



A BILL OF RIGHTS
FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

HAWAII DISABILITY RIGHTS CENTER

DEVELOPMENTAL DISABILITY means a severe chronic disability that is attributable to a mental or physical impairment or combination of mental and physical impairments;

AND ▼

Is manifested before the individual attains age 22;

AND ▼

Is likely to continue indefinitely;

AND ▼

Results in substantial functional limitations in 3 or more of the following areas of major life activity:

- Self-care
- Receptive and expressive language
- Learning
- Mobility
- Self-direction
- Capacity for independent living
- Economic self-sufficiency

AND ▼

Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

►OR

DEVELOPMENTAL DISABILITY, when applied to infants and young children means an individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition; and the individual, without services and supports, has a high probability of meeting the criteria listed above later in life.

Developmental Disabilities

Assistance and Bill of Rights Act of 2000

P.L. 106-402, 42 USC 15001

FINDINGS

(abridged)

Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society.

The goals of the Nation properly include the goal of providing individuals with developmental disabilities with the information, skills, opportunities and support to:

1. Make informed choices and decisions about their lives;
2. Live in homes and communities in which such individuals can exercise their full rights and responsibilities as citizens;
3. Pursue meaningful and productive lives;
4. Contribute to their family, community, State and Nation;
5. Have interdependent friendships and relationships with others;
6. Live free of abuse, neglect, financial and sexual exploitation, and violations of their legal and human rights; and
7. Achieve full integration and inclusion in society; in an individualized manner, consistent with unique strengths, resources, priorities, concerns, abilities and capabilities of each individual.

POLICY

(abridged)

It is the policy of the United States that all programs, projects, and activities receiving assistance under this Act shall be carried out in a manner consistent with the principles that:

1. Individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of self-determination, independence, productivity, and integration and inclusion in all facets of community life, but often

require the provision of community services, individualized supports and other forms of assistance;

2. Individuals with developmental disabilities and their families have competencies, capabilities and personal goals that should be recognized, supported, and encouraged, and any assistance to such individuals should be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of the individual;
3. Individuals with developmental disabilities and their families are the primary decision makers regarding the services and supports such individuals and their families receive including regarding choosing where the individuals live from available options, and play decision making roles in policies and programs that affect the lives of such individuals and their families;
4. Services, supports, and other assistance are provided in a manner that demonstrates respect for individual dignity, personal preferences, and cultural differences; and
5. Individuals with developmental disabilities have access to opportunities and the necessary support to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, community, State, and Nation.

RIGHTS

(Simplified Language)

Individuals with developmental disabilities have a right to:

1. Appropriate treatment, services, and habilitation designed to maximize the potential of the individual and provided in the setting that is least restrictive of the individual's personal liberty.
2. Public funds should only be provided to institutional, residential, community or educational programs that:
 - Provide treatment, services and habilitation which is appropriate to the needs of such individuals;
 - Meet the following minimum standards:
 - Provide care that is free of abuse, neglect, sexual and financial exploitation; free of violations of legal and human rights; and that subjects individuals with developmental disabilities to no greater risk of harm than others in the general population;

- Provide appropriate and sufficient medical and dental services.
 - Prohibit use of physical restraint and seclusion unless absolutely necessary to ensure the immediate physical safety of the individual or others, and prohibit the use of such restraint and seclusion as a punishment or as a substitute for a habilitation program.
 - Prohibit excessive use of chemical restraints and the use of such restraints as punishment or as a substitute for a habilitation program or in quantities that interfere with services, treatment or habilitation of such individuals; and
 - Provide for close relatives or guardians of such individuals to visit the individuals without prior notice.
3. All programs meet standards designed to assure the most favorable outcome for those served:
- Residential programs providing comprehensive health-related, habilitative, assistive technology or rehabilitative services meet standards at least equivalent to those applicable to intermediate care facilities for the mentally retarded promulgated in regulations on June 3, 1988.
 - Other residential programs assure that care is appropriate to the needs of the individual, assure that the needs of individuals admitted can be met through services provided by the facility, and assure that the facilities are sanitary, provide humane care and protect the rights of their residents.
 - Nonresidential programs assure the care provided is appropriate to the individuals served.

THESE RIGHTS ARE IN ADDITION TO ANY CONSTITUTIONAL OR OTHER RIGHTS OTHERWISE AFFORDED TO ALL INDIVIDUALS.

**If you believe you have a developmental disability,
and if you have a question or concern about your rights,
please call the
HAWAII DISABILITY RIGHTS CENTER
for more information and assistance:
Oahu Residents, call: 949-2922
Neighbor Island Residents, call: 1-800-882-1057**

Developmental Disabilities

Hawaii Revised Statutes Chapter 333-F

Summary of 1999 Amendments (Act 133)

New Requirements for an Individualized Service Plan (ISP)

1. The ISP is made by the person. The person may have help from family, friends and others he/she thinks are important in making the plan.
2. The ISP shall be in writing.
3. The ISP shall include:
 - What is important to the person;
 - How health or safety issues shall be handled; and
 - What needs to happen to support the person in the person's chosen life.

New Responsibilities for the Department of Health

1. The Department may provide available supports and services, based on a client-centered plan, resulting from client choices, decision-making and self-determination.
2. The Department shall assist the individual to develop, with the help of family and friends, the individualized service plan.
 - The plan shall state the amount of money available to carry out the plan.
 - The plan shall let the person direct how this money will be spent.

Developmental Disabilities

Hawaii Revised Statutes Chapter 333-F

Summary of 1999 Amendments (Act 133)

New Statement of Rights of People with Developmental Disabilities

People with Developmental Disabilities have a right to:

1. Receive the least restrictive and individually appropriate services, including a program of activities outside the residence in accordance the person's individualized service plan.
2. Live in the least restrictive, individually appropriate residential alternative located as close as possible to the person's home community in Hawaii.
3. As much as it is individually appropriate, after considering the wishes of the person, to:
 - Interact with people without disabilities in a non-treatment, nonservice-oriented setting;
 - Live with, or close to, people without disabilities; and
 - Live in a setting which closely approximates those conditions available to people without disabilities of the same age.
4. Reasonable access to review medical, service and treatment files, and to know their diagnoses.
5. Develop a plan with input from family and friends that has the supports needed to carry out the plan.
6. Control an identified amount of dollars to accomplish the plan, with help from family and friends, as necessary.
7. Direct provision of paid and unpaid resources that will help a person live a life in the community rich in community association and contribution.
8. Have a valued role in the community, through employment, community activities, volunteering, and spending public dollars to enhance life.
9. Privacy and confidentiality, as much as possible, in services provided to the person.



PROTECTION AND ADVOCACY FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

The Developmental Disabilities Assistance and Bill of Rights Act of first authorized the establishment of protection and advocacy systems in every State and Territory of the United States in 1975 to protect the human, civil, and legal rights of individuals with developmental disabilities. The system has the authority to:

1. Pursue legal, administrative, and other appropriate remedies to ensure the protection of, and advocacy for, the rights of such individuals within the State who are or who may be eligible for treatment, services, or habilitation, or who are being considered for a change in living arrangements;
2. Provide information on and referral to programs and services addressing the needs of individuals with developmental disabilities;
3. Have the authority to investigate incidents of abuse and neglect of individuals with developmental disabilities if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred;
4. Have access at reasonable times and locations to any resident who is an individual with a developmental disability in a facility that is providing services, supports, and other assistance to such a resident;
5. Have access (after meeting certain requirements) to all records of any individual with developmental disabilities;
6. Have authority to educate policy makers; and
7. Receive a copy of each annual survey report and plan of corrections for cited deficiencies made pursuant to section 1902(a)(31) of the Social Security Act with respect to any ICF/MR in the State within 30 days after the completion of each such report or plan.

For more information or assistance, call:

HAWAII DISABILITY RIGHTS CENTER

900 Fort Street Mall, Suite 1040, Honolulu, Hawaii 96813

Phone/TTY: (808) 949-2922 Toll Free: 1-800-882-1057 Fax: (808) 949-2928

E-mail: info@hawaiidisabilityrights.org Website: www.hawaiidisabilityrights.org

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