Commenting on § 1915(c) HCBS Waivers: A Guide for Common Issues[1]

Elizabeth Edwards

Medicaid home and community-based (HCBS) § 1915(c) waivers provide critical services for people with disabilities across the country. These waivers change because states often submit amendments to these waivers and the waivers also have to be renewed every few years. Each time a waiver is renewed or amended, states must put the waiver out for public comment.[2] The comment period is an excellent opportunity to provide input on the requested changes and also tell the state about the impact of those changes or other issues with the waiver. Although long, the waiver application document that is used by every state follows a set format and common problems are often discussed in a few key sections. And there is CMS guidance that can help advocates understand what is and is not required of a state in each section, including any CMS recommendations. Although a waiver document may seem long and potentially intimidating, this guide is intended to provide a roadmap for how to look for and craft comments on common issues.

Section 1915(c) Public Comment Requirements

The federal requirements for states regarding § 1915(c) comments are fairly minimal. States must put waivers out for public comment a minimum of 30 days prior to implementation of the

[1] This guide was produced in collaboration with the Human Services Research Institute (HSRI) with funding from the Administration for Community Living (ACL) and is based on an earlier work developed with a grant from the Training Advocacy Support Center (TASC), which is sponsored by ACL, the Substance Abuse and Mental Health Services Administration (SAMHSA), the Rehabilitation Services Administration (RSA), and the Social Security Administration (SSA). TASC is a division of the National Disabilities Right Network (NDRN).

[2] 42 C.F.R. § 441.304(f); *see also* Elizabeth Edwards & Sarah Grusin, Nat'l Health Law Program, *Opportunities for Public Comment on HCBS Assessment Tools* (Dec. 19, 2019), (describing the public comment obligations for 1915(c) waivers and other HCBS programs).

proposed change or submission of the change to the Centers for Medicare & Medicaid Services (CMS). Usually, because of the limitations about implementing certain changes retroactive to the approval date, states do the comment period before submission to CMS.[3] A state is required to summarize the public input and explain why any comments were not adopted and included in changes made in response to the comments in the final amendment submission to CMS.[4] This section of the waiver is often abbreviated and does not always accurately reflect the entirety of comments submitted. However, major concerns from commenters are typically noted and thus should alert CMS to issues.

Orientation to the Waiver Application

All 1915(c) waiver applications are long, but they follow the same template and once you have a general sense of where things are, you should be able to navigate fairly easily to the right part of the document to find what you are looking for. If you open a waiver application as a PDF, you can often use bookmarks to help you navigate the document.[5] The initial part of the application covers the basic information from the state: the name of the waiver, contact person, and basic assurances made by the state. This segment is useful because the first item describes major changes proposed in the waiver. The key pieces of the waiver for comment are appendices A-J, in which the state describes who the waiver serves, what services are included, whether participant-direction is allowed, and any restrictions on services, budgets, rates, etc. Each appendix has multiple subparts. For example, to determine whether a waiver allows family to be paid providers you would need to look at Appendix C regarding services, but particularly subsections C-2-d and C-2-e.[6]

---

[3] 42 C.F.R. § 441.304(d).

[4] Section 1915(c) Waiver Application § 6-I; CMS, Application for a § 1915(c) Home and Community-Based Waiver, Instructions, Technical Guide and Review Criteria 54-55 (Jan. 2019) [hereinafter Technical Guide].

[5] CMS maintains a website that includes all the approved waivers. To find the most recent approved waiver, open the Approved Application zip file and select the waiver PDF file with the highest number. Medicaid.gov, State Waivers List.

[6] *See* Elizabeth Edwards, Nat'l Health Law Program, *Paying Family Caregivers: State Options, Limitations, and Policy Considerations* (Dec. 12, 2023) (describing when paid family caregiving is permitted and the criteria used for 1915(c) waivers, among other HCBS programs).

The most helpful companion document to understanding any waiver application is the CMS 1915(c) Technical Guide.[7] It follows the same outline as a waiver application and can both help identify which appendix includes the information you seek and how CMS is supposed to evaluate that section. One thing to keep in mind when evaluating a waiver is that the current template does not fully reflect the requirements of the HCBS settings rule and will not reflect other rule changes, such as from the Access Rule, until it is more fully revised in a few years.[8] For more on the changes under the Access Rule, see our Overview of Key HCBS Provisions in the Medicaid Access Rule.

A quick guide to hot topics and then summaries of the most likely appendices to comment upon are below, along with some common issues for comment. In the longer explanations, there are some possible comment opportunities highlighted in **orange text.**

- **Budgets**: Individual costs limit for who is eligible can be found in B-2, while budget limits for individuals are discussed in C-4, and participant-directed budgets in E-1. The role of assessment tools may appear in this section, in eligibility, service design, or in person-centered planning.
- **Services Design & Limits:** Limits on services, who may provide services, and the purpose or goal of services is all found in C, in which everything is explained by the individual service. Overall limits, such as individual budgets, are discussed in C-4.
- **Person Centered-Planning & Complaint Processes:** A state is supposed to explain various details about the planning process in D, including dispute resolution within that process, but general complaint process should be addressed in F-3.
- **Rates:** The rate setting process is described in I-2, including when rates were set and last reviewed and how the state measured rate sufficiency, but J-2 includes the average rate the state used to calculate cost neutrality.

[7] Technical Guide, *supra* note 4.

[8] *See, e.g.,* Ensuring Access to Medicaid Services, 89 Fed. Reg. 40,542 (May 10, 2024), https://www.govinfo.gov/content/pkg/FR-2024-05-10/pdf/2024-08363.pdf (implementing regulations regarding HCBS rate transparency, measuring access to services, strengthening accountability measures, and changing stakeholder feedback mechanisms) [hereinafter Access Rule].

Quick Guide to Appendix Topics Covered:

- **Appendix B: Eligibility**
- **Appendix C: Services**
- **Appendix D: Person-Centered Planning and Service Delivery**
- **Appendix E: Participant Direction of Services**
- **Appendix F: Participant Rights**
- **Appendix G: Participant Safeguards**
- **Appendix I & J: Rates & Cost Neutrality**

Common Problem Area Appendices

Appendix B: Eligibility

- **B-1: Specification of the Waiver Target Groups:** A state may provide waiver services to any individual who requires the institutional level of care identified in the waiver, or it may provide waiver services to specific subgroups of individuals who meet the institutional level of care requirement. For example, they may have a waiver for all individuals who meet the ICF/IID level of care who meet the eligibility requirements, or the state can target children who meet that level of care. Targeting criteria may include nature or type of disability; specific disease or conditions; functional limitations, or other criteria. States may serve multiple target groups within one waiver, but the state must assure CMS that the waiver will meet the needs of each individual regardless of target group and that all individuals in the waiver will have access to all needed services. Therefore, there cannot be different packages of services within a waiver for different groups. **Advocates may want to identify limitations in this section that prohibit some individuals from accessing the waiver, and identify what changes they want the state to make so that more people can qualify for waiver services.** Such suggestions should keep in mind limitations for waiver eligibility, such as needing to meet an institutional level of care.
- **B-2: Individual Cost Limit.**[9] This is different than an individual budget found in C-4, and instead lays out whether the waiver sets an individual cost limit that a person cannot exceed to enter a waiver. States may select no cost limit, or above, at, or below the institutional cost of care. If a state selects a limit related to institutional cost, advocates may want to disagree through their comments with how the state determined this amount or argue that the state should have no individual cost limit. Often state

[9] *Id.* at 78-82.

1915(c) applications do not explain the safeguards they will maintain if they have cost limits (Section B-2-c). For instance, they rarely provide much explanation in this section of how a person who exceeds the limit will continue to live in the community. **Advocates may want to comment on how limits in this section result in needs not being met, people being institutionalized or moved to more segregated settings, or people being denied entry into the waiver.** Not all states select limits in this section.

- **B-3: Number served by the waiver and whether there are any reserved slots**. States may reserve slots for a variety of reasons (Section B-3-c). Common reasons include children aging out of other waivers, people leaving institutions, emergencies, and military families.[10] **Advocates may identify other populations that should have reserved slots and common reasons slots should be provided outside the normal waitlist process**.

  States must describe their **waitlist process** in B-3-f. **Advocate comments could propose changes to the prioritization process, screening tools (if used), or discuss the size of the waitlist and need for more slots.**[11] However, expanding slots is typically a state budget issue and often occurs through legislative action, not just through the waiver application process. In the future, this section will likely change significantly to implement new Access Rule requirements.

- **B-4: Medicaid Eligibility Groups Served in the Waiver.**[12] States may have not selected all the groups that advocates think the waiver should serve, or they may find the state's income limits insufficient. Of note, this section does not have a checkbox for the adult Medicaid expansion group, so states usually indicate this group is covered in the "other" text box.

- **B-6: Evaluation/Reevaluation of Level of Care.**[13] This section is often an area of concern for advocates. It describes how and by whom the level of care is determined, including what assessment tool is used, if any, and whether it differs from the tool used for relevant institutional settings. If a state uses a different tool, it must offer assurances

---

[10] Technical Guide, *supra* note 4, at 84.

[11] For information on recent waiver wait list numbers by state, see Alice Burns et al., Kaiser Family Found., A Look at Waiting Lists for Medicaid Home- and Community-Based Services from 2016 to 2023; KFF, Medicaid HCBS Waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility (2023).

[12] Technical Guide, *supra* note 3, at 89-91.

[13] *Id.* at 102-07; *see also* Edwards & Grusin, *supra* note 1 (commenting on assessment tools).

about the similarity between the tools. **Frequently advocates have questions about how level of care instruments or assessment tools are used both for level of care (eligibility) and for determining individual budgets**, which if used by a state, generally affect the amount and sometimes types of services a person may be approved for under the waiver.

Appendix C: Services

- **C-1-a: Summary chart of the waiver services and their type.** This chart also serves as the roadmap to the order of services as listed in the following section.[14]
- **C-1/C-3: Service Specification.** Each service is described, including
    - what the service is intended to do or achieve,
    - any limitations on who can receive the service,
    - whether it can be in combination with other services,
    - or how much of the service can be provided.

  Each description identifies eligible providers, including whether the service can be self-directed, and if parents and legal guardians may be paid providers. **All of these pieces may be effective areas for comment because the services and limitations may not be meeting the needs of waiver participants.**
- **C-2-d & e: Paid Services by Legally Responsible Individuals/Relatives/Legal Guardians.** During the COVID public health emergency, many states temporarily amended their waivers to allow for family members or legal guardians to be paid for providing services. States have long had the option to allow paid family caregivers in § 1915(c) waivers. In the waiver application, a state must indicate separately whether it will allow paid family caregivers for waiver personal care services (C-2-d) and for other waiver services (C-2-e). These sections will also include safeguards and limitations on when family caregivers may be paid, including any limitations on legal guardians. Each service description in C-3 will include indicators of whether family/legal guardian paid caregivers are allowed to provide those services. **Comments on this section could address the impact of any limits, whether advocates think additional services**

[14] *Id.* at 113-117. This chart also indicates how a service is classified, which can be relevant to the interplay with state plan services as waiver services only complement state plan services, including services for children under EPSDT. *Id.* at 7, 127-29, 131 (relationship of waiver services to EPSDT services).

should be allowed to be provided by family, and other impacts of the state's choices. Please see a separate NHeLP factsheet for more on the requirements and restrictions for paid family caregivers as well as potential advocacy and policy considerations.[15]

- **C-4: Additional Limits on Amount of Waiver Services.**[16] This section includes common problem areas like individual budget limits and limits by level of support, such as tiered services for different levels of acuity. States have several options for setting budget limits, but the basic information that should be included here often provides excellent targets for comments. **Common issues for comment include the evidence and methodologies informing the budget limits, whether the state actually provides for exceptions processes for specific limitations, and what safeguards are in place when the limit is insufficient to meet a participant's needs.**[17]

Appendix D: Person-Centered Planning and Service Delivery

- **D-1: Service Plan Development.**[18] This section should describe how, when, and by whom the person-centered planning process occurs to be consistent with the requirements of 42 C.F.R. § 441.301(c)(1), including conflict free case management. **Advocates frequently find that the description of the planning process does not accurately reflect an individual's actual experience. The state may have omitted key elements that typically impact the process for participants, such as how budgets inform planning, or the lack of choices presented regarding the full array of settings or services available under the waiver.** Notably, waiver participants are supposed to have access to the full array of services authorized in the waiver. That means a state may not deny a needed waiver service due to lack of funds.[19] The interplay between budgets and service planning can be complicated. Although assessments of need and person-centered planning should drive the identification of needed services, in practice budgets often play drive the process, sometimes impermissibly.[20]

---

[15] Edwards, *Paying Family Caregivers, supra* note 6.
[16] Technical Guide, *supra* note 4, at 143-48.
[17] *Id.* at 145.
[18] *Id.* at 190-98.
[19] Technical Guide, *supra* note 4, at 53.
[20] In North Carolina, a lawsuit challenged the budgeting process and as a result of settling that case the state issued instructions about person-centered planning and budgeting. *See* N.C.

- **D-2: Implementation and monitoring.**[21] This section explains how a state ensures and monitors that services are provided according to the service plan, the services meet the person's needs, and back-up plans are in place and effective. States must also describe the systems in place to protect and monitor the health and welfare of waiver participants. It is also supposed to include descriptions of how problems are identified and remediated. **Many waiver problems experienced by individuals should be addressed by the policies and methods discussed in this section, and so are ripe for comment about how either the processes do not occur, do not identify problems, or do not do enough to resolve them.**

Appendix E: Participant Direction of Services

States may opt to allow for participant direction of services, which CMS urges states to give serious consideration.[22] If they do so, they must make certain supports available for individuals who choose this option, including financial management services and "information and assistance."[23] A few key features of participant direction include:

- **E-1-b: Employer v. Budget Authority.** States may select either or both forms of participant direction, which provide different levels of budget control and employer authority.[24] Advocates may want to push for both to provide participants more flexibility.
- A waiver may include certain services designated for participant direction.[25] If a service is designated as either agency or participant directed, the individual may choose which method to use.[26] If a state chooses to have very separate programs for agency directed versus participant-directed services, it can create barriers to creating a plan of care that

---

Dept. Health & Human Servs, LME-MCO Communication Bulletin J297, at 2 (July 13, 2018), https://www.ncdhhs.gov/joint-communication-bulletin-j297-lme-mco-ls-v-wos/download.

[21] *Id.* at 199-201.

[22] *Id.* at 47. Note, a state may request a waiver of statewideness within the waiver to allow for participant direction in a certain geographic area, but if a state does so, individuals in that area must have access to the delivery method available elsewhere in the state, such as agency-directed care. *Id.* at 50. A waiver may also target exclusively those who want to direct at least some or all of their waiver services, but such targeting must be reflected in the eligibility section, B-1-b. *Id.* at 77. A waiver may also limit participant direction by type of living arrangement. *Id.* at 207.

[23] *Id.* at 155. These services may be called something else and may be provided as administrative services rather than waiver services. *Id.* at 115.

[24] *Id.* at 206.

[25] Technical Guide, *supra* note 4, at 141.

[26] *Id.*

works.[27] For example, in some states that have very separate programs, participant-directed services may assume the person is not trying to also use agency services and may have more services designed as day-rate services or not allow a person to also use agency-directed services. In the alternative, separate programs may create a great deal of flexibility for participant directed services to be used creatively within a set budget. **How a state designs and allows (or not) interplay between participant-directed and agency services may, in practice, work quite differently than a state expects and waiver enrollees may have significant comments about participant-directed services design within the waiver. In commenting on participant direction, it is often helpful for advocates to include examples of what is working, and why certain restrictions cause problems in practice.**

- **E-1-f: Participant Direction by a Representative.** Whether a state allows participant direction by certain individuals, such as parents of minor children, and what decisions such representatives can make may create significant limitations on how an individual or their family can hire others to provide care. In this section, that state must describe what representatives are allowed and what safeguards ensure they will function in the best interests of the participant. **Overly restrictive policies may severely limit the options of small families.[28]**
- **E-2:** This section generally details different aspects of the participant direction authorities, whether there are flexibilities in staff qualifications and payment and budgeting authorities. **Importantly, E-2-b-ii sets forth how the budget will be determined, which regardless of methodology, must be applied consistently to each participant who uses participant-direction.[29]** Also, if the budget serves as a limit on services, an individual must be able to appeal the requested budget is reduced or denied.[30]

---

[27] A state may exempt waiver participants who use budget authority from service limitations on amount, frequency, or duration as long as the exemption does not change the overall budget and the services are authorized in the person's plan. Technical Guide, *supra* note 4, at 138. For an explanation of "budget authority", see E-2 *infra* and the Technical Guide, *supra* note 4, at 226.

[28] *See* Edwards, *Paying Family Caregivers*, *supra* note 5 (discussing policy options for parent caregivers).

[29] Technical Guide, *supra* note 4, at 226-28.

[30] *Id.* at 228.

Appendix F: Participant Rights

- **F-1: Fair Hearing**. In this section, the state must describe all instances when a notice must be provided to an individual, how it is made, who is responsible, and assistance (if any) that is available.[31] **If waiver participants are commonly discouraged from requesting services, or there are other practices that deny services without due process, commenting about the difference between what the state promises in this section and what occurs may be effective.** This could include practices by care coordinators or case managers that have the effect of denying services before they are formerly requested such that the person is not able to access the fair hearing process to dispute such denials.
- **F-3: State Grievance/Complaint System**. This system is identified as optional in the Technical Guide, but CMS has stated that a person must have a way to notify the state of provider noncompliance with the HCBS settings requirements and how the state will address beneficiary feedback so this section is a likely place to address that requirement.[32] States will also be required to have complaint systems in § 1915(c) waivers by July 2026 under the Access Rule so advocates may encourage early compliance before that time.[33] Many state systems for taking complaints are not particularly responsive or effective. Features of an effective complaint process that advocates may want to discuss include:
    - clear indication of the complaint process to use for what types of issues;
    - easy to find information about the complaint process on frequently referenced information sources, such as person-centered planning documents;
    - simple and easy to access through multiple modalities, such as phone, email, and in writing;
    - provides accommodations readily;
    - includes protections against retribution from the provider or plan;
    - does not require extensive information or magic words to identify an issue that would act as barriers to the complaint; and
    - clear policies around the response to the complaint, including timelines, how the

[31] *Id.* at 232-33.
[32] CMS, HCBS Settings Rule Implementation – Moving Forward Toward March 2023 & Beyond 8 (2022).
[33] *See* David Machledt & Syd Pickern, Nat'l Health Law Program & Cmty. Living Policy Ctr., *The HCBS Settings Rule: Looking Back and Forging Ahead* 22-24 (May 2024) (describing the new requirements for HCBS complaint systems from the Access Rule and making recommendations).

participant will be informed, if the response will be in writing, and action steps to be expected, such as adjusting the care plan.

If a state's process for complaining about waiver issues is ineffective or lacks important features, advocates may want to comment about these issues. Again, providing examples may help the comments be more effective. In writing such comments, it would be most effective to explain how the complaint system does not work to resolve waiver issues rather than on whether an individual complaint was resolved to a person's satisfaction or not.

Appendix G: Participant Safeguards

- **G-1: Critical Incidents, including participant education and who is to respond to critical incident reports.**[34] **If complaints of abuse and neglect or other critical incidents do not seem to get the appropriate response or remediation, effective commenting could address the difference between the state's description and participant experience, or examples of failures to address abuse and neglect.** As mentioned in other sections, the Access Rule includes significant changes to critical incident reporting requirements, including greater transparency and a minimum definition of "incident."[35] As with other Access Rule changes, these changes do not have to be implemented until July 2027, with some pieces not until 2029, but advocates may push for states to adopt these changes sooner.
- **G-1-c: Participant Training and Education.** Although basic notice should occur about waiver participant rights as described in this section, such notice does not always explain rights in such a way that individuals will recognize when their rights have been violated and what actions they should take. This is especially true for rights related to community-based settings as many states only ended their transition to compliance with the HCBS Settings Rule in the last year. Although the training and education should reflect these requirements, after reviewing the description in this section, **advocates may identify in comments changes regarding education and training needed to ensure participants fully understand their rights regarding HCBS settings requirements and what they look like in everyday life.**
- **G-2: Restraint and Restrictive Interventions.** The state is expected to explain what, if any, restrictive interventions are allowed and how oversight is provided. Restraint

[34] Technical Guide, *supra* note 4, at 243-52.
[35] Access Rule, 89 Fed. Reg. at 40,597-608.

includes personal, chemical, and mechanical restraints.[36] Even if a state says it does not allow the use of restraints, it must still describe how it will detect unauthorized use of restraints. The state must also have safeguards concerning the use of restrictive interventions and oversight. Similar requirements apply to seclusion.[37] If settings commonly use different types of restraints, this section should reflect those practices. **Comments could express concern at the use of these interventions and describe failures by the state to properly oversee and address improper use of restraint, seclusion, and other restrictive interventions, and include any suggested changes. They could also address frequency and type of training for providers and the reporting required for any restraints.**

NOTE: As a reminder when considering comments on this section, this is an area where the Technical Guide has not been updated to reflect all changes in HCBS Settings Rule, including the requirement that a home and community-based setting, among other features, "ensures an individual's rights of…freedom from coercion and restraint."[38] Therefore, commenters may consider arguing that restraints allowed in this section should be quite limited.

Appendix I & J: Rates & Cost Neutrality

Information on rates is not as clear as advocates may want for commenting purposes in the waiver application, but there are **good opportunities to provide comment about rates and rate structures for services.** How providers are paid may also be affected by some of the service limitations in C, including whether services can be billed on the same day or if there are tiered services. Rate issues are certainly complicated by managed care for waiver services, but these sections should still give some fodder for advocacy comments. As mentioned in other section, the new Access Rule will change some of the requirements regarding HCBS rates and add new mechanisms for interested parties to engage in the process.[39]

---

[36] Technical Guide, *supra* note 4, 244. Use of restraints must also comply with 42 C.F.R.§ 441.301(c)(1), (2) & (4).
[37] Technical Guide, *supra* note 4, at 250-51.
[38] 42 C.F.R. § 441.301(c)(4).
[39] Access Rule, 92 Fed. Reg. at 40,676-756 (discussing new Interested Parties Advisory Group and rate transparency requirements).

- **I-2-a: Rate Determination Methods.**[40] The state is expected to describe how rates were determined, the methodology, how rate sufficiency was evaluated, and when rates were initially set and reviewed. There is a lot potentially to comment on here on methodology, what assumptions were made to calculate the rate and how they measured sufficiency.[41] Critically, if the rates were last set pre-pandemic, **advocates likely want to comment on the impact of the pandemic and related rate increases, especially as some of those rate increases or retention bonuses may be ending. Advocates may also consider other issues that affect the effectiveness of rates, such as inflation, whether rates are tiered for different acuity of need or geography, and other issues.**[42]
- **J-2: Cost Neutrality, Derivation of Estimates.**[43] There are a lot of issues that advocates may want to dig into regarding how the state calculates cost neutrality, but in this section the application includes charts that indicate the average cost per unit and the unit increment, which indicates the average rate for each service.

Conclusion

Waiver amendments for comment may be long, but once you learn the format and patterns of the document it is easier to navigate. Once you have your bearings, it is much easier to compare waiver enrollee experiences to how the state describes the waiver is supposed to function. And where the waiver is not meeting the needs of waiver participants. These differences help generate effective comments because they are pinpointing how the waiver does not meet the intention of the program.

[40] *Id.* at 266-68.
[41] CMS has several trainings regarding the setting of rates for waivers and HCBS generally that can help advocates call into question some of a state's methodology and assumptions. The slide decks from these trainings can be found under the Rates & Fiscal Integrity section of the HCBS Training Series website. Medicaid.gov, Home & Community Base Services Training Series.
[42] *Id.*
[43] Technical Guide, *supra* note 4, at 292-99.