Providing training in positive behavioural support and physical interventions for parents of children with autism and related behavioural difficulties

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Abstract

Though professionals working with children on the autism spectrum who display challenging behaviour routinely receive training in the use of both positive behavioural support techniques and physical interventions, such training is rarely provided for the parents of these children. This paper reports on the impact of training provided for family members associated with 8 children aged 7-11 years who were associated with the same special school. Participants were surveyed before and after training, and at a 12-week follow-up session. Data were triangulated by interviewing staff providing and supporting the training. The results suggest that attending the training increased parents' confidence in understanding and managing the child's behaviour, and reduced the use of physical interventions. Positive factors associated with parent training are discussed, as well as challenges to its provision, and the cost and potential impact of providing training is compared with other models of support. Limitations of the study and areas for further research are identified.

Keywords: parents, parent training, challenging behaviour, physical interventions.

Introduction

Challenging behaviour, autism and family life

Living with children on the autism spectrum, and in particular with children who display challenging behaviour, can impact significantly upon parental stress, family cohesion and the quality of life of mothers, fathers and siblings alike (Evans *et al.*, 2001; Hastings, 2002, 2004). Furthermore, failure to effectively manage behaviours can lead to negative long term outcomes for the child, restricting opportunities for inclusion, and sometimes requiring placement outside the family (Allen *et al*., 2007; McGill *et al.,* 2005). Such families often seek external support to help deal with their situations; however their experience may lead to dissatisfaction with that help. The presence of challenging behaviour can significantly limit access to positive relationships with schools and professionals (Visser & Cole, 2003), and can limit access to social care support such as short breaks (respite care) (Cramer & Carlin, 2008). Almost half of the 66 family carers who participated in McGill *et al*.'s (2005) study reported receiving no support, or none that was useful. The presence of challenging behaviour, and family dissatisfaction with support, may continue as the child becomes an adult (Hatton *et al*., 2010); and difficulties accessing appropriate services and are heightened in the presence of conditions such as Asperger Syndrome (Preece & Jordan, 2007) or attention deficit-hyperactivity disorder (ADHD) (National Collaborating Centre for Mental Health (NCCMH), 2008).

Managing and responding to challenging behaviour

Positive behavioural support

Over the past three decades, a range of techniques identified under the umbrella term of *positive behavioural support* (PBS) have been developed to support socially adaptive and appropriate behaviour. PBS refers to a unified, holistic and non-aversive approach that includes both *proactive* strategies to change unwanted behaviour in the long term and *reactive* strategies to manage such behaviour when it occurs (Allen, 2009; Johnston *et al*., 2006). The approach is ethically-based: its focus is to enable individuals who display challenging behaviour to be able to participate in society, to be able to make choices and to have a greater sense of personal competence and self-efficacy. Typically, PBS interventions are based

upon applied behavioural analysis and consider adaptation of ecological conditions that increase the likelihood of challenging behaviour (e.g. environmental, social, in-person and curriculum/programme factors); identification of triggers associated with challenging behaviour; individual needs and communication style; the use of differential and non-contingent reinforcement; and the teaching of new, socially adaptive strategies to develop the individual's social skills. Examples of the integration of these elements into a cohesive strategy to help individuals on the autism spectrum manage their behaviour can be found in e.g. Clements (2005) and Whitaker (2001).

Crisis intervention

As part of this approach, and to protect individuals and manage dangerous incidents at the time they occur, crisis intervention may be necessary. Therefore PBS programmes also include ethical reactive strategies that can be employed if and when incidents of challenging behaviour occur. These range from de-escalation and distraction to evasion and minimal restraint techniques. While it is clearly recognised as desirable that restraint is used as little as possible, it is acknowledged that the behavioural challenges presented by some individuals are such that physical intervention in some form is both appropriate and necessary (Jefferson, 2009). The British Institute of Learning Disabilities (BILD) developed a policy framework for the use of physical interventions – now in its third edition (BILD, 2010) – which sets the government-accepted benchmark for good practice and underpins the use of such interventions in schools and care settings across the UK.

Crisis intervention covers a spectrum of methods, ranging from the use of de-escalation to physical interventions – strategies used to respond to challenging behaviour, where direct physical force is used to minimise the impact of the behaviour and to prevent injury (Allen, 2011, Harris *et al*., 2008). These strategies include self-protective 'breakaway' techniques as well as the use of direct physical contact, using minimal force without causing pain to limit the movement of an individual presenting challenging behaviour.

Provision of training

Staff working in educational, nursing or social care settings with children on the autism spectrum who display such behaviour must be trained in appropriate and approved methods of undertaking physical interventions (Department for Education (DfE), 2011a; Department for Education and Skills (DfES)/Department of Health (DoH), 2002). These must be taught alongside proactive positive strategies for supporting appropriate behaviour: these include understanding the functions of behaviour, maximizing communication opportunities, developing adaptive interactions and de-escalating situations before behaviours occur (Allen, 2009; Koegel *et al*. 1996; Whitaker, 2001).

Training provided within such settings must be accredited by the British Institute of Learning Disabilities (BILD), and must comply both with governmental guidance (DfES/DoH, 2002) and with BILD's most current code of practice (BILD, 2010). Over thirty training providers – including local authorities, NHS trusts and private companies – are accredited within the UK. All interventions taught must have been risk-assessed, and all training must provide information about the legal framework within which such interventions can be undertaken. Providing effective training in managing challenging behaviour, including how to undertake physical interventions, has been shown to reduce the number of work-related injuries sustained by staff (Sanders, 2009) and the overall level of physical intervention and restraint (Luiselli, 2009; Richmond, 2010). Furthermore Mills and Rose (2011) suggest that helping staff to understand and perceive challenging behaviour more confidently can reduce burnout.

Despite the clear and significant benefits to staff of accessing such training, Allen *et al.* (2006) report that parents are often left to fend for themselves. Parental access to training in the use of physical interventions appears particularly problematic due to legal concerns about vicarious liability, concerns about the monitoring and control interventions, and fears of abusive practice (Allen *et al.* 2006; Shinnick & McConnell, 2003; Woodcock *et al.* 2006). However, whilst acknowledging these concerns, the fact remains that parents are facing challenging behaviour at home, and having to manage similar behaviours to those

presented at school. The absence of training may increase the likelihood of the use of disproportionate force or inappropriate management techniques.

Rationale for the training

Difficulties in parents accessing training existed within the UK local authority within which this research was undertaken, and in which I was working as a manager at the time. In 2008, consultation carried out as under the *Aiming High for Disabled Children* initiative (HM Treasury/DfES, 2007) highlighted that parents in the area considered training in physical interventions as a key need. Requests for such training from the parents of children on the autism spectrum – or complaints about the lack of such training – were regularly voiced through the local authority's complaints procedure, at children and families' service reviews, and via local parents' organisations.

The local authority and National Health Service in this area provided or commissioned a range of services supporting parents to manage their children's behaviour via positive behavioural approaches. These included family advisory workers, community nurses, Child and Adolescent Mental Health Services and a specialist sleep service. Parent education in understanding and managing challenging behaviour was provided by educational psychologists, teachers, nurses and social care staff. However, none of this training in positive approaches was supported by input regarding the use of physical interventions. No training in physical interventions had ever been provided to family members.

Fear of vicarious liability was a key barrier to providing such training – concern about the legal position if a parent injured or abused a child after training. However the literature has shown that this need not be an insurmountable problem (Green & Wray, 1999; Shinnick & McDonnell, 2003). The local authority used a single private company as its preferred provider with regard to training in physical interventions, and this company's approach was used within all schools and most children's homes within the area. Discussing insurance and liability issues with the training company and the local authority's insurance department identified that many fears voiced by professionals within the authority were unsubstantiated. The

insurance position was agreed as sufficiently robust for the provision of parent training including physical interventions under the aegis of the local authority to be feasible. Furthermore the company could provide trainers specifically licensed to deliver training to families, and who had delivered such training elsewhere.

In my then role as a local authority manager, I was able to allocate *Aiming High* funding to provide and evaluate a training course in physical interventions and positive behavioural support for a group of parents whose children regularly presented challenging behaviour at home. This service evaluation sought to identify whether the training had any impact on parents' confidence in understanding and managing their child's behaviour and on the use of physical intervention at home. The costs of providing the training were identified, to allow this intervention model to be compared with other services provided for families of children on the autism spectrum who displayed challenging behaviour, such as short breaks (respite care) and residential school placements.

Method

Setting and trainers

The parent training event was led by an external trainer, licenced to train parents, from the local authority's preferred training provider. In addition, the provider's model required a second, local accredited trainer – associated with the families – to provide ongoing support and follow-up. A primary special school was identified where the head teacher (an accredited trainer) was willing both to be the local trainer and to allow the school to be the training venue.

Participants

A number of parents associated with this school had requested training and support from the local authority with regard to challenging behaviour. Participants were purposively selected on the basis of:

- training having been requested from the school or local authority
- physical interventions being used frequently at home
- similarity of child characteristics (age, diagnosis, behaviours presented)
- and their willingness to participate in the service evaluation process.

Selection was undertaken by the head teacher and a local specialist autism practitioner – not the author – who also observed the training.

Eleven adults were trained, associated with eight children. Seven of the children were current students at the school; the eighth had left the previous summer. With regard to three children, two parents/carers attended the training; in the other five cases, one parent attended. Six participants from four of the eight families attended the follow-up session in October (one parent was unable to attend due to health problems; the invitation to another family was lost in the post).

The children (all boys) were aged between 7.3 years and 11.9 years (average age = 9.7 years, SD = 1.3 years). Seven had diagnoses on the autism spectrum: five were diagnosed with Autistic Spectrum Disorder (ASD), one with ASD/ADHD, and one with Pathological Demand Avoidance Syndrome (PDA) (Newson *et al.* 2003). The eighth child was diagnosed with ADHD. They were described by their parents before the training as '*aggressive*', '*argumentative*', '*threatening*' and '*challenging*'.

Training model

The training model was one of twelve hours initial training, followed by a twelve week period during which participants were required to record all situations requiring behavioural support in an 'intervention diary'. After twelve weeks, a follow-up session was held with the local trainer. A maximum of twelve adults could be trained at one time. This model was prescribed by the training provider. Two six-hour training sessions were held in July 2011, with a follow-up session in October 2011. The period between training and follow-up therefore included the six week summer holiday and the transition back to school in September, both of which can be stressors for children on the autism spectrum and their families (Stoner *et al*., 2007).

Content of training

The training model was a mix of lectures, group discussion and physical activities. The content comprised:

- positive behavioural components, such as conceptualising and understanding 'challenging behaviour', understanding emotions and behaviour, communication and de-escalation.

- legal implications regarding rights, responsibilities and the use of physical interventions

- a small number of physical interventions. These covered a range of situations that could happen within the family home and community, where parents may need to intervene to keep the child, siblings, others or themselves safe. Parents were taught how to respond to biting and hair-pulling; how to separate fights; safe holding, wrapping or escorting (with one and/or two adults); and how to safely disengage from holds to the arm, neck and body. Parents were given multiple opportunities to practice these interventions over the two days, and were required to demonstrate proficiency in their use.

Data collection

Questionnaire

Participants were surveyed immediately before and after the training event with regard to their confidence in dealing with situations where their children exhibit challenging behaviour, and again after the twelve week follow-up session using brief self-completion questionnaires developed by the researcher. The pre-training questionnaire gathered data concerning the child and family (child's age, sex and diagnosis; family composition); frequency of physical intervention; parental confidence; and expectations regarding the training. The post-training questionnaire gathered data regarding parental confidence and their immediate responses to having done the training. The follow-up questionnaire surveyed parental confidence, attitudes to the training and future training needs.

Ten participants completed the pre-training questionnaire (due to problems with school transport, one parent arrived after the training had begun). All eleven completed the immediate post training questionnaire. Follow-up questionnaires

were completed by the six participants, associated with four of the eight children, who attended the follow-up session. Participants were also requested to maintain an 'intervention log' between the training and the follow-up session – recording details (e.g. type, duration, effectiveness) of interventions that they carried out during this period – to be discussed at follow-up, and to be shared with the author.

Interview

Further data were collected via semi-structured interviews with the local trainer and the specialist autism practitioner immediately after the training, and again with the local trainer after the twelve week follow-up session. These interviews focused on the process of the sessions, the interaction between the trainers and the participants, and the ongoing relationship between the participants and the school. The author was also provided with the training company's evaluation summary and with details of all costs associated with the training.

Ethical issues

Permission for the evaluation study to be undertaken was given by the local authority, which also funded the training. The identities of the families involved in the study remained unknown to the author. Questionnaire distribution and collection was undertaken by the local trainer. Questionnaires were anonymous, identified only by a unique reference number. Parents/carers and local authority staff were aware that they were participating in an evaluative study which may be published, and informed consent was obtained in all cases.

Findings

Parental confidence and understanding

A four-point Likert scale was used to measure participants' confidence in managing and attitudes towards their children's behaviour (1 indicating low confidence up to 4 indicating high confidence). The aggregated results are shown in Table 1. The attrition to the sample between the training (n=11) and the follow-up (n=6) is acknowledged: however comparison of data from those who attended the follow-

up and those who did not identifies a high level of agreement between the two groups' pre- and post-test responses.

TABLE 1 HERE

The data identifies that participants' confidence increased in all areas surveyed immediately after the training. Over the following three months, confidence continued to increase in two areas – confidence in managing the child's behaviour and keeping their family safe - while decreasing slightly with regard to understanding and predicting the child's behaviour, and regarding physical intervention. Nonetheless participants remained more confident in all areas than they were before undertaking the training, and noteworthy improvements in confidence from pre-training to follow-up (≥1.0) were achieved in three areas:

- confidence in physically intervening
- confidence in managing situations without physical intervention
- confidence they can keep their child, family and themselves safe.

Use of physical intervention
Before undertaking the training, physical intervention was frequent in all of these families (see Table 2).Children were restrained multiple times per week, without their parents having received any guidance regarding either safe handling techniques or any alternative management strategies.

TABLE 2 HERE
At the follow-up session, it was identified that none of the families attending (four of the eight families) had used any physical interventions between July and October. Whereas previously physical interventions had been required in two of these families on a daily basis, and in the other two several times per week, all four had managed their children's behaviours through the school holiday and the first weeks of the new term by using alternative management techniques, including communicating more effectively and de-escalation.

Thematic analysis of the participants' responses to open questions in the questionnaires and the interviews with professionals identified a number of key themes regarding the training. These are discussed below.

Positive factors associated with the training

Three aspects of the training were identified by parents and professionals as being particularly positive.

Conceptualizing challenging behaviour

The session regarding conceptualising challenging behaviour, and the extended discussion that took place on this topic, was considered crucial. Parents identified that this helped them to understand the impact of their own behaviour and responses upon their child's behaviour. They reported that they became more tolerant as a result of this training, and were more aware of the importance of managing and regulating their own – as well as their children's – behaviour. One mother wrote at the follow-up session that '*I now know when…to remove myself or my child*', while a father identified that the training "*had definitely helped me keep my reactions under control. I have a calmer mind and a longer fuse*'.

Positive behavioural techniques

Secondly, the importance of learning positive behavioural techniques was stressed by all concerned. Learning how to employ low arousal approaches, how to provide appropriate communication opportunities and how to use de-escalation techniques was identified as helpful, enabling parents to manage situations effectively before the need for physical intervention was reached.

"*It helped us to understand what we were doing and to be in the right mind set. It gave me confidence and concrete strategies to use.*"

Training in physical interventions

Thirdly, it was identified that parents – like staff – need training both in positive behaviour management strategies and in the use of physical interventions. Adams and Allen (2001) identify that physical interventions are only one component of effective intervention plans for children with challenging behaviour, and should be

considered as part of an overall strategy to meeting their needs. Parents and professionals agreed that teaching both the positive approaches and how to safely physically intervene made the training more effective. Knowing that they had the skills to intervene if necessary empowered the parents to work on identifying the functions of behaviour and improving communication, developing their 'toolbox of strategies' for working with their children (Charman *et al.,* 2011).

Need for bespoke parent training

It was felt that training parents on courses designed for staff would not have met their needs. There were often only one or two adults in the home, whereas staff worked in teams, and interventions could be supported by staff from other classrooms if necessary. Furthermore training provided to parents needs to take account of issues regarding the scale, layout of rooms, furniture, and room contents in domestic settings. Such training should include information about the use of physical structure in regulating behaviour (Mesibov *et al.,* 2005), and auditing the physical environment.

> *"I think we should have a home visit with this, to ensure that the training is tailored to our homes and that we know how to keep people safe, what rooms to use, etc."*

Association with setting and ongoing support

It was considered important that all the participants were associated with the school, and that the children's needs were broadly similar. Association with the school allowed children's class teachers to informally support families throughout the school week and to reinforce the key messages of the training. Providing parents and school staff with training in the same model of understanding challenging behaviour gave families and professionals a shared contextual framework and a common language, which promoted greater consistency for the children. Parents and the local trainer identified this as important: participants felt

the training would be ineffective if it comprised "*only the one session with no back-up support*", while the trainer identified that '*the families needed access to ongoing support, particularly to highlight and discuss other issues related to their children's behaviour, apart from restraint.*'

Despite the benefits they felt they had gained, parents still believed the professionals who worked with their children had more expertise, greater understanding, and better ongoing support regarding behaviour management. One mother wrote, '*I still feel that staff know more than me and can handle my child better than me. This is disempowering!*' Further training, either through annual refresher sessions or as and when their children's behaviour changed (e.g. at puberty) was considered essential.

Discussion

This was a very small scale evaluation study: nonetheless parental responses indicate the training had value and it seems that providing it had, for some participants at least, a sustained impact which brought about real change, increasing their confidence in understanding and managing their child's behaviour. After the training, at least half of the families were enabled to negotiate daily life during the subsequent twelve weeks without recourse to physical restraint. This supports the findings of studies concerning the training of professionals, which suggest that providing appropriate training can increase confidence and reduce burnout and the perceived level of challenging behaviour experienced (McDonnell *et al.*, 2008; Mills & Rose, 2011).

It was disappointing that not all families attended the follow-up session and completed the questionnaires as this would have strengthened the findings – and though the decision to ask parents to complete the questionnaires at the sessions was made to maximise responses, this was a weakness in the research design. The reasons for two families' non-attendance at the follow-up have been identified above. It would be interesting to know the reasons regarding the other two. It may be that they did not find the training helpful; or perhaps having had their needs met, they felt no need to continue to engage with the research process. The interview with the head teacher identified that all eight families maintained contact

with the school on an ongoing basis, discussing behavioural issues and seeking support, and that no families had disengaged entirely from the process.

The cost of this training as a one-off event was £3,600, including payments to the training provider, venue hire (school hall and break-out room), food, refreshments and replacement costs. This gives a unit cost per parent of £327. This compares favourably with the costs of other types of support. Since April 2011, local authorities have had a statutory duty to provide short breaks (respite care) to families of children with disabilities (DfE, 2011b). Overnight short breaks (respite care) for children on the autism spectrum cost local authorities approximately £150 per night in specialist foster services, and from £190 to over £1,000 per night in residential services (London Borough of Bromley, 2012; Manchester City Council, 2012). Placements in specialist residential schools can cost £150,000 per year or more (British Broadcasting Corporation (BBC), 2013). Support for children on the autism spectrum costs more than for children with other disabilities, or for children in need in general, particularly where they have additional behavioural needs (Bebbington & Beecham, 2007);and Knapp *et al*. (2007) identified the total economic cost of supporting children on the autism spectrum in the UK as £2.7 billion per year. Most of this cost falls on local authorities.

The argument is well made that short breaks are preventive services (DfE, 2011b), reducing the need for permanent out-of-family placements (Chan & Sigafoos, 2001; PriceWaterhouseCoopers, 2007). However while short breaks provide respite from the burdens of caring, they do not by themselves improve parents' abilities to manage their children's behaviour. By comparison, effective parent education and training has been shown to improve parental self-efficacy, reduce dependence and improve the family's experience of daily life (Dale, 1996; Preece & Almond, 2008). Providing the families of children on the autism spectrum who exhibit challenging behaviour with effective training in positive behaviour support and physical interventions might satisfy a largely unmet need, and could be an important element within a preventive, proactive strategy. The costs of providing parent training compares very favourably to those of short breaks and residential

education, and, if effective, such training may potentially reduce demand for other more costly services. Further research is needed to investigate these issues.

The parent training discussed here took place between July and October 2011. Since that time, significant changes have occurred and are continuing to occur within the worlds of local government and education. In part these are driven by the impact of the national government's austerity measures, and their impact upon local government spending; in part they are driven by legislation and educational policy, such as the *Academies Act* (2010) and *Support and Aspiration: Next Steps* (DfE, 2012). The additional finances made available under the *Aiming High for Disabled Children* initiative have dwindled, and local authorities are faced with significant spending cuts; their funds are being targeted at statutory duties and responsibilities, rather than discretionary 'optional extras'. Increasing numbers of schools are now or are becoming academies, with increasing autonomy, responsibility, choice and financial independence. All of this makes the development and provision of training such as this more challenging than it would have been previously.

Nevertheless, this study suggests that such training can be beneficial to families and children. The study has clear limitations of size, and no claims of generalizability are made beyond the cohort of parents who attended the course. Further studies in this field would be beneficial to identify whether similar findings are identified across other cohorts of parents; and whether stronger claims regarding outcomes for children and families, as well as potential benefits to the public purse might be appropriate.

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Table 1   Impact of training on parental confidence

Statement	Pre-training (n=10)	Post-training (n=11)	3 month follow-up (n=6)	Change – pre- to post-training	Change - post-training to follow-up	Overall change – pre-training to follow-up
I can predict when my child's behaviour will become difficult	2.7	3.3	3.0	+0.6	-0.3	+0.3
I understand my child's behaviour	2.8	3.45	3.3	+0.65	-0.2	+0.5
I feel confident that I can manage my child's behaviour	2.8	3.45	3.5	+0.65	+0.5	+0.7
I feel confident when I have to physically intervene with my child	2.3	3.5	3.3	+1.25	-0.2	+1.0
I can manage situations so that I		3.7	3.5			

do not have to physically intervene with my child	2.4			+1.3	-0.2	+1.1
I feel confident that I can keep my child, my family and myself safe	2.5	3.45	3.8	+0.95	+0.4	+1.3

Table 2   Frequency of use of physical intervention pre-training

Frequency	Families
Several times per day	3
About once per day	1
2-3 times per week	4
Total	**8**