

Education/Psychology Update:

To sleep, perchance . . .

Autism Society meetings abound with stories about autistic children who won't go to sleep, insist on sleeping in their parents' bed, or get up dozens of times during the night. A recent study shows that such sleep problems are extremely common among children with developmental disabilities, and a separate study reports on the successful use of behavior modification and temporary medication to reduce such problems.

English researcher L. Quine studied 200 children with severe mental handicaps, and found that 51% had problems settling in to sleep, and 67% woke frequently during the night. Thirty-two percent of parents said they rarely got enough sleep. Sleep problems were strongly related to daytime behavior problems and epilepsy, as well as to poor communication, academic and self-help skills. A three-year follow-up revealed that sleeping difficulties tend to be chronic. Not surprisingly, maternal irritability, stress, and perceived impact on the family were significantly correlated to sleep problems.

A new study by Jane Summers et al. suggests that behavior modification techniques can dramatically improve disabled children's sleep patterns. Summers and colleagues worked with a profoundly retarded nine-year-old boy with Angelman syndrome who exhibited both severe daytime behavior disorders and severe sleep problems (including waking at night and climbing into his parents' bed). Their approach, first introduced in a behavioral treatment unit and then generalized to the home, involved:

- the temporary use of Benadryl to induce sleep. (*Note: many autistic children react adversely to Benadryl, so this technique should be tried cautiously if at all.*) The use of Benadryl was discontinued during the last phase of treatment; however, the child, who had been given the medication in applesauce, continued to receive a placebo spoonful of the applesauce.

- not allowing the child to fall asleep during the day, or—if he did fall asleep—waking him within 45 minutes.

- restricting access to fluids after 7:30 p.m.

- putting the child to bed at a consistent hour every night.

- not permitting the child to leave the bed if he awoke during the night. If this occurred, a staff member (or later, the child's mother) would use gestures or physical guidance to return the child to bed. When the child returned home, his mother initially remained in his room with him at night so she could direct him back to bed when he awoke. Gradually, she began sleeping closer to the hallway, eventually returning to her own room.

- refusing to provide any social reinforcement when the child got out of bed.

- at a later stage, requiring the child to remain in bed in the morning until a music alarm clock went off.

The researchers report that at nine-month follow-up, the boy was sleeping seven to

eight hours per night. Removal of the medication did not significantly affect the boy's sleep patterns—a noteworthy finding, Summers et al. say, "in light of concerns regarding long-term use of medication for patients with developmental disabilities."

"A combined behavioral/pharmacological treatment of sleep-wake schedule disorder in Angelman syndrome," Jane Summers, Patricia Lynch, James Harris, John Burke, David Allison, and Louis Sandler; *Developmental and Behavioral Pediatrics*, Vol. 13, No. 4, August 1992, pp. 284-287. Address: Jane A. Summers, Department of Behavioral Psychology, The Kennedy Krieger Institute, 707 N. Broadway, Baltimore, MD 21205.

—and—

"Sleep problems in children with mental handicap," L. Quine, *Journal of Mental Deficiency Research*, 1991, 35, pp. 269-290. Address: L. Quine, Institute of Social and Applied Psychology, University of Kent at Canterbury, Canterbury, Kent CT2 7LZ, England.

Stigma of autism studied

A 1993 study by Australian researcher David Gray confirms what parents of autistic children already know: that autism has "uniquely stigmatizing aspects," because of its bizarre symptoms, the normal appearance of most autistic children, and the lack of public knowledge about the disorder.

When Gray asked 32 parents of autistic children, "Do you feel that people treat you or your family differently because of your child's illness?" most of his subjects answered affirmatively. As a consequence of this stigmatization, Gray says, "many parents tend to isolate themselves and their families from social contact with the outside world....The social life that families do manage to maintain is often restricted to their extended family, a few friends who can deal with their child's condition, or...other families with autistic children."

Gray found that parents often have great difficulty coping with public disapproval when their children throw tantrums or exhibit strange behaviors. "The expectations violated by autistic individuals are among some of the most basic rules of social interaction," he notes. "The destruction of property, violations of personal space and inappropriate toileting represent severe tests for any parent attempting to negotiate a public encounter." The discrepancy between the child's normal appearance and his bizarre behavior, he says, leads outsiders to question the parents' competence—sometimes covertly, and sometimes openly.

In general, Gray found that mothers tended to feel more stigmatized than fathers—not a surprising finding, since mothers usually spend more time in public with their autistic children. Gray also found that mothers were more likely than fathers to blame themselves for their children's disorder, and therefore may be more likely to accept the validity of others' disapproval.

Parents whose children had severe behavior problems were more likely to feel stigmatized than parents of children with milder symptoms, and parents of young

children felt slightly more stigmatized than those with older children. "While many of the parents [of older children] had a large number of 'war stories' regarding their child's inappropriate public behavior and the negative reactions of outsiders," Gray notes, "they reported a tendency to develop a certain degree of emotional detachment over time." This may, he says, reflect the emotional exhaustion many parents feel by this stage.

Many parents said their children also were stigmatized by their autistic siblings, and some reported that the children's grandparents felt stigmatized and were embarrassed to be seen with the children in public. While most parents reported some degree of stigmatization, a substantial minority (six fathers and seven mothers) did not believe they were treated differently because of their autistic children.

Parents of disabled children in general, Gray notes, are in an interesting position. They are recipients of what he calls "courtesy stigma"—in other words, they are stigmatized not because of their own characteristics, but because they are associated with a stigmatized person. "They are regarded as 'normal but different,'" he says, and have the option of "passing" in some situations as long as their affiliation to the disabled individual is not known. "Relatives of stigmatized individuals," he says, "may go through cycles...during which they are more willing to bear the burden of a courtesy stigma at certain times than at others." This may influence their willingness to participate in groups for the disabled—thereby making their "courtesy stigma" more visible—or to be seen in public with the disabled individual.

"Perceptions of stigma: the parents of autistic children," David E. Gray, *Sociology of Health and Illness*, Vol. 15, No. 1, 1993, pp. 102-120.

Note to parents and professionals

The Autism Research Institute is working with parent Lori Altobelli of Leominster, Massachusetts, in attempting to determine if the clusters of cases of autism in Leominster—and elsewhere—may be the result of the parents being exposed to certain toxic chemicals prior to their children's conception. Lori's work received national attention last year on the *20/20* television show.

We have identified a highly qualified geneticist who will be working with us in the attempt to determine if specific genetic damage is found in these children and/or their families, and, if so, if this is associated with pollution.

If you are a parent of an autistic child and have lived in the Leominster area, or another area in which possibly pollution-caused autism clusters have appeared—or if you know of such parents—please contact our Institute.