



ANNUAL WAITING LIST REPORT

OFFICE OF DEVELOPMENTAL PROGRAMS (ODP)

2024



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MESSAGE FROM THE DEPUTY SECRETARY

ODP's mission is to support Pennsylvanians with intellectual and developmental disabilities and/or autism to achieve greater independence, choice, and opportunity in their lives. Our vision is to continuously improve an effective system of accessible services and supports that are flexible, innovative, and person-centered. These services and supports allow for more of the individuals we serve to remain in their homes and communities and to live an "everyday life."

For years, the intellectual disabilities/autism (ID/A) community asked for help addressing a growing waiting list for services and the direct support workforce shortage. Governor Shapiro heard these pleas and in February 2024 announced the Multi-Year Program Growth Strategy to end the emergency waiting list for adults with ID/A. The announcement was accompanied



by a historic proposed investment in ID/A services. The proposed and signed FY24-25 state budget was a significant commitment towards addressing issues Pennsylvanians with ID/A and the direct support professionals who care for them face. Investments in ID/A services in FY24-25 included \$354.8 million in federal and state funding to provide more resources for home and community-based services (HCBS). Of the \$354.8 million, \$280 million helped raise wages for direct support professionals who

care for Pennsylvanians; and \$74.8 million was committed to begin the process of clearing the adult emergency wait list entirely – ensuring more Pennsylvanians receive the care they need and deserve.

The Multi-Year Program Growth Strategy has been a tremendous success so far. In just the first year since the Governor's announcement, ODP reduced the emergency adult waiting list (age 21+) by 19%. By April 2025, the reduction was 24%. The emergency waiting list had been steadily growing for years so this is a

In 2024, the new Multi-Year Program Growth Strategy for ending the emergency waiting list for adults (ages 21+), resulted in a 19% reduction of the list!

By April 2025 the reduction was 24%!

remarkable reduction. During this same time period, ODP has increased total program capacity by 8% meaning that finally more than 40,000 individuals with ID/A receive HCBS. Current program capacity is 41,555.

It is important to note that this work could not have been accomplished without the passion and commitment of the disability advocates behind the Pennsylvania Waiting List Campaign. Their engagement has been essential in moving the current system forward while also anticipating the future landscape for individuals with disabilities in Pennsylvania.

Kristin Ahrens, Deputy Secretary

INTRODUCTION

Acronyms Used in this Report

Acronym	Stands For...
AE	Administrative Entity
AAW	Adult Autism Waiver
ASD	Autism Spectrum Disorder
CLW	Community Living Waiver
EDW	Enterprise Data Warehouse
FY	Fiscal Year
HCBS	Home and Community-Based Services
HCSIS	Home and Community Services Information System
ICF	Intermediate Care Facility
ID	Intellectual Disability
ID/A	Intellectual Disability/Autism
LOC	Level of Care
ODP	Office of Developmental Programs
P/FDS	Person/Family Directed Support Waiver
PROMISE™	Provider Reimbursement and Operations Management Information System
PUNS	Prioritization of Urgency of Need for Services
SC	Supports Coordinator
TSM	Targeted Services Management
YTD	Year-to-Date

An Overview of the Waiting List

The waiting list is comprised of individuals who are eligible to receive services and supports through ODP home and community-based services (HCBS) waivers¹, however, due to insufficient waiver capacity, the state cannot currently meet their needs. While individuals are on the waiting list, they are placed into one of three (3) categories of need, determined by the Prioritization of Urgency of Need for Services (PUNS) tool. These categories are:

1. Emergency—Person needs services immediately, within the next six (6) months
2. Critical—Person needs services more than six (6) months but less than two (2) years from now
3. Planning—Person needs services more than two (2) but less than five (5) years from now

The PUNS is a tool that Supports Coordinators (SCs) use to facilitate discussions with individuals and their families, about their needs. The data collected by SCs via the PUNS is entered into Home and Community Service Information System (HCSIS). The PUNS was developed in 1999, with the direct assistance of advocates, and has been modified and improved over the years. It not only helps to accurately identify needs and a timeline to meet them but also helps ODP plan for the service system years in advance. The category in PUNS for each individual on the waiting list depends on their specific situation; the people with the most urgent needs have priority for enrollment.

Population Expansions

Prior to 2017, only the Adult Autism Waiver (AAW) served individuals with autism who did not also have a diagnosis of intellectual disability. Since 2017, ODP has expanded the population eligible to receive targeted services management (TSM) and HCBS in all ODP waivers to include people of all ages with Autism Spectrum Disorder (ASD) only [Figure 28, page 32]. In 2022, ODP expanded eligibility to children with medically complex conditions (MCC) for TSM and HCBS waivers.

¹ Intermediate Care Facility for Intellectual Disability or Other Related Conditions level of care

Recent Past Increases in Waiting List Driven by Pandemic Related Needs

There was an 8% increase in the number of individuals on the waiting list from November 2021 to November 2023. In November 2021, the number of individuals on the waiting list was 12,214. This increased to 12,389 by November 2022, then to 13,244 by November 2023. This upward movement appeared to be the result of the following, which were indicative of additional stressors for individuals and families as a result of the COVID-19 pandemic:

- An overall increase of 19% in the emergency need category from November 2021 to December 2023. This number increased from 5,040 individuals in November 2021, to 5,413 in November 2022 and to 6,001 in December 2023.
- Within the emergency need category, from November 2021 to November 2023, there was a 9% overall increase in the number of individuals who responded that immediate supports (behavioral, day, in-home or other) will prevent the immediate need for residential supports. This number of individuals increased from 873 in November 2021 to 1,043 in November 2022, then decreased to 953 in November 2023.
- Also, within the emergency need category, the overall number of individuals with a single caregiver and a need for immediate supports increased 57%, from 1,137 in November 2021, to 1,254 in November 2022, to 1,779 in November 2023.

Strategies Prior to Implementation of Multi-Year Growth Strategy

During the 8-year Wolf Administration there was significant expansion of waiver capacity, which increased the number of individuals receiving HCBS by 24%. This growth provided greater availability of HCBS in two primary ways. First, expanded waiver capacity became available to people on the waiting list. For example, from December 2021 to November 2022, the Community Living waiver (CLW) had a net increase of 908 individuals, from 3,914 to 4,822, because of waiting list initiatives funded through the state budget. The second way in which program growth provided additional availability is through

turnover. Each year, people disenroll² from an ODP HCBS waiver at a rate of roughly 3% [Figure 12, page 18]. When one individual disenrolls, the County/Administrative Entity (AE) enrolls a new individual from the waiting list. As overall waiver capacity grows, so do opportunities for enrollment through turnover. To illustrate, if the waiver capacity is 10,000 each year, then approximately 400 people will leave the waiver, and 400 new people can be enrolled. If the waiver capacity is 20,000 each year, then approximately 800 people will leave the waiver, and 800 new people can be enrolled.

High School Graduate Initiative

The “transition age” group of individuals with ID/A represents the highest number of individuals on the waiting list [Figure 1, page 10]. For this reason, ODP implemented targeted initiatives to prioritize the needs of this group, as they transition to adulthood.

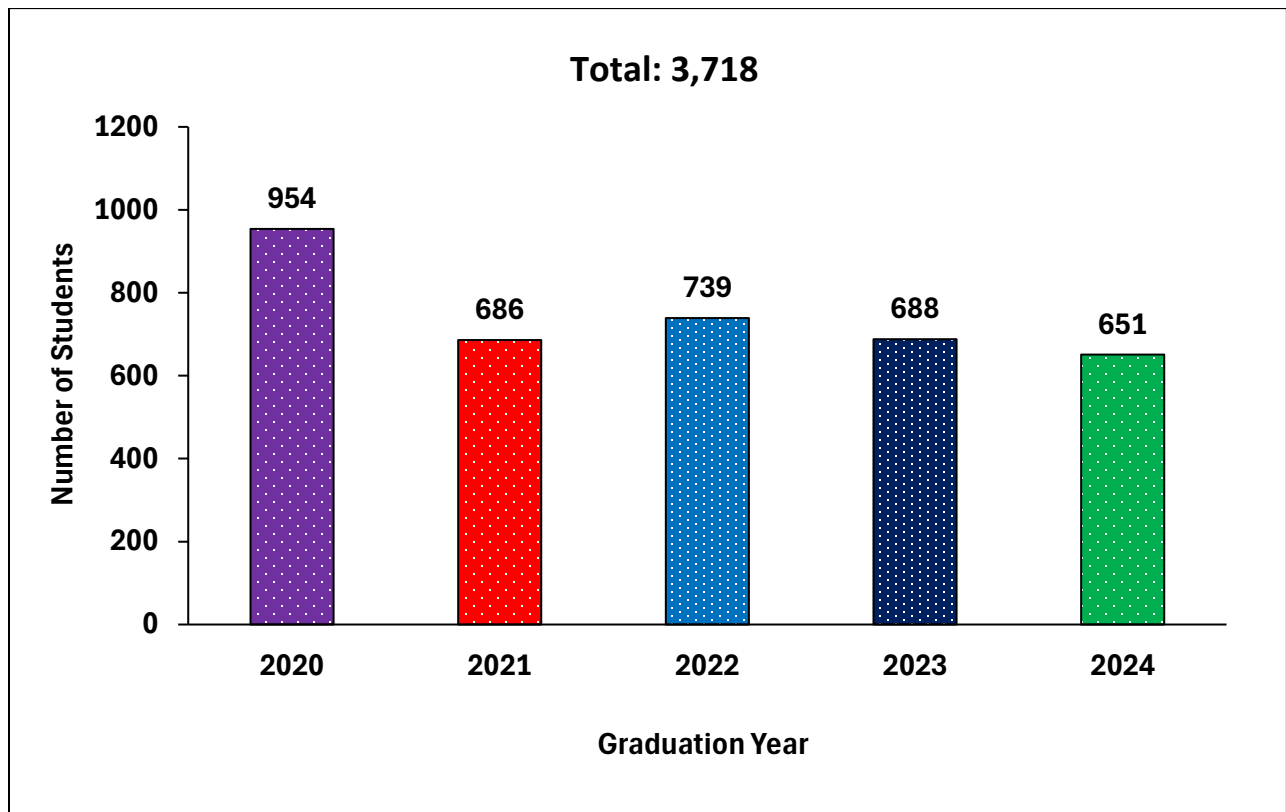
Beginning in 2012-13, ODP implemented an initiative to ensure that high school graduates, who meet eligibility requirements for an ODP waiver, can be enrolled in the Person/Family Directed Support (P/FDS) waiver at age 21. This effort led to an initial three (3) years of waiting list initiatives with new P/FDS waiver capacity that served 2,100 high school graduates.

By 2018, growth of the ODP waiver program allowed ODP to shift strategies to ensure high school graduates had waiver availability upon graduation, utilizing existing waiver capacity. For 2020 graduates, ODP did not request additional P/FDS waiver capacity through the state budget process but rather, moved to a process of working with Counties/AEs to plan for and manage, within existing waiver capacity, to address this need. 2020 included the largest group of graduates eligible for the ID/A waivers (954 students) and ODP was able to accommodate the enrollments using this new process. In 2021 and 2022, ODP enrolled an additional 1,427 graduates with this process, solidifying it as a reliable strategy. During 2023 and 2024 ODP enrolled an additional 1,339 graduates for a total of 3,718 since 2020.

² Typical reasons for disenrollment: individual moves out of state, death, no longer needs services

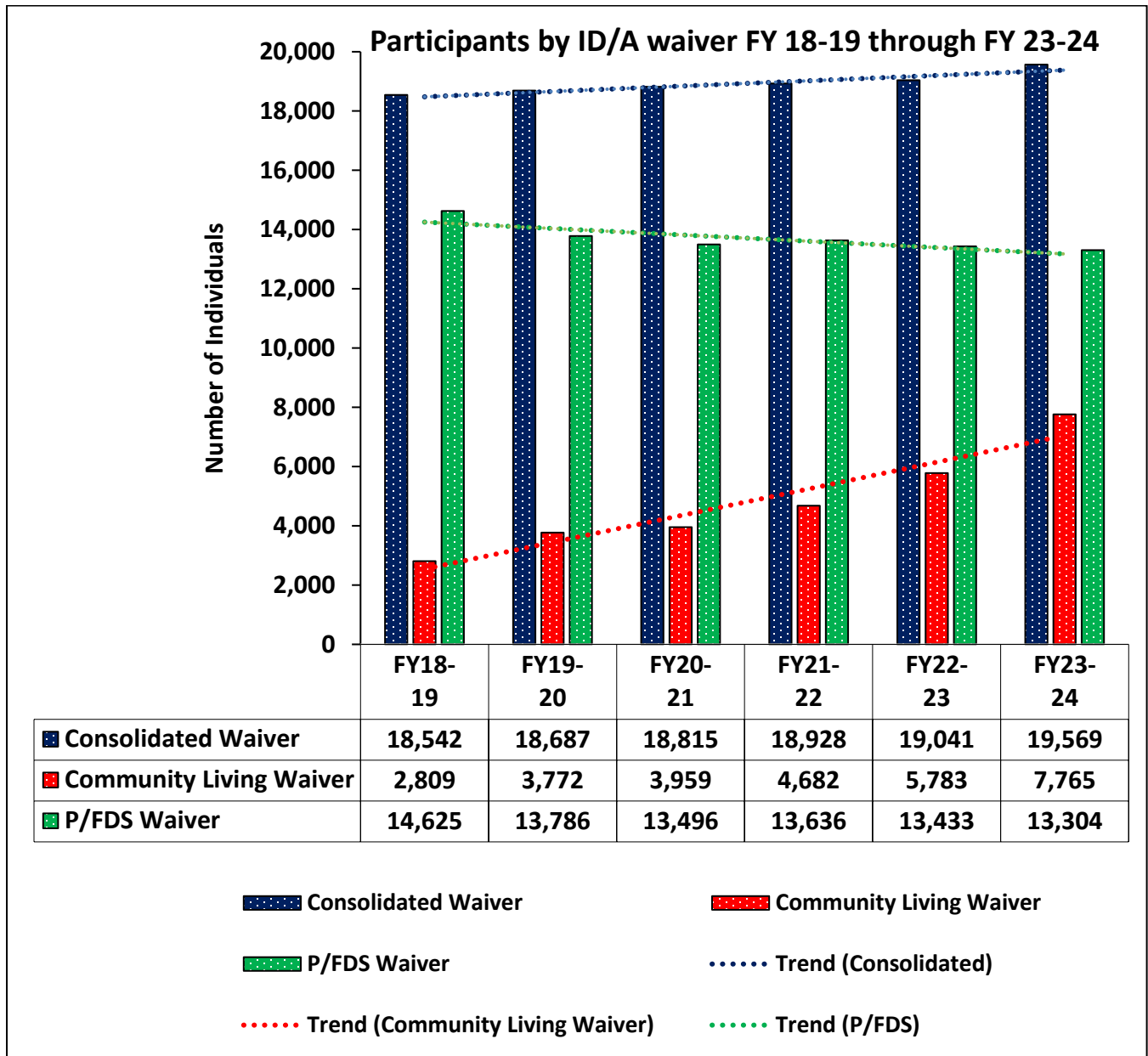
PROGRAM GROWTH

Figure 1: Number of Students who have Graduated Since 2020 by Year



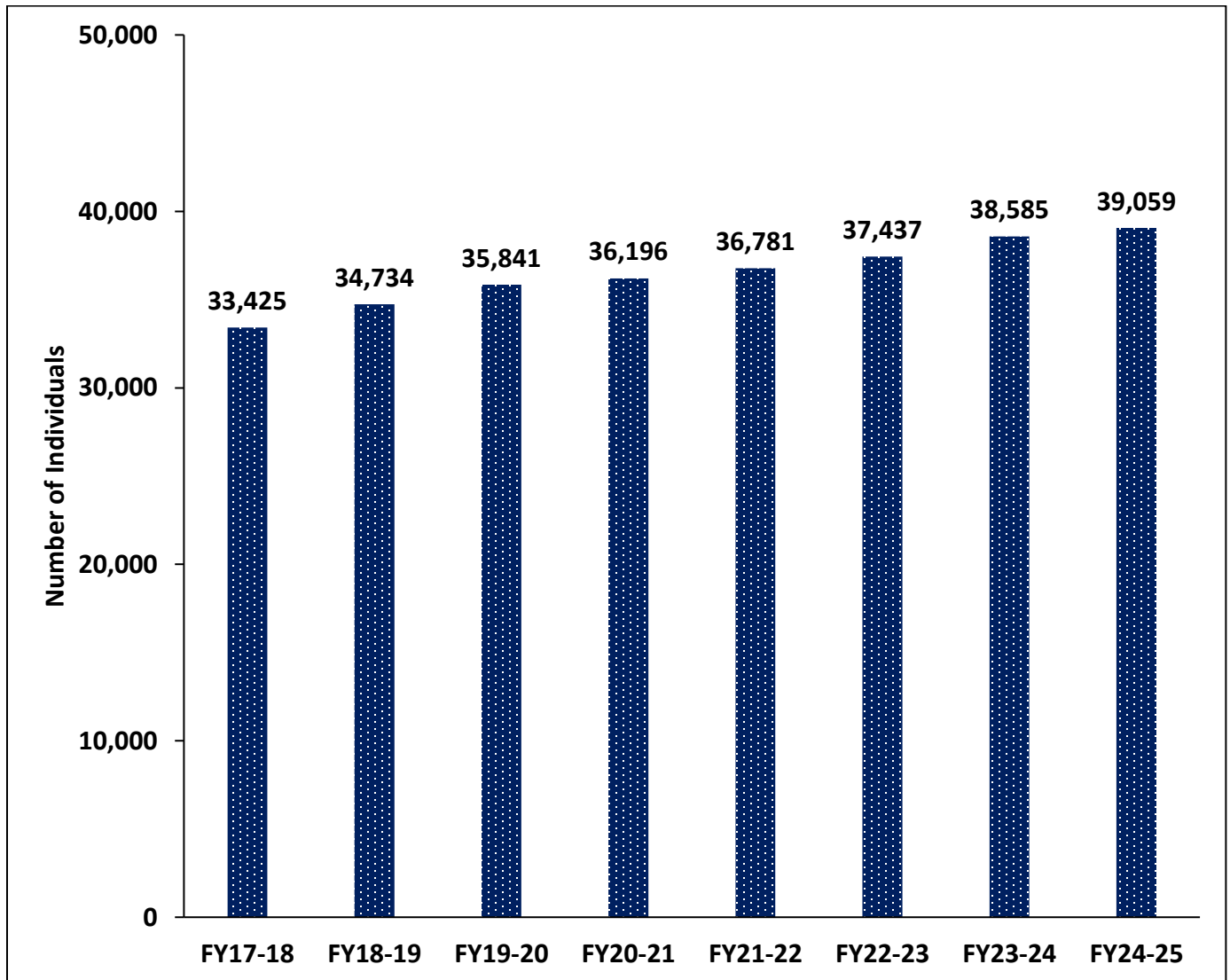
Data Source: ODP Bureau of Client Services – Graduate Tracking Sheets from 2020 to 2024

Figure 2: Individuals in ID/A Waivers by Fiscal Year



Source: HCSIS Snapshot Date: 06/30/2024

Figure 3: Individuals in ID/A Waivers - Total Enrollment by Fiscal Year



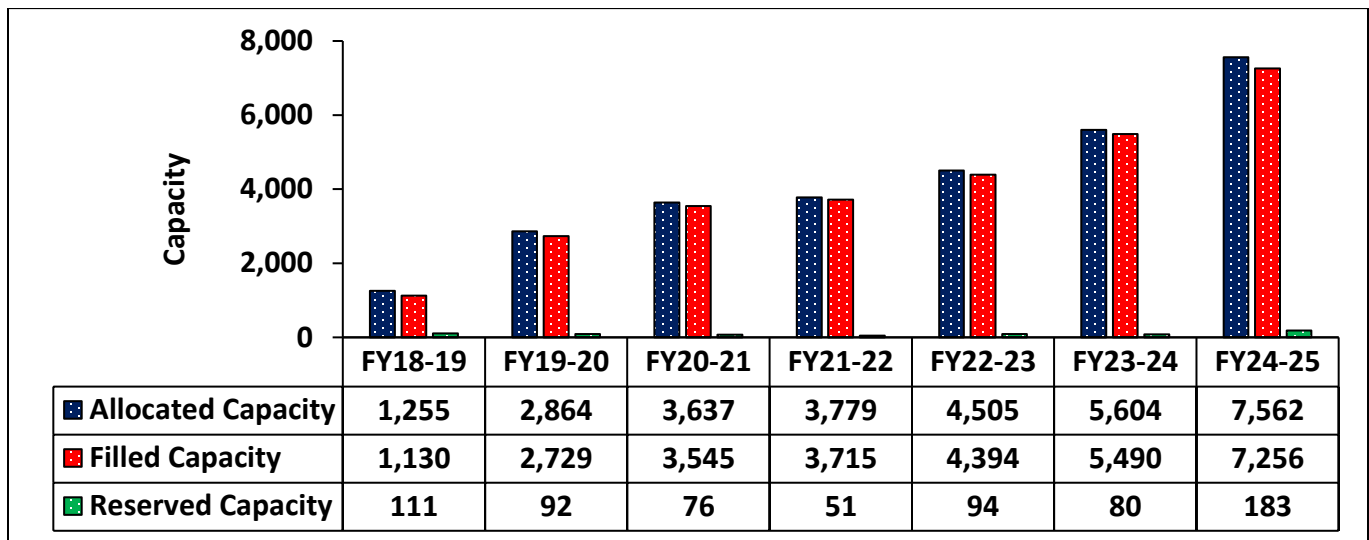
Source: HCSIS Snapshot Date: 02/28/2025

Notes: FY24-25 data in this graph is year-to-date (YTD) as of 2/28/2025. It is not a complete fiscal year.

Also note, a 17% increase over 7 years.

CAPACITY GROWTH BY WAIVER

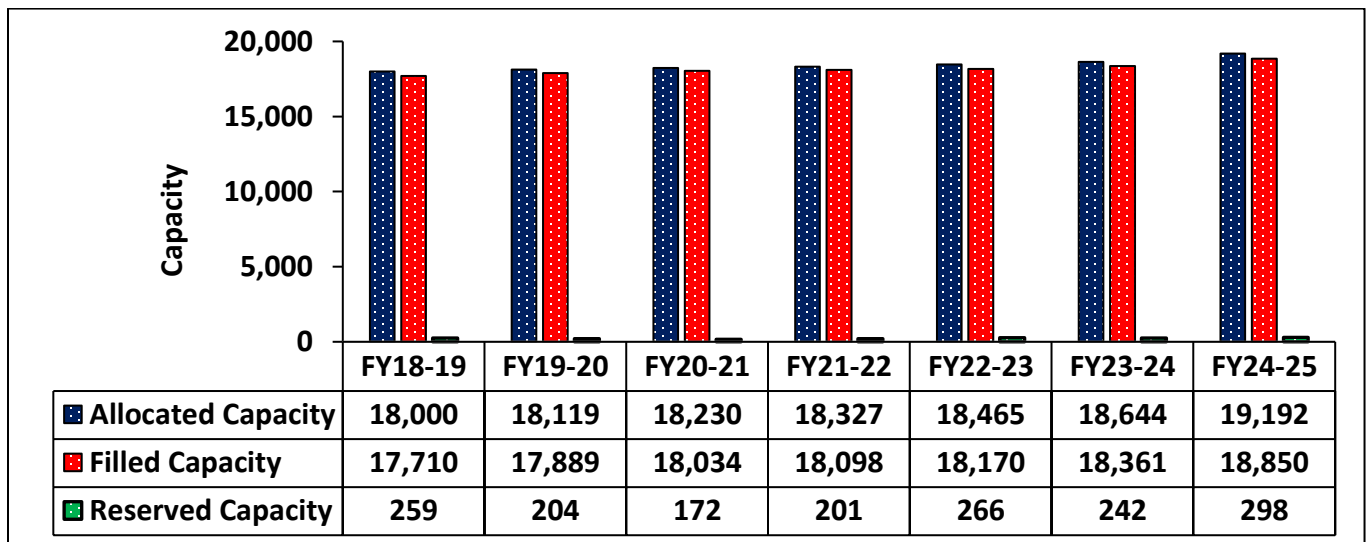
Figure 4: Community Living Waiver Capacity by Fiscal Year



Source: HCSIS Snapshot Date: 02/28/2025

Note: FY24-25 data in this graph is YTD as of 2/28/2025. It is not a complete fiscal year.

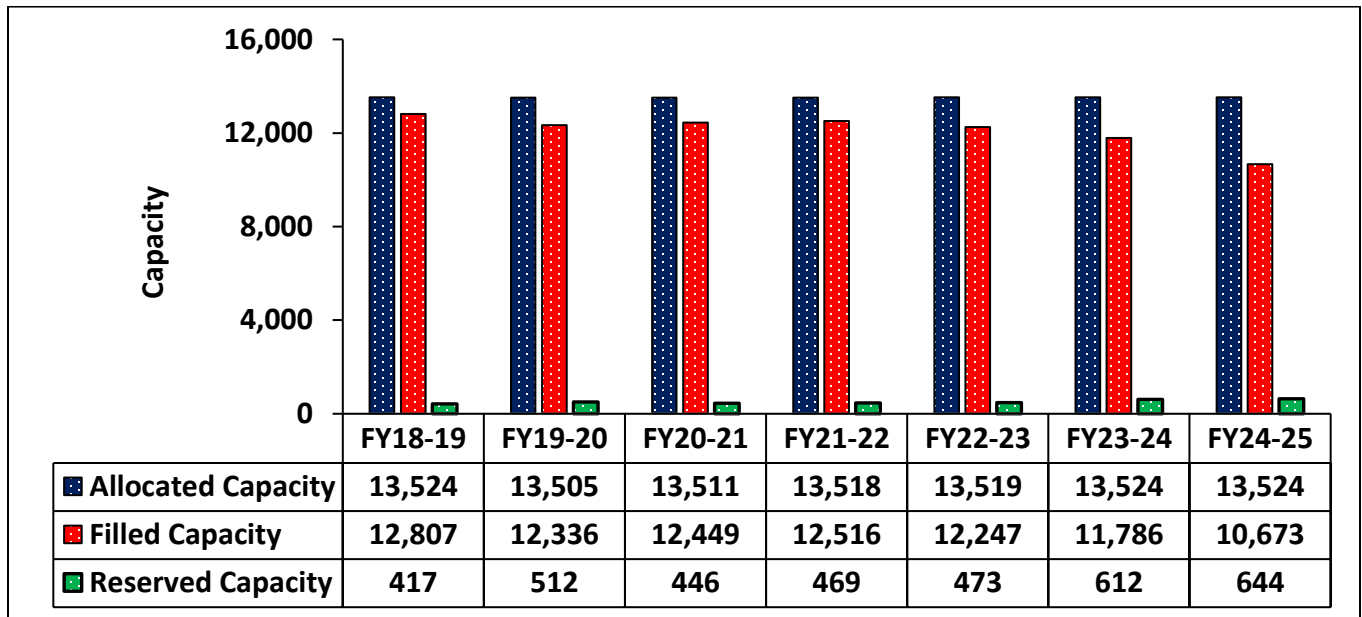
Figure 5: Consolidated Waiver Capacity by Fiscal Year



Source: HCSIS Snapshot Date: 02/28/2025

Note: FY24-25 data in this graph is YTD as of 2/28/2025. It is not a complete fiscal year.

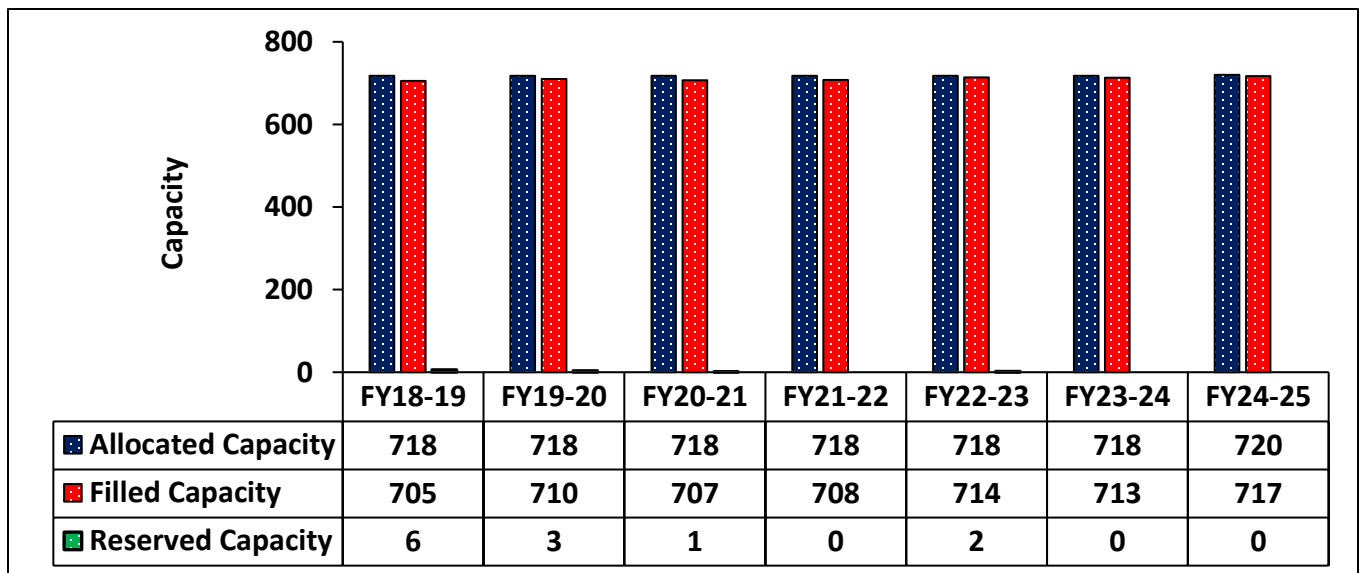
Figure 6: P/FDS Waiver Capacity by Fiscal Year



Source: HCSIS Snapshot Date: 02/28/2025

Note: FY24-25 data in this graph is YTD as of 2/28/2025. It is not a complete fiscal year.

Figure 7: Adult Autism Waiver Capacity by Fiscal Year

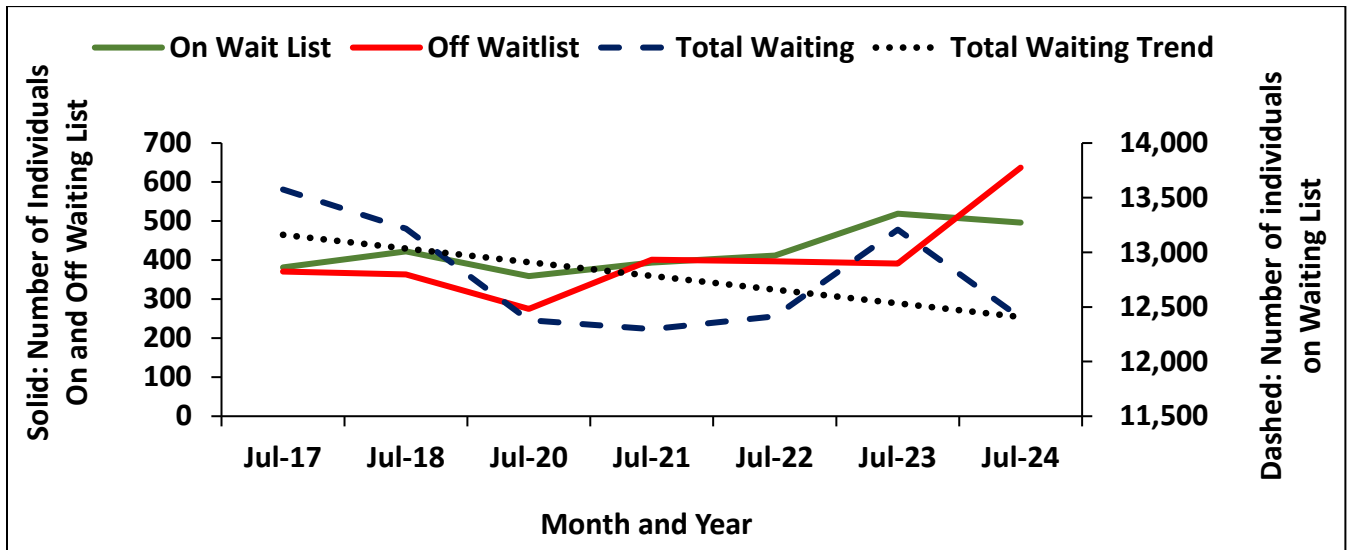


Source: HCSIS Snapshot Date: 02/28/2025

Note: FY24-25 data in this graph is YTD as of 2/28/2025. It is not a complete fiscal year.

WAITING LIST TRENDS

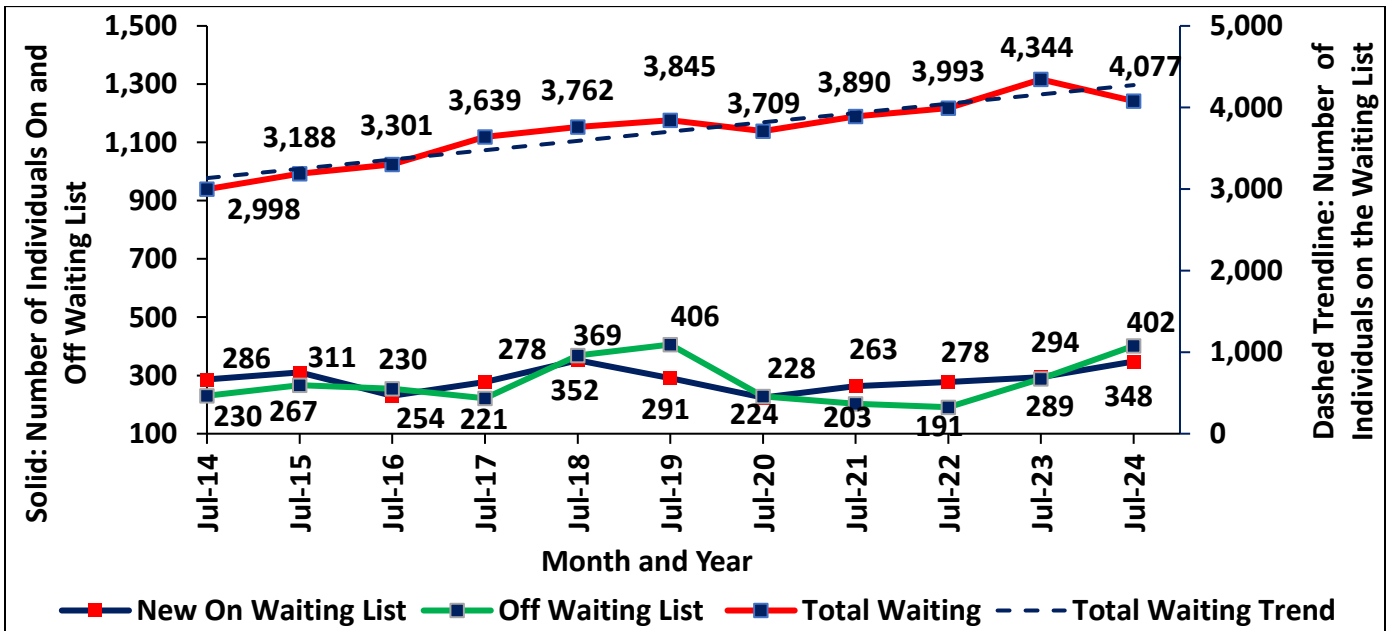
Figure 8: Individuals On & Off the Waiting List vs. On the Waiting List



Source: HCSIS/PUNS Snapshot Date: 02/28/2025

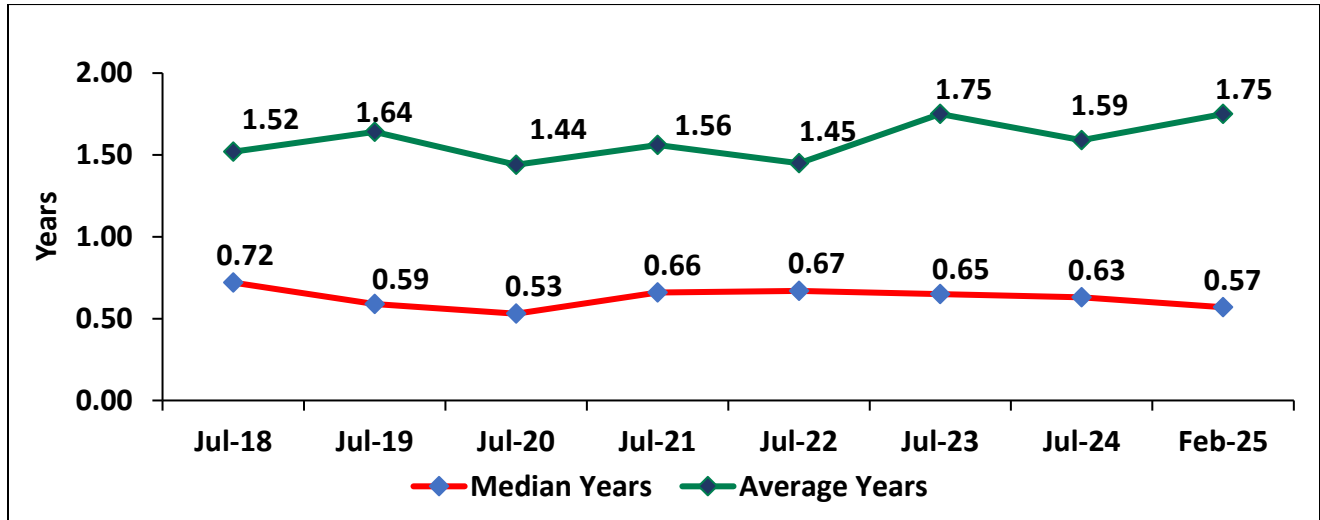
Figure 9: Individuals On & Off the Waiting List vs. On the Waiting List

Ages 21+ in Emergency Category



Source: HCSIS/PUNS Snapshot Date: 02/28/2025

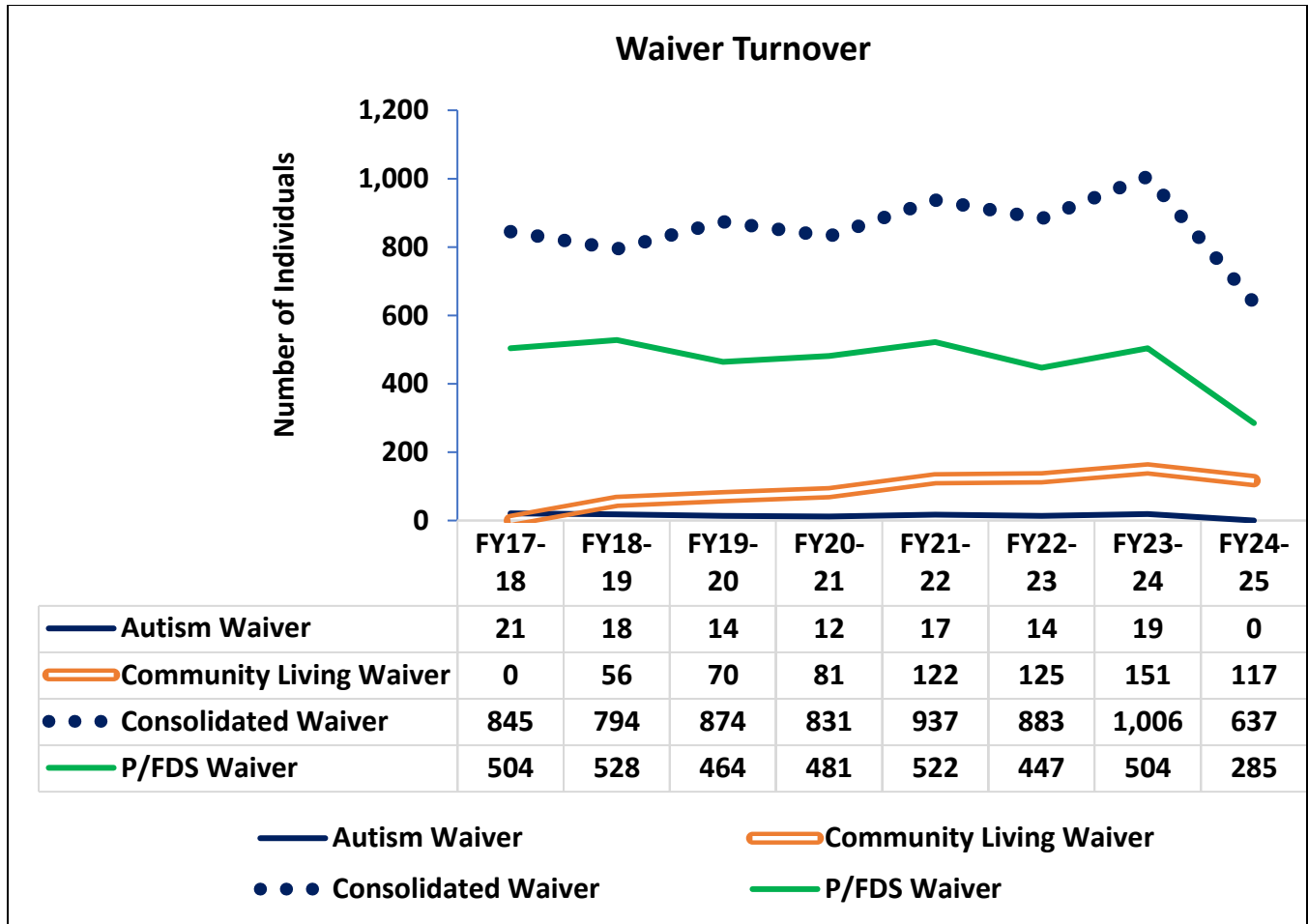
Figure 10: Median & Average Years On the Waiting List
Ages 21+ in Emergency Category



Source: HCSIS/PUNS Snapshot Date: 02/28/2025

Figure 11: Waiver Turnover

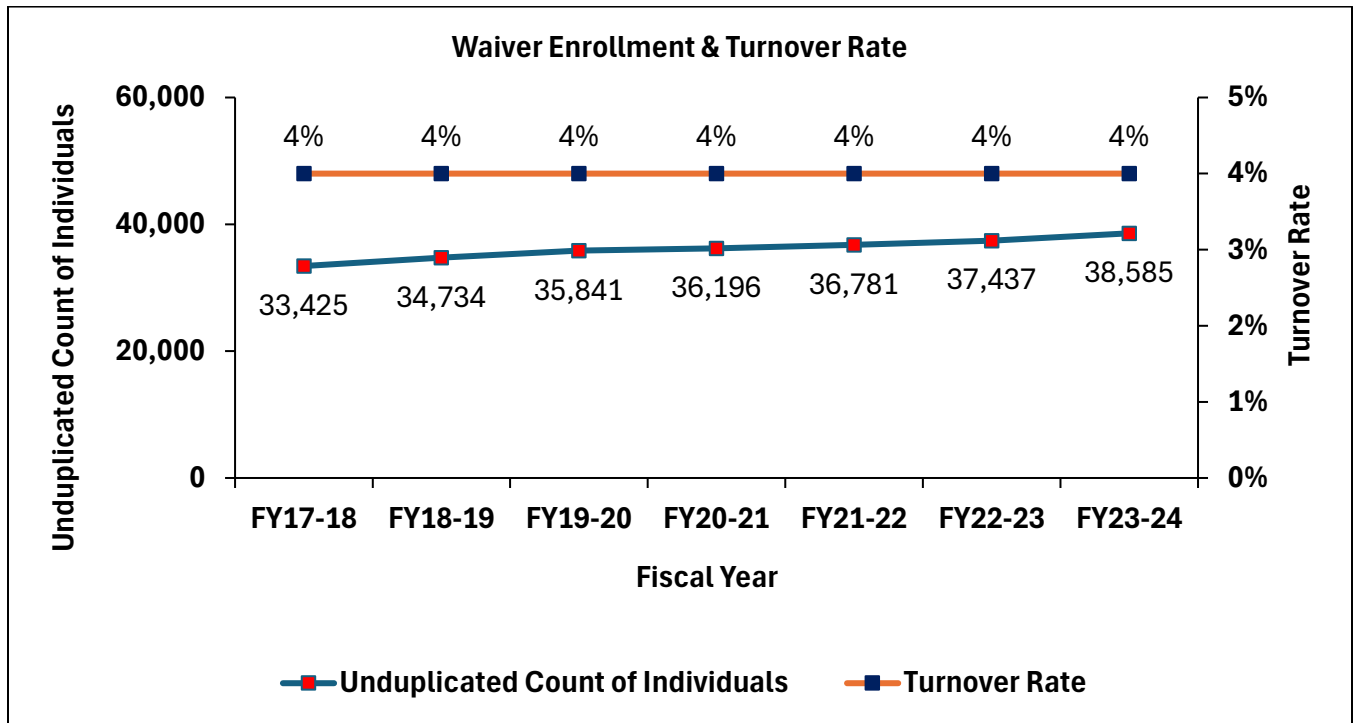
(Individuals No Longer in Any ODP HCBS Waiver After Waiver End Date)



Source: HCSIS Snapshot Date: 02/28/2025

Notes: Data greater than zero and less than 11 is not shown in the table for privacy purposes. Also, FY24-25 data in this graph is YTD as of 2/28/2025. It is not a complete fiscal year.

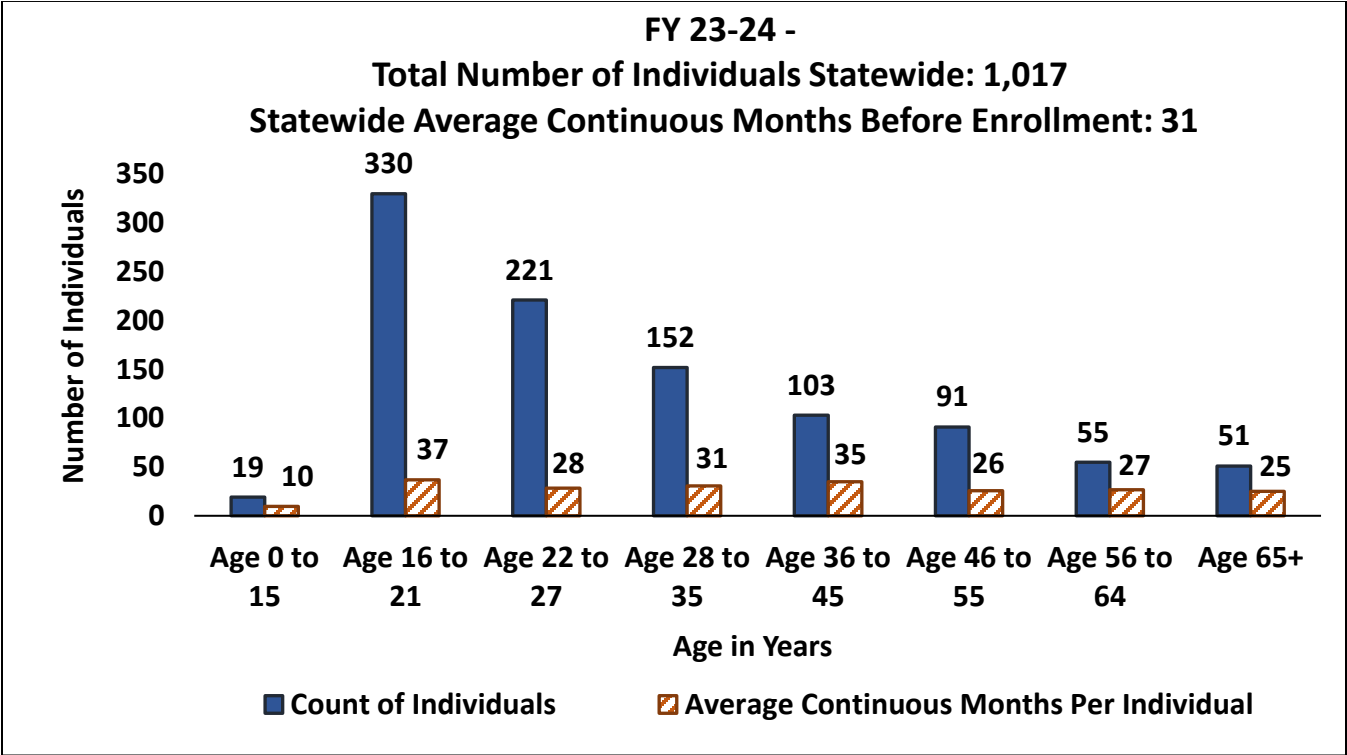
Figure 12: Waiver Enrollment & Turnover Rate



Source: HCSIS Snapshot Date: 02/28/2025

Notes: Includes all ODP waivers (Consolidated, P/FDS, Community Living and Adult Autism). Also, turnover refers to individuals who are no longer in any waiver after waiver end date.

Figure 13: New Consolidated Waiver Enrollees by Age Group & Time on Waiting List

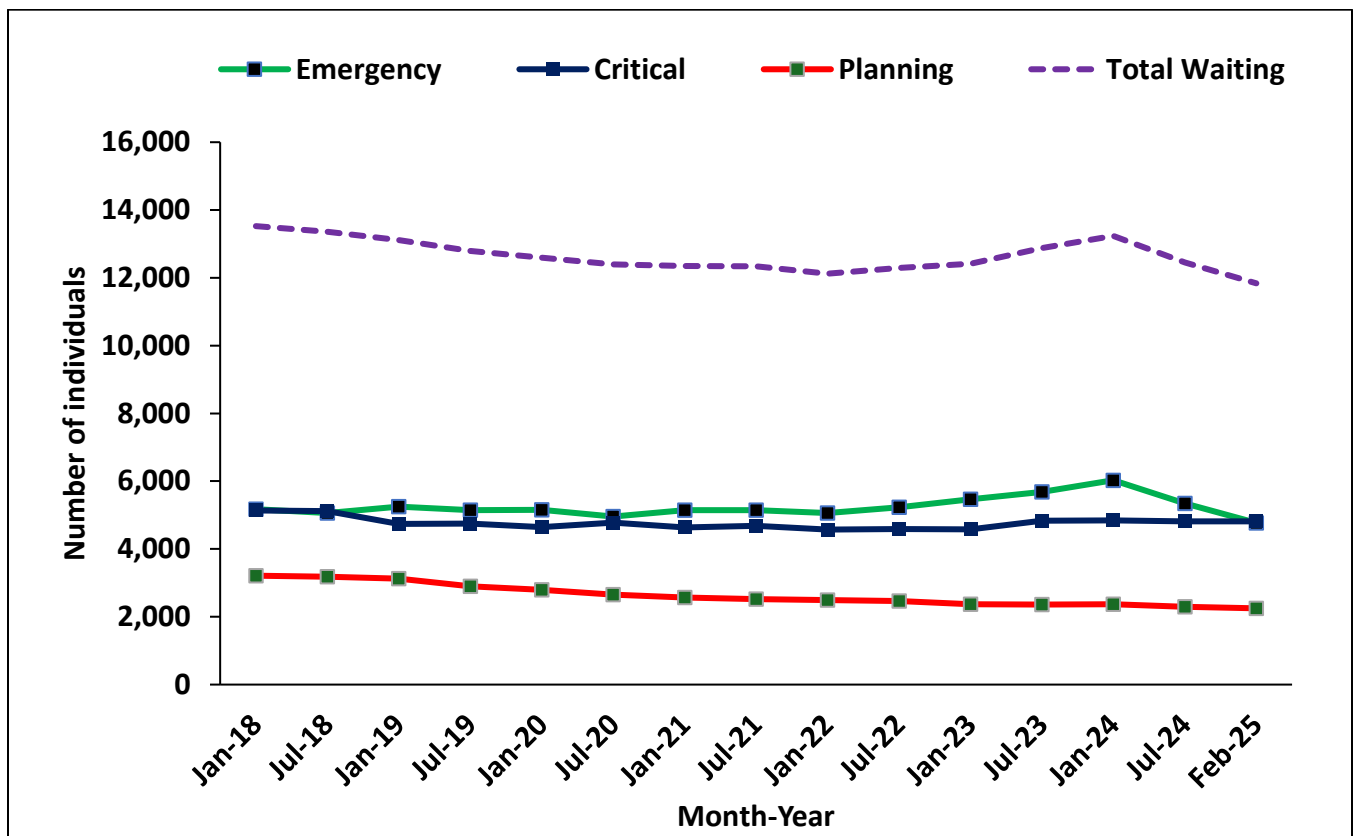


Source: PUNS Monthly Fact Data Extract Snapshot Date: 06/17/2025

NEED CATEGORIES BY REGION, AGE & RACE

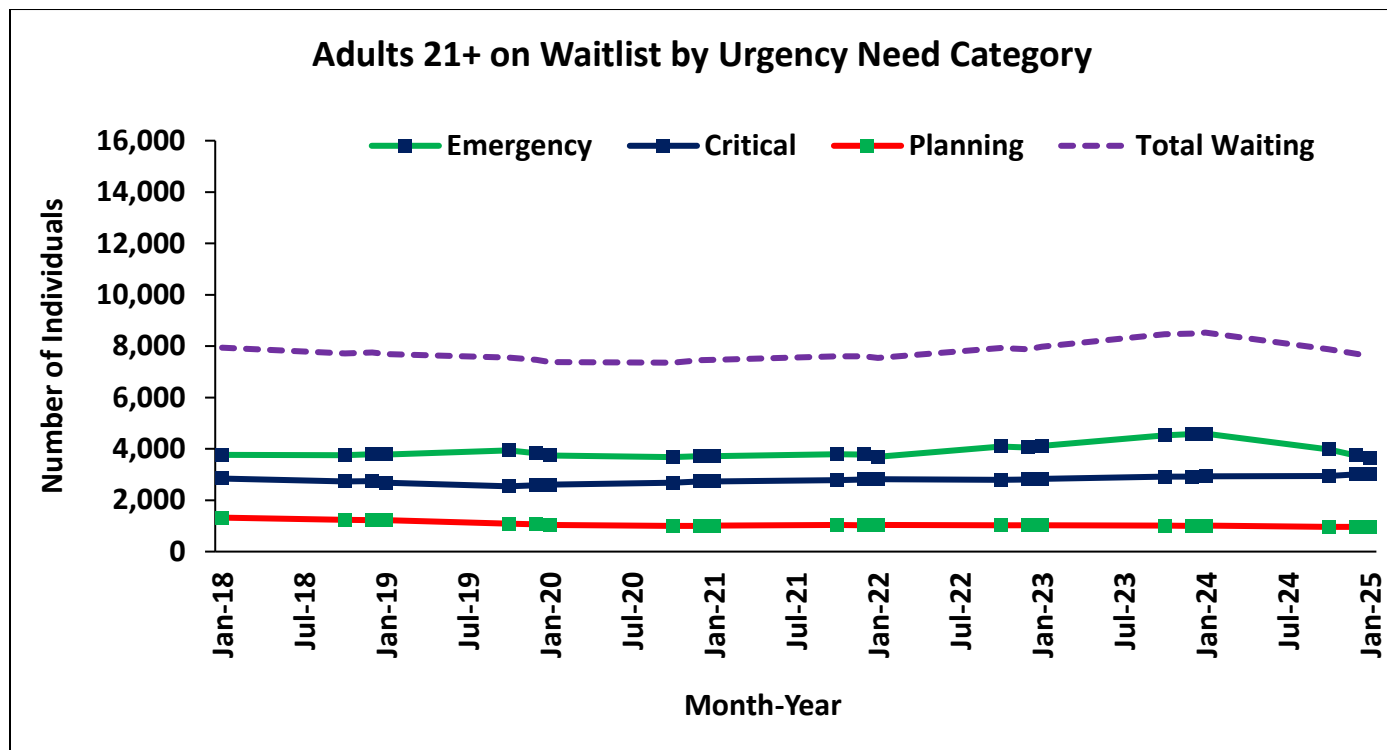
In the first figure below, data from January 2018 to January 2025 shows a 12.5% decrease in number of individuals on the ODP waiting list, for all ages and categories, from 13,524 to 11,837. The emergency category shows an 8% decrease, from 5,176 (January 2018) to 4,770 (January 2025). The critical category shows a 6% decrease, from 5,136 to 4,817 for the same time period. Lastly, the planning category during the same time period decreased by 30%, from 3,212 to 2,250. Other charts/graphs in this section include waiting list numbers by need category, county/joinder, region, age/age group and race.

Figure 14: Individuals on Waiting List by Need Category



Source: HCSIS/PUNS Snapshot Date: 02/28/2025

Figure 15: Individuals Ages 21+ on Waiting List by Need Category



Source: HCSIS/PUNS Snapshot Date: 02/28/2025

Figure 16: Individuals on Waiting List 21+ by Need Category & County/Joinder

COUNTY/JOINDER	EMERGENCY 21+	CRITICAL 21+	PLANNING 21+	All PUNS CATEGORIES 21+	All PUNS CATEGORIES ALL AGES
Allegheny	303	273	80	656	1,069
Armstrong/Indiana	17	60	13	90	135
Beaver	17	65	17	99	145
Bedford/Somerset	34	27	12	73	94
Berks	87	61	26	174	289
Blair	54	22	<11	81	140
Bradford/Sullivan	<11	<11	<11	21	36
Bucks	193	144	97	434	552
Butler	68	57	48	75	159
Cambria	49	19	<11	71	105
Cameron/Elk	<11	15	12	29	38
Carbon/Monroe/Pike	121	84	14	219	289
Centre	41	15	<11	66	106
Chester	217	122	51	390	611
Clarion	<11	0	<11	<11	11
Clearfield/Jefferson	11	21	16	48	94
Columbia/Montour/Snyder/Union	34	14	<11	50	80
Crawford	27	13	<11	43	81
Cumberland/Perry	74	50	49	173	268
Dauphin	117	45	14	176	280
Delaware	221	77	26	324	459
Erie	180	135	52	367	658
Fayette	29	22	12	63	107
Forest/Warren	<11	17	<11	21	31
Franklin/Fulton	42	61	<11	107	160
Greene	<11	14	0	18	23
Huntingdon/Mifflin/Juniata	<11	22	16	39	65
Lackawanna/Susquehanna	47	104	18	169	258
Lancaster	235	55	15	305	510
Lawrence	22	33	<11	60	104
Lebanon	66	27	11	104	168
Lehigh	54	110	23	187	313
Luzerne/Wyoming	131	112	29	272	367

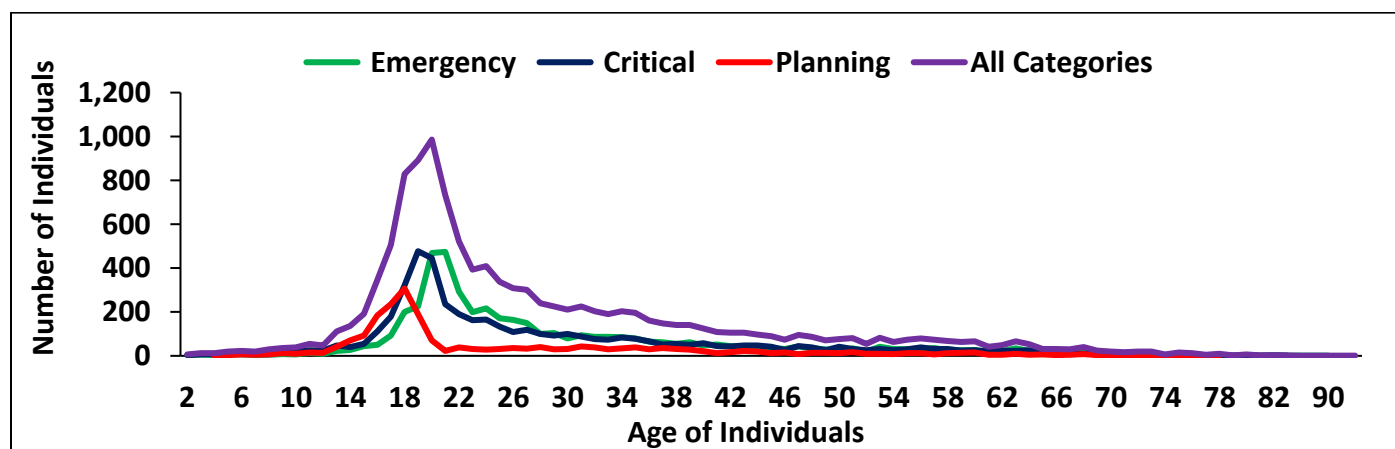
Figure 16: Individuals on Waiting List 21+ by Need Category & County/Joinder (continued)

COUNTY/JOINDER	EMERGENCY 21+	CRITICAL 21+	PLANNING 21+	All PUNS CATEGORIES 21+	All PUNS CATEGORIES ALL AGES
Lycoming/Clinton	37	11	<11	55	83
McKean	13	<11	<11	27	40
Mercer	<11	12	<11	25	49
Montgomery	240	181	72	493	807
Northampton	88	103	65	114	248
Northumberland	15	36	<11	53	87
Philadelphia	372	432	133	937	1,380
Potter	<11	<11	<11	<11	11
Schuylkill	48	24	15	87	153
Tioga	<11	10	<11	21	39
Venango	11	<11	<11	23	43
Washington	74	37	<11	116	209
Wayne	<11	11	<11	15	55
Westmoreland	35	174	33	242	388
York/Adams	191	101	23	315	440
Statewide:	3,615	3,028	992	7,635	11,837

Source: HCSIS/PUNS Snapshot Date: 02/28/2025

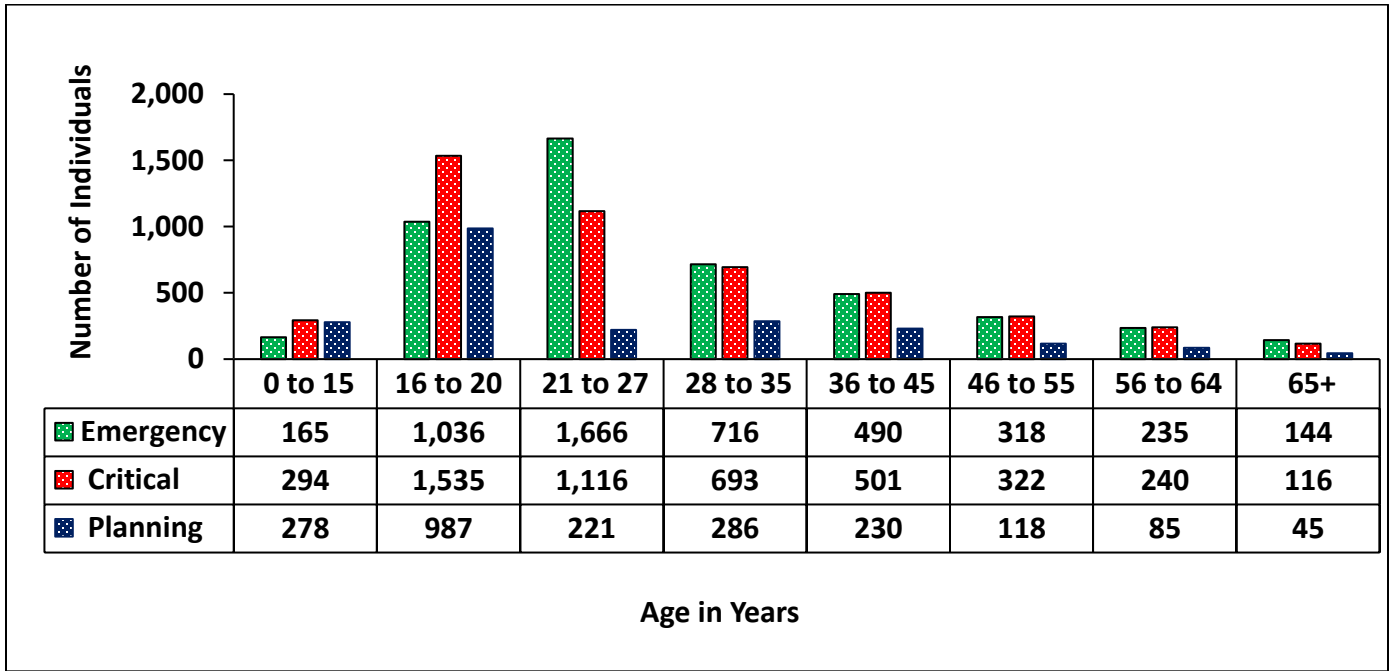
Note: Data greater than zero and less than 11 is not shown in the table for privacy purposes.

Figure 17: Individuals on Waiting List by Need Category & Age



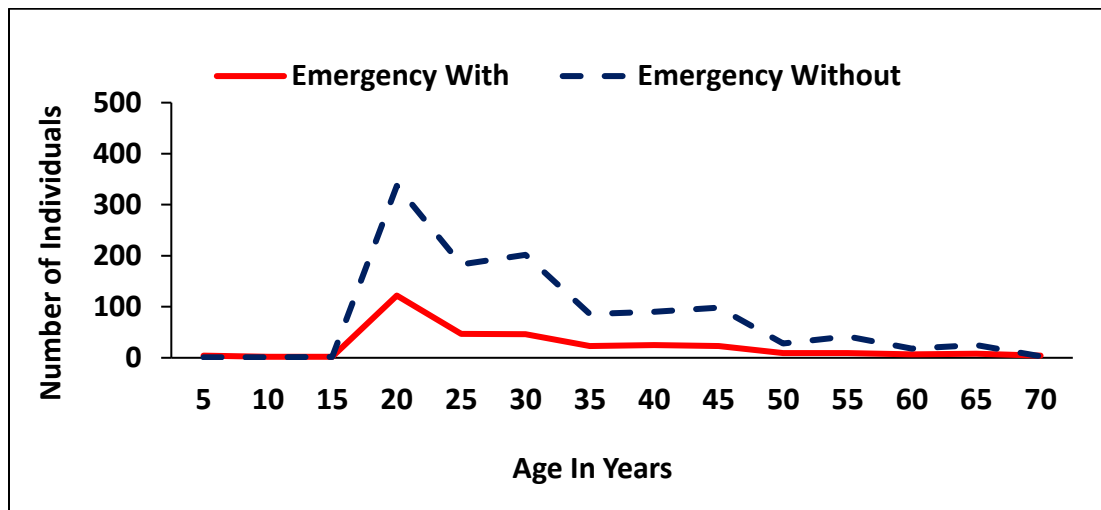
Source: HCSIS/PUNS Snapshot Date: 02/28/2025

Figure 18: Individuals on Waiting List by Need Category & Age Group



Source: HCSIS/PUNS Snapshot Date: 02/28/2025

Figure 19: Individuals on Waiting List by Need Category, Age & Served Status



Source: HCSIS/PUNS Snapshot Date: 02/28/2025

Note: Emergency “With” is defined as individuals with completed PUNS, who received non-case management services, within the 12-month period, prior to the PUNS Snapshot date.

Emergency “Without” is defined as the remaining individuals with completed PUNS, not under the “With” category.

Figure 20: Individuals Ages 21+ on Waiting list by Need Category & Race

Race	Emergency		Critical	
	Count	Percentage	Count	Percentage
White	3,380	71%	3,480	72%
Black Or African American	815	17%	764	16%
Other	382	8%	360	7%
Asian	125	3%	127	3%
Unknown	28	1%	51	1%
Multiracial	19	0%	25	1%
American Indian Or Alaskan Native	16	0%	<11	0%
Native Hawaiian Or Other Pacific Islander	<11	0%	0	0%

Source: HCSIS/PUNS Snapshot Date: 02/28/2025

Note: Data greater than zero and less than 11 is not shown in the table for privacy purposes.

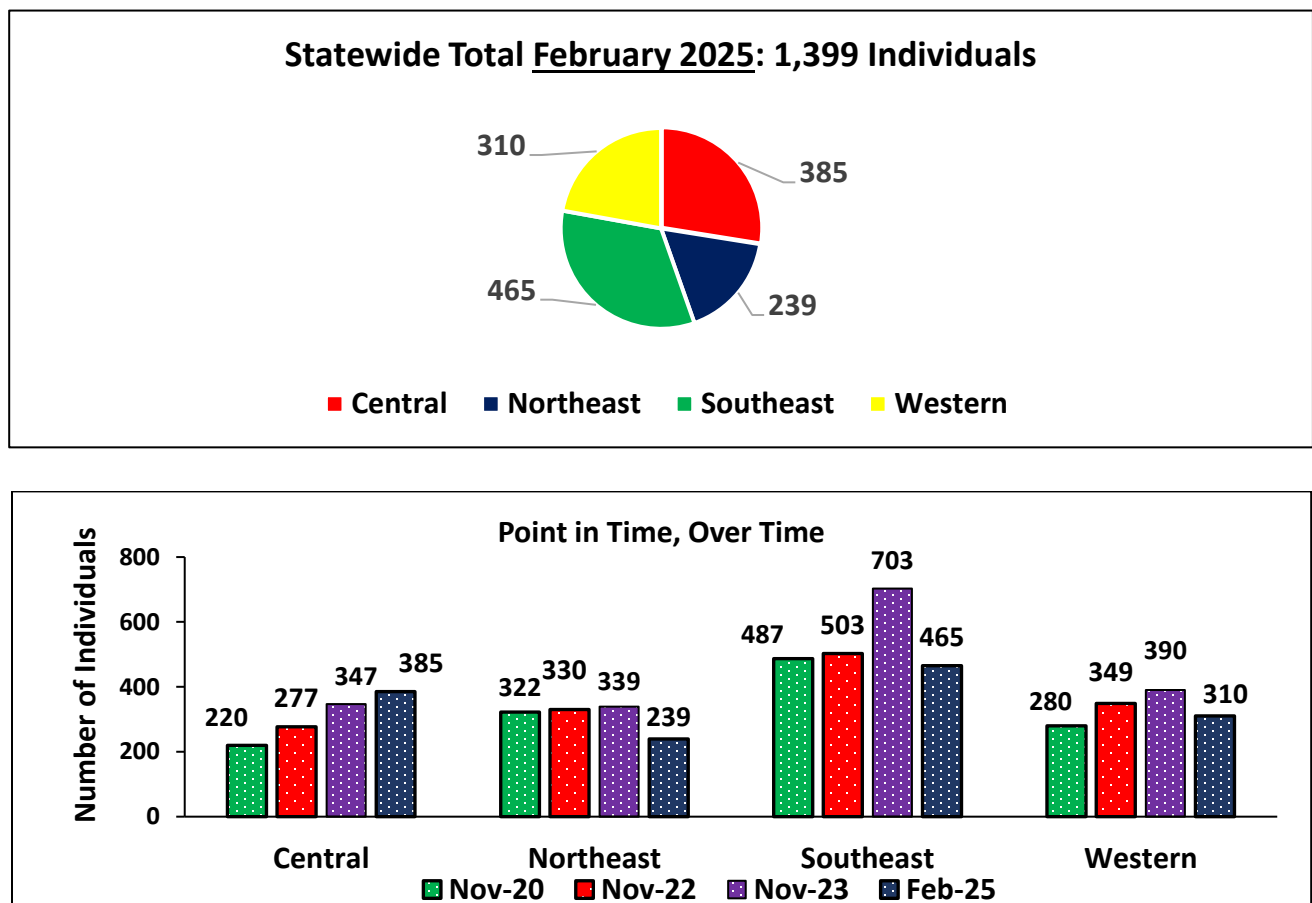
INDIVIDUALS & THEIR CAREGIVERS

The charts in this section show data for individuals on the waiting list and in the Emergency PUNS category. The Emergency PUNS category is described below.

EMERGENCY: Person has a single caregiver, and supports are needed immediately to ensure the person's health and safety. This category applies when the person's family/caregiver is the only person ensuring the person's health and safety, therefore, additional services are needed immediately. This does not apply to residential or family living providers.

Figure 21: Individuals in Emergency PUNS Category, with a Single Caregiver

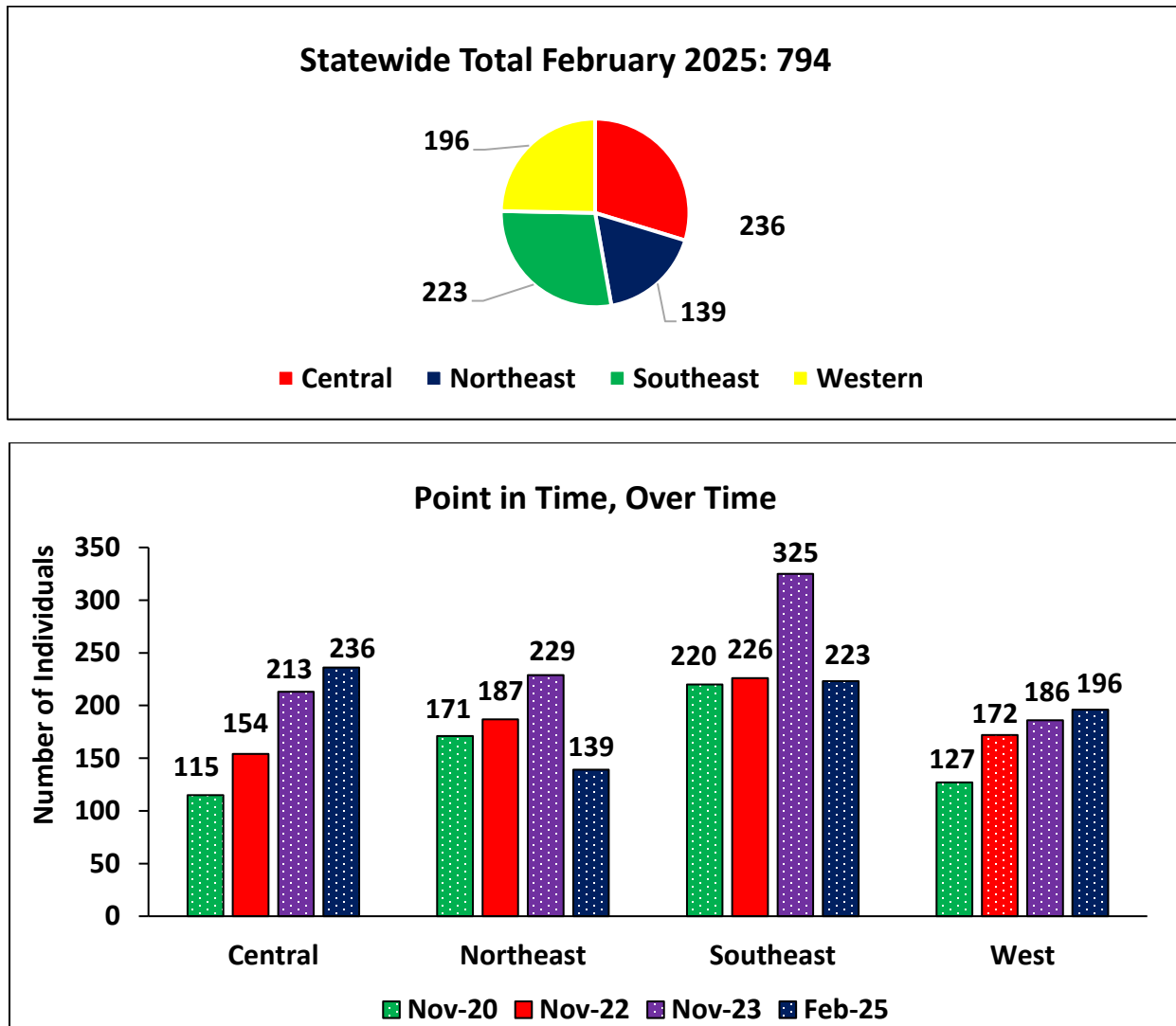
PUNS EQ9: Person has a single caregiver, and supports are needed immediately to ensure the person's health and safety.



Source: HCSIS/PUNS Snapshot Date: 02/28/2025

Figure 22: Emergency PUNS Category—Homes with 2 or More People Needing Support

PUNS EQ8: There are two or more people in the home that require support with their activities of daily living which compromises the caregiver’s ability to ensure the person’s health and safety.

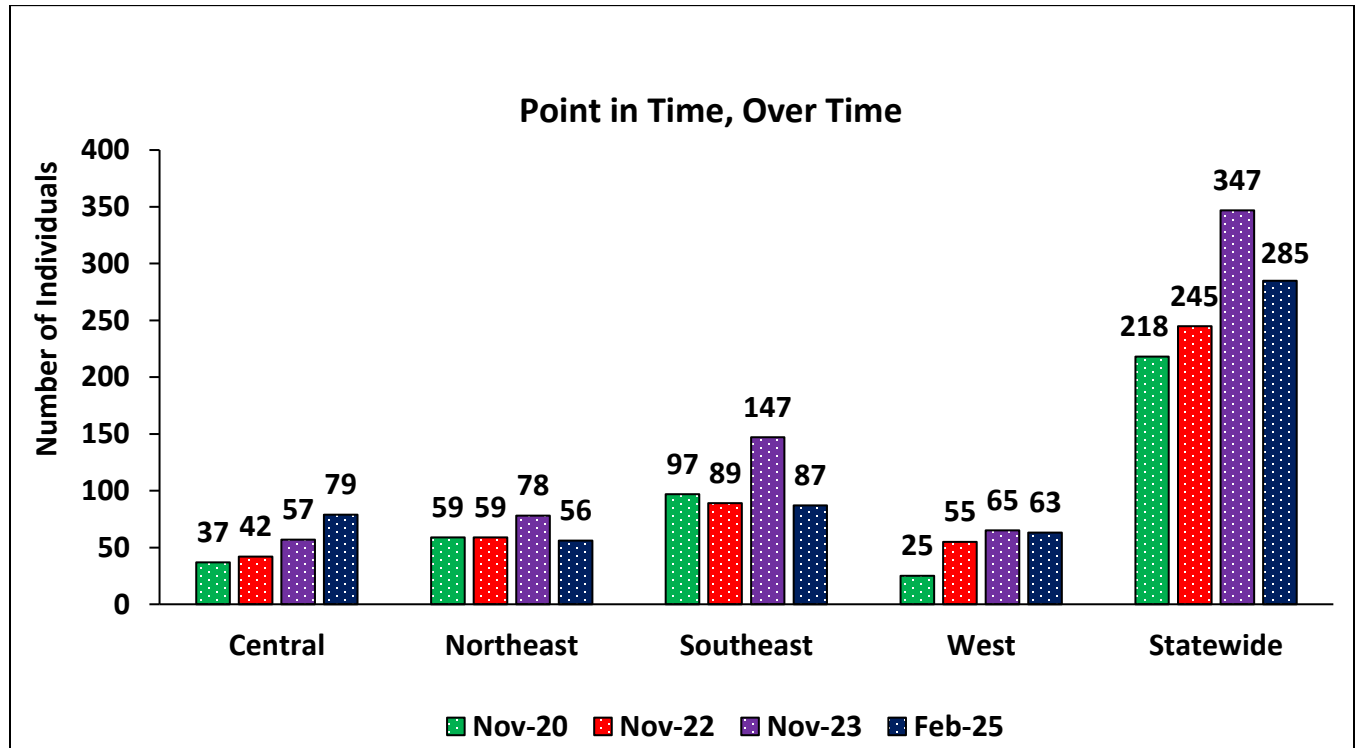


Source: HCSIS/PUNS Snapshot Date: 02/28/2025

Figure 23: Individuals in Emergency PUNS with Single Caregiver & with 2 or More People Needing Support

PUNS EQ8: There are two or more people in the home that require support with their activities or daily living which compromises the caregiver’s ability to ensure the person’s health and safety.

PUNS EQ9: Person has a single caregiver, and supports are needed immediately to ensure the person’s health and safety.



Source: HCSIS Snapshot Date: 02/28/2025

CAREGIVERS AGES 60 and OVER

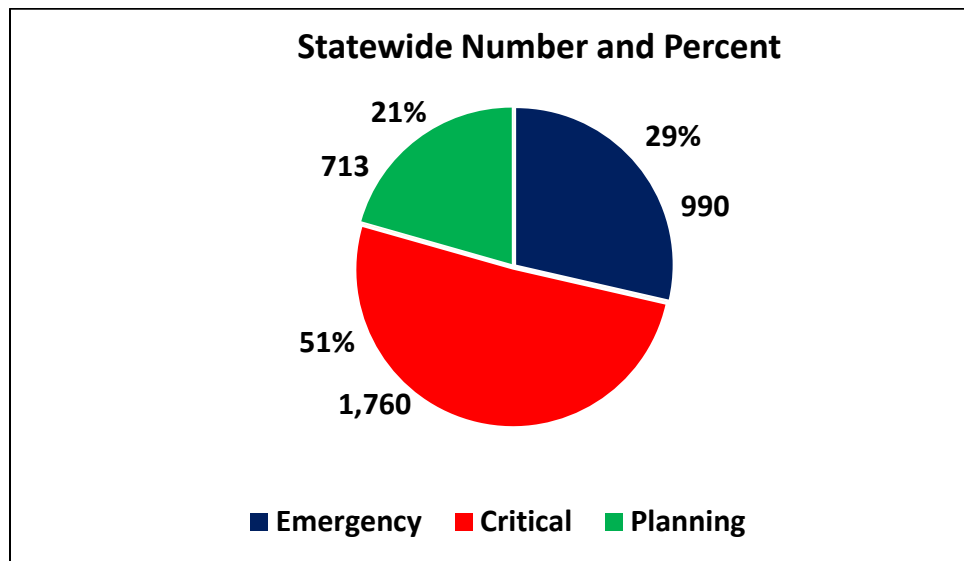
The tables in this section show data for individuals on the waiting list with caregivers who are 60 years of age or older. Waiting list categories that apply to individuals with single caregivers over the age of 60 are the Emergency, Critical and Planning categories.

EMERGENCY: This category is appropriate for persons who are supported by family or another caregiver who are no longer able to provide care to the person because of physical health and/or emotional reasons. No other caregiver is available, which places the person's health and safety at risk. The individual needs services immediately.

CRITICAL: The person has a caregiver who is age 60+ and will need supports within the next two years. This category is appropriate for persons whose caregiver is or will be age 60+ and is clearly progressing toward being unable to provide care for any number of physical, psychological, or other reasons. Although care is being provided at present, it is clear that within the next two years additional services will be needed.

PLANNING: Caregiver is or will be 60+ years of age and will need supports in the next 2-5 years. This category should be utilized when the person has a caregiver who is or will be 60+ and is clearly progressing toward being unable to provide care for any reason.

Figure 24: Individuals with Caregiver Age 60+, By Need Category, Statewide & by Region



Region	Emergency		Critical		Planning		All Categories
	Number of Individuals	% In State	Number of Individuals	% In State	Number of Individuals	% In State	
Central	288	39%	318	44%	125	17%	731
Northeast	190	30%	340	53%	113	18%	643
Southeast	356	29%	574	48%	277	23%	1,207
West	156	18%	528	60%	198	22%	882

Source: HCSIS/PUNS Snapshot Date: 02/28/2025

Figure 25: Individuals with Caregiver Age 60+, By Program Enrollment & Need Category

Program Enrolled	Emergency		Critical		Planning	
	Number of Individuals	% In State	Number of Individuals	% In State	Number of Individuals	% In State
Base	93	9.4%	182	10.3%	79	11.1%
Community Living Waiver	285	28.8%	354	20.1%	161	22.6%
P/FDS Waiver	224	22.6%	607	34.5%	239	33.5%
Private ICF/ID	<11	--	<11	--	<11	--
SC Services Only	364	36.8%	598	34%	226	31.7%

Source: HCSIS/PUNS Snapshot Date: 02/28/2025

Note: Data greater than zero and less than 11 is not shown in the table for privacy purposes.

Figure 26: Individuals with Caregivers Age 60+, Newly Enrolled from PUNS Category into All Waivers

Emergency	FY21-22	373	FY22-23	409	FY23-24	671
Critical	FY21-22	44	FY22-23	66	FY23-24	85
Planning	FY21-22	15	FY22-23	16	FY23-24	22

Source: HCSIS/PUNS Snapshot Date: 02/28/2025

Figure 27: Single Caregiver Age 60+ Supporting Multiple People by Region (Emergency PUNS Category Only)

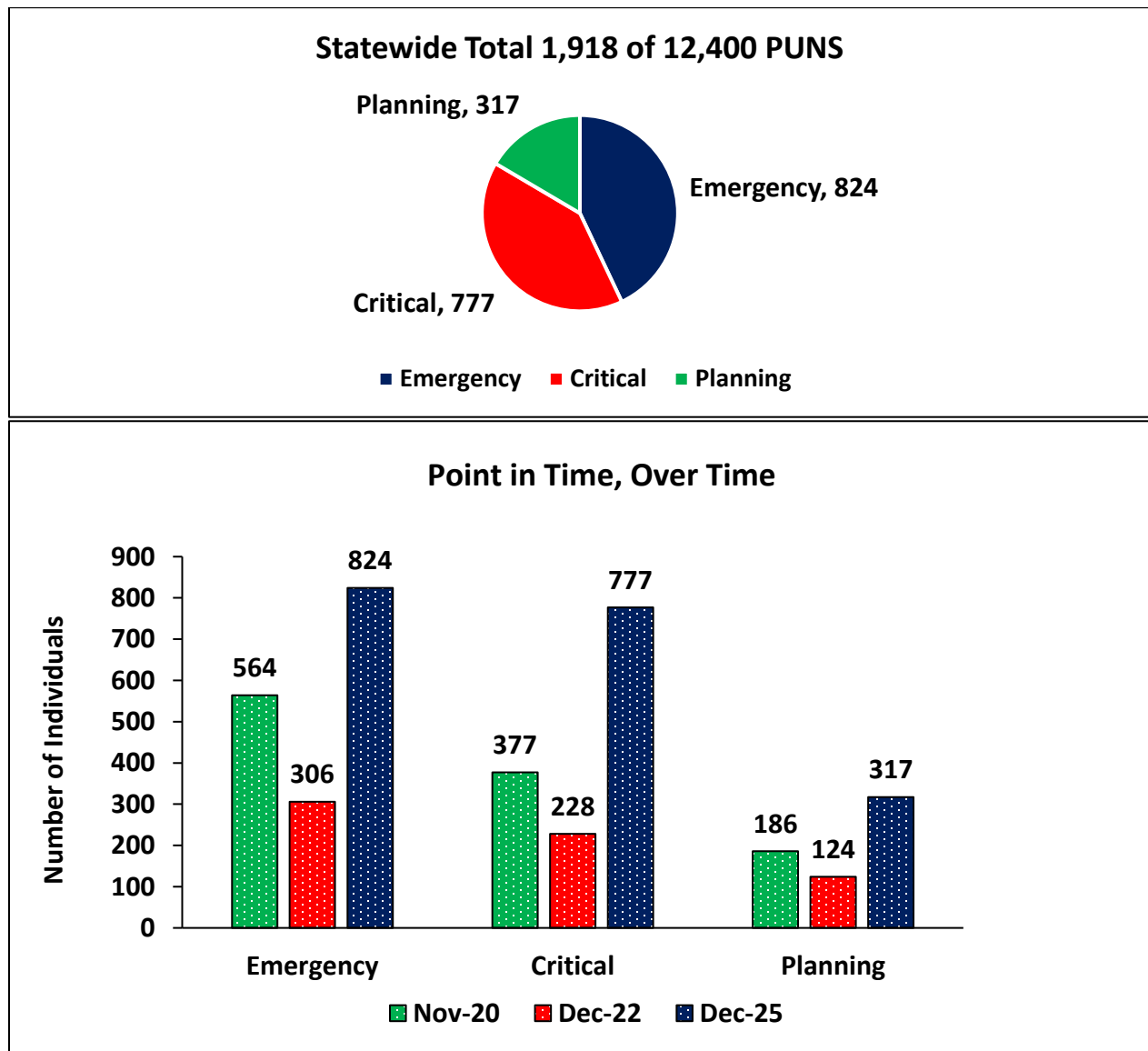
Central Region	79
Northeast Region	56
Southeast Region	87
Western Region	63
Statewide	285

Source: HCSIS/PUNS Snapshot Date: 02/28/2025

AUTISM-ONLY LEVEL OF CARE (LOC) DETERMINATION

This chart shows statewide totals for individuals on the waiting list with a LOC determination of “Individuals with Other Related Condition (ORC) related to Autism Spectrum Disorder (ASD)” by Planning, Emergency and Critical PUNS needs categories. These individuals do not have a co-occurring ID diagnosis.

Figure 28: Individuals on Waiting List with Autism Only



Source: HCSIS/PUNS Snapshot Date: 02/28/2025

The Adult Autism Waiver (AAW) “interest list” was established at the launch of the waiver in 2010 and it prioritized enrollment for the AAW on a first-come, first-served basis. Beginning in July 2017, the ODP ID/A waivers (Consolidated, P/FDS and in 2018 Community Living) included “autism only,” as an eligibility category. This eligibility expansion meant that individuals with ASD only, of any age, who met LOC requirements, could receive targeted supports management, and be enrolled in an ODP ID/A waiver as capacity becomes available.

In December 2019, ODP began transitioning the 2,228 individuals on the AAW interest list to ODP’s waiting list, so that eligible individuals could be assessed for their urgency of need and prioritized accordingly for waiver enrollment. Since December 2019, 1,248 individuals have been either enrolled into a waiver, were no longer interested, or no longer met the eligibility requirements. Of the remaining individuals, 389 have had their eligibility determined by the county and were placed on the ODP waiting list. The remaining 591 people have not completed the steps required to determine their eligibility and have their names placed on the ODP waiting list.