R1775.6
T736
#4

Government Publications

TRIMS • THERAPY • NOTES

JAN 27 1983
Dallas Public Library

Autistic persons in Texas:

Who are they?
What do they need?
How can we help them?

Kay R. Lewis, M.D.
David Wood, M.A.

January 1983

The **Diagnostic and Statistical Manual of Mental Disorders, DSM-III,** includes infantile autism in the category of pervasive developmental disorders (PDD), which it defines as disorders "characterized by **distortion** (rather than only delay) in the development of multiple social skills and language."

The definition of pervasive developmental disorders includes two major types: infantile autism, with symptom onset before age 30 months, and childhood-onset PDD, between ages 30 months and 12 years. The third, atypical PDD, includes affected children whom the other two descriptions do not fit.

Last year the Joint Committee on Autism created by the 67th Texas State Legislature recommended that "all relevant agencies" adopt these definitions in identifying the population in need of and eligible for autism services.

Unlike a 10-year-old child with Down's syndrome and an IQ of 50, who solves problems, talks, and behaves somewhat like a child half that age, the problem-solving and communication of a 10-year-old child with a pervasive developmental disorder do not resemble those of a normal child of any age.

Most autistic persons we have evaluated are also mentally retarded. They usually are nonverbal, overactive, with bizarre behaviors and an aversion to physical contact. Under stress they may become aggressive or self-abusive. Although they may have some verbal expression, their language patterns often are distorted by echolalia, pronoun reversal, atypical gestures. They may prefer objects to people and use self-stimulation of one or more senses.

For these children, both **diagnosis** and **evaluation** are essential. The diagnosis, establishing PDD, makes the patient eligible for autism programs. Evaluation involves social workers, psychologists, educators, speech pathologists, and physicians. The physician looks for treatable aspects (for example, seizures) that are a barrier to the child's education. Other professionals evaluate the child's developmental status and learning needs. All members of the team meet with parents —explaining, answering questions, identifying resources, making plans for the child, and setting priorities. If the team lacks one kind of specialist, it recruits a consultant. If one team member does not understand autism, he or she she is trained.

Although the psychiatrists who first described autism saw it as an emotional disorder caused by parents who did not nurture their infants adequately, the literature on autism for the last 20 years has depicted autism as an organic disorder marked by severe defects in communication, learning, and behavior. Intense, behaviorally oriented educational programs involving teachers and parents have been shown to alleviate many of the symptoms that bar autistic persons from community life.

Still, many parents have been unable to shake the suspicion that they are the problem, rather than part of the solution. Not until they overcome this are they able to become informed about the resources their child needs. The Texas Society for Autistic Citizens (TSAC), composed of parents and professionals, has for years worked with legislators and state agency personnel to develop effective programs.

Although Public Law 94-142 declared in 1975 that a "free, appropriate public education" is the right of all handicapped citizens between the ages of 3 and 22 years, the law was not supported by sufficient public funds. Few autistic persons were even identified.

In 1979, when an autistic teenager died in a state hospital, public concern finally focused on the needs of autistic persons. The Texas Department of Mental Health and Mental Retardation (TDMHMR) required **DSM-III** criteria to be applied in both mental retardation and mental health programs, and we received a grant in 1981 to conduct autism identification workshops at the 12 state schools.

With a team of consultants, we examined state school residents under 22 years of age who were known or suspected to be autistic. Based on this sample, we suggested that 11.5 percent of the then 3,040 state school residents were likely to have pervasive developmental disorders. Diagnoses were to be updated by routine evaluations and reexaminations. Currently, only 4.1 percent of state school residents under 22 are reported to have autism or pervasive developmental disorders, which is only a third of the number our earlier study suggested.

Mental retardation professionals hesitate to diag-

Texas Research Institute of Mental Sciences
1300 Moursund Avenue, Houston 77030
(713) 797-1976

Bulk Rate
U.S. POSTAGE
PAID
Permit No. 4
Houston, Texas

874-6202

Call the TRIMS consultation service for diagnostic or treatment advice, or for a literature search on a specific topic.

nose autism. The fact that the Texas Education Agency (TEA) still requires diagnoses by a licensed psychologist or psychiatrist before a child may receive autism services, regardless of the organic nature of the child's disorders, probably affects the diagnostic practices of Texas mental retardation professionals. TDMHMR and TEA are trying to correct this problem, and we should soon see a joint policy statement on terminology and criteria.

Neuropsychologists at TRIMS are studying autistic children's communication development, while researchers at Texas Tech University are investigating vocational assessment and training of autistic persons.

We are participating in a multicenter study of fenfluramine, a weight-loss medication for adults, on the serotonin metabolism, behavior, and communication of autistic children. The study is coordinated by researchers of the University of California at Los Angeles. It may help autistic persons, and it may also bring us closer to understanding the neurochemical basis of the disorder.

Few autistic citizens have the opportunity today to develop their best possible abilities. In Texas, most of them are lost in programs for people with other problems, particularly mental retardation; some are in programs for the emotionally disturbed; some receive no training at all.

We must find them. Professionals must screen groups likely to include autistic children, record the possibility of autism as the presumptive diagnosis, and inform parents of the possibility. Then the diagnosis must be checked.

Professionals must support parents of autistic children by identifying case managers who can guide them through the painful and laborious process of evaluation, referral, program development, implementation, and treatment. Case managers know about autism—or they must learn about it. Parents should be referred to the Texas Society for Autistic Citizens to gain support from other parents.

Professionals should: Keep records of where the children are and their service needs. Develop programs with parents. Conduct evaluations, using staff members or consultants able to articulate the child's needs and to demonstrate how to work effectively with the child. Use staff members who will recognize the child's potential and anticipate success. Provide time, training, consultation, and administrative support. Be sensitive to the autistic person's and the parents' changing needs.

TRIMS Therapy Notes
January 1983 Vol. 4, No. 1

Clinical newsletter of the Texas Research Institute of Mental Sciences, the research-training-patient care facility of the Texas Department of Mental Health and Mental Retardation, an equal opportunity employer.

Joseph C. Schoolar, Ph.D., M.D., scientific editor
Lore Feldman, editor

EDITORIAL BOARD

Joseph C. Schoolar, Ph.D., M.D.
Neil R. Burch, M.D.
James L. Claghorn, M.D.
Jack M. Fletcher, Ph.D.
Jack L. Franklin, Ph.D.
Charles M. Gaitz, M.D.
Jaime Ganc, M.D.
Jack R. Gordon, M.D.
J. Ray Hays, Ph.D., J.D.
Sergio Henao, M.D.
John W. Largen, Jr., Ph.D.
Kay R. Lewis, M.D.
Mohsen Mirabi, M.D.
George Niederehe, Ph.D.
Jon Reck, Ph.D.
Cyrus Sajadi, M.D.
Kenneth S. Solway, Ph.D.
Robert C. Smith, M.D., Ph.D.
Roy V. Varner, M.D.
Nancy Wilson, M.S.W.