

# INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES Registration and Review Report

**Fiscal Year 2024  
July 1, 2023 through June 30, 2024**



**PREPARED BY:**

SENIOR AND DISABILITIES SERVICES STAFF:

Anthony Newman, Director, SDS  
Anastasiya Podunovich, MS, Research Analyst 4, SDS  
Pam Burton, Health Program Manager 4, SDS  
Heather Chord, MS, Health Program Manager 3, SDS

**FOR:**

The DEPARTMENT OF HEALTH

**AND**

THE ALASKA LEGISLATURE

# **TABLE OF CONTENTS**

**PREFACE:** ABOUT THE INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES REGISTRATION AND REVIEW (DDRR) REPORT

**SECTION 1:** THE PURPOSE OF THE DEVELOPMENTAL DISABILITIES REGISTRATION AND REVIEW (DDRR) REPORT

**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 IN FY2024

**SECTION 6:** NUMBER OF INDIVIDUALS ON THE REGISTRY FOR MORE THAN 90 DAYS AND SDS REVIEW PROCESS – FY2024

**SECTION 7:** NUMBER OF STUDENTS WITH DEVELOPMENTAL DISABILITIES IN SPECIAL EDUCATION

**SECTION 8:** COPIES OF REPORTS, POLICIES, MANUALS, AND PROCEDURES

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

Under AS 47.80.130 (d), the Department of Health (DOH) is required to maintain a waitlist of 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 currently manages two separate waitlists: one for the Intellectual and Developmental Disabilities (IDD) Waiver and one for the Individualized Supports Waiver (ISW). The ISW waitlist was implemented July 1, 2023 when the program reached capacity (had 600 participants in active status). When an individual requests placement on the Registry they can indicate their interest in being considered for the ISW, IDD waiver, or both waivers.

Senior and Disabilities Services (SDS) employs the Developmental Disabilities Registration and Review (DDRR) as the waitlist tool to assess an individual's current service needs. When an individual is interested in being added to the IDD waitlist, information provided through the DDRR is used to place an individual onto the Registry in score order, to determine who is offered the opportunity to request services through Medicaid's Home and Community Based (HCB) Intellectual/Developmental Disabilities (IDD) waiver. When an individual is interested in being added to the ISW waitlist, only the demographic portion of the DDRR is filled out and the individual is added to the ISW waitlist in date order to determine who is offered the opportunity to request services through Medicaid's Home and Community Based (HCB) Individualized Supports waiver (ISW).

The DDRR provides predictive information the State of Alaska (SOA) uses for program planning and management. The DDRR provides the State and other stakeholders with information on the current needs and preferences of the individuals and families waiting for expanded support services.

Cost projections included in this report should be considered estimates to use in planning, rather than computation of the actual cost of comprehensive services that would be necessary to meet the needs of everyone on the list.

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

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

To be eligible to be placed on the Registry, 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 Registry and the Criteria for Ranking and Selection (AS 47.80.130 (d)(2))**

For an individual to be included on the Registry, they must complete an Eligibility Determination application:

<https://health.alaska.gov/dsds/Documents/SDSforms/idd/IDD-01-DeterminationApplication.pdf>

The application for determination of developmental disability provides SDS the information needed to determine whether 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 the next step of completing the DDRR, to be considered for long-term supports.

When a person is interested in being added to the IDD waitlist they are asked to answer questions regarding an individual's community participation skills, living situation, caregiver needs, and desired services. These questions were designed by the Registry (Wait List) Ad Hoc Committee (a community stakeholder group), and SDS remains committed to including community input before the questions are changed or updated. Answers to questions on the DDRR also provide projected timeframes for the need of a particular service. The DDRR attempts to measure the immediate needs and circumstances of everyone on the Registry and weigh those needs against the needs of all applicants.

When an individual is interested in being added to the ISW waitlist, only the demographic portion of the DDRR is filled out and the individual is added to the ISW waitlist in date order.

The DDRR can be completed by any applicant, their Developmental Disabilities Resource Connection (DDRC) provider, Care Coordinator, or designated representative, using the online form available through the Harmony data management system, or by completing the paper form and mailing or faxing the complete form to SDS (SDS will accept by email only if submitted using secure HIPAA-compliant email).

### **Criteria used for Managing the Registries**

Once a completed DDRR for the IDD waitlist is received, each question on the DDRR is reviewed and scored by a Qualified Intellectual Disability Professional (QIDP) within SDS. After scoring by a QIDP within SDS, a person's DDRR total score is tabulated electronically using the Harmony system. The applicant or their legal representative is notified in writing of their placement (score) on the IDD Registry. If an individual's life situation changes, a revised DDRR may be submitted to SDS at any time. The Registry (Wait List) Ad Hoc Committee developed the current form in use and assigned a weighted set of possible scores to each question. The form uses a numerical assessment of need; consequently, the higher the need, the greater the number of points that are given. A written explanation of the scoring system is available on Senior and Disabilities Services' website and a paper copy can also be provided upon request.

An individual's standing or rank on the IDD Registry is relative to the scores of all the other individuals on the list. Consequently, an individual's position on the Registry may change depending on the relative needs of others on the Registry. Individuals receive a copy of their scored submission each time a new DDRR is received and scored by SDS.

Once a completed DDRR for the ISW waitlist is received, the person is placed on the waitlist in date order. The applicant or their legal representative is notified in writing of their placement (date) on the ISW Registry. Individuals are drawn based on date, with those individuals waiting the longest being drawn first. An individual is required to maintain their placement on the ISW Registry by submitting the DDRR form annually. If an individual is interested in both the IDD and the ISW Registry, the complete DDRR form including questions regarding an individual's community participation skills, living

situation, caregiver needs, and desired services is filled out. The individual is then placed onto the IDD Registry based on their score, and onto the ISW Registry based on the date the DDRR form was submitted.

### **Selection Methodology for Removing Persons on the Registry**

Alaska’s ISW and IDD waivers, as approved by CMS, allow for an unduplicated count of individuals to be served on each waiver. Thus, SDS “draws” monthly the highest-scoring individuals for the HCB IDD waiver, and those individuals waiting the longest for the HCB ISW, up to the unduplicated count as identified in the approved waivers with CMS. The selected individuals are notified via certified mail of the opportunity to apply for HCB waiver services. This notice includes information about the Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) Level of Care (LOC) process.

### **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, 2023 through June 30, 2024. Since the Registry is constantly being updated, 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 Harmony data management system:

<b>IDD Registry</b>	
Number of individuals on the IDD Registry as of 6/30/2024*:	<b>443</b>
Number of individuals on IDD Registry who were 22 years old or younger as of 6/30/2024:	<b>314</b>
Number of individuals on the IDD Registry for 90 days or more:	<b>400</b>
Average length of time for individuals currently on the IDD Registry:	<b>30 months</b>
<b>ISW Registry</b>	
Number of individuals on the ISW Registry as of 6/30/2024*:	<b>158</b>
Number of individuals on ISW Registry who were 22 years old or younger as of 6/30/2024:	<b>128</b>
Number of individuals on the ISW Registry for 90 days or more:	<b>21</b>
Average length of time for individuals currently on the ISW Registry:	<b>5 months</b>

\*When an individual requests placement on the Registry they can indicate their interest in being considered for the ISW, IDD waiver, or both waivers. Individuals who indicated their

interest in both the ISW and IDD waivers are represented in both the IDD Registry and ISW Registry data. Individuals selected for the ISW may choose to remain on the registry for consideration for the IDD waiver. **It is important to note, when reviewing the numbers reported here, that 376 of the individuals on the IDD Registry have been selected for the opportunity to apply for the ISW.**

IDD Registry		
Age Range	Number of Individuals	Percentage
0 to 3 years of age	10	2.3%
4 to 17 years of age	232	52.4%
18 to 21 years of age	58	13.1%
22 to 64 years of age	141	31.8%
Over 65 years of age	2	0.5%
<b>Total</b>	443	100%

ISW Registry		
Age Range	Number of Individuals	Percentage
0 to 3 years of age	4	2.5%
4 to 17 years of age	93	58.9%
18 to 21 years of age	26	16.5%
22 to 64 years of age	34	21.5%
Over 65 years of age	1	0.6%
<b>Total</b>	158	100%

IDD Registry		
Gender	Number of Individuals	Percentage
Male	303	68.4%
Female	140	31.6%
<b>Total</b>	443	100%

ISW Registry		
Gender	Number of Individuals	Percentage
Male	113	71.5%
Female	45	28.5%
<b>Total</b>	158	100%

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

<b>Race/Ethnicity</b>	<b>Number of Individuals*</b>
Alaska Native	77
Asian	38
Black	25
Hispanic	5
Pacific Islander	7
White	186
Other	105

\*Individuals may choose to report more than one race.

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

<b>Race/Ethnicity</b>	<b>Number of Individuals*</b>
Alaska Native	26
Asian	10
Black	8
Hispanic	1
Pacific Islander	1
White	33
Other	79

\*Individuals may choose to report more than one race.

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

<b>IDD Service Region</b>	<b>Number of Individuals</b>	<b>Percentage</b>
Anchorage/Mat-Su	248	56.0%
Southeast	60	13.5%
Gulf Coast	81	18.3%
Interior	34	7.7%
Southwest	13	2.9%
Northwest	5	1.1%
Unknown	2	0.5%
<b>Total</b>	<b>443</b>	<b>100%</b>

**Geographic Distribution of Individuals on ISW Registry by Regional Service Area**

<b>IDD Service Region</b>	<b>Number of Individuals</b>	<b>Percentage</b>
Anchorage/Mat-Su	92	58.2%
Southeast	17	10.8%
Gulf Coast	25	15.8%



Interior	19	12.0%
Southwest	3	1.9%
Northwest	1	0.6%
Unknown	1	0.6%
<b>Total</b>	<b>158</b>	<b>100%</b>

#### **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 community setting. This data allows the state to project the cost of serving these individuals. 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 the individuals on the IDD 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. Of the 85 individuals drawn for the IDD waiver in FY24, 20% have active waivers in place, 19% have been closed or suspended, and the remaining are in progress. There are many reasons why individuals do not move into waiver services after being pulled from the Registry and offered the opportunity to proceed. For example, they may not qualify for Medicaid, they decline participation, they leave the state, or they do not meet the necessary level of care (ICF/IID) to qualify for waiver services.

The Medicaid Waiver program reimbursement rates provide the most accurate cost data upon which to base budget projections. Care coordinators create, and SDS approves, support plans that are tailored to meet an individual's needs. The average costs listed in the following table are based on FY 2024 payment data. These payments do not account for costs associated with provider capacity-building and infrastructure development for requested services. There are some service characteristics pertaining to payment amounts that are worth noting:

1. The Residential Habilitation rate represents an average of the costs for all the sub-categories that fall under this service definition (e.g. Family Habilitation, Group Home, In-Home Supports, and Supported Living).
2. Respite cost estimates are based on the maximum allowed amount of service and therefore represent a liberal estimate of the average total cost to provide these services.

3. The average cost of Care Coordination assumes that an individual receives this service for 12 months.

#### IDD Waitlist

Type of Service Requested	Average Annual Cost per Person	Number of Requests	Projected TOTAL Cost*
Family Habilitation	\$51,421.56	62	\$3,188,136.47
Group Home	\$137,327.24	79	\$10,848,852.05
In-Home Support	\$24,511.59	374	\$9,167,332.87
Supported Living	\$50,724.52	149	\$7,557,953.21
<b>Total Cost for Residential Habilitation Services</b>			\$30,762,274.60
Respite	\$9,265.24	403	\$3,733,890.83
Supported Employment	\$22,395.79	155	\$3,471,346.97
Day Habilitation	\$20,533.97	419	\$8,603,733.45
Care Coordination	\$3,691.88	429	\$1,583,817.19
Intensive Active Treatment	\$7,241.71	162	\$1,173,156.79
Transportation	\$6,053.58	224	\$1,356,002.82
Environmental Modification	\$4,780.00	123	\$587,940.00
<b>Total Cost</b>			\$51,272,162.65
<b>Estimated Total State Cost with FMAP at 50%</b>			\$25,636,081.33

\*The data for the average cost per individual is derived from COGNOS, a reporting tool for the Alaska Medical Assistance Health Enterprise. SDS's data source for the number of individuals on Registry who are identifying their need for specific services within the next two years is Harmony. FY2024 costs are preliminary at the time of this report, as providers have 12 months in which to bill for services rendered; future reports may show different total costs for these services as more provider claims are submitted for payment.

The following annual cost projection represents Senior and Disabilities Services' best estimate to serve all the individuals on the ISW Registry, 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. Of the 154 individuals drawn for the ISW in FY24, 40% have active waivers in place, 35% have been closed or suspended, and the remaining are in progress. There are many reasons why individuals do not move into waiver services after being pulled from the Registry and offered the opportunity to proceed. For example, they may not qualify for Medicaid, they decline participation, they leave the

state, or they do not meet the necessary level of care (ICF/IID) to qualify for waiver services.

The ISW program has a cost limit, that is adjusted for inflation annually. The current cost limit is \$25,924.00 (July 1, 2024 – June 30, 2025). The cost limit does not include Care Coordination, which is a required service for waiver participants. The following services are available to individuals on the ISW program: In-home Supports, Supported Living, Day Habilitation, Respite, Employment Services, Intensive Active Treatment, and Transportation. The following cost estimate assumes that individuals would utilize the full budget available to them on the ISW program.

#### ISW Waitlist

Cost Limit	Number of Requests	Projected TOTAL Cost*
\$25,924.00	158	\$4,095,992.00
Estimated Total State Cost with FMAP at 50%		\$2,047,996.00

#### Section 5: Number of Individuals Selected or Removed from the Registry FY2024 (AS 47.80.130(d)(5))

Selected or Removed	Number of Individuals
Selected for IDD waiver services	85
Selected for ISW services*	154
Non-responsive to request for information**	164
Not eligible for DD services	6
Moved to another state	6
<b>Total</b>	<b>415</b>

\*Individuals who indicate on the DDDR form that they are interested in both the ISW and IDD waiver will remain on the IDD Registry when they are drawn for the ISW. Individuals can receive services through the ISW, while remaining on the IDD Registry.

\*\* It is the responsibility of the applicant to keep SDS informed of current contact information. If someone is selected from the Registry for waiver services and fails to respond to the notification letter or fails to submit a new DDDR form annually they can be removed from the Registry. Applicants can be placed back on the Registry, with submission of a new DDDR as long as they have developmental disability eligibility.

For the 85 individuals who were selected for IDD waiver service during FY 2024 (7/1/2023 – 6/30/2024) the average number of months on the Registry (number of months from first application to removed date) was 11 months. For the 154 individuals selected for the ISW waiver during FY 2024 (7/1/2023-6/30/2024) the average number of months on the Registry (number of months from first application to removed date) was 4 months.

For all 415 individuals who were removed from the Registry during FY 2024 (all reasons, not just selected for waiver) the average stay was 21 months.

**Section 6: Number of Individuals on Registry for More Than 90 Days and SDS  
Review Process – FY2024  
(AS 47.80.130(d)(6))**

Of the 443 individuals who were on the IDD Registry during FY24, 400 were on for more than 90 days. The average length of time of those removed was 21 months. As of 6/30/2024, 52 individuals, or 12%, had a reviewed total score of 0.

SDS takes steps to regularly review everyone'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 DD-ineligible they are removed from the Registry.

**Section 7: Number of Students with Developmental Disabilities in Special Education  
(AS 47.80.130 (d)(7))**

Special Education provides specially designed instruction in a school setting. Local education authorities, under the regulations and statutes of the Alaska State Department of Education and Early Development (DEED), administer these programs. This is in contrast to ISW and IDD Waiver Programs services, which 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. ISW and IDD Waiver Services are administered under the Department of Health statutes and regulations.

Another key distinction between special education and the ISW and IDD Waiver programs is that, for those who qualify, Special Education is an entitlement; but the ISW and IDD Waiver Programs operates within the limits of annual legislative appropriations and the capacity of the state and community to provide the desired supports.

According to DEED, as of **October 1, 2023** (latest available DEED data) about 20,263 students aged 3 to 21 are receiving Special Education services. Among these Special Education students, approximately 2,905 may have developmental delay or cognitive impairments. 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/>)

### **Section 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 ISW and IDD Registry are available on the website of the Division of Senior and Disabilities Services at:

<https://health.alaska.gov/dsds/Pages/info/reports.aspx>  
<https://health.alaska.gov/dsds/Pages/dd/default.aspx>

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  
1835 Bragaw St., Ste. 350  
Anchorage, Alaska 99508  
(907) 269-3666  
or  
Toll Free at 1-800-478-9996**

## **Additional Information/Attachments**

### **AS 47.80.130 (d) Powers and Duties of the Department**

(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.