

# IT'S TIME TO END THE WAIT

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



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- 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).

## SYSTEM BACKGROUND: RECENT SUCCESSES



# 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: ~26%
- 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 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.



# 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:

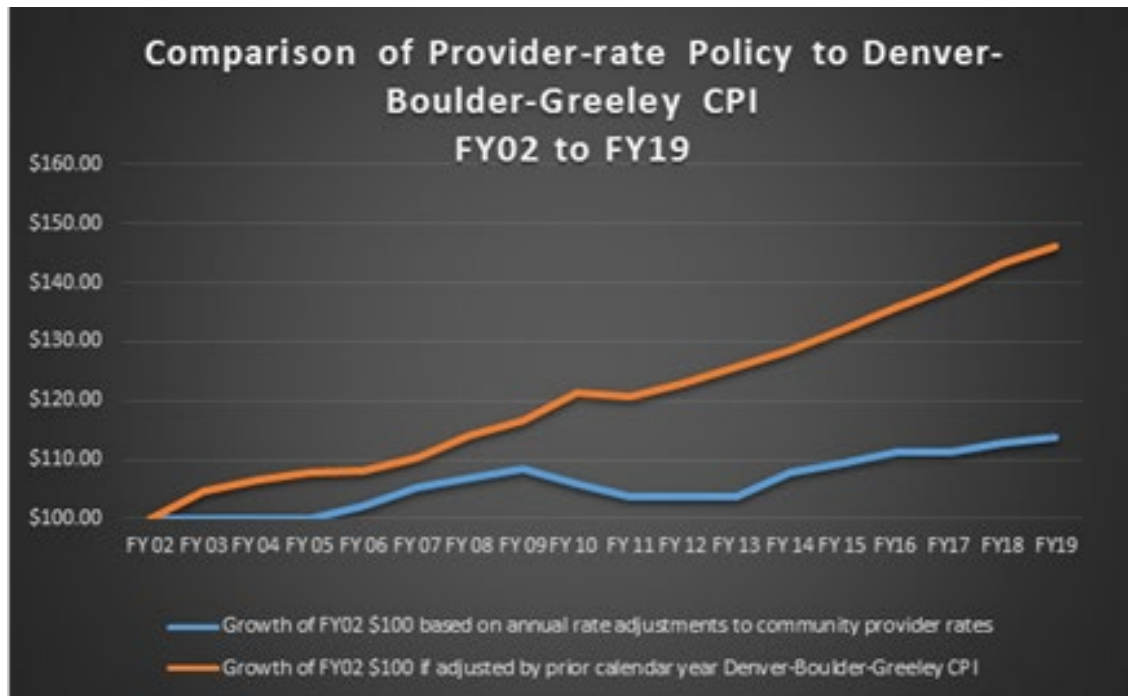
- **Stagnant** Medicaid reimbursement rates +
- **Rising** inflation & minimum wage +
- **Low** unemployment +
- **Increased** regulatory burden +
- **Costly** changes to service delivery models

=

- **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 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



@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)

## CONTACT US



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*Thank  
You!*