



**pennsylvania**  
DEPARTMENT OF HUMAN SERVICES

# **ANNUAL WAITING LIST REPORT**

## **OFFICE OF DEVELOPMENTAL PROGRAMS (ODP)**

### **2022**



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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."

The number of individuals receiving home and community-based services (HCBS) through ODP is determined by the annual approved capacity in each of ODP's four (4) HCBS waivers. There are more Pennsylvanians with intellectual disabilities and autism (ID/A) who need HCBS than the current approved waiver capacity addresses. The approved capacity of the waivers is determined annually by the state budget. Since 2001, there have been three years without waiting list initiatives in the state budget. Other years have included significant additions to capacity. While the waiting list for ID/A services does seem daunting, service expansion over the years has made a real impact. In April 2006 there were 24,500 people waiting for services. Today, despite expanding the eligible population for the waivers to include autism, the waiting list has been reduced by nearly half, with 12,389 people waiting for service, and median wait time on the list has significantly decreased from 4.1 years to 2.6 years, over the last 7 years.

Several ODP strategies and activities to reduce the waiting list are detailed in this report, which provides trends over time, as well as snapshots of the status as of the dates indicated in the individual charts and graphs. This report also offers details regarding how the Prioritization of Urgency of Need for Services (PUNS) tool has assisted ODP in evaluating the waiting list in order to better target policies to address the needs of individuals with ID/A and their families.

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
CHC	Community HealthChoices Program
CLW	Community Living Waiver
EDW	Enterprise Data Warehouse
EPSDT	Early and Periodic Screening, Diagnostic and Treatment
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
OLTL	Office of Long-Term Living
PDA	Pennsylvania Department of Aging
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

## **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 waivers<sup>1</sup>, 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 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

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<sup>1</sup> Intermediate Care Facility for Intellectual Disability or Other Related Conditions level of care

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 HCSIS (Home and Community Service Information System). 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.

### **Recent 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 (ASD) only [Figure 21]. In 2022, ODP expanded eligibility to children with medically complex conditions for TSM and home and community-based waivers.

### **Recent Increase in Waiting List Driven by Pandemic Related Needs**

In November 2021, the number of individuals on the waiting list was 12,214. The number increased to 12,389 by November 2022. This slightly upward movement appears to be the result of the following, which are indicative of additional stressors for individuals and families due to the pandemic:

- An overall increase of 7.4% in the emergency urgency of need category. This number increased from 5,040 individuals in November 2021 to 5,413 in November 2022.
- Within the emergency urgency of need category, there has been a 19.5% increase in 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 individuals in November 2021 to 1,043 individuals in November 2022.
- Also, within the emergency urgency of need category, the number of individuals who have a single caregiver and need immediate supports increased 10.3%, from 1,137 in November 2021 to 1,254 in November 2022.

### **Strategies and Activities to Address the Waiting List**

Prior to the slight upward movement in FY21-22, the waiting list had been on a steady path of shrinking. The reduction in individuals waiting for services had been accomplished through a number of activities, including:

#### **Growth Strategy**

During the 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 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 provides additional availability is through *turnover*. Each year, people disenroll<sup>2</sup> from an ODP HCBS waiver at a rate of roughly 4% [Figure 4]. 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.

***“ODP’s waiver growth strategy has resulted in an overall reduction of median wait time from 4.1 years to 2.6 years, over the last 7 years.” - Deputy Secretary Kristin Ahrens***

### **High School Graduate Initiative**

The “transition age” group represents the highest number of individuals on the waiting list [Figure 8 and Figure 9]. For this reason, ODP has implemented targeted initiatives to prioritize the needs of this group of individuals with ID/A, as they transition to adulthood.

Beginning in 2012-13, ODP implemented an initiative to assure 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 and upon graduation. 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, and a total of 3,520 having been served with new waiver capacity, since the initiative began.

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.

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

## **Community Living Waiver (CLW)**

On January 1, 2018, ODP launched the CLW to support individuals with ID/A to live more independently in their homes and communities, through the provision of a variety of services and supports that promote community living, employment, communication, self-direction, choice, and control. This program has enrolled over 4,822 individuals since 2018.

## **Improvements in Needs Assessment and Waiver Capacity Management**

In 2019, ODP revised the PUNS tool to provide better information for SCs, Counties/AEs, and ODP to both identify individual needs and plan for future services at an individual and systems level. The expansion of Supports Coordination and modifications to the PUNS provide ODP the ability to better anticipate and manage the waiting list. These changes have provided better data collection related to the needs of individuals waiting for services. Concurrently, ODP has also improved data analytics related to waiver capacity management, which has allowed for more efficient management of resources. The data has shown that some counties have greater needs, which allows ODP to more appropriately and timely allocate resources.

# WAITING LIST TRENDS

## *Individuals On & Off the Waiting List vs. On the Waiting List*

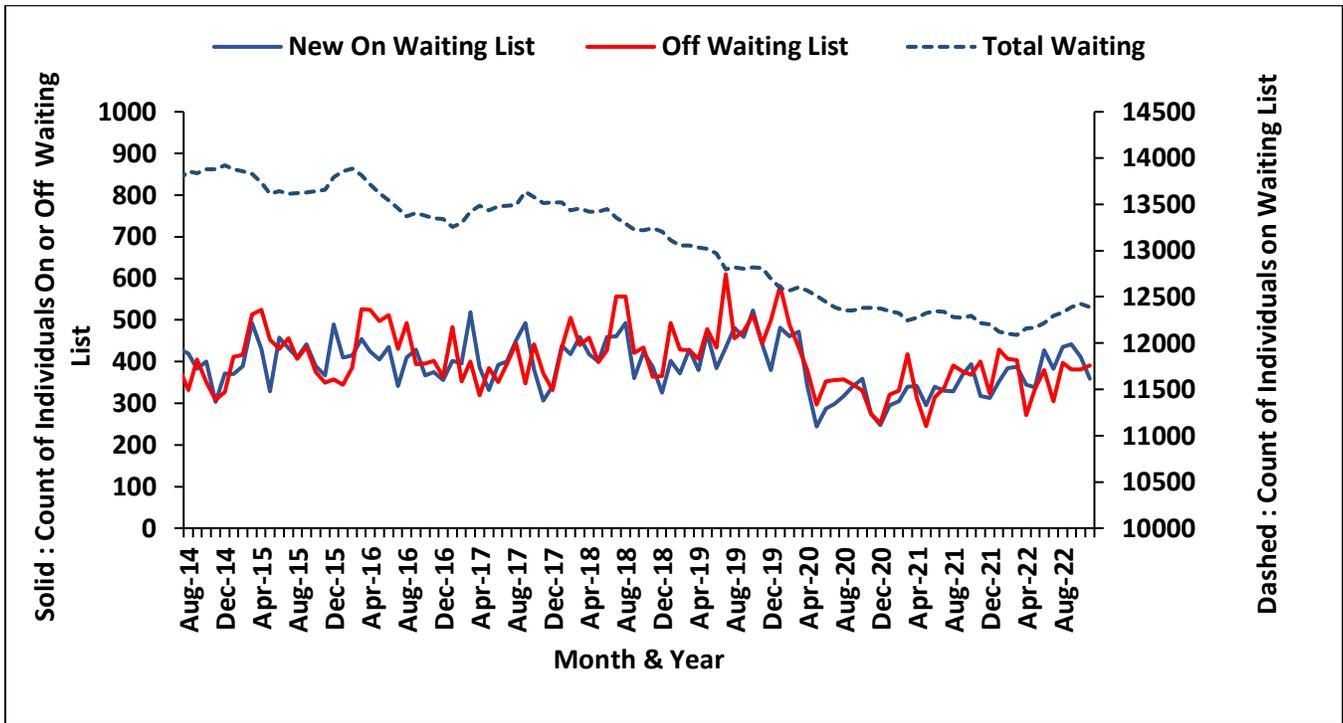


Figure 1: Individuals On & Off the Waiting List vs. On the Waiting List  
Source: EDW HCSIS Consumer Demographics Snapshot Date: 12/22/2022

## *Median & Average Years on Waiting List*

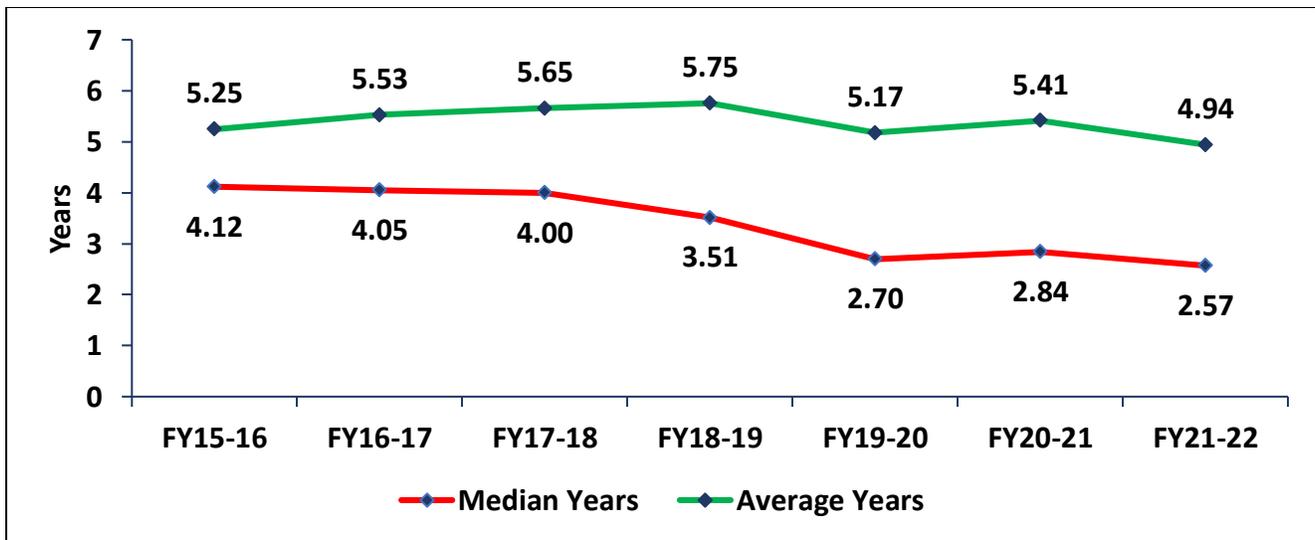


Figure 2: Median & Average Years on Waiting List  
Source: EDW HCSIS Consumer Demographics Fact Data Extraction date: 12/22/2022

## Waiver Turnover

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

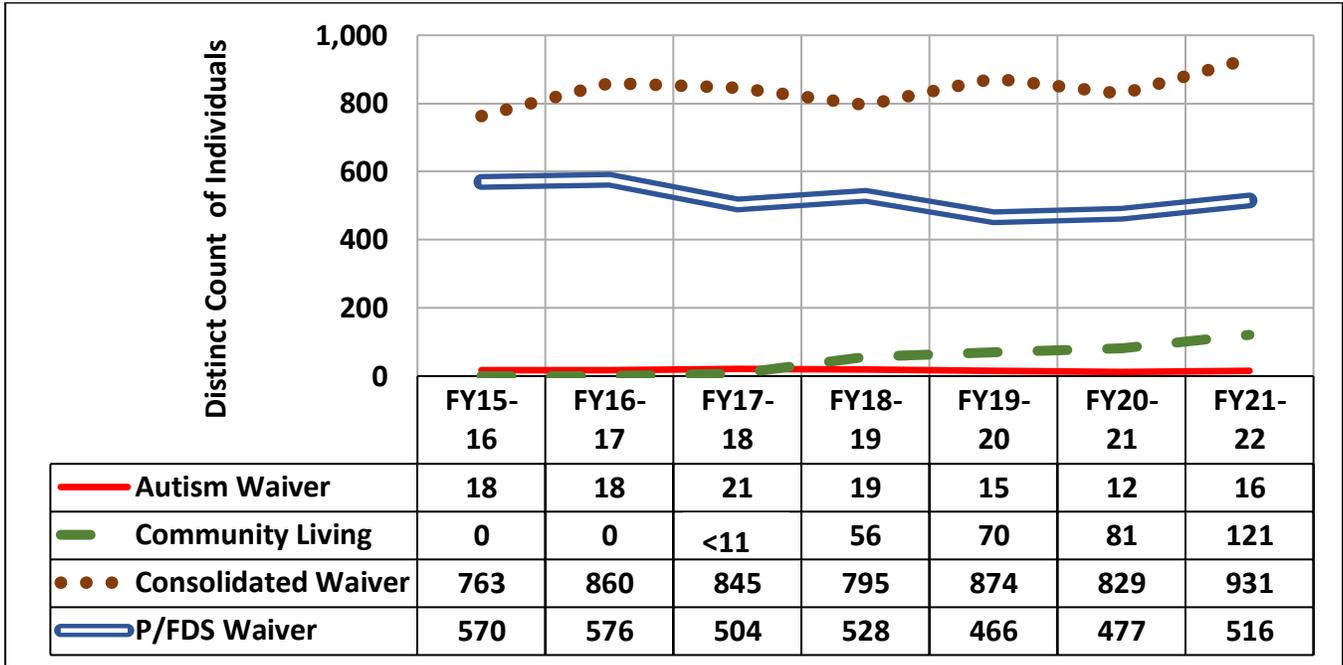


Figure 3: Waiver Turnover

Source: EDW HCSIS Consumer Demographics Fact Data Extraction Date: 12/22/2022

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

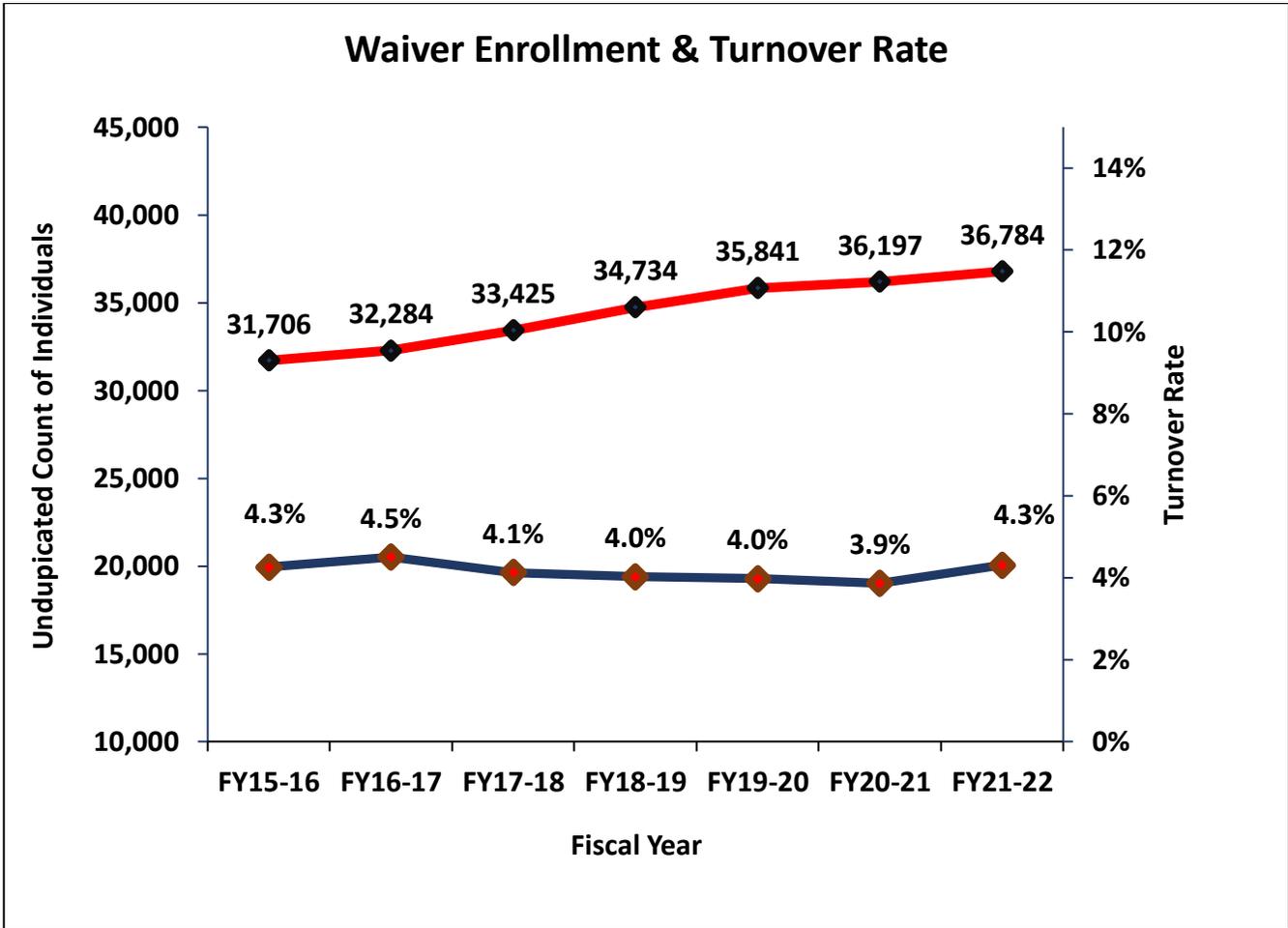


Figure 4: Waiver Enrollment & Turnover Rate  
 Source: HCSIS/PUNS Monthly Facts Extraction Date: 12/22/2022  
 Note: Includes all ODP waivers (Consolidated, P/FDS, Community Living and Adult Autism).  
 Turnover refers to individuals who are no longer in any waiver after waiver end date.

## New Consolidated Waiver Enrollees by Age Group & Time on Waiting List

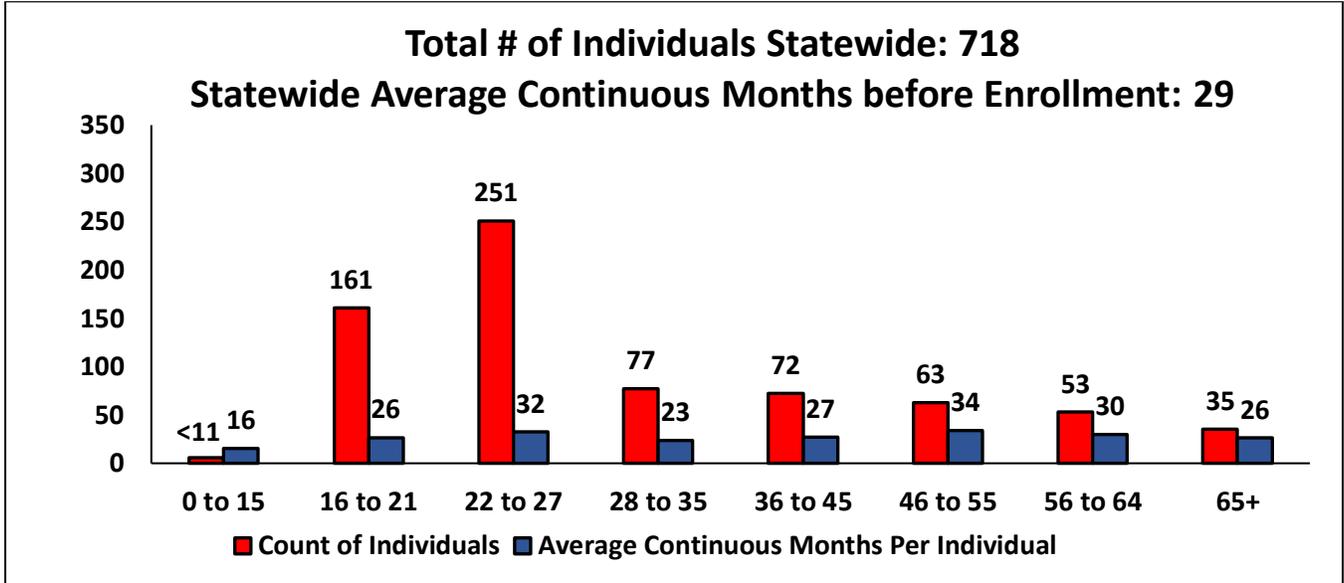


Figure 5: New Consolidated Waiver Enrollees by Age Group & Time on Waiting List (FY 21-22)

Source: HCSIS/PUNS Monthly Facts Data Extraction Date: 12/22/2022

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

# NEED CATEGORIES BY REGION, AGE & RACE

In the first figure below, data from July 2014 to July 2022 shows a 10% decrease for individuals on the ODP waiting list. Other charts/graphs in this section include waiting list numbers by need category, county/joinder, region, age/age group and race.

## *Individuals on Waiting List by Need Category*

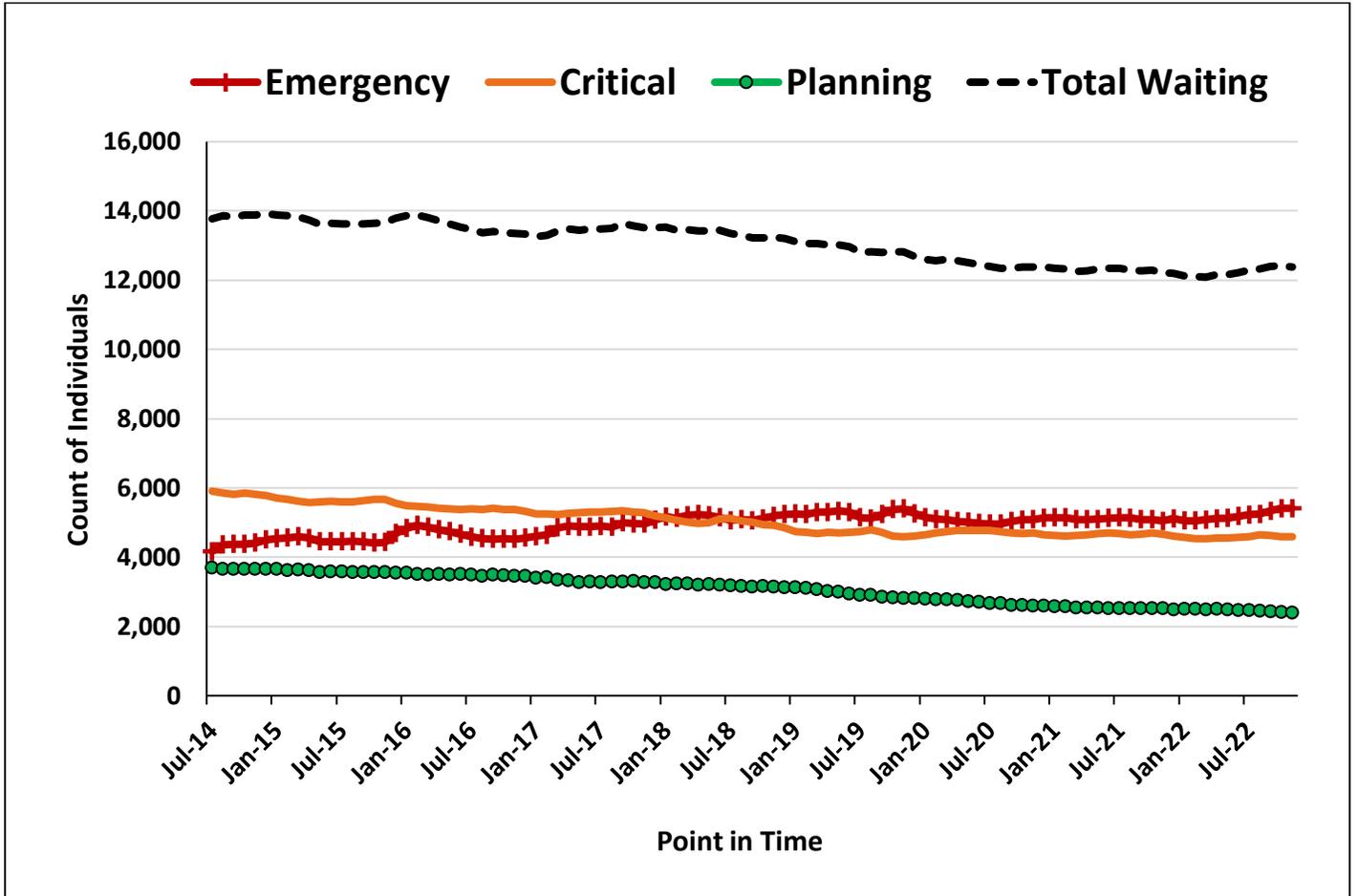


Figure 6: Individuals on Waiting List by Need Category  
Source: HCSIS/PUNS Snapshot Date: 12/22/2022

## Individuals Ages 21+ on Waiting List by Need Category

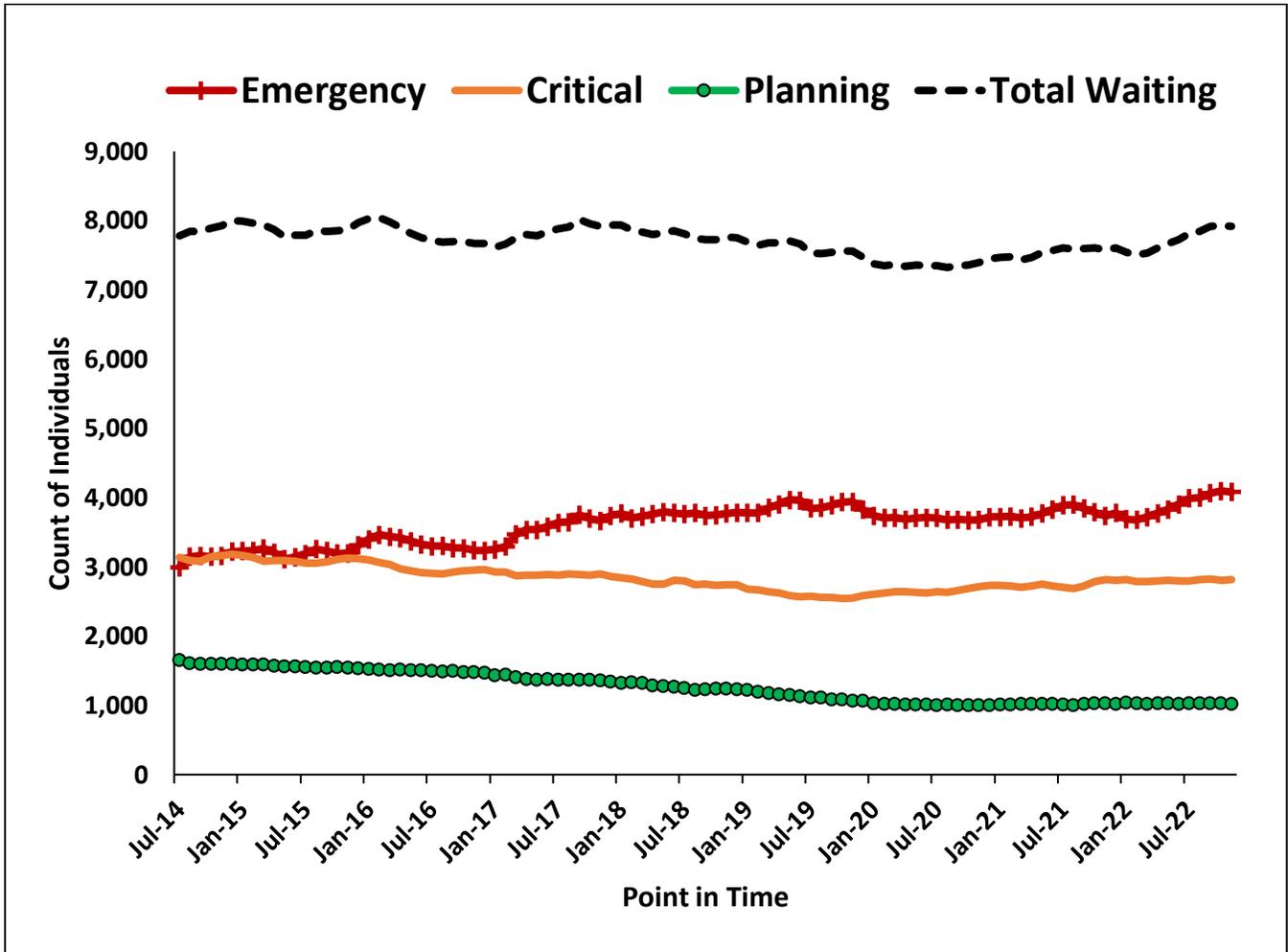


Figure 7: Individuals Ages 21+ on Waiting List by Need Category  
 Source: HCSIS/PUNS Snapshot Date: 12/22/2022

## *Individuals on Waiting List Ages 21+ by Need Category & County/Joinder*

COUNTY/JOINDER	EMERGENCY 21+	CRITICAL 21+	PLANNING 21+	ALL PUNS CATEGORIES 21+	ALL PUNS CATEGORIES ALL AGES
Allegheny	324	254	75	653	1,029
Armstrong/Indiana	51	23	<11	84	123
Beaver	34	57	20	111	159
Bedford/Somerset	53	16	15	84	113
Berks	139	59	25	223	382
Blair	52	21	<11	80	156
Bradford/Sullivan	<11	12	<11	23	38
Bucks	118	118	132	368	521
Butler	45	41	20	106	187
Cambria	36	28	<11	70	99
Cameron/Elk	<11	16	<11	24	32
Carbon/Monroe/Pike	135	42	<11	181	294
Centre	52	12	<11	74	115
Chester	237	91	56	384	603
Clarion	<11	0	0	<11	<11
Clearfield/Jefferson	<11	26	<11	36	65
Columbia/Montour/Snyder/Union	31	15	<11	53	84
Crawford	23	19	<11	49	93
Cumberland/Perry	91	48	48	187	267
Dauphin	84	39	11	134	216
Delaware	185	94	31	310	451
Erie	245	117	54	416	797
Fayette	20	11	14	45	92
Forest/Warren	<11	22	<11	27	40
Franklin/Fulton	44	54	<11	102	138
Greene	<11	<11	<11	<11	11
Huntingdon/Mifflin/Juniata	16	21	<11	44	68
Lackawanna/Susquehanna	70	82	17	169	283
Lancaster	226	60	25	311	431
Lawrence	41	19	11	71	124
Lebanon	63	40	17	120	185
Lehigh	74	88	19	181	302
Luzerne/Wyoming	219	72	21	312	435
Lycoming/Clinton	45	22	<11	75	103
McKean	16	<11	<11	22	32
Mercer	41	13	<11	56	86
Montgomery	314	170	68	552	876
Northampton	60	55	13	128	242

*Figure 8: Individuals on Waiting List 21+ by Need Category & County/Joinder – continued on next page*

**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
Northumberland	20	39	<11	66	95
Philadelphia	556	498	141	1,195	1,739
Potter	<11	<11	<11	<11	<11
Schuylkill	54	23	20	97	172
Tioga	11	<11	<11	21	36
Venango	<11	<11	<11	18	30
Washington	62	61	<11	126	211
Wayne	<11	<11	<11	13	41
Westmoreland	51	188	37	276	432
York/Adams	105	103	19	227	349
<b>Statewide:</b>	<b>4,082</b>	<b>2,816</b>	<b>1,021</b>	<b>7,919</b>	<b>12,389</b>

*Figure 8: Individuals on Waiting List 21+ by Need Category & County/Joinder*

*Source: HCSIS/PUNS Snapshot Date: 12/31/2022*

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

## **Individuals on Waiting List by Need Category, Region & Served Status**

In Figures 9 and 12 below, “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 of 12/29/22, from any of the following programs: any ODP HCBS waiver and Base programs, public and private Intermediate Care Facility (ICF) programs, Office of Long-Term Living (OLTL) and the Department of Aging (PDA) home and community-based programs, OLTL Community HealthChoices program (CHC), or Early and Periodic Screening, Diagnostic and Treatment (EPSDT) programs for ages <21. “Without” is defined as the remaining individuals with completed PUNS, not under the “With” category defined above.

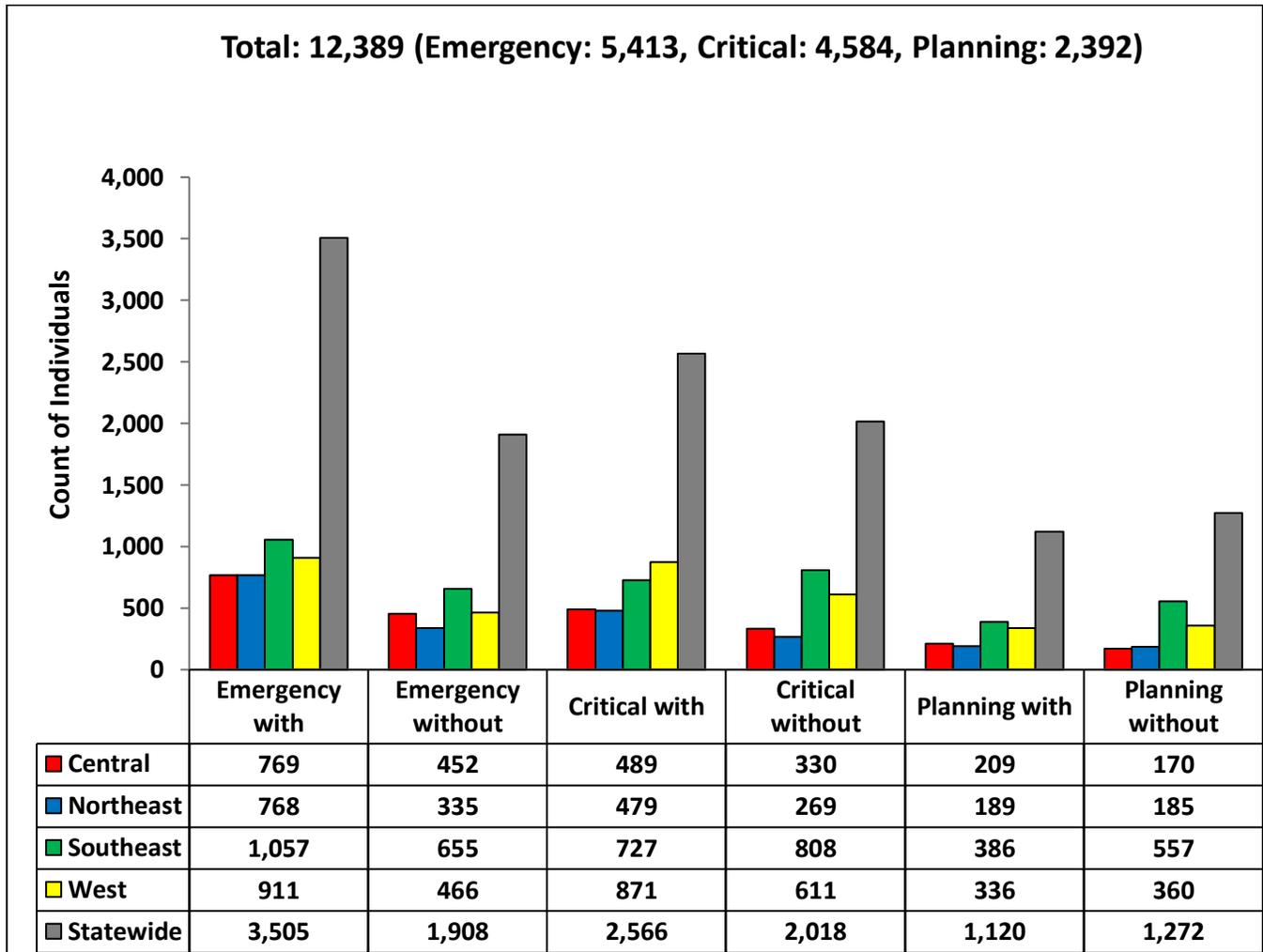


Figure 9: Individuals on Waiting List by Need Category, Region & Served Status  
 Source: EDW HCSIS PUNS Fact and PROMISe Paid Claims and Enrollment Snapshot Date: 12/29/2022

### Individuals on Waiting List by Need Category & Age

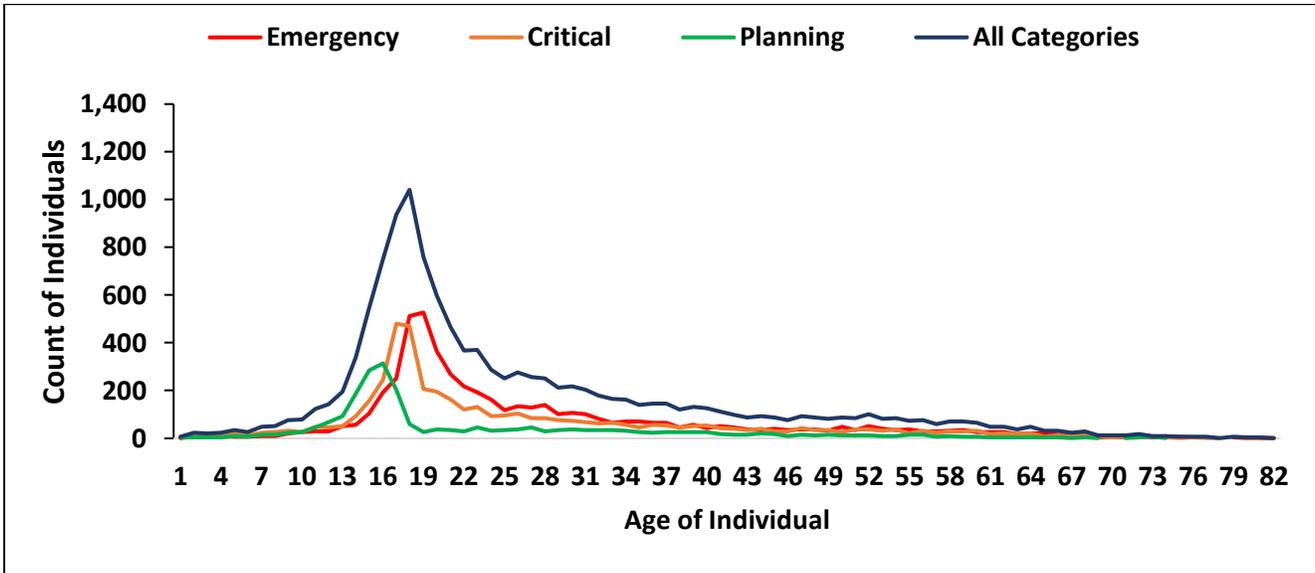


Figure 10: Individuals on Waiting List by Need Category & Age  
 Source: HCSIS/PUNS Snapshot Date: 11/30/2022

### Individuals on Waiting List by Need Category & Age Group

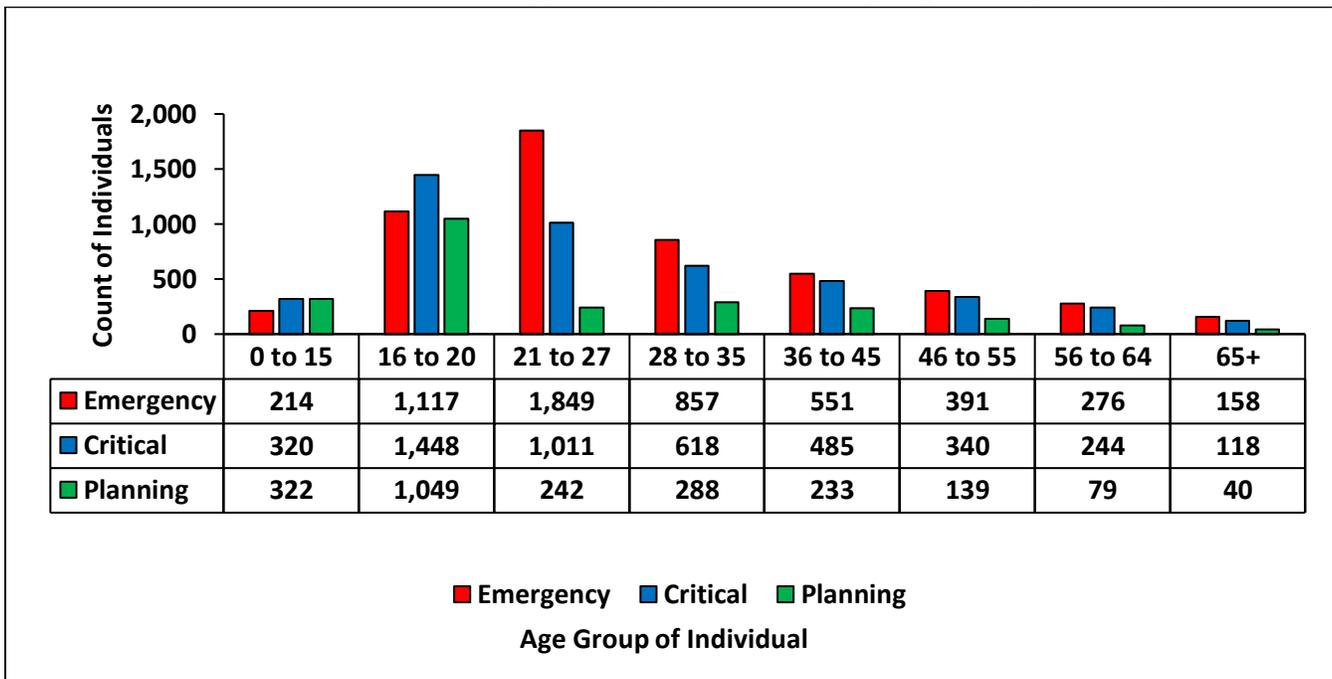


Figure 11: Individuals on Waiting List by Need Category & Age Group  
 Source: HCSIS/PUNS Snapshot Date: 11/30/2022

## Individuals on Waiting List by Need Category, Age & Served Status

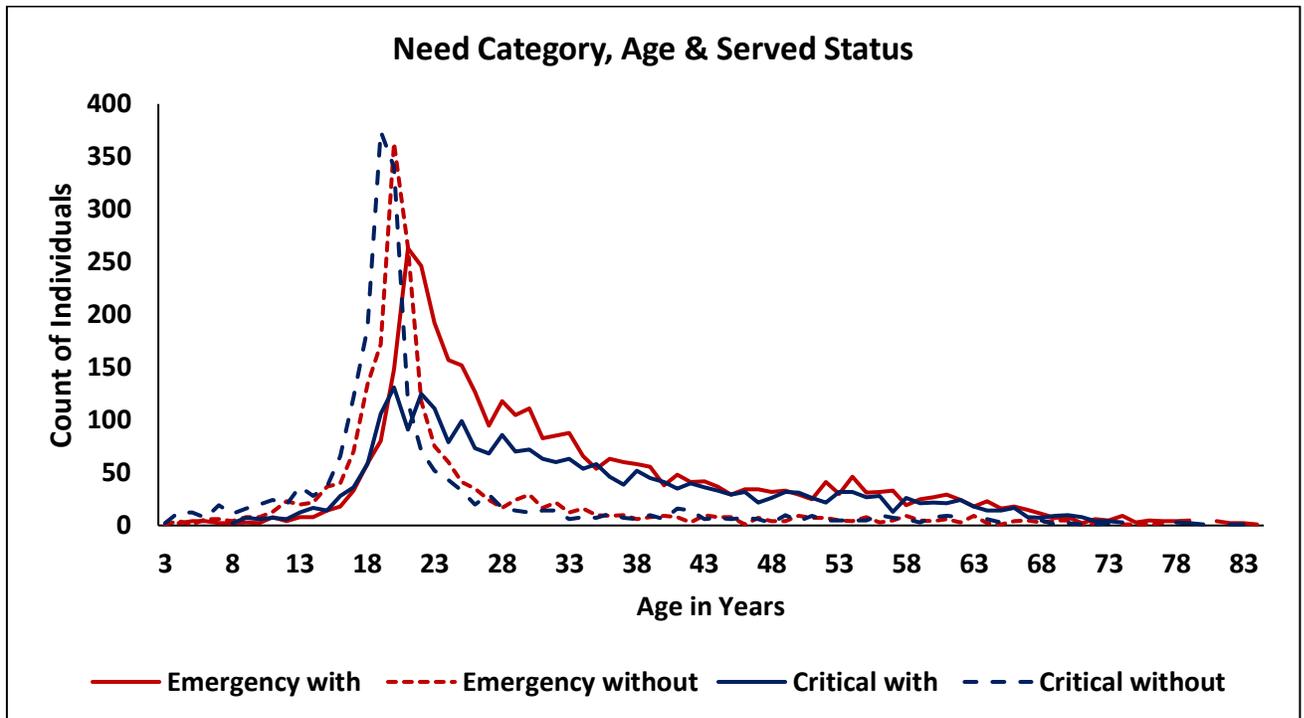


Figure 12: Individuals on Waiting List by Need Category, Age & Served Status  
Source: HCSIS/PUNS Snapshot Date: 12/29/2022

## Individuals Ages 21+ on Waiting List by Need Category & Race

Race Group	EMERGENCY 21+		CRITICAL 21+		PLANNING 21+		ALL PUNS CATEGORIES 21+	ALL PUNS CATEGORIES ALL AGES
	Count	Percentage	Count	Percentage	Count	Percentage		
White	3,819	71%	3,271	71%	1,766	74%	5,697	8,856
Black Or African American	951	18%	821	18%	326	14%	1,433	2,098
Other	427	8%	330	7%	206	9%	557	963
Asian	135	2%	110	2%	62	3%	160	307
Unknown	38	1%	23	1%	17	1%	36	78
Multiracial	29	1%	20	0%	<11	0%	23	58
American Indian or Alaskan Native	12	0%	<11	0%	<11	0%	12	26
Native Hawaiian or Other Pacific Islander	<11	0%	0	0%	<11	0%	<11	<11

Figure 13: Individuals Ages 21+ on Waiting list by Need Category & Race  
Source: HCSIS/PUNS Snapshot Date: 11/30/2022

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.

## *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.

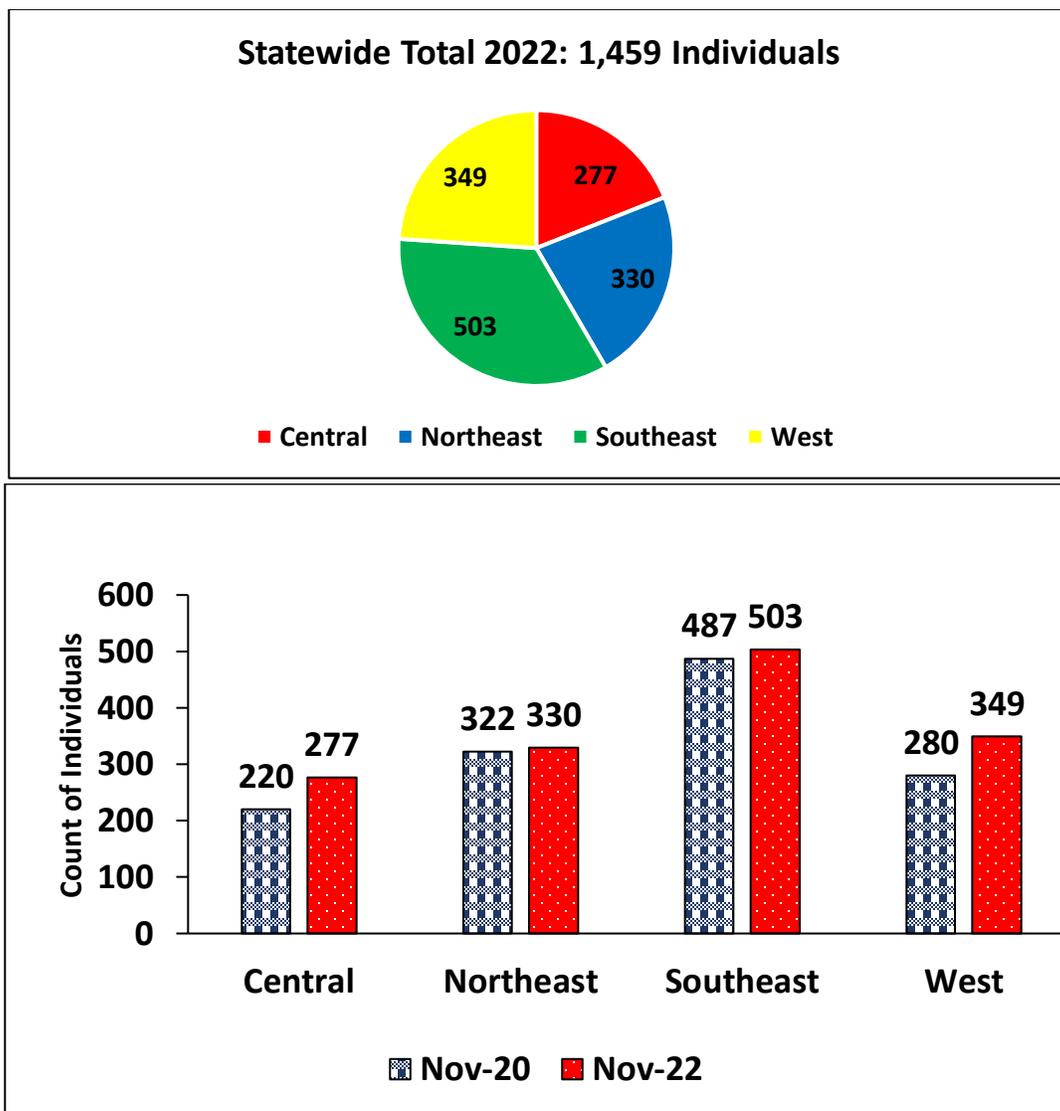


Figure 14: Individuals in Emergency PUNS Category, with a Single Caregiver  
Source: HCSIS/PUNS Snapshot Dates: 11/30/2020 and 11/30/202

## **Individuals in Emergency PUNS Category, Living in 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 or daily living which compromises the caregiver’s ability to ensure the person’s health and safety.

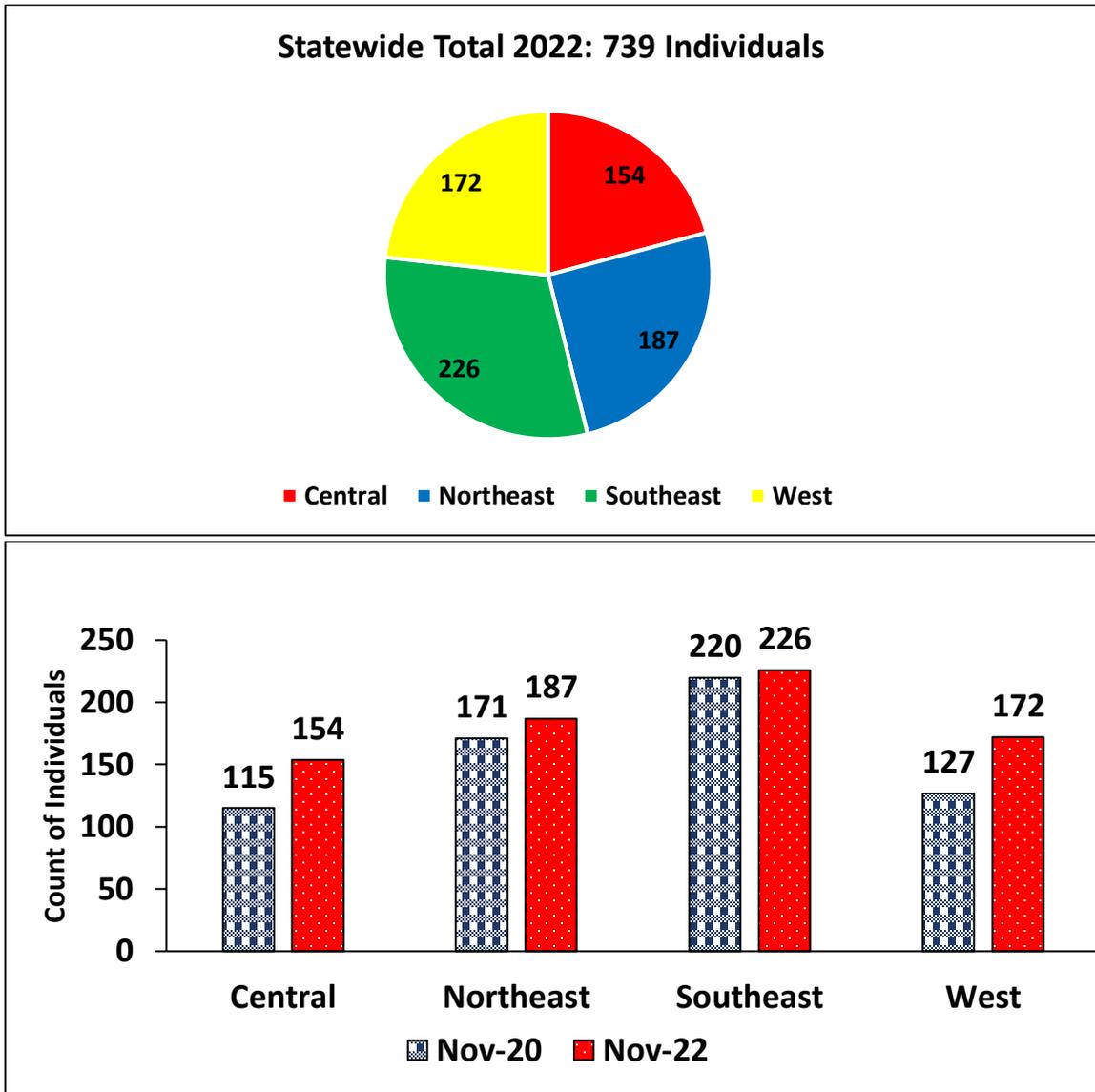


Figure 15: Individuals in Emergency PUNS Category, Living in Homes with 2 or More People Needing Support  
 Source: HCSIS/PUNS Snapshot Dates: 11/30/2020 and 11/30/2022

## **Individuals in Emergency PUNS Category, Living in Homes with a 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.

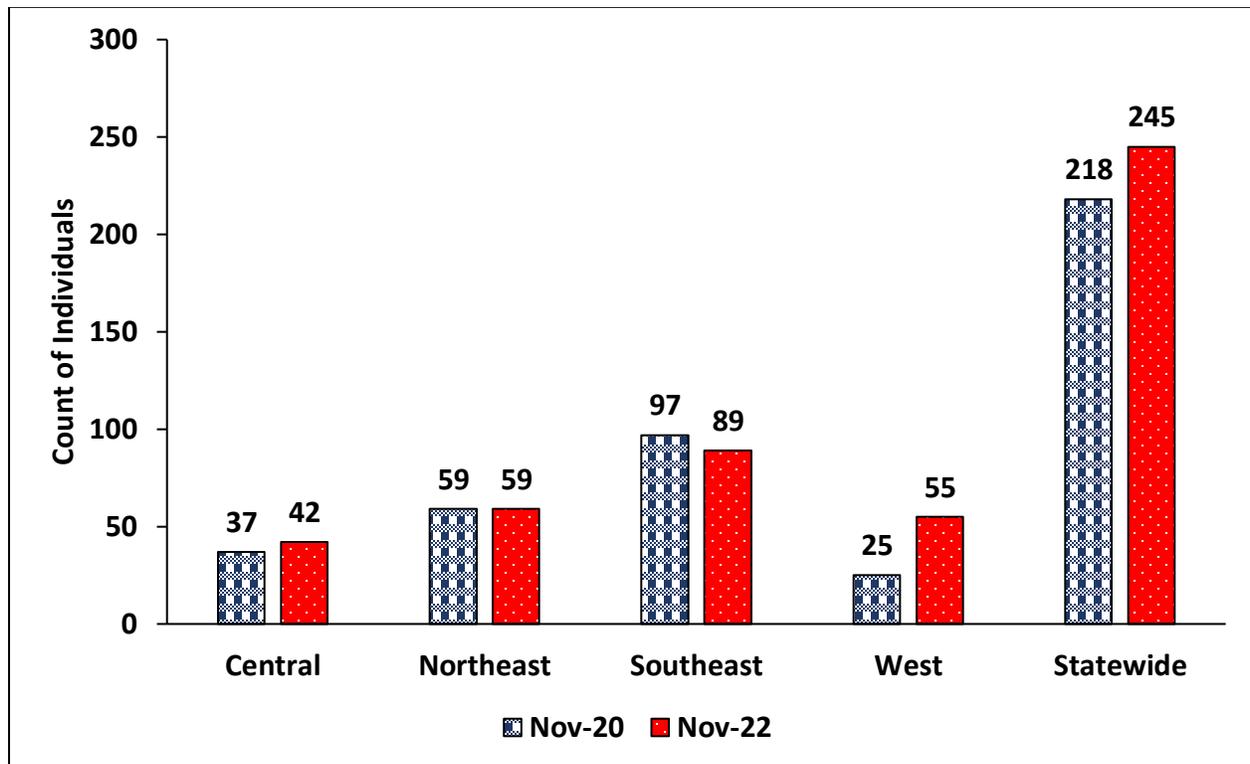


Figure 16: Individuals in Emergency PUNS Category, Living in Homes with a Single Caregiver & 2 or More People Needing Support  
Source: HCSIS/PUNS Snapshot Date: 11/30/2020 and 11/30/2022

## CAREGIVERS AGE 60 and OVER

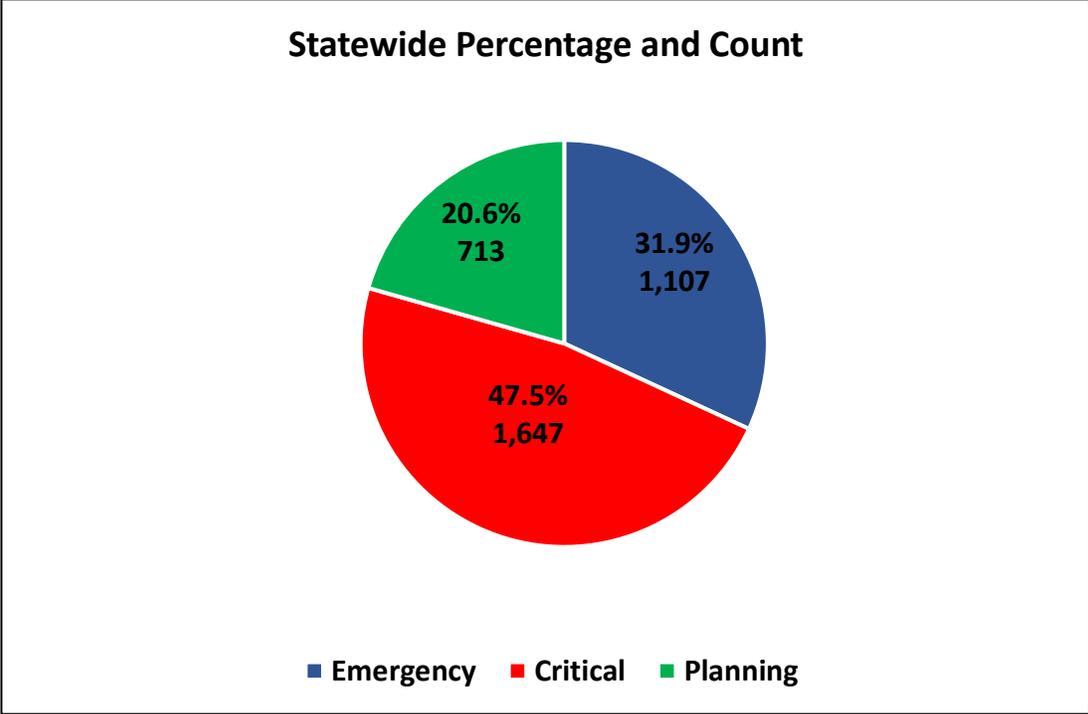
The tables in this section show data for individuals on the waiting list with caregivers who are 60 years of age or older. In the first table, at least one individual in the home requires support by their caregiver. The other tables show data in this category, but for the newly enrolled by year, over the last three fiscal years, and for those supporting multiple people. 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.

**Individuals with Caregiver Age 60+, By Need Category, Statewide & by Region**



	Emergency		Critical		Planning		All Categories
	Count of Individuals	% In State	Count of Individuals	% In State	Count of Individuals	% In State	
<b>Central</b>	214	19.3%	300	18.2%	125	17.5%	639
<b>Northeast</b>	271	24.5%	275	16.7%	86	12.1%	632
<b>Southeast</b>	435	39.3%	557	33.8%	330	46.3%	1,322
<b>West</b>	187	16.9%	515	31.3%	172	24.1%	874

*Figure 17: Individuals with Caregiver Age 60+, By Need Category, Statewide & by Region  
Source: HCSIS/PUNS Snapshot Date: 11/30/2022*

## Individuals with Caregiver Age 60+, By Program Enrollment & Need Category

Program Enrollment	Emergency		Critical		Planning	
	Count of Individuals	% In State	Count of Individuals	% In State	Count of Individuals	% In State
Base	118	10.7%	221	13.4%	84	11.8%
Community Living Waiver	194	17.5%	212	12.9%	104	14.6%
Consolidated Waiver	18	1.6%	17	1.0%	<11	1.1%
P/FDS Waiver	394	35.6%	646	39.2%	276	38.7%
Private ICF/ID	<11	0.4%	0	0%	0	0%
SC Services Only	379	34.2%	551	33.5%	240	33.7%

Figure 18: Individuals with Caregiver Age 60+, By Program Enrollment & Need Category

Source: HCSIS/PUNS Snapshot Date: 11/30/2022

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

## Individuals with Caregivers Age 60+, Newly Enrolled from PUNS into Waivers

FY 19-20			FY 20-21			FY21-22		
Emergency	Critical	Planning	Emergency	Critical	Planning	Emergency	Critical	Planning
379	32	<11	290	23	<11	371	44	15

Figure 19: Individuals with Caregivers Age 60+, Newly Enrolled from PUNS into Waivers

Source: HCSIS/PUNS Snapshot Date: 11/30/2022

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

## Single Caregivers Age 60+ Supporting Multiple People (All are in Emergency Category)

Region	Single Caregivers Age 60+ Supporting Multiple People
Central	17
Northeast	24
Southeast	33
West	12
<b>Total</b>	<b>86</b>

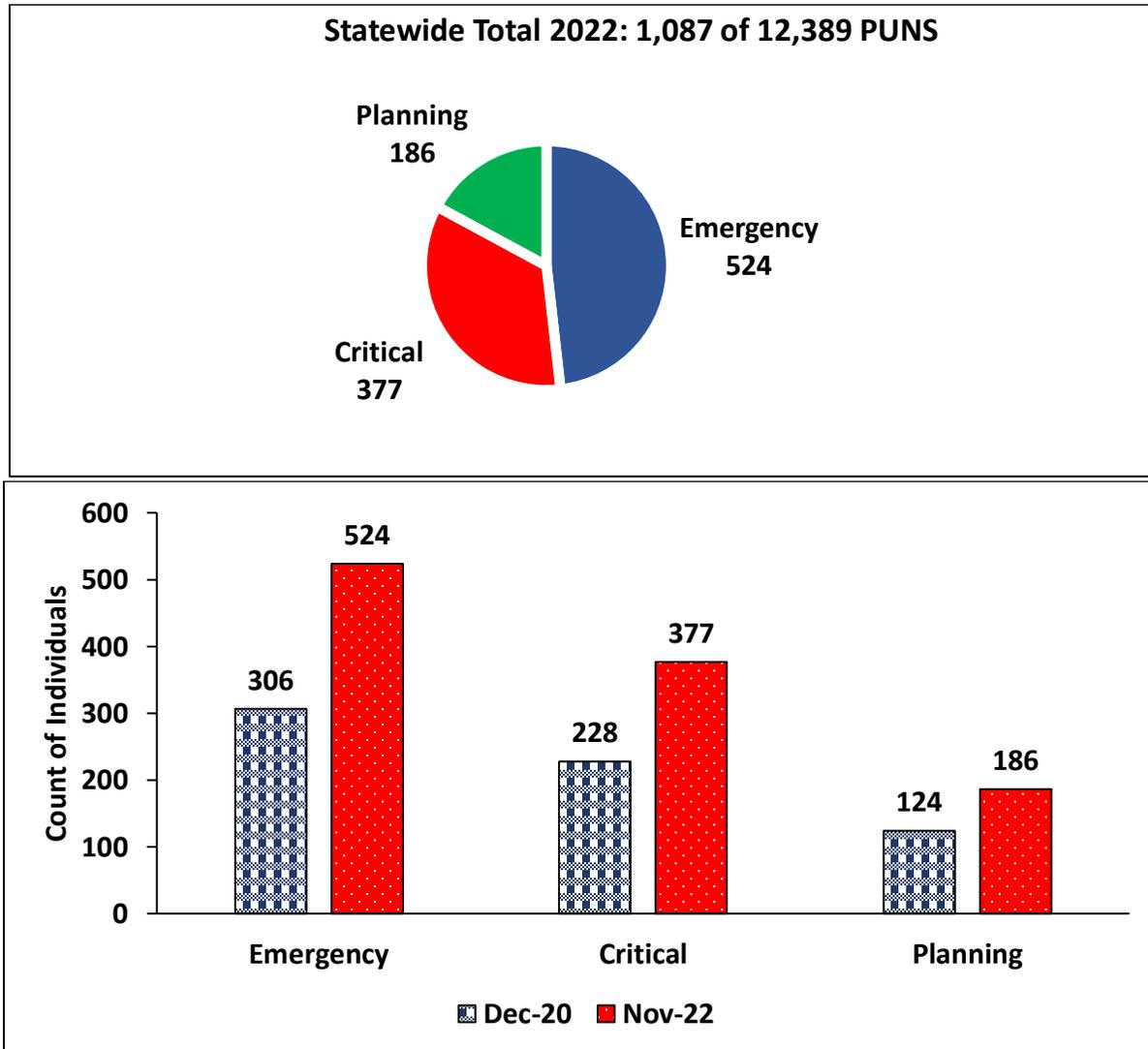
Figure 20: Single Caregivers Age 60+ Supporting Multiple People

Source: HCSIS/PUNS Snapshot Date: 11/30/2022

# 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.

## *Individuals on Waiting List with Autism Only*



*Figure 21: Individuals on Waiting List with Autism Only*  
 Source: HCSIS/PUNS Snapshot Date: 12/31/2020 and 11/30/2022

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, 537 individuals were either enrolled into a waiver, were no longer interested, or no longer met the eligibility requirements. Of the remaining individuals, 445 have had their eligibility determined by the county and were placed on the ODP waiting list. The remaining 1,246 people have not completed the steps required to determine their eligibility and have their names placed on the ODP waiting list.