

Some subjects had already undergone detailed personal assessments using the research tools described below either as part of their screening for resettlement or, in the case of four clients, as part of the research conducted by Lowe, Felce & Blackman (1996); data on the latter clients were used with the permission of the first author. Other subjects were assessed specifically for the purposes of the present research. In all cases, assessments were conducted within approximately 8 weeks from the point of referral to the service in order to minimise any potential influence of interventions on behavioural ratings. In this sense, all assessments were conducted while clients were in baseline conditions.
2.3.3 Research Measures

Three forms of data were collected on each subject. These concerned the subject's personal characteristics, the organisational characteristics of their support services, and the nature of any specialist support received.

The measures relating to personal characteristics were completed by direct care staff who had a close working relationship with the person concerned. The data relating to the organisational characteristics of the referring services were completed by personnel from the ISS who had the most detailed knowledge of a particular client or other closely involved personnel (such as senior care managers) if the client had not been on the ISS caseload. All respondents were blind to the purpose of the study. These measures were designed to assess the characteristics of staffed settings, and were therefore not completed for those subjects living in the family home or adult foster placements. Factual data regarding specialist support provided were generally abstracted from case files by the author.

The measures employed under each of the three major headings were as follows:

a. Personal characteristics

Data on the behavioural, psychiatric and adaptive characteristics of both groups were collected via the following measures: The Psychopathology Instrument for Mentally Retarded Adults, the Aberrant Behaviour Checklist, the Disability Assessment Schedule and the Adaptive Behaviour Scale (part 1). Copies of these and all the remaining research instruments are included in Appendix II.

The main features and psychometric qualities of each measure will be briefly described.

The Psychopathology Instrument for Mentally Retarded Adults - Informant Version (Matson, 1988)
The Psychopathology Instrument for Mentally Retarded Adults (PIMRA) was designed to help diagnose mental health problems in adults with learning disabilities. It contains 56 items evenly distributed across eight subscales as follows:

- Schizophrenia
- Affective Disorder
- Psychosexual Disorder
- Adjustment Disorder
- Anxiety Disorder
- Somatoform Disorder
- Personality Disorder
- Inappropriate Adjustment

The scale items were derived from categories in the American Psychiatric Association's Diagnostic and Statistical Manual III (DSM III). Two versions are available, one for direct carers and a self-report version. The former was used in the present study. Each item is rated as 'True' or 'False' for the person being assessed. Separate sub-scale scores and a total scale score may be computed.

Aman (1991) reviews ten studies which have examined the scale's psychometric features. The original authors of the scale found the test-retest reliability for the informant version to be 0.76. One study (Iverson & Fox, 1989) reports percentage agreements for inter-rater reliabilities varying between 70-95% across subscales. Overall mean agreement was 80%, and there was 89% agreement concerning the presence or absence of certain symptoms. It is claimed that the scale's validity has been supported by the fact that individuals with formal psychiatric diagnoses have been found to produce higher total scale scores. Some evidence also exists to show that total PIMRA scores correlate strongly with an early version of the Reiss Screen (Reiss, 1988) (another tool developed to assess mental health in people with learning disabilities).
Aman makes a number of criticisms of the scale in relation to the weak evidence to support its use to identify specific mental health disorders. This is not a serious concern in the present study however as PIMRA was used in a general descriptive function rather than a diagnostic function.

In the present study, the inter-rater reliability of the PIMRA scale was assessed by having a 10% sample of subjects assessed twice by raters whom it was felt knew the subjects extremely well. Reliability was calculated using the formula described by Lowe & Felce (1994) and Pett (1997):

\[
\text{Number of Agreements} \times 100 \\
\text{Number of Agreements plus Disagreements}
\]

The qualitative guidelines for assessing reliability ranges described by Cicchetti & Sparrow (1981), and cited in Aman (1991), were employed to classify the figures produced by this formula. Cicchetti & Sparrow's framework is as follows:

<table>
<thead>
<tr>
<th>Reliability Level</th>
<th>Clinical Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>less than .40</td>
<td>Poor</td>
</tr>
<tr>
<td>.40 to .59</td>
<td>Fair</td>
</tr>
<tr>
<td>.60 to .74</td>
<td>Good</td>
</tr>
<tr>
<td>.75 to 1.00</td>
<td>Excellent</td>
</tr>
</tbody>
</table>

The minimum level of reliability for items to be included in further statistical analysis was set at 0.6 for the present study.

The mean inter-rater percentage agreement for the PIMRA scale was found to be 75%; the equivalent figure for the subscales varied between 57 - 89%. Internal consistency was measured using Cronbach's alpha and calculated using the Statistical
Package for the Social Sciences (Version 7.5). Alpha can be interpreted as a correlation coefficient (Norusis, 1994). It was found to have a value of 0.76 for the overall PIMRA scale, with subscale values varying between 0.28 and 0.85. Full reliability figures are provided in table 2.1 below.

**Table 2.1** Reliability data for the Psychopathology Instrument for Mentally Retarded Adults

<table>
<thead>
<tr>
<th>Subscale</th>
<th>% Inter-rater agreement</th>
<th>Cronbach's alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia</td>
<td>68</td>
<td>0.31</td>
</tr>
<tr>
<td>Affective Disorder</td>
<td>75</td>
<td>0.28</td>
</tr>
<tr>
<td>Psychosexual Disorder</td>
<td>86</td>
<td>0.28</td>
</tr>
<tr>
<td>Adjustment Disorder</td>
<td>68</td>
<td>0.51</td>
</tr>
<tr>
<td>Anxiety Disorder</td>
<td>82</td>
<td>0.44</td>
</tr>
<tr>
<td>Somatoform Disorder</td>
<td>89</td>
<td>0.85</td>
</tr>
<tr>
<td>Personality Disorder</td>
<td>75</td>
<td>0.45</td>
</tr>
<tr>
<td>Inappropriate Adjustment</td>
<td>57</td>
<td>0.48</td>
</tr>
<tr>
<td>Whole Scale</td>
<td>75</td>
<td>0.76</td>
</tr>
</tbody>
</table>

Although inter-rater reliabilities were more than acceptable (with the exception of the Inappropriate Adjustment subscale), alpha was generally poor. Only total scale scores were therefore used in the statistical analysis.


The Aberrant Behaviour Checklist (ABC) was designed initially to measure treatment effects following behavioural, drug or other forms of intervention for challenging behaviour. Since its publication, the scale has been used to produce general descriptions of the behavioural characteristics of research samples, and it is for this purpose that the scale was employed in the present research. The scale consists of 58 items broken down into five subscales, the scale structure having been derived by factor analysis. The subscales are as follows:
1. Irritability, Agitation, Crying (consisting of 15 items)
2. Lethargy, Social Withdrawal (16 items)
3. Stereotypic Behaviour (7 items)
4. Hyperactivity, Non-compliance (16 items)
5. Inappropriate Speech (4 items).

Respondents, who must be carers who have regular contact with the individual being assessed, are required to rate each behavioural item on a four point scale (0 = behaviour is not at all a problem with the individual, 1 = behaviour is a problem but slight in degree, 2 = problem is moderately serious, and 3 = problem is severe in degree).

Aman (1991) cites 17 studies which have examined the scale's psychometric qualities. Average test-retest reliability figures are in the 0.70s, but inter-rater reliability is lower and tends to fall between the high 0.50s and low 0.60s. A number of cross-cultural studies have validated the factorial structure; this has also proved robust across different age groups. The scale has also been found for the most part to correlate strongly with other measures of challenging behaviour and may therefore be said to have good concurrent validity.

In the present study, the inter-rater reliability of the ABC scale was again assessed by having a 10% sample of subjects assessed twice by raters whom it was felt knew the subjects extremely well. Reliability was calculated using the formula on page 40. The mean inter-rater percentage agreement for the scale was found to be 60.8% with a range across subscales between 48-81%. Cronbach’s alpha for the whole scale was found to be 0.94, and varied between 0.85 and 0.92 across the subscales. The scale reliability data are presented in table 2.2 below.
Table 2.2 Reliability data for the Aberrant Behaviour Checklist

<table>
<thead>
<tr>
<th>Subscale</th>
<th>% Inter-rater agreement</th>
<th>Cronbach's alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Irritability, Agitation, Crying</td>
<td>48</td>
<td>0.88</td>
</tr>
<tr>
<td>Lethargy, Social Withdrawal</td>
<td>56</td>
<td>0.92</td>
</tr>
<tr>
<td>Stereotypic Behaviour</td>
<td>64</td>
<td>0.91</td>
</tr>
<tr>
<td>Hyperactivity, Non-compliance</td>
<td>55</td>
<td>0.89</td>
</tr>
<tr>
<td>Inappropriate Speech</td>
<td>81</td>
<td>0.85</td>
</tr>
<tr>
<td>Whole Scale</td>
<td>60.8</td>
<td>0.94</td>
</tr>
</tbody>
</table>

On the basis of these results, the overall inter-rater reliability was acceptable but was more variable for the individual subscales. Internal consistency was excellent both for the scale score overall and for individual subscales.

The Disability Assessment Schedule (Holmes, Shah & Wing, 1982)

Originally derived from the work of Kushlick, Blunden & Cox (1973) and Wing & Gould (1978), and later modified by Lowe & de Paiva (1988), this scale was designed for screening purposes and contains 9 main items. These cover mobility, continence, self help, communication, behaviour problems, stereotypies, quality of social interaction, symbolic activities, and literacy and numeracy. The scale items are rated on three to eight point scales. In the present study, only the behaviour problem items from the scale were used. Each behaviour is rated separately for frequency and severity on three point scales (1 = severe management problem, 2 = lesser management problem, 3 = no management problem). Lowe & Felce (1994) found the mean percentage agreement for these items to be 74% (range 62-88%).

A 10% inter-rater reliability sample was taken and reliability calculated according to the formula detailed on page 40. The mean inter-rater percentage agreement for the whole scale was 63.5%; the corresponding figures for the separate frequency and
severity ratings were 65.4% and 61.5% respectively. The inter-rater reliability of individual items was variable, as indicated in table 2.3 below. Cronbach's alpha for the whole scale was 0.72, indicating acceptable internal consistency; the separate alphas for the frequency and severity items were less satisfactory at 0.54 and 0.59 respectively.

Table 2.3 Reliability data for individual behavioural items from the Disability Assessment Schedule.

<table>
<thead>
<tr>
<th>Item</th>
<th>% Inter-rater agreement - Frequency</th>
<th>% Inter-rater agreement - Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Aggression</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Destructiveness</td>
<td>75</td>
<td>75</td>
</tr>
<tr>
<td>Overactivity</td>
<td>75</td>
<td>75</td>
</tr>
<tr>
<td>Attention Seeking</td>
<td>75</td>
<td>50</td>
</tr>
<tr>
<td>Self-Injury</td>
<td>75</td>
<td>75</td>
</tr>
<tr>
<td>Wandering Off</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Screaming</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Temper Tantrums</td>
<td>75</td>
<td>50</td>
</tr>
<tr>
<td>Disruption at night</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Objectionable personal habits</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>Scatters/ throws objects</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Anti-social behaviours</td>
<td>75</td>
<td>75</td>
</tr>
<tr>
<td>Sexually Inappropriate Behaviours</td>
<td>75</td>
<td>75</td>
</tr>
<tr>
<td>Total Items</td>
<td>65.4</td>
<td>61.5</td>
</tr>
</tbody>
</table>


The Adaptive Behaviour Scale is in two parts, the first dealing with adaptive behaviour, and the second with challenging behaviour. Only part 1 of the Scale was
utilised in the present study. This section is made up of 66 items arranged in 10 domains. The latter cover independent functioning, physical development, economic activity, language development, numbers and time, domestic activity, vocational activity, self-direction, responsibility and socialisation. Items vary in their format, some including up to seven graded categories to rate a single skill, others using a simple binary format. The Scale is designed to be completed by carers working with individual clients, and raw scores may be converted into percentiles based on normative data collected in the United States. The Scale was revised in 1993, but it is the 1975 version which is used in the present study. Nihira et al (1975) produced a mean correlation of 0.86 (range 0.71 to 0.93) for part 1. Raynes (1987) reviewed several studies which have reviewed the Scale's psychometric properties, and reports an inter-rater reliability of 0.86 for part 1. Stack (1984) found that the inter-rater reliability across the domains for part 1 varied between 0.48 to 0.87 with a mean of 0.73.

Inter-rater reliability in the present study was assessed on a 10% sample and calculated as per the formula on page 40. The mean inter-rater percentage agreement for the scale was 73.1% (subscale range 42.9 - 100%) and could therefore be described as good. Internal consistency for the scale was excellent, the value of Cronbach's alpha being 0.95 for the overall scale and between 0.34-.93 for individual domains. Reliability data are provided in table 2.4.
Table 2.4 Reliability data for the Adaptive Behaviour Scale (Part 1)

<table>
<thead>
<tr>
<th>Domain</th>
<th>% Inter-rater agreement</th>
<th>Cronbach's alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Development</td>
<td>91.7</td>
<td>0.64</td>
</tr>
<tr>
<td>Language Development</td>
<td>72.2</td>
<td>0.82</td>
</tr>
<tr>
<td>Numbers &amp; Time</td>
<td>70.8</td>
<td>0.93</td>
</tr>
<tr>
<td>Independent Functioning</td>
<td>71.7</td>
<td>0.9</td>
</tr>
<tr>
<td>Domestic Activity</td>
<td>70.8</td>
<td>0.85</td>
</tr>
<tr>
<td>Vocational Activity</td>
<td>100</td>
<td>-</td>
</tr>
<tr>
<td>Self-direction</td>
<td>50</td>
<td>0.81</td>
</tr>
<tr>
<td>Responsibility</td>
<td>87.5</td>
<td>0.87</td>
</tr>
<tr>
<td>Socialisation</td>
<td>42.9</td>
<td>0.34</td>
</tr>
<tr>
<td>Whole Scale</td>
<td>73.1</td>
<td>0.95</td>
</tr>
</tbody>
</table>

With the exception of the Socialisation domain and the inter-rater reliability for the Self-direction domain, all reliability results were very acceptable. Alpha could not be calculated for the Vocational domain as this consisted of a single item.

Spread (1980) conducted an assessment of the scale's criterion validity and found that a combination of the seven domains explained 34% of the variance and successfully predicted group membership for 60% of cases within three forms of residential placement status (previously institutionalised, referred for discharge, or institutionalised). Roszkowski (1980) measured its concurrent validity by examining the correlation between total ABS score and total scores on the Vineland Social Maturity Scale; the resulting Pearson correlation was 0.79.

b. Resources, internal organisation & management features of support services.

A wealth of research instruments have been developed to study service environments for people with learning disabilities. Raynes (1988), for example, reviewed no less than 62 such instruments. Unfortunately, data on service settings in the current study had to be collected retrospectively, and this meant that some of the better instruments
described by Raynes could not be used as the detailed data required for their completion was not available. Furthermore, many of the scales do not address organisational issues considered to be important in relation to challenging behaviour by contemporary authorities, and the majority have no psychometrics available on their reliability and validity. Given these various considerations, it was felt necessary to devise a scale more suited to both the objectives and the limitations of the present research.

Recent work on the determinants of high quality outcomes in community residential services for people with learning disability in general (Emerson & Hatton, 1996) suggests that three factors - the availability of appropriate resources, the internal organisation, and the quality of leadership - are important. The Service System Assessment (S.S.A) was designed to address these three areas of organisational functioning. It is a 27 item scale designed to measure service competency under each of these three headings. These will be described in turn.

**Availability of Appropriate Resources (9 items)**

Respondents were asked to rate subjects services on nine binary items covering basic resources, staff attitudes, staff energy to implement interventions, physical environment, social environment, day service support, prior knowledge of requirement to work with challenging individuals, permanency of placement (i.e. long-term versus emergency, crisis etc.), and rates of use of relief staff. Each item was presented in the form of a question (e.g. 'Were adequate resources available to meet client needs?') and respondents are required to answer 'Yes' or 'No' to each item.

**Internal Organisation (13 items)**

McGill & Toogood (1994) have outlined a number of aspects of service organisation which are likely to be of general importance in services for people with learning disabilities but which are likely to have particular significance in services supporting
individuals with challenging behaviour. The thirteen binary items in this part of the S.S.A. scale are based on the service maintenance specification suggested by these authors and cover the following areas:

• Staff deployment
• Staff meetings
• Staff supervision
• On the job training
• In-service training
• The relevance of the training received
• Maintenance of the physical environment
• The effectiveness of administrative systems
• Recording & maintaining client participation
• Recording & maintaining client development
• Recording & maintaining acceptable client behaviour
• Individual planning
• Overall structure of care system

Again, each item was presented in the form of a question (e.g. 'Were staff deployed at times when they were most needed?') and respondents required to answer 'Yes' or 'No'.
Quality of Leadership (5 items)

Kiernan (1993) has rather critically observed that:

'Many commentators have remarked that 'management' in services for people with intellectual disability frequently does not manage. There is a strong tradition of allowing autonomy of decision making by front-line staff, often bolstered by asinine arguments that they 'know the person best'. In effect, as a 'management' style, failure to direct front line staff typically conceals a poverty of skills and ideas on the part of managers about what should be done.'

(Kiernan, 1993, p.250)

Mullins (1989) has differentiated between management and leadership. The former, it is suggested, is primarily concerned with getting things done via other people in order to achieve stated organisational objectives, whereas the latter is concerned with a more interpersonal and inspirational process which does not necessarily take place within the context of an organisational hierarchy.

Numerous theories of leadership exist. Adair's (1979) action-centred approach to leadership identified three areas of need within work groups. 'Task Functions' concern achieving a work group's objectives, defining group tasks, planning the work, allocating resources, and quality review and control. 'Team Functions' include maintaining and building team morale, setting standards, developing communication systems, training the group, and appointing sub-leaders. Finally, 'Individual Functions' involve meeting the needs of individual group members, attending to personal problems, giving feedback and praise, reconciling conflict between group members, and providing individualised training. In order to gauge managerial performance in these areas, respondents completing the S.S.A. were asked to rate each area of functioning on a five point Likert scale from 1 (strongly agree) through to 5 (strongly disagree).
House (1971) stated that there are four main types of leadership, all of which can be displayed by the same person at different times.

- Directive Leadership: this involves letting subordinates know exactly what is expected of them and giving specific directions. Subordinates are expected to follow rules and regulations

- Supportive Leadership: involves a friendly and approachable manner and displaying concerns for the needs and welfare of subordinates

- Participative Leadership: involves consulting with subordinates and the evaluation of their opinions and suggestions before management decisions are taken

- Achievement Orientated Leadership: involves setting challenging goals for subordinates, seeking improvements in their performance and showing confidence in their ability to do well.

In order to take Kiernan's comment into account, a further leadership category was added to those proposed by House above. The additional category was 'Democratic Leadership' and this was defined as 'decisions were only made when staff clearly supported them, staff were allowed to make their own decisions on key issues'. Although, as stated above, managers may display different styles in different situations, for the purposes of the present study, it was desirable to obtain an evaluation of the overall management style in a particular service. Respondents to the S.S.A. were therefore asked to rate which one of five leadership styles (Directive, Supportive, Participative, Achievement-orientated or Democratic) was most prevalent in the service setting in question.
Inter-rater reliability was assessed on a 25% sample by having the same service rated twice by different workers, and test-retest reliability was assessed on a 15% sample by having the same person reassess the service at a two month interval. Cronbach's alpha was also calculated in order to assess internal consistency.

The percentage inter-rater agreement for the whole scale was 66.7% (range 51.9-85.2%). For the 9 items on resources the percentage agreement was 67.9% (range 33.3-100%), for the 13 items on internal organisation it was 75.2%, and for the five management items it was 42.2% (range 0-100%). Inter-rater reliability for the whole scale was therefore good and the reliability of its constituent sections fair to good.

Test-retest percentage agreement for the whole scale was 80.2% (range 59.3-92.6%). The corresponding figures for the resources items was 92.5% (66.7-100%), for the internal organisation items 85.9% (61.5-100%), and for the management items 43.3% (0-60%). The latter were excluded from further analyses because of their poor inter-rater reliability.

Cronbach's alpha for the whole scale was 0.68; for the resources items it was 0.74, for the internal organisation items 0.82, and for the management items 0.71. The internal consistency of the whole scale may therefore be described as good to excellent.

c. Nature of support services received

A fourteen item proforma was constructed to elicit demographic data concerning the client and basic data about their support services. The items covered:

- The person's age
• Their place of residence: this was divided into six major categories, namely the family home, group home, adult placement, bed & breakfast, emergency intervention service placement and other placement. For the maintained group, the placement coded was their normal place of residence. For the breakdown group, their place of residence prior to institutional admission was coded.

• Whether or not the person had a previous history of long-stay institutionalisation (a predictor of placement breakdown as detailed by several studies reviewed in Chapter 1)

• Whether or not the person received 24 hour support from care staff

• Whether or not the person received support from the Community Learning Disabilities Team

• Whether or not people received support from the I.S.S. and, if so, at what level.

• Whether or not they were receiving I.S.S. support at the time of their placement breakdown (coded for the breakdown group only).

• Whether or not input was provided by community team clinical psychologists

• Whether or not input was provided by psychiatrists

• Whether or not the person was receiving anti-psychotic medication (a factor associated with placement breakdown as described in Chapter 1)

• Whether or not the person's carers had received training in emergency reactive strategies (defusion strategies, self-defensive breakaway techniques and minimal restraint)
• Whether or not the person had an advocate (a factor which Schalock et al (1981) found to be associated with maintained placements)

• Where the challenging behaviours occurred (again Schalock et al (1981) found that this variable discriminated between people with challenging behaviour who were maintained in the community and those who were not).

As stated earlier, these data were obtained largely from client records by the author. If data were missing from records, details were checked with key personnel who had involvement with the client in question.

2.3.4 Qualitative Data

In order to help further inform the reader as to the nature of the clients in the sample, eight brief case studies (four each from the maintained and breakdown group) were provided outlining the nature of the challenges posed by the individuals concerned and of their service career paths. These case studies were not chosen at random, but deliberately selected in order to illustrate both the variety of client and characteristics which were relevant to the study. The case studies are contained in Appendix I.

2.4 Summary

The present research employed a natural group comparison design to examine differences between two groups of people with learning disabilities and challenging behaviour. One group experienced a breakdown in their community care placements and were subsequently admitted to long-stay institutional care, while the other group was successfully maintained in the community. In line with the literature review, it was
hypothesised that the breakdown group would present higher levels of challenging behaviour and would have been admitted from services which were deficient in terms of their organisational functioning. Three sets of data were collected on each subject. These data related to personal behavioural, psychiatric and adaptive characteristics, the organisational characteristics of the immediate support services, and the nature of specialist support service received. Eight brief descriptive case vignettes were also provided.
CHAPTER 3: RESULTS

3.1 INTRODUCTION

The results will be provided in two main sections. The first presents the results of bivariate analyses of between group differences on the independent variables; this will be sub-divided into sections covering the personal variables, service organisation variables, and service support variables. All analyses were performed using the Statistical Package for the Social Sciences Version 7.5 unless stated otherwise. A concluding summary section will then provide a brief synopsis of the overall results and their implications for the study hypotheses.

3.2 BIVARIATE ANALYSIS

The following tests were used for the bivariate analysis. For continuous variables, the Mann-Whitney U test was used as the two groups constituted two independent samples. For categorical data, the Chi-square test was used or, if the assumptions of chi-square were violated, the Fisher Exact Probability test was applied. The significance level was set at p<.05 and all reported probabilities are for two-tailed tests.
3.2.1 PERSONAL CHARACTERISTICS

The age profiles for the two groups were almost identical, the mean being 36.7 for both groups and the range being 23-51 for the maintained group and 23-50 for the breakdown group. The maintained group contained a slightly higher percentage of males (70.6%) than the breakdown group (64.3%). Forty percent of the maintained group were people who had originally been long-stay residents at Ely Hospital who had been resettled into the community; at the time that the study was conducted, their mean time in community services was 24.3 months (range 14-48 months). Only 7% (one subject) of the breakdown group were former Ely residents; this person's placement broke down less than six months after they were resettled.

Table 3.1 below shows the scores for each group on the Psychopathology Instrument for Mentally Retarded Adults; as stated in the method, only total scale scores were analysed due to the poor reliability of the individual subscales. Within each cell, the mean score, median score and score range are presented in descending vertical order. The potential score ranges are shown in brackets under each sub-scale heading. Higher scores indicate higher ratings of pathology.
Table 3.1: Mean, Median and Score Ranges for the Maintained and Breakdown Groups on the Psychopathology Instrument for Mentally Retarded Adults

<table>
<thead>
<tr>
<th></th>
<th>Maintained (n=33)</th>
<th>Breakdown (n=14)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>PIMRA Total Score</td>
<td>16.12</td>
<td>16.29</td>
<td>ns</td>
</tr>
<tr>
<td>(0-56)</td>
<td>16</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(2-30)</td>
<td>(7-27)</td>
<td></td>
</tr>
</tbody>
</table>

The results indicate that, contrary to hypothesis 1, there were no significant differences in levels of psychopathology between the two groups as measured by the overall PIMRA scores.

No norms are available for the PIMRA scale, but Lowe, Felce & Blackman (1995) reported a mean total scale score of 16.59 (range 4-31) for a group of 51 subjects with severely challenging behaviour. The means of both sub-groups in the present study were comparable to this finding, thus confirming that the groups had high degrees of pathology on this measure.

Scores on the Aberrant Behaviour Checklist are shown in table 3.2 below. Once again, the mean score, median score and score range are presented in descending vertical order within each cell. The potential score ranges are shown in brackets under each sub-scale heading. Total scores and the total number of behaviours rated at the highest level of severity (level 3) for each group are also shown. Although not advocated by the authors of the scale, the latter form of analysis has been used in previous research by Lowe, Felce & Blackman (1996). Higher scores once again indicate a greater
severity of behavioural disorder. Results for the Irritability, Lethargy, and Hyperactivity subscales are not reported as they failed to reach the required level of reliability.

**Table 3.2:** Mean, Median and Score Ranges for the Maintained and Breakdown Groups on the Aberrant Behaviour Checklist

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Maintained Group (n=33)</th>
<th>Breakdown Group (n=14)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stereotypy (0-21)</td>
<td>4.47</td>
<td>1.71</td>
<td>p &lt; .05</td>
</tr>
<tr>
<td></td>
<td>3.00</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(0-21)</td>
<td>(0-12)</td>
<td></td>
</tr>
<tr>
<td>Inappropriate Speech (0-12)</td>
<td>2.97</td>
<td>2.29</td>
<td>ns</td>
</tr>
<tr>
<td></td>
<td>1.00</td>
<td>2.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(0-11)</td>
<td>(0-9)</td>
<td></td>
</tr>
<tr>
<td>ABC Total Score (0-174)</td>
<td>58.82</td>
<td>47.29</td>
<td>ns</td>
</tr>
<tr>
<td></td>
<td>49.00</td>
<td>44.50</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(6-137)</td>
<td>(17-79)</td>
<td></td>
</tr>
<tr>
<td>No. Level 3 Behaviours (0-58)</td>
<td>11.21</td>
<td>7.36</td>
<td>ns</td>
</tr>
<tr>
<td></td>
<td>7.00</td>
<td>7.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(0-42)</td>
<td>(14-42)</td>
<td></td>
</tr>
</tbody>
</table>

Once again, the overriding impression was of the similarity, rather than of the differences, between the group scores. Only the difference on the Stereotypy subscale reached statistical significance on the Mann-Whitney U Test (z = -2.17, p < 0.05), the scores in the maintained group (4.47) indicating higher pathology than in the breakdown group (1.71). Also contrary to hypothesis 1, there was a non-significant trend towards the total ABC scores (58.82 vs. 47.29) and number of level 3 behaviours (11.21 vs. 7.36) to be higher in the maintained group.
Tables 3.3 and 3.4 below show the mean group scores for frequency and intensity respectively on each individual item on the Disability Assessment Schedule. The potential and actual range for each item was 1-3, and ranges are therefore not included in the tables. Only items with acceptable reliability are reported.

Table 3.3 shows that the only behaviour to show statistically significant differences using the Chi-square test between the groups was in the frequency of anti-social behaviours (stealing, lying, bullying etc.) which, in accordance with hypothesis 1, were more frequent in the placement breakdown group. For the purpose of this analysis, data were collapsed into two categories (marked-lesser problems and no problems) in order to meet the requirements of the statistical test. Overall, 78.6% of the breakdown group were rated as having marked or lesser problems in this area as opposed to only 33.4% of the maintained group ($X^2 = 6.04, p< 0.02$).

These results are replicated in the intensity ratings shown in table 3.4. Again, the data were collapsed into two categories (severe-lesser problems and no problems). Seventy-eight point six per cent of the breakdown group showed anti-social behaviours which were rated as being a severe or lesser management problem as compared to 36.4% of the maintained group. This difference was again significant using Chi-square ($X^2 = 7.01$) beyond the 0.01 level.
### Table 3.3: Mean Individual Item Frequency Scores (Marked, lesser or no occurrence)

for the Maintained and Breakdown Groups on the Disability Assessment Schedule

<table>
<thead>
<tr>
<th>Item</th>
<th>Maintained Group (n=33)</th>
<th>Breakdown Group (n=14)</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Marked</td>
<td>Lesser</td>
<td>None</td>
</tr>
<tr>
<td>Destructiveness</td>
<td>12</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td>Overactivity</td>
<td>17</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Self-injury</td>
<td>7</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>Attention Seeking</td>
<td>12</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Temper Tantrums</td>
<td>22</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Disruption at Night</td>
<td>10</td>
<td>7</td>
<td>15</td>
</tr>
<tr>
<td>Anti-social Behaviours</td>
<td>7</td>
<td>6</td>
<td>20</td>
</tr>
<tr>
<td>Sexually Inappropriate Behaviours</td>
<td>4</td>
<td>6</td>
<td>23</td>
</tr>
</tbody>
</table>
Table 3.4: Mean Individual Item Intensity Scores (Severe, lesser or no management problem) for the Maintained and Breakdown Groups on the Disability Assessment Schedule

<table>
<thead>
<tr>
<th>Item</th>
<th>Maintained Group (n=33)</th>
<th>Breakdown Group (n=14)</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Severe</td>
<td>Lesser</td>
<td>No problem</td>
</tr>
<tr>
<td>Destructiveness</td>
<td>10</td>
<td>11</td>
<td>12</td>
</tr>
<tr>
<td>Overactivity</td>
<td>14</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>Self-injury</td>
<td>5</td>
<td>10</td>
<td>18</td>
</tr>
<tr>
<td>Disruption at Night</td>
<td>9</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>Anti-social Behaviours</td>
<td>6</td>
<td>6</td>
<td>21</td>
</tr>
<tr>
<td>Sexually Inappropriate Behaviours</td>
<td>4</td>
<td>6</td>
<td>23</td>
</tr>
</tbody>
</table>

There were no statistically significant differences in the mean number of behaviours rated as occurring frequently (maintained group = 4.4, breakdown group = 3.6) or less frequently (maintained group = 2.8, breakdown group = 2.7), or in the mean number of behaviours rated as causing severe management problems (maintained group = 3.7, breakdown group = 3.00) or lesser management problems (maintained group = 3.00, breakdown group = 2.9).

Mean domain scores and total scores on the Adaptive Behaviour Scales are shown in table 3.5. Within each cell, the mean score, median score and score range are presented in descending vertical order. Potential score ranges are shown in brackets under each domain heading. Higher scale scores indicate a higher functional ability level. As
stated previously, the Socialisation and Self-Direction domains were excluded from this analysis because of poor reliability.

**Table 3.5:** Mean, Median and Score Ranges on the Adaptive Behaviour Scale for Maintained and Breakdown Groups

<table>
<thead>
<tr>
<th>Domain</th>
<th>Maintained Group (n=33)</th>
<th>Breakdown Group (n=14)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Development (0-24)</td>
<td>22.69 (11-24)</td>
<td>21.43 (17-24)</td>
<td>ns</td>
</tr>
<tr>
<td>Language Development (0-40)</td>
<td>17.00 (1-37)</td>
<td>26.07 (4-38)</td>
<td>p &lt;.01</td>
</tr>
<tr>
<td>Numbers &amp; Time (0-12)</td>
<td>2.94 (0-12)</td>
<td>6.86 (0-12)</td>
<td>ns</td>
</tr>
<tr>
<td>Economic Activity (0-22)</td>
<td>3.24 (0-16)</td>
<td>9 (0-20)</td>
<td>p &lt;.001</td>
</tr>
<tr>
<td>Independent Functioning (0-127)</td>
<td>52.88 (7-94)</td>
<td>75.43 (22-90)</td>
<td>p &lt;.002</td>
</tr>
<tr>
<td>Domestic Activity (0-18)</td>
<td>6.15 (0-17)</td>
<td>9.43 (0-18)</td>
<td>ns</td>
</tr>
<tr>
<td>Vocational Activity (0-2)</td>
<td>0.94 (0-2)</td>
<td>2 (0-2)</td>
<td>ns</td>
</tr>
<tr>
<td>Responsibility (0-6)</td>
<td>2.03 (0-6)</td>
<td>3.64 (0-6)</td>
<td>ns</td>
</tr>
<tr>
<td>ABS Total Score (0-297)</td>
<td>125.48 (30-236)</td>
<td>180.64 (58-260)</td>
<td>p &lt;.005</td>
</tr>
</tbody>
</table>
Highly significant statistical differences were found using the Mann-Whitney U Test between the groups on the total A.B.S score (125.48 vs. 180.64, $z = -2.85$, $p < 0.005$) and on the Language Development (17 Vs 26.07, $z = -2.70$, $p < 0.01$), Economic Activity (3.24 vs. 9.00, $z = -3.26$, $p < 0.001$), and Independent Functioning (52.88 vs. 75.43, $z = -3.04$, $p < 0.002$) domain scores. In each case, higher scores were observed in the breakdown group, indicating that subjects in this group were generally more able than individuals who were successfully maintained in the community.

The summary results of this section were therefore as follows. Individuals who experienced placement breakdown were more likely to be more able—particularly in relation to independent functioning, economic ability and language development. They were also more likely to show frequent anti-social behaviours which pose management problems for their carers. Finally, they were less likely to show stereotypic behaviour.

### 3.2.2 RESOURCES, INTERNAL ORGANISATION AND MANAGEMENT FEATURES OF SUPPORT SERVICES

Group scores on the Service System Assessment are shown in table 3.6. The mean score and median score are presented in descending vertical order. Higher scores indicate superior organisational functioning. As reported in Chapter 2, these scores were only available for a reduced sample, and the management scores were excluded because of low inter-rater reliability.
Table 3.6 Mean and Median Scores on the Service System Assessment for the Maintained and Breakdown Groups

<table>
<thead>
<tr>
<th></th>
<th>Maintained Group (n=26)</th>
<th>Breakdown Group (n=9)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resources Score</td>
<td>6.96</td>
<td>4.67</td>
<td>p &lt; .001</td>
</tr>
<tr>
<td></td>
<td>7.00</td>
<td>5.00</td>
<td></td>
</tr>
<tr>
<td>Internal Organisation Score</td>
<td>8.50</td>
<td>5.44</td>
<td>p &lt; .05</td>
</tr>
<tr>
<td></td>
<td>8.50</td>
<td>5.00</td>
<td></td>
</tr>
<tr>
<td>Total Score</td>
<td>22.77</td>
<td>18.44</td>
<td>ns</td>
</tr>
<tr>
<td></td>
<td>22.00</td>
<td>19.00</td>
<td></td>
</tr>
</tbody>
</table>

The total scale score was not significantly different across the two groups. However, in accordance with the second experimental hypothesis, the resources scores (6.96 vs. 4.67, z = -3.75, p < 0.001) and internal organisation scores (8.50 vs. 5.44, z = -2.51, p < 0.05) were significantly inferior in the placement breakdown group as measured by the Mann-Whitney U Test. These scores indicate that the clients who experienced breakdown were supported in services which were more likely to be inadequately resourced in terms of staffing, staff attitudes, and appropriate physical environments etc., and less well organised in terms of basic communication, staff support systems, and staff training.
The summary results from this section were therefore that subjects suffering placement breakdown were likely to be in pre-admission settings which were less well off in terms of basic resources and less well organised.

3.2.3 NATURE OF SUPPORT SERVICES RECEIVED

The place of residence of the two groups is shown in table 3.7 below; as stated in Chapter 2, for the breakdown group the place of residence is the location prior to institutional admission.

Table 3.7 Residential settings of the maintained and breakdown groups

<table>
<thead>
<tr>
<th>Residential Setting</th>
<th>Maintained Group (n=33)</th>
<th>Breakdown Group (n=14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Home</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Group Home</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Adult Placement</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Bed &amp; Breakfast</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Emergency Placement</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

Overall, the placement locations of the two groups did not vary significantly. Similar percentages of clients were supported in group homes (78.8% in the maintained group vs. 72.8% in the breakdown group). A slightly higher percentage of the maintained group were still living in the family home (12.12 vs. 7.14), and 21% of the breakdown group were in placements supported by the Emergency Intervention Service described in Chapter 1 whereas none of the maintained group were. Additional characteristics of
the residential support services, together with details of general support services received, are shown in table 3.8 below.

Table 3.8 Support Services

<table>
<thead>
<tr>
<th>Service Area</th>
<th>Maintained Group (n=33)</th>
<th>Breakdown Group (n=14)</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Institutional History</td>
<td>25</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Community Support Team</td>
<td>33</td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>ISS</td>
<td>31</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>ISS at admission</td>
<td>n/a</td>
<td>n/a</td>
<td>7</td>
</tr>
<tr>
<td>CST Psychologist</td>
<td>1</td>
<td>32</td>
<td>2</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>21</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Anti-psych. Medication</td>
<td>17</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Acute Admission</td>
<td>4</td>
<td>29</td>
<td>7</td>
</tr>
<tr>
<td>Reactive Strategy Training</td>
<td>27</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Advocate</td>
<td>1</td>
<td>32</td>
<td>1</td>
</tr>
<tr>
<td>24 Hour Support</td>
<td>26</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Permanent Placement</td>
<td>31</td>
<td>2</td>
<td>8</td>
</tr>
</tbody>
</table>

Seventy-eight point eight per cent of the maintained group received 24 hour support versus only 50% of the breakdown group; this trend was not significant however.
% of the maintained group were in permanent residential placements as compared to only 57.14% of the breakdown group, a difference that was significant beyond the 0.005 level on the Fisher Exact Probability Test.

The groups differed significantly on the Fisher Exact Probability Test in terms of whether or not they had a history of long-term institutional placement, this being more common in the maintained group (75.8%) than in the breakdown group (42.9%) (p<0.05). This finding is to some extent an artefact of the sampling procedure in that almost 50% of the maintained group had been referred to the ISS via the resettlement process and therefore, by definition, had been long-stay hospital residents prior to their resettlement into the community.

Differences between the groups were also evident in terms of acute psychiatric/behavioural admissions. Only 12.1% of the maintained group required short-stay admissions whereas 50% of the breakdown group had also experienced one or more acute admissions before their placement finally broke down (Fisher Exact Probability Test, p<0.01). Although such admissions (generally lasting between 2 weeks and three months) were sometimes for bona fide health reasons (e.g. medication reviews, 24 hour EEGs etc.), their primary function was more often to provide respite for services which were finding it difficult to cope with the challenging clients in their care. As such, the frequency of acute admissions provided a crude indicator of placement stability and, as such, could be viewed as prognostic of placement breakdown.
All but one (92.8%) of the breakdown group had received ISS input at some stage. For 69.2% of the group, this had involved fixed term intervention (level II), and for 30.8% the input had been long-term (level III). Only 50% of the group were receiving ISS support at the time of their admission however. By definition, all the maintained group received ISS support, 22.6% at level II and 77.4% at level III. This trend was not significant.

There were no significant differences between the groups in terms of the locations for their challenging behaviours; in both cases, the majority of subjects (82% and 64%) were equally likely to display their challenging behaviours in their place of residence or in the community.

The final significant between-group difference on the Fisher Exact Probability Test was regarding whether or not carers had received training in emergency reactive strategies as described in Chapter 1. Whereas 81.8% of carers of clients in the maintained group had received this training, only 35.7% of the carers of clients in the breakdown group had done so (p<0.005).

The summary results for this section indicated that those subjects suffering placement breakdown were less likely to have been in permanent placements, more likely to have experienced acute hospital admissions, less likely to have had a previous history of long-stay institutional care, and their carers were less likely to have received training in
emergency reactive management strategies. There was also a non-significant trend which indicated that the group were less likely to be receiving 24 hour support.

3.3 Overall Summary

The bivariate data analysis essentially failed to support hypothesis 1. There were only minimal differences between the maintained and the breakdown group on the measures of behavioural and psychiatric functioning. Significant differences were restricted to the Stereotypy Sub-scale of the Aberrant Behaviour Checklist (with higher rates of pathology being found in the maintained group) and two items from the Disability Assessment Schedule (on which greater problems were evident in the breakdown group). Although there were few behavioural and psychiatric differences between the groups, there were highly significant differences in the levels of adaptive behaviour, the breakdown group being more able than the maintained group.

In support of hypothesis 2, there were significant differences on the resources and internal organisation scores on the Service System Assessment. In both cases, the scores of the breakdown group were significantly inferior. The breakdown group were also significantly less likely to have been in a permanent placement prior to their admission, more likely to experience acute hospital admission prior to their placement failure, less likely to have had a prior history of long-term institutional placement, and their carers were less likely to have received training in emergency, reactive
management procedures. The implications of these findings will be discussed in chapter 4.
CHAPTER 4. DISCUSSION

4.1 INTRODUCTION

This final chapter discusses the results and implications of the study. Its four sections provide a brief synopsis of the issue investigated, discuss what has been learned from the study, comment on the weaknesses in the research, and finally provide some suggestions for future clinical and research activity.

4.2 THE RESEARCH QUESTION

Previous research has suggested that whether or not people with learning disabilities and challenging behaviours can be successfully supported in the community may be related to the organisational factors within their services as well as to the behaviours which they display. Furthermore, it has also been suggested that the impact of community interventions for challenging behaviour will be moderated by environmental service variables.

With the exception of studies by Willer & Intagliata (1981) and Schalock et al (1981), accounts which stress the importance of organisational variables have depended largely on anecdotal data. Both the Willer & Intagliata and the Schalock studies were however conducted at a time when the volume and sophistication of support available to challenging individuals in the community was less than optimal, and possibly with individuals who were less challenging than clients who are currently being supported in community services.
The present study attempted to measure empirically the relative differences in the behavioural characteristics and service characteristics of two groups of people with learning disabilities and severe challenging behaviour, one of which was successfully maintained in the community and one of which suffered placement breakdown and subsequent institutional admission. The study was conducted in an area in which a specialist peripatetic behavioural support team for adults was established; the clinical effectiveness of this team had been demonstrated via a number of published studies.

The hypotheses investigated in the study were that those individuals suffering placement breakdown and subsequent admission to long-stay institutional care would display higher levels of behavioural and psychiatric disturbance than individuals maintained in the community, and that the former individuals would come from service settings which were deficient in terms of the levels of support which they provided and their internal organisation.

4.3 THE RESULTS AND THEIR IMPLICATIONS

This section is in four parts. The results for each major set of independent variables -the personal factors, organisational factors, and access to support services- will be discussed in turn before a final concluding statement on the research is made. Within the latter, a summary model of placement breakdown derived from the results will be presented.
4.3.1. PERSONAL CHARACTERISTICS

Overall, the behavioural and psychiatric profiles of the two groups were remarkably similar. There was no substantial evidence that the overall number and severity of challenging behaviours was associated with increased risk of hospital admission. The breakdown group only showed statistically significant differences from the maintained group in terms of their scores on the Stereotypy Scale of the ABC and the two items concerning anti-social behaviours from the DAS. While the higher rates of anti-social behaviours found in the breakdown group were in the direction predicted by hypothesis 1, the higher rates of stereotypies found in the maintained group were in the opposite direction.

The finding regarding the stereotypies was probably a function of the significant differences in the levels of disability within the two groups (see below); the maintained group were generally less able, and the prevalence of stereotypies is usually higher in more disabled populations.

The fact that the breakdown group showed higher rates and intensities of anti-social behaviours (stealing, lying, bullying etc.) on the Disability Assessment Schedule is of interest, but it is unclear as to whether, in general, these behaviours are any harder to manage than, for example, physical aggression or destructiveness. Data from Lowe & Felce (1995) suggest that this is not the case. These authors conducted a total
population survey within a locality containing a 60,000 general population. The DAS was used to assess the behavioural characteristics of 161 people with learning disabilities identified over a five year study period. The study found an association between the frequency of a challenging behaviour and the severity of the management problem which it posed, with more frequent behaviours generally rated as posing the greater problems. Although there was some variation in results across service settings, aggression, wandering away, disturbing noises and temper tantrums were usually rated as causing severe management problems, whereas anti-social behaviours were generally rated as posing lesser management problems. These ratings proved to be extremely stable over time.

It is possible though that anti-social behaviours, whilst not being considered by staff to pose the greatest challenges, could cause more difficulties for other residents and could therefore have a major impact on the harmony of a group home. It may also be that such behaviours play a significant role in determining whether or not staff actually like the person concerned, which is in itself likely to have a major influence on how they work with that person.

The most significant difference between the two groups was in fact not related to challenging behaviours but to skilled, adaptive behaviours. The breakdown group were significantly more able than the maintained group on the Language Development, Economics, and Independence domains of the ABS as well as on the total scale score. While previous research in this area has yielded some conflicting results, this finding is
consistent with a number of studies reviewed in Chapter 1 (Sutter et al, 1980; Eyman et al, 1981; Jacobsen & Schwartz, 1983; Harder et al, 1987; Khan et al, 1993). Sutter et al (1980) observed that the goal of independence, which is a central aim of services for people with learning disabilities, was not prognostic of community placement success; they also stated that the well developed self-help and social skills evident amongst subjects in their study who were unsuccessfully placed in community services clearly failed to compensate for their challenging behaviours.

While these observations are useful, the previous research has not really offered a satisfactory explanation of why individuals of greater ability may be at higher risk of placement breakdown. Several possibilities are evident in this respect:

1. The comparative independence of such individuals may mean that they are assessed as requiring less support from care services; in other words, their service requirements may be calculated on the basis of their functional abilities rather than on their emotional and behavioural needs and may, therefore, prove to be inadequate. The findings of the present study gave some support to the notion that the maintained group received less support in that fewer people in this group were living in staffed houses, they were less likely to be receiving 24 hour support, less likely to be in a permanent placement, and less likely to be receiving ISS support at the time of breakdown (see section 4.3.3 for further discussion on these issues).
2. By definition, more able individuals are less dependent on carers and more capable of 'walking away' from service supports which they may not value. They therefore present the same problems of non-compliance as may be seen in the general population. Staff have no authority to ensure their compliance with intervention programmes, and the capacity for placement breakdown may therefore be increased.

3. More able individuals are at greatest risk of crossing legal boundaries and attracting the attention of the criminal justice system (Cullen, 1993).

4. Clinical experience suggests that staff express more feelings of frustration and get into far more 'battles of will' with more able individuals.

5. People in this group may be under greatest pressure to live 'ordinary lives' and to live up to the high expectations of contemporary service philosophies. Edgerton has referred to these pressures in his well-known ethnographic studies into the 'Cloak of Competence' (Edgerton, Bollinger & Herr, 1984); the term itself refers to processes by which more able individuals with learning disabilities strive to create an image of normality. This pressure in itself may contribute to placement breakdown for some people.

The general conclusion regarding personal characteristics is that hypothesis 1 was not supported by the results. Although some interesting between-group differences were
found in terms of adaptive behaviour, no major psychiatric or behavioural differences were evident. This suggests that factors other than personal characteristics may have influenced placement breakdown.

4.3.2 RESOURCES, INTERNAL ORGANISATION, AND MANAGEMENT
FEATURES OF SUPPORT SERVICES

The two groups were found to differ significantly on two components of the SSA - the total resources score and total internal organisation score. The former covered a number of basic resource issues including staff availability, attitudes, and energy levels, the personal and social environment, and whether or not staff were aware that they would be supporting challenging individuals when they applied for their posts. The latter included questions regarding basic organisational structures such as team meetings, staff supervision and training, and basic administrative systems. In both instances, services which broke down, with the client being admitted to institutional care as a consequence, had inferior scores to services which maintained their clients in the community.

These findings are open to competing explanations. First, it is possible, as hypothesis 2 suggests, that the poor organisational status of these services was a contributory cause to placement breakdown. Alternatively, it is possible that the challenging behaviour of the clients concerned somehow precipitated the collapse of the organisational systems within these services. It is conceivable, for example, that the presence of these
behaviours produced a number of emotional responses in staff which in turn had implications for service organisation. Thus, staff feelings of sadness, annoyance and fear provoked by client behaviours (Bromley & Emerson, 1995) could be expected to impact on energy levels, and increased staff stress as a consequence of violent client behaviour (Hatton, Brown, Caine & Emerson, 1995) may lead to sickness breaks which in turn reduces the frequency and effectiveness of staff supervision and internal service coherence and consistency.

Data from Hatton, Rivers, Mason, Mason, Kiernan, Emerson, Alborz & Reeves (1997) and Rose's (1995) model of staff stress suggest in fact that resident characteristics are poor predictors of staff burn out. In the Hatton et al study, organisational factors (including alienation from the organisation, poor support, high workloads, conflicting demands in the work situation, lack of job clarity etc.) were found to be better predictors of poor staff outcomes (job search behaviour, sickness leave, high levels of general and work related stress) than factors related to client characteristics or service resources. While challenging behaviour itself is a recognised stressor (Hatton, Brown, Caine & Emerson, 1995), its effects appear to be buffered or exacerbated by the organisational context in which staff operate. Organisational climate and structure may therefore be regarded as moderator variables (Ghiselli, 1963) which can influence the impact of workplace stressors such as difficult client behaviours.
Results in this section supported hypothesis 2 in that significant differences were found between services which were maintained and those which broke down in terms of their resources and internal organisation.

4.3.3 NATURE OF SUPPORT SERVICES RECEIVED

Clients who suffered placement breakdown appeared to have been admitted to long-stay institutional care from residential services which were far from robust. They were less likely to have been in permanent placements (with a non-significant trend towards more breakdown clients being supported in emergency placements), and more likely to have experienced acute institutional admission prior to their long-term institutionalisation. There was also a non-significant trend which indicated that subjects in this group were less likely to be receiving 24 hour support. Once again, there are at least two possible explanations of these findings. First, it is possible that the pre-admission placements of the breakdown group were the result of problems in earlier community services, the people concerned perhaps having been excluded from more stable, well resourced services which could not cope with their behaviour and subsequently placed in temporary, less well resourced residences as a consequence. The second possibility is that the behaviour of these individuals may have resulted in well-established community services refusing to provide them with places, thus necessitating the use of more improvised, short-term service options. For clients without challenging behaviour, these improvised solutions may prove sufficient to meet their needs, but for challenging individuals they are likely to be inadequate. Clinical
experience suggests that the second of these explanations was more probable. In the area under study, vacancies in staffed houses became available reasonably regularly, but they were rarely made available to individuals with challenging behaviour. A paradoxical situation often existed therefore whereby the clients who needed the most experienced staff (i.e. those on permanent contracts within well-established services) were supported by the most inexperienced individuals (i.e. who often had little or no previous contact with people with learning disabilities and who were frequently recruited on short-term contracts).

The finding that the breakdown group were less likely to have had a previous history of long-stay institutional care was in conflict with some previous research in this area (Schalock et al, 1981), and, as explained in the results, was probably a result of the fact that more of the maintained group were clients who came through the resettlement process. This may also have contributed to the fact that the breakdown group were in services which appeared to be less well resourced, as described above. It is well recognised that residents resettled from hospital are in the advantageous position of having their placements partly-funded by institutional closure and the transfer of monies from health to social care. People already living in the community, but who may need to move on into alternative accommodation (whether because of their behaviour or, for example, as a result of the death of family carers), have no such advantage. To some extent, a two-tier system of community support can be said to exist (Collins, 1992).
The fact that the carers of subjects suffering placement breakdown were less likely to have had training in emergency reactive management strategies is of considerable interest. As these carers were not trained to respond to behavioural crises, it is perhaps to be expected that their capacity to cope with such behaviours should be diminished. In the study area, training of this sort had been shown to be effective in reducing the use of major reactive strategies (such as emergency medication) and staff and client injuries (Allen, MacDonald, Dunn & Doyle, 1997). In a related study (Ahmed, Allen, Emerson, Felce, Fraser, Kerr, Kiernan, Patel & Rowe, 1997), it was found that having a policy on physical interventions and having regular refresher training in these interventions for carers discriminated between subjects who could be successfully withdrawn from anti-psychotic medication and those who could not. Training in reactive strategies would therefore appear to be a necessary component of effective community support services for people who challenge.

Although almost 93% of the breakdown group had been on ISS caseload at some time, only 50% were receiving support from the service at the time that their placements collapsed. The latter may well indicate errors in deciding to remove support from the clients concerned, or the fact that successful interventions are often subject to decay in terms of implementation by staff. Both possibilities would seem to reinforce the need to give challenging individuals long-term support. The fact that some individuals still experienced placement breakdown despite the involvement of specialist services is possible confirmation that such services cannot realistically be expected to make an impact in the absence of an effective organisational infrastructure within referring
agencies. As Lowe & Felce (1994) observed, in their evaluation of the specialist support team which served the study area:

'LUltimately, the long term consequence of the intervention depended on the collaboration of the natural settings, their commitment to the individual with challenging behaviour and their willingness to adopt effective strategies suggested by specialist personnel.'


In some cases, the input from the specialist service almost certainly came too late, referrals only being made once community services were already in an advanced state of collapse. This would suggest problems in terms of the early detection or recognition of difficulties within the service systems concerned (Mansell, McGill & Emerson, 1994).

In concluding this section, it is apparent that the study findings also offer some support to hypotheses 2 in that clients who experienced breakdown were supported in pre-admission services which were less than ideal.
4.3.4 GENERAL CONCLUSIONS: A RISK ANALYSIS OF PLACEMENT BREAKDOWN

The various findings of the study may be presented in the form of a series of risk factors which increase the likelihood that a person with learning disabilities will be subject to placement breakdown and institutional admission. Each factor in itself appears insufficient to produce placement breakdown but, collectively, they significantly increase the possibility of a negative outcome. The three main risk factors are shown schematically in figure 4.1.

The first, or entry level, risk factor is the presence of severe challenging behaviour. It is clear from past research that this condition markedly increases the chances of a person with learning disabilities experiencing placement breakdown; it is also apparent from the results of the present study and previous research that the presence of such behaviours need not inevitably lead to institutionalisation.

The second set of risk factors also concern personal characteristics. The evidence from the present research and from previous studies suggests that it is individuals who display challenging behaviour and who are more able that are at greatest risk of placement breakdown. This is especially the case if they show frequent, hard to manage anti-social behaviours, and show low rates of stereotypic behaviours.
Figure 4.1: A Cumulative Model of Placement Breakdown

Risk Factor I: Presence of Severe Challenging Behaviour

Risk Factor II: Personal Characteristics
More able, more likely to show frequent anti-social behaviours which pose severe management problems, less likely to show stereotypic behaviours

Risk Factor III: Service Characteristics
Placement less likely to be permanent, more likely to request acute hospital admission, less likely to be well resourced, less likely to be well organised, carers less likely to have received training in emergency reactive strategies

The final set of risk factors concerns organisational variables. The study suggests that effective outcomes are less likely in services which have problems in their basic
resourcing and internal organisation, and with carers who are not specifically trained to manage episodes of difficult behaviour.

As McGill & Mansell (1993) rightly observe, a service supporting people with severe challenging behaviour consists of a complex arrangement of individual components which make up an intervention package. If one or more of these components is weakened (through, for example, failing to fill vacant posts as a cost cutting exercise, or failing to support regular staff meetings because of their revenue consequences), then the service itself may not have the capacity or competence to respond to crises, and may reach a point of critical tension more easily as a consequence. Placement breakdown then occurs. This, in effect, would appear to have been the main finding of the present study.

4.4 CRITIQUE OF THE METHOD

The impact of any study has to be assessed alongside a consideration of its methodological weaknesses. Many of the criticisms of the study's design and execution emanate from its quasi-experimental nature and, in particular, the fact that it involved natural groups.

A major weakness of the study was its small sample size and the unequal numbers of subjects within its sub-groups. Whilst there are no hard and fast rules for determining sample sizes, larger samples are desirable in that they increase the likelihood that
significant between group differences will be identified. The present study concerned naturally occurring groups from a small natural population. The last point is important to emphasise; based on epidemiological data from Qureshi, Alborz & Kiernan (1990), one would expect to only find between 56-104 people with severe challenging behaviour in the area under study; taking Qureshi et al's average prevalence rate, the expected number would be 76. In this light, the size of the study sample looks rather more healthy. Given the small numbers of subjects within the total population, few options therefore existed for increasing the sample size within the time and resource limitations which applied. Within the geographical locality under study, it may have been possible to increase the numbers of subjects in the maintained group by, for example, including individuals with less severe challenging behaviours who were supported by clinical psychologists working with the community support teams. This would only have served to increase the already sizeable imbalance in the number of subjects in each sub-group however in that the new subjects would only have added to the size of the maintained group (as all subjects who experienced placement breakdown within the study period were already included in the study sample).

Mathematically it is also preferable to have equal subjects within sub-groups. In practice, there was no way that the numbers in the breakdown group could be increased without losing control of other key variables. For greater numbers to be obtained, then either the research window would need to have been opened earlier, or additional subjects would need to have been obtained from another locality. In both instances, the overall validity of the results would have been weakened in that the
additional subjects would have been admitted under different service conditions (either because they were admitted prior to the development of the full range of support services in South Glamorgan described in Chapter 1 were in place, or because they came from a different locality in which different services and policies were in operation). Although it impacted on the numbers of subjects available, the present design therefore ensured that the background service system remained constant throughout the study. In order to take account of the problems with sample size, non-parametric statistics were employed throughout.

Some data (notably the Service System Assessment) were collected retrospectively. This was far from ideal in that respondents ratings may have been subject to memory recall errors and, more seriously, may have been subject to bias in that the placement outcome for the subjects concerned (i.e. maintained or breakdown) would have been known to the respondents. This may have lead to some bias in the ratings which they made (with 'breakdown' services perhaps being rated more poorly). Two observations are offered to counter this point. First, all respondents completing the S.S.A. were, as stated in the method, blind to the purpose of the study. Second, although there were statistically significant differences between the groups on this instrument, there was also a considerable within-group variation in scores. Thus, some maintained services faired poorly on the S.S.A. and some breakdown services faired quite well, thus suggesting that respondents ratings of services were not subject to a negative halo effect linked to placement outcome.
For some subjects, data on their personal characteristics were collected while they were in hospital as part of a screening exercise conducted prior to their community placement. Lowe & Felce (1995) found that challenging behaviour more often tended to be rated as a severe management problem in community settings (family settings and group homes) than in hospital. It was unclear whether these results reflected genuine differences in behaviour, different tolerance levels, or different management competencies. With one exception, all the subjects who were assessed whilst still in hospital in the present study were in the maintained group. On the basis of the Lowe & Felce research, any bias in ratings in the present study would have presented the breakdown group as being more challenging than the maintained group. This being the case, the failure of the study to provide substantial support for hypothesis 1 was even more striking.

A further point to consider regarding the personal ratings is that, as far as possible, they were collected while clients were in baseline (that is, before any intervention was conducted). It is possible that there may have a differential impact of intervention within the two groups with, for example, greater treatment gains being achieved within the maintained group. This in itself could obviously have played a significant role in determining the outcome for the groups. Even if this were the case, it may be that differential treatment outcome was more related to service setting characteristics rather than to individual characteristics.
Another concern was the study's dependence on bivariate statistics. Although the research clearly called out for the application of multi-variate statistical techniques, their use was not really justified by the available data. The central aim in the present study was to analyse the extent to which two groups of subjects classified on the dependent variable of institutional admission varied on a series of independent variables. Whilst the bivariate analyses identified a number of independent variables on which the groups did differ significantly, they did not allow for any analysis to be made of the relative importance of these differences in determining the categorisation of subjects on the dependent variable. Multiple Discriminant Function Analysis would have been the multi-variate technique of choice for this analysis as it enables an assessment to be made of the capacity of each independent variable to discriminate between the group and then predicts group membership on the basis of this analysis. Unfortunately, the small number of subjects and the fact that the 50% of the independent measures were nominal militated against its use. As Pett (1997) observes, the absence of any non-parametric alternative to the powerful parametric multivariate analyses which exist is unfortunately a major gap in current statistical analysis.

Most of the measures of personal characteristics demonstrated acceptable levels of inter-rater reliability. The reliability results on the ABC replicated the findings of Lowe & Felce (1994) who also reported poor inter-rater reliability with this measure. Measures of internal consistency were generally acceptable throughout with the exception of the PIMRA subscales. Given the fact that it was designed specifically for the present study, greatest attention should be given to the psychometric properties of
the Service System Assessment. Acceptable overall levels of inter-rater and test-retest reliability were demonstrated for this instrument. The internal organisation items were the most reliable in terms of the sub-components, but the management items had unacceptably low levels of inter-rater reliability. One of the reasons for this may have been the fact that the scale asked respondents to indicate a single leadership style which most characterised the manager of a service, whereas House's (1971) original work proposed, as stated in Chapter 1, that the same individual could show different leadership styles in the face of different environmental demands. If House's assertion is correct, the pairs of respondents in the inter-rater reliability analysis may well have rated the same manager as displaying a different style dependent on the contexts in which they had personal experience of that individual; with hindsight, the decision to use House's categories to produce a single, global rating ensured that low-inter rater reliability was 'built in'.

Alpha coefficients showed that the scale components had acceptable levels of internal consistency. The scale itself may be criticised in that the sub-components were not derived from factor analysis but from theoretical accounts; the subject: variable ratio in the study was, however, insufficient for such an analysis to be performed.

Whereas several measures of individual characteristics were employed, only a single measure of organisational functioning - the Service System Assessment - was used. It would obviously have been desirable to have had a second measure of organisational functioning completed for services in the present study in order to produce a measure
of concurrent validity for the SSA. This was problematic because, as mentioned in Chapter 2, none of the existing measures of service organisation tap the same items assessed by the SSA. Correlations with the scores from any such assessment would therefore be hard to interpret. Despite this weakness, it may be argued that the fact that the scale successfully discriminated between services was in itself a demonstration of the scale's validity.

A final criticism relates to the time frame of the study. To qualify for inclusion in the maintained group, clients resettled from hospital had to have been placed in the community for a minimum period of one year without readmission. It may be argued that this is an unacceptably short time frame, and that it is conceivable that some of the maintained group would go on to experience placement breakdown in the longer term. It will be recalled that Scalock et al's (1981) study, described in Chapter 1, found that clients readmitted to learning disability facilities tended to suffer quite rapid placement breakdown, whereas clients readmitted to psychiatric facilities may have had 5-6 years in the community before reaching this point. Although the mean time in the community for subjects in this category comfortably exceeded the 12 month minimum set for the study, this issue could only be satisfactorily resolved with a longer term follow-up.

It may be argued that methodological problems such as those described above are to a large extent inevitable when conducting research under the typical constraints of 'real life' service systems as opposed to more contrived experimental conditions (Pett, 1997). Despite these weaknesses, it was felt that the study was nevertheless
worthwhile in that it addressed a key service question and produced results which were of clinical importance.

4.5 FUTURE DIRECTIONS

A number of future activities are apparent from the above discussion. In terms of research, it would be desirable to replicate the results on a larger sample of subjects whilst being able to control for service inputs. It would also be desirable to be able to examine whether differential treatment effects contribute to placement outcome. In particular, testing the validity of the Service System Assessment prospectively on a larger sample of services would be highly desirable, as initial results indicate that it is of value in discriminating between services. Further field testing would also allow for the weakest section of the Scale (the items referring to management) to be reformulated. A study using larger samples would also permit the use of factor analysis to examine the underlying structure of the Scale.

Any future studies should also seek to take into account the situations of persons with challenging behaviour who suffer breakdown in family care situations. The present study focused on staffed settings, and there is no reason to assume that similar risk variables would therefore be found outside of these settings. Finally, it would be desirable to conduct a follow-up study on subjects in the current research in order to deal with the criticism of the length of the community placements for some subjects identified above.
There are also a number of clinical implications from the study. In some ways, the concept of challenging behaviour being an interactional product of personal and service setting characteristics was validated by the results. The extent to which behaviour challenges services is, in part, a function of the competence of those services. Interventions for challenging behaviour therefore need to adopt a systems approach which takes into account all salient personal, inter-personal and organisational variables. In addition to being used as a research tool, the Service System Assessment could therefore also be of interest as a clinical screening measure. It could be routinely completed by specialist staff called in to support challenging clients in order to identify 'at risk' service elements which may then in themselves become a target for remedial intervention. This would constitute a form of 'Mediator Analysis' (Willis, LaVigna & Donnellan, 1993).

An awareness of the personal and service risk factors identified within the research should also serve to alert clinicians to those placements which are at greatest risk of breakdown. This would allow for the additional targeting of resources and support systems. The latter must be able to be provided long-term, and specialist services need to be able to train staff in reactive behaviour management strategies as well as proactive behaviour change plans. The internal management of community services also needs to be informed by the best examples of organisational behaviour management, and not simply by rather corrupt accounts of normalisation principles for, without the bedrock of a solid service framework, positive behavioural support plans
would seem destined to collapse. Commissioners of services also need to be aware of the importance of these issues and to produce service specifications which detail requirements for both clinical interventions and organisational competencies.

The concluding note of this study should, however, be a positive one. Although the emphasis within the study has been on a group of people with learning disabilities and challenging behaviour who fell through the net of community support services, it should be stressed that the study showed that a greater number of equally difficult individuals were maintained in the community. Read in conjunction with the research literature which has clearly shown the qualitative improvements which can accrue from community living for clients in the group (Allen & Felce, in press), the results of the research suggest that, providing the service supports are correct, we can successfully meet the challenge of caring for them in the community.
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