

# INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES Registration and Review Report

Fiscal Year 2016  
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**FOR:**

The DEPARTMENT OF HEALTH AND SOCIAL SERVICES

**AND**

THE ALASKA LEGISLATURE

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## **Preface: About the Developmental Disabilities Registration and Review**

Under AS 47.80.130 (d), the Department of Health and Social Services (DHSS) is required to maintain a waitlist denoting persons who experience a developmental disability who would be eligible to receive state –funded services. 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 all individuals determined to have a developmental disability. Senior and Disabilities Services (SDS) utilizes the Developmental Disabilities Registration and Review (DDRR) as the waitlist tool to assess an individual’s current service needs. Information provided through the DDRR is used to determine who is offered the opportunity to request services through Medicaid’s Home and Community Based (HCB) Intellectual/Developmental Disabilities (I/DD) waiver in a fiscal year. Additionally, the DDRR provides predictive information the State of Alaska (SOA) uses for program planning and management.

The DDRR is at its basic a waitlist tool. The DDRR provides the State and other stakeholders’ information on the current needs and preferences of the individuals and families waiting for expanded supports services.

Cost projections included in this report should be considered estimates to use in planning and not a computation of the actual cost of comprehensive services necessary to meet the needs of each individual on the list.

## **Section 1: The Purpose of the Developmental Disabilities Registration and Review (AS 47.80.130(d) (1))**

The DDDR is used to select individuals for enrollment in HCB I/DD waiver services when resources are available. Additionally, the DDDR assists Senior and Disabilities Services in planning for the future needs of individuals who have a developmental disability. To ensure SDS has credible information, SDS requests that individuals on the DDDR update information about changes in their condition or family circumstances at least annually.

In order to be eligible to be placed on the DDDR an individual must have a developmental disability as defined under the provisions of AS 47.80.900 (6). “Person with developmental disability” means a person who is experiencing 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 included on the DDDR, they must complete an Eligibility Determination application: <http://dhss.alaska.gov/dsds/Documents/SDSforms/IDD-01-eligibility-application.pdf>. The application for services provides SDS information needed to make a determination of if the applicant meets the standard outlined in AS 47.80.900(6). If an individual is determined to have a developmental disability the individual/guardian is notified in writing. The approval letter contains information about current grant supports available and/or the option of registering to be considered for long term supports.

The Developmental Disabilities Registration and Review (DDRR) form is available to be completed online or paper format. Questions on the form are designed to gather information about an individual's community participation skills, living situation, caregiver needs, and desired services. These questions were designed by community stakeholder group. Answers to questions on the form also provide projected timeframes for the need of a particular service. The DDDR attempts to measure the immediate needs and circumstances of each individual on the list and weigh them against the needs of all applicants.

The registration process can be completed by any participant, their Short Term Assistance and Referral (STAR) provider, Care Coordinator, or designated representative. The DDDR is available to be completed online. Online submission is the preferred method of the Division. In rare instances, the Division accepts paper copies. Once a DDDR form is received it is scored by a Qualified Intellectual Disability Professional (QIDP). The applicant or their legal representative is notified in writing of their placement (score) on the DDDR. If an individual's life situation changes a revised DDDR may be submitted to SDS at any time. The Registry is currently maintained using the SDS data management system referred to as DS3.

### **Scoring Criteria used for Managing the DDDR**

After review by SDS, a person's DDDR score is tabulated electronically using the DS3 system. The Registry (Wait List) Ad Hoc Committee developed the current form in use and assigned a weighted set of possible scores to each question. 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 DDDR is received and scored by SDS.

### **Waiver Selection Methodology for Persons on the DDDR**

SDS conducts average monthly "draws" from the list of the 4 highest scoring individuals. Per approved waiver application 50 individuals a year are "drawn" from the registry. The Selected individuals are notified via certified mail of the opportunity to possibly utilize HCB waiver services. This notice includes information about the Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) Level of Care (LOC) process.

If an individual is approved for Medicaid waiver supports any funds they might have previously been utilizing to purchase services are reallocated. To ensure that all people in need of care in Alaska have access to needed supports the SDS Grants Unit works closely with DD Community Grantee Agencies to quickly redistribute funds.

**Section 3: Basic Demographic Information  
(AS 47.80.130(d)(3))**

The following demographic information represents the status of the Registry population during the State of Alaska fiscal year beginning July 1, 2015 through June 30, 2016. 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 DDDR.

|   |                  |
|---|------------------|
| Number of individuals on the DDDR as of 6/30/2016:              | <b>535</b>       |
| Number of individuals 22 years old or younger as of 6/30/2016:  | <b>383</b>       |
| Number of individuals on the list for 90 days or more:          | <b>518</b>       |
| Average length of time for individuals currently on the DDDR**: | <b>45 months</b> |

\*\* It must be noted that while the average length of stay on the DDDR is currently estimated at nearly 4 years many of these individuals have very low scores and are receiving early intervention, school and/or grant-funded supports, or other community services. They may be on the DDDR for an extended period of time because their need for expanded supports is not acute.

For the individuals removed from the waitlist during FY 2016 (7/1/2015 – 6/30/2016) for the reason of “selected for the waiver” the average number of months on the waiver (number of months from first survey to removed date) is 27 months. 142 out of 189 participants spent less than two years on the DDDR.

For all individuals who were removed from the list during FY 2016 (all reasons, not just selected for waiver) the average stay was 39 months.

**Age of Individuals on the IDD Registry**

| <b>Age Range</b>      | <b>Number of Individuals</b> | <b>Percentage</b> |
|-----------------------|------------------------------|-------------------|
| 0 to 3 years of age   | 9                            | 2%                |
| 4 to 17 years of age  | 272                          | 51%               |
| 18 to 21 years of age | 73                           | 14%               |
| 22 to 64 years of age | 165                          | 31%               |
| Over 65 years of age  | 3                            | 1%                |
| Unknown               | 13                           | 2%                |
| <b>Total</b>          | <b>535</b>                   | <b>100%</b>       |

**Gender of Individuals on the IDD Registry**

| <b>Gender</b> | <b>Number of Individuals</b> | <b>Percentage</b> |
|---------------|------------------------------|-------------------|
| Male          | 355                          | 66%               |
| Female        | 180                          | 34%               |
| <b>Total</b>  | <b>535</b>                   | <b>100%</b>       |

**Race & Ethnicity of Individuals on the IDD Registry**

| <b>Ethnicity</b> | <b>Number of Individuals</b> | <b>Percentage</b> |
|------------------|------------------------------|-------------------|
| Alaska Native    | 158                          | 30%               |
| Asian            | 32                           | 6%                |
| Black            | 22                           | 4%                |
| Hispanic         | 30                           | 6%                |
| Pacific Islander | 5                            | 1%                |
| White            | 237                          | 44%               |
| Other            | 51                           | 10%               |
| <b>Total</b>     | <b>535</b>                   | <b>100%</b>       |

**Service Region of Individuals on the IDD Registry**

| <b>IDD Service Region</b> | <b>Number of Individuals</b> | <b>Percentage</b> |
|---------------------------|------------------------------|-------------------|
| Anchorage                 | 237                          | 44%               |
| Interior                  | 55                           | 10%               |
| Northwest                 | 16                           | 3%                |
| Southcentral              | 137                          | 26%               |
| Southeast                 | 25                           | 5%                |
| Southwest                 | 44                           | 8%                |
| Unknown                   | 21                           | 4%                |
| <b>Total</b>              | <b>535</b>                   | <b>100%</b>       |

**Grant Services Received by Individuals on the DDDR**

Analysis of program information indicates that in FY 2016, 232 individuals received some services through SDS grant funded programs. Of 535 individuals registered 43% were receiving supports.

**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 DDDR is to gather information on the services individuals feel would best help them be in the most inclusive setting within their community. This data allows the state to project the cost of serving these individuals and to 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 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. Not all individuals on the registry will be eligible for waiver services. For example, approximately 36 (19%) of individuals selected in this past year did not end up in active waiver status. There are a myriad of reasons why individuals do not move into waiver services, e.g. they may not qualify for Medicaid, they decline participation, they leave the state, or they do not meet Level of Care.

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 2016. 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. 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.
3. 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.
4. 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, 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                                     | \$41,245                   | 82                        | \$3,382,106***          |
| Group Home  | \$108,033                  | 66                        | \$7,130,204             |
| In-Home Support   | \$13,668                   | 334                       | \$4,565,095             |
| Supported Living  | \$41,534                   | 144                       | \$5,980,957             |
| <b>Total Cost for Residential Habilitation Services</b> |                            |                           | \$21,058,363            |
| Respite   | \$6,047                    | 399                       | \$2,412,691             |
| Supported Employment                                    | \$17,036                   | 197                       | \$3,356,182             |
| Day Habilitation  | \$23,292                   | 436                       | \$10,155,504            |
| Care Coordination                                       | \$2,819                    | 474                       | \$1,336,301             |
| Intensive Active Treatment                              | \$8,204                    | 131                       | \$1,074,740             |
| Transportation  | \$3,301                    | 244                       | \$805,465               |
| Environmental Modification                              | \$5,787                    | 109                       | \$630,812               |
| Chore Services  | \$2,793                    | 64                        | \$178,725               |
| <b>Total Cost</b>                                       |                            |                           | \$41,008,784****        |
| <b>Total State Cost with FMAP at 50%</b>                |                            |                           | \$20,504,391            |

\*\* The source of data for the average cost per individual comes from COGNOS a reporting tool for the Alaska Medical Assistance Health Enterprise. The source of data for the number of individuals on DDDR who are requesting the services is from the DDDR application with data stored in DS3.

\*\*\* The projected cost of Family Habilitation denoted in the 2015 Registration and Review report contained an error which distorted the projected cost for this service.

\*\*\*\* The reporting tool utilized for data in this table represents all services requested on the DDDR form. On this form, multiple services can be selected; however, some services may not be delivered at the same time.

**Section 5: Number of Individuals Selected or Removed From the Registry  
 FY16  
 (AS 47.80.130(d)(5))**

| <b>Reason for Removal</b>                  | <b>Number of Individuals</b> |
|--|------------------------------|
| Needs met by another IDD program           | 2                            |
| Selected for waiver services               | 189                          |
| Deceased                                   | 8                            |
| Moved to another state                     | 6                            |
| Non-responsive to request for information* | 135                          |
| Requested to be removed from list          | 1                            |
| Not eligible for DD services               | 42                           |
| <b>Total</b>                               | <b>383</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 DDDR form, be placed back on the list.

**Section 6: Number of Individuals on DRR for More Than 90 Days And SDS  
Review Process  
FY16**

(AS 47.80.130(d)(6))

Of the 906 individuals who were on the DRR during the time period being reviewed 826 were on for more than 90 days. The average length of time of those removed was 39 months. As of 6/30/16, 203 individuals (22%) had a reviewed total score of 0.

SDS takes steps to regularly review each individual's status while waiting for services or supports. Through community providers, families and participants are reminded they can update their profile as many times as needed. SDS attempts to regularly send notices to participants who have not updated their profile in the last 12 months.

Additionally, SDS attempts to update participant's eligibility status as identified in their original DD eligibility determination letter. If a participant does not reapply for services or is determined ineligible they are removed from the list.

**Section 7: 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 by in a 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 I/DD Waiver program is that, for those who qualify, Special Education is an entitlement; but the I/DD Waiver Program operates within the limits of annual legislative appropriations and the capacity of the state and community to provide the desired supports.

According to the Department of Education and Early Development (DEED), as of **October 1, 2015** there are about 18,390 students aged 3 to 21 in Special Education. Among these Special Education students, approximately 2,159 may have developmental disabilities. Individuals with the following types of developmental disabilities may be receiving special education services across the state: Intellectual Disabilities, Cerebral Palsy, Autism, and Seizure Disorder. Similarly, children with other conditions or presentations may qualify as having a developmental disability if they experience substantial limitations in three functional areas. (Alaska Department of Education and Early Development. Special Education Child Count by District. Retrieved from <http://education.alaska.gov/stats/>)

- Latest available DEED numbers are from October 1, 2015.

**Number 8: 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 Senior and Disabilities Services at the following address or phone number:

**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**

## **Additional Information/Attachments**

### **AS 47.80.130 (d)**

(d) When state funding is not adequate to meet service needs, the department shall establish a waiting list for persons with developmental disabilities who would be eligible to receive state-funded services under [AS 47.80.100](#) - 47.80.170 if adequate state funding were available. The department shall, on an annual basis, review the waiting list and submit a report to the governor containing the information required under this subsection. The department shall send a copy of the report to the persons chairing the house and senate finance committees and the persons chairing the house and senate health, education and social services committees and shall notify the full legislature that the report is available to all legislators. The report must:

(1) describe the purpose for the waiting list and the strategies used to notify persons about the waiting list, and must include a copy of the information used by the department to inform individuals and families about their rights and responsibilities under [AS 47.80.100](#) - 47.80.170;

(2) explain how an individual is placed on the waiting list, what criteria determine rank on the list, and how the waiting list is used to select individuals equitably and fairly across the state;

(3) give the basic demographic information across all regions about the age, sex, and racial and ethnic background of the individuals on the waiting list;

(4) identify the level of need and preferences of the individuals and families on the waiting list for the services and the supports that may be necessary to meet their needs and project an annual cost to meet this need;

(5) identify how many individuals were removed from the waiting list during the 12 months covered by the report, why they were removed from the list, and how long the individuals had been waiting for services or supports before they were removed from the list;

(6) list the number of individuals who have been on the waiting list for 90 days or more with an account of the department's steps to regularly review each individual's status while waiting for services or supports;

(7) report annual data from the Department of Education and Early Development about the number of students in special education with developmental disabilities graduating from high school, dropping out of high school before reaching age 22, or reaching age 22 without graduating from high school; and

(8) indicate that written or electronic copies of policies, manuals, and procedures used by the department to implement [AS 47.80.100](#) - 47.80.170 are available

## Explanation of Developmental Disabilities Registration & Review Scoring System

| Review of Life Concerns                 | Item Number | Score Multiplier*           | Possible Points** |
|---|-------------|-----------------------------|-------------------|
| <b>Community Participation Concerns</b> |             |                             |                   |
|   | 1           | 9                           | 27                |
|   | 2           | 7                           | 21                |
|   | 3           | 7                           | 21                |
|   | 4           | 8                           | 24                |
|   | 5           | 6                           | 18                |
|   | 6           | 7                           | 21                |
| <b>Living Situation Concerns</b>        |             |                             |                   |
|   | 7           | 11                          | 33                |
|   | 8           | 7                           | 21                |
|   | 9           | 7                           | 21                |
|   | 10          | 6                           | 18                |
|   | 11          | 9                           | 27                |
| <b>Caregiver Concerns</b>               |             |                             |                   |
|   | 12          | 10                          | 30                |
|   | 13          | 7                           | 21                |
|   | 14          | 5                           | 15                |
|   |             | <b>Total Possible Score</b> | <b>318</b>        |

\*The score multiplier is the weight each question is given as determined by the Waitlist Ad Hoc Committee and SDS staff.

\*\*Possible points is the highest number of points possible for a given question.

The points given for a question is determined by multiplying the level of need by the score multiplier:

|                             |   |
|-----------------------------|---|
| 1. = No need/Not Applicable | 0 |
| 2. = Minor need             | 1 |
| 3. = Moderate need          | 2 |
| 4. = Major need             | 3 |
| No                          | 0 |
| Yes                         | 3 |