

## EDITORIAL/Alison Blake, Assistant Editor

## Score a round for IARET—and self-injurious kids like Katie

Hats off to legislators in Ontario, Canada, for making a politically incorrect but ethically correct decision last March. And hats off to some very brave parents and professionals who persuaded them to do it.

The Ontario legislators overturned earlier legislation prohibiting treatments such as SIBIS (the Self-Injurious Behavior Inhibiting System) from being used without an individual's consent (something impossible to obtain in the case of nonverbal, severely retarded individuals). New rules will allow parents to approve the use of SIBIS under carefully regulated conditions.

Opponents of aversives will, of course, say that this legislation sanctions "torture," that it will lead parents to ignore non-aversive approaches, and that SIBIS doesn't work anyway. But they're wrong on all counts.

#### What is SIBIS?

For readers unfamiliar with SIBIS, a little history is in order. The device, developed in the late 1980s by scientists at Johns Hopkins University, consists of a lightweight headgear worn with an arm or leg band. When a severe head blow occurs, the SIBIS unit beeps, then delivers a mild electric shock to a small spot on the arm or leg.

Researchers were astonished to find that SIBIS treatment often led to an immediate, dramatic reduction in self-injurious behavior (SIB)—even in individuals who had been hitting themselves violently, sometimes dozens of times per minute, for years. Another interesting revelation was that individuals wearing the device frequently fought to put it back on when it was removed.

Initial studies of SIBIS were followed by long-term studies confirming that SIBIS is amazingly effective in stopping or reducing self-injury; that individuals wearing the device become happier, healthier, and more sociable; and that many individuals using SIBIS are able to leave restrictive environments and function in the community. Some children have been weaned off the device, with no return of SIB.

#### The controversy

The news about SIBIS was greeted by two reactions. Parents devastated by the hideous self-injury of children who couldn't be helped with drugs or nonaversive approaches said, "Hallelujah!" Opponents of aversives, on the other hand, immediately took steps to prohibit use of the device. Their arguments: that self-injury can always be controlled through non-aversive means, and that SIBIS is equivalent to the cattle prods once used to control SIB.

Argument #1 is false, even according to studies by SIBIS opponents. Research by the Association for Persons with Severe Handicaps (TASH), which opposes SIBIS and other aversives, reveals that non-aversive approaches can control behavior problems only 60 percent of the time. As for argument #2—that SIBIS is "torture"—it's quite simply a lie.

I once served on a human rights panel evaluating SIBIS treatment for a child with severe self-injurious behaviors. We decided, as a group, to test the device on ourselves. When it was my turn, I put the SIBIS armband on with a bit of trepidation (all those comparisons to cattle prods had made an impression on me), and the person holding the SIBIS main unit proceeded to administer a dozen or so consecutive shocks to my arm—more than most children using SIBIS receive over the course of several months.

My response? Astonishment at the mildness of the electrical stimulation SIBIS produced. The feeling, a little like a "zap" of static electricity, was over in an instant.

Having witnessed autistic children (including my own daughter) slamming their heads against walls for years, my first reaction was: "THIS little sensation can stop that kind of behavior?" My next reaction was excitement at the idea that hundreds of autistic children could be saved by this device from fracturing their skulls, ripping off their ears, bloodying their faces, and giving themselves seizures—and that they could be saved from restraints, straitjackets, helmets, and mind-numbing doses of neuroleptic drugs.

#### Turning the tide?

Unfortunately, that hasn't happened. Round one of the SIBIS battle went to the aversives opponents, who have brought the use of SIBIS almost to a standstill through tactics including legislative bans, misinformation campaigns, and threats to picket schools using the device.

There's evidence, however, that the tide is turning. A plucky little organization called IARET (the International Association for the Right to Effective Treatment), composed of parents of severely self-injurious children and professionals interested in helping them, is having considerable luck in helping parents gain the right to use SIBIS for their children, and in opposing legislation prohibiting the use of aversives to treat severe self-injury. The Canadian victory is the most recent of their successes.

Unlike the anti-SIBIS groups, IARET doesn't have to rely on threats or misinformation. Instead, it relies on the truth. That truth is contained in studies showing that SIBIS is safe, humane, and effective.

That truth is also contained in the testimony of family members such as Michigan parents Gregory and Denise MacKinnon, who spoke before the Ontario legislators and showed "before" and "after" photos of their daughter, Katie. The MacKinnons tried SIBIS after years of treatment, ranging from Gentle Teaching and other nonaversive approaches to drugs and restraints, failed to help Katie. I'm ending this article with their words, because their story is more compelling than any arguments I can offer in favor of SIBIS:

*"By October of 1992, Katie was hitting her head and face at a rate of 5,500 times per hour. Her wrists and upper arms were*

*festering sores. Katie was refusing to walk at all, having to be carried wherever she went. She was back in diapers, undoing two years of toilet training. Katie was eating about every third day, refusing even treats in between. She had lost 6 of her 54 pounds, and her ribs showed through her skin. Sleep only came to Katie when she was completely exhausted, and then only two or three hours a night. A daily chore at our house was to soak Katie's blood-drenched night gown in bleach.*

*"When giving Katie a shower in the evening, my wife would roll up her pants legs and stand in the shower with her to prevent her from slamming her head into the tile while I tried to wash her and clean her wounds.*

*"My wife and I watched helplessly as Katie's physical and mental health deteriorated to the point that it endangered her eyesight and even her life. It was like watching our sweet daughter get into a terrible car accident every day.*

*"At the end of October we decided to try the SIBIS. We knew of the SIBIS for about a year, but always thought that we would find a less extreme way of dealing with Katie's self-injury. When we made this decision we were well aware of some of the ramifications.... We were sure that the anti-aversive faction would come out of the woodwork to condemn us. Katie would get no services from the State of Michigan, as there is a directive prohibiting aid to families who use the SIBIS. Of course, we knew that our school district would not allow it in the classroom.... But we had to help Katie, because she had lost the ability to help herself.*

*"[SIBIS] changed Katie's life, and ours. Katie immediately responded to the SIBIS. The two hour drive home from Kalamazoo at the end of the weekend was amazing. Katie smiled, looked around and ate snacks the entire way. We hadn't seen her smile in what seemed like a year. Katie seemed as if a tremendous weight had been lifted from her.*

*"In the next few days about 99% of the hitting stopped. We later started using the SIBIS for the arm and wrist biting, and that too stopped almost immediately. Katie's face, wrists and arm were healing, she was eating and regaining her lost weight, and she was sleeping through the night....*

*"It has now been more than three years since we started using the SIBIS. Katie is injury free, her hair has grown back, and she is healthy and happy.*

*"....If, in the course of these readings, you come upon people who refer to themselves as 'advocates for children,' or 'advocates for the disabled,' who oppose the decisions that we've made to help our daughter, please ask them if all the known so-called nonaversive treatments combined have a success rate of 100% in stopping severe self-injurious behavior.*

*"When they answer 'No,' please remember Katie's story, and think of that beautiful face."*

If you would like more information about IARET, write to them at 763 Main St., #10, Waltham, MA 02154-0604.