Waiting Lists and Medicaid Home and Community-Based Services

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I. Introduction

Across the nation, there are gaps between available financing and demand for services. The University of Minnesota annual report indicates that in 2014 748,585 people with intellectual and/or developmental disabilities (I/DD) received Medicaid funded 1915(c) home and community-based services (HCBS) waivers.[1] But 36 states also report 216,328 individuals living with family waiting for services.[2] Only 12 states reported no waiting lists (and three did not furnish information).

Managing waiting lists in a Medicaid environment requires states to parse the various regulations that apply to specific authorities. Because it is the single largest source of financing, we will mainly focus on the 1915(c) HCBS waivers. We cover Medicaid State Plan requirements as well as offer a cursory look other authorities as more states are adding other options into the mix of long-term supports such as 1915(i) State Plan HCBS and 1915(k) Community First Choice. We also look at the 1115 research and demonstration waivers as a number of states have moved their systems into managed care arrangements.

Each of these authorities — along with the "regular" Medicaid state plan — come with different and specific requirements that affect waiting lists. We offer a set of questions and answers plus a matrix on the primary Medicaid HCBS authorities and their respective structures related to waiting lists to assist states in understanding the various applicable regulations.

As with any Medicaid policies, we urge states to use the source documents cited in this paper and encourage states to always check with your Centers for Medicaid & Medicare Services (CMS) analysts for definitive policy guidance.

II. Waiting Lists and Medicaid State Plan Services

Q. Are waiting lists permitted for Medicaid State Plan services contained at 1905(a) of the Social Security Act?

A. No. States may not have a waiting list for any state plan services as these services are an entitlement to all eligible individuals who have "medical necessity" for the service. This includes all "regular" Medicaid mandatory and optional services (meaning those that can be found at Section 1905(a) of the Social Security Act). Therefore, state plan services like physician's services, personal care, targeted case management, and *anything* covered under Early and Periodic Screening, Diagnostic,

[1] Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2017). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2014.* Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Access at risp.umn.edu/publications, 56. Three states did not furnish information.
[2] Ibid., 51.

and Treatment (EPSDT) requirement for children under 21 cannot have waiting lists.[3] As noted in the table below, there are additional, non-1905(a) state plan benefits, that are addressed in greater detail below.

Mandatory Services	Optional Services

• In/outpatient hospital
• Physician, midwife, and nurse practitioner
• Nursing home
• Home health
• Screening and treatment (EPSDT) for kids under 21
• Family Planning
• Rural health clinics, federally qualified health centers
	• Personal care
	• ICF-IID
	• Prescription drugs
	• Therapies-OT/PT/Speech
	• Eyeglasses
	• Dental services
	• Targeted case management
	• Mental Health Services
	• HCBS State plan services
	  ○ 1915(i) State plan HCBS
	  ○ 1915(k) Community First Choice
	  ○ 1915(j) Self-directed Personal care
	  ○ 1915(b)(4) Selective contracting

Q. What if a service isn't immediately available or will take some planning time to deliver?

A. Section 1902(a)(8) of the Social Security Act requires that states, "… provide that all individuals wishing to make application for medical assistance under the [state] plan shall have opportunity to do so, and that such assistance shall be furnished with reasonable promptness to all eligible individuals… "Although this regulation references making application, a considerable body of case law has established that this requirement also applies to service delivery."[4] In other words, states have an obligation to make sure that state plan services are available to individuals. In fact, CMS has published a regulation that holds states accountable for making sure there is sufficient access to state plan services.

Q. What is the timeframe for "reasonable promptness"?

A. Under 42 CFR § 435.911(a) the Department of Health and Human Services (HHS) addresses the statutory reasonable promptness provision setting specific time limits to determine eligibility: 90 days for applicants who apply based on disability and 45 days for all others. While this citation again is tied to eligibility determinations, it has been broadly interpreted in multiple cases to also apply to service delivery.[5] Thus, CMS has indicated expectations using this 45-90 day timeframe with regard to services initiation.

[3] See www.medicaid.gov/medicaid/benefits/epsdt/index.html.
[4] See lawcrawler.findlaw.com/LCsearch.html?restrict=lp&client=lp&entry=medicaid+reasonable+promptness.
[5] Ibid.

Q. What is "medical necessity"?

A. The federal Medicaid agency, the Centers for Medicare & Medicaid Services (CMS), does not provide a statutory definition of medical necessity. The best advice on medical necessity can be found in CMS's guidance on EPSDT services. Although this references children, the logic used may be reasonably applied to adults as well:

"The determination of whether a service is medically necessary for an individual child must be made on a case-by-case basis, taking into account the particular needs of the child. The state (or the managed care entity as delegated by the state) should consider the child's long-term needs, not just what is required to address the immediate situation. The state should also consider all aspects of a child's needs, including nutritional, social development, and mental health and substance use disorders. States are permitted (but not required) to set parameters that apply to the determination of medical necessity in individual cases, but those parameters may not contradict or be more restrictive than the federal statutory requirement…"[6]

Additionally the HCBS *Waiver Technical Guide* offers this definition of medical necessity:

"Services or supplies that are proper and needed for the diagnosis or treatment of a medical condition, are provided for

***State Strategies for Defining Medical Necessity for Children and Youth with Special Health Care Needs*, Amy Clary and Barbara Wirth, NASHP, October 2015, p. 3**

States Setting Their Own Guidelines

State	Medical Necessity Parameters
California	"A service is 'medically necessary' or a 'medical necessity' when it is reasonable and necessary to protect life, to prevent significant illness or significant disability, or to alleviate severe pain."
Colorado	The state has an EPSDT-specific medical necessity definition that, among other provisions, requires a service to be "an equally effective treatment among other less conservative or more costly treatment options," in order to be considered medically necessary.
Illinois	"Necessary medical care" under EPSDT is that which is "generally recognized as standard medical care required because of disease, disability, infirmity or impairment."
Washington	The state Administrative Code defines as medically necessary those services which are "reasonably calculated to prevent, diagnose, correct, cure, alleviate or prevent worsening of conditions in the client that endanger life, or cause suffering or pain, or result in an illness or infirmity, or threaten to cause or aggravate a handicap, or cause physical deformity or malfunction."
Wyoming	State rules and regulations define a medically necessary service as one "that is required to diagnose, treat, cure or prevent illness, injury or disease which has been diagnosed or is reasonably suspected, to relieve pain or to improve and preserve health and be essential to life. The services must be: O Consistent with the diagnosis and treatment of the recipient's condition O Recognized as the prevailing standard or current practice among the provider's peer group O Required to meet the medical needs of the recipient and undertaken for reasons other than the convenience of the recipient and the provider; and O Provided in the most efficient manner and/or setting consistent with appropriate care required by the recipient's condition.

[6] *EPSDT – A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents* www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf.

the diagnosis, direct care, and treatment of the condition, and meet the standards of good medical practice."[7]

Interestingly the *Waiver Technical Guide* only references the term medically necessary in relation to state plan services, and, in particular to EPSDT. States must develop their own guidelines for assessing medical necessity. As "traditional" Medicaid has grown to include a variety of non-medical services, the term "medical necessity" is difficult to apply to services such as chore services, case management, personal care and other home and community-based services. The term "assessed need" has gained some currency in HCBS as it includes more than medical needs.

Q. Are waiting lists permitted for Medicaid State Plan HCBS options?

A. This same requirement of not allowing a waiting list for other state plan services also applies to the *state plan HCBS* options such as 1915(i) State Plan HCBS, 1915(k) Community First Choice. These programs are an entitlement ***to all members of the specific groups covered by each authority***. It is important to understand the particular provisions of each authority related to who can or who must be covered by a state offering the benefit.

1915(i) State Plan HCBS

Under 1915(i) states can target the benefit by the categories of Medicaid eligibility groups, age, diagnosis and/or condition. States also establish "needs-based criteria" that establish, based on assessment, further eligibility requirements for entrance into the program. The needs-based criteria typically establish functional status (ADLS and IADLs) showing the type or level of supports individuals may need. They may also include risk factors (such as a history of hospitalization). So, while 1915(i) does not permit waiting lists, it is limited to the state-specified approved target group.

1915(k) Community First Choice (CFC)

1915(k) is available to any Medicaid eligible individual who meets the level of care (LOC) for institutional services. The state cannot target any specific group within this broader eligibility group, so 1915(k) serves children and adults including seniors, individuals with physical disabilities as well as individuals with I/DD. Anyone meeting the LOC requirement is eligible and cannot be placed on a waiting list.

1915(j) Self-Directed Personal Assistance Services (PAS)

1915(j) regulations allow the state to define a target population and cap the number served. So, states may have a waiting list under the 1915(j) option. But 1915(j) has a

[7] 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, Release Date: January 2015, 304.

"safety net" in that the state must also provide "traditional" personal care services to individuals eligible for 1915(j). This is because individuals eligible for 1915(j) must also be eligible for state plan (and/or HCBS waiver if available) personal care.

III. Waiting Lists and 1115 Research and Demonstration Waivers

Q. Are waiting lists permitted under the 1115 Research and Demonstration Waivers?

A. Section 1115 Research and Demonstration waivers give the Secretary of Health and Human Services authority to approve experimental, pilot, or demonstration projects that promote the objectives of the Medicaid program. Because of this, they are not at all uniform from state to state. Many 1115s that contain HCBS do seek to serve to everyone eligible, but it is important to review a specific state's 1115 structure.

IV. 1915(c) HCBS Waivers

A. General Waiting List Policies

Q. Are waiting lists allowable under 1915(c) HCBS waivers?

A. Yes. But CMS has provided guidance that states must articulate their waiting list policies as part of the waiver application subject to CMS approval. The 2015 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, (which we will refer to as the *Waiver Technical Guide*), in Item B-3-f: Selection of Entrants to the Waiver, indicates: "If it is necessary to defer the entrance of individuals to the waiver, the state must have policies that govern the selection of individuals for entrance to the waiver when capacity becomes available. These policies should be based on objective criteria and applied consistently in all geographic areas served by the waiver." [8] CMS also indicates with regard to waiting list policy, "A state may not delegate the authority to establish policies for the selection of individuals to enter the waiver to local/regional non-state entities or other types of entities."[9] CMS is careful to limit their guidance to the manner in which states establish criteria for selection of entrants into the waiver, and does not opine on state strategies for other aspects of managing a waiting list, such as criteria for placement on the waiting list or waiting list category designations.

[8] 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, Release Date: January 2015, 80.
[9] Ibid.

Q. What specific policies must states have?

A. CMS does not precisely specify a set of waiting list components. But CMS does indicate some caveats as to what states cannot do, noting, "It is not appropriate to base policies for the selection of otherwise eligible individuals on factors such as the expected costs of waiver services or the types of services that an individual might require post-entrance." [10]

Q. If you cannot use costs to deny entrance, how does this interact with capped waivers or individual cost limits?

A. The above does not mean that states cannot deny entrance to a capped supports-type waiver program if the person's health and safety cannot be assured through the resources (and other generic or non-paid) available through the waiver or through the waiver in combination with other supports. States may also specify an individual cost limit on a comprehensive waiver and may deny entrance to individuals whose costs exceed the established limit or whose individual costs cause the entire HCBS waiver to exceed its cost-neutrality calculations as compared to institutional costs.

CMS does require protections for individuals denied (or terminated from) waiver services, noting, "When there is an individual cost limit, the need for such additional services may result in the person no longer being eligible for the waiver." The *Waiver Technical Guide* goes on to specify the types of safeguards states should include for individuals denied or terminated from waivers due to costs, including assisting the individual in the transition to alternative options.[11]

Q. Does CMS offer any examples of waiting list criteria?

A. CMS offers two criteria — but as we will see in some of the approved state waiting list policies described later in this document, many other criteria are acceptable. CMS offers the following: "Examples of appropriate policies may include (but are not necessarily limited to):

- Entry to the waiver is offered to individuals based on the date of their application for the waiver; or,
- Entry to the waiver is prioritized based on the imminent need for services that is determined through an assessment process."[12]

[10] Ibid., 80.
[11] Ibid., 70-73 (Appendix B-2: Individual Cost limit).
[12] Ibid.,80.

B. Single/Multiple Waiting Lists

Q. Are states required to have only one waiting list for multiple waivers?

A. No. States may have a waiting list for each waiver. Waiting list policies and management for each waiver must be described in the approved waiver application(s). Many states elect to have a single waiting list for multiple waivers serving the same target group (i.e., multiple waivers for individuals with I/DD) and assist individuals on that waiting list to access the waiver that is best suited to meet their needs. Administration of multiple waiting lists requires strong administrative procedures to ensure that each list remains current and accurate.

Q. Can people be on more than more than one HCBS waiver waiting list?

A. Yes.

Q. If a state has multiple waivers can they still have one "comprehensive" waiting list for all the waivers serving a specific target group?

A. Yes. The state waiver operating agency may opt to manage waiver entrance with one statewide waiting list. See Section III below for examples.

Q. Can an individual already enrolled in a HCBS waiver be on a waiting list for another waiver?

A. Yes. For example, an individuals enrolled in a "supports-type" waiver may be desirous of residential services not covered by their current program. The individual may choose to be on a comprehensive waiver waiting list, and of course would have to meet the selection criteria for entrance into the other waiver.

States may not have, however, a waiting list for individuals needing a higher level of service in a waiver in which they are currently served. Once enrolled in a waiver, an individual is entitled to any service within that waiver for which they have demonstrated need. See question below on waiting for specific waiver services.

C. Use of Local/Regional Agencies to Manage Waiting Lists

Q. Some states use local/regional non-state or sub-state entities to manage HCBS waiver enrollment. Is this allowable?

A. Yes. States may allocate waiver capacity by locality or region and may use local/regional sub-state and/or non-state agencies to manage waiver enrollment.[13]

[13] Ibid., 57.

Q. Does CMS have specific expectations when waiver capacity is allocated regionally?

A. Yes. There are a number of expectations that must be met when allocating waiver capacity regionally:

- The method(s) used to allocate *capacity must, "…result in similar access to the waiver among the geographic areas where the waiver operates*."[14] This must be met to assure equal access across the state in order to meet the "statewideness" requirements of the HCBS waiver. CMS notes too that even if a state has a waiver of statewideness, within the area served equal access is still required.
- The state must *establish a methodology to reallocate unused waiver capacity* to other parts of the state where there are waiting lists. It is not permissible to have individuals waiting for services if there is unused waiver capacity. (See Section C below for additional information.)
- The allocation of waiver capacity by region or geographic area cannot inhibit freedom of movement of waiver participants from one place to another in a state. CMS indicates that, "… *waiver "slots" must be portable across areas of the state*."[15]

Q. Since states can have a waiting list for entrance into the HCBS waivers, can the state also havea waiting list for specific services once the individuals is enrolled in the waiver?

A. No. Based on the individual's assessed need, the identified services, if covered under the waiver must be delivered. CMS advises, "Any service that is offered in a waiver must be available to every waiver participant who requires the service…."[16] Lack of provider availability is not a permissible reason to not provide a needed service. CMS does recognize "community standard", understanding that access to multiple providers and choice of provider in a highly rural area may be more limited than in urban/suburban areas, but still expects states to continually identify and address potential capacity issues.

D. Unused Waiver Capacity and Waiting Lists

Q. If the approved waiver has unused capacity, can you still have a waiting list? For example, if the state's approved application indicates they will serve 5,000 individuals in the current year but the legislature only approved funding for 4,500 individuals, can the state still have a waiting list?

A. It is important to "peg" any waiver application as close as possible to the actual unduplicated count that the state's budget will permit the state to serve. If the approved

[14] Ibid., 79.
[15] Ibid.
[16] Ibid., 47.

unduplicated count is higher than the actual funded waiver capacity (often referred to as waiver slots), the state is still liable to serve up to the approved number of individuals. This becomes very important if the state has a waiting list since the state is liable for the **approved number of participants** even if the appropriation does not suffice. In this situation, the state would have to serve 500 additional individuals from the waiting list.

The *Waiver Technical Guide* indicates: "Entrance to the waiver may not be deferred when there is unused waiver capacity (except when a state has established a point-in-time limit, reserved capacity or made entrance subject to a phase-in schedule)."[17] If the state has unfunded capacity approved in the waiver and a waiting list, the state should request a reduction in waver capacity to more closely match the funding levels and actual unduplicated number of people to be served.

It is important to note that an amendment designed solely to increase unduplicated participant counts is typically very simple and usually readily gains CMS approval, so it is always easier to increase if needed than to reduce an approved waiver capacity.

E. Enrollment Policies and Waiting Lists

Q. What is reserved capacity?

A. HCBS waiver guidance permits states to reserve — that is, set-aside, waiver capacity for specific groups. States can identify populations that are a priority and set aside waiver capacity for those individuals. While CMS does not provide any list of "approved" groups they offer some examples such as individual moving to the community from institutions, individuals moving from other waivers, individuals in crisis, or individuals "aging-out" of other services. States have broad latitude in assigning reserve capacity but the purpose must only be to, "hold open capacity for specific populations and this option, "does not violate the requirement that all waiver participants enrolled in the waiver have comparable access to all services offered in the waiver."[18] Section III below offers some state examples of how reserved capacity is used to serve specific populations.

Q. How does reserved capacity interact with a waiting list?

A. Because waiver capacity is set aside for certain groups, individuals on the waiting list who do not meet the specific individual or situational factors of the "reserved" group are not eligible for this waiver capacity. The Waiver Technical Guide advises that, "Reserved capacity is not available to persons who are not in the state-specified priority population." 19 States often address reserved capacity categories in their description of policies related to selection of entrants into the waiver in Appendix B-3-f.

[17] Ibid., 79.
[18] Ibid., 76.
[19] Ibid.

Q. What is a point-in-time limit? How does this affect individuals on waiting lists?

A. In the *Waiver Technical Guide***,** Item B-3-b: Limitation on the Number of Participants Served at any Point in Time, permits states to specify enrollment numbers at specific times. The state can limit the maximum number of participants are served at any point in time during the waiver year. The state may do this for only one year of the waiver or multiple years. It is completely at state discretion.

Setting a maximum point-in-time number, may help the state manage waiver expenditures impacted by turnover (individual leaving the waiver and new individuals "replacing" them) during the course of a waiver year. The *Waiver Technical Guide* offers an example of why a state might use this type of limit: "For example, a waiver may provide for the enrollment of no more than 1,000 unduplicated participants during a waiver year. Taking turnover into account, a state might establish a point-in-time enrollment limit of 950 individuals. Establishing such a limit may avoid a state's having to freeze entrance to the waiver before the end of the waiver year."[20] This limit means that once the point-in-time limit is met, individuals on the waiting list would have to wait for vacancies due to turnover.

Q. What is a phase-in schedule? How does this affect individuals on waiting lists?

A. In order to manage waiver enrollment, a state may decide to enroll a specific number of individuals each month For example the state may plan to enroll 4800 individuals by the end of a year. To manage workload or financial resources, the state may wish to limit monthly new enrollment to 40 individuals per month. Once this number is reached, the state could have individuals on the waiting list for the next month's allotment.[21]

V. Examples Of HCBS Waiver Waiting List Policies

While CMS does set some policy requirements regarding waiting lists, states have considerable latitude in how they design and manage waiting lists for HCBS. Typically, states first assure the individual is eligible for I/DD services. Some states require that the person also be Medicaid eligible and others actually require that the person meet HCBS waiver eligibility before placement on a waiting list.[22] Typically all states provide some type of emergency waiting list category that gives priority to individuals who are in crisis. Most commonly a loss of primary caregiver, homelessness, risk of harm to self or

[20] Ibid., 74.
[21] Ibid., 77.
[22] See, Nuss, Laura," Waiting Lists for Medicaid Waiver Programs: A Report of Findings from an Environmental Scan of the Use and Management of Waiting Lists for the Ohio Department of Developmental Disabilities", prepared for the Ohio Department of Developmental Disabilities, National Association of Directors of Developmental Disabilities Services, March 2017.

others and/or abuse, neglect or exploitation are situations when an individuals can "jump the queue" no matter what other waiting list protocols are in place.[23]

A. Waiting List Criteria for Order of Selection into HCBS Waivers

1. First Come, First Served

Other than for individuals who meet an emergency criteria, some states opt to manage their waiting list on a first come, first served basis. Individuals are offered waiver services based on the length of time they are on the waiting list.

North Carolina uses a variation of first come first served. They use an annual assessment tool to establish needs but the length of time the applicant has been waiting for wavier services is factored into the prioritization. Individuals who are not considered 'emergent" are deemed to have routine needs.[24] North Carolina also used reserved capacity to establish higher priority for individuals transitioning from the Money Follows the Person Project, or two other waivers (CAP-C Waiver or Innovations Waiver).

2. Prioritization by Age, Diagnosis, or Situational Factors

Some states assess an individual against a set of criteria that may reflect characteristics of the individual or their situation. As an example, Iowa uses a variety of factors in establishing priority for services, establishing emergency or urgent needs.[25] Iowa's criteria also indicate that, "[i]f applicants meet an equal number of criteria, the position on the waiting list shall be based on the date of application and the age of the applicant. The applicant who has been on the waiting list longer shall be placed higher on the waiting list. If the application date is the same, the older applicant shall be placed higher on the waiting list. Applicants who do not meet emergency or urgent need criteria shall be placed lower on the waiting list than the applicants meeting urgent need criteria, based on the date of application. If the application date is the same, the older applicant shall be placed higher on the waiting list." [26]

3. Screening Tools Used to Set Priority

A number of states set waiting list priority using assessment tools. These tools typically assess functional skills and intensity of support needs. Some states use nationally recognized tools such as the Supports Intensity Scale (SIS)[27] and InterRAI[28], while others have been developed by a specific state such as the NC-SNAP[29] or

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[23] Ibid., 4.
[24] North Carolina Comprehensive waiver: www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/NC0662.zip.
[25] Iowa Intellectual Disabilities Waiver, B-3-f. Selection of Entrants to the Waiver: www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/IA0242.zip.
[26] Ibid.
[27] SIS: aaidd.org/sis#.WYyvLYWcGHs.
[28] InterRAI: www.interrai.org.
[29] NC-SNAP: www.ncdhhs.gov/providers/provider-info/mental-health/nc-support-needs-assessment-profile.

IOWA WAITING LIST

Emergency Need Criteria

The usual caregiver has died or is incapable of providing care, and no other caregivers are available to provide needed supports.

The applicant has lost primary residence or will be losing housing within 30 days and has no other housing options available.

The applicant is living in a homeless shelter and no alternative housing options are available.

There is founded abuse or neglect by a caregiver or others living within the home of the applicant, and the applicant must move from the home.

The applicant cannot meet basic health and safety needs without immediate supports

Urgent Need Criteria

The caregiver will need support within 60 days in order for the applicant to remain living in the current situation.

The caregiver will be unable to continue to provide care within the next 60 days.

The caregiver is 55 years of age or older and has a chronic or long-term physical or psychological condition that limits the ability to provide care.
The applicant is living in temporary housing and plans to move within 31 to 120 days.

The applicant is losing permanent housing and plans to move within 31 to 120 days.

The caregiver will be unable to be employed if services are not available. There is a potential risk of abuse or neglect by a caregiver or others within the home of the applicant.

The applicant has behaviors that put the applicant at risk.

The applicant has behaviors that put others at risk.

The applicant is at risk of facility placement when needs could be met through community-based services.

Pennsylvania PUNS[30]. Scores on these assessments may figure into to determining the intensity of support needs, thus affecting waiting list status. North Carolina uses the NC-SNAP in waiting list judgements. Minnesota has developed the DD Waiver Waiting List Category Determination Tool to use in assessing waiting list priority.[31] Virginia uses their own priority protocol called the Virginia Individual DD Eligibility Survey (VIDES) as one aspect of assessing the priority of needs.[32]

B. Waiting List Management

As with the waiting list criteria, states also have varying approaches to managing waiting lists. Some states have a single statewide list while other may allocate waiver capacity to regional entities who then manage the "local' list. Some states may also maintain multiple waiting lists allowing individuals to be on more than one waiting list.

1. Waiting List Managed by Local/Regional Agencies

Pennsylvania, Minnesota, Virginia, and Ohio area few of the states that use regional entities to manage waiting lists. As noted earlier, this is permissible but states must assure that the state allocates waiver capacity in a manner that assures equitable access to waiver services across the state. The state must also have a method to reallocate unused waiver capacity and the use of regional allocation cannot interfere with the "portability" (the individual's right to move and retain services) of an individual's waiver services.

[30] PUNS: dhs.pa.gov/communitypartners/intellectualdisabilities/prioritizationofurgencyofneedforservicespuns/index.htm.
[31] edocs.dhs.state.mn.us/lfserver/Public/DHS-7209-ENG.
[32] www.dbhds.virginia.gov/library/developmental%20services/dd%20waiver%20wait%20list%20slot%20assignment%20process%2008-22-16.pdf.

As an example, the Ohio county boards are responsible for adding the names to Ohio's statewide waiting list of any individual who requests services from a waiver that has no available funded capacity or who simply requests to be added to the waiting list. Each year, boards send the state Department of Developmental Disabilities an allocation request with the numbers of individuals they anticipate enrolling in the various waivers serving individuals with I/DD. Using a web-based application called PICT, DODD allocates waiver slots every quarter to each board.[33] PICT has a population-based algorithm to make sure that the statewide allocation is equitable.

When states use local/regional entities, to assure equity of access, the state must monitor the local/agencies to assure waiting list protocols are carried out in similar way throughout the state. The state must assure that there is no local "drift' from required, statewide protocols that affects required equal access across the state. Also, when local/regional entities have unused capacity, the state will want to assure that this is due to all eligible individuals being served in that area and not to other factors such as lack of providers.[34]

2. Statewide Waiting List

Many states manage the waiting list centrally, using one statewide list. While local or regional case managers may assist individuals to get on the waiting list, management and selection of individuals is done centrally. As an example, in Massachusetts the state central office waiver unit receives and reviews all applications and required assessments. Using a state-developed assessment tool, the MASSCAP, individuals are prioritized. The central office waiver unit, based on available waiver capacity and on the individual's priority status, make the offer of enrollment.[35] Some other states with a single centrally managed waiting list are Alaska and Connecticut.

3. Multiple Waiting Lists

Some states opt to have multiple waiting lists. These lists are tied to specific waivers. As noted earlier, CMS offers no prohibition for individuals to be on multiple lists. As an example, Colorado allows individuals to be on waiting lists for the supported living services (SLS) and/or residential services (DD waiver) starting at age 14.[36]

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[33] The Preliminary Implementation Component Tool information is found at dodd.ohio.gov/CountyBoards/PICT/Pages/default.aspx.

[34] For a comprehensive look at Medicaid access rules, see *Report to Congress on Medicaid and CHIP*, Chapter 4: Monitoring Access to Care, MACPAC, 2017, found at www.macpac.gov/wp-content/uploads/2017/03/March-2017-Report-to-Congress-on-Medicaid-and-CHIP.pdf.

[35] Massachusetts HCBS Waiver Application, B-3-f. Selection of Entrants to the Waiver www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/MA0826.zip.

[36] At present Colorado has eliminated their waiting list for the SLS waiver but there is still a waitlist for the DD waiver. Individuals may be enrolled in the SLS waiver and also be on the DD waiver waiting list. Many individuals are able to access services through the SLS waiver which provides all the services they need and the DD waiver is not sought. If SLS capacity becomes full, individuals may be on waiting lists for both programs.

To manage their waiting lists Colorado has established the following:

Timeline Choices for Adult Wait Lists

There are three choices an individual and their family can make when deciding when the individual will actually want SLS or residential services. Those choices are a specific date, as soon as available, or safety net.

- Specific Date: Specific Date refers to the want for a service at a specific date. For example, the date a person turns 18 or 21, the date of graduation, or any other date determined by the person or their family
- Safety Net: Safety Net means the person does not want or need the service currently, but will want or need a resource if current supports are lost or otherwise change.
- As Soon As Available: ASAA means the service is needed right now and the resource would be accepted "As Soon as Available."[37]

One concern about multiple waiting lists is accurately assessing unmet need. With multiple waiting lists states have to 'cross-reference' the lists to ascertain an accurate unduplicated count of individuals waiting for services.

4. Managed Care

Some states utilize managed care delivery systems to provide home and community-based services. The particular authorities used by states to design their managed care programs and the services that are included are important factors in whether and how waiting lists can be utilized. Some states use 1915(b) / 1915(c) concurrent waivers to effectuate managed care, while others use 1115 demonstrations or, in a more limited fashion, 1915(a) contracting authority. The details of the authority design really dictate the state's access strategies for services so it is important to look carefully a state's specific program aspects. Some states have utilized managed care structures to address waiting list backlogs, but, again, each state and program is different.

5. Periodic Review of Waiting Lists

CMS sets no particular guidance on maintaining the accuracy off waiver waiting lists. But for state purposes, assuring the integrity of waiting list data is essential to accurately demonstrating unmet need and conducting budgetary forecasts — as well as to monitor progress in moving people off the waiting lists (which of course is useful for *Olmstead* compliance). Some states annually review their waiting lists to establish that it is a correct picture of unmet need. Other may do a "clean-up" of the list on a longer timeframe, but the more accurate the list, the better able the state will be in projecting budget needs.

[37] www.rmhumanservices.org/faq-types/wait-list-waiver-services

VII. Conclusion

Although CMS sets some criteria for the establishment of waiting lists, states have considerable flexibility in how they design and operate waiting lists. State structure, the kinds of waiver options available and the resources available all affect waiting lists. Assuring equitable access to waiver and comparable application of waiting list protocols throughout the state are essential foundations for state waiting list policy. And accurate information on unmet needs is essential for establishing future budgets and service priorities.

	Waiting Lists and Medicaid HCBS Authorities				
	§1915(c) **Home and Community-Based Services Waiver**	**§1915(i) SPA** **State Plan Home and Community-Based Services**	**§1915(j) SPA** **Self-Directed Personal Assistance Services (PAS)**	**§1915(k) SPA** **Community First Choice Option**	**§1115** **Research and Demonstration Project Waiver**
Authority Type	Waiver Information found at: www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.html *Waiver Technical Guide*: www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/downloads/technical-guidance.pdf	State plan option Information found at: www.medicaid.gov/medicaid/hcbs/authorities/1915-i/index.html	State plan option Information found at: www.medicaid.gov/medicaid/hcbs/authorities/1915-j/index.html	State plan option Information found at: www.medicaid.gov/medicaid/hcbs/authorities/1915-k/index.html	Secretarial waiver Information found at: www.medicaid.gov/medicaid/section-1115-demo/index.html
Are Waiting Lists Permitted?	Yes	No	Yes	No	Depends on demonstration structure and objectives
Can states target this benefit to specific groups?	Yes. Can target by Medicaid eligibility group, age, disability or condition. Must meet institutional level of care (LOC).	Yes. Can target by Medicaid eligibility group, age, disability or condition	Yes. Must be eligible for State plan or HCBS waiver personal care.	Only allowed to use institutional level of care eligibility—no other targeting permitted	Yes. Will vary greatly by state and demonstration depending on state's design.

	§1915(c) **Home and Community-Based Services Waiver**	§1915(i) SPA **State Plan Home and Community-Based Services**	§1915(j) SPA **Self-Directed Personal Assistance Services (PAS)**	§1915(k) SPA **Community First Choice Option**	§1115 **Research and Demonstration Project Waiver**
Can states cap the number served?	Yes	No	Yes	No	It depends. Will vary greatly by state and demonstration depending on state's design.
Other relevant features	States are liable to serve the number approved in their waiver application. If the state has unused capacity, the state must serve people from their waiting list. States can defer entrance if the state has approval for a point-in-time limit, reserved capacity for specific groups or made entrance subject to a phase-in schedule.	Requires states establish "needs-based criteria" which are, "the individual's particular need for support, regardless of the conditions and diagnoses that may cause the need." May "take into account" the inability of the individual to perform a specific number of activities of daily living (ADLs). May also assess other risk factors. May include Instrumental ADLs (ex.: meal prep, housework, financial management.			1115s provide a wide array of system design opportunities for states unavailable in other Medicaid authorities. As such, these programs are highly state-specific, requiring individual review to ascertain the particular program design features.

Acronyms

CFC	Community First Choice (1915(k))
HHS	[Department of] Health and Human Services
EPSDT	Early Periodic Screening, Diagnosis and Testing
HCBS	Home and Community-Based Services
ICF-IID	Intermediate Care Facility for Individuals with Intellectual Disabilities
I/DD	Intellectual and Developmental Disabilities
LOC	Level of Care
PAS	Personal Assistance Services