

DEVELOPMENTAL DISABILITIES WAITLIST REPORT

FOR THE PERIOD OF JULY 1, 2007 THROUGH JUNE 30, 2008
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PREPARED BY:

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FOR:

The DEPARTMENT OF HEALTH AND SOCIAL SERVICES

AND

THE 25TH 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 (DD) 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 self-report 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.

The Division of Senior and Disabilities Services (SDS) and stakeholders from the advocacy community continue to work together to redevelop the policies and procedures that govern the management of the Waiting List. One of the recommendations made and adopted by the Ad Hoc Committee on the Developmental Disability Waitlist was that the Waiting List needed to be re-designed as the **DD Registry** to serve as a management tool that would provide SDS with:

- A way to differentiate when people need services
- A way to determine who meets the level of care for waiver services
- An algorithm to determine placement on the waitlist
- A way to better determine what services people need
- A way to better determine what services people already receive (including natural supports from family and friends)
- A way to get information to people about what other services they might access while they are waiting
- A way to plan and budget better
- A process for data-based decision-making
- A way to best target resources in non-crisis situations and avert future crisis (e.g., students transitioning from school to adult life, people with aging parents, those with minimal or no supports)
- A way to target requests for increments

An additional recommendation made, adopted, and implemented over FY07 was a new tool for applicants to report needs called the Developmental Disabilities Registration and Review. The Division of Senior and Disabilities Services continues to remove at least 200 individuals annually from the DD Registry via quarterly draws. The information individuals provide on the Developmental Disabilities Registration and Review tool is used to select those with the immediate and significant need from the DD Registry.

SDS is committed to eliminating the DD Registry in conjunction with the Governor's Council on Disabilities and Special Education, The Alaska Mental Health Trust Authority (AMHTA), representatives of the Alaska Association on Developmental Disabilities (AADD), and with the support of the Department of Health and Social Services and Centers for Medicaid and Medicare Services.

**SECTION 1:
THE PURPOSE OF THE DEVELOPMENTAL DISABILITIES WAITING LIST
(AS 47.80.130(d)(1))**

The 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 having 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 to be placed on the DD Registry or to participate in the Community Developmental Disabilities Grant (CDDG) program requires an individual have a developmental disability as 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 individuals must complete an Eligibility Determination application. This application provides the information needed for a DD Health Program Manager to determine eligibility. Once an individual is determined to have a developmental disability, they are notified in writing along with instructions regarding the Developmental Disabilities Registration and Review form that must then also be completed.

The Developmental Disabilities Registration and Review (DDRR) form collects information about an individual's community participation concerns, living situation concerns, caregiver concerns, and need for services, including projected timeframe for the need of a particular service. The questions attempt to measure immediate need and circumstances that might make a person vulnerable to crisis. A provider agency, Care Coordinator, SDS Staff, or any applicant representative can assist a person or their family member with completing this form either using an online submission form, emailing completed forms, or submitting completed paper copies of the form. Once a DDRR form is received and the individual is placed on the DD Registry, the applicant or their legal representative are notified in writing with information about the DD Registry and their placement status. If an individual's life situation changes significantly, a revised DDRR may be submitted at any time. The DD Registry is maintained using the SDS data management system referred to as DS3.

Scoring Criteria used for Managing the DD Registry

A person's DD Registry score is figured electronically using the DS3 system. Each question was assigned a weighted set of possible scores by the Ad Hoc Committee on the Developmental Disability Waitlist which also developed the form. 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. Individuals receive a written explanation of the scoring system along with a copy of their submission each time a new DDRR is received and scored by SDS.

Selection Methodology for Removing Persons on the DD Registry

Selection from the DD Registry is completed quarterly with the selection of at least 50 individuals with the highest need as evidenced by the highest numerical scores at the time of the draw. Individuals who have been selected from the DD Registry are notified via certified mail of their selection, including information about the "next steps". SDS Grants Unit works with DD Community Grantee Agencies to reallocate grant funds freed up by individuals selected from the DD Registry for MRDD Waiver 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 DD Registry population during the State of Alaska fiscal year beginning July 1, 2007 through June 30, 2008. Since the registry is constantly evolving, this data represents 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 was taken from the DS3 data management system, which is used by SDS to maintain the DD Registry.

Number of individuals on the list as of 6/30/2008:	845
Number of individuals 22 years old or younger as of 6/30/2008:	610
Number of individuals on the list for 90 days or more	806
Average length of time for individuals on the Registry	46 months

Age Range	Number of Individuals	Percentage
0 to 3 years of age	51	6.0
4 to 17 years of age	423	50.1
18 to 21 years of age	118	14.0
22 to 64 years of age	252	29.8
Over 65 years of age	1	<1
Total	845	100%

Gender	Number of Individuals	Percentage
Male*	508	60.1
Female	337	39.9
Total	845	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 DD Registry

Ethnicity	Number of Individuals	Percentage
Alaska Native	210	24.9
Asian	44	5.2
Black	33	3.9
Hispanic	31	3.7
Pacific Islander	10	1.2
White	496	58.7
Other	21	2.5
Total	845	100%

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

DD Service Region	Number of Individuals	Percentage
Anchorage	377	44.6
Interior	144	17.0
Northwest	48	5.7
Southcentral	172	20.4
Southeast	68	8.0
Southwest	36	4.3
Total	845	100%

Services Received by Individuals on the DD Registry

Analysis of program data indicates that in FY 2008, 517 individuals (61.2%) 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
DD Registry
(AS 47.80.130(d)(4))**

One of the functions of the Developmental Disabilities Registration and Review is to gather information on the services individuals feel they need. This data allows the state to project the cost of serving these individuals, and target 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. Approximately thirty percent of individuals selected in the quarterly draws do not end up in service because they either do not qualify for the Medicaid Waiver, decline the program or are otherwise unavailable to participate. 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 2008. Not accounted for in the cost estimates below are costs associated with provider capacity building and infrastructure to support the provision of requested services. The rates in the table shown below do reflect the 4% increase for Home and Community-Based Services that was approved by the legislature in FY08. There are some service characteristics pertaining to rates that are worth noting:

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	\$42,796.00	80	\$3,423,680
Group Home	\$99,423.76	37	\$3,678,679
In-Home Support	\$25,103.52	327	\$8,208,851
Shared Care	\$15,908.88	47	\$747,717
Supported Living	\$48,807.20	127	\$6,198,514
Total Cost for Residential Rehabilitation Services			\$22,257,441
Respite	\$6,951.36	527	\$3,663,366
Supported Employment	\$12,077.52	207	\$2,500,046
Day Habilitation	\$16,868.80	400	\$6,747,520
Care Coordination	\$2,948.40	525	\$1,547,910
Intensive Active Treatment	\$5,444.40	174	\$947,325
Transportation	\$1,746.16	270	\$471,463
Environmental Modification	\$10,000	149	\$1,490,000
Chore Services	\$1,769.04	69	\$122,063
Total Cost			\$ 39,747,134
Total State Cost with FMAP at 50.53%			\$ 19,662,907

**SECTION 5:
NUMBER OF INDIVIDUALS SELECTED OR REMOVED FROM THE DD REGISTRY
FY08
(AS 47.80.130(d)(5))**

Reason for Removal	Number of Individuals
Moved to another state	1
Requested to be removed	44
Selected for waiver services	150
Deceased	3
Not eligible for DD services	32
Total	231

* It is the responsibility of the applicant to keep SDS informed of their current contact information. Should someone be selected from the DD Registry for comprehensive services and fail to respond to notification, they can be removed from the list. If these applicants eventually contact SDS they may, with submission of a new DD Registration and Review form, be placed back on the list.

**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 17,536 students age 3 to 22 in Special Education. Among these Special Education students, approximately 4057 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
3601 C Street, Suite 310
Anchorage, Alaska 99503
(907) 269-3666
or
Toll Free at 1-800-478-9996**