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A pilot evaluation of positive behavioural support workshops for families of adults with intellectual disabilities who present challenging behaviour: 'It should have been offered years ago'

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Abstract

Background: Positive behavioural support (PBS) workshops were designed for families supporting their adult son or daughter with an intellectual disability engaging in challenging behaviours. This was in recognition of the impact of their challenging behaviour, in particular the level of stress carers often experience and positive reports from other studies incorporating multi-family learning.

Method and materials: Two sets of pilot workshops were completed, incorporating modules in PBS and physical interventions. Workshops included presentations and self-directed/group learning tasks, recorded in a specifically designed workbook.

Results: Quantitative data was analysed using non-parametric tests. Positive results were found for changes in various areas including self-reported stress levels. Positive trends were also found in pre and post application of the Aberrant Behaviour Checklist (Aman and Singh, 1994).

Conclusions: This study showed very encouraging results in regard to the impact of this model of training for the carers involved. Further research is required to assess any longer term effects, and to explore the impact on larger numbers of participants.

Keywords: challenging behaviour, positive behavioural support, intellectual disability, family support

Introduction

Many people with intellectual disabilities who present with behaviours that are difficult to manage are primarily supported by their families. Emerson et al (2001) suggested it could be as many as half of this population who are living in the family home. Mansell's 2010 report, 'Raising our Sights', highlighted the need to provide high quality health and social care provision to such families, who may be faced with high levels of carer stress. When families cannot cope, there can be a huge impact on the individual, the family and services, especially if there is a subsequent need for support to be provided outside of the home (McGill et al, 2006; McIntyre et al, 2002).

The impact of caring for a son/daughter who presents with challenging behaviour has been well documented (eg Kenny and McGilloway, 2007). In growing

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recognition of the specific stressors that family carers face, there has been an understandable increasing focus on support for this group. In the UK, recent changes in education, health and social care policy reflect this focus, with school children and families being empowered through the Children and Families Act (2014). This places a duty on local authorities to draw up Education, Health and Care plans and to set out a 'local offer' of services available to parents and young people.

A small but encouraging literature exists evaluating group-based training to parents of young children with developmental delay who present challenging behaviours (Gore and Umizawa 2011). Wodehouse and McGill (2009) interviewed family carers about the support they had received from services. One of the factors highlighted was a lack of physical intervention training. Allen, Hawkins and Cooper's (2006) survey found that physical interventions had been used by 87.5 per cent of parent respondents, with 20.8 per cent reporting frequent use. In spite of this high rate of use only 25 per cent had actually had training in physical intervention. This particular survey involved parents of both children and adults. Any variation in the needs of these populations was not differentiated. However, it is likely that the use of physical intervention would perhaps be more likely and almost certainly would have greater associated risks with adult offspring.

A small literature has focused on training provided to families in the use of physical interventions. Shinnick and McDonnell (2003) presented a case study where carers of a 34 year old woman with an intellectual disability who presented challenging behaviour were trained in specific low arousal techniques and physical intervention. They reported encouraging results including some limited evidence that the carers were using the low arousal techniques, that they could recall the physical techniques (although rarely used them), some increase in confidence and subjective evidence of a decrease in the challenging behaviours being presented. Hawkins et al (2011) have also highlighted a need for training in physical intervention for families supporting children who engage in challenging behaviour. In this particular study, training included both theoretical and practical aspects of managing challenging behaviours within a PBS framework. Families reported fears around being able to keep themselves safe but also a fear of hurting their son or daughter during any interventions. Follow-up data suggested the use of physical interventions decreased and families reported finding the sections on the law and reflecting on their

approaches especially useful. Of note, a proportion of the families who were trained together also highlighted the benefits of learning from each other.

Family members learning from other families facing similar problems has been emphasised within multi-family group therapy literature. This approach highlights the importance of families learning that they are not alone in experiencing a problem, the benefits that can come from learning from and teaching others, and the hope that can be inspired in such settings. These settings have also been described as 'safe spaces' to experiment with new ideas and approaches (Howe, 1994). Whilst we were unable to find examples of this approach for families supporting individuals with intellectual disabilities who challenge, the approaches and themes described above appear to fit well with what families within the current literature have said they want.

Having PBS as the overarching framework for multi-family learning for this population seems especially important. There is evidence for improved outcomes in relation to PBS, specifically: decreased frequencies of difficult behaviours (eg Binnendyk and Lucyshyn, 2008); improved quality of life for the individual in question (eg Tifft and Cushing, 2002); and improved quality of life for family members (eg Boettcher et al, 2003). Lucyshyn et al (2002) in their book, *Families and Positive Behaviour Support*, highlight the benefits of the use of PBS with families and argue that they have previously been overlooked by the PBS literature.

The research described above indicates that parents/families:

- have often been excluded from training in managing challenging behaviour

- report having to use physical interventions with both their adult and child offspring

- want to know how to manage the behaviour when it occurs

- want other strategies as well as physical interventions to manage challenging behaviour

- report a great deal of stress in coping with challenging behaviour

- see a benefit in learning from/spending time with other parents going through similar situations

The current study

Given the above findings, the use of a group or multi-family approach to supporting families appears to offer a good fit for this population. This led to the development of local pilot PBS workshops for families. These were designed by NHS workers within a social service setting alongside carer support services.

The aims of the workshops were to:

- help families develop an understanding/formulation of how their son/daughter's needs relate to incidents of challenging behaviour

- help families develop an understanding of primary and secondary preventative strategies that may help to avoid or minimise incidents of challenging behaviour

- support families to develop an understanding of the legal framework surrounding physical intervention and, where required, to teach the skills necessary to manage crisis situations safely

- give parents the opportunities to learn from each other and to develop supportive relationships with others in their local area.

Materials and method

Design

Due to the pilot nature of the workshops it was felt that exploratory questionnaires would be developed to gather views of the participants before, during and after the training. In addition, data was gathered via the Aberrant Behaviour Checklist – Community (Aman and Singh, 1994). This is a frequently used standardised assessment of challenging behaviour where scores can be compared with a normative sample of people with learning disabilities living in community settings, who are the same age and/or have a similar degree of learning disability. This was completed by each attendee prior to the course starting and four weeks after completion.

This evaluation was registered with local NHS and County Council audit registers.

Participants

Ten people took part in two pilot courses of workshops. There were two different groups (divided by location of the workshops) who all received the same material:

- Workshop 1: An introduction to challenging behaviour and positive behavioural support

- Workshop 2: Developing communication skills

- Workshop 3: What helps? Preventative and early intervention techniques and an introduction to reactive strategies

- Workshop 4: Optional module for physical intervention training (PBS Sussex) including important aspects of the legal framework around this.

All modules were facilitated by the lead author (a clinical psychologist) and co-facilitated by local Carers Support Services representative. Modules 2 and 4 were also co-facilitated by a speech and language therapist. Throughout the course the participants completed a 'Behaviour Passport', a pack of information and support plan about their son/daughter that they developed over the course that could be shared with other important people in the individual's life.

The participants consisted of eight mothers, one step-mother and one father. They were all supporting their sons/daughters at home (apart from one who lived separately but frequently stayed over at the family home), all of whom were aged between 18 and 26. The parents reported that their children had a range of difficulties associated with their diagnoses of intellectual disability and other diagnoses, including Autistic Spectrum Disorder and Cornelia de Lange syndrome. All were reported to engage in behaviours that were at times hard to support, including physical aggression to others, self-injury, property destruction and refusing to do things.

The participants were self-selecting in that they applied for the workshop following information being distributed from various sources within the local area about the course. The majority of participants were already being supported by local intellectual disability services, either the specialist challenging behaviour community team, local community intellectual disability teams or the Carers Support Service. All care managers were approached following requests for places to inform them of the planned workshops, and to gather support should the parents wish to attend the physical intervention element of the workshops.

Materials

The participants were asked to complete the following information:

1. A pre-course questionnaire, which included:

- their son/daughter's age, diagnoses and any sensory difficulties

- services involved

- topography and frequencies of challenging behaviour experienced

- ratings of how stressful the behaviours are to manage

- carer's confidence levels in managing the challenging behaviour

- carer's rating of how problematic the behaviours are to their family

- current intervention strategies

- whether physical intervention training had been accessed before

2. Aberrant Behaviour Checklist (Aman and Singh, 1994): pre-course rating

3. Individual session evaluation forms, which included:

- rating of how helpful the session had been

- most/least helpful elements of the session

4. Aberrant Behaviour Checklist: post-course rating

5. A post-course questionnaire, completed four weeks after the course, which included:

- frequencies of challenging behaviour

- ratings of how stressful the behaviours are to manage

- carer's confidence levels in managing the challenging behaviour

- carer's rating of how problematic the behaviours are to their family

- frequency of use of physical interventions

- current intervention strategies

- whether the training had been felt to be relevant to their needs

Analysis

As only six of the ten participants returned fully completed data sets, all questionnaire feedback was predominantly analysed using descriptive statistics. Any qualitative feedback provided by the participants is expressed in direct quotes.

Results

The following results are based on the information provided on the five measures described above. Not all items were completed by the participants (and indeed they were told they did not have to supply information if they did not want to). All analyses are therefore based on the data that was provided in three areas of feedback:

- Carer ratings of the challenging behaviours

- Aberrant Behaviour Checklist ratings

- Qualitative feedback

Carer ratings of the difficult behaviours

The participants were asked to rate (using a five-point Likert scale from 'never' to 'daily') how frequently different challenging behaviours occurred over a four-week period, both prior to and four weeks after the end of the course. Only four of the participants returned a complete data set for this section, with changes in their rating for each behaviour shown in *Figure 1* below.

Figure 1: Frequency change in challenging behaviour categories before and after the workshops
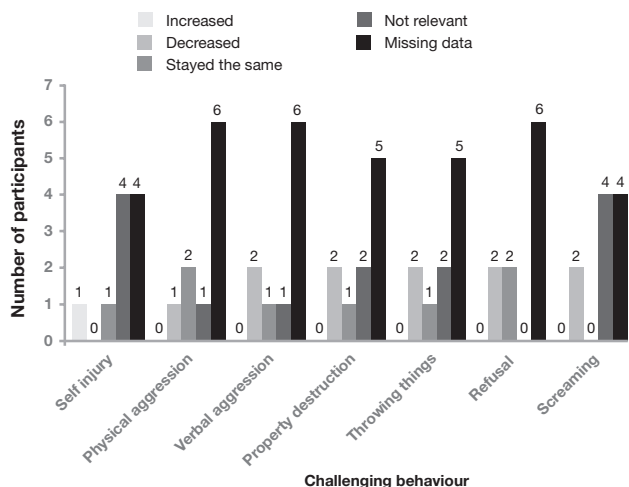
Overall the ratings of the frequency of the challenging behaviours indicated that they had either decreased or maintained the same frequency, with the exception of one rating of self-injury, rated as having increased in frequency.

Figure 2 highlights change in the participants' pre and post ratings on:

- the carer's confidence in dealing with the behaviours
- the stress the difficult behaviours cause them when they occur
- how problematic the behaviours are when they occur

Figure 2: Change in carer perceptions of confidence, stress and problematic nature of managing the challenging behaviours
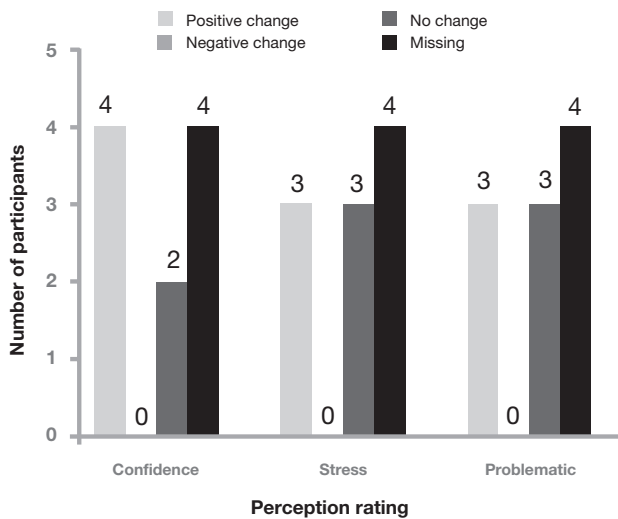

Figure 2 shows that for those who returned data:

- 4 of the 6 participants felt more confident in managing the challenging behaviour
- half of the respondents felt the amount of stress the challenging behaviour caused them had decreased, with the other half reporting no change
- half of the respondents felt the challenging behaviour was less problematic to them as a family when it occurred, with the other half reporting no change
- there were no reports of participants feeling less confident, more stressed or finding the behaviour increasingly problematic.

Aberrant Behaviour Checklist (ABC)

Of the ten participants, 6 people provided pre and post data on the ABC questionnaire. *Figure 3* highlights the total pre and post scores, while *Figure 4* shows changes in the number of behaviours that were rated as a '3', the highest rating possible, indicating a behaviour that is having a severe impact on the person's functioning. Blank fields indicate missing data.

Figure 3: Changes in the total score obtained from the Aberrant Behaviour Checklist before and after the workshops
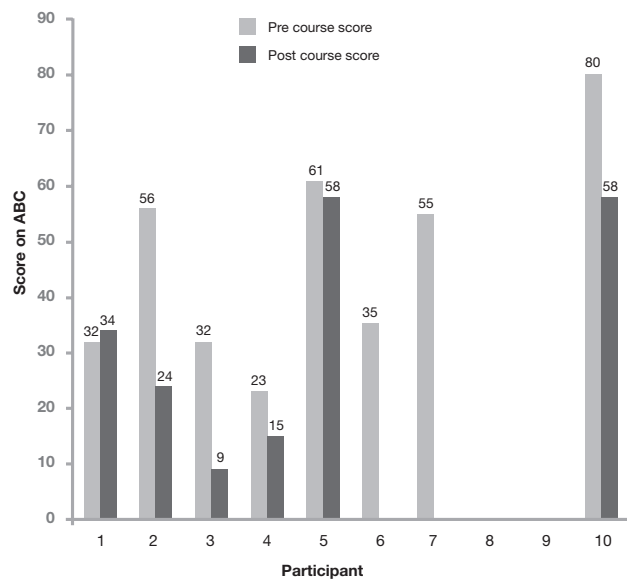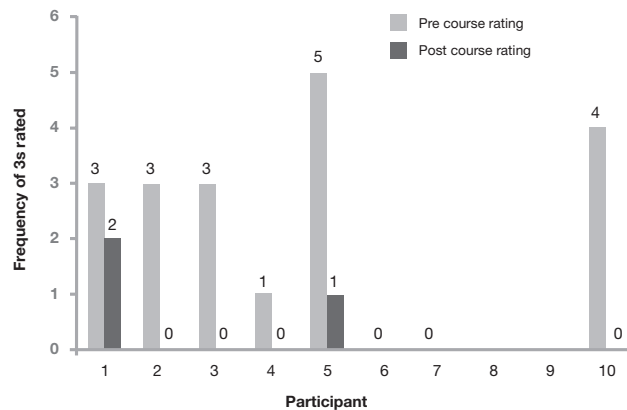

Figure 4: Changes in the frequency of a rating of '3' (severely problematic) obtained from the Aberrant Behaviour Checklist before and after the workshops

Figures 3 and 4 highlight predominantly positive change in the ratings of impact of the difficult behaviours for each of the participants for whom data was provided. Five of the six participants who provided pre and post data reported a decrease in their ratings of the problematic behaviours and their impact on their son's/daughter's functioning over the duration of the course, with one reporting a very small increase. All six respondents reported a decrease in the number of behaviours rated as 'severely problematic', suggesting that even when they did still occur, they were now perceived as being less stressful in their impact.

Wilcoxon signed rank tests were performed on the two sets of data described in *Figures 3 and 4* for the six complete data sets.

1. Total ABC score: The Wilcoxon signed rank test showed there was a significant difference between the pre and post test scores with the post test scores being lower ($T=1$, $P<0.05$, 1 tailed).

2. Rating of behaviour as 'severely impactful': The Wilcoxon signed rank test showed there was a non-significant difference between the pre and post test scores with the post test scores being lower ($T=0$, $P=0.025$, 1 tailed).

The significant difference between the total ABC scores suggests a positive effect of the workshops on decreasing the impact of the challenging behaviours. The lack of statistical significance in the test for severity ratings may be due to the very small number of participants in the evaluation.

Though there may have been other factors occurring outside of the workshops that influenced these findings (eg clinical input from the local learning disability teams) the relatively short period of time between ratings (approximately 8 weeks) and the fact that all of the participants reported some positive changes, suggests the course may have been at least one of the factors responsible for this change. It is of course noteworthy that some participants chose not to provide post-course data, and it could be hypothesised that a lack of change in outcome might be one of the reasons for this.

Qualitative feedback

Participants were given the opportunity on the pre and post course questionnaires to provide more detailed, qualitative feedback about their experiences of the course. When asked what the most helpful parts of the workshops were, participants reported:

- 'The taught material and developing the passport'

- 'Analysing the specific behaviours my son suffers from'

- 'Very valuable session, very relevant, it should have been offered years ago'

The final point was one that was raised by several of the attendees, who felt that the material would have had greater impact on the trajectory of the difficult behaviours and their coping resources as a family had they received this form of training at an earlier stage. It should be noted that the sons/daughters of the participants were all young adults.

The attentees also highlighted the benefits of learning alongside and from other parents:

- 'Interacting with others in the group'

- 'Sharing my experiences with others in the group'

- 'Learning from other parents'

Others also found the environmental set-up of the course helpful:

- 'Relaxed atmosphere – friendly but professional'

Participants were also asked what they would change about the course. One attendee felt that there was 'too much diversity between other attendee's children', relating this to level of intellectual disability and associated communication and adaptive functioning skills. One father, discussing the 'what helps' module commented that 'most of it was not relevant' to his daughter, although he did cite that he felt the session on communication aids would be helpful. This perhaps relates to the issue of the range of communication skills that were seen within the families' sons/daughters and the difficulties in 'pitching' intervention ideas that were at a helpful level for the majority of the attendees. This was an issue raised by both groups and suggests that workshops may be more helpful if they are tailored towards the degree of intellectual disability of the focal person with perhaps two different groups – those supporting people with more mild and those who have more significant impairments.

Some people requested increased workshop time or sessions, for example 'it would be great to go into more depth and have more time', although feedback from others was that the workshops' length (3 hours) sometimes meant there was more information than they could

comfortably concentrate on. This may be an expression of personal preference. Others also commented that it would have been helpful to have been able to bring their partners to the course but the day-time timings meant this would not be possible. Evening and/or weekend workshops were requested by several of the participants. There were also concerns raised that one of the workshop venues required participants to pay to park and it was felt this could have deterred some families from attending.

Discussion

Implications of the findings

Overall the results of this pilot study are encouraging. The families who attended reported predominantly positive changes in a reduction in challenging behaviour as demonstrated by the pre and post ABC scores. Half of the respondents also reported a positive change in their subjective experiences of the challenging behaviours they were managing at home (including in their levels of reported stress and confidence in managing the behaviours).

These findings suggest that the format of support may well be appropriate and acceptable to these families in terms of tackling the difficult behaviours. They reported positive experiences in learning from each other and, in one group, many of the members had made plans to meet again once the course finished. Facilitating the course jointly with the local Carers Support Services may also help to keep families 'linked in' with each other, allowing this peer support to continue.

This study suggests that, with some amendments, these workshops could provide an effective way of providing clinical support to those families who have an adult son/daughter with intellectual disabilities who engages in difficult behaviours.

Critique of the study

As a support provision that took place within a busy community service, the use of a group intervention has demonstrated that for many people, individualised input (which is likely to have taken many more hours of direct clinical input) need not be required in all cases. However, because the course was self-selecting, it may be that those who attended the course were not fully representative of parents supporting a son or daughter with an intellectual disability. For example, it may be that those families dealing with especially high levels

and/or particularly problematic behaviours may already have been receiving more individualised support and so may have felt their attendance at the course was not appropriate or necessary. Given the pilot nature of the course and the relatively small numbers of attendees, this factor was difficult to evaluate and further work on the limitations and/or usefulness of a group setting may be needed.

The extremely small n of this study has implications for the robustness of the data collected. Additionally, the voluntary nature of participation and the reliance on questionnaire methods resulted in some missing data. Furthermore, resources only allowed a short follow-up period leaving questions regarding long-term sustainability unanswered.

Due to the reliance on questionnaire methods of data collection, with only very brief opportunities for parents to give more in-depth, individualised feedback, it is also possible that there were other viewpoints or experiences that were not captured. Wodehouse and McGill's (2009) study demonstrated that parents do not always receive the type or level of support that they would like, and cited factors such as 'professionals unable to provide effective interventions', 'parental disagreement with suggestions' and 'difficulties implementing strategies due to obstacles within family life or need for practical assistance' (p 648). These could all have been factors experienced by the participants that may not have been identified due to the relatively brief nature of the audit, the questionnaire design and also the short follow-up time frame. These areas all warrant further and more in-depth investigation to consider whether these potentially detrimental factors were adequately addressed by the format of the training provided.

Wodehouse and McGill also highlighted several areas of service provision that families felt were important that were not addressed within these workshops. These included problems in sourcing respite provision and managing exclusions from school/respite. The latter issue was attempted to be partially addressed through the development of the Behaviour Passports, which were designed to share the formulation and intervention ideas developed throughout the course with other parties working with the named individual. However, it is possible that greater co-working or information sharing with the care managers for each of the discussed individuals may have helped to inform a more coherent intervention for the family as a whole.

Future uses

Despite the limitations described above, there appears to be sufficient evidence from this pilot study that these PBS workshops for families warrant further exploration and use. As an intervention provided solely from a specialist challenging behaviour service, there may also be scope for considering whether it could also be offered to, or provided by, more generic local intellectual disability services, many of whom are also likely to be supporting individuals who present with challenging behaviours. It is vital that any further developments of this initiative are genuinely 'family friendly' – making adjustments in timing, getting input from families about what they would find useful and thinking about a co-production approach.

The workshops were provided within an adult intellectual disabilities setting but it is possible that a greater degree of support to families when their son/daughter is younger may have a greater impact on the long-term development of the difficult behaviour. It therefore seems pertinent that the workshops be considered for use with those accessing local children's services and indeed there are discussions underway locally for how the workshops could be adapted for a team supporting families with children with intellectual disabilities.

Acknowledgements

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