STATE OF CALIFORNIA GEORGE DEUKMEJIAN, *Governor*

COMMISSION ON CALIFORNIA STATE GOVERNMENT ORGANIZATION AND ECONOMY

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May 1, 1987

The Honorable George Deukmejian
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and Members of the Senate

The Honorable James Nielsen
Senate Minority Floor Leader

The Honorable Willie L. Brown, Jr.
Speaker of the Assembly
and Members of the Assembly

The Honorable Patrick Nolan
Assembly Minority Floor Leader

Dear Governor and Members of the Legislature:

On January 29, 1987, the Commission on California State Government Organization and Economy, also known as the Little Hoover Commission conducted a public hearing on the access of the disabled population to substance abuse treatment. The hearing focused on determining if methods of enforcing the current federal and State mandates for program access and nondiscrimination are effective, identifying the size of the disabled abusing population, and determining if there are adequate methods of coordinating information and referrals to ensure the delivery of services.

The Commission believes that California has made great strides in establishing a network of referral and treatment centers to serve people who abuse drugs and alcohol. However, many members of the disabled community still lack access to existing treatment programs despite federal and State mandates.

The Commission's study found that there may be as many as 500,000 disabled Californians with alcohol or drug related impairments that are not able to obtain treatment. Specifically, our review identified the following problems:

- Drug and alcohol abuse is a much larger problem among people with disabilities than commonly believed.
- The disabled population is unable to access treatment programs due to several different types of barriers.
- State and local agencies need to coordinate more effectively the delivery of substance abuse treatment programs to the disabled population.

To help solve these problems, the Commission believes that the Governor and the Legislature should establish a special ad hoc commission to develop a more accessible alcohol and drug service system for persons with physical, mental, sensory or developmental disabilities.

The remaining sections of this letter presents background information pertaining to our review, a discussion of our major findings, and the Commission's recommendations for addressing the problems identified during the study.

BACKGROUND

The Federal Rehabilitation Act of 1973 prohibited all publicly-funded programs, including alcohol and drug abuse treatment programs from discriminating against persons otherwise eligible to receive services on the basis of physical or mental impairment. In 1977, the State Legislature passed AB 803 which made it a civil offense to discriminate on the basis of physical or mental disability in programs funded with State tax monies. This was followed by the passage of AB 2086 in 1980 which had, as one of its major objectives, better accessibility to substance abuse programs for the disabled. In addition, a large number of court decisions over the last 10 to 12 years have upheld the right of access by disabled persons to publicly-funded programs and facilities. These federal and State legislative enactments provide the legal basis for assuring that publicly funded drug and alcohol treatment programs provide services to the disabled.

However, despite federal and State legislation and mandates, equal access to alcohol and drug treatment facilities does not exist for many disabled people. To date, there has been only limited enforcement activity at the State, federal or local levels of these requirements.

It is well recognized that alcoholism and drug abuse are massive problems in the United States. During the last ten years, there has been increasing attention paid to the causes, effects, and consequences of alcohol and drug abuse. Public concern has focused on the prevention and treatment of substance abuse. Publicly and privately-funded programs on the national, state, and local levels have been rapidly established or expanded to deal with these problems. Minority groups, children, and women have each had programs either specifically tailored to meet their needs or have had specific efforts made to bring them into existing treatment programs. However, with all this activity and concern, the needs of people suffering from some form of physical or neurological disability have not been effectively addressed in treatment programs in California.

This problem of access to drug and/or alcohol abuse treatment is particularly important to people with disabilities because of the interrelation between the original, disabling condition and the abuse of alcohol or drugs. Rehabilitation professionals and concerned individuals have long recognized that, in order to have an effective rehabilitation program, the program participants must be willing to work towards rehabilitation. Both rehabilitation and substance abuse experts agree that attempting to help a person overcome a physical, mental,

sensory, or developmental disability without recognizing and effectively treating the "primary" disability, alcohol or drug abuse, is simply not cost-effective.

The State of California funds substance abuse treatment programs through the State Department of Alcohol and Drug Programs. For the 1986-87 fiscal year, the Department has a total budget of $120,116,000 which includes $13,906,000 for drug prevention, $39,335,000 for drug treatment and rehabilitation, $11,030,000 for alcohol prevention and $31,812,000 for alcohol treatment and rehabilitation. However, the Department does not have the ability to distinguish program clients who are disabled, nor can it determine how much of the total program funding is used to provide treatment for the disabled community.

Additionally, the State of California funds programs for the disabled population through the Departments of Mental Health, Rehabilitation, and Developmental Services. The total programs in each of the departments for the 1986-87 fiscal year are $941,696,000, $187,786,000 and $854,011,000 respectively. Each of the departments have stated that substance abuse treatment is provided on an individual basis, and therefore, the aggregate number of disabled clients receiving substance abuse treatment and dollars expended is not available.

DRUG AND ALCOHOL ABUSE IS A MUCH LARGER PROBLEM AMONG PEOPLE WITH DISABILITIES THAN COMMONLY BELIEVED

One of the major obstacles in approaching the problem of access of the disabled community to substance abuse programs is the lack of current data on the need for substance abuse programs by those who are disabled. The State agencies charged with oversight of treatment programs have no current information on the size of the disabled abusing population. The most recent State data stems from a Department of Rehabilitation survey done in 1980. The results of the survey showed that 248,750 persons had both severe alcohol abuse problems and some other form of impairment. No information was gathered on the number of disabled who had significant drug abuse problems.

Currently, the Department of Rehabilitation estimates that between 10 and 18 percent of the State's population has some form of serious functional impairment. Conservatively, this means that between 2.3 and 4.1 million Californians have some form of significant, life-impairing disability.

For the general population, it has been accepted that approximately 10 percent of the population has a major problem with alcoholism, and an additional 10 percent are impaired by drug abuse. Most rehabilitation professionals working with the disabled, however, believe that the percentage of alcohol and drug abuse among the disabled populations is much higher. There are many reasons for this: the disabled feel a sense of "isolation and despair"; they have easy access to prescription drugs; the attitude of others that "they (the disabled) deserve some pleasure/relief"; and the lack of treatment and correction programs. However, if the estimate for the general population of 20 percent impaired by alcohol or drugs is conservatively applied to the State's

disabled population, at least 500,000 disabled Californians have alcohol or drug related impairments.

Other experts believe that the percentage is much higher. For example, a 1985 paper entitled "Alcohol Use by Persons With Disabilities" written by Al Buss, an expert in the field, reports that disabled people are 50 percent more likely to be heavy drinkers than the general population. Specifically, he stated that those disabled with the highest proportion of "heavy drinkers" were the blind, or the medically handicapped, and spinal cord injured.

A report entitled "The Multiple Dilemmas of the Multiply Disabled," prepared by the New York State Commission on Quality of Care for the Mentally Disabled, states that "approximately 20 percent of all psychiatric admissions in the New York City area are of patients suffering from problems related to the abuse of crack, a form of cocaine."

Additionally, the Executive Director of the Darrell McDaniel Independent Living Center, which provides services to 3550 persons with disabilities, testified at the Commission's hearing that research conducted by its Van Nuys office found the following statistics regarding the size of the disabled abusing populations:

- 35 percent of the clients using their attendant referral service have problems with substance abuse.

- 25 percent of the clients needing housing assistance have had problems with housing due to substance abuse.

- 40 percent of the clients using emergency food and shelter program services have a history or current abuse of drugs or alcohol.

Therefore, it is not unreasonable to assume that the percentage of alcohol and drug abuse among the disabled population is much higher than the 20 percent estimate for the general population.

THERE ARE SEVERAL DIFFERENT TYPES OF BARRIERS THAT THE DISABLED COMMUNITY IS FACED WITH EVEN WHEN SEEKING ACCESS TO TREATMENT

Although State and federal laws have been enacted to ensure that the disabled population has access to treatment programs, the President of the World Institute on Disability testified that the Office of Enforcement within the Department of Rehabilitation responsible for insuring the enforcement of State and federal mandates regarding nondiscrimination "does not exist." Representatives of the disabled contend that State and local agencies and programs continue to ignore the clear mandates of law. For example, in Los Angeles, it was not until 1984 that legal mandates for wheelchair access to public buildings and programs were fully enforced.

A study entitled, "Network Development: Linking the Disabled Community to Alcoholism and Drug Abuse Programs," prepared by Alan

Lowenthal, Ph.D. and Pete Anderson, Executive Director of the Disability Substance Abuse Task Force, found that alcohol treatment centers deny the disabled clients the full benefit of their services. Disabled Californians with substance abuse problems often are prohibited from participating in treatment programs in a number of ways including: (1) architectural barriers to treatment programs; (2) lack of materials for those with severe vision impairments; (3) lack of interpretive services for people with hearing impairments; (4) lack of programs conducted in a manner understandable to those with major intellectual/neurological limitations; and (5) program staff who have a limited understanding of disabilities other than alcohol or drug addiction. Each of these barriers can effectively exclude the disabled from receiving rehabilitation.

For example, with regard to physical access, those programs that are located in buildings without wheelchair access, or without restroom cubicles large enough to accommodate wheelchairs, effectively deny access to the physically disabled. Signs or low-hanging light fixtures can make a hallway into an obstacle course for those with severe vision problems. And the lack of sign interpreters effectively closes off access to programs for the hearing impaired, because group dialogue is central to most treatment programs.

Treatment facilities and recovery homes in several Southern California counties have, in effect, been denied permission to serve the disabled because of county fire and building ordinances that require specific building renovations which would exhaust the program's funding. As an example, in 1980 a survey was conducted in Los Angeles County to determine whether county-funded alcohol treatment programs had sufficient capacity to handle the needs of disabled alcoholics. Out of one hundred such programs, all but a few even provided basic access for those in wheelchairs. In addition, few were equipped to work with the blind or the deaf, and none had extensive experience dealing with disabled alcoholics or were able to accommodate a wide range of disabilities.

The problem is even more extreme and programs are even less available to the disabled within private sector treatment facilities. For example, many treatment programs will not provide sign interpreters for the deaf, or will take those with severe physical disabilities "only if they can walk". Program directors allegedly have also stated that they prefer not to have anyone with more than a very minor impairment in their programs. The reasons that they give for this position included: "distracts other participants and disrupts treatment"; "consumes valuable program resources"; and "we simply don't known how to deal with them". In each of these cases, the programs allegedly received tax-generated funds.

The fundamental difficulty of access is two-fold. First, those who operate many of these programs may not want to deal with the presence and special requirements of the disabled. Second, the general feeling is that the cost of bringing facilities into line with the needs of the disabled and of maintaining appropriate staff may be more than the total budget.

Part of the problem is that eligibility criteria effectively discriminates against the disabled population. For example, the Darrell McDaniel Independent Living Center testified at a Commission hearing that their offices conducted a survey of the treatment programs in their area. Twenty-seven programs were surveyed. The survey resulted in the following:

- 25 percent of the facilities they surveyed would not permit persons using prescription medication to enter their programs.
- Only 7 percent of the facilities surveyed accepted Medi-Cal or Medicare as payment for treatment.
- Only 59 percent of the programs would use a sliding scale according to the client's income level.
- 40 percent of the treatment programs were not accessible to persons using wheelchairs.
- 30 percent of the treatment programs were in areas where there was no public transportation for persons in wheelchairs even though all treatment programs receiving federal or California State funding are required by law to have facilities accessible to persons in wheelchairs.
- In 99.7 percent of the treatment programs surveyed, American sign language interpreters for the deaf or hearing impaired were not available and would not be paid for by the treatment program or the person's insurance. Even though 45 percent of the programs were required to provide these interpreters.

The impact of the program limitations and barriers imposed by the substance abuse treatment system on the disabled populations are significant. For example, the quarterly newsletter from the Coalition on Disability and Chemical Dependency entitled, "The Seed" reported that in one Bay Area county, a 1984 survey of publicly-funded treatment programs found no physically disabled clients among a client population of more than 500. Further, the newsletter stated that preliminary analysis indicated that there may be several thousand disabled individuals in the Bay Area who have an untreated alcohol and/or drug abuse problem.

THERE IS A NEED TO MORE EFFECTIVELY COORDINATE STATE AND LOCAL SUBSTANCE ABUSE PROGRAMS FOR THE DISABLED

Ultimately, it is the responsibility of the Department of Alcohol and Drug Programs to take the lead in promoting and facilitating the accessibility of the State's substance abuse treatment programs for the disabled. The Department is directly responsible for publicly funded, low income programs, those which are more likely to have clients with disabilities. Although there has been ample legislation in California designed to ensure access to publicly funded programs and facilities, it appears that neither the letter nor the spirit of these laws have been honored.

One key problem is that there is little emphasis on sharing resources among programs. In addition, training between agencies is limited and there is no effective coordinated network to ensure the delivery of substance abuse treatment to the disabled population. For example, the Commission received numerous letters from individuals and organization including the Los Angeles County Commission on Alcoholism, the Catholic Deaf Community, the Short Stature Foundation, and the Darrell McDaniel Independent Living Center which described the lack of coordination among substance abuse treatment programs in trying to serve the disabled.

In each of these cases, the message was the same--substance abuse treatment programs are unaccessible to many members of the disabled population. However, the Department of Alcohol and Drug Programs testified before the Commission that there have only been two complaints from citizens in California that they have not received services because of their disability. In response, a representative from the disabled community submitted written testimony that "people find the (complaint) system overwhelming."

To further illustrate that the system is fragmented, the Department of Alcohol and Drug Programs was developing a handbook three and a half years ago regarding substance abuse programs available to the abusing disabled population. However, this handbook was never disseminated because, as the represeeeentative from the Department testified, "It was not thought highly of." He further stated, "It did provide information about various types of disabilities, things to be concerned with when you're responding to those disabilities and treatment settings but the information was thought to be outdated and in some cases inappropriate so we just did not issue the handbook because of the complaints of organizations."

These examples demonstrate that the State, local and private entities responsible for ensuring that the disabled population receives adequate treatment are not effectively meeting the needs of the disabled. Specifically, the existing alcohol and drug treatment system is not providing a coordinated cohesive network for the delivery of substance abuse treatment to the disabled community.

RECOMMENDATIONS

The existing alcohol and drug service system has not fully addressed the needs of the disabled population or the barriers they face in seeking treatment to allow them to recover and become productive citizens.

The Commission believes that the main issue is not new funding dedicated to special programs for the disabled community, but rather integrating the disabled community into existing substance abuse treatment facilities. To successfully address this problem, the State must establish authority, control, and leadership in the provisions of substance abuse programs for the disabled. The Commission believes that the critical unmet needs of this population can no longer be bounced among different agencies with no definitive focus of responsibility, leadership and accountability. The costs are too great to the disabled, to their families, and to the taxpayers of California.

The Commission recommends the following:

1. The Governor and the Legislature should establish a special adhoc commission to develop a more accessible system of alcohol and drug services for persons with disabilities. The special ad hoc commission should include representatives from each of the involved State agencies, county representatives and representatives from the disabled community.

2. The Governor and the Legislature should require the Department of Alcohol and Drug Programs to develop a data base to identify the disabled population that is receiving and/or requesting substance abuse treatment.

3. The Special Commission should consider requesting that the Governor and the Legislature incorporate alcohol and drug abuse peer counseling as part of the core services of Independent Living programs. This would require amending AB 204 to allow all independent living programs to provide this service.

The Commission believes that the Governor and the Legislature should adopt the measures in this report to ensure that the disabled population receives equal access to all public funded treatment programs as required by State and Federal laws.

Respectfully submitted,

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