

## A Mother's Perspective on Developing and Implementing Behavior Support Plans

Anne T. Kayser

My son Tom was diagnosed with autism shortly before his third birthday. At the time of his diagnosis, Tom understood and used very little language. He rarely made eye contact with people outside his immediate family and usually ran away from people who tried to talk or play with him. His play was perseverative rather than imaginative: He lined up toy cars or figures instead of pretending with them; he spilled and threw blocks instead of building with them. He seemed to have a high tolerance for pain, as he almost never cried when he scraped his knee or bumped his head. In fact, he often hit himself on the place where he was scraped or bumped immediately after the injury. His father and I could not understand why Tom did this. The only thing we found that soothed him and stopped him from making a sore spot more sore was to embrace him, holding back his fists and pressing firmly on the place that hurt. Holding Tom firmly also became our standard method of dealing with his frequent tantrums.

As Tom grew, he hit his head more often, especially when someone tried to command his attention and teach him something. He also hit me, his teachers, and his therapists sometimes, but this behavior was easier to ignore and redirect. Seeing my child strike himself on the head and even occasionally on the face was terribly upsetting to me. I would plead with Tom to stop hitting himself. When my words failed to change his behavior, I would catch and hold his fists tightly or wrap my arms around his so that he could not hit himself for a while. Often, I would weep and kiss the place on his handsome head that he had just pounded. Sometimes I would sing one of Tom's favorite songs as I held him, hoping that the music would calm him. These responses to Tom's self-injurious behavior usually did calm him down, but only for a short time. With increasing frequency, as soon as I (or another adult) insisted that he sit and attend to instruction, Tom started hitting himself again.

It was during this time of escalating self-injurious behavior, when Tom was about 4½ years old, that I first contacted a specialist in positive behavior support (PBS). I had heard that this consultant was experienced in helping parents overcome problem behaviors in children with severe developmental disabilities. I called him and explained the problems that we were having. I expected that he, like so many of the other specialists we had taken Tom to see, would have a particular therapy or treatment to sell us, but I found his approach to be much more individualized than others that I had seen or read about. He listened carefully and asked many specific questions about the setting in which Tom was most likely to hit himself, as well as the things that usually preceded and followed his self-injury. After gathering this information, the consultant hypothesized that Tom was hitting himself to escape demands to sit and look at nonpreferred materials (e.g., flashcards, books, craft projects). He also surmised that Tom might find my strong emotional reaction to his head hitting rather entertaining, and I realized that Tom probably enjoyed the deep pressure he was getting when I held his fists or his whole body immediately after he hit himself. Although Tom had my mental attention throughout a teaching session, after he hit his head he enjoyed my physical and emotional attention as well. Thus, it became clear to me that in my effort to prevent my son's self-injury, I had inadvertently reinforced it.

What to do? The PBS consultant taught me that there were several proactive ways to prevent the negative behavior and to teach Tom a better behavior in its place. First, I would make the environment more predictable for Tom so that he would know how much work he had to do, when it would be over, and what he would get to do when the work was finished. These strategies were familiar to me because of my experience with structured teaching (through Project TEACCH, University of North Carolina at Chapel Hill), and they were fairly easy to implement. I made a simple visual system with multiple cards denoting "Tom's Choice" and "Mommy's Choice," and I put them in a row on the wall of the bedroom that was designated as our teaching room. When it was my choice, I either selected an activity with a clear ending (e.g., a small deck of flashcards to identify, a puzzle to assemble, a finite set of cups to name by color and stack) or I set a timer to show when a less-structured activity would be over.

The second strategy that the consultant recommended I liked less: reducing demands and the duration of instructional activities temporarily while Tom learned what the visual system and timer meant and if he used words instead of fists to communicate his desire for a break. I did not like this strategy because I felt that it would be a step backward in our instruction time. We had built up to naming 25 flashcards at a time, and the consultant wanted me to drop back to 8 or 10—even fewer if Tom said, "I want a break." In time, however, I began to see the wisdom of this strategy. Even though it would allow less time to teach Tom nouns, verbs, and adjectives for a while, it would give more opportunities to demonstrate how the new visual turn-taking system worked and how the timer worked. Tom would be reinforced more quickly and frequently for completing what I asked him to do. Gradually, as Tom became more cooperative, I would be able to add cards to the flashcard deck, pieces to the puzzle, or minutes to the timer. Indeed, this is what happened over the course of about a month after we introduced the new system.

The third strategy that the consultant proposed was the hardest but perhaps the most important for me to implement. I had to learn to reinforce desired behaviors and not to reinforce problem behaviors. Specifically, this meant giving Tom lots of hugs, kisses, favorite music, deep pressure play, and emotionally charged attention when he did the right things (which was relatively easy for me) and never when he hit himself (which was difficult for me). A math teacher by training, I found it natural to show excitement whenever a child edged toward a new skill; what felt unnatural, to say the least, was to ignore his violent

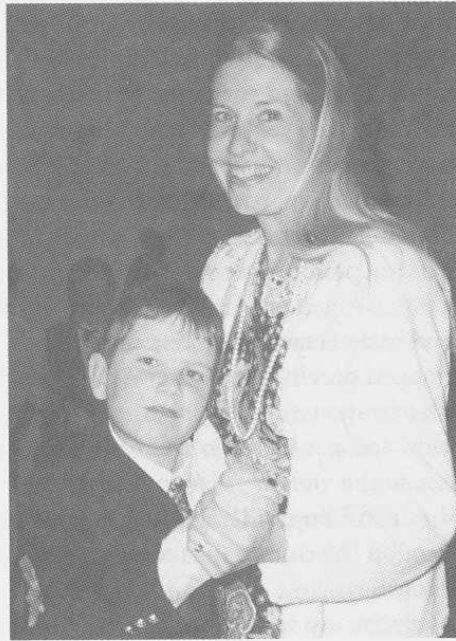
outbursts. Before recommending this strategy, the consultant carefully probed as to whether my son's head hitting actually resulted in an injury to the head. After I reassured the consultant that it had not, he indicated that this opened up the possibility of using the technique of extinction. This procedure required me *not* to react in any noticeable way to Tom's head hitting. The consultant also cautioned that this technique would only work if it was used in tandem with the proactive, positive strategies in the plan.

Putting my son's head hitting on extinction (i.e., actively ignoring head hitting) took concentrated self-discipline on my part and on the part of everyone else working with him, but the payoff was well worth it. When we did not react to Tom's self-injurious behavior in any physically or emotionally detectable way but just blandly redirected him to complete the task at hand, we stopped playing his game. At first, as the consultant predicted, Tom was confused by our lack of response to head hitting; for 2 days this behavior increased as he tried to get our attention and get us to do what we used to do. I would sit silently, knowing that I must not react to the violent behavior but wishing I could grab those little fists before they struck my beautiful boy, willing my face not to betray my heart, praying that "this too shall pass." Then, on the third day of our new program, Tom stopped hitting himself during teaching sessions.

I wish that I could report that my son stopped hitting himself forever and in all situations, but this is not the case. He still has autism. He still has a high threshold for pain. He still has difficulty negotiating verbally. Thus, he still has an occasional outburst of head hitting when he is faced with too many changes, too many demands, not enough predictability, or a combination of these factors. I wish I could report that I always handle it well, that I remain emotionally neutral, calm, and rational. This is not the case either. Times that are stressful for my son are usually stressful for me, too, and in these times, I often let my guard down. I go back to catching his fists, to pleading for gentleness, to tears. The difference now is that I can recognize what I am doing and how it is affecting Tom's behavior, and this makes it possible for me to stop, rethink my response, and prevent myself from getting trapped in an unhelpful interaction pattern with Tom. Now, I have a tool for understanding and solving problem behaviors.

This tool, PBS, has been incredibly useful. With it, we successfully toilet trained Tom, helped him get over his fear of our VCR, got him to sleep through the night consistently in his own bed, taught him to cooperate with medical and dental professionals at checkups, helped him discover the fun of Halloween, and included him in his neighborhood school. The consultant guided my husband and me through several of these solutions, but as he did this he also taught us the process so that we could use it on our own. Now, for most of the challenges that we face with Tom at home and at school, I feel confident in my ability to perform a functional assessment and develop a workable support plan. Some problems are very complex, but the structure of the Functional Assessment Summary Statement that the consultant has taught us to use makes it possible for us to thoroughly comprehend and address all of the features of subtle or convoluted issues. Then, we are able to develop a combination of support strategies that set the stage for success, prevent problems, teach needed skills, and reinforce these skills powerfully. This approach has helped us create complete and lasting solutions to problems that used to drive us crazy!

Because there is so much suffering among families whose children have autism spectrum disorder and because positive behavior support has so much practical help to offer such families, the consultant wanted to start a support group to teach parents and professionals how to use this tool. My husband and I agreed to host monthly meetings in our home, at which the consultant or I led a discussion focused on one family's most pressing problem. Everyone who attended the meetings participated in analyzing and solving the



problem; in the meantime, all of us were learning a powerful process for solving problems with our own children. It was gratifying for me to watch other families experience successes similar to those that we experienced. Some of the problems that we solved together were life-threatening: A teenage girl with autism repeatedly opened the door of the family van as it sped down the freeway. Some problems were exhausting: A 12-year-old boy with autism continually did destructive things at home, like submersing telephones and computer keyboards in water when his mother tried to work in another room. Some problems were annoying or embarrassing: A 5-year-old boy with pervasive developmental disorder wet his pants on the school bus every morning. Regardless of the severity or complexity of the problems that families had to face, positive behavior support proved to be a really effective process for building practical plans that quickly brought desired results. For us and for many families in our support group, it brought about welcome changes in our children and in the quality of life that we enjoy with them.

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# Families and Positive Behavior Support

Addressing Problem Behavior in Family Contexts

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The photographs on this book's cover and throughout the text have been graciously provided by many families that have found improved quality of life through positive behavior support.

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