

# Biomedical/Education Update:

## Doughnuts, naps, and the right to choose

Does an autistic child or adult have the right to stay up too late, eat too much junk food, choose between watching a movie or going skating, or select classroom tasks? How can a parent or professional balance a disabled person's right to make choices with concerns for the individual's safety, and welfare? Diane Bannerman et al. examined the issue, and relevant research findings, in the *Journal of Applied Behavior Analysis*.

People "enjoy making simple choices," Bannerman et al. say, "such as whether to engage in unproductive . . . activities, like watching sitcoms or television, eating too many doughnuts, taking the afternoon off from work, or taking a nap before dinner. People typically decide for themselves when to take a shower, what to eat, and with whom to spend their time." Such choices, they say, are "cherished" by both nondisabled and developmentally disabled people.

According to Bannerman et al., research shows that both normal and developmentally disabled individuals allowed to make choices participate more in activities, are more compliant, sometimes perform better at tasks, and enjoy the tasks they select more than if the same tasks were chosen for them. For instance, they say, studies by other researchers show that:

- developmentally disabled students had fewer behavior problems when they controlled the pace of vocational tasks.
- non-disabled women who chose their own exercise routines had better attendance at a fitness program than women assigned exercises.
- children given a choice of weight loss treatments did somewhat better than children who assigned to a program.
- autistic children exhibited fewer problem behaviors when allowed to choose tasks, materials and reinforcers than when therapists made these choices for them, and were more social and made better eye contact when engaging in activities they preferred.

In addition, they say, current law (in the U.S. and some other countries) guarantees the right of disabled individuals to make choices to the greatest degree possible. Learning to make choices, they say, can prepare a disabled individual for adult life in the community where decision-making is a part of daily life.

### How much choice is too much?

People with developmentally disabilities, Bannerman and colleagues say, "should be encouraged to make as many choices as their abilities allow, as long as these choices are not detrimental to the client or others." They note, however, that many such individuals "do not have a repertoire of skills [to choose from], and . . . do not understand the consequences of their behavior."

"Although other members of society enjoy the right to . . . engage in . . . unproductive, even unsafe, activities," they say, "they typically have a vast repertoire of learned skills and behaviors and are presumably aware of most of the consequences of their behavior." They point out that society traditionally has abridged the rights of minors who likewise do not always have the experience or knowledge needed to make good decisions.

In addition, the researchers say, problems can occur when clients' choices—for instance, choosing to be dressed by parents rather than dressing independently—can hinder the individual's progress toward independent living.

Another argument in favor of sometimes abridging the right to choice, they say, is that people with developmental disabilities, like nondisabled people, have obligations to meet. In the case of a retarded or autistic individual, those obligations might include meeting agreed-upon school or vocational goals—rather than choosing activities that do not contribute to meeting these goals.

### Rights—with responsibilities

In conclusion, the researchers say, "All people have the right to eat too many doughnuts and take a nap. But along with rights come responsibilities." They recommend four steps to encourage independent choice-making:

1. Emphasize the teaching of independent living skills and activities preferred by the disabled individual. This, they say, will give individuals "a repertoire of appropriate, as well as preferred, behaviors from which to make choices."
2. Allow individuals to have a say in what skills they will learn and how these skills will be taught. Ask verbal individuals for input, use existing rating scales, or observe nonverbal individuals' preferences and consult with parents or care providers.
3. Teach developmentally disabled individuals how to choose. All individuals, they say, should have the opportunity to make choices—even those functioning at the lowest levels. Some people may only be able to decide which dessert they want, while others might learn to make higher-level choices such as how to spend a paycheck.

Schedules should be set up to allow for choices, they say; for instance, a scheduled bath-time could be changed to allow an individual to watch a favorite TV show.

One problem, they note, is that current bureaucratic regulations may force facilities to create over-programmed and inflexible schedules, reducing chances for choice.

"Balancing the right to habilitation with the right to personal liberties: the rights of people with developmental disabilities to eat too many doughnuts and take a nap," Diane J. Bannerman, Jan B. Sheldon, James A. Sherman, and Alan E. Harchik; *Journal of Applied Behavior Analysis*, Vol. 23, No. 1, Spring 1990, pp. 79-89. Address: Diane Bannerman, Dept. of Human Development and Family Life, 1034 Haworth, University of Kansas, Lawrence, Kansas 66045.

## The melatonin theory

Researchers Ronald Chamberlain and Barbara Herman propose a theory that they say could explain the abnormal levels of serotonin, opioids, and other hormones seen in many autistic individuals. Chamberlain and Herman suggest that a "cascade of biochemical effects," initially set off by the pineal gland over-secreting a substance called melatonin, may cause one subgroup of autism.

The tiny pineal gland, which lies between the cerebral hemispheres of the brain, releases melatonin in amounts controlled by the amount of light outside the body. (Less melatonin is released during light periods, and more during darkness.) According to Chamberlain and Herman, "a variety of lines of data suggest that the pineal may play an important role in the biological elaboration of emotions and psychiatric disorders."

Melatonin affects — directly or indirectly — a number of substances in the brain. Chamberlain and Herman propose that in some autistic individuals:

1. The pineal gland releases too much melatonin.
2. The excess melatonin in turn causes levels of serotonin to rise in the brain and blood.
3. Melatonin also inhibits the release of corticotrophin-releasing hormone (CRH) from the hypothalamus.
4. Reduced levels of CRH in turn reduce the levels of pituitary B-endorphin and adrenocorticotrophin hormone (ACTH). This in turn causes decreased concentrations of B-endorphin, ACTH, and cortisol (another hormone) in the blood.
5. It is also possible that some autistic individuals have genetic defect that causes the hypothalamus to secrete too much b-endorphin, which leads the body to react by further inhibiting the amount of b-endorphin released by the pituitary.

The researchers note that there is strong evidence linking abnormal levels of serotonin and endorphins to autistic-like behaviors in humans or animals. While there currently is no direct evidence linking melatonin abnormalities to autism—possibly, Chamberlain and Herman say, because levels of the substance are very difficult to measure—excess melatonin secretion in animals causes learning dysfunctions and reduced motivation and emotional response.

One possible way to test their theory, the researchers say, would be to "investigate the effects of the 'light boxes' used in the treatment of seasonal affective disorder to inhibit or shift melatonin secretion of autistics."

"A novel biochemical model linking dysfunctions in brain melatonin, proopiomelanocortin peptides, and serotonin in autism," Ronald Chamberlain and Barbara Herman; *Biological Psychiatry*, 1990, 28, pp. 773-793. Address: Barbara Herman, Brain Research Center, Children's National Medical Center, 111 Michigan Ave., N.W., Washington, D.C. 20010.