

LNUSS
Group

Report to the Colorado Department of Health
Care Policy and Financing:

A Review of National I/DD Medicaid Home and
Community Based Services 1915(c) Waiver Waiting List
Management Practices

And

Analysis of Colorado's Home and Community Based
Services-Developmental Disabilities Waiver Waiting List
Statute, Policies and Procedures

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Background and Methodology

The Henry J. Kaiser Family Foundation 2014 waiting list enrollment data for 1915(c) Home and Community-Based Services (HCBS) Waivers serving people with intellectual and developmental disabilities (I/DD) indicates that thirty-five (35) states maintained waiting lists for ID/DD services.¹ The Colorado Department of Health Care Policy and Financing (the Department) engaged the LNUSS Group to research and propose revisions to waiting list statute, rule policies, and procedures, and provide a cost-effective and informed solution for Colorado to effectively and equitably manage the I/DD waiting list. An initial report provided on May 16, 2017 included research on comparable I/DD waiver services waiting list management practices in other states, and a preliminary review of Colorado's waiting list management practices. The initial report considered the potential impact(s) of Colorado's unique rural areas, and provided initial recommendations for changes to Colorado's emergency enrollment criteria.

Included in this report are results from an environmental scan of waiting list practices conducted by the LNUSS Group under contract with the National Association of State Directors of Developmental Disabilities Services ("NASDDDS") on behalf of the Ohio Department of Developmental Disabilities (DODD). Ohio DODD requested the review specifically include the following states: Pennsylvania; New Jersey; Minnesota; Michigan; and, North Carolina. NASDDDS in consultation with Ohio DODD selected an additional twelve states to include in the review: Massachusetts; Washington; Connecticut; New York; Colorado; Virginia; Illinois; Utah; Texas; Louisiana; Alabama; and, Maryland.

The LNUSS Group and NASDDDS prepared an eighteen-question survey to solicit information to address six primary elements to be queried:

1. Eligibility requirements to be placed on waiting lists;
2. Definitions of how "need" is defined;
3. Order of enrollment onto a waiver including use of priority categories;
4. Determination of type of waiver to offer if more than one waiver is available in a state;
5. Circumstances under which an individual can be removed from a waiting list; and,
6. Due process when someone is placed on or removed from a waiting list.ⁱ

That survey was sent to the seventeen (17) states on or about October 21, 2016. As of December 1, 2016, 12 states responded to the survey or 71% including: Pennsylvania, New Jersey, Illinois, New York, Virginia, Michigan, Minnesota, North Carolina, Connecticut, Colorado, Washington, and Maryland. One state, New York, reported that it did not maintain waiting lists and therefore did not provide a response to the survey. Michigan reported that it maintained a waiting list only for its children's waiver, and did not have a waiting list for adults with I/DD. As a result, Michigan and New York were excluded from the NASDDDS findings.

For Colorado's statement of work, additional research has been completed with additional focus areas. The additional analysis included how states manage enrollment when there is more than one HCBS waiver program available, how a waiting list operates during transition between a children's waiver and the state's adult waiver program(s), and how waiver enrollments are allocated, especially in states with rural areas where there are local entities, such as counties or other government management entities, involved in enrollment decisions and/or functions pertaining to HCBS waiver services. Additional states

¹ [Kaiser Foundation Report on Waiting Lists for HCBS Services 2014](#)

were added in this review that were not part of the NASDDDS survey to expand on those focus areas including: Massachusetts, South Carolina, Missouri, Louisiana, Oklahoma, Nevada, Wyoming and Montana.

The findings included in the initial report were also presented to Division for Intellectual and Developmental Disabilities stakeholders during the week of May 22, 2017. Stakeholder meetings were held in Grand Junction, Greeley, Pueblo and Denver, in addition to one statewide Webinar, all facilitated by the LNUSS Group. Attendees were asked to provide feedback regarding their experience with Colorado's I/DD waiting list management practices, on the recommendations provided by the LNUSS Group in the presentation and any other recommendations or observations regarding the management of the HCBS-Developmental Disabilities (HCBS-DD) Waiver waiting list. The PowerPoint presentation and the report on specific observations and recommendations made at each stakeholder session are included in the Appendices of this report.

Results and Findings of Comparable State I/DD HCBS Waiver Services Waiting List Management Practices

Eligibility requirements to be placed on waiting lists

All states (twenty-one) reported or included in state policies or rules that prior to placement on a waiting list the person is first determined to be eligible for state I/DD services. Nine states further determine Medicaid eligibility, 9 states determine eligibility for the HCBS waiver, and one additional state determines potential eligibility for the HCBS waiver, prior to placement on a waiting list for HCBS enrollment. Colorado determines eligibility for the HCBS waivers serving individuals with intellectual and developmental disabilities and confirms Medicaid eligibility when enrollment in the waiver is requested or placement on a waiting list is required using the ULTC 100.2.

Based on available information, 8 states limit placement on the waiting list to a time-period within which services are expected to be needed. One state limits placement on the waiting list to persons who will need services within 12 months, 2 states limit placement on the waiting list to those persons who will need services within 24 months, one state limits placement to target groups (e.g. emergency, transitioning youth, and "current need"), and 3 states limit placement to those who will need services within 6 months to 5 years. The determination of when services will be needed follows a guided interview or assessment tool process completed by the government entity responsible for entering individuals on the waiting list. Colorado maintains data regarding when services will be needed by the individual, as requested by the individual, using three waiting list statuses:

- As Soon as Available - The individual has requested enrollment as soon as available.
- Date Specific – The individual does not need services at this time but has requested enrollment at a specific future date.
- Safety Net – The individual does not need or want services at this time, but requests to be on the waiting list in case a need arises at a later time.

Increasingly, states are also using "reserved capacity" to effectively manage access to specific HCBS waivers that have different benefit packages, use "additional criteria" in the HCBS waiver application to target the eligible population group, or use different waiting list prioritization criteria for the different

waivers within the state, as a method to manage access to each program. Reserved capacity and additional criteria for the target group of the waiver are technical terms used by the Centers for Medicaid and Medicare Services (CMS). Reserving waiver capacity “means that some waiver openings (a.k.a., “slots”) are set aside for persons who will be admitted to the waiver on a priority basis for the purpose(s) identified by the state”.² Additional criteria allows the state to specify more discrete targeting criteria over and above the target group/subgroup and age-ranges selected in the waiver application.³ These strategies will be discussed in more detail later in this report.

Definitions of how “need” is defined

This element is closely related to whether states establish priority categories within the waiting list to distinguish an “urgency” of need. All states included in this report establish basic information regarding a person’s specific circumstances as it pertains to his or her current living situation and/or life stage. Twelve states complete a specific assessment of either the person’s specific needs or identify the services the person likely will need prior to placement on a waiting list. Information regarding potential need and current status is either collected during initial intake and placement on the waiting list, or, by the case manager assigned to the person after I/DD eligibility for state services is determined. In those states, the data is maintained and used to determine a priority ranking, likely eligibility for a specific HCBS waiver, or reserved capacity status. The evaluation does not necessarily include determination that the person meets financial or level of care requirements for waiver eligibility prior to placement on the waiting list. What is important is that a standardized methodology is employed to categorize a person’s priority need for services.

Colorado maintains a waiting list for the Home and Community Based Services for Persons with Developmental Disabilities (HCBS-DD) Waiver. Eligibility for the HCBS-DD waiver is limited to those individuals who have been determined to have a developmental disability, are eighteen years of age or older, require access to services and supports 24 hours a day, meet ICF-IID level of care as determined by the ULTC 100.2, and meet the Medicaid financial determination for long-term care eligibility as specified in 10 CCR 2505-10, Section 8.100, *et. seq.*⁴ Community Centered Board (CCB) personnel make the determination of need for access to 24-hour a day services and support. The ULTC 100.2 is the state’s universal assessment tool for determining the functional level of care determination, but does not evaluate the *amount* of services and support an individual may or may not need. Colorado does not mandate specific assessment tools prior to placement on the waiting list to make that determination, but many individuals who seek enrollment in the HCBS-DD Waiver are receiving services under the Colorado Home and Community Based Services Supported Living Services (HCBS-SLS) Waiver or the Colorado Home and Community Based Services Children’s Exceptional Support Waiver (HCBS-CES). For those individuals, the CCB has access to individualized assessments and support plans to evaluate the need for access to 24-hour services and supports. For those individuals who are not enrolled in the HCBS-SLS or HCBS-CES Waivers, there are no additional standardized assessments required to determine the level of support need and subsequent eligibility for the HCBS-DD Waiver.

² *Application for a 1915 (c) Home and Community-Based Waiver [Version 3.5, Includes Changes Implemented through November 2014] Instructions, Technical Guide and Review Criteria*. January 2015. Centers for Medicare and Medicaid Services. Page 76.

³ *Ibid.* Page 68

⁴ 10 – CCR – 2505 10 8.500.7.A

Order of enrollment onto a waiver including use of priority categories

Nineteen states in this report explicitly provide for an “emergency” (may be named emergency, priority 1, crisis resolution) category or definition to supersede any other order of enrollment, although “reserved capacity” does impact the number of available enrollments at any one time depending upon how the HCBS waiver program is designed. In 15 states, what would constitute an emergency is in effect the first priority group to gain entrance to the waiver program(s), and in 2 states (Missouri and Massachusetts) only people considered to be in emergency status can gain access to the state’s comprehensive waiver (e.g. waiver that provides out-of- home and extensive supports).

The order of enrollment in states that have more than one waiver program for adults can be complex and influenced by three separate factors:

- 1) B-1: Specification of the Waiver Target Group(s) - b. Additional Criteria
- 2) B-3: Number of Individuals Served - c. Reserved Capacity
- 3) B-3: Number of Individuals Served – e. Allocation of Waiver Capacity

The design and use of these three management tools influences both the order of enrollment and which HCBS waiver program may be offered to individuals seeking services.

The most common factors considered to constitute an emergency for people on a waiting list and the number of states that utilize the emergency factor is detailed in Table 1 below (* indicates criteria in use in Colorado):

Table 1: Most Common Emergency Factors for Waiting List Prioritization

| Emergency Situation | Number of States |
|---|------------------|
| Incapacitation or impairment of caregiver places person at serious risk of physical harm. (e.g. the caregiver is in a nursing home placement; has serious health or mental health concerns) | 10 |
| Loss of caregiver | 10 |
| Individual is subject to abuse, neglect or exploitation* | 8 |
| Individual is homeless*, living in inappropriate housing (e.g. prison, shelter) | 8 |
| Individual in current, or to prevent imminent, placement in an ICF/IID or institution** | 6 |
| Individual presents a significant danger of physical harm to self or others* | 5 |
| Significant risk to health and safety of the person | 3 |

| | |
|---|---|
| Individual faces court action or commitment | 3 |
| Individual creates a risk of harm to others | 2 |
| Prevention of an out-of-home placement of a child | 1 |
| Need for services exceeding current HCBS waiver | 1 |

* Used by Colorado

** Current ICF/IID or institution placement used by Colorado

Beyond an emergency, priority for enrollment varies across the states included in this report. As illustrated below in Table 2, all states utilize more than one priority categorization group to organize those persons who are waiting for services, and to determine order of enrollment. All prioritization groups unless otherwise noted rely on situational characteristics such as status of the caregiver, health and safety of the person or others and/or loss of living arrangement. As noted above, additional enrollment factors may also be prescribed through the use of reserved capacity and/or the use of prescribed additional criteria for the target group for the waiver program.

Table 2: Priority Categorizations used for Waiting Lists

| State | Priority Categorizations in Order of Importance | Additional Order of Enrollment Factors | Emergency Definition |
|---|---|---|--|
| Minnesota One waiver serving ages 0+ | 1. Immediate Need 2. Defined Need 3. Future Need | 1. Institutional Exit ¹ 2. Reserved Capacity (must need services within 12 months) | 1. Sudden loss of caregiver (death; life threatening condition; abandonment). 2. Immediate risk of out of home placement of a child (natural or other disaster. unsafe living conditions). 3. Immediate risk of institutional placement. |
| Washington One children's waiver serving ages 8-20 Two waivers serving ages 0+ (tiered levels of supports) One waiver serving ages 18+ (Protection) | 1. Current waiver participant needs services in different waiver. 2. Second priority: priority population identified by legislature; immediate risk of ICF/IID placement due to unmet health and safety needs; people identified as a safety risk to the community; currently receiving state only | Each adult waiver uses Additional Criteria to specifically narrow target population for enrollment into the respective waiver programs. | Same as Priority Categorization |

| State | Priority Categorizations in Order of Importance | Additional Order of Enrollment Factors | Emergency Definition |
|--|--|---|--|
| One waiver serving ages 3+ (Individual and Family Support) (IFS) | funds; on a waiver that exceeds needs. 3. Third priority: persons in need of waiver services available in the support waivers to maintain status in the family or own home. | | |
| Maryland One waiver serving ages 0+ (Two others under development) | 1. Crisis Resolution 2. Crisis Prevention 3. Current Request 4. Transitioning Youth; Knott Class; Inappropriate Institutionalization ² | 1. Length of time on waiting list or in some cases the age of the caregiver. 2. Day services only: the time since exit from high school or date of application, whichever is greater. | <u>Crisis Resolution:</u> 1. Homeless 2. Serious risk of physical harm to self or others 3. Caregiver impairment places person at risk of serious physical harm |
| Pennsylvania Two waivers serving ages 3+ Comprehensive Support and Individual and Family Support (IFS) waivers | 1. Emergency 2. Critical Need: within 2 years. 3. Planning for Need: needs within 2-5 years. | 1. <u>Reserved capacity:</u> <ul style="list-style-type: none"> • Emergency • Money Follows the Person program • Hospital discharge 2. Date of application. <u>Additional criteria used to target group in IFS waiver to those living in natural homes and independent living.</u> | <u>Out of-Home Residential:</u> 1. Caregiver no longer can provide care placing person's health and safety at risk. 2. Death of caregiver with no other supports. 3. Committed by court. 4. Intolerable living situation (shelter; prison; homeless). 5. Needs support to protect health and safety and prevent institutionalization. <u>Day/In-home Support:</u> 1. Caregiver needs immediate support to keep person at home. 2. Person needs immediate support to maintain or gain employment or post-school outcomes. |

| State | Priority Categorizations in Order of Importance | Additional Order of Enrollment Factors | Emergency Definition |
|--|---|---|---|
| <p>Connecticut</p> <p>Three waivers serving ages 3 +</p> <p>(one Comprehensive, one Individual and Family Support, one day/employment supports)</p> | <ol style="list-style-type: none"> 1. Emergency 2. Priority 1: need services within 1 year. 3. Priority 2: need services within 2 or more years (Planning list). 4. Priority 3 (Planning List). | <ol style="list-style-type: none"> 1. <u>Additional criteria</u> used to target groups for enrollment in each respective waiver. 2. Date of application. 3. Availability of waiver enrollment in waiver that will meet needs. 4. Legislative target population. | <p><u>Emergency:</u></p> <ol style="list-style-type: none"> 1. The individual's behavior(s) may place others at imminent risk of significant harm, either intentional or unintentional. 2. The individual is homeless i.e., the person is in the hospital (or other temporary setting) and they cannot return home. 3. Caregiver or individual is so ill (physically or mentally) that the individual cannot remain at home without state I/DD agency support. 4. The loss of the caregiver due to death or placement in long-term care facility. 5. An Immediate Protective Service Plan is in place due to abuse or neglect. |
| <p>North Carolina</p> <p>Two waivers serving ages 0+</p> <p>One comprehensive support, one Individual and Family Support</p> <p>One medically fragile children's waiver</p> | <ol style="list-style-type: none"> 1. Emergency. 2. First come first served. | <p><u>Reserved Capacity:</u></p> <ol style="list-style-type: none"> 1. Movement from support waiver to comprehensive support waiver. 2. Money Follow the Person program. 3. Age out of Children's waiver. 4. Military transfer. 5. Deinstitutionalization. | <p><u>Emergent (Crisis)</u></p> <ol style="list-style-type: none"> 1. Homelessness. 2. Documented risk of serious physical harm in current environment. 3. Documented risk of causing serious physical harm to others in current environment. 4. Requiring protection from abuse, neglect, or exploitation as confirmed by DSS report. 5. Caregivers unable to provide adequate care due to caregivers' significantly impaired health as documented. |

| State | Priority Categorizations in Order of Importance | Additional Order of Enrollment Factors | Emergency Definition |
|--|---|---|---|
| <p>Colorado</p> <p>Two waivers serving ages 18+ (DD waiver providing access to 24- hour support, and Support Living Service (SLS) waiver)</p> | <p>Reserved Capacity – DD Waiver</p> <ol style="list-style-type: none"> 1. Children 18-21 Transitions. Children transitioning from foster care or the HCBS-CES waiver 2. Emergency 3. Deinstitutionalization 4. Legislative criteria for appropriations <p>Reserved Capacity – SLS Waiver</p> <ol style="list-style-type: none"> 1. Deinstitutionalization 2. Children 18-21 transitions. 3. Emergency | <p>The placement date used to establish a person's order on a waiting list shall be:</p> <ol style="list-style-type: none"> 1. The date on which the person was initially determined to have a developmental disability by the community centered board; or 2. The fourteenth (14) birth date if a child is determined to have a developmental disability by the community centered board prior to the age of fourteen. | <p><u>Emergency:</u> health, safety and welfare of the person or others is greatly endangered and the emergency cannot be resolved in any other way. Defined as:</p> <ol style="list-style-type: none"> 1. Homeless: does not have a place to live or is in imminent danger of losing place of abode. 2. Abusive or neglectful situation: is experiencing on-going abuse or neglect and health, safety or well-being are in serious jeopardy. 3. Danger to others: the person's behavior or psychiatric condition is such that others in the home are at risk of being hurt by him/her. Sufficient supervision cannot be provided by the current caretaker to ensure safety of the person in the community. 4. Danger to self: a person's medical, psychiatric or behavioral challenges are such that the person is seriously injuring/harming self or is in imminent danger of doing so. |
| <p>Kentucky³</p> | <ol style="list-style-type: none"> 1. Emergency 2. Urgent | <ol style="list-style-type: none"> 1. <u>Reserved capacity:</u> <ul style="list-style-type: none"> • Emergency • MFP | <p><u>Emergency:</u></p> <ol style="list-style-type: none"> 1. Abuse, neglect. 2. Death of caregiver. |

| State | Priority Categorizations in Order of Importance | Additional Order of Enrollment Factors | Emergency Definition |
|--|--|---|---|
| Two waivers serving ages 3+ | 3. Future Planning | 2. Date of enrollment | 3. Health and safety risk to due to caregiver health status. 4. Lack of appropriate housing. 5. Imminent or current ICF/IID placement. |
| New Hampshire³ One waiver serving ages 0+ One children's waiver age 0-21 | Priority 1: current or need within 1 year. Priority 2: need within 1-2 years. Priority 3: need exists now to within 2 years but do not place person at imminent risk | | <u>Priority 1:</u> Need places person at risk of substantial physical or emotional harm or regression. |
| Virginia Two waivers serving ages 0+ (comp and IFS) One waiver serving ages 18+ (Building independence) | Priority 1: Immediate jeopardy. Priority 2: may need services within 1-5 years to meet health and safety needs. Priority 3: may need services in 5 years or more. | Waiver slot assignment committee based on needs of person and risk factors. IFS slot offered before others. | <u>Priority 1:</u> 1. Immediate jeopardy exists to health and safety of the person due to the unpaid primary caregiver having a chronic or long-term physical or psychiatric conditions that significantly limit the ability of the primary caregiver to care for the person and there are no other caregivers available. 2. Immediate risk to the health and safety of the person, primary caregiver or other person living in the home due to either of the following - person's behavioral or physical health cannot be managed with generic or specialized supports. 3. Lives in institutional setting and has a discharge plan. |
| New Jersey One waiver serving ages 0+ | 1. Priority List 2. General Waiting List | 1. Reserved capacity: <ul style="list-style-type: none"> • Deinstitutionalization • Emergency | <u>Emergency:</u> Homeless or imminent peril and the Division cannot provide adequate services in the |

| State | Priority Categorizations in Order of Importance | Additional Order of Enrollment Factors | Emergency Definition |
|---|--|---|--|
| | | 2. First come first serve | existing situation or provide for the individual's personal safety. |
| <p>Illinois</p> <p>One waiver serving ages 18+</p> <p>Two waiver serving ages 3-21 (One Residential and one Family Home Support)</p> | <p>1. Emergency</p> <p>2. Critical Need: within 2 years.</p> <p>3. Planning for Need: need within 2-5 years.</p> | <p>1. Length of time and randomness within the priority categories.</p> <p>2. Separate WL population criteria to prioritize enrollment for Residential vs. In-Home Supports.</p> | <p><u>Residential Crisis:</u></p> <p>1. Lost caregiver</p> <p>2. Abuse and neglect</p> <p><u>Home-based 1st priority:</u></p> <p>Caregiver 60+ not yet in crisis.</p> |
| <p>Oklahoma</p> <p>One waiver serving ages 3+ (Comprehensive)</p> <p>One waiver serving ages 18+ (Home Support)</p> <p>One children's waiver serving ages 3-17</p> | <p>1. Emergency</p> <p>2. Legislative directed groups</p> <p>3. Children leaving ICF/IID services</p> | <p>Additional Criteria.</p> <p>Different Reserved Capacity based on waiver.</p> <p>1. Children exiting children's waiver gain access to Supports waiver serving adults 18+.</p> <p>2. Exit from public ICF/IID's</p> <p>3. Emergencies</p> <p>4. First come first served after emergencies and reserved capacity.</p> | <p><u>Emergency:</u></p> <p>1. Health and safety of the person or others is endangered and there is no other resolution. An emergency exists when the person is unable to take care of him/herself and: a) the caretaker is hospitalized; moved into a nursing facility; is permanently incapacitated; or died, b) there is no caretaker, c) the person is living in a shelter or on the street.</p> <p>2. Person needs protective services due to abuse and neglect.</p> <p>3. Behavior causes serious risk to others, or causing serious injury to self.</p> |
| <p>Massachusetts</p> <p>Three waivers serving ages 22+</p> | <p>1. Immediate/imminent health and safety risk (30-90 days)</p> | <p>1. Each waiver has "additional criteria" to target the eligible population group. One</p> | <p>All admission based on MASSCAP that takes into account individual and caregiver circumstances.</p> |

| State | Priority Categorizations in Order of Importance | Additional Order of Enrollment Factors | Emergency Definition |
|--|---|--|---|
| (Different tiered levels of supports – one with residential) | 2. Priority 2: planning for services in 18 – 24 months | waiver for out of home residential. 2. Different reserved capacity groups for 3 different waivers. 3. Access to residential limited to Priority 1 and highest need within 30 days. | Access to residential supports based on immediate/imminent health and safety needs. MA stresses all evaluations are based on what people need, not what people want. |
| Missouri Two waivers serving ages 0+ (Comprehensive and Home support) One children’s waiver | 1. Priority based on results of Prioritization of Need (PON) results (tool scores personal and situational characteristics) with multiple levels of priority. | 1. Uses Additional Criteria to target access to comprehensive waiver. 2. First come first served. 3. Access to residential further restricted to those with highest need. | <u>Emergency:</u> 1. Health and safety conditions pose a serious risk of immediate harm or death to the individual or others. 2. Loss of primary caregiver support or change in caregiver status to the extent the caregiver cannot meet the needs of the individual. 3. Abuse, neglect or exploitation of the individual. <u>Comprehensive waiver:</u> Emergency criteria and face imminent out of home placement and needs cannot be met through other waivers according to PON score. |
| Ohio Four waivers serving ages 0+ | 1. Emergency 2. Refinancing of supported living and family support services. 3. Refinancing of adult services. | 1. Emergency. 2. Maximization of federal funding. 3. Mix of individuals in each priority category. 4. Living arrangement factors if applicable. | <i>Under Revision</i> |

| State | Priority Categorizations in Order of Importance | Additional Order of Enrollment Factors | Emergency Definition |
|--|--|--|--|
| | 4. Aging caregiver or intensive needs. 5. Resident of an ICF/IID. 6. Resident of a nursing home. | 5. First come first served. | |
| Wyoming Two waivers serving ages 21 + One children's waiver ages 0-20 | <u>Comprehensive</u> 1. Emergency. 2. People with health and safety support needs exceeding the Support waiver limits. 3. Highest Level of Need (1-6) in excess of 30K of services. <u>Supports Waiver</u> 1. Emergency. 2. First come first served. | 1. Additional Criteria used to target enrollment group. 2. Reserved capacity-transition from state centers. | <u>Emergency:</u> Approved by Committee 1. Documented loss of caregiver. 2. Documented behavior or health conditions placing person at significant risk. 3. Documented abuse and neglect placing person at risk. |
| Nevada One waiver serving ages 0+ | 1. Residents of ICF/IID. 2. Risk of institutionalization. 3. All others. | | No additional criteria |
| Montana One waiver serving ages 0+ | 1. Emergency. 2. First come first serve. | | <u>Emergency:</u> 1. Individuals in immediate need of life-sustaining services. 2. Individuals needing immediate services to protect another person from imminent physical harm. 3. Individuals transitioning from long-term institutional services. 4. Individuals still requiring significant levels of service who are no longer eligible for another program or services (another waiver, etc.). |

| State | Priority Categorizations in Order of Importance | Additional Order of Enrollment Factors | Emergency Definition |
|---|--|---|---|
| | | | <p>5. Individuals in care and custody of Children's Division for whom there is a formal agreement in place with Division of DD.</p> <p>6. Individuals under age 18 requiring coordinated services through several agencies to avoid court action.</p> <p>7. Individuals subject to ongoing or pending legal action requiring immediate delivery of services.</p> |
| <p>South Carolina</p> <p>Two waivers serving ages 0+</p> | <ol style="list-style-type: none"> 1. Critical Need. 2. Reserved capacity (child custody, discharge from ICF/IID). 3. First come first serve. | <ol style="list-style-type: none"> 1. Separate WL for Residential services via comprehensive waiver overall. 2. Priority 1 critical. 3. Priority 2 residential may be needed in the future (more than 1 year). | <p><u>Critical Need:</u> Life threatening situations requiring immediate services or are in situations that present an imminent risk of jeopardizing their health and safety requiring immediate action. Typically limited to situations in which the person:</p> <ol style="list-style-type: none"> 1. Has been recently abused/neglected/exploited by the primary caregiver. 2. Is homeless. 3. Has seriously injured self or others and continues to pose a threat to health and safety to self or others. 4. Has been judicially admitted to agency. 5. Has recently lost primary caregiver or at imminent risk of same. 6. Has a primary caregiver who is 80 years old + with diminished ability to provide care that is likely to continue indefinitely and lack of alternative caregiver. <p><u>Residential:</u></p> |

| State | Priority Categorizations in Order of Importance | Additional Order of Enrollment Factors | Emergency Definition |
|--|---|--|--|
| | | | All efforts to address the situation through HCBS must be exhausted prior to consideration for residential services. Refusal of in-home support services does not constitute the presence of a critical need. |
| Louisiana Residential waiver serving ages 0+ Supports waiver serving ages 18+ New Opportunities waiver serving ages 3+ Children’s waiver age 0-18 | 1. Reserved Capacity 2. First come first serve | Additional criteria are used to target groups for enrollment into each adult waiver. | 1. Residential waiver reserved entirely for transition from institutional placements. 2. Very limited enrollments for priority populations for Supports waiver. 3. New Opportunities waiver serves majority of people and is 1 st come 1 st serve. |

¹ Minnesota has an active Olmstead action in place.

²Persons in these categories must also be in one of the first three priority groups.

³ Kentucky and New Hampshire are included in this portion of the report only.

These results align with the results of the 2002 report prepared by the Research and Training Center on Community Living Institute on Community Integration/UCEDD, University of Minnesota on waiting list policies and resources. In that report, 47 states responded to a survey regarding the relative importance of factors used to determine access to services and supports among persons on waiting lists. The authors concluded from those findings that “the factors of immediate crisis, emergencies, substantial concern for loss of present services were more important than length of time of waiting, age of caregiver, or severity of disability”.⁵

The review also indicates that states when defining what constitutes an emergency are using health and safety considerations specifically, and not the more generic term of health and *welfare*. There is also a

⁵ *Policies and Resources Related to Waiting Lists of Persons with Mental Retardation (sic) and Related Developmental Disabilities*. (2002). Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Page 6

clear emphasis on the use of terms such as *immediate* or *imminent* risk to describe the urgency of the situation, and, the use of the term *significant* or *serious* to describe the severity of the situation. Where an emergency is predicated specifically on the status of the caregiver, all states are specific that the caregiver has been lost (e.g. death, admitted to a nursing home), the caregiver has a life threatening or serious persistent illness, and the situation of the caregiver places the person at serious physical harm or the person's needs cannot be met because of that change in caregiver status. The specificity is in place to make the distinction between caregivers who choose to no longer provide support for adult children and those who no longer can provide those supports due to health, mental health or physical limitations. The same is noted for the emergency criteria of "homeless". Homeless is considered to be living in a shelter, prison, hospital, on the street, have no place to live, or at imminent risk of the same, and the state has no way to provide for the personal safety of the individual. Once again, the specificity attempts to define the concept of homelessness more literally due to significant adverse events, versus one that results from an expectation of transition to adulthood.

In states with a waiting list, using additional criteria and/or reserved capacity to reflect the intent of the legislature and/or the resource management strategies of the state, and tightly defining what will rise to a level of an emergency to supersede the policy strategies and priorities, are critical to ensuring both transparency and equity in the administration of the state waiting list.

Determination of type of waiver to offer if more than one waiver is available in a state

Fifteen states, including Colorado, in the review operate more than one adult waiver for HCBS I/DD waivers. Eight of those states, including Colorado, also operate at least one children's I/DD waiver program. One of the 8 states in the review operated a single children's waiver and a single adult waiver program (New Hampshire). Three states (Washington, Massachusetts, and Missouri) maintain separate waiting lists for each waiver program in operation, and an individual may only be on a single waiting list. Pennsylvania maintains separate waiting lists for each waiver program in operation and an individual may be on more than one waiting list at a time.

As noted previously in this report, the use of "Additional Criteria" found in section B-1 of the HCBS 1915(c) waiver application is employed by a number of states (8) *as part of* the strategy to target to population groups when a state operates more than one HCBS 1915 (c) waiver program for the same age group. The additional criteria specify the amount of supports an individual needs or is eligible for, expressed in dollars or level of need, and/or prescribes where the individual lives or will live once enrolled in the waiver program. As noted in Table 2 above, reserved capacity can and often is also employed to further structure the order of enrollment once the additional criteria definition has been met.

The use of reserved capacity supersedes other waiting list criteria set by the state until the number of reserved enrollments for that population group is exhausted. Only two states (Oklahoma and Colorado), provide for automatic enrollment of children who are served by the state's children's specific waiver program to an adult waiver program. Oklahoma only provides automatic enrollment into the In-Home Supports waiver program. Colorado permits automatic enrollment into either the HCBS Supported Living Services Waiver or the Developmental Disabilities Waiver depending upon the current level of needed services. Washington State reserves capacity in its Supports waiver for adults age 18 and older for children exiting the children's waiver.

In all states with more than one waiver program, the state or local authority determines which waiver program is offered. This determination is based on the identified need(s) of the person, caregiver situation, and/or where the person lives and whether the waiver program can meet the health and safety needs accordingly. The determination of need is based on either a developed service plan or a formal assessment of the individual's needs and in most cases caregiver situational factors.

Methods for allocation of enrollments

Local Entities

Allocation of waiver enrollments occurs when there are new enrollments available at the beginning of a waiver year or because of new appropriations and waiver authority, and, when a person vacates a waiver enrollment, usually referred to as "turnover". The immediate availability of turnover enrollments is also governed by whether a state limits enrollment in the waiver program to a set number of individuals at any one time in a waiver year, or, if the state permits the aggregate number of individuals in the waiver to simply remain within the total number of authorized enrollments for that year.

Where local entities exist, the state may choose to manage the waiting list on a state-wide basis or at the local entity level. In either case, the management of the waiting list must be consistent across the state. In some states, there is a combination of state and local waiting list management practices due to the use of both local and state matching funds. In Missouri, Ohio, North Carolina, Minnesota, Virginia, and Pennsylvania, the state allocates waiver enrollments to the local entity at the beginning of the waiver year following the established allocation methodology for the state. The local entity then determines who will be enrolled during the waiver year following the state waiting list policies and rules for HCBS program enrollment and reserved capacity.

In Missouri and Ohio, a portion of the enrollments are funded by the county or county boards so always remain in the control of the local entity. Missouri does allow a county to retain turnover enrollments that are state funded in the in-home support waiver, but does not in the comprehensive waiver. The state controls access to the comprehensive waiver and manages access to residential services through the Priority of Need process, and may take into consideration where residential vacancies exist. This means people may be offered access to residential services in a different geographic area of the state. Ohio allocates state funded enrollments to the county boards for specific purposes based on reported waiting list data and state initiatives (e.g. WL reduction, ICF/IID diversion, ICF/IID exit) at the beginning of the waiver year, but all state funded turnover enrollments are returned to the state for re-allocation the following waiver year. Ohio officials report that waiting list reduction waiver enrollments are typically returned to the same county board the following year if there continue to be individuals waiting in the priority or reserved capacity categories.

In Pennsylvania, Virginia, North Carolina and New Hampshire, the waiver match is all state funded, local entities manage enrollment into the waiver programs, and, the local entity retains turnover vacancies for re-use. If the local entity does not have individuals on the waiting list that meet the reserve or priority categories, then the state may reallocate the turnover enrollment to another local entity. The local entities are not required to limit enrollment in those turnover enrollments to emergency situations only as long as the individual meets a reserved capacity, emergency and/or priority 1 status. In Minnesota, the HCBS waiver program is also state funded, but is managed by the counties or tribes within an aggregate budget rather than by the number of people. The county or tribe's budget is set

each year and the county or tribe can then operate within that budget and serve as many people as possible within that allocation. The county or tribe retains that allocation each year, and the state adjusts the total allocation each year using its' allocation methodology found in the attachments to this report.

In states that distribute waiver enrollments to local entities at the beginning of the waiver year, the allocation methodology considers factors such as historical utilization, current numbers of people in priority and/or reserve categories, the percentage of people on the waiting list in reserve and/or priority categories relative to the statewide average, population distribution, and/or Medicaid population distribution. The state typically holds some number of enrollments in reserve to address emergencies that arise during the waiver year that exceed a local entities' allocation, and hold waiver enrollments for specific reserve populations that cannot be predicted in advance by geographic area (e.g. ICF/IID diversion or exit). In all cases, the waiver enrollments follow the person if the person moves to another local entity as is required by federal regulation.

The impact of waiting list management practices on local provider capacity was discussed with officials in Washington, Missouri, Virginia, Pennsylvania, Maryland, South Carolina, Oklahoma, Ohio and Minnesota. Washington manages the waiting list allocation at the state level, and reported that it manages potential long-term vacancies in residential settings by changing the rate methodology and payment for the setting to adjust for the number of people living in the setting. The District of Columbia also uses this methodology to maintain provider stability over time. Missouri manages out-of-home residential settings directly and as such offers known vacancies to people with the highest level of need and urgency to people considering geographic proximity to the person's home residence. These strategies are not common. The financing strategies employed by Washington State and the District of Columbia are currently approved by the Centers for Medicare and Medicaid Services, but are not typical and could be under future scrutiny. Missouri's practices raise questions regarding provider choice for residential habilitation services and need further information to fully understand the implementation of its' practices.

Virginia, Pennsylvania, Ohio and Minnesota reported that they are not aware of any concerns with provider vacancies or capacity in services in rural areas primarily because those states allow the local entities to manage both an initial annual allocation of enrollments, and, the local entity maintains control over those enrollments year over year.⁶ The initial allocation methodology takes into consideration current needs organized by urgency and reserved capacity, historical utilization and turnover, and ensures there is a proportional distribution of enrollments across the geographic areas of the state. Urban areas typically experience more turnover whereas rural areas do not. Minnesota reported that in fact there were times that the rural areas had difficulty with provider capacity in meeting new enrollment volume.

Statewide Management

The remainder of the states, including Colorado, in this study manage the waiting lists directly at the state level. Connecticut and Massachusetts can manage provider capacity or residential inventory effectively simply because of the size of the state (Connecticut), or the number of people waiting is

⁶ Ohio county boards control county funded slots year over year, and typically retain state funded waiting list reduction slots in practice.

sufficiently proportionate across the geographic areas (Massachusetts). Louisiana has very specific access criteria for the residential HCBS program, and otherwise awards enrollments on a first come first serve basis. South Carolina has reported that it does not take into consideration the impact on the provider capacity or stability across the state as it simply awards the next waiver enrollment based on order of placement on the waiting list. Oklahoma reported that growth in its' HCBS waiver programs was extremely limited and could only address limited emergency situations and could not address geographic concerns. Maryland reported that it is not aware of any concerns with geographic distribution or provider capacity or stability because of its' statewide management practices.

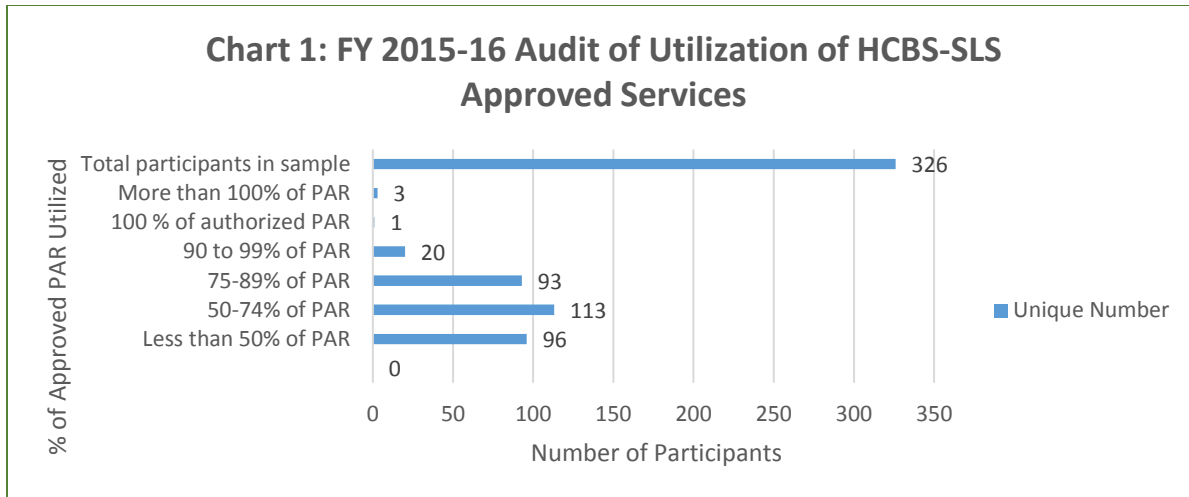
Colorado's Use and Management of a Waiting List for HCBS services

Overview

The Department's Division for Intellectual and Developmental Disabilities (DIDD) operates three 1915 (c) HCBS waivers: the Children's Extensive Support Waiver (HCBS-CES); the Supported Living Services Waiver (HCBS-SLS) and the DD Waiver (HCBS-DD). The focus of this study concerns the state's two adult waivers. As a result of executive and legislative initiatives, Colorado has eliminated the waiting list for those eligible for the HCBS-SLS Waiver. As of an April 2017 Division data request, there were 2,680 people registered as waiting for enrollment into the HCBS-DD waiver with a timeline of "As Soon As Available". The HCBS-DD Waiver provides for access to 24-hour supports and services provided in or out of the individual or family home, and higher number of hours or dollar limits for other HCBS services than offered under the HCBS- SLS Waiver. The state manages the waiting list for the HCBS-DD Waiver pursuant to Colorado 10 CCR 2505-10 8.500.7. The HCBS-DD Waiver limits the number of participants at any one time in the waiver year. There is reserved capacity for children ages 18-21 aging out of state foster care or the HCBS-CES (estimated at 125 people per year), people meeting the emergency criteria (estimated at 150 people per year), and for deinstitutionalization (estimated at 48 people per year) according to the approved waiver application CO.007.R07.01.

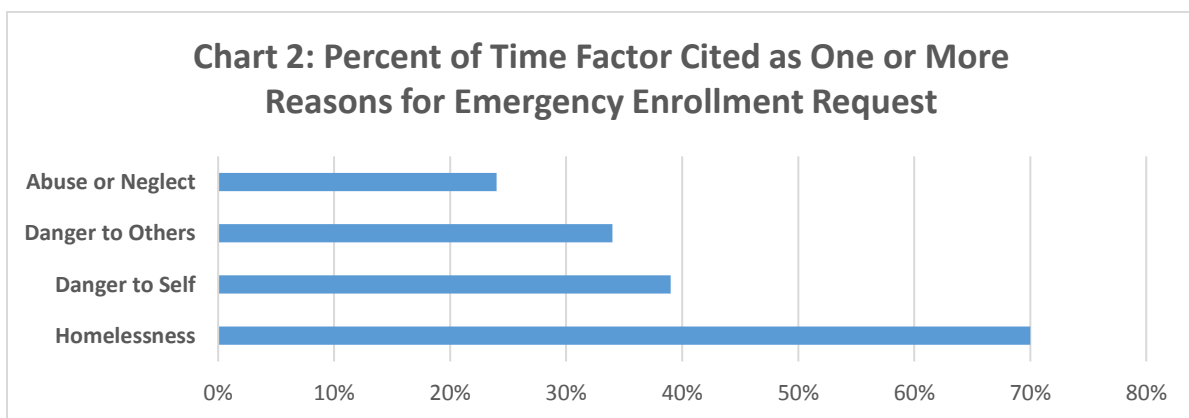
According to the Department of Health Care Policy and Financing report, *Update to the Strategic Plan for Assuring Timely Access to Services for People with Intellectual and Developmental Disabilities* (House Bill 14-1051), November 1, 2016, 88% of people who were registered as waiting for HCBS-DD Waiver services "As Soon as Available" were receiving other Medicaid services. It is not clear from this report how many of those persons are enrolled in the HCBS-SLS Waiver specifically, and that data has been requested from the Division. According to more recent data provided by the Division for April 2017, of the 2,430 individuals waiting for enrollment in the HCBS-DD Waiver with a Medicaid ID number, 78% of those individuals were currently enrolled in one of the state's other HCBS waivers. This illustrates a consistent data point that most individuals waiting for enrollment into the HCBS-DD Waiver are currently receiving some type and amount of community-based supports and services.

The Division also provided a report from an audit of HCBS-SLS service utilization for 326 participants for Fiscal Year 2015-16. The chart illustrated below displays the percent of approved benefits identified in their service plans utilized for this sample group. These participants may or may not be waiting for the HCBS-DD Waiver, but it is the type of data that can inform the Division if HCBS-SLS participants who are waiting for the HCBS-DD Waiver are effectively utilizing currently approved services. This is significant as it relates to how individuals are determined to be in an emergency category for enrollment into the HCBS-DD waiver to be discussed further below.



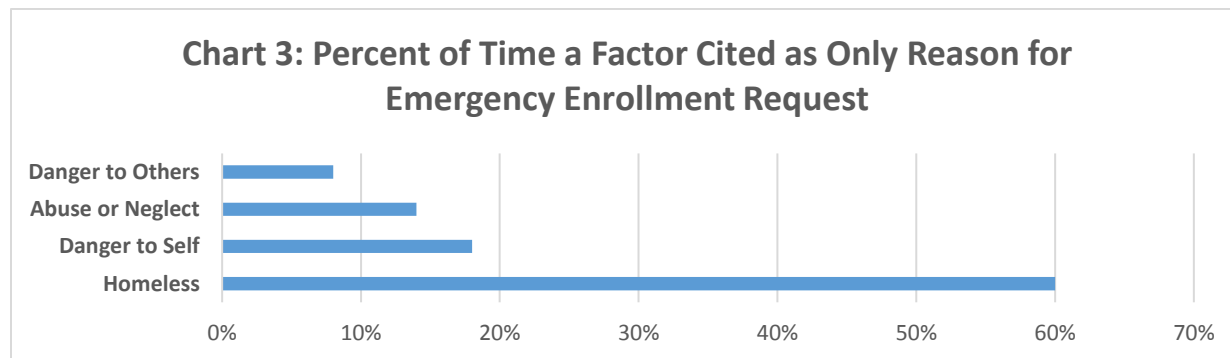
The 2016 HB14-1051 Strategic Plan Update noted above reported that in FY 2015-16, 223 enrollments into the HCBS-DD Waiver qualified as emergency enrollments 98 enrollments represented children ages 18-21 meeting the criteria for aging out of state foster care or the HCBS-CES Waiver. The enrollment number for emergencies exceeded projections for reserved capacity, and there were no resources available for people who did not meet one of the criteria for reserved capacity. The Division for Intellectual and Developmental Disabilities provided data for FY 2016-17 emergency enrollments through June 20, 2017, and once again authorized enrollments based on emergency requests (261) are exceeding projections for that reserved capacity group.

For emergency enrollments, the Division collects data regarding what circumstances exist for people to meet the emergency criteria for enrollment. The Division provided a report detailing the circumstances supporting the emergency enrollment request for 219 people for FY 2016-17 for this report. The current factors that can support an emergency enrollment request are: homelessness, a danger to self exists, a danger to others exists, or the individual is experiencing on-going abuse or neglect. The CCB can cite one or more of these factors when submitting the request for emergency enrollment. That report revealed the following data as it relates to Colorado’s requirements to meet emergency status for enrollment in the HCBS-DD Waiver.



As illustrated in Chart 2, 70% of all requests for emergency enrollment cited homelessness as at least one of the factors for the emergency request, or 44% more frequently than any other factor. When a

single factor is cited, the variance between homelessness and the next frequently cited factor, again danger to others, grows to 70% as illustrated below in Chart 3.



Finally, the age of individuals waiting based on data reported to the General Assembly in response to Waiting List questions regarding the Division waiting list dated February 2016 indicates that the majority of persons (65%), as of November 2015, waiting for entrance to the HCBS-DD Waiver “As Soon as Available” are under 30 years of age. An additional 26% (547) of all persons waiting are between 35 and 47 years of age, and, 9% are 48 years of age or older.

Analysis and Discussion

Access to the HCBS-DD Waiver

All individuals placed on the HCBS-DD Waiver waiting list must be screened and found to be eligible for the HCBS-DD Waiver by the CCB. All individuals must be assessed with the ULTC 100.2 to determine eligibility/level of care for ICF/IID, be eligible for Medicaid, and, meet the single eligibility requirement distinguishing access to the HCBS-DD Waiver - the need for access to 24-hour supports and services. The Division has not defined how the need for access to 24-hour services and supports is to be evaluated or measured and as such is left to individual CCBs to make this determination.

The benefit package available under the HCBS-SLS Waiver has implications for the eligibility requirements for the HCBS-DD Waiver. The HCBS-SLS Waiver benefit is determined based on an assessed level of need using the Supports Intensity Scale along with additional factors, with increasing levels of supports as expressed in a dollar limit provided to participants. There is a robust array of services and supports provided for individuals living in their own or family home.⁷ The HCBS-SLS benefit in terms of the number of hours of support and individual is eligible for does not, however, necessarily increase with increased levels of need. This can be the case if the individual is receiving day supports where the rate for the service increases based on the individual’s level of need such that the number of hours an individual may receive does not change, just the cost of the service to provide a higher level of staff supervision and support.

In the Division stakeholder sessions, the participants agreed that there was a perceived gap between where the HCBS-SLS Waiver benefits ended and the HCBS-DD Waiver benefit started (e.g. access to 24-hour services and supports). One solution recommended in the stakeholder sessions was to streamline the Support Level Review so CCBs could react more rapidly to emergent increased needs and avert

⁷<https://www.colorado.gov/hcpf/supported-living-services-waiver-sls>, accessed June 16, 2017.

potential emergencies. This included increasing the amount of increased funding that could be made available. The stakeholder meetings also brought into focus how the eligibility determination for access to 24-hour services and supports is not clearly defined, and can be interpreted as any individual who may need more services than is available under the HCBS-SLS Waiver. Examples included individuals who were recommended for emergency enrollment who were living independently and did not want 24-hour oversight. This led to discussions regarding the need for case managers to accurately explain the HCBS-DD Waiver eligibility requirements and to ensure that individuals who are seeking enrollment in the HCBS-DD Waiver understand what the 24-hour support service includes. In general, there is some basis to question whether all individuals currently on the HCBS-DD Waiver waiting list meet the HCBS-DD Waiver eligibility.

Children enrolled in the HCBS-CES Waiver may enroll in either the HCBS-SLS Waiver or the HCBS-DD Waiver depending upon assessed level of need and continued eligibility for the adult waivers. If eligible the waiver participant is free to choose either waiver that best meets the needs of the individual.

Emergency access to the HCBS-DD Waiver

As noted earlier in the report, Colorado regulations 10 CCR 2505-10 8.500.7F 8.500.7.F, persons whose name is on the waiting list shall be considered for enrollment to the HCBS-DD Waiver in order of placement date on the waiting list. Exceptions to this requirement shall be limited to:

1. An emergency situation where the health and safety of the person or others is endangered and the emergency cannot be resolved in another way. Emergencies are defined by the following criteria:
 - a. Homeless: the person does not have a place to live or is in imminent danger of losing the person's place of abode.
 - b. Abusive or neglectful situation: the person is experiencing ongoing physical, sexual or emotional abuse or neglect in the person's present living situation and the person's health, safety or well-being is in serious jeopardy.
 - c. Danger to others: the person's behavior or psychiatric condition is such that others in the home are at risk of being hurt by him/her. Sufficient supervision cannot be provided by the current caretaker to ensure safety of the person in the community.
 - d. Danger to self: a person's medical, psychiatric or behavioral challenges are such that the person is seriously injuring/harming self or is in imminent danger of doing so.

Colorado uses the *Request for Emergency Enrollment* form to document the reason for the emergency request which requires the CCB to indicate which factor(s) substantiates the request and provides for an open-ended section to describe the situation in greater detail. Colorado does not currently utilize a standardized format to evaluate an individual's level of need, an individual's health, behavioral, psychiatric or functional status and/or living situation while on a waiting list or prior to enrollment in a waiver program. Colorado also does not collect data regarding the caregiver(s)' status (e.g. age, number of caregivers, health status) of individuals who are on the waiting list for the HCBS-DD Waiver. Caregiver status is the most frequently cited criteria for establishing an emergency in this review. Fourteen (14) states cited either a loss of the caregiver, incapacitation, or impairment of caregiver that places the person at serious risk of physical harm and/or both. Four (4) states required the complete loss of the

caregiver to qualify as an emergency, and one additional state that did not cite caregiver status included a need for life-sustaining services as one criteria which could certainly include the loss of a caregiver. In all cases the states clearly defined the status of the caregiver as one that involved impairment or incapacitation for reasons of health or mental health, and, that impairment placed the person at serious risk of harm. The status of the caregiver is especially important when accessing the state's comprehensive waiver program where out-of-home residential supports may be offered.

Colorado defines homelessness as not having a place to live or being in imminent danger of the same, but the other states in this study generally are more prescriptive as to what constitutes being homeless. States may also specify that the person was in fact homeless at the time of the emergency, and/or provided specific examples of living in a shelter, on the street, in a prison, or in a hospital with no place to go upon discharge. Colorado's definition of homeless is not as specific when defining where a person may be living at the time. Given that "homelessness" is the single most relied upon reason to establish an emergency, cited as the only reason three times more than any other criteria and in 70% of all cases, this criterion should be evaluated in more detail and the state should consider expanding upon what constitutes being homeless or at serious risk for the same.

Colorado's HCBS-DD Waiver Residential Habilitation service benefit can be provided in either the individual's own home, family home or in a provider supported setting. This is a progressive service definition and is effective in assisting individuals to remain in their own or family home if desired for as long as possible. The use of homelessness in Colorado as the reason for the emergency suggests, however, that the person is seeking residential support either in one's own home or in a provider controlled setting as provided for under the HCBS-DD Waiver. Stakeholders suggested that the increasing and high costs of housing in Colorado may be driving the high incidence of homelessness as the reason for individuals entering an emergency status for enrollment in the HCBS-DD Waiver. That suggestion raises the question of whether the individual's family or current unpaid caregivers are facing homelessness, or is it only the individual with I/DD who is homeless. Stakeholders also noted that often the loss of the caregiver is what has precipitated the emergency and leads to the individual being homeless.

Out-of-family home residential services, typically the most expensive HCBS service, has become an increasing subject of policy debate across the country as state budgets struggle to keep pace with rising Medicaid costs and continued waiting lists for services. In 2012, the Administration on Intellectual and Developmental Disabilities funded a grant to establish a Supporting Families Community of Practice to identify and support best practices in systems of support for families throughout the lifespan of their family member with intellectual and developmental disabilities. The goals of this project grew out of the National Agenda on Family Support developed primarily at the Wingspread Conference in 2011, where the increasing demand for services and funding limitations acknowledged the need to transform the way I/DD systems provide services and supports, and recognize the key role of the family as the primary source of support throughout the lifespan⁸. The five-year grant project initially included six states, and NASDDDS continued the effort in 2017 at the conclusion of the grant project with 17 states now participating in the effort.

⁸ *Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities*. Wingspread Conference, Racine WI. March 6- March 8, 2011.

It is estimated that only 14.7% of all caregiving families of individuals with I/DD nationally are currently receiving support by state I/DD agencies.⁹ Of the approximately 25% who do receive supports, over half live with their families, and in some states, that number is as high as 80%.¹⁰ With the clear majority of people with I/DD nationally living in a family home, it is clear that equitable and transparent access to costly residential services is a priority in many states. The majority of states in this review required a high bar to gain access to its comprehensive waiver program defined by “need” versus “want”. This is a policy decision of each state, but those states with large waiting lists used multiple strategies (e.g. additional entrance criteria, evaluations of support needs, caregiver assessment, and limiting definitions of emergencies) to ensure access to the most comprehensive services was limited to those with the most urgent need, and employed support style waiver programs to support individuals and families in place. All the states in this report that offered more than one waiver program restricted access to the comprehensive waiver program to those with support needs that could not be met under the support waiver, or to those who no longer had a caregiver available due to death or significant incapacitation or impairment that jeopardized the health and safety of the waiver participant.

Beyond reserved capacity and emergency enrollment

Colorado allocates enrollments for the HCBS-DD general waiting list by the order of the placement date on the waiting list, or the date of the 14th birthdate if the individual was found I/DD eligible prior to the 14th birthday. Seven states (Louisiana, North Carolina, New Jersey, Oklahoma, Nevada, Wyoming, and Montana) in addition to Colorado of the 21 states included in this report manage waiting lists in this manner. Eight other states (South Carolina, Pennsylvania, Illinois, Ohio, Kentucky, Connecticut, Missouri, and Maryland) prioritize the waiting list further after reserved capacity and emergency categories, either by when services are expected to be required or by urgency or priority of need, and then apply date of placement on the waiting list within those additional categories. Five states (Minnesota, Washington, New Hampshire, Massachusetts, and Virginia) manage the waiting list using a priority methodology that does not follow the date of placement on the waiting list.

The discussions during the stakeholder engagement sessions were mixed regarding the current practice using date of placement as the single factor for managing the general waiting list. The CCBs noted that many individuals who present as emergency enrollments were never known to the system until the emergency arose, highlighting that there are a number of individuals and families who have not applied for I/DD services and been not placed on the waiting list or may not know that they should. A similar observation was made in a stakeholder session that the current system rewards individuals and families who are more well informed and penalizes those who may be less so. The consultant further explored this issue to query how or if the state should manage urgency or level of need when resources are available to support more individuals who are on the general waiting list. Although some stakeholders expressed concern regarding the consideration for anything other than date of placement on the waiting list, the majority of stakeholders were willing to explore a method to prioritize those who are waiting by additional factors, as long as how long an individual was waiting was one of the factors considered.

⁹ *The State of the States in Developmental Disabilities*. University of Colorado. <http://stateofthestates.org/>

¹⁰ [Supporting Families of Individuals with Intellectual and Developmental Disabilities. The National Community of Practice](#). National Association of State Directors of Developmental Disabilities Services, Alexandria, VA.

Since Colorado has eliminated the waiting list for the HCBS-SLS Waiver, it would suggest that all individuals who are waiting for the HCBS-DD Waiver in the As Soon as Available status should also be enrolled in the HCBS-SLS Waiver or one of the state's other HCBS waivers. The primary difference between the two adult I/DD waiver benefits is the total amount of support hours available within the natural home and for day/vocational and supportive services, and the RHSS benefit that can be provided outside of the natural home. If an individual needs access to 24-hour services and supports and is not in an emergency situation, then one would expect that the individual would also be in need of the benefits available under the HCBS-SLS Waiver.

Department data for April 2017 for all individuals on the HCBS-DD waiting list As Soon as Available category indicates that 76% of all individuals waiting are enrolled in one of the state's other HCBS waivers, and 82% of those not enrolled are receiving some other Medicaid support services. This is a significant percentage of individuals receiving HCBS services while waiting for the additional benefits available under the HCSB-DD Waiver. It would be informative to evaluate how many individuals actually were removed from the HCBS-DD waiting list once enrolled in the HCBS-SLS Waiver. One would expect that for some number of individuals the HCBS-SLS benefit would in fact meet the current needs and mitigate the need for access to 24-hour services and supports. There are also likely situations where individuals are on the As Soon as Available waiting list who do not want any services at this time, but who know that due to the size of the waiting list it is better to obtain a placement date for that date in the future when services may be wanted or needed. This type of behavior while understandable inflates waiting list numbers for planning and budgeting purposes, hence why a number of states including Colorado have waiting list categories that permit identification of need at a future date.

Louisiana, for example, is completing a yearlong review of all individuals on its waiting list using an assessment protocol based on person-centered discussions that collects information on all possible services and supports the person is currently receiving, identification of what the individual needs help with, and an assessment of when those supports will be needed (90 days, within 12 months, 13-24 months, and within two to 5 years). Louisiana officials report that the review process assisted support coordinators to make numerous referrals and connect people to currently available services and supports, and is providing the state with more accurate data to plan for an aggressive waiting list reduction strategy.

Allocation of waiver enrollments

Colorado manages the waiting list for services on a statewide basis, allocating enrollments to those on the waiting list according to reserved capacity first, followed by a person's placement date on the waiting list which is established by their order of selection date. Colorado has experienced several years of new annual enrollments to the HCBS-DD Waiver filled by either those who meet the reserved capacity criteria for children age 18-21 aging out of state foster care or exiting the HCBS-CES Waiver, individuals leaving institutional settings and those individuals who meet the Emergency criteria. Statewide management of a waiting list by regulation does not permit allocation practices that may account for where an individual may live, provider capacity in a certain geographic area, or overall demand.

During the stakeholder engagement sessions, CCB representatives from rural areas of the state recommended that the Division account for geographic differences when managing the waiting list for the HCBS-DD Waiver. The specific issue raised in the stakeholder engagement sessions relative to geography was keeping providers at "capacity" by ensuring there is a new enrollment in that CCB'

catchment area whenever an individual leaves the HCBS-DD Waiver or the area. To evaluate how waiting list practices should or could be modified for geographic differences, evaluation of enrollment allocation practices as it relates to geographic differences found in Colorado is necessary. First, the distribution of those waiting for enrollment for the HCBS-DD Waiver as compared to the total population of people served by the respective CCBs is considered as illustrated below in Table 3:

| Table 3: Individuals Waiting for the HCBS-DD Waiver, by CCB and/or Region Ranked by Total Population | | | |
|---|--|-------------------------------------|--|
| CCB/Region in Order of Total Population Served | Number of Individuals Waiting¹/% of Total Population | Total Population² | County(ies) Served |
| Developmental Pathways | 466 (.05%) | 894,267 | Arapahoe, Douglas |
| The Resource Exchange | 423 (.06%) | 684,887 | El Paso, Park, Teller |
| Rocky Mountain Human Services | 332 (.05%) | 634,542 | Denver |
| Developmental Disabilities Resource Center | 350 (.06%) | 588,184 | Jefferson, Gilpin, Clear Creek, Summit |
| North Metro Community Services | 310 (.07%) | 460,057 | Adams |
| Northeastern Colorado¹¹ | 60 (.02%) | 374,971 | Weld, Sedgwick, Phillips, Yuma, Kit Carson, Cheyenne, Lincoln, Elbert, Washington, Morgan, Logan |
| Imagine! | 403 (.11%) | 363,608 | Boulder, Broomfield |
| Foothills Gateway, Inc. | 111 (.04%) | 310,686 | Larimer |
| Southwestern Colorado¹² | 47 (.02%) | 308,257 | Conejos, Costilla, Alamosa, Rio Grande, Mineral, Saguache, Archuleta, La Plata, Montezuma, Dolores, San Juan, Hinsdale, Ouray, San Miguel, Montrose, Delta, Gunnison, Custer, Fremont, Chaffee |
| Southeastern Colorado¹³ | 39 (.02%) | 230,134 | Baca, Kiowa, Prowers, Crowley, Otero, Pueblo, Las Animas, Huerfano, Bent |
| Northwestern Colorado¹⁴ | 27 (.01%) | 192,075 | Eagle, Lake, Pitkin, Garfield, Grand, Routt, Jackson, Moffat, Rio Blanco |
| Mesa Developmental Services | 60 (.04%) | 147,790 | Mesa |

¹Data Source: Community Contract Management System, as of April 2017

²Data Source: US-Places.com/Colorado/population-by-county.html (2012 Census estimates, accessed June 9, 2017)

¹¹ Northeastern Colorado includes these CCBs: Envision and Eastern Colorado Services

¹² Southwestern Colorado includes these CCBs: Blue Peaks Developmental Services, Community Connections, Inc., Community Options, Inc., and Starpoint

¹³ Southeastern Colorado includes these CCBs: Southeastern Developmental Services, Inspiration Field, Colorado Bluesky Enterprises, and Southern Colorado Developmental Services

¹⁴ Northwestern Colorado includes these CCBs: Mountain Valley Developmental Services and Horizon Specialized Services

The distribution of people waiting for enrollment for the HCBS-DD Waiver relative to total population illustrates some variances that warrant additional investigation. The proportion of people eligible for Medicaid can influence demand for HCBS services, although adults who are eligible for I/DD services are more often also eligible for Medicaid based on disability and income. The distribution of individuals with I/DD is an obvious factor that can only be estimated as a percent of total population. The age of potentially eligible individuals, and the age of potentially eligible individuals' caregivers can also influence demand for adult HCBS-DD Waiver services. People who live in more rural and frontier areas of the state may not be as knowledgeable of available services, or be less inclined to seek state support. The distribution of individuals waiting in a designated geographic area could also reflect past enrollment practices, indicating historical high or low enrollment rates relative to other areas. At minimum, lower waiting list rates indicates a need to ensure there is sufficient outreach and education in those regions of the state.

To evaluate enrollment practices over time, the percent of individuals in each CCB or geographic region and the percent of all individuals enrolled in the HCBS-DD Waiver by CCBs or geographic region was also reviewed and is presented below in Table 4.

| Table 4: Individuals Waiting for and Enrolled in the HCBS-DD Waiver, by CCB and/or Region Ranked by Total Population | | | |
|---|---|---|---|
| CCB/Region in Order of Total Population Served | Number of Individuals Waiting¹/% of all Waiting | % of All Served/ Active Enrollments as of January 2017³ | Total Population²/% of Total Population |
| Developmental Pathways | 466 (18%) | 12% | 894,267 (17%) |
| The Resource Exchange | 423 (16%) | 13% | 684,887 (13%) |
| Rocky Mountain Human Services | 332 (13%) | 13% | 634,542 (12%) |
| Developmental Disabilities Resource Center | 350 (13%) | 11% | 588,184 (11%) |
| North Metro Community Services | 310 (12%) | 8% | 460,057 (9%) |
| Northeastern Colorado¹⁵ | 60 (2%) | 6% | 374,971 (7%) |
| Imagine! | 403 (15%) | 8% | 363,608 (7%) |
| Foothills Gateway, Inc. | 111 (4%) | 6% | 310,686 (6%) |
| Southwestern Colorado¹⁶ | 47 (2%) | 5% | 308,257 (6%) |
| Southeastern Colorado¹⁷ | 39 (1%) | 7% | 230,134 (4%) |
| Northwestern Colorado¹⁸ | 27 (1%) | 6% | 192,075 (4%) |
| Mesa Developmental Services | 60 (2%) | 5% | 147,790 (3%) |

¹Data Source: Community Contract Management System, as of April 2017

²Data Source: US-Places.com/Colorado/population-by-county.html (2012 Census estimates, accessed June 9, 2017)

³PAR Counts by Provider 02/2017

¹⁵ Northeastern Colorado includes these CCBs: Envision and Eastern Colorado Services

¹⁶ Southwestern Colorado includes these CCBs: Blue Peaks Developmental Services, Community Connections, Inc., Community Options, Inc., and Starpoint

¹⁷ Southeastern Colorado includes these CCBs: Southeastern Developmental Services, Inspiration Field, Colorado Bluesky Enterprises, and Southern Colorado Developmental Services

¹⁸ Northwestern Colorado includes these CCBs: Mountain Valley Developmental Services and Horizon Specialized Services

Historical enrollment can be influenced by policy and legislative initiatives over time that compounds attempts at simple analysis (e.g. waiting list initiatives targeted at older caregivers in a single year), but the data in Table 4 does illustrate that current enrollment in the HCBS-DD Waiver is generally well distributed across CCBs and geographic areas of the state. The Imagine! CCB stands out in both a relative higher percentage of individuals waiting relative to all individuals waiting and relative to total population as compared to other CCBS and geographic areas of the state. The Developmental Pathways CCB is slightly underrepresented in total enrollments relative to total population and total number of individuals waiting for enrollment in the HCBS-DD Waiver.

The total population served by each geographic area or CCB and the total number of individuals waiting for enrollment in the HCBS-DD Waiver may also impact the number of people who enter an emergency status while waiting for enrollment. This would be expected for contributing factors related to the characteristics of the individual waiting which would be likely more broadly represented across the state. Contributing factors related to homelessness and abuse and neglect may also be influenced by the cost of housing, cost of living, household income and other socioeconomic factors. The current distribution of emergency enrollments by CCB or geographic area during FY 2016-17 as of June 20, 2017 is displayed below in Table 5.

| Table 5: Individuals Waiting for and Emergency Enrollments in the HCBS-DD Waiver, by CCB and/or Region Ranked by Total Population | | | |
|--|--|---|--|
| CCB/Region in Order of Total Population Served | Number of Individuals Waiting¹/% of all Waiting | % of Total Emergency Enrollments³ | Total Population²/% of Total Population |
| Developmental Pathways | 466 (18%) | (24%) | 894,267 (17%) |
| The Resource Exchange | 423 (16%) | (23%) | 684,887 (13%) |
| Rocky Mountain Human Services | 332 (13%) | (10%) | 634,542 (12%) |
| Developmental Disabilities Resource Center | 350 (13%) | (3%) | 588,184 (11%) |
| North Metro Community Services | 310 (12%) | (1%) | 460,057 (9%) |
| Northeastern Colorado¹⁹ | 60 (2%) | (3%) | 374,971 (7%) |
| Imagine! | 403 (15%) | (11%) | 363,608 (7%) |
| Foothills Gateway, Inc. | 111 (4%) | (8%) | 310,686 (6%) |
| Southwestern Colorado²⁰ | 47 (2%) | (3%) | 308,257 (6%) |
| Southeastern Colorado²¹ | 39 (1%) | (5%) | 230,134 (4%) |
| Northwestern Colorado²² | 27 (1%) | (2%) | 192,075 (4%) |
| Mesa Developmental Services | 60 (2%) | (7%) | 147,790 (3%) |

¹Data Source: Community Contract Management System, as of April 2017

²Data Source: US-Places.com/Colorado/population-by-county.html (2012 Census estimates, accessed June 9, 2017)

³DHCPF Office of Community Living HCBS-DD Waiver Enrollment Tracking as of June 20, 2017

¹⁹ Northeastern Colorado includes these CCBs: Envision and Eastern Colorado Services

²⁰ Southwestern Colorado includes these CCBs: Blue Peaks Developmental Services, Community Connections, Inc., Community Options, Inc., and Starpoint

²¹ Southeastern Colorado includes these CCBs: Southeastern Developmental Services, Inspiration Field, Colorado Bluesky Enterprises, and Southern Colorado Developmental Services

²² Northwestern Colorado includes these CCBs: Mountain Valley Developmental Services and Horizon Specialized Services

This view of the data illustrates far more variance across CCBs and geographic areas of the state relative to simple population and number of people waiting for enrollment in the HCBS-DD Waiver. As noted, this may be influenced by other cost of living, other socioeconomic factors, and natural support networks, and can also be sensitive to qualitative factors such as how effective case management services may be in helping to connect individuals and families to all available services and supports and resolving short-term crisis situations. There was a concern expressed in one of the stakeholder sessions that CCBs may be “gatekeeping” emergency enrollment requests. The variance in emergency enrollments does suggest that the process should be evaluated further.

What is apparent from the review of enrollment, waiting list and population data is that the current system of statewide management of the waiting list and use of reserved capacity groups is not adversely impacting rural and frontier areas versus urban and suburban areas. While rural and frontier areas may experience vacancies in existing group residential settings and other facility based services as a result of natural movement of individuals either out of the area or out of the HCBS-DD Waiver, the distribution of new enrollments or overall enrollment in the HCBS-DD Waiver does not appear to be disproportionately low in those areas. Rural and frontier areas may need to increase marketing of their available services and pursue new business models if there are concerns regarding capacity and long-term viability in those provider networks.

[Recommendations for Colorado for Management of the HCBS-DD Waiver Waiting List](#)

The following recommendations are offered for consideration by Colorado officials as they consider options to continue to explore with the broader stakeholder community.

1. The Department should provide specific guidance and methodology in implementing regulations to assess “need for access to 24-hour supports and services”, one of the eligibility requirement for the HCBS-DD Waiver, that may be evaluated on an inconsistent basis by Case Management Agencies without such guidance. The structure of the HCBS-SLS Waiver provides very limited in-home and community access supports if an individual requires day/vocational supports five days a week, which may be leading to a number of individuals seeking access to the HCBS-DD Waiver who need or want additional supports than is available under the HCBS-SLS Waiver, but who do not rise to the eligibility requirement level of a need for access to 24-hour supports and services.
2. The need for access to 24-hour supports and services is also related to whether individuals are seeking enrollment in the HCBS-DD Waiver as a means to access out-of-home residential services. A “need” for those services as the basis for enrollment in the HCBS-DD Waiver program needs to be explored as a policy matter given the high incidence of homelessness as the reason for emergency enrollment in that waiver program. While this recommendation applies to the eligibility requirements for the HCBS-DD Waiver at this time, the issue will have merit under the waiver redesign where a level of need assessment could be similarly impacted.
3. The definition of “homelessness” should be more clearly defined so that there is consistent application of that criteria across the state. This can include specific situations that rise to this emergency situation, such as the individual is living in a shelter or is hospitalized or in a correctional facility pending discharge or release and does not have a residence to return to.

4. Related to recommendation # 3, the absence of the status of the current unpaid caregiver(s) as one of the factors that may be creating the emergency situation for the individual may be part of what is driving the high use of homelessness as the criteria establishing the emergency status. To improve clarity and collection of data to inform future policy, Colorado should include the loss or incapacitation of the caregiver as one of the factors to justify an emergency enrollment request. Refer to Pennsylvania, Connecticut, Virginia and Oklahoma for examples of considering caregiver status in emergency requests.
5. The current *Request for Emergency Enrollment* Form is dependent upon the Case Management Agency to describe the emergency situation in detail and provide information regarding previous efforts to resolve the situation. The Department should require supporting documentation to substantiate the circumstances supporting the emergency enrollment request and of the efforts implemented to resolve the situation. The Department should also review the form itself and evaluate if there can be additional information that can be standardized to support the request. See the format utilized by Virginia in the appendix for example.
6. Expanding on recommendation number 5, consider utilizing a standardized questionnaire/assessment and scoring methodology to ensure both consistent information is obtained from the Case Management Agencies and evaluated to further prioritize the general waiting list by urgency, time waiting and level of need. Examples are included in the appendices to this report from Virginia, Massachusetts, Missouri, South Carolina, and Connecticut. This may include only adding one additional category to the waiting list to identify those individuals who are of highest priority and then follow order of placement on the waiting list, or include date of placement on the waiting list as one of the weighted factors in the prioritization methodology for all individuals waiting. Given that individuals may wait for HCBS-DD services for a number of years, it could be effective to identify individuals and circumstances that are most critical prior to reaching an emergency status.
7. Evaluate all individuals currently on the HCBS-DD Waiver As Soon as Available category to ensure they are currently receiving all available and appropriate benefits. Ensure that those individuals who were part of the HCBS-SLS enrollment initiative are still in need of HCBS-DD Waiver supports.
8. Implementing a level of need and prioritization assessment for those individuals who are waiting for I/DD services will improve the Department's ability to forecast expansion requests and plans for long-term reduction of the waiting list. The new LTSS Eligibility Assessment Tool under development may be an ideal data source to inform potential level of need and priority for enrollment.

The primary purpose of a waiting list for HCBS waiver services should be to establish as accurately and transparently as possible those individuals who are in urgent need for services to allocate state resources effectively to meet the health and safety needs of its citizens. Maintaining an expanded waiting list for HCBS waiver services to include those individuals who anticipate the need for HCBS services in the future should be time limited to be practical and useful for planning and budgeting purposes, and include the sufficient information regarding individual and caregiver characteristics to both be predictive of service needs and eventual urgency of need.

Colorado does include two categories in the waiting list for individuals who have a specific date when they expect to seek services (See Date) or who wish to be on the waiting list should a future need arise

(Safety Net). For the HCBS-DD Waiver, predicting a specific date when an individual will need access to 24-hour services and supports may be difficult to implement consistently. The availability of the HCBS-SLS Waiver and its benefits would suggest that those who know of a future date when the HCBS-DD Waiver is required would be anticipating the loss of the current network of natural supports. This category can also be used to plan for when an individual is aging out of the HCBS-CES Waiver or out of other state funded supports.

The Colorado DIDD waiting list practices as it is currently structured and defined does not provide sufficient information regarding the level of support a person may need or provide information about the caregiver(s) circumstances in a structured manner. As a result, it is difficult to forecast potential budget impact or future emergency demand. Certainly, past experience provides trend data to build upon, but as the waiting list ages and unmet need builds, this kind of data can be invaluable for short and long-term planning. This can also create challenges with the management of the waiting list in a consistent, transparent and equitable manner across the state, which may be occurring based on the distribution of emergency enrollments across the state.

Complicating this scenario are two factors. The first is the structure of benefits available under the HCBS-SLS Waiver versus the HCBS-DD Waiver. There appears to be a space between the two where individuals may need more support than is available under the HCBS-SLS Waiver, but would not typically meet a standard of need for access to 24-hour supports and services. The phrase “access to” is a difficult standard in and of itself to measure. Enrollment in the HCBS-DD Waiver requires receipt of comprehensive residential habilitation services and support either within one’s own or family home, or in a provider supported setting. Typically, in states where such a waiver operates, the entrance criteria is strictly controlled and reserved for individuals with some combination of moderate to complex support needs and compromised caregiver/natural supports. In Colorado, in practice it appears that the HCBS-DD Waiver is sought for any individual who simply needs or wants more service than is available under the HCBS-SLS Waiver. The waiver redesign project where Colorado will move to a single waiver will most likely address this specific pressure on the waiting list.

The second factor is the need to address those individuals who have been waiting for the services and supports available under the HCBS-DD Waiver for many years. Any modification to the I/DD waiting list management practices must account for those who have been waiting for the longest periods of time. The fact that there has been a long-standing waiting list for the I/DD services found under the HCBS-DD Waiver reinforces the need to prioritize those waiting to ensure that those who are in most urgent need are served in a priority order, but, the length of time waiting can and should also be a factor and weighted accordingly when developing the methodology. There are a number of assessment tools in use by state I/DD agencies that query the individual’s specific support needs, the status of his/her caregiver(s) or natural support network (age, health, knowledge, other caregiving responsibilities, etc.), health and safety status, stability and safety of the living arrangement, stability of employment of the individual and caregiver(s), support for community inclusion, etc., that can be considered to increase the standardized information available to the Case Management Agencies and the state to collectively plan for the most effective way forward to support individuals who continue to wait for HCBS-DD Waiver services. The current case management information system also has the capacity to collect additional information regarding those individuals waiting, and could be considered as an immediate source of improved information.




In the short-term, management practices can be improved by standardizing how Case Management Agencies establish eligibility for the HCBS-DD Waiver, standardizing required supporting evidence for an emergency enrollment, by adding the loss or incapacitation of the caregiver to the emergency criteria, and by requiring the Case Management Agencies to collect additional information regarding individuals on the HCBS-D Waiting list via the existing case management information system. In the long-term, Colorado should consider these recommendations as it develops the new LTSS Eligibility and Case Management system and proceeds with the I/DD waiver redesign project.

Appendices



MASS Caregiver and
consumer assessment

A. Massachusetts Priority Tool, MASSCAP

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- B. Massachusetts Description of the Implementation of the MASSCAP
 SHORTMASSCAP
(1).docx
 - C. Connecticut WL Decision Tool for I/DD Comprehensive Support HCBS Waiver
 CTattachment_a_prio
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 - D. Missouri Priority of Need Tool for I/DD HCBS Waiver
 MO-PON.pdf
 - E. South Carolina I/DD Policy for Determining Critical Need
 SC WL
502-05-DD-Revised(0
 - F. Virginia Wait List Slot Assignment Procedures for the I/DD HCBS Waivers
 VA DD Waiver Wait
List Slot Assignment F
 - G. Louisiana I/DD Screening for Urgency of Need (SUN) Tool
 SUN tool.pdf
 - H. Colorado Waiting List Stakeholder PowerPoint Presentation
 CO WL Stakeholder
Presentation(r4).pptx
 - I. Colorado Stakeholder Sessions Report
 Stakeholder Sessions
Report.docx