

Centers for Medicare & Medicaid Services
Open Door Forum: Long Term Services and Support

Moderator: Jill Darling

October 4, 2022

2:00 pm ET

Coordinator: Good afternoon, and thank you all for holding. Your lines have been placed on a listen-only mode until the question-and-answer portion. And I would like to remind all parties, the call is now being recorded. If you have any objections, please disconnect at this time. And I would now like to turn the call over to Jill Darling. Thank you. You may begin.

Jill Darling: Great. Thank you, (Elon), and good morning and good afternoon, everyone. I'm Jill Darling in the CMS Office of Communications, and welcome to today's Long-Term Services and Supports Open Door Forum. I have one announcement.

This open door forum is open to everyone, but if you are a member of the press, you may listen in, but please refrain from asking questions during the Q&A portion of the call. If you have any inquiries, please contact CMS at press@cms.hhs.gov.

Today, we have Alison Barkoff, who is Acting Administrator at the Administration for Community Living, and Assistant Secretary for Aging. And we also have Greg Link, who is the Director in the Office of Supportive and Caregiver Services at the ACL.

They will be presenting information about the 2022 national strategy to

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support family caregivers. And after Alison and Greg speak, CMS will discuss their role in the development and implementation of the strategy. So, now, I'd like to hand the call off over to Alison.

Alison Barkoff: Great. Thank you so much, Jill, and thank you so much to CMS for the opportunity to present today on the national strategy to support family caregivers, which was just released to the public and submitted to Congress about two weeks ago.

For those of you who aren't familiar with the Administration for Community Living, we're an agency in the US Department of Health and Human Services, whose mission is to ensure that all people have the opportunity to live and participate in their communities, regardless of age, type of disability, or level of needed supports.

And we have a number of disability and aging programs, including many that support family caregivers. We fund a network of disability and aging community-based organizations that provide a wide range of direct services, legal advocacy, information, and referral, and support systems change, and we fund research and education around community living.

ACL serves as the advisor to the Secretary of HHS on aging and disability policy. And we work closely across HHS and the federal government. And one of our closest relationships is with CMS because, of course, they play such an important role in community living as the primary funder of home and community-based services.

So, let me start by just highlighting the incredible importance that family

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caregivers play in the long-term services and support system. Truly, family caregivers are the backbone of long-term care systems. More than 53 million people provide support to older adults and people with disabilities to help them stay in their own homes and communities and out of nursing homes and other institutions.

And caring for a family member is, of course, rewarding, but family caregivers, and Greg will talk a little more about this, often lack training and support, can't access respite to be able to take care of themselves, and face financial consequences for caregiving, including themselves having to leave the workforce.

Many people and such a huge topic in LTSS is about the direct care workforce, and the issues facing family caregivers are just intertwined with the paid direct care workforce. Many family caregivers take on their roles or take on more care in their roles as family caregivers, because they are unable to find a direct care worker to provide paid support.

And our home and community-based system has faced such a direct care workforce crisis for quite a while, with high turnover rates and vacancy rates due to low wages and lack of benefits in the job. Like COVID has turned that direct care workforce crisis into a true emergency, with nearly 75% of providers, HCBS providers, turning down referrals, and 50% cutting services at a time when demand is higher than ever, and that supporting people in the community is not only about what people want, but it is about their safety.

And as you'll hear in more detail later, addressing the direct care workforce crisis is a critical part of the strategy for supporting family caregivers. And I'll

just mention, while we're talking about the direct care workforce, that one of the commitments that ACL made in this national strategy, and something that we are thrilled to be doing, and that was informed by our partners, including CMS, is that later this month, we will be launching a national technical assistance and capacity building technical assistance center around the direct care workforce.

So, I will lean on Jodie and Jill to invite us back once that is launched, to share some information about that. So, we have family caregivers. We have the tie with the direct care workforce. And I just want to touch on, before I talk a little bit about what the strategy is, the impact of COVID on this issue.

COVID has absolutely shone a spotlight on the importance of family caregivers. During COVID, so many people lost supports and services, and so many family caregivers had to step in to fill those gaps. As I mentioned, COVID has absolutely highlighted the risks of nursing homes and other institutional settings, with more than a third of deaths in those settings.

And these issues are all part of what our president calls the caregiving infrastructure, and they have never had more visibility, by the public, by the policymakers. Literally every day, you can open a major newspaper or turn on the news and hear about these caregiver issues.

And COVID and what we've seen happen to the workforce and to family caregivers, has truly created an unprecedented momentum to expand home and community-based services, and to strengthen and support the direct care workforce and family caregivers.

And that's one reason why strengthening the caregiving infrastructure is a top priority for the administration and for HHS. And that's why we are so thrilled at the timing of being able to deliver this first ever national strategy to support family caregivers to the public and Congress, which you can find on [acli.gov](https://acli.org).

So, in a minute, I'm going to turn over the telephone stage to my colleague, Greg, to walk you through the national family caregiver strategy, but I just want to highlight a couple of important points. First is inter-agency collaboration.

This is the first time that federal agencies across the federal government, have come together to identify strategies and the levers we have in each of our programs and coordinate on supporting family caregivers. There were 15 different federal agencies, including, of course, CMS, participating in the development of this strategy. And the agencies have come forward with more than 350 commitments, not things that they could do, but commitments about what each of us will do.

And Jodie, at the - after Greg, will talk about a couple of those from CMS. As the next step in our inter-agency collaboration, we are going to be working to identify areas where federal agencies can collaborate to increase the reach, the impact, and the efficiency of the programs we each administer.

The second point I want to make, there is something in this national strategy for everyone. As the strategy makes clear, the federal government cannot alone meet the needs of family caregivers. The strategy includes recommendations for State government, for local government, for advocates,

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for businesses, for community organizations, and for philanthropy. Again, this is a big problem, and we are going to need solutions from everyone to start chipping away at it.

Finally, I just want to say, this is a great first step, this national family caregiver strategy, but it is a first step. This strategy is the result of three years of input from committee members, federal agencies, and broad stakeholder engagement. But we know that public input is critical as we move forward on implementing and continuing to update this strategy.

So, later this week, we will be putting this document out for public comment, and we need to hear from all of you, from all of the different stakeholders involved, because we will be providing an update to Congress every single year. And every two years, we will be updating this strategy.

So, we need your voices about, what did we get right? What more can we do? What are the things that are most impactful to inform the report and update to Congress? And Greg will be sharing more information about how to contact - how to submit that public comment.

I just want to close by, again, highlighting how important we believe this national family caregiver strategy is to all of our shared goals, to strengthen our system of long-term services and supports, and to ensure that people are able to live in their own homes and in their own communities.

It's a key part of the administration's efforts to strengthen the caregiving infrastructure and ACL feels incredibly privileged to be helping lead its

development and implementation. So, thanks again for joining today, and I will turn it now over to Greg to walk you through some of the details.

Greg Link: Great. Thank you, Alison, and thank you to CMS for having Alison and me with you today to talk about the national family caregiving strategy that was just released almost two weeks ago. I want just start by talking about how the genesis of the national strategy and some of the critical underpinnings that went into developing it.

But I think it's really important to talk about what the bottom line is here that we're talking about. As Alison shared, we know that there's approximately 53 million family members who call themselves family caregivers. And that's the number that we know about.

But I can tell you from my own personal experience, and probably many of you, or all of you on the call, have had personal experience with family caregiving in some way, whether you've been a caregiver or have needed support yourself, this is something that is likely to hit every single individual in some way.

And so, in order for us to really address the needs of family caregivers fully and to the best of our ability, it's going to require an all-hands on-deck approach. And so, this national strategy to support family caregivers is really the first step towards that endeavor.

So, the national strategy grew out of the passage of what's called the RAISE Act, which stands for Recognize, Assist, Include, Support, and Engage Family

Caregivers Act, was signed into law in January of 2018, and it has three key components.

First is the establishment of an advisory committee, a family caregiving advisory council that's made up of both federal and non-federal individuals. There's 15 non-federal members that come from a variety of sectors that touch on the issue of family caregiving, including health and long-term services and supports, healthcare service providers, State and local government officials, veterans, as well as people who need supports and services themselves, and family caregivers.

The second component is an initial report to Congress, which was delivered in September of 2021. And that report contained a series of 26 recommendations that ultimately formed the basis and the foundation for the national caregiving strategy. And that strategy is the third component of the RAISE Act, and it's what I'm here to talk to you about today.

What I want to back up and talk about for just a second is the fact we would not be here today, and we would not have this first national strategy, were it not as a result of, and were it not for this incredibly unique and powerful public-private partnership that developed early in the RAISE Act's existence, and has really enabled ACL, as well as all of our partners, to move very quickly and very comprehensively in the development of the strategy.

Shortly after the RAISE Act was passed, the John A. Hartford Foundation approached ACL about how they could be supportive in implementing the requirements of the RAISE Act. And we worked with them, my colleagues at ACL, and I, worked with them to develop a resource and technical assistance

dissemination center that they would fund completely with their private dollars, to support the implementation of the RAISE Act.

And they wound up funding the National Academy for State Health Policy, and they have been working with us side by side, both as a resource to the advisory council, but also to support the implementation of the various recommendations and actions that are contained in the strategy.

This has been truly a wonderful partnership that has enabled us to do so much with relatively modest resources. And I would be remiss if we didn't acknowledge these key partners. So, as Alison talked about, there are 53 million caregivers that we know about, and family caregivers are predominantly women.

This is definitely a gender issue, but family caregivers are also spouses and partners and parents and siblings. And we also consider grandparents and other relatives, as well as young people, children and youth who get into the caregiving role, because that is the makeup of their family system.

And we also know that family caregiving is an incredibly complex dynamic. It comes with both - there's a high value to it in terms of personal satisfaction and also the value that - the support that family caregivers provide brings to the long-term services and support system, but there's also incredibly high cost on the caregiving side.

Caregivers do everything from very simple and - very simple day-to-day tasks like driving somewhere, or maybe helping with a grocery list, to incredibly complex medical tasks and long-term, very skilled care that oftentimes, and

up until, you know, the past several years, has been largely done by very skilled professionals in the healthcare field.

Caregiving is also very culturally and racially complex. Family caregiving dynamics and systems are viewed very differently from culture to culture and from society to society. And so, it has to be treated as a very individual and personalized experience. We also know that family caregivers can experience numerous financial and legal barriers, physical and emotion strain from interrupted childhood and young adulthoods, and also risk of isolation.

And so, the national strategy to support family caregivers is really based in what we know, what these truths about family caregiving are and the complexities of the situation. The RAISE Act is the most recent in really a long series of recent legislative milestones in family caregiver support, dating back more than 20, 25 years or so.

You know, thinking back to 2000 and the reauthorization of the Older Americans Act, where the National Family Caregiver Support Program, and the Native American Caregiver Support Program, became the first federal recognition of the value that family caregivers bring to the table, and also the critical need to support them.

Soon after that, we had the passage of the Lifespan Respite Care Program, which looked across age and disability populations at the need for ensuring that we have coordinated and cohesive and accessible programs and systems of respite services.

The VA has its own family caregiver support program to support the needs of

wounded warriors and their family caregivers dating back to 2010, and that program has only continued to grow and become more robust.

We have the Families First Prevention Act, which really looks at some of the issues of kinship families, and ensuring that the child welfare system is there, and recognizes the needs of kinship and grandparent caregivers.

And then most recently in 2021, with the passage of the rescue package, was the development of the National Technical Assistance Center on Kinship and Grandfamilies, and the RAISE Act and the grand - and Supporting Grandparents Raising Grandchildren Act, fell right in there before that, to really begin focusing our efforts to better support family caregivers.

As the Family Caregiving Advisory Council began working on the strategy, they looked very carefully at who they were calling family caregivers, and who they referred to. And I touched on this just a second ago. The advisory council adopted the very broadest possible definition of family caregivers that they could, and they include people of all ages, youth to grandparents, people with and without disabilities, those providing care from a distance.

The definition of family caregivers and how their needs and preferences are addressed, really speaks to the diversity that we bring to the caregiving experience. And the term family caregiver for the advisory council, also recognizes that a single person may receive care from multiple family caregivers, but also that family caregivers may be caring for more than one individual.

It's truly a comprehensive approach to how we considered the needs of family

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caregivers. The national strategy as it exists today, the first iteration of the strategy, consists of four components. There is the narrative, which is organized around five goals that the advisory council adopted early in its existence, goals around improving awareness about the issues of family caregiving, but also awareness by family caregivers to understand that what they are doing deserves and needs to be supported, and they need to be supported and recognized.

There's also the goal around making sure that family members, where appropriate and possible, are included as members of the care team, as part of the team of healthcare professionals that are there to support the individual who needs to be supported.

There is a goal around strengthening a broad array of services and supports, another goal around addressing the financial and workplace issues associated - that oftentimes come with being a family caregiver. And then there's the final goal and priority area around strengthening our research and data collection, and improving and strengthening our understanding of the needs of family caregivers.

So, the narrative part of the strategy really helps to define the goals and then talk about a series of outcomes under each of those goals. The next component of the strategy is what we call our first principles or cross-cutting considerations for family caregiver support.

Because of the incredible diversity and the nuanced nature of family caregiving, the advisory council felt that it was critically important to address

several key truths right up front. And they did so in this cross-cutting principles document.

The first cross-cutting principle is that every action that is contained in the next two sections of the strategy, must be implemented with an eye towards ensuring that they are person and family-centered in their approaches, that they recognize and understand and acknowledge the impact that trauma has on the lives of the person being supported, as well as how that trauma can also impact the family dynamic, and really has helped to alter how services and supports are acknowledged and received.

The third cross-cutting consideration is the critical need to upfront, recognize that diversity, equity, and inclusion are a key part of how we design services and supports and how we deliver them. And so, within these cross-cutting considerations, we provide a good deal of information about resources that are available to support the needs of diverse populations of caregivers, and it points readers and users to these various resources to enable them to implement the actions in a way that are person and family-centered, trauma-informed, and with respect to diversity, equity, and inclusion.

And the final cross-cutting consideration, as Alison mentioned, is that we must take into consideration the fact that we are in a workforce crisis, and family caregivers - without the direct care workforce, family caregivers couldn't do what they do and vice versa.

They're not mutually exclusive. They're intricately connected. And as one of the members of the Family Caregiving Advisory council said - put it so eloquently, if family caregivers are the backbone of the long-term services and

support system, then the direct care workforce is the connective tissue that kind of keeps everything together.

And I think he was so right in phrasing it that way. And so, we have to look at this interconnection between the workforce, because every single action in the strategy will require a workforce that is able to implement that piece of the strategy.

To develop the national strategy, we undertook a very extensive three-year public engagement effort, beginning with the release in 2019 of a request for information. This was at the direction of the advisory council following their first in-person meeting in August of 2019.

ACL published a request for information in the Federal Register that asked caregivers, stakeholders, advocates, providers, talk to us about the challenges that family caregivers face, what are - what needs to be done to improve the system of services and supports, offer recommendations.

We received over 1,600 individual comments, 75% of which came from family caregivers and provided incredibly poignant, sometimes heartbreaking accounts of what their caregiving struggles were, but also some of their triumphs and challenges. It was really an eye-opening exercise.

But that request for information, then provided the basis for a series of focus groups, listening sessions, and key informant interviews that through our collaboration with NASHP, under their grant from the John A. Hartford Foundation, enabled us to operationalize each of the recommendations that are

contained in the initial report to Congress, and then develop the actions that you all see in the national caregiving strategy.

And the stakeholder organizations that were part of this public input process, included State and local entities, employers of all sizes, unions, health and long-term services providers, faith-based and community-based organizations, respite providers, philanthropies, you name it. School systems were part of it as well.

As the strategy began to be envisioned, the council members very much had a vision for what they wanted the strategy to be. They recognized the significance of the strategy at this point in time. And as Alison alluded to, the release of this first national strategy to support family caregivers, really has occurred at a very pivotal time.

There's a tremendous interest in understanding and supporting family caregivers, but the council members envisioned that this strategy would help a nation better understand and recognize the important role that all family caregivers play, and that it's going to lay the groundwork for enabling family caregivers to more easily access needed services and supports.

It's going to create opportunities for families to maintain their health, their wellness, and their vitality. And then it would also help to ensure that people receiving support, maintain their autonomy, their independence, and their right to self-determination. It's absolutely critical that we focus on both components, both individuals within this caregiving, care receiving diad.

The national strategy is intended to have many audiences. It isn't simply a

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federal strategy. It's simply not a State - it's not only just a State strategy. The strategy is intended to be a tool for States, tribes, and communities, for community-based providers, for child welfare agencies, healthcare systems, business leaders, and employers, academic institutions, and researchers. And it's also, we see, as a critical tool for advocates, care recipients, and the public.

In fact, the narrative portion of the strategy contains a real roadmap for advocacy around - and talks about some key areas where needed legislative and policy changes, will absolutely be necessary if we're really going to move the ball on improving and strengthening family caregiver supports.

In this regard, the advisory council does see the strategy as a driver of legislative and policy change. We have recommendations in there around improving the planning and infrastructure development for caregiver supports, more universal adoption of assessments where appropriate, expansion of LTSS options, and then accessing issues that impact family caregivers, including, you know, employment and employer concerns, expanding the availability of services and supports, as well as the negative financial impacts oftentimes associated with family caregiving.

And while the strategy is a great deal, and we believe it's an important first step, it also has its limits, and the advisory council recognizes that. It was - it is not intended to be the be-all and end-all. Instead, as Alison said, it's the first step, and it's a vision and a roadmap for meaningful change, but it's - but the strategy is not a timeline or a how-to document.

It lays out the options and then communities and the intended sectors that it's meant to address, can look within to determine, where do they need to make

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the first step in beginning to improve their response to services and supports for caregivers.

It provides a baseline for action and progress, but it doesn't have requirements or musts. It offers strategies that - for many stakeholder groups, but as I said, it's not exhaustive or final by any means. And this is the first national strategy, and it is by no means the last.

So, I would like to just end by saying that we have actions in here for States, communities, and other sectors. And I know that there's a huge audience and a wide variety of folks attending this conference call today. Please take a look at the national strategy.

Look at the actions for States and communities. Look at the actions for federal agencies. As you're going to hear from Jodie in just a couple of minutes, CMS has committed to several very significant actions that can really move the ball on how we address family caregivers support needs moving forward.

But there's a lot in here for States, communities and other sectors, training of professionals that work with family caregivers, caregiver inclusion in healthcare teams, employment protections, workplace and leave policies. There's something in here for everything.

As Alison mentioned, we just opened up the public comment period yesterday, and that is on acl.gov/raise. If you go to that part of ACL's Web site, there's an entire section devoted to the RAISE Act work and the national strategy, and you can link to the public comment section from there.

The public comments will be open for a period of 60 days, and will definitely be a basis for the next iteration of the Family Caregiving Advisory Council being able to make revisions and grow and develop and morph the national strategy to be truly reflective of where we are as a nation right now and moving forward.

So, with that, I'm going to turn it over to Jodie, to talk a little bit about some of CMS's work as they supported and worked very closely with ACL, but also some of the things that they're going to be looking to do as part of their commitment to the national strategy. Jodie?

Jodie Sumeracki: Thanks, Greg. So, this is Jodie Sumeracki. I'm the Senior Policy Advisor in the Disabled and Elderly Health Programs Group at CMS in the Centers for Medicaid and CHIP Services. And I am delighted to be here today, and, you know, I'm really grateful that we were able to have Alison and Greg join us today to provide such a fulsome overview of the work that's been happening over the last few years and what's to come, and really appreciate your leadership with regard to this important work.

You know, I'm really excited about the release of the strategy and CMS having had a seat at the table as an ongoing federal partner in the development, and as a member of the RAISE family caregiving council, it's been an honor to serve as a member of the council and to be part of this work.

As noted in the strategy, and I think Greg touched on this, the federal actions that were included in support of the strategy were really constrained by the

RAISE Family Caregivers Act requirement that they be within the scope of existing programs.

So, the federal actions that are listed that you all can see within the strategy, were really limited to activities that were possible under existing budgets, programs, and authorities. And I think that's an important aspect to think about because I think, you know, a lot of people would have a lot more to say, but we had to really be careful to make sure that it fell within those guidelines.

I'm grateful, though, that given the focus of many of our programs at CMS, we actually had a good amount of existing work that we were able to leverage to support the strategy. And much of that work and much of the actions that we offered and committed to as part of the strategy and to support it, really center around sharing of information about CMS programs that impact and support family caregivers, providing technical assistance to States, development of trainings, stakeholder engagement materials and webinars, and the like.

In particular, one of the actions that we included from the DEHPG perspective, was identification and reporting by next fall on the ways that State Medicaid agencies have expanded access to caregiver supports and respite services under Medicaid through Section 9817 of the American Rescue Plan of 2021.

There's already a wealth of information available on [Medicaid.gov](https://www.medicaid.gov) regarding Section 9817, including general information about the law, related implementation efforts, and State spending plans, and how they plan to enhance, expand, and strengthen HCBS under Medicaid.

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We're also excited about the potential development of a Medicaid home and community-based services quality measure that focuses on caregiver support and access to resources by fall of next year as well. Our Office of Program Operations and Local Engagement, also committed to a number of actions to get additional information and resources out to various State and local entities across the country, to increase caregiver awareness of and access to CMS programs benefiting caregivers and individuals in their care.

As Greg and Alison shared, you know, this strategy really is just a critical first step in developing and implementing and adapting policies and programs to support family caregivers, and CMS is committed to advancing HCBS and other forms of caregiving supports across the lifespan, to give caregivers the recognition and the resources they need and deserve.

My colleagues at CMS, and I, look forward to continuing to work with ACL and our other partners across the Administration to make this a reality. With that, I know we're getting kind of close on time, so we wanted to have some time for Q&A. So, I'll hand it back over to Jill.

Jill Darling: Thank you, Jodie, and to Alison, and Greg. (Elon), will you please open the lines for Q&A, please?

Coordinator: Certainly. At this time, if you would like to ask a question, please press Star 1. Please unmute your phone and record your name clearly when prompted. Once again, if you would like to ask a question, please press Star 1. Once again, to ask a question, please press Star 1. I do have one question. Our first question, I believe it's from (Carrie).

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(Carrie): Hi. Thank you for taking my questions. So, I know that the ACL was accepting applications for new community members, and they were supposed to originally be notified earlier this summer and that didn't happen. Have those members been notified yet of who is going to be able to go on to this committee?

Greg Link: Hi. This is Greg, and we are still working to make selections from among those people who nominated themselves or were nominated. So, no decisions have been made. We got a little pushed behind on this because of all of the work it took to get the strategy out the door. So, that is still coming.

(Carrie): Thank you.

Coordinator: And once again, if you would like to ask a question, please press Star 1. I am showing no further questions on the queue at this time.

Jill Darling: Okay, great. Well, thank you, everyone. I'll open it back up if Jodie, or Greg, have any closing remarks.

Greg Link: I don't, other than to say thank you to Jodie for flagging this opportunity for ACL. We really appreciate it, and we are really excited about, you know, the opportunities created, I think, by the release of the national strategy, but also of our continued opportunity to work together as federal partners and with stakeholders from across the country to really strengthen our ability to support the needs of families and family caregivers. So, thank you, and look forward to connecting again.

Jodie Sumeracki: And I would just echo the thanks and encourage folks to go to the ACL Web site and do look at the opportunity to provide comment and review the strategy. I think it's just such an important body of work. So, everybody's feedback and voice is important. So, we'd love to have it. Thank you.

Jill Darling: Great. Thank you, everyone, for joining. Have a wonderful day. And this concludes today's call.

Coordinator: Thank you. This does conclude today's conference. You may disconnect at this time.

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