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A REDEFINITION OF
STATE RESPONSIBILITY
FOR CALIFORNIA'S
MENTALLY RETARDED

Assembly Ways and Means Committee
Subcommittee on Mental Health Services

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LETTER OF TRANSMITTAL

Assembly Interim Committee on Way and Means
California Legislature

March 31, 1965

To the Speaker and Members of the Assembly

Dear Mr. Speaker and Members:

In accordance with House Resolution 64, 1963 General Session, your Interim Committee on Ways and Means herewith submits its final report on state mental health services.

The committee is indebted to the many persons, both private citizens and public officials, who were of invaluable assistance in the course of this study.

Respectfully submitted,

ROBERT W. CROWN, *Chairman*

CARLOS BEE
FRANK BELOTTI
CARL A. BRITSCCHI
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Report of the
ASSEMBLY INTERIM COMMITTEE ON
WAYS AND MEANS

Robert W. Crown, Chairman

SUBCOMMITTEE ON MENTAL HEALTH SERVICES

A REDEFINITION OF STATE RESPONSIBILITY
FOR CALIFORNIA'S MENTALLY RETARDED

MEMBERS OF SUBCOMMITTEE

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NICHOLAS PETRIS

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ED JUERS, *Legislative Intern*
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Assembly
California Legislature

JEROME R. WALDIE
ASSEMBLYMAN, TENTH DISTRICT
CONTRA COSTA COUNTY
MAJORITY FLOOR LEADER

March 3, 1965

HONORABLE ROBERT W. CROWN, *Chairman*
*Assembly Interim Committee on Ways
and Means*

Dear Mr. Crown:

The Subcommittee on Mental Health Services was appointed following adjournment of the 1963 General Legislative Session in accordance with House Resolution No. 64.

The subcommittee wishes to express its appreciation to the professional personnel of various agencies and to the thousands of private individuals who provided information and opinions for the committee's consideration.

Respectfully submitted,

JEROME R. WALDIE, *Chairman*
FRANK LANTERMAN
NICHOLAS C. PETRIS



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INTRODUCTION

About 5 percent of California's mentally retarded population have traditionally been a responsibility of state government. These are the ones who require care and services their families are unable to provide. Since 1850, the state has maintained state hospitals for these people.

This is the first of two reports about these retarded persons, their families, and the state system designed to meet their needs. This first report describes an organizational weakness.

The second report, to be published later this year, will review the state's hospitals for the retarded and will include suggestions for improving the services in these state facilities.

* * * * *

In 1963, House Resolution No. 64 created an interim committee to study mental health services in California. Three assemblymen have served as a special subcommittee of the Assembly Ways and Means Committee to conduct this study.

The interim committee members are: Jerome R. Waldie (D), of Antioch, Chairman; Frank Lanterman (R), of La Canada, and Nicholas Petris (D), of Oakland.

The first few months of the subcommittee's activities were devoted to investigating general problems in the Department of Mental Hygiene, culminating in a public hearing on October 22, 1963. In December 1963, the subcommittee selected the field of mental retardation for intensive study and since then has been conducting an analysis of the state's program for the retarded.

There were several reasons for concentrating on mental retardation:

a *Federal funds had recently been made available to speed the development of state programs for the retarded, and the Legislature would have to be prepared to make effective use of these funds.*

b *In 1962 the Department of Mental Hygiene, at the request of the Legislature, prepared a "Long Range Plan for Mental Health Services in California." That plan suggested a sharp change of direction in state services for the retarded, but the Legislature had not yet taken steps to enact laws to accomplish the recommended changes.*

c *In 1963, the California Study Commission on Mental Retardation was created to suggest additional legislation to the 1965 General Session. The Legislature should be prepared to evaluate the commission's proposals.*

d *From time to time questions have been raised regarding conditions in our state hospitals. Previous legislative committees had probed specific incidents, but a comprehensive review of hospital programs and policies was needed.*

e *The Legislature has long been frustrated in its efforts to solve the chronic problem of families with children on the "waiting list" of state hospitals. Despite the rapid expansion of the state hospital system and the development of community mental health programs, the "waiting list" remains a constant problem. The subcommittee determined to focus a major portion of their energy in an effort to understand and solve this problem.*

The subcommittee conducted its activities in a somewhat unique manner and a brief chronology of their work may be interesting to students of the legislative process in California:

Step No. 1—(December – January)

A questionnaire was submitted to each of the state hospitals serving the mentally retarded. The 48-page questionnaire covered every major aspect of program from admission policies to "after-care" services. Responses to the questionnaire were thorough and complete. They were analyzed and a number of problems were noted. During this same period, hospitals were visited and discussions were held with hospital employees, parents with children in the hospitals, and representatives of professional and citizen groups interested in problems of the retarded.

Step No. 2—(February – March)

Two public hearings were held (February 21st and March 26th). These hearings were concerned with some of the problems uncovered in visits to the hospitals and through the questionnaire. The hearings focused on: educational services, uniformity of standards and policies, aftercare services, training of psychiatric technicians and several other administrative problems.

Step No. 3—(April – June)

In the early spring the subcommittee decided to prepare and publish a preliminary report describing their initial findings and conclusions regarding the problem of the "waiting list." The report was issued in June under the title "*A Preliminary Proposal to Eliminate Waiting Lists for State Hospitals for the Mentally Retarded.*" The report was mailed to over 1,000 individuals and organizations for the purpose of soliciting reactions and suggestions.

Step No. 4—(July – October)

During the summer months, the subcommittee conducted a survey of the 225 private facilities licensed to care for the mentally retarded in California. The results of the survey were published in October under the title "*Supplementary Factual Report No. 1.*"

On October 2nd the subcommittee held a public hearing in Los Angeles to give citizens from southern California an opportunity to react to the preliminary proposal.

Step No. 5—(November – December)

Because the subcommittee's preliminary proposal suggests major changes in the state's pattern of services for the retarded, it was vital to determine the reactions of those who would be most directly affected. A questionnaire was therefore submitted to every family in California with a retarded child on the "waiting list" to a state hospital. Through the questionnaire and numerous letters the subcommittee was able to communicate with over 1,200 families facing this problem. (There are over 1,800 on the "waiting list.") In December the results of this survey were published under the title "*Supplementary Factual Report No. 2.*"

On December 5th a public hearing was held at Santa Cruz to enable citizens from northern California to react to the preliminary proposal.

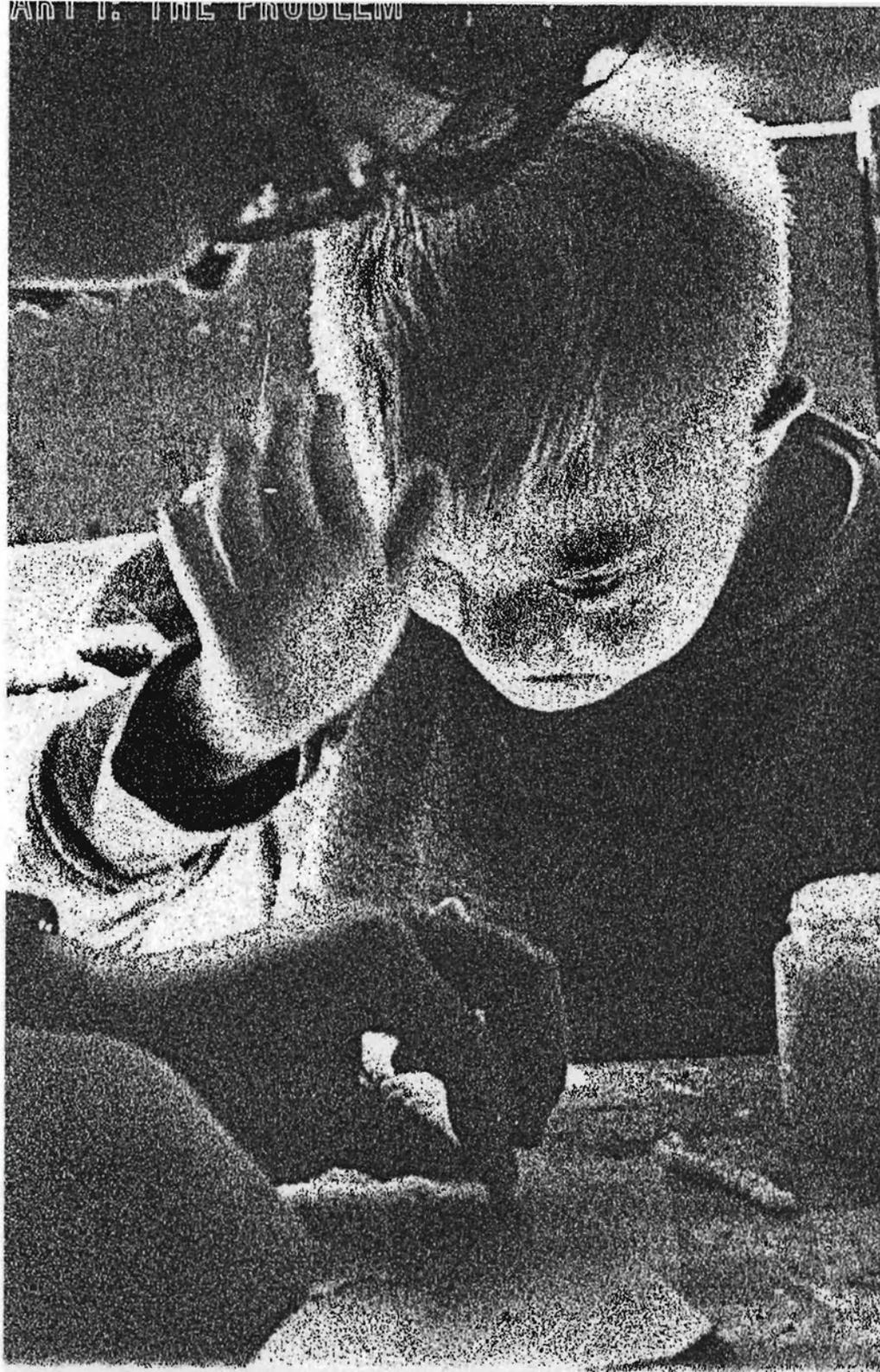
The report that follows summarizes the results of the subcommittee's investigation of the "waiting list" problem.

SUMMARY OF FINDINGS

- 1 Procedural weaknesses in existing state programs to aid the mentally retarded have resulted in an inability to provide badly needed services on a timely basis.
- 2 By making admission to state hospitals the sole route to gain state support for the costly care of the mentally retarded, lengthy waiting lists have resulted which have worked undue hardships on the afflicted and their families.
- 3 Many mentally retarded persons not requiring hospital care are unnecessarily forced to seek state hospital placement rather than being placed directly in community facilities or receiving other services more suited to their individual needs.
- 4 Public and private community-based services, including residential facilities, are not used to full advantage. While state hospital facilities for the mentally retarded are filled to capacity and lengthy waiting lists exist, state-licensed private facilities have substantial numbers of vacant beds.
- 5 Private residential facilities and professional home care services may be more suited to individual needs and in most instances can be secured at a cost less than the \$300-\$400 monthly cost of maintaining a mentally retarded patient in a state hospital.
- 6 Mentally retarded children, who can receive proper care in the community and whose parents prefer such service, should remain in the community whenever possible. Few families can now afford this.
- 7 Expanded state support for community residential care of the mentally retarded, in addition to supplying more appropriate care to the patients involved, would ease the strain on state hospital facilities and would reduce the need for the extremely costly construction of new facilities.
- 8 Privately operated facilities providing care for the mentally retarded are hampered by conflicting policies regarding licensing, inspection and standard setting administered by different state agencies.

SUMMARY OF RECOMMENDATIONS

- 1 State responsibility for the mentally retarded should be shifted from the time the patient enters a state hospital to the earlier point when expert diagnosis determines that special care is needed that the family is unable to provide.
- 2 The State Department of Public Health should be given the responsibility for contracting with appropriate community-based medical agencies to provide regional services, including the initial diagnosis determining whether special care beyond that available in the home is necessary.
- 3 The regional centers, in addition to diagnostic services, should:
 - a. Provide counseling services to affected families;
 - b. Determine eligibility for state support of patients in community facilities;
 - c. Assist families in selecting appropriate community services;
 - d. Provide continuing supervision and case management services for patients receiving state supported care;
 - e. Periodically inspect community service facilities for compliance with established standards.
- 4 In addition to the above actions, the budget for 1965-66 of the Department of Mental Hygiene should be augmented in whatever amount necessary, up to \$500,000, to expand its private placement program to open space in the hospitals for some of the more urgent cases on the waiting list.
- 5 A position "Director of Mentally Retarded Care Standards" should be established in the Health and Welfare Agency having the responsibility to:
 - a. Set licensing standards for institutions contracting with regional centers to provide care to the mentally retarded;
 - b. Set rates which will permit licensed institutions to meet and maintain established standards.
- 6 An advisory body should be established composed of representatives of agencies rendering services to the retarded and representatives of families of retarded patients to review and advise on standards established for various kinds of care.
- 7 Families of the mentally retarded should be permitted to transfer personal guardianship of their children to the Director of the State Department of Public Health after appropriate screening by a regional center.



A Greek myth tells of Sisyphus, an evil king of Corinth, condemned in Hades to roll up a bill, a huge stone which constantly rolled back.

Each year, hundreds of families plead for help when the problems of caring for their mentally retarded children become overwhelming. And each year the State of California increases the capacity of its hospitals in response to this pressure. But as California's population grows, and as medical science finds new ways of keeping retarded infants alive, the problem of the "waiting list" stubbornly remains. We've grown accustomed to a "waiting list" for our state hospitals. The ever-present "waiting list" is tragic testimony to an organizational weakness in state services.

The State of California and its elected officials have been responsive to this problem. The state has always accepted its responsibility for the care of retarded children. Year after year the Legislature has appropriated additional funds to eliminate the problem. Since 1955 the support budget for state hospitals for the retarded has increased from \$15.2 million to \$44.7 million. Nevertheless at almost any time during the past 10 years a "waiting list" of 2,000 or more retarded persons was knocking at the door.

There are now over 13,000 retarded persons in our state hospitals. To meet the total need for residential care in the traditional manner, the Department of Mental Hygiene has estimated the state should build over 3,000 new hospital beds during the next four years. The estimated capital outlay for this expansion would be \$47.6 million.¹

(Plans are already in motion to construct such facilities. The Department of Mental Hygiene now recommends the construction of 2,000 of these new hospital beds and the Department of Finance has already been granted \$75,000 for working drawings for one 500-bed facility.)²

Should the *only* response to the problem be to construct 3,000 new beds, by 1968 there would be 16,000 retarded persons in our state hospitals. In addition to the \$47.6 million the state would have spent on construction, the yearly support budget for hospitals for retarded would be at least \$11 million more than the present \$44.7 million.

But, as this is done, a new "waiting list" would accumulate and by 1968 it would be necessary to build again!

¹ See appendix for complete discussion of hospital bed projections and costs.

² Tentative Proposal for a Five-Year Program, California Department of Mental Hygiene, October 5, 1964.

The dilemma is not unique to California. New York State has twice the number of state hospital beds that we do, but they are also involved in a Sisyphean struggle with a "waiting list."

AN ORGANIZATIONAL WEAKNESS

The state now assumes responsibility for the care of a retarded child *only after that individual enters the state hospital. As a result, the number of beds available, posed against the steadily growing population, creates an ever-present bottleneck.* As the system now operates, the pathway to state-supported service can be reached only through the state hospital door whether or not hospital care is needed or desired.

The Department of Mental Hygiene has determined that *less than half of the children on the present "waiting lists" require care in a state hospital.*³

Of the 2,171 retarded persons on the "waiting list" on April 30, 1963, only 924 were found to be in need of hospital care after thorough clinical diagnosis. Nevertheless, all 2,171 were placed on the preadmission list for state hospital placement.

The fact that more than half of our present state hospital population and more than half of our "waiting list" must be channeled unnecessarily through state hospitals is testimony to a basic flaw in the way state responsibility is structured. Other alternatives simply are not available to parents of these children.

For over a century the narrow definition of state responsibility has meant that children who cannot be maintained at home must be fitted into the state hospitals.

The state hospitals are required to be "all things to all people" and provide a wide range of services for their varied clientele. In fact, for over half the "patients", these hospitals do not really serve as hospitals at all. For some, the hospital attempts to be a school, for others a nursing home, for some a home for the aged, for others a sheltered workshop and boarding home, and for some "patients" the hospital is a way station before transfer to a foster home or other community facility.⁴

³ Department of Mental Hygiene, *Survey of Patient Needs for Residential Care and Assistance, Bulletin No. 34, August, 1963, p. 8.*

⁴ *Ibid.*, 33, *The Department of Mental Hygiene has studied the needs of the present population in our state hospitals for the retarded and concluded that "only 36.3 percent require hospitalization for medical, surgical, or psychiatric reasons." Also see appendix for more complete discussion of characteristics of the retarded population.*

In 1963, the state financed care for 1,600 moderately retarded persons in foster homes and 115 profoundly retarded "crib cases" in small private nursing homes. All these people had to go from the "waiting list" into the state hospitals before being placed in their present homes. This peculiar arrangement makes "waiting lists" inevitable. Under the present arrangement, hundreds of children are moved from their own homes into the large wards of state hospitals, only to be moved again into foster homes or nursing homes. And in many cases, the present procedure results in years of hospital living for people who should never have been placed in a state hospital in the first place.

The heart of the problem is that most families who are unable to care for their retarded child at home have no choice other than to place the child in a state hospital.

MANY FAMILIES WANT ALTERNATIVES

*The subcommittee's survey indicates that about half the families with children on the current waiting list for state hospitals for the retarded would not place their children in a state hospital if other alternatives were available.*⁵

These families state they would prefer to hire help to assist them in caring for their children at home, or would elect to place their children in private care facilities such as foster homes or private institutions if funds were available to help them pay for these services.

The present state system does not offer such alternatives to state hospital care. The following quote from one of the many letters to the committee illustrates the dilemma:

"Our son is four years old, and living for the past few months in a foster home licensed by the State Department of Mental Hygiene.

"He was diagnosed by Dr., at the Birth Defect Center at Children's Hospital in San Francisco, as neurologically damaged and severe sensory receptive aphasia. We were advised to make an application for him at Sonoma State Hospital The hospital told us that he was eligible but not suitable—that they could not duplicate the care and education he was receiving in San Francisco.

"Naturally we were delighted that he can be here in San Francisco where we can visit him, and that he is

⁵ *Special Committee on Mental Health Services, Assembly Ways and Means Committee, Supplementary Factual Report No. 2, December, 1964.*

showing progress in the classes for aphasic children at the San Francisco Hearing and Speech Center.

"But, I'm afraid we are classic examples of the middle-income family unable to afford the \$150 a month for his care. My husband makes an adequate salary for a family of seven with normal expenses we are not eligible for any aid from public welfare We're a bit stymied at this point. We are praying that funds will be made available as a result of new legislation and it is on that premise that we are taking a loan to help us take care of our son for the next several months."

For children needing special care, the only present way to circumvent the state hospital is through privately financed placement in a school, foster home or nursing home. About 2,500 retarded persons are now cared for in this manner. Unfortunately only the wealthy can afford this alternative for long periods—or the very poor whose children qualify for public welfare support in private institutions.

At the present time there are many vacancies in private facilities specifically licensed by the California State Department of Mental Hygiene to provide residential care for the mentally retarded.⁶ The evidence indicates that lack of funds is a major reason preventing families from placing their children in these facilities.⁷ (Another important fact is that over 55 percent of the families who have placed retarded children in private facilities are receiving some form of public assistance to help them pay for all, or part of, the cost of care. This fact suggests that low income families who are eligible for financial assistance and upper income families who can better afford the long-term expense are able to make greater use of private placements than middle-income families who cannot manage a continual drain on their family resources.)⁸

THESE FINDINGS CLEARLY SHOW THAT FAMILY INCOME IS A PRIMARY FACTOR LIMITING THE USE OF PRIVATE COMMUNITY FACILITIES FOR THE RETARDED. FEW FAMILIES CAN AFFORD TO HIRE HELP AT HOME OR PAY THE FEES IN PRIVATE FACILITIES AND HALF OF THOSE NOW IN PRIVATE FACILITIES WILL EVENTUALLY BE SHIFTED TO THE STATE HOSPITALS WHERE THE FAMILIES ARE REQUIRED TO PAY ONLY \$20 A MONTH.⁹

⁶ Special Committee on Mental Health Services, *Assembly Ways and Means Committee, Supplementary Factual Report No. 1, October, 1964.*

⁷ *Supplementary Factual Report No. 2, op. cit., p. 10.*

⁸ *Supplementary Factual Report No. 1, op. cit., p. 15.*

⁹ See Appendix, Table VIII, for information regarding movement of retarded persons from community to state hospital facilities.

As one parent put it: "Upon admission to the state hospital the parent's contribution to the care of the child drops to \$20 per month and remains at that figure even after the child is placed back in the community by the hospital . . . the state is, in fact, providing a financial reward to the family for the utilization of state hospital services."

In summary, a major cause of the lengthy state hospital "waiting lists" stems from the fact that despite the needs of children or the desires of their families, the state offers no alternatives other than the state hospital for these retarded children. Each year almost 1,000 retarded children are being funneled into a single system and family finances are a primary factor in determining where these children will go.

A HIGH PRIORITY MUST BE GIVEN TO CHANGING THE SYSTEM WHICH FORCES FAMILIES AND THEIR CHILDREN TO WAIT FOR A SERVICE WHICH IS OFTEN INAPPROPRIATE.

THE EFFECTS OF INSTITUTIONALIZATION OF CHILDREN

There is a massive body of professional knowledge and opinion that clearly documents the effects of institutionalization in large facilities remote from the natural family and the normal community.

Typical of research findings on this matter is the recent comparison of two groups of equally retarded children in California—one group residing in the community and the other at Sonoma State Hospital. The researchers conclude:

"The fact that the institution groups showed significant decreases in their social competency scores over the two-year study period, whereas the community groups showed significant increases, would indicate that the general environmental situation within the institution was not conducive to the development of trainable retarded children. The school within the institution apparently cannot counteract the pervasive lack of stimulation by providing a few hours of training each day.

"It is questionable whether the school within the institution can carry out a consistent and systematic program for trainable mentally retarded children, as institutions are presently constituted. Although no formal observational procedures were employed, the general impression of the institutional wards in which the children participating in the study resided, was that there was little opportunity for developing social competence. The children, when seen on the wards, were wearing hospital-

type smocks, no shoes and no socks, thus minimizing many learning experiences relative to dressing. A review of the items included in the San Francisco Social Competency Scale with one of the institution's administrative staff members indicated that there are a number of social competency skills that cannot be learned on the wards by the children because of restrictive institutional policies or limited environmental opportunities. For example, the children living on the wards involved in this study are permitted to use only spoons for eating, and learning to eat with a fork or cut with a knife is therefore not possible.

"The data of this study supports the point of view that the institution is not as desirable a setting as is an adequate home environment for the development of trainable mentally retarded children. It would appear that the present trend to keep such children at home is desirable despite the varied services available within the institution. There is also evidence to support the premise that a similar investment on the part of communities in providing professional services for trainable children would lead to an increased preference by parents for keeping their children at home."¹⁰

There is no doubt that we will better serve the interests of trainable retarded children, and perhaps even other more severely retarded children, if we redesign our system to provide home care help and other community-based alternatives to state hospital placement for those families who desire such choices.

The committee wishes to make it quite clear that its purpose is to expand the choices available to families. This does not exclude the state hospital choice. For families who prefer state hospital services (50 percent of those on the waiting list indicate this preference) and for families whose children may require state

¹⁰ Leo F. Cain and Samuel Levine, *A Study of the Effects of Community and Institutional School Classes for Trainable Mentally Retarded Children*, (San Francisco State College, 1961), Study done under contract number S.A.E. 8257, U. S. Office of Education, Department of Health, Education, and Welfare.

See Also: William Goldfarb, "The Effects of Early Institutional Care on Adolescent Personality," *Journal of Experimental Education*, Vol. 11-12, 1942-1944, pp. 106-129.

N. O'Connor and J. Tizard, *The Social Problem of Mental Deficiency*, (London: Pergamon Press, 1956).

Gerhart Saenger, Ph.D., *Factors Influencing the Institutionalization of Mentally Retarded Individuals in New York City, A report to the New York State Inter-Departmental Health Resources Board*, January, 1960.

Philip Marden and Bernard Farber, "High-Brow versus Low Grade Status Among Institutionalized Mentally Retarded Boys," *Social Problems*, 8 (1961), pp. 300-312.

hospital services, state hospitals should be available. It is the committee's intention to publish another report within the next year analyzing state hospital programs with a view toward improving the services in these institutions.

It will take time to develop adequate alternative services to hospital care. In view of this, it is most important that those interested in services for the retarded avoid the mistake of placing this issue in "either/or" terms. The state hospitals have, and will continue to have, a significant job to do. But they are not the only way in which the state should honor its obligation to this group of children.

HOW DO THE PARENTS FEEL ABOUT INSTITUTIONAL PLACEMENT?

In addition to analyzing information provided by agencies, professional persons, and organizations, the subcommittee has probed another dimension. Of major importance is the attitude of the individuals who use these services. What do parents of retarded children want the state to do? How do they view their problem, and what solutions are they seeking? The subcommittee attempted to find answers to these questions through correspondence with over 100 families with retarded children and a questionnaire answered by more than 1,200 families with children on the waiting list for state hospitals.

The results indicate that half the families most directly affected would like to have the state provide alternatives which are not now available.

Fortunately, and quite coincidentally, at almost the same time the subcommittee was conducting its research, another study was being carried out. On December 5th, Dr. Carolyn M. Fowle reported to the subcommittee the results of her study of 140 parents of retarded children.¹¹ Half of the families concerned had children on the waiting list and half had placed their children in Porterville State Hospital during the past five years. Dr. Fowle's observations provide further confirmation of the committee's findings.

In the face-to-face interviews conducted by Dr. Fowle almost 75 percent of the families stated a preference for a community-centered residential facility. In view of the timely significance

¹¹ Carolyn Fowle, "The Effect of the Severely Mentally Retarded Child on His Family" (unpublished doctoral dissertation, University of the Pacific).

of this new information, we will quote portions of Dr. Fowle's testimony: ¹²

"... Of the 70 parents interviewed who had hospitalized their retarded child, 56 said they would prefer a community-centered residential facility. Of the other 70 parents interviewed who had their retarded child at home, 40 stated that they would like a small 24-hour facility closer to home than the present state hospital. It should be noted that the question was not worded, 'Do you favor such and such?', but rather the question was, 'What additional services would *you* like to have?' The responses were spontaneous, and seemingly this item generated more force than many of the others.

"In summary, the need for *community* residential care was the need most frequently mentioned by the 140 parents interviewed.

"It was my impression that for the most part retarded children are loved children; their families seem to care for them just as much as they do their other children—if not more. The parents are pained when they must send them off 150 to 200 miles to a large hospital; many parents do *not* want to forget their retarded children—they want to see them frequently—they want them in their own communities. Many parents are plagued by the fear that they are shirking their parental duties when they place their retardate miles away; if the child or young adult could remain in the families' own community, I feel the separation would not be so difficult.

"Generally speaking, the parents seem to want to include their retarded children in their family life whenever possible—and only if the child were in a community facility, would this be possible.

"Listen to a few excerpts from the parents' statements:

'It's so far to Porterville . . . we can't go very often . . . and I feel so guilty . . . sometimes it's so long in between that S. doesn't even recognize me.'

'I'll tell you institutions are not the answer—as institutions are now. If there were more and smaller, it would be different. We want S. to come home—but there's nothing for him here.'

'We didn't want S. to go to Porterville, but we couldn't take the expense. We didn't always live this way; before this all happened, we had a good home and five rooms of furniture. Just one year cost us over \$5,000; I finally had to take bankruptcy.'

¹² Testimony given by Carolyn Fowle before the Assembly Ways and Means Subcommittee on Mental Health Services. The hearing was held December 5, 1964, in Santa Cruz.

'I don't like huge institutions—you just feel you're letting someone else take care of your problems. Better to have smaller community facilities.'

'Well, there's no hesitation for me on what I'd like to see—community 24-hour care. We would like to see S. more often. The trip is really hard on us. We're older. Our car is older. There's so much traffic on Highway 99. If it were only 40 to 50 miles, we could go for a Sunday, or bring him home for a weekend.'

"The second need most often stated by the interviewed parents was that of counseling. The occurrence of mental retardation in a family is usually an event in which the parents have had no previous experience in adapting to the problem. The dilemmas produced by the incident do not end but rather continue throughout the entire life of the retardate and his family members. Counseling only at the time of the diagnosis of the child seems to be insufficient. This was evidenced by the expressed need for counseling services by a significant number of the parents.

"It is believed that with available counseling services some parents would be able to cope with the presence of a retarded child without resorting to placement outside of the home. Parents sometimes stated that they just didn't know what to do, so they institutionalized; occasionally they were influenced by neighbors or relatives to do this. Again some statements:

'There was just no one to talk to—we took her to Porterville because we didn't know what to do. In two weeks we brought her home again.'

'You go down to the probation office . . . just fill out the forms . . . nothing is explained . . . you don't know if you're doing right or wrong. Even another parent would help . . . but they won't give out any names. So you're all alone.'

'A lot of times I just wish I had someone to talk to . . . It really helps me, but there is no one . . . I'd like to ask about Porterville. Do they ever get to come home again?' (Their child is one of those on the current waiting list.)

'People talk about you if you keep the child and they say you're sacrificing the other children. And then other people think you're awful if you put the child away, so you just don't know what to do.'

'There's nothing more hopeless than to have no place to go. We need a place for authoritative advice.'

"I knew very little of the plight of the parents of severely retarded children when I began this study; I inadvertently stumbled on to their overwhelming need for

community residential facilities, such as your committee is proposing. Perhaps, as one parent expressed, this study will indicate to you in some small way, the desire of many parents for community residential care for the retarded."

The evidence clearly indicates that many families would prefer and would use alternatives to the state hospital if they were made available.

FINANCIAL IMPLICATIONS OF THE PRESENT SYSTEM

The cost of constructing and the cost of operating state hospitals is the most expensive of all the alternatives the committee has investigated.¹³

THE COST OF CONSTRUCTION

The cost of building a state hospital facility for one patient is between \$15,000 and \$20,000.

In contrast, several excellent private agencies serving the retarded have reported to the subcommittee that their construction costs range from \$3,500 to \$7,000 per bed.¹⁴

Private agencies are able to build these facilities at lower cost than the state for several reasons: They can eliminate state administrative overhead, and because they are located in the community their "patients" are able to use community hospitals for acute illnesses, thereby eliminating the need to construct separate surgery, laboratory, and other very costly medical facilities now required in state hospitals. State hospitals are designed to meet the total needs of their patients and the resulting laundries, repair shops, surgeries, schools, etc., boost the cost of construction.

THE COST OF CARE

The average cost of caring for a retarded person in a state hospital is \$300-\$350 per month. (This figure does not reflect the cost of construction.)¹⁵

¹³ See appendix for a discussion and breakdown of hospital costs.

¹⁴ Testimony given by Dr. Dennis Marks before the Assembly Ways and Means Subcommittee on Mental Health Services at a public hearing at Sonoma Hospital, February 21, 1964, pp. 104-105.

¹⁵ See appendix, Table V, for detailed analysis of hospital operating costs prepared by Legislative Analyst.

In contrast we quote some statistics gathered in the subcommittee's survey of private agencies:

"Eight out of every 10 persons presently placed by their families in private facilities are being cared for at a cost of less than \$300 per month. The monthly rates being paid to the private institutions for the care of 1,429 children were broken down as follows:

- (a) 371 (25.9 percent) are maintained in private institutions at a cost of less than \$150 per month;
- (b) 790 (55.4 percent) are maintained at a cost of \$150 to \$300 per month;
- (c) 268 (18.7 percent) of the children are maintained at a cost in excess of \$300 per month.

Therefore, 1,161 (81.3 percent) are being maintained in private institutions at a cost of less than \$300 per month—the minimum cost necessary to maintain a child in a state hospital.¹⁶

The cost of care in nurseries and foster homes—even for profoundly retarded crib patients—was less than \$300 per month in over 90 percent of the facilities surveyed.¹⁷

Even though the retarded who are on the waiting list represent the more severely retarded in a community, over three-fourths of them are living at home. The cost of care very likely prevents many parents from placing their child in a private facility. However, the fact that such a large percentage are cared for at home may also indicate that with some type of assistance to the parents some of these children could continue to live at home, utilizing such services as day care centers and homemaker service, rather than being placed away from the family.¹⁸ (The cost of employing a "homemaker" 30 hours a week would cost about \$125 a month and a licensed vocational nurse about \$300 a month.)¹⁹

It is clear that the cost of community care is generally the same or less than the cost of state hospital care.

¹⁶ See appendix for detailed review of costs in community residential facilities.

¹⁷ Supplementary Factual Report No. 1, *op. cit.*, p. 13.

¹⁸ Supplementary Factual Report No. 2, *op. cit.*, p. 5.

¹⁹ Information provided by State Department of Employment.

A HIDDEN STATE EXPENSE

At the present time the state provides and pays the total cost of all medical, recreational, educational, and child care services utilized by a child in the state hospital.²⁰

In contrast, retarded children living in the community are eligible for child welfare, medical, surgical, recreational and educational services provided by local public and private agencies.

Even more important than the cost savings to the state, the retarded child who is in a position to receive the same community services as all other children benefits from being assimilated into the mainstream of community life.

Most experts agree that services for the retarded should be in the community:

Stuart Knox, M.D.:

*"The medical profession feels that to be most effective, services must be continuous, close to home, and given as early as possible."*²¹

Mrs. Vivian Walter:

*"Even the most profoundly mentally handicapped (those requiring 24-hour nursing care) could be near to home in a wing of a private or county hospital."*²²

Richard Koch, M.D.:

*"By forcing parents to face state hospital placement, we predispose them toward emotional disturbances . . . we must not require hospitalization as a prerequisite for state services."*²³

California Department of Mental Hygiene:

*"The mentally retarded should receive general medical and psychiatric services from local resources as do other members of the community."*²⁴

There is general agreement, and the facts support the conclusion, that whenever possible *retarded children, who can be properly served in the community and whose parents prefer community services, should remain in the community.*

Financial and human welfare considerations all point to the need to extend state responsibility to include the provision of community-based alternatives to state hospitalization.



²⁰ Families or counties do contribute a token fee of \$20 per month.

²¹ Testimony given before the Assembly Ways and Means Subcommittee on Mental Health Services on behalf of the California Medical Association at a public hearing held in Los Angeles, October 2, 1964.

²² Testimony given before the Assembly Ways and Means Subcommittee on Mental Health Services on behalf of the California Council for Retarded Children at a public hearing held at Sonoma State Hospital, February 21, 1964.

²³ Testimony given before subcommittee at the Los Angeles hearing, October 2, 1964, *op. cit.*

²⁴ Department of Mental Hygiene, *A Long Range Plan for Mental Health Services in California*, March, 1962, p. D-18.



WE PROPOSE THAT THE STATE SHIFT ITS RESPONSIBILITY FROM THE TIME WHEN THE CHILD ENTERS THE STATE HOSPITAL TO THE TIME WHEN EXPERT DIAGNOSIS ESTABLISHES THE FACT THAT SPECIAL CARE IS NEEDED THAT THE FAMILY CANNOT PROVIDE

The result of the redefinition of state responsibility will be to expand the number of state-supported choices available to that group of children who are placed on the "waiting list" under current procedures. This group of children, about 5 percent of the retarded, has traditionally been accepted as a state responsibility. This proposed change will alter the *manner* in which the state provides help. It substitutes a flexible system for a rigid one.

The essential question to be answered in determining eligibility for state-supported services in the alternative system will be: "Is this a child whose needs and problems are such that he would normally be placed in a state hospital if no community based services are provided?" (It is further suggested that at the beginning, first priority will be given to those on the state hospital waiting list as of January 1, 1965.)

Under the provisions of the recommended arrangement, certain families would receive professional guidance and financial aid to help them in placing their children in privately operated and state-approved community residential facilities. Financial aid for visiting nurses, homemakers, and baby sitters, and day care services would also help many families to keep their children at home.

The subcommittee has received endorsement of this concept from many segments of the professional community as well as from the overwhelming majority of parents of retarded children who corresponded and testified.

The remainder of this report will discuss the specific steps necessary to develop the alternate system.

THE REGIONAL DIAGNOSTIC-COUNSELING-SERVICE CENTERS

WE PROPOSE THAT THE CALIFORNIA DEPARTMENT OF PUBLIC HEALTH BE GIVEN RESPONSIBILITY FOR ESTABLISHING STANDARDS AND FOR CONTRACTING WITH APPROPRIATE COMMUNITY BASED MEDICAL AGENCIES WHICH WOULD PROVIDE REGIONAL SERVICES, AND FOR TRANSMITTING STATE FUNDS TO THESE REGIONAL CENTERS FOR DISBURSEMENT ON BEHALF OF THOSE FAMILIES WHOSE CHILDREN ARE FOUND TO BE ELIGIBLE

In testimony before the committee, the Department of Public Health indicated its reactions to the committee proposal:²⁵

"The Department of Public Health favors the first principle of the above proposal, namely 'that the state shift its responsibility from the time when the child enters the state hospital to the time when expert diagnosis establishes the fact that he needs special care his home cannot now provide.' This would be a major step forward, both toward curtailing unnecessary hospitalization and toward getting appropriate guidance to families and care to patients when these are urgently needed. Following this principle would also permit making the maximum, planned use of all private and public resources available for care of the mentally retarded.

"State support of regional diagnostic-counseling-service centers would provide on a statewide basis the highly skilled early diagnosis and counseling for such patients now available only on a limited basis. This type of comprehensive service has demonstrated its value as a means of meeting the need for prompt, definitive diagnosis and counseling as to proper care. It aids in minimizing the 'shopping around' which plagues so many families with a mental retardation problem.

²⁵ Testimony given by Dr. Breslow before the Assembly Ways and Means Subcommittee on Mental Health Services, Department of Public Health, at a public hearing in Santa Cruz, December 5, 1964.

"Administration of these regional centers would properly fit, as the proposal suggests, in the Crippled Children Services of the Department of Public Health. Placement here would permit taking maximum advantage of experience in developing specialized facilities for several types of handicapping conditions such as congenital heart disease, cerebral palsy and others. Developing of a high-quality service uniformly throughout the state is the pattern to be followed."

It has been estimated by public health officials that 10 such centers could provide service to the number of retarded persons needing service each year. The regional approach is the best way to guarantee a uniform standard of service throughout the state and—as has been demonstrated by the Child Development Clinic of Los Angeles—traveling teams can effectively "reach out" to serve remote rural areas.²⁶

It is further recommended that at least two of the regional centers be based in medical schools and serve as research centers and manpower training programs for mental retardation specialists in the various disciplines.

The importance of the role of these centers in the development of the alternative system cannot be underestimated. Skillful early diagnosis and careful planning with the family is essential. The regional centers would provide diagnosis for any child suspected as being retarded.²⁷ They would also carry responsibility for establishing the eligibility of retarded children for state-supported services and would assist families in placing these children in community facilities, state hospitals, or in caring for the child at home.

Since publication of the committee's preliminary proposal in June 1964, several questions have been asked with regard to the organization of the proposed regional centers. While it is not possible in this report to deal with all the professional and administrative issues that have been posed, some of the major questions will be briefly discussed since the regional centers are of such critical importance in developing the alternative system.

²⁶ For a description of the "traveling clinic" see "California Health", Vol. 19, No. 24, June 1962.

²⁷ The details and values of such clinical services are well established. See Public Health Programs for the Mentally Retarded in California (California Department of Public Health, March 1964). Also, The Evaluation and Treatment of the Mentally Retarded Child in Clinics, National Association for Retarded Children, 1956.

QUESTION: *Why is the committee recommending that the centers be established under the jurisdiction of the Department of Health's Crippled Children's Services Division?*

In making this recommendation, the committee has been guided by the views of the majority of professional persons who have studied this matter.

The *California Medical Association* has indicated its concurrence; the *California State Department of Public Health* believes they are well equipped to do the job; the *American Academy of Pediatrics* has supported this proposal of the committee, as has the *California Council for Retarded Children* and the *California Study Commission on Mental Retardation*. The *California Department of Mental Hygiene* also recommended that this service be developed under Public Health auspices in their *Long-range Plan for Mental Health Services in California* (March 1962) and reaffirmed this position in 1963 in their special report to the Legislature, "*Legislation to Implement a Long-range Plan.*"

All these authorities indicate that the retarded should be integrated into the general health services of the community and that the Department of Public Health is ideally suited to accomplish this objective in the most effective and economical way. Some authorities have also cautioned against setting up a separate stream of psychiatrically oriented health services for these children, believing that to do so would further isolate the retarded from general health services and perpetuate a long-standing confusion between mental illness and mental retardation.

QUESTION: *Why does the committee use the term "centers"? Doesn't this term imply that the Department of Health would create new and separate clinics that may duplicate other existing community medical services?*

The committee uses the term "center" to express the concept of a *unified and coordinated* service in each region of the state. The Department of Public Health would not construct or operate any new clinics but would contract with existing agencies to perform the diagnostic counseling and other services required. These services may be coordinated under one roof or may be conducted through contractual arrangement with a federation of agencies—depending on the resources available in each region. Regardless of the arrangement employed, it would be the responsibility of the Department of Health to clearly determine the functions of each participating agency to avoid duplication and to assure that families will be served swiftly and without red tape.

QUESTION: *Are the regional centers just for the retarded?*

"Yes" and "no."

It must be kept in mind that the committee is primarily concerned in this proposal with the development of an alternate system for that 5 percent of the retarded who have been and will continue to be a state responsibility. Therefore state funds would be appropriated to contract for services which would enable the state to expand the types of services offered to this group of retarded children. In order to accomplish this objective, it is essential that the centers be staffed with people whose major activity would be devoted to this problem.

The difficult and complex problems of diagnosis, counseling, and servicing the retarded require specialized knowledge and interest on the part of professionals.²⁸

This does not mean that the regional centers cannot now or in the future be part of general purpose clinics which provide similar services for other handicapped children. But if they are integrated with general purpose clinics they must designate certain persons whose primary responsibility will be to execute the retardation program as defined by the state's Department of Public Health.

QUESTION: *The idea of "diagnostic counseling centers is not new. But the committee talks about "diagnostic counseling service" centers. What is meant by "service," and how would this work?*

Diagnostic and counseling centers for the mentally retarded are becoming more available throughout the nation, but a common weakness in these programs is that when, after diagnosis, it is determined that a child needs specialized care his family cannot afford, the state hospital remains the only practical referral. (There is only limited value in providing a better diagnosis if the end result is still the same.)

The committee views the regional centers as the appropriate agency to supervise the community treatment program prepared for the child as a result of the diagnosis. This view is consistent with the Department of Health's concept of the "one-door" approach, as opposed to a fragmented approach where families

²⁸ Many doctors are too quick to classify children as mentally retarded. In two years 800 children, supposedly backward, were sent for observation to the University of Oklahoma Child Study Center. After thorough testing, 373 of these 800 were found to be normal or near normal, and 5.4 percent actually checked out as superior on intelligence tests. Warns Dr. Harris D. Riley, Jr., professor of pediatrics: "It is imperative not to use lightly the diagnosis of mental retardation, since few misdiagnoses can be so catastrophic."

are referred to a variety of agencies, each handling a small piece of the problem. The fragmented approach is more expensive, confusing, and is impossible to administer effectively.

For these reasons, the committee's proposal includes the provision of funds to enable the regional center to employ enough staff to diagnose, to counsel, and to supervise the treatment and child care services required by children who require specialized care. About 50 percent of the personnel budget allocated for each center would be used to carry out this activity.

Under provisions of this system, the State Department of Public Health would provide funds to each center to be used by the service team to assist families in purchasing homemaker, foster care, day care, residential services, etc., as alternatives to state hospital placement. The service team would help the family select the proper service, would periodically review the child's progress, would assist the family in any required change of services, would help the family make maximum use of the services and funds available, and would continue to serve as case management consultants to the family as long as state funds are being used to help purchase services for the child.

In this manner diagnosis, counseling, treatment and professional supervision would be integrated into a single system which eliminates duplication. This pattern has been well established in the Crippled Children's Services Program. The only difference in this instance would be the use of a few regional centers rather than 58 county health departments. (The county health department would still serve as a major community resource if the regional center finds the child needs services available through that agency.)

This new method of organizing services for the retarded would be a significant departure from our present system. The committee is proposing the establishment of a totally "new track" which must be very carefully tested and evaluated during the first year or two. For this reason, the committee suggests that although more centers may be ultimately needed, two should be established at the present time—one in southern and another in northern California on a pilot basis. The new system should be very carefully evaluated for the purpose of providing the Legislature evidence of the value of this alternative to state hospitalization.

Personnel for the two pilot centers would cost roughly \$300,000. About half the funds would be needed to pay for diagnostic-counseling work with 600-700 new cases; the balance of the funds would provide salaries for service staff to assist about 500 families—whose children would otherwise go to state hospitals—in finding and supervising home or community residential care. To staff the regional centers with personnel to

place children in community facilities implies providing funds to assist families in making such placements.

The yearly cost of purchasing home or community care for about 500 children is estimated at \$1,200,000. (In contrast, the cost in the state hospital would be about \$2,000,000—excluding the cost of construction.)

Since there are now at least 1,000 retarded children on the state hospital waiting lists whose families would prefer community care, and since the new system may take six to eight months to become fully operative, the committee further recommends that the Department of Mental Hygiene be allocated additional funds up to \$500,000 to expand its "private placement" program as an expedient measure to create space in the hospitals for urgent cases on the waiting list.

Since 1961 the department has been allocated \$250,000 each year to contract for private care for 115 hospitalized patients. The authorization for this program is provided in the State Welfare and Institutions Code, Section 6726.6:

"Any patient may be placed for leave of absence for care in a licensed hospital or other suitable licensed facility. The Department may pay for such care at a rate not exceeding the average cost of care of patients in the state hospitals as determined by the Director. Such payments shall be made from funds available to the Department for that purpose or for the support of patients in the state hospitals."

The following dialogue between Chairman Waldie and Anderson Pollard took place at the committee's public hearing on October 2, 1964, and documents the feasibility of expanding the department's private placement program:

MR. ANDERSON POLLARD: I'm Anderson Pollard. I'm the supervising program consultant for the Bureau of Private Institutions of the Department of Mental Hygiene. We receive all complaints in our department that affect our licensed facilities, and to my recollection we have received about two complaints from relatives who were dissatisfied with the placement of patients from a state hospital into private facilities.

CHAIRMAN WALDIE: Out of how many placements?

MR. POLLARD: I don't know how many placements there have been.

CHAIRMAN WALDIE: Have there been a hundred?

MR. POLLARD: I believe there have been over 100, and out of this we feel that two complaints is pretty minimum.

CHAIRMAN WALDIE: Do you have anything to do with the licensing of the private facilities we have been using during the past four years? The program on which we are spending a quarter of a million dollars a year for private care of the retarded?

MR. POLLARD: Yes, we do. We license all the facilities for the mentally retarded.

CHAIRMAN WALDIE: What experience have you had with that?

MR. POLLARD: We've had a very favorable experience. When the program first started we found few facilities that wanted to participate, but now we have a surplus of facilities. We have a large number which we have certified. By certified I mean that certain standards, certain criteria above the basic minimum licensing standards were asked for these particular facilities. We have a large list with a great many vacancies waiting, just anticipating that this program will expand.

CHAIRMAN WALDIE: Have you had complaints from parents of children who have been in those institutions?

MR. POLLARD: When the program first started in 1962, the program was new, we ran into problems, we received a few complaints, not from parents but from the state hospitals, social workers, who were involved in supervising these children. Since that time I feel that the program has been very successful. We have received compliments on it, and as I said, we are anticipating a time when this can be expanded.

CHAIRMAN WALDIE: How many children have been placed?

MR. POLLARD: Not even 120.

CHAIRMAN WALDIE: And these were 120 children that would have been in a state hospital? These are children that were taken from the state hospital and placed in private institutions?

MR. POLLARD: Placed directly in private facilities, yes.

The suggestion to expand the department's private placement program is not an alternative to creating a system to bypass the state's hospitals. But by relocating some patients, immediate relief can be provided for urgent cases now on the hospital waiting lists.

In summary, during the first full year of operation, the committee's proposals would create a new system for diagnosing and counseling 600-700 new cases and could provide for community

care of 700-800 persons who would otherwise require state hospitalization. The total yearly cost would approximate \$2,000,000. (The yearly cost of care in state hospitals for 700 patients is \$2,400,000—excluding construction costs.)

If the committee's proposals regarding improvements in the standards and licensing system are also approved, an additional \$30,000 to \$50,000 may be required.

STANDARDS—FEES—LICENSING—INSPECTION

Since the alternative system would expand the use of community-based facilities by the use of state funds, it is absolutely essential that these facilities be of good quality.

The subcommittee received considerable testimony in support of new and more effective machinery to assure a better quality of service in community facilities.

Some existing community facilities are excellent and others are poor. There is no uniformity at present. The regional centers should be able to assist families to use services which will meet only the highest standards in much the same manner as the Crippled Children Program is now able to refer families to an approved physician for medical services.

Increased use of community facilities would pose problems in setting standards, rates, licensing and inspecting. The present system in California is not good. There is general agreement that we must considerably improve quality control if we are to use public funds to support children in private facilities.

On December 5 the subcommittee heard testimony from the San Francisco Coordinating Council on Mental Retardation. (This council represents 40 public and private agencies concerned with planning for the retarded.) They stated:

"The coordinating council has firmly endorsed centralized licensing and standard-setting for private facilities.

"The multidisciplinary standard-setting, licensing, and inspection machinery to establish standards and insure a high quality of service we believe to be essential. It is also essential that this machinery be separated from any one functional agency since standards and procedures are currently totally confused through the number of licensing organizations, their particular jurisdictional lines and emphases. The present procedure increases rather than decreases poor quality of service.

"Therefore, the council urgently recommends enactment of the organization proposal for a multidisciplinary standard-setting team independent of any existing functional agency."

At this same hearing the California Council for Retarded Children, an organization representing thousands of families with retarded children in California, made the following comments:

"In our view the most urgent need is the establishment of a multidisciplinary standard-setting, licensing, and inspection body."²⁹

Many witnesses have indicated that confusing licensing procedures, and the fact that many different agencies have different requirements for licensing, complicates and hampers the development of additional privately operated facilities.

"There is an extremely high mortality rate among original inquiries offering to supply foster home care. Only 1 out of 10 who apply are licensed to take children. One of the policies that limits the kind of home acceptable for licensing is the 'principle of only accepting facilities with first floor bedrooms for patients.'"³⁰

*"The problems of finding foster homes is complicated not only by a lack of funds for persons under 18, but also by rigid licensing regulations. For example, certain homes required that the children all be boys or all girls, or that they be ambulatory or nonambulatory, or that they fit into cribs of certain sizes."*³¹

*"You now have in any community the Youth Authority, the Veterans Administration (which pays \$175, and therefore beats us all in terms of money available), the child welfare programs of the various county welfare departments, the juvenile courts, and the Department of Mental Hygiene, and the Department of Social Welfare all out hunting homes. One of the major needs for this state is to get into some kind of more coordinated approach."*³²

At the present time, in California, different agencies (and even different bureaus within the same agency), set different standards, pay different rates, and have different licensing and inspection procedures. It is a bureaucratic tangle that defies all logic.

Hopefully, the Legislature will eventually solve the entire problem, but until a completely revised system has been created,

²⁹ Testimony given by Fred Krause, executive secretary for C.C.R.C., before the Assembly Ways and Means Subcommittee on Mental Health Services at a public hearing in Santa Cruz, December 5, 1964.

³⁰ Testimony given by William Wilsnack (D.M.H.), before the Assembly Ways and Means Subcommittee on Mental Health Services at the Sacramento public hearing, March 26, 1964, pp. 21-22.

³¹ Testimony given by Mrs. N. England, Sacramento Community Welfare Council, before the Assembly Ways and Means Subcommittee on Mental Health Services at the Sacramento public hearing, March 26, 1964, pp. 40-41.

³² Testimony given by Mrs. Elizabeth MacLatchie, Department of Social Welfare, before the Assembly Ways and Means Subcommittee on Mental Health Services at the Sacramento public hearing, March 26, 1964, pp. 35-36.

it is essential to make several immediate changes if the alternative system for the retarded is to develop properly.

The committee recommends that:

- a A Director of Mentally Retarded Care Standards position should be established under the State Health and Welfare Administrator.
- b It is recommended that the director's office be permitted to contract for consultation from experts in education, child care, pediatrics, nursing care, institutional management, etc. (In this way it will be possible to secure expert advice from the nation's leading authorities.) Standards should be established that insure that the total needs of various categories of retarded children will be met.
- c It is recommended that an advisory committee whose membership shall include parents of the retarded and directors of private agencies rendering services for the retarded be established to review and to advise the director in establishing standards for various kinds of care.
- d It is recommended that the Director of Mentally Retarded Care Standards have the additional responsibility of fixing rates which will enable private agencies to meet the recommended standards, including the cost of amortizing their capital investments. (*Rates and standards must be viewed as inseparable and the state should be prepared to pay for high-quality services.*)
- e It is further recommended that the proposed regional centers not refer families to, or use public funds to help pay for, services in any community facility which does not meet the standards established by the coordinator's office—*regardless of any other licenses the facility may hold.* (This means that the regional centers would only "do business" with individuals and agencies whose services are of guaranteed quality and who agree contractually to adhere to the standards required for participation in the program.)
- f *The staff of the regional centers should be required to periodically visit each child the center has helped place in a community facility.* The purpose of this visit is twofold—to evaluate the child's progress and condition and to review the agencies' compliance with standards.
- g It is also recommended that parents of children placed through the regional centers immediately report to the

regional center any unfavorable conditions they may find when visiting their children. If the regional center has any evidence that an approved facility is negligent in complying with their contractual agreement, and so recommends, state support funds should immediately be withdrawn for all children in that facility.

It may be argued that insistence on high standards may inhibit the use of many private community facilities and retard the rapid development of the alternative system. This may be true, but in the committee's judgment it is essential that the new system start off properly. Experience in other programs has shown that it is very difficult to correct inadequate programs once they have been established and have gained momentum.³³ In beginning the alternative system for the retarded it is possible to avoid past mistakes.

It may also be argued that the proposed new standards and fee schedules will not solve the existing duplication of state activity in this field but will only increase the multiplicity of agencies involved. It is quite true that the committee's proposal will not solve some of the long-standing anachronisms in the organization of California's licensing programs. But to wait for a resolution of that entire problem would mean authorizing the use of substandard facilities in this new program—a risk the committee is not willing to consider.

Hopefully, the proposed new system of standards will have the effect of forcing standards in other programs to rise. Quite possibly, in the future, standards for all mental retardation programs, including our state hospitals, will be governed by the same machinery.³⁴

³³ Our recent experience in the field of nursing home care for the aged provides many lessons. (See final report, *Assembly Ways and Means Subcommittee on Institutions*, 1965.)

³⁴ "It is worthy of note that by long established tradition state institutions are exempt from the requirements of law pertaining to child care. The state institutions must obey the law concerning licensing of motor cars or gasoline pumps or dogs, but what the state demands in essential standards from private child care institutions it does not demand from its own state facilities serving children. The question here is not on the technical aspects of applying for and securing a license but rather on the essence of the licensing process . . . the protection of children. Thus a mode of accrediting state residential facilities for the mentally retarded will create a means wherein the state meets its ethical responsibilities." *Accreditation of Residential Care Facilities for the Mentally Retarded*, Gunnar Dybwad, J.D., Executive Director, National Association for Retarded Children, presented at American Association on Mental Deficiency, Portland, Oregon, May 1963.

GUARDIANSHIP IN THE NEW SYSTEM

As the California Study Commission on Mental Retardation points out, "There is no more poignant or challenging question than the cry of the parent: 'What will happen to my retarded child when I am no longer able to care for him?'"³⁵ The state hospital—because of its permanency—has provided an answer. The subcommittee has received considerable testimony indicating that although many families would like an expanded use of home care and private community care, they are anxious about the long-term stability of these alternative arrangements:

*"We must provide a legal guarantee for continuity of care if we establish the private residential plan."*³⁶

*"There is a deep concern that we will detract from the stability and inherent protection provided by the state in a hospital with continuity of care and protection for these children after the parent has gone."*³⁷

*"The hospital is seen by the parent as a stable and permanent institution. The foster home, on the other hand, is a private enterprise that may go out of business for a variety of reasons. Parents of children in foster homes must always be concerned with the possibility of its closing necessitating the relocation of the child."*³⁸

THE COMMITTEE RECOMMENDS THAT GUARDIANSHIP BE AVAILABLE AS PART OF THE NEW SYSTEM

In order to provide families with full assurance of continuity of care for their retarded children, it is essential that whenever the state assumes responsibility, either in a state hospital or in a community facility, that, upon parental request, the state will agree to supervise the care of that child after the parents are no longer able to participate.

The committee is recommending a shift in the time and form of state responsibility. But the content of state responsibility—

³⁵ Report of the California Study Commission on Mental Retardation, *The Undeveloped Resource (State of California: January 1965)*, p. 77.

³⁶ Testimony given before the Assembly Ways and Means Subcommittee on Mental Health Services by Mrs. Vivian Walter at the Sonoma public hearing, February 21, 1964.

³⁷ Testimony given before the Assembly Ways and Means Subcommittee on Mental Health Services by Mrs. Bess Hearne Toretzky at the Los Angeles public hearing, October 2, 1964.

³⁸ Letter to committee from Ronald L. Hunt, December 21, 1964.

our collective permanent concern for the well-being of the dependent individual—remains.

Notwithstanding any other guardianship services now available or any which may be created in the future, the committee recommends that families be permitted to transfer personal guardianship of their children to the Director of the California State Department of Public Health after their child has been screened by a regional center. The Director of the Public Health Department will carry out his responsibility for the proper placement of the retarded person through the regional center.

Under provisions of this system, the regional center, which has diagnosed the child and worked with the parents during their lifetime, will continue to provide supervision regarding the appropriate placement of the child after the death of the family.

It is reasonable that the child should not have to be moved to the state hospital from a community facility where he is doing nicely just because his parents have died.

It is also logical that the regional center, where the child is known and which is staffed by mental retardation experts, should continue to supervise his placement rather than transfer responsibility for his future care to some other agency.

The fact that a child may be moved from one foster home to another would have the same significance in the suggested program as if a child in a state hospital was moved from one hospital ward to another. The continuity of knowledgeable concern and supervision would be provided by the regional center and the stability of the State Department of Public Health would provide the same assurance of lifetime care as is now available through the Department of Mental Hygiene's state hospitals.

Furthermore, if after the parents' death, the regional center should determine that the retarded person will benefit from being moved from a community facility to a state hospital, such a transfer can be effected. (The state hospital will still remain one of the choices, but the decision to place in the state hospital will be made because the retardate *needs* state hospital services not because it is the only stable agency providing long-term care.)

* * * * *

The foregoing proposals do not attempt to answer all the many questions posed to the subcommittee during the past year. There is the issue of parental participation in the cost of care; the issue of relating the new system to older existing programs; the matter of coordinating other community services—such as education, recreation, etc. The subcommittee has attempted to develop a simple, direct answer to a chronic state problem. The proposed new system should be studied carefully during its first two years.

The system is flexible enough to be integrated into any comprehensive program for handicapped persons which may develop in the future. The proposed system does provide alternatives to state hospital care for those who seek alternatives. The subcommittee is convinced the proposal is professionally sound and economically advantageous.

APPENDIX

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The expense of building state hospitals is illustrated in Tables I and II. The estimates for these projections are based on information developed by the Department of Mental Hygiene and the Department of Finance and reported in Hospital Bed Needs for Mentally Retarded Patients in California—1963—1968.¹

The department's estimates for bed needs are based on a formula of 80 state hospital beds for the retarded per 100,000 state population. This estimate was developed by adding the number of persons in the state hospitals and the number of persons on the waiting list and comparing this sum to the total state population. The result is a projection of the number of beds per 100,000 population that will be needed.

The estimate of 80 beds per 100,000 population, however, must be considered as a minimum estimate of the facilities needed because the critical factor in preparing the projection (the present hospitalized population) is limited by the number of services now available. (For example, if there were more state hospital beds available, the number of persons in the state hospital would be higher, and an estimate of future beds needed based on the present hospital population would yield a higher figure.)

Also, the characteristics of the waiting list are affected by the services that are available. Since there are fewer beds available than there are persons who need some form of specialized care, an administrative decision is made as to who goes on the waiting list and who does not. Those who are designated as being in most urgent need of specialized care are placed on the waiting list, while those whose needs are relatively less urgent are not placed on the waiting list. They are therefore not counted in the estimates of beds needed per 100,000 population.

Table I shows the state hospital population increase from 1955 to the present, and projects the population figures from the present through 1968 on the basis of the 80 beds per 100,000 population estimate. It also shows the steady rise in the support expenditures for the hospitals, and projects the minimum support budget which would be required to operate the number of beds estimated to be needed by 1968.² This table indicates that by 1968 the support budget would have to be raised from the present \$44.7 million to at least \$55.8 million. The state would also have to increase the number of state hospital beds from the present 13,000 that are now available to 16,170.

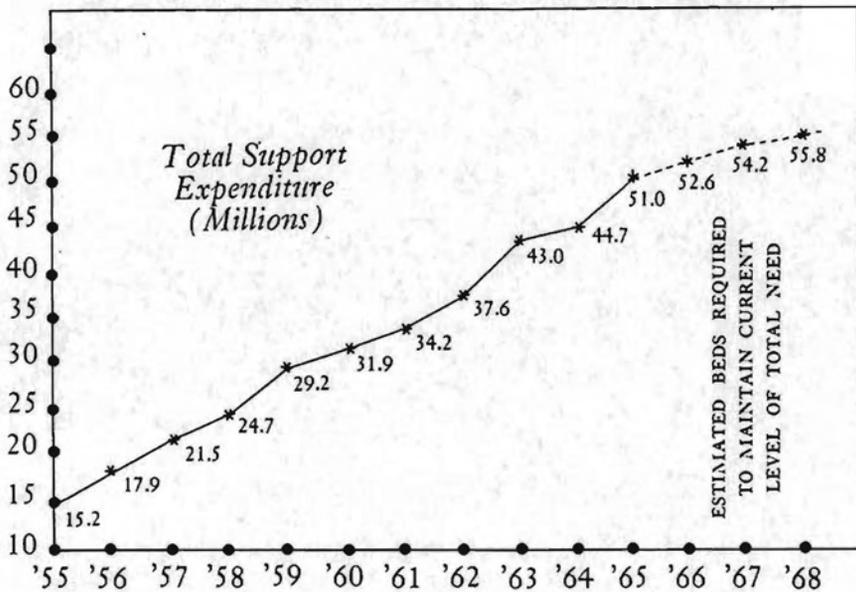
¹ *Biostatistics Bulletin No. 32, Department of Mental Hygiene, May 1963.*

² *Statistics provided by the California Legislative Analyst's office.*

Table II shows the capital outlay California has expended since 1955 for the purpose of building hospital beds for the retarded. The projected construction cost estimates are based on the Department of Mental Hygiene figures which report that the cost of construction of a 500-bed hospital would run between \$6,000 to \$20,000 per bed, with an average cost of \$15,000 per bed.

TABLE I

STATE HOSPITALS FOR THE MENTALLY RETARDED
HOSPITAL POPULATION AND SUPPORT EXPENDITURES



	'55 TO '61						
Hospital Population:	8,527	9,185	9,415	10,004	10,879	11,427	11,561
Per Capita Cost:	1,788	1,949	2,285	2,471	2,683	2,790	2,962
	'62 TO '68						
Hospital Population:	11,910	12,500	13,000	14,796	15,248	15,706	16,190
Per Capita Cost:	3,326	3,439	3,436	3,500	3,500	3,500	3,500

TABLE II

CAPITAL OUTLAY FOR STATE HOSPITALS
FOR THE MENTALLY RETARDED

	Annual Outlay	Total Investment
Before 1955	-----	\$46.1 million
1955	\$4.2 million	50.3
1956	5.1	55.4
1957	1.3	56.7
1958	3.9	60.6
1959	4.8	65.4
1960	1.5	66.9
1961	2.9	69.8
1962	0.7	70.5
1963	2.5	73.0
1964	0.6	73.6 present investment

PROJECTED OUTLAY

Estimated	} 1965 1966 1967 1968	\$47.6 million
3,170 more beds		
needed to maintain		
current level *		

* (An additional complication results from the fact that over 1/3 of the existing 13,000 state hospital facilities are considered by the department to be substandard and in need of replacement.)

A REDEFINITION OF THE NEEDS OF THE RETARDED POPULATION

The results of a study done by the Department of Mental Hygiene and reported in *A Survey of Patient Needs for Residential Care and Assistance*³ indicates the potential for the use of facilities other than the state hospitals for caring for the retarded. This survey included all of the retarded who were in the hospitals and on the waiting list during the first few months of 1963. In doing this study, the Department of Mental Hygiene tried to determine the type of residential care most appropriate for each patient. The determination of the most suitable type of residential care facility was made according to the need of the patient, regardless of whether or not such a facility existed in the community at the time of the survey.

There were four categories of residential care utilized in the study:

- 1 HOSPITAL CARE—the patient needs placement in a hospital for intensive treatment for medical, surgical, or psychiatric services.
 - 2 24-HOUR NURSING HOME CARE—the patient needs placement in a nursing care environment with occasional medical, surgical, or psychiatric assistance.
 - 3 FOSTER HOME CARE—the patient's needs could be most adequately met in a home other than the patient's own home or that of a close relative.
 - 4 HOME CARE—the patient could benefit most by placement in the home of parents, siblings, or other close relatives.
- OTHER—a category used only where previously defined categories did not apply.

Each one of the patients in the state hospitals and on the "waiting list" to a hospital was placed in one of the above categories. The results of the survey are presented in Table III.

³ *Biostatistics Section Bulletin No. 34, Department of Mental Hygiene, Research Division, August 1963.*

TABLE III

Type of residential care most appropriate	Population	Percent
1. Hospital care	5,129	36.7
2. 24-hour nursing care	3,837	27.5
3. Foster home care	3,882	27.8
4. Home care	1,114	7.9
5. Other	16	0.1
TOTALS	13,978	100.0

The most significant fact brought to light in this study is that less than 40 percent of those who were in the state hospitals or on the "waiting list" were placed in the category of needing hospital care. Over 60 percent of the patients studied could have their residential care needs more adequately met in a setting other than a hospital. The importance of these findings is most significant in terms of the change in emphasis which must be made in future state planning. Not only is the hospital bed building approach an expensive way for the state to provide services for the retarded, but it is a method which does not fulfill residential needs for the patient in the most satisfactory way in over half of the cases.

Since the publication of *Biostatistics Bulletin No. 34*, the Department of Mental Hygiene has redefined the original four categories of residential care needs and grouped the patients into two broader and more general categories. Table IV shows the manner in which the reclassification was accomplished and indicates the two broad categories from which the department now projects future bed needs.⁴

⁴ *The most recent projection of hospital bed needs published by the Department of Mental Hygiene based on the regrouping of the categories found in Biostatistics No. 34 may be found in the Department of Mental Hygiene's Tentative Proposal for a Five-year Program, October 5, 1964.*

TABLE IV

BIOSTATISTICS NO. 34 CATEGORIES (1963)		REDEFINED CATEGORIES (1964)	
Type of residential care	Population	Type of residential care	Population
Need hospital care	5,129	Need hospital care	8,966
Need 24-hour nursing care	3,837		
Need foster home care	3,882	Need residential care (other than hospital care)	4,996
Need home care	1,114		
TOTAL		13,962	

The redefined "need hospital care" category shown in Table IV is a combination of the "need hospital care" and "need nursing care" categories used in Biostatistics Bulletin No. 34. The redefined "need residential care" category is a combination of the "need foster home care" and "need home care categories" of Biostatistics No. 34. These redefined categories modify the impact of the findings of Biostatistics No. 34, for upon redefinition the department now believes 64 percent of the patients in state hospitals and on the waiting lists need hospital care as compared to the 37 percent listed as needing hospital care a year ago.

In the Department of Mental Hygiene's *Tentative Proposal for a Five-year Plan*, the department projects state hospital bed needs for the retarded in California on the basis of the figures in the redefined categories. The accuracy of these projections rest on the assumption that all who are in the redefined "need hospital care" category are, in fact, in need of hospital care. There is some evidence to indicate, however, that many of those who were in the original "need 24-hour nursing care" category and are now redefined as needing hospital care, could actually be cared for very adequately in community facilities. (The department has conducted what they believe to be a successful program of placing persons who were categorized as "needing nursing care,"

into family care nursing homes where they are "making a very satisfactory adjustment.")^{5, 6}

The classification of patients according to their residential needs as is done in Biostatistics No. 34 and in the department's *Tentative Proposal* represents a more sophisticated approach to planning services for the retarded. Even though the exact number of persons actually needing hospital care rather than other types of residential care could not be precisely estimated in either of the reports, both reports point out the need for the development of residential services which can serve as alternatives to state hospitalization.

⁵ A letter to the subcommittee from Dr. William Beach of the Department of Mental Hygiene on October 9, 1964, stated that placements from the state hospitals into private nursing homes have resulted in the majority of the patients being correctly placed: "The key to successful placement lay in the careful selection and screening of facilities and patients. A period of intensive followup supervision immediately after placement was also indicated to facilitate adjustment. When this has been done the adjustment of those placed appeared to be adequate, with the facilities currently caring for patients rendering satisfactory to excellent care."

⁶ There is one additional problem in the projections for bed needs in the department's *Tentative Proposal*. In addition to the patients in the hospitals and on the waiting list who are included in the redefined "need hospital care" category, the department also includes in their figures some 650 retarded who are now residing in private nursing homes. A survey of private facilities conducted by the subcommittee found that 51.3 percent of those in private nursing homes were also on the waiting list. As a result, over 300 retardates are being counted twice in developing projections for state hospital bed needs.

EXAMPLE OF COSTS OF CARE IN A STATE HOSPITAL

SONOMA STATE HOSPITAL

Monthly Per-patient Costs *

Personal Services ¹	JOHNSON WARD (138 patients) Crib patients—adult		CORCORAN WARD (92 patients) Crib patients—children	
	Actual cost, April 1964	Comments	Actual cost, April 1964	Comments
1. Ward nursing staff	\$155.64	Cost would have been \$222.23 if fully staffed as classified	\$171.71	Cost would have been \$221.91 if fully staffed as classified
2. Rehabilitation services	0.72	Based on fractional time by more than one employee	0.34	Based on fractional time by more than one employee
3. Social services	0.42	Same as above	0.11	Same as above
4. Psychology		No psychology services given to this ward	0.21	One psychologist devotes 0.02 of his time to this ward
5. Ward physician	2.06	Ward physician devotes 0.2 of his time	4.25	Ward physician devotes 0.25 of his time
6. Administrative and supervisory	3.45	Comprised of supervising nursing service personnel, plus assistant and associate superintendents	6.06	Same as Johnson
7. Public health (hospital per capita)	0.70		0.70	
8. Clinical services (hospital per capita)	1.79		1.79	
9. O.D. (hospital per capita)	1.32	Physician on 24-hour call for all wards	1.32	Physician on 24-hour call for all wards
10. Miscellaneous care and welfare services (hospital per capita)	3.86	Pharmacy, X-ray labs, EEG, dental, etc.	3.86	Same as Johnson
11. Support and subsistence (hospital per capita)	11.77	Food preparation, laundry and clothing personnel	11.77	Same as Johnson
12. Plant operation (hospital per capita)	12.86	Hospital maintenance personnel	12.86	Same as Johnson
13. Administration (hospital per capita)	12.75	Nonmedical administrative personnel	12.75	Same as Johnson
Gross salaries and wages	207.34		227.73	
Staff benefits (9.2)	19.08		20.95	
Total Personal Services	226.42	Cost would be \$299.12	248.68	Cost would be \$303.5

	Actual cost, April 1964	Comments	Actual cost, April 1964	Comments
OPERATING EXPENSES				
14. Hospital per capita	44.18		44.18	
MISCELLANEOUS				
15. Central office administration	6.40		6.40	
16. Depreciation on improvements and equipment	11.23		11.23	
17. Interest on capital investment	14.75		14.75	
18. Premium on auto insurance	0.05		0.05	
19. Attorney General's charges	0.12		0.12	
20. State administrative overhead	3.76		4.12	
21. Workmen's compensation	4.24		4.24	
Total miscellaneous	<u>\$40.55</u>		<u>\$40.91</u>	
<i>Recapitulation</i>				
Personal services (1 through 13)	\$226.42		\$248.68	
Operating expenses (14)	44.18		44.18	
Micellaneous (15 through 21)	40.55		40.91	
Grand total	\$311.15	<i>\$384.93 if fully staffed at classified level</i>	\$333.77	<i>\$389.36 if fully staffed at classified level</i>
Estimated 1963-64 monthly hospital per capita cost—Sonoma (all wards)	\$328.00			

¹ Cost figures for 1 through 8 are based on the actual gross payroll checks dated May 1, 1964, for the employees assigned to the wards surveyed. The remaining cost figures are based on data appearing in the Governor's 1964-65 Budget and/or information furnished by the Department of Mental Hygiene.

In addition to the above costs, each of the three wards makes use of acute hospital services when the need arises. These services are, of course, more expensive than ward care. The following indicates the extent to which hospital care was required for the past six months.

Acute Hospital Care (Six-month Totals)		
Ward	Number of patients	Total patient-days
JOHNSON	10	325
CORCORAN	13	275

COST OF COMMUNITY RESIDENTIAL SERVICES

The costs of community services that can be used as alternatives to state hospitalization are less easily estimated than the costs of state hospitalization.

On the basis of the studies and hearings conducted by the subcommittee, however, some rough estimates regarding the costs of some alternative services can be made.

The results of a survey of private residential facilities done by the subcommittee are presented in Table V. This study indicated that about 8 out of 10 retarded who were in these facilities at the time of the survey were being cared for at less than \$300 a month. It can be seen, however, that there are differences in the costs of private care, depending on the type of facility being utilized.

In addition to these studies, testimony given before the subcommittee at its hearings gives further indication of some of the costs of community care. The Department of Mental Hygiene now spends about \$165 per month for the foster home care of the retarded who are included in their "aftercare" program. (This includes administrative overhead.) If a retarded person is eligible for welfare support, however, the fees paid by some counties for foster care may exceed this amount.¹¹ (Fees in excess of \$175 per month paid by governmental agencies for the purpose of placing the retarded in foster care facilities appear to be the exception, and not the rule.)

Under the present system any discussion of the true cost involved in subsidizing the placement of persons in community facilities is open to question. The system, as it now exists, requires that any parents wanting to place their child in a residential facility other than a state hospital must pay the fees.¹² The rate of utilization of private facilities is high only among the higher income families (see Table VII).¹³ The rates charged by private

¹¹ At a public hearing in Santa Cruz, December 5, 1964, in testimony given before the Assembly Ways and Means Subcommittee on Mental Health Services, it was pointed out the Santa Clara County Welfare Department has paid over \$300 per month for support of children in private residential schools.

¹² The only exceptions are children whose parents are on welfare and children placed out of the state hospitals on aftercare basis, in which case the state pays for the placement.

¹³ Supplementary Factual Report No. 2 indicates that rate of utilization of private facilities increases significantly in families with a yearly family income in excess of \$10,000. (See Table VII.)

facilities tend to reflect the amount which these agencies know parents can afford, rather than a fee which is truly equitable. As one witness stated, "Due to a lack of funds on the part of a majority of parents, most private facilities are forced to keep their fees at a bare minimum. Therefore, we should not set our fees according to costs as they now exist."¹⁴

¹⁴ Testimony given before the Assembly Ways and Means Subcommittee on Mental Health Services by Mrs. Mary Jeffrey at a public hearing in Los Angeles, October 2, 1964.

TABLE VI

COST OF CARE PER MONTH IN PRIVATE FACILITIES

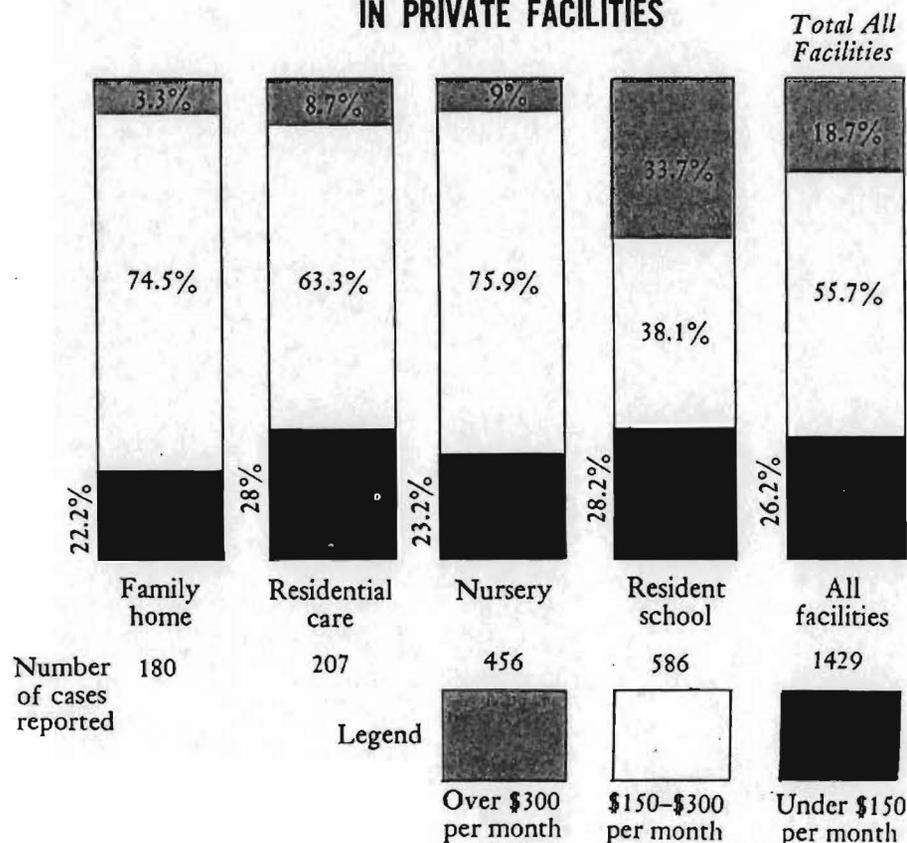
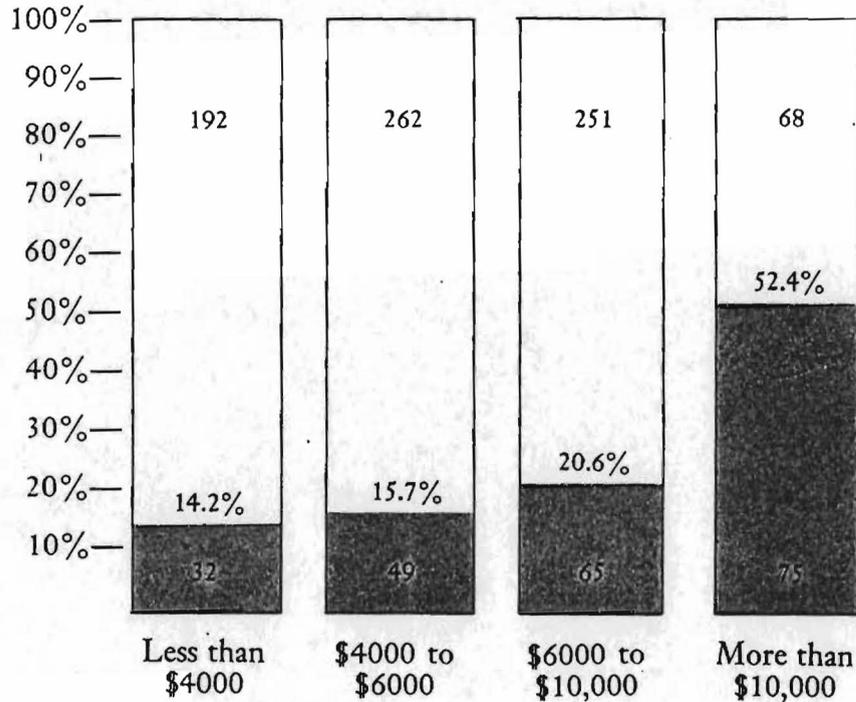
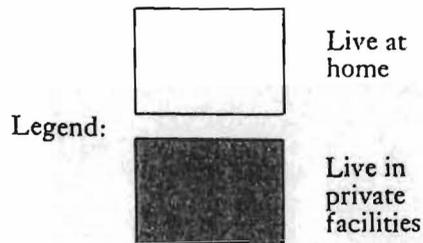


TABLE VII

RATE OF UTILIZATION OF PRIVATE FACILITIES
BY INCOME GROUPS



YEARLY FAMILY INCOME



The foregoing indicates that although there is a great deal of evidence supporting the notion that community care is less costly than care in a state hospital, caution must be exercised in trying to state the case too strongly. If the state is to adopt a system which subsidizes placement in community facilities, then fees which reflect the true cost of good service will have to be established. The result may be an increase in the fees as we now know them.

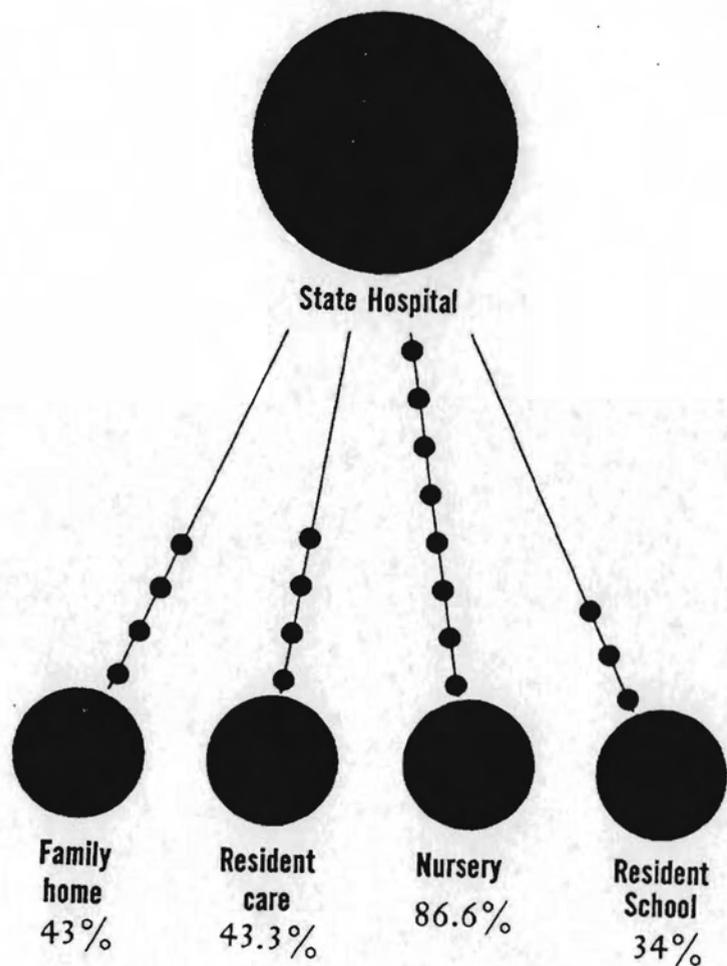
There is still evidence which indicates that payments would not exceed the \$300 per month cost of state hospitalization for most cases.¹⁵ Even if the support costs for community care did exceed \$300 per month in some cases, the state would still save money by not having to build as many additional hospital beds.

IT SHOULD BE MENTIONED THAT COMMUNITY CARE IS NOT SYNONYMOUS WITH PRIVATE RESIDENTIAL CARE. COMMUNITY CARE COULD INCLUDE SUPPORT FOR CHILDREN PLACED IN PUBLIC AGENCY FACILITIES SUCH AS PUBLIC SCHOOL DAY CARE CENTERS AND NURSERY SCHOOLS, PAYMENT FOR HOME CARE AIDS SUCH AS HOMEMAKERS, PAYMENT FOR ANY OTHER APPROVED SERVICES NEEDED BY THE CHILD AS AN ALTERNATIVE TO THE STATE HOSPITAL.

¹⁵ Mr. Jewell Trumbo in testimony given before the Assembly Ways and Means Subcommittee on Mental Health Services at a public hearing, Los Angeles, California, October 2, 1964, says, "I operate a home for retarded children privately. We charge approximately \$200 a month, with which we have been giving the kids something that we think is better than they can receive at the state hospitals . . . and we are not going in the hole, we're not going broke, and we can certainly build a lot cheaper than \$15,000 a bed."

TABLE VIII

PERCENT OF POPULATION IN PRIVATE INSTITUTIONS WHO TRANSFER TO STATE HOSPITALS



For all private institutions combined, 49.5% eventually transfer to state hospitals

ENDORSEMENTS

Since the publication of the "Preliminary Proposal" in June, the committee has received expressions of support from hundreds of families of retarded children as well as from numerous knowledgeable professional persons.

The following organizations have also expressed their endorsement:

- AMERICAN ACADEMY OF PEDIATRICS
- CALIFORNIA COUNCIL FOR RETARDED CHILDREN
- CALIFORNIA MEDICAL ASSOCIATION
- CALIFORNIA ASSOCIATION OF NURSING HOMES
- CALIFORNIA NURSES ASSOCIATION
- SAN FRANCISCO COORDINATING COUNCIL FOR MENTAL RETARDATION

The following letters are typical of the majority of responses the committee has received.

THE WHITE HOUSE

WASHINGTON

December 24, 1964

Dear Mr. Waldie:

I want to let you know that I have received and carefully reviewed the materials from your special subcommittee relating to mental retardation.

I think that they are the finest materials of the kind that I have ever seen. They show a great deal of careful thought.

We are in the process of analyzing the waiting list group, and I will forward to you some more complete comments on this in the very near future.

Sincerely yours,

EDWARD H. FORGOTSON, M.D.
Deputy Special Assistant
to the President
for Mental Retardation

Honorable Jerome R. Waldie
Assembly California Legislature
State Capitol
Sacramento, California 95814

November 10, 1964

Assemblyman Jerome Waldie
The Capitol
Sacramento, California

Dear Mr. Waldie:

I have noted in communication from the National Association of State Mental Health Program Directors (Commissioners of Mental Health) that you are advocating out of hospital aid for the retarded.

I don't know whether you have seen the remarks that were made but these certainly are a credit to you and I want to congratulate you on taking this stand. You may recall that we discussed various matters related to this particular effort on your part and I am delighted to know that you are personally backing such an effort.

I would like at this time to reiterate my previous thanks to you for your strong support of good mental health programming in the state of California.

With every good wish,

Sincerely yours,

DANIEL BLAIN, M.D.
President
American Psychiatric Association

DB:ii
cc: Dr. James Lowry

RESOLUTIONS

Subcommittee on Mental Health Services

RESOLVED that the California Council for Retarded Children endorses the preliminary proposal of the Subcommittee on Mental Health Services, which provides a modern concept for utilizing untapped community resources for California's mentally retarded and serves as a means to effectively eliminate the waiting list for admission to State hospitals through ten regional diagnostic-counseling centers throughout the State; and

BE IT FURTHER RESOLVED that appreciation for the creative and bold approach in the preliminary proposal be and is hereby expressed to the Subcommittee on Mental Health Services.

Study Commission on Mental Retardation

RESOLVED that the California Council for Retarded Children does hereby express its appreciation for the diligence in preparation, scope of effort, and reflected sincerity of the Study Commission on Mental Retardation for its tentative recommendations for services to the mentally retarded in California; and

BE IT FURTHER RESOLVED that the California Council for Retarded Children does hereby approve and endorse the philosophy contained therein.

California State Hospitals

RESOLVED that any addition to or new construction of State hospital facilities for the mentally retarded be held in abeyance until alternative programs may be introduced and developed.

* * * * *
The above resolutions were unanimously supported by the CCRC Board of Directors at a meeting held in Sacramento, California on September 26, 1964

October 2, 1964

Copies to—CCRC Board of Directors
Presidents of Member Units
Public Affairs Committee Chairman (CCRC)
CCRC Newsletter

September 17, 1964

Mr. Arthur Bolton, Consultant
Subcommittee on Mental Health
State Capitol, Room 2140
Sacramento, California

Dear Mr. Bolton,

Thank you for your letter of August 26th together with the preliminary proposals suggesting significant reforms in the State programs for the mentally retarded child.

The American Academy of Pediatrics would wholeheartedly support these proposals and believe this would be a significant improvement for the welfare of the mentally retarded child and his family. I have requested Dr. Jack W. Bills, Chairman of the Committee on Mental Retardation, Section II of District X of the Academy, to testify at the public hearing to be held October 2, 1964, in Los Angeles. Dr. Bills' address is 14914 Sherman Way, Van Nuys, California. He would prefer to testify at the morning session.

The American Academy of Pediatrics is vitally interested in the welfare of children and appreciates the opportunity to give our endorsement to these proposals.

Sincerely yours,

RUSSELL W. MAPES, M.D.
Chairman, District X
American Academy of Pediatrics

RWM-em
Copy to Dr. E. H. Christopherson

Introduced by Assemblymen Waldie, Greene, and Petris
(Coauthor: Senator McAteer)

February 1, 1965

REFERRED TO COMMITTEE ON PUBLIC HEALTH

An act to add Article 7.6 (commencing with Section 416.3) to Chapter 2 of Part 1 of Division 1 of the Health and Safety Code, relating to the mentally retarded.

The people of the State of California do enact as follows:

SECTION 1. Article 7.6 (commencing with Section 416.3) is added to Chapter 2 of Part 1 of Division 1 of the Health and Safety Code, to read:

Article 7.6. Office of Standards of Care for the Mentally Retarded

416.3. There is in the Health and Welfare Agency an office which shall be known as the Office of Standards of Care for the Mentally Retarded. The office shall be administered by the Director of Standards. The director shall be appointed by and shall serve at the pleasure of the Governor. He shall receive an annual salary as provided in Section _____ of the Government Code.

416.4. The Director of Standards shall adopt reasonable rules and regulations prescribing standards regarding physical welfare, health, education, safety, and sanitation which shall

1 be satisfied and maintained as a condition to the receipt of
2 state funds by any public or private facility in which mentally
3 retarded persons are placed by a regional center.
4 The director shall provide regional centers with current lists
5 of approved public and private facilities. The regional center
6 may not expend state funds for services in any facility which
7 is not approved by the director, notwithstanding any other
8 certification, licensing, or approval of the facility.
9 The director shall consult with, or contract with, and obtain
10 the advice and recommendations of such other public or pri-
11 vate authorities in the various professional fields as he deems
12 advisable in order that the standards prescribed pursuant to
13 this article shall give proper recognition to the mental, physi-
14 cal, social, and educational needs of mentally retarded persons.
15 416.5. The Governor shall appoint an advisory committee
16 consisting of 12 persons, 6 of whom shall be parents of men-
17 tally retarded persons and 6 of whom shall be directors of
18 community based agencies engaged in providing services for
19 the mentally retarded. The committee shall consult with and
20 advise the Director of Standards in the adoption of standards
21 pursuant to Section 416.4.
22 416.6. If there is evidence that a facility does not meet
23 the standards prescribed by the director, state funds may be
24 immediately withdrawn for all children in the facility.
25 416.7. The Director of Standards shall establish rates of
26 state payment for the care of mentally retarded persons in
27 public and private facilities utilized by the regional centers.

0

LEGISLATIVE COUNSEL'S DIGEST

AB 690, as introduced, Waldie (Pub.H.). Mentally retarded.

Adds Art. 7.6, Ch. 2, Pt. 1, Div. 1, H. & S.C.

Establishes Office of Standards of Care for the Mentally Retarded in Health and Welfare Agency, to be administered by a Director of Standards appointed by the Governor.

Requires the director to adopt standards regarding physical welfare, health, education, safety, and sanitation, which must be met by public or private facilities caring for mentally retarded persons, as a condition to the receipt of state funds.

Requires director to consult with authorities in various professional fields and with advisory committee provided for by the act.

Requires director to establish rates of state payment for care of mentally retarded persons in facilities.

R) L-1891 5M

ASSEMBLY BILL

No. 691

Introduced by Assemblymen Waldie, Greene, Lanterman
Alquist, Burgener, Petris, and Warren
(Coauthor: Senator McAteer)

February 1, 1965

REFERRED TO COMMITTEE ON PUBLIC HEALTH

An act to add Article 7.5 (commencing with Section 415) to Chapter 2 of Part 1 of Division 1 of the Health and Safety Code, relating to the mentally retarded.

The people of the State of California do enact as follows:

1 SECTION 1. Article 7.5 (commencing with Section 415) is
2 added to Chapter 2 of Part 1 of Division 1 of the Health and
3 Safety Code, to read:

4 ARTICLE 7.5. MENTALLY RETARDED PERSONS

5 415. As used in this article, "regional centers" means re-
6 gional diagnostic, counseling, and service centers for mentally
7 retarded persons and their families.

8 415.1. It is desirable that there be a shift in state responsi-
9 bility for mentally retarded persons from the time they enter
10 a state hospital to the time when they are diagnosed as needing
11 specialized care.

12 In order to provide fixed points of referral in the commu-
13 nity for the mentally retarded and their families; establish
14 ongoing points of contact with the mentally retarded and their
15 families so that they may have a place of entry for services
16 and return as the need may appear; provide a link between
17 the mentally retarded and sources in the community, including
18 state departments, to the end that the mentally retarded and
19 their families may have access to the facilities best suited to
20 them throughout the life of the retarded person; and offer
21 alternatives to state hospital placement, it is the intent of this
22 article that a network of regional diagnostic, counseling, and
23

1 service centers for mentally retarded persons and their fam-
2 ilies, easily accessible to every family, be established through-
3 out the state.

4 415.2. The State Department of Public Health, within the
5 limitations of funds appropriated, shall contract with appro-
6 priate agencies for the establishment of regional centers.

7 415.3. Regional centers shall be near centers of population
8 where most needed and wherever possible connected to or in
9 close proximity to institutions of higher learning and research.

10 415.4. The regional centers shall provide and perform or
11 cause to be performed services including, but not limited to,
12 the following:

13 (a) Diagnosis.

14 (b) Counseling on a continuing basis. Counseling shall in-
15 clude advice and guidance to any mentally retarded person
16 and his family, to assist them in locating and using suitable
17 community facilities, including, but not limited to: special
18 medical services; nursery and preschool training; public edu-
19 cation; recreation; vocational rehabilitation; and suitable resi-
20 dential facilities.

21 (c) Provide state funds to vendors of service to the re-
22 tardated, when failure to provide such services would result in
23 state hospitalization.

24 (d) Maintain a registry and individual case records.

25 (e) Systematic followup of the mentally retarded and re-
26 activation of cases as indicated.

27 (f) Assist, where necessary, in state hospital placement of
28 the mentally retarded.

29 (g) Call public attention to unmet needs in community care
30 and services, defining and interpreting standards of community
31 care and services as used by the regional center, and stimulat-
32 ing the community to develop such services as needed.

33 (h) Maintain a staff according to standards set by the State
34 Department of Public Health.

35 415.5. Upon referral by a physician, or other qualified
36 professional person authorized by the regional center, any
37 person suspected of mental retardation shall be eligible for
38 initial intake and for diagnostic and counseling services in
39 the regional centers.

40 ~~415.7.~~

41 415.6. The State Department of Public Health may receive
42 and expend all funds made available to the department by the
43 federal government, the state, its political subdivisions, and
44 other sources, and, within the limitation of the funds made
45 available, shall act as an agent for the transmittal of such
46 funds for services through the regional centers. The depart-
47 ment may use any funds received under Article 2 (commenc-
48 ing with Section 249) of this chapter for the purposes of this
49 article.

50 416. The parents or guardian of a mentally retarded per-
51 son may designate the Director of Public Health as guardian
52 of the mentally retarded person on the death of the parents or

1 guardian, if the state has assumed responsibility for providing
2 care to the retarded person, through the regional center. Such
3 guardianship shall be for the purpose of carrying out the
4 recommendations of the regional center and to provide the
5 retarded person with the assurance of continuity of care.

6 416.1. This article does not authorize the care, treatment,
7 or supervision or any control over any mentally retarded per-
8 son without the written consent of his parent or guardian.

9 416.2. The agency operating a regional center may enter
10 into agreements with parents, guardians, persons responsible
11 for the care of the mentally retarded, or estates of mentally
12 retarded persons, to use such amounts as they may be able to
13 pay toward the cost of services for such mentally retarded
14 persons. In no event, however, shall there ~~by~~ be any charge for
15 diagnosis or counseling.

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