

DEVELOPMENTAL DISABILITIES Registry Report

Fiscal Year 2010
JULY 1, 2009 THROUGH JUNE 30, 2010



PREPARED BY:

THE DIVISION OF SENIOR AND DISABILITIES

Duane Mayes MS, CRC, CDMS, Director SDS
Kathi Potter RN, MA, Chief of Operations, SDS
Chris Hamilton, MBA, Research Analyst SDS
Missy Williams, IDD Unit Manager, SDS

FOR:

The DEPARTMENT OF HEALTH AND SOCIAL SERVICES

AND

THE 27TH ALASKA LEGISLATURE

TABLE OF CONTENTS

PREFACE: ABOUT THE DEVELOPMENTAL DISABILITIES REGISTRY REPORT

SECTION 1: THE PURPOSE OF THE DEVELOPMENTAL DISABILITIES REGISTRY

SECTION 2: PLACEMENT ON THE REGISTRY AND THE CRITERIA FOR RANKING AND SELECTION

SECTION 3: BASIC DEMOGRAPHIC INFORMATION

SECTION 4: NEEDS, PREFERENCES, AND ESTIMATED COST TO SERVE INDIVIDUALS ON THE REGISTRY

SECTION 5: NUMBER OF INDIVIDUALS SELECTED OR REMOVED FROM THE REGISTRY

SECTION 6: NUMBER OF STUDENTS WITH DEVELOPMENTAL DISABILITIES IN SPECIAL EDUCATION

SECTION 7: COPIES OF REPORTS, POLICIES, MANUALS, AND PROCEDURES

ABOUT THE DEVELOPMENTAL DISABILITIES REGISTRY

Under AS 47.80.130 (d), the Department of Health and Social Services is required to maintain a Registry denoting individuals who 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, an individual on the Registry is receiving, how services relate to their needs as expressed in their individual assessment form, or whether the services requested are needed immediately or may be needed sometime in the future. Therefore, cost projections included 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 individual on the list.

The Division of Senior and Disabilities Services (SDS) and stakeholders from the advocacy community, continue to work together to review and update the policies and procedures that govern the management of the Registry, renamed by the Ad Hoc Committee to more appropriately reflect its intent and use. The Developmental Disabilities Registration and Review is the tool that is used to assess the individual's needs. The information individuals provide on the Developmental Disabilities Registration and Review tool is used to select those with the immediate and significant need for services. The Division of Senior and Disabilities Services continues to remove at least 200 individuals annually from the DD Registry via quarterly draws.

In conjunction with the Governor's Council on Disabilities and Special Education, the Alaska Mental Health Trust Authority (AMHTA), 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 (CMS), SDS is committed to eliminating the DD Registry.

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

The DD Registry includes eligibility criteria outlining what is required to be determined qualified for developmental disability services and is used to select individuals 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 individuals who have 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.

In order to be eligible to be placed on the DD Registry or to participate in the Community Developmental Disabilities Grant (CDDG) program, an individual must 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 REGISTRY AND THE CRITERIA FOR RANKING AND SELECTION (AS 47.80.130(d)(2))

In order for an individual to be eligible for the DD Registry, they must complete an Eligibility Determination application. The application provides information needed in order for a DD Health Program Manager to determine their 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 the individual must complete.

The Developmental Disabilities Registration and Review (DDRR) form incorporates 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 an individual vulnerable to crisis. A provider agency, Care Coordinator, or SDS Staff, or any applicant representative can assist an individual or their family member to complete the form using an online submission form, emailing completed forms, or submitting completed paper copies. Once a DDRR form is received and the individual is placed on the DD Registry, the applicant or their legal representative is notified in writing of their placement status on the DD Registry. 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 Waiting List

A person's DD Registry score is tabulated electronically using the DS3 system. The Registry (Waiting List) Ad Hoc Committee developed the form and assigned a weighted set of possible scores. An individual's standing or rank on the registry is relative to the scores of all of the others individuals on the list. Consequently, an individual's position may 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 that are 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 Waiting List

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 for services, 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 Registry population during the State of Alaska fiscal year beginning July 1, 2009 through June 30, 2010. 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 6/30/2010:	1052
Number of individuals 22 years old or younger as of 6/30/2010:	740
Number of individuals on the list for 90 days or more	823
Average length of time for individuals on the Registry	52 months

Age Range	Number of Individuals	Percentage
0 to 3 years of age	55	5.2%
4 to 17 years of age	482	45.8%
18 to 21 years of age	166	15.8%
22 to 64 years of age	348	33.1%
Over 65 years of age	1	<1
Total	1052	100%

Gender	Number of Individuals	Percentage
Male*	643	61.1%
Female	409	38.9%
Total	1052	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 List

Ethnicity	Number of Individuals	Percentage
Alaska Native	262	24.9%
Asian	41	3.9%
Black	40	3.8%
Hispanic	21	2.0%
Pacific Islander	13	1.2%
White	601	57.1%
Other	74	7.0%
Total	1052	100%

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

DD Service Region	Number of Individuals	Percentage
Anchorage	475	45.2%
Interior	154	14.6%
Northwest	44	4.2%
Southcentral	216	20.5%
Southeast	83	7.9%
Southwest	80	7.6%
Total	1052	100%

Services Received by Individuals on the DD Waiting List

Analysis of program data indicates that in FY 2010, 560 individuals (53.2%) 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
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 2010. 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 FY10. 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	126	\$ 5,392,296
Group Home	\$ 99,423.76	99	\$ 9,842,952
In-Home Support	\$ 25,103.52	540	\$ 13,555,901
Shared Care	\$ 15,908.88	88	\$ 1,399,981
Supported Living	\$ 48,807.20	238	\$ 11,616,114
Total Cost for Residential Rehabilitation Services			\$ 41,807,244
Respite	\$ 6,951.36	705	\$ 4,900,709
Supported Employment	\$ 12,077.52	393	\$ 4,746,465
Day Habilitation	\$ 16,868.80	652	\$ 10,998,458
Care Coordination	\$ 2,948.40	808	\$ 2,382,307
Intensive Active Treatment	\$ 5,444.40	273	\$ 1,486,321
Transportation	\$ 1,746.16	473	\$ 825,934
Environmental Modification	\$ 10,000	216	\$ 2,160,000
Chore Services	\$ 1,769.04	111	\$ 196,363
Total Cost			\$ 69,503,801
Total State Cost with FMAP at 50.53%			\$ 34,383,531

**SECTION 5:
NUMBER OF INDIVIDUALS SELECTED OR REMOVED FROM THE REGISTRY
FY10
(AS 47.80.130(d)(5))**

Reason for Removal	Number of Individuals
Needs met by another DD program	5
Selected for waiver services	205
Deceased	1
Moved to another state	5
Non-responsive to request for information	17
Requested to be removed from list	1
Not eligible for DD services	51
Total	285

* It is the responsibility of the applicant to keep SDS informed of their current contact information. Should someone be selected from the 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 17,893 students age 3 to 22 in Special Education. Among these Special Education students, approximately 4,054 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
550 W. 8th Ave.
Anchorage, Alaska 99501
(907) 269-3666
or
Toll Free at 1-800-478-9996**