

OASIS · AT A GLANCE

Only One State Has No Waiting List. Here's What It Costs.

Most of the states people name as having eliminated their waiting lists did not. California is the real answer, because the Lanterman Act makes services a legal entitlement, and Louisiana offers the mechanism a capped state could actually copy.

PILLAR: WHERE | COMPANION TO BLOG POST B168 | 2-PAGE BRIEF

1

STATE, ONE MECHANISM

California is the only state providing an entitlement to services.

Why lists form, and the two ways they end

CAP, ENTITLE, OR SORT

STAGE 1

A state caps the program

Waivers are optional and capped. When demand exceeds the cap, a list forms. This is the default nearly everywhere.

→

STAGE 2

Or a state creates an entitlement

California's Lanterman Act makes services a statutory right. An entitlement cannot form a list, because eligibility itself creates the obligation.

→

STAGE 3

Or a state re-sorts the list

Louisiana replaced first-come-first-served with a five tier urgency assessment, which does not require an entitlement.

What each state actually did

CHECKED AGAINST PRIMARY SOURCES

States named as having eliminated waiting lists

Every claim below was checked against a state agency source or contemporaneous reporting.

STATE	HAS A LIST?	WHAT ACTUALLY HAPPENED
California	No	Lanterman Act entitlement, roughly 450,000 served
Louisiana	No	List retired in 2019 via urgency tiers, 12,000 screened
Connecticut	Yes	961 waiting in 2013, 928 in 2023
New Jersey	Yes	Community Care Program list, worked chronologically
Illinois	Yes	Opened a new I/DD list in 2025
Michigan	Capped	Habilitation Supports Waiver held to 7,481 slots

600,000

Still waiting nationally

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

\$19 billion

California's price

Proposed developmental services budget for 2025-26, including \$12.4 billion General Fund.

74%

Have I/DD

Of everyone on a waiver waiting list. This is a disability problem inside a long term care program.

WHAT AN ENTITLEMENT SOUNDS LIKE

“

California is the only state in the country that provides entitlement to services and supports for all residents of the State, after other sources of services and supports have been exhausted.

CALIFORNIA DEPARTMENT OF DEVELOPMENTAL SERVICES.

THE TAKEAWAY

An entitlement is expensive and a waiting list is expensive. The difference is that only one of those costs shows up in a budget document.

TURN THE PAGE

The three asks, ranked by what a capped state could actually pass, starting with urgency tiering.

Arguing this in your own state

SLOTS SHORTEN. ENTITLEMENT ENDS.

ESTABLISH

Get the local facts first

☐ Ask your CMHSP in writing whether your region holds a list

☐ Ask how many people are on it

☐ Ask how long the average wait has been

☐ Ask what priority groups exist

☐ Get every answer in writing, or the refusal in writing

COMPARE

Get the cost figures

☐ What the state pays per person for institutional placement

☐ What it pays for the waiver services avoiding it

☐ Request both in writing from the Medicaid agency

☐ Ask for a legislative fiscal analysis of both options

☐ Getting the question scored is itself a win

ASK FIRST

Urgency tiering, the winnable one

☐ Louisiana's model is built and documented

☐ It does not require an entitlement

☐ Five tiers, from emergent within 90 days to no unmet need

☐ It puts families in crisis at the front

☐ It replaces registration date with actual need

ASK NEXT

Transparency and entitlement

☐ Ask the state to publish waiting counts by region

☐ Ask how long people have waited, in months

☐ Ask whether any bill would create an entitlement

☐ Expect no, and ask anyway

☐ The question forces the distinction into the open

BRING ONE PAGE, NOT A BINDER

The waiting list sheet

01

Local

Whether your region holds a list, and how long it is.

02

National

600,000 waiting, 41 states, 74% with I/DD.

03

Autism

63 months average, against 37 for I/DD waivers.

04

Ask

Urgency tiering first, transparency second, entitlement third.

YOUR MOVE

When you are told the list cannot be fixed

1

Separate the reforms

Slots shorten a list. Entitlement removes the mechanism.

2

Name Louisiana

Urgency tiers, five levels, already documented.

3

Name California

And include the price, honestly, before you are asked.

4

Demand the numbers

A queue nobody publishes cannot be argued about.

5

Ask for a score

A fiscal analysis of both options is a real win.

Advocates who hide the cost of an entitlement lose the second meeting. Bring the \$19 billion figure yourself.

SOURCES

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KFF. A Look at Waiting Lists for Medicaid Home- and Community-Based Services from 2016 to 2025, published November 20, 2025.

CT Mirror, June 11, 2023, on Connecticut Department of Developmental Services waiting list figures; New Jersey Division of Developmental Disabilities, Community Care Program waiting list page.

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