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**Let the Sunshine In: Assuring Public Involvement in
State Medicaid Policy Making**

by

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The AARP Public Policy Institute, formed in 1985, is part of the Policy and Strategy Group at AARP. One of the missions of the Institute is to foster research and analysis on public policy issues of importance to mid-life and older Americans. This publication represents part of that effort.

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Let the Sunshine In: Assuring Public Involvement in State Medicaid Policy Making

Why the AARP Public Policy Institute Did This Study:

As states receive more discretion to change their Medicaid programs in ways that directly affect beneficiaries, it is important to ensure effective public involvement in Medicaid policy decisions. Hallmarks of effective involvement of the public include transparency, meaningful opportunities for engagement, and availability of accurate, objective, and timely information. This paper explores opportunities for public involvement in the Medicaid policy process and identifies policy options for improvements.

Summary of Recommendations

- Congress should set minimum standards for public participation in the Medicaid policy process, including requiring states to document these processes before filing waivers or SPAs and after significant changes during the waiver negotiation process.
- CMS should provide opportunities for public input at the federal level for Section 1115 waivers and certain SPAs, and should clarify the role of Medical Care Advisory Committees.
- States should be required to inform the public about anticipated changes to Medicaid policies that directly impact beneficiaries, create meaningful opportunities for public involvement, and make policy documents widely available.

Highlights:

The processes for Section 1115 waiver and SPA development and implementation were examined in eight states—California, Connecticut, Florida, Illinois, Indiana, Michigan, Nevada, and Texas—to learn what processes were in place for public input into Medicaid policy changes that affect benefit design and cost sharing.

Opportunities to provide public input into the waiver and SPA process varied among and even within the case study states, depending on how embedded benefit design and cost-sharing provisions are in state statute and how the Medicaid agency viewed the significance of the policy change.

All states acknowledged the federal requirement for public input before a Section 1115 waiver is filed; however, there is no similar requirement for SPAs. All of the study states had a process of public input before implementation of a SPA, most often through rule promulgation, but any public input before filing was at the discretion of the Medicaid agency or as a result of the policy change initiated through legislation. The format for public input opportunities varied widely, from a single public hearing in the state capital to statewide community hearings or work groups of stakeholders. Few of the study states reported relying on the federally required Medical Care Advisory Committee to provide significant public input into proposed benefit or cost-sharing changes.

Advocacy groups interviewed agreed that public input into the process is most effective when it takes place throughout the process. Advocates felt strongly that the federal government should assure that public input is a part of the policy-making process and that both the federal and state government should be required to post waiver, SPA, and rule change documents on their respective websites. Advocates also expressed concern that there was no public input assured during federal review of SPAs and waivers.

Medicaid officials and advocates both agreed that the state's attitude toward public input was a key factor in how meaningful the process was. Medicaid officials acknowledged that effective public engagement can increase the likelihood for political success of substantial reform.

INTRODUCTION

Medicaid is a joint federal-state program that purchases basic health and long-term care services on behalf of 51 million Americans, including low-income families, persons with disabilities, and the elderly. Due to the magnitude of the population it covers and the cost of the services it buys, Medicaid is the federal government's largest program of financial assistance to state governments. Although state participation in Medicaid is voluntary, since 1982 every state has chosen to participate.¹ The size and design of Medicaid programs vary from state to state, but all states' programs must comply with federal guidelines to receive federal matching funds.

Reliance on Medicaid has increased as a result of a range of factors, including the ongoing erosion of employer-sponsored health coverage, the impact of a strong economic recession, and an increase in the number of aged or disabled citizens. As a result, the rate of Medicaid expenditure growth has become an ongoing challenge for the states. Annual rates of growth over the last decade have exceeded the rate of state revenue growth, with Medicaid expenditures increasing from 19.5 percent of total state budgets in 1999² to an estimated 22.3 percent of total state budgets in 2004.³ This has led some policymakers to declare the current program "unsustainable," and has caused states to seek more options in implementing their Medicaid programs.

In response to increasing pressure from state policymakers and federal budget pressures, Congress recently enacted significant Medicaid reforms through the Deficit Reduction Act (DRA) of 2005. These reforms included establishment of new options for states to adopt modified benefit packages and increase cost sharing for certain Medicaid populations. Before the DRA reforms, states were required to submit waiver requests, authorized by Section 1115 of the Social Security Act, to pursue these kinds of changes. With passage of the DRA, states now can make certain benefit and cost-sharing changes using the State Plan Amendment (SPA) process instead.⁴ Because seeking federal approval of Section 1115 waivers is a far more cumbersome process for states than the SPA approval process, and it involves more discretion on the part of the Secretary of Health and Human Services over whether proposed changes will be allowed,⁵ states welcomed this new flexibility under DRA.

Today, states can use either Section 1115 waivers or SPAs to obtain federal approval of major reforms to their Medicaid programs. Although many reforms end up having a positive effect on Medicaid consumers—such as eligibility expansions, the addition of coverage for new technology, and the expansion of home and community-based service options—other reforms, such as restricting benefits or imposing new costs, could restrict consumer access to needed services. For this reason, it is important to understand whether stakeholders, including consumers and consumer advocates, have opportunities for effective participation at each stage of the Medicaid policy-making process.

This report explores whether and how states ensure public input during various phases of both the Section 1115 waiver process and the SPA process—including policy development, federal review, and policy implementation—from the perspectives of state

officials and consumer advocates. In addition, we make recommendations about how states and the federal government can improve or enhance existing opportunities for public involvement in the Section 1115 waiver and SPA processes.

PURPOSE AND METHODOLOGY

With input from the AARP Public Policy Institute, eight states—California, Connecticut, Florida, Illinois, Indiana, Michigan, Nevada, and Texas—were selected for case studies to learn what, if any, processes they have to solicit public input into Medicaid policy changes developed and implemented through Section 1115 waivers or SPAs. These states represent a diverse cross-section of states based on geography, political persuasion, and Medicaid program size. Appendix A includes a detailed case study for each of the states.

Methods used to collect the information presented in this report included: 1) review of state statutes and administrative regulations; 2) telephone interviews with Medicaid directors (or designees) in each of the case study states as well as selected legal counsel or compliance officials for state Medicaid programs; and 3) telephone interviews with a consumer advocacy group or provider association in each case study state—California Protection and Advocacy, Inc.; Connecticut Voices for Children; Florida Legal Services; Shriver Center (Illinois); Indiana Primary Health Care Association; Michigan League for Human Services; Legal Services Statewide Advocacy Coordinator (Nevada); and Center for Public Policy Priorities (Texas).⁶ The interview protocols used with state Medicaid agency staff and advocacy groups are attached as Appendix B and Appendix C, respectively. Follow-up questions were also submitted to the advocacy groups, and the advocacy groups had the opportunity to review responses to the follow-up questions before they were incorporated into this report. Finally, staff persons from the Centers for Medicare and Medicaid Services (CMS) were consulted by telephone regarding the federal waiver review process. All interviews took place in the fall of 2006; any changes in state or federal policy made after this date are not reflected in this report. Representatives from AARP State Offices in the eight case study states had the opportunity to respond to the findings. Their responses are presented in Appendix D.

BACKGROUND

Federal Oversight of the Medicaid Program

The Medicaid program, authorized under Title XIX of the Social Security Act, is administered through a federal-state partnership. The U.S. Department of Health and Human Services (HHS), through the Centers for Medicare and Medicaid Services (CMS), is responsible for federal oversight. Federal law, regulation, and guidance establish the parameters of the Medicaid program,⁷ and every state is required to administer its program in accordance with these parameters. In exchange, states can claim federal matching funds as partial reimbursement for the costs of the program. The federal government matches the cost of covered services provided to Medicaid-eligible individuals on an open-ended basis at a rate that varies among states from 50–76 percent.⁸

State Involvement in the Medicaid Program

Federal law requires the executive branch in each state to designate a state agency as the Medicaid Single State Agency (the “Medicaid agency”), which assumes responsibility for establishing Medicaid policy for the state and ensuring that the program is administered according to federal and state requirements.⁹ At the state level, Medicaid programs are authorized and implemented through a combination of state legislation, state regulation, guidance from the legislature or executive branch, and Medicaid agency action. Each state’s relative dependence on state statute for program oversight and policy varies. In some states, the legislature is heavily involved in oversight and control of the program, leaving little room for agency discretion. For example, some states codify program specifics, such as definitions of covered populations, services, cost-sharing requirements, and provider reimbursement methodologies. Other states simply establish a statutory framework for the Medicaid program and authorize the Medicaid agency to establish program details through regulation or other policy guidance.

The Medicaid State Plan

The Medicaid agency is responsible for filing a document, called the Medicaid State Plan (the “State Plan”), for federal approval. State Plans document the details of each state’s Medicaid program, including the mandatory and optional obligations each state assumes under Title XIX of the Social Security Act. The Medicaid agency negotiates with CMS to obtain federal approval of State Plan provisions. An approved State Plan is binding on the Medicaid agency, and Medicaid agencies are required to operate their programs in accordance with approved State Plans with applicable state and federal law and regulation.

Medicaid State Plan Amendments

When a state wants to modify its Medicaid program, the Medicaid agency files a State Plan Amendment (SPA) with CMS. CMS reviews SPAs for the sole purpose of ensuring

that they meet federal requirements. CMS does not independently review SPAs to ensure consistency with applicable state laws. Typically, the Secretary of HHS approves any change in Medicaid policy proposed in the SPA if the proposal complies with federal requirements.¹⁰ However, when there are inconsistencies between federal and state interpretation of federal requirements associated with a SPA submission, there can be significant discussion and negotiation between the federal government and state officials during the SPA review process. If a SPA is approved, the State Plan is modified to reflect a state's new obligations under the program.

Section 1115 Waivers

Section 1115 of the Social Security Act gives the Secretary of HHS (the "Secretary") broad authority to waive provisions in the federal Medicaid statute to approve demonstration projects that test new approaches to program operation, as long as the projects promote the objectives of the Medicaid program.¹¹ In recent years, states have used Section 1115 waiver authority to expand coverage to otherwise ineligible populations, to develop new mechanisms for providing mental health coverage, to resolve federal funding disputes, and to modify benefits and cost sharing for certain populations. The Secretary has broad discretion regarding whether to grant waiver requests.

Federal Requirements Related to Public Input into the SPA and Section 1115 Waiver Process

Each state follows its own rules or processes regarding when and how SPAs are proposed and developed at the state level, and there is no explicit federal requirement demands that states provide for public input into the development, review, or implementation of a SPA that modifies benefits or cost sharing. CMS has, however, established federal protections relating to public input regarding Section 1115 waivers.

In response to stakeholder concerns that Section 1115 waivers were being approved without adequate opportunities for public input, HHS issued a *Federal Register* notice in 1994 indicating its intent to ensure that opportunities for public input were taking place at both state and federal levels.¹² Acknowledging that "people who may be affected by a demonstration project have a legitimate interest in learning about proposed projects and having input into the decision making process prior to the time a proposal is submitted,"¹³ this policy required states to provide as part of the waiver application a brief description of how the state provided opportunities for public input into developing its Section 1115 waiver proposal.

The 1994 *Federal Register* notice lists examples of potential approaches states can use to solicit public input. These include the use of one or more of the following¹⁴:

- conduct one or more public hearings, including opportunities for public comment;
- establish a commission whose meetings are open to the public;
- enact a proposal by the state legislature;

- provide for a formal notice and comment period pursuant to the state administrative procedures act (as long as notice is given at least 30 days before the policy change is submitted to the federal government);
- publish notice in a local newspaper;
- provide opportunity for the public to receive a copy of the draft proposal and provide for a 30-day period for public comment; and
- conduct any other process that provides interested parties with an opportunity to learn about and comment on the contents of the proposal.

In addition to requiring a process for public input at the state level, the 1994 *Federal Register* notice established a process for public input at the federal level. HHS indicated that it would provide public notice of all new and pending Section 1115 demonstrations, as well as a 30-day comment period, before taking official action on a Section 1115 waiver request.¹⁵ Initially, the Health Care Financing Administration (now CMS) published information on waiver applications in the *Federal Register* every 90 days. However, CMS has not provided a federal-level notice and comment period pursuant to this policy since 1998,¹⁶ reasoning that it now considers states a more appropriate venue for public input.^{17, 18}

In May 2002, HHS issued a State Medicaid Director Letter reinforcing the importance of public input into the Section 1115 waiver process at the state level. This letter reiterated HHS's commitment to "ensur[ing] adherence to the public notice procedures outlined in the September 27, 1994 *Federal Register* notice."¹⁹ A similar reinforcement of HHS's original intent to provide federal notice and a comment period was missing from this letter.

As indicated above, federal guidance specifically requires public involvement in the Section 1115 waiver process, but is silent on the SPA process. This does not mean, however, that there is a complete lack of federal regulation regarding public input into Medicaid policy. Federal regulations require all state Medicaid agencies to establish a Medical Care Advisory Committee (MCAC) with provider and beneficiary representation.²⁰ The purpose of the MCAC is to advise the state Medicaid agency on matters of health and medical care services.²¹ In serving its purpose, the MCAC is supposed to have an opportunity to participate in policy development and program administration.²² Although there is no specific federal requirement that state Medicaid officials must discuss Section 1115 waiver or SPA plans with MCAC members, in theory, the MCAC represents a possible venue for discussion of these types of policy initiatives.

A summary of the federal requirements that affect public involvement in the Section 1115 waiver and the SPA process is presented in Table 1.

Table 1. Federal Requirements for Public Input

Section 1115 Demonstrations	
59 Fed. Reg. 49249	<p>States are expected to follow one or more of several public input processes identified by HHS in developing a Section 1115 waiver proposal.</p> <p>This federal guidance also indicated HHS intent to provide for a federal notice and comment period on submitted Section 1115 waiver proposals. However, HHS has not provided this notice and comment period since 1998.</p>
SMDL #02-007	<p>This State Medicaid Director Letter reinforced HHS’s intent to continue to review Section 1115 demonstration applications for state compliance with the public notice requirement outlined in <i>59 Fed. Reg. 49249</i>.</p>
Policy and Program Administration	
42 CFR 431.12	<p>States are required to establish a Medical Care Advisory Committee with provider and beneficiary representation to advise the Medicaid agency about policy development and program administration. States may, but are not required to, use the Committee to provide input into the waiver/SPA process.</p>

Changes Authorized by the Deficit Reduction Act of 2005

In 2005, the National Governors Association (NGA) endorsed bipartisan recommendations for the federal government to give states increased flexibility to reform Medicaid, claiming that states could better tailor Medicaid benefits to meet the needs of different groups, encourage consumer involvement in making health care choices, improve the cost effectiveness of care, and better tailor delivery of services to those most in need.²³ The federal Medicaid Commission endorsed many of the NGA recommendations in its September 1, 2005, report to the HHS Secretary and the U.S. Congress.²⁴

In February 2006, Congress enacted the Deficit Reduction Act (DRA) of 2005. The DRA includes provisions that allow states to alter the Medicaid benefit package for certain populations and impose increased cost-sharing obligations on certain populations using the SPA process instead of the Section 1115 waiver process.²⁵ Soon after enactment of the DRA, three states requested and received approval for SPAs filed under the new

provisions. Kentucky received the first SPA under the DRA to alter the benefit package and increase cost sharing for certain populations,²⁶ followed quickly by West Virginia's plan to alter the benefit package.²⁷ Idaho also received an early SPA under DRA authority to alter its benefit package for certain populations.²⁸ States have continued to file and receive approval of program modifications under DRA provisions.²⁹

PRESSURE POINTS: OPPORTUNITIES TO ENGAGE IN THE MEDICAID POLICY PROCESS

Three major activities are associated with the Medicaid policy-making process, whether a state pursues that policy through a Section 1115 waiver or a SPA: policy development, federal review, and policy implementation. Depending on the state or the proposed policy change, these activities may occur in concert or in separate and distinct phases. In theory, each stage of the process provides a “window of opportunity” for public engagement in the process. In some states, or for some reforms, the “window” opens early and wide; in other states or other reforms, the “window” opens later and offers more limited opportunities for public engagement.

Policy Development

Ideas for change are generated during the policy development phase, when the pros and cons of proposed policy changes are considered, culminating in a general or detailed policy proposal. States can create opportunities for public involvement at this stage by holding meetings with key stakeholders and by conducting public forums for the general public. In most states, there is no formal process for involving the public during the policy development phase, unless policy development is initiated through statutory reform. With regard to Section 1115 waivers, the policy development phase may involve development and dissemination of concept papers that describe the proposed policy change in broad brush strokes, public hearings, community meetings, legislative committee review, or other opportunities for input. Policy development culminates in creation of formal waiver or SPA documents to be filed with CMS. Appendix E presents a state-by-state chart depicting a summary of opportunities for public input into the Section 1115 waiver and SPA process before submission to the federal government.

Federal Review

The federal review process officially begins after a Section 1115 waiver or SPA is submitted to CMS for approval. The opportunities for public engagement at this stage are extremely limited. As noted earlier in this report, CMS no longer publishes *Federal Register* notices nor does it solicit comment when Section 1115 waiver applications are received from states.³⁰ Nor does CMS provide formal opportunities for public input into SPAs.³¹ CMS has stated a clear preference for all public input to occur at the state level.

Despite the absence of formal opportunities to provide public input at the federal level, advocates who felt they were not afforded an opportunity to provide meaningful input at the state level about Section 1115 waivers have reported contacting CMS directly.³²

Implementation

Depending on how a state manages its Medicaid program, implementation of a federally approved waiver or SPA is likely to require changes to state law, budget appropriations, rules, and/or other program guidance. These official governmental processes can allow the public to challenge or shape changes to Medicaid policy. There are typically formal and sometimes informal opportunities for public engagement in legislative, appropriation, and rule-making processes. These opportunities are not always transparent to the general public and may require a significant amount of monitoring by advocates to avoid missed opportunities for public input. Further, in states that may use program guidance instead of legislative or regulatory mechanisms (which have built-in public input opportunities) to implement a waiver or SPA, the state Medicaid agency has significant discretion regarding what kind of public input process, if any, will occur.

In some states, implementation activities generally are conducted concurrently with policy development; in others, implementation activities are more likely to occur after a separate process of policy development and federal review. Because State Plan and waiver provisions have to be consistent with state law and regulations, this can become an iterative process. For example, changes to the proposed policy that occur during federal review must be reflected in state rules, and any changes negotiated during rule promulgation at the state level might require revising the federal filing. Appendix F presents a state-by-state chart depicting a summary of opportunities for public input into the Section 1115 waiver and SPA process before and during implementation.

SUMMARY OF FINDINGS

State Medicaid Directors

Opportunities to provide input into the waiver and SPA process varied among the eight case study states and even within a particular state. The variation was driven in part by differences in how embedded benefit design and cost-sharing provisions are in current state statute and how significant the Medicaid agency viewed the nature of the policy change being contemplated. Medicaid directors uniformly reported giving heightened attention to public input when policy changes had a “significant impact” on the program, regardless of the presence or absence of a statutory obligation or other mandate to seek input. All case study states were inclined to view changes to the benefit package, especially restriction of benefits and increased cost sharing, as “significant.”

What was most striking about the processes described in the case study states was the variation in the timing of public input opportunities. States described instances in which waivers or SPAs were filed with the federal government before state authorizing legislation was enacted and/or before rules were promulgated. In other examples, even within the same state, state law or rules would be modified before obtaining federal approval. These timing differences might be driven by how quickly state policymakers sought to implement the policy change, whether the policy change was controversial, whether there was an anticipated budgetary impact, or whether the Medicaid agency or the legislature initiated the change.

Policy Development

In every state, Medicaid officials acknowledged the federal requirement for public input into the development of Section 1115 waivers, though the actual processes used varied from state to state and from waiver to waiver. Some states had additional requirements for legislative review of waiver proposals; in others, legislative involvement in waiver policy development was at the discretion of the Medicaid agency and ranged from informal briefings and consultation with key legislators to requests for formal legislation authorizing specific waiver policy.

There was more significant variation among states, and even within states, regarding public input into the development of policy that is implemented through SPAs. Policy-makers might engage advocates in a very meaningful public input process before committing to some program changes, but not to others.

In some states, the legislature played a significant role in driving Medicaid policy, thereby directing much of the Medicaid agency’s SPA development activities. In states where the Medicaid agency had more discretion in making policy, legislative involvement was less predictable. Also in these states, legislatures were engaged if budget appropriations were needed or if legislative authority for a specific change was needed, but there was no routine or required legislative involvement in the development of every change in policy that might affect benefits or cost sharing for Medicaid

consumers. Table 2 describes the variation among states in the amount of legislative involvement versus state agency discretion in the Medicaid policy-making process.

Table 2. Level of Legislative Involvement in Medicaid Policy

Substantial Legislative Influence	Ad Hoc or Issue-Dependent	Substantial Agency Discretion
California	Connecticut	Michigan
Florida	Illinois	Nevada
Texas	Indiana	

In most states, officials believed that obtaining legislative approval had “built-in” opportunities for public input through formal legislative hearings and informal meetings with state lawmakers and their staff. State agency officials offered mixed views on whether they perceived the legislative process as providing meaningful opportunities for public input. Some (California, Connecticut, Michigan) described the relationship between consumer advocates and the legislature as “close and effective,” while others (Indiana, Illinois, Nevada) noted that much legislative negotiation and decision making occurs outside the formal public process, which can place some stakeholders at a disadvantage. Officials in these states believed that the formal rule-making process is more transparent.

Most Medicaid directors indicated that their governor’s office could be involved in significant policy reform development, especially if waivers were involved. The extent of this involvement tended to vary; however, there executive branch staff did not initiate any formal public input process. Two states (Indiana, Michigan) noted that the governor’s budget agency was required to review or even to approve Medicaid waivers and some SPA proposals, generally before filing with CMS or approaching the legislature. The budget agency review process did not provide opportunities for public input.

Two states—Michigan and Nevada—described how the state agency used its discretion to routinely provide opportunities for stakeholder engagement in policy development through public hearings, policy committees, work groups, and the use of websites to improve public access to reform information. Such efforts to engage the public appeared to reflect the values of the administration or state agency leadership regarding the importance of public input as well as a pragmatic acknowledgement that stakeholder support can play an important role in the ultimate success or failure of changes in Medicaid policy. According to at least one Medicaid official, states with substantial agency discretion regarding whether and how to engage the public in the policy process

did not want to see the informal process replaced or augmented with a more formal state legislative and/or rule-making process, so they put much effort into soliciting and responding to stakeholder input. In addition, all of the Medicaid directors who were interviewed for this study reported being acutely aware of the need for public discussion and consensus building to ensure the political success of substantial reforms.

Two states—Illinois and Michigan—reported that their MCAC typically reviews SPAs and waivers during the policy development phase. California also reported that its MCAC would become engaged in any proposal to modify benefits or cost sharing. Some of the case study states—Connecticut, Indiana, Nevada, and Texas—reported little or no role for the MCAC in developing SPAs or most waivers. Some state officials expressed confusion over the intended role of the federally required MCAC, and one state—Florida—reported having replaced the function of its MCAC with other stakeholder advisory groups.

Most state Medicaid officials indicated that MCACs in their current form, including membership makeup, meeting frequency, or focus, do not provide the best opportunities for meaningful public engagement in the Medicaid policy process, and the advocates interviewed generally agreed with this assessment.

Federal Review

State Medicaid agencies communicate directly with CMS during waiver and SPA review processes, with much of this communication taking place informally and without written documentation. None of the case study states identified specific opportunities for stakeholder input during CMS review of state plan amendments or waivers. Likewise, state Medicaid officials did not report any federal expectation of stakeholder involvement during this phase.

Implementation

The implementation phase of waivers or SPAs provided the most predictable opportunity for public input in every state. Opportunities for input at this stage were triggered by administrative procedures act requirements associated with rule promulgation, or by a statutory requirement to obtain enabling legislation and/or budget authority before implementation. Medicaid directors viewed public input during administrative rule-making process as meaningful, even in states where the advocacy group interviewed disagreed. States with authority to pursue implementation without promulgating formal administrative rules (Michigan, Nevada) generally had alternative processes in place for public review and input into agency-established Medicaid policy. States that reported burdensome rule-making processes and timelines (California, Connecticut) were more likely to seek specific legislative authority to implement changes without promulgating rules first. Texas noted that, while its MCAC was not engaged in the review of waivers and SPAs, it did submit all proposed rules to the MCAC for comment.

Advocacy Groups

Advocates generally agreed that there need to be opportunities for public engagement at each stage of the policy-making process. In particular, advocates stressed the importance of public input as the state considers its goals and options for achieving those goals, rather than after the state has established a policy direction.

Many of the advocates interviewed acknowledged that effective relationships with the Medicaid leadership and staff are critical to creating effective opportunities for public input in Medicaid policy development. Many also noted that effective public input during the legislative process is enhanced by positive working relationships between advocates and legislators and/or legislative staff.

Policy Development

In states where Medicaid policy development relied heavily on legislative direction, some advocates reported being able to work effectively within legislative processes to make their views and concerns known. However, other advocates voiced concerns over limited access to decision makers, limited opportunities to provide public testimony, and the possibility of important policy reforms or last-minute changes being “buried” in lengthy bills.

Advocacy organizations in the two case study states where the state agency had the most discretion over policy development and implementation—Michigan and Nevada—tended to be satisfied with the opportunities afforded for public input during the policy development phase. Advocates in these states felt that the agency did not abuse its discretion and tended to engage stakeholders early on in the process. However, advocates in these same states expressed concern that future administrations might not be as supportive of such transparent and open processes, highlighting a need for more established processes.

Advocates also expressed a preference for policy development processes that allowed stakeholders to interact directly with policymakers. They described the most meaningful public input as involving two-way dialogue (e.g., workshops where stakeholders are engaged in policy development versus one-way communications in formal hearings with state staff or legislators). Regional hearings and meetings were seen as more effective than hearings and meetings held just in the state capital, because the latter afforded the greatest opportunity for statewide consumer engagement.

Advocates from each of the study states expressed a strong preference for a federally enforceable requirement that meaningful opportunities for public input occur before submission of waivers or SPAs that affect Medicaid benefits or cost sharing. Advocates from Indiana recommended enforceable requirements at the state level as well.

In many states, public input and discussion at the policy development stage focused on proposed policy, not actual waiver or SPA language. Advocates in at least one state—

Florida—were especially concerned about the lack of public availability of draft waiver documents at this stage and desired access to actual documents filed with CMS. All of the advocates strongly supported easy access to program notices, public comments, state responses to public comments, and final approvals. Advocates were strong proponents for using state-sponsored websites to post notices, rules, SPAs, and waiver documents.

Federal Review

Because state Medicaid agencies communicate directly with CMS during the waiver or SPA review process, and because much of this communication takes place informally without written documentation, more than one advocacy group expressed concern that the federal approval process is generally void of opportunities for meaningful public involvement. Some advocates were especially skeptical of how their views were represented to federal decision makers when the federal government rejected advocate-endorsed proposals. In these cases, advocates questioned whether the state had adequately represented and/or advocated for the policy. At least one advocacy group—in California—felt that the solution to this problem is for the federal government to make access to communications between state officials and CMS publicly available. Another group—in Texas—recommended a more direct approach that allowed stakeholders to participate in federal review discussions.

Implementation

Advocates agreed that implementation of approved waivers or SPAs involved some sort of public input, most often through a formal rule-promulgation process and, depending on how embedded benefit and cost-sharing provisions are in each statute, possibly through formal legislative action as well. Within the framework of formal processes, however, (e.g., public hearings required for rule promulgation or public hearings before legislative committees), advocacy groups identified differences in the quality of opportunities for public involvement. For example, Medicaid agency hearings that did not include decision makers, hearings that did not facilitate inclusion of people with disabilities, or artificial restrictions on the length of testimony before legislative committees were seen as reducing the effectiveness of public input opportunities.

Advocates agreed that to effectively influence the formal processes during the implementation phase, they needed to be well versed in state legislative and rule-making processes and to have timely and complete notice of the Medicaid agency's intent to file SPAs or 1115 waivers. Advocates also noted that when members of the general public are unaided, they typically do not have the knowledge necessary to engage effectively in the formal processes available.

Reactions from AARP State Offices

AARP state offices in the study states had an opportunity to weigh in on the study's findings. Representatives from each of the responding state offices generally agreed with the advocate's perspective in their respective state.* However, some were more vocal in describing the lack of opportunity for meaningful public input, particularly during the waiver process. Representatives in these states believed that the executive branch leadership in their respective states were not open to opportunities for public input.

One AARP representative agreed that the legislative arena offers the best opportunity for advocacy organizations such as AARP to affect Medicaid policy because legislative committees take the concerns of advocacy organizations very seriously. Outside the legislature, however, representatives from this state office believed the administration—while working closely with provider organizations—worked less closely with consumer advocates. This AARP representative agreed with our findings that, while the administration routinely offers some forum for public input outside the legislative process, it is questionable whether the agency addresses or even responds to any advocate concerns raised.

A representative from another AARP state office expressed similar concern that, although opportunities for public input are made available during the legislative process and through Medicaid agency-sponsored forums, these opportunities are not meaningful because key Medicaid policy decisions are often made before public input is solicited. Representatives from this state office felt that, by the time an opportunity to provide public input arises, the administration is already committed to a particular policy direction.

Some AARP officials balked at the methods their state administration uses to communicate proposed Medicaid program changes. Often, these changes are announced through archaic methods such as publication in administrative rule publications or legislative publications. Advocates believed many Medicaid consumers do not have access to these resources. Further, if the announcement is made through a more public method, such as the governor's State of the State address, the description of the policy is at a rather high level and advocates do not have enough detail about the new policy to react to. Another common complaint was the failure of state agencies to respond to comments received during the public input process provided, making the process seem fairly superficial.

To improve their state's public input process, one local chapter underscored the importance of seeking legislative change. In that state, advocates pushed for posting Medicaid reform waiver applications on the Medicaid agency website and requiring additional legislative approvals before the waiver could be submitted to CMS.

Whether public input opportunities at the state level are meaningful was not the only complaint of local AARP chapters. At least one local chapter, as well as a representative from the national organization, emphasized the total lack of transparency during waiver

negotiations between state and federal officials. Many AARP chapters believed this stage was a closed-door process, and that advocacy organizations would benefit from additional opportunities for public input during the federal review process, particularly because waiver applications can be changed significantly during this period without any input from stakeholders.

Some AARP chapters noted that even after their state administration has established meaningful opportunities to solicit public input, consumer involvement may be lacking. One chapter believed that additional avenues for gathering public input outside of posted government hearings would result in greater consumer involvement. Another noted that although there was a seat for a Medicaid consumer on a state Medicaid advisory committee, the Medicaid consumer rarely participated.

PUBLIC POLICY IMPLICATIONS AND RECOMMENDATIONS

As states gain more discretion in the design of the Medicaid benefit package and the imposition of increased cost-sharing obligations on beneficiaries, it is important to ensure thorough and effective public involvement in the design and implementation of state policy decisions. Effective opportunities for public involvement in state and federal policy making are an essential component of a participatory democracy. The hallmarks of effective public processes are transparency in the policy-making process; assurance of predictable and meaningful opportunities for public engagement; and the public availability of accurate, objective, and timely information. The following recommendations address opportunities for improving the public process for changing the Medicaid benefit package and cost-sharing obligations at both federal and state levels.

Recommendations for the Federal Government

- Congress should establish minimum standards for public participation in the Medicaid policy-making process to reduce variation in these opportunities among states. This includes ensuring that there is meaningful public notice and input at the state level regarding Section 1115 waivers and SPAs, and at the federal level regarding discretionary decisions by the Secretary of HHS in the case of Section 1115 waiver proposals.
- CMS should require state Medicaid agencies to document a public input process, including comments received and the state's responses to those comments, as part of any waiver or SPA submission that makes significant changes to Medicaid benefit design or cost sharing. CMS should be responsible for reviewing and determining the sufficiency of such processes before considering the proposals on their merits.
- If negotiations between states and the federal government result in significant changes to waiver or SPA submissions, the federal government should require state Medicaid agencies to seek, respond to, and document additional public input before receiving final approval. This will help ensure that stakeholders have the opportunity to respond to any changes in waivers or SPAs during the federal review process and/or negotiations.
- The federal government should clarify the role of the Medical Care Advisory Committee (MCAC) and require that Medicaid agencies actively engage the MCAC in all Medicaid policy changes that directly affect consumers. In addition, the federal government should monitor state compliance with the MCAC requirement.
- CMS should be required to post waiver and SPA applications that propose significant reforms to Medicaid benefit design or cost sharing within 15 days of receipt from the state. Filings should be posted on the Internet, using a dedicated web page, to facilitate the broadest opportunity for

public notice. Waiver and SPA documents should be posted as filed, as modified, and as approved.

- CMS should provide an opportunity for the public to comment on Section 1115 waiver proposals and SPAs that affect benefits and cost sharing at the federal level.

Recommendations for State Governments

- Opportunities for meaningful public engagement should ensure timely public notice of the state's intent to develop a waiver or SPA that affects Medicaid benefits or cost sharing and should provide an opportunity for input at three critical points: before the SPA or Section 1115 waiver is filed; during federal negotiations if these negotiations result in significant policy reforms; and before implementation, regardless of whether such implementation involves adoption of implementing rules or guidance. A sufficient amount of time (e.g., 30 days) should be allowed for public input at each phase of the reform process.
- States should ensure that public notices contain sufficient detail to enable informed public consideration. Therefore, public notices should include draft waiver proposals, proposed legislative language, and/or the draft SPA proposal. The public should never be required to use a formal Freedom of Information Act request to obtain information about Medicaid waiver or SPA proposals from the state.
- State Medicaid agencies should document and respond to all comments they receive through the public input process; all comments and responses should be publicly available.
- State Medicaid agencies should post public notices, documents, and comments/responses to a dedicated web page. States should use any other available information technology-supported strategies for improving public notice and to facilitate public input, including use of listservs, use of telephone and/or web-based information sessions, and creation of chat rooms or other web-assisted options to gather input and exchange information.
- State Medicaid agencies should increase the effectiveness of public input opportunities by adopting best practices, including conducting statewide hearings or meetings; conducting workshops that facilitate two-way communication between the public and state policymakers; providing transportation and child care assistance to encourage consumer participation; using fully accessible meeting facilities with appropriate translation services; and using outside facilitators to improve the focus and effectiveness of public meetings.

- State Medicaid agencies should reexamine the composition and role of the Medical Care Advisory Committee and use this and other formal advisory groups more effectively.
- State Medicaid agencies should reach out to established advocacy and other stakeholder groups by attending these groups' regularly scheduled meetings and by being open to having face-to-face meetings.

CONCLUSION

Opportunities for public input on policy changes that affect Medicaid benefits and beneficiary cost sharing vary from state to state, policy to policy, and administration to administration (state and federal). Established methods for engaging the public in Section 1115 waivers and SPA policy discussion are highly desirable, because they guarantee predictability in an otherwise variable policy-making process. To maximize the effectiveness of these opportunities, they must be available early in the Medicaid policy-making process, before the state has committed to a particular policy position.

Because it has authority to approve or disapprove waivers and SPAs, the federal government is in the best position to develop and enforce requirements for meaningful public input on changes in Medicaid policy. As an additional consumer protection, the federal government can create and actively participate in processes that provide a federal-level venue for public engagement. States can better ensure the adequacy of public engagement in waiver and SPA policy making by creating predictable processes and using best practices to provide opportunities for public engagement.

Recently, it was reported that federal policymakers have been contemplating federal legislation to improve the public process for Section 1115 waivers and DRA-related SPAs addressing benefits and cost sharing.³³ This legislation would require, at the state level: 1) mandatory notice to the state MCAC of 1115 waivers and SPA proposals; 2) a 60-day public comment period for 1115 waivers and DRA-related SPAs; 3) posting of the 1115 waiver or SPA proposal on the state's website; 4) two public hearings on the 1115 waiver proposals (SPAs would not be included in this requirement); and 5) publication and summary of all comments received on 1115 waiver proposals and state responses to comments received, including changes made to the waiver proposal (SPAs would not be included in this requirement). At the federal level, the contemplated legislation would require: 1) monthly notice of 1115 waiver and SPA proposals and amendments in the *Federal Register*; 2) a 30-day public comment period for 1115 waiver and SPA proposals; 3) publication of proposed terms and conditions of 1115 waivers and a 15-day period for public comment (SPAs would not be included in this requirement); 4) posting of all approved 1115 waivers and SPAs on HHS's website; and 5) monthly notice of all section 1115 waivers and SPAs, whether approved, denied, or sent back to the state.³⁴

In the absence of adequate federal oversight, advocates can be expected to seek public input protections in state law. For example, a bill was introduced in the Connecticut General Assembly that would provide for increased oversight by the state legislature in the Section 1115 waiver process.³⁵ Advocates are supporting this bill and are requesting similar legislative oversight of the SPA process, particularly when proposed changes could have negative effects on consumers.³⁶ Another bill introduced in the West Virginia legislature would require public notice of proposed amendments to the State Plan to be filed in the *State Register*.³⁷

Finally, formal processes do not, by themselves, guarantee meaningful opportunities for public engagement in policy making. The attitude of state officials toward public engagement and the strength of established relationships between stakeholders and policy makers clearly play a role. Therefore, advocates must make concerted efforts to develop and nurture strong, ongoing relationships with federal and state officials.

APPENDIX A: SUMMARY OF STATE CASE STUDIES

California, Connecticut, Florida, Illinois, Indiana, Michigan, Nevada, and Texas were selected for case studies to learn what, if any, processes are in place to solicit public input into Section 1115 waiver or SPA development, review, and implementation. Each case study below describes the process the state used to develop and implement reforms that affect Medicaid benefits or cost sharing and explores how those processes vary if implemented through a waiver versus a SPA. Each case study then summarizes where in the process there are opportunities for public input. Finally, each case study presents a local advocacy organization's perspective on opportunities for public input.

CALIFORNIA

Policy Reform Development and Implementation

The Department of Health Services (DHS) administers Medi-Cal, California's Medicaid program, with strong influence from the California state legislature. Medi-Cal covered services and co-payment amounts are detailed in statute, and most program changes occur during the legislative session. Additional clarification of statutes, including amount, duration, and scope of covered services, may be provided in administrative rule or the *Medi-Cal Manual of Criteria*, a manual used in administering the Medi-Cal program that is incorporated into the administrative rules by reference. However, DHS views the California rule-making process as arduous, often taking up to two years to complete. To avoid this cumbersome process, DHS often seeks legislative authority to implement legislative changes through All County Welfare Director Letters³⁸ and provider bulletins³⁹ instead.

Legislative Oversight

Benefits, covered services, and co-payment provisions, as well as general and specific waiver authorizations, all appear in state statute, requiring constant legislative involvement in Medi-Cal policy making. The California legislature typically directs DHS to accomplish a particular result, but gives the department discretion to determine whether to use a waiver or SPA to achieve the result. In cases where the legislature has given DHS broad authority to apply for a particular kind of waiver, DHS may need to obtain further legislative approval before proceeding if the proposal has budgetary impact. Because of the impact of Medicaid on the state's budget, the legislature becomes involved in most Medi-Cal changes through the budget process. DHS reported that, because any substantive change in Medi-Cal is likely to require an amendment to existing statute and to have budget impact, such changes would require both a policy bill and a budget bill.

Executive Branch Involvement

Although the governor's office may be consulted about waivers and SPAs, DHS reported that it is not typical for the governor's office to be involved in Medi-Cal policy making. However, when the issue is significant to the administration's policy agenda, or if the governor's involvement is needed in state or federal negotiations, there can be significant involvement.

Opportunities for Public Input

DHS reported that the amount of public input solicited will depend on the significance of the policy, not whether a waiver versus a SPA is the vehicle for change. The current administration views itself as open to stakeholder involvement and recognizes the value of testing new ideas with the public. In addition, because the legislature is very involved in the Medi-Cal program, opportunities for public input during policy development arise at the legislative level, through public hearings before legislative committees as well as less formal interactions with legislators and their staff. Depending on the proposed policy change and how sensitive the issue is, DHS may hold public hearings or otherwise solicit input in conjunction with the legislative process.

DHS reported that it will publish notice of its intent to apply for a Section 1115 waiver. The notice is not required under state law, but is considered to be part of the department's compliance with the 1994 *Federal Register* notice requirement. Hearings will be held and, if the issue is sensitive, possibly stakeholder meetings as well. Two years ago, when the state was considering substantial Medi-Cal Redesign, DHS held 25 stakeholder meetings across the state and posted information and updates on a special website dedicated to the effort. DHS reports that the stakeholder meetings helped the department understand public attitudes toward the reform and identify consumers' readiness for change.

Before implementing changes approved under either a waiver or a SPA, DHS may be required to promulgate administrative rules. According to DHS, its rule-making process requires notice of intent to promulgate rules at least 45 days before 1) a public hearing on the proposed rules or 2) the filing of a draft text of the rules. This notice will include a reasons statement, other findings, etc. If DHS does not hold a public hearing, there will be a comment period. Following these activities, DHS will issue the final rules with both a summary of comments received and its response to the comments received. The Office of Administrative Law, which reports to the legislature, will review the rule-making process before final rule adoption. Legislators can request a review of rules, but formal legislative review is not provided for.

As described above, DHS reported that it may seek legislative authority to implement changes through All County Welfare Director Letters and provider bulletins instead of the rule promulgation process, especially if the legislation is detailed regarding the program change. DHS is not required by law to hold public hearings or to facilitate other opportunities for public input before drafting All County Welfare Director Letters and

provider bulletins, but it may do so, or the legislature may direct it to do so, especially if the policy is controversial or complex. This was true when the state sought to implement the new Medicaid citizenship documentation requirements under the DRA,⁴⁰ which resulted in DHS holding stakeholder meetings across the state. When implementing through All County Welfare Director Letters and provider bulletins, DHS eventually may be required to promulgate rules at a later date, depending on the authorizing legislation.

Medical Care Advisory Committee Involvement

DHS reported that the MCAC in California plays a role in Medi-Cal policy by making recommendations to the program, including recommendations regarding changes in benefits or cost sharing. In comparison to the legislature, however, DHS believed the role MCAC plays in affecting policy is rather limited.

Advocate's Perspective

Respondents from Protection and Advocacy, Inc. (PAI), agreed that the California legislature plays a strong role in Medi-Cal policy development, including in the design of benefits and cost sharing. The legislature may give DHS the general authority to implement a program, but in most cases, according to PAI respondents, additional legislative approval is required.

PAI explained that there are many opportunities for public input into the legislative process. Advocates can help draft bills, support or oppose bills, meet with legislative staff, and participate in committee hearings. Although there are committee hearings on most issues, thus allowing stakeholder input, respondents from PAI felt that hearings were brief and that participation in committee hearings was not the most effective method for providing public input at the legislative level. Advocates felt that they have more opportunities to influence policy by working with key committee staff and helping to draft legislative language. However, advocates acknowledged that working at the committee level does not ensure that bill language will not be changed, removed, or added at the end of a legislative session, with very little or no opportunity for public input. Advocates also said that opportunities for public input at the legislative level were more meaningful when they took place outside the appropriations process, because the budget is usually passed in a rush and behind closed doors. PAI agreed with representatives from the state that the formal rule-making process in California is very lengthy and complicated, and that DHS tries to avoid this process when given the opportunity.

PAI had mixed reactions to the effectiveness of the public input processes DHS provides at the state agency level. At times PAI has found opportunities for public input to be meaningful, and at other times found them to be superficial and bureaucratic. For example, DHS may hold only one stakeholder meeting, in Sacramento, making it extremely difficult for consumers to attend (although PAI did note that consumers are given an opportunity to call in). In addition, no transportation may be provided for people with disabilities to attend and participate, resulting in a lack of representation from

certain affected groups. At times when advocates and others have given significant input, for example, regarding the Olmstead implementation processes, PAI believed the state failed to take any significant action. Also, on more than one occasion, PAI has had to request that DHS publish comments received at stakeholder meetings on the DHS website. In some cases, DHS only published a summary of comments received and left out major points raised in the stakeholder meeting, making the summary, from PAI's perspective, an inaccurate reflection of the meeting.

On the other hand, respondents from PAI strongly approved of the stakeholder process DHS used in the 2006 Medi-Cal Redesign initiative, which proposed a managed care expansion, hospital financing reform, and some benefit and cost-sharing changes. The process included the use of special website postings, statewide meetings and hiring an outside, facilitating consultant. Although the end result of the Medi-Cal Redesign process was unsuccessful in the legislature, PAI believed DHS saw it as a productive process and appears to have improved DHS's willingness to fully engage stakeholders. PAI noted that continued use of the effective public input processes provided during Medi-Cal Redesign would add greater public acceptance to any proposed changes to Medi-Cal, including all waivers and SPAs.

Respondents from PAI recommended a variety of options DHS and the state could pursue to facilitate meaningful opportunities for public input. These include active solicitation of public input and accountability for responding to and acting on that input, including offering written feedback on public comments received. Advocates also expressed a desire to have written responses mailed to public hearing participants and posted publicly on the DHS website in a timely fashion. PAI respondents want to see more opportunities for public input from people with disabilities, supported by stipends for participants, paid transportation costs, handicapped-accessible meeting sites around the state, translation services, and pre-meetings for consumers with cognitive disabilities. PAI strongly urged that the state deliver fully on any commitments made, for example, to amend waivers, set timelines, or dedicate funding. In PAI's view, failure to do so results in loss of credibility for the state, and in consumers, advocates, and providers becoming discouraged with the process.

Respondents from PAI recommended that the federal government require the state to solicit and respond to all public input in a timely manner. PAI noted that CMS only requires documentation that a stakeholder meeting occurred for Section 1115 waivers; there is no requirement regarding the content of materials shared, nor is there any requirement for a state response. Such requirements would ensure that a state actually receives meaningful public input and acts on that input. PAI would also like to see all notices, waivers, SPAs, etc., posted online. SPAs and waivers should be posted when applied for and when denied, including CMS comments received, so advocates have an opportunity to comment or offer suggestions.

CONNECTICUT

Policy Reform Development and Implementation

Many Medicaid benefit provisions are published in the Medical Services Policy manual (policy manual), rather than in statute. The policy manual is issued through the rule-making process and describes Medicaid policies such as those related to participating providers, covered services, benefit limits, and other aspects of the program. Currently the policy manual does not require cost sharing.

According to DSS, only “friendly” changes to the Medical Services Policy manual (e.g., technical reforms or updates) would be made without first going through the rule-making or legislative process. Benefit or cost-sharing reforms authorized under either a SPA or a waiver would require a legislative mandate or a formal rule amendment pursuant to the Uniform Procedures Act. Because the Connecticut rule-making process can take up to two years, DSS reported that the General Assembly sometimes makes Medicaid program changes in implementation bills during the budget process instead. In these cases, DSS will be able to implement the program change pending rule promulgation as long as the implementation bill is specific in detail and authorizes DSS to do so.

Legislative Oversight

State Statute requires DSS to notify the General Assembly’s joint standing committees with cognizance over matters relating to appropriations and human services of any intention to file a waiver.⁴¹ DSS must also submit the waiver application to the joint standing committees before filing it with CMS.⁴² The joint standing committees have 30 days to advise DSS of their approval, denial, or recommended modifications to the waiver application.⁴³ DSS reported that, in many cases, the committees conduct extensive public hearings before advising DSS, and that these hearings are televised and well attended. While the department generally follows the committee’s recommendations, DSS officials reported that committee approvals, denials, or recommendations are not binding on the department. For example, DSS once submitted a transfer of assets waiver to CMS despite the committee’s denial.

Connecticut’s Medicaid program has no similar statutory requirement for legislative review of SPAs before filing for federal approval.⁴⁴ DSS indicated, however, that the General Assembly has authorized and even mandated the department to apply for specific SPAs in the past, including SPAs for a Partnership for Long-Term Care program, home leave absences, and mammogram coverage. In addition, DSS reported that, if the department sought Medicaid benefit changes, it would most likely do so through legislative action during the appropriations process, before filing.

Executive Branch Involvement

DSS reported that the governor’s office is not routinely involved in the waiver or SPA process in Connecticut.

Opportunities for Public Input

Connecticut law protects public input in the waiver process. Before DSS submits a waiver application to the joint standing committees as detailed above, it must publish notice in the *Connecticut Law Journal* of its intention to seek a waiver.⁴⁵ The notice must include a summary of the waiver proposal and the manner in which individuals may submit comments.⁴⁶ The public has 15 days to submit written comments, and DSS is required to submit all public comments received with the materials it provides to the joint standing committees of the General Assembly.⁴⁷

There is no similar requirement regarding SPA filings. However, as described above, DSS reported that changes to benefits or cost sharing most likely would be enacted by the General Assembly before filing a SPA. Legislative action offers some opportunity for public input before legislative committees, as well as informal contact with individual legislators and their staff. Further, DSS reported that it publishes notice of intent to file a SPA in the *Connecticut Law Journal* 30 days before filing and that, after filing, it advises the joint committees of the General Assembly of the filing.

Before implementing waiver or SPA reform, especially if the Medicaid program change has political exposure, DSS would generally need to promulgate administrative rules to reform the Medicaid Services Policy manual. The rule promulgation process in the Uniform Procedures Act⁴⁸ provides for notice in the *Connecticut Law Journal*, a 30-day comment period, a formal public hearing or opportunity to leave voice recordings for the department, review by legislative committees, review by the Attorney General, and a fiscal analysis. However, if the bill is specific, and the General Assembly authorizes it to do so, DSS would be able to implement a program change pending administrative rule promulgation, limiting public input outside the legislative process.

Medical Care Advisory Committee Involvement

DSS reported that the MCAC does not play a formal role in the waiver or SPA process in Connecticut.

Advocate's Perspective

Connecticut Voices for Children (Voices) agreed that the Connecticut General Assembly is always involved in substantive policy changes in Medicaid, with much policy enacted through implementation bills. Voices stated that only limited public input is obtained in the General Assembly before passing an implementation bill, because only a small group of people are party to the negotiations. Voices also agreed that Medicaid benefits are generally established in rules and stated that the rule promulgation process requires opportunities for meaningful public input. Voices indicated that, in addition to the public input processes required under the Uniform Procedures Act, the department may pursue other informal processes for soliciting public input. For example, the department may solicit input from specific stakeholders or may bring the policy before the Medicaid

Managed Care Council. These activities typically occur if the proposed Medicaid program change is substantial or if the department desires outside expertise in addition to the advocates that have already voiced opinions.

Voices noted that DSS has complied with the established state process for waivers. With a behavioral health waiver, the waiver proposal was published on the DSS website, and there was an opportunity for public comment. Voices indicated that the department may even conduct further discussions with stakeholders outside the established state process if the waiver is controversial. Voices pointed out that the SPA development process does not have the same requirements for public input before filing.

The current governor and state Medicaid director were viewed as being more open to meaningful public input on benefits or cost sharing than were previous administrations, but respondents for Voices did not believe that the policy-making process and opportunities for public input should have to depend on who is in the executive office. Voices recommended that DSS be required to respond in a timely fashion to all public comments regarding waivers and SPAs and should post comments and responses on the state's website. Interestingly, Voices noted that a statute requiring legislative approval of all SPAs could become a double-edged sword by creating an opportunity to inhibit good program change. Voices would support, however, a state law requiring legislative review when DSS proposes to reduce benefits or impose cost sharing.

Voices stressed the importance of transparency in the waiver and SPA process, with information made available to the greatest number of people possible. Recommendations for process improvement included using a listserv of interested parties, e-mail alerts to announce new website postings, publishing comments received, using a more systematic process to post notices of proposed changes, and posting relevant laws and regulations on the DSS website. Voices also supported additional legislative oversight of waivers and SPAs, including public hearings at the legislative level. Ideally, Voices felt that advocates should have an opportunity to provide input early on in the process, before the state has committed to a particular policy.

FLORIDA

Policy Reform Development and Implementation

The Agency for Health Care Administration (AHCA) administers Florida's Medicaid program. Florida statute requires legislative oversight of waivers.⁴⁹ In addition, the Florida legislature establishes most benefit and cost-sharing policy. As a result, ACHA reported that, in most instances, it would seek legislative direction before initiating changes to benefits or cost sharing through either a waiver or a SPA. Other triggers for initiating a waiver or SPA include a change in a federal mandate or an executive order from the governor.

Major Medicaid policy initiated in the Florida legislature becomes operational through the rule-making process. After receiving legislative direction to implement a new policy,

such as a change in the amount, duration, or scope of covered services, AHCA indicated that it will amend its Medicaid Services Coverage and Limitations Handbooks accordingly. These handbooks, which detail Medicaid program operations, are incorporated into the Florida Administrative Code by reference, so any changes must go through the rule-making process established in Chapter 120, Florida Statutes.

Legislative Oversight

AHCA reported that, in practice, the Florida legislature initiates most, if not all, benefit and cost-sharing changes in the Medicaid program, usually during the appropriations process. As a result, AHCA reported that advocacy groups often have an opportunity to provide input to the legislature during policy development before AHCA begins preparing the actual waiver or SPA application for filing with the federal government. This was true in the case of Florida's partial dentures benefit⁵⁰; the legislature acted first, and then AHCA filed a SPA with CMS.

AHCA reported that, in the past, the legislature has authorized the agency to apply for certain waivers. For example, s. 409.912(4)(b)(8), Florida Statute authorized AHCA to apply for a federal waiver to provide behavioral health services for children through specialty prepaid health plans. However, AHCA noted that such specific legislative authorization is not always required to apply for a waiver.

There is a general state statute requiring AHCA to notify the legislature before submitting a waiver proposal to the federal government.⁵¹ However, during the recent development of a major Medicaid reform initiative in Florida that entails significant changes to the benefit package and a transition from a primarily fee-for-service to a primarily managed care delivery system, the legislature enacted additional legislative oversight of the waiver proposals submitted to CMS. AHCA was required to submit waiver documents for review and approval by appropriate committees in both the Florida House and Senate before the waiver was submitted to CMS.⁵² In large part due to comments received, the legislature required AHCA to amend its 2005 Medicaid Reform waiver proposal several times before it was finally submitted to CMS.

Executive Branch Involvement

AHCA reported that the governor's office has been very involved in waiver proposal preparation and frequently collaborates with AHCA during the waiver development process. For example, the governor's office helped establish the guiding principles behind Medicaid Reform.

Because most if not all benefit and cost-sharing changes are initiated in the Florida legislature, AHCA indicated that the governor's office is much less involved in the SPA process than is the legislature.

Opportunities for Public Input

Because the Florida legislature is very involved in developing specific Medicaid benefit and cost-sharing policy, various opportunities for public input arise at the legislative level during policy development, and generally before waiver or SPA documents are submitted for federal approval. Opportunities include public hearings before legislative committees and private meetings with legislators and their staff. In some cases, advocates can be asked to engage in drafting proposals.

AHCA reported that, for Section 1115 waivers, the agency generally provides additional opportunities for public input before filing a proposal for federal approval. As an example, AHCA described what it considered to be an exhaustive public input process undertaken before the Medicaid Reform waiver proposal was submitted to CMS. In its earliest stages, AHCA asked for ideas from anyone who had anything to contribute. AHCA staff researched a range of potential reform opportunities, in part by reaching out to experts across the country to help narrow down what works and what does not work in Medicaid reform efforts.

AHCA began receiving general comments from the public about Medicaid Reform in late 2004 and early 2005. Representatives from AHCA could not remember if a formal announcement seeking public input was made, but the governor's 2005 State of the State Address mentioned Medicaid Reform, and AHCA believed that stakeholders were aware that major program change was under consideration. Beginning in late 2004, AHCA held a series of public workshops about Medicaid Reform. Public announcements about the workshops were made, and some of the workshops were televised. An expert panel participated in the workshops to discuss proposed reform opportunities, and a white paper was published after the public workshops. Although the workshops did not leave much time for questions and answers, AHCA said that the audience was invited to submit public comments to AHCA afterward. AHCA received many public comments, but did not indicate whether formal responses to public comments were distributed. According to AHCA, interested parties also requested and participated in informal meetings with agency staff.

As a result of this public process for Medicaid Reform, AHCA explained that some of its original reform concepts were altered, others were discarded, and new ones were added. Respondents from AHCA also emphasized that the public process surrounding the Medicaid Reform waiver was more in depth than it was for other Florida waivers because of the magnitude of the changes involved.

AHCA is required by law to provide notice and an opportunity for public comment before implementing a Medicaid waiver.⁵³ While there is no similar legislative requirement for SPAs, implementation of most SPAs does require amending the Florida Medicaid Services Coverage and Limitations Handbooks to reflect the approved policy change. Because the Handbooks are incorporated into Florida's Administrative Code by reference,⁵⁴ any change to them must go through the rule-making process established in

Chapter 120, Florida Statutes. AHCA indicated that the rule-making process includes public notice in the *Florida Administrative Weekly* and an opportunity for public comment. Opportunities for public comment include an ability to request a public workshop or a public hearing. AHCA did not specify the manner in which public comments were disposed of or indicate whether public comments were published. However, s. 120.54, Florida Statute requires persons responsible for preparing the proposed rule to be available to answer questions and respond to comments during public workshops. The statute also requires that during public hearings affected persons must have an opportunity to present “evidence and argument,” and that these items must be considered by the rule-making agency and made part of the record of the rule-making proceeding.

Medical Care Advisory Committee Involvement

AHCA reported that Florida’s Medical Care Advisory Committee has not met since 2000. Instead, AHCA indicated that it relies on a number of committees and advisory groups to provide feedback, information, public input, and open forums on a variety of issues, which may include waiver and SPA issues. According to AHCA, the use of several committees in lieu of a single Medical Care Advisory Committee results in broader stakeholder participation. An example of an active advisory committee is the KidsCare Advisory Council for the State Children’s Health Insurance Program (SCHIP).

Advocate’s Perspective

Respondents from Florida Legal Services (Legal Services) agreed that the Florida legislature and/or the governor will provide direction to AHCA before AHCA seeks federal approval for a policy change that affects benefits or cost sharing. Although opportunities for public input occur during the legislative process, Legal Services viewed these opportunities as very formal, limited, and on an accelerated timeline. Also, while the legislative input process can be effective, Legal Services reported that there can also be surprises as a result of last-minute changes buried in complex bills.

Legal Services identified several barriers to effective public input on waivers and SPAs, including the absence of any requirement for advance public notice regarding the filing of SPAs with CMS and/or any effort by AHCA to solicit public comments during the policy development phase, before seeking CMS approval for a SPA. Legal Services noted that SPAs typically are not posted on the AHCA website, rather, advocates must make a state public records request to AHCA for the information. While the Medicaid agency is required to file a notice with the legislature before a federal waiver filing, Legal Services stressed that this notice is not routinely shared with the public. In addition, Legal Services noted that the details of a waiver or SPA filing are often developed without significant input (with the noted exception of the Medicaid Reform waiver development, as described below).

Although public input was solicited during the Florida Medicaid Reform waiver process, Legal Services noted that no specific proposal was provided for the public to comment on

until 30 days before submission of the waiver application to CMS, which made it appear that the state was just “going through the motions.” Legal Services was concerned that AHCA was already negotiating with federal officials about the proposal at the same time it was seeking public comment, raising further doubts about the state’s interest in public input.

Ultimately, the Florida legislature required a 30-day public comment period on the specific Medicaid Reform waiver proposal, and state officials posted the proposed waiver application on the state’s website. Multiple public comments were submitted; however, Legal Services was not aware of any changes to the proposal based on the comments received. Although Florida advocates made multiple state public records requests, Legal Services found that the records provided by the state were outdated and of no use. To date, a response to a federal Freedom of Information Act request still has not been received. Legal Services also noted that there are no opportunities for public input during negotiations between the state and federal agency regarding waivers and SPAs, creating doubts about whether the public’s concerns are seriously considered during the process.

Legal Services reported that there is an opportunity for public input before Medicaid policy reforms are implemented; however, rule promulgation typically occurs after CMS has approved a SPA. Legal services also noted that some policy development and implementation occurs with no public input. For example, Legal Services reported that HMOs and AHCA negotiated with each other on benefit packages, cost sharing, and other Medicaid policies behind closed doors during implementation of Medicaid Reform.

Legal Services recommended that opportunities for public input into the waiver and SPA process could be improved by requiring the state to follow state Administrative Procedures Act (APA) rule-making procedures before submitting a waiver or SPA application to the federal government. This would require the state to provide public notice of the proposed SPA or waiver, an opportunity for public comment, and a hearing before a SPA could be submitted to CMS for approval. For approved waivers, all terms, conditions, and amendments should be made publicly accessible on the state’s website and/or through other venues.

Legal Services also recommended that CMS mandate a public process for waiver or SPA submissions. The mandate should include a detailed requirement for public posting of the state’s intent to file a waiver or SPA, public posting of the draft waiver or SPA, a mandated 30-day public comment period, and a requirement for the state to post specific responses to comments, before discussions with CMS. If CMS does not have the authority to require a mandated public input process, Legal Services recommended that Congress should consider the issue for future legislation.

ILLINOIS

Policy Reform Development and Implementation

The Department of Healthcare and Family Services (DHFS) administers the Illinois Medicaid program. Benefits and cost-sharing provisions for Illinois Medicaid are generally spelled out in administrative rules, although statute has specifically detailed some elements.⁵⁵ Waivers and SPAs that affect benefits and cost sharing typically require amending the Illinois Administrative Code, and DHFS must complete the rule-making process to implement the policy. While not common, the rule-making process could be initiated before filing a waiver or SPA with CMS.

Legislative Oversight

DHFS reported that most benefit and cost-sharing provisions are spelled out in administrative rule, and that Medicaid program changes typically occur as part of the state budget process. The Illinois General Assembly has provided DHFS with general authority to “[e]stablish demonstration programs,”⁵⁶ and the General Assembly’s involvement in developing waiver proposals is largely informal. DHFS noted that although there is no state statute requiring legislative review of waivers or SPAs, it would likely seek informal input from interested legislators during policy development, especially on proposals that might require a specific legislative appropriation or other legislative action before implementation. For example, the General Assembly was consulted in the development of DHFS’s Pharmacy Plus waiver. DHFS reported that there have also been some program reforms initiated by the General Assembly, including creation of a particular home and community based services waiver.⁵⁷

The General Assembly is involved more formally in implementing waivers and SPAs after they are approved by the federal government, through the Joint Committee on Administrative Rules (JCAR). DHFS reported that implementing waivers and SPAs that affect benefits and cost sharing requires a change in administrative rule. DHFS must provide the JCAR with a notice of proposed rules and, although JCAR does not have to approve the rules, it may be able to slow the process with its objections.⁵⁸

Executive Branch Involvement

DHFS reported that the department typically will brief and/or work with the governor’s office before submitting a waiver proposal to CMS. Depending on the significance of the proposed program change, DHFS may also brief the governor’s office regarding SPAs, but there is no formal or routine role for the governor’s office before filing a request.

Opportunities for Public Input

State law does not mandate legislative oversight and opportunities for public input in the development and filing of waivers and SPAs, but DHFS reported that it typically seeks input from the Illinois General Assembly, the governor's office, and the public before submitting a waiver or SPA that substantially affects program policy. DHFS reported that if the waiver or SPA affects benefits or cost sharing, it will want to engage the public. In cases where formal legislative action is taken to initiate a Medicaid change, legislative committees offer public hearings for stakeholders to provide input.

DHFS reported that it provides a notice of waiver proposal to stakeholders, along with detail regarding the nature of the changes involved. DHFS did not specify how it provides notice of the waiver and changes involved, but explained that it gives stakeholders an opportunity to ask questions and comment on the proposed program. DHFS noted that this process enables DHFS to better understand what will and will not work in the proposed waiver program, but that DHFS is not required to respond formally to all comments it receives during the process.

DHFS reported that the public process surrounding development of a SPA will vary depending on the nature of the policy change, as judged by DHFS. For example, before developing the SPA to implement the state's new Primary Care Case Management program (Health Connect), DHFS described what it considered an extensive process of public input and noted that the Department is working to address many of the concerns raised by stakeholders. DHFS reported that stakeholder groups were formed and had already met nine times to advise the state regarding the proposed program. DHFS officials also met with stakeholders individually, in one-on-one meetings, but noted that it did not share the actual SPA, which was rather boilerplate, with stakeholders. Instead, it shared a description of the new PCCM program.

Public input is required before implementing any waiver or SPA through the Illinois process for administrative rule promulgation. According to DHFS, the rule promulgation process provides a meaningful opportunity for public input. There is public notice, including electronic notices and online publication, and a structured public comment period. The final rule, along with DHFS responses to comments received, is published. In addition, JCAR, which is a legislative committee, will review the rules and has the opportunity to object. JCAR can ask the General Assembly to invalidate the rule through legislation. DHFS stated that it is responsive to concerns expressed during the rule promulgation process, and that there is always an opportunity for public comment. For example, DHFS adjusted some of the rules of its All Kids program after receiving public input into the rule-making process.

For certain reforms, such as establishing co-payments above current limits, a statutory change would be required. In addition, many reforms would require legislative action through the appropriations process. Formal legislative action offers both formal public

hearing opportunities before legislative committees and informal meetings with legislators and staff.

Depending on the waiver or SPA involved, DHFS reported that the department might choose to initiate the legislative and/or rule-making process before obtaining approval from the federal government. For example, the Primary Care Case Management program SPA will be submitted after the rule-making process and other public input has occurred.

Medical Care Advisory Committee Involvement

DHFS reported that the Medical Care Advisory Committee is active in Illinois and may, depending on the circumstances, review waiver or SPA proposals. However, because the MCAC only meets six times a year, its ability to review a proposal depends, at least in part, on scheduling.

Advocate's Perspective

The Shriver Center reported that the public input process around waiver and SPA policy development is very ad hoc in Illinois; there is no written procedure for public input into waivers or SPAs. The amount of public input received depends on politics and the magnitude of the change, and it is always dependent on DHFS's determination of whether the issue is politically sensitive. Generally speaking, however, the Center was satisfied with the public input opportunities available to advocates.

According to the Center, if a proposed change has a budget impact, the proposed policy will move through the legislative budget process, which offers opportunities for public input before committees in the General Assembly as well as informal meetings and policy work with individual legislators and their staff. The Center noted that additional opportunities for public input during the rule-making process are few, as the change is typically implemented through an emergency rule. The Center reported that, regarding controversial waiver or SPA changes, DHFS will hold working groups with concerned stakeholders. Although there has been some variation from administration to administration regarding willingness to obtain public input, the Center did not report experiencing significant change.

Respondents from the Center noted that the state spent years gathering public input for development of a managed care waiver for Illinois Medicaid. While the federal government eventually approved the waiver, the managed care program was never implemented, which was partly a reflection of the public input received throughout the process. The Center stressed that the input gathered through current processes is adequate and meaningful. However, respondents from the Center also noted that, because there are no written policies or procedures guiding the process, advocates or consumers who are not familiar with the Illinois policy-making environment may not find the process as meaningful as do their more seasoned counterparts. For this reason, the Center believed that the "uninitiated" would definitely benefit from a more formal process.

According to respondents from the Center, good relationships with state officials are critical to a meaningful public process. Respondents from the Center stressed that effective advocacy strategies include the use of media, grassroots organizing, and sustained pressure on key policymakers. Having opportunities to intervene early in any waiver or SPA process holds the promise of having greater impact on any proposed change, and regular interaction with the state administration provides advocates with more opportunities for informal, early input into policy making.

The Center said that the federal government should ensure an effective process for public input into both waivers and SPAs. This would include requiring the state to distribute information to the public, actively solicit comments, and respond to comments. According to the Center, approval of proposed waivers or SPAs by the state Medical Care Advisory Committee, or release of information in an obscure publication, should not be considered adequate public input. The Center believed it would be useful if DHFS published a list of proposed SPAs or SPAs that were under consideration.

INDIANA

Policy Reform Development and Implementation

The Office of Medicaid Policy and Planning (OMPP) in the Family and Social Services Administration (FSSA) administers Indiana's Medicaid program. Although state law in Indiana does not mandate public input in the waiver and SPA processes, OMPP reported that public input will occur nonetheless due to Indiana's expansive statutory and administrative process. All benefit and cost-sharing provisions are set forth in statute and/or rule. Rules often provide further interpretation of the policies established in statute. This means that program changes require a legislative and/or regulatory amendment before implementation.

Legislative Oversight

OMPP described the Indiana General Assembly's participation in the waiver and SPA process as varied. The General Assembly can initiate changes in Medicaid policy, which may necessitate OMPP filing waivers or SPAs to implement the mandated changes. In one recent example, the General Assembly directed OMPP to explore the possibility of a care management waiver. OMPP can also initiate proposed changes and reported that it may consult with key legislative representatives on an informal basis during its preparation of a waiver or a SPA. However, since many benefit or cost-sharing provisions are contained in Indiana statute, changes to these provisions require legislative action before implementation.

Executive Branch Involvement

OMPP reported that the Office of Management and Budget (OMB) is significantly involved in Medicaid policy and must approve all changes. Depending on the magnitude of the change, the governor's office may be consulted as well in the early stages of the

waiver and SPA process. The executive branch is also involved in the rule-making process. The governor signs all rules, and the Office of Economic Development⁵⁹ must approve them.

Opportunities for Public Input

OMPP indicated that the current administration has created more of an “open door” policy than in the past to public input and understands the importance of building consensus. The opportunities for public input OMPP offered during policy development for both waivers and SPAs depend on the magnitude of the policy change involved and whether OMPP judges that an adequate public process has already occurred at the legislative level. For example, the General Assembly initiated a recent waiver affecting foster children and wards of the state, and hearings occurred in the General Assembly. Involved state agencies and providers helped write the waiver proposal, a process overseen at the legislative level. As a result, OMPP did not pursue additional hearings or public input before filing the final waiver. In the case of creating a care management program, the General Assembly directed OMPP to explore the possibility of a waiver. Forty public meetings were held in various parts of the state, and OMPP reported that the industry was very engaged.

There are no formal requirements for the state to solicit public input during development of a SPA, although OMPP reports that it may do so. OMPP noted that it may hold working sessions with selected stakeholders to assist in developing proposed policies.

Administrative rules are required before implementation of any reforms approved in a SPA or waiver. OMPP indicates that the rule-making process in Indiana, which takes on average seven to nine months, requires public notice and a public hearing to solicit comments on the intent behind the policy and then a second public notice and hearing to solicit comments on the proposed rule.⁶⁰ All rules, proposed rules, and notices are published online. IC 4-22-2-24 also requires publication in a newspaper of general circulation in Marion County and publication in the *Indiana Register*. In addition, OMPP must develop an analysis of the impact the proposed rule would have on small businesses in the state. The FSSA Rules Committee must approve all rules, and the attorney general and governor must sign off on them.

Medical Care Advisory Committee Involvement

Indiana’s Medical Care Advisory Committee, the Medicaid Advisory Council, meets every three months, but OMPP reported that the Advisory Council does not have a clearly defined role in policy development, including any review of proposed waivers and SPAs.

Advocate’s Perspective

The Indiana Primary Health Care Association noted that the General Assembly has informally deemed all “health” issues as bipartisan in Indiana. The governor’s office and

FSSA have helped to maintain this bipartisan approach. As a result, an all-inclusive government health care policy system has been created in Indiana, with everyone working toward a “Healthier Indiana.”

To create a “Healthier Indiana,” the administration, the General Assembly, and the involved agencies have gathered key Indiana stakeholders to discuss local issues and access to care. Leadership has held general consumer meetings to garner state support, distributed information on the programs, ensured that all questions were responded to in a timely fashion, and created forums for interested parties to come together.

The Association recommended that the federal government play a stronger role in ensuring public input during the waiver and SPA processes, including requiring states to create strong communication systems, and stated that the public input process in any state would be improved by a state statute requiring the appropriate checks and balances of public input and legislative approval regarding Medicaid benefit and cost-sharing changes.

The Association stressed that a strong communication plan is vital to any successful waiver or SPA proposal for Medicaid reform. The Association reported that the current administration e-mails descriptions of proposed Medicaid program changes to advocates and holds town hall meetings with presentations about the proposed change. Respondents from the Association noted that, when Indiana applied for changes to its 1915(b) waiver, regional CMS representatives contacted the Association to inquire if they were aware of the requested change(s) and to obtain feedback on how the proposed change(s) would affect consumers. The Association noted that even a five-minute telephone call from CMS made the public input process more meaningful and urged more frequent communication between the federal government and advocacy organizations.

MICHIGAN

Policy Reform Development and Implementation

The Michigan Department of Community Health (MDCH) administers Michigan’s Medicaid program. Unlike most of the other case study states, Michigan sets forth many substantive provisions of its Medicaid program in program policy (issued as “Policy Bulletins”) rather than by statute or rule. MDCH is specifically authorized by statute to administer the Medicaid program through program policies, which have the force of administrative rules but are not subject to the rule-making process. Most Medicaid benefit provisions and all Medicaid cost-sharing provisions are set forth in program policy, not statute; however, the legislature and the governor play a significant role in Medicaid policy making, since most Medicaid benefit and cost-sharing changes are made in the budget process.

Legislative Oversight

MDCH reported that the Michigan legislature often provides direction or authorization of specific waiver policy through legislative enactment during the annual appropriations process. Michigan statutes do not require the Michigan legislature to review or approve waivers before filing. However, because waivers typically seek significant program changes, MDCH reported that key legislators usually have an opportunity to review and discuss waiver proposals with MDCH officials before their submission. Likewise, the Michigan legislature often provides direction or authorization for the policies behind SPAs when it approves or amends MDCH's annual appropriation during the budget process. However, the legislature does not review the SPA document, however, before filing.

Prior to implementation of any waiver or SPA reforms, MDCH is required to modify program policy to reflect the program change. MDCH must provide members of the Joint Committee on Administrative Rules with copies of the proposed policy as well as an opportunity to comment, before implementing the new program policy.⁶¹

Executive Branch Involvement

While there is no formal requirement, MDCH reported that it normally consults with the governor's office and the Department of Management and Budget (DMB) before submitting a waiver proposal to the federal government, because most waivers have a substantial impact on the budget and on program policy. MDCH indicated that there is no executive review of SPA filings, but the governor's office could be involved in developing the policy behind a SPA because benefit and cost-sharing changes sometimes occur as the result of an executive order.

Opportunities for Public Input

MDCH reported that the Department provides for public input in its preparation of Section 1115 waivers, with the specific process offered varying based on the Department's judgment of the significance of the reforms proposed in the waiver. In the case of two very comprehensive waivers submitted to CMS in the past five years, MDCH held large public hearings across the state. For a more narrowly focused family planning waiver, MDCH provided formal written notice and an opportunity for advocates to provide written input. The family planning waiver was also discussed at a stakeholder meeting called for another purpose. MDCH posts information about proposed/approved waivers on a specific page on its website. At public hearings held on waivers, MDCH noted that stakeholders are able to ask any questions and voice any concerns about the proposed waiver. MDCH makes knowledgeable staff available to respond.

MDCH noted that the major difference between the public input process involved in waivers and the one involved in SPAs is the public hearings and broad stakeholder notice that occurs during development of Section 1115 waivers. However, it also indicated that, for both waivers and SPAs, some form of public input, including hearings before

legislative committees, will occur at the legislative level during the appropriations process.

MDCH reported that the public input process for SPAs is the same as the process used to amend program policy. Pursuant to state law MCL 400.111a, amendment of the Medicaid program policy requires consultation with the Medical Care Advisory Committee and affected providers and advance public notice of the proposed policy to the Michigan legislature's JCAR, before implementation.⁶² Statute does not require specifically consultation with consumers; however, the current administration includes stakeholders in the consultation process, which includes a 30-day consultation period.

Medical Care Advisory Committee Involvement

To implement a benefit or cost-sharing change through a waiver or SPA, MDCH must amend its program policies. The amendment process requires consultation with Michigan's Medical Care Advisory Committee, which meets quarterly and routinely receives an opportunity to comment on and discuss proposed policies and amendments.⁶³ All policy proposals are forwarded electronically for comment to the MCAC. MDCH noted that, although only the Department can decide to hold a public hearing about a proposed policy, advice from the MCAC may influence its decision. The MCAC takes part in many advocacy and education activities with state legislators.

Advocate's Perspective

The Michigan League for Human Services reported that the governor or the legislature proposes most Medicaid benefit and cost-sharing changes during the appropriations process. At legislative budget hearings, written and oral testimony is accepted from all advocacy groups, consumers, providers, and members of the general public who wish to testify. The League reported that stakeholder input is generally well organized and extensive at the legislative level.

Any waiver or SPA filing with CMS that results in a change to program policy triggers a 30-day public consultation period. Although MCL 400.111a only requires MDCH to consult with the MCAC and providers during this consultation period, the League indicated that the current MDCH administration in fact consults with all interested stakeholders. Policy proposals are filed on the state's website with a request for public comment. The MCAC receives copies of all draft policy changes by e-mail, including advance copies of proposed waivers. Public comments received, and the state's responses to them, are posted on the website. In some instances, MDCH has been willing to modify a policy proposal in response to public comments.

The League reported that stakeholders have the opportunity to provide input on proposed waivers or SPAs through issue papers, letters, face-to-face meetings with MDCH staff, legislative meetings, and public hearings. For example, the governor's office and MDCH staff are holding stakeholder meetings for the proposed Michigan First Healthcare Plan across the state, before formally submitting the waiver to CMS. The League noted that it

has found the current Medicaid director willing to sit down personally with any stakeholder and listen to his or her concerns, and reported that it has seen great acceptance of public comment and input under the current administration. The League characterized MDCH as willing to work collaboratively with providers, advocates, and consumers to develop and implement waivers and SPAs. The League also reported that Michigan's advocacy organizations have often joined forces on common policy agendas, sharing resources and forming coalitions to better leverage and coordinate efforts to greater effect.

The League recommended that the federal government require detailed documentation of the public input process as a condition for approving a waiver or SPA. State accountability for public input should be encouraged from leadership at the federal level.

NEVADA

Policy Reform Development and Implementation

The Division of Health Care Financing and Policy (HCFP) in the Nevada Department of Health and Human Services administers Nevada's Medicaid program. Like Michigan, Nevada is a state in which many provisions of the Medicaid program are outlined in the Nevada Medicaid Services Manuals, rather than in statute or rule. The Services Manuals are based on Nevada's Medicaid State Plan, but they provide much more detail. Only in cases where the state legislature has decided to act affirmatively on an issue will a benefit or cost-sharing policy be listed in statute. For example, the legislature established Nevada's preferred drug list guidelines by statute.

Legislative Oversight

Nevada law does not require legislative oversight or approval of Section 1115 waivers or SPAs. At times, the legislature may become involved in policy development for both waivers and SPAs by sending HCFP a "Letter of Direction," which outlines specific policies the legislature would like HCFP to pursue. HCFP noted, however, that there is no mandate that HCFP pursue a potential policy set forth in a Letter of Direction, especially in cases where the requisite appropriation is not attached.

In the past, the legislature has authorized or mandated HCFP to apply for specific waivers, including a Section 1115 HIFA waiver⁶⁴ and a home and community-based services waiver⁶⁵ for disabled persons. HCFP reported that it is authorized to pursue waivers without such direction and has initiated waivers on its own in the past. The legislature has mandated HCFP to apply for particular SPAs, such as the Medicaid hospice benefit, but, like waivers, HCFP also has the authority to initiate SPAs on its own.

HCFP reported that, on an informal basis and depending on the nature of a waiver or SPA, the department will consult with the legislature, particularly fiscal staff. Legislative authorization is required before implementation if the waiver or SPA will have an impact

on the state budget. Most Medicaid and benefit changes are initiated in the budget process.

Executive Branch Involvement

The governor's office does not usually get involved in the waiver and SPA process. Depending on the policy involved, however, HCFP may consult that office informally.

Opportunities for Public Input

Nevada statutes do not specifically protect advocate involvement in the waiver and SPA process. However, HCFP reported that there are opportunities for public input in the policy-making process in general because all benefit and cost-sharing changes must go through the Services Manuals amendment process before implementation. HCFP must amend the Services Manuals pursuant to a process identified in state statute.⁶⁶ This process requires HCFP to give a 30-day notice of intended action, offer an opportunity to comment orally or in writing on the proposed amendment to the Services Manuals, and fully consider all comments received.⁶⁷ HCFP noted that the process typically includes holding a public hearing, after which HCFP will either adopt the proposed amendment to the Services Manuals or agree to modify the proposed amendment. If a revision is proposed, a second notice and public hearing could occur. The process for amending the Services Manuals falls outside Nevada's Administrative Procedures Act and lacks a specific legislative oversight requirement.

HCFP reported that its general practice is to initiate the Services Manual amendment process before submitting a waiver or SPA to CMS, giving advocates an opportunity to provide input early in the policy development process. In addition, HCFP noted that it has adopted the practice of holding public workshops, in advance of the formal process for amending the Services Manual or filing a waiver or SPA for federal approval, if HCFP believes the proposed amendment to the Manuals will have a material impact on the Medicaid program. HCFP stated that it believes these public workshops, which can be held throughout the state, provide stakeholders with an effective opportunity to influence policy in the initial development stage, as opposed to after the fact. HCFP reports that it publishes information regarding Medicaid program changes online.

On the other hand, HCFP reported that it is not likely to hold public hearings before filing a waiver or SPA if such activity has already occurred in the legislature. For example, the public input obtained before submitting the HIFA waiver currently pending before CMS occurred in the legislature. The concept behind this waiver was first developed in a legislative committee, and public testimony was taken at the legislative level over a one-year period. As a result, the state attorney general determined that HCFP was not required to solicit any additional public input before submitting the actual waiver documents to CMS.

HCFP noted that an additional check on the department's authority occurs during the legislative appropriations process, if the policy change has an impact on the state budget. The appropriations process provides the opportunity for stakeholders to testify before legislative committees and otherwise provide input to legislative decision makers.

Medical Care Advisory Committee Involvement

HCFP reported that Nevada's Medical Care Advisory Committee does not play a significant role in Medicaid policy making. Due to scheduling issues, HCFP has considerable difficulty scheduling a quorum in time to review pending policies, SPAs, and waivers.

Advocate's Perspective

The Statewide Advocacy Coordinator (SAC)⁶⁸ agreed that most of Nevada's Medicaid benefit provisions are contained in the Nevada Medicaid Services Manuals, and few Nevada statutes specifically relate to benefit and cost-sharing provisions. Nevada law does establish a process for amending the Nevada Medicaid Services Manuals, however; amendments require public notice and hearings. SAC reported that HCFP also holds initial public workshops to develop proposed amendments to service delivery and may hold informal meetings with advocates. There is a 30-day notice on public workshops. Public notice of any proposed program policy is posted on the state's website.

SAC reported that advocacy groups meet with HCFP regularly to discuss any proposed Medicaid changes, with meaningful opportunities to participate in the process. However, SAC believes that the general public's participation is lacking, outside of providers, and would like to see more consumer and advocate willingness to be involved.

SAC reported that the concept and funding behind waivers and SPAs generally comes from the legislature or executive, and that public input on waivers and SPAs occurs in the legislature. SAC described a recent waiver reform process that began with the creation of an Interim Committee on Health in the Legislature. This committee held hearings on Nevada's proposed HIFA 1115 waiver, and an outside consultant was engaged and a lay task force established to debate and discuss different expansion ideas. The committee recommended a bill draft, which passed the House and Senate, and then HCFP worked on details.

SAC described the current process for public input into Nevada Medicaid as quite adequate. However, it noted that once a waiver concept has been approved, many details involved in negotiating the waiver with CMS are outside of the public eye. SAC recommended that the federal approval process should require all states to hold a public hearing after a 30-day notice for waivers and SPAs, and that if terms of the waiver or SPA are changed during federal/state negotiations, an additional public input process should be required. While generally satisfied with the current opportunities for public input in Nevada, SAC noted that advocacy groups could definitely benefit from a state

statute requiring either a public input process conducted by the Medicaid agency or legislative approval (with its associated public input) for SPAs.

TEXAS

Policy Reform Development and Implementation

The Texas Health and Human Services Commission (HHSC) administers the Texas Medicaid program. Texas statutes generally outline categories of Medicaid-covered services and authorize cost sharing. Texas also has a comprehensive set of administrative rules providing further governance over the Medicaid program. HHSC indicated that it must generally pursue a rule change before implementing a waiver or SPA that affects benefits or cost sharing.

Legislative Oversight

Texas law requires HHSC to notify the legislature before submitting a waiver or SPA to the federal government.⁶⁹ This notice includes a brief synopsis of the waiver or SPA policy as well as a copy of the actual waiver proposal or SPA. The notice goes to various committees, including the budget board, but their review or approval is not required before HHSC may proceed with the filing.

HHSC reported that the legislature is routinely involved in the early stages of the waiver development process in Texas. The legislature may also provide direction or approval in the SPA process, because most benefit and cost-sharing changes have budgetary implications and are initiated in the budget process. As described by HHSC, the legislature's involvement is directed at the policy level; HHSC normally has the discretion to determine whether the best way to pursue a benefit or cost-sharing change is through a waiver, a SPA, or both. If HHSC decides it must pursue a waiver to implement the legislatively directed policy, HHSC would generally consult with the legislature informally during its preparation for federal filing.

Executive Branch Involvement

By law, the governor's office must be notified before any waiver or SPA is sent to CMS.⁷⁰ This notification will consist of a brief synopsis of the waiver or SPA policy and will include a copy of the actual waiver proposal or SPA. It is not necessary for HHSC to obtain the governor's approval before proceeding. However, HHSC reported that, like the legislature, the governor's office is informally involved in preparing waiver proposals, providing direction and input on how HHSC should proceed.

Opportunities for Public Input

State law requires HHSC to provide public notice in the *Texas Register* before filing for a Medicaid waiver and to respond to any requests for information that result from the

notice.⁷¹ HHSC indicated that it takes all comments received regarding waiver design into consideration, but does not formally respond to each comment. HHSC noted that it also often consults with advisory committees in developing waiver policy. Public input can also occur during any formal legislative consideration of a Medicaid policy change, through testimony before legislative committees.

State law also requires HHSC to publish a public notice in the *Texas Register* after receiving an approved SPA.⁷² HHSC reported that, while it is not required to do so, it files public notice in the *Texas Register* before submitting the SPA to CMS. Again, HHSC reported that it considers all comments received, but does not formally respond to all of them. If the legislature directs a policy change regarding benefits or cost sharing in Medicaid that requires a SPA, public testimony can be offered before legislative committees.

Before any change in Medicaid benefits or cost sharing can be implemented, whether approved federally under a waiver or a SPA, HHSC must promulgate administrative rules. For SPAs, HHSC reported that it most often initiates rule promulgation at the state level before submitting the SPA for federal approval. HHSC indicated that the rule promulgation process requires it to publish proposed rules in the *Texas Register* and to hold a public hearing where stakeholders can offer testimony. HHSC noted that it also accepts e-mail communications regarding rules and will meet with advocates individually. At times, HHSC may involve stakeholders in developing the proposed rules.

If HHSC expects that a proposed SPA might meet with a challenge from CMS, HHSC may choose to file the SPA for federal approval before beginning the rule promulgation process.

Medical Care Advisory Committee

The Texas MCAC meets every other month, but it does not play a significant role in reviewing SPAs or waivers during development. However, all rules must go before the MCAC for review and recommendation, which means that it will review waiver or SPA policy before implementation. This occurs before notice of the proposed rule is published in the *Texas Register*.

Advocate's Perspective

Respondents from the Center for Public Policy Priorities agreed that the state statutes and rules govern the Texas regulatory framework for services, benefits, and cost sharing. However, the Center suggested that the statutes and rules are poorly constructed, with no consistency in which policies are provided in statute and which are provided in rule. For example, some rules are specific, while others give more administrative flexibility to HHSC. Also, there seems to be no consistency regarding what type of policy triggers the rulemaking process. Respondents from the Center suggested that this is largely a subjective decision on the part of HHSC, so HHSC's leadership has a strong impact. The

Center did indicate, however, that controversial changes to the Medicaid program will go through the -making process.

The Center viewed the current processes for public input into waiver and SPA policy development as inadequate for advocacy organizations and consumers, especially at the legislative level. The Center described legislative hearings as offering minimal opportunities for meaningful testimony; legislative hearings are held at a single location, and each advocate's testimony is limited to three minutes. In addition, proposed changes to Medicaid policy can be buried in a 300-page bill, sometimes making it difficult for stakeholders even to be aware of proposals or to track last-minute changes.

According to the Center, the public input process HHSC engages in with waiver policy development is highly variable and differs from waiver to waiver. The Center noted that it does not often see changes made as a result of public input received. However, the Center believed that the public input process surrounding a recent family planning waiver has been well received. HHSC has involved stakeholders in a continuous process and holds meetings to which stakeholders can call in.

The Center did not believe that the statute requiring public notice of waivers and SPAs to be filed in the *Texas Register* ensured that stakeholders will have sufficient time for meaningful input to HHSC before filing for federal approval. The Center agreed that SPA notices are generally published in the *Texas Register* before submission to CMS for approval; however, respondents believed the notice is filed *after* the Department has already committed itself to the particular policy. The Center also noted that announcements or notices for proposed program changes, waivers, or SPAs are not posted on the HHSC website. The Center clearly articulated that advocates want to be more involved in policy development in Texas, with opportunities for input before HHSC is committed to a particular policy. In addition, the Center expressed its concern that some policy making may occur between the state and its contractors (HMOs) without any public involvement.

The Center noted that, before a major reorganization of the state health and human services agencies in 2003, the Texas Medicaid program operated with an agency rule-making board that had authority to approve program rules. With the reorganization, all health and human services rule-making authority was consolidated with the Texas Secretary for Health and Human Services. Individual agency rule-making boards are now advisory only, and the Secretary can choose to accept or ignore the boards' recommendations. In addition, although the Medical Care Advisory Committee must review all rules, if HHSC is in a hurry, it may ask its rule-making board to review the rules first, lessening the impact of the MCAC in providing meaningful input.

The Center recommended that the public input process in Texas should have more consistency and a higher public profile. Specific recommendations included: 1) notice of public hearings should be posted on the web in a timely fashion; 2) HHSC should use listserv alerts; 3) public hearings should be held in more than one location; and 4) public hearings should involve state officials who have actual decision making authority.

Because the legislature only meets every other year, respondents from the Center did not believe that legislative approval of all waivers and SPA filings would be an effective alternative for public input.

Advocates from the Center recommended that the federal government establish a “floor” for meaningful public policy input, with an appropriate balance between state flexibility and “real” opportunities for advocate and consumer recommendations. In addition, advocates from the Center felt that the federal government should require the state to share information regarding the nature of the public process, responses, and outcomes before receiving federal approval for waivers and SPAs. The Center also recommended that the federal government require stakeholder participation in any state negotiations between the state Medicaid agency and CMS on a proposed waiver or SPA regarding program benefit or cost-sharing changes.

APPENDIX B: STATE MEDICAID DIRECTOR INTERVIEW PROTOCOL*

**The following general interview protocol was adapted to apply to each state interviewed, based on the state's statutory and regulatory scheme.*

AARP SPA Public Input Project Discussion Guide

The Deficit Reduction Act of 2005 (DRA) redefines the process in which states may make changes to their Medicaid programs. Prior to the DRA, states had to seek Section 1115 demonstration waivers if they wished to modify a benefit package or implement cost sharing. Now states have the opportunity to make these changes using the less onerous State Plan Amendment (SPA) process.

Federal process does not specify the same requirements regarding public involvement in SPAs that it does for Section 1115 waivers. Therefore, the purpose of this Discussion Guide is to explore the public input opportunities and requirements available under *state* law with respect to the SPA process.

I. Contact Information

a. Name of Medicaid Director:

- i. Phone Number:
- ii. Address:
- iii. How long have you been working with your state's Medicaid program?

b. Name of Legal Counsel:

- i. Title:
- ii. Phone Number:
- iii. Address:
- iv. How long have you been working with your state's Medicaid program?

II. Background

- a. Is your Medicaid program currently operating under any Section 1115 demonstration waivers?

If the answer is yes:

- i. How many?
 - ii. What populations do they cover?
 - iii. Do they affect benefit design or cost sharing for specific populations?
- b. Has the SPA process been used to implement benefit or cost-sharing changes in your Medicaid program in the last five years? If the answer is yes, please describe what changes were made and when:
- c. Have you already filed, or are you contemplating filing, a SPA to make benefit or cost-sharing changes under the DRA? If the answer is yes, please describe:
- d. In many states, Medicaid benefits and cost sharing are specifically enumerated by statute, rule, or both. The following questions relate to your state's regulatory framework for benefits and cost sharing:

- i. What kinds of benefit and cost-sharing provisions are set forth in statute?

For Legal Counsel: If possible, could you please provide the citation to these statutes?

- ii. What kinds of benefit and cost-sharing provisions are set forth in rules?

Benefits/Covered Services:

Cost Sharing:

For Legal Counsel: If possible, could you please provide the citation to these regulations?

Benefits/Covered Services:

Cost Sharing:

- iii. When, if ever, can benefit or cost-sharing changes be made to the Medicaid program without a corresponding change in statute or rule?
- iv. When benefit or cost-sharing changes are made, do these changes typically occur as part of the budget process or outside the budget process?

III. Pre-Filing Process: Waivers and SPAs

The following questions relate to the processes involved in *applying* for a Section 1115 waiver or SPA, including the source and scope of the Department’s authority to initiate the application; they do not relate to the Department’s ability to implement programmatic changes after CMS approves the waiver or SPA. We ask you how changes are implemented under an approved waiver or SPA in the following section.

We understand that the processes involved in applying for Section 1115 waivers and SPAs may vary, depending on the kind of changes being made. For the purposes of this interview, we are only interested in the public input process involved in waivers and SPAs as they affect benefits and cost sharing.

- a. What is the source and scope of the Department’s authority to develop and file a Section 1115 waiver? Is specific direction from the legislature or administration required, or is the application process within the Department’s complete discretion?

Is a legislative mandate always required?

What role does the governor’s office play?

- i. Does the legislature or administration review or approve the waiver application before it is submitted to CMS?
- ii. Is there a statute or rule that sets forth any of the requirements you have just described, or is this a “voluntary” process that the Department follows?

For Legal Counsel: If there is a statute or rule, what is the citation?

- iii. Please describe the public input process for Section 1115 waivers, including any provisions for notice and/or formal hearings before the waiver is submitted to CMS:
 1. As an example, please walk me through the public input process involved in the most recent Section 1115 waiver submitted to CMS (if there is one):
 2. In your view, is this public input process meaningful?

[Note to Interviewer: Please probe into the interviewees’ definition of “meaningful.”]
 3. Are the public input processes just described formally required by a statute or rule?

For Legal Counsel: If there is a statute or rule, what is the citation?

- b. Is the fundamental process for developing and filing SPAs different from the Section 1115 waiver process? If it is, please answer the following questions, remembering to answer them only as they relate to the developing and filing of SPAs that affect benefits or cost sharing:

- i. What is the source of the Department's authority to apply for SPAs? Is specific direction from the legislature or administration required, or is the application process within the Department's complete discretion?

Do you think such direction from the legislature is necessary to change benefits or implement cost sharing through the SPA process?

What role does the governor's office play?

- ii. Does the legislature or administration review or approve the SPA application before it is submitted to CMS?
- iii. Is there a statute or rule that sets forth any of the requirements you have just described, or is this a "voluntary" process that the Department follows?

For Legal Counsel: If there is a statute or rule, what is the citation?

- iv. Please describe the public input process for SPAs, including any provisions for notice and/or formal hearings before the SPA is submitted to CMS:
1. As an example, please walk me through the public input process involved in a recent amendment to your State Plan:
 2. In your view, is this public input process meaningful?
 3. Are the public input processes just described formally required by a statute or rule?

For Legal Counsel: If there is a statute or rule, what is the citation?

- v. In general, please specify any significant differences in the Department's ability to initiate the Section 1115 waiver application

process compared to the SPA application process. Does the Department have more or less discretion to apply for SPAs than for Section 1115 waivers?

IV. Post-Approval Implementation Process: Waivers and SPAs

The following questions relate to the process involved in *implementing* a Section 1115 waiver or SPA after CMS has approved it. Because this process may differ based on the nature of the change involved, please describe only those processes involved in implementing a waiver or SPA that affect benefits and cost sharing.

- a. Do you believe that the Department must generally pursue a statutory or regulatory change (or both) to implement a waiver or SPA approved by CMS if the waiver or SPA:

1. Takes benefits away (statutory or regulatory change or both)?
2. Adds benefits (statutory or regulatory change or both)?

For Legal Counsel: If the answer to either of these questions is yes, is there a specific statute or rule that would need to be changed, or does it depend on the benefit?

3. Establishes or alters premiums (statutory or regulatory change or both)?

For Legal Counsel: If the answer is yes, is there a specific citation to the statute or rule that would need to be changed?

4. Establishes or alters co-insurance amounts (statutory or regulatory change or both)?

For Legal Counsel: If the answer is yes, is there a specific citation to the statute or rule that would need to be changed?

5. Establishes or alters co-payment amounts (statutory or regulatory change or both)?

For Legal Counsel: If the answer is yes, is there a specific citation to the statute or rule that would need to be changed?

- ii. If the answer to any of these questions is yes, do you believe you would start the legislative or rule-making process before or after obtaining approval from CMS?
- b. In your opinion, does your legislative process or your rule-making process provide meaningful opportunity for public input? Please explain:
 - i. Does the meaningfulness of your public input process in the legislature vary depending on whether it takes place within the budget process or outside it?
- c. Are there any cost-sharing or benefit provisions set forth in a Medicaid manual or other guidance that would not involve a public process and/or legislative approval to change?
 - i. For Legal Counsel: Where are these provisions located (e.g., manual, guidance, etc.)?
 - ii. Do you believe the Department could alter these provisions without a formal public process and/or legislative or other approval if changes were pursued under either a waiver or SPA?
- d. For Legal Counsel: Please summarize the *major* provisions regarding notice and opportunity for public hearing set forth in your Administrative Procedures Act:
 - i. Is the legislature required to have notice of, or approve, rules promulgated under the Administrative Procedures Act?
 - ii. What is the citation of your Administrative Procedures Act?
 - iii. What role does the following statute play in rule making for CHIP?

V. Additional Information

- a. Do you believe the SPA provisions of the DRA provide you with a strategic advantage in making benefit or cost-sharing changes in your Medicaid program (compared to the Section 1115 waiver process)?
- b. Assuming, in the future, that the Department intends to apply for a SPA under the DRA that will significantly affect benefits or cost sharing, do you expect that the Department will use its “standard” SPA filing and implementation process (as described above), or do you anticipate that you would engage in a different process? In either case, when will stakeholders first have meaningful opportunity for public input? Before the SPA is

submitted to CMS? After it is submitted to CMS? After it is approved?
Never?

[Note to Interviewer: Please probe into the interviewees' definition of
"meaningful."]

- i. When will stakeholders first receive notice that a SPA affecting benefits and/or cost sharing will be (or has been) submitted to CMS?
 - ii. For Legal Counsel: Is this process set forth in a statute or regulation? If the answer is yes, please specify:
 - iii. Do you believe the Department's decision to solicit public input regarding a SPA will depend on whether you are adding benefits or taking them away?
- c. In your view, what are the major similarities and/or differences involved in the public input process for Section 1115 waivers versus SPAs?
 - i. For Legal Counsel: Do any relevant statutes or regulations support this answer?
- d. In your view, have certain stakeholder groups and other advocates lost an opportunity to provide meaningful input regarding benefit or cost-sharing changes under the DRA?
- e. What role does your Medical Care Advisory Committee play in the Section 1115 waiver process? The SPA process?
 - i. For example, does your Medical Care Advisory Committee routinely review or hold public hearings in relation to waivers and/or SPAs?
 - ii. Does the review or public hearing typically occur before or after the waiver or SPA is filed with CMS?
 - iii. For Legal Counsel: If the Medical Advisory Committee process is set forth in statute or regulation, please provide the citation:
- f. For Medicaid Director Only: In your opinion, what are the most effective ways that stakeholders and other advocates can influence the Section 1115 waiver or SPA process (e.g., issue papers, face-to-face meetings, legislative relations, through the rule promulgation process)?
- g. Any additional comments?

APPENDIX C: STATE ADVOCATE INTERVIEW PROTOCOL*

**The following general interview protocol was adapted to apply to each state interviewed, based on Heath Management Associate's interview with the state Medicaid director and the state's statutory and regulatory scheme.*

AARP SPA Public Policy Institute Discussion Guide

The Deficit Reduction Act of 2005 (DRA) redefines the process by which states may make changes to their Medicaid programs. Before the DRA, states had to seek Section 1115 demonstration waivers if they wished to modify a benefit package or implement cost sharing. Now states may make these changes using the less onerous State Plan Amendment (SPA) process.

Federal process does not specify the same requirements regarding public involvement in SPAs that it does for Section 1115 waivers. Therefore, the purpose of this Discussion Guide is to explore the public input opportunities and requirements available under *state* law with respect to the SPA process.

I. Contact Information

- a. Name of Interviewee:
- b. Phone Number:
- c. Address:
- d. How long have you been working on Medicaid issues in your state?

II. Background

1. In many states, statute, rule, or both specifically enumerates Medicaid benefits and cost sharing. The following questions relate to your state's regulatory framework for benefits and cost sharing:
 - a. Are benefit provisions set forth in regulation and/or statute?
 - b. Can you please summarize the major components of your state's rule-making process?
2. Does the Department use policy manuals in administering the Medicaid program?
 - a. Do the policy manuals contain substantive benefit or cost-sharing provisions not otherwise provided in statute or rule?
 - b. Please describe the process use to amend the policy manuals:

- c. What kind of amendments to the policy manuals, if any, have to go through your state's rule-making process?
3. What kind of information, notices, etc., regarding program changes is posted on the Department's website?

III. Pre-Filing Process: Waivers and SPAs

The following questions relate to the processes involved in *applying* for a Section 1115 waiver or SPA, including the source and scope of the Department's authority to initiate the application; they do not relate to the Department's ability to implement programmatic changes after CMS approves the waiver or SPA. We ask you how changes are implemented under an approved waiver or SPA in the following section.

We understand that the processes involved in applying for Section 1115 waivers and SPAs may vary, depending on the kind of changes being made. For the purposes of this interview, we are only interested in the public input process involved in waivers and SPAs as they affect benefits and cost sharing.

1. Is specific direction from the legislature or the governor's office required to file Section 1115 waivers or SPAs?

Waiver:

SPA:

2. Does the legislature or governor's office review or approve the waiver or SPA application before it is submitted to CMS?

Waiver:

SPA:

3. Please walk me through the public input process involved in developing one of the Section 1115 waivers recently submitted to CMS:

- a. Is the Department required to publish notice and share waiver proposals with the legislature? If the answer is yes, how well does the Department comply with this requirement?

- b. Do advocates have a meaningful opportunity to provide input?

4. Please walk me through the public input process involved in a recent amendment to your State Plan:

- a. In your view, was this public input process meaningful?
 - b. Is there a statute that requires notice or legislative review of SPAs?
5. Does the Department have more or less discretion at the state level to apply for SPAs than for Section 1115 waivers?
- a. Are there more opportunities for public input in the waiver process than there are in the SPA process?

IV. Post-Approval Implementation Process: Waivers and SPAs

The following questions relate to the process involved in *implementing* a Section 1115 waiver or SPA after CMS has approved it. Because this process may differ based on the nature of the change involved, please describe only those processes involved in implementing a waiver or SPA that affects benefits and cost sharing.

1. Do you believe that the Department must generally pursue a statutory or regulatory change (or both) to implement an approved waiver or SPA if the waiver or SPA affects benefits or cost sharing?
 - a. If the answer is yes, does the Department typically initiate the statute or rule-making process before or after obtaining CMS approval of the waiver or SPA?
2. Is it your impression that most Medicaid benefit and cost-sharing changes are initiated during the appropriations process?
3. In your opinion, is more meaningful opportunity for public input provided in your legislative process or your rule-making process? Please explain:
 - a. Does the meaningfulness of your public input process in the legislature vary depending on whether it takes place within the budget process or outside it?
4. In general, what role does the legislature play in the waiver and SPA process in your state? Does it merely authorize changes initiated by the Department during the budget process? Or does it often direct program changes by passing substantive policy legislation?

V. Additional Information

1. Are you generally satisfied with the opportunities for public input by advocacy groups like yours in the development of waivers and SPAs, especially when a benefit is being taken away or additional cost sharing is being imposed?

2. Assume, in the future, that the Department applies for a SPA under the DRA that will significantly affect benefits or cost sharing. Do you expect that the Department will use its “standard” SPA filing and implementation process (as described above), or do you anticipate that it would engage in a different process? In either case, when will stakeholders first have meaningful opportunity for public input? Before the SPA is submitted to CMS? After it is submitted to CMS? After it is approved?
 - a. When do you think stakeholders will first receive notice of a SPA under the DRA?
 - b. Do you believe the Department’s decision to solicit public input in regard to a SPA under the DRA will depend on whether it is adding benefits or taking them away?
 - c. Do you believe advocacy groups like yours would benefit from a state statute requiring public input into, or legislative approval of, SPAs?
 - d. Can you think of any other ways to improve the public input process associated with SPAs?
3. In your view, have certain stakeholder groups and other advocates lost an opportunity to provide meaningful input regarding benefit or cost-sharing changes under the DRA?
4. What role does the Medical Advisory Committee play in the waiver and SPA processes?
5. In your opinion, what are the most effective ways stakeholders and other advocates can affect the Section 1115 waiver or SPA process (e.g., issue papers, face-to-face meetings, legislative relations, through the rule promulgation process)?
6. Any additional comments?

VI. Follow-Up Questions:

1. Have you experienced barriers to using the state’s processes effectively for public input?
2. If so, can you identify them?
3. What specific recommendations do you have for overcoming the barriers or improving the process?

4. What if any role do you see the federal government playing in ensuring an effective process for public input into the waiver/SPA process?

APPENDIX D: RESPONSES FROM REPRESENTATIVES FROM AARP STATE OFFICES

AARP state offices in the eight study states were given an opportunity to comment on study findings; four of them—Connecticut, Florida, Indiana, and Nevada—responded. Representatives from the responding state offices generally agreed with the advocate’s perspective in their respective state.*

The representative from the Connecticut state office described the state as having a history of no process for the public to have input into the waiver development process. This lack of openness led the legislature to enact a law requiring DSS to publish a notice in the *Connecticut Law Journal* whenever it intends to seek a federal waiver. The law further requires that the commissioner of DSS allow 15 days for written comments on the application before submitting it to legislative committees for review and to include the comments with the submitted waiver application.

The respondent from the AARP state office in Florida expressed frustration that opportunities for the public to comment on Medicaid policy often come after major policy changes are already decided. One example is during the legislative process. According to the Florida respondent, although advocates can testify during legislative hearings, “often by this point major decisions have been made.” The respondent generally agreed with comments made by Florida Legal Services.

The AARP respondent from Indiana commented that the Indiana case study is accurate in observing that Indiana has an unusually high degree of legislative review of changes to Medicaid policy and agreed that the legislative process offers the best opportunity for advocacy organizations to voice opinions about Medicaid policy. The respondent felt that legislative committees take the concerns of advocates seriously, while their concerns are often ignored by the administration. According to the respondent, “the administration usually offers some sort of forum for public input outside of the legislative process, but it is far from clear that the concerns voiced in these are incorporated in Medicaid waiver and SPA applications.”

The AARP Nevada respondent agreed with SAC’s analysis in Nevada and expressed the belief that although public input is solicited, most participation comes from provider groups, and there needs to be a better way to garner consumer input. This respondent felt that additional avenues for gathering public input outside posted government hearings could result in greater consumer involvement. Finally, the respondent from Nevada agreed with study findings that the waiver negotiation process would benefit from additional opportunities for public participation.

APPENDIX E: PUBLIC INPUT BEFORE SUBMITTING WAIVER/SPA TO CMS

California Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓	✓	Legislature typically develops the policies behind waivers and SPAs and provides authorization for DHS to apply for particular waivers. Therefore, significant opportunities for public input occur in the legislative session.	No
✓		The governor's office may be consulted on waiver proposals.	No
✓		DHS provides notice of intent to apply for waivers.	No
✓	✓	If the issue or proposed policy change is contentious, DHS will hold hearings and may also convene stakeholder meetings.	Sometimes—it depends on the specific legislation authorizing or mandating the program change. The particular legislative directive or authorization may require DHS to obtain public input.

Connecticut Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓		DSS must notify joint standing committees of its intention to file a waiver and must submit the waiver application to the committees before filing it with CMS. The committees have 30 days to advise of their approval, disapproval, or modifications.	Yes Sec. 17b-8
✓		The joint standing committees that review waivers often hold public hearings.	No
✓	✓	The governor's office may be consulted on waivers or SPAs, but this is not typical.	No
✓		DSS must publish notice of its intention to seek a waiver, along with a summary of the waiver, in the <i>Connecticut Law Journal</i> . The public has 15 days to submit written comments, and their comments will be provided to the joint standing committees that review the waivers.	Yes Sec. 17b-8

APPENDIX E: PUBLIC INPUT BEFORE SUBMITTING WAIVER/SPA TO CMS, CONT.

Florida Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓	✓	Legislature typically develops the policies behind waivers and SPAs, so the first opportunity for public input is usually in the legislative session.	No
✓		The governor's office is typically consulted on waiver proposals.	No
✓		AHCA required to provide notice to legislature before applying for a waiver. Additional legislative review, opportunity to comment, and approval required for waivers submitted during Medicaid Reform.	Yes S. 409.912(11), Florida Statute Yes S. 409.91211(6), Florida Statute
✓		Twenty-eight--day notice and opportunity for public comment required for waivers. Medicaid Reform waiver application required to be posted on AHCA's website 30 days before being submitted to CMS.	Yes S. 409.912(11), Florida Statute Yes S. 409.91211(6), Florida Statute
✓	✓	Technical advisory panel created to advise the agency in rate setting, benefit design, and choice counseling during Medicaid Reform.	Yes S. 409.91211(6), Florida Statute

Illinois Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓		In some circumstances, the legislature will instruct DHFS to apply for a particular waiver, and public input will occur at the legislative level.	No
✓	✓	Legislature and governor's office typically consulted on waivers and SPAs that have a material effect on program policy.	No
✓		Public given notice and opportunity to comment on waivers.	No (but provided pursuant to federal policy in 59 <i>Fed. Reg.</i> 49249)
	✓	Depending on the potential impact of a proposed SPA, the public will be given notice and an opportunity to provide input.	No

APPENDIX E: PUBLIC INPUT BEFORE SUBMITTING WAIVER/SPA TO CMS, CONT.

Indiana Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓		In some circumstances, the legislature will instruct OMPP to apply for a particular waiver, and public input will occur at the legislative level.	No
✓	✓	Legislature may be consulted on waivers and SPAs that have a material effect on program policy.	No
✓		The Office of Budget and Management (OBM) must review and approve all waivers.	No
✓		Public given notice and opportunity to comment on waivers.	No (but provided pursuant to federal policy in 59 <i>Fed. Reg.</i> 49249)
	✓	Depending on the potential impact of a proposed SPA, the public will be given notice and an opportunity to provide input.	No
✓	✓	Most benefit and cost-sharing changes require amendment to state statute or the administrative rules. OMPP will initiate this process, which includes opportunities for public input, before submitting a waiver or SPA to CMS.	Yes IC 4-22-2 (if administrative rule making is necessary)

Michigan Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓		The legislature commonly provides direction regarding waivers in boilerplate language during the annual appropriations process.	No
✓		Representatives from the governor's office, Department of Management and Budget (DMB), and legislature are typically consulted on waivers and given an opportunity to review.	No
✓		Public given notice and opportunity to comment on waivers.	No (but provided pursuant to federal policy in 59 <i>Fed. Reg.</i> 49249)

APPENDIX E: PUBLIC INPUT BEFORE SUBMITTING WAIVER/SPA TO CMS, CONT.

Nevada Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓	✓	The legislature sometimes sends nonbinding "Letters of Intent" to HCFP, asking it to pursue a particular policy. It also sometimes directs or authorizes HCFP to apply for particular waivers or SPAs.	No
✓	✓	Representatives from the legislature, particularly fiscal staff, and the governor's office may be consulted on certain waivers and SPAs, depending on their impact.	No
✓		Public given notice and opportunity to comment on waivers, but public hearings may occur in the legislature if that is where the waiver was initiated.	No (but provided pursuant to federal policy in 59 <i>Fed. Reg.</i> 49249)
✓	✓	If HCFP believes the proposed policy behind a waiver or SPA will have a material impact on the program, it typically holds public workshops to develop the policy before initiating the Medicaid manual amendment process.	No
✓	✓	Benefit and cost-sharing changes require amending the Medicaid manuals. HCFP must provide notice and an opportunity to comment. It is required to consider all comments.	Yes NRS422.2369

APPENDIX E: PUBLIC INPUT BEFORE SUBMITTING WAIVER/SPA TO CMS, CONT.

Texas Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓	✓	The legislature commonly provides direction regarding waivers and sometimes SPAs.	No
✓	✓	The governor and various legislative committees, including the budget board, must be given notice before a waiver or SPA is submitted to CMS.	Yes Rider 45a to the General Appropriations Act
✓		The governor's office is typically consulted during the waiver process.	No
✓		The public must be given notice of any attempt to obtain a waiver before the waiver proposal is submitted to CMS, and HHSC must respond to all requests for information.	Yes <i>Tex. Hum. Res. Code Ann. s. 32.0231(a)(3).</i>
	✓	The public must be given notice of any SPA, and although the statute does not require it, HHSC provides notice before submitting the SPA to CMS.	Yes <i>Tex. Hum. Res. Code Ann. s. 32.0231(a)(3).</i>
✓		Advisory committees participate in the waiver process.	No
	✓	Texas's rules reflect the State Plan, so all SPAs must go through the rule-making process. This process includes notice and public hearings.	Yes Chapter 2001, Title 10 of the Government Code

APPENDIX F: PUBLIC INPUT DURING POLICY IMPLEMENTATION

California Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓	✓	Benefit and cost-sharing changes may require implementation through California’s rule-making process. Typically, however, the legislature grants DHS an exemption from having to go through rule making and allows DHS to issue All County Welfare Director Letters or provider bulletins instead. Formal rule making may be required by a future date, but is not always required.	Depends on the specific program change and authorizing legislation.
✓	✓	In cases where the formal rule-making process is used, 45-day notice and a public hearing or comment period is required. If the proposal is complex, public discussions about the proposed regulation must be held before publishing notice. The Office of Administrative Law reviews the rule-making process before rule adoption and reports to the legislature.	Yes <i>Cal. Gov. Code</i> Sections 11340 to 11348.

Connecticut Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓	✓	Some benefit changes may require amending the Medical Services Policy under the Uniform Procedures Act, which includes review of proposed rules by the attorney general and legislative committees, public hearings, fiscal analysis, and other processes.	Yes Uniform Procedures Act
✓	✓	Because rule making is burdensome, DSS sometimes looks to the legislature to make changes in an “implementation bill” during the appropriations process. Public hearings in the legislature will take place.	Depends on “implementation bill”

APPENDIX F: PUBLIC INPUT DURING POLICY IMPLEMENTATION, CONT.

Florida Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓	✓	Most benefit and cost-sharing changes require amendment to the Medicaid manuals, which are incorporated into Florida's administrative code by reference. This requires notice of rule development. Affected persons may request a public workshop. After a rule is developed, notice of proposed rule and an opportunity for public input is required. Affected persons may request a public hearing.	Yes S. 120.54, Florida Statute
✓	✓	Administrative Procedures Committee is given notice and opportunity to comment on all rules.	Yes S.120.54(3)(a)(4), Florida Statute

Illinois Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓	✓	Most benefit and cost-sharing changes require amendment to the administrative rules. ⁷³ This requires notice of proposed rule and opportunity to comment. Affected persons may request a public hearing.	Yes 5 ILCS 100/5-40(b)
✓	✓	Joint Committee on Administrative Rules is provided notice and opportunity to object or comment on all rules.	Yes 5 ILCS 100/5-40(c)
✓	✓	If a waiver or SPA increases cost-sharing above current limits, a change in statute will be required. This process will include public input at the legislative level.	Yes 305 ILCS 5/5-4.1

Indiana Waiver and SPA Process			
Additional opportunities for public input occur after CMS has approved the waiver or SPA are limited.			

APPENDIX F: PUBLIC INPUT DURING POLICY IMPLEMENTATION, CONT.

Michigan Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓	✓	The legislature provides authorization during the appropriations process for waivers and SPAs that affect benefits or cost sharing.	No
✓	✓	Benefit and cost-sharing changes require amending Medicaid program policy. Affected providers and the Medical Care Advisory Committee must be given notice and an opportunity to comment. MDCH must respond to all comments received and publish the final policy with 30-day advance notice.	Yes <i>MCL 400.111a</i>
✓	✓	The Joint Committee on Administrative Rules must be given notice and opportunity to review all proposed program policies.	Yes <i>MCL 400.111a</i>

Nevada Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓	✓	The legislature provides authorization during the appropriations process for waivers and SPAs that affect benefits or cost sharing.	No

Texas Waiver and SPA Process			
Waiver	SPA	Opportunity for Public Input	Required by State Statute or Rule?
✓	✓	Some waivers and SPAs that add or eliminate a new service or provider type may require statutory change.	Yes Tex. Hum. Res. Code Ann. s. 32.024.

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Nevada—Legal Services Statewide Advocacy Coordinator

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Texas—Center for Public Policy Priorities

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ENDNOTES

¹ Miller, V., and Schneider, A. (2004, September). *The Medicaid matching formula: Policy considerations and options for modification*. Washington, DC: AARP.

² National Association of State Budget Officers. (2002). *NASBO analysis: Medicaid to stress state budgets severely into fiscal 2003*. Washington, DC: NASBO.

³ National Association of State Budget Officers. (2006). *The Fiscal Survey of States*. Washington, DC: NASBO.

⁴ The Deficit Reduction Act (DRA) of 2005 allows state Medicaid programs to deviate from current federal Medicaid requirements and alter their existing package of services for some groups of people, replacing the current federal benefit requirements with new “benchmark” standards of coverage (the Federal Employees Health Benefits Program, the state’s own state employees health benefits plan, the HMO with the largest non-Medicaid enrollment in the state, the actuarial equivalent of any of these plans, or Secretary-approved coverage). Some services can be less than actuarially equivalent to the benchmark plans: mental health, hearing, vision, and pharmacy. The DRA also allows states to impose enforceable cost-sharing provisions for certain populations (e.g., providers can refuse to deliver the service if the cost sharing is not paid), to allow co-payment amounts to inflate over time and to establish higher cost sharing for certain drugs and other services; *see* The Deficit Reduction Act of 2005, Public Law No 109-171.

⁵ When a state wants to modify its Medicaid program by making changes to its Medicaid State Plan, the state must file a State Plan Amendment (SPA) with CMS. CMS review is largely procedural—the SPA contains boilerplate language, and CMS checks to make sure that it meets the statutory and regulatory requirements for Medicaid. A decision is typically rendered within 90 days (as required by federal law).

In contrast, Section 1115 waivers are used to make program changes by obtaining a federal government waiver of certain provisions of the Medicaid and SCHIP statutes. It is not surprising that, federal review of waivers is a much more involved process. The waiver proposal is reviewed by CMS, HHS’s Office of the Assistant Secretary for Resources and Technology (ASRT) and Office of the Assistant Secretary for Planning and Evaluation’s (ASPE) Office of Health Policy, the Health Resources and Services Administration (HRSA), Office of Management and Budget (OMB), and the submitting state’s corresponding regional CMS office. The substance of the proposal is reviewed to ensure it does not violate federal law, and the budget is reviewed to ensure budget neutrality over the course of five years. At various points in the process, the state has the opportunity to make revisions based on reviewers’ comments. When a recommendation is finalized, CMS forwards it to the Secretary for approval or disapproval. This whole process can take up to a year or more, and approval of a Section 1115 waiver proposal is within the Secretary’s complete discretion.

⁶ Researchers sought to interview a range of advocacy groups and deliberately sought a group in each state that was actively engaged with state Medicaid policy on a frequent and ongoing basis. We wanted groups that were sophisticated in their understanding of the state’s policymaking processes.

California: Protection & Advocacy, Inc. is a statewide group focused on advancing public policy for people with disabilities. Connecticut: Connecticut Voices for Children is a child advocacy group that includes health care policy as one focus. Florida: Florida Legal Services, Inc., advocates and litigates for Medicaid consumer rights. Illinois: Sargent Shriver National Center on Poverty Law, dedicated to ending poverty through policy development and other avenues, focuses on health care and is active in the state regarding state Medicaid policy development. Indiana: Indiana Primary Health Care Association represents Indiana’s federally qualified health centers (public and not-for-profit clinics). Michigan: Michigan League for Human Services is a statewide citizen advocacy organization that includes a focus on health care for low-income and vulnerable populations. Nevada: Legal Services Statewide Advocacy Coordinator represents the legal services organization in Nevada, advocating and litigating on behalf of Medicaid consumer rights. Texas:

Center for Public Policy Priorities is a nonpartisan research organization focused on improving public policy to support low- and moderate-income populations; it is active in Texas in Medicaid policy development.

⁷ Medicaid law and regulation are generally set forth in Title XIX of the Social Security Act and Title 42 of the Code of Federal Regulations.

⁸ *Federal Financial Participation in State Assistance Expenditures; Federal Matching Shares for Medicaid, the State Children's Health Insurance Program, and Aid to Needy Aged, Blind, or Disabled Persons for October 1, 2006 through September 30, 2007*. Notice, 70 *Fed. Reg.* 71856-71857 (November 30, 2005).

⁹ *See* 42 *CFR* 431.10.

¹⁰ Federal review of state plan amendments is based on federal statutes and regulations; 42 *CFR* 430.15. In contrast, federal review of Section 1115 waivers is discretionary.

¹¹ Section 1115(a)(1) of the Social Security Act authorizes the secretary of HHS to waive provisions of Section 1902 to operate a demonstration project; Section 1115(a)(2) authorizes federal financial participation for costs that cannot otherwise be matched under Section 1903. *See* <http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/03Research&DemonstrationsProjects-Section1115.asp>.

¹² U.S. General Accounting Office. (2002, July). *MEDICAID AND SCHIP: Recent HHS approvals of demonstration waiver projects raise concerns* (GAO-02-817). Washington, DC: GAO.

¹³ *See* 59 *Fed. Reg.* 49249 (September 27, 1994).

¹⁴ *Ibid.*

¹⁵ *Ibid.*

¹⁶ U.S. General Accounting Office. *MEDICAID AND SCHIP*.

¹⁷ *Ibid.*

¹⁸ CMS does, however, generally post demonstration applications on its website upon receipt. Many state waiver proposals are available at <http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/MWDL/list.asp>.

¹⁹ Centers for Medicare and Medicaid Services. (2002, May 3). State Medicaid Director Letter #02-007.

²⁰ *See* 42 *CFR* 431.12.

²¹ 42 *CFR* 431.12 (b).

²² *See* 42 *CFR* 431.12 (c).

²³ National Governors Association. (2005, July). *Medicaid Reform Policy*, Policy Position, *EC-16*.

²⁴ The Medicaid Commission. (2005, September 1). *Report to the Honorable Secretary Michael O. Leavitt, Department of Health and Human Services, and the United States Congress*. Washington, D.C.: Medicaid Commission

²⁵ *See* note 5.

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- ²⁶ Kentucky Medicaid created four benefit packages targeted to different populations. Each incorporates new cost-sharing provisions as allowed by the DRA. Beneficiaries are required to enroll in employer-sponsored plans if they are cost effective, with the state paying the premium and supplementing benefits and establishing new “Get Healthy Accounts.” See Kentucky Cabinet for Health and Family Services. (2006). *KyHealth Choices: Kentucky’s Medicaid Transformation Initiative*. Available at <http://www.chfs.ky.gov/NR/rdonlyres/70AC8C04-BDEF-4A64-AB06-45FEE8285A04/0/COMPLETEPACKAGE.pdf>
- ²⁷ West Virginia Medicaid created a basic benefit plan for “healthy adults and children” whose benefits are more benefits than those of the traditional Medicaid plan. An enhanced benefit plan is available to members of this population if they comply with a Member Agreement regarding health-promoting behaviors. West Virginia also established “Healthy Rewards Accounts.” See Kaiser Commission on Medicaid and the Uninsured. (2006). *West Virginia Medicaid State Plan Amendment: Key Program Changes and Questions*.
- ²⁸ Idaho Medicaid created a basic benefit package for AFDC adults, pregnant women, infants, low-income Medicaid children, and SCHIP children that does not include LTC benefits, limits mental health services, and includes a “Personal Health Account.” Idaho created an enhanced benefit package for SSI, certain disabled children, people receiving LTC, and other groups. See National Conference of State Legislatures. *Idaho State Plan Amendment*. Accessed November 11, 2006, at <http://www.ncsl.org/programs/health/idmedicaid.htm>
- ²⁹ To date, Kentucky, West Virginia, Idaho, Kansas, and Virginia have received CMS approval of SPAs filed under the DRA. See Centers for Medicare & Medicaid Services, Deficit Reduction Act (DRA)-related Medicaid State Plan Amendments, available at http://www.cms.hhs.gov/DeficitReductionAct/03_SPA.asp.
- ³⁰ In the past, advocates who felt they did not have an opportunity to provide meaningful input to a waiver proposal at the state level contacted CMS and/or HHS directly. See United States General Accounting Office. (2002, July). *MEDICAID AND SCHIP: Recent HHS approvals of demonstration waiver projects raise concerns* (GAO-02-817). Washington, DC: GAO.
- ³¹ While CMS has a great deal of discretion during the Section 1115 waiver approval process, it has much less discretion in approving SPAs. In general, an SPA that complies with federal requirements must be approved.
- ³² U.S. General Accounting Office. *MEDICAID AND SCHIP*.
- ³³ *Inside CMS*, XX, Vol. 10, Issue No. 8, April 19, 2007.
- ³⁴ The legislation being contemplated would address filings regarding home and community-based services and include measures to ensure that waivers are evaluated in a professional manner.
- ³⁵ See Public Act No. 07-83. *An Act Concerning Legislative Review and Approval of Waiver Applications Submitted by the Commissioner of Social Services to the Federal Government*, effective July 1, 2007.
- ³⁶ Advocates for Connecticut’s Children and Youth, a partner lobbying organization for Connecticut Voices for Children, provided testimony in support of this legislation on February 21, 2007.
- ³⁷ See West Virginia HR 2886.
- ³⁸ The California Department of Health Services (DHS) uses All County Welfare Directors Letters (ACWDLs) to notify county public social services agencies about new or changed policies or procedures regarding eligibility for Medi-Cal benefits. A public comment period precedes finalization of ACWDLs.

³⁹ DHS issues Provider Bulletins to make changes to Medi-Cal Provider Manuals, which include detailed information for Medi-Cal providers regarding covered services, billing, claims reimbursement, and recipient eligibility.

⁴⁰ The Deficit Reduction Act of 2005 included a requirement that most applicants for Medicaid benefits must document identity and citizenship before receiving benefits, Public Law No. 109-171, §6036.

⁴¹ *Conn. Rev. Statutes*, Sec. 17b-8.

⁴² *Ibid.*

⁴³ *Ibid.*

⁴⁴ In contrast, DSS indicated that all revisions to the State Plan for the Children's Health Insurance Plan (CHIP) must be submitted to the joint standing committees of the General Assembly that oversee human services, public health, insurance, appropriations and the budgets of state agencies for their approval, denial or modifications. *See Conn. Rev. Statutes*, § 17b-291 and § 17b-302.

⁴⁵ *Conn. Rev. Statutes*, § 17b-8(c).

⁴⁶ *Conn. Rev. Statutes*, § 17b-8.

⁴⁷ *Ibid.*

⁴⁸ *Conn. Rev. Statutes*, Chap. 54.

⁴⁹ *See* s. 409.912(11), F.S. and s.409.91211 F.S.

⁵⁰ The 2006 Florida legislature provided funding for Medicaid consumers age 21 and over to obtain partial dentures and the services required to seat dentures. Subsequently, AHCA filed an SPA to add a new partial denture benefit to the Florida State Plan.

⁵¹ *See* s. 409.912(11) F.S.

⁵² *See* s. 409.91211 F.S.

⁵³ *See* s. 409.912(11) F.S.

⁵⁴ The provisions that incorporate the Handbooks into the Rules by reference are located in various places in Chapter 59G, Florida Administrative Code.

⁵⁵ For example, 305 ILCS 5/5-4.1 places limits on allowable co-payments.

⁵⁶ 305 ILCS 5/12-4.30.

⁵⁷ *See* 305 ILCS 5/5-5a.

⁵⁸ *See* 5 ILCS 100/5-40(c).

⁵⁹ *Indiana Code* 4-22-2-28.

⁶⁰ *See generally*, *Indiana Code* 4-22-2 et al.

⁶¹ *Ibid.*

⁶² See *MCL* 400.111a.

⁶³ *Ibid.*

⁶⁴ See *NRS* 422.2726.

⁶⁵ See *NRS* 422.396.

⁶⁶ See *NRS* 422.2368.

⁶⁷ See *NRS* 422.2369.

⁶⁸ The Statewide Advocacy Coordinator (SAC) is an attorney under contract with Nevada Legal Services, Washoe Legal Services, and Clark County Legal Services.

⁶⁹ See Rider 45a to the General Appropriations Act.

⁷⁰ *Ibid.*

⁷¹ See *Tex. Hum. Res. Code Ann.* s.32.0231.

⁷² *Tex. Hum. Res. Code Ann.* s. 32.0231(3).

⁷³ Depending on the policy, DHFS may initiate the rulemaking process before submitting the waiver or SPA to CMS or receiving its approval.