

OASIS · AT A GLANCE

63 Months: The Average Wait for Autism Services

More than five years is the national average wait for an autism-specific Medicaid waiver, against 37 months for I/DD waivers. Autistic people wait longer than any other group being counted.

PILLAR: WHY | COMPANION TO BLOG POST B170 | 2-PAGE BRIEF

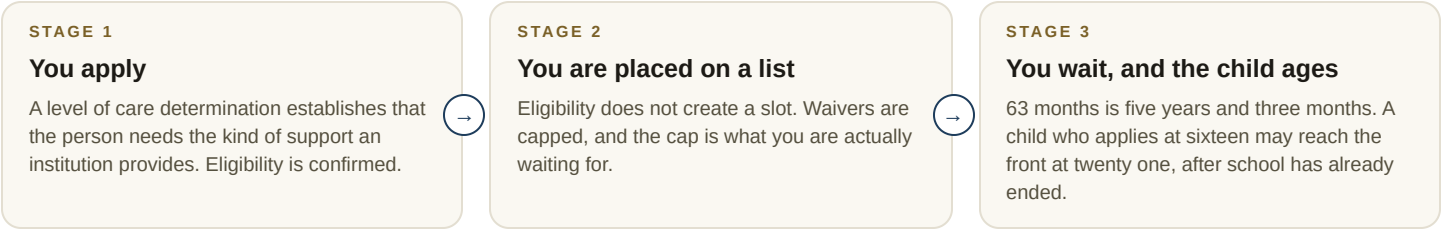
63

MONTHS, ON AVERAGE

The national wait for an autism-specific Medicaid waiver.

How eligibility becomes five years

QUALIFY, QUEUE, AGE



Average wait by waiver type

KFF, NOVEMBER 2025, ALL STATES BUT FLORIDA

Average months waiting, by population

From KFF's twenty third annual survey of Medicaid home care officials, fielded April to July 2025.

Autism waivers	63 months
I/DD waivers, unscreened states	49 months
I/DD waivers, all states	37 months
All populations	32 months
I/DD waivers, screening states	32 months

600,000

People waiting

On Medicaid HCBS waiting or interest lists in 2025, up 14% from 2024, across 41 states.

325,000

In six states

Six states do not screen for eligibility and account for more than half of everyone waiting.

74%

Have I/DD

Nearly three quarters of everyone on a waiver waiting list has an intellectual or developmental disability.

WHAT FIVE YEARS DOES TO A PLAN

“

We applied when he was sixteen because everyone told us to apply early. He turned twenty one and left school with nothing in place. The call came the following spring.

REPORTED BY A WASHTENAW COUNTY PARENT.

THE TAKEAWAY

Five years is not a wait. It is a period during which your family provides the care the state agreed your family member needs and does not fund.

TURN THE PAGE

How to find your placement date, invoke the right priority, and get services while you wait.

Working the list you are actually on

YOU CONTROL WHICH QUEUE, NOT ITS LENGTH

ESTABLISH

Get the three facts

☐ Confirm in writing that you are on a list

☐ Get the date you were placed on it, not the date you called

☐ Get your position, or a written statement that it is unknown

☐ Confirm which waiver the list is for

☐ Ask who recorded the placement and when

INVOKE

Name your priority group

☐ Private duty nursing need at age 21 or older

☐ Children's Waiver transition, at least 6 months ahead

☐ High risk of institutional placement

☐ Ask that the group be documented in the file

☐ Resubmit in writing whenever circumstances change

FILL

Do not wait empty

☐ Ask what Medicaid state plan services are available now

☐ Ask about Home Help

☐ Ask about CMHSP services outside the waiver

☐ Ask for the answer in writing

☐ A written no is appealable; a verbal no is nothing

APPEAL

If it is a denial, not a wait

☐ Get any ineligibility finding in writing

☐ File for a Medicaid fair hearing

☐ Attach your dated log of every call

☐ Attach the level of care determination

☐ Bring the hour by hour week you documented

BRING ONE PAGE, NOT A BINDER

The waiting list sheet

01

Date

When you applied, who recorded it, and the proof.

02

Level of care

Which determination was done and the result.

03

Priority

Which group applies, and the evidence for it.

04

Week

A typical week, hour by hour, kept for two weeks.

YOUR MOVE

When nobody can tell you where you stand

1

Ask in writing

Placement date, position, and priority group.

2

Invoke the priority

Name the group and ask that it be documented.

3

Update on change

High risk of institutional placement is a status, not a label.

4

Ask what exists now

State plan services, Home Help, CMHSP services.

5

Get the refusal

A system that cannot report its own queue is a finding.

None of this shortens a queue by itself. Together they determine which queue you are in, and that is the part you control.

SOURCES

KFF. A Look at Waiting Lists for Medicaid Home- and Community-Based Services from 2016 to 2025, published November 20, 2025. Twenty third annual survey of Medicaid home care officials, fielded April to July 2025, all states responding except Florida. Source of every wait time and population figure on this sheet.

Medicaid and CHIP Payment and Access Commission. State Management of Home and Community-Based Services Waiver Waiting Lists.

Michigan Department of Health and Human Services. Habilitation Supports Waiver, MI.0167, slot capacity and regional allotment.

Wayne State University Developmental Disabilities Institute. Habilitation Supports Waiver priority groups and application process.

ABOUT THE AUTHOR

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