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## ***The Right to Treatment***

### ***Including Aversive Stimuli***

*The use of aversive stimuli with the retardate is controversial. This paper describes the successful application of electrical stimulation to eliminate self-abusive behavior. It is presented as an advocacy for a form of treatment which has its rightful place in our armamentarium and can be of benefit to many severely-profoundly retardates. To deny them this benefit is considered unethical, inhumane, unfair and absolutely wrong.*

The current discussion regarding the human rights of the retardate is a subject that has been neglected too long. It leads to changes of attitude which are accompanied by emotions and feelings of guilt. Whenever emotions rather than rationale become the judges of what kind of changes are to be made, many good things are discarded with the bad. Obviously, this is detrimental to many individuals. One example is the use of aversive stimuli, a topic which kindles many emotions. If viewed dispassionately, however, one can find good reasons to become convinced that this is but another form of treatment a retardate is entitled to, whenever it appears indicated and useful. We are referring here in particular to electrical stimulation as described below.

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Since the rights of the retarded have been abused in the past, it is understandable that there is pressure for an outright ban of any treatment that might open a loophole for improper care. To yield to this pressure indiscriminately and adopt an oversafe policy of "benign neglect" may be a failure to generate the courage and effort it takes to make difficult judgments in individual cases. No rules or regulations fit every individual at all times and under all circumstances. Flexibility and individuality is, therefore, a must. It is certainly possible to match the proper treatment with the proper retardate, at the proper time, under proper safeguards. We believe that the application of electricity as an aversive stimulus to control self-abusive behavior is one of those proper matches.

Since this treatment causes pain, it has become in some people's minds a "materia non grata." But what is the balance of pain in the self-abusive individual? Either his own abusive behavior is causing him pain or it is not. If it is, then the electrical charge is certainly less severe and less damaging than his own actions. If, on the other hand, he is insensitive to pain, then a fleeting electrical charge will not hurt him either. Furthermore, applying pain as a means of achieving certain benefits is not unusual among "normal" people. How often do we voluntarily submit to an injection for medication or vaccination; or undergo surgery which we know to be painful, but still accept in order to eliminate suffering. Why not accord that same option to the retardate? He may not be able to express himself, but does he not have the right to act similarly to any other human being in need? Are we not responsible to act as advocates for this right as well as all the other rights he is entitled to enjoy?

#### ELECTRICAL STIMULATION THERAPY WITH DEBBIE AND JANE

At our school we were unsuccessful with the use of positive reinforcement techniques on the self-abusive behavior of some of our severely-profoundly retarded residents. In our search for a different method to pull residents out of physical or pharmacological restraint and restore them to a life of some useful activity, we came across electric shock, which has been described in the literature as effective for reducing self-abuse and other undesirable behaviors (Tate and Baroff, 1966; Bucher and Lovaas, 1968; Whaley and Tough, 1968; Lovaas and Simmons, 1969).

Since aversive stimuli have been controversial, we took precautions to provide all necessary safeguards. To avoid confusion between our use of electric shock and electroconvulsive therapy, we groped for a different term and finally arrived at "Electrical Stimulation Therapy" (EST). We took pains to comply with criteria prescribed by the Joint Committee on Accreditation of Hospitals, Section 2.1.8.9., which require parental consent and review by a Research Review Committee and Human Rights Committee. At the Wilton Developmental Center both of these committees are composed of members of the institution's staff and representatives from the community—i.e., one psychologist from the local school system and another from a nearby college, two representatives from local chapters of the Association for Retarded Children, and two from the Wilton Parent Association. These committees reviewed and approved the project and have since been meeting on a regular basis to supervise its application. New residents are added to the program only with the consent of these committees. Below are descriptions of our EST with two residents, Debbie and Jane.

Debbie is profoundly retarded, legally blind, and walks with a very unsteady gait. She has been institutionalized since age six and was 15 at the start of the treatment. Various drugs failed to control her self-abuse which was noted from the time of admission. The two years before treatment were spent in complete restraints almost 24 hours a day. Any time they were removed, she would immediately pound her face with her fists, bang her head against objects and kick herself. The treatment plan consisted of two parts: a penalty for self-abuse and positive training in alternative behaviors. The penalty was the electrical stimulation administered by selected and trained therapy aides from a device akin to a flashlight containing four C-cell batteries. Each self-abusive act was immediately followed by an electrical stimulation paired with the word "no." In the first session her self-abuse dropped from the pre-treatment baseline rate of 37 times a minute to four times a minute. By the seventh session she ceased to be self-abusive during scheduled treatments. Restraints were no longer needed and EST instead of being planned, was given only when indicated. At this point, training in alternative behavior was begun, using positive reinforcement. It focused first on improving her walking in order to develop new sources of satisfaction. Attention was directed again to Debbie's cataracts. They were always considered operable but her self-abuse made surgery impractical heretofore. Her newly controlled behavior made it possible to perform operations on both eyes. She now wears

glasses and moves about the ward easily. Relapses of self-abuse still occur occasionally and require EST.

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Jane is severely retarded and at the start of treatment was 33 years old. Of the 22 years in institutions, 13 were spent in restraint almost continuously. The severity of her self-abuse made the determination of baselines impossible. By a single blow with her forehead, she once split a  $\frac{3}{4}$  inch particle board table and on another occasion dented a steel bedstead. The same treatment apparatus and plan was used as with Debbie. EST was given after each self-abusive act. During the third session her self-abuse was completely eliminated. After a month of daily scheduled treatment sessions, during which Jane continued to be non-abusive, the ward staff dared to leave her out of restraint for slowly increased periods of time. Four months after treatment had begun, restraints were no longer needed at all. As with Debbie, EST is still used from time to time.

#### DISCUSSION AND CONCLUSION

We have been privileged to see remarkable changes with EST in these two residents as well as others not described here. At times these treatments are still needed, but we consider this similar to a maintenance dose for a diabetic who must take medication without which he would not be able to function properly; but he gladly takes this in stride in order to be able to live a useful life. We still hope to be able to eliminate EST entirely; yet even if this goal is not reached, such occasional applications are a small price to pay for greater freedom and opportunities.

This project was not an attempt at replication but something absolutely dictated by our conscience—that is, to explore every avenue that might give a retardate a chance to live like a human being again. We maintain that to do less would be a neglect of our duty. Withholding a potentially valuable therapeutic tool from our residents is unethical, inhumane, unfair and absolutely wrong. Unfortunately, a false sense of what may be humane has relegated too many retardates to useless lives on the “back wards.” It must be stressed that we do not consider EST an end in itself but only a means for more effective positive training. It is amazing and rewarding to see an individual come to life and begin to participate in activities that nobody thought possible. We are deeply concerned that the current controversy about aversive stimuli may lead to an error of omission rather than commission. It is easier to avoid a problem by doing nothing than

to take action and risk criticism. Such an over-cautious stand also deprives deserving individuals of a potential benefit. And they continue to suffer because they are ignored and handled as mute non-entities who must make do with what happens to be left over or with what others graciously consider good enough for them to have.

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