

DEVELOPMENTAL DISABILITIES WAITING REGISTRY REPORT

FOR THE PERIOD OF JULY 1, 2006 THROUGH JUNE 30, 2007
DECEMBER 2007



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FOR:

The DEPARTMENT OF HEALTH AND SOCIAL SERVICES

AND

THE 24TH ALASKA LEGISLATURE

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ABOUT THE DEVELOPMENTAL DISABILITIES WAITING LIST REPORT

Under AS 47.80.130 (d), the Department of Health and Social Services is required to maintain a Waiting List denoting individuals whom experience a developmental disability as defined under AS 47.80.100 - 47.80.170. It is further required that an annual Report to the Governor and specified legislative committees be presented when there is not adequate funding to meet the needs of these individuals. As noted elsewhere in this report, Alaskans who experience developmental disabilities may receive a variety of services administered and funded by multiple federal, state and local agencies. A centralized database has been developed to more easily determine what services, if any, a person on the Waiting List is receiving, how services relate to the client's needs as expressed in the client's assessment form, or whether the services requested are needed immediately or may be needed sometime in the future. Therefore cost projections contained in this report should be considered estimates to use in planning and not a computation of the costs of comprehensive services that may be necessary to meet the needs of each person on the list.

At the present time, the Division of Senior and Disabilities Services (SDS) and stakeholders from the advocacy community are working together to redevelop the policies and procedures that govern the management of the Waiting List. The first phase of the process is drafting recommendations regarding how assessments are performed, the assessment tool(s) to be used, and procedures for removing new persons selected from the Registry for services. One of the recommendations made and adopted by the Ad Hoc Committee was to rename the DD Waitlist to more appropriately reflect its intent and use to the DD Registry. With the additional \$3 million in legislative funding intended to address the needs of persons on the registry provided during FY07, the Division of Senior and Disability Services implemented quarterly registry draws, which should result in the placement of at least 100 individuals into Medicaid Waiver Services through FY08.

In conjunction with the Governor's Council, The Alaska Mental Health Trust Authority (AMHTA), and representatives of the Alaska Association on Developmental Disabilities (AADD), SDS initiated through Centers for Medicaid and Medicare (CMS) approval to remove 200 persons annually from the registry. SDS is targeting FY10 as the year for complete elimination of the "waitlist."

SECTION 1:
THE PURPOSE OF THE DEVELOPMENTAL DISABILITIES (DD) WAITING REGISTRY
(AS 47.80.130(d)(1))

The DD Waiting List, henceforth in this report referred to as the DD Registry, presents information regarding people who have been determined eligible for developmental disability services and is used to select people for enrollment in services when resources are available. Additionally, the DD Registry assists the Division of Senior and Disability Services in planning for the future needs of people with a developmental disability. At least annually, the Division contacts those on the DD Registry to update personal information about changes in their condition or family circumstances.

Eligibility for the Community Developmental Disabilities Grant (CDDG) program is defined under the provisions of AS 47.80.900 (7). The term “developmental disability” means an individual with a severe, chronic disability that:

- Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- Is manifested before the individual 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:
 - Self care;
 - Receptive and expressive language;
 - Learning;
 - Mobility;
 - Self-direction;
 - Capacity for independent living;
 - Economic self-sufficiency, and;
- Reflects the person’s need for a combination and sequence of special, interdisciplinary, or generic assistance, supports or other services that are of lifelong or extended duration and are individually planned and coordinated.

SECTION 2:

PLACEMENT ON THE LIST AND THE CRITERIA FOR RANKING AND SELECTION (AS 47.80.130(d)(2))

In order for a person to be eligible for the DD Registry they must fill out an Eligibility Determination application. This application provides the information needed for a DD Program Specialist to determine eligibility. In addition to the Eligibility Determination application, a Waiting List Criteria Assessment (renamed Registry Assessment) must also be completed. However, these forms are currently under review and revision by the Ad Hoc Committee and SDS and are being “piloted” at this time.

The current assessment collects information about an individual’s living situation, need for services, and desired services. The questions attempt to measure immediate need and circumstances that might make a person vulnerable to crisis. A provider agency, Care Coordinator, or a Regional Program Specialist can assist a person or their family member with completing these two forms. Once a determination of eligibility is made, the applicant is notified of the results and placed on the DD Registry. If an individual’s life situation changes significantly, a revised DD Registry Criteria Assessment may be submitted. The DD Registry is maintained by staff in the SDS Office located in Juneau, Alaska.

Scoring Criteria used for Managing the Waiting Registry

A person’s DD Registry score is figured by adding the results of the Assessment of Need determination and the credit for the length of time a person is on the registry. Each person’s standing or rank on the registry is relative to the scores of all others on the list. Consequently, a person’s rank can change depending on the relative needs of others on the registry. The form uses a numerical assessment of need; consequently the higher the need, the greater the number of points given.

Selection Methodology for Removing Persons on the Waiting Registry

Selection from the DD Waiting Registry has historically been based on crisis, not a planned methodology. With the scheduled removal of fifty persons per quarter from the registry crisis is no longer the only means by which an individual may be selected for services. However, crisis draws will always be a consideration. The number of people selected is limited by the amount of appropriation funding from the legislature including limits on enrollments in the MRDD Waiver. Quarterly reviews are conducted by SDS with DD providers and grantees to identify and allocate available funds to others in need of services.

**SECTION 3:
BASIC DEMOGRAPHIC INFORMATION
(AS 47.80.130(d)(3) & (AS 47.80.130(d)(6))**

The following demographic information represents that status of the Waiting Registry population during the State of Alaska fiscal year beginning July 1, 2005 through June 30, 2006. Since the registry is constantly evolving, these data represent the specified time period and may not reflect the current state of the registry. The historical demand for services reflects minimal variance in population, geographic distribution, and services requests over time. The following data were taken from the Praxis database the Division of Senior and Disabilities Services uses to maintain the Developmental Disabilities Waiting Registry.

Number of individuals on the list as of 11/15/2007:	943
Number of individuals 22 years old or younger as of 11/15/2007:	719
Number of individuals on the list for 90 days or more	836
Average length of time for individuals on the Registry	43 months

Age Range	Number of Individuals	Percentage
0 to 3 years of age	66	6.9
4 to 17 years of age	493	51.5
18 to 21 years of age	136	15.2
22 to 64 years of age	247	26.3
Over 65 years of age	1	<1
Total	943	100%

Gender	Number of Individuals	Percentage
Male*	584	61.9
Female	359	38.1
Total	943	100%

* This statistic is consistent with statistics on the national prevalence rate of developmental disabilities among males and females.

Race & Ethnicity of Individuals on the Waiting Registry

Race and ethnic information are being collected during the process of placement on the Registry. SDS had never collected this information prior to FY07 and such information will be provided in the FY08 report.

Geographic Distribution of Individuals on the Waiting Registry by Regional Service Area

DD Service Region	Number of Individuals	Percentage
Anchorage	413	43.8
Interior	163	17.3
Northwest	45	4.8
South-central	201	21.3
Southeast	79	8.4
Southwest	42	4.5
Total	943	100%

Services Received by Individuals on the DD Waiting Registry

Analysis of program data indicate that in FY 2007, 322 individuals on the DD Registry received some services through the DD grants program administered by SDS.

SECTION 4: NEEDS, PREFERENCES, AND ESTIMATED COST TO SERVE INDIVIDUALS ON THE WAITING REGISTRY (AS 47.80.130(d)(4))

One of the functions of the Registry Assessment is to gather information on the services individuals feel they need. These data allow the state to project the cost of serving these individuals, and assist with registry draws. Most people on the registry request more than one service, although there are some who have not requested specific services.

Projected Annual Cost

The following annual cost projection represents the Division of Senior and Disabilities Services' best estimate to serve all of the individuals on the registry who indicated a service need(s), with the assumption that they would be served in the Medicaid Waiver program. It is well-documented that not all individuals on the registry are eligible for waiver services. However, the Medicaid Waiver program reimbursement rates provide the most accurate cost data upon which to base budget projections.

In accordance with state law, SDS attempts to tailor services to meet individual needs. The average annual costs listed in the following table represent an average of the rates for service in FY 2007. Since rates were frozen in 2004, these cost estimates represent the current cost of service with the following exceptions:

1. The Care Coordination service rate is calculated assuming that an individual receives this service for an entire year.
2. Intensive Active Treatment (IAT) rates are variable depending upon the service, provider, and community in which the service is obtained. The IAT average is a good-faith estimate of the cost for this service.
3. Respite and Chore service estimates have been calculated at the maximum allowed cost, and therefore represent a liberal estimate of the cost to provide these services.
4. The Environmental Modifications cost represents the maximum allowable cost over three years of service, with the presumption that the entire cost would be granted during the first year of service.
5. The Residential Habilitation rate represents an average of the costs for all of the sub-categories that fall under this service definition (e.g. Family Habilitation, Group Home, In-Home Supports, Shared Care, and Supported Living).

Type of Service Requested	Average Annual Cost	Number of Requests	Projected Cost
Family Habilitation	\$41,150	75	\$ 3,086,250
Group Home	\$93,796	71	\$ 6,659,516
In-Home Support	\$24,138	279	\$ 6,734,502
Shared Care	\$15,297	3	\$ 45,891
Supported Living	\$46,930	83	\$ 3,895,190
Total Cost for Residential Rehabilitation Services			\$20,421,349
Respite	\$ 6,684	610	\$ 4,077,240
Supported Employment	\$11,613	234	\$ 2,717,442
Day Habilitation	\$16,220	477	\$12,067,680
Care Coordination	\$ 2,835	606	\$ 1,718,010
Intensive Active Treatment	\$ 5,235	235	\$ 1,230,225
Transportation	\$ 1,679	296	\$ 496,984
Environmental Modification	\$10,000	191	\$ 1,910,000
Chore Services	\$ 1,701	84	\$ 142,884
Total Cost			\$ 44,781,814
Total State Cost with FMAP at 50.53%			\$ 22,153,563

**SECTION 5:
NUMBER OF INDIVIDUALS SELECTED OR REMOVED FROM THE WAITING REGISTRY
(AS 47.80.130(d)(5))**

Reason for Removal	Number of Individuals
2007 Waiting registry survey never returned	290 *
Moved to another state	15
Requested to be removed	16
Selected for waiver services	100
Needs met by another DD program	344
Deceased	3
Non-responsive to division staff	4
Not eligible for DD services	33
Total	805

* It is the responsibility of the applicant to keep SDS informed of their current contact information. Should someone be selected from the Waiting Registry for comprehensive services and fail to respond to notification, they can be removed from the list. If these applicants eventually contact SDS after a prolonged absence from the state or after being taken off the list they may, with proper documentation, be placed back on the list as of the original date they were first deemed eligible for DD services. Many people have re-secured placement on the list under these conditions.

**SECTION 6:
NUMBER OF STUDENTS WITH DEVELOPMENTAL DISABILITIES IN SPECIAL EDUCATION
(AS 47.80.130 (d)(7))**

It is important to note that Special Education and the services provided through the DD Programs are different. Special Education provides specially designed instruction by in the school setting. Local education authorities under the purview of the Alaska State Department of Education and Early Development (DEED) administer these programs. The DD Program provides for services and supports in the home or community to assist the individual and their family to participate in community life and avoid institutional placement. Another key distinction between special education and the DD program is that, for those who qualify, Special Education is an entitlement; but the DD Program operates within the limits of annual legislative appropriations and the capacity of the state and community to provide the desired services.

According to the Department of Education and Early Development (DEED) there are about 17,760 students age 3 to 22 in Special Education. Among these Special Education students, approximately 3928 may have developmental disabilities. Individuals with the following types of developmental disabilities may be receiving special education services across the state: mental retardation, cerebral palsy, autism, and seizure disorder. Similarly, children with a severe emotional disorder or Fetal Alcohol Syndrome may qualify as having a developmental disability if they experience substantial limitations in functional abilities.

**SECTION 7:
COPIES OF REPORTS, POLICIES, MANUALS, AND PROCEDURES
(AS 47.80.130 (d)(8))**

Copies of this report and the forms used to manage the Registry are available on the Website of the Division of Senior and Disabilities Services at:

<http://www.hss.state.ak.us/dsds/dd/default.htm>

Copies of this report, policies, and forms used to manage the Registry may also be obtained by requesting them from the Division of Senior and Disabilities Services at the following address or phone number:

**The Division of Senior and Disabilities Services
P. O. Box 110680
Juneau, Alaska 99811-0620
(907) 465-3165
or
Toll Free at 1-866-465-3165**