



Engrossed HB1012 Overview – Developmental Disabilities

Senate Appropriations | Human Resources Division

Senator Dick Dever, Chairman

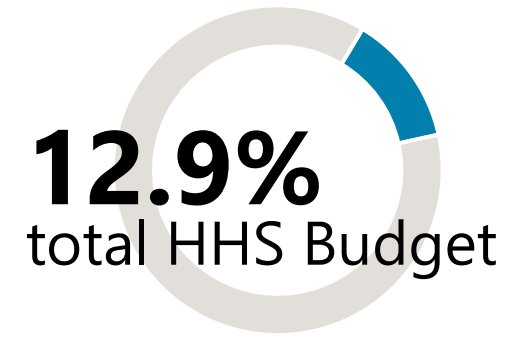


Health & Human Services

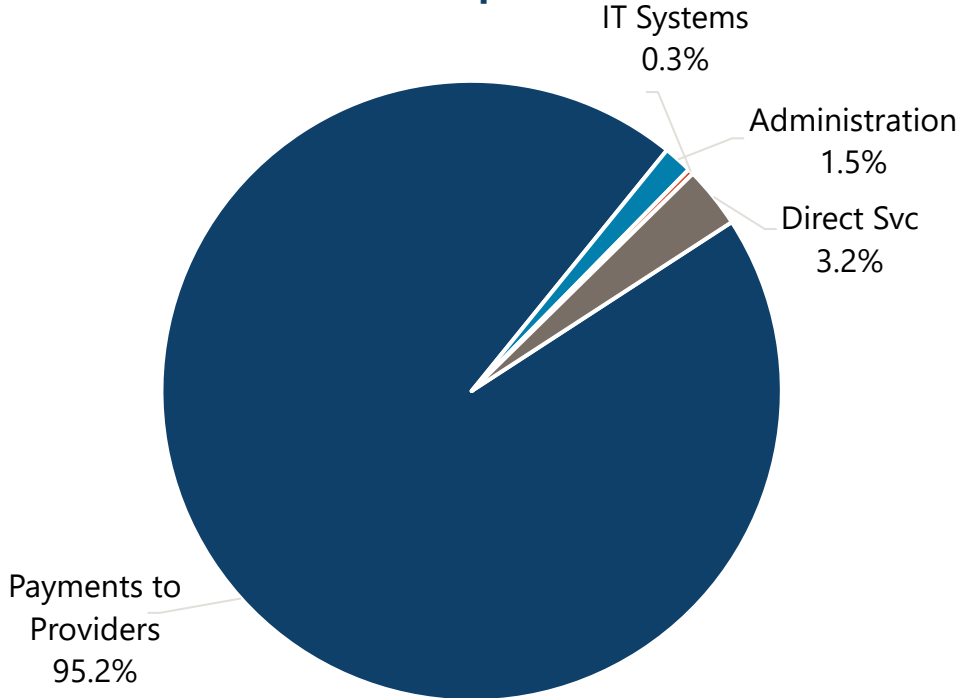
March 14, 2025, Tina Bay | Director, Developmental Disabilities Section

Budget Overview

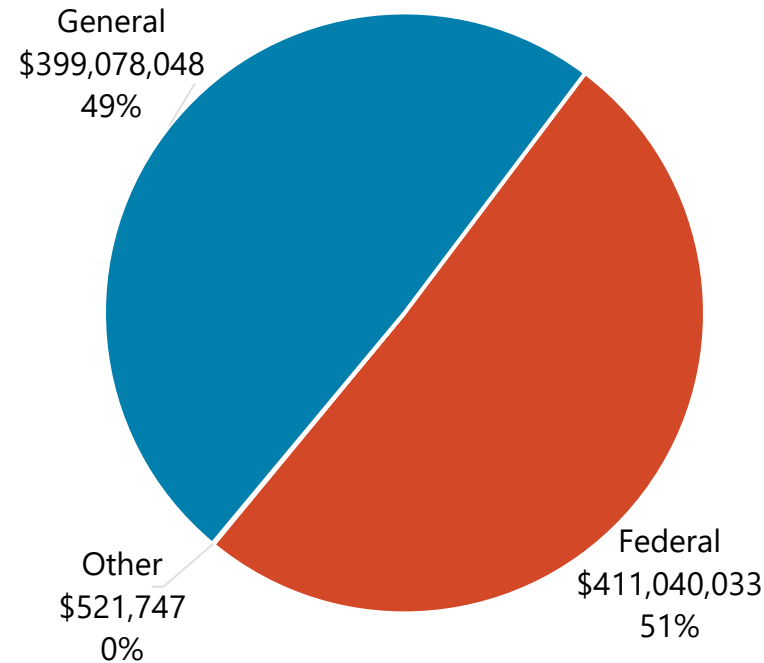
Developmental Disabilities: \$810.6 million total budget



25-27 EBR – Developmental Disabilities



25-27 EBR – Dev Disab



- **8,410 people** receiving DD program mgmt (2024) – 3,413 age 0-2 and 4,997 age 3+
- **110.15 case managers (DDPMs)**
- **35.5% increase in referrals** 2021 to 2024
- **451 ICF beds** (licensed capacity) and 1,216 people in Res Hab setting
- **45 agency providers 5,000+ direct service professionals (DSP)** and 580 individuals delivering self directed services

The Developmental Disabilities section is dedicated to ensuring that individuals with developmental and intellectual disabilities have access to comprehensive, person-centered services that promote independence, inclusion, and quality of life.

HHS builds the DD budget based on utilization-related costs, both actuals and projections

North Dakota Department of Health and Human Services
 Developmental Disabilities
 Unit and Cost Comparison
 12 Month Average to Executive Budget Request (EBR) 2025 - 2027 Biennium

Program	12 Month Average in Units (April 2023 - March 2024)	Monthly average units for EBR 2025 - 2027	Change from EBR to 12 mo Avg units	12 Month Average in Cost per Unit (April 2023 - March 2024)	Monthly average cost per unit for EBR 2025 - 2027	Change from EBR to 12 mo Avg cost per unit	Monthly average units for first 14 months of 23-25	Monthly average unit cost for first 14 months of 23-25
ICF/ID (Daily)	12,207	12,505	298	\$689.90	\$731.90	\$42.00	12,536	\$705.75
Residential Habilitation (Daily)	35,139	36,107	968	\$313.69	\$333.15	\$19.46	35,383	\$322.01
Day Programs (15 min.)	657,065	669,190	12,125	\$7.09	\$7.55	\$0.46	668,822	\$7.27
Infant Development (Pay point)	6,331	6,503	172	\$230.64	\$247.29	\$16.65	6,633	\$234.61
Family Support - In Home Supports (15 min.)	121,005	137,887	16,882	\$9.63	\$10.26	\$0.63	120,746	\$9.81

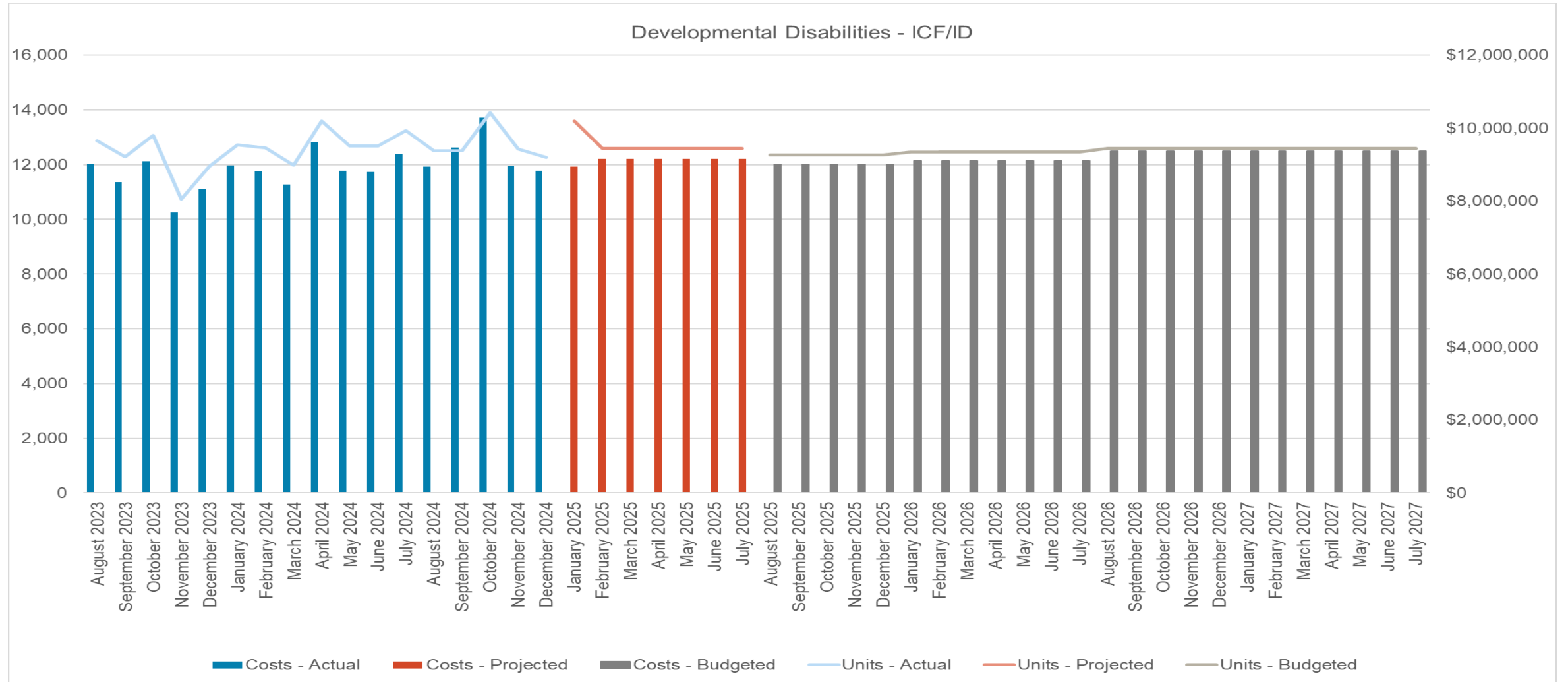
Actual

Actual

Actual

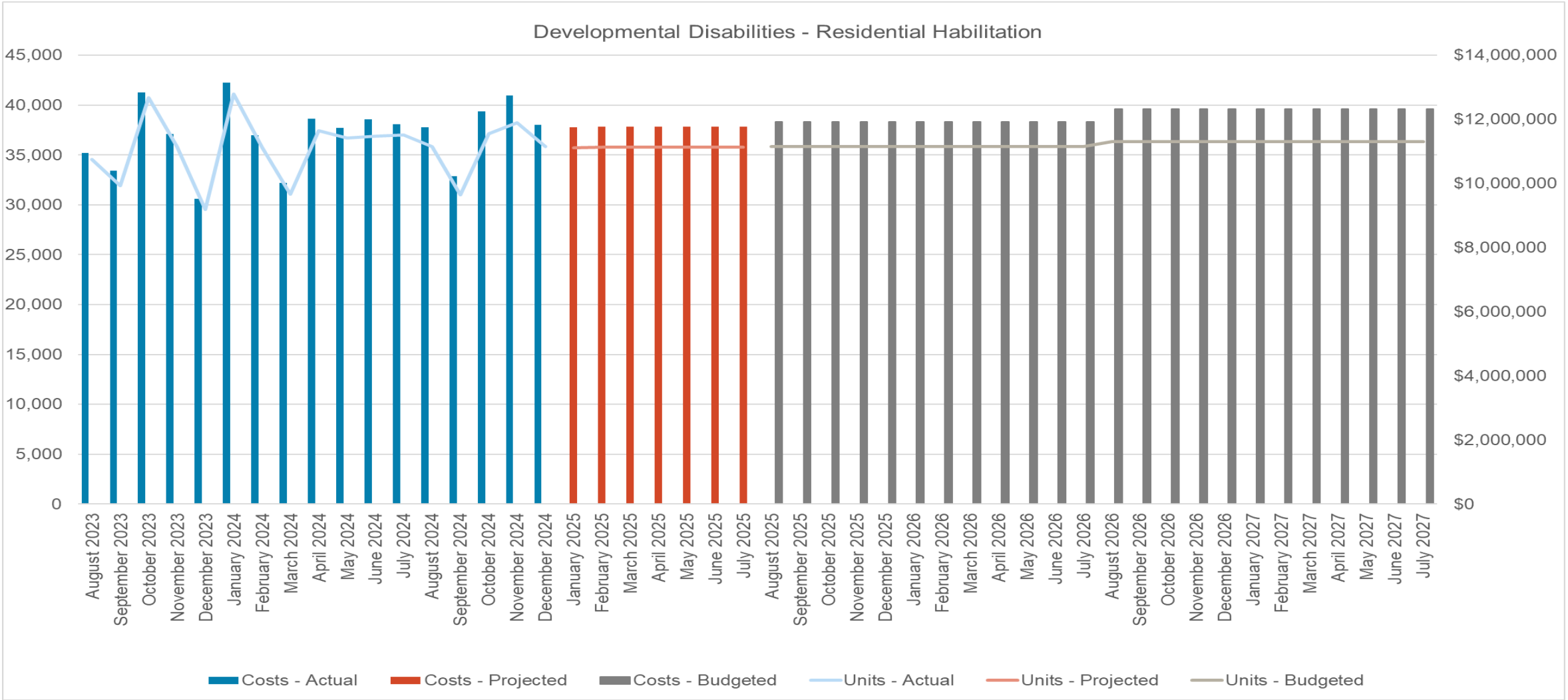
For the purpose of this analysis, "Unit" varies by program (daily, 15 minute, or pay point)

DD Service: Intermediate Care Facility (ICF)



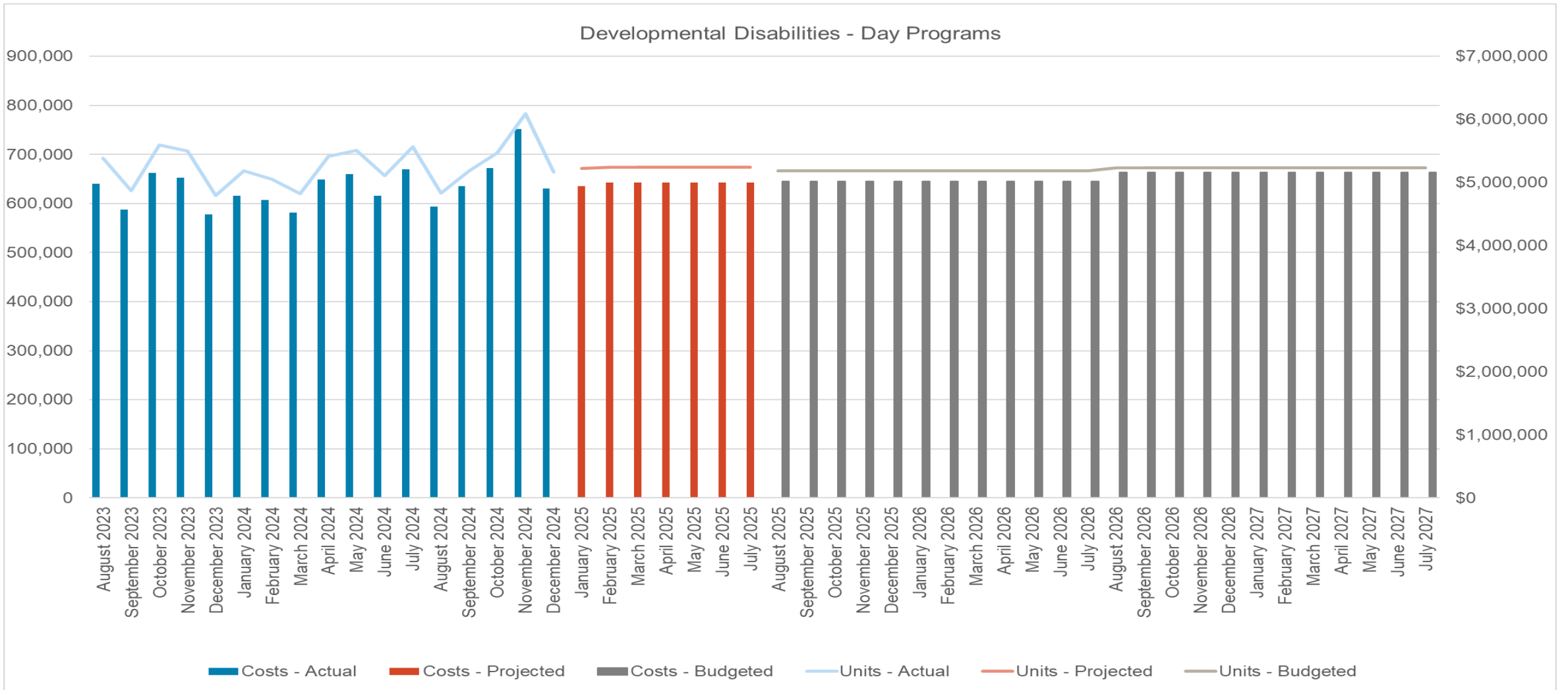
Units – Daily Rate

DD Service: Residential Habilitation (ResHab)



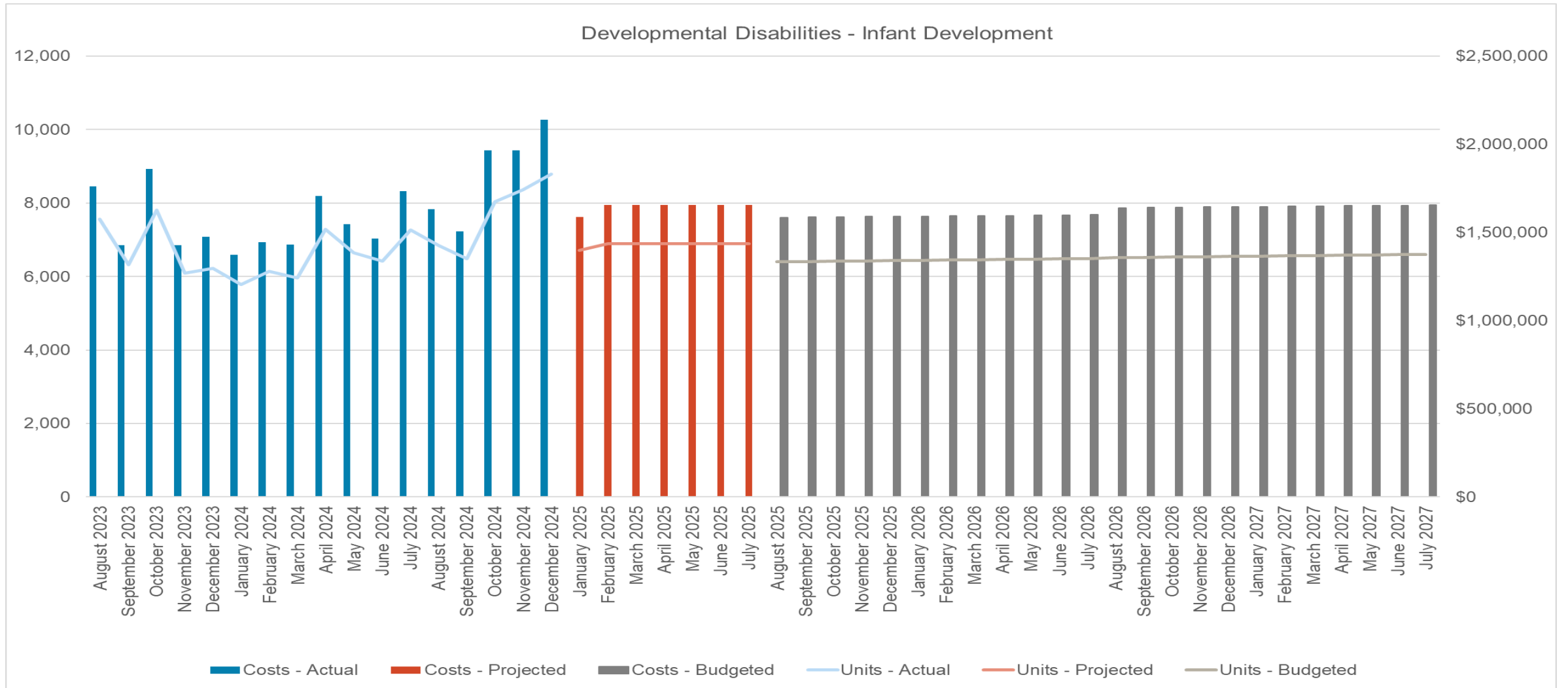
Units – Daily Rate

DD Service: Day Programs



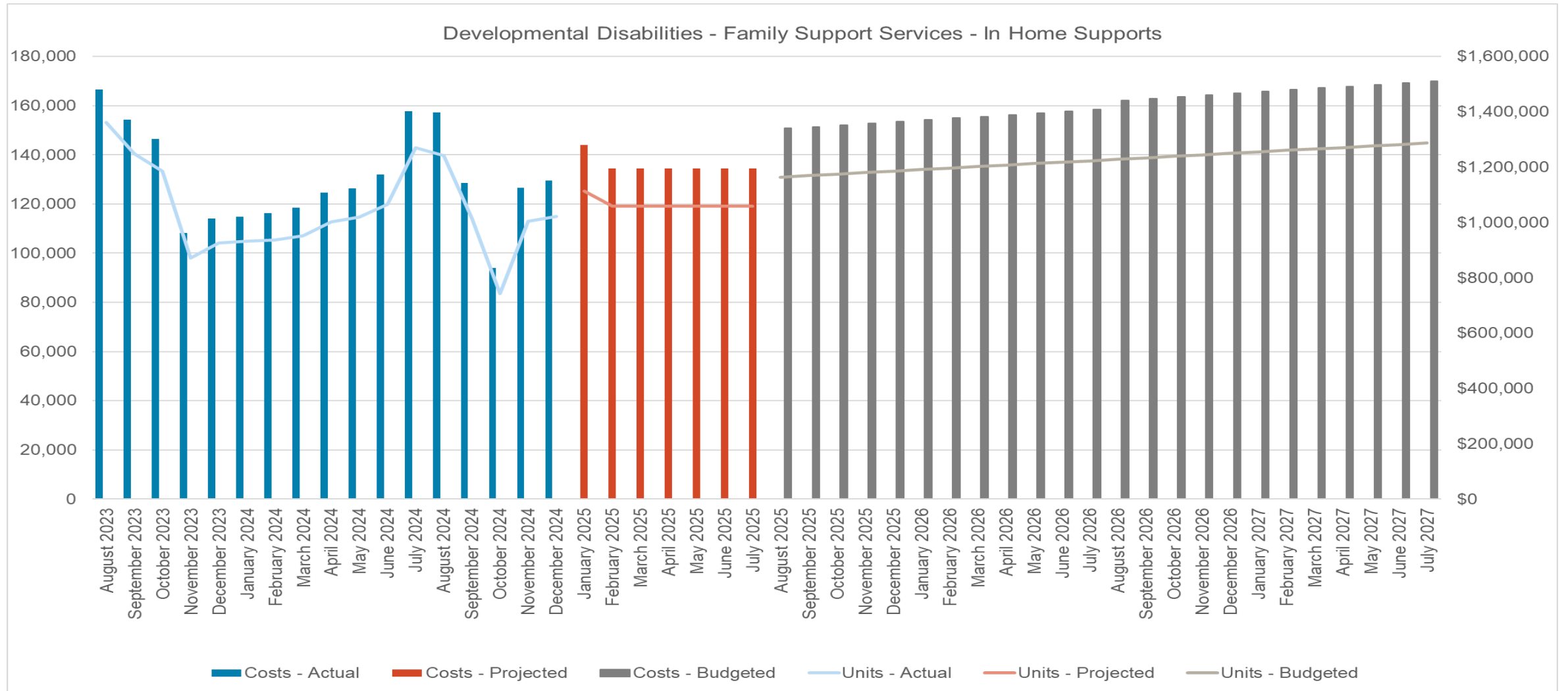
Units – 15 minutes

DD Service: Infant Development



Units – Fee for Service

DD Service: In Home / Family Support Service



Units – 15 minutes

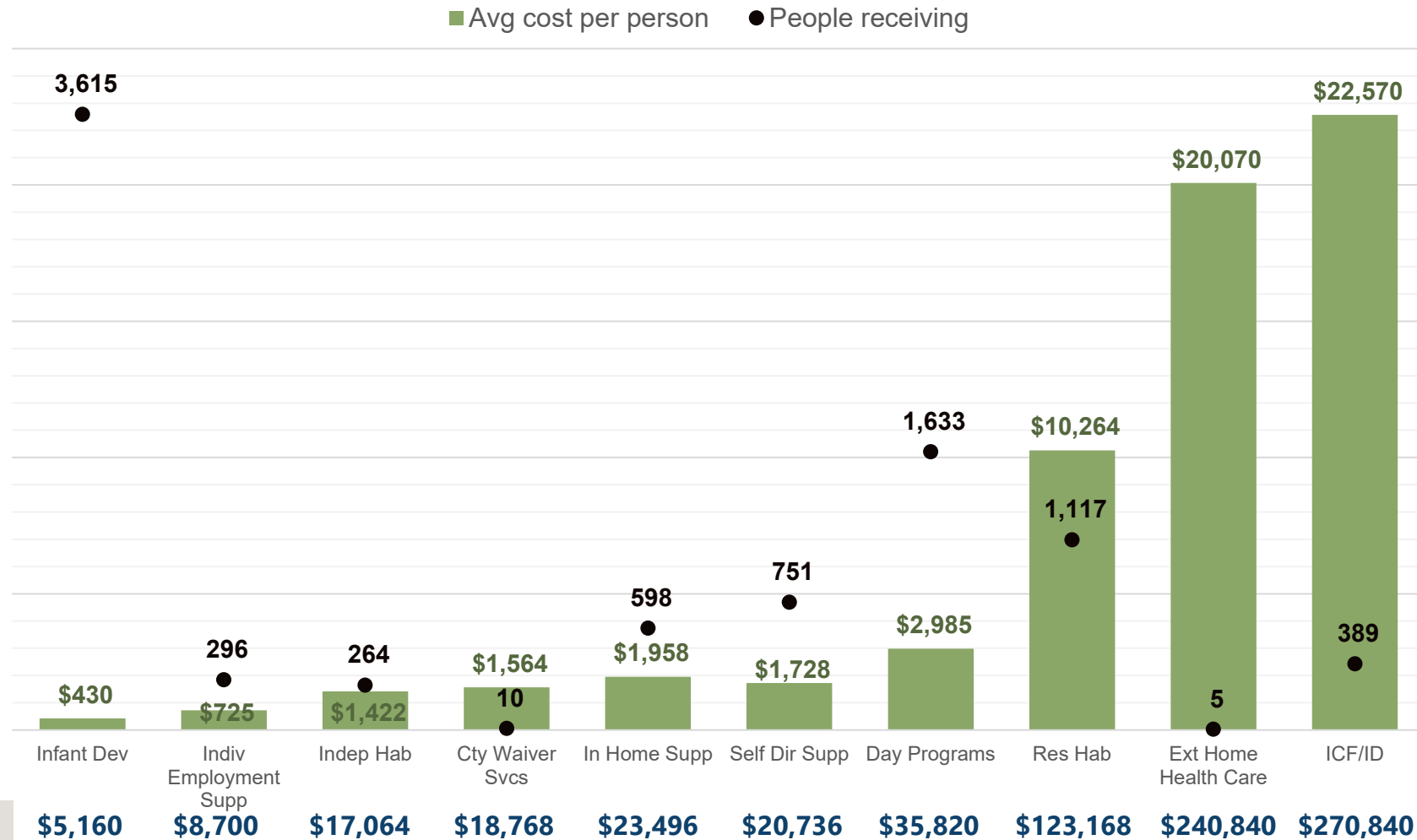
Grants on a Walkthrough

DESCRIPTION	2025-27 BASE BUDGET	COST TO CONTINUE	FMAP	TOTAL CHANGES	TO GOVERNOR	INFLATION 1.5% / 1.5%	SERVICES - HCBS	TOTAL CHANGES	TO HOUSE	INFLATION 2% / 2%	ICF ACC PMT	TOTAL CHANGES	TO SENATE
INTERMEDIATE CARE FACILITY (ICF/ID)	\$ 233,291,959	\$(18,500,231)	\$ -	\$(18,500,231)	\$ 214,791,728	\$ 4,865,574	\$ -	\$ 4,865,574	\$ 219,657,302	\$ 1,636,277	\$ -	\$ 1,636,277	\$ 221,293,579
<u>DD HOME AND COMMUNITY BASE SVC</u>	514,123,745	16,620,019	-	16,620,019	530,743,764	11,881,461	-	11,881,461	542,625,225	3,995,757	-	3,995,757	546,620,982
RESIDENTIAL HABILITATION	284,026,875	(1,727,474)	-	(1,727,474)	282,299,401	6,394,310	-	6,394,310	288,693,711	2,150,382	-	2,150,382	290,844,093
DAY PROGRAMS	117,517,263	1,077,483	-	1,077,483	118,594,746	2,684,341	-	2,684,341	121,279,087	902,722	-	902,722	122,181,809
INFANT DEVELOPMENT	36,888,505	852,360	-	852,360	37,740,865	854,952	-	854,952	38,595,817	287,518	-	287,518	38,883,335
IN HOME SUPPORTS	36,704,331	(3,512,172)	-	(3,512,172)	33,192,159	756,729	-	756,729	33,948,888	254,514	-	254,514	34,203,402
REMAINING SERVICES*	38,986,771	19,929,822	-	19,929,822	58,916,593	1,191,129	-	1,191,129	60,107,722	400,621	-	400,621	60,508,343
COST SETTLE, DISC SERV & UNDERFUND	(4,622,143)	4,622,143	(3,545,420)	1,076,723	(3,545,420)	-	3,379,800	3,379,800	(165,620)	-	-	-	(165,620)
ANNE CARLSEN PAYMENT	-	-	-	-	-	-	-	-	-	-	3,457,736	3,457,736	3,457,736
TOTAL FUNDS	\$ 742,793,561	\$ 2,741,931	\$ (3,545,420)	\$ (803,489)	\$ 741,990,072	\$ 16,747,035	\$ 3,379,800	\$ 20,126,835	\$ 762,116,907	\$ 5,632,034	\$ 3,457,736	\$ 9,089,770	\$ 771,206,677
GENERAL FUND	\$ 351,680,400	\$ (132,057)	\$ 13,683,876	\$ 13,551,819	\$ 365,232,219	\$ 8,287,885	\$ 1,689,900	\$ 9,977,785	\$ 375,210,004	\$ 2,671,545	\$ 3,457,736	\$ 6,129,281	\$ 381,339,285
FEDERAL FUNDS	\$ 391,113,161	\$ 2,873,988	\$ (17,229,296)	\$ (14,355,308)	\$ 376,757,853	\$ 8,459,150	\$ 1,689,900	\$ 10,149,050	\$ 386,906,903	\$ 2,960,489	\$ -	\$ 2,960,489	\$ 389,867,392
OTHER FUNDS	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -	\$ -

* Remaining services: Homemaker, Independent Habilitation, Individual Employment, Extended Home Health Care, Adult Foster Care, Behavioral Consultation, Community Transition Services, Environmental Modifications, Equipment & Supplies, Family Care Option, Parenting Supports, and Respite

Developmental Disabilities Service Continuum

Cost per month per person per type of service – SFY24



Developmental Disability Regulations

Federal Government	Social Security Act (SSA)	Title XIX - Medicaid	
	Code of Federal Regulations (CFR)	42 CFR Part IV	
	State Medicaid Director Letters (SMDLs) and State Health Official (SHO) Letters	Supplemental guidance issued by the Center for Medicare and Medicaid Services (CMS) containing CMS policy interpretations of the SSA or CFR.	
State Government	Medicaid State Plan & Medicaid Waivers	Acts as a contract between the state and the federal government describing how North Dakota administers the state's Medicaid program and waivers of the Medicaid program.	
	Century Code	25-01.2 – Developmental Disability 25-04 – Care of Dev. Disabled 25-16 – Residential Care and Services	25-16.1 – Receivers for Dev. Disabled Facilities 25-18 – Fee for Service Rate Setting 50-06 – Dept of Health & Human Services
	Administrative Code	75-02-05 – Provider Integrity 75-02-13 – Family Paid Caregiver Program 75-04 – Developmental Disabilities	65.5 – Protection and Advocacy

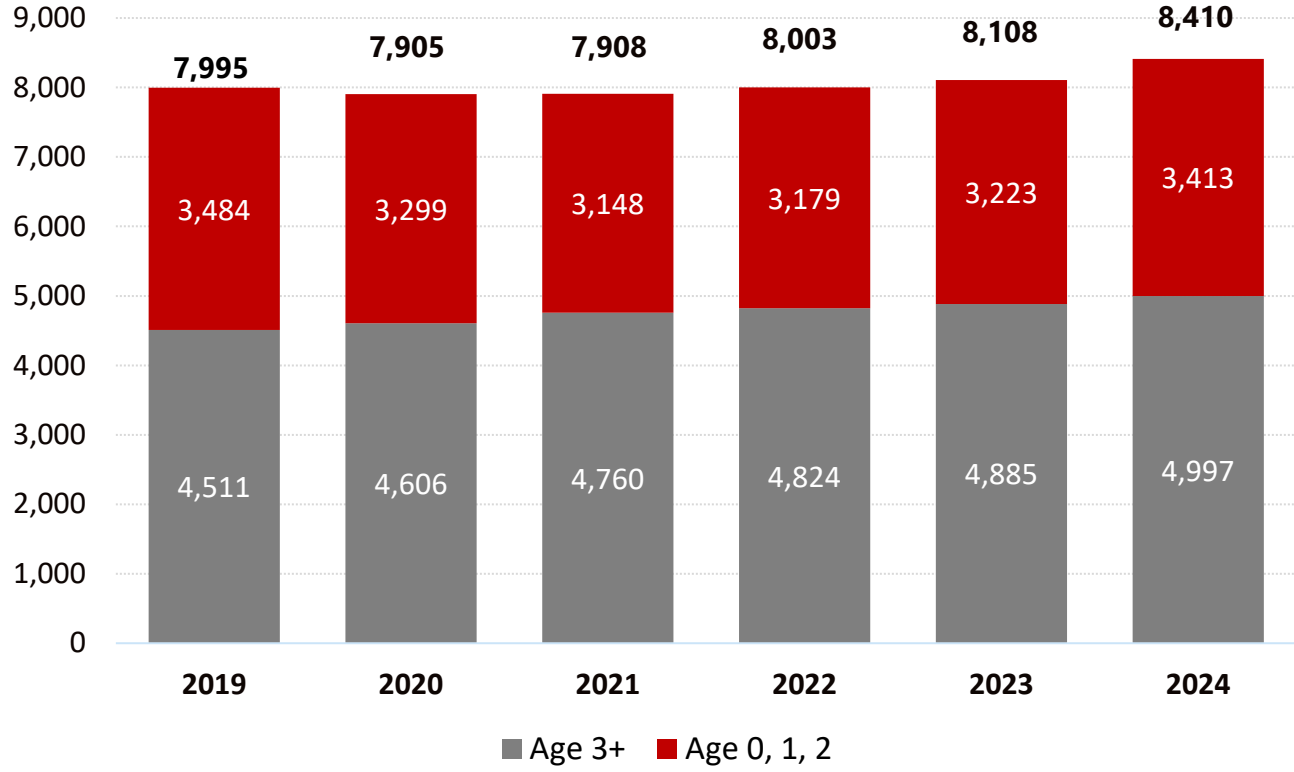
Developmental Disabilities Program Managers served over 8,400 children and adults in SFY 2024

NDs 1915(c) waived services for people with a range of developmental disabilities are coordinated by **110.15 DD program managers** and delivered by **45 licensed providers** and **580 self directed providers** who served **8,400 people** ages 0-90+ in 2024



41% of individuals served are younger than age 3

Count of individuals by age group



*Age is calculated at the beginning of each SFY and may not reflect age at time service was active

Developmental Disabilities programs and services



Early Intervention

Services in a family's home, teaching parents' hands-on activities that they can do with their child (birth through age 2) to promote child development.



Program Management

Provides information, referral and support to eligible individuals so they can access services and achieve their outcomes.



Corporate Guardianship

Support vulnerable individuals 18 years and older who need assistance making life choices.



Intermediate Care Facilities

Residential facility that provides health or rehabilitative services for individuals who require active treatment.



Home and Community Based Waiver Services

Provides individuals the opportunity to receive services in their own home and community rather than an institution.

Meet Anna



Anna is 1 ½ years old

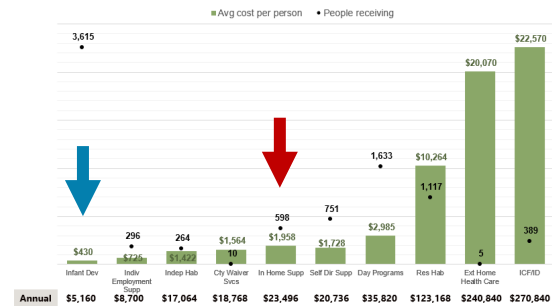
- Born prematurely at 28 weeks
 - Documented vision concerns and seizures
 - Delayed in all areas of development
- Eligible for Early Intervention at 13 weeks old

Anna's Family

- Mom, Dad and older brother
- Anna's dad works full-time while mom stays at home with Anna and her older brother.

Anna and her family are supported through these services:

1. Regular **Service Coordination (DD Program Management)**
2. **Infant development** services which include:
 - Weekly **home visits** with their Primary Early Intervention Professional
 - **Occupational Therapy** and **Speech consultations** monthly
3. **In-Home Supports** services through the DD Waiver



Anna “graduated” from services when she turned 3 years old. She was meeting developmental milestones and no longer qualified as DD-eligible.

Early Intervention is often a family's very first opportunity to interact with support services that are specially designed to help their child and family thrive

Early Intervention Services are offered to children **birth to age three** who have a developmental delay or high-risk condition.

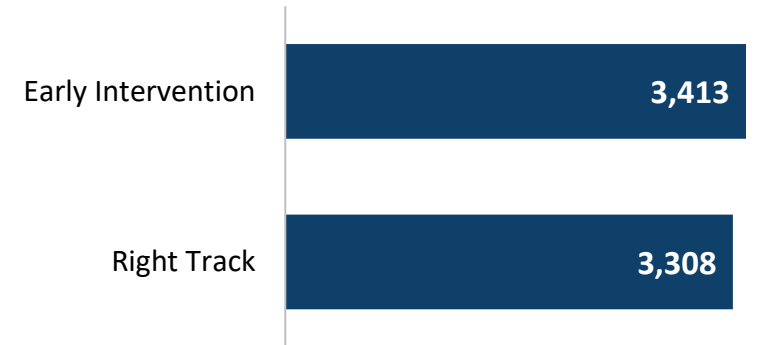
The program utilizes a **parent coaching model** to provide routines-based services that support the primary caregiver(s) to maximize the child's development in the child's natural environment.



Right Track is North Dakota's "**Child Find**" program.

- Helps identify infants and toddlers who may qualify for Early Intervention services.
- Offers developmental screenings and follow-along services at no cost to all families in North Dakota.
- These services support families to learn about their child's development and strategies they can use to help their child.

Children Served Jul 2023-Jun 2024



Funding for Early Intervention

💰 Medicaid 1915(c) Traditional IID/DD Home Based Services Waiver

💰 Part C Of the Individuals with Disabilities Education Improvement Act (IDEA) through the Office of Special Education

Meet Morgan



Morgan is 18 years old.

Found eligible for DD Services at age 7.

Morgan is her own guardian and **self directs** services. She has a **DD Program Manager** to help her coordinate care.

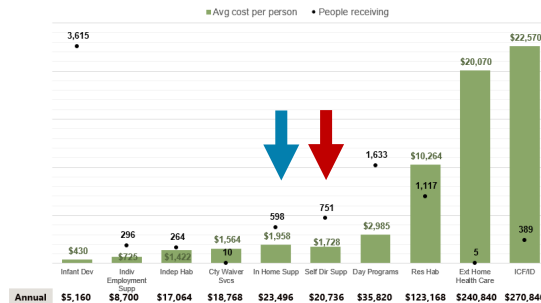
- Income: Supplemental Security Income (SSI)
- Diagnosis: Moderate intellectual disability, Cerebral Palsy, and epilepsy

Morgan needs assistance with preparing meals, bathroom cares, & transfers. Cannot be left alone due to seizures.

- Living at home with dad. Has been attending school with peers with a late start (9am).
- Dad works Full-time Monday-Friday, 7am-4pm.

Morgan and Dad receive the following services:

1. Medicaid State Plan **Personal care** for QSP to assist with morning cares of showering, brushing teeth, making breakfast (10 hours/week)
2. **In-Home supports** for staff to provide **supervision** for after school (10 hours/week)
3. **Respite** (600 hours/year standard) to allow dad to get periodic breaks from caregiving responsibilities



ID/DD Medicaid Home and Community Based Services Waiver (aka "DD Waiver")

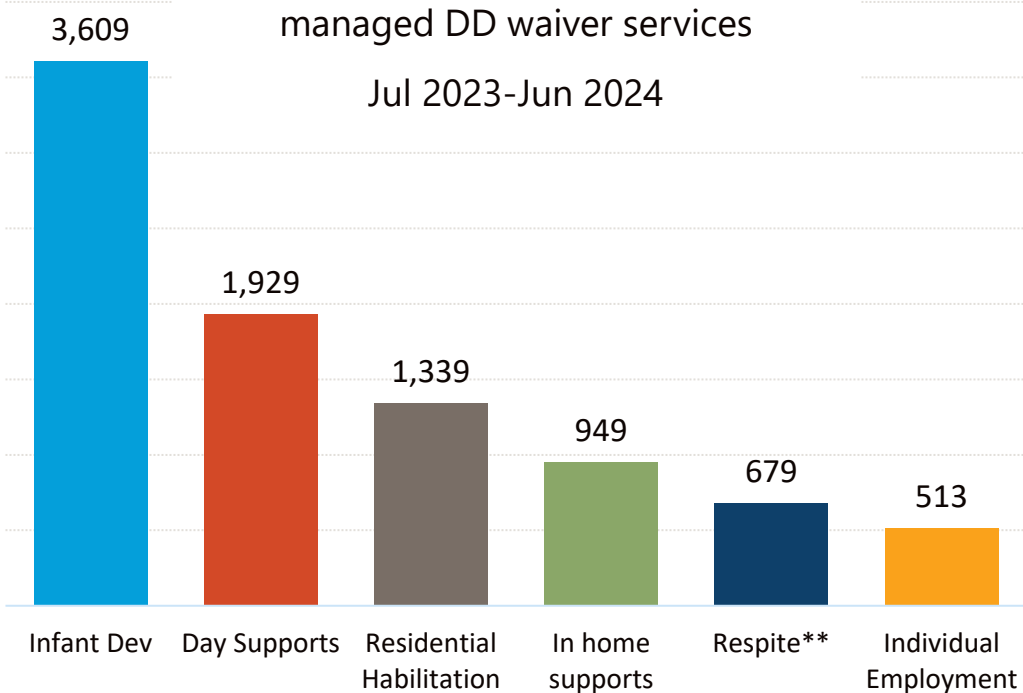
Medicaid waivers allow the state to use Medicaid funds to provide services enabling eligible individuals who would otherwise require institutional care to remain in their homes or communities.

- The DD waiver serves individuals across the life span (birth to death)
- Offers a variety of services that are available based on the person's needs and preferences
- Recipients must be both functionally and financially eligible.
 - Note: Parental income and assets are disregarded when determining financial eligibility for children utilizing waiver service.
- Federal funds matched with state funds (FMAP)

6,314

people authorized for provider-managed DD waiver services

Jul 2023-Jun 2024



*Note: Data includes duplicated individuals as it represents individuals receiving each type of service

**Respite was only available as a separate service starting April 2024

Federal Poverty Level & HHS Programs

Medicaid	
Parent/Caretaker	34%
Aged/Blind/Disabled	90%
Expansion Adults	138%
Pregnant Women	175%
Children	205%
SNAP	130%



More details about [Medicaid Eligibility](#)

2025 CALENDAR YEAR FEDERAL POVERTY GUIDELINES														
Annual Amount at Various Income Percentage Levels														
Family Size	Annual 34%	/Mo	Annual 90%	/Mo	Annual 130%	/Mo	Annual 138%	/Mo	Annual 175%	/Mo	Annual 185%	/Mo	Annual 205%	/Mo
1	\$5,321	\$443	\$14,085	\$1,130	\$20,345	\$1,695	\$21,597	\$1,798	\$27,388	\$2,282	\$28,953	\$2,413	\$32,083	\$2,674
2	\$7,191	\$599	\$18,396	\$1,533	\$27,495	\$2,291	\$29,187	\$2,432	\$37,013	\$3,084	\$39,128	\$3,261	\$43,358	\$3,613
3	\$9,061	\$755	\$23,244	\$1,937	\$34,645	\$2,887	\$36,777	\$3,065	\$46,638	\$3,887	\$49,303	\$4,109	\$54,633	\$4,553
4	\$10,931	\$911	\$28,080	\$2,340	\$41,795	\$3,483	\$44,367	\$3,697	\$56,263	\$4,689	\$59,478	\$4,957	\$65,908	\$5,492

Most people who receive DD services qualify as a member of **ABD** or **SSI Medicaid coverage groups**



Medicaid Coverage
Individuals who are Aged, Blind and Disabled (ABD)

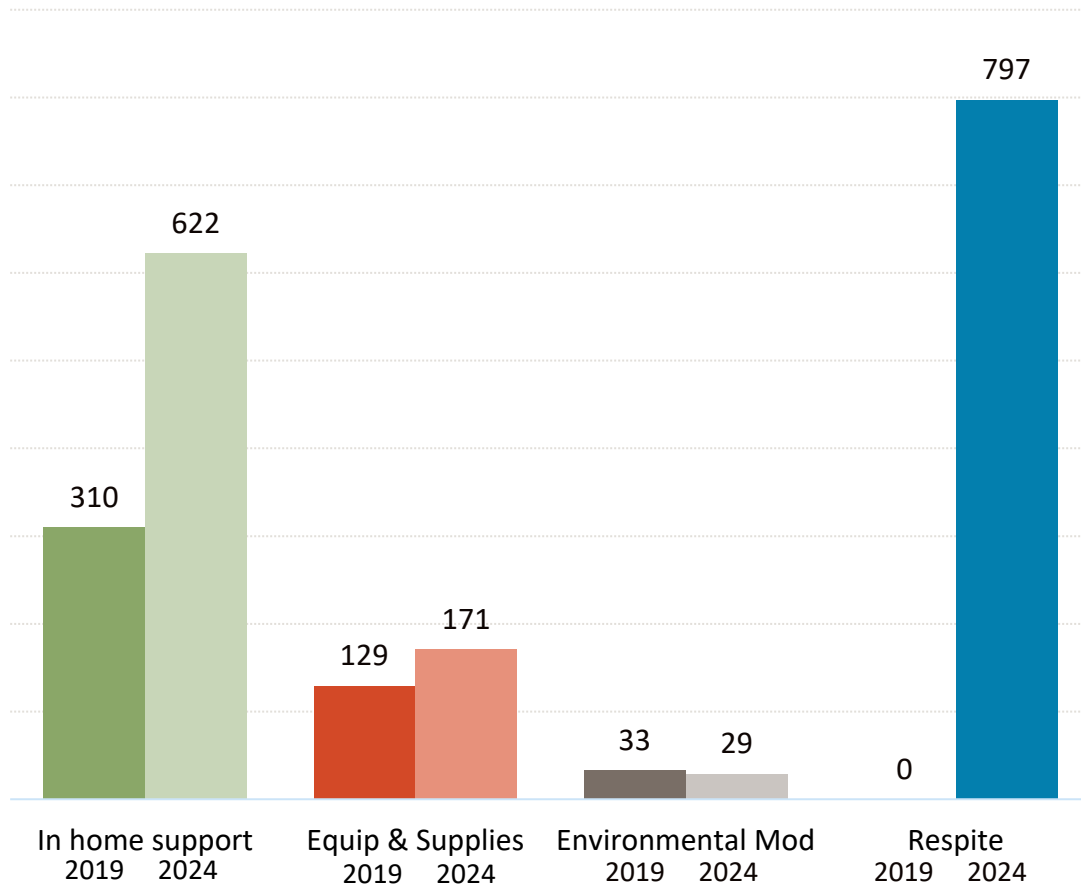
- ✓ Income up to 90% FPL
- ✓ <\$3,000 countable assets (single person)

People who qualify for SSI, qualify for Medicaid
Supplemental Security Income (SSI)
*Available via Social Security Administration
As of January 1, 2023*

Family size – 1	\$943
Family size – 2	\$1,415

Self Direction is a mode of DD waiver service delivery that is growing

people using Self Directed Services
Claims Data | DD Waiver SFY 2024



What are “Self Directed Services”?

With the support of a fiscal agent, families can hire their own staff, set wages, provide training, and create schedules for staff they hire, offering greater flexibility and personalization in the care and support they receive.

- **Respite & In home supports**
- **Equipment & Supplies**
 - Nutritional supplements
 - Adaptive kitchen utensils
 - Switches/adaptive controls
 - Sensory items (noise cancelling headphones, weighted vests/blankets)
 - Assistive technology (smart thermostat, smart lock, smart lights, sensors, alarms, automatic soap dispenser, switches, and iGuard stove controller)
- **Environmental Modifications**
 - Widening of doorways in homes
 - Track lift system
 - Lifts for vehicles
 - Accessible showers
 - Ramps

Meet Nora



Nora is 70 years old.

Was found eligible for DD Services at age 29.

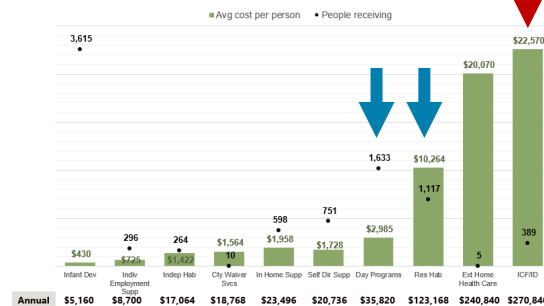
- **Diagnosis:** Mild intellectual disability, below knee amputation both legs, depression, anxiety, and tremors.
- **Income:** Supplemental Security Income, SNAP, and has a housing voucher from her local public housing authority to help with a portion of her rent.

For many years Nora's receipt of DD services was limited. She has received coverage for health care and long term services and supports via Medicaid. In general, Nora has needed:

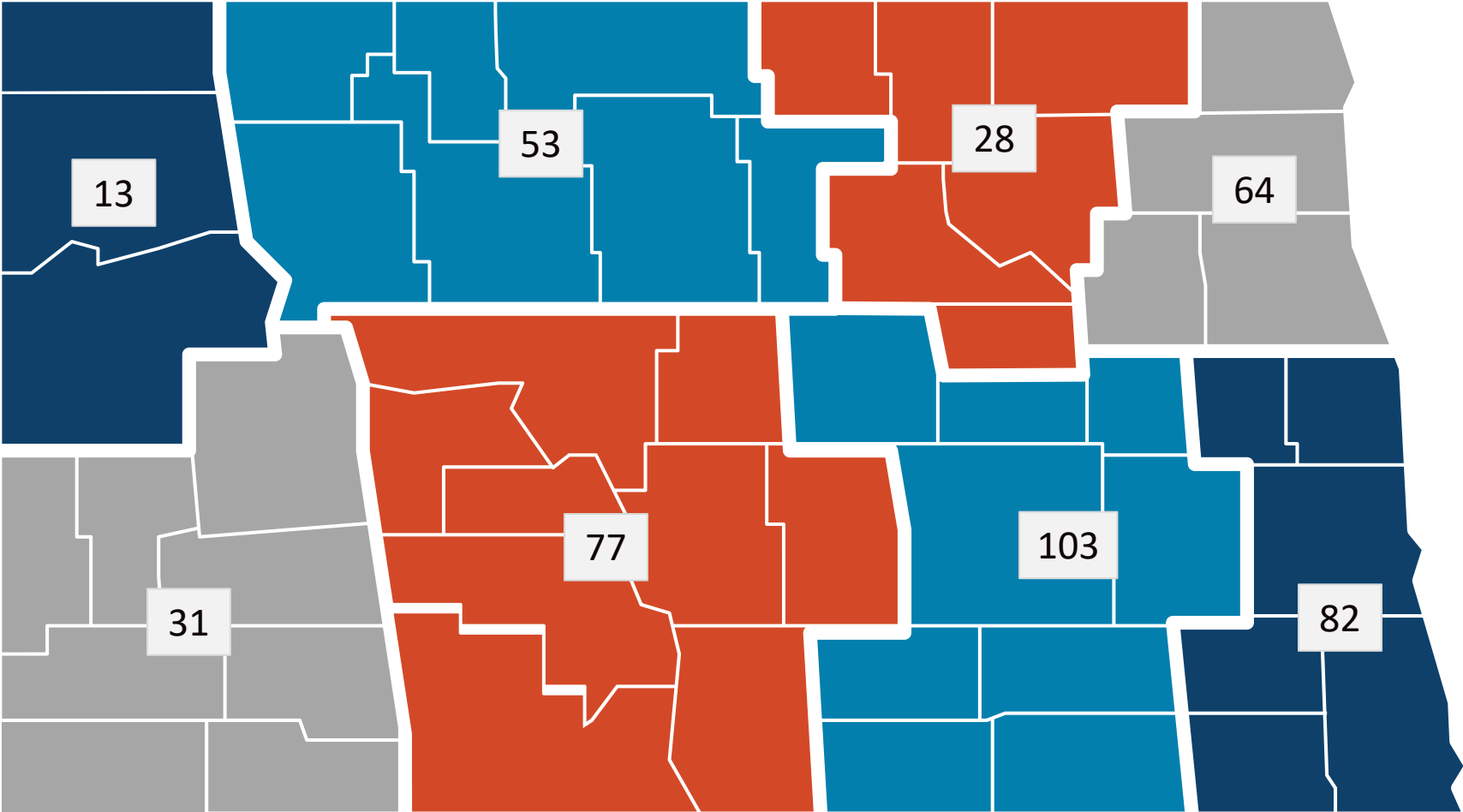
- Help with medications and managing blood sugar
- Assistance with transfers (ex. toileting) and personal care (dressing, housework, and meal prep)

Nora's services have included:

1. **AT AGE 29: Residential Habilitation** to support daily needs while living in her own apartment, and a **Day Habilitation** program from 9-4 pm, Monday through Friday. Plus **Case Management** from HHS DDPM, a rep payee, and health care coverage from **Medicaid**.
2. **AT AGE 52: Corporate Guardianship** to assist Nora with decision making and managing her affairs.
3. **At AGE 62: Intermediate Care Facility** (replaced ResHab; personal income reduced to \$135/mo as personal needs allowance in ICF).



Intermediate Care Facilities licensed bed capacity by region



451 licensed beds

The average monthly **bed** usage
July 23 – June 24
389

(**86%** utilization rate)



One area we would like to explore is whether there is a way to repurpose the available beds for crisis situations, while still avoiding the incentivization of institutional services.

Where do people served by the DD section live?

people authorized for service over 12 mo period by type of service by type of residence | Jul '18-Jun '19 & Jul '23-Jun '24

	2019		2024	
Intermediate Care Facility (ICF) (Provider-owned facility, daily rate)	565	7%	502	6%
Residential Habilitation (Pvt housing, provider-supported daily rate)	1,313	16%	1,278	15%
Family/Own Home (Provider-supported, incl Ind Hab)	1,600	20%	1,100	14%
Family/Own Home (DDPM only)	600	7%	620	7%
Family Home (Self-Directed)	310	4%	622	7%
Family Home (Infant Development)	3,830	47%	4,250	51%
TOTAL	≈8,000		≈8,400	



Meet Brady



Brady is 26 years old.

Found eligible for DD Services at age 16.

Brady has a **DD Program Manager** to help coordinate care.

- Diagnosis: Mild intellectual disability, Cerebral Palsy, and Scoliosis
- Income: Supplemental Security Income, limited income from employment, SNAP

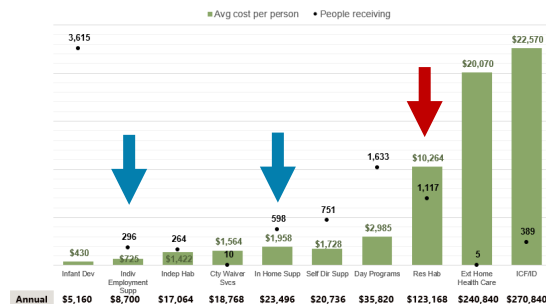
Lives on his own in an accessible apartment on the ground floor. Brady is responsible for his own rent. Needs assistance with most activities of daily living (ADL's) as well as accessing many areas in his home.

Brady receives the following services:

1. Works in the community, M-F 3-6pm with **Individual Employment Supports** & attends **Day Habilitation** M-F 10am-3pm.
3. Has staff for 7-8 hours per day and a overnight (sleep) staff through **Residential Habilitation**.
4. DD waiver **Equipment and Supplies Service** utilized to complete an Assistive Technology assessment of his home.
 - Smart Home Package recommended which included: Smart plugs, smart thermostat, smart lock with wireless keypad, smart light switches, and an Echo Show (used to run the smart home features).

✓ With the use of Equipment & Supplies, Brady has been able to increase his independence in his own home. Has also reduced staff time down to 4-5 hours per day and a sleep overnight staff.

✓ Currently trialing **assistive technology** during the *overnight hours* to potentially eliminate need for staffing during that time.



New technologies & new ideas mean “staffing” does not have to be the only solution

Assistive devices and various home and vehicle modifications have always been part of how families and providers have worked together to modify the physical environment to meet a person’s unique needs.

- Ramps and Lifts
- No-step showers, grab bars
- Walkers, canes

The environment, expectations, and opportunities surrounding environmental modification are ever-changing.

- Sensory issues
- Technology-enabled devices
- Smart-home improvements paired with physical home modification

Same Idea – Many Paths

- Assistive Device
- Environmental Modification
- Equipment & Supplies
- Durable Medical Equipment
- Assistive Technology
- Accessibility Improvements



Access to assistive devices/technologies is growing.

Navigating how to access a growing array of options can be difficult for families.

	Medicaid State Plan	DD waiver	Autism waiver	Med Fragile waiver	Aged & Disabled waiver	Other (MFP, SPED, ExSPED)	Other (housing rehab)
Benefit Limits	Specific to individual need	Equip & Supplies - \$5k/yr Env Mod - \$40k (over 5 yrs)	Assistive Tech - \$5k (over 5 yrs)	Assistive Tech & Env Mod - \$25,300/waiver yr (all services)	Specific to individual need	Unique to each program	Unique to each program
Eligible settings	Own home (rent or own)	Own home (rent or own)	Own home (rent or own)	Own home (if mod cannot be moved, must own)	Own home (rent or own)	Unique to each program	Unique to each program
How to access	Enroll as Medicaid provider	Veridian (contracted intermediary)	Purchased by HHS and shipped to home	Veridian (contracted intermediary)	Enroll as Medicaid provider	Each program has a pathway	Each program has a pathway
Eligible items	Medically necessary as defined in NDAC 75-02-02	All 4 Medicaid 1915c waivers note that approval of any item is dependent on the disability and the need (i.e., prevent institutionalization by addressing ADL/IADLs)				Unique to each program	Unique to each program

- For waivers that serve children, if an item is generic, availability depends in part on the age of the participant. As a general principle, if a child without a disability would need it, Medicaid will not cover it because the need is not specific to a child's disability. (ex. a highchair for a 3-year-old v a 15-year-old)

Example: Eligibility across programs

List of items noted by P&A during budget presentation related to ARPA-funded pilot project

Item from P&A List	DD waiver	A&D waiver	Autism	Med Fragile
Accessible Blinds	Yes	Yes	Yes (blackout)	No
Air Purifier	Yes	Yes	No	Yes
Amazon Echo/Show	Yes if it is needed to access AT	Yes if it is needed to access AT	Yes if it is needed to access AT	Yes if it is needed to access AT
Automatic Door Opener	Yes under environmental mod	Yes under environmental mod	No	Yes
Bathing Chair	Yes	Yes	No	No
Bean Bag	Yes	No	Yes	No
Bike Basket	Yes	Yes	Yes	Yes
Bike Cargo Rack	No?	No	No	No
Bike Lock	No	No	No	No
Bluetooth Neckband	No	No	No	No
Brick	Yes	Yes	No	No
Cabinet Lock w/Code	Yes	Yes	Yes	Yes
Cabinet Lock w/Key	Yes	Yes	Yes	Yes
Cable Management	Yes	Yes	Yes	Yes
Colored Wall Lights	Yes	Yes	Yes	Yes
Door Security Bar	Yes	Yes	Yes	Yes
Door Sensor	Yes	Yes	Yes	Yes
Dry Erase Calendar	No - generic	No	Yes	No
Echo Wall Mount	Yes if it is needed to access AT	Yes	Yes if it is needed to access AT	Yes if it is needed to access AT
Fidgets	Yes	No	Yes	Yes
Floor Lamp	Yes if accessibility features for on/off	Yes if accessibility features for on/off	Yes if accessibility features for on/off	Yes if accessibility features for on/off
Grocery Bag Carriers	Yes	Yes	No	No
Hearing Protection	Yes	Yes	Yes	Yes
Hospital Bed	Yes	Yes	No	No

Item from P&A List	DD waiver	A&D waiver	Autism	Med Fragile
LEVO tablet stand	Yes	Yes	Yes	Yes
Montessori Knives	Yes	Yes	No	No
No Drill Furniture Anchors	Yes	Yes	Yes	Yes
Open Sesame Accessory - Standard Transmitter	Yes	Yes	Yes	Yes
Phone Mount	Yes	Yes	Yes	Yes
Pull Down Shelf - 5pd Series	Yes	Yes	Yes	Yes
Recliner Switch	Yes	Yes	Yes	Yes
Ring Doorbell	Yes	Yes	Yes	Yes
Ring Doorbell Mount	Yes	Yes	Yes	Yes
Smart Bulbs	Yes	Yes	Yes	Yes
Smart Lock	Yes	Yes	Yes	Yes
Smart Plugs	Yes	Yes	Yes	Yes
Sofa Armrest Organizer	Yes	Yes	Yes	Yes
Stair Climber Cruiser Cart	Yes	Yes	Yes	Yes
Switch Bot	Yes	Yes	Yes	Yes
Timer	Yes	Yes	Yes	Yes
Veggie Chopper	Yes	Yes	No	Yes
Visual "Stop" Banner	Yes	Yes	Yes	No
Weighted Blanket	Yes	Yes	Yes	Yes
Wyze Lock	Yes	Yes	Yes	Yes

ND's April 2024 DD Waiver amendment enhanced access to environmental mods & supplies

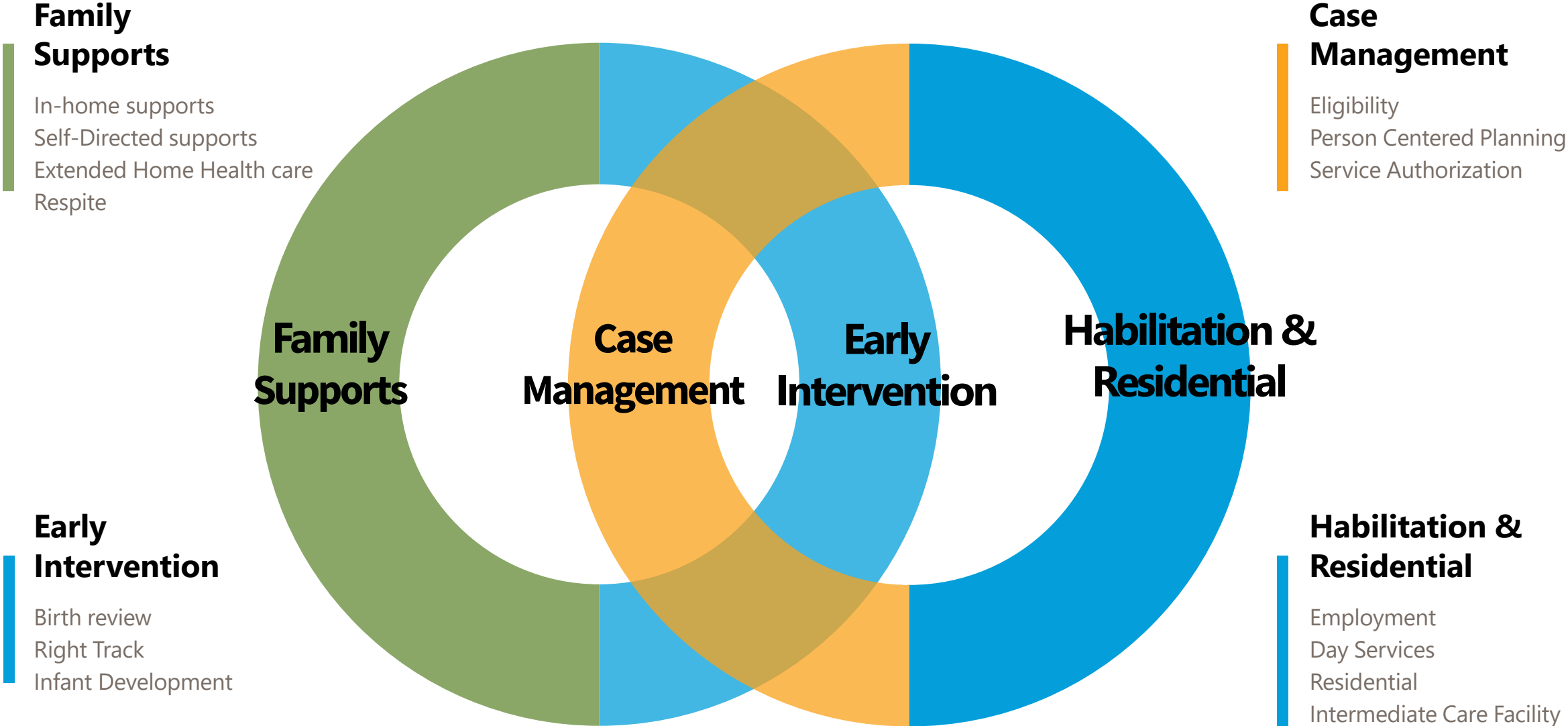
Equipment & Supplies

- Increase in limit: from \$4,000 to \$5,000 per waiver year.

Environmental Modifications

- Increase in limit: from \$20,000 to \$40,000 per waiver period (5 years)
- Added that modifications can be made to homes rented by participant or primary caregiver.

Program management & early intervention are a key intersection within the continuum of services available to people with ID/DD



Developmental Disabilities

Program Management is an essential Direct Service

DD Program Managers

Assist clients, families, and guardians in navigating available services, with a focus on helping clients maintain their health and safety while working toward achieving their personal goals.

What do they do?

- Intake & eligibility
- Person-centered planning coord/dev
- Service authorization
- Crisis support planning
- Referrals to provider agencies
- Face to face visits with clients
- Direct care

110.15

DD program managers

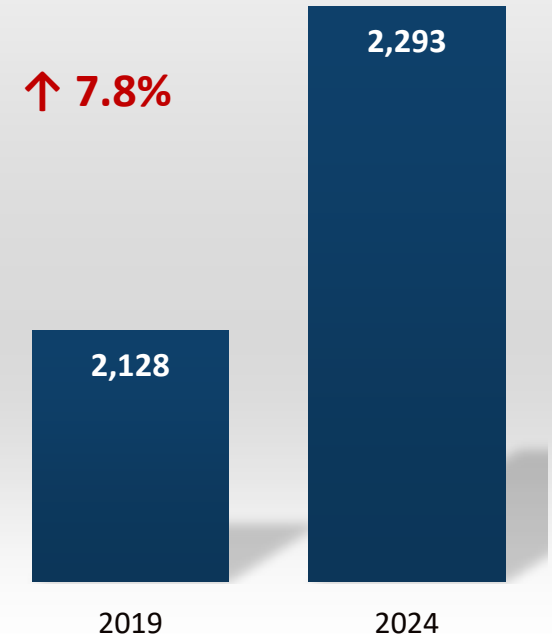
240 and **191**

On average, 240 new referrals and 191 new eligibilities conducted each month

8,410

Individuals with developmental disabilities receiving program management services

DD Eligibility Determinations



How does the supportive role of the DDPM change based on the setting where someone lives?

Task	DDPM Only	SNF	Personal Care (MSP)	LSTC	ICF/IID	Waiver-provider	Waiver- without provider (SDS)	Infant Development	Medically Fragile
Avg Utilization	400-800	100-150	50-100	60-80	450-500	2,200-2,600	800-1,000	3,200-3,800	20-30
Face to Face Visits	Annual	Annual & with each PASRR	Every 6 months	Annual	Annual	Every 3 months	Every 3 months	Every 3 months	Every 3 months
Direct Care	As needed	NA	NA	NA	NA	As needed (primarily Indep Hab)	NA	NA	NA
Guardian Contacts	Annual	Annual and with each PASRR	Every 6 months	Annual	Annual	Every 3 months	Every 3 months	Every 3 months	Every 3 months
Service Plan Development	Develops Svc Plan – initial & annual (short-version)	Develops Service Plan – initial, annual & options counseling	Develops Service Plan – initial, every 6 months & annual	Develops Service Plan – initial & annual (short-version)	Plan Approver	Plan Approver	Develops Service Plan –initial & annual (either full or short version)	Plan Approver – initial, annual, every 6 months and 2-7 and 2-9 transition	Develops Service Plan – initial & annual (full version)
Risk Assessment	Initial	Initial & annual	Initial, 6 mo & annual	Initial	Initial & annual	Initial & annual	Initial & annual	Initial & annual	Initial & annual
PAR (Level of Care)	NA	NA	Annual	NA	Annual	Annual	Annual	Annual	NA
Case Actions	NA	NA	Initial & annual	NA	Initial & annual	Initial & annual	Initial & annual	Initial & annual	Initial & annual
QER	NA	NA	NA	NA	Annual	Every 6 months	Every 6 months	Every 6 months	Every 6 months
Service authorizations	NA	NA	NA	NA	Yes	Yes	Yes	Yes	Yes

Team Structure and Function

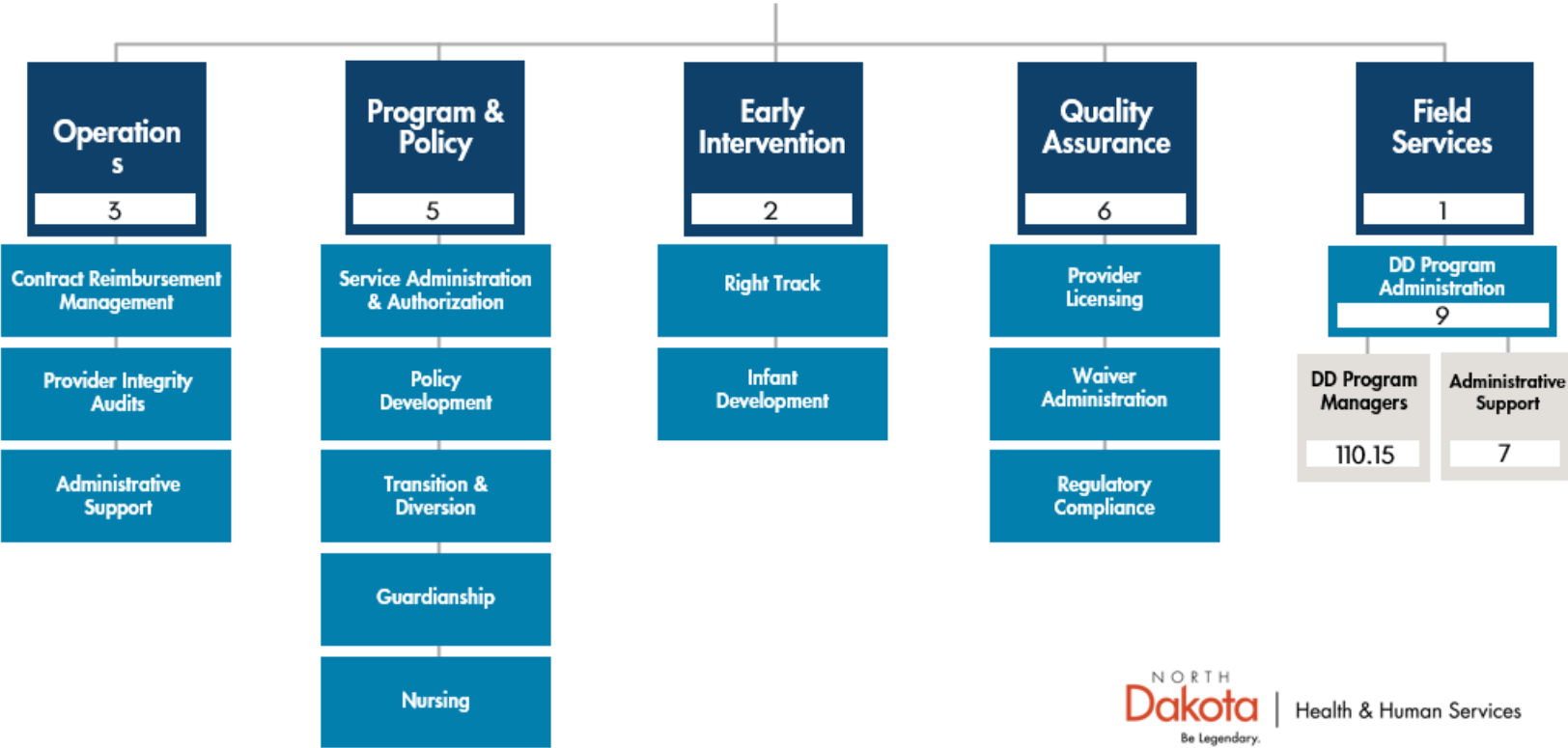
Developmental Disabilities

Position #s Assigned / Funding Exists	Positions Filled	# of Vacancies	# of Temporary Staff
144.15	141.15	3*	3*

*As of 12/01/2024

Average Age	42
Avg Years of Service	11
Retirement Risk	6%
Turnover 2021	4%
Turnover 2022	3%
Turnover 2023	6%
Turnover 2024	7%

Developmental Disabilities Director *Tina Bay*



Meet Caden



Caden is 23 years old.

AT AGE 17: Found eligible for DD services. Diagnosed with Autism, moderate Intellectual Disability, and Post-traumatic stress disorder. Caden has a **DD Program Manager (DDPM)** to help coordinate care.

AT AGE 18: Caden moved out of mom's home into a **Residential Habilitation** service environment (apartment with 2 roommates, owned and staffed by DD provider).

- Started experiencing difficulties with increasing frequency and severity, prompting the team to request assistance from the LSTC Crisis team (**CARES**).

AT AGE 20: After several incidents with staff and a housemate, Caden was taken to local hospital.

- When Caden was at the hospital, DD provider issued an involuntary discharge, citing safety concerns for other residents.

AT AGE 21: DDPM was able to coordinate transition to an **Intermediate Care Facility**.

- **Outlier** request allow for additional staff coverage in the facility.
- Cycling of varying aggressive behaviors continued and resulted in several hospital admissions.
- During a hospital stay, DD provider issued a discharge from ICF.
- No providers accepted statewide referral due to (inability to staff).

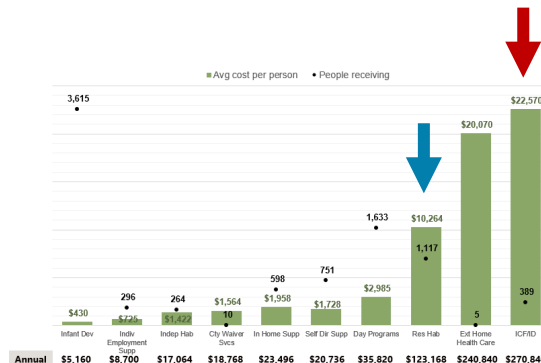
AT AGE 22: Caden is admitted to specialized ICF at **Life Skills Transition Center (LSTC)** for stabilization.

- Cycle of aggressive behaviors continued, with active efforts to adjust medications, establish behavior support plan and effective interventions.

✓ Over the last 5 years (since becoming eligible for DD services), Caden's DDPM has sent out **230+ individual referrals** to try to find Caden a place to live, with service providers willing/able to serve Caden's needs.

✓ He has experienced **35 discharges** from acute care hospitals and DD providers.

What's next for Caden? What does a stable situation look like for him?



Discharge can be Voluntary or Involuntary

Voluntary Discharge: the person chooses to exit services or choose another provider

- Personal preference
- Move to a different city
- Move to a short term stay in a skilled nursing facility (ex. rehab, recovery)

Involuntary Discharge: the person is discharged from services against his or her own wishes (i.e., individual's care team did not concur with the discharge decision).

- Provider "not able to meet needs"
 - Short staffing
 - Safety needs for both client and staff
 - Client-to-client interactions
 - Guardian or family challenges, including preventing the provider from providing supports

5,527 people living in ICF or ResHab setting (12-31-24 snapshot)

9 Involuntary Discharges (July-December 2024)

- **1** medical needs, **1** substance abuse, **7** behavior
- **2** continued with provider (team problem solving), **5** accepted by new provider, **1** back with family, **1** homeless (due to substance abuse)



Examining opportunities to think differently about discharge

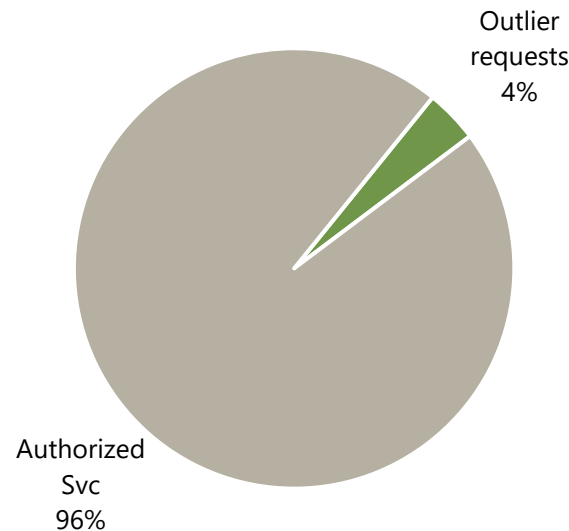
- HHS assembled a "Discharge Policy Work Group" to develop recommendations to improve involuntary discharge practices and policy. Work group is examining:
 - Reasons for involuntary discharge
 - Current challenges in the system related to involuntary discharge
 - Multiple case studies of those that have been given notice of involuntary discharge
- Work Group membership includes: HHS DD section policy (2) and field staff (2), P&A (2), DD provider CEOs (3), Guardians (2), LSTC (1)
- Results from the group's recommendations could potentially lead to policy change.

Outlier Requests are a systematized part of the service auth process designed to account for extraordinary needs

If an individual's needs exceed the support service hours authorized as per the information gleaned from the SIS or ICAP assessment, they can request consideration for additional Medicaid-funded staff support.

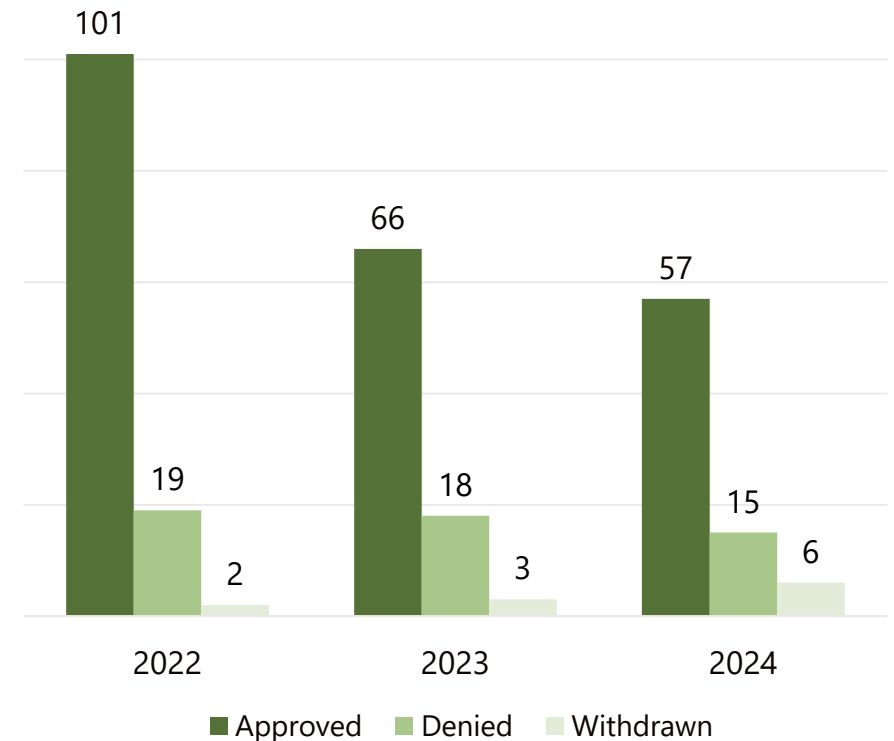
1. Meet a medical or behavioral qualifier, and
2. Pose an imminent risk of harm to health/safety (self or others), and
3. Support needs exceed hours identified, and
4. Other mitigation options were pursued before requesting additional staffing

People authorized to receive services 2022



The Outlier Policy helps ND **apply consistent principles** across unique situations and helps ensure that the system is supporting the **least restrictive level of staffing** that is *necessary to meet a person's needs*.

Outlier Requests and Resolution 2022-24



Common Denial reasons

- Hours in setting meet the level of staffing requested
- No data included or it is incomplete
- Frequency or intensity does not meet the policy requirements

Included in Executive Budget Request

Implement a Host Home Service in the DD HCBS Waiver

- One of the highest priority gaps in the DD service delivery system involves appropriate service settings for youth who need at least some level of residential care outside of their family home.
- This request establishes a host home service in the DD waiver.
- Host homes will infuse therapeutic level supports for both the youth and for the youth's family / support system to foster continued opportunities for family involvement as the youth navigates challenging symptoms and nears adulthood.
- Funds are for service delivery (paid to providers) in support of 20 operational host homes serving approximately 20 youth ages birth through 21.

Total	General	Federal	Other
\$3,379,800	\$1,689,900	\$1,689,900	\$0

This is an ongoing funding request.



Host Homes are an important alternative living option

Family-Centered Environment

- Private residence where trained caregivers or families provide one-on-one care, tailored to the youth's needs.
- Focuses on maintaining the youth's connection with their biological family or guardians, facilitating regular visits and communication.

Comprehensive Wraparound Services

- Youth receives specialized therapeutic services depending on their needs (ex. behavioral therapy).
- Host families receive thorough training on how to best support a youth with DD. This includes training in communication techniques, behavior management, and addressing unique needs.

Community Integration & Reunification Focus

- Youth living in host homes can continue participating in local activities, schools, and social interactions within their community, ensuring they remain connected to their peers and familiar surroundings.



The overarching goal of the program? Support preservation of family connection / reunification

How? The host family works closely with caseworkers and bio family to monitor progress and do everything they can to make sure family reunification is a realistic, attainable goal.



Included in Executive Budget Request

Convert the DD Youth Assessment Tool from ICAP to SIS-C

- Currently HHS-DD section uses the ICAP assessment for the resource allocation process for children birth - 15.
- The tool was selected in 2018 in part because the child-version of the SIS assessment (which ND uses for adults) was not yet available. As of 2024, the ICAP is no longer being normed or updated.
- HHS has proposed replacing the ICAP with the child-SIS (SIS-C) to reduce the impact of changing from the child assessment to adult, as both assessments will focus on support needs rather than deficiencies.
- This is expected to be a multi-year project that involves both testing the new assessment and adjusting the allocation formula based on the scoring results in the new assessment. This funding is for the use of the assessment and the consultant needed to do the allocation work.

Total	General	Federal	Other
\$400,000	\$200,000	\$200,000	\$0

This is a one-time funding request.



Included in Executive Budget Request

Provider Inflation

- Provider Inflation 1.5%/1.5%
 - 45 agency providers
 - 580 individual providers (self-directed)

Total	General	Federal	Other
\$16,808,241	\$8,293,006	\$8,515,235	\$0

This is an ongoing funding request.



Components of Quality

*How are we doing?
Can we do it better?*

National Standards

Evidence Based Practices

Applying or translating research findings into care practices and decision making that will result in the best client outcomes

Accreditation

Assures quality, consistency and relevant approaches through application of research-based standards and a peer-review process

State Standards

Licensure and Certification

Granting of authority to practice within health and safety guidelines and/or scope of practice

Incident Reporting

Tracking of health and safety events that occur in the course of delivering care to clients



Outputs and Outcomes

National Core Indicators

Standard measures used across states to assess the outcomes of services provided to individuals and families

Core Set Performance Measures

National standards of care and treatment processes for common health conditions

Processes

Quality Assurance / Quality Control

Monitoring desired level of quality in service delivery by examination of processes and procedures

Accreditation as part of the ND Quality Framework

Accreditation is about more than regulatory compliance. It represents a quality standard that evaluates how well an agency is supporting the people it serves.

- Allows for an outside, unbiased, third-party review of policies and practices and the experiences of those receiving services.
- Measures these items against national practices, experiences, and established standards. In turn, this allows for the ability to keep North Dakota services and supports truly person-centered.
- Encourages providers to collect data and use the data to make informed decisions or changes toward policy and practices.

Regulatory Monitoring

Licensing, monitoring and training, and the HCBS survey process focus on ensuring that providers meet minimum standards for health, safety, and compliance with state policies.

Accreditation

Accreditation goes further by emphasizing person-centered care and aligning practices with nationally recognized best practices.



Factor 1: Rights Protection and Promotion

Council on Quality and Leadership (CQL) [2023 Data Report](#) | ND Developmental Disabilities (n=12)

System (policies and procedures)	Org Self Assessment	CQL Review	National Benchmark
1a. The organization implements policies and procedures that promote people’s rights.	100.0%	58.3%	43.8%
1b. The organization supports people to exercise their rights and responsibilities.	100.0%	66.7%	38.3%
1c. Staff recognize and honor people’s rights.	100.0%	83.3%	58.3%
1d. The organization upholds due process requirements.	83.3%	58.3%	47.1%
1e. Decision-making supports are provided to people as needed.	91.7%	66.7%	28.8%
Practice (evidence of practice)	Org Self Assessment	CQL Review	National Benchmark
1a. The organization implements policies and procedures that promote people’s rights.	100.0%	75.0%	54.3%
1b. The organization supports people to exercise their rights and responsibilities.	100.0%	66.7%	39.7%
1c. Staff recognize and honor people’s rights.	100.0%	91.7%	68.3%
1d. The organization upholds due process requirements.	75.0%	50.0%	39.8%
1e. Decision-making supports are provided to people as needed.	91.7%	66.7%	33.6%

Meet Eve



Eve is 4 ½ years old.

- Born prematurely at 30 weeks
 - Diagnosed with Down Syndrome
 - Experienced delays in all areas of development
- Eve was found eligible for Early Intervention services at 10 weeks old.
- Eve qualified for **Medicaid** due to her eligibility for the DD waiver, which provided additional support to her family.

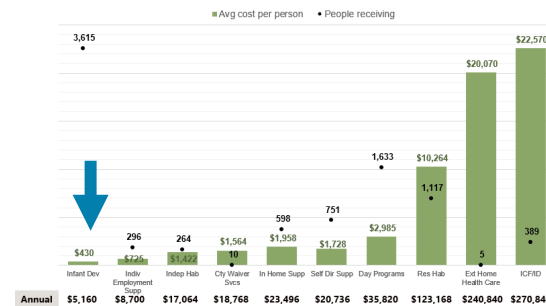
Eve and her family were supported through these services:

1. Regular **Service Coordination** (DD Program Management)
2. **Infant Development** Services (aka “Early Intervention”)
 - Weekly **home visits** with their Primary Early Intervention professional
 - **Occupational Therapy** and **Speech** consultations monthly

When Eve turned three, she was meeting her developmental milestones and no longer qualified as DD-eligible. Her Medicaid eligibility ended.

Eve did go on to receive **Part B** services through **IDEA**.

At the age of 4 ½, her family began to see regression in her developmental milestones, **so they reached out** to their regional DD unit to discuss eligibility and service options.



Included in Executive Budget Request

Cross Disability Waiver Implementation

- Address existing disparities in access to home and community-based services for children with disabilities, taking meaningful steps to expand access and resources to people who may not be well served by the current system of care.
- Modernize the current system, ensuring equitable access to essential services for children aged 3 to 21 who have mild to moderate support needs.

2025-2027 Biennium Activities:

1. Design and Test New Level of Care for Cross Disability Waiver and Developmental Disabilities Waiver
 2. Design Cross Disability Waiver (Service Array, Access, Quality, Provider Qualifications & Rates)
 3. Start Building Service Infrastructure
- Anticipated start date for delivery of services is July 2028.

Total	General	Federal	Other
\$4,948,452	\$2,474,226	\$2,474,226	\$0

This is an ongoing funding request.



Part of the Cross-Disability Waiver work will change what it means to be “DD-eligible”

Modifying and Refining Level of Care



CURRENT STATE

North Dakota uses an older federal definition of developmental disability to decide who qualifies for services. This definition focuses mainly on things like learning, self-care, and mobility.

NEXT STEP

Update North Dakota’s definition to match more modern standards, like those used by the AAIDD, DSM-5, and ICD-11.

- The update will include "social" functioning as part of what qualifies someone for services.
- This change will help the state better identify and support people with intellectual and developmental disabilities.














HOW DO WE GET THERE?

To make this happen, the state will work with a contracted entity to:

- ✓ Review the best practices from across the country,
- ✓ Test new tools alongside the current system,
- ✓ Select a new tool and work with CMS re approval,
- ✓ Develop an implementation plan incl IT system mods, &
- ✓ Training/change mgmt. with stakeholders.

What does it actually mean to modify the DD “level of care”?

4 primary domains affect a person’s ability to execute life activities

	ND Today	ND Future
1 Intellectual or Developmental Significant limitations in both Intellectual functioning (general mental capacity) & adaptive behavior; originates before age 22	 + 	 + 
2 Conceptual Language and literacy, money, time, number concepts, self direction	 + 	 + 
3 Social Interpersonal skills, social responsibility, self-esteem, gullibility, naivete (wariness), social problem solving, ability to follow rules/obey laws, avoid victimization	+ 	 + 
4 Practical Activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone		



What stays the same?

- Definition of and understanding of each individual element of diagnosis / deficit
- Definition of an ICF/IDD level of care

What changes?

Our understanding, assessment and recognition of the interplay between the diagnosis of intellectual disability and various adaptive deficits (conceptual, social, practical), and the impact the cumulative effect has on a person’s ability to execute life activities

Changes to Base Budget

By Ongoing, One-Time and Funding Source

BASE BUDGET CHANGES	DESCRIPTION	2025-27 EXECUTIVE BUDGET		ENGROSSED HB 1012	
		GENERAL	OTHER	GENERAL	OTHER
Compliance & Quality	Conversion of DD Eligibility Assessment tool for kids (ICAP to SIS)	\$200,000	\$200,000 (Federal)	\$200,000	\$200,000 (Federal)
Services HCBS	Implement a Host Home service in DD HCBS waiver	\$1,689,900	\$1,689,900 (Federal)	\$1,689,900	\$1,689,900 (Federal)
Additional Executive Decision Packages	Provider Inflation 1.5%/1.5% - V2%/2%	\$8,287,885	\$8,479,150 (Federal)	\$10,959,430	\$11,419,639 (Federal)
Underfunding	FTE Block Grant Reduction			-\$1,201,777	
Underfunding	Operating Reduction			-\$437,463	
Additional House Decision Packages	Intermediate care facility grant to Anne Carlsen			\$3,457,736	

Comparison of budget expenditures and projections

By Program

PROGRAMS	2023-25 LEGISLATIVE BASE	ONE-TIME / CARRYOVER	2023-25 EXPENSES THROUGH DECEMBER	2023-25 PROJECTED EXPENDITURES	2025-27 EXECUTIVE BUDGET RECOMMENDATION	INCREASE / (DECREASE)	ENGROSSED HB 1012	GENERAL	FEDERAL	OTHER
DD ADMIN & RELATED PROGRAMS	\$ 8,330,349	\$ 2,500,000	\$ 5,731,580	\$ 8,551,173	\$ 12,055,271	\$ (153,059)	\$ 11,902,212	\$ 4,649,030	\$ 7,253,182	-
GUARDIANSHIPS	4,788,545	-	3,156,844	4,049,631	6,109,355	\$ (380,000)	5,729,355	5,729,355	-	-
DD CASE MANAGEMENT (DDPM)	22,635,279	-	18,452,295	24,861,662	26,457,120	\$ (1,125,000)	25,332,120	12,167,692	13,164,428	-
EARLY INTERVENTION PROGRAMS	3,650,698	804,825	1,912,762	2,711,577	2,857,680	\$ 18,819	2,876,499	-	2,876,499	-
DD SERVICE GRANTS	742,793,592	-	514,859,734	730,079,538	762,116,908	\$ 5,632,033	767,748,941	377,480,409	390,268,532	-
HCBS CAPACITY (10% REINV)	-	-	633,852	688,764	1,043,494	-	1,043,494	-	521,747	521,747
PROVIDER RETENTION GRANTS (10% REINV)	-	1,593,594	300,300	920,031	-	\$ 3,457,736	3,457,736	3,457,736	-	-
TOTAL	\$ 782,198,463	\$ 4,898,419	\$ 545,047,367	\$ 771,862,376	\$ 810,639,828	\$ 7,450,529	\$ 818,090,357	\$403,484,222	\$414,084,388	\$ 521,747

Comparison of budgets and funding

By Major Expense

DESCRIPTION	2023-25 LEGISLATIVE BASE	INCREASE / (DECREASE)	2025-27 EXECUTIVE BUDGET RECOMMENDATION	INCREASE / (DECREASE)	ENGROSSED HB 1012
Salaries & Benefits	\$ 25,750,507	\$ 5,243,716	\$ 30,994,223	\$ (1,201,777)	\$ 29,792,446
Operating	12,482,544	1,191,250	13,673,794	(437,463)	13,236,331
IT Services	191,850	2,346,941	2,538,791	-	2,538,791
Capital Asset Expense	-	-	-	-	-
Capital Assets	10,000	-	10,000	-	10,000
Grants	743,763,562	19,659,458	763,423,020	9,089,769	772,512,789
Total	\$ 782,198,463	\$ 28,441,365	\$ 810,639,828	\$ 7,450,529	\$ 818,090,357
General Fund	\$ 372,688,337	\$ 26,389,711	\$ 399,078,048	\$ 4,406,173	\$ 403,484,221
Federal Funds	409,372,626	1,667,407	411,040,033	3,044,356	414,084,389
Other Funds	137,500	384,247	521,747	-	521,747
Total Funds	\$ 782,198,463	\$ 28,441,365	\$ 810,639,828	\$ 7,450,529	\$ 818,090,357

Developmental Disabilities as a % of HHS Budget

- 12.9%

Budget by Funding Source

- 49.2% General
- 50.7% Federal
- 0.06% Other

Budget by Pass Through

- 95.2% Paid to private providers
- 3.2% Direct Service
- 1.5% Admin
- 0.3% IT

**Note: Technology for DD eligibility determination is supported by SPACES (EA budget) and for DD claims processing by MMIS (MS budget).*

DD-related Policy Bills with Budget Impact

		Federal	General
SB 2305	Family Paid Caregiver Pilot		\$7,300,000
SB 2029	Establishment of Office of Guardianship Council (transfers HHS guardianship establishment funds to Supreme Court)		(\$6,109,355)





On the horizon for DD

- Host homes
- Level of Care redesign
- Cross disability waiver design
- Process redesign for DD system
- Youth-oriented Employment / Day Services

Contact Info

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HHS Developmental Disabilities [website](#)

