IT’S TIME TO END THE WAIT

2020 LEGISLATION TO END THE DD WAIT LIST & BUILD COMMUNITY CAPACITY

JOSH RAEL, EXECUTIVE DIRECTOR
ELLEN JENSBY, SENIOR DIRECTOR OF PUBLIC POLICY & OPERATIONS
Alliance Membership is comprised of:

- Over 70 Program Approved Service Agencies (PASAs)
- 17 Community Centered Boards (CCBs)

Alliance members:

- Serve over 10,000 individuals with IDD
- Serve ~80% of people on DD Waiver
SYSTEM BACKGROUND: RECENT SUCCESSES
Medicaid HCBS waiver programs

- Support the person to live in their own home and community instead of an institution
- Assistance with daily activities like eating, bathing, taking medications, finding a job, taking care of the home, and more.
- Not an entitlement = waiting lists allowed
- Funding:
  - 50% state funds
  - 50% federal funds
WAIT LIST BACKGROUND: ADULT IDD WAIVERS

**Supported Living Services Waiver**
- Intermittent supports to supplement natural/unpaid supports
- Person is responsible for his/her own living arrangements
- Avg. annual cost per-person: $14,257
- No waiting list

**Developmental Disabilities Waiver**
- “Comprehensive” - access to 24-hour supervision and support
- Provider supports person to find living arrangement: residential habilitation
- Avg. annual cost per person: $72,808
- 3,000 people on the waiting list
WAIT LIST BACKGROUND: HOW THE LIST WORKS

Two ways to access enrollment:

**Reserve Capacity**
- Emergencies, including new caregiver emergency criteria
- People transitioning from children’s waivers
- Deinstitutionalization from nursing facilities, ICF/IID, and State Mental Health Institutes
- HCPF predicts how many needed annually and requests funding

**Order of Selection**
- “First-come-first served”
- Offered enrollment in order of date added to the list (for As Soon As Available)
- Enroll when:
  - New enrollments are allocated by the General Assembly, or
  - Enrollments are vacated (death, ineligibility)
WAIT LIST BACKGROUND: HOW THE LIST WORKS

Two categories of people waiting:

<table>
<thead>
<tr>
<th>As Soon As Available (ASAA)</th>
<th>Safety Net</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Have indicated that they would like to be offered enrollment as soon as it is available, suggesting they would enroll when offered the chance</td>
<td>• Want to be on the waiting list, but don’t need to enroll immediately. May need to enroll at some time in the future, when existing supports are no longer enough.</td>
</tr>
<tr>
<td>• However, declination rate: ~26%</td>
<td>• Can switch to ASAA at any time</td>
</tr>
<tr>
<td>• About 3,000 people</td>
<td>• About 3,000 additional people</td>
</tr>
</tbody>
</table>
Of Colorado’s 10 waiver programs, the DD waiver is the *only* one with a waiting list

Longstanding priority for disability community & General Assembly

HB 14-1051 called for a strategic plan to end the waiting list by 2020

- HCPF presents annually with cost to eliminate (~$200 million)

The General Assembly has allocated $ for new enrollments in recent years:

- In 2018 via HB 1407: 300 + 150 reserve capacity for caregiver concerns
- In 2019 via long bill: 150

**But, no long-term, affordable, multi-year plan currently exists**
WAIT LIST BACKGROUND: KEY TAKE-AWAYS

1. 3,000 people on the ASAA list
2. People wait years, decades for DD services
3. No affordable, multi-year plan to eliminate the list

And:

If we are going to eliminate the waiting list, we must ensure community capacity to serve new and existing enrollees.
Waiver services provided by private service agencies
Paid on a fee-for-service basis
Reimbursement rates set by state, non-negotiable
Compete with minimum wage employers - McDonald’s, King Soopers - who can raise prices, pay more
Unlike other Medicaid providers, IDD providers rely on Medicaid reimbursements for 90-98% of their revenues, because:
  - Medicaid is the only payor for the vast majority of IDD supports
  - Very few people with IDD can afford to private-pay
  - Providers cannot access other payment streams, like private insurance, or charge customers for their services
COMMUNITY CAPACITY: THE PROBLEM

A FINANCIAL PERFECT STORM:

- **Stagnant** Medicaid reimbursement rates +
- **Rising** inflation & minimum wage +
- **Low** unemployment +
- **Increased** regulatory burden +
- **Costly** changes to service delivery models

= 

- **Reduced** purchasing power for providers,
- **Low** pay & **high** turnover for DSPs,
- **Reduced** continuity of support & service options,
- **Lack** of system sustainability & efficiency, and
- **Reduced** access to services & choice of provider
Recent rate investments have been helpful, but have not been enough

- In 2008, IDD rates were set at 76% of the cost to deliver services. For every $1 of service provided, IDD agencies were paid $0.76.
- Rates have never increased enough to fill this gap

Meanwhile…

- From 2001 to 2018, the cost of living in the Denver metro area rose 47%, while IDD rates rose only 14%
- In last 5 years, Colorado’s minimum wage has increased 34.7%, while IDD rates increased only 11.6%
- Denver just passed a $15/hr MW, with no rate increase
- The Governor’s budget requests only 0.29%, compared to 2019 inflation at 1.8%
COMMUNITY CAPACITY: WHY IS IT IMPORTANT?

- Reduced availability of supports
  - Rural communities = canaries in the coal mine
  - Dropping services to survive
- SLS and CES WLs were eliminated without a long-term approach to system capacity and sustainability
- Result: the “invisible wait list”
  - People can enroll, but wait months to find a provider
  - May never find a provider for some services
- Wait list elimination can’t be an empty promise
COMMUNITY CAPACITY: KEY TAKE-AWAYS

1. Without rate increases, IDD providers can’t increase their revenues to keep pace with the cost of doing business.
2. The cost of doing business keeps going up in a number of ways.
3. Adding hundreds of people to an under-funded system doesn’t work long-term.
4. If we don’t ensure community capacity, access to and quality of services will decline.

So, again…

If we are going to eliminate the waiting list, we must ensure community capacity to serve new and existing enrollees.
THE SOLUTION: END THE WAIT
PROPOSAL

- Six-year buy-down of the DD ASAA wait list
  - Enroll 500 people each year for 6 years
  - Then, enroll anyone eligible
  - Addresses the “first-come-first-served” WL category

- Tie IDD rates to inflation moving forward
  - Impacts rates reimbursed on a non-negotiated, unit basis
  - Use the prior year’s average Denver-Aurora-Lakewood Consumer Price Index

- *JBC discussion
END THE WAIT PROPOSAL: PROCESS

- Bill title pulled
- Engagement from JBC members
- Currently accepting pre-file cosponsors
- Major budget barriers:
  - Polis budget priorities
  - TABOR
- Grassroots campaign!
END THE WAIT PROPOSAL: HOW YOU CAN HELP

- **Must** have community engagement to make this happen!
- Follow Alliance on social media and share our posts
- Sign the petition – get friends, family, neighbors to sign too!
- Have your organization publicly endorse the bill
  - We also welcome individual endorsements from parents, family, and friends
- Contact your legislators - 100 Legislator Outreach Campaign
  - **Every** legislator needs to know this is a priority!
- Visit [www.coidd.com](http://www.coidd.com) for all the END THE WAIT information
  - Fact sheets, talking points, FAQs, testimonials, and more!
  - Email: info@alliancecolorado.org
- Attend the wait list hearing at the Capitol in January (date TBA)
CONTACT US

Ellen Jensby
Senior Director of Public Policy & Operations
ejensby@alliancecolorado.org

Josh Rael
Executive Director
jrael@alliancecolorado.org

Thank you!