



pennsylvania
DEPARTMENT OF HUMAN SERVICES

ANNUAL WAITING LIST REPORT

OFFICE OF DEVELOPMENTAL PROGRAMS (ODP)

2021



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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 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 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, over the years, service expansion has made a real impact. In April 2006 there were 24,500 people waiting for service. Today, in spite of expanding the eligible population to include autism for the waivers, the waiting list is nearing half that size with 12,357 people and wait time on the list has significantly decreased from 4.1 years to 2.3 years, over the last 5 years.

Several ODP strategies and activities to reduce the waiting list are detailed within 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

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, 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

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.

Strategies and Activities to Address the Waiting List

In July 2014, 13,767 individuals were on the waiting list. As of December 2020, the waiting list was substantially reduced to 12,377 people. This 10.1% reduction in individuals waiting for services has been achieved through a number of activities, including:

Growth Strategy

During the Wolf Administration there has been significant expansion of waiver capacity, which has increased the number of individuals receiving HCBS by 20%. This growth has provided greater availability of HCBS in two primary ways. First, expanded waiver capacity becomes available to people on the waiting list. For example, in 2021, ODP will have newly enrolled 732 additional people into the Community Living Waiver because of the waiting list initiative funded through the state budget. The second way in which program growth provides additional availability is through *turnover*. Each year, people disenroll¹ 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 average wait time from 4.1 years to 2.3 years, over the last 5 years.” - Deputy Secretary Kristin Ahrens

¹ Typical reasons for disenrollment are: individual moves out of state, death, no longer needs services

High School Graduate Initiative

The “transition age” group represents the highest number of individuals on the waiting list [Figures 8 and 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 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.

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 3,515 individuals since 2018.

Expansion and Improvements in Supports Coordination and Needs Assessment

Since 2017, ODP has expanded the population eligible to receive HCBS in all ODP waivers to include people with autism (ASD) only [Figure 18]. Prior to 2017, only the Adult Autism Waiver served individuals with autism who did not also have a diagnosis of intellectual disability. Additionally, ODP expanded eligibility to Targeted Supports Management, known as “Supports Coordination,” to this population. 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.

WAITING LIST TRENDS

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

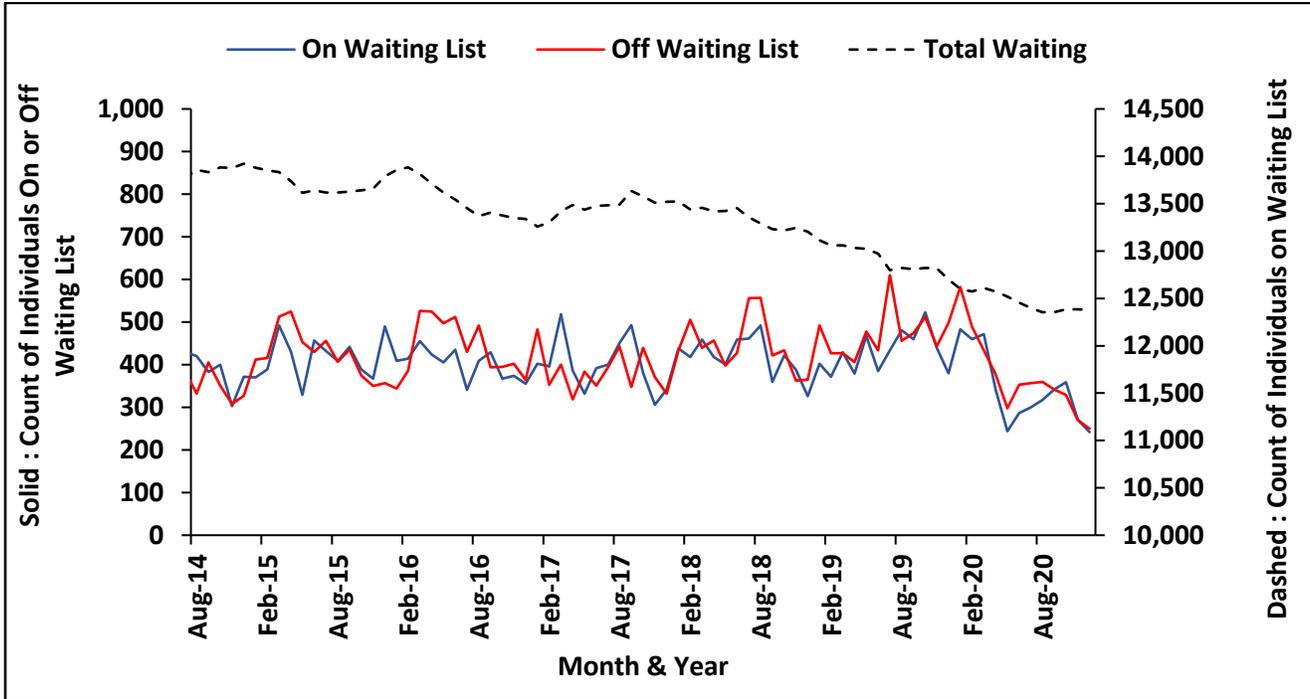


Figure 1: On & Off the Waiting List

Source: EDW HCSIS Consumer Demographics Snapshot Date: 12/31/2020

Average Years on Waiting List

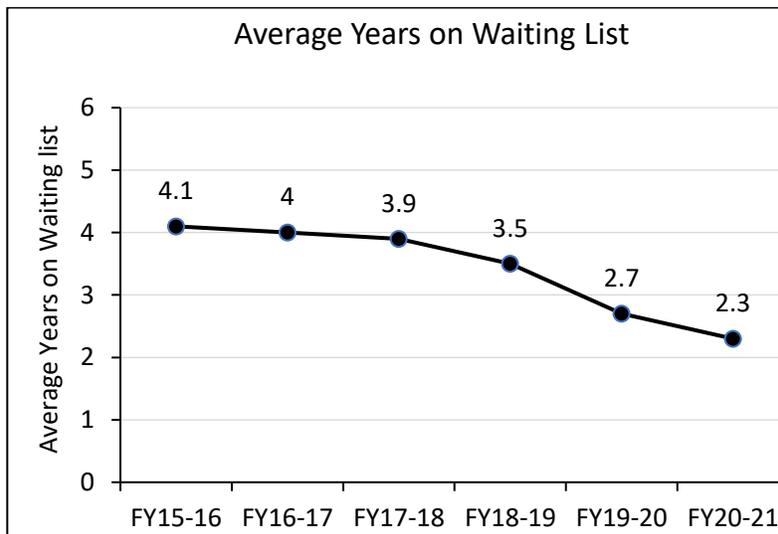


Figure 2: Average Years on Waiting List

Data Sources: EDW HCSIS Consumer Demographics Fact Data Extraction date: 09/22/2021

Individuals No Longer in Any ODP Waiver After Waiver End-Date

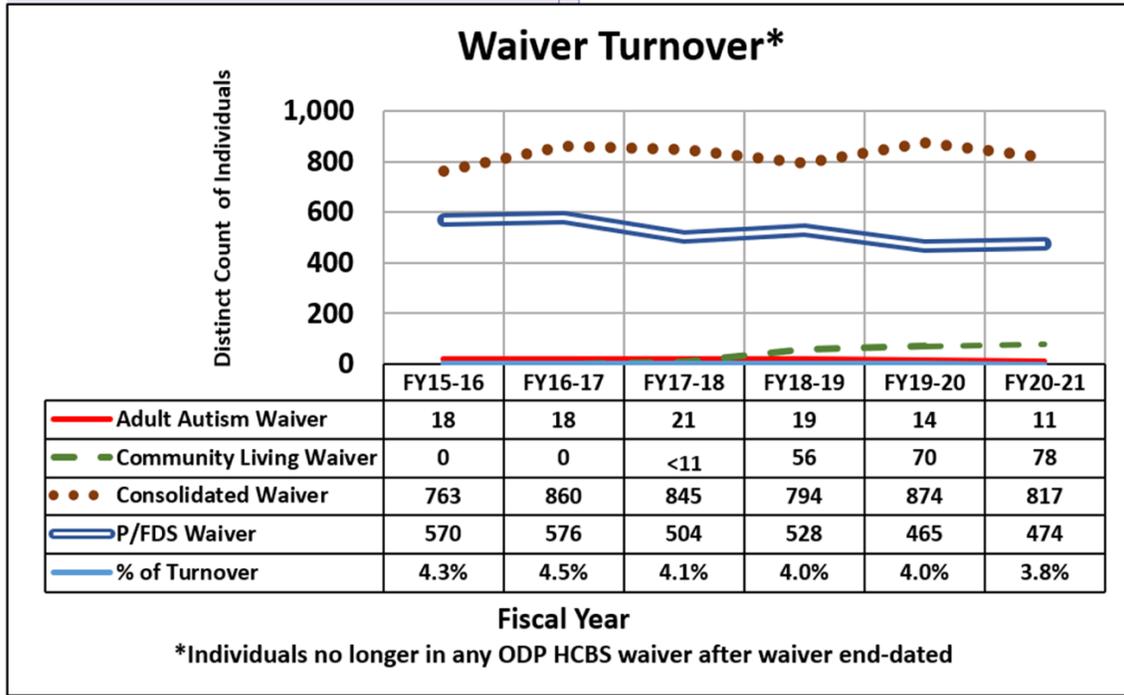


Figure 3: No Longer Receiving Waiver

Data Sources: EDW HCSIS Consumer Demographics Fact Data Extraction Date: 09/22/2021

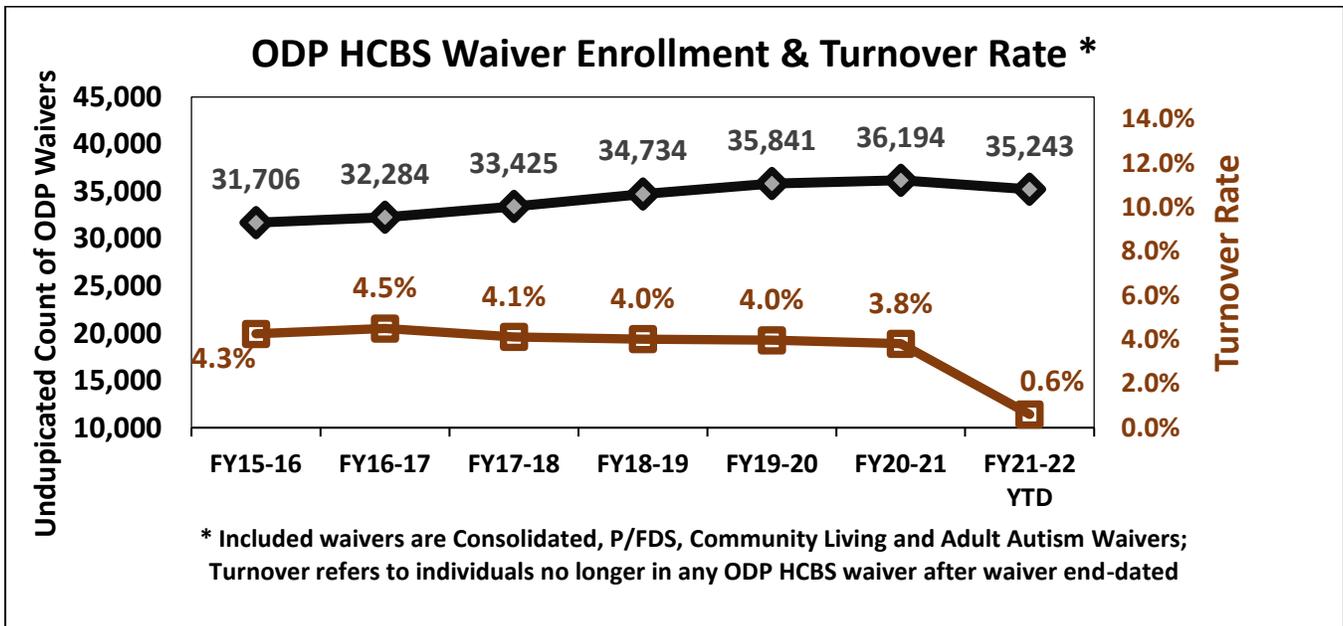


Figure 4: ODP HCBS Waiver Enrollment and Turnover Rate

Source: HCSIS/PUNS Monthly Facts Extraction Date: 09/22/2021

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

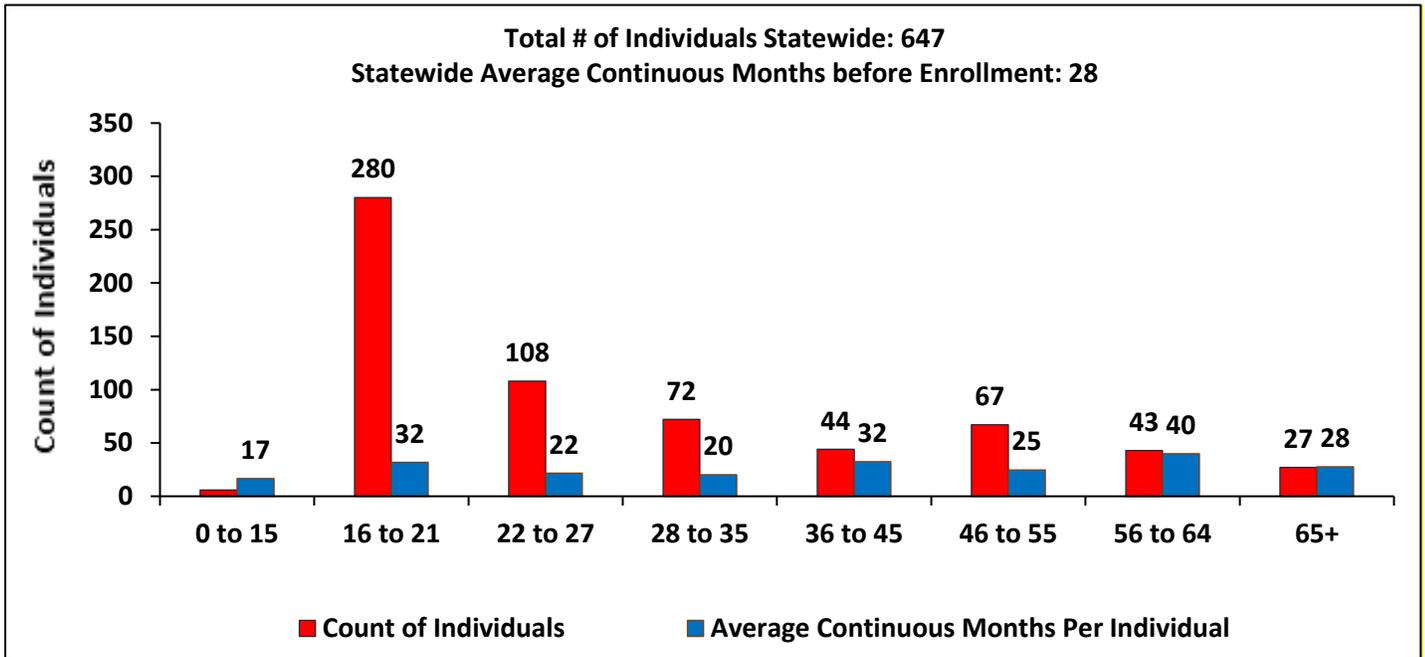


Figure 5: New Consolidated Waiver Enrollees by Age Group & Time (FY 19-20)
Source: HCSIS/PUNS Monthly Facts Extraction Date: 01/28/2021
Data for under 11 individuals was suppressed for privacy purposes

NEED CATEGORIES BY REGION, AGE & RACE

In the first two figures below, data from July 2014 to Dec 2020 shows a 10.1% 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

Category	July 2014	December 2020	Total Difference	% Change	% of Total
Emergency	4,170	5,140	+970	+23.3%	41.5%
Critical	5,906	4,654	-1,252	-21.2%	37.6%
Planning	3,691	2,583	-1,108	-30%	20.9%
TOTAL	13,767	12,377	-1,390	-10.1%	100%

Figure 6: Need Category 2014-2020
Source: HCSIS/PUNS Extraction Date: 12/31/2020

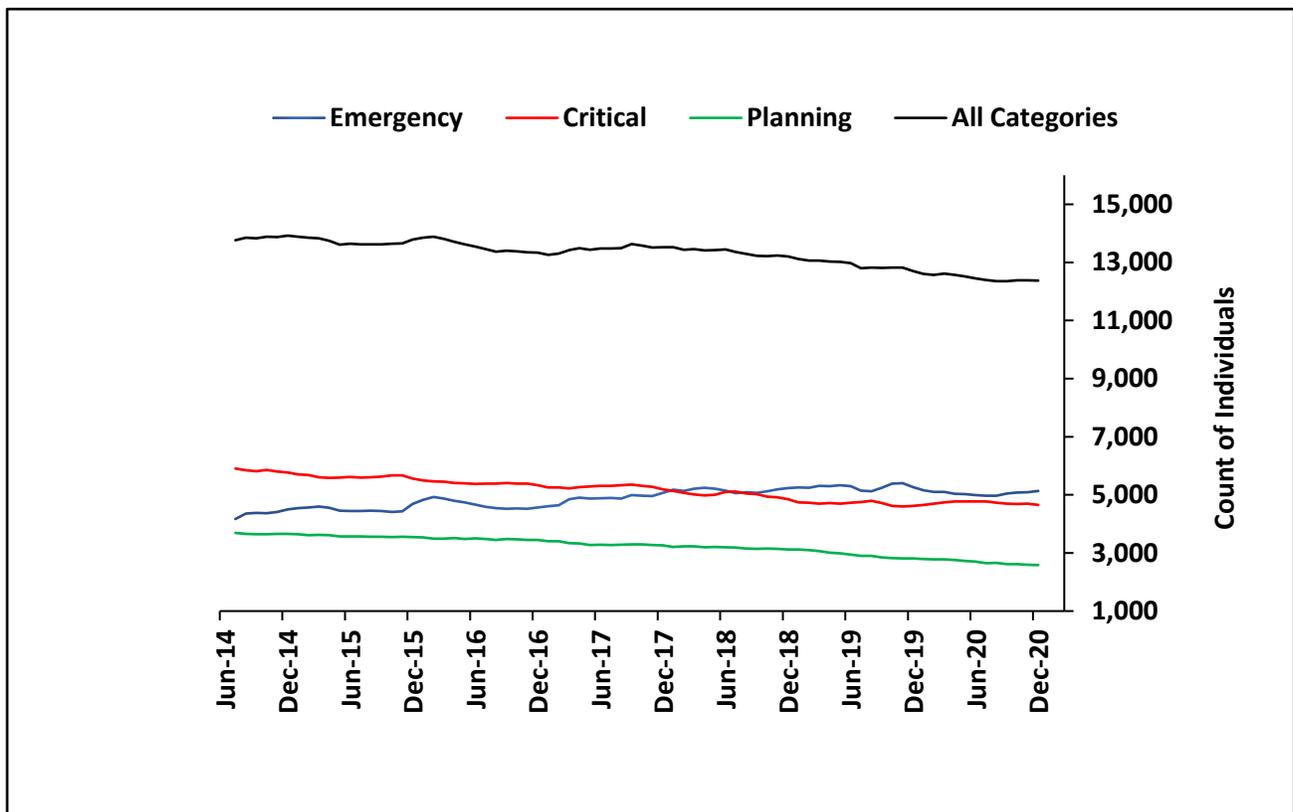


Figure 7: Need Category 2014-2020
Source: HCSIS/PUNS Snapshot Date: 12/31/2020

Individuals on Waiting List by Need Category & County/Joinder

COUNTY/JOINDER	EMERGENCY	CRITICAL	PLANNING	ALL PUNS CATEGORIES
Allegheny	402	380	221	1,003
Armstrong/Indiana	72	38	32	142
Beaver	45	91	44	180
Bedford/Somerset	40	40	28	108
Berks	276	92	96	464
Blair	75	58	28	161
Bradford/Sullivan	16	35	12	63
Bucks	112	182	206	500
Butler	68	57	48	173
Cambria	26	49	24	99
Cameron/Elk	11	25	<11	40
Carbon/Monroe/Pike	181	107	35	323
Centre	69	22	15	106
Chester	227	167	133	527
Clarion	<11	<11	<11	14
Clearfield/Jefferson	<11	24	15	46
Columbia/Montour/Snyder/Union	41	23	26	90
Crawford	48	40	24	112
Cumberland/Perry	99	98	77	274
Dauphin	71	95	43	209
Delaware	158	151	78	387
Erie	299	272	160	731
Fayette	18	38	26	82
Forest/Warren	<11	26	<11	37
Franklin/Fulton	62	64	13	139
Greene	<11	<11	0	11
Huntingdon/Mifflin/Juniata	23	30	17	70
Lackawanna/Susquehanna	94	121	43	258
Lancaster	221	93	68	382
Lawrence	47	48	30	125
Lebanon	87	53	31	171
Lehigh	185	105	74	364
Luzerne/Wyoming	228	92	43	363
Lycoming/Clinton	75	32	13	120
McKean	15	11	<11	34
Mercer	44	28	10	82
Montgomery	368	289	203	860
Northampton	88	103	65	256
Northumberland	31	49	19	99
Philadelphia	725	768	358	1,851
Potter	<11	<11	<11	<11
Schuylkill	98	54	41	193
Tioga	16	14	12	42
Venango	<11	<11	<11	19
Washington	102	94	25	221
Wayne	<11	25	10	<50
Westmoreland	62	276	58	396
York/Adams	170	182	49	401
Statewide:	5,140 (41.5%)	4,654 (37.6%)	2,583 (20.9%)	12,377

Figure 8: Need Category & County/Joinder
Source: HCSIS/PUNS Snapshot Date: 12/31/2020

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

In Figures 7 and 10 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 12/31/20, 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 (DOA) home and community-based programs, OLTL Community HealthChoices program (CHC), or Early and Periodic Screening, Diagnostic and Treatment (EPSDT) programs for age <=21. “Without” is defined as the remaining individuals with completed PUNS, not under the “With” category defined above.

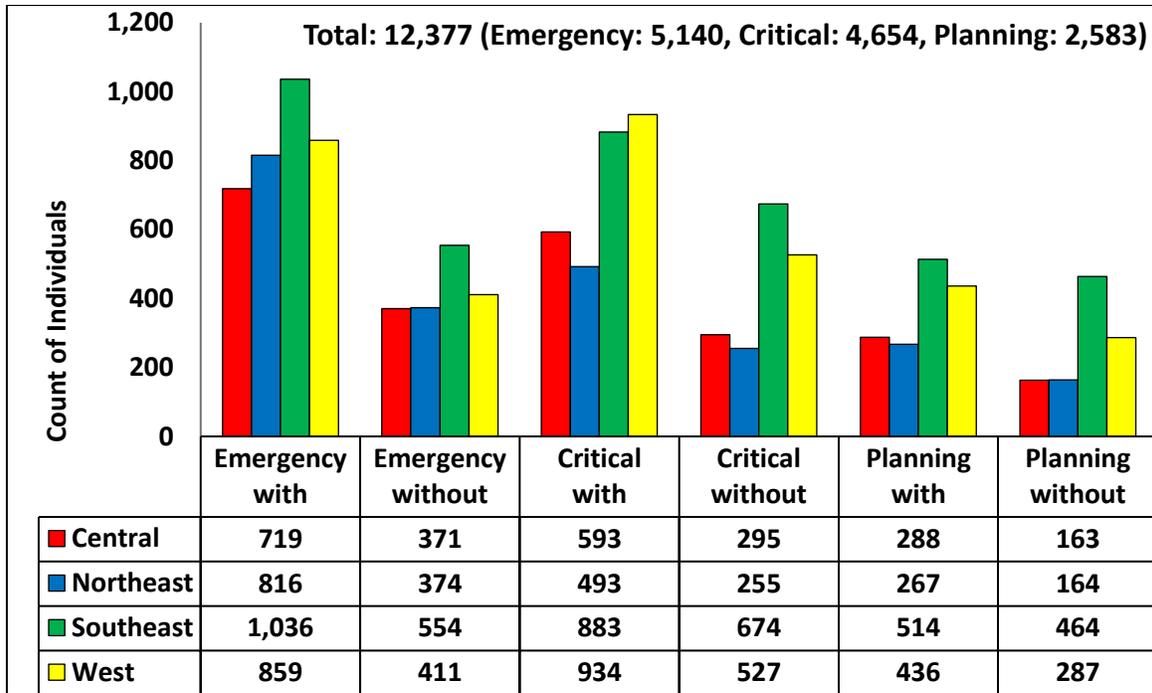


Figure 9: Need Category, Region & Served Status

Source: EDW HCSIS PUNS Fact, PROMISe Paid Claims and Capitation Table Snapshot Date: 12/31/2020

Individuals on Waiting List by Need Category & Age

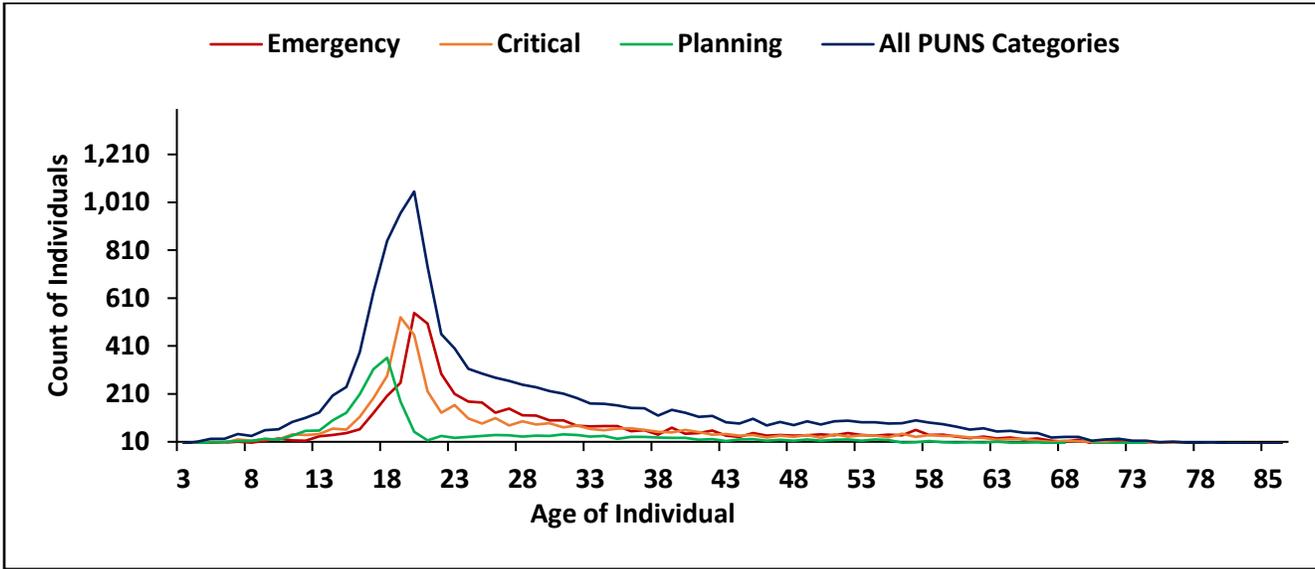


Figure 10: Need Category & Age
Source: HCSIS/PUNS Snapshot Date: 12/31/2020

Individuals on Waiting List by Need Category & Age Group

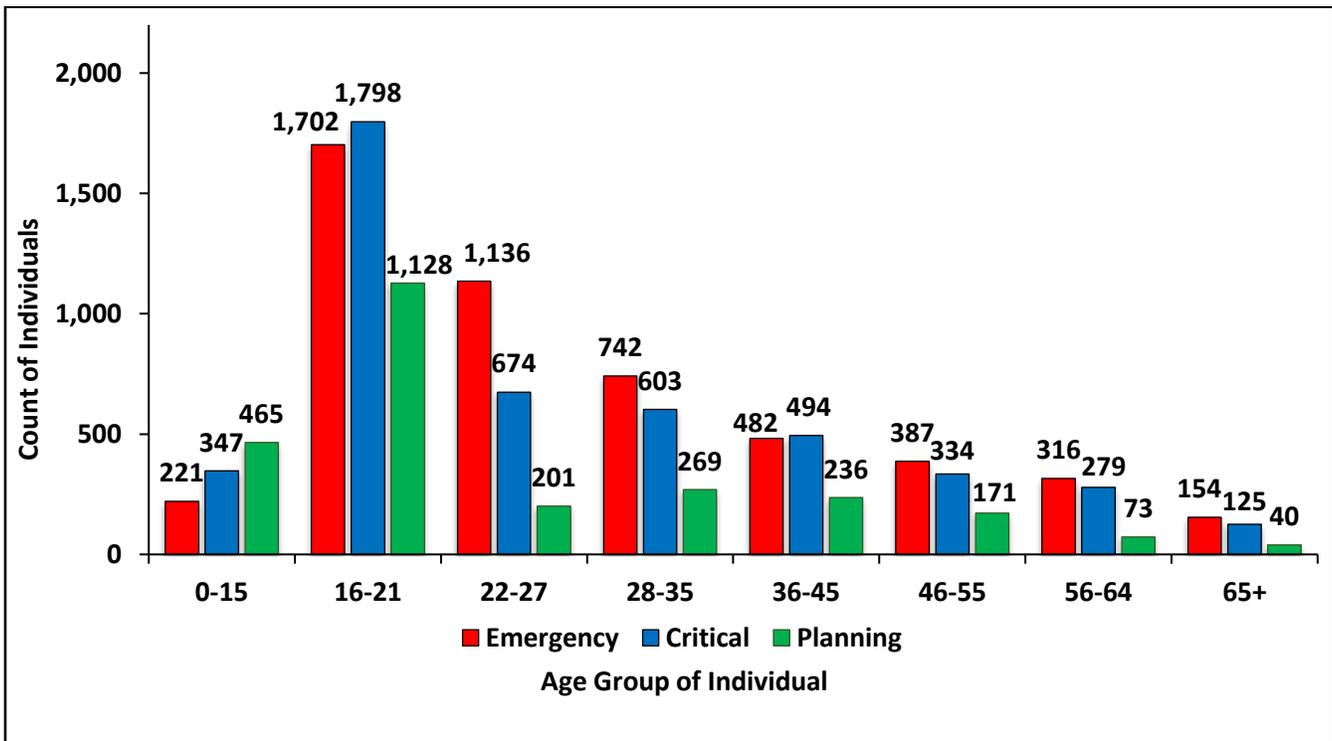


Figure 11: Need Category & Age Group
Source: HCSIS/PUNS Snapshot Date: 12/31/2020

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

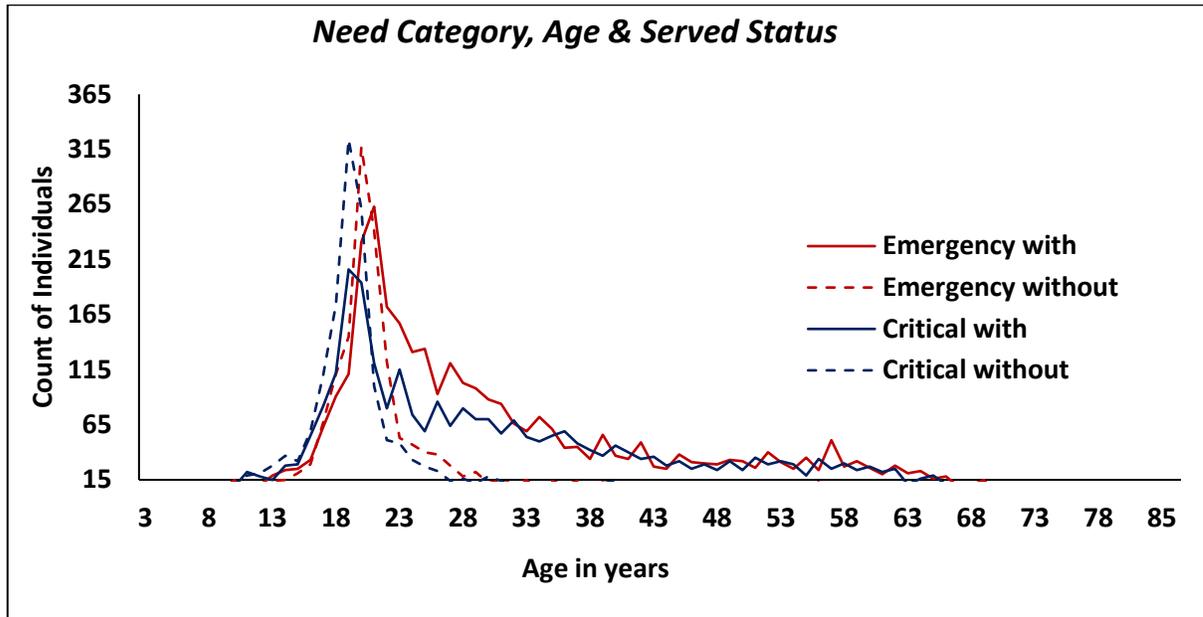


Figure 12: Need Category, Age & Served Status
 Source: HCSIS/PUNS Snapshot Date: 12/31/2020
 Data for under 15 individuals was excluded for privacy purposes

Individuals on Waiting List by Need Category & Race

The table below shows the status of waiting list needs categories by race. For comparison purposes, the total enrollment for the 4 ODP waivers as of 6/30/21 was 34,957 (Data Source: Tableau). The racial categories breakdown of those individuals was as follows: White, 26,805 (76.7%); Black or African American, 5,520 (15.7%); Asian, 432 (1.2%); American Indian or Alaskan Native, 37 (0.1%); and Native Hawaiian or Pacific Islander, 4 (0.01%).

Race Group	Emergency		Critical		Planning		All PUNS Categories
	#	%	#	%	#	%	
White	3,630	70.6%	3,358	72.2%	1,881	72.8%	8,869
Black or African American	960	18.7%	812	17.4%	359	13.9%	2,131
Other	395	7.7%	340	7.3%	237	9.2%	972
Asian	103	2%	100	2.1%	76	2.9%	279
Multiracial	29	0.6%	18	0.4%	11	0.4%	58
Unknown	16	0.3%	22	0.5%	12	0.5%	50
American Indian or Alaskan Native	<11	<1%	<11	<1%	<11	<1%	<16
Native Hawaiian/Other Pacific Islander	<11	<1%	<11	<1%	<11	<1%	<11
All Race Groups	5,140	100%	4,654	100%	2,583	100%	12,377

Figure 13: Need Category by Race
 Source: HCSIS/PUNS Snapshot Date: 12/31/2020

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.

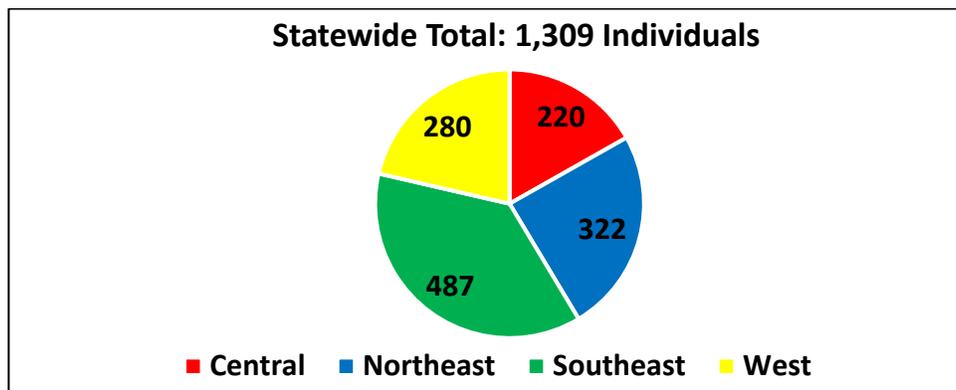


Figure 14: Individuals in Emergency PUNS Category, with a Single Caregiver
Source: HCSIS/PUNS Snapshot Date: 12/31/2020

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.

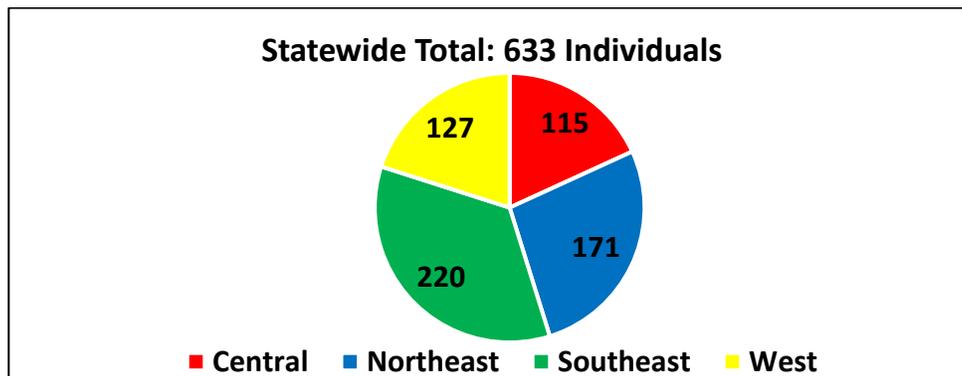


Figure 15: Individuals in Emergency PUNS Category, Living in Homes with 2 or More People Needing Support
Source: HCSIS/PUNS Snapshot Date: 11/30/2020

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.

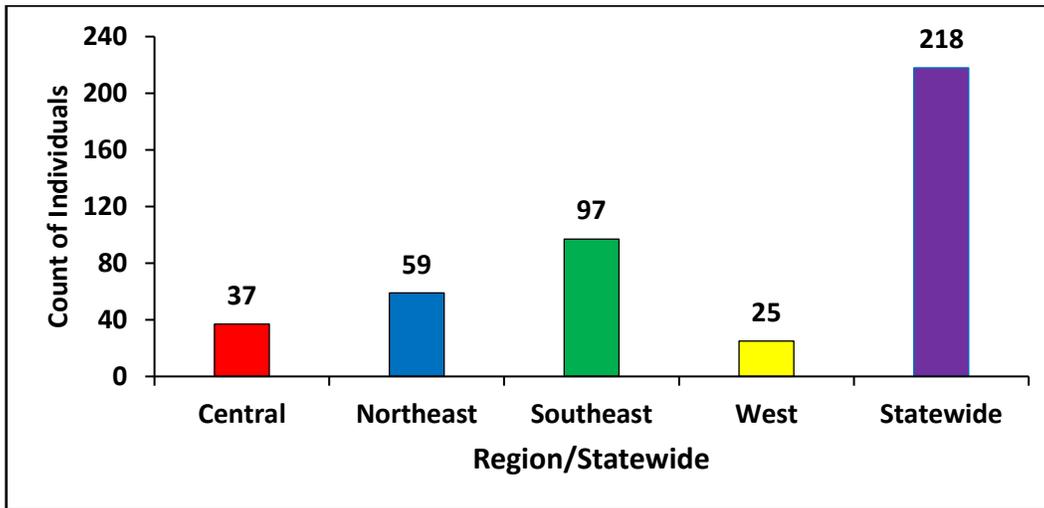


Figure 16: Individuals in Emergency PUNS Category, Living in Homes with a Single Caregiver & 2 or More People Needing Support
Source: HCSIS/PUNS Snapshot Date: 12/31/2020

CAREGIVERS OVER 60

The tables in this section show data for individuals on the waiting list with caregivers who are at or over 60 years of age. 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 Region & Need Category

Region/ State	Emergency		Critical		Planning		All Categories
	Count of Individuals	% in Region/ State	Count of Individuals	% in Region/ State	Count of Individuals	% in Region/ State	
Central	171	28.1%	300	49.3%	137	22.5%	608
Northeast	261	41.2%	263	41.5%	109	17.2%	633
Southeast	398	29.7%	607	45.4%	333	24.9%	1,338
West	151	18.4%	494	60.2%	176	21.4%	821
Statewide	981	28.9%	1,664	48.9%	755	22.2%	3,400

*Figure 17: Caregiver Age 60+, Region & Need Category
Source: HCSIS/PUNS Snapshot Date: 12/31/2020*

**Individuals with Caregivers Age 60+,
Newly Enrolled from PUNS into ID/A Waivers**

	FY 17-18			FY 18-19			FY19-20		
Individuals Newly Enrolled with Caregiver Age 60+	Emergency	Critical	Planning	Emergency	Critical	Planning	Emergency	Critical	Planning
	386	63	19	463	91	24	379	32	<11

*Figure 18: Single Caregiver Age 60+ & Newly Enrolled
Source: HCSIS/PUNS Snapshot Date: 12/31/2020*

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

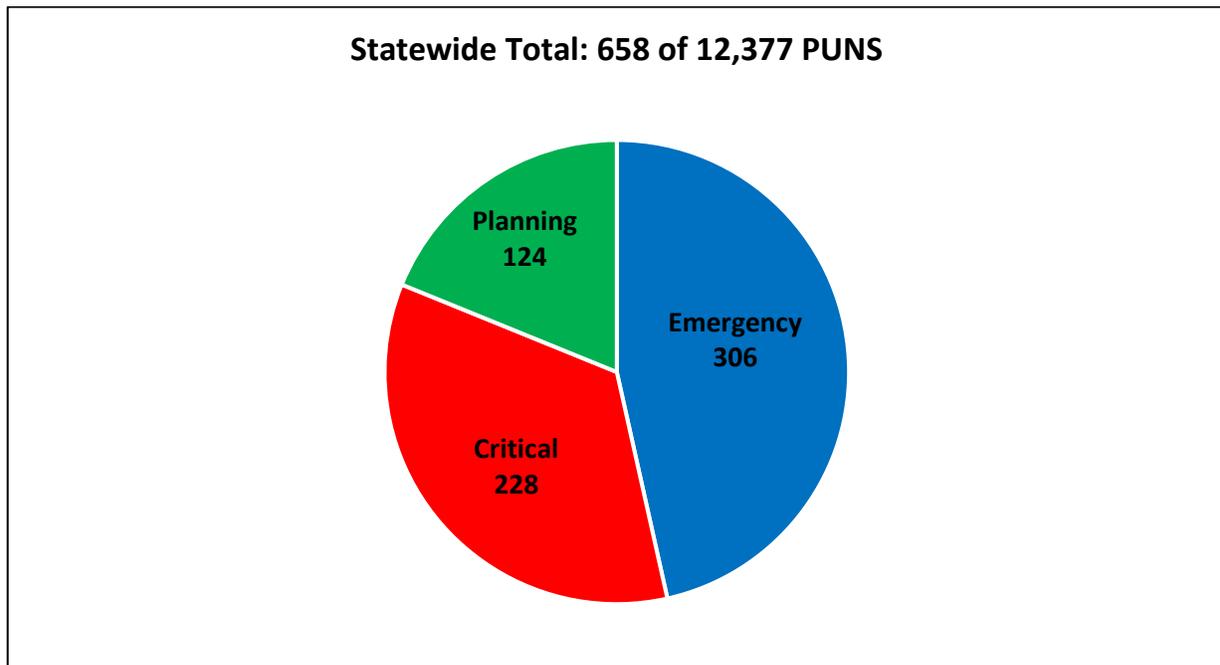
Region	Single Caregivers Age 60+ Supporting Multiple People
Central	11
Northeast	22
Southeast	45
West	<11

*Figure 19: Single Caregiver Age 60+ Supporting Multiple People
Source: HCSIS/PUNS Snapshot Date: 12/31/2020*

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 20: Autism Only & LOC Determination of ICF/ORC ASD
Source: HCSIS/PUNS Snapshot Date: 12/31/2020*

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, 473 of these individuals have had their eligibility determined by the county and were placed on the ODP waiting list. The remaining 1,491 people have not completed the steps required to determine their eligibility and have their names placed on the ODP waiting list, for the ID/A waivers.