



## **A Guide to Developmental Disability Services**

All parents' skill sets grow with their children, but parents of individuals with developmental disabilities develop an extra set of skills in their role as the primary source for their child's care and support. For much of what is needed, families are the **best** resource. However, there may come a time when additional help from outside the family becomes not only helpful, but necessary.

In response to this need, Alaska has developed a comprehensive system of **community-based** services and supports to provide families and individuals opportunities to live the way they desire.

Understanding the system that makes services available and building successful relationships with the community-based service **providers** are two of the new skills you will need to add to your list.

Alaska's individualized service system for people with developmental disabilities operates in a maze of regulations. Parents often struggle to understand eligibility, planning, billing, reporting, and assessment rules. A Guide to Developmental Disability Services was written to help parents understand what Developmental Disabilities services are and how these services can work for you.

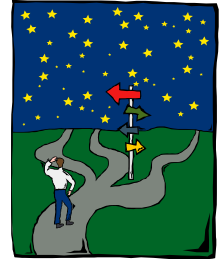
Many of the terms and processes to apply for and to receive services will be unfamiliar to you. This guidebook is in the order needed to begin your journey.

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## Alaska's Developmental Disability Services

Describes the type of services and supports available to individuals and families and how to access them.

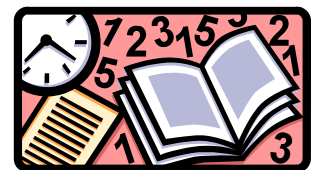
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## Other Resources

Provides information on other resources and entitlement programs. Alaska's Service Principles, Consumer Rights, and a list of commonly used acronyms are included in this section.

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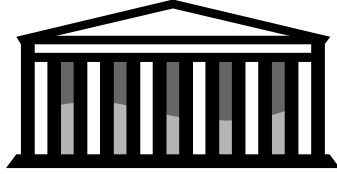
## Introduction

You may not know if you or your family member is **eligible** for services provided through Alaska's Developmental Disabilities program. This Guide explains what a developmental disability is and how the developmental disability system works.

The Division of Senior and Disabilities Services under the Department of Health and Social Services provides oversight of the service system that supports individuals with disabilities and their families. The mission of the Division of Senior and Disabilities Services is to improve and enhance the quality of life for consumers impacted by intellectual disorders or developmental disabilities.

This Guide describes **what services are, who provides them and how you can use them.** There are many kinds of services and you need to know enough about them to choose which the best are for you. You also will want to know who provides the services – how they do business, who works for them, and how you can best use the services.

Before we begin, it is important to understand that all of the programs described in A Guide to Developmental Disability Services, were created to **help** people with developmental disabilities. There are many laws and regulations that explain how these programs should operate, and they are here to improve the lives of people with developmental disabilities.



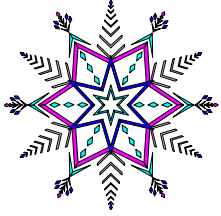
## **The Division of Senior and Disability Services**

The Division of Senior and Disabilities Services (DSDS) has three offices (Juneau, Anchorage and Fairbanks) to serve individuals with developmental disabilities. These offices are responsible for determining eligibility for services and for working with agencies to provide a plan of care for eligible individuals.

Fairbanks Office  
751 Old Richardson Highway, Suite 123  
Fairbanks, Alaska 99701  
(907) 451-5045  
1-800-770-1672  
TTY: (907) 451-5093

Anchorage Office  
3601 "C" Street, Suite 878  
Anchorage, Alaska 99503  
(907) 269-3666  
1-800-770-3930  
TTY: (907) 269-3624

Juneau Office  
350 Main Street  
Juneau, Alaska 99811  
(907) 465-3370  
1-800-465-4828  
TTY: (907) 465-4827



## What is a developmental disability?

The word "disability" has different meanings for different people. For some, the word suggests specific medical conditions; others think of how well a person does the tasks of everyday living.

Below is the official definition of developmental disability that is used by Alaska's Developmental Disability Program to decide if someone is eligible for services.

*A developmental disability is a severe, chronic disability that an individual experiences for the first time before he or she is 22. It is a condition that is lifelong and which will not go away. It is due to an intellectual or physical or a combination of intellectual and physical impairments. Some of the problems an individual with a developmental disability might experience are difficulty taking care of themselves, difficulty understanding other people or making themselves understood, having a hard time going places and finding it difficult to live on their own or hold a job.*

*The state of Alaska has adopted the federal definition of "developmental disability." People who meet this definition are eligible for services.*

*The person seeking services must have a severe, chronic disability that:*

- *is attributable to a mental or physical impairment or combination of impairments*
- *is manifested before the age of 22.*
- *is likely to continue indefinitely.*
- *results in substantial functional limitation in three or more of the following areas of life activity:*
  - *Self-care*
  - *Receptive and expressive language*
  - *Learning*
  - *Mobility*
  - *Self-direction*
  - *Capacity for independent living*
  - *Economic self-sufficiency and*

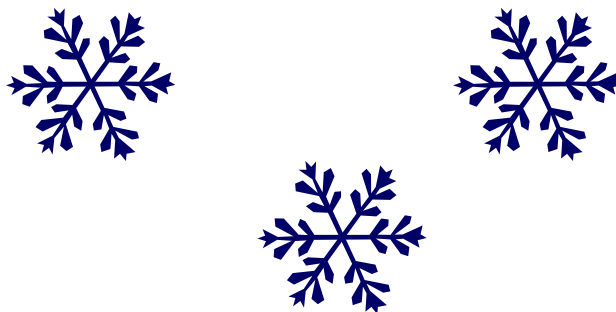
- *reflects the individual's need for a combination and sequence of special interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated.*

The key parts of the definition to remember are:

- the disability happens before the person is **22** years old;
- the person will most likely have the disability his **whole life**;
- the disability is either **physical**, mental, or **both**; and
- the disability is severe enough that the person needs **help** in at least **three** of the following areas of life: taking care of himself, communicating, learning, getting around, making important decisions, living on his own or making enough money to live on.

Children or adults with developmental disabilities are able to do many things that others can, but often need help. Most of this help is provided by the families.

How do individuals who experience a developmental disability get help?

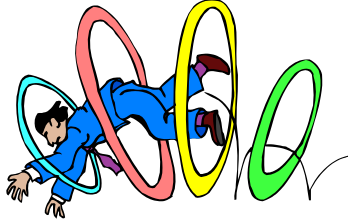


## Division of Senior and Disabilities Services

### Service Principles

- ❖ Individuals are actively involved in the design and implementation of their service plans.
- ❖ Individuals have access to a system of comprehensive and integrated community-based services.
- ❖ Services promote natural and community supports that include their families, friends, and other community members.
- ❖ Services are appropriate for the individual's age, abilities and life goals.
- ❖ Services demonstrate respect for the rights and dignity of all persons.
- ❖ Services incorporate the culture and value system of the individual.
- ❖ Services have as their goals individual choice, safety, satisfaction, and positive outcomes for the individuals served.
- ❖ Individuals are offered the support and services necessary to their success as they live, work, and recreate.
- ❖ Services are designed to foster communities where all members are included, respected, and valued.





## Eligibility

In order for a person with a developmental disability to receive help they must be found “**eligible** for services.”

Being eligible for services means a person has been **diagnosed** with a mental or physical disability and has been found to have a **high level of difficulty** doing things that are important to everyday life. For example, they may have a hard time getting around, or they may not be able to communicate with other people very well, or it may be very hard for them to do things like budgeting, caring for themselves, or holding a job.

There is a special **form** to fill out in order to be found eligible for services. It is called an [eligibility determination form](#).







## Applying for Eligibility

If you think you or a family member may be eligible for services and supports, you may contact your local office of the Division of Senior and Disabilities Services (DSDS).

**Juneau:** P.O. Box 110680, Juneau 99811-0680, 907-465-3135, Fax: 465-1170 Toll Free: 1-800-465-0316

**Anchorage:** 550 W. 8<sup>th</sup> Ave., Anchorage 99501, 907-296-3666, Fax: 269-3689, Toll Free: 1-800-478-9996

**Fairbanks:** 751 Old Richardson Highway, Suite 100-A, Fairbanks 99701, 907-451-5045, Fax: 451-5046, Toll Free: 1-800-770-1672

One of the program staff at DSDS may help you with the eligibility forms or you will be referred to an agency that works with people with developmental disabilities. A family service worker with the service agency will help you fill out the eligibility determination form.

The eligibility form will ask questions about the help you or your family member needs. You will be asked to show that there is a significant enough disability to fit the description of developmental disability as described on page five. These “substantial limitations” must be documented. You will need to submit doctors’ reports, hospital records, school district evaluations, or other proof of a significant disability.

Shortly after submitting the application you will receive a letter from DSDS telling you if you or your family member has been determined eligible for developmental disability services. If you or your family member is found eligible for developmental disability services, this letter will tell you of community service agencies in your area where you can access some limited services through the agency “grant” program. You will want to check with these agencies regarding the services they provide and how they might meet

the needs of you or your family member. You can receive grant support services while waiting for more comprehensive services you need.

If you are not deemed eligible, you may appeal this decision. This is done through your local Developmental Disability Program office. You may also contact the Disability Law Center of Alaska for more information about your rights.



## **The Developmental Disabilities Registration and Review (Waitlist)**

Developmental Disability (DD) services are available based upon funding provided by the state legislature. Because there are more people needing services than there is money, there is a registry or “waitlist” for DD services administered by DSDS. Your place on the waitlist is determined by the score you receive on a [“Developmental Disabilities Waiting List and Registration Review”](#).

A waitlist assessment consists of a series of questions about how well you or your family member is doing from day to day. Based upon your response to the questions, a score is assigned and you are then placed on the waitlist registry. You may complete the waitlist registry paperwork once you have received a letter from DSDS deeming you or your family member eligible for services. A service provider or a program specialist at DSDS can help you complete the registry paperwork.

The assessment will show DSDS how urgently you or family member need services. Your score will determine your standing on the list compared to other people waiting for services. You will receive a letter from DSDS

explaining the score they assigned you. You will also have the opportunity to respond to or clarify anything you disagree with.

PLEASE be sure and submit an UPDATED registry form when there are significant changes in your circumstances as this could change your “score” and placement on the registry.



### **How will you be selected for services?**

At the beginning of each quarter (July, October, January, and April), fifty individuals are selected for services. These individuals are selected based on the severity of need as determined by their score on the waitlist registry review form. You may update this form at any time and are encouraged to do so when there are changes in circumstance or need for support.



### **Alaska’s Developmental Disability Services**

When you or a family member is selected to receive services, an individual support plan will be developed based on your needs and preferences. It is

important to stress that this plan should be person-centered and based on supports which promote independence. **Services are community-based and can be provided in the community in which the family lives.**

Services vary depending upon the age of the individual and with the disability. For children, services may include respite, community inclusion supports, and caregiver support. For youth and adults, services might include assistance in the activities of daily living skills in the home or community, transportation to shop, work, budgeting or paying bills, a job coach and respite (a break) for the primary care provider(s).

If the applicant involved has acute medical needs for nursing or medication, these services may be written into the plan. Other services may include speech therapy, occupational therapy and/or physical therapy. Some home modifications or the cost of traveling to a medical center outside of Alaska will be covered.

When medically necessary, based upon unique need of the individual, things as computer software and assistive technology devices can be paid for.

**Services will not include paying rent or living expenses**

### **Comprehensive Services**

Comprehensive Services are provided to individuals who are on the waitlist and need more support than can be provided through limited grant funds. If you are selected from the waitlist to receive comprehensive services, DSDS will notify you in writing and a list of independent care coordinators and provider agencies will be sent to you. You will need to choose a care coordinator and an agency to provide your services. The agency will help you develop your plan of care and will send it to DSDS for their approval.

While not all comprehensive plans are Home and Community Based “**WAIVERS**”, many are. Many of you may have heard the term *waiver* and wonder what it means. Services provided through a waiver are the same as those provided through an individualized comprehensive plan. The difference is the funding source. Waivers are partially paid by the federal

government. In order to receive a waiver, you must meet several specific Medicaid waiver eligibility criteria, one of which is “**level of care**”. This level of care means the applicant would need the same services that would be provided in an institution that serves people with mental retardation and developmental disabilities. If a child meets the strict disability guidelines, his/her income may be separated from the family’s income, thus making him/her eligible for Medicaid and other support services.

The purpose of the Home and Community Based Waiver is to allow for services to be provided to individuals with disabilities in their home and community rather than institutions, hospitals and nursing facilities.

Alaska has three Home and Community Based Waivers for individuals with disabilities. These are the Waiver for Children with Complex Medical Conditions (CCMC Waivers), the Waiver for Children and Adults with Developmental Disabilities (MRDD Waivers) and waivers for adults with developmental disabilities who also have physical disabilities (APD Waivers.) Alaska has a fourth waiver which serves seniors needing nursing level of care services.

***All four waivers are administered by the Division of Senior and Disability Services***

### **The Waiver for Children with Complex Medical Conditions (CCMC)**



This waiver provides services to children from birth through the age of 21.

To be eligible for a CCMC Waiver, a child must:

- Have a severe and chronic medical condition that is expected to continue for more than 30 days.
- Be so sick that his condition is life threatening and he or she must need to be very carefully monitored all day every day (24/7.)
- Be dependent on medical care and/or technology in order to live.
- Have medical needs so serious that he or she requires the same sort of care usually found in a hospital or nursing facility.

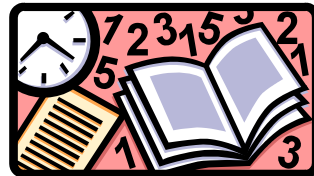


## **The Waiver for Children and Adults with Developmental Disability (MRDD)**

This waiver is for individuals with mental retardation, autism, cerebral palsy, a seizure disorder, or a condition that means they function as if they had mental retardation.

In addition to these diagnoses, the individual must have a serious limitation on how he or she functions in everyday life. For example, it might be hard or impossible to take care of personal needs, for themselves, communicate with other people, handle their finances, move around, make safe decisions, or hold a job.

The level of support required must be the same level of care that would be provided by an institution.



### **Other Resources**

While a person is waiting to be selected from the wait list for core or comprehensive services, there are other resources that are available.

- STAR Projects offer short term help to prevent emergencies when possible. Your local Developmental Disability Program Specialist can provide more information about these projects and if they are available in your area.

- Stone Soup Group is Alaska's Parent Training and Information center and supports families in navigating special education services. 561-3701
- Governor's Council on Disabilities and Special Education helps to shape policy and guide system change for individuals and their families. The Council often holds forums for individuals and families to report on the status of services in their community. 269-8990
- Center for Human Development: UCED provides training and technical assistance to providers and families. 272-8270
- Disability Law Center or Alaska offers educational training and legal assistance to individuals with developmental disabilities. 565-1002
- Aging and Disability Resource Center: Helps people more easily access long-term supports in their community. 1-877-625-2372 toll free



## Entitlement Services

Some of Alaska's Entitlement Services are Denali KidCare, EPSDT, TEFRA, Medicaid, and Supplemental Security Income (SSI). You must meet eligibility requirements in order to qualify for these entitlements.

### **Denali KidCare**

Denali KidCare is a State of Alaska program that provides health insurance for children through 18 years of age and pregnant women who meet **income guidelines**.

Denali Kid Care includes doctor's visits, vision exams and eyeglasses, dental care, mental health care, hospital care, speech therapy, physical therapy and prescription medications.

To find out more about Denali Kid Care you can call 1-888-318-8890 or, in Anchorage, 269-6529.

### **Early Periodic Screening, Diagnosis and Treatment (EPSDT)**

EPSDT is a package of benefits available to children and youth under the age 21 years old who are enrolled in Medicaid. It involves regular exams for all eligible children and all services prescribed by these exams free of charge. The four types of screening are: medical, dental, vision, and hearing.

You can learn more about EPSDT from:  
The Division of Medical Assistance at 1-800-211-7470



## **TEFRA**

TEFRA stands for Tax Equity and the Fiscal Responsibility Act. It is a type of Medicaid program for children under the age of 19 years old who meet certain medical and disability guidelines. Only your child's income and resources are considered when you apply for TEFRA. The child's income may be no more than 300% of the federal poverty standard and his or her resources must be less than \$2,000.

Children who meet the eligibility requirements for TEFRA receive all Medicaid services. Medicaid covers many hospital and doctors' charges as well as wheelchairs, therapies and medical supplies.

Information about TEFRA may be obtained by calling:

PRO-West

Robin Oyler Terry, R.N.

In the Anchorage area at (907) 562-2755

Or toll free at 1-800-878-7170

## **Supplemental Security Income (SSI)**

Supplemental Security Income provides Medicaid and income to low-income individuals who are unable to work because they experience a disability, blindness, or are over 65 years of age. Children with disabilities who are from low-income families may also qualify to receive SSI.

To obtain information about SSI you may call:

The Social Security Administration

In Anchorage at 271-4455

TTY at 271-4799

Or toll free at 1-800-325-1213 [National Help Line]

1-800-325-0778 [National Help Line / TTY]

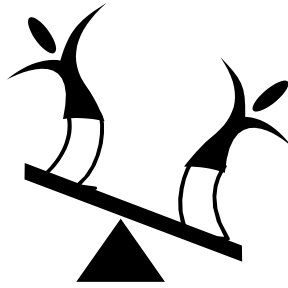


## **About Service Provider Agencies**

Services are provided by Developmental Disability (DD) service provider agencies across the state. In larger communities, you may have several agencies from which to choose your services. Many smaller communities only have one or two providers to choose from. Before you select a service provider agency, you may want to talk with other parents and meet with agency staff to see which agency best suits you or your family.

For a listing of DD Provider Agencies in you area log on to: <http://www.alaskachd.org/providers/ddproviders.html> or ask the program specialist in the Division of Senior and Disability Service office nearest you (see page 4).

## Consumer Rights and Responsibilities



DSDS promotes services that focus on consumer satisfaction and positive outcomes for individuals and families. DSDS strives to provide consumers with services in a manner that respects the rights and dignity of individuals with disabilities.

- ❖ Consumers are to be treated with respect.
- ❖ Consumers are to participate in developing and implementing your plan of care.
- ❖ Consumers are entitled to privacy and confidentiality.
- ❖ Consumers are provided with a complete assessment of their health and abilities.
- ❖ Consumers are able to obtain any health or social services that they may need.
- ❖ Consumers are told the cost of any service they receive.
- ❖ Consumers can refuse any service offered as a part of their plan of care.
- ❖ Consumers can withdraw from the process at any time
- ❖ Consumers can choose between institutional care and waiver services
- ❖ Consumers must be provided written notice of:
  - Decisions made on their applications and plans
  - Their rights if they disagree with any decision
  - Where to go for help in understanding their rights

Contact your DSDS program specialist for more information on your rights (listed on page 4).

## Glossary of Acronyms



ADD	Administration on Developmental Disabilities (federal agency on disabilities)
AADD	Alaska Association on Developmental Disabilities (service providers)
ADRC	Aging and Disability Resource Center
AMHTA	Alaska Mental Health Trust Authority
ANMC	Alaska Native Medical Center
APA	Adult Public Assistance Program
ATAP	Alaska Temporary Assistance Program
DD	Developmental Disability
DMHDD	Division of Mental Health and Developmental Disabilities
DHSS	Department of Health and Social Services (either state or federal)
DMA	Division of Medical Assistance
DPH	Division of Public Health
DVR	Division of Vocational Rehabilitation
DEED	Department of Education and Early Development
EPSDT	Early Periodic Screening, Diagnosis and Treatment (a Medicaid service for children)

FAE	Fetal Alcohol Effects
FAS	Fetal Alcohol Syndrome
ICC	Interagency Coordinating Council (Part of Governor's Council on Disabilities and Special Education)
ICF	Intermediate Care Facility
ICF/MR	Intermediate Care Facility for the Mentally Retarded
IDEA	Individuals with Disabilities Education Act
IEP	Individual Education Plan
IEP	Individual Education Program
IFSP	Individual Family Service Plan
ILP	Infant Learning Program
LD	Learning Disabled
LRE	Least Restrictive Environment
MCH	Maternal, Child and Family Health (section of DPH)
MH/DD	Mental Health and Developmental Disabilities (Division of DHSS)
NADDC	National Association of Developmental Disabilities
NARC	National Arc
NECTAS	National Early Childhood Technical Assistance System
OCR	Office of Civil Rights
OSEP	Office of Special Education Programs (federal)

OSERS	Office of Special Education and Rehabilitative Services (federal)
SESA	Social Education Service Agency
TA	Technical Assistance
TASH	The Association of Persons with Severe Handicaps
UCED	University Center on Disabilities (formerly UAP)
WIC	Women, Infants and Children Supplemental Food Program
WIN	Work Incentive Program