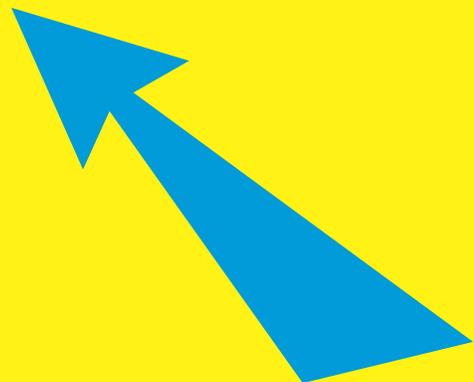


**Guide to  
Developmental  
Disability Services**



## Guide to Developmental Disability Services



All parents 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 would make all the difference in the world.

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 new skills you 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. The **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 organized in the order needed to begin your journey.

### **This guide was made possible by:**

The Governor's Council on Disabilities and Special Education

The Division of Senior and Disability Services

UAA Center for Human Development

Creative contribution from the Stone Soup Group.

The most updated version of this guide is available online in Adobe pdf format at:  
[www.alaskachd.org/ddguide/](http://www.alaskachd.org/ddguide/)

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## Introduction



You may not know if you or your family member are **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 Developmental Disabilities Program within the Division of Senior and Disability Services (DSDS) provides oversight of the service system that supports individuals with disabilities and their families. The mission of the Developmental Disabilities Program is to improve and enhance the quality of life for consumers impacted by 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 are the best 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 the **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.



## Developmental Disabilities Program

The Developmental Disabilities Program has three regional offices to serve individuals with developmental disabilities. In each office there are one or more Program Specialists who are responsible for determining eligibility for services and for working with agencies to provide a plan of care for eligible individuals.

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

Anchorage and Southcentral Regional Office  
3601 "C" Street, Suite 310  
Anchorage, Alaska 99503  
(907) 269-3666  
1(800) 478-9996  
TTY: (907) 269-3624

Southeast Regional Office  
240 Main Street  
Juneau, Alaska 99811  
(907) 465-3165

**Statewide Website**  
<http://hss.state.ak.us/dsds/>

## Developmental Disabilities 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.



### 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 will not go away. It is due to a mental or physical or a combination of mental 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 lifelong or of 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 for a lifetime;
- 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 personal needs, communicating, learning, getting around, making important decisions, living alone 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?

## 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 **Application for Eligibility**.

## Applying for Eligibility

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



Anchorage and Southcentral Region/Anchorage:  
269-3666 or 1-800-478-9996

Northern Region/Fairbanks:  
451-5045 or 1-800-770-1672

Southeast Region/Juneau:  
465-3165

One of the Developmental Disabilities Program Specialists may help you apply for eligibility, or you will be referred to an agency that works with people with developmental disabilities. A family service worker with the agency will help you fill out an application for eligibility.

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 four. 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 telling you if you or your family member are eligible for developmental disability services.

If you are not deemed eligible, you may appeal this decision. This is done through your Regional Developmental Disabilities Program Specialist.

## The Waitlist



Developmental Disability (DD) services are available based upon funding provided by the state legislature. Because there are more people needing services than money, there is a “**waitlist**” for DD services administered by the Developmental Disabilities Program. Your place on the waitlist is determined by the score you receive on a “**waitlist assessment**”.

A waitlist assessment consists of a series of questions about how well you and your family member are doing from day to day. A service provider or a Regional Developmental Disabilities Program Specialist can do the assessment at the same time as your application for eligibility is completed.

The assessment will show how urgently you or your family member needs services. Your score will determine your standing on the list compared to other people waiting for services.

## How will you be selected for services?



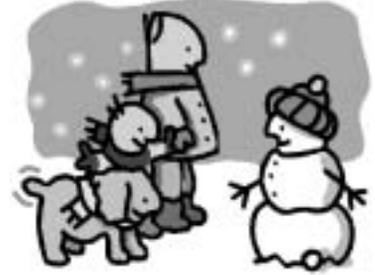
As money becomes available, people are selected to receive services.

Once you are on the waitlist, you can call the office of your Regional Developmental Disabilities Program Specialist to find out where you or your family member currently are on the waitlist. Your position on the waitlist can change as new individuals are added or removed.

## Alaska's Developmental Disability Services

When you or a family member are selected to receive services, a support plan will be written. This plan will be tailored to the individual needs of the person being served. **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 with the disability. For children, services may include respite (a break), community inclusion supports, assistance with household responsibilities, and caregiver support. For older individuals, services might include transportation to shop, work, or attend community activities; in home help doing chores, budgeting or paying bills; a job coach; or respite for care providers.



If the individual 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. Sometimes the cost of traveling to a medical center outside of Alaska can be covered.

There are some things that are not generally covered. Services usually will **not** include paying rent or living expenses. Only in certain special cases will such things as computer software, assistive devices, and home modifications be approved.

## Core Services

One of the first services individuals and families find helpful are **Core Services**. These services are administered by the Developmental Disabilities Program for individuals who are on the waitlist. The individual may use up to \$2,550 a year to pay for such things as respite, specialized equipment, home modification, job support, case management, speech, occupational or physical therapy and other services that meet the individual needs of the person.

If you are selected to receive **Core Services**, you will be notified by letter. You will be provided with a list of provider agencies in your community. You choose which agency you wish to receive services from. Before selecting the agency, you may want to visit and meet with agency staff to see which agency is the best match for you or your family. Once you have selected an agency, they will help you develop your support plan (a list of services you need).

**You can still be on the waitlist for comprehensive services while you are receiving Core Services.**

## Comprehensive Services



**Comprehensive Services** are provided to individuals who are on the waitlist and need more support than can be provided through **Core Services**. If you are selected from the waitlist to receive additional services, DSDS will notify you in writing with a list of provider agencies. You choose an agency to provide your services. The agency will help you develop your plan of care and will send it to the Developmental Disabilities Program for 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 for your plan to be paid through a waiver, you must meet specific Medicaid waiver eligibility guidelines including “**level of care**”. This level of care means the applicant needs the same services that would be provided in an institution serving people with mental retardation and developmental disabilities. If a child meets the strict disability guidelines, his or her income is separated from the family’s income, thus making him or her eligible for Medicaid and other support services.

The purpose of the Home and Community Based Waivers is to keep individuals with disabilities in their home communities and out of 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.)

## 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 the condition is life threatening, and needs very careful monitoring 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, communicate with other people, learn new things, 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 waitlist 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.
- **PARENTS, Inc.** offers families special education supports. Web: <http://www.parentsinc.org/> (907) 337-7678
- **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. The **Where to Turn** booklet is available online at <http://health.hss.state.ak.us/gcdse/Publications/publications.htm>. (907) 269-8990 or 1 (800) 709-8990
- **UAA Center for Human Development** provides training and technical assistance to providers and families. Web: <http://www.alaskachd.org/> (907) 272-8270



- **Disability Law Center of Alaska** offers educational training and legal assistance to individuals with developmental disabilities. Web: <http://www.dlcak.org/> (907) 565-1002
- **Stone Soup Group** offers information referral and training for children with special health care needs. (907) 561-3701

## 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 KidCare 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 KidCare you can call 1(888) 318-8890 or, in Anchorage, (907) 269-6529.

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

EPSDT is a package of benefits available to children and youth under 21 years of age who are enrolled in Medicaid. It involves regular exams for all eligible children, and all services prescribed by these exams are 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: Qualis Health, 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 (907) 271-4455

TTY at (907) 271-4799

Or toll free at 1 (800) 772-1213

[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.



For a listing of DD provider agencies in your area log on to: **http://www.alaskachd.org/providers/ddproviders.html** or ask your Regional Developmental Disabilities Program Specialist.

## Consumer Rights and Responsibilities



The Developmental Disabilities Program promotes services that focus on consumer satisfaction and positive outcomes for individuals and families. The Program 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 their 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 Regional Developmental Disabilities Program Specialist for more information on your rights (listed on page 2).

## Glossary of Common Acronyms

ADD	Administration on Developmental Disabilities (federal agency on disabilities)
AADD	Alaska Association on Developmental Disabilities (service providers)
AMHTA	Alaska Mental Health Trust Authority
ANMC	Alaska Native Medical Center
APA	Adult Public Assistance
ATAP	Alaska Temporary Assistance Program
DD	Developmental Disability
DHSS	Department of Health and Social Services (either state or federal)
DMA	Division of Medical Assistance
DPH	Division of Public Health
DSDS	Division of Senior and Disability Services
DVR	Division of Vocational Rehabilitation
D EED	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)
MR	Mentally Retarded
NARC	National Arc (advocacy organization)
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	Special Education Service Agency
TA	Technical Assistance
TASH	The Association of Persons with Severe Handicaps
UCEDD	University Center for Excellence in Developmental Disabilities
WIC	Women, Infants and Children Supplemental Food Program
WIN	Work Incentive Program