



Opportunities for Public Comment on HCBS Assessment Tools¹

[Elizabeth Edwards](#) & [Sarah Grusin](#)

Medicaid home and community-based services (HCBS) are critical to ensuring people with disabilities and older adults are supported in their communities. State Medicaid agencies and their contractors rely on assessment tools to make eligibility decisions, allocate services, and inform person-centered planning processes. As a result, the assessment tools play a central role in determining access to home and community-based services. However, these assessment tools can be difficult to understand or sometimes even see the tool itself. There is significant variation in assessment tools both among and within states, and different tools can result in different outcomes, even for similarly situated individuals. For more information on the variations in assessment tools and common problems, see previous NHeLP factsheets.²

Given the importance of assessment tools, it is critical that individuals and advocates have a clear understanding of the assessment tools. Assessment tools, as well as the processes used by a state Medicaid agency to select a tool, however, are commonly quite opaque and difficult to understand. Moreover, states are increasingly automating their assessment tools, putting data from an in-person assessment into a computer program, which then uses an algorithm to produce a level of care determination, service budget, or other service allocation. As a result, it can be difficult to understand why an assessment tool determined a person eligible, decided the service budget, or set the service amount at a particular level. This lack of information can

¹ Produced with a grant from the Training Advocacy Support Center (TASC), which is sponsored by the Administration on Intellectual and Developmental Disabilities (AIDD), 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 Rights Network (NDRN).

² David Machledt, *Evaluating Functional Assessments for Older Adults: Resource Allocation*, NAT'L HEALTH LAW PROGRAM (June 2017), <https://healthlaw.org/resource/evaluating-functional-assessments-for-older-adults/>; David Machledt, *Medicaid Assessments for Long-Term Supports and Services (LTSS)*, NAT'L HEALTH LAW PROGRAM (May 2015), <https://healthlaw.org/resource/medicaid-assessments-for-long-term-supports-services-ltss/>.

create significant due process issues, as discussed in previous NHeLP factsheets.³ Transparency problems also occur when Medicaid agencies make changes to a tool that affect LOC determinations or service allocations without fully informing advocates and participants.

Depending on the type of HCBS in question—i.e., 1915(c) waiver or state plan services—advocates may be able to use notice and comment requirements to press a state Medicaid agency to provide greater transparency. This factsheet reviews federal requirements for notice and comment that apply to assessment tools within 1915(c) waivers as well as assessment tools used to implement state plan services (including 1915(i) and 1915(k)), and offers advocacy recommendations on how to use these requirements to get Medicaid agencies to provide more information about assessment tools. Individual states may have additional transparency requirements, such as rulemaking or specific requirements regarding the HCBS programs. Enforcing state rulemaking requirements has proven to be an effective tool for advocates to get more information about assessment tools, but those additional state requirements and advocacy options are not covered in this fact sheet.

Overview of Federal Requirements for Notice and Comment

Assessment tools are used in several different HCBS programs. Most prevalent, are assessment tools used to determine eligibility or allocate 1915(c) waiver services. Assessment tools are also used for certain HCBS services offered directly through the state plan, or through a 1915(i) or 1915(k) state plan option.

It is important to understand the context in which the assessment tool is used because the notice and comment opportunities vary depending whether the tools are used for waiver or state plan services. This fact sheet describes the requirements for each category of HCBS services: 1915(c) waiver services, general state plan services, services under the 1915(i) state plan option, and services under the 1915(k) state plan option.

³ Jane Perkins, Q&A: *Using Assessment Tools to Decide Medicaid Coverage: Case Developments*, NAT'L HEALTH LAW PROGRAM (May 2016), <https://healthlaw.org/resource/qa-using-assessment-tools-to-decide-medicaid-coverage/>; Jane Perkins, *Demanding Ascertainable Standards: Medicaid as a Case Study*, Clearinghouse Community (Mar. 2016), https://www.povertylaw.org/files/docs/article/ClearinghouseCommunity_Perkins.pdf; Jane Perkins, *Ensuring that Assessment Tools are Available to Enrollees*, Nat'l Health Law Program (Sept. 2015) <https://healthlaw.org/resource/ensuring-that-assessment-tools-are-available-to-enrollees/#.V1mM67srKM9>.

The summary chart below provides an overview of what notice and comment requirements apply when states adopt or change a waiver or state plan amendment (SPA). The chart lists three broad columns (1) circumstances where there are no federal requirements for notice and comment, (2) circumstances in which federal law only requires public notice, without expressly requiring a comment opportunity, and (3) circumstances where federal law requires notice and an opportunity to comment. Additional details regarding each requirement are described in the text that follows the chart.

No Requirement ⁴	Notice Only	Notice and Comment
<p>State Plan Amendments not changing rates, including:</p> <p>1915(i): Modification of needs-based eligibility criteria with CMS prior approval</p>	<p>1915(i): Modification of needs-based eligibility criteria, if the state is <i>not</i> seeking CMS approval prior to change.</p>	<p>1915(c): state-defined public input process</p> <p>Initial submission of waiver</p> <ul style="list-style-type: none"> • changes in services or operations of the waiver • substantive changes that are proposed in the renewal or amendment process. • Transition Plans⁵ <p>1915(i): Transition Plans</p> <p>State Plan Amendments with a significant proposed change to the state's methods and standards for setting payment rates for services.⁶</p>

⁴ If a SPA is making significant changes in payment methods or standards, public notice is required. 42 C.F.R. § 447.205; 42 C.F.R. § 441.304(e); see also CMS Informational Bulletin, [Federal Public Notice and Public Process Requirements for Changes to Medicaid Payment Rates](#) (June 24, 2016). Advocates should also be aware of the fast-track process CMS has setup for certain SPAs and 1915 waivers. This process does not affect notice and comment, but may impact how an amendment moves through the approval process. See CMS Informational Bulletin, [Update on State Plan Amendment and Section 1915 Waiver Process Improvements](#) (Aug. 16, 2018); CMS Informational Bulletin, [State Plan Amendment and 1915 Waiver Process Improvements to Improve Transparency and Efficiency and Reduce Burden](#) (Nov. 6, 2017).

⁵ States must provide at least a 30–day public notice and comment period regarding any transition plan that the State intends to submit to CMS. 42 C.F.R. §441.301(c)(6)(iii).

⁶ Notices regarding changes to methods or standards for setting rates have specific content requirements, including estimating the expected increase or decrease in annual expenditures and a

A. 1915(c) Waiver Services

1. When Public Input Is Required

The agency must establish and use a public input process, “for any changes in the services or operations of the waiver.”⁷ The public input process must also be used for new waivers and “substantive changes” that are proposed in the renewal or amendment process.⁸ Substantive changes include “revisions to services available under the waiver including elimination or reduction of services, or reduction in the scope, amount, and duration of any service, a change in the qualifications of service providers, changes in rate methodology or a constriction in the eligible population.”⁹ Substantive changes may only take effect once approved by CMS and may not be made retroactive.

While the text of the regulation is broad, and requires a public input process for “any changes in the services or operations of the waiver,” in practice, it seems that there is little distinction between how CMS and states interpret “any changes in the services or operations of the waiver,” and “substantive changes.”¹⁰

In the 1915(c) Technical Guide, for instance, CMS focuses on public input surrounding substantive changes only, noting that “[t]he state is required to establish a public input process specifically for HCBS changes that are substantive in nature.”¹¹ Elsewhere, the Guide states that “CMS requires states to obtain public input during the development of a waiver (or a waiver renewal or a waiver amendment with substantive changes).”¹² Finally, the instructions for describing the state’s public input process similarly suggest that public input is required only for the “development of the new waiver, waiver renewal, or waiver amendment.”¹³ The Guide does not reference the required public input for “any changes in the services or operations.”

The distinction between such “substantive” changes and “any” change, however, could be important for purposes of monitoring assessment tools. For instance, if the state makes

description of why the state is making the change. *Id.* The notice must also include “an address where written comments may be sent and reviewed by the public.” 42 C.F.R. § 447.205(c)(5).

⁷ 42 C.F.R. § 441.304(f).

⁸ *Id.* § 441.304(f)(3).

⁹ *Id.* § 441.304(d)(1).

¹⁰ *Id.*

¹¹ Technical Guide at 26.

¹² Technical Guide at 54.

¹³ *Id.* (“In the text field, describe how public input into the development of the new waiver, waiver renewal, or waiver amendment was secured”). The Guide does not reference the required public input for “any changes in the services or operations.”

changes to the assessment process or tool, but that process is not described in detail in the waiver (e.g. is only listed by name), then nothing in the waiver text technically has to change. Whether or not states offer an opportunity for public comment may, in practice, depend on the extent to which the assessment tool or algorithm is described in the waiver and whether the change is substantive. However, regardless of the level of detail in the waiver, a change in the assessment tool should, at minimum, be considered a change in the operations of the waiver. And in most cases, a change to the assessment tool would likely impact services and therefore should go through public notice and comment for substantive changes.

Advocates should press the state agency to treat major changes to LOC or service allocation assessment tools or algorithms as “substantive changes,” requiring notice and comment and CMS prior approval. Advocates can point out that changes to service allocation algorithms or tools (such as how the availability of informal care is factored in, or how the algorithm weighs different elements, like clinical condition or cognitive function) can significantly change the amount or type of services available to individuals. Changes to LOC tools, of course, can restrict eligibility.

Finally, advocates can also consider pushing states to interpret the “any change[.]” language more broadly to increase transparency and public input around changes to level of care or service allocation instruments and tools. That said, it may not be advantageous for every change in an assessment tool or algorithm to require public comment. For instance, if advocates or the state identifies an error in the way the tool is coded, a public input process could delay implementation of a fix. However, it may be better to know of every change even if it creates a delay.

2. Description of the Public Input Process

CMS’s 1915(c) Technical Guide establishes a few substantive requirements for how states must conduct their public input processes. First, it requires the state to provide written summaries of the comments received, explain what changes were adopted as a result of comments, and describe the reasons why comments were not adopted.¹⁴ Second, the Guide specifies that the “state must provide at least a 30 day public notice and comment period.”¹⁵ And the public input process be completed in a minimum of 30 days prior to implementation of the proposed change or submission of the proposed change to CMS, whichever comes first.¹⁶

¹⁴ *Id.* at 54-55.

¹⁵ Ctrs. for Medicare & Medicaid Servs., *Instructions, Technical Guide and Review Criteria, Version 3.6*, 54 (Jan. 2019).

¹⁶ 42 C.F.R. § 441.304(f)(2).

As explained above, a state may request a non-substantive change be approved retroactively. As a result, a non-substantive change could be put out for public notice and submitted to CMS, but the change is backdated to an implementation date 30 days after the comment period.

Beyond these requirements, states have discretion over the details of the public input process, but that process should be “described fully” in the waiver itself and must “ensure meaningful opportunities for input for individuals served, or eligible to be served, in the waiver.”¹⁷ The Technical Guide further specifies that the public input process should “be sufficient in light of the scope of the changes proposed.”

In practice, states vary widely in how they describe their public input processes. For example, Florida’s Long Term Care 1915(c) waiver states:

The Agency provides public notice as specified in 42 CFR 441.304(f) to solicit meaningful input from recipients, providers, and all stakeholders on waiver amendments or renewals at least 30 days prior to submission. The Agency posts the waiver renewal or amendment request and a description of the proposed changes to the Agency website for public review and comment. The Agency also publishes a notice of the Agency’s intent to renew the waiver or amend the waiver through the Florida Administrative Register and through a provider alert.¹⁸

Pennsylvania’s Consolidated Waiver application, on the other hand, is much more detailed and includes a more robust description of the comment process used for the waiver application itself.¹⁹ But the description does not explain what the public input process will be for changes going forward.²⁰

Advocates should carefully review their state’s waiver applications and described public input process. If the state has not provided sufficient detail or has failed to describe the process it

¹⁷ 42 C.F.R. § 441.304(f)(1).

¹⁸ Florida Long-Term Care 1915(c) Waiver (0962.R01.00), § 6.I, *available at* <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/?entry=12086> (“Approved Application” link). Florida’s Long Term Care waiver provides services to individuals age 65 and older and adults ages 18-64 with physical disabilities, brain injuries, HIV/AIDS or who are medically fragile.

¹⁹ Pennsylvania’s Consolidated Waiver provides services to individuals with autism, developmental disabilities, and intellectual disabilities.

²⁰ Pennsylvania Consolidated 1915(c) Waiver (0147.R06.00), § 6.I, *available at* <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/?entry=8361>. (“Approved Application” link).

will use going forward, advocates should consider submitting comments highlighting the regulations and requesting that the state provide more robust public input processes

3. Content of the Waiver Regarding Assessment Tools & Algorithms

As described above, including more detail about assessment tools in the text of the waiver itself can be an important step in increasing transparency. The application form and instructions for 1915(c) waivers, however, do not require many specifics about assessment tools and algorithms. The most likely place to find specifics about an assessment and algorithm is in the descriptions regarding LOC, but services, budgeting, and service limitations also often reference assessment tools and algorithms. Unfortunately, nothing specifically directs the state to make available the actual assessment tool or algorithm for comment.

The Technical Guide directs that, when the state uses the public input process, “the state must share with the public the entire waiver.”²¹ The waiver includes the State’s description of the process the state uses to evaluate an individual’s level of care and the processes the state uses allocating services. Therefore, advocates have an argument that the entire waiver is not published unless the associated assessment tools and algorithms are also published, or at least sufficient information to understand their impact on waiver participants and their services. As noted below, the 1915(c) Technical Guide does discourage copying the entirety of the tool into the application, so states may object to this advocacy strategy. However, there should be room to advocate for knowledge of the tool and its impact given the requirements of describing LOC, service limitations, etc., even if the entirety of the tool for LOC criteria is not typically included in the application.

a. Required Disclosure of Level of Care Tools

Assessment tools are only specifically mentioned in the Technical Guide in the discussion of the requirements around LOC criteria. For LOC determinations, the waiver must identify the minimum number of services that an individual must require and the minimum frequency those services must be needed to qualify for waiver service.²² The state must also describe the agency performing the level of care determinations and the professional and educational qualifications of individual evaluators.²³

²¹ Ctrs. for Medicare & Medicaid Servs., *Instructions, Technical Guide and Review Criteria, Version 3.6*, 54 (Jan. 2019).

²² Technical Guide at 102.

²³ *Id.* at 103.

The waiver application must include a description of the level of care criteria used to evaluate whether and how frequently an individual needs waiver services. States must “[s]pecify the level of care instrument [or] tool that is employed.”²⁴ If the tool differs from the tool used to determine institutional level of care, states must explain how they differ and provide assurances that the level of care determinations are reliable, valid, and fully comparable to the institutional evaluation.²⁵ Although states are required to specify the tool, the Technical Guide does not require, and even cautions against, providing a complete copy of the tool or algorithm itself.²⁶ The state is not supposed to copy the tool or even the protocol into the application, but is supposed to reference the tool used by the name of the tool, form, or automated system.²⁷

b. Required Disclosure of Service Allocation Process

States must also describe in the waiver application, certain information about service allocation tools and processes. For instance, if a state uses a budget allocation process, the state must describe “the processes and methodologies that are used to determine the amount of the limit to which a participant’s services are subject.”²⁸ And “[w]hen the amount of the limit is based on assessment information or other factors, how such information is used to determine the limit should be fully explained.”²⁹

Despite these instructions for information regarding services and budget allocation tools, states do not always include more than the name of the tool they are using, even if they have made state-specific changes to the commercial tool. For instance, Pennsylvania’s Consolidated Waiver for individuals with developmental and intellectual disabilities explains that the state uses “a multifaceted assessment process,” to develop the service plan. Included in that process is:

a statewide standardized needs assessment using the Supports Intensity Scale (SIS™) and other assessment tools for population groups for whom the SIS™ is

²⁴ *Id.* at 104.

²⁵ *Id.* at 105.

²⁶ *Id.* at 104 (“Do not “paste” an instrument/tool or applicable protocols or regulations into the “text field . . . Also specify the instruments/tools that are used (e.g., by referencing the name of the instrument or form or the name of the automated system)”).

²⁷ *Id.*

²⁸ *Id.* at 145.

²⁹ *Id.*

not designed and utilized. . . . The SIS™ is administered by an independent contractor, and the results are available to the participant and team members in the form of the summary report.³⁰

Note the waiver only identifies the SIS by name, without describing *how* the SIS allocates resources, and that the results are available only in a “summary report.” It is not clear how much information is made available in this summary report, nor if the report helps individuals understand how the tool impacts the resource allocation. Furthermore, the waiver does not even identify the “other assessment tools” for groups for whom the SIS is not designed.

Advocates should review the waiver applications carefully and push states to provide additional detail to ensure that the required descriptions of LOC tools and service allocation processes are meaningful. Additional detail in the waiver itself about the tools used will also help advocates demonstrate that changes to those tools are changes to the waiver that trigger public notice and comment.

B. State Plan Services

Assessment tools and algorithms have significant impact on state plan services like home health, personal care services, and private duty nursing as well as state plan HCBS programs under 1915(i) and 1915(k). Community First Choice 1915(k) plans have specific requirements about assessments for functional need, but public comment is not listed in these requirements. Despite the programmatic differences in traditional state plan services like home health and more comprehensive state plan programs, such as 1915(i), they are all state plan programs are authorized by and changed through state plan amendments (SPAs).

1. General State Plan Amendment Requirements

Public comment is typically only required for SPAs that affect rate setting. Otherwise, there is no general federal requirement for a state to provide public notice or opportunity for comment on a SPA.³¹ CMS posts approved State Plan Amendments on its website:

³⁰ Pennsylvania Consolidated 1915(c) Waiver (0147.R06.00), Appendix D-1(d), Service Plan Development Process, available at <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/?entry=8361> (“Approved Application” link).

³¹ See generally 42 C.F.R. pt 430, subpart B (including no requirements for public notice and comment).

<https://www.medicaid.gov/state-resource-center/medicaid-state-plan-amendments/index.html>.

States also commonly post planned SPAs on their state SPA websites.

Notice and comment for SPAs is required in narrow circumstances related to rate setting. Federal statute requires public notice and comment when states alter the rates for hospital services, nursing facility services, or services of intermediate care facilities for the cognitively disabled.³² Public notice is also required for a “significant proposed change in [the state’s] methods and standards for setting payment rates for services.”³³ The notice must include “an address where written comments may be sent and reviewed by the public.”³⁴

Although assessment tools and algorithms associated with services authorized by SPAs may not themselves be required to be put out for public comment, there may be certain circumstances under which advocates could cite the association with rate setting to try to get greater transparency around the tools themselves. For example, if an assessment tool is used such that it sets budgets and rate of pay available for providers, there may be a sufficiently strong connection to the reimbursement rate process to make the argument. Or if the services and planning process are so closely intertwined with rates that the assessment tool results impacts rates. Such arguments would be somewhat novel, but could be successful under the right circumstances.

2. 1915(i) State Plan Option

States are required to have established needs-based eligibility criteria for individuals enrolled in the HCBS benefit.³⁵ The regulations do not create any additional public comment requirements for 1915(i) SPAs. However, when establishing a 1915(i), the state must include the institutional and needs-based criteria for inspection by CMS.³⁶ For a 1915(i) program, the needs-based criteria must be less stringent than the state’s LOC criteria for the institutional settings in the state.³⁷ The 1915(i) needs based criteria may also not have the effect of limiting who can benefit from the HCBS program “in any unreasonable way,” as determined by CMS.³⁸

³² 42 U.S.C. § 1396a(a)(13)(A); 42 C.F.R. § 447.250.

³³ 42 C.F.R. § 447.205(a); *see also id.* § 447.253(h).

³⁴ 42 C.F.R. § 447.205(c)(5).

³⁵ 42 C.F.R. 441.715(a).

³⁶ 42 C.F.R. § 441.715(b)(1)(ii).

³⁷ 42 C.F.R. § 441.715(b).

³⁸ 42 C.F.R. § 441.715(b).

States may modify the needs-based eligibility criteria without seeking prior CMS approval of a revised SPA, but in that case, must provide 60-days notice to the public.³⁹ If the state also needs to modify its institutional LOC criteria to ensure that they are more stringent than the state plan criteria, the state may adjust the institutional LOC under this same authority. Moreover, any changes in service due to the modification of needs-based criteria under this adjustment authority are treated as “actions” that trigger notice and hearing rights.

3. 1915(k) State Plan Option:

While there are no specific public notice and comment requirements for 1915(k) SPAs, states must “consult and collaborate with” a Development and Implementation Council when “developing and implementing” the SPA.⁴⁰ The majority of the Council must be comprised of individuals with disabilities, elderly individuals, and their representatives.⁴¹

Regulations also require states to “elicit and incorporate feedback from individuals and their representatives, disability organizations, providers, families of disabled or elderly individuals, members of the community and others to improve the quality of the community-based attendant services and supports benefit.”⁴² The regulations do not specify how the state must elicit that feedback, but the state plan preprint includes a section for states to describe how the state will elicit that feedback. Notably, 1915(k) has specific regulatory requirements about assessments of functional need.⁴³ Therefore, advocates may be able to cite the requirements to get more information about those assessments during the feedback and SPA processes.

As in the 1915(c) context, the level of detail provided in states’ 1915(k) state plan amendments is often lacking. For instance, in Alaska’s SPA, the state simply states that it uses the “Inventory for Client and Agency Planning (ICAP) adaptive behavior tool” to determine if an individual has an Intermediate Care Facility for Individuals with Intellectual Disabilities Level of Care (ICF-IID LOC). While the SPA states that an individual must have a “qualifying score on the ICAP,” it does not describe what score is needed to qualify.⁴⁴ Thus, Alaska could conceivably change the qualifying score without needing to amend the SPA.

³⁹ *Id.* § 441.715(c).

⁴⁰ See 42 C.F.R. § 441.575.

⁴¹ *Id.*

⁴² 42 C.F.R. § 441.585.

⁴³ 42 C.F.R. § 441.535.

⁴⁴ Alaska, State Plan Amendment No. 17-0011, 3 (Mar. 22, 2018), <https://www.medicaid.gov/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/AK/AK-17-0011.pdf>.

Maryland's SPA does not even identify the tool used to determine LOC by name, stating only that initial and annual eligibility will be done with a "standardized assessment instrument" by either a local health department or a contractor.⁴⁵ To allocate personal assistance services, Maryland's application simply states that it will be based on Resource Utilization Groups identified through the InterRAI Assessment process. The only additional information given is that the highest RUG grouping budget is \$76,370 annually.

C. Managed Care

Medicaid managed care commonly adds a layer of opacity to assessment tools and algorithms. Managed care entities often rely on data and related automated decision making; using automation to assist in coordinating care and monitoring service authorizations, among other tasks. Managed care entities may also consider such automated decision systems as proprietary information.⁴⁶ This means that it can be even more difficult for individuals and advocates to access how and why a decision is made under managed care or what algorithm is being used in the first place, much less the data and assumptions made to create the algorithm.

However, in addition to meeting due process obligations, there are other mechanisms under which managed care plans should be providing information that may be relevant to assessment tools. Managed care entities are supposed to provide information about the amount, duration, and scope of benefits provided and for LTSS, involve stakeholders in the oversight of the program.⁴⁷ The State also has obligations about Medicaid managed care oversight that include utilization review oversight.⁴⁸ Plans are also supposed to adopt practice guidelines based on valid and reliable clinical evidence or a consensus of providers, with utilization management decisions being made consistent with practice guidelines.⁴⁹ The plan is to share the guidelines with enrollees and potential enrollees upon request.⁵⁰ These provisions

⁴⁵ Maryland State Plan Amendment No. 13-0017, 12 (Apr. 2, 2014), <https://www.medicaid.gov/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/MD/MD-13-17.pdf>.

⁴⁶ See, e.g., *Salazar v. District of Columbia*, 596 F.Supp.2d 67 (2009) reconsidered in part in 750 F.Supp.2d 65 (2010) (addressing the protective order limitations and ensuring plaintiffs could access proprietary authorization tools regarding services for children).

⁴⁷ 42 C.F.R. §§ 438.10; 438.70. The provisions about information on scope of services may be useful for enforcing access to information. They have been used in the litigation context to get access to proprietary information. See, e.g., *Salazar v. District of Columbia*, 596 F.Supp.2d 67 (2009) reconsidered in part in 750 F.Supp.2d 65 (2010) (addressing the protective order limitations and ensuring plaintiffs could access proprietary authorization tools regarding services for children).

⁴⁸ 42 C.F.R. § 438.66.

⁴⁹ 42 C.F.R. § 438.236.

⁵⁰ *Id.*

set general standards about access to information and are not specific to assessment tools but could be useful for pressing states and managed care plans for information. The lack of specificity about the depth of information that is supposed to be provided may be limiting. Although managed care entities may use proprietary information protections as a shield, both public records/information and due process requirements may be useful tools in overcoming the proprietary information defenses, depending on the state.

Advocacy Recommendations:

- Encourage states to adopt additional transparency requirements in state law, state regulation, and/or managed care contracts.
- Be specific when requesting additional transparency requirements: make sure that any transparency process requires disclosing a sufficient level of detail to understand the algorithm or assessment tool. Advocates should ask for copies of the tools and instruments themselves, including specifically requesting the back-end information that determines the scoring outcome of the assessment.
- Review the public input process described in 1915(c) waivers and comment if the state has not described the process “fully” or has failed to explain what process will govern future changes to the waiver. Advocate for the state to include more robust public comment processes in the waivers.
- Sign up for the email list or other mechanism the state uses to announce SPA changes and work to build a good relationship with state staff working on SPAs. The earlier advocates can be involved in the amendment process to help shape the amendment, the more effective the advocacy will likely be.
- If a State has failed to comply with the notice requirements described in federal regulations, write to CMS alerting them to the failure to provide meaningful opportunity for comment. For example, if a 1915(c) waiver simply references a state regulation for LOC but the state makes changes to that regulation such that waiver eligibility is changed, this should be a substantive change in eligibility that requires advance public notice and comment.
- Closely compare the information available for institutional LOC and waiver LOC or state plan needs-based requirement to ensure all the information is available to understand any differences in the assessment processes and outcomes to ensure there are not inappropriate biases towards institutionalization.

- Review the public input process described in 1915(k) state plan amendments and encourage the state to adopt more robust measures for soliciting public input.
- Review state requirements for changes to 1915(i) programs and ensure that any changes to the needs-based criteria, including any assessment tools or algorithms used to establish whether a person has met that criteria, are published for public comment.
- For 1915(c) waivers, comment on the state’s description of the assessment process, and ask for more detail on the assessment tools themselves to ensure “meaningful input” on the process.