

OASIS · AT A GLANCE

Understanding Long Waitlists and What to Do While You Wait

The HCBS waiver waitlist is rationing dressed in administrative language. The wait is real, the wait is long, and the wait is also productive territory if the family uses it deliberately. Four tactics that compound over the years on the list.

BY JIM PALASTY · OASIS FOR AUTISM · 9 MIN READ

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TACTICS THAT COMPOUND

Apply to every program. Document the risk. Request interim supports. Build community-based routines now. Years on the list pay you back on the day the call comes.

How it works

THREE STEPS

Multiple programs, day one

Every waiver in the state. Every Medicaid program. Every adjacent service. Time on the list is the only seniority.



Build the risk file

Caregiver age. Health incidents. Behavioral escalations. Housing instability. Documentation is what moves priority.



Interim supports + routines

State plan Medicaid services, school transition, ABA, vocational rehab, private respite. Build the routine the waiver will eventually fund.

Where to apply and what to track

HCBS waivers	State Medicaid agency, every waiver that fits an adult with autism
State Medicaid	State plan benefits, separate from waiver enrollment
DD council list	Some states maintain a separate interest list at the DD council
Arc / CIL	Local Arc affiliate and Center for Independent Living service lists
Vocational Rehab	State VR agency, employment services without the waiver
School transition	IDEA Part B services through age 22 in most states
Risk log	Caregiver age, health events, behavioral, housing changes

WHAT IT LOOKS LIKE

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We put our daughter on every list we could find when she was twelve. By the time she was twenty-two, we had been waiting for ten years. Her name came up two months after my husband's first heart attack. The case manager said the heart-attack documentation, filed the week it happened, was what moved the file. We had been keeping the log for years because somebody at the Arc told us to. We did not know it would matter until it did.

LINDA, MARQUETTE

What matters, at a glance

The list is rationing

Federal law lets states cap waiver slots. KFF surveys consistently document hundreds of thousands of people on HCBS waiver waitlists nationally, with wait times measured in years for many states. The cap is policy, not nature.

Apply to every list

Most states operate more than one waiver. Most have multiple Medicaid pathways. The Arc maintains an interest list. The CIL maintains an interest list. Apply to all of them.

Risk documentation

States that prioritize by risk move people up when need increases. A documented health incident, caregiver hospitalization, or behavioral escalation moves the file. Keep the log current.

Typical wait

Median IDD waiver waits run several years in most states, with some over a decade. Some states under one year. The variance is policy, not population.

Interim supports exist

State plan Medicaid covers some services without the waiver. Vocational rehab funds work-related services. School transition services run until 22. ABA insurance benefits cover therapy. None of these require the waiver.

Build the routine now

The day program, social schedule, transportation rhythm, and DSP rotation that the waiver will eventually fund can mostly be assembled in advance with family, community, and small private spend. Build it. The waiver fills in.

BRING THESE · CHECK AS YOU GO

- | | |
|---|--|
| ☐ HCBS waiver applications submitted (every available) | ☐ State Medicaid plan benefits enrolled |
| ☐ Arc / CIL interest list confirmed | ☐ Vocational Rehab open case |
| ☐ Risk-documentation log started | ☐ Interim service routine in place |
| ☐ Six-month list re-check on calendar | |

YOUR MOVE

Working the list

- 1 Apply to every state waiver, state Medicaid pathway, and adjacent interest list this month.
- 2 Start the risk-documentation log. Caregiver age, health incidents, behavioral escalations, housing instability.
- 3 File state-plan Medicaid service requests for what does not require the waiver.
- 4 Enroll in Vocational Rehab, school transition, and any insurance-funded ABA available.
- 5 Recheck waitlist status in writing every six months. Update risk documentation at each check.

The wait is policy, not destiny. The years on the list are billable hours toward the day the call comes.

RESOURCES NAMED IN THIS POST

oasisforautism.com · <https://oasisforautism.com>

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ABOUT THE AUTHOR



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