

# A Right to Person-Centered Care Planning

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### INTRODUCTION

Person-centered planning (PCP) is now almost universally understood as a necessary component of an effective delivery system for long-term services and supports (LTSS). Done well, person-centered planning can ensure greater independence and a better quality of life for seniors and people with disabilities receiving LTSS. Ideally, these consumers take an active, leading role in the planning process, armed with the information they need to make informed choices about services and supports that comport with their needs, as well as their preferences, goals, and desired outcomes.

But there is still a lack of clarity about what exactly person-centered planning is and how to make sure it is delivered. All too often, LTSS consumers receive barebones or one-size-fits-all service plans driven exclusively by functional needs assessments, a danger that

Table of Contents	
Introduction	1
The Planning Process	4
The Written Service Plan	9
The Review Process	14
Conclusion	15
Acknowledgments	15

is potentially greater when LTSS are delivered through managed care systems. The provision of PCP must not be left to the voluntary policies or business practices of governmental agencies, insurance companies, or managed care plans. Strong laws, including federal and state regulations, as well as detailed contractual language in states implementing Medicaid managed long-term services and supports (MLTSS), are essential to ensure that person-centered care becomes a right for all consumers.

Efforts to develop a strong legal framework to define a right to person-centered planning took a tremendous step forward when the Centers for Medicare and Medicaid Services (CMS) promulgated new rules for PCP in Medicaid waiver and home and community-based services (HCBS) programs in 2014. These rules provide robust consumer protections on paper, but the challenge is to make sure states and managed care plans implement them in a manner that truly benefits LTSS consumers as was intended.

The new person-centered planning rule brings us one step closer to making PCP a right for all consumers, but gaps remain and more work is needed to fully realize its potential. This issue brief will provide background context for the new person-centered planning and service plan rule; analyze the requirements of the new rule; give examples of how selected states are implementing provisions of the rule<sup>1</sup>; and identify gaps where additional federal guidance, more detailed state rules, or better managed care plan contractual terms are needed to ensure that the promise of person-centered planning is made real. Because it impacts more LTSS consumers than the other HCBS rules, this issue brief will focus on the rule that

The provision of personcentered planning must not be left to the voluntary policies or business practices of governmental agencies, insurance companies, or managed care plans. applies to LTSS delivered through Medicaid 1915(c) HCBS waivers, but it will flag instances where the rules diverge in important ways.<sup>2</sup>

## Person-Centered Planning Requirements in Medicaid Waivers: A Brief Background

Person-centered planning encompasses the idea that the individual is at the heart of all decisions about services, supports, and care. The focus of PCP planning should be the goals, wants, needs, and strengths of the individual. In the late 1970s, the concept of person-centered planning arose in the disability community, as persons with disabilities, practitioners, and caregivers worked together to try to build more autonomy into the delivery of care. By the early 1990s, some states were using person-centered thinking in designing programs surrounding intellectual and developmental disabilities.<sup>3</sup>

During this period, CMS regulations required a "written service plan" for HCBS waivers, but there was no regulatory requirement that the planning process or the resulting plan be person-centered.<sup>4</sup> In 2008, in a technical guidance to states applying for 1915(c) waivers, CMS laid the groundwork for its 2014 PCP rule.<sup>5</sup> But to the extent PCP principles were expressed in guidance rather than regulations or statutes, they were mostly aspiration. The 2008 technical guidance "encourages and supports the use of person/family-centered planning methods in service plan development," but included no explicit requirement.

The focus of personcentered planning should be the goals, wants, needs, and strengths of the individual.

In May 2013, CMS provided guidance to states using 1115 demonstrations or 1915(b) waivers for MLTSS, and included PCP processes among the ten essential elements of a high quality MLTSS program.<sup>6</sup> Under the MLTSS guidance, states must require managed care plans to use a person-centered

<sup>&</sup>lt;sup>1</sup> The selected states include Tennessee, Minnesota, New Jersey and Wisconsin.

<sup>&</sup>lt;sup>2</sup> 42 C.F.R. §441.301(c) (HCBS waivers), 42 C.F.R. §441.725 (HCBS state-plan services), 42 C.F.R. §441.540 (Community First Choice). The PCP rule for 1915(c) HCBS waivers also applies to LTSS services delivered through §1115 demonstration waivers where the "§1115 Demonstration refers to the 1915(c) authority for HCBS services" and if there is not a waiver of 1915(c) authority in the demonstration. See Letter from Cindy Mann, Director, Center for Medicaid and CHIP Services, to Valerie Harr, Director, New Jersey Department of Human Services (Dec. 4, 2014) (on file with author).

<sup>&</sup>lt;sup>3</sup> Connie Lyle O'Brien & John O'Brien, The Origins of Person-Centered Planning: A Community of Practice Perspective, 3-4 (2000), available at http://www.nasddds.org/uploads/documents/The\_Origins\_of\_Person\_Centered\_Planning\_Obrien\_and\_Obrien.pdf.

<sup>4 42</sup> U.S.C. \$1396n(c) and 42 C.F.R \$441.301.

<sup>&</sup>lt;sup>5</sup> Centers for Medicare & Medicaid Services, Instructions, Technical Guide and Review Criteria, Application for a \$1915(c) Home and Community-Based Waiver [Version 3.5], 178 (2008), available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/Technical-Guidence.pdf [hereinafter CMS Technical Guide].

<sup>&</sup>lt;sup>6</sup> Centers for Medicare and Medicaid Services, Guidance to States using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Supports Programs, 3-4 (May 20, 2013), available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/1115-and-1915b-MLTSS-guidance.pdf ("This guidance is intended to share what CMS has learned from states, stakeholders, and advocates in terms of best practices for establishing and implementing MLTSS programs and to clarify expectations of CMS from states using 1115 demonstrations or 1915(b) waivers combined with another long term service and supports (LTSS) authority in an MLTSS program. The ten key elements in this document are those that CMS expects to see incorporated into new and existing state Medicaid MLTSS programs.") [hereinafter CMS 1115/1915(b) Guidance].

planning process, including examples that can be found in the 2012 PCP regulations governing the 1915(k) Community First Choice program.<sup>7</sup> In addition, "MLTSS programs must require and monitor the implementation and use of person-centered needs assessment, service planning, and service coordination policies and protocols."

Then, in 2014, CMS took its biggest step to date toward establishing regulations that inform a right to person-centered care planning. The agency amended Medicaid waiver regulations to include the person-centered planning and written service plan requirements. While the previous guidance was important, the new regulations finally provided clear direction for states in implementing person-centered planning in HCBS contexts, and the codification of these protections forms the basis of much of the "rights based" approach to person-centered planning. 10

## Standards for Person-Centered Planning under the 2014 HCBS Regulations

The standards for person-centered planning in the new HCBS waiver rule are comprehensive, detailed, and intended to establish strong consumer protections in the PCP process and resulting written plans. In response to a question of whether any substantive rights are established for the individual under the new PCP rule, CMS clearly stated that it considers "the requirements outlined [in the rule] to confer to individuals *the right* to a person-centered service plan, and a planning process," that meets the requirements of the rule.<sup>11</sup> [emphasis added]

The new rule includes person-centered standards in three subsections:<sup>12</sup>

- The person-centered planning process
- The resulting written service plan
- Requirements for review of the plan

The specific requirements in these three subsections are set forth in a chart in Appendix A of this brief, which compares how the new regulations treat several separate types of waivers and HCBS programs – 1915(c) HCBS waivers, 1915(i) HCBS state-plan services programs, and 1915(k) Community First Choice programs. CMS is working to bring all the PCP rules into harmony, but at this time they are not identical due to some statutory differences.<sup>13</sup>

Below, this issue brief analyzes selected provisions of the 1915(c) HCBS waiver rule central to an effective and meaningful PCP process. The brief focuses on provisions within each of the three subsections of the rule (see bullets above). <sup>14</sup> Regulatory provisions are set out along with a brief discussion of why the particular requirements are important in a rights based PCP process. Attention is drawn to aspects of the rule where more rules, regulations, and requirements are necessary to ensure the rights of LTSS consumers to effective and robust person-centered care. State examples highlight promising efforts to ensure that the right to PCP envisioned by the new regulation is actually delivered.

<sup>8</sup> CMS 1115/1915(b) Guidance, supra note 6, at 10-11.

<sup>&</sup>lt;sup>7</sup> 77 Fed. Reg. 26,827 (May 7, 2012).

<sup>&</sup>lt;sup>9</sup> 1915(c) regulations were modified at 79 Fed. Reg. 3029 (Jan. 16, 2014). Regulations for 1915(i) HCBS state-plan benefits were modified at 79 Fed. Reg. 3036 (Jan. 16, 2014).

<sup>&</sup>lt;sup>10</sup> In addition, HHS has recently issued guidance to HHS agencies, which applies more broadly to all HHS funded HCBS programs, but includes standards for person-centered planning that are consistent with CMS's PCP rules. See Centers for Medicare & Medicaid Services, Guidance to HHS Agencies for Implementing Principles of Section 2402(a) of the Affordable Care Act: Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Service Programs (June 6, 2014), available at http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf [hereinafter CMS 2402(a) Guidance].

<sup>&</sup>lt;sup>11</sup> 79 Fed. Reg. at 3004 (Jan 16, 2014).

<sup>&</sup>lt;sup>12</sup> For a detailed comparison of the 1915(c) and 1915(i) rules, as well as the 2014 HHS Guidance, see Elizabeth Edwards, Q&A: Person Centered Planning Changes, NATIONAL HEALTH LAW PROGRAM (NHeLP) (April 2015), available at http://www.healthlaw.org/component/jsfsubmit/showAttachment?tmpl=raw&id=00Pd000000JNFieEAH.

<sup>&</sup>lt;sup>13</sup> 79 Fed. Reg. at 3004 (Jan 16, 2014).

<sup>&</sup>lt;sup>14</sup> This brief does not analyze every provision of the rule or explore all gaps, for example, the conflict of interest and choice of setting provisions of the rules, as well as the cultural considerations and language access requirements. More work to identify gaps in all areas of the rule will need to be undertaken in the coming years.

#### THE PLANNING PROCESS

The first subsection of the new rule lays out requirements for the person-centered care planning process, including two key principles that must be part of the planning process. The first is that the consumer leads the PCP process, and the second is that the consumer must be empowered to make informed choices.

## The Consumer Leads the Planning Process

The new rule could not be clearer that the intent is to empower the LTSS consumer: "The individual *will lead* the person-centered planning process where possible." [emphasis added.] To this end, especially from a logistical perspective, the planning process must be timely; and occur at times and locations of convenience to the LTSS consumer; include people chosen by the LTSS consumer; and, to the extent the consumer's representative has a participatory role, that role should be as needed and defined by the LTSS consumer, unless state law confers decision-making authority to the legal representative. <sup>16</sup>

Letting the consumer choose who participates in the meeting is key to a productive process and to creating an environment where the consumer feels comfortable and supported.

Why this is important: The rule recognizes the importance of the basic idea that a person-centered planning process must be led by the person.<sup>17</sup> It is unambiguous that this means allowing the person to control where, when, and who shall attend care planning meetings.

Allowing the consumer to choose where a meeting occurs is essential to ensuring both that they can participate and that the meeting is effective. In most cases, LTSS consumers – who may be wheelchair users or have difficulties leaving the house – will choose to have planning meetings in their own homes. But there may be occasions when an alternative location would better suit the consumer. For example, a resident transitioning back home may want the care planning meeting to happen in the nursing home prior to discharge, so that the plan can be in place upon return home.

Similarly, holding meetings at days and times of the consumer's choice helps ensure that they are ready to fully participate in the meeting. For

example, an LTSS consumer may take medication that affects cognitive functioning, such that the consumer is more alert during the morning rather than the afternoon, or vice versa, and meetings should be planned with this in mind.

Finally, letting the consumer choose who participates in the meeting is key to a productive process and to creating an environment where the consumer feels comfortable and supported. For example, a senior LTSS consumer may want his or her adult child to attend the planning meeting because that child helps the consumer with getting to doctor appointments or problem-solving when an aide fails to show up. Conversely, that consumer may be adamant that certain individuals not be part of the process. For example, she may not want a difficult or controlling adult child or an uncooperative aide present. In another example, a mother may not want to discuss intimate personal information, like incontinence, in front of her adult son. Or she may be on medications for medical problems that she has not yet shared, and so may want to exclude her son from the process to avoid embarrassment or disclosing

<sup>&</sup>lt;sup>15</sup> In 1915(k) and 1915(i), the "person-centered planning process is driven by the individual." See 42 C.F.R. §441.540(a) and 42 C.F.R. §441.725(a).

<sup>&</sup>lt;sup>16</sup> 42 C.F.R. §441.301(c)(1)(i) and (iii). See also 42 C.F.R. §441.735, which defines the scope of decision-making authority of the "individual's representative" in 1915(i) HCBS state-plan programs. The 1915(k) rule does not explicitly address decision-making by representatives.

<sup>&</sup>lt;sup>17</sup> In response to a concern that some LTSS consumers may not want to lead PCP, CMS clarified that the regulatory language does not require individuals to be more involved than they choose to be in their own planning process, and may decline to participant if they so choose. 79 Fed. Reg. at 3005 (Jan 16, 2014).

<sup>&</sup>lt;sup>18</sup> CMS has emphasized that LTSS consumers can "choose who does or does not attend the meeting." 79 Fed. Reg. at 3005 (Jan 16, 2014).

personal information before she is ready.

Where more guidance and rules are needed: The rule is clear on the need for the planning process to be led by the LTSS consumer, but only provides limited direction in cases where the person has diminished capacity. More guidance is needed to ensure that states develop PCP policies that encourage consumers with diminished capacities to participate in a person-centered planning process to the maximum extent possible, and incorporate principles of substituted judgment and supported-decision making where legal representatives are involved in the process.

The rule does speak explicitly to the role a consumer representative may play, but does not provide sufficient protection to beneficiaries. Initially, the regulatory language limits the decision-making authority of representatives: representatives should have a participatory role, as needed and as defined by the consumer. However, the rule continues, "unless state law confers decision-making authority to the legal representative."<sup>19</sup>

This deference to state laws is a serious concern in a person-centered process that values personal choices and allows individuals to take risks. Historically, state guardianship laws conferred plenary authority upon legal representatives to make decisions in the best interests of the ward, without any legal requirement that due regard be given to the ward's preferences – even with respect to decisions about fundamental rights, such as whether to live in an HCBS setting or nursing home. While states may be moving in the direction of limited guardianship and substituted judgment standards (which promote the self-determination of the ward), the risk in the absence of clear guidance from CMS is that circumstances will arise where surrogate decision makers impose their decisions unilaterally in the PCP process to the detriment of the express wishes, preferences, and choices of LTSS consumers.

Areas of the rule that apply to services provided in a 1915(i) HCBS state plan benefit (instead of 1915(c) waivers) take a more person-centered approach to cases involving authorized representatives.<sup>20</sup> Under the 1915(i) PCP rule, the individual's representative is defined to include a legal guardian or other person authorized under state law to represent the individual for the purpose of making decisions related to care and well-being. The rule curtails the decision-making authority of that individual: "In instances where state law confers decision-making authority to the individual representative, the individual will lead the service planning process to the extent possible."<sup>21</sup> [emphasis added] With respect to other individuals authorized by the state to act as representative (e.g., representatives permitted by the state Medicaid agency), state policies must have "safeguards to ensure that the representative uses substituted judgment on behalf of the individual" and must "address exceptions to using substituted judgment when the individual's wishes cannot be ascertained or when the individual's wishes would result in substantial harm to the individual."<sup>22</sup>

As these new rules are implemented, policymakers, advocates, plans and providers must work together to refine these rules to include surrogate decision-making principles, including those of substituted judgment and supported-decision making, where legal representatives are part of the process. Policies that maximize the decision-making and participation of individuals with diminished capacity are essential.<sup>23</sup> The rights to self-determination and a written service plan that reflects the values of the LTSS consumer are as important to individuals with diminished capacity as they are to all waiver participants. The rule anticipates, that in many cases, if not most, a person with diminished capacity can choose to live at home. Guided by principles of substituted judgment, legal representatives should advocate for services and supports that promote independence and safely meet the consumers fully identified need without risk of substantial harm.<sup>24</sup>

<sup>&</sup>lt;sup>19</sup> 42 C.F.R. §441.301(c)(1).

<sup>&</sup>lt;sup>20</sup> 42 C.F.R. §§441.725(a), 441.735.

<sup>&</sup>lt;sup>21</sup> 42 C.F.R. §441.735(a).

<sup>&</sup>lt;sup>22</sup> 42 C.F.R. §441.735(b).

<sup>&</sup>lt;sup>23</sup> See CMS 2402(a) Guidance, supra note 10, at 4, 6, ("PCP should involve the individuals receiving services and supports to the maximum extent possible, even if the person has a legal representative" and "People under guardianship or other legal assignment of individual rights, or who are being considered as candidates for these arrangements, should have the opportunity in the PCP process to address any concerns").

<sup>&</sup>lt;sup>24</sup> The 1915(c) HCBS waiver rule recognizes that consumers may make choices that have some level of risk. The written service plan must "reflect risk factors and measures in place to minimize them, including individualized back-up plans and strategies when needed."

#### THE RULE IN PRACTICE

Several states have found ways to incorporate these planning process requirements into the rules governing their Medicaid HCBS programs:

- New Jersey: In the CMS-approved Special Terms and Conditions (STC) to New Jersey's §1115 demonstration waiver, STC #52 governs plans of care (PoC) and requires that meetings related to a PoC must "be held at a location, date, and time convenient to the enrollee and his/her invited participants."<sup>25</sup> The NJ managed care contract provides that a face-to-face visit to initiate service planning must be within 10 days of enrollment, or later as requested by the Member.<sup>26</sup>
- Tennessee: Under the Tennessee managed care contract, the person-centered planning process is directed by the member with long-term support needs, and may include a representative whom the member has freely chosen and others chosen by the member to contribute to the process.<sup>27</sup>
- Wisconsin: In Wisconsin, the managed care plan is "required to ensure that each member has a meaningful opportunity to participate" in the development of the plan, and is expected to ensure that "the member, the member's authorized representative, and any other person identified by the member will be included in the care management processes of assessment, member outcome identification, member-centered plan development, and reassessment."<sup>28</sup>

## The Consumer is Empowered to Make Informed Choices

The rule's subsection on the person-centered planning process also requires that consumers be empowered to make informed choices. State Medicaid agencies (or managed care plans) must provide the necessary information and support to ensure that LTSS consumers direct the process to the maximum extent possible, and are enabled to make informed choices and decisions.<sup>29</sup> They must also offer informed choices to LTSS consumers regarding the services and supports they received and from whom.<sup>30</sup> Finally, they must record alternative home and community-based settings that were considered by the individual.<sup>31</sup>

Why this is important: The PCP processes can only be effective when LTSS consumers have the skills necessary to lead a planning process and make decisions, and they have the information necessary to make the choices about services and providers. States must ensure both aspects of the rule.

First, because the planning process must enable LTSS consumers to direct the process and make decisions, consumers must be educated in principles of self-advocacy, self-determination, and person-centered principles.<sup>32</sup> This is important because Medicaid recipients are frequently hesitant to challenge government or health plan authority, and are sometimes too willing to accept without question the decisions of those authority figures. And historically, many Medicaid programs and managed care plans have not embraced person-centered principles and, in some cases, are

<sup>42</sup> C.F.R. §441.301(c)(2)(vi). CMS emphasizes that provisions of the rule are meant to ensure that "reducing risk for individuals receiving Medicaid HCBS does not involve abridgment of their independence, freedom, and choice," and that "[r]estricting independence or access to resource is appropriate only to reduce specific risks, and only when considered carefully in the person-centered plan." 79 Fed. Reg. 3008 (Jan 16, 2014).

 $<sup>^{25}\</sup> NJ's\ Comprehensive\ Waiver,\ STC\ \#52,\ 40\ (August\ 2014),\ available\ at\ http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/nj/nj-1115-request-ca.pdf.$ 

 $<sup>^{26}</sup>$  New Jersey Contract, Article 9.6.2(B)(2) (July 2014), available at http://www.state.nj.us/humanservices/dmahs/info/resources/care/hmo-contract.pdf.

<sup>&</sup>lt;sup>27</sup> Tennessee Contract, Article A.1 (Definitions) (Jan. 2015), available at http://www.tn.gov/tenncare/forms/MCOStatewideContract.pdf.

<sup>&</sup>lt;sup>28</sup> Wisconsin Contract, Article V.A.1 (Jan, 2015), available at https://www.dhs.wisconsin.gov/familycare/mcos/cy2015mcocontract.pdf.

<sup>&</sup>lt;sup>29</sup> 42 C.F.R. §441.301(c)(1)(ii).

<sup>&</sup>lt;sup>30</sup> 42 C.F.R. §441.301(c)(1)(vii).

<sup>&</sup>lt;sup>31</sup> 42 C.F.R. §441.301(c)(1)(ix).

<sup>&</sup>lt;sup>32</sup> CMS envisions that the supports required under this provision of the rule may include professionals trained and skilled in person-centered planning techniques who can facilitate the PCP process. 79 Fed. Reg. 3006 (Jan 16, 2014).

viewed by consumers as adversarial.

Second, because consumers must make decisions from among offered choices, they must receive meaningful and easily understood information about available services, supports, and providers, as well as the consequences of those choices.<sup>33</sup> In achieving a balance between too much information and too little information, the rule requires that the choices offered are informed, which means, in part, that they are relevant to the needs and preferences of the consumer, and are actually possible choices.<sup>34</sup> For example, managed care plans should not point LTSS consumers

to web-based lists of HCBS providers, none of whom have staff available to meet the needs of the consumer, and call that informed choice. LTSS consumers also need to receive information in a manner that is complete and that they understand. For example, care managers should be sure to explain the difference between medical adult day services and social adult day services when both options are available.

Providing the person-centered skills, education, and information required by the rule in a timely fashion is essential to ensuring that LTSS consumers are actively engaged in the PCP process.<sup>35</sup> Frequently, MLTSS consumers report that services and supports are first explained to them at the service planning meetings, which leaves no meaningful opportunity to review and consider options, or to discuss options with trusted family, friends, or physicians.

Informed choice means consumers must receive meaningful and easily understood information about available services, supports, and providers, as well as the consequences of those choices.

Equally important, these provisions of the rule inherently require care managers and other professionals involved in the PCP process to have knowledge, training, and expertise in both the scope of 1915(c) HCBS waiver services available and person-centered service delivery principles.<sup>36</sup> Without this training, providers will be unable to ensure that consumers are aware of and able to exercise their choices.

Where more guidance and rules are needed: Despite the rule's requirements around ensuring that LTSS consumers are able to make informed choices about services and providers, the rule does not provide direction to states, plans, and providers on how to do so. Nor does it set a standard that regulators can easily monitor.

One of the keys to ensuring that consumers are empowered to make choices is training. As described above, both providers and consumers need training on person-centered principles to ensure this works. Requirements around both provider and consumer training should be developed to ensure that these elements of the rule will be effectuated.

In addition, more specificity is needed to define how plans must empower informed choice among beneficiaries. It is common for agencies and plans to present one option to a consumer and then report that the consumer made an informed choice. In one recent example, managed care plan enrollees living in a decertified nursing facility were told by their health plan that they had to move and were presented with only one other facility as an option. More rules are needed to outline what it means to present appropriate and relevant options and allow the consumer to make informed choices among them.

Finally, while the rule requires that the planning process document the settings that the individual considered, it does not go into specifics on what such "consideration" must entail. The language of the rule also does not explicitly

<sup>&</sup>lt;sup>33</sup> 79 Fed. Reg. 3007 (Jan 16, 2014).

<sup>34</sup> CMS recognizes that it is difficult to achieve a perfect balance between too much and too little information, and so requires informed choices that are relevant to the needs and preferences of the consumer. 79 Fed. Reg. 3007 (Jan 16, 2014).

<sup>35</sup> See CMS Technical Guide, supra note 5, at 180 ("The participant should be furnished supports that are necessary to enable the participant to actively engage in the planning process, including providing information about the range of service and supports offered though the waiver in advance of the service plan development...") [emphasis added].

<sup>&</sup>lt;sup>36</sup> See CMS 1115/1915(b) Guidance, supra note 6, at 11. See also CMS 2402(a) Guidance, supra note 10, at 8 ("In order for PCP principles to be fully realized leadership, administrative, and other staff are strongly encouraged to receive competency-based training in PCP.").

require that the consumer have setting options, only that what options the consumer considered were noted. In its June 2014 guidance on self-direction, HHS uses clearer phrasing, stating that the individual's needs are "not associated with any particular residential setting, 'one size fits all' rubric, or other arbitrary methodology disassociated

from the individual."<sup>37</sup> As states, providers and plans develop models for PCP, they must develop ways to allow consumers first to choose where they want to live and then to determine what services are necessary to make that primary choice possible.

#### THE RULE IN PRACTICE

Several states have found ways to incorporate requirements about the provision of necessary support and informed choice into the rules and practices governing their Medicaid HCBS programs:

Minnesota: Minnesota contracts with the University of Minnesota's Research and Training Center on Community Living at the Institute on Community Integration to provide training in person-centeredness for state and tribal provider agencies and lead agencies. This year-long training not only helps agency staff learn and understand person-centered planning, but also assists agencies in undertaking the structural and organizational changes necessary to implement and support true person-centeredness.<sup>38</sup>

As states, providers and plans develop models for person-centered planning, they must develop ways to allow consumers first to choose where they want to live and then to determine what services are necessary to make that primary choice possible.

- New Jersey: New Jersey's managed care contract requires managed care plans to engage in "options counseling" with all MLTSS consumers, a process designed to enable participants to make informed choices and decisions. Options counseling is defined in the contract as "an interactive process where individuals receive guidance in their deliberations to make informed choices about long-term supports based on their assessed need," and includes "a facilitated decision support process which explores resources and service options and supports the individual in weighing pros and cons." The contract mandates that care managers are trained and certified by the state to provide options counseling.<sup>39</sup>
- Wisconsin: Consumer education and training services are among the benefit package services available under Wisconsin's HCBS waivers. This service is defined as "designed to help a person with a disability develop self-advocacy skills, support self-determination, exercise civil rights, and acquire skills needed to exercise control and responsibility over other support services." The education and training is available to LTSS consumers as well as their caregivers and legal representatives. Covered expenses include enrollment fees, books, and other educational materials, and transportation to training courses, conferences, and other similar events. MLTSS consumers may spend up to \$2500 per participant annually.<sup>40</sup>

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<sup>&</sup>lt;sup>37</sup> CMS 2402(a) Guidance, supra note 10, at 9. The same guidance is less clear in its person-centered planning sections, saying "Employment and housing in integrated settings must be explored, and planning should be consistent with the individual's goals and preferences, including where the individual resides, and who they live with." This language does not effectively sever the link between setting and service, though it does go farther than the regulation itself.

<sup>&</sup>lt;sup>38</sup> Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, http://rtc3.umn.edu/pctp/training/OrgChangeTA.asp (last visited Apr. 28, 2015).

<sup>&</sup>lt;sup>39</sup> New Jersey Contract, Article 1 (Definitions), Article 9.5.3(D), Article 9.6.5(C) (July 2014).

<sup>&</sup>lt;sup>40</sup> Wisconsin Contract, Addendum X § (A)(6) (Jan. 2015).

#### THE WRITTEN SERVICE PLAN

The second section of the HCBS waiver rule lays out the requirements for the written service plan that results from the person-centered planning process. This section includes three key principles. The first is that the plan must reflect the identified need and individual preferences of consumers. The second is that the plan must include paid and unpaid services and supports, as well as the providers of those services. The third is that the final plan must be agreed to, through the written informed consent of the LTSS consumer and must also be signed by parties responsible for its implementation.

# The Plan Must Reflect the LTSS Consumer's Identified Need and Individual Preferences

The new 1915(c)HCBS waiver rule envisions written service plans that are holistic and goal-oriented, addressing both the needs and preferences of the LTSS consumer. Standards in the rule require that the written plan must reflect the LTSS consumer's strengths and preferences, include individually identified goals and desired outcomes, and reflect clinical and support needs of the consumer as identified through an assessment of functional need.

Why this is important: These provisions of the rule are important because they integrate "objective" functional assessments and person-centered inquiry focused on strengths, preferences, goals, and desired outcomes. A well-done person-centered written service plan should address the "array of HCBS needs in the context of personal goals, preferences, community and family supports, financial resources, and other areas important to the person."<sup>45</sup> The rule embodies the growing recognition that assessments of functional need may be a necessary and important part of service plan development, but that the PCP process should yield "quality-of-life goals that exceed the ability of any set of program-specific services and supports to meet them."<sup>46</sup> The purpose is to encourage the development of

Consideration must now be given to a broader discussion and analysis of consumers' strengths, preferences, goals and desired outcomes – all of which must be incorporated into cohesive written plans. written plans that include goals and outcomes that are not defined exclusively by covered Medicaid services, and to find innovative ways to meet these broader goals and desired outcomes.

Too often, service plans rely exclusively on functional assessments and are nothing more than a recitation of Medicaid-approved services that address a consumer's need for assistance with activities of daily activities (ADLs) such as bathing, dressing, and meal preparation. Even worse, managed care service plans sometimes use complicated and inaccessible language (e.g., prior authorization, utilization management, or medically necessary services) or describe plan services in units (e.g., 3865 units of PCA) that are impossible for LTSS consumers to decipher. The rule's new standards establish the right of LTSS consumers to have service plans based on more than objective assessments of functional need; due consideration must now be given to a broader discussion and analysis of consumers' strengths, preferences, goals,

and desired outcomes – all of which much be incorporated into cohesive written plans.

Where more guidance and rules are needed: Clearly, these provisions of the rule, which require the integration of clinical and support needs (e.g., assistance with ADLs) with strengths, preferences, identified goals, and desired outcomes, create significant new rights for LTSS consumers. However, more guidance or rules may be needed to

<sup>&</sup>lt;sup>41</sup> 42 C.F.R. §441.301(c)(2).

<sup>&</sup>lt;sup>42</sup> 42 C.F.R. §441.301(c)(2)(ii)-(iv).

<sup>&</sup>lt;sup>43</sup> 42 C.F.R. §441.301(c)(2)(v).

<sup>&</sup>lt;sup>44</sup> 42 C.F.R. §441.301(c)(2)(ix).

<sup>&</sup>lt;sup>45</sup> CMS 2402(a) Guidance, supra note 10, at 4.

<sup>&</sup>lt;sup>46</sup> Id.

ensure that states and managed care plans develop and implement mechanisms to effectively elicit information about strengths, preferences, goals, and desired outcomes, and then incorporate that information, under the direction of the consumers, into holistic, effective, person-centered written service plans.

The list of potential risks in the absence of more federal guidance, stricter state rules, or state-specific contractual language include:

- States will focus on the development and implementation of objective functional assessment tools that fail to incorporate person-centered domains or processes, with the result that service plans continue to be driven by the algorithms embedded in these tools that only assess functional need.<sup>47</sup>
- States and managed care plans will not be motivated to develop effective methods to elicit information about individual strengths and preferences, or identified goals and desired outcomes, and so service plans may include only perfunctory lists of generalized goals or desired outcomes (e.g., the consumer wants to live at home).
- States and managed care plans will fail to implement strategies to effectively review plans to ensure that goals
  and desired outcomes are being met. (In the experience of many LTSS consumers, service plan reviews are
  merely opportunities for states or managed care plans to cut services.)

#### THE RULE IN PRACTICE

Several states have found ways to incorporate requirements about the inclusion of strengths, preferences, goals, and desired outcomes along with need, as identified through functional need assessments, into the rules governing their Medicaid HCBS waiver programs:

- Minnesota: The new Minnesota assessment tool, MnCHOICES, includes person-centered questions, most significantly the "Quality of Life" domain, focusing on learning "what is important to the individual and what brings them satisfaction, happiness, and comfort." The domain includes questions on: routines and preferences; strengths and accomplishments; relationships; and traditions and future plans. Many of the questions are open-ended such as "How do you want to spend your time?" and "What are some things you have done that you feel proud of?" It also provides more directed questions which can serve as guides or prompts for further discussion such as, "Typically in your life, do you . . .Play cards, a board game or video game with a friend?" and whether the participant has limitations on achieving the amount of interaction they would otherwise choose.<sup>48</sup>
- New Jersey: The NJ contract mandates that, in addition to options counseling and the use of the state-developed functional assessment tool, the service plan be informed by a face-to-face discussion with the LTSS consumer that includes a systematic approach to the assessment of the consumer's strengths and needs in the following areas: functional abilities, medical conditions, behavioral health, social/environmental/cultural factors, and existing support system. MLTSS consumer goals must be developed through this process that are consumer specific, measurable, include a plan of action to meet the identified goals, and include a timeframe for attainment of desired outcomes. Progress toward goals must be discussed and reviewed during care manager visits with the consumer.<sup>49</sup>

<sup>&</sup>lt;sup>47</sup> For more information on the development of person-centered assessments, see Carolyn Ingram, Alice Lind & Brianna Ensslin, Uniform Assessment Practices in Medicaid Managed Long-Term Services and Supports, Center For Health Care Strategies (August 2013), available at <a href="http://www.chcs.org/media/Uniform\_Assessment\_in\_MLTSS\_9-6-13\_FINAL.pdf">http://www.chcs.org/media/Uniform\_Assessment\_in\_MLTSS\_9-6-13\_FINAL.pdf</a>. See also Barbara Gage, et al., Charting a Path Forward for Uniform Assessment of LTSS Needs, Roundtable Report, Long Term Quality Alliance (June 10, 2014), available at <a href="http://www.ltqa.org/wp-content/themes/ltqaMain/custom/images//LTQA-Charting-A-Path-Forward-Report-Final-Report-6-10-14-.pdf">http://www.ltqa.org/wp-content/themes/ltqaMain/custom/images//LTQA-Charting-A-Path-Forward-Report-Final-Report-6-10-14-.pdf</a>.

<sup>&</sup>lt;sup>48</sup> Minnesota Choices, Qualify of Life Domain Assessment (August 6, 2014), available at http://www.dhs.state.mn.us/main/groups/county\_access/documents/pub/dhs16\_180272.pdf.

<sup>&</sup>lt;sup>49</sup> New Jersey Contract, Article 9.6.3(C) and (D) (July 2014).

# The Plan Must Include Paid and Unpaid Services and Supports, as well as the Providers of Those Services

The next requirement for the written service plan is that it must clearly identify all of the services and supports the LTSS consumer will receive on a regular basis and indicate specifically who will provide those services. Notably, the rule is explicit that the written plan include both services available under a state's HCBS waiver as well as unpaid support, such as that provided by a family caregiver, but also makes clear that unpaid natural supports are voluntary.<sup>50</sup>

Why this is important: Paid Medicaid service and supports are the bread-and-butter of service plans, and consumers tend to be familiar with the inclusion of these services in their written service plans. But, in fact, most HCBS recipients receive at least some services from unpaid family caregivers. Approximately \$450 billion worth of services in 2009 were provided by unpaid family caregivers, more than double what was paid for (\$203 billion). 52

The health of the consumers and of the system as a whole depends on these caregivers being able to continue to provide such care, but the toll on caregivers can be enormous. They may struggle financially because they are paying many of the bills of HCBS recipients while also absorbing the sometimes substantial impact caregiving has on their employability.<sup>53</sup> Such caregivers are often volunteers, but may not feel they have a choice whether to provide care, because of societal or financial pressures.<sup>54</sup> And the stress of caregiving has an impact on the caregivers' health, well-being, and ability to continue in the role.<sup>55</sup> These caregivers are often called upon to complete demanding skilled nursing tasks without significant training,<sup>56</sup> to make life-or-death decisions for loved ones, and to do strenuous, intimate, and difficult tasks daily out of affection or duty. All of these impacts fall disproportionately on female family members.<sup>57</sup>

The standards in the rule regarding unpaid natural supports address some of these problems in two important ways: first, they make clear that natural supports are voluntary and so cannot be compelled in the written plan; and, second, they invite more discussion about including caregiver assessment in a person-centered planning process.

Where more guidance and rules are needed: More guidance is needed here in two areas. First, while the rule is clear that unpaid natural supports are voluntary, it must also be clear that LTSS consumers can object when paid Medicaid services are reduced because of the alleged availability of natural supports. Second, the rule must be more explicit that caregiver assessments are essential where unpaid caregivers are relied upon to implement any element of the service plan.<sup>58</sup>

The rule is clear that LTSS consumer service plans may include both paid and unpaid services and supports,

<sup>&</sup>lt;sup>50</sup> 42 C.F.R. §441.301(c)(2)(v).

<sup>&</sup>lt;sup>51</sup> Susan C. Reinhard, et al., Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers, 41-45, AARP Public Policy Institute (2d ed. 2014), available at http://www.aarp.org/home-family/caregiving/info-2014/raising-expectations-2014-AARP-ppi-health.html.

<sup>&</sup>lt;sup>52</sup> Lynn Feinberg, et al., Valuing the Invaluable Factsheet: 2011 Update: The Economic Value of Family Caregiving in 2009, 1, AARP PUBLIC POLICY INSTITUTE (2011), available at http://assets.aarp.org/rgcenter/ppi/ltc/fs229-ltc.pdf.

<sup>&</sup>lt;sup>53</sup> National Alliance for Caregiving, Caregiving in the US, NATIONAL ALLIANCE FOR CAREGIVING IN COLLABORATION WITH AARP, 51-55 (November 2009), available at http://www.caregiving.org/data/Caregiving\_in\_the\_US\_2009\_full\_report.pdf [hereinafter Caregiving in the US].

<sup>&</sup>lt;sup>54</sup> Id. at 50.

<sup>&</sup>lt;sup>55</sup> Id. at 47-55; see also Susan C. Reinhard, Carol Levine & Sarah Samis, Home Alone: Family Caregivers Providing Complex Chronic Care, 28-9, AARP Public Policy Institute (October 2012), available at http://www.aarp.org/content/dam/aarp/research/public\_policy\_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf [hereinafter Home Alone].

<sup>56</sup> Home Alone, supra note 9, at 18.

<sup>&</sup>lt;sup>57</sup> Caregiving in the US, supra note 7, at 14

<sup>&</sup>lt;sup>58</sup> CMS emphasized in the context of 1915(i) HCBS state-plan services that "when caregivers are being relied upon to implement the person-centered plan, it is important that a caregiver assessment be required in order to acknowledge and support the needs of informal family caregivers." 79 Federal Reg. 2985 (Jan 16, 2014); see also 42 C.F.R. § 441.720(a)(4). This same requirement, however, does not appear in the regulations applied to 1915(c) programs.

but that unpaid natural supports may be included only to the extent that the services are offered voluntarily.<sup>59</sup> In practice, some states or managed care plans offset paid Medicaid services that reflect need identified through the functional assessment process with unpaid natural supports. In some circumstances, the reason given is that Medicaid services cannot be provided "for the convenience of the caregiver." Yet, CMS has emphasized that unpaid natural supports must be provided voluntarily, and cannot be compelled in the written service plan. Additional federal guidance as well as state rules or, in MLTSS states, contractual provisions are necessary to ensure that LTSS consumers have access to Medicaid appeal and fair hearing rights in these situations.<sup>60</sup>

While assessments of need are the norm for LTSS consumers, caregiver assessments are also crucial where unpaid caregivers will be relied upon to implement any elements of the person-centered service plan. <sup>61</sup> Identifying the preferences and needs of caregivers and incorporating those preferences and needs into the written plan should be part of a person-centered planning process that relies on both covered services and community support. <sup>62</sup> More work is needed to ensure this is done and to ensure that agencies and plans use effective tools for conducting these assessments. There is also a need to further identify the responsibility of agencies and plans to offer services and resources to actually meet the caregiver needs identified in the written plan.

#### THE RULE IN PRACTICE

Several states have requirements that include caregiver assessments:

- Minnesota: Minnesota uses a Caregiver Questionnaire in its LTSS program. The Questionnaire allows the assessor to understand the informal caregiver's needs, to inform the planning process, to create back-up plans, and to identify resources that may be available to ease caregiver stressors or better allow caregivers to flourish. The Questionnaire asks open-ended questions about the caregiver's health, stress levels, employment, supports, and many other aspects of their lives that can impact their ability to provide care. <sup>63</sup>
- Tennessee: The TENNCARE managed care contract requires the care coordinator to conduct a caregiver assessment using a tool approved by the state as part of a certain face-to-face visit intake visits. The caregiver assessment must include: an overall assessment of the family member(s) and/or caregiver(s) providing services to the member to determine willingness and ability to contribute effectively to the LTSS consumer's needs. The assessment must consider the employment status and other care-giving responsibilities of the caregiver as well as the stress level and need for knowledge or skills training.<sup>64</sup>

# The Plan Must be Finalized and Agreed to, with the Written Informed Consent of the LTSS Consumer

The HCBS waiver PCP rule requires that the written plan be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its implementation.<sup>65</sup> In the context of signed finalized plans, CMS emphasizes that the fair hearing requirements of 42 C.F.R. §431, Subpart E

<sup>&</sup>lt;sup>59</sup> 42 C.F.R. §441.301(c)(2)(v). See also 42 C.F.R.§441.540(b)(5)(Under the 1915(k) rule, "[n]atural supports cannot supplant needed paid services unless the natural supports that are provided voluntarily to the individual in lieu of an attendant."

<sup>&</sup>lt;sup>60</sup> CMS emphasizes, in the context of 1915(i) HCBS state plan services, that all available services and support options must be discussed in the PCP process and that states must adhere to the fair hearing requirements found at 42 C.F.R. §431, Subpart E. <sup>61</sup> See 42 C.R.F. § 441.720(a)(4).

<sup>&</sup>lt;sup>62</sup> CMS 1115/1915(b) Guidance, supra note 6, at 11.

<sup>&</sup>lt;sup>63</sup> Minnesota Choices, Caregiver Questionnaire (December 2014), available at https://edocs.dhs.state.mn.us/lfserver/Public/DHS-6914-FNG.

<sup>&</sup>lt;sup>64</sup> Tennessee Contract, Article 2.9.6.2.16 (Jan. 2015).

 $<sup>^{65}</sup>$  In the PCP process section of the rule,  $^{42}$  C.F.R.  $^{9441.301(c)(1)(v)}$  requires that the process include strategies for solving conflict and disagreement, which is necessary to achieve a finalized plan. However, both the PSP process and the finalized plan must afford LTSS Medicaid due process and appeal rights as discussed herein.

apply to all Medicaid services.66

Why this is important: This is important because crucial Constitutional due process protections are at stake. Federal Medicaid regulations require that Medicaid LTSS consumers are provided with written notice and appeal rights whenever a state Medicaid agency or managed care plan denies, reduces, terminates, suspends, or limits authorization of requested services, including the type or level of services.<sup>67</sup> Initial and revised service plans may include action that is adverse to LTSS consumers' rights (e.g., an initial service plan authorizes fewer Medicaid services than the individual requested). While it is essential that LTSS consumers give informed consent to the final written service plan for all the reasons discussed above, that written consent must always be consistent with the principles of due process and must always afford LTSS consumers adequate written notice and clear access to the Medicaid appeal and fair hearing process.<sup>68</sup>

Where more guidance is needed: While CMS is clear in its adoption of the new PCP rules that all of the Medicaid fair hearing protections apply to finalized service plans signed by LTSS consumers, the risk is that consumers will believe they have no choice but to sign plans at the conclusion of service planning meetings in order for those services to begin or continue. They may feel pressured to sign finalized plans, even where they disagree. And absent clear written notice of appeal rights, LTSS consumers will not understand that they retain the right to challenge the state's or managed care plan's adverse action, even after the service planning meeting is over. CMS must make clear through additional guidance, or the Medicaid waiver approval process, that LTSS consumers always retain the right to appeal service plans that do not provide the Medicaid services they need consistent with due process requirements.

More work is also needed to determine how best to resolve disagreements in the person-centered planning process. If the individual is truly driving the process and making informed choices about their care, it is likely that disagreements will arise before the plan is actually finalized. More thought needs to be given by advocates, providers, and policymakers on developing, and operationalizing in the real world, opportunities to resolve these disagreements without slowing the planning process or impeding existing and important appeal rights.

#### THE RULE IN PRACTICE

Several states have found ways to incorporate clear appeal and fair hearing rights into the rules governing their Medicaid HCBS programs:

- New Jersey: The New Jersey contract requires an LTSS consumer to sign the plan of care, but also requires the care manager to document the LTSS consumers agreement or disagreement with certain aspects of the written plan (e.g., whether the individual agrees with the plan or had the freedom to choose services or providers). Where the consumer disagrees, a written notice of action including appeal and fair hearing rights must also be provided.<sup>69</sup>
- Wisconsin: By regulation, Wisconsin mandates that MLTSS recipients have the right to request a fair hearing for any managed care "decision or order ... which ... adversely affects the individual." The Wisconsin contract defines appealable actions to include the development of a member-centered plan that is unacceptable to the member because the plan is contrary to the member's wishes insofar as it requires the member to live in a place that is unacceptable to the member; the plan does not provide sufficient care, treatment or support to meet the member's needs and support the member's identified outcomes; and the plan requires the member to accept care, treatment, or support items that are unnecessarily restrictive or are unwanted by the member.<sup>70</sup>

Justice in Aging • www.justiceinaging.org • ISSUE BRIEF • 13

<sup>66 79</sup> Fed. Reg. 2991 (Jan 16, 2014) (included in 1915(i) comments and responses).

<sup>&</sup>lt;sup>67</sup> 42 C.F.R. §431, Subpart E. See also 42 C.F.R. §438, Subpart F (managed care regulations).

<sup>&</sup>lt;sup>68</sup> See also 79 Fed. Reg. 2989 (Jan 16, 2014) ("It is our expectation that during the person-centered planning process and development of the person-centered plan, all services and support options available will be articulated and discussed with the individual. States must adhere to the fair hearing requirements at part 431, subpart E for all Medicaid programs.").

<sup>&</sup>lt;sup>69</sup> New Jersey Contract, Article 9.6.3(G), Article 9.6.5(L) (July 2014).

<sup>&</sup>lt;sup>70</sup> Wisconsin Contract, Article XI(B)(1)(a)(vi)(Jan. 2015).

#### THE REVIEW PROCESS

# The Person-Centered Service Plan is Reviewable and Subject to Change

The final area of the rule relates to the process for reviewing the person-centered service plan. The rule recognizes the important principle that written service plans will need to be revised over time. The rule requires that review happen at least every 12 months, when the individual's circumstances or needs change significantly, or at the request of the individual.<sup>71</sup> CMS was particularly explicit about the right of consumers to request a revision of the service plan.<sup>72</sup>

Why this is important: A person-centered LTSS delivery system needs to respond in a timely manner to changes in consumers' needs.<sup>73</sup> For example, an LTSS consumer with pneumonia or recovering from a fall may need additional services hours for a brief period of time. It is crucial that in a circumstance like this the plan can be quickly reviewed and modified to meet the changing needs of the consumer. This section of the rule also guarantees

that consumers have the right to request review and revision of service plans without having to show a change in circumstances as a prerequisite to the request. LTSS consumers know best when a plan is not meeting their needs and there needs to be simple, easy to understand, accessible ways for consumers to trigger timely plan revision.

Where more guidance and rules are needed: The rule allows states and managed care plans to reassess more frequently than every 12 months. But many LTSS consumers have long-standing functional ADL and IADL needs and medical conditions that are unlikely to change, and so need stability and predictability in written service plans. It can be detrimental to their needs when states or managed care plans reassess LTSS consumers too frequently (e.g., quarterly). Reassessments may lead to unwarranted reductions or

A person-centered long-term services and supports delivery system needs to respond in a timely manner to changes in consumers' needs.

termination of services, which can place health and safety at risk, as well as lead to the loss of trusted providers, or the uncertainty that comes with appeals. More work is needed to provide guidance and set standards for when a state agency or plan may initiate a reassessment of need that is not triggered by a request from the beneficiary or an acute event. A balance needs to be achieved, and, in the absence of additional guidance from CMS, states may want to consider limiting reassessments to once every 12 months absent a change in circumstances or a request by an LTSS consumer.

#### THE RULE IN PRACTICE

New Jersey has incorporated contractual provisions that require managed care plans to adhere to the PCP review rule:

New Jersey: The New Jersey managed care contract requires that managed care plans have written policies about how MLTSS member can access the MCO after hours for emergency or urgent issues and how that information will be reported to the MLTSS care manager. There must be a system of back-up care managers in place, and any member whose primary care manager is unavailable must be given an opportunity to be

 $<sup>^{71}</sup>$  42 C.F.R. \$441.301(c)(1)(viii) also requires that the PCP process include a method for the individual to request updates to the plan as needed.

<sup>&</sup>lt;sup>72</sup> In response to concerns raised that reassessments done at the request of the LTSS consumer could lead to inflated service hours and costs, CMS made clear that it supports revisions to services plans more frequently than every 12 months, including at the request of the consumer. 42 Fed. Reg. at 2991 (Jan 16, 2014).

<sup>&</sup>lt;sup>73</sup> See CMS 2402(a) Guidance, supra note 10, at 8 ("This includes a mechanism to ensure ... that changes can be made in an expedient manner.")

referred to the back-up for assistance. Most crucially, managed care plans must have a mechanism to ensure members have access to a registered nurse or other qualified, licensed health professional who can review the plan of care and back-up plan and can authorize services to ensure health and welfare during times when the plan is closed (e.g., holidays, weekends and overnights).<sup>74</sup>

## CONCLUSION

Person-centered planning is a significant component in Medicaid LTSS, and ensuring that it is done well requires diligence and an honest appraisal of the current system. As we look at where person-centered planning comes from and where it is now, we can better see the potential this way of providing care has for promoting the independence, autonomy, and well-being of older adults and persons with disabilities.

This paper has focused on both the rules as they exist now and the gaps that should be filled. It has not been an exhaustive exploration of the rules or of the gaps, but a beginning exploration of this very complex topic. The coming months and years will see old gaps being filled and new gaps being found. This dynamic world of person-centered care and planning will require consumers, advocates, CMS, state agencies, health plans, and providers to work together to create better rules, better language, and better understanding of what is necessary to ensure a right to person-centered care.

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<sup>&</sup>lt;sup>74</sup> New Jersey Contract, Articles 9.4.1(A)(6), Article 9.5.4(H)(3), Article 9.5.4(H)(5) (July 2014).

# Person-Centered Planning Process Rules

42 C.F.R. §441.540	42 C.F.R. §441.301 (c)(1)	42 C.F.R. §441.725
(a) Person-centered planning process. The person-centered planning process is driven by the individual. The process	1) Person-centered planning. The individual will lead the person-centered planning process where possible. The individual's representative	a) Person-centered planning process. Based on the independent assessment required in § 441.720*, the State must develop (or approve, if the plan is developed
	should have a participatory role, as needed and as defined by the individual, unless State law confers decision-making authority to the legal representative. All references to individuals include the role of the individual's representative. In addition to being led by the individual receiving services and	by others) a written service plan jointly with the individual (including, for purposes of this paragraph, the individual and the individual's authorized representative if applicable). The person-centered planning process is driven by the individual. The process:
	supports, the person-centered planning process:	*§ 441.720 requires that independent assessments must be done using a person-centered process that meets the requirements of § 441.725(a)
(1) Includes people chosen by the individual.	(i) Includes people chosen by the individual.	(1) Includes people chosen by the individual.
(2) Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.	(ii) Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.	(2) Provides necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions.
(3) Is timely and occurs at times and locations of convenience to the individual.	(iii) Is timely and occurs at times and locations of convenience to the individual.	(3) Is timely and occurs at times and locations of convenience to the individual.
(4) Reflects cultural considerations of the individual.	(iv) Reflects cultural considerations of the individual and is conducted by providing information in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter.	(4) Reflects cultural considerations of the individual and is conducted by providing information in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter.
(5) Includes strategies for solving conflict or disagreement within the process, including clear conflict-of-interest guidelines for all planning participants.	(v) Includes strategies for solving conflict or disagreement within the process, including clear conflict-of-interest guidelines for all planning participants.	(5) Includes strategies for solving conflict or disagreement within the process, including clear conflict of interest guidelines for all planning participants.

# Person-Centered Planning Process Rules (continued)

42 C.F.R. §441.540	42 C.F.R. §441.301 (c)(1)	42 C.F.R. §441.725
	(vi) Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual must not provide case management or develop the person-centered service plan, except when the State demonstrates that the only willing and qualified entity to provide case management and/or develop person-centered service plans in a geographic area also provides HCBS.	
	In these cases, the State must devise conflict of interest protections including separation of entity and provider functions within provider entities, which must be approved by CMS. Individuals must be provided with a clear and accessible alternative dispute resolution process.	
(6) Offers choices to the individual regarding the services and supports they receive and from whom.	(vii) Offers <b>informed</b> choices to the individual regarding the services and supports they receive and from whom.	(6) Offers choices to the individual regarding the services and supports the individual receives and from whom.
(7) Includes a method for the individual to request updates to the plan.	(viii) Includes a method for the individual to request updates to the plan <b>as needed</b> .	(7) Includes a method for the individual to request updates to the plan, <b>as needed</b> .
(8) Records the alternative home and community-based settings that were considered by the individual.	(ix) Records the alternative home and community-based settings that were considered by the individual.	(8) Records the alternative home and community-based settings that were considered by the individual.

## Person-Centered Service Plan

42 C.F.R. §441.540	42 C.F.R. §441.301 (c)(2)	42 C.F.R. §441.725
(b) The person-centered service plan. The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports. Commensurate with the level of need of the individual, and the scope of services and supports available under Community First Choice, the plan must:	(2) The Person–Centered Service Plan. The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports. Commensurate with the level of need of the individual, and the scope of services and supports available under the State's 1915(c) HCBS waiver, the written plan must:	(b) The person-centered service plan. The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports. Commensurate with the level of need of the individual, and the scope of services and supports available under the State plan HCBS benefit, the written plan must:
(1) Reflect that the setting in which the individual resides is chosen by the individual.	(i) Reflect that the setting in which the individual resides is chosen by the individual. The State must ensure that the setting chosen by the individual is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.	(1) Reflect that the setting in which the individual resides is chosen by the individual. The State must ensure that the setting chosen by the individual is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.
(2) Reflect the individual's strengths and preferences.	(ii) Reflect the individual's strengths and preferences.	(2) Reflect the individual's strengths and preferences.
<ul><li>(3) Reflect clinical and support needs as identified through an assessment of functional need.</li><li>(4) Include individually identified goals and desired outcomes.</li></ul>	(iii) Reflect clinical and support needs as identified through an assessment of functional need.  (iv) Include individually identified goals and desired outcomes.	<ul><li>(3) Reflect clinical and support needs as identified through an assessment of functional need.</li><li>(4) Include individually identified goals and desired outcomes.</li></ul>

# Person-Centered Service Plan (continued)

42 C.F.R. §441.540	42 C.F.R. §441.301 (c)(2)	42 C.F.R. §441.725
(5) Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports cannot supplant needed paid services unless the natural supports are unpaid supports that are provided voluntarily to the individual IN LIEU OF AN ATTENDANT.	(v) Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of 1915(c) HCBS waiver services and supports.	(5) Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of State plan HCBS.
(6) Reflect risk factors and measures in place to minimize them, including individualized backup plans.	(vi) Reflect risk factors and measures in place to minimize them, including individualized back-up plans and strategies when needed.	(6) Reflect risk factors and measures in place to minimize them, including individualized backup plans and strategies when needed.
(7) Be understandable to the individual receiving services and supports, and the individuals important in supporting him or her.	(vii) Be understandable to the individual receiving services and supports, and the individuals important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter.	(7) Be understandable to the individual receiving services and supports, and the individuals important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient, consistent with § 435.905(b) of this chapter.
(8) Identify the individual and/or entity responsible for monitoring the plan.	(viii) Identify the individual and/or entity responsible for monitoring the plan.	(8) Identify the individual and/or entity responsible for monitoring the plan.
(9) Be finalized and agreed to in writing by the individual and signed by all individuals and providers responsible for its implementation.	(ix) Be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its implementation.	(ix) Be finalized and agreed to, with the informed consent of the individual in writing, and signed by all individuals and providers responsible for its implementation.
(10) Be distributed to the individual and other people involved in the plan.	(x) Be distributed to the individual and other people involved in the plan.	(10) Be distributed to the individual and other people involved in the plan.

# Person-Centered Service Plan (continued)

42 C.F.R. §441.540	42 C.F.R. §441.301 (c)(2)	42 C.F.R. §441.725
(11) Incorporate the service plan requirements for the self-directed model with service budget at § 441.550, when applicable.	(xi) Include those services, the purpose or control of which the individual elects to self-direct.	(11) Include those services, the purchase or control of which the individual elects to self-direct, meeting the requirements of § 441.740.
(12) Prevent the provision of unnecessary or inappropriate care.	(xii) Prevent the provision of unnecessary or inappropriate services and supports.	(12) Prevent the provision of unnecessary or inappropriate services and supports.
(13) Other requirements as determined by the Secretary.		
	(xiii) Document that any modification of the additional conditions, under paragraph (c)(4) (vi)(A) through (D) of this section, must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:	(13) Document that any modification of the additional conditions, under § 441.710(a)(1)(vi)(A) through (D) of this chapter, must be supported by a specific assessed need and justified in the person-centered service plan. The following requirements must be documented in the person-centered service plan:
	(A) Identify a specific and individualized assessed need.	(i) Identify a specific and individualized assessed need.
	(B) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.	(ii) Document the positive interventions and supports used prior to any modifications to the person-centered service plan.
	(C) Document less intrusive methods of meeting the need that have been tried but did not work.	(iii) Document less intrusive methods of meeting the need that have been tried but did not work.
	(D) Include a clear description of the condition that is directly proportionate to the specific assessed need.	(iv) Include a clear description of the condition that is directly proportionate to the specific assessed need.
	(E) Include a regular collection and review of data to measure the ongoing effectiveness of the modification.	(v) Include a regular collection and review of data to measure the ongoing effectiveness of the modification.
	(F) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.	(vi) Include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated.
	(G) Include informed consent of the individual.	(vii) Include informed consent of the individual; and

## Person-Centered Service Plan (continued)

42 C.F.R. §441.540	42 C.F.R. §441.301 (c)(2)	42 C.F.R. §441.725
		(viii) Include an assurance that the interventions and supports will
	cause no harm to the individual.	cause no harm to the individual.

### Review of the Person-Centered Service Plan

42 C.F.R. §441.540	42 C.F.R. §441.301 (c)(3)	42 C.F.R. §441.725
(c) Reviewing the person-centered service plan. The person-centered service plan must be reviewed, and revised upon reassessment of functional need, at least every 12 months, when the individual's circumstances or needs change significantly, and at the request of the individual.	(3) Review of the Person–Centered Service Plan. The person-centered service plan must be reviewed, and revised upon reassessment of functional need as required by § 441.365(e), at least every 12 months, when the individual's circumstances or needs change significantly, or at the request of	(c) Reviewing the person-centered service plan. The person-centered service plan must be reviewed, and revised upon reassessment of functional need AS REQUIRED IN § 441.720, at least every 12 months, when the individual's circumstances or needs change significantly, and at the request of
	the individual.	the individual.

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