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A national UK survey of peripatetic support teams for children and adults with intellectual and developmental disability who display challenging behaviour

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Abstract

Background: The service provision model of peripatetic support teams for people with intellectual disabilities who present challenging behaviour has been well established in the United Kingdom, with a small but growing evidence base. The current context in the UK would appear to indicate an ever-increasing role for such teams, in order to support people in their own communities and reduce the reliance on out-of-area placements. This study sought to establish the current position of such teams within the UK.

Method and materials: 46 teams were given the opportunity to complete an online questionnaire regarding the team's day to day functioning.

Results: 20 services responded to the survey providing a range of data. The results suggested that the services were mainly targeted towards adults, had a range of working practices and therapeutic orientations, with broadly successful outcomes (albeit self reported). The data would also suggest that this type of provision had diminished in recent years.

Conclusions: The implications of the survey are discussed within the context of the current policy in the UK. In particular, the lack of provision for children, the use of evidence based practice and what appears to be a diminishing resource just at the time when it is most needed are explored.

Keywords: Intellectual disability, challenging behaviour, peripatetic teams

Introduction

The use of peripatetic behavioural support teams as a model for meeting the needs of people with learning disabilities and challenging behaviour was first reported by Donellan et al (1985). In the UK, the influential King's Fund paper, *Facing the Challenge* (Blunden and Allen, 1987) promoted the team model as an alternative to specialist residential treatment units in the post-institutional era and, by 1993, 65 teams were operating in England and Wales, 46 of which took part in an exploratory national survey by Emerson et al (1996). The majority (71 per cent) of teams described their therapeutic orientation as behavioural, though 38 per cent reported using an 'eclectic' approach, 24 per cent cognitive-behavioural, 9 per cent psychotherapeutic and 4 per cent psychoanalytic approaches (figures not mutually exclusive). Nurses and psychologists made up the bulk of team members, with only 1 per cent of teams including a psychiatrist. Caseload ranged between 1 and 25 service users. Estimates suggested that the teams employed over 450 staff, had running costs of £10 million (at 1993 prices) and served around 2000 people (or 48 per cent of people with severe challenging behaviour estimated to live in the team's catchment areas). Traditionally in the UK these teams operated as tertiary services, independent from community intellectual disability services.

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Allen and Felce (1999) summarised some of the early outcome data associated with peripatetic team input. They reviewed a number of studies that had demonstrated changes in challenging behaviour, quality of life, service user adaptive skills, carer skills and competence, and suggested that team intervention may be more cost-effective and require less intervention time than specialist residential units. They also reported that very different rates of effectiveness could be identified both within and across teams, that their caseload could be prone to silting up (something that had also been a major criticism of residential treatment units), they could be subject to rates of high personnel turnover, and be unable to prevent placement breakdown in all cases. The latter finding was viewed as unsurprising given that team input would be only one variable of many variables determining outcome (the other critical features being the quality of and competence within referring environments, basic deficiencies in the support provided, and the motivation of mediators to implement recommended interventions).

More recently, Hassiotis et al (2009) employed a single-blind randomised controlled trial design to assess the differential impact of treatment as normal via community teams versus treatment as normal plus intervention by a specialist behavioural team. Enhanced treatment produced significant differences in transformed total scores on the Aberrant Behaviour Checklist (Aman et al, 1983), on the transformed Lethargy and Hyperactivity subscales and improved mental health as measured by the PAS-ADD co-morbid organic disorder subscale (Costello et al, 1997). It was concluded that enhanced intervention was more effective than standard treatment. In a quasi-experimental study, Allen et al (2011) reported outcome data on two teams which showed significant reductions in challenging behaviour (as measured by total and all subscale scores on the Aberrant Behaviour Checklist, total number of behaviours rated, total number of behaviours rated at the highest level of severity and pre-post frequency of behaviours), significant increases in community participation, as indicated by changes in the mean range score on the Guernsey Community Participation and Leisure Assessment (GCPLA) (Baker, 2000) and in adaptive behaviour (as measured by changes in mean total score on the Adaptive Behaviour Scale). There were also clear trends in terms of reduced use of restrictive practices (breakaway procedures, restraint, use of medication and seclusion).

At a time when UK policy is articulating a desire to move away from the use of large-scale assessment and treatment services (ATUs), such as that seen in the Winterbourne View scandal, the role of such specialist teams could appear to be crucial in terms of both helping to prevent admissions to such facilities and enabling successful subsequent resettlement. The aim of the present study was therefore to establish the current position of such teams within the overall landscape of services for people with learning disability and challenging behaviour in the UK.

Method

Participants and settings

As the information from the Emerson et al (1996) study was also no longer available, a new search took place to identify potential participants. This initially involved an internet search (using the terms ‘peripatetic service’ and ‘challenging behaviour’ and ‘challenging behaviour services’ or ‘challenging behaviour teams’), a search of professional network websites, and telephone inquiries with a range of professionals working within the intellectual and developmental disability field. For the purposes of this study a peripatetic service was defined as one which:

- had two or more members of staff
- focused on addressing the behavioural needs of the individual
- was an additional input to the services that referred individuals received on a day-to-day basis

This initial search identified 20 services that were currently operational. All were contacted and given a brief verbal explanation of the study and its requirements. They were also asked if they were aware of or had come into contact with any other peripatetic type of service which could be contacted. As a result these enquiries allowed for the identification of six further teams.

In an attempt to pursue greater coverage for the study, the Learning Disabilities Nurses Network and the Applied Behaviour Analysis Forum agreed to send out a fact sheet about the study via electronic mail. The fact sheet outlined a brief background history of peripatetic services, what the aims of the study were and finally offered contact details if they wished to take part in the study or were aware of services which may be suitable.

Finally, a brief presentation was delivered at the bi-annual meeting of the Challenging Behaviour Foundation's National Strategy Group. This event was attended by a range of key professionals and academics working in the field, as well as families and carers of individuals who benefit from this type of support. Contact details regarding the study were also provided to the audience.

As a result of these various initiatives, a total of 46 peripatetic services for people with challenging behaviour were identified. Forty of these were in England, four in Scotland, and one each in Wales and Northern Ireland. All services met the agreed criteria and were offered the opportunity to participate in the study.

Measures

The questionnaire utilised within this study was developed using the common themes identified in the Emerson et al (1996) study. Though the original questionnaire was no longer available, the published results from the study made it possible to identify the type of questions that were asked and to develop an approximate equivalent. Additional questions were also added in order to reflect practice changes since the completion of the earlier work. The Challenging Behaviour Foundation's National Strategy Group acted as a focus group for the construction of the questionnaire. This consisted of a range of academics and leading practitioners in the field of challenging behaviour, together with families and carers supporting challenging individuals. An iterative process was followed whereby the group commented on a draft copy of the questionnaire, added further questions and modified question structure.

The final tool had 79 questions split into five different sections that covered service remit, staffing, use of service, service aims and philosophies, and service user characteristics. The service remit section was composed of 14 closed questions relating to who services were provided for, where referrals were received from, whether services used waiting lists and how services actively identified referrals. It also contained a number of open questions regarding services' annual budgets, whether funding was time limited or under review, and the general population in the territory served. The staffing section required participants to complete a table which enabled them to provide details for each staff member, their role within that service, their professional background, their weekly hours and any requirement to complete specialist training in relation to their role. Use of service comprised eight questions which were predominantly open in nature and required participants to provide nominal data relating to the number of service users accessing the service, caseload size, time on caseload and discharge rates over the preceding 12 months. The service aims and philosophies section required respondents to answer both open and closed questions giving details of the service orientation (eg behavioural, positive behavioural support etc), proactive case work, crisis intervention, types of behavioural assessment used, time frames for completion, proportion of time spent within different tasks (such as teaching, assessment or providing one to one support, and barriers to delivering effective support). Finally, the service user section asked participants to answer 14 questions regarding the last three service users to be discharged from their teams. The questionnaire was hosted on an internet site and utilised Qualtrics software.

Procedure

Participants meeting the inclusion criteria were contacted via telephone following initial identification. They were provided with a brief description of the study, its aims and what their required involvement would be. If a service expressed interest in being involved on the basis of this information, it was asked to provide an email address for the manager or senior clinician within the service who could be sent a formal invitation to participate in the study. The invitation gave further details of the study and a blank copy of the survey which the manager or clinician would be able to complete. Participants were given a period of six weeks to complete the questionnaire. Approximately three weeks following receipt of the initial invitation, all 46 services were contacted again via email in order to thank them if they had completed the data and to prompt them to do so if not. Similar email prompts were issued at five weeks but with an additional note that the survey would only be available for completion for a further seven days. Once the full six weeks had passed, the online survey software was closed.

Ethical approval

Discussion with the National Research Ethics Service established that the research proposal constituted a service evaluation, that National Health Service ethical approval would not be required, and that the approval of the supervising academic institution would be sufficient. This was subsequently obtained in July 2012.

Analysis

Upon completion of the survey, the returned data were downloaded from the online provider and transferred into SPPS 19 in order to complete the analysis.

Results

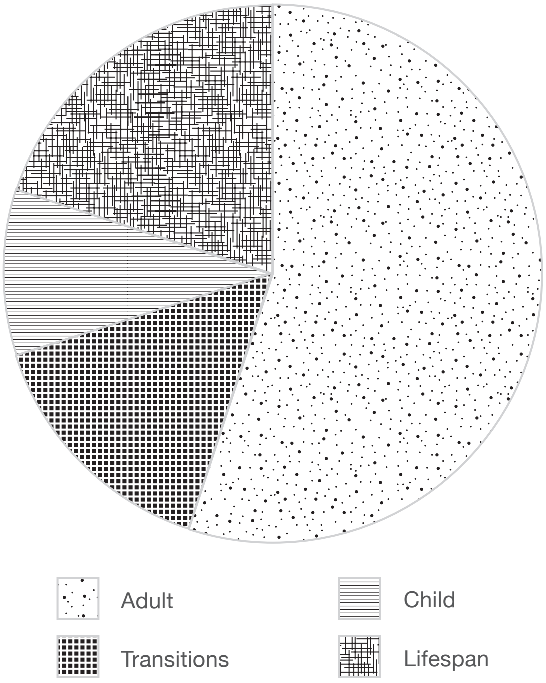
Survey responses

Twenty of the 46 services contacted returned the questionnaire, giving a response rate of 43 per cent. Eighty per cent were provided by the NHS, 10 per cent (3) by the Local Authorities and 5 per cent by the voluntary sector. Forty-seven per cent of responding teams were based in England and 32 per cent in Scotland; services from Northern Ireland and Wales did not respond to the survey.

Service remit

Two general descriptors were used by respondents to describe their services: these were 'challenging behaviour service/team' or 'behaviour support service/team'. Fifty-five per cent of teams served adults only, 20 per cent worked with both children and adults, 10 per cent with children only and 15 per cent with people in transition from child to adult services (see *Figure 1* below).

Figure 1: Service offered to people in respect of age



Seventy-five per cent indicated that they worked with the full range of intellectual and developmental disability, while 25 per cent of the services stipulated that they did not provide a service for people with profound intellectual disability. The majority of teams (95 per cent) stated that they supported people who displayed challenging behaviour as well as those with additional mental health needs, and service users who had experienced placement breakdown.

Teams that were active for 10 years or more represented 45 per cent of the sample, between five and ten years 15 per cent, three to five years 20 per cent and three years or less 20 per cent.

Sixty per cent were funded by the National Health Service, 10 per cent via local authority social services and 5 per cent via the voluntary sector. The average annual budget for services was £371,500. Forty-seven per cent either had time-limited funding or funding that was currently under review.

Services were provided to general populations ranging from 230,000 to 1.8 million in size (mean 711,285). Referrals to the teams were received from the community learning disabilities services in 50 per cent of services; 40 per cent of services identified that they had an open policy which included taking referrals from families/carers and other professionals. Referrals were pro-actively identified in 50 per cent of the services. All teams stated that referrals were allocated according to perceived urgency. This was either assessed on the basis of clinical judgement or by the use of screening tools, protocols or care pathways which had been developed to standardise the process. Forty per cent maintained a waiting list to manage the cases that had been referred to the service, the average number on which was 15.75 (range 2–30).

Staffing

Sixty-one per cent of teams were managed by a nurse, 16 per cent by a psychologist, 16 per cent by a Behaviour Analyst and 6 per cent by a social worker. The size of staff teams varied in range from 2 to 13 with an average of 8 staff on each service. *Table 1* shows the make-up of the teams as compared to Emerson's data.

Although strict comparisons are not possible because of the two different samples, these data are suggestive of there being a decline in psychology and nursing team members over time. Eighty-three per cent of

Table 1: Team membership

Designation	Results from 2012 Survey		Emerson et al study 1996	
	N	%	N	%
Nursing	57	39	117	50
Psychologist	12	8	33	14
Assistant Psychologist	1	0.5	23	10
Social Work	3	2.5	15	6
Occupational Therapist	3	2.5	4	2
Speech Therapist	5	4	3	1
Teaching	0	0	3	1
Psychiatry	1	0.5	3	1
Other	63	43	33	14
Total	145	100	234	100

respondents indicated that staff required specialist training as part of their role. In 40 per cent of the services this required completion of a post graduate diploma or degree. Training developed by the services themselves was identified in 33.3 per cent, and 20 per cent of services failed to identify the training in question. One team identified that training was required from the Institute of Applied Behavioural Analysis (IABA).

Use of Service

Team caseloads averaged 47 (range 14–120) with an average individual caseload of 8 (range 0–15). Mean referral rates were 33 cases per 12 month period; referral rates showed no correlation with team size or the size of population served. Average length of time on the caseload was 47 weeks (range 12–104). The mean number discharged was 27 (range 4–125) per 12 month period with an average of 5 cases (range 0–40) re-referred. Factors influencing re-referral were given as: service placements failing to follow the recommendations made by the peripatetic services (66.7 per cent), transition to a new placement (13.3 per cent), relapse in displayed behaviours was described (13.3 per cent), and implementation of formal safeguarding procedures (5 per cent). On average, teams had 10 service users accessing their service for longer than a 12-month period.

Service aims and philosophies

Participants were asked to identify their therapeutic orientation from a list of options. The most common answer was positive behavioural support (47 per cent). Twenty-seven per cent described their orientation as ‘eclectic’, 20 per cent as using a behavioural model, and 7 per cent as ‘positive psychology’. While 93 per cent described working proactively with service users, 79 per cent also indicated an ability to support people in crisis.

Eighty-seven per cent reported a standard approach to the assessment of challenging behaviour. Common measures cited included ABC charts, scatter plots and The Behavioural Assessment Guide (Willis, LaVigna and Donnellan, 1993). The length of time taken to complete this assessment averaged 11 weeks (range 1–24 weeks).

The most commonly identified area of work was direct face to face contact with service (identified by 50 per cent); working with front line staff was identified as a response by 41 per cent, while family support was only highlighted by 5 per cent.

Services were also asked to identify the barriers that are experienced by them in their day-to-day work. The most common response was a lack of funding available to commission appropriate services or the lack of appropriate services being available in the local area (72 per cent of respondents). Difficulties of working with front line staffing were identified and a lack of understanding of the role of peripatetic teams were both highlighted by 5 per cent.

Service user characteristics

Of the 20 participants that responded to the survey, 13 services provided information on the last three people discharged. Based on these data, 70 per cent of users served were male, 68 per cent were of white ethnic origin, and only 5 per cent were of Black or mixed ethnicity. Their mean age was 35 (range 14–61). Sixty-seven per cent were identified as being on the Autistic continuum, 51 per cent had additional physical or sensory needs, 60 per cent were reported to have a diagnosis of mental health needs, and 30 per cent had engaged in behaviour that could be viewed as offending; only 5 per cent were currently detained under the Mental Health Act.

Key themes identified in relation to the reason for referral included: increase in severity or frequency of challenging behaviour (36 per cent), supporting transition to a new service setting (22 per cent), the development of risk assessment and management plans (8 per cent) of identified cases, reviewing support/behaviour plans (8 per cent), risk of placement breakdown (8 per cent), safeguarding alerts (8 per cent), and presentation of behaviour limiting access (8 per cent).

Eighty-three per cent of service users were identified as displaying challenging behaviour at the time of their referral. Physical assault to staff, other service users and families or carers was the most commonly identified form of behavioural challenge (54 per cent) of the results, followed by self-harm (22 per cent) and property destruction (11 per cent).

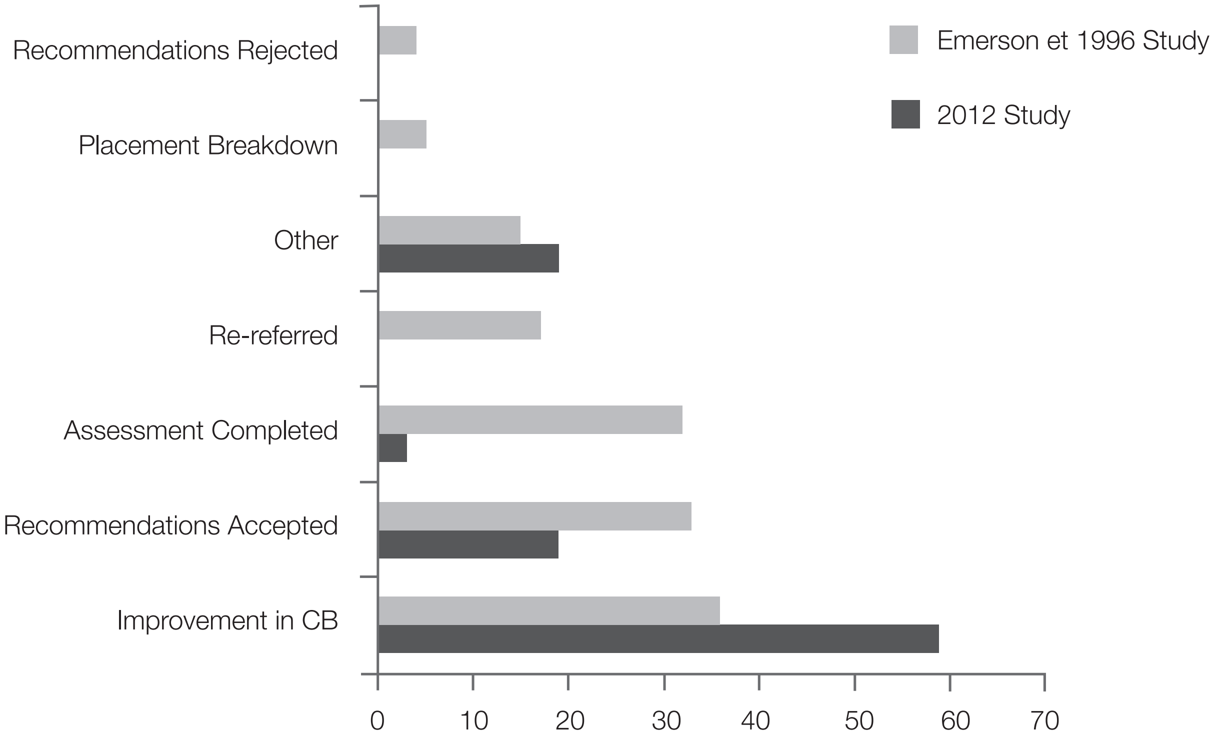
Thirty-two per cent of supported users resided in the family home, 38 per cent in supported living placements, and 27 per cent in residential care; in 32 per cent of cases, the placement had recently or was about to be changed due to its unsuitability. The majority of service users (87 per cent) were living with their own areas of birth place and geographical area of their choice (as opposed to in an ‘out of area’ placement).

Participants were identified as having a functional assessment of the displayed challenging behaviours completed in 81 per cent of cases and intervention/advice was offered in all of these. A reduction in the display of challenging behaviour was identified as an outcome for 81 per cent of service users and an increase in quality of life for 87 per cent.

Reasons for discharge are shown in *Figure 2* below.

An improvement in challenging behaviour was cited as the most common reason for discharge (60 per cent), with teams in the present survey rating themselves as more effective in this respect than those studied by Emerson et al (1996); 19 per cent were discharged as a result of team recommendations having been accepted by the referring service or service user’s family, 13 per cent were referred on to another service.

Figure 2: Reasons given for discharge (current study and Emerson et al, 1996)



Discussion

This paper presents a snapshot of the current position of specialist peripatetic teams for people with learning disability and challenging behaviour in the United Kingdom. A search identified 46 such teams, 20 of which agreed to take part in an online survey.

As the contact details and tools from the earlier research were no longer available, it was not possible to replicate the Emerson et al (1996) study. The number of teams common to both studies is therefore unknown, and any comparisons therefore have to be treated with caution. While there appeared to have been a change in team make up between the two research points, this may have simply reflected the fact that the studies were made up of two entirely separate samples.

The teams in the present work rated their effectiveness in terms of achieving behavioural change as greater than those in Emerson. In the latter, approximately 37 per cent of discharges were as a result of reductions in challenging behaviour, whereas the equivalent figure in the present study was 60 per cent. Self-assessments of service efficacy in an online survey obviously need to be viewed with extreme caution, although evidence from more objective studies does suggest the model can produce a range of positive outcomes.

In the main, these services were targeted at adults, although some services were specifically for children and others included children; the youngest service user supported in the sub-sample was aged 14 years. This raises serious concerns regarding the provision of support to children given that it is estimated that 40,000 children in England alone are likely to have an intellectual disability and present challenging behaviour (Challenging Behaviour Foundation, 2014). As a result they are at greater risk of social exclusion, institutionalisation, deprivation, physical harm, abuse, misdiagnosis, exposure to ineffective interventions, and failure to access evidence-based interventions (Emerson and Einfeld, 2011).

The large number of services that described their approach as predominantly eclectic is noteworthy and begs the question of the extent to which such services can be adhering to available evidence based practice. Early research indicated that the most effective teams used interventions that were underpinned by and derived from applied behavioural analysis, though McKenzie (2011) concluded that it is unlikely that any one model of service provision can meet the needs of all clients with challenging behaviour. There is, however, a risk in that this more liberal framework could result in the utilisation of therapeutic interventions that lack an adequate evidence base (Inchley-Mort et al, 2014). Also of concern was the ability of services with large caseloads to provide the levels of intensive support that are often required by this population. One service reported a caseload of 125 people, although this is of course not without precedent as a service in the original Emerson et al survey had a caseload of 230.

If 46 is an accurate reflection of the number of such teams in existence, this represents a 30 per cent reduction from 1996. The actual reduction may be even greater, as the first study was conducted in England and Wales whereas the present work also included Scotland and Northern Ireland. It is of further interest (and concern) that almost half the teams who responded to the survey reported they had either time-limited funding or funding that was being reviewed. The vulnerability of such services to organisational change with specialist challenging behaviour staff being placed within local generic teams was raised by Inchley-Mort et al (2014). They suggested an enhanced service model where the challenging behaviour team was fully integrated within the community intellectual disability service with staff working across boundaries. Such a model may well provide a suitable alternative; however, the authors do not address how the necessary time for intensive work with individuals can be ring fenced, with the obvious risk that the team will be overwhelmed by the day-to-day work of the community team eating into the time needed for the more intense challenging behaviour work. Somewhat ominously, the National Audit Office Care services for people with learning disabilities and challenging behaviour (2015) commented that ‘Some specialist learning disabilities teams in the community have been run down, which has contributed to delays in introducing appropriate care packages. This has also increased the risk of hospital admissions, and readmissions, and the pressures on hospital resources’ (p 36), seemingly confirming that the existence of peripatetic teams might be at risk just at the time when the successful implementation of national policy requires them most.

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