

DEVELOPMENTAL DISABILITIES WAITING LIST REPORT

AN ANNUAL REPORT ON THE DEMOGRAPHICS AND PUBLIC POLICY ISSUES

FOR THE PERIOD OF JULY 1, 2004 THROUGH JUNE 30, 2005



DECEMBER 2005

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FOR:

DEPARTMENT OF HEALTH AND SOCIAL SERVICES
AND
THE 24TH ALASKA LEGISLATURE

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PREFACE:
ABOUT THE DEVELOPMENTAL DISABILITIES WAITING LIST REPORT

Under AS 47.80.130 (6)(d), the Department of Health and Social Services is required to operate a Waiting List and provide an annual Waiting List Report to the Governor and specified legislative committees when there is not adequate funding to meet the needs of people with developmental disabilities who would be eligible to receive state-funded services under AS 47.80.100 - 47.80.170. The full text of the statute governing generation of this report is found in attachment A and each Section of this report matches a specific requirement in the law.

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. No centralized database exists to easily determine what services, if any, a person on the Waiting List is currently receiving, how services a client is receiving relate to the client's needs as expressed in the client's Waiting List Criteria 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 at best 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 (DSDS) and stakeholders from the advocacy community are working together to redevelop the policies and procedures that govern the management of the Waiting List. This committee is currently in the process of drafting recommendations to present to the Department of Health and Social Services in the spring of 2006. At the same time DSDS staff and individuals from Central Information Technology (CIT) are working together to develop a new database, and tracking methodology for individuals on the waitlist.

SECTION 1:
THE PURPOSE OF THE DEVELOPMENTAL DISABILITIES (DD) WAITING LIST
(AS 47.80.130 (6)(d)(1))

The DD Waiting List is a tool used to gather information regarding people who have been determined eligible for developmental disability services and used to select people for enrollment in services when resources are available. Additionally, the DD Waiting List 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 List 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;
- Reflect 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 (6)(d)(2))

In order for a person to be eligible for the DD Program they must fill out an Eligibility Determination application. This form provides the information needed for a DD Program Specialist to determine eligibility. In addition to the Eligibility Determination application, a Waiting List Criteria Assessment must also be completed.

The Assessment asks about an individual's current 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 Waiting List. The DD Waiting List is maintained in the Central Office by staff located in Juneau, Alaska.

If an individual's life situation changes significantly, a revised DD Waiting List Criteria Assessment may be submitted. Some types of life changes, such as the death of a parent or the individuals declining health, may put the person at risk of institutionalization. Consequently, a "reassessment" may increase the original score.

Scoring Criteria used for Managing the Waiting List (thru FY 05)

A person's DD Waiting List score is figured by adding the results of the Assessment of Need and the credit for the length of time a person is on the Waiting List. The maximum points from the DD Waiting List Assessment of Need are 225. For a total not to exceed 60 points, an applicant also receives one point for each month they are on the list. Each person's standing or rank on the list is relative to the scores of all others on the list. Consequently, a person's rank order can change depending on the relative needs of others on the Waiting List.

In order to understand the scoring associated with Waiting List Criteria Assessments, refer to the scoring definitions located after each of the five questions on the enclosed attachments. Twenty points are automatically awarded for question #5 about adequate supports if no other questions are answered "yes." An additional point is then awarded for the first month's wait time. The maximum number of points a consumer can receive is 285. This is only possible if the individual fully meets the criteria of all five questions and gets the maximum 60 points for their months on the list. The form uses a numerical assessment of need; consequently the higher the need, the greater the number of points given. For example: if the consumer is a documented threat to him/herself or others, homeless, or among a category of individuals prioritized for services by a legislative appropriation, 100 points are allocated toward the total score.

Given the financial resources available to the Division of Senior and Disabilities time has not been a significant factor in determining an individual's selection from the Waiting List. The individuals who have been selected from the Waiting List within the past year have been persons in crisis or with the highest immediate needs.

DSDS has convened an Ad Hoc Waiting List Committee to review these procedures and make recommendations on how to more equitably manage the Waiting List.

Selection Methodology for Removing Persons on the Waiting List

Using the method of ranking described above, selection from the DD Waiting List has been historically based on who has the highest need and who has been on the list the longest. The number of people selected is limited by the amount of appropriation from the legislature including limits on enrollments in the MRDD Waiver. Besides an increase in legislative appropriation, resources may become available when a person leaves the DD Program or a family does not utilize all the resources allocated to them. Quarterly reviews are conducted with DD providers and grantees to identify and allocate available funds to others in need of services.

“Highest Need” can be defined as those consumers whose circumstances are determined to require immediate and comprehensive long-term supports. After all else has failed, intermediate interventions have been tried, and the need for long-term care persists, individuals may be selected from the Waiting List according to the following “Highest Needs” criteria that may place them at imminent risk of harm:

- Those who are in imminent risk of substantial harm or significant regression;
- An individual living in an unsafe or unhealthy circumstance;
- An individual whose medical or behavioral needs are creating a hazard;
- An individual without supports who is at risk of involvement with the Justice System;
- An individual at risk of institutionalization in a psychiatric hospital, nursing home, or jail who would be unable to live in the community without supports, or;
- An individual living with a caregiver who no longer is able to continue in that capacity such as in the death of a parent.

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

The following demographic information represents that status of the Alaska Developmental Disabilities Waiting List population during the State of Alaska fiscal year beginning July 1, 2004 through June 30, 2005. Since the waitlist is a constantly revolving registry, this data only represents a snapshot of the waitlist during the specified time period and may not be reflective of the current state of the waitlist. Given historical precedent and the steady demand for developmental disabilities services however, the waitlist data sees minimal variance in population, geographic distribution, and demand for services over time. Therefore, the following data can be viewed with a high degree of reliability.

All of the following data was culled from the Praxis database that the Division of Senior and Disabilities Services uses to maintain the Developmental Disabilities Waiting List. This information represents the most comprehensive and accurate information to date regarding the Waiting List.

Basic Data for Individuals on the Developmental Disabilities Waiting List

Number of individuals on the list as of 6/30/2005:	1,233
Number of individuals 22 years old or younger as of 6/30/2005:	1,004
Number of individuals on the list for 90 days or more	1,142
Average length of time for individuals on the Waiting List	3.1 years

Age Ranges of Individuals on the Waiting List

Age Range	Number of Individuals	Percentage
0 to 3 years of age	110	9%
4 to 17 years of age	683	55.4%
18 to 21 years of age	175	14.2%
22 to 64 years of age	264	21.4%
Over 65 years of age	1	>1%
Total	1,233	100%

Gender of Individuals on the Waiting List

Gender	Number of Individuals	Percentage
<i>Male*</i>	757	61.4%
<i>Female</i>	476	38.6%
Total	1,233	100%

**This statistic is consistent with statistics on the national prevalence rate of developmental disabilities among males and females. In general, there are more males with developmental disabilities than females.*

Race & Ethnicity of Individuals on the Waiting List

Because race and ethnic background is not considered when determining eligibility for developmental disabilities services or in the selection process from the Waiting List, the Division of Senior and Disabilities Services have never collected this information. As a result, we are unable to report the race or ethnicity at this time. In order to meet the mandate of AS 47.80.130 (6)(d)(3), the Division of Senior and Disabilities Services has begun to collect data on the race and ethnicity of individuals on the Waiting List, and will be able to report on this statistic in next year's Waiting List report.

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

DD Service Region	Number of Individuals	Percentage
Southcentral Region: includes Anchorage, Mat-Su, Kenai Peninsula, PW Sound, Kodiak, Aleutian Chain, and Dillingham	797	64.6%
Northern Region: includes Fairbanks, the Interior, Bethel, and NW Alaska	328	26.6%
Pacific Coast Region: includes Cordova, Haines, Juneau, Sitka, south to Ketchikan	108	8.8%
Total	1,233	100%

Services Received by Individuals on the DD Waiting List

Analysis of program data indicates that in FY 2005, 565 (46%) individuals on the DD Waiting List received some services through the DD grants program administered by DSDS. Another 177 (14.4%) individuals received short-term assistance through the DSDS administered Short Term Assistance and Referral (STAR) program.

**SECTION 4:
NEEDS, PREFERENCES, AND ESTIMATED COST TO SERVE INDIVIDUALS ON THE
WAITING LIST
(AS 47.80.130 (6)(d)(4))**

One of the functions of the Waiting List assessment is to gather information on the services individuals feel they will need. This data allows the state to rank individuals who have more intensive service needs, project the cost for serving these individuals, and target Waiting List draws when a slot opens up for a specific service. The DD Program has developed an array of residential care ranging from supporting people in their own homes or the homes of their parents, to out of home placements. A definition of each of the services provided by the DD program is included at the end of this report as Attachment C.

Most people on the developmental disabilities Waiting List request more than one service, although there are some who have not requested any specific services. One of the service categories listed in the Waiting List database is "Unknown Service 11". This service category was removed from the service list in the table below. 10 individuals were listed as needing "Unknown Service 11". There are also 342 individuals on the Waiting List that did not identify a specific service that they needed. For this report, these two groups have been combined for a total count of 352 individuals with unidentified service needs.

Projected Annual Cost

Based upon the responses for types of services requested by persons when they complete a DD Waiting List Assessment, the following annual cost projection represents the Division of Senior and Disabilities Services' best estimate to serve all of the individuals on the Waiting List who indicated a service need(s), with the assumption that they would be served in the Medicaid Waiver program. Although it is well-documented that not all individuals on the Waiting List are eligible for waiver services, the Medicaid Waiver program service rates provide the most accurate cost data upon which to base budget projections.

These cost projections should at best 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. In accordance with state law, the DD Program attempts to tailor services to meet individual needs. Because the services that people receive are the result of individualized planning, determining the exact cost of meeting the needs of those on the DD Waiting List is difficult at best.

The average annual costs listed in the following table represent an average of the rates for service in FY 2004. Since rates were frozen in 2004, these cost estimates represent the current cost of service with the following exceptions:

1. \$8.65 per day has been added to 24-hour care rates to reflect the recent regulatory change in this service category.
2. The Care Coordination service rate is calculated assuming that an individual receives this service for an entire year, and therefore represents a generous estimate of the cost of this service.
3. 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.

4. 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.
5. 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.
6. 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). As such it represents an estimate of the cost for serving the 196 individuals who specified this service.
7. There is no rate given for Specialized Equipment since the range of equipment requested and the demand for equipment is highly variable and does not lend itself easily to calculating an average cost.

Services Requested by Individuals on the Waiting List and Projected Cost

Type of Service Requested	Average Annual Cost	Number of Requests	Total Projected Cost
Residential Habilitation	\$34,167	196	\$ 6,696,732
- Family Habilitation	\$30,700	8	\$ 245,600
- Group Home	\$70,300	14	\$ 984,200
- In-Home Support	\$16,569	210	\$ 3,479,490
- Shared Care	\$15,414	9	\$ 138,726
- Supported Living	\$37,854	154	\$ 5,829,516
Total Cost for All Requested Residential Rehabilitation Services			\$17,374,264
Respite	\$12,673	714	\$ 9,048,522
Supported Employment	\$ 9,996	351	\$ 3,508,596
Day Habilitation	\$10,725	289	\$ 3,099,525
Care Coordination	\$ 3,150	277	\$ 872,550
Specialized Equipment	N/A	159	N/A
Intensive Active Treatment	\$ 5,000	141	\$ 705,000
Transportation	\$ 806	93	\$ 74,958
Environmental Modifications	\$10,000	23	\$ 230,000
Chore Services	\$ 8,980	15	\$ 134,700
		Total Cost	\$35,048,115
		Total State Cost with FMAP at 50%	\$17,524,058
		Total State Cost with FMAP at 57%	\$15,070,689

**SECTION 5:
NUMBER OF INDIVIDUALS SELECTED OR REMOVED FROM THE WAITING LIST
(AS 47.80.130 (6)(d)(5))**

The following table represents the individuals removed from the Waiting List in FY 2005.

Number of Individuals Removed From the Waiting List in FY 2005

Reason for Removal	Number of Individuals
2004 Waiting List survey never returned	606*
Moved to another state	11
Requested to be removed	9
Selected for waiver services	63**
Needs met by another DD program	8
Deceased	4
Non-responsive to division staff	4
Not eligible for DD services	3
Total	705

** It is the responsibility of the applicant to keep DSDS informed of their current contact information. Should someone be selected from the Waiting List for comprehensive services and fail to respond to notification, they can be removed from the list. If these applicants eventually contact DSDS 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.*

*** Although 60 individuals have been selected for MRDD services only 49 Plans of Care have been submitted to DSDS at the present time.*

During FY 05, the DD Program selected a total of 63 consumers from the DD Waiting List for comprehensive services or long-term care. Those who were selected had the highest scores on the Waiting List because a crisis situation placed them at risk of harm that could not be addressed with short-term assistance measures. There were also 8 individuals who were removed from the List after their needs were met by other programs.

Other individuals were removed from the List for various reasons such as moving to another state (11) or they died (4) as a result illness or accident unrelated to their needs for more comprehensive services or long term care.

SECTION 6:
NUMBER OF STUDENTS WITH DEVELOPMENTAL DISABILITIES IN SPECIAL EDUCATION
(AS 47.80.130 (6)(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 18,000 students age 3 to 22 in Special Education. Among these Special Education students, approximately 4000 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 function.

The numbers below reflect DEED categories for students with Autism, Mental Retardation, Traumatic Brain Injury, & Multiple Disabilities.

As of December 15, 2005, the Department of Education and Early Development reports that:

- The number of students in Special Education with developmental disabilities graduating from high school with a regular diploma was 61;
- The number of students in Special Education with developmental disabilities dropping out of high school by age 22 was 14, and 3 students aged out of special education services; and
- The number of students in Special Education with developmental disabilities who by age 22 do not graduate from high school with a regular diploma but receive Certificate of Completion was 31.

**SECTION 7:
COPIES OF REPORTS, POLICIES, MANUALS, AND PROCEDURES
(AS 47.80.130 (6)(d)(8))**

Copies of this report and the forms used to manage the Waiting List 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 Waiting List 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
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Juneau, Alaska 99811-0620
(907) 465-3165
or
Toll Free at 1-866-465-3165**