

Developmental Disabilities 101





Who are Individuals with Intellectual and Developmental Disabilities?

Your family members, friends, neighbors, classmates & co-workers

- People with I/DD experience lifelong conditions such as autism, Down syndrome or cerebral palsy
- Affects person's ability to think, learn and develop skills at the same rate as others
- Often need support for everyday activities
- Family members, friends, neighbors, classmates & co-workers



What do Individuals and their Families Want?

What everyone else wants....

- To live, have access to, and belong in the community
- The opportunity to learn & grow
- A safe, affordable, accessible, inclusive place to live
- Meaningful things to do, including real jobs for real pay
- To be healthy and have access to appropriate healthcare, including mental and behavioral health
- Happy, healthy relationships
- Appropriate, adequate support available when needed
- A transparent, easy-to-use service system
- Economic stability



Where Does the Data Come From?

All data comes from Developmental Disabilities Community Services (DDCS) 2025 Caseload & Cost report as well as additional data requests from DDCS.



What is the DDCCS Caseload?



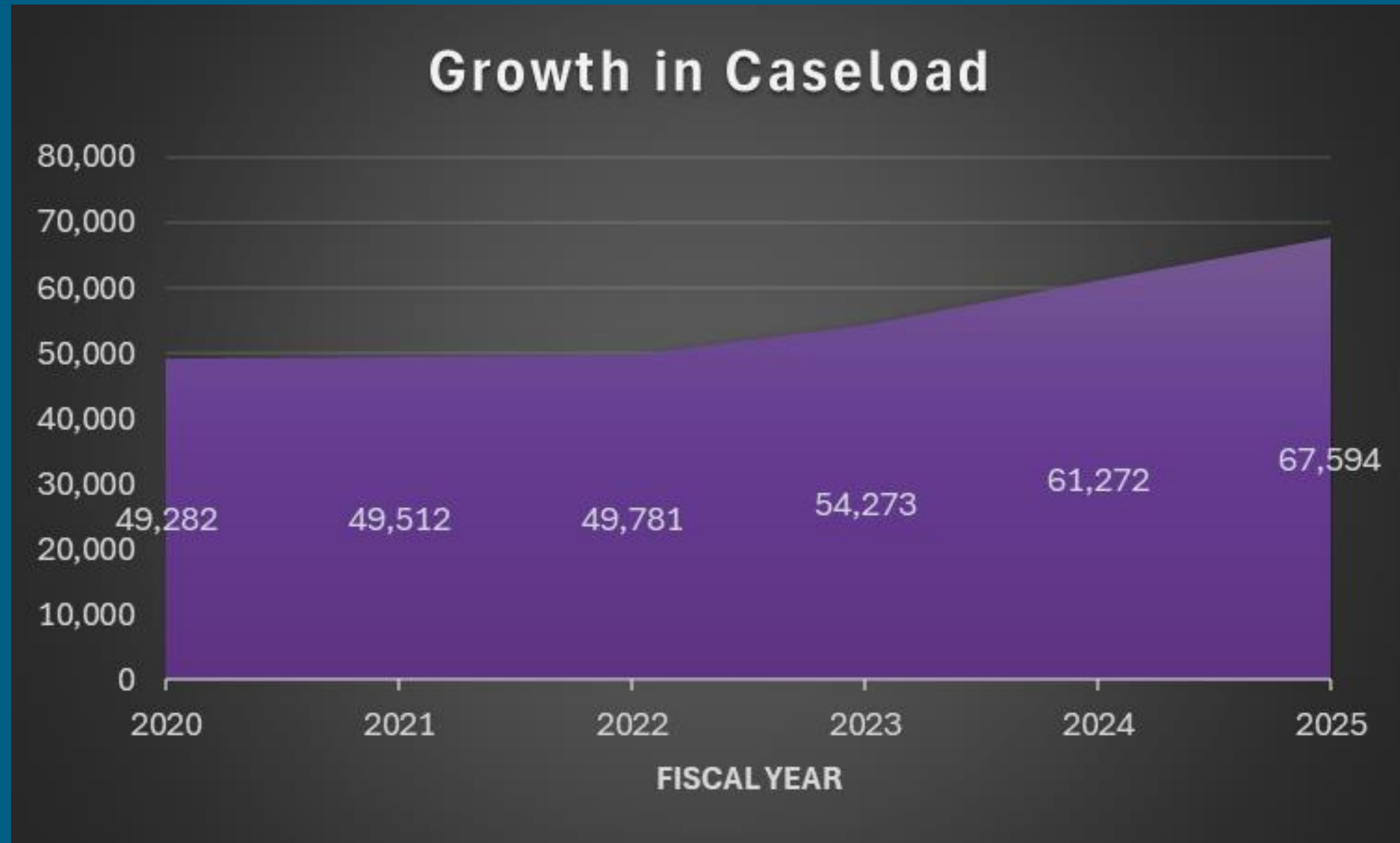


DDCS Snap Shot

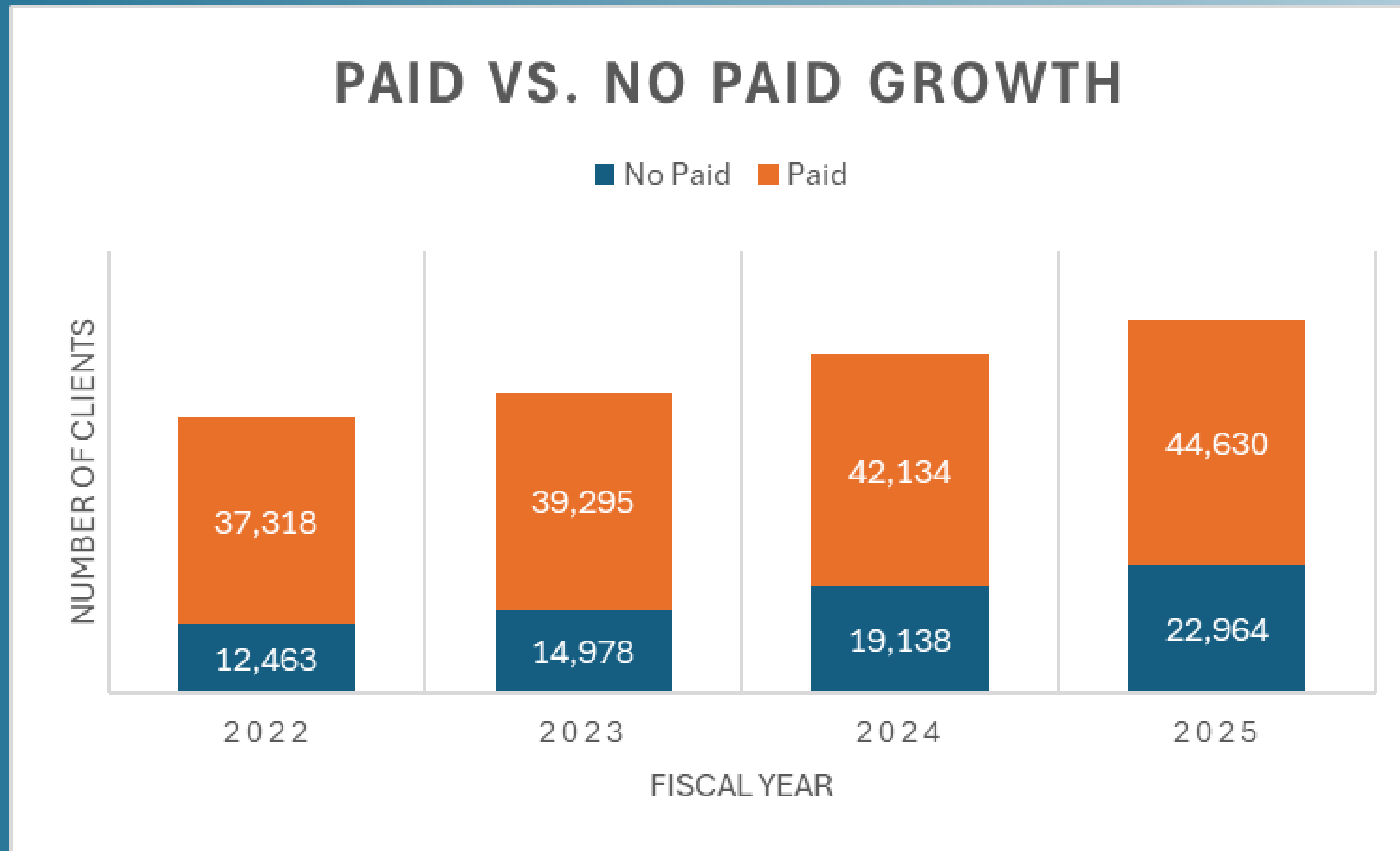
- 1–3% of the population has an intellectual or developmental disability (170,000)
- 67,594 number of DDCS clients
 - 36,881 Children
 - 30,713 Adults
- Of those adults, 17,382 (56.5%) live with and receive care from a parent or a relative.



This is more than 37% growth since 2020



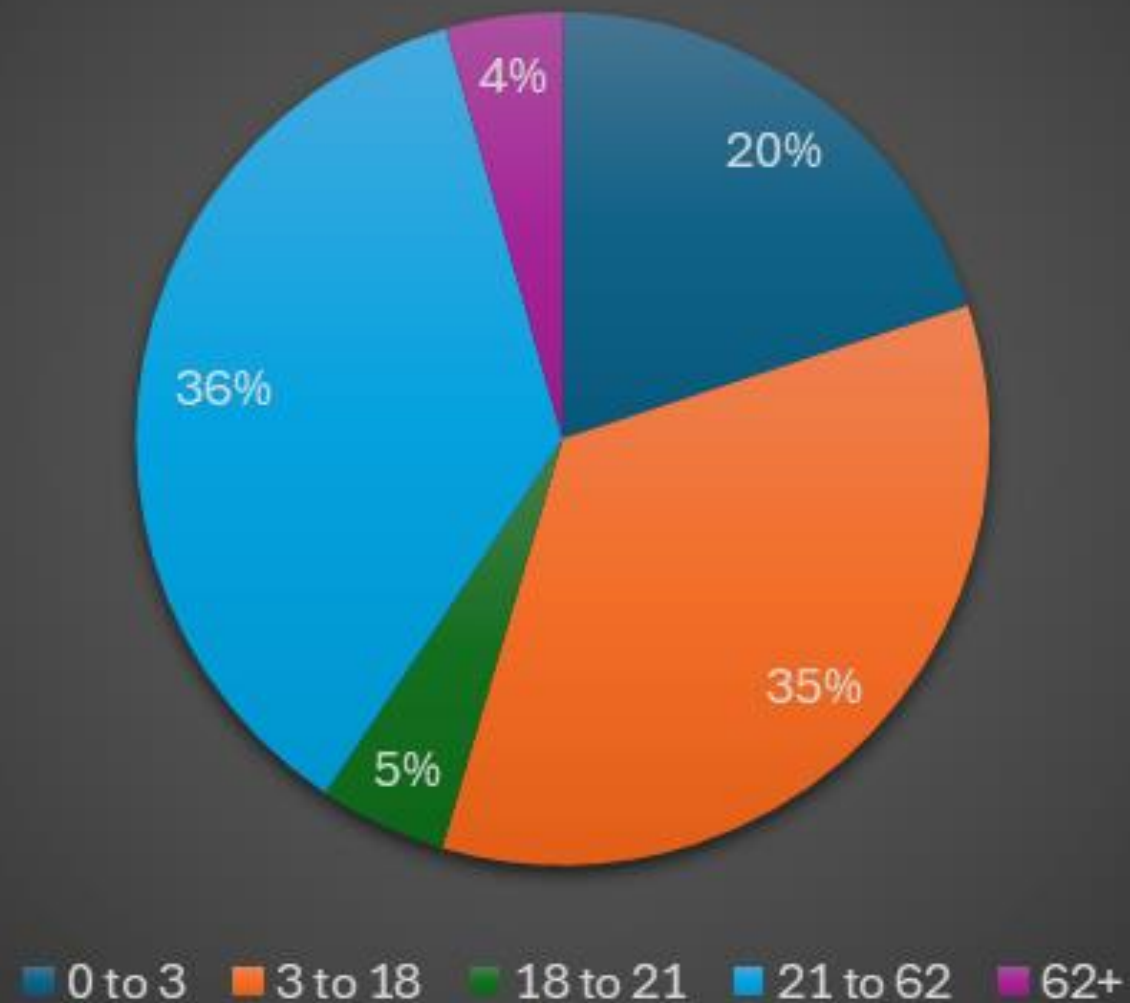
22,964 Receive No Paid Services



A 45% Growth over the past 4 years

Who DDCS Serves by Age

Caseload by age



Age range	Number enrolled
0 to 3	13,483
3 to 18	23,398
18 to 21	3,268
21 to 62	24,452
62+	2,993
Total	67,594

More than Half are Children



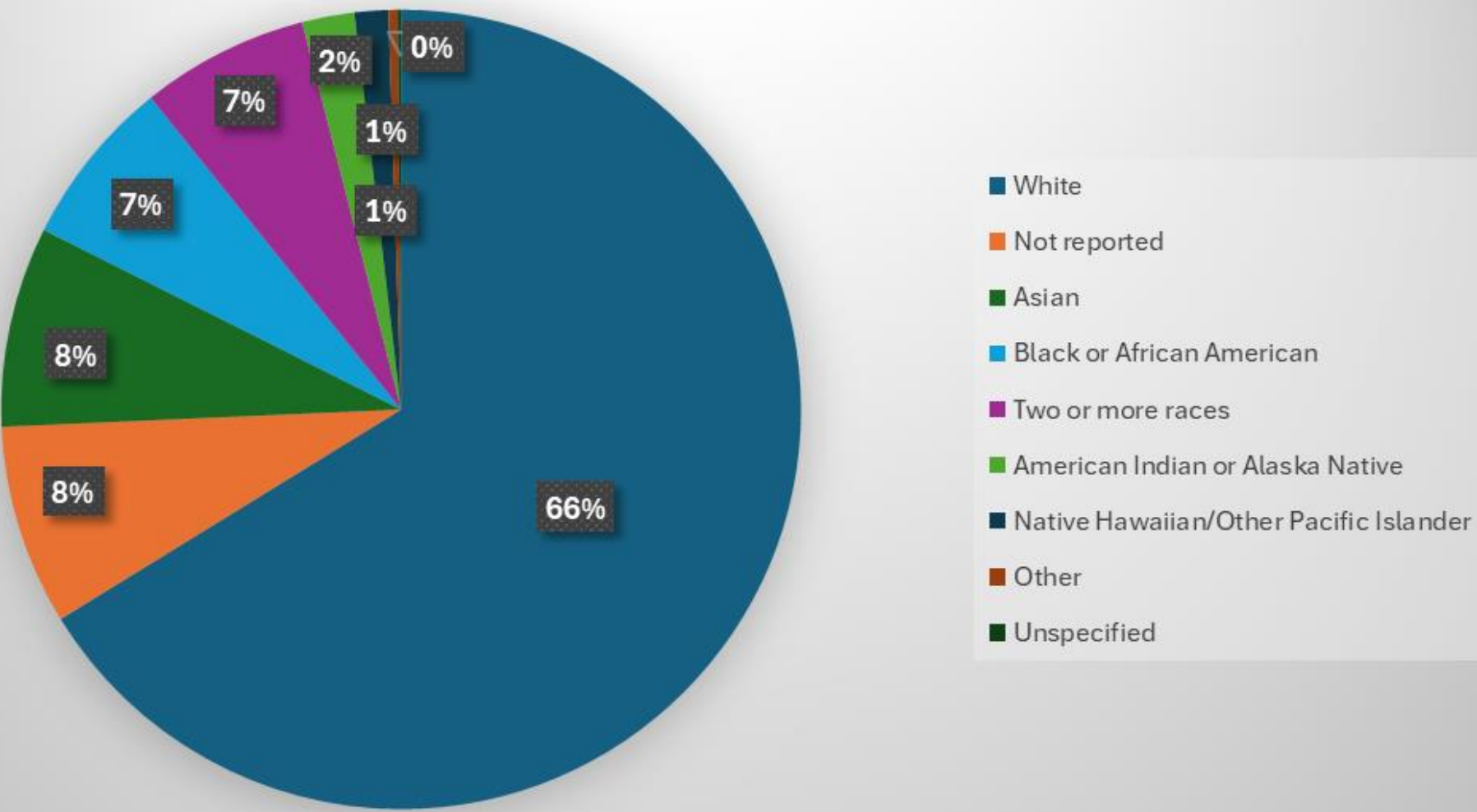
Caseload by Disability



Disability	Adult	Child
	684	1591
Another Neurological Condition	162	
Another Neurological Condition or Other Condition	1220	735
Autism	5096	2250
Cerebral Palsy	2046	449
Developmental Delay	113	28765
Epilepsy	559	133
Intellectual Disability	16882	836
Medically Intensive Children's Program		35
Other Condition	1724	
Two or More Disabilities	2227	2087
Total	30713	36881

Who DDCS Serves by Race & Ethnicity

Eligible Caseload by Race/Ethnicity



Race	Adult	Child	Total
White	23,588	21170	44,758
Not reported	989	4482	5471
Asian	1828	3649	5477
Black or African American	1906	2707	4613
Two or more races	1011	3572	4583
American Indian or Alaska Native	844	584	1428
Native Hawaiian/Other Pacific Islander	370	552	922
Other	93	158	251
Unspecified	84	7	91
Total	30713	1301	67594

Tribal Affiliation	Adult	Child	Number
Affiliated with one or more tribes	662	468	1,130
Unspecified	2344	24	2,368
Total	3006	492	3498

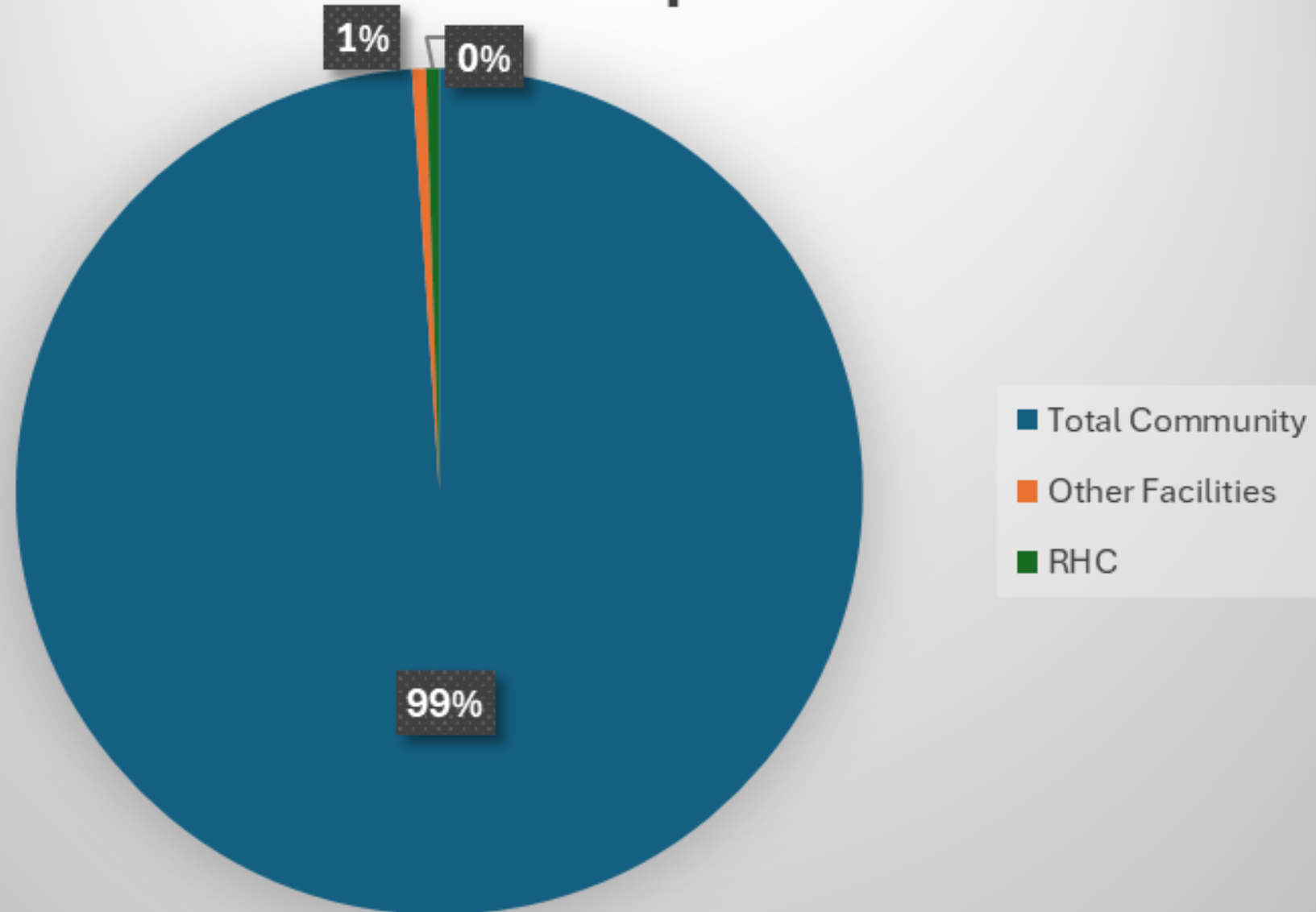
Hispanic	Adult	Child	Total
	3,407	8806	12,213

Community Living



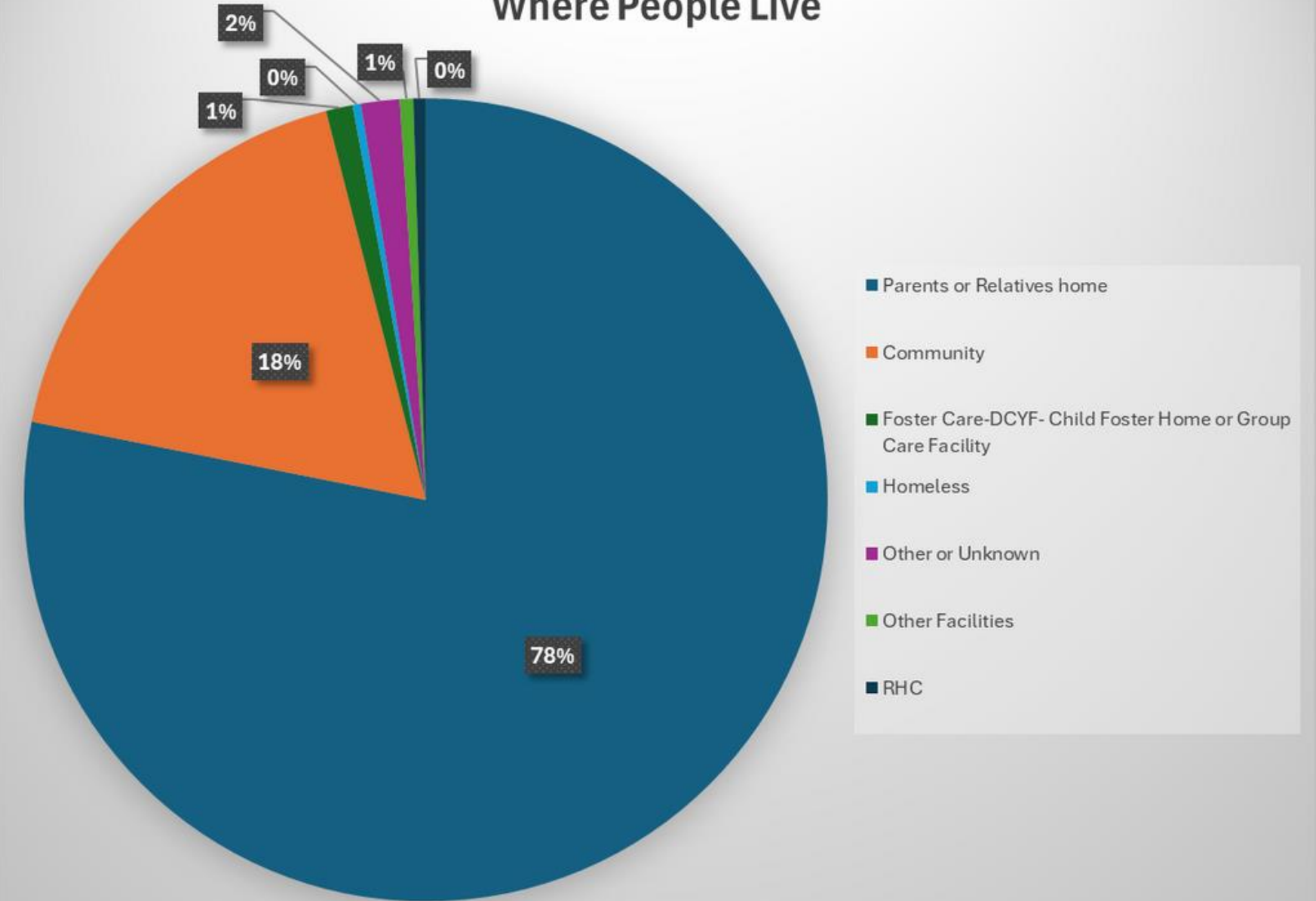
Where People Live

Where People Live



99% of DDCS Clients live in the Community

Where People Live



78% of DDCS Clients live with a parent or relative



Home & Community Based Services

What's a Waiver & What are you Waiving?

HCBS waivers are a set of Medicaid services that are available to a specific population of people. Waivers are state-specific and have a 50/50 federal match.



Waives services in an institution to receive services in the community



Washington has 5 DD Waivers



The number of DD Waiver slots are capped



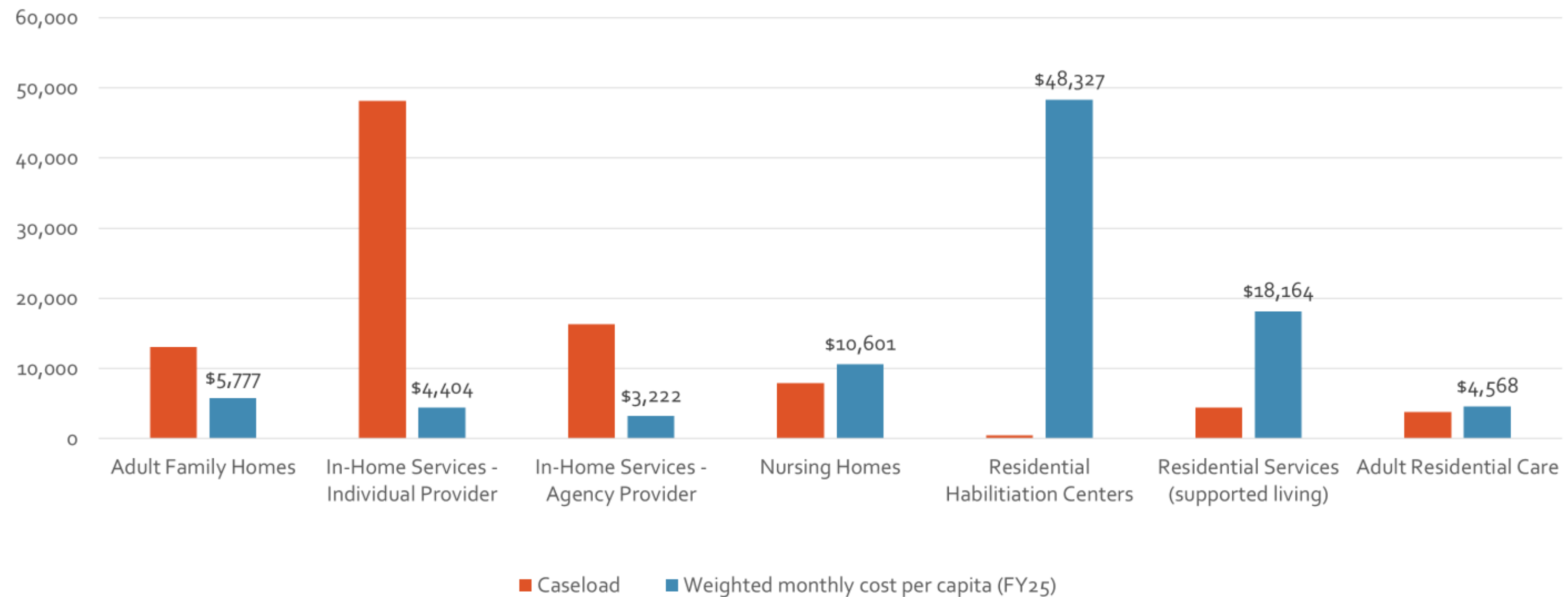
Waivers by the Numbers



Waiver	Capacity	Enrolled
Individual & Family Services	8000	7,208
Basic Plus	13,400	12,490
Core	5702	4801
Community Protection	504	301
Childrens In Home Behavior Support	200	190
TOTAL	27,806	24,990

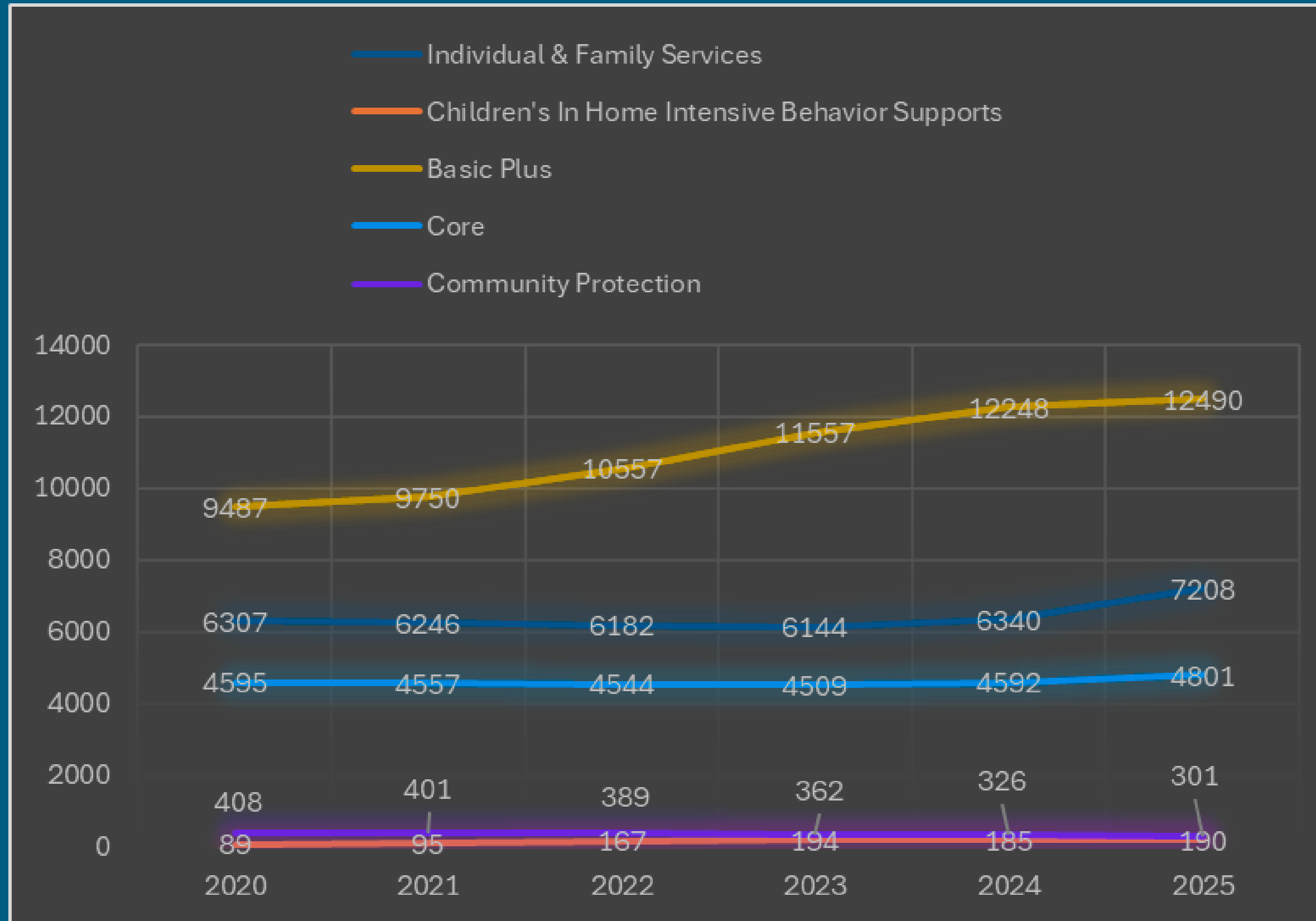
HCBS is extremely popular & saves the State money

Caseload and weighted average monthly cost for LTSS services in Washington state



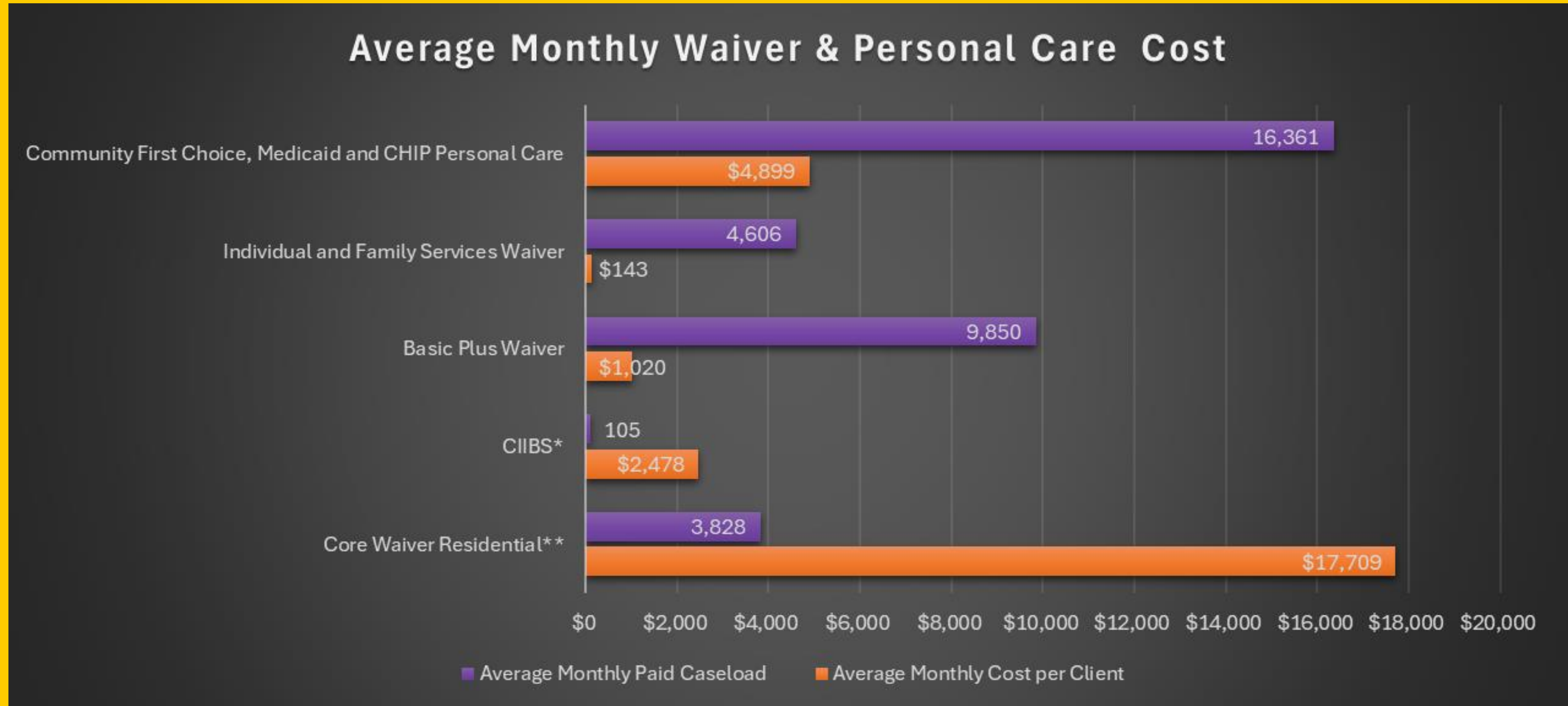
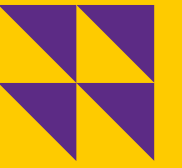
Source: own elaboration with information from DSHS - ALTSA & DDA Per Capita Costs Winter 2024 Forecast

The Demand for Waivers Continues to Grow





Average Monthly Waiver Cost

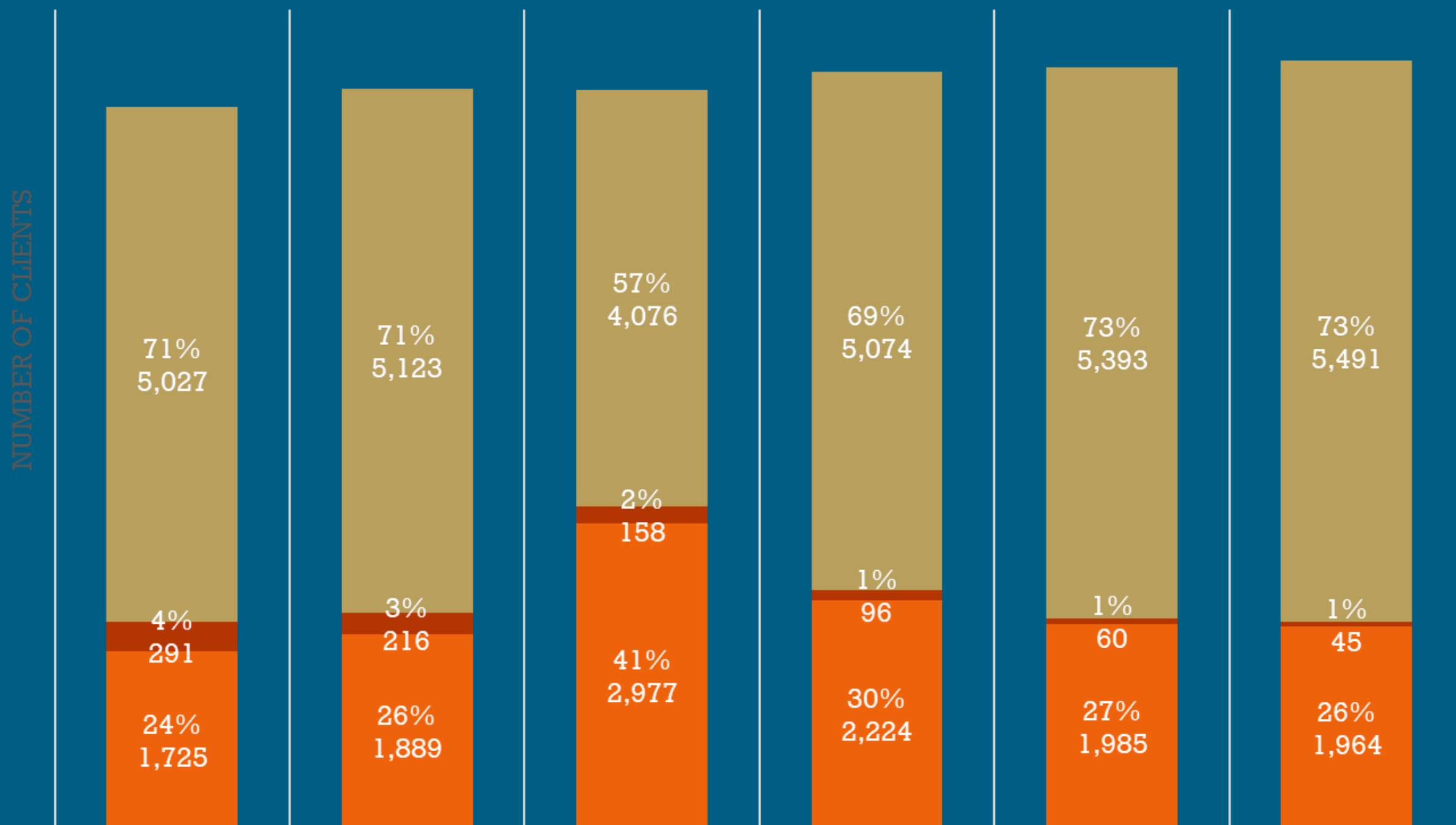


Data from
2024



People Working

■ Job Seeking - No Wages Reported ■ Subminimum Wage ■ ≥Minimum Wage and/or Self-Employed



2024 Data

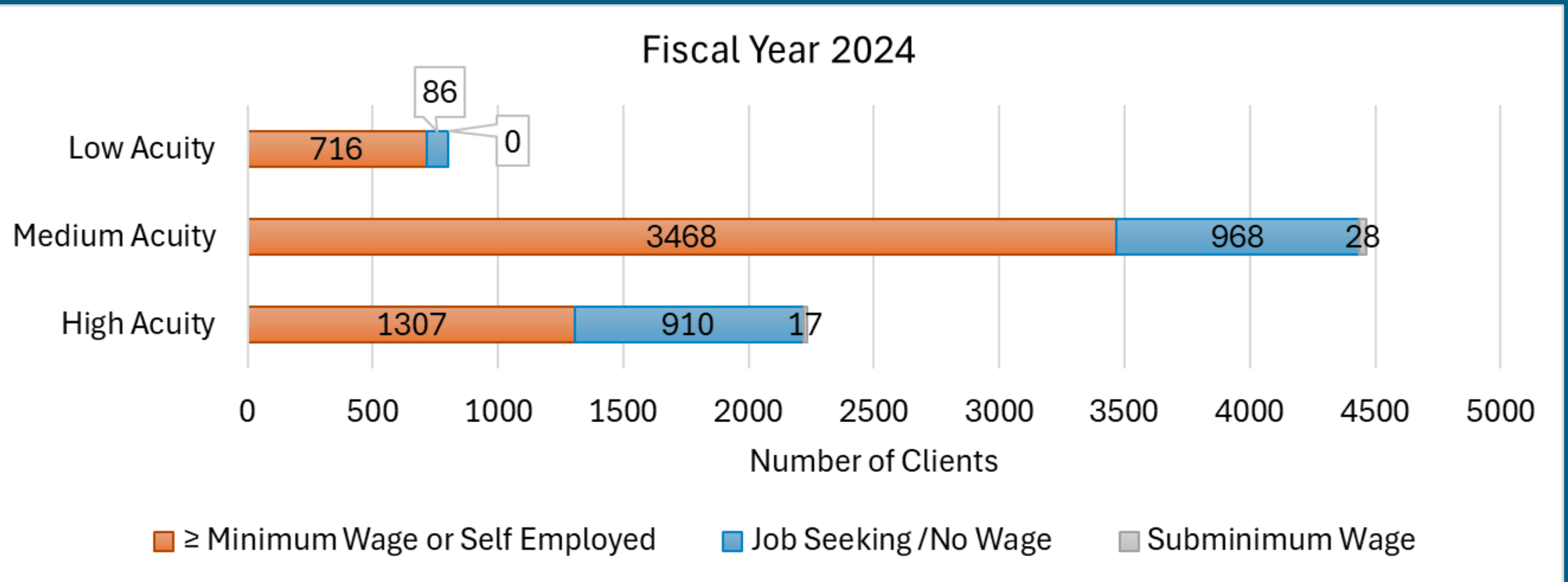




Support for Working

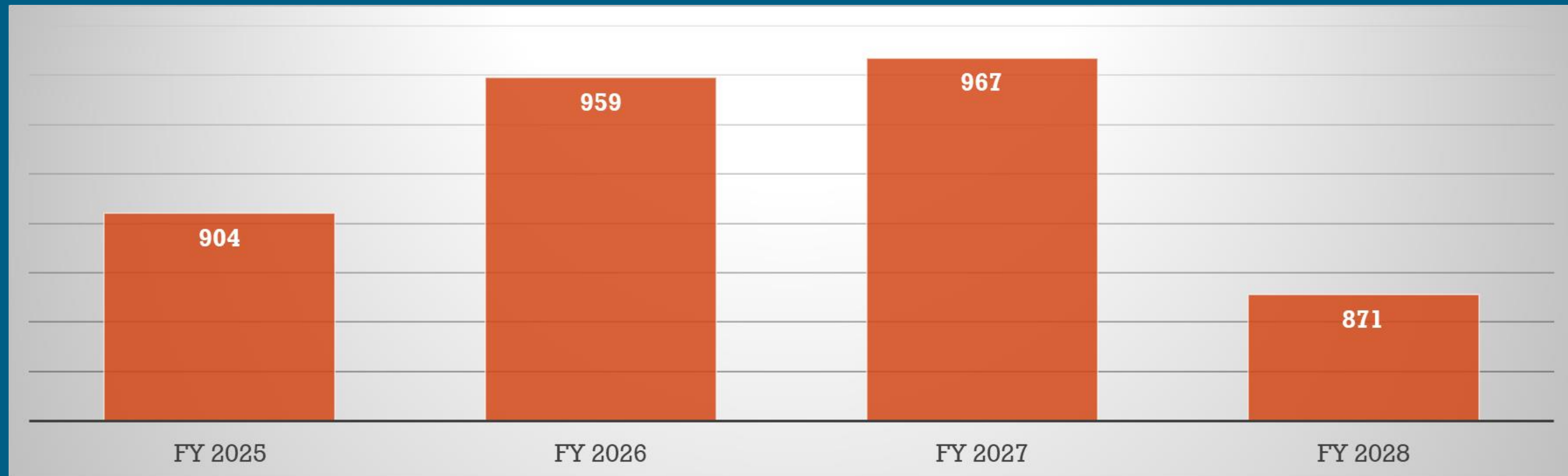
Service	Support Hours Per Week	Work Hours Per Week	Wages Per Week
Individual Employment	2.4	10	180.7
Group Supported Employment	2.4	7.6	125.78

Wages & Acuity Level





Projected Transition Age Students



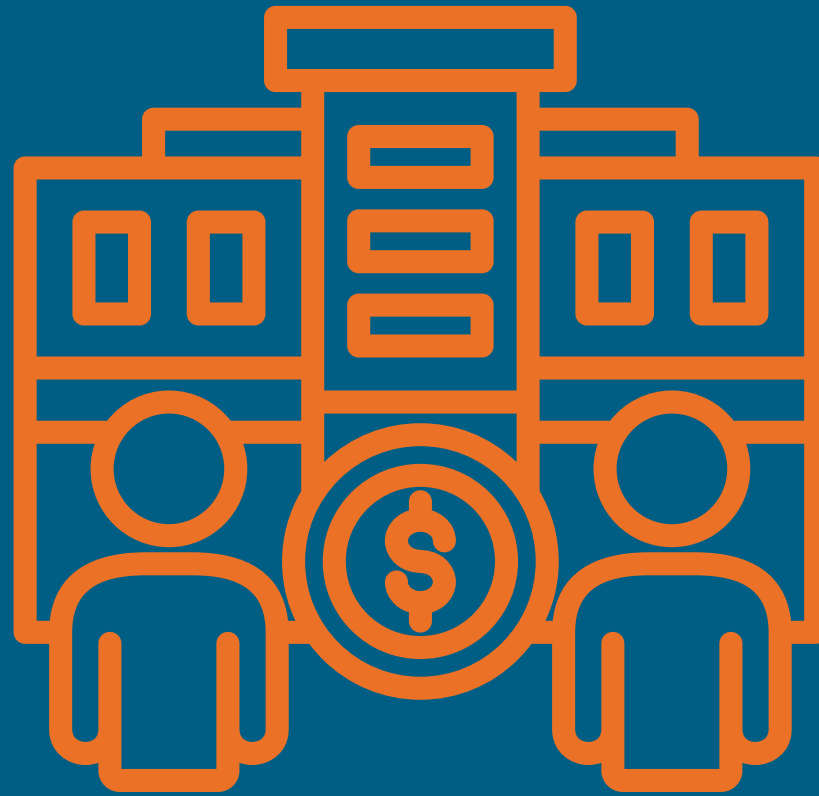


Access to the Community

Number of
Individuals
Served **2526**

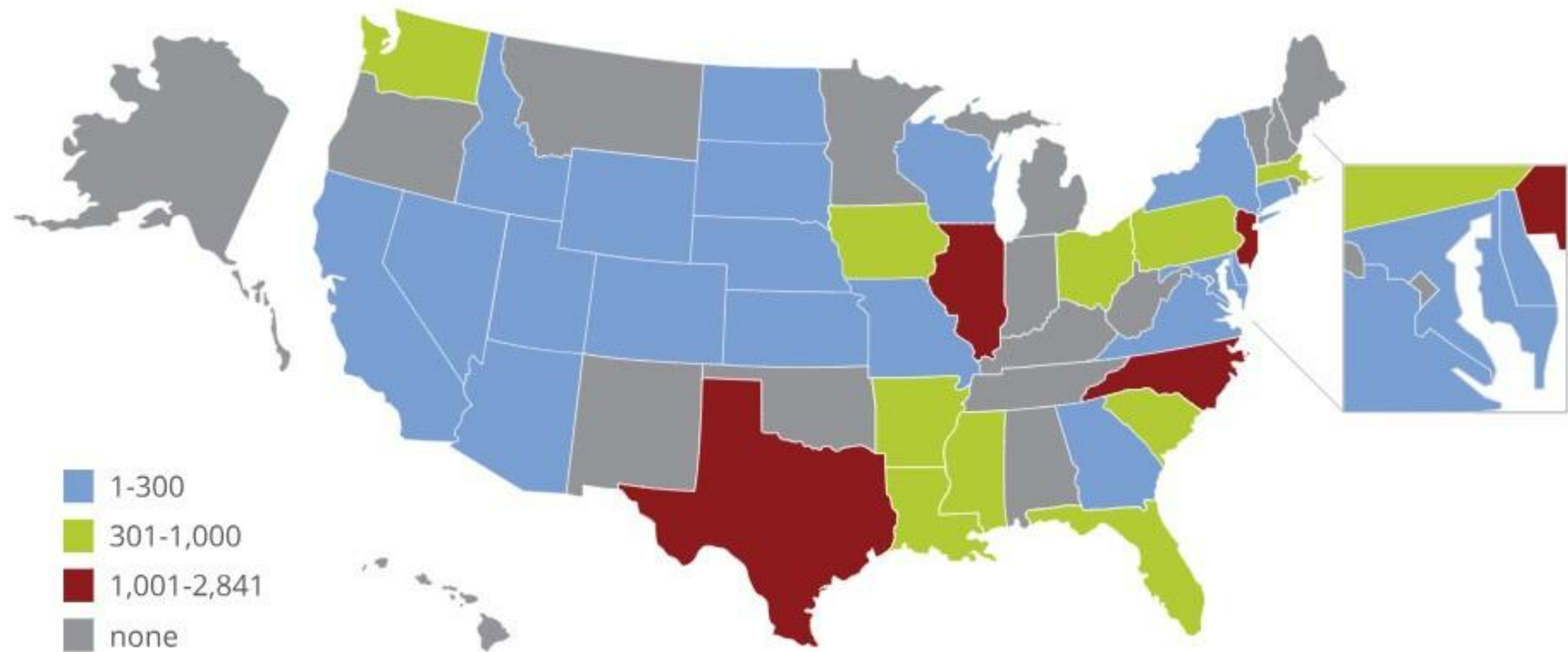
Community
Inclusion Average
Support Hours
Per Week **2.2**

Residential Habilitation Centers



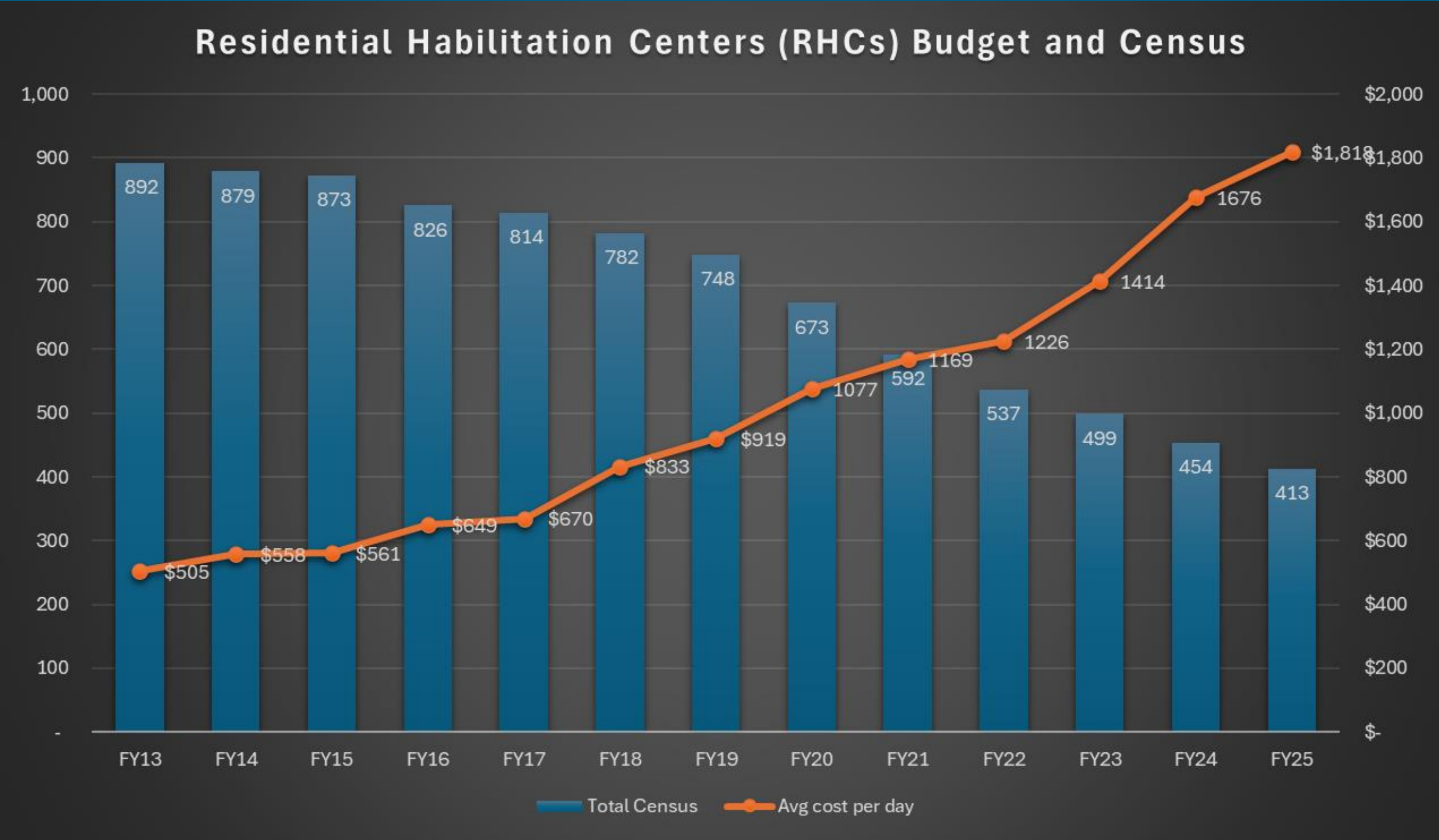
18 States have Completely Eliminated RHCs

On June 30, 2020, 15,322 people lived in state-run IDD facilities serving 16 or more people.



By 2020, there were 15,322 people with IDD living in 103 state-run facilities in 33 states.

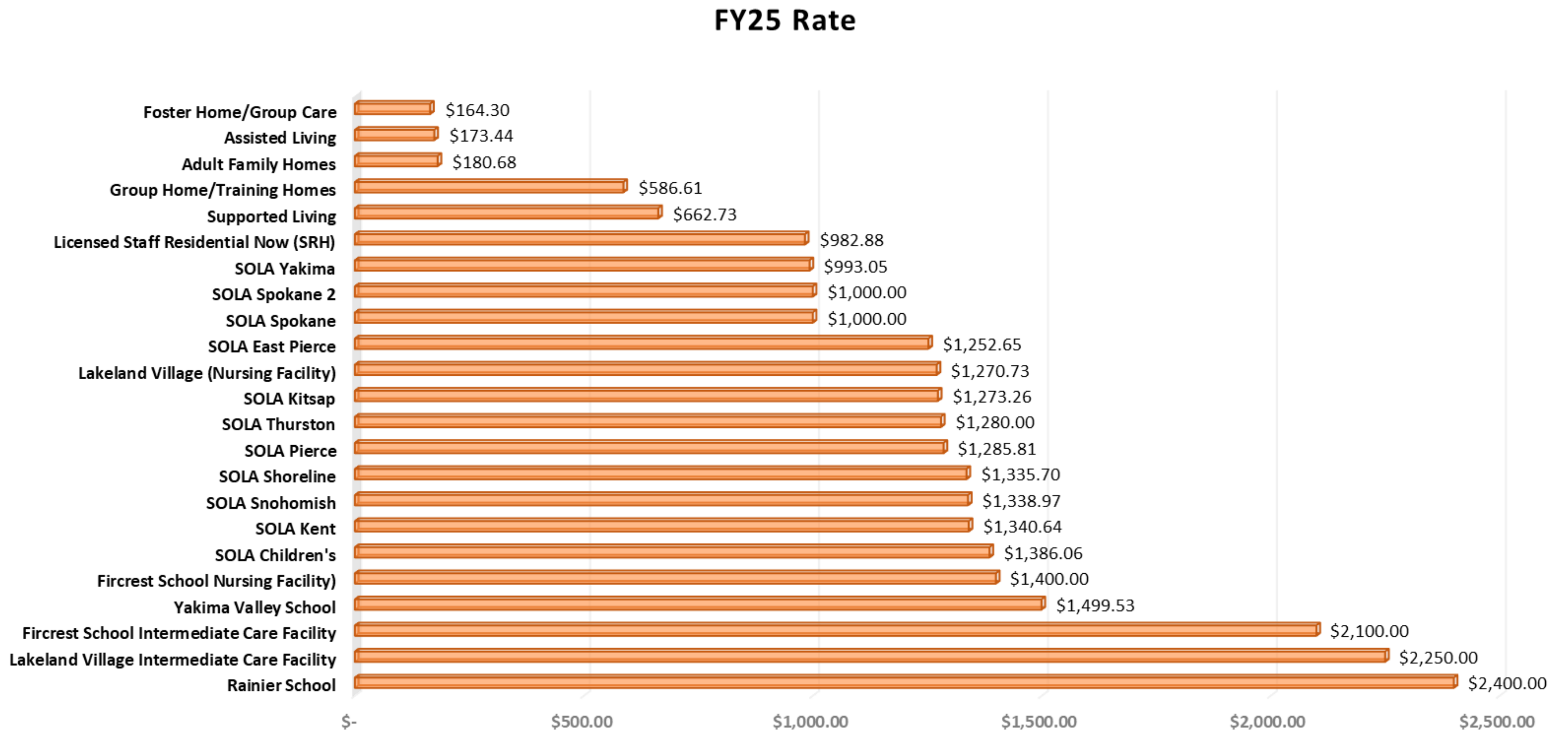
In the last 12 years the number of people at RHCs has dropped by more than **half**, while the cost has more than **tripled**



RHC Census

Setting	18 through 21	22 through 62	63 +
Lakeland Village	1	61	81
Rainier	2	50	19
Yakima Valley School	4	31	14

Cost Per Day By Residential Setting

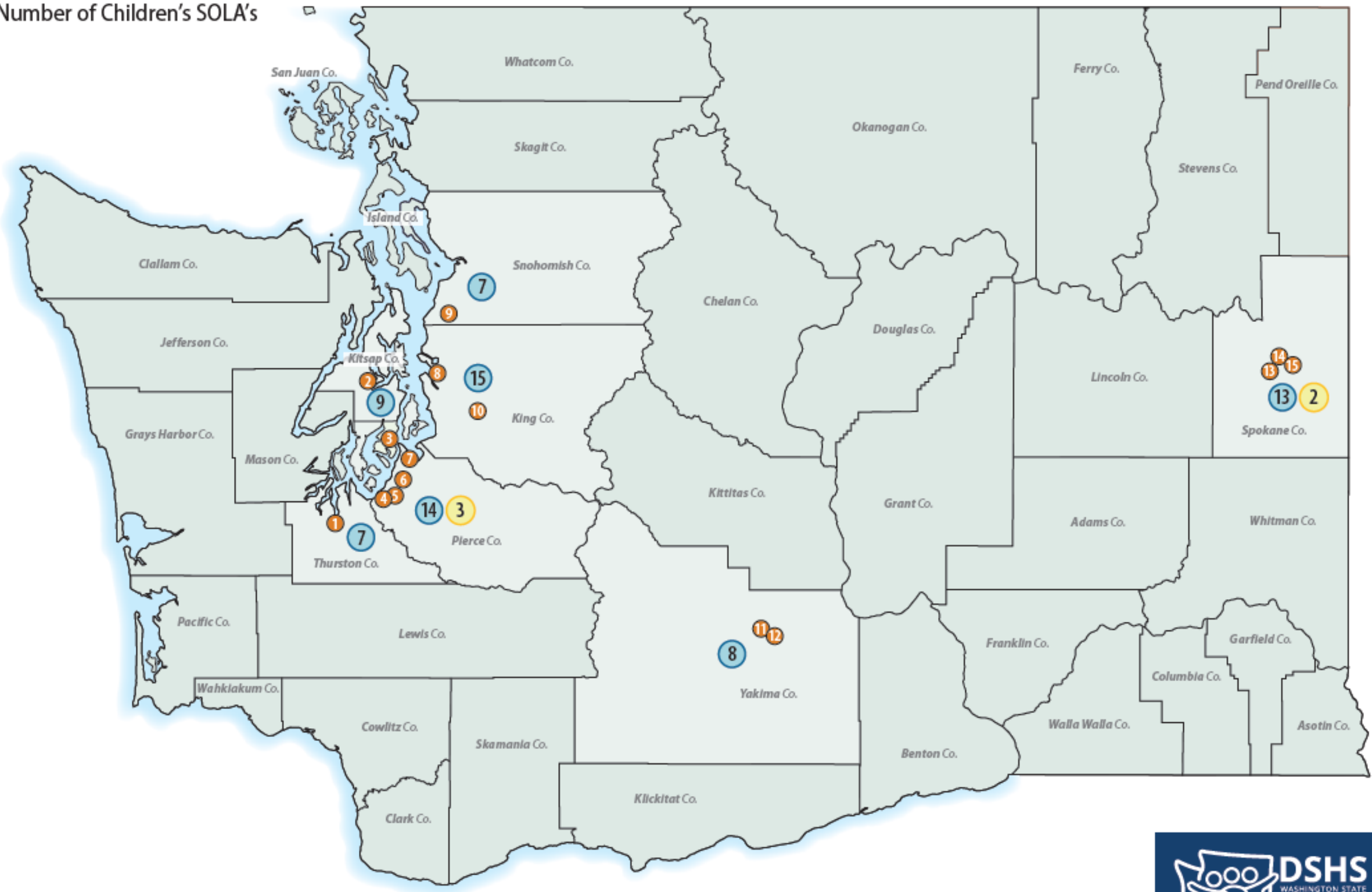


State
Operated
Community
Residential

Our state-operated
living alternative homes
Behavioral Health and Habilitation Administration

Number of Adult SOLA's
Number of Children's SOLA's

- State Operated Living Alternatives regional offices – managing 80+ community homes
- 1 Thurston SOLA
 - 2 Kitsap SOLA
 - 3 Stabilization Assessment and Intervention Facility (SAIF)
 - 4 Pierce SOLA
 - 5 Children's SOLA West (CSW)
 - 6 Intensive Habilitation Services (IHS)
 - 7 East Pierce SOLA
 - 8 Shoreline SOLA
 - 9 Snohomish SOLA
 - 10 Kent SOLA
 - 11 Yakima SOLA
 - 12 SOCR Transitions
 - 13 Spokane 1 SOLA
 - 14 Spokane 2 SOLA
 - 15 Children SOLA East (CSE)

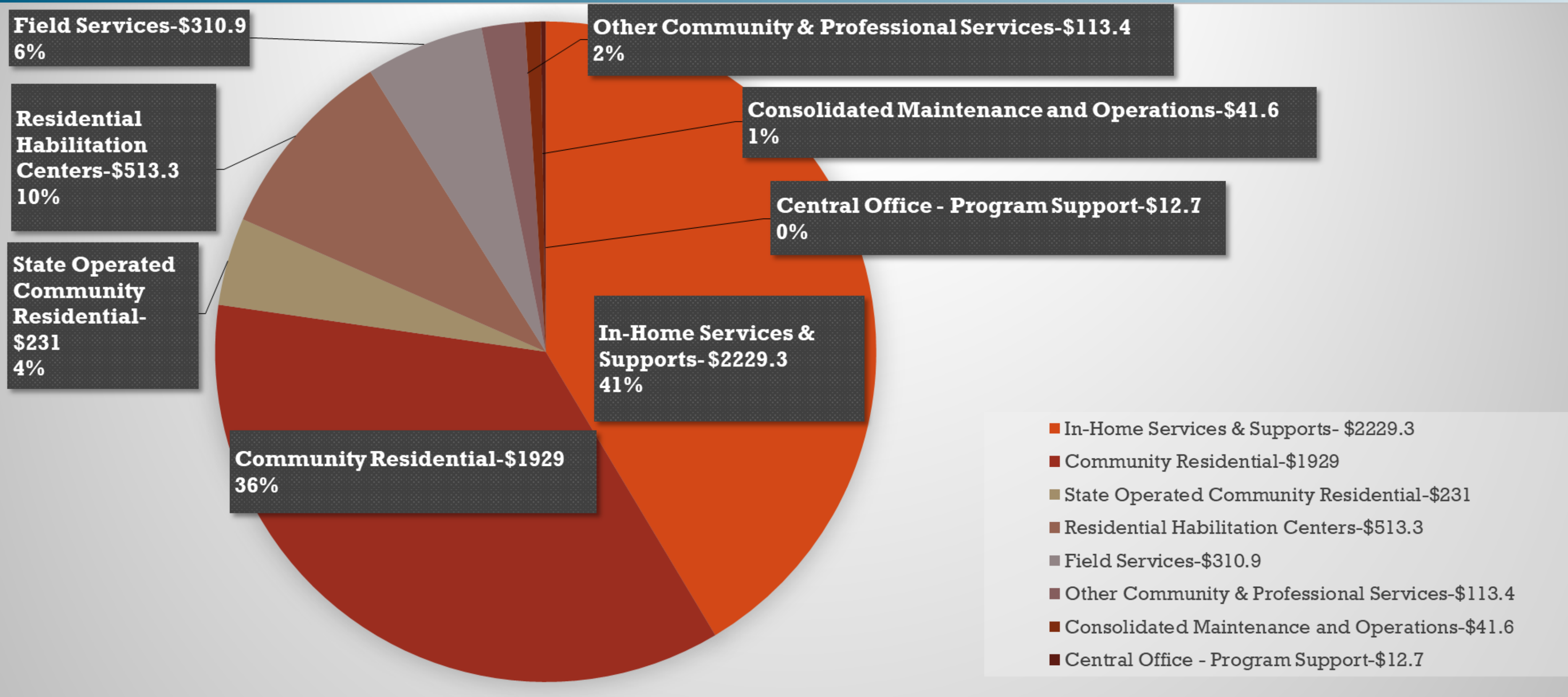




DDCS Budget



DDCS's Budget FY 2024

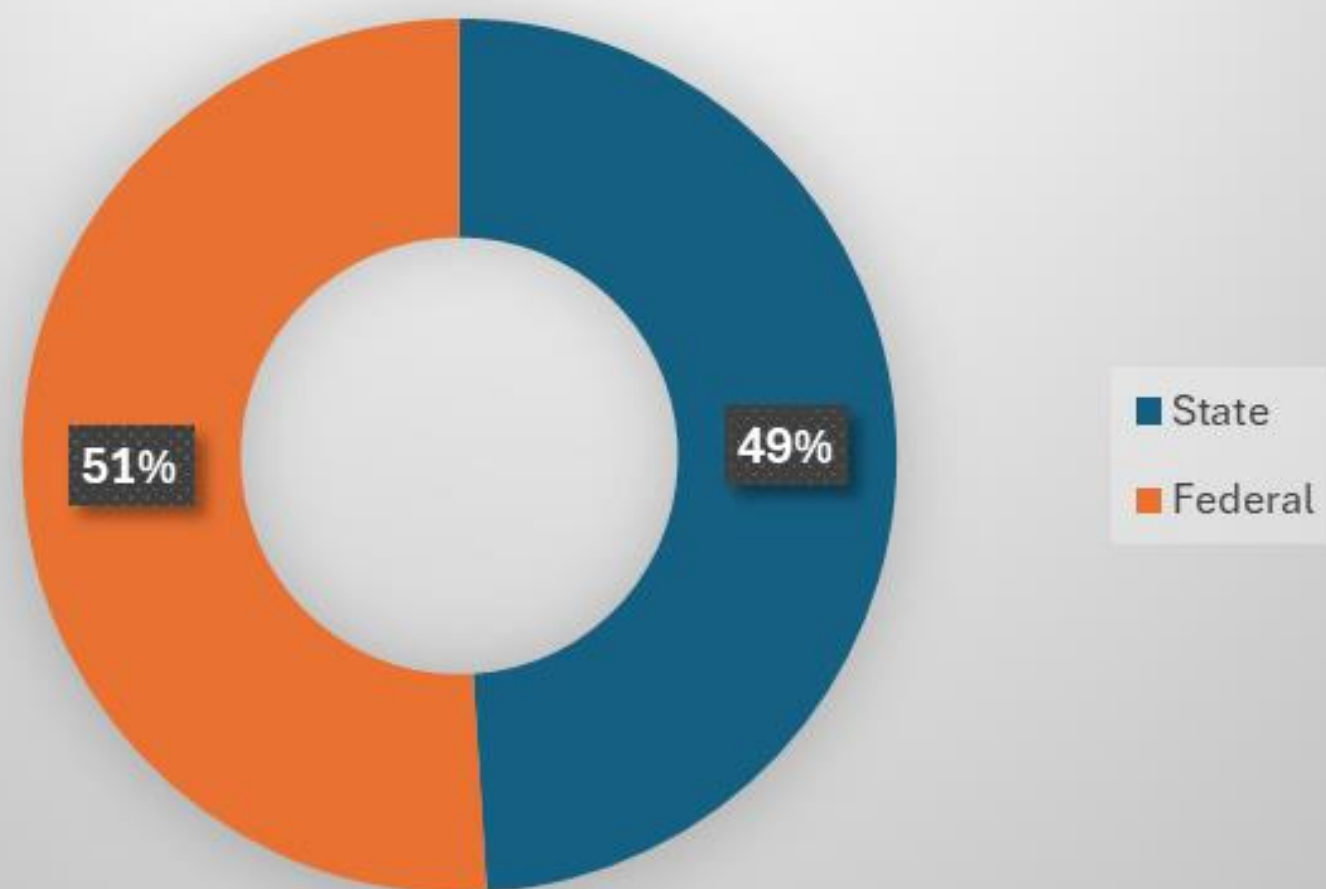


TOTAL: \$5381.2 Million

\$2,659.8 Million State Funds, \$2721.4 Million Federal Funds



State Funds are Federally Matched



State & Federal Partnership

WASHINGTON STATE RANKS 38TH IN PER CAPITA SPENDING FOR I/DD SERVICES

**Almost one-third of
DDCS clients
receive no paid
services (22,964)**





Challenges Ahead

Lack of Capacity
Workforce Shortage
Insufficient Housing
Inadequate Family Supports
Access to Inclusive Education
Limited Reliable Transportation

Bricks & Mortar Housing



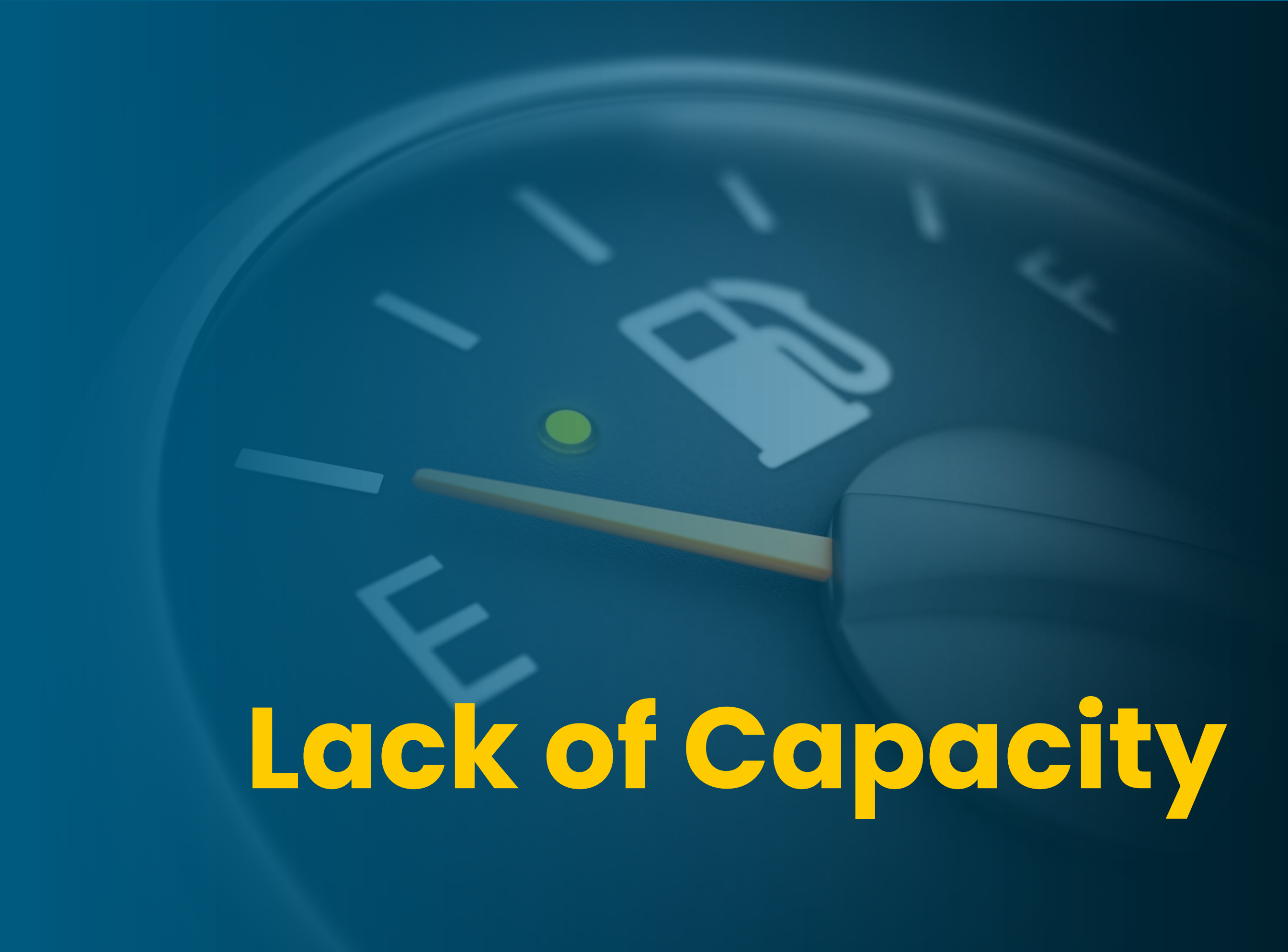
Supports & Services



Caregiver Workforce



All the
Elements are
Necessary for
Success

A large, semi-transparent fuel gauge is centered in the background. The needle is pointing towards the 'E' (Empty) mark. A green light is visible near the needle. The gauge has markings for 'E' and 'F' (Full).

Lack of Capacity



Lack of Capacity Leads to Crisis

- **Individuals**

- Don't get the care they need
 - End up isolated
 - End up in the hospital or jail

- **Families**

- Have to quit work
 - Go into financial crisis
 - Are separated

- **Agencies**

- Can't adequately serve new people
 - Go out of business

- **Students**

- Don't get an appropriate education
 - Are isolated and/or restrained
 - Get sent out of state



Workforce Shortage

Lack of Appropriately and
Adequately Trained
Caregiving Professionals

Low
Wages/Rates

Less available care
AND lower-quality
care



+



=



The Workforce Shortage Affects ALL Services

- 1 Healthcare
- 2 Mental/Behavioral Health
- 3 Employment
- 4 Local Community Programs
- 5 Homecare/Residential Services
- 6 Childcare
- 7 Education

Insufficient Housing



There isn't enough Safe, Affordable, Accessible, Inclusive Housing

- People with I/DD are considered extremely low income (SSI= \$967 a month)
- \$2000 asset limit
- **Projected need for 39,000 units in WA**
- Housing Trust Fund has 1,382 DD Set aside units
- There is NO housing market in the US where you can rent an apartment solely on SSI





Inadequate Family Supports

Families are the long-term care system for individuals with I/DD



78% of adult clients live with and receive care from a parent or a relative



It is estimated that more than 2000 individuals over the age of 40 are living with a parent



Families Need.....



- Affordable, Accessible, Reliable Childcare and after school programs
- An Occasional break from caregiving (respite)
- A reliable network of well trained, care providers
- Timely and easy to use services
- Accurate information & culturally responsive support
- Assistance navigating systems
- Adequate funding for supports that give individuals meaningful things to do while family members work, which provides financial stability to the family



Aging Parents Need...



**Support to plan for
the Future**



**Assurance there will
be things in place
when they are no
longer able to
provide care**



Education Reform is Needed

- Washington is 44th in the nation in use of inclusive practices
- Washington continues to send many of our high acuity students with I/DD out of state
- Washington continues to disproportionately restrain and isolate students with disabilities



☒ Limited Reliable Transportation ☒



- Individuals with disabilities often are unable to drive. They need reliable, accessible public transportation to get to:

- Work
- The store
- Medical appointments
- Recreation
- To church
- To visit friends & family

to live the lives they want.....



What's Next?





Community services are **not** optional -
they are lifelines.

The state has a **moral obligation** to
ensure people with IDD are cared for.

#Cuts#Cause#Crisis

Protect DD Services



Equal cuts across state agencies are **not equitable** for people with IDD

Individuals with IDD receive services from **many agencies**, so they end up taking multiple cuts.

#Cuts#Cause#Crisis

Protect DD Services



Protect Disability Rights



Individuals with disabilities have a right to live, work, learn, and play in the community

Ensure that people with disabilities are not denied services, provided unequal treatment, or relegated to segregated settings and they have equal opportunities to benefit from state services and programs.





How Can you Help?

Thank You!



Cathy@arcwa.org