

W A I T N O M O R E

A DETAILED STRATEGY TO EXPAND SERVICES & REDUCE YOUR STATE'S WAITING LIST

Since the 2006 Case for Inclusion, the number of Americans served by Home and Community-Based Services (HCBS) waivers has increased by 79 percent, from 433,000 in 2005 to 775,000 today.

Yet the need for services is still greater, demonstrated by the fact that the number of people on the HCBS waiting list has tripled

in that same time period—from 138,000 in 2005 to 424,000 today. States like Alaska are showing how investments in DSPs are directly related to expanding community capacity to meet the needs of the people on the waiting list. The section that follows shares lessons from Alaska that can be insightful for advocates in other states.

» THE CHALLENGE

Waiting lists are one indicator of how effectively a state is connecting people with quality, inclusive HCBS services. In the past decade, states' progress in moving people off HCBS waiting lists has varied wildly.

According to data from the Kaiser Family Foundation, from 2005 to 2016, six states (Alaska, Indiana, Montana, Oklahoma, Pennsylvania and Wisconsin) saw a significant decline in the number of individuals on their waiting lists. Another 13 states (Arizona, California, Delaware, Hawaii, Iowa, Idaho, Massachusetts, Michigan, North Dakota, New Hampshire, New York, Oregon and South Dakota) and the District of Columbia reported having no waiting list or only a small waiting list in 2016. But on the other end of the spectrum, 31 states have significant waiting lists, suggesting that most of the country has much room for improvement.

Regardless of the size of a state's waiting list, waiting indefinitely for critical services is an intensely frustrating experience for individuals with intellectual and developmental disabilities (I/DD) and their families. Meanwhile, battles for additional funding to reduce waiting lists are a common feature of states' legislative sessions, leaving advocates to constantly fight the same fights with victories few and far between.

» INSIGHTS FROM THE FIELD

Despite these frustrations, a handful of states are making leeway in terms of how waiting lists are publicly maintained and what information is made available.

This matters because information and personalization of the waiting list empowers advocates to successfully make the case for funding and for policymakers to know the waiting list is real, current, and urgent.

Alaska is a good example of this approach. **By cutting its waiting list in half over the past decade, Alaska has doubled the number of people served via HCBS waivers.**

In part, Alaska's success can be attributed to its laws governing data collection and reporting about individuals on the state's HCBS waiting list.

The Alaska statute covering I/DD services explicitly dictates seven sets of data on those waiting for HCBS services that must be reported each year:

- Purpose of waiting list (including individual's rights)
- Process, ranking criteria and management of waiting list
- Basic demographic information, such as age, sex, and racial and ethnic background by region
- Level of need and services and supports required
- Individuals removed from the waiting list during the past year by number, along with reason for removal and length of wait
- Number of individuals waiting more than 90 days
- Number of people with I/DD graduating from, dropping out of and/or turning 22 years old without graduating from K-12 education

The Alaska waiting list, which is now called the Registry, is a strong example of how transparency in data reporting can yield significant results. Alaska's 2017 report on these data reveals a series of improved outcomes from stronger and more transparent reporting practices:

- » The number of people on the waiting list dropped 37 percent—from 1,006 in 2006 to 629 in 2017.
- » The number of individuals under 22 years old on the waiting list dropped 50 percent, from 818 in 2006 to 409 in 2017.
- » Nearly two-thirds (65 percent) of those on the waiting list are under 22.
- » The average wait time for someone on the waiting list is less than 30 months (compared to 38 months in 2006).
- » 41 percent of those on the waiting list in 2017 were already receiving at least some level of state-funded supports.
- » In 2017, 183 people (29 percent of all those waiting) moved off the waiting list, including 45 who were moved off the waiting list because they received services.

» HOW OTHER STATES CAN FOLLOW ALASKA'S LEAD

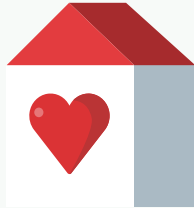
Alaska proves that states can improve outcomes related to their HCBS waiting lists, even without spending their limited financial resources. Advocates should consider Alaska's waiting list transparency laws as a promising option as they seek alternatives to perennial fights with state legislatures over funding hikes. Sample legislation modeled off Alaska's success is provided at the end of this section for advocates considering such an approach in their own states.

Public policy change is always accomplished by a small but vocal group of tireless advocates. By borrowing plays from Alaska's playbook and adapting some of the strategies above in your own state, you have an opportunity to advance major change in your state through a series of manageable, meaningful and moveable strategic steps.



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There are several complimentary public policy approaches to reducing waiting lists that advocates can use. Below are six strategies for advocates to consider.



Partner with the state developmental disabilities department on a de-institutionalization initiative and use fiscal savings created by the closure of institutions to reduce the waiting lists.



Build long-term relationships with legislators in both chambers and from both parties to champion and publicize a multi-year campaign to reduce waiting lists. Indeed, many policymakers are looking for a cause, and such a campaign would represent a noble, non-partisan cause that could serve your purposes and theirs.

Pass a law—either on its own or through your state's budget appropriations process—requiring that any surplus funds or balance lapses in the developmental disabilities department at the end of the fiscal year be automatically redirected to waiting list reductions in the subsequent year.



Host a "Wait No More" Day at the legislature or during off-session legislative visits with waiting list families to personify those waiting for services.



Share your successful strategies and tactics with the ANCOR Foundation and UCP so that we can partner with your counterparts in other states to replicate your success.



Celebrate small victories and incremental progress. Rarely in policymaking does big change happen quickly; it is often the sum of several incremental steps, often taken over the course of many years, that together amount to monumental and transformative change.

An Act to Create a Transparent Waiting List for Those with Intellectual and Developmental Disabilities in Need

[To amend State statute delineating the duties of the Department serving those with intellectual and developmental disabilities]

When State funding is not adequate to meet service needs, the department shall establish a waiting list, to be called the registry, for persons with developmental disabilities who would be eligible to receive State-funded services under [reference relevant statute] if adequate State funding were available. The department shall, on an annual basis, review the waiting list and submit a report to the governor containing the information required under this subsection. The department shall send a copy of the report to the persons chairing the House and Senate finance committees and the persons chairing the House and Senate health, education and social services committees and shall notify the full legislature that the report is available to all legislators.

The report must:

1. Describe the purpose for the waiting list and the strategies used to notify persons about the waiting list and must include a copy of the information used by the department to inform individuals and families about their rights and responsibilities under [relevant section of State law].
2. Explain how an individual is placed on the waiting list, what criteria determine rank on the list, with at least quarterly updates to such assessments, and how the waiting list is used to select individuals equitably and fairly across the State.
3. Give the basic demographic information across all regions about the age (under 22 years old, from 23 to 39 years old, from 40 to 59 years old and more than 59 years old), gender, and racial and ethnic background of the individuals on the waiting list.
4. Identify the level of need and preferences of the individuals and families on the waiting list for the services and the supports that may be necessary to meet their needs and project an annual cost to meet this need and show these costs by age and length of time the individual has remained on the waiting list.
5. Identify how many individuals were removed from the waiting list during the 12 months covered by the report, why they were removed from the list, and how long the individuals had been waiting for services or supports before they were removed from the list, shown by age.
6. List the number of individuals who have been on the waiting list for 6 months, 12 months, 24 months, 36 months, 48 months, or more by age and with an account of the department's steps to regularly review each individual's status while waiting for services or supports.
7. Report annual data from the [education department] about the number of students in special education with developmental disabilities graduating from high school, dropping out of high school before reaching age 22, or reaching age 22 without graduating from high school.