

# INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES REGISTRY REPORT

Fiscal Year 2011  
July 1, 2010 through June 30, 2011



PREPARED BY:

THE DIVISION OF SENIOR AND DISABILITIES SERVICES

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And the

27<sup>TH</sup> ALASKA LEGISLATURE

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## **ABOUT THE INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES REGISTRY**

Under Alaska Statute at AS 47.80.130(d), the Department of Health and Social Services is required to maintain a Registry of individuals who have been assessed and found to experience an intellectual or developmental disability as defined in 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 intellectual or developmental disabilities may receive a variety of services administered and funded by multiple federal, state, and local agencies.. The Developmental Disabilities Registration and Review (DDRR) is the process used to assess an individual's needs. The information individuals provide on the DDRR tool is used to select those with the most immediate and significant need for services. The DDRR also reflects what services, if any, an individual on the Registry is receiving, how services relate to their needs as expressed in their individual assessment form, and whether the services requested are needed immediately or may be needed sometime in the future. Therefore, cost projections included in this report are estimates for 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) continues to select at least 200 individuals annually from the Registry for consideration of their eligibility for a Medicaid waiver.

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 INDIVIDUALS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES (IDD) REGISTRY (AS 47.80.130(d)(1))**

The IDD Registry is used to select individuals for enrollment in services when resources are available. Additionally, the IDD Registry assists the Division of Senior and Disabilities Services (SDS) in planning for the future needs of individuals who have an intellectual or developmental disability. To ensure information is current, SDS requests that those on the IDD Registry update information about changes in their condition or family circumstances annually.

In order to be eligible to be placed on the IDD 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 6. 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 an individual to be eligible for the IDD Registry, they must complete an Eligibility Determination application. If an applicant is determined to have an intellectual or developmental disability as defined by AS 47.80.900(6), the individual and/or their guardian is notified in writing along with instructions regarding the Developmental Disabilities Registration and Review form that the individual and/or their guardian must complete in order to be placed on the Registry.

The Developmental Disabilities Registration and Review (DDRR) form incorporates information about an individual's community participation, living situation, caregiver, and need for services, including projected timeframe for when the service may be needed. The questions assess immediate need and circumstances that might make an individual vulnerable to crisis. A Short Term Assistance and Referral (STAR) provider, Care Coordinator, SDS staff, or any applicant representative can assist an individual or their family member to complete the form using the online submission form, by emailing completed forms, or submitting completed paper copies. Once a DDRR form is received and the individual is placed on the IDD Registry, the applicant or their legal representative is notified in writing of their placement status on the IDD Registry. If an individual's life situation changes significantly, a revised DDRR may be submitted at any time. The IDD Registry is maintained using the SDS data management system referred to as DS3.

#### **Scoring Criteria used for Managing the IDD Registry**

A person's IDD Registry score is tabulated electronically using the DS3 system. The Registry 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 IDD Registry**

Quarterly, SDS selects the 50 highest need individuals from the IDD Registry. Individuals who have been selected are notified via certified mail of their selection for services, including information about the "next steps". The SDS Grants Unit works with IDD Community Grantee Agencies to reallocate grant funds freed up by individuals selected from the IDD 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, 2010 through June 30, 2011. Since the registry population does not remain static, 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 IDD Registry.

Number of individuals on the IDD Registry as of 6/30/2011:	<b>916</b>
Number of individuals 22 years old or younger as of 6/30/2011:	<b>663</b>
Number of individuals on the list for 90 days or more	<b>840</b>
Average length of time for individuals on the IDD Registry	<b>50 months</b>

Age Range	Number of Individuals	Percentage
0 to 3 years of age	63	6.9%
4 to 17 years of age	431	47.1%
18 to 21 years of age	136	14.9%
22 to 64 years of age	284	31.0%
Over 65 years of age	2	<1
<b>Total</b>	916	100%

Gender	Number of Individuals	Percentage
Male*	575	62.8%
Female	341	37.2%
<b>Total</b>	916	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 IDD Registry**

<b>Ethnicity</b>	<b>Number of Individuals</b>	<b>Percentage</b>
Alaska Native	261	28.5%
Asian	42	4.6%
Black	49	5.3%
Hispanic	33	3.6%
Pacific Islander	14	1.5%
White	473	51.6%
Other	44	4.8%
<b>Total</b>	916	100%

**Geographic Distribution of Individuals on the IDD Registry  
by Regional Service Area**

<b>IDD Service Region</b>	<b>Number of Individuals</b>	<b>Percentage</b>
Anchorage	408	44.5%
Interior	123	13.4%
Northwest	19	2.1%
Southcentral	210	22.9%
Southeast	87	9.5%
Southwest	69	7.5%
<b>Total</b>	916	100%

**Services Received by Individuals on the IDD Registry**

Analysis of program data indicates that in FY 2011, 552 individuals (60.3%) on the IDD 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 estimate 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's best estimate of funds needed to serve all of the individuals on the registry who indicate 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 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 2011. Not accounted for in the cost estimates below are costs associated with provider capacity building and infrastructure to support the provision of requested services. 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).

<b>Type of Service Requested</b>	<b>Average Annual Cost</b>	<b>Number of Requests</b>	<b>Projected Cost</b>
Family Habilitation	\$ 42,135.43	112	\$4,719,168
Group Home	\$104,073.41	121	\$12,592,883
In-Home Support	\$ 13,615.26	499	\$6,794,015
Shared Care	\$ 19,628.37	86	\$1,688,040
Supported Living	\$ 42,075.39	237	\$9,971,867
<b>Total Cost for Residential Rehabilitation Services</b>			<b>\$35,765,973</b>
Respite	\$6,471.76	634	\$4,103,096
Supported Employment	\$13,659.05	347	\$4,739,690
Day Habilitation	\$19,765.23	646	\$12,768,339
Care Coordination	\$2,525.85	731	\$1,846,396
Intensive Active Treatment**	\$5,444.40	226	\$1,230,434
Transportation	\$3,040.87	410	\$1,246,757
Environmental Modification	\$6,753.62	198	\$1,337,217
Chore Services	\$2,319.94	91	\$211,115
<b>Total Cost</b>			<b>\$ 63,249,016</b>
<b>Total State Cost with FMAP at 50.53%</b>			<b>\$ 31,959,728</b>

\*\* Average Annual Cost for Intensive Active Treatment from FY 2010 was used because no services IAT services were paid for during FY 2011

**SECTION 5**

**NUMBER OF INDIVIDUALS SELECTED OR  
REMOVED FROM THE REGISTRY  
FY11  
(AS 47.80.130(d)(5))**

<b>Reason for Removal</b>	<b>Number of Individuals</b>
Needs met by another IDD program	1
Selected for waiver services	208
Deceased	1
Moved to another state	10
Non-responsive to request for information	88
Requested to be removed from list	6
Not eligible for IDD services	102
<b>Total</b>	<b>416</b>

\* 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 IDD 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 IDD Waiver Program are different. Special Education provides specially designed instruction 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 IDD Waiver 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 IDD Waiver program is that, for those who qualify, Special Education is an entitlement; but the IDD Waiver 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 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 or intellectual 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 IDD 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. 8<sup>th</sup> Ave.**

**Anchorage, Alaska 99501**

**(907) 269-3666**

**or**

**Toll Free at 1-800-478-9996**