

OASIS · AT A GLANCE

When waiting lists act like policy tools

A waiting list is not a queue that eventually empties. On an HCBS waiver, it is a rationing mechanism, sized by legislative appropriation, that will never clear on its own because clearing it was never the design. Individual pleading rarely moves it. Collective advocacy sometimes does.

BY JIM PALASTY · 13 MIN READ · SCARCITY AS POLICY CHOICE

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DOORS SCARCITY CAN'T LOCK

Public comment. Agency boards. Media-safe storytelling. None of them require you to out-lobby a budget line alone.

How it works

THREE STEPS

STEP 1

Public comment



STEP 2

Agency boards



STEP 3

Media-safe storytelling

Collective advocacy calendar

Public comment	Tied to waiver renewal cycles, roughly every 5 years, plus annual budget hearings.
DD council meetings	Usually monthly, open to the public, public comment on the agenda.
CMH board meetings	Usually monthly, local, most attended by zero families most months.
Legislative budget hearings	Annual, tied to the state fiscal calendar, written testimony accepted.
Media pitch	Ongoing, strongest tied to a hearing date or a new data release.

A STORY WE KNOW

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Yolanda had waited three years for a waiver slot and spent most of that time calling her caseworker alone, getting nowhere. A parent support group connected her with eleven other families on the same list in her county. Together they split up the county's public comment periods, its DD council meetings, and its CMH board agenda, so that every single month, at least one parent gave three minutes of testimony citing the same growing number. Six months in, a local reporter covering a budget story called Yolanda after seeing her name on three separate meeting minutes. The story ran. The county board voted to recommend two additional slots in the next budget cycle. Not everyone got in. But the number moved, and it moved because twelve families showed up instead of one.

SCARCITY SURVIVES ISOLATION. IT STRUGGLES AGAINST A ROOM FULL OF MATCHING TESTIMONY.

What matters, at a glance

Why lists exist

HCBS waivers are not a Medicaid entitlement. States can cap enrollment. The waiting list is the visible edge of that cap, not a processing delay.

Enrollment caps

The number of funded waiver slots is set by state appropriation and approved by CMS. More applicants than slots means a list, by design, every year.

"Right to apply" isn't a right to receive

State plan Medicaid services are an entitlement. HCBS waiver services are not. That legal distinction is why the list can legally never clear.

Public comment periods

Waiver renewals and state budgets require public comment windows by law. Most go nearly unused. That is your opening.

Standard testimony window

Most CMH boards and DD councils give public commenters about three minutes. Write it, time it, and show up every month, not just once.

Media-safe storytelling

Share the wait time, the cost, and the policy, not your family member's private medical details. Reporters need the pattern, not the diagnosis.

BRING THESE · CHECK AS YOU GO

- | | |
|--|---|
| ☐ A three-minute testimony script, timed and rehearsed | ☐ A shared fact sheet with your county's wait time and list size |
| ☐ A list of every family willing to testify or submit comment | ☐ A calendar of every board meeting and comment deadline this year |
| ☐ One media-safe family story, cleared with the family in advance | ☐ A local reporter's contact information, saved before you need it |

YOUR MOVE

When you are tired of waiting alone, here is how you build the collective case

- 1 Find your county's DD council and CMH board meeting schedules.
- 2 Find the next public comment period on your state's waiver or budget.
- 3 Ask your parent support group who else is on the waiting list.
- 4 Split the meetings and comment windows across the group by month.
- 5 Draft one shared, media-safe fact sheet everyone can cite consistently.
- 6 Pitch a local reporter once you have three or more months of documented testimony.

The list was never going to clear itself. It was built to be argued with, out loud, in a room.

RESOURCES NAMED IN THIS POST

kff.org · <https://www.kff.org/>
 regulations.gov · <https://www.regulations.gov/>
 respectability.org · <https://www.respectability.org/>
 ancor.org · <https://www.ancor.org/>

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ABOUT THE AUTHOR



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