

Investigation: group home problems widespread

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—Employees at community homes "are often under-trained, poorly paid and inadequately screened," and owners frequently have no experience in the field.

The subcommittee found that "in many states, virtually anyone can open a home. Little regard is given to an owner's track record in other states. Owners need not have any experience with the special needs of the mentally retarded community." The pressure to move people quickly from institutional settings to community settings, the committee notes, has forced states to turn a blind eye to the poor quality of many programs.

The situation is further complicated, the report says, by the replacement of "mom and pop" foster homes with multi-state, multi-home chains which sometimes place profits ahead of clients' welfare. The subcommittee found "incestuous" relationships between providers and for-profit corporations to lease-back housing, provide employment and offer consulting therapies; "these relationships," they say, "appear to be designed to maximize profitability of these ventures for managers" rather than to improve services for clients.

Despite the medical and behavioral problems of many clients, subcommittee investigators found that providers often offer employees only basic training—sometimes as little as a two-week crash course in first aid. "They're hiring people off the street for \$5 or \$6 an hour to care for patients who have extremely complicated seizure disorders, feeding tubes, all kinds of problems," Dr. Cindy Ochs told the subcommittee.

On average, the subcommittee investigation found, workers in community group homes are paid 54 percent less than workers performing similar functions at institutional settings, and receive much poorer benefits. "Not surprisingly," the report says, "staff turnover is a major problem. Furthermore, experts link dissatisfaction over low wages with a tendency to abuse or neglect the clients." Employee turnover at private community facilities was almost three times as high in 1992 as in institutional settings, and the national mean length of service for full-time staff in institutions was about 50

months, compared to only 14.7 months for those working in private community facilities. "More than half of the direct care staff separating in private community facilities leaves before completing one year on the job," the report states, "compared to less than one third of the workers in institutions."

The report concludes that "although indications are that most homes provide quality care in an efficient, caring and lawful manner, too many providers have routinely taken advantage of complex rules and regulations for personal gain." The subcommittee suggests that steps be taken to ameliorate the problems they found, including:

—offering a variety of residential options rather than relying solely on small community facilities.

—requiring states to have aggressive quality assurance programs, and establishing a national service to track information about the track records of providers and personnel.

—requiring states to establish minimum training requirements for employees, and creating incentives for improved employee pay and benefits.

—discouraging over-reliance on any single provider.

—improving financial auditing of providers.

Looking at alternatives

The report notes that a number of parents believe the government has moved too precipitously in closing down institutions, and feel that many disabled individuals—particularly those with severe behavior problems—could be better served in such well-monitored, centralized institutions than in community homes, where caregivers may lack the expertise needed for their care. Meanwhile, other parents and professionals are urging the creation of more rural residential facilities, such as the highly successful Bittersweet Farms in Ohio. (*Editor's note: a new book on successful farm-style programs, Adults with Autism in European Farm Communities, is due to be published this summer and will be available from ARI.*) But whatever their preferences, most parents agree that a wider range of programs is needed, and that all programs—whether institutional or community-based—need to be supervised much more intensely than they are now.

"Residential programs for the mentally retarded," report of the Subcommittee on Regulation, Business Opportunities, and Technology, U.S. House of Representatives. Address: Ron Wyden, subcommittee chairman, B-363 Rayburn House Office Building, Washington, D.C. 20515-6318.

Dietitians: group home diets lacking

The American Dietetic Association (ADA) is calling for all individuals with developmental disabilities to receive comprehensive nutrition services as part of residential, vocational, and educational planning services.

The ADA notes that developmentally disabled individuals often are at special risk of poor nutrition because of drug-nutrient interactions, physical and behavioral eating problems, metabolic disorders, altered growth patterns, or lack of mobility. For instance, the association notes, "nutrient needs may be altered as a result of long-term medication therapy for conditions such as epilepsy, recurrent urinary or respiratory infections, chronic constipation, and behavioral problems. Disorders of vitamin D, calcium, and bone metabolism result when the anticonvulsants phenytoin and/or phenobarbital are used for an extended period, especially when taken by a nonambulatory person. Use of other medications may also affect food and nutrient intake; for example, antibiotics may produce gastrointestinal symptoms, psychotropics may alter appetite, and extended use of mineral oil [for constipation] may lower stored reserves of some fat-soluble vitamins."

A recent study by dietitians Kathleen Clark Mercer and Shirley Walberg Ekvall of five group homes and one intermediate care facility found that all fell short of providing adequate nutrition for residents. The dietitians found that "none of the dinner menus analyzed met one third of the

Recommended Dietary Allowances (RDAs) for all 10 nutrients" investigated. They add that if dinner meals fail to provide one-third of the RDA, "the chance that the entire diet will provide adequate nutrients is slight."

The researchers found that 64% of the meals that were individually selected and prepared by group home residents "consisted of foods from two or fewer food groups," and say that "residents in group homes and apartment settings are given more responsibility for their food choices but often possess insufficient nutrition knowledge or food skills."

The ADA says that while individuals in institutions or group homes meeting federal standards appear to be fairly well nourished, "for persons living in small board-and-care homes or independent living facilities, requirements for...protective professional monitoring may not exist." The association recommends incorporating nutrition objectives into Individual Habilitation Plans, Individual Family Service Plans, or Individual Education Programs.

"Position of the American Dietetic Association: nutrition in comprehensive program planning for persons with developmental disabilities," *Journal of the American Dietetic Association*, May 1992, Vol. 92, No. 5, pp. 613-615.

—and—

"Comparing the diets of adults with mental retardation who live in intermediate care facilities and in group homes," Kathleen Clark Mercer and Shirley Walberg Ekvall; *Journal of the American Dietetic Association*, March 1992, Vol. 92, No. 3, pp. 356-358.

Researchers at Stanford University School of Medicine are studying the genetics of autism and pervasive developmental disorders. The researchers are interested in recruiting families who have more than one person with autism or PDD. Participation will include a two-hour interview about each child in the family; a short behavioral observation of each child by the researchers; and the taking of blood samples. Families interested in participating may contact Donna Spiker, Project Director, at (415) 723-7809. (Please leave a message if you reach the answering machine.)