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hawaii

REPORT TO THE

dd COUNCIL

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S O K O L O F F · H A M I L T O N · B E N N E T T A I A
A R C H I T E C T S A N D P L A N N E R S

THE ROLE OF THE HAWAIIAN
STATE DEVELOPMENTAL DISABILITIES
PLANNING AND ADVISORY COUNCIL
IN THE DEVELOPMENT OF THE
SERVICE SYSTEM

SOME FUTURE OPTIONS FOR
WAIMANO TRAINING SCHOOL
AND HOSPITAL AS A COMPONENT
OF A COMPREHENSIVE SERVICE
SYSTEM

Prepared by
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April 1974

This report is based on a four day visit to Honolulu which only allowed a cursory look at the service system for the Developmentally Disabled.

Although Waimano Training School and Hospital was visited, little time was available to visit or to study existing facilities and programs.

Appreciation is expressed for the information and help given by Dr. Angie Connor, Tad Mayeda, Florence Momeyer, Edwin Murayama, Lambert Wai, Garret Yanagi, and particularly, Mary Smith, the competent and hardworking staff planner to the Developmental Disabilities Council.

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INTRODUCTION - THE NATIONAL SCENE

At one time or another in their lives, large numbers of developmentally disabled persons, at different levels of chronological development, and with different kinds of handicaps, will require some kind of care outside the normal home situation.

In the immediate past there was a singular solution - the state institution. Twenty-four hour a day care in a totally self-contained facility is not required for a large number of developmentally disabled people, even when they may need residential care outside their homes.

Our ideology of human services is changing. We are moving away from an emphasis on "care" delivered in large isolated and segregated multi-purpose institutions. We now consider that every handicapped person is a human being with a potential for development, and that as a citizen he or she has the right to the opportunity to develop that potential in order to learn to live as independently as possible and to work as productively as possible.

The new developmental ideology starts with the open ended expectation of growth and prescribes a variety of as-close-to-normal and normal residential arrangements so that each handicapped person can find the best setting for his or her particular stage of development.

New treatment concepts which are geared towards helping the developmentally disabled person appear and behave as normal as possible require an environment which is as near normal as possible. New accreditation procedures developed by the Joint Commission on Accreditation of Hospitals are based on this new ideology.

Action to implement this philosophy is now being mandated by the courts in decisions all over the United States exemplified by the right to treatment case in Alabama and the right to education case in Pennsylvania.

We are moving towards Revenue Sharing which will cause priorities to be set at the state and local levels for allocation of resources. We are moving towards accreditation as a method of ensuring quality. We are moving towards a national health insurance which will fund people rather than programs. We are looking at the effect of uncontained growth on the quality of life.

Hawaii must plan for the future - not for the past.

"If we could first know where we are, and whither we are tending, we could better judge what to do, and how to do it."

Abraham Lincoln

IDEOLOGY - Its power, method for development, and strategic use.

Henry Kissinger once said, "In the absence of a generally understood doctrine, our actions will of necessity prove haphazard; conflicting proposals will compete with each other without an effective basis for their resolution."*

A generally understood doctrine can be termed ideology. It is the combination of beliefs and attitudes that are derived from one's values. Ideology is a powerful force that affects and often determines our behavior.

In the last few years we have been moving away from our perception of the handicapped as sick or as subhuman, or as children, or as a menace. We have been reconceptualizing them as human beings with potential for development and as citizens with rights to opportunity for development. These new attitudes and beliefs are the basis for an increasingly pervasive developmental ideology which has been officially adopted by the United Nations, the United States Congress, the National Association for Retarded Citizens, the United Cerebral Palsy Association, the Joint Commission on the Accreditation of Hospitals, etc., etc.

Hawaii should develop an official ideology which must become:

*Henry A. Kissinger, "Strategy and Organization", Foreign Affairs, No. 3, Vol. 35, April 1957, P.394.

- (1) The criterion for evaluating existing programs, services and facilities.
- (2) The planning basis for the design of new programs, services and facilities.

During its development and implementation it must be:

- (1) Discussed and examined
- (2) Articulated and encapsulated
- (3) Understood and internalized
- (4) Publicized and interfused
- (5) Ratified and repeated
- (6) Legitimized and legislated.

The development of the ideology must have input from, be accepted by, and relate to all the developmentally disabled. This includes those with cerebral palsy, epilepsy and autism.

The ideology must take into account:

- (1) The extent to which we desire to protect the handicapped from exposure and risk.*
- (2) The extent to which our goal for developmentally disabled people is increasing independence, productivity and fulfillment.

*Robert Perske, "The Dignity of Risk", The Principle of Normalization in Human Services, National Institution of Mental Retardation, 1972.

- (3) The extent to which they shall be considered as human beings, regardless of the severity of their handicaps.
- (4) The extent to which the purposes of the service system shall be to insure their right to the opportunity to develop whatever potential they possess.

The State Developmental Disabilities Council should stimulate the development of this ideology and insure that a continuing planned activity be undertaken to interfuse it into Hawaiian consciousness.



THE HAWAIIAN SCENE

Hawaii needs a comprehensive coordinated system of services and facilities which will serve all developmentally disabled people, whether they need 24-hour nursing care or are able to live productively with minimum support in their own communities.

Hawaii, with almost 800,000 people spread across a chain of Islands five hundred miles long, has no interisland public transportation system other than aircraft.

Any planning for programs and facilities must be sensitive both to the needs and desires of all the islands as well as to the political power of their representatives in the legislature. It is often assumed that rural areas are poorer than urban areas and therefore cannot support local services; this is questionable.

The service system for developmentally disabled people living in the Hawaiian Islands is dominated by the Waimano institution which houses some 700 residents. In addition to the Waimano facility, approximately 450 persons are served by community programs. Educational services are supplied at Waimano by Department of Health staff. Fort Ruger vocational training facility in Honolulu is run by the Hawaiian Association for Retarded Children. The Association receives a per capita amount from the Department of Education to deliver this service. The Department of Education limits, by policy, its services to those children it can serve with comparative ease.

The total Developmental Disabilities system depends almost completely on Federal funds augmented by volunteer agency contribution. The Hawaii Association for the Retarded has built and operates the Fort Ruger Vocational Training Center in Honolulu. Almost all the Association's energy and resources are absorbed in supporting this important and successful program.

Few State funds have been or are available to this badly underfunded system. The precariousness of the situation at Waimano cannot be over-estimated particularly now that the Federal Government is withdrawing its support from categorical programs, and priorities for resource allocation will be made more and more at the local level.

At present there is a considerable divergence of views for and against the institution or the community as the appropriate base for the service system. Proponents, with some justification, see the funding of one as a threat to the other. Experience elsewhere has given cause for concern that a community support system is difficult to create and that community residential facilities are often ill-supervised and have no programs available to the residents.

What is needed in Hawaii is a single system of services which can deliver institutional care for those who need it as well as community based support services and facilities for those who can learn to be more independent and productive by being in their own communities.

Strategy must be developed to get state support for the service system. ★

For the State Council to be effective it must understand how the present system works. The locus of decision making must be determined in the areas of program design, budgeting, evaluation, ideology, created data collection, priority setting, etc.



The Council must understand who is planning, what is their authority, their relationships, what product they produce, and the effect of their product.



The Council must then determine the tools and resources which are available, and must conceptualize potential resources with which it can affect the service system.



ROLE OF THE STATE DEVELOPMENTAL DISABILITIES PLANNING AND
ADVISORY COUNCIL

The State Council is set up under Federal law representing all elements of the service system both public and private, in order to assist in developing overall policy. The Council is the only body in a position to do this effectively. From its position it must develop the ability to influence the service system.

The present council has built a reservoir of good will which is being manifested in communication and cooperation. This is in part due to council staff who has the confidence of the public and private agencies. It is also due in part to the lack of Federal developmental disabilities funding available to Hawaii which has insulated the council from the difficulties associated with allocation of resources.

It is however puzzling that the National Advisory D.D. Council should encourage the assumption of leadership by State Councils while at the same time denying it the funds which would make this possible. It should be brought to the attention of the National Council that the minimum amounts assigned to the smaller states are so inadequate as to be below what might be termed the "critical mass" necessary to allow the Council the resources to exercise leadership in policy.



Mr. Frank Laski in his report to the National Developmental Disabilities Conference in November 1972 stated the position of the federal government agency charged with administering the Developmental Disabilities Program:

"The importance of planning is clearly set forth in the Developmental Disabilities Act. The purpose of the Act speaks first to the need for "developing and implementing a comprehensive and continuing plan for meeting the current and future needs for services to persons with developmental disabilities." The rules and regulations under the D.D. Act reinforce the central role of planning and pinpoint the responsibility of the State D.D. Councils "to provide leadership in planning and evaluation." The regulations also stress the interagency aspects of planning and the need to coordinate with other state-federal plans.*

The Council faces a difficult task because it is involved with many organizations, each with its own planning and decision-making processes. At present the Council has difficulty in developing effective action; the Council is not seen as a policy authority, and could not allocate D.D. funds on a strategic basis even if adequate funds were available.

The Council must ensure that ongoing planning is related, that policy issues are highlighted, and that the consequences of policy choices are clear.

*The Planning Process for the Developmentally Disabled, a paper presented by Frank J. Laski, Office of the Commissioner, Rehabilitation Services Administration, S.R.S., H.E.W., at the National Conference for State Planning and Advisory Councils on service and facilities for the developmentally disabled, Washington, D.C., November 1972

The Council is charged with overall policy planning and leadership for all services for the developmentally disabled in Hawaii

No one else has the responsibility or is in the position to advise from the overview of:

- (1) Public and private programs
- (2) Statewide allocation of effort
- (3) Client oriented perspective
- (4) A non-operator of programs with an objective viewpoint.

If the Council does not plan overall policy, no one else will.

For the State Council to be effective it must understand how the present system works. The location of decision making must be determined in the areas of program design, budgeting, evaluation, ideology, created data collection, priority setting, etc.

The Council must understand who is planning, what is their authority, their relationships, what product they produce, and the effect of their product.

The Council must then determine the tools and resources which are available, and must imaginatively conceptualize potential resources with which it can affect the service system.



The following is a suggested list of service elements in the D.D. system. This report, which is a cursory review based on a short visit and

ELEMENTS OF THE DEVELOPMENTAL DISABILITIES SYSTEM

<u>SERVICES</u>	<u>MANAGEMENT AND PLANNING PROCESSES</u>	<u>MECHANISMS</u>
Diagnosis and Counseling	Goal Setting	Rates
Residential	Establishing Priorities	Standards
Education	Programming	Licensing
Vocational Rehabilitation	Budgeting	Zoning
Employment	Controlling	Research
Health Care	Evaluation	Manpower Training
Rehabilitation	Information Management System	Public Awareness
Recreation		Ideology
Religion		Facility Development Process
Personal Advocacy		Accreditation
Legal		Life Safety Codes
Prevention		
Intensive Behavioral Interpretation		
Behavioral Reinforcement		
Respite		

In order to conceptualize and implement a planning process which will coordinate and make comprehensive the system of services to the developmentally disabled it is necessary to:

- (1) Identify the necessary key elements without which the service system will be deficient.
- (2) Analyze each element so that it is fully understood in itself and in its interinvolvement with other elements of the system.
- (3) Obtain agreement for the acceptance of responsibility for the creation and/or support of each element.
- (4) Devise strategy to ensure that each necessary element is perceived as a legitimate part of the service system regardless of whether it is supplied by public or private agencies.
- (5) Select areas which need critical attention and develop strategy and initiate implementation action.

Those who are affected by decisions must be party to the decisions which affect them. Therefore the designing of a planning process and its application to the total system must truly be a joint venture in which the goals and objectives of all concerned are properly considered.



"LIVING SYSTEMS" GUIDELINES

It is necessary to develop the guidelines which will determine the kinds of facilities and programs needed and desired to serve the developmentally disabled in Hawaii.

These guidelines should include the philosophy, the goals and objectives of the programs, the characteristics of those to be served, the qualifications of staff, the type of environment, the supportive services, the required licensing, the designated standards, the desired maximum and minimum sizes, etc., etc.

Wisconsin, Pennsylvania and Douglas County Nebraska are among those who have developed such guidelines. The Wisconsin publication entitled, "Community Living System Guidelines" ^{*} is a model both of content and of development process, and should be carefully examined.

Guidelines should also be developed for institutional facilities as well as community facilities. The role of the institution must be clearly defined and the definition accepted by the public and private agencies and the parents of individuals, etc. There is, hopefully, a considerable area of agreement about the desired life style of a developmentally disabled person who needs to reside in the institution, including desirability of the following:

- (a) privacy
- (b) small group living

- (c) personal choice
- (d) freedom to socialize
- (e) absence of regimentation
- (f) opportunity to increase independence
- (g) opportunity to increase competence

If the developmentally disabled are to enjoy the life style embodied in the above-listed points, the institution must decentralize to the level of the living unit, with as much authority as is consistent with keeping the whole institution on course towards its major operational objectives.

Creative work must be done to change the orientation of Waimano so that it can serve the residents within the new ideology.

An unusual instance of a successful change has taken place at Fairview State Hospital in Costa Mesa, California, under the leadership of Dr. Toto. It is interesting to note that although facilities, residents, staff and money support have remained the same, changes have taken place in staff attitudes, organizational structure, role relationships, ideological concepts and creative productivity.

*Guidelines to Community Living Systems for the Developmentally Disabled, June 1972, Wisconsin Department of Health and Social Services, Bureau of Mental Retardation, Madison, Wisconsin.

Pennsylvania Residential Service Types

1. Life support
2. Infant nursery
3. Child development (5 and 7 day/week residence)
4. Habit shaping - Youth development
5. Behavior habilitation (corrective)
6. Training Hostel A - Young adult development
7. Training Hostel B - Sheltered living
8. Training Hostel C - Minimal supervision
9. Crisis assistance

Wisconsin Residential Service Types

Children's living systems

1. Foster homes
2. Group homes
3. Child welfare institutions
4. Boarding homes
5. Temporary care homes

Adult living systems

1. Foster homes
2. Group foster homes
3. Boarding homes
4. Residential care facilities long-term
5. Residential care facilities short-term
6. Nursing home care and public medical institutions

Douglas County Nebraska Residential Service Types

1. Maintenance of life
2. Infant development
3. Child development
4. Pre-vocational
5. Habit shaping
6. Structured correctional
7. Training hostel - young adults
8. Sheltered living
9. Minimal supervision
10. Crisis assistance

THE WAIMANO INSTALLATION - INTRODUCTION

This consultant was caught unawares by the conditions at Waimano. The contrast between the gentle climate, the beauty of the island, the affluence of Honolulu, the gentleness and hospitality of the people, the pleasant administration building - all left me unprepared for the cruel reality of the understaffed, underprogrammed prison.

It would be unfortunate indeed if the harsh criticism of this report were to place the blame on the staff, the institutional administration or on the Department of Health. The blame must be placed where it belongs -- on the State of Hawaii, the Governor and the Legislature and those who control the priorities for financial support.

All possible efforts of the D.D. Council, the Department of Health, the parents, the Hawaiian A.R.C. must be focused on obtaining adequate program funds from the state to correct this intolerable situation.

The enclosed letter to Governor Burns expresses a viewpoint which should be brought to the attention of the legislature and the public.

Waimano Training School and Hospital is located 12 miles west of Honolulu on Waimano Ridge. The ridge runs from the mountains toward Pearl City. The facilities are spread like a narrow village along the ridge for more than a mile; they are divided into three separated areas; at the seaward end in the new Waimano Hale, an 84-bed facility for the less severely retarded and which also houses the top administration; in the center are the facilities for men; at the mountain end are the facilities for female residents, children and the profoundly impaired of both sexes.

There are four buildings* under consideration for renovation to meet intermediate care standards. They are spread through all three sections of the site. A proposed expenditure of approximately \$100,000.00, if it can be obtained from the Bureau of Budget and Finance, will be used to bring them to intermediate care facility standards. This will generate Title XVI Program funds in the amount of 20 dollars a day per resident. This would be extremely helpful and should be encouraged.

Two of the buildings, serving as residences for 100 males, are almost 40 years old, while the women's facilities are 20 years old.

Except for Waimano "Hale" the thirteen main buildings do not lend themselves easily to remodelling to meet skilled nursing care or even intermediate care facility standards.

*Waimano Hale, Men's Buildings #4 and #5, and Girls Building and Administration #9.

Although the site itself and the views from it are beautiful, neither are available to the residents whose facilities turn inwards. The outdoor courtyards are surrounded by buildings for the most part. Those living in the buildings do not benefit from the climate, the flora and the views.

The site layout appears to be the end result of continual "expedient" decisions. The distances between the different parts of the institution are too great to walk. The adjacent high school which is built on land taken away from Waimano is now separated from the institution by a fence. A 22-acre area between "Hale" and Men's Building #4 may be lost to the institution and turned into a park; while this may be useful in bringing the community to Waimano, this consultant has misgivings that the park may be fenced to protect it from the Waimano residents. The park will separate the new Waimano "Hale" facility from the rest of the institution.

National Association for Retarded Citizens

SERVING RETARDED CHILDREN AND ADULTS

8

22 April 1974

The Honorable Governor John A. Burns
State Capitol
Honolulu, Hawaii

Dear Governor Burns:

I was deeply touched by the expressions of affection and respect which were given to you last Friday in the Legislature by leading Hawaiian citizens; they obviously expressed the love which the people of Hawaii have for a great and good man approaching the end of a long career of dedicated service.

I watched the ceremony at the end of a week spent as a consultant to the State Planning and Advisory Council on Developmental Disabilities.

It was my third visit to the islands, and again I was captivated by the soft warmth of the climate, the gentleness and hospitality of the people, the beauty of the children and the young people, the openness and kindness of the government employees, and the charm of Hawaiian customs. (When I participated in a panel discussion, I was kissed and decorated with a fragrant hand-made lei of ginger blossoms.)

All of these experiences made up my perception of Hawaii, that is until I visited the Waimano Training School and Hospital above Pearl City. Waimano is the State institution which serves as the home for seven hundred mentally retarded people.

There I found human beings condemned to live worse than animals, trapped by lack of training into cruel, endless helplessness. The staff is overworked, some working double shifts illegally and sleeping in cars. Patients lie bed-ridden in a hospital with no fire escapes from the upper floors, and their parents live frustrated in daily fear. The hospital administration and the Department of Health have been continually frustrated by the refusal of needed funds to increase staff.

CAROL BURNETT
NATIONAL HONORARY CHAIRMAN

MARION P. SMITH
PRESIDENT

PHILIP ROOS, Ph.D.
EXECUTIVE DIRECTOR

THE GREATER DALLAS-FORT WORTH METROPLEX

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FORMERLY THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN

The Honorable Governor John A. Burns
22 April 1974
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There are no programs at all for the more severely handicapped. Only a few of the more able get any training at all, which the Department of Education, by policy, refuses to serve any of the Waimano residents.

So I came away with the uneasy feeling that my former vision of Hawaii was a view of the surface; that the warmth and beauty and affluence is paid for in part with funds which should be spent correcting the hidden horrors of Waimano.

If my 23-year old retarded daughter Lucy were by circumstance unlucky enough to be a ward of the State of Hawaii at Waimano, her fragile nature and limited abilities would quickly make her silent and withdrawn, and within a short time she would die - and I would be glad that her suffering would end.

The system of services for the developmentally disabled is financed only with federal funds which are becoming less and less available. The State of Hawaii has made no commitment to its less fortunate citizens who cannot fend for themselves without help.

What a lasting monument you would leave if you were to change this.

With respect and best wishes,

A handwritten signature in dark ink, reading "H. David Sokoloff". The signature is written in a cursive, flowing style with some capital letters.

H. David Sokoloff
Member of the Board of Directors, National Association for Retarded Citizens
Member of the California State Planning and Advisory Council on Developmental
Disabilities

cc: Marion P. Smith, President, N.A.R.C.

THE HOSPITAL AT WAIMANO

The hospital is a three-story building built in 1950 and added to in 1957. It houses 150 severe and profoundly retarded and/or physically handicapped people.

It is completely medically oriented. No services are available other than a few foster-grandmothers to stroke the residents or even to talk to them. There are no educational programs, no social training programs.

It is medically efficient and spotlessly clean. It is with pride, and appropriately so, that the medical director can boast that none of his patients have bed sores. But what about mind sores?

We spoke to a hydrocephalic young lady who chatted intelligently with us. We spoke with a young man who has muscular dystrophy and is at Waimano because no one else wants him; he was shy and self-deprecating about his ability to play the harmonica, his only visible possession - an intelligence dying for want of nourishment.

No one ever goes outside in a climate in which one can be out of doors almost all the time all year round as long as you are protected from the wind and the rain. Open lanais and shutters allow for natural air conditioning.

No evidence was present of any stimulation activity connected with feeding or bathing.

No photos or instructions or equipment was visible in the hospital which would have indicated that anyone lying in bed ever got up.

No music was being played and none was available under the control of residents other than a derelict piano in one of the courtyards.

No orthopedic equipment was visible; no positioning or orthopedic activity of any kind seemed to be taking place anywhere with the children.

Immediate examinations of the fire safety conditions must be undertaken. If a fire were to occur, it appears that there is no way to evacuate bed-ridden patients.



An immediate assessment of the situation must be made and feasibility and costs of a temporary solution must be made.

It is interesting to note that Hilo Hospital, Kau Hospital, Kona Hospital, Kohala Hospital and Monokaa Hospital are all considerably underutilized.

In addition a new acute general hospital is about to open at only one third of its utilization capacity. Some of these facilities might be used on a temporary basis until the future of the Waimano Hospital is decided.

MEN AND WOMEN'S WARDS

The nine buildings which are used as wards for men, women and children (other than Waimano Hale, which is discussed in the next chapter) are built on the old institutional model. There was no evidence that any dental work or orthodontal work was available or had been available in the past. In one ward there were 30 physically handicapped people sitting in 3 rows of wheelchairs, wheel to wheel, on the back porch, doing nothing.

A severely physically handicapped man had developed a small territory in the corner of Building #4. He had a scrapbook, a collection of paintings made by holding the paint brush with his foot. He was like a prisoner on a desert island with no one to talk to - yet of sufficient drive and ability to hold a job. He could converse intelligently in spite of being locked up permanently with others who were vastly less intellectually capable than he.

A head-banger with his face swollen sat banging his head - no operant conditioning programs were in evidence for him or for anyone else. In most of the wards there were no personal possessions.

Honolulu is more than replete with clothing stores which are filled with colorful shirts and brilliant mu-mus, but the residents walk around in clothes which are shapeless, drab, and overlaundered. The staff is dressed in white as though they were all medical orderlies. Every door is locked, even in Waimano "Hale", where the able residents live. That conditions are no worse than they are is in large part due to the selfless dedication of overworked staff assisted by a few foster grandmothers.

FACILITY/PROGRAM DEVELOPMENT PROCESS - The Need for Examination

The Waimano "Hale" facility exemplifies the difficulties which are more and more likely to be encountered in the process of conceptualizing a program and designing and constructing the facility which the program requires.

Waimano "Hale" which was constructed with Federal funds (PL-88-164) was initiated only three years before it was completed and occupied in 1973. The design of the service program was developed by competent professionals with intimate knowledge of the institution and the service system. The interpretation of the service goals and objectives into an architectural solution was carried out by a firm of proven technical competence and design ability. Furthermore, this consultant was impressed by the humanistic concern and ideological commitment of the programmers and the architects.

The facility was never used for the purposes for which it was planned; it has changed some of its functions since it was occupied, and is in process of changing them again. A large waste of funds has occurred because specially designed, fully equipped training kitchens have never been used, special cabinet work remains empty, specially designed areas are used as offices, orthopedic rooms are used for storage, etc., etc. Now it is necessary to invest further funds into the facility to bring it up to I.C.F. standards in order to obtain Title XVI funds.

In order to ensure that the facilities resulting from careful planning by competent people are appropriate to the requirements of the programs, it is necessary to suggest some possible reasons why Waimano Hale has failed.

1. The program concept which the building was designed to serve may not have been an integral part of the Waimano institution, nor was the institution itself seen as part of the total service system.
2. The facility was built to house a static program in a time of rapid ideological and technical change.
3. Regulations mandated planning solutions inappropriate to program goals.
4. Professional behavioral-psychological input was not available during the planning process.

The process of the development of service programs, their translation into architectural guidelines, the interpretation of these guidelines into facility design should be analyzed and corrected. Although at present funds are not available for facility construction, it is advisable to prepare for that eventuality.

The sequence of steps and decision points in the programming, planning, design and construction of facilities must be defined so that the

roles and responsibilities of the sponsors, the consultants, the architects and the agencies are clear.

Potential sponsors of community facility projects are not likely to have the expertise necessary to organize a project. In such a situation a great deal of time is wasted, decisions - and often design decisions - are made by default. It is important that those involved in the process understand the implication of their decisions. For example, a decision to have separate toilets for staff and clients will radically affect their role-relationships and their self-image.

Experience also shows that attitudes are shaped during the planning process and that one is afforded a singular opportunity to examine the goals and the roles at that time.

This consultant visited an architecturally stunning facility in Copenhagen which had been in use for less than a year. It became clear that the staff did not like either the sunken living room or the fixed dining table. Their dissatisfaction stemmed from poor relationships built up during the planning phase, which resulted in staff feeling that headquarters was not sensitive to their problems and their abilities. Clearly, the dissatisfaction was affecting the program itself.

The Waimano Hale building illustrates the difficulty of obtaining a desired end result even when all the decision makers are competent, ethical people. The development of community-based facilities may not have as many pluses to start with.

WAIMANO "GOALS AND PROGRAM GUIDELINES"

Before any further capital expenditures beyond the \$100,000. are made, the role of Waimano as a part of the total developmental disabilities service system must be defined.

This will necessitate examining the objectives of the hospital in realistic terms. It is interesting to read the "Introduction and Program" guidelines in the Policies and Procedures Manual published by the Waimano Institution and to compare what is written with reality.



Manual

Waimano Training School and Hospital recognizes and accepts its responsibilities toward the retarded. It gives service to meet their needs, recognizing the rights of the retarded to develop their potentialities to the maximum and their requirements for acceptance, respect, security, care, training, education, recreation, job satisfaction and guidance.

Reality

Waimano Training School and Hospital recognizes its responsibilities toward the retarded but is not in a position to accept them. It cannot give the services to meet their needs, it cannot recognize their rights to develop their potential to the maximum, neither can it serve their requirements for acceptance, respect, security, care, training, education, job satisfaction and guidance.

Manual

- 1. No retarded person will be admitted to Waimano Training School and Hospital whose needs can be met in the community.*

Reality

Retarded and in some cases other handicapped people will be remanded to Waimano as a first choice.

Manual	2. <i>No retarded person will remain at Waimano Training School and Hospital whose needs can be met outside of an institutional setting; such retardates will be placed in community work and living situations, or with families and relatives, or in subsidized care, foster homes or half way houses. The needs of the retardates living in the community will be identified and resources and services to meet the needs will be developed.</i>
Reality	More than half the retarded at present at Waimano could be better served in the community if services and facilities were available.
Manual	3. <i>The institution will provide a healthful, safe environment and proper medical care. It will provide habilitation and training to develop each resident to his maximum potential.</i>
Reality	The institution will provide an unhealthy, unsafe environment with minimum medical care. It will provide habilitation training to a very small number on a level which will preclude them from developing their potential.
Manual	4. <i>The institution will provide:</i> <i>a. Recreation and leisure time activities.</i> <i>b. Opportunities to earn money for services rendered.</i> <i>c. Opportunities for day work to familiarize residents with actual working conditions in the community.</i> <i>d. Individualized attention to meet emotional and physical needs.</i> <i>e. Supervision, training and counseling to develop desirable attitudes and behavior.</i> <i>f. Religious education programs.</i>
Reality	The institution will <u>not</u> provide any of the above listed.

Manual	5. <i>The programs are decentralized into semi-autonomous units but work cooperatively in order to more adequately meet the needs of the residents.</i>
Reality	The programs are so understaffed and so geographically spread across the site that they cannot work cooperatively.
Manual	6. <i>Specialized education will be given to residents capable of profiting from such training, insofar as our resources and staff permit.</i>
Reality	Specialized education will be given to very few residents and only in minimal amounts by unqualified staff.
Manual	7. <i>Staff development will be strengthened by in-service training and out-service training with clear delineation of duties and responsibilities.</i>
Reality	Staff development will have the benefit of little or no in or out service training.
Manual	8. <i>The institution will encourage research, new concepts of organization, programs and management to better serve the retarded.</i>
Reality	The institution is not in a position to encourage any research new concepts of organization, programs or management to better serve the retarded.

It becomes apparent that there is a discrepancy between the stated goals and the ability to carry them out.

ALTERNATIVES FOR WAIMANO

Although any acceptable future role for the Waimano institution depends upon adequate funding being brought into the service system, an assessment of the range of options must be developed now since the future of the Waimano institution is key to future of the D.D. service system. Its determination will bring into focus problems which must be confronted rather than avoided, including:



- The difficulties of obtaining community acceptance of the handicapped.
- The skyrocketing cost of land.
- The apprehension of families of involvement in the lives of their handicapped members.
- The fears of parents about the permanence of facilities and programs after they are no longer around.
- The tendency of management to underestimate the potential of individuals when they are part of a group.
- The ability of the institution to continue to supply inadequate programs in substandard facilities.
- The role of the volunteer agencies as advocates.
- The commitment of the state to handicapped citizens.

- The rewards to management for efficiency rather than effectiveness.
- The tendency of any institution or organization to become sterile, self-serving and resistant to change.
- The tendency of institutions to rationalize their faults as virtues and necessities.
- The implication of high cost investment in heavy-duty permanent construction in a time of ideological and service concepts are changing.
- The inability of the institution to be "academically" oriented.
- The ability of the institution to make use of community resources.

The options for Waimano range from making Waimano the single delivery deliverer of service for all the developmentally disabled people of Hawaii, to phasing out the institution completely.

Both of these extremes have disadvantages which are programmatic, economic and political. Therefore, two intermediate possibilities are suggested in this report in order to assist in conceptualizing a range of practical solutions, and to illuminate the process by which acceptable decisions can be reached.

ALTERNATIVE 1 - WAIMANO AS A REVITALIZED INSTITUTION

Convert the Waimano Training School and Hospital from an isolated, segregated custodial institution to an intensive and comprehensive developmental training and management center, open and outreaching to the community.

Establish satellites on neighbor islands so that adults and children remanded to state care need not be separated from their families.

The institution at Waimano would serve the following functions:

- (1) Residential medical-nursing facilities for the most severely handicapped.
- (2) Intensive behavior-shaping programs to bring under control aggressive, self-destructive and other unacceptable behavior, and to transfer that control to the individual.
- (3) Behavioral reinforcement training combined with preliminary social living training.
- (4) Pre-placement, and community living skills training.
- (5) Community-care staff and parent training.
- (6) Respite care and 24-hour crisis assistance.
- (7) Placement training.

With the most seriously handicapped at the upper end of the Waimano Ridge the programs and facilities would become progressively more advanced and community oriented until at the lower end of the site they would merge with the outside community.

The Waimano institution would become the center of service system. It would take the leadership role in encouraging and assisting the community in developing facilities and programs, in training community care staff, and in removing the barriers that isolate public residential facilities, as well as private ones, from neighboring academic, professional, and social communities.

ALTERNATIVE 2 - WAIMANO AS A SPECIALIZED SERVICE CENTER

Develop Waimano as one component of a comprehensive community based service system to serve only those who cannot be served elsewhere. Community services would be developed as a series of residential settings supported by a continuum of services to develop the individual's full potential and to sustain him in the community, as far as possible.

After the placing of many of the Waimano residents into the community there will still remain behind in the institution a number whose physical, psychological and social needs will require a concentration of specialized services in such a degree that it may not be feasible to support them in the community. Many will be those who are so profoundly retarded and/or physically handicapped that they will require skilled nursing care on a 24-hour basis.

Some of them may be supported in converted medical facilities which are now significantly under-utilized. Some, however, will have to remain at Waimano.

The emphasis on provision of service would be transferred to the community. The emphasis could be on using generic services where possible and in making the whole organization of services itself as near "normal" as possible.

The community based system would rest on the following precepts

quoted from "The Guiding Environment: The Dynamics of Residential Living",
by Karl Gruneweld, M.D.:

"The environment must be socially real, not an instructional situation only similar to that in which he is going to function.

"The emphasis on provisions for services should be transferred to the community.

"We must be consistent when we build up services for retarded individuals in separating residential living, occupation, and leisure time."

Waimano would be master planned to take care of the majority of the 275 profoundly handicapped. (The number would depend on the availability of other facilities.)

Existing wards would be adapted to intensive behavior shaping programs for approximately 55 persons. Some 15 to 25 might be expected to be in this program at all times.

Existing facilities at Waimano would have to be remodelled, or new facilities constructed to house behaviorial reinforcement and preliminary social-living training programs. (25 to 30 places might be needed.)

"Half-way" houses for pre-placement training and general community living skills training would be needed (programs similar to that which now exist in Doctors' Cottage "B".) These could also serve for respite-care and community-care staff training. (Some 15 to 20 places might be needed.)

Waimano might eventually have facilities to serve only 200 - 250 people, the majority of whom might be profoundly retarded.

An investigation could be made to assess the feasibility of abandoning all the buildings and site above the road between Building #4 and the Auditorium if the upper part of the site could be exchanged for capital funding to remodel Waimano Hale Building #4 and to build additionally required facilities for the profoundly handicapped. This consultant has insufficient knowledge to tell whether this suggestion is feasible; nevertheless, the suggestion illustrates the kind of ideas which must be investigated in order to bring radical changes to the status quo of the present service system.

THE PLANNING AND IMPLEMENTATION PROCESS

The following activities are necessary to assess the practicality, acceptability and potential effectiveness of the suggested solution.

By this process the necessary committment and support can be obtained from those who will be affected.

- (1)
 - a. Develop ideology (See Page 3).
 - b. Develop spectrum of community and institutional living systems (See Page 15).
 - c. Obtain cost/benefit comparison information between community and institutional services.
 - d. Assess the potentials and problems of developing community based programs and services.
 - e. Assess the availability and appropriateness of existing under-utilized federally funded facilities.
 - f. Assess the impact of J.C.A.H. requirements on Waimano program and facilities.
 - g. Assess the implications of new transportation systems (See Page 42).
- (2)
 - a. Assess the impact of change in federal funding posture, and the move to "revenue sharing."
 - b. Assess possible effects of changes in land use due to environmental concerns, population growth limitation, energy shortage.

- c. Assess the potential impact of future national health insurance.
 - d. Assess the impact of changing values and beliefs on the social system as it applies to the handicapped.
- (3) Develop both of the proposed alternatives schematically, including:
- a. Required program costs and staffing,
 - b. Required facilities, including costs.
- (4)
- a. Assess the physical condition of buildings and utility systems at Waimano, including their potential remaining life, maintenance and repair costs.
 - b. Assess the physical and programmatic potential of existing buildings for remodelling.
 - c. Apply construction remodelling formula (See page 44.) to assess economic practicality.
 - d. Develop a capital outlay estimate for proposed construction, including the maintenance and repair for the life of the facility. (Translate costs in units of dollars per resident per year.)

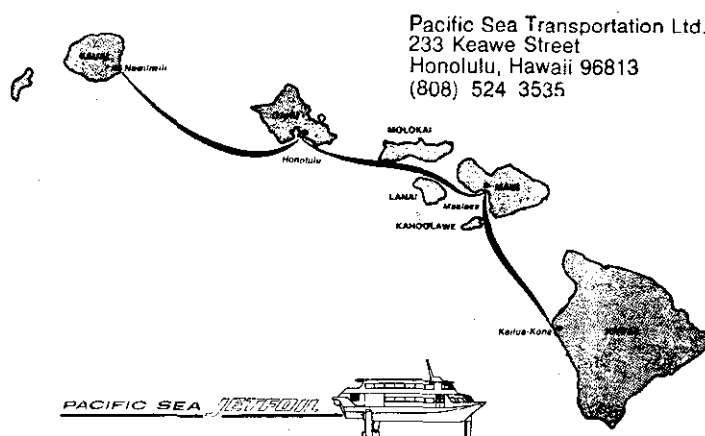
- (5) With the above information examine the two proposed alternatives for:
- a. financial feasibility
 - b. physical feasibility
 - c. programmatic and therapeutic feasibility
 - d. Political feasibility.
- (6) Obtain feedback on the perceived pros and cons of the proposed solutions from the point of view of:
- a. The residents themselves, where possible
 - b. The institutional staff
 - c. Community care staff
 - d. Parents
 - e. Administrators
 - f. Professionals
 - g. Private agencies
 - h. Public agencies
 - i. Federal government
 - j. State legislators
 - k. Other appropriate councils.

TRANSPORTATION

By the end of 1974 an interisland sea ferry source is expected to be operating using 190-passenger ocean-going, jet powered, hydrofoil craft.

The potential for this service affecting interisland travel may well have planning implications for the D.D. service system.

Discussion should be initiated between the State Department of Transportation, the State Department of Health to see what options may be opened by the new transportation linkage. Investigation should determine whether capital outlay funding might be traded for transportation subsidy, to the economic and programmatic benefit of the service system and the State. Locations for facilities and programs which have not been previously thought possible may be considered.



- ... 3 round trips/day Oahu to Maui
- ... 2 round trips/day Oahu to Kauai
- ... 1 round trip/day Maui to Hawaii

This map shows the proposed hydrofoil routes and terminals.

DEVELOPMENTAL DISABILITIES CENTER

Consideration should be given to the future creation of a D.D. center which might serve as the focus of applied research, training, experimentation for the Pacific basin. Here different disciplines might work with children and their families, in a continuum, on individual client problems which cut across the jurisdictional boundaries of the agencies.

A center could make it possible for various special interest groups, including those connected with mental health, the aged, and the delinquent, to work cooperatively to develop and implement programs, to test them, and when successful, to spin them off into the system.

A center could also serve as a training focus with special ties to the University and colleges. It could provide a training resource for medical interns, field placement for social work students and other professionals. It could become the focal point in the service system for the development of new techniques.

The center might become the fountainhead of information, knowledge, thinking, training, and experimentation to which volunteers and professionals in the field of developmental disabilities throughout the Pacific Basin would gravitate.

Consideration should be given to the interest of the University of Hawaii in developing a "University Affiliated Facility" for developmental disabilities. The concepts proposed here could be brought to their attention.



CONSTRUCTION RENOVATION FORMULA

Often the discussion as to whether it is better to rebuild or renovate becomes an issue highly charged emotionally and politically.

It is difficult to make wise decisions under such circumstances. It is difficult to convince either bureaus responsible for finance or legislation that the decisions under such circumstances are logical and reasonable.

The following construction-renovation formula was developed for the State of New York, Department of Mental Hygiene. It is based on the easily understood proposition that when the functional worth of a structure, after it has been renovated will be less than the amount of money required to do the renovation, the proposed renovation is uneconomical.

The formula takes into account:

1. Cost of renovation
2. Age of the building
3. Increased life due to renovation
4. Cost of replacement
5. Inherent inefficiencies in outmoded design.
6. Potential ineligibility for future rehabilitation.

The numerical values used in the formula were developed for New York State and may not be appropriate without modification, to Hawaii.

It is recommended that this formula be discussed with the State Facilities and Construction Bureau with a view to developing a strategy for the adoption of such a procedure with appropriate modifications.

This procedure should then be applied to Waimano facilities in determining the feasibility and desirability of alternatives under consideration.



RENOVATION COST ESTIMATES

CRITERION AND PROCEDURE FOR THE ECONOMIC EVALUATION OF RENOVATED STRUCTURES

(From Brooklyn State Hospital Master Plan - Urban Assoc., Nissim Zelouf)

CRITERION

WHEN THE FUNCTIONAL WORTH "F" OF A STRUCTURE AFTER RENOVATION WILL BE LESS THAN THE SUM OF MONEY "C" REQUIRED TO DO THIS RENOVATION, THE PROPOSED RENOVATION IS UNECONOMICAL.

As extreme examples:

- (1) Spend \$3,500,000 to renovate a mansion which, when completely rehabilitated, will only accommodate 100 guests and will then be worth only \$2,000,000.
- (2) Or: Rebuild a 1960 model car by spending \$1,500. on it, to find that, when finished, the car is only worth \$200.

The only justification for going through such uneconomical endeavors would be for sentimental reasons or other factors divorced from the purpose of this analysis.

PROCEDURE

The succeeding analyses are based strictly on economic considerations. Other factors such as urgency, need, social and fiscal limitations are assumed to be outside the scope of this study.

To analyze whether a building is worth being renovated, the following evaluation is made:

Step 1. A sketch is carefully prepared outlining the alterations and additions that would meet the minimum requirements of a functional structure.

Step 2. An estimate is prepared of the probable cost of this renovation. Denote this cost by the letter "C".

Step 3. The replacement value of the building is approximated by applying an appropriate unit cost "U" to the area "A" of the structure. Call this replacement value by the letter "R". $R = UA$

Step 4. Given the age of the building "G" and assuming a life expectancy of 50 years for structures of this category, the normal remaining life "N" is obtained: 50 years less "G" = Normal Remaining Life "N". Or $N = 50 - G$.

Step 5. Denote the Physical Worth of the structure for one year of its normal life span by the letter "Y".

$$Y = \frac{R}{50} = 0.02 R \text{ which is the Replacement Value divided by Life Span of the building.}$$

Step 6. Find the Life Extension "E" acquired for the building as a

result of past renovations of a value "K", and proposed future renovations of a value "C". Since expenditures on renovations yield a construction return of only 70% of the money input,

$$E = \frac{0.7 (K + C)}{Y}$$

Step 7. Total Remaining and Acquired Life of the Building "T" is equal to $N + E$. $T = N + E$

Step 8. Physical Worth of the building "P" is equal to the total Normal and Acquired Life multiplied by the Physical Yearly Worth. $P = TY$

Step 9. It is a fact that a renovated building still suffers from handicaps inherent in its outmoded design. Although rehabilitated, it will not provide the proper function obtained from a present design compatible with current hospital requirements. Secondly, being subjected to one extensive renovation makes it highly ineligible for further future rehabilitation, thus depriving it of an "intrinsic worth asset." Because of these two preceding ineptitudes, the functional worth "F" of the structure, after being renovated, is only 75% of its physical worth.

$$F = 0.75 P$$

Step 10. Conclusion: If "F", which is the functional worth of the building after being renovated, is less than "C", which is the money to be spent in order to do this renovation, the proposed renovation is uneconomical.

DERIVATION OF FORMULA

Derivation of Formula for Functional Worth of Building After Renovation:

$$F = 0.75 P$$

$$F = 0.75 T Y$$

$$F = 0.75 (N + E) 0.02 R$$

$$F = 0.015 R \left[50 - G + \frac{0.7 (K + C)}{0.02 R} \right]$$

$$F = 0.015 U A \left[50 - G + \frac{0.7 (K + C)}{0.02 U A} \right]$$

$$F = 0.015 U A \left[50 - G + \frac{35 (K + C)}{U A} \right]$$

This formula was developed under the direction of:

George V. Gray, A.I.A.
Director of Mental Hygiene
Facilities Planning



STATE OF NEW YORK
DEPARTMENT OF MENTAL HYGIENE
44 HOLLAND AVENUE
ALBANY, N. Y. 12208

COMPRESSING THE PLANNING PROCESS

The development of a master plan for service delivery, or the development of a service program for a facility and its translation into conceptual design, both lend themselves to analysis which can identify the sequence of steps and decision points, the responsibilities and roles of the various participants, the costs and time involved, and the predictability and implications of the outcome.

The process is usually inefficient because each of the small steps has to fit into the ongoing schedules of people whose involvement is intermittent and, at the time, peripheral.

Compressed planning has been used effectively by large corporations, by junior colleges and by volunteer associations to shorten the planning period and to increase the effectiveness of the planning.

The Dallas Association for the Retarded used this process last August when, after three years, they had made little progress with the development of a vocational training facility and offices for their association, both to be built on the same site. The Federal government was threatening to withdraw funds unless progress was made quickly. Investigation showed that during the previous 3 years many things had changed - the posture of the Federal, State, and local government agencies, the ideology of treatment and

management; the use of the volunteer association, the membership of the Board and the executive director. With careful preparation and with good administrative and political groundwork a planning and decision-making conference was held.

The conference was attended by the leadership of the volunteer associations, the public agencies, federal, state, and local, parents, staff and retarded people themselves. Everyone who was required for input was there to supply it. Everyone who was required to make decisions was there with the authority to make them. Everyone who needed to be informed of what was taking place came to observe; an important political consideration.

In a 1-1/2-day conference the following was accomplished:

- (1) Development of ideology and ratification.
- (2) Development of service programs for both facilities.
- (3) Translation of service programs into architectural guidelines.
- (4) Development of conceptual schematic designs with approximate costs and program implications.
- (5) General consolidation, ratification and evaluation.
- (6) Development of "critical path" plan from the end of the conference to the occupancy of the buildings.
- (7) Development of agreements for cooperative action from agencies not previously involved.
- (8) Informal enthusiastic approval by federal government of new proposal.
- (9) Infusion of energy and enthusiasm into the volunteer association and the system.

The following three weeks were spent consolidating and refining the results of the conference, which were then approved by the Board of Directors. Authorization was then given to the architects to proceed. The project has been on schedule with full design development, and it appears that the facilities will be exemplary.

The work which was accomplished during the 1-1/2-day conference as the result of careful planning over a 2-month period, would normally have taken a year. The saving in time of 10 months with the rate of construction cost inflation increasing from 1% to the present 2% a month has effected a savings in excess of \$100,000.00 on a \$750,000.00 project.

Compressing the planning process is discussed here to the Council's attention a technique which may have implications for future activities.

Further information can be obtained from:

Allan Bergman, Executive Director
Dallas Association for Retarded Children
3121 N. Harwood
Dallas, Texas 75201

★ RECOMMENDATIONS (In suggested order of priority)

1. Continue all possible effort to obtain \$100,000.00 remodelling funds from Bureau of Budget and Finance to bring four buildings to Intermediate Care Facility Standards, and obtain Intermediate Care Facility accreditation and apply for Title XVI funding.
2. Continue ongoing efforts toward implementation of an information and referral mechanism and agency coordination and communication.
3. Develop, plan, and implement strategic use of "ideology".
4. Examine immediately the fire exit situation at the "Hospital".
Assess the feasibility and costs of a temporary solution and demand immediate remedial action. Publicize the "liability" position of the State.
5. Develop strategy and use any possible resources or methods to get the State to increase its funding commitment to the D.D. service system.
6. Develop strategy and use any possible resources or methods to get the Department of Education to accept its responsibility for all educational programs for all citizens who are entitled by constitutional right.

Recommendations (Continued)

7. Assist the H.A.R.C. in developing a long-range plan to get out of the service delivery business and into the advocacy business.
8. Give full consideration to the creation of a single placement, evaluation, and purchase of service agency as proposed in Alternative 5 of the Bolton Report of May 1972.
9. Assess the physical and programmatic potential for the Waimano site and existing facilities, including utility systems and maintenance and repair requirements, including costs.
10. Work with the Department of Health County/State Hospitals administration to assess the incidence of under-utilization of all federally funded facilities and their potential for use by the Developmentally Disabled. Investigate new transportation possibilities.
11. Assess the impact of J.C.A.H. requirements on Waimano programs and facilities now and in the future.
12. Assess the potential and the problems of developing community-based programs and facilities.
13. Develop a project which will give some cost/benefit comparison between community and institution services.

Recommendations (Continued)

14. Develop and organize the Federally required master plan in such a way that it can be used as a policy document for the D.D. Service system, and also to advise and educate the Governor, the Legislature, and the departments to an overview of the total system.
15. Use D.D. funds and any other funds or assistance you can get your hands on to assist the State Council in
 - (a) understanding the present system
 - (b) determine where decisions are being made and by whom
 - (c) conceptualizing and assessing council resources
 - (d) setting policies and priorities
 - (e) developing implementation strategies.
16. Assess the existing and required components which are necessary to a D.D. service system. Develop comprehensive strategies for reinforcing weak components and stimulating the creation of missing components.
17. Develop spectrum of community and institutional "living system" components.
18. Assess the problems connected with the institutional and community facility planning and development process.

Recommendations (Continued)

19. Investigate proposed inter-island transportation system and assess its potential advantages to the developmental disabilities system.
20. Obtain and modify, or develop, and then introduce procedures for the economic evaluation of renovated structures.
21. Stimulate an investigation of the potential advantages of agency reorganization which will afford greater coordination between the institutional, community service, and placement components of the system.
22. Give consideration to the creation of a D.D. applied research, training and information center for Pacific basin.
23. No capital expenditures should be made at Waimano at this time other than emergency construction at the hospital and remodeling of four wards to bring them to I.C.F. standards.

Further capital outlay planning must wait until the future role of the institution is decided and a master plan is developed.

in a time of rapid and continuous change, there are no shortcuts to creating a comprehensive service system which will be acceptable to those whom it will affect.

In such a situation planning is a sort of social learning. The challenge is for the State Council, with its representatives of both providers and consumers, to influence the future.

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He is a past president of
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for the Retarded; he is a
director of the National
Association for Retarded
Citizens and past chairman
of the Residential Services
and Facilities Committee.
He is a director of the
San Francisco Mental Health
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