

# IT'S TIME TO END THE WAIT

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



Welcome! The webinar will begin at 2:00 pm

- All lines will be muted for this webinar
- There is no need to broadcast video from your computer
- Call in number: (515) 739-1015 Access Code: 279-066-230#
- This webinar will be recorded
- How to ask a question:
  - Type it in the chat box
  - Email us after the webinar at [info@alliancecolorado.com](mailto:info@alliancecolorado.com)



**ELLEN JENSBY, SENIOR DIRECTOR OF PUBLIC POLICY & OPERATIONS, ALLIANCE**

**EMMA HUDSON, LOBBYIST, EMMA HUDSON CONSULTING, LLC**

# AGENDA

- What is Alliance?
- Definitions
- Wait list background
- Community capacity background
- END THE WAIT bill
- Bill process
- How you can help
- FAQ
- Contact us





- 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

ALLIANCE IS A NONPROFIT, STATEWIDE ASSOCIATION OF COMMUNITY CENTERED BOARDS (CCBs) AND PROGRAM APPROVED SERVICE AGENCIES (PASAs) THAT IS DEDICATED TO STRENGTHENING SERVICES AND SUPPORTS FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (IDD).

# DEFINITIONS

- IDD
- HCBS
- DD Waiver
- SLS Waiver
- CES Waiver
- Enrollments
- HCPF
- DSPs



# WAIT LIST BACKGROUND: WAIVER PROGRAM BASICS

- 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

vs.

## 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:

## **As Soon As Available (ASAA)**

- Have indicated that they would like to be offered enrollment as soon as it is available, suggesting they would enroll when offered the chance
- However, declination rate: ~46%
- About 3,000 people

## **Safety Net**

- 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.
- Can switch to ASAA at any time
- About 3,000 additional people



# WAIT LIST BACKGROUND: PRIOR EFFORTS TO ELIMINATE

- 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 directed HCPF to create 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: REAL COLORADANS



## Thank You for ENDING MY WAIT for comprehensive services



### Meet Jean Marie:

- I currently live in Ft. Collins.
- I waited 28 years before receiving comprehensive services
- After living in a nursing home setting for ten years, I got community-based services in July 2008.
- I now live in a host home with a peer housemate and I love it!
- My dream was to see Rascal Flatts. My provider took me to see them for my birthday and I sat in the front row and got to sing on stage. I'm now part of a concert special on TV!

"Before living with my current provider I had very little choice and there wasn't enough staff to help. Now I choose nearly every aspect of my day. What I eat, who I interact with, and what activities I participates in."

-Jean Marie

**The Time Has Come to END THE WAIT!!!**

For more information, or to share your story, visit  
[www.COIDD.com](http://www.COIDD.com) or contact [info@alliancecolorado.org](mailto:info@alliancecolorado.org).



# WAIT LIST BACKGROUND: REAL COLORADANS



## END MY WAIT for comprehensive services

### END THE WAIT for Brennan

- I currently live in Centennial with my parents.
- I've been waiting for comprehensive disability services since July 2007.
- I love being with my friends and people who help me succeed.
- A Personal Goal: I want to live successfully independent of my parents, to be cared for by people who know my needs, to be safe, loved, and happy.

"I could have roommates and live with my friends in my own place. I could be more independent! My parents would not have to be my 100% caregivers."

-Brennan

**The Time Has Come to END THE WAIT!!!**

For more information, or to share your story, visit [www.COIDD.com](http://www.COIDD.com) or contact [info@alliancecolorado.org](mailto:info@alliancecolorado.org).



## 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.



# COMMUNITY CAPACITY: SERVICES BASICS



- 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:

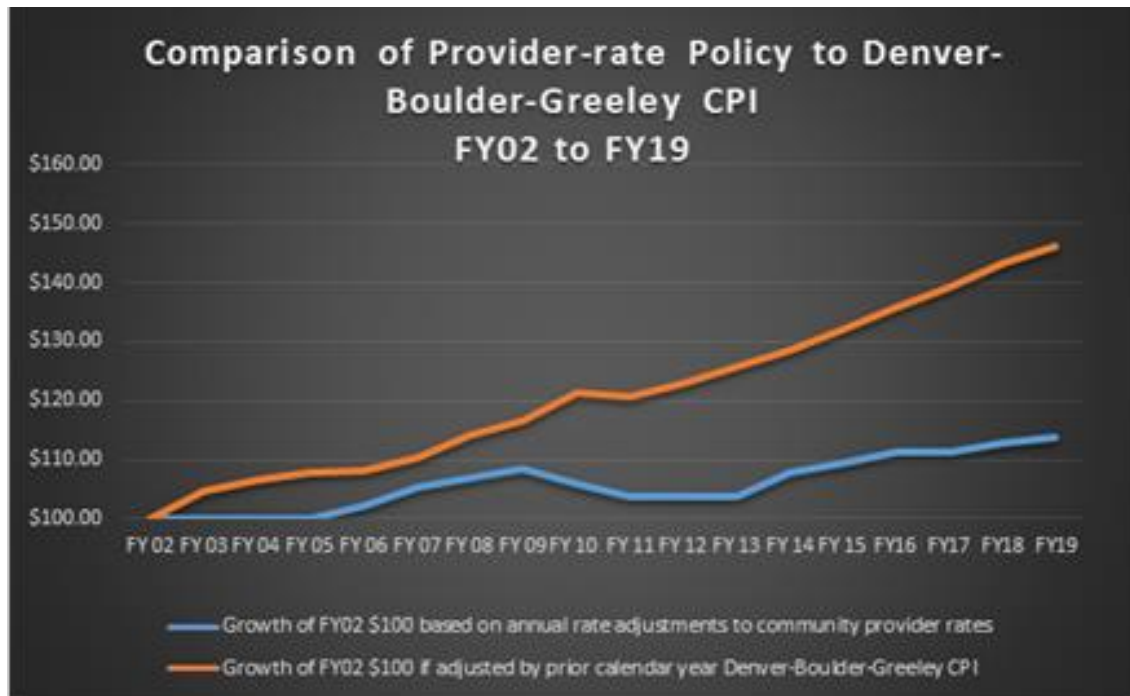
- **Stagnant** Medicaid reimbursement rates +
- **Rising** inflation & minimum wage +
- **Low** unemployment +
- **Increased** regulatory burden +
- **Costly** changes to service delivery models

=

- **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



# COMMUNITY CAPACITY: WHAT ABOUT RECENT INCREASES?



**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 considering 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
  - Rates reimbursed on a non-negotiated, unit basis
  - Use the prior year’s average Denver-Aurora-Lakewood Consumer Price Index

# 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



@Alliance\_CO



@AllianceCOIDD

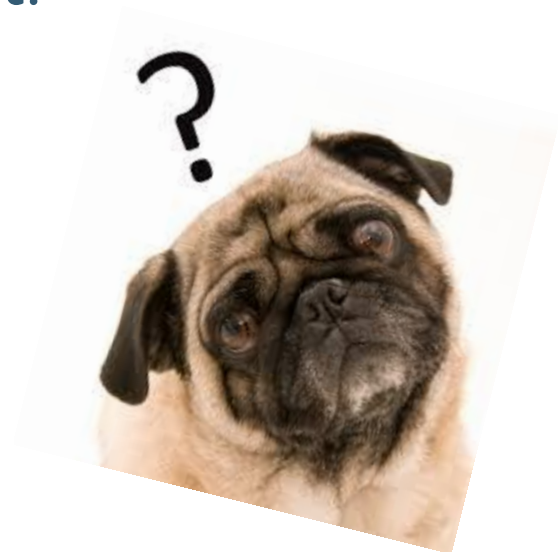


Alliance Colorado

- **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](mailto:info@alliancecolorado.org)
- Attend the wait list hearing at the Capitol in January (date TBA)

# F.A.Q.

- How will the rate increase be allocated?
- What about DSPs?
- What about the 3,000 additional people on the safety net list?
- Should we study the wait list first?
- Can the system handle this many new enrollees?
- What about waiver redesign?
- What about other disability services?



# JOIN ALLIANCE



- As members, Program Approved Service Agencies and Community Centered Boards get the most up-to-date information on the bill!
- For more information on membership, contact:  
Kylie Kampbell, Membership Coordinator  
[kkampbell@alliancecolorado.org](mailto:kkampbell@alliancecolorado.org)  
(303) 832-1618 ext. 12



# CONTACT US



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*Thank  
You!*