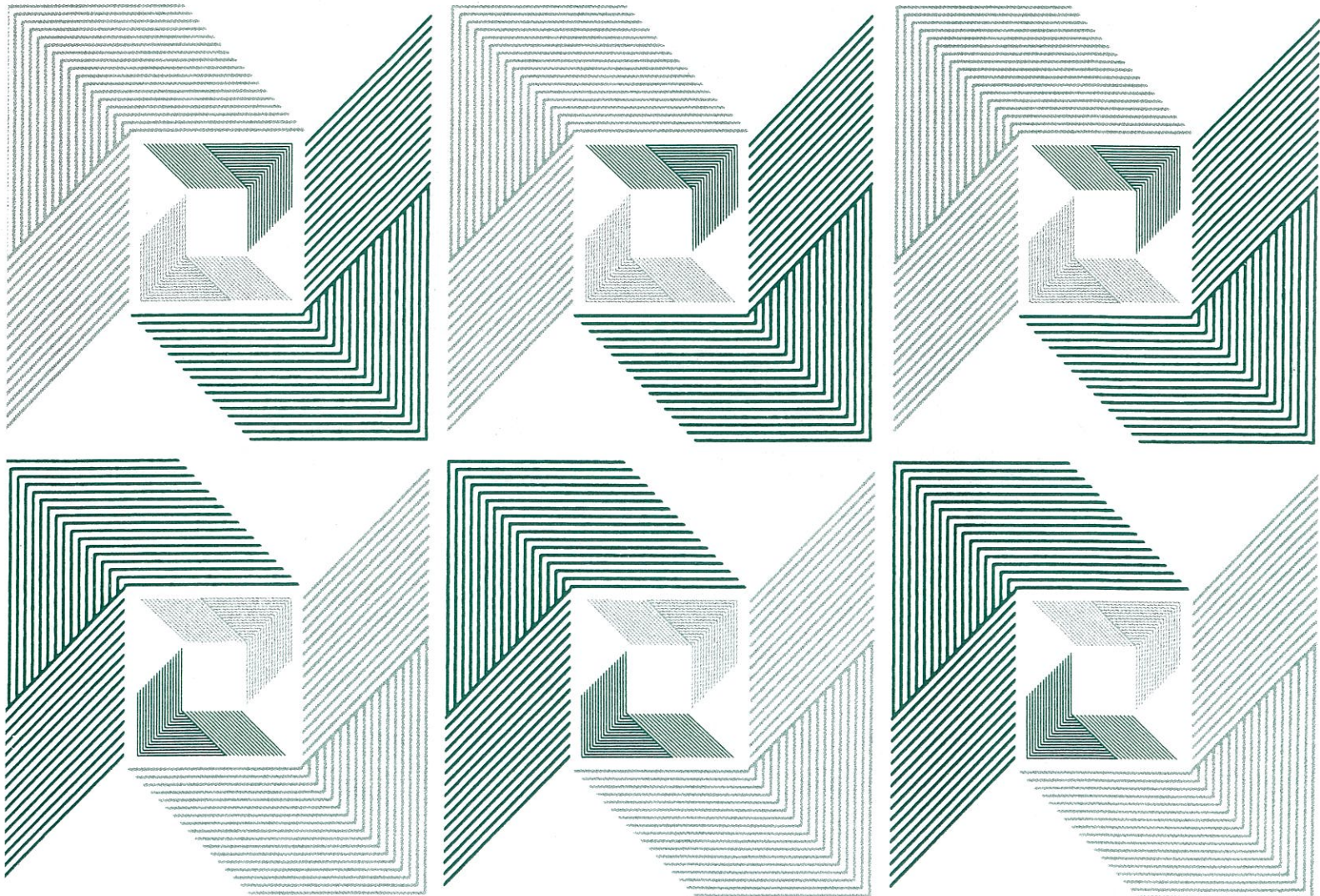


Report No. 90-8
January 1990

EVALUATION OF THE QUALITY OF CARE IN HOMES SERVING PEOPLE WITH DEVELOPMENTAL DISABILITIES

A REPORT TO THE GOVERNOR AND THE LEGISLATURE OF THE STATE OF HAWAII



THE OFFICE OF THE LEGISLATIVE AUDITOR

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3. *Sunset evaluations* are conducted of professional and occupational licensing programs to determine whether the programs should be terminated, continued, or modified. These evaluations are conducted in accordance with a schedule and criteria established by statute.
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LEGISLATIVE AUDITOR
KEKUANAO'A BUILDING, RM. 500
465 SOUTH KING STREET
HONOLULU, HAWAII 96813

Legislative Auditor

OVERVIEW

EVALUATION OF THE QUALITY OF CARE IN HOMES SERVING PEOPLE WITH DEVELOPMENTAL DISABILITIES

Honolulu, Hawaii

January 1990

Summary

Developmental disabilities are mental and/or physical impairments that occur during childhood, are likely to continue indefinitely, and limit a person's ability to carry out activities of daily living. The most common developmental disabilities are mental retardation, cerebral palsy, epilepsy, and autism. More than 700 adults with developmental disabilities live in care homes that also serve residents who are frail and elderly, chronically mentally ill, or otherwise in need of assistance. More than 130 adults live in group

homes that only serve residents with developmental disabilities.

In response to Senate Concurrent Resolution 57, Senate Draft 1, Regular Session of 1989, the auditor hired the Human Services Research Institute to evaluate the quality of care in homes serving adults with developmental disabilities. The consultants evaluated residential services and quality assurance activities and recommended improvements in state laws, rules, and program operations.

FINDINGS

Care homes are run by caring families, create a stable living environment for most residents, and are reasonably safe places to live. However, care home operators lack the time and support services to address the needs of residents with developmental disabilities and to manage behavioral problems effectively. In some group homes, high staff turnover creates an unstable living environment.

Psychotropic medications are used to control the behavior of nearly half of the care home residents with developmental disabilities and nearly 40 percent of the group home residents. Many residents with developmental disabilities do not have family members or legal guardians to look after their interests.

Care home licensing regulations do not encourage homelike living arrangements or the development of independent living skills. Group home operators complain about the rigidity, intrusiveness, and institutional nature of the regulations. Some group homes do not meet any state standards.

Department of Health case managers do not have adequate administrative or support services to carry out planning, coordination, and monitoring. Many home operators do not receive training that meets their specific needs in caring for residents with developmental disabilities. Essential information about resident rights and the procedures for filing complaints is not available to interested parties.

RECOMMENDATIONS

Specialized care homes serving only residents with developmental disabilities should be established. The Department of Health should develop a certification program for these homes and waive unnecessary licensing regulations for certified homes. It should ensure that operators of these homes receive training, support services, and additional compensation in recognition of their special expertise.

The Developmental Disabilities Division should strengthen the psychotropic medication monitoring

system and the case management system. It should encourage the development of residential service agencies and consider raising day activity program rates. Guardians should be appointed for residents without active family members, and home operator training programs should be decentralized. The State Planning Council on Developmental Disabilities should develop more social activities for residents and together with protection and advocacy agencies develop a handbook on resident rights.

RESPONSE

The Department of Health agreed that there is a need to strengthen the informed consent process for psychotropic medications, improve the case management system, and develop a certification program. The State Planning Council on Developmental Disabilities and the Protection and Advocacy Agency of Hawaii supported most of the findings and recommendations in the report.

**EVALUATION OF THE QUALITY OF CARE
IN HOMES SERVING PEOPLE WITH
DEVELOPMENTAL DISABILITIES**



Conducted by

**Office of the Legislative Auditor
State of Hawaii**

and

**Human Services Research Institute
Consultant**

A Report to the Governor and the Legislature of the State of Hawaii

Submitted by

**Legislative Auditor of the State of Hawaii
Honolulu, Hawaii**

**Report No. 90-8
January 1990**

FOREWORD

Senate Concurrent Resolution No. 57, Senate Draft 1, Regular Session of 1989, requested the Legislative Auditor to evaluate the quality of treatment, including behavior management, in community facilities serving people with developmental disabilities.

To obtain the professional expertise for the study, we asked several consultant firms to submit proposals in response to specifications developed by our office and we selected the Human Services Research Institute to conduct the study. The consultant conducted the research, fieldwork, and analysis for the study and submitted a draft report. Our office participated in the review and finalization of the report.

We join the Human Services Research Institute in expressing our appreciation for the assistance extended by officials and staff of the Department of Health and many other agencies involved in the delivery of services for people with developmental disabilities in the state.

Newton Sue
Acting Legislative Auditor
State of Hawaii

January 1990

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Chapter 1

INTRODUCTION

Senate Concurrent Resolution No. 57, Senate Draft 1, requested the Office of the Legislative Auditor to evaluate the quality of treatment, including behavior management, provided in community facilities serving people with developmental disabilities. The Human Services Research Institute, a national consulting firm based in Cambridge, Massachusetts, was hired by the Office of the Legislative Auditor to conduct this study.

Objectives of the Study

The objectives of the study were:

1. To evaluate the quality of treatment and care, including behavior management, provided in residential facilities serving people with developmental disabilities.
2. To evaluate the adequacy of quality assurance activities, including the case management monitoring system.
3. To evaluate the adequacy of staff training standards with regard to treatment and care.
4. To recommend improvements in state laws, Department of Health rules, and program operations.

Scope of the Study

The study focused on the quality of care provided to adults with developmental disabilities living in care homes and group homes in Hawaii. Care homes provide basic nursing care and personal care (help with activities of daily living such as bathing or dressing) to residents who

are frail and elderly, chronically mentally ill, disabled, or otherwise in need of assistance. Group homes provide personal care and individualized services to residents with developmental disabilities.

The study looked at residents' experiences outside as well as inside the home to develop an understanding of the service system. It also looked at quality assurance activities such as case management and training.

Organization of the Report

This report consists of four chapters: Chapter 1, this introduction, the framework for evaluation, and study methodology; Chapter 2, background information on residential services and quality assurance activities; Chapter 3, the evaluation of residential services; and Chapter 4, the evaluation of quality assurance activities.

Framework for Evaluation

The definition of quality used in this report is based on the principles set forth in Chapter 333F, *Hawaii Revised Statutes*, and national standards issued by The Accreditation Council on Services for People with Developmental Disabilities.¹

Section 333F-8, HRS, states that people with developmental disabilities served by or through the Department of Health (DOH) have a right to receive the least restrictive, individually appropriate services, including a program of activities outside the home based on an individualized service plan. As appropriate,

they should be able to live in a home that closely approximates conditions available to nondisabled persons of the same age; live in close proximity to nondisabled persons; interact with nondisabled persons; and be involved in the community. They also have other rights, such as the right to participate in individualized service planning; and rights to privacy, confidentiality, and due process.

The national accreditation standards are based on similar principles acknowledging that people with developmental disabilities have the same rights as other people and should be allowed to live with the least restriction appropriate to their individual circumstances. The standards call for the delivery of services that meet individual needs and increase independence, productivity, well-being, and community integration. Services should be based on a single plan of care developed by the individual, the family (as appropriate), and a properly constituted team of professionals.

Study Methodology

Background interviews were conducted with key informants knowledgeable about services for people with developmental disabilities living in care homes and group homes in Hawaii. Statutes, administrative rules, plans, policies, and procedures relating to residential services, were reviewed with an emphasis on quality assurance activities. Reports evaluating different aspects of the service system were also examined. Finally, reports, articles, and monographs describing residential services and quality assurance activities in other states were reviewed.

A random survey was made of care homes and group homes to obtain information on the quality of treatment and care, including behavior management. A sample of 75 homes was compiled from lists supplied by the DOH Hospital and Medical Facilities Branch, the DOH Developmental Disabilities Division, the U.S. Department on Housing and Urban Development, and private agency representatives.

Survey activities included home visits; interviews with home operators, verbal residents, parents, and guardians; and a review of records. Participation in the survey was voluntary; appointments were made for each home visit and parent or guardian interview. Consent to interview residents and review records was obtained in advance from their parents or legal guardians. Some residents signed their own consent forms.

In September 1989, experienced surveyors visited 45 care homes and 11 group homes on Oahu, Maui, Kauai, and the Big Island. They interviewed 44 care home operators, 12 group home staff, and 58 residents with developmental disabilities. Telephone interviews were conducted with the parents of 9 group home residents.

Case files from the DOH for 29 care home residents and 5 group home residents on Oahu were also reviewed. Numerous public and private officials involved in the delivery of residential or support services for people with developmental disabilities in Hawaii were interviewed. Many experts in the field of developmental disabilities at the national level and in other states were consulted.

Chapter 2

BACKGROUND

This chapter reviews national trends shaping (1) residential services for people with developmental disabilities, and (2) quality assurance activities. It looks at the impact these trends have had on Hawaii's services and quality assurance activities. It also describes key characteristics of care home and group home residents in Hawaii.

Developmental disabilities are mental and/or physical impairments which occur during childhood, are likely to continue indefinitely, and limit a person's ability to carry out activities of daily living. The most common developmental disabilities are mental retardation (significantly subaverage general intellectual functioning), cerebral palsy (impaired brain and motor functioning occurring before birth or during the first three years of life), epilepsy (chronically recurring seizures), and autism (absorption in self-centered subjective mental activity such as daydreaming, usually accompanied by marked withdrawal from reality).

There are approximately 10,000 people with developmental disabilities in Hawaii.¹ Many live with their families or in the community with the support of family and friends. Some live in residential settings that offer services such as supervision, personal care, and training. More than 800 adults with developmental disabilities live in the care homes and group homes that are the focus of this study.²

National Trends

Until the 1960s, many individuals with developmental disabilities were placed in large public institutions providing medical and custodial care with little concern for their

developmental potential and community integration. After media reports, parent-consumer advocacy, and litigation exposed the dehumanizing conditions in these institutions, many residents were moved to "community-based" residential arrangements. Between 1967 and 1987, the population of state institutions declined from about 228,000 to less than 100,000.³

Proponents of "normalization" shaped the move from institutions to the community. They saw that people with developmental disabilities would continue to be devalued members of society as long as they lived in remote and isolated circumstances. They advocated for residential services making commonly accepted patterns and conditions of everyday life available to these individuals. Services based on the normalization principle try to be as culturally appropriate as possible to the age, sex, and other characteristics of individuals with developmental disabilities.

Values underlying community-based services. A number of other values underlie the delivery of community-based services. Minimum standards for nursing homes and related facilities are attempts to protect vulnerable individuals from harm. The principle that services should relate to individual needs and provide the *least restrictive* intervention necessary to carry out a treatment program is based on constitutional protections against loss of liberty and cruel or unusual punishment.

The belief that everyone has a core of personal integrity has led to support for the rights of people with developmental disabilities to make choices, to be treated with respect, and to live in surroundings allowing for privacy and personal expression. Institutional settings where residents

are treated as "patients" have gradually been replaced by community-based settings where they are treated as individuals with unique strengths and weaknesses.

The concept of "active treatment" recognizes that people with developmental disabilities should be able to function with as much self-determination and independence as possible. Active treatment mobilizes resources to help them learn necessary life skills. A team of professionals designs "individualized service plans" with the individuals being served and their families or legal guardians (as appropriate).

More recent values touch upon the need to ensure that people with developmental disabilities have a quality of life that is congruent with that enjoyed by society in general. Services that promote independence, productivity, and integration are emphasized.

Independence means helping disabled individuals overcome barriers to community participation. Productivity suggests that every disabled person should, to the maximum extent possible, be employed in a regular job--working side-by-side with non-disabled employees and earning a regular salary. Integration assumes that disabled individuals should have friends (who are not paid staff), be involved in community activities, and be able to conduct their lives not just in the community but as a part of the community.

Residential services. The move to community-based settings has been accomplished in three phases: (1) movement into existing types of residential arrangements, (2) development of specialized programs, and (3) creation of supported living arrangements that are tailored to the individual.

The unifying theme across each phase has been privatization and the development of smaller residences. Nationally, the proportion of people with mental retardation living in nonstate facilities increased from 37 percent in

1977 to 61 percent in 1987.⁴ The number of small facilities (serving less than 16 residents) more than tripled during this time period.⁵

Many people with developmental disabilities were initially placed in nursing homes, care homes, or boarding homes. Nationally, nursing homes provided nursing care and personal care (help with activities of daily living such as bathing or eating) to nearly 52,000 people with mental retardation in 1988.⁶ Care homes provided personal care to residents in small family-run homes or larger convalescent centers. Boarding homes provided limited supervision to fairly independent residents.

Specialized nursing homes, known as intermediate care facilities for the mentally retarded (ICFs/MR), were established after the federal government discovered that nursing homes were not providing adequate training and support for residents with mental retardation. ICFs/MR provided active treatment, nursing care, and personal care to about 145,000 residents in 1987.⁷

Many states converted care homes and boarding homes to specialized foster homes or family care homes to provide more training and social activities when it was learned that residents with developmental disabilities were not acquiring life skills or becoming well-integrated into the community. Some states moved these residents to other specialized settings such as group homes.

In general, specialized foster homes provide normal living experiences and community involvement for a few residents with developmental disabilities. Specialized family care homes provide skills training and related services. Group homes provide active treatment.

The most recent wave of residential program development is based on a recognition that independence and integration are best fostered by helping disabled individuals live in their own homes. The emphasis is on providing resources

and support services that promote independent living and community participation.

In one type of supported living arrangement, residents live in their own homes but have access to support staff who often live nearby. The residents are responsible for day-to-day activities such as shopping and cooking. They are visited periodically by staff who may teach them to use public transportation and carry out other activities of daily living. Staff may also help with budgeting, problem-solving, or crisis management.

Federal financial support for community-based services. The Medicaid Home and Community-Based Waiver program allows states to use federal matching funds to deliver personal care, day activity, and other support services for people with developmental disabilities who (1) are at risk of institutionalization, or (2) need help moving from institutions into the community. Nationally, the waiver program supported about 30,000 residents living in community-based settings in 1988.⁸

Quality assurance activities. Quality assurance activities also evolved in three phases. They initially focused on protecting individuals from harm. Facility-based standards were adopted that covered such things as daily schedules, staffing ratios, and the number of residents per toilet. Monitoring and oversight activities were developed to protect residents' human rights.

The second phase focused on developing service standards for specialized residential programs. The concept of quality was broadened to promote more normalized living arrangements and active treatment. Standards centered on individual needs and the extent to which they were being met.

The third and current phase supports less-intrusive quality assurance mechanisms that allow people with developmental disabilities to take control of their own lives. Some states are

relaxing licensing requirements that disrupt daily life in regulated facilities. They are also including the achievement of individualized objectives in certification program standards, and requiring case managers to provide continual monitoring of service delivery and technical assistance to providers. Most states are encouraging the training of providers in the values and principles of services for people with developmental disabilities.

Hawaii Trends

The State began to deinstitutionalize people with developmental disabilities in the 1960s. The number of residents at Waimano Training School and Hospital (a public institution caring for individuals with developmental disabilities) declined from more than 1,000 in 1967 to less than 200 today.

Unlike other states, Hawaii did not place a large number of residents in nursing homes. It relied on care homes providing nursing care and personal care to frail elderly, chronically mentally ill, or disabled residents.⁹ It also relied on boarding homes providing a lower level of assistance than care homes.

DOH began licensing care homes in 1960, and the Department of Social Services and Housing (now the Department of Human Services) began licensing boarding homes shortly thereafter. In 1985, the two programs were consolidated into a single licensing program for adult residential care homes (ARCHs) administered by DOH.

The ARCH licensing program was established because the State wanted to allow residents to remain in what were then known as boarding homes--instead of forcing them to move to care homes when their health began to deteriorate. The State also wanted to delay entry of care home residents into more expensive nursing homes or hospitals.

Values underlying the delivery of community-based services. Act 341, SLH 1987, modernized the State's approach to serving people with developmental disabilities by endorsing the principles of least restrictive intervention, active treatment (including individualized service planning), and protection of human rights. This legislation requires DOH to develop and administer a community service system for people with developmental disabilities.

The DOH Developmental Disabilities Division administers the community service system. Its regulations emphasize least restrictive alternatives and community integration. Regulations focusing on individual dignity, active treatment, and civil rights are to be adopted in the near future.

Residential services. Hawaii's nursing homes serve about 100 residents with developmental disabilities. Licensed care homes serve more than 700 residents, including about 400 DOH clients. ICFs/MR serve about 70 residents, specialized foster homes serve about 125, and group homes serve more than 130. There are a few supported living arrangements.

In the near future, some nursing home residents with developmental disabilities may move to other settings because federal law discourages the use of nursing homes for people who do not require nursing care. Care homes and group homes will continue serving large numbers of residents with developmental disabilities. Private agencies are developing new ICFs/MR, and the Developmental Disabilities Division is expanding the specialized foster home program.

Medicaid waiver services are being provided to about 85 former Waimano residents living in care homes, group homes, or foster homes. An application is being developed to bring the

number of waiver program participants to 700 by 1994.

Quality assurance activities. A number of quality assurance mechanisms protect residents from harm. Care homes are required to meet stringent licensing standards, and group homes serving DOH clients are also required to meet these standards. The Developmental Disabilities Division has established committees to review the use of psychotropic medications (drugs that alter behavior, mood, or thought processes) and to protect human rights. It is also developing an informal grievance procedure for DOH clients. The division's case managers plan, coordinate, and monitor services to clients.

A number of other agencies monitor the delivery of residential services. These include public agencies, such as the Judiciary's Office of the Public Guardian, which provides guardianship services for individuals who cannot participate in decisions relating to their care and who do not have relatives or friends to provide these services. They also include private agencies, such as the Protection and Advocacy Agency of Hawaii, which investigates complaints filed by or on behalf of people with developmental disabilities.

The Developmental Disabilities Division has performance standards for group homes serving DOH clients, and certification standards for specialized foster homes. It is providing funds for the University of Hawaii to train residential providers; and it hopes to hire a coordinator to help improve training programs for group homes.

Characteristics of care home residents. Based on the sample of care homes reviewed for this study, it is estimated that 722 people with developmental disabilities live in 230 licensed care homes throughout the state.¹⁰ These homes also serve about 580 residents

who are elderly, chronically mentally ill, or otherwise in need of assistance.

The median age of care home residents with developmental disabilities is 53 years. Slightly more than half are male. Most lived in other care homes (42 percent), at Waimano Training School and Hospital (34 percent), or with their families (13 percent) before their current placement.

According to care home operators, residents with developmental disabilities have the following level of mental retardation: severe or profound (31 percent), moderate (21 percent), mild (28 percent), none (11 percent), and unknown (6 percent). Nearly half of the residents with mental retardation have a second diagnosis--usually epilepsy, mental illness, or cerebral palsy. Major behavioral problems are found in 18 percent of the residents. Minor problems are found in 40 percent.¹¹

Care home operators reported that 76 percent of their residents with developmental disabilities expressed themselves using words, phrases, or sentences. One-step or multi-step directions could be followed by 92 percent; and 58 percent needed assistance with activities of daily living. Three out of four residents could avoid dangerous situations with minimal to no assistance.

Characteristics of group home residents. The median age of group home residents is 31 years (22 years younger than care home residents with developmental disabilities). Slightly more than half are male. Most lived with their families (35 percent), in another home (31 percent), or at Waimano Training School and Hospital (20 percent) prior to their current placement.

According to group home operators, residents have the following level of mental retardation: severe or profound (30 percent), moderate (37 percent), mild (20 percent), none (2 percent), or unknown (8 percent). Of the residents with mental retardation, 45 percent have a second diagnosis. Major behavioral problems are found in 22 percent of the residents. Minor problems are found in 63 percent.

Group home operators reported that 75 percent of their residents expressed themselves using words, phrases, or sentences. Nearly all of the residents could follow directions, but 44 percent required substantial assistance with activities of daily living and 12 percent required more than minimal assistance with home safety.

Chapter 3

RESIDENTIAL SERVICES

This chapter presents our assessment of the quality of treatment and care, including behavior management, provided in care homes and group homes serving adults with developmental disabilities.

Summary of Findings

- 1. Care homes are run by caring families and they are reasonably safe places to live. However, many living arrangements are not homelike (normalized), and residents suffer from social isolation and inactivity.*
- 2. Care homes create a stable living environment for most residents with developmental disabilities. However, care home operators do not encourage residents to develop independent living skills or help them work toward individualized objectives.*
- 3. Care home operators do not have access to support services that are essential in caring for residents with developmental disabilities, especially those with behavioral problems.*
- 4. Behavioral problems among care home residents are poorly managed, and psychotropic drug usage by both care home and group home residents exceeds the national average.*

- 5. A significant number of care home residents do not have active family members or legal guardians to look after their interests.*
- 6. High staff turnover prevents some group homes from creating a stable living environment for residents.*

Care Home Services

The greatest strength of the care home program lies in the commitment of the families who have taken people with developmental disabilities into their homes. Surveyors were impressed by their concern and found excellent examples of what community living should mean. Some extended families involved residents in their own social networks and included them in church, social outings, and vacations.

Surveyors reported that most care home operators appeared to have close and warm relationships with their residents. They found many examples of operators going out of their way to help the residents. One operator proudly stated that her two disabled residents were her best friends and would be with her until she died. Most residents said they liked where they were living.

A desire to help people and the ability to remain at home were cited as the main reasons for becoming a care home operator. Surveyors reported that most operators appeared to be caring, tolerant, industrious, and willing to learn. A psychologist who instructed care home

operators on the use of psychotropic medications was impressed to find that most had purchased manuals explaining the effects of these medications. Most operators wanted more training courses, especially in the area of behavior management. They also asked for morning classes rather than afternoon or evening classes.

Surveyors found no evidence of physical abuse, and only one potentially unsafe situation (where a door could be locked from the outside barring exit in an emergency). The relative stability of care home living arrangements is shown by the fact that the operators had been in business for a median of ten years.

Many living arrangements are not normalized. One of the basic values set forth in Chapter 333F, HRS, and national accreditation standards, is that people with developmental disabilities should live in homes that closely approximate conditions available to non-disabled persons of the same age. Many care homes do not meet this criterion.

Surveyors found that many resident living quarters were separate and removed from family living quarters. The most common arrangement was for the residents to live downstairs with the family living upstairs. These residents were often forced to contact the care home operator by ringing a bell. This arrangement isolates residents and offers little opportunity for normal family interaction.

The living quarters assigned to many care home residents were depressing. Surveyors described totally sterile environments with no personal items, few clothes in the closet, bare walls (very common), drab linoleum floors, and vinyl furniture "like one finds in a dentist's waiting room." They found mini-institutions rather than normalized living arrangements. One care home looked like a nursing home--with an observation window, a long corridor, and barren rooms.

Most care home operators were genuinely pleased with the living arrangements they had fashioned. They reported being responsive to DOH licensing requirements and suggestions made by licensing staff. However, a number of residents with developmental disabilities felt that they were merely boarders in another person's home. Surveyors confirmed this impression. A significant reorientation will be needed to develop more normalized living arrangements.

Many residents are socially isolated and inactive. Chapter 333F, HRS, and national accreditation standards, stress that people with developmental disabilities should be able to interact with non-disabled persons and participate in community activities. However, many care home residents were isolated from their non-disabled relatives, neighbors, and friends. They also had little involvement in the community.

Two-thirds of the residents had not been visited by a relative for a year or more; 80 percent of the operators reported that the residents had visitors (other than care home family members) one day a week or less. Most residents were not known by name to people in the neighborhood.

The residents reported that their favorite out-of-home activity was going to beaches and parks. This was reportedly done alone, with the care home operator, or with other residents several times a week. However, only one operator mentioned planning outside activities.

Care home operators seldom have time for outside activities. Often they must stay at home to care for residents who are elderly and frail, or chronically mentally ill, or to look after residents with behavioral problems. They do not have ready access to respite, counseling, or crisis support services to help with these duties. Of the operators surveyed, 42 percent cited the

lack of free time and respite as the biggest drawback to their occupation; 40 percent cited this as the second biggest drawback.

Case managers believe that inactivity is the source of many behavioral problems, and case notes contain numerous observations supporting this belief.

Given the concentration of care homes in Waipahu and Kalihi, it was somewhat surprising to find no organized social activities for residents with developmental disabilities. Activities that are open to disabled as well as non-disabled persons could be based in these and other communities to provide opportunities for socialization.

The State Planning Council on Developmental Disabilities is responsible for identifying gaps in services and for coordinating public or private agency responsibilities for missing services.¹ The council should explore the feasibility of establishing a calendar of planned social activities for developmentally disabled adults residing in Waipahu, Kalihi, and other communities.

Residents are not encouraged to develop independent living skills. Most care home operators do not help residents with developmental disabilities acquire life skills so they can become more independent. These operators have a strong tendency to do things for residents instead of teaching them to do more for themselves. The surveyors characterized them as overly protective--stifling the independence and spirit of residents. They also found some operators to be unnecessarily restrictive (detentive) and aggressively custodial.

Less than 25 percent of the residents interviewed (presumably among the highest functioning residents) indicated that they were receiving help to improve their skills, working to improve their skills, or doing more around the house than when they arrived. Only one-

third reported that they chose their own clothing; and only a few were involved with planning meals, cooking, or doing the laundry. Two-thirds of the operators did not feel that the residents could do more for themselves or more to help around the house.

Residents do not receive help in working towards individualized objectives. Chapter 333F, HRS, and national accreditation standards, state that services for people with developmental disabilities should be based on an individualized service plan. This plan should describe a person's needs, establish individualized objectives, and specify what services are needed to meet these objectives.

Surveyors found that 44 percent of the care home residents with developmental disabilities were not DOH clients. These residents did not have individualized service plans, and they depended on care home operators for help in meeting personal goals. However, most operators cannot address the individual needs of residents due to a lack of time and support services.

Surveyors also found that care home operators were not participating in individualized service planning for DOH clients, and case notes confirmed this observation.

Specialized care homes are needed. Quality-of-care improvements will only come about when there are specialized care homes that are (1) dedicated to serving residents with developmental disabilities, and (2) supported by training, respite, crisis support, individualized planning, and case management services.

Most states that had relied on care homes have taken this approach. The common practice has been to (1) establish family-run homes serving only two or three residents with developmental disabilities, (2) develop a network of specialized residential programs that provide the training and support services needed for caregivers to

provide individualized services, and (3) increase the level of payment to caregivers in recognition of their extra effort.

For example, Maine has moved residents with developmental disabilities from personal care homes to specialized homes providing active treatment. New Hampshire has placed residents with developmental disabilities in "enhanced family care homes" providing personal care and active treatment. Connecticut has converted homes serving nearly 500 residents with mental retardation into "community training homes" providing supervision and skills training. Each state provides additional compensation for the more specialized services.

The Legislature should amend Chapter 333F, HRS, to authorize the Department of Health to establish specialized care homes for residents with developmental disabilities. The department should ensure that operators of these homes receive training, support services, and additional compensation in recognition of their special expertise.

Many residents do not participate in outside activities during the day. Hawaii's day activity programs help people with developmental disabilities acquire independent living skills. They also provide opportunities for care home residents to make friends and engage in work activities.

Surveyors found that nearly 20 percent of the care home residents with developmental disabilities were not enrolled in a day activity program, and they did not have a job or other organized activity. Many of these residents had behavioral problems (that generally grow with inactivity) or medical and physical needs requiring attendant care. They were dependent on care home operators for skills training and social interaction.

Private day activity providers are reimbursed by the Developmental Disabilities Division when they serve DOH clients. Providers believe that

the division's rates are too low to develop services meeting the needs of clients with behavioral problems or medical and physical needs. They maintain that if the rates were increased, they could serve these individuals and locate programs closer to Waipahu and Kalihi.

One former provider talked about the perverse results of inadequate rates. He operated a program (including transportation) for 30 clients at \$40,000 a year (or about \$1,350 per client). When he was able to obtain a funding increase of only \$5,000 (or about \$150 per client), he turned the program over to a group that later went bankrupt. A third group took over and survived by dropping lower-functioning participants.

The division's current reimbursement rates are between \$3,500 and \$6,500 per client. However, a recent survey of 27 states found that the average annual cost of day activity programs was \$6,800 per client.² The rates for programs serving people with behavioral problems or medical and physical needs in other states generally run between \$6,000 and \$11,000 per client.

The division's rates may have to be increased to ensure that residents with behavioral problems or medical and physical needs have access to day activity programs.

Behavioral problems are managed inappropriately. The management of behavioral problems among residents with developmental disabilities should be non-aversive. Gentle techniques instead of force or undue restraint should be used. Restrictive practices, such as administering psychotropic medications (drugs that alter behavior, mood, or thought processes), should only be used under carefully controlled conditions along with other behavior management techniques.

Care home operators reported that about 40 percent of their residents with developmental disabilities had minor behavioral problems and

20 percent had major problems. Minor problems are allowed to fester and grow because many operators are tolerant of aberrant behaviors and reluctant to seek help until things have gotten out of hand.

In addition, DOH case managers and behavior specialists (e.g., psychologists) have limited involvement with care home residents. Of particular concern is a provision in the State Medicaid Plan discouraging clinical psychologists from visiting care homes. This forces operators to transport residents to office visits. It also reduces the effectiveness of intervention strategies by limiting follow-through on treatment programs. Other serious problems include the lack of 24-hour crisis support and in-home respite services for operators.

Behavior management plans target specific behaviors for improvement and include strategies for working with individuals. However, operators are not required to use planned approaches for managing and improving the behaviors of residents. What might pass as a behavior management plan could be found for only one DOH client out of a sample of 29 files reviewed. This plan was abandoned when it was found that the operator did not follow it.

A common pattern among many care home operators is to turn to physicians for psychotropic medications to control residents' behavioral problems. Operators find this habit difficult to break for residents who were using the medications when they were placed in the home. It is also difficult for operators to use other approaches because they have neither the time nor support services to work with residents on an individual basis.

Psychotropic medications are being used inappropriately. Psychotropic medications are being used more frequently than they should be. National figures show that only 26 percent of people with mental retardation living in community-based residences used psychotropic medications in 1979 (the latest year for which

figures are available).³ The current emphasis on individualized service planning and behavior management should have reduced the percentage of residents using these drugs during the past ten years. However, Hawaii's care home operators reported that 47 percent of their residents used psychotropic medications.

The use of psychotropic medications to control behavior in the absence of other behavior management techniques violates the principle of least restrictive intervention. It appears to violate residents' rights to due process and constitutional prohibitions against cruel or unusual punishment. It also violates the Developmental Disabilities Division's behavior management standards that specifically prohibit the use of chemical restraints in the absence of other behavior management techniques.⁴ There was little evidence that such techniques were being used with care home residents.

A review of DOH case files turned up a number of instances where psychotropic medications were used inappropriately. Particularly disturbing were cases where drugs were used to calm residents who appeared to be justifiably angry with care home operators. For example, one resident wanted to wear a clean dress instead of one which she believed to be dirty. Another resident was told that he could not keep his bike at home because the operator was afraid he would be hurt in traffic. These disagreements escalated to the point where a physician was asked to prescribe psychotropic medications. This escalation reflects poorly on the behavior management skills of some care home operators.

DOH case managers do not have sufficient time or resources to help care home operators manage clients with behavioral problems. Their help is usually sought at or near a crisis point when the operator is threatening to evict a resident. The request may be the first time the case manager has heard of the problem, or it may have to be resolved along with other competing demands. The case manager tries to

reconcile the situation by talking with the operator (first by phone and later in person) and consulting with a psychologist (who usually advises the case manager without visiting the home). With no 24-hour crisis support or alternative placements, the case manager is often forced to authorize the use of psychotropic medications to pacify the resident and placate the operator.

Medications need to be more carefully monitored and controlled. The need for better monitoring and control is clear from the high medication rates and the many instances where drugs are used to calm residents.

DOH case managers represent the director of health as legal guardian for many care home residents. They often have no grounds to refuse permission to use psychotropic medications, and they are reluctant to disrupt the relationship between care home operators and private physicians for fear of losing a placement.

After a number of case managers raised concerns about over-medication by physicians, the Developmental Disabilities Division established a medication review committee to look at psychotropic drug usage by clients living in the community. This committee includes two registered nurses, a physician, a pharmacist, and a psychiatrist. It has no authority to control the medical practice of private physicians; and it can only *recommend* that the physicians change medications or medication administration procedures, attempt to reduce dosages, or take similar actions.

The committee sent polite letters to many physicians expressing concern about their prescription policies. Some physicians took exception to the committee's review, stating that they adhered to informed consent standards set out in Section 671-3, HRS. However, these standards do not require *written* informed consent to treatment. In the absence of a written consent, it is not clear that residents or legal guardians

understand the reasons why medication is necessary, appreciate the risks involved, or know of the alternative therapies that can be used.

The committee has recommended that the division establish a medication clinic at Waimano Training School and Hospital because some physicians were not responsive to its suggestions. This should be done only after the division has explored the feasibility of using other private physicians whose practices are more congruent with division standards.

The division should also establish more effective controls over the use of psychotropic medications. It should (1) require *written* informed consent from residents or their legal guardians before the nonemergency use of psychotropic medications, and within 72 hours of emergency use (Appendix A contains guidelines for informed consent and a sample form used in the State of Minnesota); (2) develop written procedures for monitoring emergency, routine, and maintenance psychotropic medication treatment programs; and (3) require providers to use emergency and non-emergency medication initiation forms that encourage alternative therapies (Appendix B contains sample forms used in Minnesota). Such forms request information on the specific emergency behavior to be controlled, other procedures that have been attempted or considered, and the behavioral outcomes.

Copies of the division's behavior management and informed consent standards should be distributed to residents, legal guardians, home operators, case managers, and physicians. The division should also develop training programs to help these individuals understand the standards.

The division has established a human rights committee to investigate possible violations of client rights. This committee needs to know about cases where psychotropic medications are being used inappropriately. The division

should require the medication review committee to notify the human rights committee about these cases.

Legal status of some care home residents needs to be clarified. National accreditation standards state that people with developmental disabilities should be assumed capable of exercising their individual rights and taking responsibility for their actions when they reach the age of majority, unless they are legally determined incapable of doing so. In such cases, guardians should be available to represent their interests and protect their civil liberties.

Care home operators reported that they could not identify a guardian for 16 percent of their residents with developmental disabilities. They did not feel that these residents could look after their own interests, and the residents did not have active family members or friends to do so. About half were using psychotropic medications. By default, the operators were looking after the interests of the residents. This is a serious problem because the interests of providers and residents can conflict.

Care home residents without active family members, friends, or legal guardians need to be identified. It is imperative that their competency to give informed consent to psychotropic medications be assessed. Legal guardians should be appointed and trained in the informed consent process for all residents judged to be in need of assistance.

The Protection and Advocacy Agency of Hawaii is mandated by federal law to protect the rights of people with developmental disabilities. It has the authority to review client records, if authorized to do so by the client or the client's legal representative, and to review the records of any person with developmental disabilities who is a ward of the State or does not have a legal representative. It can pursue legal, administrative, and other remedies to protect individual rights.

This agency should survey care homes to identify residents with developmental disabilities needing guardianship services, and to determine whether they are using psychotropic medications. Where necessary, residents without family members or friends to provide these services should be assigned a public guardian.

The director of health's guardianship responsibility for DOH clients with developmental disabilities will soon be transferred to the Judiciary's Office of the Public Guardian. The director of health and the public guardian should place top priority on obtaining public guardians for care home residents using psychotropic medications or at risk of using these medications (i.e., having major behavioral problems).

Group Home Services

Surveyors found group homes to have more normalized living arrangements than care homes. There was stronger family involvement in some homes and residents were more active. The residents went to the beach or park several times a week, visited with relatives on a weekly basis, and engaged in sports or shopped several times a month.

Group home operators were providing active treatment. They had individualized service plans on file for most residents and the plans were followed. The residents were generally more independent than care home residents; 98 percent had jobs or were enrolled in a day activity program.

Like their counterparts in care homes, group home residents were not known by name to their neighbors. The legal status for 6 percent of the residents needed clarification, and 38 percent used psychotropic medications.

Group home residents might benefit if there were more social activities in their neighborhoods and a survey to determine if guardianship services

are needed. Better monitoring and controls over the use of psychotropic medications would also benefit these residents.

Some homes have high staff turnover. Group homes are run by families (houseparents) who live in the home, or by staff members who live elsewhere. The surveyors found that turnover in staffed group homes was unacceptably high. The more senior employees in these homes had been on the job a median of two years; the average stay of their subordinates was less than a year. The staff was transient, with new faces appearing at the breakfast table every few months. This creates an unstable living environment.

The high staff turnover was attributed to low pay, poor training, too much paperwork, too many hours, frustration with the system, and too little free time. These homes would benefit from additional resources and support.

Residential service agencies could enhance quality of care. Several states (including New Hampshire and Oregon) contract with private residential service agencies to provide a network of homes with support services. These agencies have training programs to help operators provide active treatment, manage behavioral problems, and carry out administrative duties. They have on-call staff to provide crisis support and transportation services. And they arrange for respite care and relief services through member homes.

The consensus among national accreditation and state officials interviewed for this report is that these agencies should support a network of homes serving a total of no less than 30 and no more than 60 residents. A minimum threshold of 30 is needed for the bed and staff capacity to provide respite, crisis support, and behavior management services. A ceiling of 60 is needed to ensure effective delivery of individualized services. Smaller agencies also appear to be more responsive to families, legal guardians, and state officials.

There was also agreement that the agencies should not provide daytime activities (such as day activity programs). This would avoid creating an institutional model of care where nearly all aspects of life are controlled by a single agency. There is an advantage to having a variety of residential arrangements within each agency--such as staffed group homes, family-run homes, and foster homes. This promotes individualized planning, makes moving less cumbersome and traumatic, and avoids creating an agency with a vested interest in limiting the options available to residents. Many residential service agencies are organized in this way or moving in this direction.

Section 333F-5, HRS, authorizes DOH to create systems to implement necessary services for people with developmental disabilities. The Developmental Disabilities Division could contract with private agencies under purchase-of-service agreements to provide support services to a network of homes. This would greatly enhance the capacity of group homes and care homes to deliver quality care.

Recommendations

- 1. The Legislature should amend Chapter 333F, HRS, to authorize the Department of Health to establish specialized care homes for residents with developmental disabilities.*
- 2. The Department of Health should ensure that operators of specialized care homes receive training, support services, and additional compensation in recognition of their special expertise.*

3. The Developmental Disabilities Division should encourage the establishment of residential service agencies to provide support services to a network of homes through the purchase-of-service contracting mechanism.

4. The State Planning Council on Developmental Disabilities should explore the feasibility of establishing a calendar of planned social activities for people with developmental disabilities living in Waipahu, Kalihi, and other communities in the state.

5. The Developmental Disabilities Division should consider raising day activity program rates so that these programs can accommodate care home residents with behavioral problems or medical and physical needs. Priority should be given to the development of programs located in or near Waipahu and Kalihi.

6. The Protection and Advocacy Agency of Hawaii should survey care home and group home residents to identify persons needing guardianship services, and to determine whether they are using psychotropic medications. Where necessary, residents should be assigned a public guardian.

7. The director of health and the public guardian should place top priority on obtaining public guardians for care home and group

home residents using psychotropic medications or at risk of using these medications (i.e., having major behavioral problems).

8. The Developmental Disabilities Division should immediately strengthen the psychotropic medication monitoring system as follows:

- Require physicians to obtain written informed consent from residents or legal guardians before the nonemergency use of psychotropic medications, and within 72 hours of emergency use.

- Develop written procedures for monitoring emergency, routine, and maintenance psychotropic medication treatment programs.

- Require providers to use emergency and nonemergency initiation forms that encourage alternative therapies.

- Distribute copies of behavior management and informed consent standards to residents, legal guardians, home operators, case managers, and physicians; and develop training programs to help them understand the standards.

- Require the medication review committee to notify the human rights committee about cases where psychotropic medications are being used inappropriately.

Chapter 4

QUALITY ASSURANCE ACTIVITIES

This chapter presents our assessment of quality assurance activities. It looks at standards, the case management system, staff training requirements, and protection and advocacy services.

Summary of Findings

- 1. The Developmental Disabilities Division is relying too heavily on care home licensing standards that are overly restrictive. There are no standards to ensure that active treatment is provided to care home residents.*
- 2. Case managers do not have adequate administrative or support services to carry out their duties. They are burdened with paperwork, forced to act in a crisis mode, and inadequately supported by the central interdisciplinary team.*
- 3. Care home and some group home operators do not have access to training programs that are based on their specific needs in caring for residents with developmental disabilities.*
- 4. Essential information about resident rights and procedures for filing complaints is not available to interested parties.*

Quality Assurance Standards

Many standards based on the values and principles of developmental disabilities are not enforceable through licensing programs which must rely on measurable standards to substantiate violations. It would be nearly impossible to take disciplinary action for a provider's failure to comply with some value-laden standards. For example, a standard requiring providers to include residents in all aspects of family life would be difficult to enforce because of the subjectivity of such a judgement.

Most state quality assurance systems have emphasized minimum licensing standards relating to health, safety, and welfare. These standards look at the capacity of providers to deliver an acceptable level of care by focusing on such service elements as the adequacy of the facility and staff. They do not look at the quality of interaction between providers and residents, or whether services are appropriate for people with developmental disabilities. Often, the licensing standards conflict with efforts to provide better services.

A review of quality assurance systems found that they were not striking a reasonable balance between quality assurance efforts focusing on minimum standards, and quality enhancement efforts encouraging providers to develop better services.¹ Many states that concentrated on minimum standards unwittingly built mediocrity into their systems.

In the past five years, some states have begun to relax minimum licensing standards

that prevent the development of normalized living arrangements and individualized services for people with developmental disabilities. A number of states have begun to certify residential providers using standards that are individually centered and embody developmental disabilities values and principles. Certified providers may also be required to meet licensing standards.

In some states, conflicts have arisen between developmental disabilities officials seeking to impose service standards on residential providers, and licensing officials. For example, when Maine's developmental disabilities program issued behavior management standards for care homes, state licensing officials said the standards were inappropriate and suggested that residents with developmental disabilities be transferred to more restrictive licensed settings (such as intermediate care facilities for the mentally retarded). Developmental disabilities officials disagreed, saying that care home operators must be able to manage behavioral problems. In New Hampshire, the licensing program was transferred to developmental disabilities officials in an effort to develop more normalized standards.

In Hawaii, the Developmental Disabilities Division continues to rely heavily on licensing standards to ensure that clients of the Department of Health (DOH) are protected from harm. It will only place clients in licensed care homes, and it requires group homes serving clients to obtain a care home license. Some group home providers object to the rigidity of the care home licensing regulations and are reluctant to serve DOH clients.

A certification program using individually centered service standards, coupled with relaxation of unnecessary care home licensing standards, might encourage these providers to continue serving residents with developmental disabilities. This approach would also enable the state to comply with federal requirements under the Social Security Act, and enhance quality of care.

Care home licensing standards are overly restrictive. The care home licensing program is administered by the DOH Hospital and Medical Facilities Branch. It emphasizes compliance with minimum standards that are designed to protect frail elderly, chronically mentally ill, disabled, and sick residents from harm. The standards are facility-centered, addressing such things as staff qualifications, written policies and procedures, food service, and physical environment.

The care home licensing standards reflect a medical and custodial approach to service delivery that care home operators accept as doctrine, and group home operators reject as the antithesis of the developmental model advocated by professionals in the field of developmental disabilities. In general, the standards call for small, family-run nursing homes, although many residents with developmental disabilities do not require nursing care. Only one in five residents had a condition severe enough to demand continuing attention from medically trained personnel, or motor skill needs requiring attendant care.

The standards pay little attention to services promoting the principles of normalization, least restrictive intervention, and active treatment. This finding is similar to a U.S. General Accounting Office (GAO) critique of nursing homes serving residents with developmental disabilities across the nation.² The GAO report led to a federal law requiring states to transfer residents not needing nursing care to other facilities.³

Virtually every developmental disabilities professional in Hawaii has complained about the rigidity, intrusiveness, and institutional nature of the care home licensing regulations. They are especially concerned about (1) a requirement that care home operators have nurse aide training, (2) standards requiring operators to strictly adhere to menu plans, (3) standards preventing operators from creating a normalized living

environment--such as a requirement that evacuation plans be posted on the wall, and (4) the licensing staff's lack of expertise in developmental disabilities.

The most troublesome standard is the nurse aide training requirement. Care home operators must complete 75 hours of training to qualify for a license. The department would like to raise this to 240 hours, which would conform with federal standards for nursing home aides. No other state uses such stringent standards for families serving residents with developmental disabilities who do not have severe, chronic medical problems.

There is a need to relax care home licensing standards so that services can meet the individual needs of residents with developmental disabilities. Developmental disabilities officials and licensing officials should work together to identify what standards are essential for safety and sanitation, and what standards can be waived. The Legislature should amend Section 321-15.6, HRS, to authorize DOH to waive unnecessary licensing standards for care homes serving residents with developmental disabilities.⁴

A certification program should be developed. The Developmental Disabilities Division has standards for group homes that are enforced through the purchase-of-service contracting mechanism. However, the standards do not apply to group home residents who are not DOH clients or to care home residents. The division has drafted standards that would cover all residential programs serving DOH clients, but the standards would also have limited applicability.

The division should establish a certification program for specialized care homes serving residents with developmental disabilities.

Certified providers should receive additional funds, support services, and benefits in recognition of their special effort.

This approach would enable the State to comply with federal requirements under the Social Security Act. In 1976, Congress enacted the Keys Amendment permitting Supplemental Security Income (SSI) payments to persons living in publicly supported residences serving 16 or fewer residents. This amendment requires each state to establish, maintain, and enforce standards for residential arrangements in which a significant number of SSI recipients live or are likely to live. The standards must cover such matters as admission policies, safety, and protection of civil rights.

Most adults with developmental disabilities receive SSI payments, but some group homes in Hawaii are not required to meet any state standards. Forcing them to comply with restrictive care home licensing requirements, or putting them out of business, is not in the best interest of their residents. A better approach would be to require the homes to comply with certification standards.

The Legislature should amend Chapter 333F, HRS, to require DOH to establish a certification program for specialized care homes serving residents with developmental disabilities. The program should be voluntary for three years to allow providers to meet certification standards. It should be mandatory after three years.

The program should use individually centered standards based on the values and principles of services for people with developmental disabilities. The standards issued by The Accreditation Council on Services for People with Developmental Disabilities would be an appropriate starting point. They address the

needs of individuals and their families, and the processes through which these needs are to be met.

Case Management System

Case management is an important quality assurance mechanism. Case managers plan, coordinate, and monitor service delivery for people with developmental disabilities. They also advocate for the needs and interests of clients.

The case management function should be independent so that case managers can plan the best combination of services without being tied to any one service provider. Case managers should continually monitor service delivery to ensure that client needs are being met, to resolve problems before they reach crisis proportions, and to prevent the abuse and neglect of clients or violations of their rights. They should also provide technical assistance.

Case managers in the Developmental Disabilities Division are unable to effectively plan, coordinate, and monitor service delivery because of a lack of administrative and support services.

Case managers lack administrative and support services. Division case managers are burdened by many administrative tasks and a deluge of paperwork associated with keeping clients in service. These tasks, which have grown significantly over the years, detract from their primary case management duties.

The administrative tasks and related paperwork fall into three general categories. First, there is the routine paperwork that must be processed and signed every time a change occurs in provider or medication. Many forms are used to collect information for the division's client-tracking and service-monitoring system.

Second, there are the guardianship services that case managers must carry out on behalf of the director of health and other public guardians. These include such things as processing requests for the withdrawal of savings to pay for purchases, and researching and monitoring the financial status of clients to insure their continued eligibility for Medicaid, Supplemental Security Income, and Social Security Disability Insurance.

Case managers must also make eligibility and level-of-care determinations for clients. The function of determining level-of-care was recently passed from the Department of Human Services to the Department of Health through an interdepartmental agreement. No additional positions were allocated to the division to support this time-consuming function.

Division case managers contend that these tasks are not legitimate case management functions, and that they detract from the more central job of planning, coordinating, and monitoring client services. The continual increase in administrative duties seems to be a move away from an independent case management system to one that relies on service providers. The division's plans to expand the Medicaid waiver program would transfer service planning, coordination, and monitoring activities to providers, leaving the division to handle more routine work such as placement and guardianship activities.

The vacancy rate in the division's case management section is approaching 40 percent--with caseloads averaging between 45 and 50 clients. Some case managers report having 70 or more clients. Many case managers say poor morale and the lack of administrative and support services cause vacancies. One said they only have time to respond to crises and fill out paperwork so clients can obtain benefits. They are often called upon to help clients in crisis situations because there are inadequate administrative and support services. Additional

support would help them plan, coordinate, and monitor services more effectively.

The department is planning to transfer the director of health's guardianship role to the Judiciary's Office of the Public Guardian--relieving case managers of one task. However, it could do more. It could relieve them of routine administrative tasks by hiring case management clerks or aides; it could streamline planning, monitoring, tracking, documentation, and accounting processes; and it could use other personnel to make eligibility determinations. These techniques have been employed successfully in other states.

The division should reaffirm the importance of an independent case management system. It should also hire a case management consultant to analyze the flow of paperwork and recommend improvements such as streamlining documentation requirements, reassigning routine administrative tasks to clerks or aides, and developing more automated systems.

Interdisciplinary planning process is inadequate. Chapter 333F, HRS, and national accreditation standards, require individualized service plans to be developed by an interdisciplinary team of professionals.

Two interdisciplinary teams serve DOH clients: (1) a "central team" that is based in the division's community support and resource development unit, and (2) a "Medicaid waiver team" that is based at Waimano Training School and Hospital. Both teams conduct individualized service planning and consult with providers. However, the waiver team's performance is far superior to that of the central team.

The difference in performance can be traced to a number of factors:

- . The waiver team serves approximately 100 clients; the central team serves approximately 1,000.

- . The waiver team is responsible for the Honolulu area; the central team covers the entire state.
- . The waiver team provides case management services directly to clients; the central team assists DOH case managers from a distance as time permits.
- . The waiver team operates under a contract that clearly delineates its responsibilities; the central team's responsibilities for individualized service planning have never been clear. The division's functional statement for the central team does not mention individualized planning. It merely states that the team provides interdisciplinary assessments, consultation, and training to programs and staff.
- . The central team has had longstanding vacancies in key positions (especially the psychologist's position), and the division often reassigns team members to special projects. For example, the team's psychologist is now managing a special treatment facility at Waimano Training School and Hospital.

The central team does not have time to work closely with case managers in preparing individualized service plans. A review of 30 plans confirmed that relatively little time was spent considering the unique interests, capabilities, and needs of individual clients. There was little variation among the plans, and they lacked the substance and integrity necessary for responsible case management and quality assurance efforts.

Central team members are also too remote from case managers and home operators to provide sound advice, particularly in crisis situations. For example, one provider was advised inappropriately to place a resident with behavioral problems in a halfway house for

drug and alcohol abusers. Another provider who asked for advice on a resident's shoplifting habit was advised to call all the stores frequented by the resident (reportedly hundreds) and let them know he might be coming in to remove things. At least one case manager has stopped using the central team, preferring to pay private psychologists instead.

The division should adopt the more successful approach used by the Medicaid waiver team and make the interdisciplinary planning process an integral part of the case management system. It should decentralize the planning process, and allow its placement units (case management units that are geographically based) to form their own interdisciplinary teams through purchase-of-service contract arrangements.

Advocacy is limited. Advocacy must be carried out at two levels: the case level, where managers press for the needs and best interests of their clients; and the state level, where they lobby, negotiate, and mediate for systemwide changes that benefit everyone.

The usual state agency view is that advocacy merely involves interceding on behalf of clients to ensure that they receive a fair share of available services. This is the prevailing view in Hawaii. Case managers mentioned advocacy only in terms of obtaining and maintaining placements within the *existing* array of services.

The limitations of a case management system that is bound to existing services has led at least six states to take a different approach known as "personal futures planning."⁵ This approach focuses on mobilizing community resources, rather than relying on existing services. The division should consider piloting this approach in Hawaii.

The division should also involve case managers more directly in planning activities to ensure that gaps in services are recognized and addressed. Case managers should more formally contribute to the division's program planning and budgeting process. They should also have

more say in the planning process administered by the State Planning Council on Developmental Disabilities. This could be accomplished through an annual meeting between case managers and the council's planning staff.

Case managers can be more effective. The division's case managers have been reduced to paper pushers and their status has correspondingly declined. To become more effective, they must be given more administrative and service system support so they can carry out their planning, coordination, monitoring, and advocacy duties.

Personal relationships are essential for enhancing service quality, and case managers should be encouraged to spend more time with their clients. They should be required to be in frequent touch with service providers to help resolve problems before they escalate into crises and before residents are summarily ejected from their homes or day activity programs.

It is also important that the case management function remains independent. The interests of service providers and residents do conflict. The need for independent case management is underlined by the tendency among some providers to dismiss unmanageable residents, and the overreliance on psychotropic medications to pacify angry residents.

Staff Training Requirements

There is a growing consensus that residential service providers can benefit from training before they take any clients. More and more states are requiring this kind of training which generally includes (1) an introduction to developmental disabilities and service philosophies, (2) an overview of the service system, and (3) a review of consumer rights. Other important features of orientation training are the acquisition of first aid and cardiopulmonary resuscitation (CPR) skills, and an introduction to job duties. Providers also need ongoing training to enhance their capacity to deliver quality care.

The most effective training programs are (1) "owned" by service providers, (2) based on specific competencies required for the job, (3) tailored to the needs of residents, and (4) supported by on-site followup activities.

Some group home agencies have orientation training programs for new employees. However, there are no specialized training programs for new care home operators. Operators are required to complete a number of courses to qualify for a license, but the courses do not focus on developmental disabilities or address the specific needs of individual providers.

Ongoing training is provided through the University of Hawaii's Community College System, and the University Affiliated Program for Developmental Disabilities. However, these training activities are not as pertinent as they could be to the needs of individual providers because they are highly centralized.

Residential service agencies would be better equipped to provide care home and group home operators with specialized training. These agencies could assess training needs, design programs meeting these needs, and provide on-site followup activities to ensure that the training is used. They could also work with university officials to develop specific training programs.

Published training materials are widely available and curricula (including model curricula, videotapes, self-instructional modules, and competency-based evaluations) have been developed to train virtually every type of provider. These curricula could be adapted to meet the specific needs of Hawaii's care homes and group homes.

A database of training materials is available through the American Association of Mental Retardation. The university-affiliated program at the University of Iowa has published a catalogue listing its collection of training materials, and the Training Resources and Information Center in Helena, Montana,

publishes periodic updates of its training library. These and similar materials should be made available in Hawaii.

Protection and Advocacy Services

A number of public and private organizations advocate for and protect the rights of people with developmental disabilities in Hawaii. The major organizations include (1) the Protection and Advocacy Agency of Hawaii, (2) the Judiciary's Office of the Public Guardian, (3) the State Planning Council on Developmental Disabilities, (4) the long-term care ombudsman in the Executive Office on Aging, (5) the DOH Developmental Disabilities Division's medication review and human rights committees, and (6) the DOH Hospital and Medical Facilities Branch's care home licensing program. In addition, an adult protective services program will soon be established in the Department of Human Services.

This network of protection and advocacy agencies is not yet integrated--common understandings and cooperative agreements are still being drafted. The agencies are struggling with the problem of determining who is responsible for what activities, and how overlapping responsibilities should be handled. Consequently, individuals wishing to file complaints or obtain advocacy assistance have incomplete information about available services.

Parents of group home residents reported that they had very limited knowledge about resident rights or procedures for filing a complaint. Only three of nine parents recalled being informed about resident rights. Six were knowledgeable about complaint procedures, but four would hesitate to file a complaint for fear of losing a residential placement.

It is important that the efforts of the protection and advocacy agencies be synchronized so that complaints about abuse or neglect and about rights violations can be dealt

with effectively. Interested parties need to be made aware of the ways in which problems can be brought to light and the procedures for handling complaints. They also need to be assured that residents will not suffer retribution when a complaint is filed.

The State Planning Council on Developmental Disabilities should collaborate with other protection and advocacy agencies to develop a handbook describing resident rights, the organizations established to protect these rights, procedures for filing complaints, and what to expect after a complaint is filed. This handbook should be distributed to residents, family members, legal guardians, case managers, and other interested parties.

Recommendations

1. *The Legislature should amend Chapter 333F, HRS, to require the Department of Health to establish a certification program for specialized care homes serving residents with developmental disabilities. The program should be voluntary for three years and mandatory thereafter. It should use individually centered standards based on the values and principles of services for people with developmental disabilities.*
2. *The Legislature should amend Section 321-15.6, HRS, to authorize the Department of Health to waive care home licensing regulations for certified homes.*
3. *Developmental disabilities officials and licensing officials should work together to identify what standards are essential for safety and sanitation, and what standards can be waived.*

4. *The Developmental Disabilities Division should strengthen the case management system as follows:*

Reaffirm the importance of an independent case management function.

Hire a case management systems consultant to analyze the flow of paperwork and recommend improvements such as streamlining documentation requirements, reassigning routine administrative tasks to clerks or aides, and developing more automated systems.

Make the interdisciplinary planning process an integral part of the case management system; decentralize the central interdisciplinary team; and allow each placement unit to form its own team largely through the purchase-of-service contracting mechanism.

5. *Training for care home and group home operators should be decentralized, and residential service agencies should be encouraged to develop comprehensive training programs meeting the individual needs of providers.*
6. *The State Planning Council on Developmental Disabilities should collaborate with other protection and advocacy agencies to develop a handbook describing resident rights, the organizations established to protect these rights, procedures for filing complaints, and what to expect after a complaint is filed.*

NOTES

Chapter 1

1. ACDD National Quality Assurance Program, *1990 Standards for Services for People with Developmental Disabilities*, Field Review Edition, Landover, Maryland, The Accreditation Council on Services for People with Developmental Disabilities, 1988.

Chapter 2

1. Hawaii, State Planning Council on Developmental Disabilities, *Two-Year Transitional State Plan Fiscal Years 1990-1991 for Services for Citizens with Developmental Disabilities*, Honolulu, August 1989, p. 3.
2. Estimate derived from a random survey of care homes and group homes serving residents with developmental disabilities in Hawaii, Human Services Research Institute, Cambridge, Massachusetts, September 1989.
3. C.C. White, et al., *Persons with Mental Retardation in State-Operated Residential Facilities: Year Ending June 30, 1987 with Longitudinal Trends from 1950 to 1987*, Department of Educational Psychology, Report No. 26, Minneapolis, University of Minnesota, November 1988, p. ES-1.
4. Carolyn White, et al., *Populations of Residential Facilities for Persons with Mental Retardation: Trends by Size, Operation and State, 1977 to 1987*, Center for Residential and Community Services, Brief Report No. 32, Minneapolis, University of Minnesota, February 1989, p. 13.

5. K. Charlie Lakin, et al., *Medicaid Services for Persons with Mental Retardation and Related Conditions*, Center for Residential and Community Services, Minneapolis, University of Minnesota, May 1989, p. 30.
6. David Braddock, et al., *Public Expenditures for Mental Retardation and Developmental Disabilities in the United States, State Profiles*, 3rd ed., Chicago, The University of Illinois at Chicago, May 1989, p. 15.
7. K. Charlie Lakin, et al., *Medicaid Services for Persons with Mental Retardation and Related Conditions*, Table 4.
8. *Ibid.*, p. 101.
9. Hawaii's care homes are unique in the nation because they provide nursing care.
10. The 300 other licensed care homes do not serve residents with developmental disabilities.
11. Major behavioral problems include behavior that is disruptive, endangering, or life threatening; poses a threat to the well being of living creatures; or is destructive of property.

Chapter 3

1. Section 333E-3(2)(C), HRS.
2. Paul Wehman, John Kregel, and Michael Shafer, *Emerging Trends in the National Supported Employment Initiative: A Preliminary Analysis of 27 States*, Rehabilitation Research and Training

Center on Supported Employment, Richmond, Virginia Commonwealth University, January 1989, p. 84.

3. Bradley Hill, Elizabeth Balow, and Robert Bruininks, "National Study of Prescribed Drugs in Institutions and Community Residential Facilities for Mentally Retarded People," *Psychopharmacology Bulletin*, vol. 21, no. 2, 1985, p. 282.
4. Hawaii, Department of Health, "General Standards for Behavior Management Procedures," Honolulu, p. 1.
3. U.S. Public Law 100-203 (The Omnibus Reconciliation Act of 1987).
4. The Department of Health also licenses special treatment facilities (STFs) that provide "therapeutic" residential services. STF licensing regulations are less restrictive than care home licensing regulations, but they are based on a medical model that is not appropriate for most residents with developmental disabilities. In addition, STF residents do not qualify for level-of-care payments from the Department of Human Services.

Chapter 4

1. Valerie Bradley, et al., *Assessing and Enhancing the Quality of Services, A Guide for the Human Services Field*, Cambridge, Massachusetts, Human Services Research Institute, May 15, 1984.
2. U.S., General Accounting Office, *Medicaid: Addressing the Needs of Mentally Retarded Nursing Home Residents*, Report No. GAO/HRD-87-77, Gaithersburg, Maryland, 1987.
5. Beth Mount and Kay Zwernik, *It's Never Too Early It's Never Too Late, A Booklet about Personal Futures Planning*, Publication No. 421-88-109, St. Paul, Minnesota, Metropolitan Council, 1988.

APPENDIXES

APPENDIX A

Guidelines for Informed Consent

DOH informed consent forms should verify that the client or legal guardian has received the following information:

- . The reason for medication.
- . A description of the behavior or condition in specific, observable, and measurable terms.
- . The rate and intensity of the behavior or condition.
- . The benefits of the medication.
- . The alternative therapies available.
- . The risks, including possible side-effects and their treatment.
- . Specific aspects of the medication such as name, dose, maximum dose, route, etc.
- . The fact that one may refuse consent or, if given, change one's mind at any time.
- . The fact that consent expires in one year (or less), and must be renewed.
- . The names, addresses, and phone numbers of the people to contact if questions arise.

APPENDIX A

| | | |
|---|--------------|----------------------------|
| INFORMED CONSENT FORM FOR PSYCHOTROPIC MEDICATION(S) | INDIVIDUAL | ID |
| | DATE (M-D-Y) | CONSENT EXPIRATION (M-D-Y) |
| | PHYSICIAN | CASE MANAGER |

PSYCHOTROPIC(S)

| | |
|--|---|
| <input type="checkbox"/> Current <input type="checkbox"/> Proposed Generic name : _____ Trade name : _____ Dose : _____ mg/day Maximum dose : _____ mg/day Route : _____ <input type="checkbox"/> Current <input type="checkbox"/> Proposed Generic name : _____ Trade name : _____ Dose : _____ mg/day Maximum dose : _____ mg/day Route : _____ | <input type="checkbox"/> Current <input type="checkbox"/> Proposed Generic name : _____ Trade name : _____ Dose : _____ mg/day Maximum dose : _____ mg/day Route : _____ Comments/Other: _____ _____ _____ _____ |
|--|---|

ORAL COMMUNICATION

No could not reach
 Yes
 Telephone on _____ (date)
 Meeting

PERSON TO CONTACT FOR QUESTIONS OR CONCERNS

Name : _____
 Address : _____

 City/State/Zip : _____
 Phone : _____

**WRITTEN INFORMATION INCLUDING POSSIBLE
SIDE-EFFECTS (*)**

Given at meeting Sent with this form
 Not provided

TARDIVE DYSKINESIA (TD) (*)

Present Not present
 Not applicable to the psychotropic and case
 (*) Specify the exact side effects and/or TD forms provided:

THE FOLLOWING INFORMATION HAS BEEN EXPLAINED ABOUT THE PSYCHOTROPIC MEDICATION(S) LISTED AND WRITTEN INFORMATION HAS BEEN PROVIDED ABOUT:

1. The reasons for the medication(s).
2. A description of the behavior/condition in specific observable and measurable terms.
3. The rate and intensity of the behavior/condition.
4. The benefits of the medication(s).
5. The alternative therapies available.
6. The risks including possible side-effects and their treatment.
7. Specific aspects of the medication(s) such as name, dose, maximum dose, route, etc.
8. The fact that I may refuse consent or, if given, that I may change my mind at any time.
9. The fact that my consent expires in one year (or less), and must be renewed.
10. The names, addresses, and phone numbers of people to contact if questions arise.

BASED UPON THE ABOVE (CHECK ONE):

- I approve the use of the psychotropic(s) listed.
 I do not approve the use of the psychotropic(s) listed.
 I only approve as follows (specify in comments).

Signature : _____

Date : _____

COMMENTS: _____

INFORMED CONSENT INFORMATION SHEET

(Attach additional information as needed)

INDIVIDUAL: _____ CONSENT EXPIRATION: SEE OTHER SIDE

PSYCHOTROPIC MEDICATIONS: SEE OTHER SIDE

INFORMATIONAL

1. Pertinent diagnoses: _____

2. Target behavior(s): _____

3. Data collection method(s): _____

4. Current target behavior rate/level: _____

5. Expected benefits, including rate/level the medication should increase/decrease the behavior to:

6. Risks (side effects sheets are are not attached): _____

7. Alternative therapies: _____

8. Non-medication program(s) addressing the target behavior or condition: _____

9. Estimated duration of the medication(s): _____
10. Medication reduction to be reviewed or attempted by: _____
11. Individual to contact if questions or problems: see other side
12. Signature(s) and title of staff completing this form:

APPENDIX B

| | | | |
|---|---|---|------|
| PSYCHOTROPIC INITIATION: EMERGENCY | INDIVIDUAL | | I.D. |
| | DATE | DATE TO BE REVIEWED BY INTERDISCIPLINARY TEAM MEMBERS (not to exceed seven days) | |
| PSYCHOTROPIC | PSYCHOTROPIC | | |
| DOSE (mg) MAXIMUM DOSE | DOSE (mg) MAXIMUM DOSE | | |
| ROUTE OF ADMINISTRATION | ROUTE OF ADMINISTRATION | | |
| TYPE OF ORDER (check one) <input type="checkbox"/> One time stat <input type="checkbox"/> One or more days | TYPE OF ORDER (check one) <input type="checkbox"/> One time stat <input type="checkbox"/> One or more days | | |
| SPECIFIC EMERGENCY BEHAVIOR IN OBSERVABLE AND MEASURABLE TERMS | | | |
| OTHER PROCEDURES WHICH WERE ATTEMPTED AND FAILED (INCLUDING DATA) OR CONSIDERED AND REJECTED (INCLUDING REASONS) | | | |
| ACTUAL BEHAVIORAL OUTCOME | | | |
| HAS THE LEGALLY AUTHORIZED REPRESENTATIVE AND CASE MANAGER BEEN INFORMED? (note: must be within 72 hours) <input type="checkbox"/> Yes <input type="checkbox"/> No (specify date to be informed by) | | CIRCUMSTANCES <input type="checkbox"/> Physician present <input type="checkbox"/> Physician approval over phone | |
| SIGNATURE AND TITLE | SIGNATURE AND TITLE | SIGNATURE AND TITLE | |

Note. Use other side for additional comments. Also see documentation such as Physician Orders. If medication continues beyond seven days, written informed consent required. If medication continues, begin Psychotropic Medication Review Form.

PSYCHOTROPIC INITIATION: NONEMERGENCY

INDIVIDUAL

I.D.

PERTINENT DIAGNOSES

DATE

PROPOSED PSYCHOTROPIC

PROPOSED PSYCHOTROPIC

PROPOSED DOSE (total mg/day)

ROUTE OF ADMINISTRATION

PROPOSED DOSE (total mg/day)

ROUTE OF ADMINISTRATION

MAXIMUM DOSE (total mg/day)

- Oral
- Liquid/Elixir/Suspension
- Injection
- Other (specify)

MAXIMUM DOSE (total mg/day)

- Oral
- Liquid/Elixir/Suspension
- Injection
- Other (specify)

ESTIMATED DURATION OF THERAPY (should not exceed 3-12 months without explanation)

ESTIMATED DURATION OF THERAPY (should not exceed 3-12 months without explanation)

IS A DOSAGE TITRATION INVOLVED?

- Yes (specify)
- No

IS A DOSAGE TITRATION INVOLVED?

- Yes (specify)
- No

CURRENT PSYCHOTROPIC(S), ANTICHOLINERGICS, AND DOSE (total mg/day). If none, enter "none".

_____ mg/day
 _____ mg/day
 _____ mg/day
 _____ mg/day

Will any of these psychotropics be discontinued as a result of the start of the proposed psychotropic?

- Yes (specify medication and reduction method)
- No

COMMENTS

over

BEHAVIORAL SUMMARY

See other chart locations for a more complete description of target behaviors and programs (such as Annual Reviews). If necessary cross-reference these locations or additional comments.

| | | |
|--|---------------|----------------------------|
| TARGET BEHAVIOR #1 | | BASELINE DATES (from - to) |
| DATA COLLECTION METHOD | BASELINE RATE | CURRENT PROGRAM |
| CRITERION LEVEL REPRESENTING TREATMENT EFFECTIVENESS | | |
| TARGET BEHAVIOR #2 | | |
| DATA COLLECTION METHOD | BASELINE RATE | CURRENT PROGRAM |
| CRITERION LEVEL REPRESENTING TREATMENT EFFECTIVENESS | | |
| TARGET BEHAVIOR #3 | | |
| DATA COLLECTION METHOD | BASELINE RATE | CURRENT PROGRAM |
| CRITERION LEVEL REPRESENTING TREATMENT EFFECTIVENESS | | |

ADAPTIVE BEHAVIOR/SKILLS TO BE MONITORED

AUXILIARY ITEMS (if any item checked "no", do not start psychotropic or justify in comments)

- Previous behavior or therapeutic intervention reviewed? Yes No
- Previous psychotropic interventions reviewed? Yes No
- Organic or medical pathology reviewed? Yes No
- Psychosocial and environmental factors reviewed?..... Yes No
- Possible side effects documented? Yes No
- General side effects baseline taken? Yes No
- Tardive dyskinesia baseline taken? (neuroleptics/amoxapine only) Yes No
- Written informed consent obtained? Yes No
- Date for minimal effective dose program consideration if the psychotropic is successful (specify) _____ (must not exceed one year)
- Date for one month review (specify) _____

| | | |
|---------------------|---------------------|---------------------|
| SIGNATURE AND TITLE | SIGNATURE AND TITLE | SIGNATURE AND TITLE |
| SIGNATURE AND TITLE | SIGNATURE AND TITLE | SIGNATURE AND TITLE |

(To be made one and twelve copies)

THE SENATE

..... LEGISLATURE, 19

STATE OF HAWAII

S.B. NO.

A BILL FOR AN ACT

RELATING TO DEVELOPMENTAL DISABILITIES.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

1 SECTION 1. The purpose of this Act is to implement the
 2 recommendations of the legislative auditor in the report
 3 entitled "An Evaluation of the Quality of Care in Homes Serving
 4 People with Developmental Disabilities".

5 SECTION 2. Section 333F-1, Hawaii Revised Statutes, is
 6 amended by adding a new definition to be appropriately inserted
 7 and to read as follows:

8 "Specialized care home" means an adult residential care
 9 home as defined under Section 321-15.1, that serves only
 10 residents with developmental disabilities."

11 SECTION 3. Section 333F-2, Hawaii Revised Statutes, is
 12 amended by amending subsection (c) to read as follows:

13 "(c) Programs of the department may include, but shall not
 14 be limited to:

15 (1) Early identification and evaluation of persons with
 16 developmental disabilities or mental retardation;

17
18

- 1 (2) Development, planning and implementation in
- 2 coordination with other federal, state, and county
- 3 agencies, of service programs for persons with
- 4 developmental disabilities or mental retardation;
- 5 (3) Development and provision of service programs in the
- 6 public or private sectors through chapter 42, for
- 7 persons with developmental disabilities or mental
- 8 retardation;
- 9 (4) Establishment of a continuum of comprehensive services
- 10 and residential alternatives in the community so as to
- 11 allow persons with developmental disabilities or
- 12 mental retardation to live in the least restrictive,
- 13 individually appropriate environment;
- 14 (5) Development and implementation of a program for single
- 15 entry access by persons with developmental
- 16 disabilities or mental retardation to services
- 17 provided under this chapter as well as referral to and
- 18 coordination with services provided in the private
- 19 sector or under other federal, state, or county acts,
- 20 including case management, and development of an
- 21 individualized service plan by an interdisciplinary
- 22 team;

- 1 (6) Collaborative and cooperative services with public
2 health and other groups for programs of prevention of
3 developmental disabilities or mental retardation;
- 4 (7) Informational and educational services to the general
5 public and to lay and professional groups;
- 6 (8) Consultative services to the judicial branch of
7 government, to educational institutions, and to
8 health and welfare agencies whether such agencies are
9 public or private;
- 10 (9) Provision of community residential alternatives for
11 persons with developmental disabilities or mental
12 retardation, including specialized care homes, group
13 homes, and homes meeting ICF/MR standards; and
- 14 (10) Provision of other programs, services, or facilities
15 necessary to provide a continuum of care for persons
16 with developmental disabilities or mental
17 retardation."

18 SECTION 4. Chapter 333F, Hawaii Revised Statutes, is
19 amended by adding a new section to be appropriately designated
20 and to read as follows:

21 "Section 333F- Certification program for specialized
22 care homes. (a) The department is authorized to certify
23 specialized care homes according to standards that
24
25

1 address the individual needs of residents with developmental
2 disabilities.

3 (b) The rate of payment for certified homes is to be
4 determined on the same basis as domiciliary care homes as
5 provided under section 346-53.

6 (c) The department may provide certified homes with
7 training, support services, and additional compensation in
8 recognition of their special expertise.

9 (d) The department shall adopt rules pursuant to chapter
10 91 necessary for the purposes of this section.

11 SECTION 5. Section 321-15.6, Hawaii Revised Statutes, is
12 amended to read as follows:

13 "Section 321-15.6 Adult residential care homes. (a)
14 All adult residential care homes shall be licensed to ensure
15 the health, safety, and welfare of the individuals placed
16 therein; provided that the department may issue a temporary
17 permit to operate an adult residential care home if an operator
18 or applying operator is temporarily unable to conform to all
19 minimum licensing standards. A temporary permit shall be valid
20 for not more than six months.

21 (b) The director shall adopt rules regarding adult
22 residential care homes in accordance with chapter 91 which
23 shall be designed to:
24
25

- 1 (1) Protect the health, safety, and civil rights of
2 persons residing in facilities regulated;
- 3 (2) Provide for the licensing of adult residential care
4 homes; provided that the rules shall allow group
5 living in two categories of adult residential care
6 homes as licensed by the department of health: type I
7 allowing group living by five or fewer unrelated
8 persons, and type II allowing six or more persons
9 including, but not limited to, the mentally ill, the
10 elderly, the handicapped, the developmentally
11 disabled, or the totally disabled persons who are not
12 related to the home operator or facility staff. For
13 purposes of this section, "mentally ill person" means
14 a mentally ill person as defined under section 334-1;
15 "elderly person" means an elderly person as defined
16 under section 359-52; "handicapped person" means an
17 individual with a physical handicap as defined under
18 section 515-2; "developmentally disabled person" means
19 a person with developmental disabilities as defined
20 under section 333E-2; and "totally disabled person"
21 means a person totally disabled as defined under
22 section 235-1;

23
24
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- 1 (3) Comply with applicable federal laws and regulations of
2 Title XVI of the Social Security Act, as amended; and
3 (4) Provide penalties for the failure to comply with any
4 rule.

5 (c) The director may waive all or some of the rules
6 adopted under this section for adult residential care homes
7 that are certified under Section 333F- .

8 [(c)] (d) The department may provide for the training of
9 and consultations to operators and staff of any facility
10 licensed under this section, in conjunction with any licensing
11 thereof, and shall adopt rules to ensure that adult residential
12 care home operators shall have the needed skills to provide
13 proper care and supervision in a home environment (i.e., first
14 aid, cardiopulmonary resuscitation, and nutrition training as a
15 minimum).

16 [(d)] (e) Rules adopted under this section shall be
17 enforced by the director.

18 [(e)] (f) The department shall maintain an inventory of
19 all facilities licensed under this section and shall maintain a
20 current inventory of vacancies therein to facilitate the
21 placement of individuals in such facilities."

22 SECTION 6. There is appropriated out of the general
23 revenues of the State of Hawaii the sum of \$50,000, or so much
24
25

1 thereof as may be necessary for fiscal year 1990-1991, to carry
2 out the purposes of this Act, including the hiring of necessary
3 staff. The sum appropriated shall be expended by the
4 department of health.

5 SECTION 7. Statutory material to be repealed is
6 bracketed. New statutory material is underscored.

7 SECTION 8. This Act shall take effect upon its approval.

8

9

INTRODUCED BY: _____

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RESPONSES OF THE AFFECTED AGENCIES

COMMENTS ON AGENCY RESPONSES

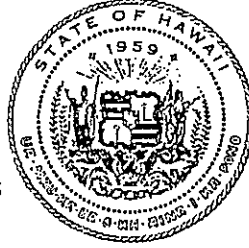
We transmitted a preliminary draft of this report to the Department of Health on December 29, 1989. The State Planning Council on Developmental Disabilities, the Protection and Advocacy Agency of Hawaii, and the Chief Justice of the Supreme Court also received drafts of the report for their comment. A copy of the transmittal letter to the Department of Health is included as Attachment 1. Similar letters were sent to the other agencies. The response from the Department of Health is included as Attachment 2, the response from the State Planning Council on Developmental Disabilities is included as Attachment 3, and the response from the Protection and Advocacy Agency of Hawaii is included as Attachment 4. No response was received from the Judiciary.

The Department of Health concurred with the recommendations on strengthening the informed consent process for psychotropic medications and developing a certification program. It also agreed that there is a need to improve the case management system. The department had some questions about the survey such as the source of the sample and the kinds of residents surveyed. The answers to the questions can be found in the report. For example, the survey was based on a random sample of *homes* serving residents with developmental disabilities (not a random sample of DOH clients), and questions on behavior management and psychotropic medication were only asked about residents with developmental disabilities.

The State Planning Council on Developmental Disabilities and the Protection and Advocacy Agency of Hawaii supported most of the report's findings and recommendations.

ATTACHMENT 1

STATE OF HAWAII
OFFICE OF THE AUDITOR
465 S. King Street, Room 500
Honolulu, Hawaii 96813



(808) 548-2450
FAX: (808) 548-2693

C O P Y

December 29, 1989

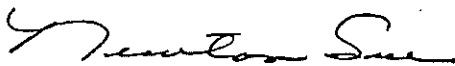
John C. Lewin, M.D.
Director of Health
Department of Health
1250 Punchbowl Street
Honolulu, Hawaii 96813

Dear Dr. Lewin:

Enclosed are three copies, numbers 6 to 8 of our draft report, **An Evaluation of the Quality of Care in Homes Serving People With Developmental Disabilities**. We ask that you telephone us by January 4, 1990, on whether you intend to comment on our recommendations. Should you decide to respond, please transmit the written comments to us by January 17, 1990. We will append your response to the report submitted to the Legislature. The Governor and the presiding officers of the Legislature have also been provided copies of this draft report.

Since the report is not in final form and changes may be made, access to it should be restricted to those persons whom you might wish to assist you in preparing your response. Public release of the report will be made solely by our office and only after the report is published in its final form.

Sincerely,


Newton Sue
Acting Legislative Auditor

Enclosures

ATTACHMENT 2

JOHN WAIHEE
GOVERNOR OF HAWAII



JOHN C. LEWIN, M.D.
DIRECTOR OF HEALTH

STATE OF HAWAII
DEPARTMENT OF HEALTH

P. O. BOX 3378
HONOLULU, HAWAII 96801

In reply, please refer to:
File:

January 17, 1990

Mr. Newton Sue
Acting Legislative Auditor
Office of the Auditor
465 S. King St., Rm. 500
Honolulu, HI 96813

RECEIVED

JAN 18 10 54 AM '90

STATE OF HAWAII

Dear Mr. Sue:

The Department of Health (DOH) appreciates the opportunity to comment on the draft report, An Evaluation of the Quality of Care in Homes Serving People with Developmental Disabilities. We concur with the recommendations made in this report regarding strengthening the written, informed consent process on use of psychotropics and the need for certification of care homes and group homes serving residents with developmental disabilities. These recommendations are very timely as the Developmental Disabilities Division (DDD), in recognizing the uniqueness of this population, has initiated actions to improve these systems. For the past six months, DDD staff have been discussing with the Hospital and Medical Facilities Branch within DOH the need for special certification of homes caring for individuals with developmental disabilities. Staff consensus is that the DDD will complete special regulations for such homes by July, 1990.

The need to improve the case management system has long been recognized and the low pay scale of social workers only adds to our dilemma. Since the study was initiated, the vacancy rate in our units has increased from 40 percent as mentioned on Page 22 of the report to 50 percent.

There are discrepancies noted in the report which we wish to point out.

1. The study methodology is not very clearly defined. A sample of 75 homes were compiled from lists but surveyors actually visited 56 homes. They interviewed 44 care home operators, 12 group home staff and 58 residents with developmental disabilities. However, it's not clear whether a representative sample was interviewed. It's important that the sample group be clearly identified as some of the conclusions of this

study may be inaccurate; we are not certain whether all residents in the care homes were considered (including the aged and the mentally ill) when developing blanket statements on psychotropic medication use or behavior problems.

2. On page 3, the report states, "more than 800 adults with developmental disabilities live in the care homes and group homes that are the focus of this study" and yet on page 6, the estimate is that 722 people with developmental disabilities live in 230 licensed care homes throughout the state. The group homes are licensed as care homes and therefore should be in the total count.

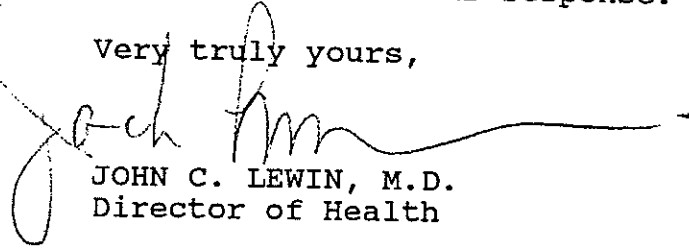
Our data on our clients shows that there are 382 in Type I care homes and 15 in Type II care homes for a total of 397. We are in a quandary as to the 800 or the 722 individuals with developmental disabilities in care homes as our understanding is that the Department of Human Services had only about 40 individuals with developmental disabilities unknown to our DDD about five years ago. Even if this figure doubled, the estimate from the study is inflated.

3. Again, when the surveyors indicated that 44 percent of the care home residents with developmental disabilities were not DOH clients, this is confusing as the sample was drawn from DOH's active client list. Did the 56 homes visited have non-DOH individuals with developmental disabilities living there as well?
4. The surveyors indicated that psychotropic medications use is higher than Hawaii's figure of 26 percent in 1987. We are not clear what client group was studied to cause the surveyors' report of 47 percent. The DDD's 1987 estimate was based on case reviews of all clients.
5. The report should indicate the sample group from which the percentages are drawn for prevalence of behavior problems found in care homes. Although the surveyors define major behavior problems, a definition of minor behavior problems is also needed to provide information to the reader on the range of behaviors perceived as problems by the care home operators.
6. Including a sample of the questionnaire used in the interviews with care home operators and residents would be helpful in providing the reader with an

understanding of the standards used by the surveyors as the basis of their study.

Thank you again for your consideration of our response.

Very truly yours,

A handwritten signature in cursive script, appearing to read "John C. Lewin", written in black ink. The signature is fluid and extends across the width of the page.

JOHN C. LEWIN, M.D.
Director of Health

ATTACHMENT 3



STATE OF HAWAII
STATE PLANNING COUNCIL
ON DEVELOPMENTAL DISABILITIES
P. O. BOX 3378
HONOLULU, HAWAII 96801
TELEPHONE: 548-5994; 548-8482; 548-8483; 548-8469

January 17, 1990

RECEIVED

JAN 17 3 55 PM '90

OFFICE OF THE AUDITOR
STATE OF HAWAII

Mr. Newton Sue
Acting Legislative Auditor
465 South King Street, Room 500
Honolulu, Hawaii 96813

Dear Mr. Sue:

The State Planning Council on Developmental Disabilities has reviewed the Legislative Auditor's report, "An Evaluation of the Quality of Care in Homes Serving People with Developmental Disabilities." The Council is impressed with the comprehensiveness of the report and commends Human Services Research Institute (HSRI) for its efforts.

In 1989 the Council supported a citizen monitor project that evaluated the quality of life of persons living in community residential settings. Although not as extensive as the HSRI evaluation, the project's findings support the findings and many of the recommendations of the HSRI draft. Additionally, findings and recommendations contained in the Council's federally mandated analysis and evaluation of services, "1990 Visions," are similar to several of the recommendations in the Residential Services chapter, and five out of six of those made in the Quality Assurance chapter.

There are several more specific comments we would like to make.

Regarding the recommendation that the State Planning Council on Developmental Disabilities explore the feasibility of establishing a calendar of planned events, the Council agrees with the findings leading up to this recommendation. The consumer satisfaction survey (Sunderland Smith Research Associates, 1989) done for the Council found that the majority of persons surveyed wanted more recreational activities; the 1990 Report found a lack of specialized and integrated recreation activities. However, the Commission on Persons with Disabilities' monthly newspaper does contain a calendar of events for persons who are disabled, including recreational activities such as the monthly dances at Wahiawa. Therefore, we feel that a more appropriate activity for the Council would be to advocate for: 1) an increase in

Mr. Newton Sue
Page 2
January 17, 1990

specialized recreational activities, 2) an increase in the number and types of integrated generic activities available, and 3) more support and training for care providers in order to enable them to provide more "in the community" activities. We have already taken some action in addressing Activity No. 2 by sponsoring workshops for generic service providers on Kauai, Maui, and the Big Island on how to integrate people with disabilities.

Regarding Council action to involve case managers in the planning process, we wholeheartedly agree that the Council needs such input. The 1990 process has impressed upon us the importance of setting up a mechanism to facilitate a broader spectrum of input. While an annual meeting might be the solution, the Council will also explore other actions to achieve more input.

The lack of information regarding residential rights has been identified as a problem by consumers, parents, the Quality Assurance Task Force, and the CHAMP project. The Council agrees that a handbook would be useful and accepts the responsibility of seeing that it is developed.

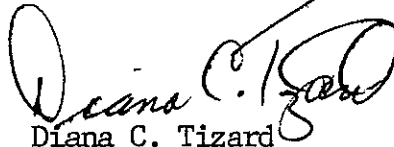
We are extremely concerned regarding the findings regarding psychotropic medication. We agree that steps must be taken to insure that persons who are incapacitated in their decision making ability are protected in the area of psychotropic medication and medical care. As a member of the Guardianship Task Force, we have urged that Hawaii look at alternatives to full guardianship such as New York's surrogate decision-making law. Perhaps the responsibilities of the Governor's Reproductive Rights Committee could be expanded to address these issues rather than flood the system with lengthy guardianship proceedings.

Thank you for the opportunity to respond to this draft. If we can be of further assistance, please contact us.

Sincerely,



David Woll
Chairperson



Diana C. Tizard
Executive Secretary

DW/DCT:stk

JAN 18 3 58 PM '90

TO: Legislative Auditor of the State of Hawaii
 FROM: Protection and Advocacy Agency of Hawaii
 RE: Report to the Governor and the Legislature of the State of Hawaii: An Evaluation of the Quality of Care in Homes Serving People with Developmental Disabilities

OFFICE OF THE AUDITOR
 STATE OF HAWAII

CHAPTER 3

COMMENTS TO RECOMMENDATIONS 1 THROUGH 8.

RECOMMENDATIONS 1 & 2:

The P&A supports the intent of recommendations 1 and 2 (p. 16 of the Audit Report). However, we question the necessity of amending 333 F as we feel such "specialized care homes" can be developed and established without amending the statute. Residential operators clearly need more training and support services. Additional compensation which is linked to training and the quality and quantity of services provided is also necessary.

RECOMMENDATION 4:

This is a good idea and worthy of implementation by the Department of Health or its designee.

RECOMMENDATION 5:

This should be seriously considered, as the denial of services to persons with behavioral problems or medical/physical needs could potentially violate Section 504 of the Rehabilitation Act of 1973. This federal law prohibits discrimination based on handicapping conditions. Such denials are very suspect.

RECOMMENDATION 6:

P&A is willing to conduct another survey in coordination with assigned case managers, social workers and family members. The P&A's main focus is to advocate for the rights of persons with DD or mental illness. Therefore, as long as the purpose of the survey is to assure the protection of rights, as opposed to obtaining guardians, the Protection and Advocacy Agency could feasibly coordinate this project. The Agency already monitors many community residential facilities through its' site visitations, follow through on ICF/MR deficiency reports, follow up on individual cases as well as research/survey projects. *See: Changing Places: A Study of the Transition of Residents from Waimano Training School and Hospital to Community Facilities and P&A Annual Report. Therefore, such a survey would complement our existing individual, systems and outreach advocacy activities.

RECOMMENDATION 7:

We would agree that a guardian be obtained for those D.D. care home residents who meet the criteria for guardianship. However, we do not believe that all care home residents using psychotropic medicines are necessarily candidates for guardianship. Alternatives to guardianship and limited guardianships should be considered initially, when appropriate.

RECOMMENDATION 8:

We would agree that the monitoring of psychiatric drugs is essential. The recommendations listed are a good start, however, we would add that the right to refuse treatment be given sufficient consideration in all trainings and educational opportunities for clients, guardians, care home operator's as well as staff. Department procedures should also reflect this and other clients' rights.

CHAPTER 4

RECOMMENDATION 1:

Again, we question the necessity of amending 333F as such certification can be accomplished under the present statutory authority. However, we support the intent of the recommendation: provision of a quality continuum of residential/care home services. We support and encourage the use of individually-centered standards in all group and care homes that service persons with disabilities. We also support the utilization of standards liberal enough to allow persons with disabilities to receive any and all services and assistance they need to meet their individual needs. We agree that the home should address the needs of the individual and not the medically based standards of an entire population. For instance, homes that do not service the medically fragile should not be required to meet paramedical certification where it is unnecessary. These requirements often work against the best interests of the individual with disabilities.

RECOMMENDATION 2:

We agree that HRS 321-15.6 be amended to allow the DOH to waive care home licensing regulations in specific situations when appropriate. Alternatively, DOH can change licensing requirements to meet the specific needs of individual with disabilities. We agree, as stated above, that when no medically fragile individuals will reside in the home, the home be designated as such and the standards be appropriately

relaxed without jeopardizing the safety and rights of the residents. Possible suggestions could be to have homes subcategorized (e.g. Group Home level 1, Care home level 1, etc.) according to abilities and needs of the residents. Therefore, overly burdensome regulations would not discourage caring home operators who do not meet/nor wish to meet unnecessary licensing requirements.

In addition, where home operators who have shown themselves to be capable, caring and supportive operators, yet do not meet the technical requirements of licensure, the DOH could assist them in meeting the requirement rather than close the home (eg. DOH attempted to close and impose fines on a care home due to technical non-compliance). This potentially deprives residents of a secure home and a caring operator.

RECOMMENDATIONS 3 THROUGH 5:

We agree with Recommendations 3 through 5 and would support and assist in any way we can with their implementation. We agree with the report that internal advocacy is limited, but would like to clearly distinguish this advocacy from the external, professional advocacy provided by the Protection and Advocacy Agency of Hawaii. It is our policy and practice to advocate for what the client wants and/or needs and not depend on the existing array of services. Our Agency would be willing to assist the Department of Health in training its employees eg., case managers in the "Art of Creative Advocacy" and "How to Advocate Effectively and Get Results."

RECOMMENDATION 6:

Recommendation 6 is confusing as the Protection and Advocacy Agency is the only Agency which is federally mandated to protect the human, civil and legal rights of persons who are developmentally disabled. See 42 U.S.C. 6000. The Governor through Executive Order 89-2 designated the Protection and Advocacy Agency of Hawaii as the "only eligible system" to ensure the protection and rights of individuals with disabilities. While the other organizations listed in the report provide some protection of rights, such activities are ancillary to their main function. Whereas, it is the main function of the Protection and Advocacy Agency of Hawaii to provide these protection and advocacy services to developmentally disabled persons. Therefore, we would suggest that any handbook developed be reflective of this. We would strongly emphasize that handbooks/pamphlets and after information/materials have been distributed to the community and that it will certainly continue on an on going basis by the Protection and Advocacy Agency of Hawaii as part of its overall advocacy services.

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