Positive behaviour support for a child with severe learning disability

A strategy based on functional assessment of behaviour has improved the life of one patient and his family's understanding of his condition, say Tandy Palmes and Penelope Millington

Abstract

This case study describes the implementation of positive behaviour support by a learning disability child and adolescent mental health team. Care was planned and carried out in the family setting for a young child with severe learning disability and self-injurious behaviour, after a full assessment. The parents' perspectives are included, and the theory and evidence base are considered. The outcomes of the interventions are evaluated as positive and sustainable.

Keywords

Positive behaviour support, child mental health service, learning disability

CHANGING IDENTIFIED triggers of problems that affect children with a learning disability can challenge all those involved in their care. However, implementation of positive behaviour support (PBS) - a strategy based on functional assessment of behaviour - can help solve these difficulties and teach new skills. Quality of life (QoL) is used as an intervention method as well as an outcome measure (Allen et al 2005), focusing on developing individual goals to improve a person's behaviour, enhancing QoL and maintaining change (Horner 1994).

Allen et al (2005) commented that PBS reflects principles of applied behaviour analysis but that it has been developed into a more sophisticated approach. The PBS approach recognises that there is a need for 'proactive and reactive interventions because, even with the most effective plan, risk behaviours may not be eradicated totally from a person's repertoire' (Allen et al 2005).

The emphasis of PBS on non-aversive intervention and QoL outcomes makes it more 'socially valid' than aversive methods. For an intervention to be socially valid it should 'address socially significant problems, be carried out in a manner that is acceptable to the main constituencies involved and result in socially important outcomes or effects' (Emerson 2001). Three areas need to be considered when looking at validating behavioural work socially:

- Are the goals socially significant?
- Are the interventions you are asking stakeholders to carry out socially appropriate?
- Are the stakeholders satisfied with the outcomes?

Allen et al (2005) propose that PBS is the most socially acceptable and effective measure that services can offer to people with a learning disability who exhibit challenging behaviour.

Modern learning disability philosophies favour person-centred plans, where services support the client's goals rather than limit the goals to meet service needs (Department of Health 2001), and it is important that all opportunities in a person's life are available, such as being able to go to the dentist or to the cinema (Beadle-Brown 2006).

Lucyshyn et al (2002) define PBS as 'a collaborative, assessment-based approach to developing effective, individualised interventions ... emphasising the use of proactive, educative and reinforcement-based strategies to achieve meaningful and durable behaviour and lifestyle outcomes ... both child- and family-centred'.

The work of the learning disability child and adolescent mental health service (LD-CAMHS) of Cheshire and Wirral Partnership NHS Foundation Trust is with children who have a severe learning disability and their families. The service's objectives include making long-term changes to children's
behaviour that improve their community access and presence. Plans are child- and family-centred; the goals are theirs, not those of allied services, and are always in the best interests of the family and child.

Case study
A referral was made by Adam’s (pseudonym) mother via the LD-CAMHS drop-in advice service at the local special education school, which he attended. At the time he was six years old. His mother attended the advice session because she was concerned about her son biting his hand. At his point initial behaviour advice was given, but at the next session the mother said that the difficulty had not improved, so a referral to the team was made. Subsequently there was discussion with the family about taking the PBS approach to improve Adam’s QoL and, in the process, reduce the difficult behaviour.

Adam has a unique chromosome abnormality that influences his genetic condition, medical condition and behaviour. As a result of his genetic condition, he has a global developmental delay and failure to thrive. He is small for his age and putting on little weight since he was about three years old. His weight is static, around 12kg, and his growth has been minimal. He is the younger of two children and goes to school, which he loves. He particularly enjoys swimming, music therapy and intensive interaction, such as a carer following Adam’s lead in vocalisation, tapping and body language.

His mother reported: ‘I initially approached the LD-CAMHS team through advice we were holding at Adam’s school following the advice of the paediatrician. The initial contact was to discuss Adam persistently biting his own hand, which they were worried may at some stage become infected as he had created a sore.

‘Within a few weeks, Adam was taken on [as a case by the team] because of his difficult behaviour, which began to escalate over a period of months. Assessment showed that Adam’s behaviour became multifunctional – for example, he hits himself if he is unhappy, if he is excited, if he is in pain or if he wants attention. Adam is unable to communicate verbally and this was his only form of letting the outside world know how he was feeling.’

Identifying goals
Adam’s medical history includes cardiac problems, gastric reflux, allergies and food intolerances. Law (2011) suggests that the collection of information on goals and QoL should be completed at the start of an intervention and again after six months. Goal-based outcomes were used in the assessment to identify the goals that the family wished to achieve.

Adam’s assessment included the use of the Contextual Assessment Interview (McAtee 2004), the Motivational Assessment Scale (Durand 1990) and the Functional Assessment Interview (O’Neill et al 1997).

O’Neill et al (1997) discuss how behaviours can often be confusing, causing distress to the family members, teachers and carers, as well as to the young person. These authors go on to state that ‘a good functional assessment is to bring clarity and understanding to an otherwise chaotic and confusing situation’, engaging all concerned. Functional assessment, as in Adam’s case, is described as having five primary outcomes: description, predictors, consequences of behaviours identified, summary statement, and direct observation data collection.

O’Neill et al (1997) identify three approaches to obtaining these primary outcomes:

- Reports from informants.
- Direct observation.
- Functional analysis manipulation.

From the functional assessment of Adam, four behaviours were identified: hand biting, causing tissue damage; elbow bashing, bruising the joint; face bashing with his right fist on to his left cheek and head banging. The assessment further identified a sequence from face bashing to elbow bashing to hand biting and finally head banging. Previous interventions recommended by others had been:

- Bandaging Adam’s hands.
- Using splints on his arms so that he could not hit himself.
- Wearing a helmet.

Direct and indirect observations were carried out with family members, school staff and respite carers.

For direct observation, momentary time sampling was used with 20-second recordings in all the circumstances of the child for eight hours. Indirect observation involved the three-term contingency antecedents, behaviour and consequence (ABC) charts; these charts were completed by school staff, respite carers and family members who were asked to record as many incidents as they were able to each day for two weeks.

Functional analysis manipulation was not used in this case.

Management of physical health
Luiselli (2006) emphasised the need to manage physical health issues because these can reinforce responses. The information collected by direct observation, indirect observation and interview suggested that Adam’s physical health was a major concern, as he showed self-injurious behaviour when in pain. He had a history of recurring otitis media, bowel problems, allergies and gastric reflux, all of
Feature

Percentage of time spent in self-injurious behaviour before and after intervention

Key

- Pre-intervention
- Post-intervention

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<thead>
<tr>
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<th>Percentage of time engaged in behaviour</th>
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<tbody>
<tr>
<td>Face bashing</td>
<td>14</td>
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<tr>
<td>Head bashing</td>
<td>12</td>
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<tr>
<td>Hand biting</td>
<td>10</td>
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<tr>
<td>Elbow bashing</td>
<td>8</td>
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Intervention

which were being treated in isolation. Using the PBS process, we were able to co-ordinate the medication and monitoring of each of these medical issues and the effects on the self-injurious behaviour. This improved the communication between the medical staff and Adam’s parents. It was important not to forget to monitor the behaviours and implement an intervention plan to work alongside the medical investigations.

At this point, Adam’s parents commented: ‘Our initial impressions of the assessment process was that it was invasive and intrusive into our home and family life, in that the community nurse spent a lot of time in the home environment monitoring his [Adam’s] behaviour and she even visited my husband at work (with permission) to discuss our son. Sometimes it felt like the advice that was being given was not helping. However, we stuck with it and followed the instructions given because we were told that things would often get worse before they got better.

‘Through the assessment process, which involved observations and a diary of Adam’s behaviour, food and drink intake, bowel movements and gastric reflux, we managed to ascertain that Adam had an underlying health need that required further exploration and that he was using the behaviour for a number of functions. The primary reason was personal pain control, the second to seek attention and thirdly to escape situations that he did not want to be in, for example, a hospital appointment, an activity that he did not enjoy or an environmental factor: it was too noisy, too hot, too cold, too busy.’

Multi-element model

The intervention used in this case was the multi-element model (LaVigna and Willis 1995). In this model, any intervention used should be socially valid; replacement behaviour, changes to the environment or interaction from others should result in ‘socially significant [or meaningful] outcomes’ (Emerson 2001). Intervention also needs to be purposeful (constructional) and functional, so that the child develops new skills and repertoires that have a legitimate purpose (Carr et al 1994). The plan builds on the findings of the functional assessment.

Adam’s parents reflected: ‘The LD-CAMHS team has provided continuity in its care and is always looking at how to improve Adam’s quality of life. I have at times found the process quite challenging because initially we did not know what to expect from the service having had no previous experience of it.

‘The amount of paperwork and forms to fill in about how we perceive our son and his behaviours can at times feel overwhelming and it was like we were on an emotional roller coaster as the forms brought to the forefront the issues and problems we were having to overcome with our child.

‘The programme has always been devised together and the team has always listened to our suggestions and incorporated them into Adam’s plan.’

The following plan was advised by the LD-CAMHS

Environmental manipulations:

- At meal times Adam should sit at a different position at the school table to the position he sits in when he is doing school work.
- Adam should be moved to any new activity only when that activity is ready. For example, food should be ready for him to eat before he is placed in his chair for the meal.
- Instructional methods should be altered. When starting or finishing a task, carers should explain what is happening now, using an object of reference to, or pictorial reference of, the activity to back up verbal communication.
- Adam should have scheduled time with children who are able to interact with him.
- The changing mat should be padded, to reduce sensation when head banging.
- There should be a visual schedule of activities used throughout the day.
- Adam should be able to make a choice of activity during the day.
Positive programming comprised:

- Teaching Adam to ask for help by interacting with his vocalisation and tapping because one of the functions of the self-injurious behaviour was to obtain assistance.
- Encouraging Adam to vocalise, responding interactively to this instead of to self-injurious behaviour.

General skill development included teaching Adam to feed himself. He was also taught functional skills, such as hand-slapping a drum and clapping hands; these related to the sensory function of his behaviour.

Focused support comprised:

- Ensuring toys were available which Adam found enjoyable and accessible.
- Telling Adam what was going to happen and where he was going, using pictures or objects of reference to back up verbal communication.
- Completing pain assessment and following his pain pathway. The pain profile lays out a clear pathway for all carers to follow and was devised by parents, a community consultant paediatrician and Adam’s GP. The aim is to help in assessing and monitoring pain in children with severe neurological impairments and for those unable to communicate pain through speech (RCN Institute 2003).

Reactive strategies included distraction, moving Adam away from the self-injurious behaviour and redirection to a different activity.

Monitoring behaviour

The data collection methods used to evaluate the behaviour support plan included repeat momentary time sampling to establish any frequency changes of the behaviours (Figure 1). Goal-based outcomes were repeated with Adam’s mother to measure achievements by using the Likert scale (0-10) to determine how close a person is to reaching his or her goal. The goal of ten was reached, with a score of two being achieved before interventions and eight after PBS.

There was a clear relationship between pain and the presentation of behaviours. Adam appeared to be happier with PBS, and the family reported that he was trying to vocalise. Adam’s mother said: ‘I now feel I have a child who is trying to talk to me.’

Positive outcome

The last word comes from Adam’s mother: ‘Overall as a family, the positive behavioural support programme has enhanced Adam’s life and has provided us with a greater insight into our child and why he behaves the way he does. The LD-CAMHS’s programme has provided us with greater control over how Adam is looked after and cared for because without the evidence it would be impossible. ‘Adam is now a happy little boy and when he isn’t happy we know the reasons why and what we can do about it. We would definitely encourage other parents to go down this route, and although some of the things we were asked to do appeared monotonous and things appeared to get worse before they got better, persevere because when they get better the benefits are definitely worth it.

‘The programme can be invasive and intrusive at times, particularly into home life and it can be difficult for Adam, his carer and us as parents to try to break old behavioural habits. Our son is always going to have behavioural issues because of the nature of his condition. But, with LD-CAMHS’s input it means that the majority of these issues can be curtailed and that Adam won’t grow up continually beating the hell out of himself.

‘As a family, we are glad that we followed the programme. I think that we would be in a dark place now if we hadn’t.’

References


Conflict of interest
None declared