Quadriplegics In Hawaii

GAYLE M. MIYASAKI
Researcher

Report No. 3, 1993

Legislative Reference Bureau
State Capitol
Honolulu, Hawaii 96813

FOREWORD

This report on services for quadriplegics was prepared in response to House Resolution No. 185 (1992). Special thanks are extended to the following individuals for their valuable assistance in preparing this report: Philip Ana, Dan Anderson, Kathleen English, Mike Flores, Steve Forer, Donna Fouts, Debbie Goebert, Raymond Gota, Jill Hurt, Richard Isa, Debbie Jackson, Virginia Joseph, Millie Ng, Mark Obatake, Michele Otake, Kirby Shaw, Dr. John Sheedy, Neil Shim, Hiromi Shiramizu, Mitsuo Shito, Norman Tam, and Leslie Tawata.

Samuel B. K. Chang
Director

January 1993

TABLE OF CONTENTS

TABLES

APPENDICES

Chapter 1

INTRODUCTION

The House of Representatives of the Sixteenth Legislature, Regular Session of 1992, adopted House Resolution No. 185 (attached as Appendix A) requesting a study regarding the provision of specialized services for quadriplegics residing in the State of Hawaii. The Legislature found that there is no state agency or department that specifically administers services to quadriplegics and that there is a need to administer specialized services to this population.

The Legislature requested that the Legislative Reference Bureau examine the following issues:

(1) The number of quadriplegics currently residing in Hawaii;

(2) The needs of quadriplegics;

(3) How the needs of quadriplegics are being met and whether services are adequate; and

(4) Whether a center or an independent living project for quadriplegics should be established, and if so what would be the design, construction, and administrative costs of establishing a center or project.

The study has seven chapters including this one. Chapter 2 reviews the national movement on independent living which has shaped the programs available to the disabled population in general. Chapter 3 is a general overview of the services provided to the quadriplegic population in Hawaii. Chapter 4 attempts to ascertain some information on the quadriplegic population including needs, and delineates the different organizations that deal specifically with this population. Chapter 5, Part I is a survey of residential programs in the continental United States and attempts to ascertain various models of residential settings that are currently in existence. Chapter 5, Part II is a survey of known residential programs in Hawaii that provide services to other disabled populations in order to provide additional models of residential settings including costs. Chapter 6 discusses the feasibility of a residential setting specifically for quadriplegics. Chapter 7 contains findings and recommendations.

Chapter 2

THE INDEPENDENT LIVING MOVEMENT FOR THE DISABLED

There has been a strong movement in the United States, referred to as the Independent Living Movement, with respect to how the disabled population is dealt with in terms of programs and assistance. The movement appears to have influenced many important pieces of federal legislation which in turn has affected state and county programs.

Independent Living for Physically Disabled People, published in 1983, which presents a "broad, intensified coverage of independent living as it has emerged...." was edited by Nancy M. Crewe, a rehabilitation psychologist and associate professor in the Department of Physical Medicine and Rehabilitation at the University of Minnesota, and Irving K. Zola, professor and chair, Department of Sociology, Brandeis University.[1] Basically, according to Crewe and Zola, the Independent Living Movement has attempted to structure programs and assistance so that the disabled may move out of institutional settings and into the community. Generally, this entails removing barriers both intangible, such as discrimination, and physical that prevent the disabled from participating freely in the community. It also entails providing essential services such as attendant care, accessible and adaptable housing, medical care, and accessible transportation. Again it is important to emphasize that the Independent Living Movement has attempted to structure programs and assistance to enable the disabled to be integrated into the community rather than remain isolated in institutional settings. "Central to the Independent Living Movement is the belief that the management of medically stabalized disabilities is primarily a personal matter and only secondarily a medical matter. A constant medical presence in the life of a disabled person gives rise to behavior on the part of both practitioner and patient that induces dependency and thus hinders achievement of rehabilitation and independent living goals."[2]

In subchapter VII of the Vocational Rehabilitation Act,[3] Congress enacted legislation for comprehensive services for independent living. The purpose of the law is to "authorize grants ... to assist States in providing comprehensive services for independent living designed to meet the needs of individuals whose disabilities are so severe that they do not presently have the potential for employment but may benefit from vocational rehabilitation services which will enable them to live and function independently" [4] Part B allows the commissioner "to make grants ... to provide for the establishment and operation of independent living centers",[5] for the purpose of offering certain services to foster independent living.

According to Crewe and Zola, the Independent Living Center "has become the primary self-help unit for the disabled". The Centers "seek to serve both as an adjunct to the present human service system and as an alternative service provider. As an adjunct, the center serves as a conduit for funding human services such as attendant care. As an alternative, the

center provides peer counseling and advocacy services not available through mainline human service organizations."[6]

In an extensive 1978 survey, the Independent Living Research Utilization project (ILRU)[7] identified three major types of programs for independent living: centers, residential programs, and transitional programs.[8] "As originally conceived, an independent living center must provide a minimum set of services, including housing assistance, attendant care, readers and/or interpreters, peer counseling, financial and legal advocacy, and community awareness and barrier-removal programs."[9] Because this somewhat restrictive definition excludes programs of a residential or transitional nature, the term **independent living program** has evolved to include independent living centers, residential programs, and transitional programs. According to Crewe and Zola, "independent living program" is a generic term that subsumes the several different types of programs and is understood to be what was intended by the initiators of subchapter VII of the Vocational Rehabilitation Act on independent living for the severely disabled when they refer to independent living centers. Thus according to the authors, an independent living program can include residential programs, both transitional and permanent.[10]

The authors define **independent living residential program** as a "live-in program that provides or coordinates attendant services and transportation, and may also provide related services", and **independent living transitional program** as "one which helps severely disabled people move from comparatively dependent to more independent living situations. The primary service provided by these programs is skill training in such areas as attendant management, financial management, consumer affairs, mobility, educational/vocational opportunities, medical needs, living arrangements, social skills, time management, functional skills, sexuality, and so forth. Transitional programs are usually goal oriented and/or time linked."[11]

Thus, although the Independent Living Movement has focused on keeping the disabled out of the institutional setting, there is room for permanent and transitional residential settings that foster independent living.

For purposes of this study, it is helpful to understand that there has been a national movement dedicated to keeping the disabled population in general out of institutional settings and integrated into the community. Efforts have been made to structure programs and assistance in that direction, therefore any attempt (however well intended) to segregate the disabled population, or a portion thereof such as quadriplegics, will have to deal with the efforts of this national movement. Chapter 3 provides an overview of programs to provide basic services for daily living needs that are available to quadriplegics. Many of these programs are designed to keep the disabled population independent and living in the community rather than in institutional settings and reflects the efforts as well as the strength of the national Independent Living Movement.

However, the tenets of the Independent Living Movement do not prohibit or oppose any type of residential program. Programs operated in the spirit of the Movement include residential settings which foster independent living. Chapters 5 and 6 reflect various organizations for disabled populations both in Hawaii and the continental United States which have successfully operated some type of residential setting for disabled populations. Further, some federal programs have been structured to provide residential assistance for the disabled.

ENDNOTES

1. Nancy Crewe and Irving Zola, (ed.), Independent Living for Physically Disabled People (San Francisco, California: Jossey-Bass Publishers, 1983), p. xii.

2. Gerben DeJong, "Defining and Implementing the Independent Living Concept", Independent Living for Physically Disabled People, ed. Nancy Crewe and Irving Zola (California: Jossey-Bass Publishers, 1983), p. 15.

3. 29 U.S.C.A. sec. 796 et seq. (1992).

4. 29 U.S.C.A. sec. 796 (1992).

5. 29 U.S.C.A. sec. 796e (1992).

6. DeJong, p. 14.

7. *The Independent Living Research Utilization project is a national center established to provide information, training, research, and technical assistance in independent living.*

8. Lex Frieden, "Understanding Alternative Program Models", Independent Living for Physically Disabled People, ed. Nancy Crewe and Irving Zola (California: Jossey-Bass Publishers, 1983) p. 63.

9. Ibid., p. 64.

10. Ibid.

11. Ibid., p. 64-65.

Chapter 3

OVERVIEW OF SERVICES AVAILABLE TO THE QUADRIPLEGIC POPULATION

House Resolution No. 185 requested an examination of how the needs of quadriplegics are being met. Because no individual or organization possesses the data that would make it possible to conduct the survey needed to truly ascertain these needs, the Bureau has attempted to draw together the relevant information available. This chapter provides general information on the programs and services now available to quadriplegics. As such, it is intended not as an in-depth discussion of each program, but a general overview of the basic services which quadriplegics utilize for daily living needs. Some programs are offered to persons of low to moderate incomes generally which includes many if not most quadriplegics as they are often not able to work or hold jobs with high salaries. Some programs are more specifically tailored to the needs of the entire disabled population which of course includes quadriplegics. There are no programs that are offered or limited solely to quadriplegics.

It should be noted that it is apparent that some of the services currently provided to the disabled including quadriplegics in Hawaii focus on the theme of attempting to enable the disabled to live independently and integrated into the community. An attempt will be made to point out those programs that specifically have that theme in mind.

Public Assistance for Indigent Quadriplegics

Indigent and low-income quadriplegics receive the basic welfare benefits generally available to low-income persons including financial assistance, food stamps, and medicaid for their medical benefits. The following are the medical needs covered by medicaid that quadriplegics are most likely to utilize:

- Inpatient hospital care
- Physician services
- Outpatient hospital services
- Psychiatric service and treatment
- Nursing facility (NF) services at skilled nursing facilities (SNF) or intermediate care facilities (ICF)

- Intermediate care facilities (ICF-MR), and services for mentally retarded patients
- Preventive services
- Rehabilitative services
- Home health services
- Family planning services
- Hysterectomy
- Sterilization
- Respiratory care services
- Ancillary medical services including:
    - drugs
    - durable medical equipment
    - medical supplies
    - prosthetic and orthotic appliances
    - dental services
    - visual services
    - speech, hearing and language disorders
    - hearing evaluations and devices
    - physical therapy and occupational therapy services
    - podiatrist's services
    - pediatric or family nurse practitioner services
    - intra-state transportation

- out-of-state transportation
- allogenic bone marrow transplant
- kidney transplant
- hospice care[1]

Under the "spend-down" program, a person who is earning an income and therefore not financially eligible for medicaid may obtain medicaid funds under certain circumstances; for example, where the person's income is low and for a brief period of time the person has a chronic illness where he or she may need medical assistance.[2] Persons who are not receiving financial assistance but need medical assistance may still qualify for medical assistance if they are "medically needy".[3]

Social Security Benefits

The Social Security system also provides benefits to help with basic living needs. The Social Security system has two programs which specifically help disabled individuals. Supplemental Security Income (SSI) is an income payment for persons who are age 65 or older, or blind or have a disability. They must also not have income or assets that exceed specified thresholds. "Disabled" means that the person has a physical or mental problem that keeps the person from working, and that is expected to last at least a year or to result in death.[4] A person may still receive other welfare benefits such as food stamps or Medicaid. The Social Security laws and regulations also have special rules that enable people with disabilities receiving SSI to work and still receive monthly cash payments and Medicaid. These are called **work incentives.** Payments in the SSI program are based on financial need.[5]

The Social Security disability insurance program is a program that pays benefits to disabled persons who have worked and have contributed to the Social Security system. For purposes of this program, a person is considered disabled if unable to do any kind of work for which that person is suited, and only if the disability is expected to last for at least a year or to result in death. A person must also have worked for a certain period of time before the disability started. After being in this program for two years, a disabled person is eligible for Medicare. A disabled person will receive payments under this program for as long as the person is eligible (considered disabled in the case of quadriplegics). There is also a work incentives program in this program.[6]

Housing Services for the Disabled

Although not technically considered a "service," housing is essential to the basic living needs of quadriplegics and disabled persons in general. The following is a brief description of housing programs and regulations that affect quadriplegics as part of the disabled population and as part of the low-income population.

Rental Assistance Program

The first group of programs are the rental assistance programs. Rental assistance programs target the low-income population in general, but many quadriplegics are included in the low-income population. Accordingly, these rental assistance programs are essential for many quadriplegics.

There are three rental assistance programs that are available to low-income tenants. The state and county housing agencies receive funds from the U.S. Department of Housing and Urban Development (HUD) and administer the programs. In the first of these programs, the certificate program, the housing agency establishes a fair market rent. Tenants must then find housing with a rent level that does not exceed that fair market rent. The unit must also meet established housing quality standards. The tenants then pay either 30 percent of their adjusted income or 10 percent of their gross income, whichever is higher. The housing agency will then pay the remainder. This "section 8" payment follows the tenant so if the tenant moves, he or she will still receive the section 8 payment benefit at the new unit. The tenant may reside anywhere in the State of Hawaii.[7]

The second program is the voucher program. HUD gives the housing agency a lump sum to be utilized for five years at the discretion of the agency. The housing agency sets a payment standard level which is not necessarily the fair market value. The payment standard level is supposed to reflect the amount that the housing agency is willing to pay for a unit of that size. The tenants then pay either 30 percent of their adjusted income or 10 percent of their gross income, whichever is higher. The housing agency will then pay the remainder up to the payment standard. The tenant may select a unit that is more costly and pay the excess amount. With a voucher, the tenant may move and reside anywhere where there is a housing agency that has a voucher program.[8]

The third program is the Moderate Rehabilitation Program, which is designed to encourage landlords to rehabilitate housing units by guaranteeing them a steady stream of tenants who receive section 8 payments. The housing agency selects a structure where the units to be utilized are substandard and need to be rehabilitated. The rehabilitation cost must exceed $1,000 per unit. The landlord has two years to obtain financing and to rehabilitate the units. The housing agency then ties the section 8 payments to these units for another 15 years. The landlord, in return, must continue to provide the units for section 8 tenants for 15

years. Unlike the certificate and voucher programs where the funds move with the tenant, the section 8 payments stay with the units for a total of 17 years under this program. Consequently, if tenants choose to move, they must go back on the waiting list for section 8 payments.[9]

Anti-Discrimination Requirements for Housing

There are three pieces of legislation relating to the disabled with which the state and county housing agencies must comply when building housing projects. Section 504 of the Rehabilitation Act of 1973 prohibits discrimination against the disabled by entities utilizing federal funds in whole or part.[10] Out of this came the requirement that five percent of the federally funded housing be made handicapped accessible.

The Federal Fair Housing Amendments[11] require that all multi-family dwellings with four or more units be made handicapped adaptable and that the common areas be handicapped accessible. "Handicapped adaptable" means that a unit is constructed according to various architectural specifications depending on the statute, which makes it possible for a disabled person to alter the unit to make it handicapped accessible. This might mean, for instance, that walls have certain reinforcements so that a person needing them can install grab bars or other helpful features. This law applies to private developments as well as all government developments whether federal funds are used or not.

Hawaii law requires that any state or county building be made accessible pursuant to certain national standards.[12] The Americans with Disabilities Act[13] does not add requirements for providing housing for the disabled. It merely underscores the requirement that all government housing be made accessible in a reasonable manner to the disabled.

Additionally, if a government sponsored project built before the enactment of the anti-discrimination legislation is subsequently renovated, and the building has 15 or more units and the cost of the alterations is 75 percent or more of the replacement cost of the completed facility, then five percent of the units in the building must be made handicapped accessible.[14]

Federal Programs Which May be Utilized for Housing for the Disabled

The counties receive certain community development moneys through HUD.[15] Funding received by the counties through the HUD Community Development Block Grants (CDBG) program is required to be directed toward neighborhood revitalization, economic development, and provision of improved community facilities and services.[16] Seventy percent of those funds must be expended for the benefit of low or moderate income persons.[17] These

moneys may be expended for the benefit of disabled persons, but the counties are allowed to determine how they will spend them.

There are also direct loans for the construction or substantial rehabilitation of rental or cooperative buildings for the elderly or disabled. Previously, these loans were called "Section 202 loans" and covered settings for the elderly and disabled. The law has since been changed. Section 202 now covers only the elderly, and Section 811 covers the disabled. Section 811[18] allows HUD to basically make outright grants to groups to provide housing for the disabled. The recipient group must be a private, non-profit organization, must have a specific plan to provide supportive services, and the building must be operated for the disabled for at least 40 years or the money must be returned.[19]

Mortgage Insurance Program

There are also three types of mortgage insurance programs to provide incentives for entities to provide housing for the disabled and the elderly. These programs are administered by HUD. The "Section 221"[20] program provides mortgage insurance to lenders making loans to finance rental or cooperative housing for displaced or moderate-income families. This can also be used to serve the disabled. An eligible entity may be a for-profit organization as well as a non-profit or a government agency.[21] The "Section 231"[22] program provides mortgage insurance for the elderly (but it is unclear whether this includes the elderly handicapped), and the "Section 232"[23] program provides mortgage insurance for nursing homes, intermediate care facilities or boarding care.[24]

Housing Alteration Revolving Loan Program

The State has a housing alteration revolving loan program for the disabled.[25] The housing alteration revolving loan fund, administered by the Hawaii Finance Development Corporation, provides low-interest loans up to $25,000 per residence for the purpose of making alterations to an individual's home to make it handicapped accessible.

Community Long-term Care Services

The Department of Human Services has programs which are targeted to enable disabled persons to remain integrated in the community.

For those quadriplegics who are medically stabilized, there are programs in the Community Long Term Care Branch of the Department of Human Services, Health Care Administration Division. The purpose of the Community Long Term Care Branch (CLTCB) is to provide home and community-based long-term care services to severely and chronically ill

and disabled individuals. The CLTCB services the disabled, among other groups, and these services are in keeping with the primary aim of the Independent Living Movement to integrate the disabled into the community rather than keep them in institutional settings. According to the mission statement in the CLTCB's Annual Report of 1991, the CLTCB attempts to help the disabled:

1. Acknowledge their willingness and support their ability and that of their families and caregivers to help themselves;

2. Respect their right to self-determination;

3. Enable them to live in the least restrictive environment;

4. Assure access to qualified care which is holistic, comprehensive and economical;

5. Support them in the pursuit of individual dignity; and

6. The CLTCB intends to provide leadership in the development and implementation of approaches which will promote the home and community as the preferred setting for the provision of long term care.[26]

The history of some of the programs in the CLTCB underscore how the Independent Living Movement has affected federal legislation and in turn, state and county programs.

Prior to 1981, "the Medicaid program provided little coverage for long term care services in a non-institutional setting, but offered full or partial coverage for such services in an institution. In an effort to expand coverage of services, Section 2176 of P.L. 97-35 was enacted, adding Section 1915(c) to the Social Security Act.[27] This section allowed the Secretary of Health and Human Services to waive certain Medicaid statutory requirements in order to enable the state to cover a broad array of home and community-based services as an alternative to institutionalization."[28]

The programs which quadriplegics utilize are: the Nursing Home Without Walls, Home and Community-Based Services for the Developmentally Disabled/Mentally Retarded, Non-medicaid Nursing Home Without Walls, and the Non-Medicaid Personal Care programs. The Nursing Home Without Walls (NHWW) program provides the following services:

- Case management
- Personal care attendants
- Skilled nursing

- Environmental modifications
- Home delivered meals
- Habilitation (training for living skills)
- Moving assistance (moving apartments, etc.)
- Non-medical transportation (i.e. Handivan for nonmedical purposes)
- Adult day health
- Home maintenance
- Nutritional counseling
- Homemaker services
- Respite care (allowing care while the primary caretaker takes some time off)
- Emergency alarm response[29]

The clients in this program must be federally Medicaid eligible,[30] certified to be in need of nursing facility (either SNF or ICF) level of care, and determined by an NHWW staff as being able to be kept at home with reasonable assurance of health and safety at less cost than institutional costs.[31]

There is also a program for the developmentally disabled (DD) and mentally retarded (MR). A person could be developmentally disabled or mentally retarded and also be quadriplegic. However, if a person is developmentally disabled or mentally retarded, there are specific requirements under the laws for services for the DD/MR populations, so a different program was established.[32] If a person's primary disabling condition is DD/MR, that person will qualify for the DD/MR programs. Generally, persons are categorized by the cause of their disability such as multiple sclerosis, muscular dystrophy or spinal cord injury and thus are not categorized by symptom such as quadriplegic or paraplegic. Consequently, a person who suffers from a developmental disability such as muscular dystrophy will have that disease considered the primary disabling condition and be placed in the DD/MR sets of programs. The Home and Community-Based Services for the Developmentally Disabled/Mentally Retarded program offers the following services to the disabled to enable them to remain in the community rather than in institutionalized settings:

- Case management

- Habilitation (life skills training)
- Personal care attendants
- Respite care
- Skilled nursing
- Environmental modifications
- Adult day health programs[33]

The eligibility requirements for the Home and Community- Based Services for the DD/MR program are that the individual must be at the ICF-MR level of care, must be federally Medicaid eligible, and the average cost of services provided must not exceed the cost of institutional ICF-MR care.[34]

The Non-Medicaid Nursing Home Without Walls program was authorized by Act 208, Session Laws of Hawaii 1988. The purpose was to provide home services to the "gap group" population which earned a low level of income but was ineligible for Medicaid. The program extends the NHWW services to this gap group on a sliding fee scale basis. The Non-Medicaid Personal Care Program was authorized by Act 209, Session Laws of Hawaii 1988, for the purpose of extending personal care services to the Medicaid ineligible gap group on a sliding fee scale basis.

Chore Services

Another type of service that the Family and Adult Services Division of the Department of Human Services provides that a quadriplegic would likely utilize are chore services. To be eligible, a person must have a low income.[35] Chore services are "essential housekeeping and related activities".[36]

The scope of the chore services program is broad and includes a variety of activities such as cleaning the home, caring for the laundry, marketing, preparing meals, yard work, running errands, assisting in daily grooming among other activities.[37]

Vocational Rehabilitation Act

The federal Vocational Rehabilitation Act, among other things, authorizes programs specifically to aid the disabled. The main focus of the federal Vocational Rehabilitation Act[38] is to provide rehabilitation to the disabled to enable them to become employed. The Vocational Rehabilitation Division of the state Department of Human Services administers the programs at the state level. Subchapter VII of the Act,[39] which was recently added by Congress, allows states to foster independent living skills and environments for those persons who are severely disabled, and does not have employment goal requirements.[40] Thus, *although the thrust of the Vocational Rehabilitation Act is to provide rehabilitation for* vocational purposes, subchapter VII added programs which target severely disabled persons who may not have potential for employment, to help them live more independently and out of the institutional settings. There are four parts to this subchapter:

Part A:[41] authorizes grants to assist states in providing comprehensive services for independent living designed to meet the needs of individuals whose disabilities are so severe that they do not presently have the potential for employment but may benefit from vocational rehabilitation services which will enable them to live and function independently.

Services to be included are:

- Counseling services;
- Housing incidental to the purpose of this section;
- Appropriate job placement services;
- Transportation;
- Attendant care;
- Physical rehabilitation;
- Therapeutic treatment;
- Needed prostheses and other appliances and devices;
- Health maintenance;
- Recreational services;
- Services for children of preschool age; and

- Appropriate preventive services to decrease the needs of individuals assisted under the program for similar services in the future.

Part A requires the state agency (in this case the state Vocational Rehabilitation Division of DHS) to develop a plan.[42] The division has adopted its Three-Year State Plan for the Independent Living Rehabilitation Services Program Under the Rehabilitation Act of 1973, as Amended for Fiscal Year 1991 to Fiscal Year 1993.[43] Among other items, the services available under the plan include:

- Counseling services;
- Physical and mental restoration services;
- Transportation;
- Interpreter services for individuals who are deaf;
- Reading services and other services for individuals who are blind;
- Recreational services;
- Services to family members of an individual with severe handicaps if necessary for improving the individual's ability to live and function more independently, or the individual's ability to engage or continue in employment;
- Vocational and other training services;
- Referral services;
- Telecommunications, sensory and other technological aids and devices; and
- Any other vocational rehabilitation services available under the state plan for vocational rehabilitation services under Title I of the Act and 34 CFR part 361 which are appropriate to the independent living rehabilitation needs of an individual with severe handicaps; and modifications to client's vehicles; and minor modifications to clients' residences.

Part A also establishes a State Independent Living Council.[44] The Council is appointed by the Governor and its purpose is to address the independent living needs of persons with disabilities. Specifically, the State Independent Living Council is required to provide guidance to various entities and to address the needs for independent living services and programs for the disabled in the State. It is distinct from the Commission on Persons with Disabilities which is a clearinghouse of information and a liaison to a Presidential

Commission for all issues, laws, and programs dealing with the disabled, not just independent living issues or the Vocational Rehabilitation Act. The Council developed a five-year plan for Hawaii in reference to addressing the independent living needs of persons with disabilities. The Council does not undertake any functions or programs exclusively for quadriplegics.

Purpose of the five-year plan is:

(1) To provide guidance to the Council in developing system advocacy positions for community options development; and

(2) To inform other community agencies of the independent living goals of the Council to encourage further networking.[45]

The plan listed eleven issue areas with the underlying rationale for that issue area and the needed action steps to achieve the goals as well as the agencies targeted to support and implement the action steps. The issue areas are as follows:

- Housing and Residential Services;
- Transportation;
- Employment;
- Independent Living Skills;
- Accessibility;
- Personal Assistance Services;
- Education;
- Peer counseling;
- Benefits;
- Disability Awareness;
- Technology and Equipment.[46]

Hawaii Centers for Independent Living

Part B of Subchapter VII [47] establishes and funds independent living centers in each state. In Hawaii, the center is a private, non-profit center called the Hawaii Centers for Independent Living (HCIL) with branches on Maui, Kauai, and two on the Big Island. Part of the funding for these centers comes directly from the federal government through the Rehabilitation Services Administration of the United States Department of Education. The remainder comes from private funding and contracts with the State. The Center provides the following services:

1. Skill training for help in living independently;

2. Transportation;

3. Peer counseling;

4. Attendant referral: help in hiring, training, and managing personal care attendants;

5. Housing: assistance in obtaining housing;

6. Assistance in obtaining benefits for which the disabled are entitled on the federal, state, and local level; and

7. Advocacy.[48]

Part C of this subchapter addresses programs for older, blind individuals and Part D contains general provisions which currently include an advocacy provision.

Institutional Programs Under Medicaid

Although there have been programs with the purpose of aiding disabled persons, including quadriplegics, to live independently in the community, many quadriplegics are housed in some type of institutional facility.

Presently, Medicaid pays for disabled persons who require certain levels of care and who cannot live independently to live in different types of care facilities. Title XX of the Social Security Act[49] allows funding to be paid for care homes. However, according to Dr. John A. Sheedy, Medical Consultant to the Department of Human Services (DHS), Health Care Administration Division, Health Care Authorization Branch, care homes generally do not accept quadriplegics because they require a great deal of attention. For example, strong handlers are often needed to lift them out of bed.[50] Funds administered by DHS often pay for

quadriplegics to reside in nursing homes. There are two types of nursing facilities: skilled nursing facilities (SNF) and intermediate care facilities (ICF). There are also intermediate care facilities for mentally retarded individuals (ICF-MR). As previously mentioned, it is possible for a person to be a quadriplegic mentally retarded individual but programs for the developmentally disabled and mentally retarded are subject to a different set of laws and requirements and are beyond the scope of this study.

The difference between an SNF and an ICF is the difference in the level of care. In an SNF, the staff provides daily nursing care. In an ICF, there is at least one licensed nursing person on staff but there is no provision for daily nursing services.[51] If a person is receiving Medicare, that program will provide funding in a nursing facility for 100 days. At the end of that period, the individual either is under private care or another program such as the DHS Medicaid program. Dr. Sheedy estimates that 85 to 90 percent of all persons in nursing homes today are funded in some manner through DHS.[52]

The Commission on Persons with Disabilities

The Commission on Persons with Disabilities provides informational services to the public in general, including the disabled. It is also available as an informational source to the different agencies and other organizations working with the disabled population.

The Commission is the Hawaii liaison to the President's Committee on Employment of People with Disabilities. It was created by the state legislature as part of Act 204, Session Laws of Hawaii 1977,[53] for the following purposes:

1. To advocate and promote the full integration of persons with disabilities into society; and

2. To serve as a clearinghouse of information.

The Commission is often a source for other agencies and organizations to come to for information regarding the disabled.[54] The Commission is part of the Department of Health for administrative purposes,[55] and created a Plan of Action for 1992-1995 to establish guidelines as to how it will operate.

The purpose of the plan is to formalize the Commission's policy statements in terms of philosophy, mission, goals, and objectives, and to set forth the action steps by which the staff will implement those goals and objectives.[56] The plan describes the philosophy of the Commission; includes a mission statement and a goal statement; and describes the Commission's objectives on the following issues:

- Education and Training;

- Employment;
- Transportation Facilities and Means;
- Community-Based Support Services and Independent Living;
- Housing Units and Residential Services;
- Civil Rights and Advocacy;
- Future Planning;
- Assistive Technology Devices and Services. [57]

The plan also lists the "action steps" of activities which the Commission will undertake in each of the above categories as well as general action steps.[58]

In the general action steps, number 8, the Commission will "[a]ssist existing data collection agencies to conduct statistical, demographic, and needs assessment studies of the population of persons with disabilities in Hawaii... (FY 92-93)."[59] In the area of housing units and residential services, among other things, the Commission plans to "[s]upport State and County administrative action or legislation, as needed, for funding for additional housing units and residential services for persons with disabilities. (FY 92-93; Ongoing)"[60] The plan does not list advocating centers or residential facilities for any specific group of persons with disabilities.

Developmentally Disabled/Mentally Retarded

Disabled persons who have developmental disabilities receive services through a set of programs which are distinct from those available to other disabled populations. These programs will be listed but not covered in depth as they are beyond the scope of this study.

As previously mentioned, some adults who are quadriplegic either:

(1) Have been quadriplegic since childhood due to a developmental disability and thus are classified as adults with a developmental disability; or

(2) Became quadriplegic but have as their primary disabling condition a developmental disability. Persons with developmental disabilities including the mentally retarded usually have been tracked and given training as children through agencies serving the disabled.

The federal definition of developmental disability is: "a severe, chronic disability of a person 5 years of age or older which is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the person attains age 22; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care; (ii) receptive and expressive language; (iii) learning; (iv) mobility; (v) self-direction; (vi) capacity for independent living and (vii) economic self-sufficiency; and reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are of a lifelong or extended duration and are individually planned and coordinated.[61]

The state Department of Education has extensive programs for disabled children.

The state Department of Health houses the Developmental Disabilities Division which has two branches that provide services to persons with developmental disabilities: the Community Services for the Developmentally Disabled Branch and the Waimano Training School and Hospital. The Department of Health devised a Plan for Services for Persons with Developmental Disabilities and/or Mental Retardation 1990-1994. The plan describes the goals the Department has for the DD/MR population as well as the organization of the Department and the services provided.[62]

Summary

With the exception of some areas, such as programs for the hearing or visually impaired, it can be seen from this overview of programs and services available to quadriplegics that the general approach to providing assistance has generally been one of *providing for quadriplegics as members of larger populations rather than isolating or singling* them out for special treatment. The Bureau was not able to locate any programs designed or operated solely for the benefit of quadriplegics. The thrust of modern programs targeting this general disabled population has been to encourage them to live independently, although institutional programs are still utilized. Quadriplegics can live independently in the community by utilizing programs available to low-income persons in general such as the welfare programs and rent subsidy programs, and by utilizing programs which have been created to encourage independent living on the part of the disabled population in general, such as the CLTCB programs, Social Security benefits for the disabled, the anti-discrimination housing requirements and the independent living programs in the Vocational Rehabilitation Act. This approach of aiding the general disabled population to live independently appears to be consistent with the Independent Living Movement discussed in the previous chapter. Accordingly, it should be noted that any program or service intended to benefit quadriplegics only, and solely for the reason of their being quadriplegic, would generally run against the grain of the system for providing social services in this country and this State.

ENDNOTES

1. Correspondence from John Sheedy, M.D., Medical Consultant, Health Care Administration Division, Health Care Authorization Branch, Department of Human Services, November, 1992.

2. Section 17-1370-31, Hawaii Administrative Rules, (Department of Human Services).

3. Section 17-744-68, Hawaii Administrative Rules, (Department of Human Services). (Currently being revised).

4. U.S., Department of Health and Human Services, Social Security Administration, SSI, Supplemental Security Income, SSA Publication No. 05-11000 (Washington: U.S. Government Printing Office, 1992), p.3.

5. Ibid.

6. U.S., Department of Health and Human Services, Social Security Administration, Disability, SSA Publication No. 05-10029 (Washington: U.S. Government Printing Office, 1992).

7. 24 C.F.R. sec. 882, as cited in an interview with Raymond Gota, United States Department of Housing and Urban Development, Honolulu office, November 9, 1992.

8. 24 C.F.R. sec. 887; Gota interview.

9. 24 C.F.R. sec. 882; Gota interview.

10. 29 U.S.C.A. sec. 794 (1992).

11. 42 U.S.C.A. sec. 3601 et seq. (1992).

12. Hawaii Rev. Stat., sec. 103-50 (1992).

13. 42 U.S.C.A. sec. 12101-12213 (1992).

14. 24 C.F.R. 8.23.

15. Telephone interview with Frank Johnson, Environmental Protection Specialist, United States Department of Housing and Urban Development, Honolulu office, December 21, 1992.

16. 42 U.S.C.A. sec. 5301 (c) (1992).

17. Ibid.

18. 42 U.S.C.A. sec. 8013 et seq. (1992).

19. Interview with Jill Hurt, Housing Development Director, United States Department of Housing and Urban Development, Honolulu office, November 9, 1992.

20. 12 U.S.C.A. sec. 1715l et seq. (1992).

21. Hurt interview.

22. 12 U.S.C.A. sec. 1715v et seq. (1992).

23. Ibid.

24. Hurt interview.

25. Haw. Rev. Stat., sec. 201E-190 et seq. (1992).

26. Annual Report, Community Long Term Care Branch, Department of Human Services, State of Hawaii (Honolulu: 1991), p. 4.

27. 42 U.S.C.A. sec. 1396n(c) (1992).

28. Community Long Term Care Branch Annual Report, p. 4.

29. Ibid., pp. 11-12.

30. Interview with Leslie Tawata, Program Specialist, Nursing Home Without Walls program, Community Long Term Care Branch, Department of Human Services, October 28, 1992.

31. Community Long Term Care Branch Annual Report, p. 11.

32. Tawata interview, October 28, 1992.

33. Community Long Term Care Branch Annual Report, p. 14.

34. Ibid., p. 14.

35. Telephone interview with Linda Chun, Assistant Program Administrator, Adult Services Staff, Family and Adult Services Division, Department of Human Services, November 24, 1992.

36. Ibid.

37. Section 17-1419-S, Hawaii Administrative Rules, (1992).

38. 29 U.S.C.A. sec. 701 et seq. (1992).

39. 29 U.S.C.A. sec. 796 et seq. (1992).

40. 29 U.S.C.A. sec. 796 (1992).

41. 29 U.S.C.A. sec. 796 et seq. (1992).

42. 29 U.S.C.A. sec. 796d (1992).

43. Hawaii, Department of Human Services, Three-Year State Plan for the Independent Living Rehabilitation Services Program Under the Rehabilitation Act of 1973, as Amended, FY 1991-FY 1993 (Honolulu: 1990), pp. 6-8.

44. 29 U.S.C.A. sec. 796d-1 (1992).

45. Hawaii, State Independent Living Council, Five Year Plan, December 11, 1989 (Honolulu: 1989), p. 2.

46. Ibid., pp. 3-20.

47. 29 U.S.C.A. sec. 796e et seq. (1992).

48. Hawaii Centers for Independent Living, Independent Living Skills (Honolulu: Hawaii Centers for Independent Living).

49. 42 U.S.C.A. sec. 1397(4) (1992).

50. Interview with Dr. John A. Sheedy, Medical Consultant, Health Care Authorization Branch, Health Care Administration Division, Department of Human Services, September 2, 1992.

51. Section 17-1370-31, Hawaii Administrative Rules, (1992).

52. Sheedy interview.

53. Hawaii Rev. Stat., sec. 348E-1 et seq. (Suppl. 1992).

54. Interview with Deborah Jackson, Program Specialist V, Commission on Persons with Disabilities, August 20, 1992.

55. Hawaii Rev. Stat., sec. 348E-2 (1992).

56. Hawaii, Commission on Persons with Disabilities, Plan of Action, 1992-1995 (Honolulu: July, 1992), p. 2.

57. Ibid., pp. 3-13.

58. Ibid., p. 14.

59. Ibid.

60. Ibid., p. 20.

61. 42 U.S.C.A. sec. 6001 (1992).

62. Hawaii Department of Health, A Plan for Services for Persons with Developmental Disabilities and/or Mental Retardation, 1990-1994 (Honolulu: 1990).

Chapter 4

STATISTICAL INFORMATION ON THE NUMBER OF QUADRIPLEGICS IN HAWAII

House Resolution No. 185 requested the Bureau to determine the number of quadriplegics residing in Hawaii. While this might appear to be a fairly straightforward undertaking, the reality is in fact very much the opposite. There is not much information available on the number of quadriplegics in Hawaii if for no other reason than that no individuals or entities appear to have any particular reason to obtain and maintain a count.

Viewed broadly, the national movement for physically disabled has concentrated on a relatively few major disability groups, persons disabled by: (1) spinal cord injury; (2) muscular dystrophy; (3) cerebral palsy; (4) multiple sclerosis; (5) postpolio disablement. It seems that the movement does not group the disabled by the category "quadriplegic".[1]

The five listed groupings are organized around different causes of disabilities. Quadriplegia is not the factor that causes a disability--it is the symptom, the disability itself. Accordingly, quadriplegics are distributed among the five groups because any of those causes of physical disabilities could result in a person becoming a quadriplegic. Persons and entities who work with individuals in a particular disability group would work with or provide services to all those suffering from the same source of disability whether they are quadriplegic, paraplegic, or suffer a lesser degree of disability.

In attempting to ascertain any type of statistical information on the number of quadriplegics residing in Hawaii, or even the United States in general, the Bureau contacted a number of agencies and reviewed a survey to see what type of statistical information, if any, was maintained with respect to quadriplegics. The following organizations responded that they did not keep statistics on quadriplegics:

1. Department of Health, State of Hawaii, Office of Health Status Monitoring.

2. Department of Business, Economic Development, and Tourism, State of Hawaii, Statistics Branch. There were no questions on the 1990 United States Census regarding specific handicaps. The United States Bureau of the Census affirmed that the Bureau does not have data on the number of quadriplegics residing in the United States or Hawaii.[2]

3. Department of Health, State of Hawaii, Children with Special Needs Division. The Division does not keep statistics on quadriplegics. Rather, the disabled

are grouped according to their condition such as cerebral palsy, multi-handicapped, heart condition, and so forth.

4. Department of Health, State of Hawaii: Developmental Disabilities Division.

5. Disability Statistics Program, funded by the National Institute for Disability and Rehabilitation Research: No data specifically on quadriplegics. The clearinghouse has unpublished data from a 1990 survey on quadriplegics, paraplegics, and hemiplegics for the United States: 119,00 or approximately 0.4 percent of the total population.

The U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, publishes a series called Vital and Health Statistics.[3] One of the issues was devoted to "Impairments Due to Injuries: United States, 1985-87", published in August, 1991.[4] This report presented "[n]ational estimates of the average annual prevalence of selected impairments due to injuries in the civilian noninstitutionalized population of the United States..."[5] The data did not isolate quadriplegia, rather a larger group was used: "paralysis, complete or partial, of extremities or parts of extremities."[6] This category was too broad to be of much use because it would include anyone who was at least partially paralyzed in one of the extremities.

In attempting to get statistical information on the number of quadriplegics who received some type of assistance as children, specifically those who are considered developmentally disabled, several organizations in Hawaii were contacted.

Shriner's Hospital for Crippled Children, Honolulu Unit, is a pediatric orthopedic hospital. It provides medical care to children afflicted with a variety of orthopedic deformities, diseases and injuries, including clubfoot, scoliosis, spina bifida and orthopedic problems associated with polio and cerebral palsy. It provides care at no cost to children under 18 years of age with a treatable orthopedic condition when their parents cannot afford the cost of such care. The hospital responded that they do not keep statistics on the number of quadriplegic children who are residents of Hawaii and who have been treated at the hospital. The hospital serves other populations from the Pacific Basin area in addition to children in Hawaii.[7]

Kapiolani Medical Center for Women and Children provides occupational therapy, physical therapy, speech/language therapy, audiology and rehabilitation nursing for children who may be quadriplegic. The center reported that it treated one spinal cord injured quadriplegic who was a child in the ten-year period from 1982 to 1991. This child was also known to the Rehabilitation Hospital of the Pacific.[8]

The Multiple Sclerosis Society of Hawaii reported that they do not keep statistics on quadriplegics they serve, but estimates that ten percent of their statewide population of 307 is quadriplegic.[9] The majority of their clients, 219, live on Oahu.

United Cerebral Palsy of Hawaii is established to affect positively the lives of those who have cerebral palsy and other similar service needs. At least 95 percent of the group's target population is developmentally delayed. The organization does provide services to other developmentally delayed populations depending on how the service is funded. They do not assess their clients according to whether they are quadriplegic, and therefore have no statistics on the number of quadriplegics they serve. The organization's director estimates that not more than 10 to 20 percent of the total population of 330 served by the organization is quadriplegic.[10]

Waimano Training School and Hospital is a division of the Department of Health and provides services, including residential services, to persons with mental retardation and other developmental disabilities. Mike Tamanaha, Training Section Administrator, reported that the hospital does not keep statistics on their quadriplegic population, but estimated that 40 to 50 percent of their residential population is quadriplegic.[11] The total number of clients in their residential program is 101. Therefore, there are at least 40 to 50 mentally retarded or developmentally disabled quadriplegics in the facility.

No response was received from the Muscular Dystrophy Association of Hawaii.

The Easter Seals Society deals primarily with developmentally delayed children and adults, including those with mobility impairments. The program director for Home and Community-Based Services estimates there are four quadriplegics out of approximately 35 clients that they serve.[12]

An additional group was contacted that is unrelated to the DD/MR population. The House, Inc., provides residential services for the chronically mentally ill. The organization's director estimated that there is a minute demand for services for quadriplegic mentally ill persons, not more than one percent of their population of approximately 87.[13]

AVAILABLE STATISTICS

A two-year study of spinal cord injury in Hawaii was undertaken by the Pacific Basin Rehabilitation Research and Training Center and The Rehabilitation Hospital of the Pacific using the clients at the Rehabilitation Hospital of the Pacific (REHAB). REHAB is an acute care hospital which specializes in physical rehabilitation. In order to be admitted to the hospital, a patient has to: (1) have rehabilitation potential; (2) be medically stable; (3) be able to do physical therapy and occupational therapy; (4) have a viable discharge plan; (5) need an

interdisciplinary team, nursing, and a rehabilitation doctor.[14] REHAB is not a nursing facility as it provides short-term care only. In this two-year study, 59 persons were treated for spinal cord injury at REHAB. Three were from the Pacific Basin area and 56 were from Hawaii. The study did not include patients that were transient or patients on a specific, managed-care insurance plan that does not pay for inpatient rehabilitation outside of its hospital system. Of the 59 persons, 16.2 percent were high quad and 45.9 percent were low quad.[15] Total percentage of the spinal cord injured who were quadriplegic was 62.1 percent.[16] Thus, it is apparent that a substantial number of persons who have a significant spinal cord injury are quadriplegics.

REHAB also supplied the Bureau with an unduplicated count of quadriplegics living in the State who have been admitted as inpatients to REHAB from 1981-1992. This includes neurologically complete and incomplete spinal cord injuries at level T1 and above.[17] According to REHAB very few of the patients are admitted for congenital disabilities.[18]

1992*	1991	1990	1989	1988	1987	1986	1985	1984	1983	1982	1981
8	21	38	19	26	23	26	26	23	32	35	25

*1992: discharges through 06/30/92

There have been 19 to 38 new quadriplegics admitted to REHAB for the past 11 years from 1981-91. The average number is 26.73 new quadriplegics per year. The medical consultant to the DHS, who helps administer the long-term care programs for quadriplegics, believes that most adult quadriplegics in Hawaii are treated at REHAB at one time or another. Of these, he also believes that only a few are developmentally disabled.[19]

The Community Long Term Care Branch (CLTCB) of DHS whose services were previously described in Chapter 3 stated that there were 61 quadriplegics in their program last year. The people are quadriplegics who are integrated into the community and not living in an institutional setting, and are receiving financial help from DHS.[20]

It is apparent that no one has done a survey or even keeps track of the number of quadriplegics who are currently residing in Hawaii. It appears that the greatest number of quadriplegics occurs in the spinal cord injured group rather than the developmentally disabled/mentally retarded group. On one extreme, it is known that there are an estimated 119,000 paraplegics/quadriplegics/hemiplegics residing in the United States as a whole.[21]

Simply adding the estimates provided by the Hawaii agencies and organizations discussed earlier, and using the highest estimate where a range was given, would produce a figure of 213 individuals without including the figures from REHAB. If the REHAB average of 27 new cases a year is arbitrarily multiplied by 30 to cover the 30-year period, the numbers generated by this group would total 810 adding this figure to that obtained for the other agencies and organizations would produce a grand total of a little over 1,000 quadriplegics.

This number is at best, however, a very rough estimate because there is no way to know if and how many individuals have been double or multiply counted (if they receive services from more than one organization), the number who may have died or moved away, or moved to Hawaii from elsewhere.

It can also be estimated that the quadriplegic population in the spinal cord injured group in Hawaii is presently growing at a rate of 26 to 27 new cases each year. However, it cannot be estimated from these figures how many are residing in Hawaii as some of them may have been placed in facilities in the continental United States.

In a more specific context, the Department of Human Services is presently attempting to survey those persons who receive support from DHS who can be identified through departmental medical records as being quadriplegic.[22] This survey may provide valuable information on a population who can only be identified through the Department's own confidential records.

ENDNOTES

1. This text was published in 1983, but it is apparent from the attempts made to gather statistical information on quadriplegics that this has not changed much. Gerben DeJong, "Defining and Implementing the Independent Living Concept", Independent Living for Physically Disabled People, ed. Nancy Crewe and Irving Zola (California: Jossey-Bass Publishers, 1983), p. 6.

2. Memorandum from Jack McNeil, Special Assistant, United States Bureau of the Census, Housing and Household Economic Statistics Division, to Gaye Miyasaki, Researcher, Legislative Reference Bureau, October 8, 1992.

3. U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, Vital and Health Statistics (Hyattsville, Maryland: Department of Health and Human Services).

4. U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control, National Center for Health Statistics, Vital and Health Statistics, Series 10, No. 177: Data from the National Health Survey, Impairments Due to Injuries: United States, 1985-87, DHHS Publication No. (PHS) 91-1505 (Hyattsville, Maryland: Department of Health and Human Services, August, 1991).

5. Ibid., p. 1.

6. Ibid., p. 5.

7. Written response to questionnaire, Laurine Lum, Medical Social Worker, Shriner's Hospital for Crippled Children, Honolulu Unit, October 31, 1992.

8. Written response to questionnaire, Kitty O'Reilly, Director of Rehabilitation Services Department, Kapiolani Medical Center for Women and Children, October 31, 1992.

9. Written response to questionnaire, Debbie Ellison, Chapter Services Director, November 4, 1992; telephone interview with Debbie Ellison, December 18, 1992.

10. Interview with Donna Fouts, Director, United Cerebral Palsy Association of Hawaii, June, 1992.

11. Telephone interview with Mike Tamanaha, Training Section Administrator, Waimano Training School and Hospital, Department of Health, State of Hawaii, December 21, 1992.

12. Telephone interview with Kathleen L. English, Director, Home and Community Based Services, Easter Seals Society of Hawaii, December 18, 1992.

13. Written response to questionnaire, Director, The House, Inc., October 13, 1992.

14. Interview with Steve Forer, Vice President of Patient Care, Rehabilitation Hospital of the Pacific, August 4, 1992.

15. "High quad" and "low quad" designate where the break in the spine is. In a "high quad" the break is higher toward the neck and is more likely to have a more pervasive effect on body functioning.

16. "Traumatic Spinal Cord Injury in Hawaii", Hawaii Medical Journal, February, 1991, p.44.

17. "Neurologically complete and incomplete" describes how extensively the spinal cord was injured; whether it was completely damaged or partially damaged. "Level T1 and above" describes the level of the spine at which the damage occurred.

18. Letter from Virginia Joseph, Health Information Systems Specialist, Clinical Information Department, Rehabilitation Hospital of the Pacific, to Gaye Miyasaki, Researcher, Legislative Reference Bureau, July 1, 1992.

19. Telephone interview with Dr. John Sheedy, Medical Consultant, Health Care Administration Division, Health Care Authorization Branch, Department of Human Services, July 29, 1992.

20. Interview with Leslie Tawata, Program Specialist, Nursing Home Without Walls Program, Community Long-Term Care Branch, Health Care Administration Division, Department of Human Services, October 28, 1992.

21. Telephone interview with Julianna Cyril, Project Assistant, Disability Statistics Program, Institute for Disability and Rehabilitation Research, October 15, 1992.

22. Telephone interview with Dr. John Sheedy, Medical Consultant, Health Care Administration Division, Health Care Authorization Branch, Department of Human Services, November, 1992.

Chapter 5

RESIDENTIAL PROGRAMS

I. Survey of Residential Settings on the Continental United States

House Resolution No. 185 asked whether a center or an independent living project should be established for quadriplegics in Hawaii. It was determined that there is a non-residential center serving the disabled in general: the Hawaii Centers for Independent Living (HCIL) with branches on Oahu, Maui, Kauai, and two on the Big Island. As described more fully in Chapter 3, HCIL provides services that aid the disabled in living independently outside of institutional settings. The centers do not provide residential facilities. Therefore, the Bureau concentrated its efforts on obtaining information on residential facilities.

A survey was undertaken by the Bureau in order to obtain information on programs that provide residential facilities for quadriplegics both on the continental United States and in Hawaii. The surveys attempted to determine what types of residential settings existed (such as whether the setting is transitional or permanent), the percentage of quadriplegics in the residential setting, the costs of constructing or renovating the facilities and of staffing and running them, the sources of funding both for the construction and staffing of the facilities, the services provided in the facilities and the care needs of the quadriplegic population. The survey of the residential settings in the continental United States revealed that there was a variety of ways in which a residential setting could be financed, constructed and staffed, providing several models of residential settings. The survey of residential settings in Hawaii provided information on the sources of funding, the manner in which the setting is structured, as well as information on costs.

Independent Living Research Utilization project is a national center for information, training, research, and technical assistance in independent living. Its goal is to expand the body of knowledge in independent living and to improve the utilization of results of research programs and demonstration projects in this field. It is a program of the Institute for Rehabilitation and Research, a nationally recognized, free-standing rehabilitation facility for individuals with physical disabilities.

Since ILRU was established in 1977, it has developed a variety of strategies for collecting, synthesizing, and disseminating information related to the field of independent living. The majority of the staff consists of disabled people, and serve independent living centers, state rehabilitation agencies, federal and regional rehabilitation agencies, consumer organizations, rehabilitation service providers, educational institutions, medical facilities, and other organizations involved in the field, both nationally and internationally.[1]

The ILRU project provided the Bureau with a list of residential settings for the disabled in the United States. A questionnaire (see Appendix B) was sent to 50 organizations from a list compiled by the ILRU as well as a few others that were referred by persons involved in the field that were reputed to have residential programs for the disabled. The list of organizations surveyed is attached as Appendix C. Twenty-four of the organizations responded that they in fact do not operate or no longer run residential programs. Five responded that they operate residential programs but do not include quadriplegics. Three did not respond, three questionnaires were returned with no forwarding address and fifteen responded that they operate some type of residential program that includes quadriplegics.

Table 1 organizes the responses received from the organizations that operate residential programs which include quadriplegics.

Five organizations run both permanent and transitional residential programs. Seven run programs that are transitional only and two run programs that are permanent only. One organization, the Space Coast Disability Rights Association in Orlando, Florida, recently built their facility and are currently attempting to determine how it will be used. The organization provided no other information, and therefore could not be included in the table.

All programs serviced populations other than quadriplegics and three designated themselves as ICF-MR (intermediate care facility for mentally retarded adults). The range of quadriplegics currently being served ranged from 0 percent to 80 percent of the resident population, with the average being 45 percent.

The total number of clients served in the residential setting ranged from 4 to over 200 with the average number being 40. This average is somewhat skewed, however, as two of the programs served 150 individuals and over, while one facility served 62. The other 11 facilities ranged from 4 to 29 individuals served, with the average number of clients being 14.

All but two programs reported that their quadriplegic population needed some care with seven reporting that the level of care was attendant care only. Three programs reported that their clients must provide for their own attendant care; four provided attendant care only; five provided other types of care such as nursing, physician and therapy in addition to attendant care; one reported providing only skilled care such as nursing, physician and therapy; and one did not respond as to the type of care provided.

Table 1

RESIDENTIAL SETTINGS ON THE CONTINENTAL UNITED STATES

	Transi-tional	Perm-anent	Other Popula-tions	% Quads	Max. No. of Clients Served	Care Needs of Quads	Year Facility Built
Center for People with Disabilities Denver, Colorado	Yes		Yes	Currently 0%	9	Attendant care only	1950
Center for Independent Living of N.W. Florida, Inc. Pensacola, Fla.		Yes	Yes	50%	14	Attendant care, trans-portation, house-keeping	1980
Space Coast Disability Rights, Assoc. Orlando, Fla.	Currently attempting to determine how the facility will be used.						
North Idaho Center for Independent Living (Disability Action Center/NW) (ICF-MR) Moscow, ID	Yes	Yes	DD/MR	8.33%	24	Nursing	3-homes: 1983, 1985, 1991
Independent Living Options (housing only: must arrange for own attendants)		Yes	Yes	25%	28	Must get their own attendants	1982-1983
Boston Center for Independent Living Boston, MA	Yes		Yes	15-20%	15	Usually only attendant care	1988-1989
Community Support Services, Inc. (ICF-MR) Portland, ME	Yes	Yes	Yes	About 9%	Over 200	All levels	1984 & 1989
Sunrise Opportunities Maine	Yes	Yes	Yes	25%	12-15	Usually only attendant care	
Herndon House Austin, TX	Yes		Yes	20-30%	5	Attendant care	1983
Our Way, Inc. Little Rock, AR	Yes	Yes	Yes	10%	150	Nursing Care - Attendant Care	1979
Aberdeen Adjustment Training Center (DD) Aberdeen, SD	Yes		DD	Currently 0%	62		Group homes-varies
Viviente I Apartments San Jose, CA	Yes		Traumatic brain injury/ spinal cord injured	80%	29	Attendant care only	1990
Rehabilitation Services Augusta, GA	Yes		Yes	50%	6	Depends on level of injury	1990
Stratford Home Kansas City, MO	Yes	Yes	Head injury	25%	4	Attendant care	1992
Disabled Ability Resource Environment El Paso, TX	Yes		Yes	50%	6mo.-1yr. 4		1989

Table 1

RESIDENTIAL SETTINGS ON THE CONTINENTAL UNITED STATES
COSTS OF FACILITY

	Constructed	Renovated	HUD	State Funding	County Funding	Private Funding
Center for People with Disabilities Denver, Colorado		Yes	Sect. 202		Yes	Yes
Center for Independent Living of N.W. Florida, Inc. Pensacola, Fla.		Yes				Yes
Space Coast Disability Rights, Assoc. Orlando, Fla.	Currently attempting to determine how the facility will be used.					
North Idaho Center for Independent Living (Disability Action Center/NW) (ICF-MR) Moscow, ID				Yes	Possibly	Possibly
Independent Living Options (housing only must arrange for own attendants)	Yes		Sect. 202		Yes (land)	Yes
Boston Center for Independent Living Boston, MA		Yes	CDBG	Yes		
Community Support Services, Inc. (ICF-MR) Portland, ME				Yes		Yes
Sunrise Opportunities Maine	Yes		Sect. 202			
Herndon House Austin, TX		Yes	CDBG			Yes
Our Way, Inc. Little Rock, AR	Yes		Sect. 202			
Aberdeen Adjustment Training Center (DD) Aberdeen, SD	No information	No information	Funding no information			
Viviente I Apartments San Jose, CA	Yes		Sect. 202		Yes	Yes
Rehabilitation Services Augusta, GA		Yes	Funded under the state vocational rehabilitation plan.			Yes
Stratford Home Kansas City, MO	Already constructed accessible home which was purchased.					Yes
Disabled Ability Resource Environment El Paso, TX		Yes			Yes	

Table 1

RESIDENTIAL SETTINGS ON THE CONTINENTAL UNITED STATES
STAFFING

	Medicaid	Title VII	State	County	Private	Client Fees	Cost of Facility	Cost of Staffing and Running
Center for People with Disabilities Denver, Colorado	Yes				Yes		$400,000 most recent renovation	$150,000/yr.
Center for Independent Living of N.W. Florida, Inc. Pensacola, Fla.					Yes	Yes	No information	$110,000/yr.
Space Coast Disability Rights Assoc. Orlando, Fla.	Currently attempting to determine how the facility will be used.							
North Idaho Center for Independent Living (Disability Action Center/NW) (ICF-MR) Moscow, ID	Yes				Yes		No information	$1.5 million
Independent Living Options (housing only - must arrange for own attendants)						Yes	No information	
Boston Center for Independent Living Boston, MA	Yes				Yes		$1.6 million	$310,000 + maintenance
Community Support Services, Inc (ICF-MR) Portland, ME	Yes						12-person $480,000 2-4 person $210,000	12-person: $800,000 2-4 person: $360,000
Sunrise Opportunities Maine			Yes			Yes	$437,000	$200,000
Herndon House Austin, TX			Yes	Yes			$30,000	$150,000
Our Way, Inc Little Rock, AR	Yes and Medicare		Yes				$3.2 million	$550,000
Aberdeen Adjustment Training Center (DD) Aberdeen, SD	Yes and Medicare		Yes					
Viviente I Apartments San Jose, CA	Residents must provide own attendant care.						Unknown	$18,000
Rehabilitation Services Augusta, GA	Yes	Yes	Yes				$5,000	$237,450
Stratford Home Kansas City, MO	Yes				Yes		$62,000	approx. $38,924*
Disabled Ability Resource Environment El Paso, TX	Clients get own attendants.						County provides building at $1/mo.	

*Includes mortgage payment

Table 1

RESIDENTIAL SETTINGS ON THE CONTINENTAL UNITED STATES
SERVICES PROVIDED

	Nursing	Physician	Occupational Therapist (OT)	Physical Therapist (PT)	Speech Therapist	Personal Care Attendant
Center for People with Disabilities Denver, Colorado	Yes but not daily		Yes	Yes	Yes	Yes
Center for Independent Living of N.W. Florida, Inc. Pensacola, Fla.						Yes
Space Coast Disability Rights, Assoc. Orlando, Fla.	Currently attempting to determine how the facility will be used.					
North Idaho Center for Independent Living (Disability Action Center/NW) (ICF-MR) Moscow, ID	Yes	Yes	Yes	Yes		Yes
Independent Living Options (housing only: must arrange for own attendants)						
Boston Center for Independent Living Boston, MA	Yes	Yes	Yes			Yes
Community Support Services, Inc. (ICF-MR) Portland ME	Yes	Yes	Yes	Yes	Yes	Yes
Sunrise Opportunities Maine						Yes
Herndon House Austin, TX						Yes
Our Way, Inc. Little Rock, AR	Yes		Yes			Yes
Aberdeen Adjustment Training Center (DD) Aberdeen, SD						
Viviente I Apartments San Jose, CA						
Rehabilitation Services Augusta, GA						Yes
Stratford Home Kansas City, MO	Yes	Yes on-call	Yes as needed			
Disabled Ability Resource Environment El Paso, TX						

Source: Legislative Reference Bureau questionnaire.

The cost of staffing and running the facilities ran from $0 where the county provided the building and the clients found their own attendants and medical care to $1.5 million. However, the responses did not always distinguish whether their figures included payments on loans for the building and land. The cost of staffing and running the facilities varied greatly, depending upon the number of clients served, the type of care provided, how often it was provided, and in all probability, the cost of living in the particular area. Three programs charged the clients fees to defray the cost of staffing the programs, eight used Medicaid funds with two of the programs also using Medicare funds, five used private funds from grants and fundraising, five used state funds, one used Title VII (Vocational Rehabilitation Act) moneys, and one reported that the county donated the building for $1 per month. Programs often utilized several sources of funding such as state funds and private fundraising.

The cost of constructing or renovating the facilities ranged from $5,000 to $3.2 million. The organization reporting a cost of $3.2 million serviced 150 individuals. Rehabilitation Services in Augusta, Georgia, reported the $5,000 figure for a renovated building servicing six individuals and funded under the state vocational rehabilitation plan. The source of funding most often cited was the section 202 program under the Department of Housing and Urban Development (HUD).[2] As explained in Chapter 3, HUD previously made funds available (most often through low-interest loans) for housing for the elderly and disabled called "section 202" loans. Recent amendments have separated the two programs with section 202 funds now strictly for elderly, and section 811 funds for the disabled. The section 811 program basically provides outright grants to private non-profit organizations to build or renovate facilities to be used for the disabled for 40 years. The funding must be returned if and when the building is transferred to another entity that does not service the disabled. Other sources of funding were Community Development Block Grants also administered by HUD through the states and counties, state funding, county funding and private funding. Programs usually used a combination of funding. Four programs constructed their buildings, six programs renovated buildings, one purchased an already accessible building, and three did not respond to this question.

II. *Survey of Residential Settings in Hawaii*

The Bureau surveyed a group of residential programs in Hawaii in order to provide some information as to how such programs are structured and the costs involved. As the study progressed, organizations which dealt with the disabled were asked about any information they may have regarding residential programs for the disabled in Hawaii.

There are several organizations which run residential settings for their particular disability group in Hawaii. A questionnaire was sent to all organizations that were identified as having residential programs by the Hawaii Centers for Independent Living and the Department of Health's Waimano Training School and Hospital (see Appendix D). The Department of Housing and Community Development of the City and County of Honolulu also

provided the Bureau with a list of non-profit organizations running residential programs on city-owned land (see Appendix E). These programs, however, could include virtually any type of residential program ranging from programs for the mentally retarded or runaway youths to substance abusers. Time limitations prevented the Bureau from ascertaining whether these programs were for the disabled, much less available to quadriplegics. The listing was included, however, in recognition that other residential programs may be available to quadriplegics in addition to those mentioned.

The Waimano Training School and Hospital, was not included in the survey as it is an ICF-MR and is thus an institutional setting as opposed to a residential program. As an ICF-MR, it houses mentally retarded and developmentally disabled individuals. Most of the residential section of the facility was built in the 1960's using state funds. The facility currently houses 101 individuals of which 40 to 50 percent are quadriplegic.[3]

Table 2 is the table of organizations responding to the questionnaire. The questionnaire (copy attached as Appendix F) was sent to six organizations of which four responded.

All four ran residential programs that were both transitional and permanent. None currently have residents who are quadriplegic. Three received funding from HUD, section 202 loans. One of these also received state and private funding, and another of these also received private funding. The home run by United Cerebral Palsy is unique in that the building itself was built and donated by Gentry Companies, a private developer. Three of the groups had homes that were constructed with two groups subsequently renovating the homes, and one group had renovated homes.

Research Center of Hawaii runs nine homes for the mentally retarded. Six of them are designated as ICF-MR and three of them are group homes. Seven of the homes were built by the families who are the caretakers and will not be discussed. Two of the homes were financed through the section 202 program of HUD. Seventy-eight percent of all of the units are wheelchair accessible and the staffing is financed through Medicaid and private fundraising. The cost for the two HUD homes was $350,000 for the land and the two homes in 1983, with the cost of the land being $55,000 and the cost of the homes $295,000. The land was remnant land from the State that was not needed for a public works project. The two HUD homes presently service eight clients and the cost of the staffing is approximately $46,000 for each home per year, excluding the mortgage payments on the loan.

Table 2

RESIDENTIAL SETTINGS IN HAWAII

	Opportunities for the Retarded, Inc. Helemano Village (No quadriplegics)	The House, Inc. (4 projects)	Research Center of Hawaii 6 ICF-MR/3 Group Homes	United Cerebral Palsy Assoc. of Hawaii
Permanent Facilities	Yes	Yes	Yes	Yes
Transitional Facilities	Yes	Yes	Yes	Yes
Description of populations	Adult MR/DD	Chronically mentally ill adults	Mentally retarded	Developmentally disabled
Percent Quadriplegic	0%	0%	0%	0%
No. of Clients	36	87	36	5
Nursing Care				
Physician Care				
Occupational Therapy		Daily living, social and vocational skill		
Physical Therapy		Daily living, social and vocational skill		
Attendant Care			Yes	Yes
Year Built	1984	Various	1983 for 2 HUD homes	1987

Table 2

CONSTRUCTION OF FACILITIES

	Opportunities for the Retarded, Inc. Helemano Village (No quadriplegics)	The House, Inc. (4 projects)	Research Center of Hawaii 6 ICF-MR/3 Group Homes	United Cerebral Palsy Assoc. of Hawaii
Constructed	Yes		Yes	Yes
Renovated		Yes	Yes	Yes
Federal Funding				
HUD Funding		Sect. 202	Sect. 202	
State Funding		Yes		Yes
County Funding				Yes
Private Funding	Yes	Yes		Gentry donation
Other	Farmers' Home Administration Loan	AUW	Family caretaker	
Staffing	SSI, fundraiser, assistance from DHS	Mainly through State/private fundraisers	Medicaid; private fundraisers	Paid by clients with their assistance from DHS
% Wheelchair Accessible	100%	10%	78%	100%
Description of Building	1-story; 5-bdrm with kitchen and 3-bath			
Cost of Construction (9 homes)	$1.2 million		$350,000 for 2 HUD homes	Donation
Cost of Staffing	$500,000-$600,000 per year	$150,000 per project	$46,000/home	$1,200-$1,300 month per client

Source: Legislative Reference Bureau questionnaire.

Opportunities for the Retarded, Inc. Helemano Village has nine homes financed through the HUD section 202 program, Farmers Home Administration loans, and private sources.[4] The cost for the nine homes was $1.2 million, but the director was not able to provide the cost of each individual home. If the $1.2 million was allocated equally among the nine homes, the cost would be $134,000 each. The homes are each one-story, five-bedroom homes with a kitchen and three bathrooms. Together the nine homes serve 36 clients averaging four clients per home. One hundred percent of the homes are wheelchair accessible. The homes were built in 1984. The cost of staffing and running the program is $500,000 to $600,000 per year, which comes out to $56,000 to $67,000 per four clients or $14,000 to $17,000 per client per year.

REHAB is planning to build a transitional residential facility for the disabled which will also house families of patients at REHAB. The structure planned is a two-story facility with twenty units. The units will be one hundred percent wheelchair accessible and there will be an elevator. The estimated cost, not including the cost of the land, is $1.7 million.[5]

ENDNOTES

1. Independent Living Research Utilization Project, ILRU, Information (Houston: Independent Living Research Utilization Project, 1992).

2. The current citation for "section 202" is 12 U.S.C.A. sec. 1701q; however, it is only supportive housing for the elderly. Before 1990, it was a direct loan program for housing for the elderly and the disabled. After 1990, the program for the disabled was included in a different statute and became the "section 811" supportive housing for the disabled.

3. Telephone interview with Mike Tamanaha, Training Section Administrator, Waimano Training School and Hospital, Department of Health, State of Hawaii, December 21, 1992.

4. Telephone interview with Yvonne Custodio, Director, Opportunities for the Retarded, Inc. - Helemano Village, December 23, 1992.

5. Telephone interview with Millie Ng, Trauma Rehabilitation Program Manager, Rehabilitation Hospital of the Pacific as reported to her by Les Fujitake, Chief Operating Officer, Rehabilitation Hospital of the Pacific, December 22, 1992.

Chapter 6

FEASIBILITY OF A RESIDENTIAL SETTING

It is apparent from the overview of services that the national Independent Living Movement's goal of integrating the disabled into the community as opposed to keeping them in institutional type settings has had an effect on programs and services available to the disabled. The State and counties provide income sources and medical payments for indigent and low-income individuals who may be quadriplegics which aids them in remaining integrated in the community. The federal government through the Social Security programs provides other sources of entitlement programs for certain disabled persons. These funds from entitlement programs are separate from other sources of income that might be available to certain individuals such as workers' compensation, private insurance, or proceeds from personal injury suits.

The federal Vocational Rehabilitation Act as administered by the state Vocational Rehabilitation Division of Department of Human Services (DHS) provides programs to retrain the disabled in order to encourage them to remain employable. The CLTCB provides programs to help the disabled remain in the community as long as the cost is equal or less than the cost of institutionalizing them. Recent amendments to the federal Vocational Rehabilitation Act have established programs to help the severely disabled remain integrated into the community rather than institutionalized and has spawned, among other things, Hawaii's Centers for Independent Living which provides services to the disabled with the goal that they remain in the community as much as possible. Lastly, the most important ingredient in keeping the disabled in the community is accessible housing. Congress has enacted several pieces of legislation which culminated in the requirements that the county and state developers make five percent of their housing units handicapped accessible, and all developers of multi-family dwellings with a certain number of units must make their units handicapped adaptable. There is also a rent subsidy program which the disabled may utilize if they have a low income and the State has a housing alteration loan revolving fund program which makes low-interest loans available specifically for use by the disabled to make their homes handicapped accessible. The goals of the Independent Living Movement do not necessarily oppose residential programs for the disabled as long as the residential program fosters independent living. There are grant programs administered by HUD which can provide funding for residential settings. One avenue is through CDBG moneys and another is through the section 811 program. One residential setting in the continental United States was funded through the State's vocational rehabilitation division.

In order to determine the feasibility of a residential program, it is important to know the demand for services and whether a residential program would be cost effective. Not enough information has been kept regarding the quadriplegic population in Hawaii. Dr. John A.

Sheedy, Medical Consultant to the Department of Human Services, Health Care Administration Division, Health Care Authorization Branch, has targeted a population of quadriplegics that may benefit from a residential program. Dr. Sheedy believes that there are some quadriplegics who are currently being housed in either SNFs or ICFs who could be placed in a more independent setting with less skilled care such as a residential home of some sort.[1] Steve Forer, Director of the Rehabilitation Hospital of the Pacific (REHAB), stated that there currently are approximately four quadriplegics at REHAB on a maintenance program. REHAB is supposed to be for short-term care only to rehabilitate the disabled. REHAB is keeping these patients on a long-term basis simply because there is nowhere else for them to go.[2]

In order to determine how many quadriplegics are currently being supported by DHS in institutional settings that could be placed in a facility that provided less care (and therefore a greater degree of independent living), Dr. Sheedy is currently preparing and distributing a questionnaire to quadriplegics that DHS is supporting in Hawaii. He will additionally attempt to ascertain an estimate of the number of quadriplegics that DHS is supporting. This is an important initiative being undertaken by the department. First, the only means of identifying the individuals to be surveyed requires the use of confidential departmental records. Second, determining whether a quadriplegic is being housed in a setting that provides more skilled care than the individual needs, requires an assessment of that person's condition by a specialist in this field. Dr. Sheedy has prepared questions directed at making such a determination.[3]

Additionally, the Pacific Basin Rehabilitation Research and Training Center is a center established in 1984 under a Cooperative Agreement between the U.S. Department of Education, National Institute on Disability and Rehabilitation Research, and the John A. Burns School of Medicine of the University of Hawaii at Manoa. The center's goals are (1) to improve services to persons with handicaps through relevant rehabilitation research and training; and (2) to assist the coordination of rehabilitation services provided by a broad range of agencies and entities in the Pacific Basin. One of the things that the center is currently in the process of doing is a needs assessment of the disabled in Hawaii. The center could also do a needs assessment of the State's quadriplegic population, but the study would have to be funded by the State. In addition to a needs assessment, it is possible that if the quadriplegic population is growing at a rate of approximately 27 per year (if nothing else, from spinal cord injury cases treated at REHAB), the State may want to set up a registry to keep track of this population.

There is some available data on the cost of care of quadriplegics for purposes of ascertaining the cost-effectiveness of a residential program. The CLTCB stated that the average cost for care of quadriplegics in that program year was $14,703/year during fiscal year 1991-1992. An estimated 95 percent of that cost went to pay for personal care or other skilled attendants required, with the remainder being for case management, and some transportation and miscellaneous expenses.[4] By comparison, the cost of care of a

quadriplegic in an institutional setting varies depending on the level of care required. However, the average cost is $125/day if the person is in an ICF and $150/day if in an SNF. That amounts to an average of $45,625 per year for an ICF and $54,750 per year for an SNF. The figure of $14,703 from CLTCB does not include rental payments and general maintenance such as utility bills and food, whereas the cost figures for the ICF and SNF are all inclusive. To be cost effective as compared to the present program, the cost of placing the individual clients in the residential program would have to be less than $45,625/year for those quadriplegics relocated from an ICF, and $54,750/year for those quadriplegics relocated from an SNF.

A large portion of the cost of a residential setting is the cost of the facility itself. The figures available for institutions operating residential programs for disabled individuals in Hawaii are for two homes serving eight clients, built in 1983 at a cost of $350,000 for the land and the homes; and another project involving nine homes built in 1984 serving four clients per home at a cost of $134,000 per home. Rehabilitation Hospital of the Pacific is planning a two-story, twenty-unit residential facility at an estimated cost of $1.7 million for the facility alone.

Federal funding is available for the cost of a facility for a residential program for the disabled either through Community Development Block Grants which is administered by HUD through the counties, or by a section 811 grant from HUD.[5] The section 811 grant provides a grant to a private, non-profit organization for construction of facilities for a disabled group. The requirements are that the facility be run for the disabled for 40 years and that the non-profit group have a plan for services to be provided to the disabled. Also, HUD prefers that each grant be restricted to one particular type of disability (such as quadriplegics) but will grant variances.[6] A group applying for such a grant may want to combine quadriplegics with paraplegics, for example, but would have to apply for a variance to this requirement.

An alternative to building a residential facility would be to fund programs which currently help persons remain in the community such as the CLTCB.[7] In order for this plan to be feasible, there also needs to be sufficient housing in the community that is accessible to quadriplegics.

The three entities on Oahu which provide government-sponsored housing are the Department of Housing and Community Development of the City and County of Honolulu, the state Housing Finance and Development Corporation, and the Hawaii Housing Authority (HHA). Each agency provided figures as to the number of handicapped accessible units currently available and the projected number of units based on housing projects which are in the planning stage. The Department of Housing and Community Development currently has 19 handicapped accessible units available on Oahu and was not able to provide a projected amount.[8] The Housing Finance and Development Corporation now has 44 completed handicapped accessible units on Oahu, 27 on the Big Island, 38 on Maui, none on Kauai, 2 on the islands of Lanai and Molokai. Their projected number of accessible units as of the year 2000 are 339 on Oahu, 33 on the Big Island, 51 on Maui, 10 on Kauai, 0 on the islands of

Lanai and Molokai, and 2 miscellaneous statewide, for a total of 435 units. Some of these units may be double counted as they included units which were built in conjunction with either the HHA or the City and County of Honolulu.[9] The Hawaii Housing Authority lists 91 handicapped accessible units in the State in addition to nine units that can be used by wheelchair-bound persons in their homeless villages or homeless elderly projects. Projected units that can be used by wheelchair-bound persons are 15 units in elderly or family housing complexes and three to fifteen units in homeless villages.[10] If the quadriplegic population grows at a minimum rate of 27 per year (the average number of new cases treated at REHAB for the past eleven years as spinal cord injury cases, although Dr. Sheedy believes the bulk of quadriplegic clients are treated there), there will be at least 216 additional quadriplegics by the year 2000. In other words if the rate of new spinal cord injured quadriplegic cases arising each year holds steady for the next eight years, the number of new quadriplegic clients alone will equal about one-half the number of handicapped accessible housing units that the HFDC expects to have available for the entire disabled population. Accordingly, these quadriplegics will be competing with all other disabled persons seeking those handicapped accessible units. Additionally, low-income quadriplegics will have to compete with other low-income individuals for rent subsidies which are funded federally through HUD.

Finally, it is important to consider the arguments on both sides of creating a residential program for quadriplegics from those in the community and elsewhere who work with the disabled. Both Mark Obatake of the Hawaii Centers for Independent Living (HCIL) and the Commission on Persons with Disabilities do not favor a residential program for quadriplegics. Obatake feels that the focus of his organization has been to integrate disabled persons into the community as much as possible. He fears that a residential program might foster segregation and discrimination against the disabled which goes against what his organization has worked towards, and at worst, might create something of a "disability ghetto".[11] The Commission has provided an official statement on their position on a center or a residential program for quadriplegics as reiterated in their testimony on H.R. No. 185:[12]

> ...the Commission feels strongly that generic services which are available to all citizens whether they have a particular type of disability or not should be accessible to and available to persons with disabilities....
>
> This is not to infer that persons with quadriplegia do not have additional needs for specialized services. However, the Commission would caution the Legislature on the need for a specialized agency or program only for persons with quadriplegia. If the need is for better coordination of available services, or for better access to services then this should can [sic] be accomplished without creating another government entity.[13]

There are, however, different levels in which a person could be integrated into the community: skilled nursing facilities and care homes for example. This is in keeping with what the

authors of the text Independent Living for Physically Disabled People as referred to in Chapter 2 believe.

Those authors also delineated the differences in opinions generally about establishing residential programs:

> Some people hold that residential programs are institutional, segregated, and do not promote optimal normalization in the community. Others argue that they provide suitable alternatives to institutionalization for severely disabled people, that they represent one step on a continuum of independence, and that they need not necessarily be segregated;
>
> Some people argue that transitional programs are simply residential programs in disguise, that they are too much like traditional rehabilitation programs, and that they do little to insure the long-term support of severely disabled people in their communities. Others hold that transitional programs differ significantly from residential programs in that they force participants to move into the community after a specified period of time, or after the participants have met certain goals. They argue that transitional programs are much more cost-effective than other sorts of independent living programs and that they enable severely disabled people to live independently in their communities without the need for ongoing services other than those provided to the general population.[14]

Mark Obatake of HCIL pointed out that although a transitional residential program might be helpful to help ease a quadriplegic back into the community, practically speaking, such an effort may turn into a permanent setting because the reality is that it is difficult to move quadriplegics into the community because of a lack of accessible, affordable housing and difficulty with obtaining personal care attendants.[15]

Summary

The feasibility of a residential setting for quadriplegics depends in large part on the needs of quadriplegics. Because there were not sufficient data on quadriplegics in Hawaii that were readily available, it was not possible to do a needs assessment on that population for this study. The DHS has targeted a group of quadriplegics that are currently residing in institutional settings at state expense who may require less care. The Department is currently in the process of surveying these individuals and other quadriplegics receiving assistance from DHS as to their needs, and whether a residential program would be cost-effective. The two categories of cost involved in a residential setting would be the cost of the facility and the cost of staffing and running the facility. The Rehabilitation Hospital of the Pacific is currently

planning a residential facility on their grounds for limited purposes. Their estimate for the facility alone is $1.7 million for a two-story facility with twenty units and an elevator.

The current cost of institutionalizing quadriplegics is approximately $46,000 per person per year in an ICF and $55,000 per person per year in an SNF. In order to be cost effective, the cost allotted to each resident, including a proportional cost of the facility itself and the staffing and maintenance of the facility needs to be below these figures.

A possibly cost-effective alternative are the programs operated by the CLTCB, which reported an average cost of approximately $15,000 per year for services, primarily attendant care, for quadriplegics in their programs who are currently integrated into the community. To this figure, however, must be added costs for medical needs as well as the basic care needs such as food, rent, and utilities. There is currently a waiting list of approximately 200 individuals for the Nursing Home Without Walls program, forty individuals for the Non-medicaid Nursing Home Without Walls Program and twenty individuals for the Non-medicaid Personal Care Attendant program.[16]

ENDNOTES

1. Interview with Richard Isa, Administrator of Program and Policy, and Dr. John Sheedy, Medical Consultant, Department of Human Services, Health Care Administration Division, September 2, 1992.

2. Interview with Steve Forer, Vice President of Patient Care, Rehabilitation Hospital of the Pacific, July 30, 1992.

3. Telephone Interview with Dr. John Sheedy, Medical Consultant, Department of Human Services, Health Care Administration Division, November, 1992.

4. Interview with Leslie Tawata, Program Specialist, Nursing Home Without Walls Program, Community Long Term Care Branch, Department of Human Services, October 28, 1992.

5. 42 U.S.C.A. sec. 8013 et seq. (1992).

6. Interview with Jill Hurt, Housing Development, Director, United States Department of Housing and Urban Development, Honolulu Office, November 9, 1992.

7. Services not provided by CLTCB such as housing assistance, food, and utilities, are provided by the various sources described in Chapter 3, such as the public welfare and Social Security programs.

8. Memorandum from Hiromi Shiramizu, Housing Services Administrator, Department of Housing and Community Development, City and County of Honolulu, to Gaye M. Miyasaki, Researcher, Legislative Reference Bureau, November 10, 1992.

9. Memorandum from Michele Otaka, Housing Planner, Housing Finance and Development Corporation, Department of Budget and Finance, State of Hawaii, to Gaye M. Miyasaki, Researcher, Legislative Reference Bureau, November 27, 1992.

10. Letter from Mitsuo Shito, Executive Director, Hawaii Housing Authority, Department of Human Services, to Gaye M. Miyasaki, Researcher, Legislative Reference Bureau, November 6, 1992.

11. Interview with Mark Obatake, Director, Hawaii Centers for Independent Living, August 18, 1992.

12. Telephone interview with Debbie Jackson, Program Specialist V, Commission on Persons with Disabilities, as provided by Francine Wai Lee, Director, Commission on Persons with Disabilities, December 21, 1992.

13. Hawaii, Legislature, Richard Westover, Chairperson, Legislative Committee and Francine Wai Lee, Executive Director, Commission on Persons with Disabilities, Testimony to the House Committee on Health regarding House Resolution No. 185 and House Concurrent Resolution No. 173 requesting a study regarding the provision of specialized services for quadriplegics residing in the State of Hawaii, Sixteenth Legislature, March 24, 1992.

14. Lex Frieden, "Understanding Alternative Program Models", Independent Living for Physically Disabled People, ed. Nancy Crewe and Irving Zola (California: Jossey-Bass Publishers, 1983), p.66.

15. Obatake interview.

16. Telephone interview with Leslie Tawata, Program Specialist Nursing Home Without Walls Program, Community Long Term Care Branch, Health Care Administration Division, Department of Human Services, December 14, 1992.

Chapter 7

FINDINGS AND RECOMMENDATIONS

Findings

1. The growth and development in recent decades of the Independent Living Movement appears to have influenced federal legislation and in turn state and county programs to emphasize deinstitutionalization of the disabled and integration into the community.

2. Programs and services available to quadriplegics to provide the basic necessities of life include the entire range of public assistance and social service programs such as the federal Social Security programs, food stamps, medical assistance programs, rent subsidies, and community long-term care programs which include financial assistance for personal care attendants or skilled nursing attendants. These programs are targeted toward all disabled persons, or all lower income persons without regard to whether or not a person is a quadriplegic. Programs for the disabled generally focus on the cause of the disability, such as spinal cord injury or multiple sclerosis, rather than the outcome (e.g., quadriplegic, paraplegic). Accordingly, programs do not target quadriplegics simply because they are quadriplegic any more than they focus upon people who are left-handed or have red hair.

3. The goals of the national Independent Living Movement include residential settings that foster independent living. Federal programs that provide funds that may be used to establish these settings include Community Development Block Grants given to state and local government for their use as they choose provided it aids low to moderate income persons for neighborhood revitalization, and "Section 811" grants administered by HUD given to private, non-profit organizations for providing supportive housing for the disabled.

4. Fifteen out of 50 centers for the disabled contacted on the continental United States reported that they run some type of residential program for the disabled, either transitional, permanent, or both. Most programs used a combination of state, county and/or private funding and some type of federal assistance for the construction or renovation of the facility. The source of federal funding most often cited was HUD's former "section 202" program (which has currently been revised to be "section 811" supportive housing for the disabled). Funds for staffing and running the facilities were most often obtained through a combination of sources ranging from Medicaid and Medicare to charging the clients fees, with Medicaid being the most often cited program.

5. There is a dearth of information on the quadriplegic population in Hawaii. No agency or organization keeps track of all the quadriplegics in this State if only because there

is no reason to do so. Agencies and service organizations will keep records of their clients. The fact that a client is a quadriplegic may magnify a particular need, but there is otherwise no need to consider a quadriplegic client as being different from any other client who has that same need (e.g., food stamps or medicaid). To date, there does not appear to have been any agency or organization formed to assist only quadriplegics with any problem they might have.

However, it can be estimated that the number of quadriplegics in Hawaii is growing at the rate of at least 27 per year. This is a conservative estimate based solely on the spinal cord injured population treated at the Rehabilitation Hospital of the Pacific--but is believed to include the bulk of new cases each year.

6. Persons contacted in the field estimate that the quadriplegic population in the developmentally disabled and mentally retarded population is low--in the 10 to 20 percent range, and a study done at the Rehabilitation Hospital of the Pacific shows that approximately 60 percent of the spinal cord injured group is quadriplegic.

7. The developmentally disabled population is subject to a distinct branch of laws and programs. Under HUD's "section 811" program for supportive housing for the disabled, the mixing of disabled populations is not allowed without a variance.

8. The area most frequently identified as an area of need for the disabled population is accessible housing. The issue of accessibility is particularly pressing for quadriplegics who are generally more severely disabled. The Housing Finance and Development Corporation estimates it will have approximately 440-plus additional units that are handicapped accessible by the year 2000. Other agencies also operate and maintain handicapped accessible units but were not able to supply projections for new units. The projected new units are intended to be available to the entire disabled population. At present rates of increase, the number of spinal cord injured quadriplegics alone will grow by 27 per year for a total of 189 by the year 2000. While it is not likely that all will seek handicapped accessible units in HFDC projects, their numbers would be equal to 43 percent of the number of projected new units available for all disabled persons.

9. The Rehabilitation Hospital of the Pacific is planning a residential structure that is to be transitional and to house some of the patients at the hospital and their families.

10. The Department of Human Services' medical consultant believes there are at least some quadriplegics currently housed in nursing facilities at state expense who could potentially be housed in a residential facility with less skilled care. The cost of housing a patient in an intermediate care facility or skilled nursing facility falls in the range of approximately $46,000 to $54,000 per individual per year. The Department is presently attempting to ascertain the number of individuals receiving medicaid assistance who might be able to live in a more independent setting.

11. The average cost of maintaining an individual quadriplegic in one of the programs operated by the Department of Human Services' Community Long Term Care Branch is approximately $15,000 per year.

Recommendations

1. If the Legislature deems it necessary to identify quadriplegics in this State more clearly (for example, if the Legislature is contemplating additional programs or services directed solely to persons who are quadriplegic), then more detailed information on the quadriplegic population in Hawaii and their needs will be necessary. This could be obtained by directing the Department of Human Services (or alternatively the Department of Health) to serve as the lead agency in developing a needs assessment of the quadriplegic population, and appropriating funds for the agency to conduct the assessment either on its own, or through a contract with a private entity. The Pacific Basin Rehabilitation Research and Training Center (PBRRT) is a private organization established to assist agencies in providing services to the disabled. The PBRRT is presently conducting a needs assessment of the disabled population in general. A needs assessment of the quadriplegic population would probably cost in the vicinity of $20,000 to $40,000, depending upon the extent of information desired.

2. Consultations with a wide range of individuals and entities providing services to the disabled indicate a fairly strong consensus that accessible housing is the single area of greatest need not only among quadriplegics, but the disabled generally. Based on the limited information available, it is impossible to determine whether and the extent to which the need for housing is any greater among quadriplegics capable of living outside an institutional setting than any other segment of the disabled population, such as persons confined to wheelchairs who are not quadriplegics. Accordingly, it is impossible to say whether on the basis of need, the State should build residential facilities specifically for quadriplegics as opposed to other disabled persons.

3. Rather than focus on the needs of quadriplegics generally, the Legislature may be able to better promote the State's interests by focusing on the disabled population now receiving medical assistance from the State. The Department of Human Services is presently attempting to ascertain whether and the extent to which public funds are being used to house quadriplegic individuals in nursing facilities even though they could live in less restrictive (and less costly) settings. The Department should be directed to maintain this information on an ongoing basis and report regularly to the Legislature on the number of disabled individuals (quadriplegic and otherwise) who are capable of living in less restrictive settings (subject to appropriate medical guidelines) and the estimated cost-savings to the State if those less restrictive settings could be provided.

4. The question of building a residential facility for quadriplegics or any other segment of the disabled population should not be viewed in isolation. The cost of building and operating a residential facility can vary considerably depending upon a number of diverse factors including land acquisition costs and the mix of residents (which may affect the level of staffing required). While not mutually exclusive, alternatives exist to having the State build a residential facility. These alternatives include placing people through the programs of the Community Long Term Care Branch of the Department of Human Services, such as the Nursing Home Without Walls Program, and encouraging private non-profit organizations to build housing for the disabled with funds provided by the "Section 811" Program administered by the U.S. Department of Housing and Urban Development. The decision to have the State build a residential facility for quadriplegics or other disabled persons should not turn solely upon a need for housing, but whether the building of a particular facility will be the most cost-effective alternative in serving the need.

5. The Department of Human Services should be directed to develop a plan to:

(1) Continually identify those disabled individuals who are receiving state assistance who are capable within medical guidelines of living in less restrictive settings;

(2) Provide housing for those individuals in appropriate settings; and

(3) Encourage and assist private entities seeking to provide housing for the disabled to obtain federal or other funds to increase the supply of accessible housing.

APPENDIX A

HOUSE OF REPRESENTATIVES
SIXTEENTH LEGISLATURE, 1992
STATE OF HAWAII

H.R. NO. 185

HOUSE RESOLUTION

REQUESTING A STUDY REGARDING THE PROVISION OF SPECIALIZED SERVICES FOR QUADRIPLEGICS RESIDING IN THE STATE OF HAWAII.

WHEREAS, each person, regardless of their disability has:

(1) The right to develop to their fullest potential, make real decisions and choices, and to live as independently as possible in the least restrictive yet most appropriate environment;

(2) The potential to be full, contributing citizens of an innovative, progressive society; and

(3) The right to a quality of life that is of their own, personal choosing;

and

WHEREAS, in Hawaii, there is no state agency or department that specifically administers services to quadriplegics; and

WHEREAS, instead, there are a combination of services offered from various branches of state and city agencies or departments, as well as non-profit organizations, that provide very general services to all persons with any mental or physical disability; and

WHEREAS, despite these services, there is a great need to administer specialized services that quadriplegics can especially identify with and rely upon to address their specific concerns, and assure their right to a quality of life that is of their own personal choosing, as well as enable them to be full, contributing members of society; now, therefore,

BE IT RESOLVED by the House of Representatives of the Sixteenth Legislature of the State of Hawaii, Regular Session of 1992, that the Legislative Reference Bureau is requested to conduct a study examining the current and future needs of quadriplegics in this State and that the study shall include, but not be limited to, the examination of the following issues:

(1) The number of quadriplegics currently residing in this State;

H.R. NO. 185

(2) The needs of quadriplegics;

(3) An examination of how the needs are being met and whether services are adequate; and

(4) An examination of whether a center or an independent living project for quadriplegics should be established, and if so, what would be the design, construction, and administrative costs of establishing a center or project;

and

BE IT FURTHER RESOLVED that the Legislative Reference Bureau submit a report with its findings, recommendations, and suggested legislation to the Legislature at least twenty days before the convening of the 1993 Regular Session; and

BE IT FURTHER RESOLVED that a certified copy of this Resolution be transmitted to the Legislative Reference Bureau.

OFFERED BY: Eleanor C. Dantiago

APPENDIX B

QUESTIONNAIRE ON RESIDENTIAL SETTINGS FOR THE DISABLED

1. Name of your organization _____

2. We run ____ or are affiliated with ____ a residential program for the disabled. (Check what is applicable)

   If neither of the above items apply to your organization, please skip to question 17.

3. What is the name of the residential program for the disabled that you either run or are affiliated with?

4. What is the residential setting?

   _____ Permanent _____ Transitional _____ Both

5. Does the program serve quadriplegics? Yes ____ No ____

6. What other populations does the program serve?

   If the residential home serves quadriplegics, please answer the following questions. If not, please go to question 17.

7. What percentage of your client population is quadriplegic?

8. What are the eligibility requirements for admittance to the residental program?

9. What types of services for quadriplegics are provided in the residential home?

   a. Nursing? Yes _____ No _____

      If yes, how often (i.e., 2 hours per day, etc.)?

   b. Any other medical care (i.e., physician care, etc.)?

      Yes _____ No _____

      If so, what types and how often?

   c. Paraprofessional care (i.e., occupational therapy, physical therapy, etc.)?

      Yes _____ No _____

      If so, what types and how often?

   d. Non-skilled care (i.e., personal care attendants, janitorial services or maid services)?

      Yes _____ No _____

      If so, what types and how often?

10. How many disabled clients in total do you serve at one time?

11. What type of care does your quadriplegic population require (i.e., skilled nursing 8 hours/day, attendant care only, etc.)?

12. What year was your facility built?

13. Was your facility constructed _____ or is it a renovated building _____?

14. Sources of funding (check what is applicable, fill in the blanks):

a. For the construction or renovation of the facilities:

(i) The Vocational Rehabilitation Act: Yes _____ No _____

If yes, what provision (i.e. Title I, section xxx, etc.)?

(ii) If so, was it:

_____A direct appropriation
_____A low-interest loan
_____Other (please specify) _____

(iii) HUD: Yes _____ No _____

If yes, what provision?

(iv) If yes, was it:

_____A direct appropriation
_____A low-interest loan
_____Other (please specify) _____

(v) State funding: Yes _____ No _____

If yes, please specify:

(vi) County funding: Yes _____ No _____

If yes, please specify:

(vii) Private sources such as foundation grants and fundraising:

Yes _____ No _____

If yes, please specify:

(viii) Other (please specify):

b. For staffing and running the programs, please list your sources of funding (i.e., medicaid payments, grants, fundraising, etc.):

15. Please describe your facilities (e.g., 2-story dormitory style with a kitchen and bathroom on each floor, etc.).

16. What was the cost of constructing or renovating your facility?

17. What does it cost per year to run and staff your facility?

18. Do you know of any other residential program that services quadriplegics?

Yes _____ No _____

If so, please send our office the name of the program, an address, and a contact person.

APPENDIX C

INDEPENDENT LIVING PROGRAMS PROVIDING PERMANENT RESIDENTIAL SERVICES*

NAME OF PROGRAM	ADDRESS	CITY	STATE	ZIP	TELEPHONE	TDD
Our Way, Inc.	10434 W. 36th Street	Little Rock	AR	72204	(501)225-5030	(501)225-5030
ILC of Southern California	14402 Haynes Street, Ste. 103	Van Nuys	CA	91401	(818)988-9525	(818)988-3533
Independent Living Resource Center San Francisco	70 Tenth Street	San Francisco	CA	94103	(415)863-0581	(415)863-1367
Community Resources for Independent Living, Inc.	439 "A" Street	Hayward	CA	94541	(510)881-5743	(415)881-5743
Pueblo Goodwill Center for Independent Living (PGCIL)	250 South Santa Fe Avenue	Pueblo	CO	81003	(719)543-4483	(719)543-4483
Center for People with Disabilities	948 North Street, #7	Boulder	CO	80304	(303)442-8662	(303)442-8662
Center for Independent Living in Central Florida, Inc.	720 N. Denning Drive	Winter Park	FL	32789	(407)623-1070	(407)623-1186
Self-Reliance, Inc. Center for Independent Living	12310 N. Nebraska Ave., Suite F	Tampa	FL	33612	(813)975-6561	(813)977-6368
Center for Survival and Independent Living	1335 NW 14th Street	Miami	FL	33125	(305)547-5444	(305)547-5446
Heart of Georgia	P.O. Box 6117	Macon	GA	31208	(912)742-4185	none
RAMP, Inc.	1040 N. 2nd Street	Rockford	IL	61107	(815)968-7467	(815)968-7467
Access Living	310 South Peoria, #201	Chicago	IL	60607	(312)226-5900	none
Illinois Independent Living Center, Inc.	710 E. Ogden, Suite 207	Naperville	Il	60540	(312)357-0077	none
Damar Homes, Inc.	P.O. Box 41	Camby	IN	46113	(317)856-5201	none
Independence, Inc.	1910 Haskell Avenue	Lawrence	KS	66046	(913)841-0333	(913)841-1046
ALPHA ONE, Center for Independent Living	85 E Street, #1	South Portland	ME	04106	(207)767-2189	(207)767-2189
Northest Independent Living Program, Inc.	130 Parker Street, Lower Level	Lawrence	MA	01840	(617)687-4288	(617)687-4288
Independent Living Center	88 Kingston Street	Boston	MA	02111	(617)727-5550	6178003926556
Grand Rapids Center for Independent Living	3375 S. Division Avenue	Grand Rapids	MI	49508	(616)243-0846	(616)243-0846
CIL/Participants Advocate Group	200 S. Court Street; P.O. Box 3087	Gaylord	MI	49735	(517)732-1078	none
Southeastern MN Center for Independent Living	1306 7th Street NW	Rochester	MN	55901	(507)285-1815	(507)285-1815
Alpha Group Homes, Royal Maid Association f/t Blind	P.O. Drawer 30	Hazlehurst	MS	39083	(601)894-1771	none
League of Human Dignity	1701 P Street	Lincoln	NE	68508	(402)471-7871	signal
Central Nebraska Goodwill Center for Independent Living	1804 South Eddy	Grand Island	NE	68801	(308)384-7896	(308)384-7896
Center for Independence of the Disabled in New York, Inc.	841 Broadway, Suite 205	New York	NY	10003	(212)674-2300	(212)674-2300
Corning AIM (Access to Independence and Mobility)	P.O. Box 548	Corning	NY	14830-0548	(607)962-8225	(607)962-4235
Glens Falls ILC	P.O. Box 453; Quaker Bay Center 6	Glens Falls	NY	12801	(518)792-3537	(518)792-3548
Fraser Hall	711 S. University Drive	Fargo	ND	58103	(701)232-3301	none
Total Living Concepts, Inc.	2433 Harrison Avenue	Cincinnati	OH	45211-7927	(513)661-2600	(513)761-3408

*Information based on research conducted by ILRU RESEARCH & TRAINING CENTER ON INDEPENDENT LIVING AT TIRR in 1988.

INDEPENDENT LIVING PROGRAMS
PROVIDING
PERMANENT RESIDENTIAL SERVICES*

NAME OF PROGRAM	ADDRESS	CITY	STATE	ZIP	TELEPHONE	TDD
Caddo County Independent Living Projects	132 E. Broadway Street, #208	Anadarko	OK	73005	(405)247-7331	(405)247-7331
Ocean State Center for Independent Living	59 Westshore Road	Warwick	RI	02889	(401)738-1013	(401)738-1015
Aberdeen Adjustment Training Center	612 10th Avenue SE	Aberdeen	SD	57401	(605)229-0263	none
Dallas CIL	8625 King George, Ste. 210	Dallas	TX	75235	(214)631-6900	(214)630-5411
Foundation of Resources for Equality & Employment for the Disabled	*154 Hughes Road, Ste. #1*	*Grass Valley*	CA	95945	(916)272-1732	(916)272-1733

*Information based on research conducted by ILRU RESEARCH & TRAINING CENTER ON INDEPENDENT LIVING AT TIRR in 1988.

INDEPENDENT LIVING PROGRAMS PROVIDING TRANSITIONAL RESIDENTIAL SERVICES*

NAME OF PROGRAM	ADDRESS	CITY	STATE	ZIP	TELEPHONE	TDD
ILC of Southern California	14402 Haynes Street, Suite 103	Van Nuys	CA	91401	(818)988 9525	(818)988 3533
Independent Living Resource Center San Francisco	70 Tenth Street	San Francisco	CA	94103	(415)863 0581	(415)863 1367
Foundation of Resources for Equality & Employment for the Disabled	154 Hughes Road, Suite #1	Grass Valley	CA	95945	(916)272 1732	(916)272 1733
Center for People with Disabilities	948 North Street, #7	Boulder	CO	80304	(303)442 8662	(303)442 8662
Center for Independent Living of Southwestern Conn	959 Main Street	Stratford	CT	06497	(203)378 6977	(203)378 6977
Chapel Haven, Inc.	1040 Whalley Ave	New Haven	CT	06515	(203)397 1714	none
Center for Survival and Independent Living	1335 NW 14th Street	Miami	FL	33125	(305)547 5444	(305)547 5446
Center for IL of Northwest Florida, Inc	3789 Nobels Street	Pensacola	FL	32514	(904)477 8200	(904)477 9044
North Idaho Center for Independence	124 East Third Street	Moscow	ID	83843	(208)883 0523	(208)883 0523
Damar Homes, Inc	P.O. Box 41	Camby	IN	46113	(317)856 5201	none
Independent Living, Inc.	26 East Market Street	Iowa City	IA	52240	(319)338 3870	(319)338 3870
Independent Living Program	2200 Gage Blvd., VA Med Center 667 117A	Topeka	KS	66622	(913)272 3111	none
Maine Independent Living Services	74 Winthrop Street	Augusta	ME	04330	(207)622 5434	(207)622 5434
Student Independent Living Experience (SILE)	Mass. Hospital School 5 Randolph Street	Canton	MA	02021	(617)828 1139	none
Boston Center for Independent Living	95 Berkeley Street, Suite 206	Boston	MA	02116	(617)338 6665	(617)338 6662
Grand Rapids Center for Independent Living	3375 S. Division Ave	Grand Rapids	MI	49508	(616)243 0846	(616)243 0846
Life Skills Services	1608 Lake Street	Kalamazoo	MI	49001	(616)344 0202	
Alpha Group Homes, Royal Maid Association f/t Blind	P.O. Drawer 30	Hazlehurst	MS	39083	(601)894 1771	none
The Whole Person, Inc.	6301 Rockhill Rd., Suite 305E	Kansas City	MO	64131	(816)361 0304	(816)361 7749
Central Nebraska Goodwill Center for Independent Living	1804 South Eddy	Grand Island	NE	68801	(308)384 7896	(308)384 7896
Staten Island CIL, Inc.	150 Walker Street	Staten Island	NY	10302	(718)720 9016	(718)667 1216
Corning AIM (Access to Independence and Mobility)	P.O. Box 548	Corning	NY	14830 0548	(607)962 8225	(607)962 4235
Glens Falls ILC	P.O Box 453; Quaker Bay Center 6	Glens Falls	NY	12801	(518)792 3537	(518)792 3548
Fraser Hall	711 S. University Drive	Fargo	ND	58103	(701)232 3301	none
Caddo County Independent Living Projects	132 E. Broadway Street, #208	Anadarko	OK	73005 2837	(405)247 7331	(405)247 7331
Resources for Living Independently Center	One Winding Way, Suite 108	Philadelphia	PA	19131	(215)581 0666	(215)581 0664
Ocean State Center for Independent Living	59 Westshore Road	Warwick	RI	02889	(401)738 1013	(401)738 1015
Aberdeen Adjustment Training Center	612 10th Ave. SE	Aberdeen	SD	57401	(605)229 0263	none

*Residential Services are transitional, not permanent.

Information based on research conducted by ILRU RESEARCH & TRAINING CENTER ON INDEPENDENT LIVING AT TIRR during the summer of 1988.

INDEPENDENT LIVING PROGRAMS
PROVIDING
TRANSITIONAL RESIDENTIAL SERVICES*

NAME OF PROGRAM	ADDRESS	CITY	STATE	ZIP	TELEPHONE	TDD
Dallas CIL	8625 King George, Ste. 210	Dallas	TX	75235	(214)631 6900	(214)630-5411
Austin Resource CIL	5555 North Lamar, Suite J 125	Austin	TX	78751	(512)467 0744	(512)467-0744
Disabled Ability Resource Environment	8929 Viscount, Suite 101	El Paso	TX	79925	(915)591 0800	(915)591-0800
Center for Independence	407 14th Ave , S.E.	Puyallup	WA	98372	(206)848 6661	(206)848 6661

*Residential Services are transitional, not permanent.

Information based on research conducted by ILRU RESEARCH & TRAINING CENTER ON INDEPENDENT LIVING AT TIRR during the summer of 1988.

Appendix D

ADDRESSES FOR QUESTIONNAIRES TO LOCAL HOMES

Kathleen L. English
Director, Home & Community Based Services
Easter Seal Society of Hawaii
710 Green Street
Honolulu, Hawaii 96813

Donna Fouts
Director
United Cerebral Palsy
245 N. Kukui Street
Honolulu, Hawaii 96817

Ann Sumida
Association for Retarded Citizens
3989 Diamond Head Road
Honolulu, Hawaii 96816

Director
The House, Inc.
4510 Sierra Drive
Honolulu, Hawaii 96816

Director
Opportunities for the Retarded, Inc.
64-1510 Kamehameha Highway
Wahiawa, Hawaii 96786

Director
Research Center of Hawaii
2879 Paa Street, Rm. 207
Honolulu, Hawaii 96819

APPENDIX E

CITY LANDS LEASED TO NON-PROFIT ORGANIZATIONS FOR HOUSING

	Project	Lease Expires	Current Rent
1.	Academy Apts.	6/97	$1/yr.
2.	Banyan Street Manor	10/2028	$1/yr.
3.	Halawa - HARC II	7/2032	$1/yr.
4.	Home No Ka Kuli	7/2032	$1/yr.
5.	Institute of Human Services*	5/2041	$132/yr.
6.	Kailua - HARC III	11/2031	$1/yr.
7.	Jack Hall Memorial	12/2053	$1/yr.
8.	Kaimuki - HARC IV	12/2034	$1/yr.
9.	Kaneohe Elderly	9/2047	$1/yr.
10.	Lowell Place	3/2001	$482/mo.
11.	Maili Court - HARC I	10/2039	$2,800/yr.
12.	Maili Court-Self Help		$600/yr.
13.	Maili Homeless	8/92	$1/yr.
14.	Maili Sands	6/2030	$2,200/yr.
15.	Pauahi Elderly	6/2040	$1/yr.
16.	Pualani Manor	11/2040	$1/yr.
17.	River-Pauahi Apts.	11/2040	$1/yr.
18.	Smith-Beretania Apts.*	9/2037	$15,600/yr. Lot 1-A $1/yr. Lot 2
19.	Waipahu Aux. - Ota Camp	2/2009	$1/yr.
20.	HARC - Lusitana St.	9/2038	$1/yr.
21.	HARC - Fern St. (Par A,B,C)	9/2038	$1/yr.
22.	HARC - Fern St. (Par D)	9/2038	$1/yr.
23.	HARC - Kamehame Ridge	7/2033	$1,300/yr.
24.	Group Homes - Hale Kipa	3/2010	$157/mo.
25.	Group Homes - Hawaii Addiction Center	9/2010	$1,333/yr.
26.	Central Oahu Youth Services	9/2010	$275/mo.
27.	Haloa Drive Elderly Group Home- Catholic Services to the Elderly	10/2000	$1/yr.
28.	Kunawai Small Group Home	3/2009	$525.25/mo.
29.	Maluna Street Group Home - Catholic Services to Families	12/2010	$1/yr.
30.	Ewa Elderly	6/2055	$1/yr.
31.	ARC - 1314 - 1316 Dominis St.	9/2037	$1,000/yr.
32.	ARC - 865 6th Avenue	9/2037	$1,000/yr.

CITY LANDS LEASED TO NON-PROFIT ORGANIZATIONS FOR HOUSING

	Project	Lease Expires	Current Rent
33.	Kuakini Street Transitional Hsg.- Child and Family Services	2007	$2,200 or res./mo.
34.	ARC - Ewa Estates	2047	$1,000/yr.
35.	Ewa Villages-Gentry Dev. Co.	7/1/92	$2,000/mo.
36.	Hoakea Expandables		$300/yr.
37.	Acacia		$300-$360/yr.
38.	Pauahi Block A (Non-profit Hsg. Corp.) Hale Pauahi		$1/yr.
39.	Lanakila Gardens (Pacific Housing Assistance Corp.)		$1/yr.

*Fiscal Will continue collecting rents, per Beryle Wharton.

APPENDIX F

QUESTIONNAIRE ON RESIDENTIAL SETTINGS FOR THE DISABLED

1. Name of your organization _____

2. We run _____ or are affiliated with _____ a residential program for the disabled. (Check what is applicable)

   If neither of the above items apply to your organization, please skip to question 17.

3. What is the name of the residential program for the disabled that you either run or are affiliated with?

4. What is the residential setting?

   _____ Permanent _____ Transitional _____ Both

5. Does the program serve quadriplegics? Yes ____ No ____

6. What other populations does the program serve?

7. What percentage of your client population is quadriplegic?

8. What are the eligibility requirements for admittance to the residental program?

9. What types of services for quadriplegics are provided in the residential home?

   a. Nursing? Yes ____ No ____

      If yes, how often (i.e., 2 hours per day, etc.)?

   b. Any other medical care (i.e., physician care, etc.)?

      Yes ____ No ____

      If yes, what types and how often?

   c. Paraprofessional care (i.e., occupational therapy, physical therapy, etc.)?

      Yes ____ No ____

      If yes, what types and how often?

   d. Non-skilled care (i.e., personal care attendants, janitorial services or maid services)?

      Yes ____ No ____

      If yes, what types and how often?

10. How many disabled clients in total do you serve at one time?

11. What type of care does your quadriplegic population require (i.e., skilled nursing 8 hours/day, attendant care only, etc.)?

12. What year was your facility built?

13. Was your facility constructed ____ or is it a renovated building ____?

14. Sources of funding (check what is applicable, fill in the blanks):

a. For the construction or renovation of the facilities:

(i) The Vocational Rehabilitation Act: Yes ____ No ____

If yes, what provision (i.e. Title I, section xxx, etc.)?

(ii) If yes, was it:

____A direct appropriation
____A low-interest loan
____Other (please specify) _____

(iii) HUD: Yes ____ No ____

If yes, what provision?

(iv) If yes, was it:

____A direct appropriation
____A low-interest loan
____Other (please specify) _____

(v) State funding: Yes ____ No ____

If yes, please specify:

(vi) County funding: Yes ____ No ____

If yes, please specify:

(vii) Private sources such as foundation grants and fundraising:

Yes ____ No ____

If yes, please specify:

(viii) Other (please specify):

b. For staffing and running the programs, please list your sources of funding (i.e., medicaid payments, grants, fundraising, etc.):

15. Please describe your facilities (e.g., 2-story dormitory style with a kitchen and bathroom on each floor, etc.).

a. Are the units wheelchair accessible?

Yes ____ No ____

b. What percent are wheelchair accessible? _____%

c. Are there elevators in the units?

Yes____ No ____

If yes, how many? _____

16. What was the cost of constructing or renovating your facility?

17. What does it cost per year to run and staff your facility?

18. Do you know of any other residential program that services quadriplegics or other disabled populations in Hawaii?

Yes ____ No ____

If yes, please send our office the name of the program, an address, and a contact person.

19. Does your organization keep statistics on the number of quadriplegics you serve?

Yes ____ No ____

If yes, please indicate how many, for what year (e.g. 22 for fiscal year 1991).

If you keep track of quadriplegics by year, please state the number you have served each year for the past ten years or as far back as possible.

Please indicate whether these could have been double-counted (e.g., whether some of the ones counted in 1989 could also have been counted in 1990 or 1991).

20. What is your best estimate of the percentage of the population you serve that is quadriplegic? _____%

21. In your opinion, is there a need for additional residential quarters to house the quadriplegics you serve?

Yes ____ No ____

Why or why not?