

ARTICLE

An evaluation of positive behavioural support for people with very severe challenging behaviours in community-based settings

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Abstract This study employs a multiple baseline across individual design to describe positive behaviour support for five people in community settings. The individuals represent all people with intellectual disability residing in one county with long standing challenging behaviour resulting in serious physical injury. Five types of outcome are presented: rates of behaviour, rates of medication, psychiatric symptomatology, quality of life and revenue costs. The systems of support required to maintain outcomes and develop real lifestyles include behaviour support planning, mental health review, on-call intensive support and emergency respite care. Behaviours reduced to near-zero levels following implementation of positive behaviour support and improvements were sustained over 24 months. The use of psychotropic medications reduced by 66 percent over the same period. Quality of Life Questionnaire scores improved significantly for three of the five participants. The results are discussed in the context of a framework for supporting people with severe challenging behaviours in the community.

Keywords Keywords to be supplied

Introduction

Community participation and the development of real lifestyles are accepted aims of services for people with intellectual disabilities. However, the extent to which these aims have been achieved for people with severe challenging

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behaviours and additional mental health needs is questionable. Crises, placement breakdowns, out of area placements and the admission of people to segregated specialist treatment facilities are all potential outcomes for people with severe challenging behaviours. While de-institutionalization and subsequent placement in community settings has been associated with overall increases in measures of adaptive behaviour, placement alone in community settings does not necessarily impact positively on the occurrence of challenging behaviour (Kim et al. 2001; Larson and Lakin, 1989). This observation combined with the high numbers of individuals with challenging behaviours living in community settings have led to calls for effective planning and systems community support (Joyce et al., 2001).

A number of behavioural support and crisis response systems have been created to respond to the needs of individuals with challenging behaviours and mental health needs without resorting to institutionalization (e.g. Allen, 1999; Rudolph et al., 1998). These have typically involved the creation of specialist teams allocated to generally small numbers of clients with significant challenging behaviour in order to support them effectively in community settings. Unfortunately, only a relatively small number of evaluations on the effectiveness of these teams with regard to this endeavour are available (Emerson and Emerson, 1987; Golding et al., 2005; Mansell et al., 2001). Some interesting findings have emerged which may help to explain why community placements may break down. First, it appears that the occurrence of severe challenging behaviour is not, in and of itself, a reliable predictor of placement breakdown. For instance, Allen (1999) compared characteristics of individuals with significant challenging behaviour supported in community settings and those whose placements had broken down and who were subsequently admitted to a specialist treatment facility. No significant differences were observed in the behavioural and psychiatric profiles of the two groups and there was no substantive evidence that the overall number and severity of challenging behaviour was associated with increased risk of hospital admission. Of particular interest was the observation that carers of those individuals in the placement breakdown group were not trained to respond to behavioural crises. Recent research also indicates that subsequent out of area placement is often related to the poor quality of local services in effectively supporting individuals with challenging behaviour in local community settings (Beadle-Brown et al., 2006). Second, one consistent theme is that the absence of an effective organizational infrastructure, including not having a model of effective support, can mitigate against the adoption of known effective strategies and contribute to placement breakdown (Allen, 1999; Lowe et al., 1996). Third, it appears that the degree of effectiveness of teams in supporting individuals with challenging behaviour is in part mediated by the model of assessment

and intervention employed by a team, with those teams having a cohesive shared model being more effective than a team with multiple and often competing models (Emerson and Emerson, 1987; Lowe et al., 1996).

One particular model that has emerged over the past 15 years is positive behaviour support (PBS: e.g. LaVigna and Willis, 2005). As a model it is defined by a number of key characteristics: (1) the use of comprehensive functional assessment for problem behaviour; (2) altering deficient environmental conditions; (3) altering deficient behavioural repertoires; and (4) achieving lifestyle change and improved quality of life through multi-component treatment plans while decreasing the frequency of challenging behaviour. A substantial evidence base for PBS has developed indicating its effectiveness as a model of support for individuals with challenging behaviour (Donnellan et al., 1985; Grey and McClean, 2007; McClean et al., 2005). This base also includes a major meta-analytic review of studies conducted between 1985 and 1996 which indicated that PBS was effective in almost two-thirds of cases and that success rates almost doubled when intervention was based upon prior functional assessment (Carr et al, 1999). Hieneman and Dunlap (2000) have proposed 12 factors potentially related to increased likelihood of successful outcome of PBS in community settings based upon interviews with experts in the area. These include characteristics of the individual with challenging behaviour, the nature of the behaviour and its history, support workers' capability and degree of personal investment in implementing interventions, behavioural support plan design, implementation integrity, system responsiveness, and the alignment of a behaviour support plan with the values of support providers and collaboration among providers.

However, apart from a seminal study by Donnellan et al. (1985), there have been remarkably few demonstrations of the outcomes of positive behavioural support in everyday community settings for individuals with very severe challenging behaviours. As a consequence, very little is known about the actual systems of support that are necessary for generating and sustaining behavioural change in the community. For example, Golding et al. (2005) report that a specialized community-based system of residential supports was associated with significant changes in (1) an increase in domestic activity skills, (2) an increase in quality of life, (3) an increase in engagement and quality of life and (4) a decrease in some observed challenging behaviours. However, the actual system of supports provided is not described. Moreover, outcome studies rarely address the myriad of factors that may affect challenging behaviours, such as medication, mental health change or the availability of resources. Furthermore, people who are admitted to segregated settings are likely to be placed there because of challenging behaviour of exceptional severity. There is therefore a need for

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studies that evaluate the effectiveness of positive behavioural support in the community for people where behaviours are exceptionally severe.

This study was conducted in a rural county in the west of Ireland with an extent of approximately 1000 square miles (pop. 52,000). This study evaluates the implementation of positive behavioural support for five individuals with the most severe challenging behaviours resident within the county.

Method

Participants

The five people with the most severe challenging behaviours in the county were selected for inclusion in the study. A single state funded voluntary organization is the sole service provider to 350 children and adults with intellectual disabilities or autism. The region has no large residential setting or specialist treatment facility for people with challenging behaviour.

Severity of behaviour was established using the severity subscale from the Harris Challenging Behaviour Checklist (Harris, 1993). All five were on the Irish National Intellectual Disability Database and presented with challenging behaviours which were rated as 5 on the Harris severity scale, defined as behaviours that 'caused very serious tissue damage to other person/self (e.g. bones broken, deep lacerations/wounds). Hospitalisations and/or certified absences from work necessary during the past month.' No other person's challenging behaviour in the region met this criterion. Key characteristics of the group are presented in Table 1.

Four of the participants presented with long-standing severe aggressive behaviour and one (Sean) presented with severe self-injurious behaviour. Major wounds had formed on Sean's forehead and on the back and sides of his head from hitting his head against hard surfaces, and these required daily dressing. Numerous head X-rays were required to evaluate the possibility of skull fracture due to severity of this behaviour. Áine¹ and Andrew's physically aggressive behaviours had each resulted in two staff requiring extended certified absences from work due to serious injuries. One of these injuries occurred during the baseline period. Ciara's behaviour of biting and kicking had resulted in certified absence from work for two staff, and Tom's behaviour had resulted in severe injuries to a work colleague, including a broken jaw.

Review of historical records indicated that behaviours had continued to worsen in frequency and severity for Áine, Andrew and Ciara over the previous 3, 2 and 7 years respectively. Tom's behaviour appeared to be relatively stable in both frequency and severity since age 20. Sean's behaviour

Table 1 Characteristics of the participants

	Age	Level of intellectual disability	Additional diagnosis	Target behaviour	Daily medication at baseline	Period of medication for behaviour
Áine	38	Moderate	Rapid cycling mood disorder	Aggression (punching, slapping, kicking, hairpulling)	Risperidone 5 mg Tegretol 1200 mg	7 years
Andrew	22	Severe	Autism, psychosis	Aggression (punching, slapping, kicking, hairpulling)	Hypersensitive to medication	Medications tried over previous 2.5 years
Sean	24	Severe	Autism, depression	Self-injury (head banging)	Risperidone 1 mg	3.2 years
Ciara	21	Mild	Cerebral palsy, mood disorder	Aggression (biting, punching, kicking)	Largactil 400mg Diazepam 5 mg Lamictal 50 mg Zispin 45 mg Kemedrin 5 mg	4.9 years
Tom	37	Moderate	?Paranoid schizophrenia	Aggression (punching, use of weapons)	Largactil 25 mg Modecate (1.25 mg/2 weeks)	18 years

showed a recurrent pattern: records showed that there were at least three previous occurrences of self-injury, of duration 11, 16 and 28 months respectively.

All five experienced significant communication disabilities. Sean had no expressive communication, while Andrew conversed using repetitive phrases of up to six words. Áine could communicate well using short phrases of up to six words. Tom and Ciara had relatively fluent speech, although in Tom's case, psychometric reports indicated that his expressive skills often masked significant deficits in receptive abilities. Ciara's speech was impaired by severe articulation difficulties, and she refused to avail of a recommended augmentative communication device. All participants were capable of carrying out some one-step requests, and both Tom and Ciara were capable of carrying out two-step requests.

Áine was living at home with her mother and brother at the start of the study. Andrew lived in a group home for 5 days per week and with a

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foster family for 2 days per week. The remaining participants lived in full-time residential care in the community. Residential staff allocations ranged from 1:3 (Tom) to 1:1 (Ciara). Áine attended a training centre with 29 other adults until her placement broke down. She had a 1:6 staff to trainee ratio, although in actuality she frequently received 1:1 staffing throughout her day due to the frequent challenging behaviours. Ciara had no day placement at baseline, due to challenging behaviour. Tom attended a mobile work group with eight co-workers and three support staff. Andrew and Sean both attended the same day activity centre with one other adult. Each had 1:1 staffing at baseline.

One consistent theme in the life stories of the five individuals was separation from parents. Both Andrew's parents died when he was a child. Tom was separated from both parents from early childhood, and was both a witness to and a victim of repeated domestic violence. Both Tom and Ciara were admitted to 5 day residential schools as children (Ciara from the age of 6), necessitating separation from their family, and multiple lengthy admissions to psychiatric hospitals due to challenging behaviour. Both Tom and Ciara had frequent changes of residential placement throughout their lives because of their challenging behaviour, and both had previous admissions to acute psychiatric facilities.

Assessments

Behaviour recording

In each case, the frequency of behaviours was recorded in real time throughout the duration of the study. Each behaviour was assigned a start and a stop definition (Johnson and Pennypacker, 1993) and these definitions were agreed with other caregivers responsible for implementation of positive behavioural supports. For three participants (Áine, Andrew and Tom) the reliability of recording was tested by comparing them against the daily report books completed by independent staff members over a 1 month period during baseline. The overall inter-rater reliability coefficient for these three participants was 94 percent. For Sean and for Ciara, reliability testing consisted of two staff independently rating the frequency of behaviours over 2 days and 5 days respectively. Inter-rater reliability coefficients of 96 and 87 percent, respectively, were found. Reliability of recording was reassessed during the 18th month of the study by the method of comparison with daily report books for all five participants. Inter-rater reliability coefficients of 100 percent were established for all five clients.

The duration of baseline was determined by naturally occurring phenomena. Interventions were introduced after a 1 month period of

assessment in the case of Áine, and once a hypothesis of function was established. In the case of Andrew and Sean, functional assessments were conducted over a 2 month period, whereas 4 months of data collection were required before a firm hypothesis of function was generated for Ciara. Tom presented with a low frequency, high impact behaviour, and there were so few incidents that it was possible to calculate the baseline rate of the behaviour retrospectively. In no case were recommended interventions withheld for the purposes of gathering of baseline data.

Mini PAS-ADD (Prosser et al., 1998)

The Mini PAS-ADD is a widely used assessment schedule for the detection of mental health problems in adults with developmental disabilities. It comprises six scales: depression, anxiety, hypomania, psychosis, obsessive compulsive and unspecified disorder. The psychosis scale relies on self-reports of symptoms, and consequently had limited validity for the current group. Similarly, scores on the obsessive and unspecified disorder scales were negligible throughout the study. For these reasons, only the results of the depression, anxiety and hypomania scales are presented. These ratings were made by programme staff who knew the participant for at least 6 months prior to assessment. Ratings were taken at baseline, and at 6 and 12 months after commencement of interventions.

Quality of Life Questionnaire (QoL-Q: Schalock et al., 1989)

The QoL-Q is a clinical tool designed as an outcome measure for persons with developmental disabilities and mental retardation. Scales include: satisfaction ($\alpha = 0.78$), competence/productivity ($\alpha = 0.90$), empowerment/independence ($\alpha = 0.82$) and community integration ($\alpha = 0.67$). The internal consistency of the total score is estimated at 0.90. Inter-rater reliabilities are reported between 0.73 and 0.83 with a test-retest coefficient of 0.87.

Medication

The amount of medication prescribed to a person was taken from the medication cardex at the last day of every month. Units of medication were calculated according to the drug equivalence information provided in the British National Formulary.

Periodic service review

Periodic service review (PSR: LaVigna et al., 1994) is a system of quality assurance that yields a self-report measure of the proportion of an overall behaviour support plan that has been implemented. A criterion for the implementation of each intervention is operationally defined, and at the

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end of each month a PSR score records the number of interventions implemented that meet the specified criterion. The inter-rater reliability of the PSR was calculated by comparing PSRs completed independently by two staff at the end of 1 month for Andrew, Sean, Ciara and Tom. This yielded an inter-rater reliability coefficient of 81.4 percent.

Support systems

Five systems were identified which could be used to support the implementation of behaviour support plans. Use of these supports was tracked throughout the study. Supports were:

- 1 *Behaviour support planning meetings.* These were defined as planning meetings with the first author and frontline staff responsible for implementing the plan. The frequency of behaviour support planning meetings was recorded.
- 2 *Mental health reviews.* These were multi-disciplinary team meetings, attended by the participant and the clinical psychologist, consultant psychiatrist, behaviour therapist, frontline staff and family members. The frequency of mental health reviews was recorded.
- 3 *Intensive support workers.* The primary role of the intensive support worker is to work alongside the existing staff team. The number of intensive support worker hours allocated to each individual was recorded.
- 4 *Emergency respite care.* At times of behavioural crisis, a place of safety may be made available at a two-bed emergency respite care facility. This may be staffed by members of the behaviour support team, or behaviour support team members may cover for regular staff so that they can remain with the service user during the emergency. The number of days stay at emergency respite care was recorded.
- 5 *Crisis response.* Members of the behaviour support team may be designated to be available on-call at night time or at weekends in the event of a change in the participants' behaviour. The frequency of emergency callouts was recorded.

Costs

The revenue costs of the service to each of the individuals was calculated at baseline and at 18 months. In each case, pay costs were estimated by

- 1 Calculating the costs q of staff allocated to a day or residential service.
- 2 Calculating the proportion p of the overall service allocated to an individual, i.e. the number of days the person availed of the service expressed as a proportion of all the days of service given to all of the people who availed of the service.

- 3 Calculating the additional cost r of frontline staff allocated to the individual, i.e. including outreach workers or intensive support workers allocated to the individual alone.

The pay costs associated with an individual were then estimated as $(q + p) + r$. Additional pay costs associated with relief staffing for sick leave are not included. Complete information about non-frontline pay costs (e.g. administration, psychology, psychiatry) was not available, and the costs of these are not included. Non-pay costs associated with staffing, training, telephone, travel are estimated at 5 percent of pay costs. Other revenue costs associated with the everyday living expenses of the person, such as light, heat, food, rent etc. are assumed not to fluctuate from baseline to intervention and are not included in the overall estimate of costs. Finally, in order to make comparison between baseline and follow-up more meaningful, baseline costs were adjusted according to inflation and pay awards that occurred during the period under study.

Procedure

A comprehensive behavioural assessment and intervention plan was completed which met the standards established in the Behaviour Assessment Report and Intervention Plan Evaluation Instrument (Willis et al., 1993). The assessment was multi-modal, and included: (1) informant assessments, i.e. review of files and interviews with the individual and key informants such as family members and staff, which consisted of cognitive, communicational, ecological, medical and psychiatric assessments; (2) descriptive assessments, behavioural observation, historical analysis, antecedent analysis and consequence analysis; and (3) hypothesis development and systematic observation to test hypotheses. Pre and post measures (Mini-PAS-ADD, Quality of Life Questionnaire) were taken at the informant interview phase of the assessment and again at 18 months after commencement of the study. Pre and post staffing costs were calculated independently by the financial controller for the service. Definitions of behaviour were also agreed at the informant interview phase of the assessment. Behaviour recording, medication, periodic service review and number of emergency callouts were logged as part of each behaviour support planning meeting and as part of each mental health review.

Hypotheses of the communicative function of challenging behaviour were developed for each individual, and were used as a basis for designing multi-element behaviour support plans, based on the model developed by LaVigna and Willis (2005). The main elements of each behaviour support plan are presented in Table 2.

Table 2 Hypotheses of function and multi-element behaviour support plans

<i>Hypothesized communicative function</i>	<i>Environmental accommodations</i>	<i>Skills teaching</i>	<i>Direct interventions</i>	<i>Reactive strategies</i>
<i>Aine</i>	Individualized environment Low arousal interaction style Structured timetable Supported employment	Beauty care skills training Escape communication training: 'Too noisy' Escape training (puts on personal stereo) Relaxation training	Antecedent control (request to put on personal stereo) DRO	Facilitated relaxation
<i>Andrew</i>	Individualized environment Low arousal interaction style 15 minute schedule of activities	Escape communication training: 'Too noisy'	Antecedent control (reduce noise, no unnecessary demands, refer to picture sequence) DRL	Active listening Physical withdrawal Redirect Principles of physical safety
<i>Stop</i> (noise, coughing, crying)	Two-way choice format for requesting			
<i>I don't understand</i>	Activity sampling			
<i>Don't refuse me</i>	Picture sequencing			
<i>Sean</i>	Two-way choice format for requesting	Phone home Communication training: 'stay' Relaxation training Shaping (staff withdrawal) Stimulus control (hat and ointment)	Antecedent control (transition protocol, reduce unnecessary demands) Satiation (sinus/head massage) Momentary DRO	Physical shadowing Low arousal response Redirection
<i>Attention maintenance: 'Stay'</i>				

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Table 2 continued

<i>Hypothesized communicative function</i>	<i>Environmental accommodations</i>	<i>Skills teaching</i>	<i>Direct interventions</i>	<i>Reactive strategies</i>
<i>Ciara</i>	Own apartment Structured timetable Third-level training Power chair Medication reduction Choices	Communication training: 'I want/I don't want' Shaping (tolerance to work tasks) Shaping (tolerance to family contact)	DR0 Satiation (chat time)	Physical withdrawal Non-contingent attention (every 30 minutes)
<i>Tom</i>	Complaints book Mentor system Activity sampling	Supported employment Line dancing Escape communication training: 'Quit it!'	Antecedent control (withdrawal from teasing/criticism) Satiation (explanation time)	Redirection
<i>Escape:</i> 'I cannot cope with my family/my disability'				
<i>Attention:</i> 'I want attention'				
<i>Escape:</i> 'Don't tease/criticize me'				

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It was hypothesized that the function of Áine's behaviour was to respond to over-stimulation. An individualized day programme was designed for her for 16 hours per week. Activities were selected from her preference assessment and offered to her every 45 minutes. These included job planning and job search, household chores, shopping and going for coffee, food preparation and beauty care. Skills teaching involved prompt fading and verbal praise. Áine was taught to put on her personal stereo in response to over-stimulation and to communicate spontaneously 'It's too noisy.' She was reinforced with activity-based rewards for every half-day in which target behaviours did not occur. Staff were trained in a low-arousal response to her verbal communications. Reactive strategies involved facilitating relaxation and staff withdrawal.

It was hypothesized that Andrew's behaviour was a way of communicating escape from a range of events such as noise, use of verbal language, specific noises such as coughs or cries, change of routine and refusal. His behaviour support plan included activity sampling, picture sequencing to improve the predictability of daily events, reduction of unnecessary speech, and offering him requests using a visual two-way choice format. Escape training included prompting him to escape to his room and prompting him to make the verbal communication 'too noisy'. Antecedent control procedures included, for example, turning off a television or radio after he had left a room and removing unnecessary demands. Staff were trained in non-violent crisis intervention, and withdrew from violent or potentially violent situations.

It was hypothesized that Sean's head banging was an attention seeking behaviour. Staff withdrawal was a frequent trigger to head banging and it was hypothesized that the restoration of attention reinforced the behaviour. He was offered reflexology sessions once per week and was offered a head massage every 15 minutes, not contingent upon his behaviour. Ointment and a hat paired with conditions associated with the non-occurrence of behaviour and he was rewarded for non-occurrence of head banging under those conditions. Sean was taught to press a bell as a more appropriate form of communicating 'stay'. He was offered frequent opportunities to listen to his mother by telephone. Physical shadowing was used to protect his head during high risk events (transitions, doorways, bathroom). Inter-positioning was used to protect his head during bouts of self-injury, and staff were trained to lower the arousal level of their response to his self-injury.

It was hypothesized that there were two functions to Ciara's aggressive behaviours: to avoid situations in which limitations imposed by her physical disability were apparent to her (walks, contact with babies, work) and to avoid contact with family members. Her behaviour was also associated with

fluctuations in mood which were hypothesized to be secondary to an excess of the hormone prolactin. This in turn was hypothesized to be a side effect of Lergactil. Finally, her behaviour was hypothesized to be reinforced by staff attention. Environmental accommodations included a structured timetable of age appropriate activities, reducing Lergactil, a two-way choice format for making requests, a counselling session every 2 weeks, reinforcing her communications of the verbal message 'I want ...' or 'I don't want ...', shaping her tolerance to work tasks and systematically desensitizing her to family contact. Ciara was reinforced for every 2 days in which she did not use physical aggression and was offered attention (chat time) non-contingently.

It was hypothesized that Tom's behaviour functioned to escape from teasing or criticism. The key interventions included withdrawal from a group of peers who provided him with criticism, providing a mentor, offering explanation time every 2 hours and reinforcing more appropriate ways of escaping from criticism, such as 'writing a complaint into a complaints book' and using the phrase 'quit it'.

Results

Figure 1 presents a monthly summary graph of the frequency of target behaviours for each of the five participants, as well as monthly ratings of the implementation of the behaviour support plans. For all plans, reductions to near-zero levels in the monthly rates of behaviour were observed following the implementation of positive behaviour support. For Áine and Andrew, reductions in behaviour were observed immediately on implementation of positive behavioural support. For Andrew, Sean and Ciara, behavioural reductions to near-zero levels were observed. Figure 1 also presents the periodic service review scores, which measure the proportion of the overall behaviour support plan implemented. It shows that implementation of Áine's plan increased to 95 percent over 3 months; 95 percent of Ciara's plan was implemented by the end of the 10th month; and implementation of Tom's plan rose to 80 percent over 5 months. Andrew's and Sean's plans were not fully implemented, reaching maximum implementation rates of 74 and 48 percent respectively.

Figure 2 presents the number of units of medication at the end of each month for each person. Of the four participants in receipt of medication, overall levels of medication were reduced for three participants (Áine, Ciara and Tom), while Sean was placed on a new anti-depressant medication 11 months after implementation of positive behavioural supports. The graph may suggest a link between Ciara's medication reduction and the subsequent reduction in her behaviour.

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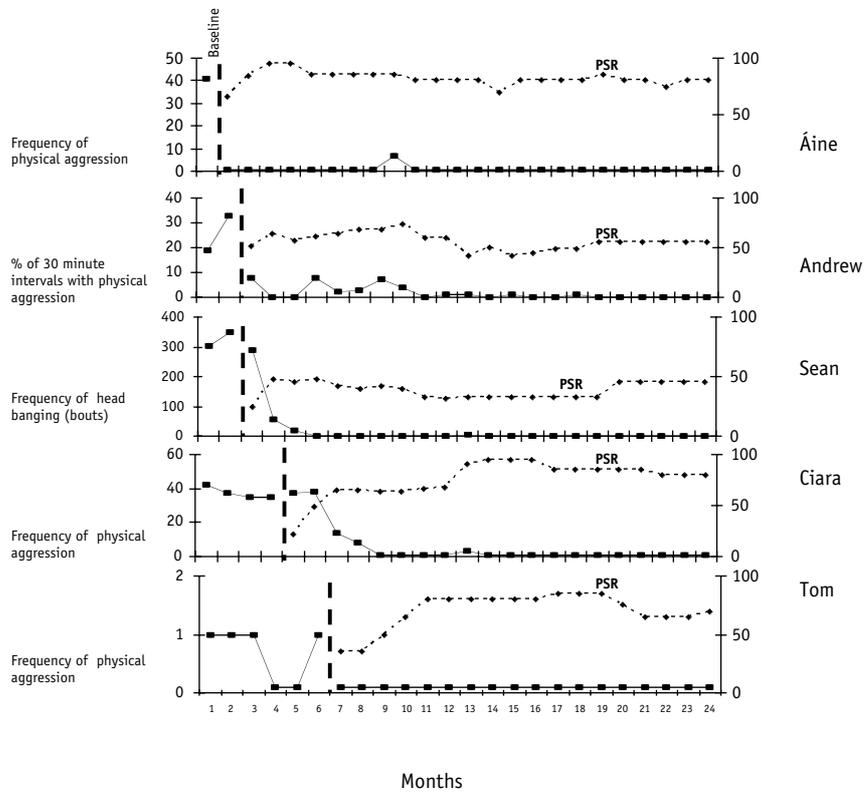
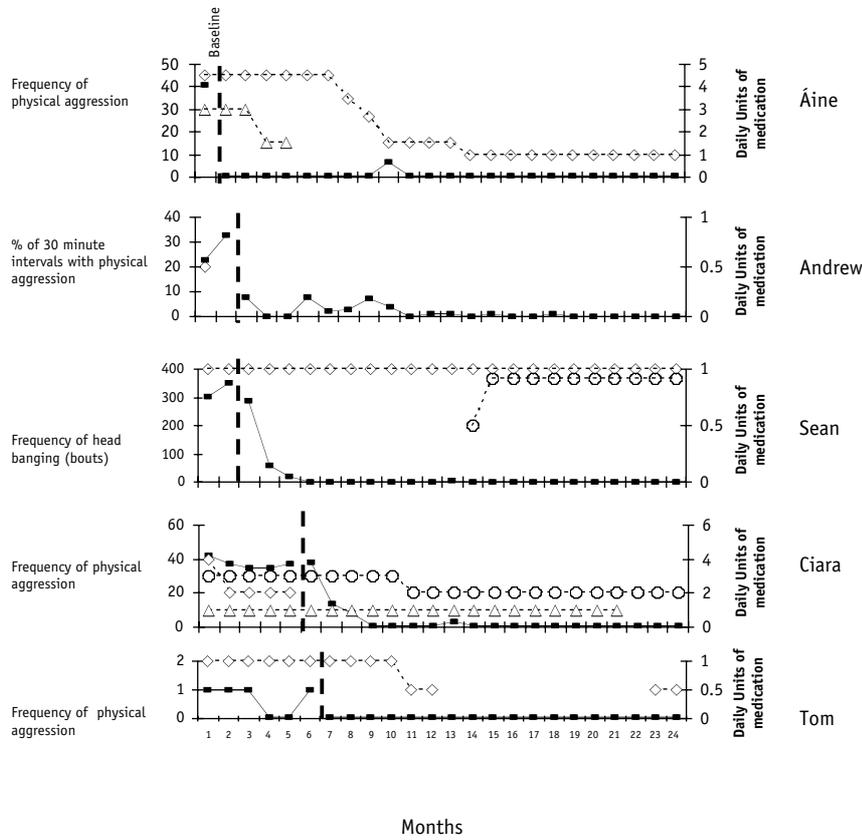


Figure 1 Monthly rates of behaviour pre and post intervention and monthly rates of implementation of intervention as per periodic service reviews (PSRs)

Figure 3 presents mini PAS-ADD ratings for each individual for the depression, anxiety and hypomania scales. Results indicate that four individuals have shown considerable reduction in PAS-ADD ratings during the study, but that Andrew's PAS-ADD ratings remained relatively unchanged.

Results of the Quality of Life Questionnaire (QoLQ) are presented in Figure 4. Four of the participants had quality of life scores below the first percentile for their level of intellectual disability. The fifth participant, Tom, had a quality of life score at the 2nd percentile of people with mild intellectual disability. Figure 4 shows that three participants (Áine, Ciara and Tom) had significantly improved their quality of life over the 24 months of the study. Áine and Tom both secured supported employment: Áine was working 1 day per week, and Tom had started two forms of paid employment for 2 days per week each. Ciara had commenced a third-level training course in computers. Ciara acquired a power chair and was trained to use it, which improved her independent access to the community. She moved

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Key	
--■---	Target behaviour
--◇---	Anti-psychotic medication (e.g. Risperidone, Largactil)
--⊗---	Anti-depressant medication (Efexor, Zispin)
--△---	Mood stabilizers (Tegretol, Lamictal)

Figure 2 Monthly rates of behaviour and daily units of medication as per the end of each calendar month (note that 5 mg per day of diazepam, an anxiolytic, was administered to Ciara for the first 10 months; for ease of interpretation this is not presented on the graph)

to her own apartment, only 10 miles from her family home, and now visits home two times per week and receives frequent visits from family members. Of the five, Tom made the greatest improvement in quality of life. His QoLQ score increased from the 2nd percentile to the 92nd percentile. He moved to a smaller house with 1:1 staffing by day and 1:2 staffing in the evening. He participates in a wide range of leisure activities

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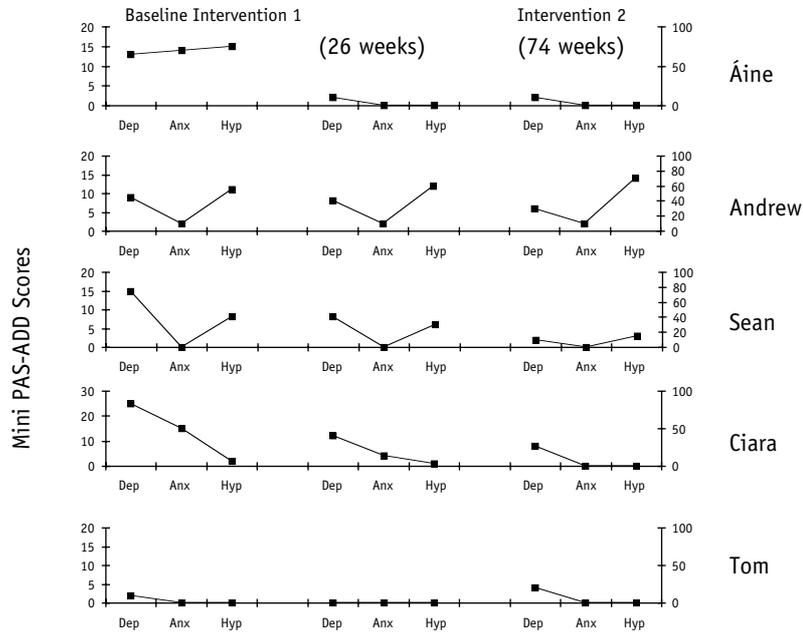


Figure 3 PAS-ADD scores for depression (Dep), anxiety (Anx) and hypomania (Hyp) for each of the five participants

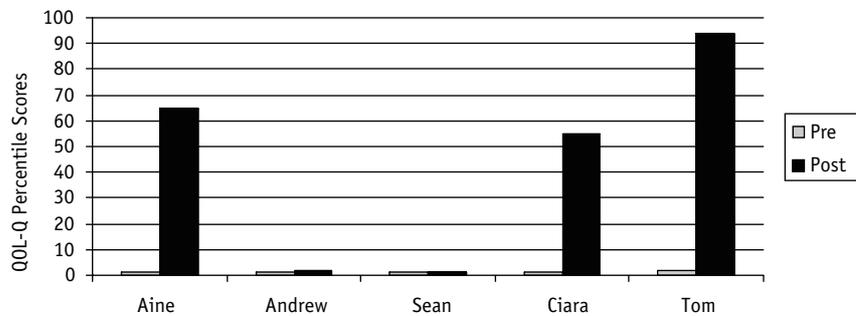


Figure 4 Quality of life questionnaire percentile scores at baseline and follow-up

including greyhound racing, cycling, owning a pet and supporting his beloved Roscommon football team. Through these activities and others, he is building a network of friendships and establishing a profile for himself within his local community. QoLQ scores did not increase in either Andrew or Sean's case. Andrew continues to refuse 82 percent of the activities offered to him, although programme staff approach him with a two-way

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picture choice of preferred activities every 30 minutes. Sean's behaviour support plan, on the other hand, appears to require more complete implementation.

Table 3 presents a summary of the supports that each participant received over the course of the study. Overall, the staff allocation to the five participants decreased by 12.3 percent in day services and by 7.2 percent in residential services. Although a crisis respite facility was available to all five residents, it was required on only one occasion by Áine, for a period of 1 week in month 11. The crisis was preceded by a switch in medication from Risperidone to Olanzapine. Instead of crisis respite admissions, the participants tended to avail of callouts from the behaviour support team. A total of 38 crisis callouts were recorded, and typically these were 30 minutes to 6 hours in duration. The table also documents the numbers of mental health clinic appointments (lasting approximately 25 minutes in duration) and the numbers of behaviour support planning meetings (lasting approximately 60 minutes each). Andrew refused to attend most mental health clinic appointments, and instead members of the team visited him regularly. All other service users attended the mental health clinic; Áine and Sean were accompanied by programme staff, Ciara and Tom attended independently. Ciara and Tom attended most behaviour support planning meetings.

Table 4 presents the revenue cost of the service to each individual at baseline and after 18 months. The table shows that revenue costs for the five individuals reduced from £418,492 to £301,596, a reduction of almost 28 percent. However, this finding is skewed by the significant savings of one individual, Ciara. For the first 12 months of the study, Ciara had an allocation of two staff, including one senior nurse for day and residential staffing. From 12 months this was reduced to one personal assistant during residential hours and a day placement involving a one-to-nine staff to client

Table 3 Summary of systems of support

	<i>Day staff allocation</i>		<i>Residential staff allocation</i>		<i>Crisis respite admissions</i>	<i>Crisis callouts</i>	<i>Mental health clinic appointments</i>	<i>Behaviour support planning meetings</i>
	<i>Pre</i>	<i>Post</i>	<i>Pre</i>	<i>Post</i>				
Áine	0.16	0.5	None		1	7	16	12
Andrew	1.0	1.3	0.5	0.5	0	14	11	58
Sean	1.0	1.0	0.5	0.5	0	12	12	29
Ciara	2.0	0.12	2.0	1.0	0	5	26	23
Tom	0.33	1.0	0.33	0.5	0	0	7	14
Total	4.49	3.92	3.33	2.5	1	38	72	136

Table 4 Costs of services in £ sterling at baseline and at month 18

	<i>Pre</i>	<i>Post</i>
Áine	9,422	12,376
Andrew	56,000	58,520
Sean	115,000	115,000
Ciara	212,800	63,000
Tom	25,270	52,700
Total	£418,492	£301,596

ratio, representing a saving of over 70 percent. On the other hand the cost of service to another individual (Tom) more than doubled. The costs of services for Áine and Andrew increased by relatively small amounts (less than £3000 each) and the costs of Sean's service showed no appreciable change.

Discussion

The present study adds to the limited database on supporting people with severe challenging behaviour in the community. The implementation of positive behaviour support plans was associated with substantial reductions in challenging behaviour for all five individuals. Moreover, in four of the five cases, significant reductions in the frequency of challenging behaviour were observed within either 1 or 2 months of implementation of the behaviour support plan. Behaviour improvements cannot be attributed to medication, and in one case at least (Ciara), medication reduction may have in fact contributed to behavioural improvement. This was hypothesized to be due to the effects of excess of the hormone prolactin. Abnormal prolactin levels can be a side effect of Largactil (chlorpromazine). In Ciara's case, prolactin levels returned to the normal range 6 weeks after the withdrawal of Largactil (chlorpromazine).

For the four individuals who received psychotropic medication, medication rates reduced by 66 percent. Psychiatric symptomatology, as measured by the Mini PAS-ADD, also reduced. These findings question the levels of medication used with the four individuals, and support a findings that medications can be successfully reduced and removed when appropriate behavioural interventions are introduced.

All five individuals presented with behaviours of sufficient severity to warrant the admission of the person to a special treatment facility. Because no such facility was available to residents of the county, it was necessary to provide systems of support to maintain their placement in the community.

This resulted not only in the elimination of challenging behaviour, but also in significant amelioration of psychiatric symptoms for four of the individuals. It is significant that two behaviour support plans in the present study (Áine's and Andrew's) required the application of a low arousal environment, and a further two subjects' plans recommended that they live on their own and in smaller group settings. These environmental accommodations would have been very difficult, if not impossible, in the context of congregative environments for people with challenging behaviours, such as a special treatment unit. Three individuals improved their quality of life scores from below the 1st percentile to above the 50th percentile, and it is also difficult to envisage how these gains could have occurred in the context of a special treatment unit.

Lack of resources is often used as a reason for failure to deliver significant outcomes for people with challenging behaviours in intellectual disability services. In the present study, however, significant outcomes were achieved without significant additional resources. Indeed, in the present study the small increases in total allocation of resource to three individuals is outweighed by a major saving in the costs of staff supports to one individual. One possible implication of this finding is that individualized models of supporting people with challenging behaviour not only offer greater possibility for effectiveness, but can be less expensive than congregative alternatives.

As with all single case research, caution must be exercised in drawing conclusions from such a small sample size. Positive behaviour support is multi-element, and it is not possible in the present context to isolate the effect of individual interventions, to account for the contribution of non-specific therapeutic factors such as staff-client rapport (Carr et al., 1994), or to separate the effects of behavioural interventions from the effects of the range of support systems illustrated above. This will require multivariate research with a much larger sample.

The study illustrates that people with severe challenging behaviours can maintain their place in the community if given the supports they need to do so. However, these supports need to be established on a case by case basis, from a comprehensive range of service options, including;

- Acute (short stay) psychiatric treatment in mainstream psychiatric hospitals for some individuals with mild intellectual disability or where challenging behaviour is not unduly disruptive (this was not availed of in the current study).
- Small (one or two bed) community-based respite facilities, adapted for challenging behaviour, which receive outreach psychiatric support (this was availed of for one client, Áine, for 7 days in the current study).

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- Individualized residential and day services. Two individuals in the present study lived alone, and two individuals worked alone.
- High-support homes in the community for people with chronic psychiatric difficulties and/or persistent challenging behaviour. Two of the five clients in the present study resided in high-support group or individual homes.
- On-call intensive support service. In this study there were a total of 38 callouts, a majority of which were for two individuals, Andrew and Sean. In many cases the behaviour support team member who responded provided no overt action once on-site. Further research is needed to evaluate the role of the on-call service.

Notes

- 1 Participants' names have been changed to protect their identity.

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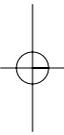
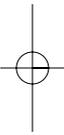
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