

### The CHIPRA Quality Demonstration Grant Program

In February 2010, the Centers for Medicare & Medicaid Services (CMS) awarded 10 grants, funding 18 States, to improve the quality of health care for children enrolled in Medicaid and the Children's Health Insurance Program (CHIP). Funded by the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA), the Quality Demonstration Grant Program aims to identify effective, replicable strategies for enhancing quality of health care for children. With funding from CMS, the Agency for Healthcare Research and Quality (AHRQ) is leading the national evaluation of the program.

The 18 CHIPRA quality demonstration States are implementing 52 projects in five general categories:

- Using quality measures to improve child health care.
- Applying health information technology (IT) for quality improvement.
- Implementing provider-based delivery models.
- Investigating a model format for pediatric electronic health records (EHRs).
- Assessing the utility of other innovative approaches to enhance quality.

The CHIPRA quality demonstration began on February 22, 2010, and will conclude on February 21, 2015. The national evaluation of the grant program started on August 8, 2010, and will be completed by September 8, 2015.



## How are CHIPRA quality demonstration States designing and implementing caregiver peer support programs?

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This *Evaluation Highlight* is the seventh in a series that presents descriptive and analytic findings from the national evaluation of the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA) Quality Demonstration Grant Program.<sup>1</sup> The *Highlight* focuses on how four States—Maryland, Georgia, Utah, and Idaho—are working to expand access to peer support for caregivers of children with special health care needs (CSHCN). The analysis is based on work completed by the States during the first half of their 5-year projects.

### KEY MESSAGES

Key messages from the States' early experiences include:

- Caregiver peer support programs train, and in some cases certify, a group of caregivers to directly support other caregivers, foster better communication between health care providers and families, or both.
- Caregivers deliver peer support to other caregivers in a variety of ways, including helping them navigate the health care system and connect to community resources. Caregivers' training and health care providers' comfort level with peer support influence the type and level of peer support provided.
- Caregivers providing peer support need both initial and ongoing training to understand their roles and responsibilities, feel confident about providing support to others, and communicate effectively with other caregivers and health care providers.
- It is important to address the needs of caregivers who support other caregivers.
- Educating health care providers about caregiver peer support helps to increase their interest in supporting this service.

## Background

Caregivers of CSHCN, including children with chronic conditions or complex behavioral and mental health needs, spend more time managing their children's health, have more health-related financial difficulties, and feel more stress than other caregivers.<sup>2,3</sup> Through peer support programs, caregivers who have learned how to navigate the health care system effectively can provide emotional support to other caregivers and help them identify and connect with community resources. Caregivers supported by other caregivers value having someone they can call on, enjoy receiving practical tips from others like them, and feel relieved to know they are not alone.<sup>4,5,6</sup> However, findings on the effects of caregiver peer support are mixed. Some research suggests that it may reduce stress and improve the ability to care for one's children, while other studies did not find an effect.<sup>4</sup>

Caregiver peer support has traditionally been provided through nonprofit organizations and federally funded programs such as the Health Resources and Service Administration's (HRSA) Family-to-Family Health Information Centers.<sup>7</sup> HRSA's centers encourage health care providers to refer families to them for caregiver support services. Likewise, the American Academy of Pediatrics encourages pediatricians to "facilitate peer-to-peer support and networking" for caregivers as a component of family-centered care.<sup>8</sup>

Four of the 18 CHIPRA quality demonstration States are using grant funds to both expand, and improve the quality of, caregiver peer support services (see Figure 1). The strategies used by these States and the early lessons they have learned may be helpful for other States and pediatric

## Figure 1. CHIPRA Quality Demonstration State Strategies for Expanding Caregiver Peer Support Services

- Maryland is working to integrate peer support services for caregivers of children with complex behavioral health needs with other State-sponsored services and to increase Medicaid reimbursement for these services from the current level of \$50.00 for a session of at least 1 hour.
- Georgia is both developing a peer support training curriculum and certification process for caregivers of children with complex behavioral health needs and exploring ways to increase Medicaid reimbursement for peer support caregivers from the current level of \$20.78 per 15-minute session.
- Pediatric practices participating in CHIPRA quality demonstration medical home efforts in Utah and Idaho are engaging "parent partners" to provide both peer support to other caregivers of CSHCN and advice on quality improvement activities.

practices interested in expanding access to caregiver peer support services.

The data for this *Highlight* come primarily from semi-structured, in-person interviews conducted in the spring and summer of 2012 by the national evaluation team with CHIPRA quality demonstration State staff, staff in pediatric practices and care management entities,<sup>9</sup> caregivers providing peer support, and other stakeholders. Data also come from semiannual progress reports submitted by the States to CMS.

## Findings

States and many providers view caregiver peer support as a promising strategy, and some offered anecdotal evidence that these services are helping caregivers of CSHCN. Success stories include the following:

- Connecting a mother who feels isolated with a lunchtime support group of other caregivers of CSHCN.
- Helping a caregiver broach the topic of medication affordability with her child's provider and find financial assistance to help defray medication costs.

- Helping caregivers navigate the special education system and facilitating discussions between caregivers and school staff about their children's individualized education plans.

Although all four States implemented caregiver peer support programs differently, the staff in these States indicated that such programs offer important services. They also noted that developing and implementing these programs can be challenging.

## States structured their peer support programs differently

The CHIPRA quality demonstration States have approached the development of their caregiver peer support programs in two ways. Maryland and Georgia are creating cohorts of trained caregivers who work full time providing peer support services to other caregivers. When this approach is fully implemented, all caregivers providing Medicaid-reimbursable peer support will be trained and certified by the State or an organization accredited by the State. A variety of organizations, including care management entities,<sup>9</sup> crisis stabilization units, and family support organizations contract with or hire certified caregivers, and Medicaid

reimburses the organization for the peer support services.

In contrast, Utah and Idaho are using a provider-driven approach in which pediatric practices are partnering with caregivers of CSHCN. Known as “parent partners,” these caregivers volunteer to spend a set number of hours every month (typically 10 to 12) providing peer support to other caregivers whose children are served by the practice and advising the practice on other quality improvement projects. The two States help pediatric practices recruit and train parent partners, who receive a small stipend from CHIPRA quality demonstration grant funds.

Regardless of the approach, State staff, caregivers, and providers believe that in-person peer support is the most effective kind of support for caregivers of CSHCN, whether delivered one-on-one, through support groups at a provider’s site, in a caregiver’s home, or at another convenient location in the community. Some pediatric practices noted that technology-driven methods for providing peer support, such as Web sites and caregiver-run blogs, are also helpful.

“Whenever you bring parents together, it empowers them. It eliminates isolation and that hopeless feeling, and they become enthusiastic.”

— Georgia Family Advocate, June 2012

### Peer support services must be flexible enough to meet diverse caregiver needs

Support services include providing emotional support, recommending community resources, helping caregivers fill out complex insurance forms, and finding ways to make them feel comfortable talking with providers

**Figure 2. Features of a Utah Pediatric Practice’s Caregiver Peer Support Program**

- Direct phone line to a parent partner.
- Blog developed by a parent partner that includes lists of local resources and support groups.
- An electronic forum in which families can discuss their concerns.
- Training for caregivers, including a session on individualized education plans and focus groups on the practice’s operations, both led by a parent partner in collaboration with the practice’s care manager.

about barriers to complying with clinical recommendations (see Figure 2 for examples). One practice noted that caregivers can be more comfortable talking “mom-to-mom” or “dad-to-dad” about barriers and that advice on resources and supports can have more impact when it comes from another caregiver instead of a provider.

The topics covered by peer support caregivers vary with their training and provider preferences. For example, caregivers with limited training or those working with practices that prefer them to play a more limited role are sometimes restricted to sharing resources pre-approved by the practice or are asked to follow a semi-structured script when interacting with caregivers of CSHCN.

### All States carefully recruited potential peer support caregivers

Maryland, Georgia, Utah, and Idaho recruited caregivers in different ways, such as targeting outreach to caregivers viewed as leaders or using open recruitment through family advocacy organizations or flyers posted in pediatric practices. Some interviewees indicated that targeted recruitment can help providers feel comfortable with the selected caregivers, but others cautioned that good candidates are sometimes overlooked because of narrow recruitment approaches.

Most interviewees agreed that individuals recruited to provide peer support should also be a caregiver of a child with special health care needs so that they can draw on their own experiences. Some interviewees also indicated that caregivers should reflect the population they will support. For example, pediatric practices in Utah and Idaho with more than one parent partner often selected caregivers with different demographic characteristics, education levels, and language skills and who represent children with different health care needs.

Some States prefer caregivers who meet specific selection criteria (for example, 6 years of relevant experience), have worked with family advocacy organizations to establish a formal screening process, or both. Other States rely primarily on a caregiver’s own judgment about his or her ability to provide peer support. Irrespective of other selection criteria, peer support caregivers must (1) be in a period of relative stability in their own lives and in their children’s lives, (2) have enough time to provide peer support, and (3) be committed to supporting other caregivers.

States learned that caregivers need an accurate understanding of their peer support role, responsibilities, and time commitment to assess their ability to participate effectively. Several pediatric practices in Utah and Idaho experienced high turnover rates because caregivers misunderstood the parent partner job

description or found that supporting other caregivers and advising practices on quality improvement activities took more than the original estimate of 10 to 12 hours per month. Both States also found that if parent partners directly contacted other caregivers to provide information and referrals, the practices actually needed two such individuals to meet the demand for support services instead of one as originally planned.

### Caregivers need training and emotional support to provide peer support effectively

Caregivers providing peer support draw on their personal experiences navigating the health system and caring for CSHCN. While this experience is invaluable, caregivers also need formal training to be effective in a peer support role. Such training helps them not only to understand this role and how to execute it effectively, but also to develop a broader knowledge of the resources available to them and to the parents they support. Georgia even involves caregivers in the development of training curricula to ensure that they feel a sense of ownership for the program and understand its content.<sup>10</sup>

States also indicated that it is imperative to educate caregivers about any limits on the peer support services they can provide. For example, without proper training, caregivers sometimes attempt to play the role of a care coordinator or provide medical advice to other caregivers, two sources of concern for providers. Pediatric practices and other providers noted that this element of training reduced their liability concerns.

Other important training topics include ensuring patient confidentiality, identifying which resources are appropriate to share with other caregivers, recognizing stressors, and using communication strategies such as

reflective listening. States also trained caregivers to understand health care terms such as “medical home” and taught them how to write up notes on their meetings with other caregivers so they could communicate with providers about what they observed during the meetings. While these topics are similar from State to State, Maryland and Georgia require caregivers to be certified through a process involving mandatory, formal training before caregivers can be reimbursed by Medicaid.

States indicated that initial *and* ongoing training for caregivers is important. In all four States, family advocacy organizations host meetings for caregivers to discuss challenges that arise while providing peer support and to learn about new resources. In addition, caregivers in Utah use an online platform for exchanging resources and ideas; they also have access to the “Medical Home Portal,” a State-run online database with information on pediatric health conditions and community resources.<sup>11</sup> Some caregivers in all States begin by providing peer support that focuses on a narrow set of issues; with experience and continued training, they then address a broader range of topics.

Caregivers who provide peer support may themselves need support if they are faced with a medical emergency or other crisis involving their children. One caregiver described the work as a “give and take.” The CHIPRA quality demonstration States are developing reciprocal models in which caregivers providing support can also receive peer support from other caregivers, family advocacy organizations, or both. A few pediatric practices in Utah indicated that emotional support provided by Utah Family Voices, the State’s Family-to-Family Health Information Center, is essential to keeping parent partners engaged.

“I know what it is like to experience crisis in your household. If you are helping someone else put out a fire and you are not taking care of yourself, then everyone crashes and burns.”

— Georgia Caregiver,  
June 2012

### Paying caregivers who provide peer support is important but challenging

The States acknowledged that they do not fully compensate caregivers for time spent supporting other caregivers. Utah and Idaho are using CHIPRA quality demonstration funds to cover stipends (\$500 per quarter) that are intended to help offset gas and child care expenses associated with providing peer support and advising a practice. However, the two States recognize that the amount is often insufficient given the high cost of child care for CSHCN.

In Maryland and Georgia, organizations contracting with caregivers to provide peer support are reimbursed by Medicaid (for example, Maryland Medicaid reimburses \$50 for a support session of at least 1 hour). Depending on the contracting arrangement, the organization either pays the caregiver a specified salary or passes on the Medicaid payment directly to the caregiver. However, the reimbursement rates do not account for additional hours that caregivers spend preparing for support sessions or traveling to visit a caregiver. Maryland and Georgia are exploring ways to increase reimbursement through new Medicaid waivers or by using only State funds, although they have indicated that increasing reimbursement will be challenging. They also reported that reimbursing caregivers with Medicaid funds requires family advocacy organizations and the caregivers who

work for them to understand Medicaid reimbursement rules. To address this challenge, Georgia is providing all certified caregivers with “Medicaid 101” training on such topics as anti-referral and anti-kickback regulations.

“Peer support organizations are not . . . traditional providers that know how to handle billing, and there are some aspects of peer support that don’t lend themselves to billing. The financing is really a challenge.”

— Maryland Demonstration Staff, May 2012

### Educating providers is critical to their acceptance of peer support

According to the CHIPRA quality demonstration States, caregivers provide peer support most effectively when they work with providers who trust them, value their contributions, and integrate their services into the existing care model. However, building the necessary level of trust has been a challenge. Many pediatric practices in Utah and Idaho have limited experience with peer support caregivers and were concerned about patient privacy, their own liability, and the accuracy of information provided during support sessions. Even pediatric practices that were more comfortable with the concept of peer support were not sure how to fully integrate caregivers into the delivery of care.

The States are using a variety of strategies both to build trust between providers and caregivers and to educate providers on working with caregivers. Utah and Idaho described the caregiver training requirements to pediatric practices and are giving them an opportunity to learn about peer support from other practices using this approach. Some practices reported being less concerned about liability after reviewing the caregiver training

curriculum, and a few indicated that they integrated caregivers in many of the same ways as other practices did, including handing out caregivers’ business cards to parents when they bring children to an appointment.

Georgia held “get to know you” events in which providers and peer support caregivers in the same area could meet and begin to build a relationship. The State also sponsored lectures on best practices in peer support. As a result, some provider organizations that were initially unclear on the benefits of contracting with State-certified caregivers are now planning to use these services.

### Conclusions

Maryland, Georgia, Utah, and Idaho are using different approaches to test and refine caregiver peer support programs as a vehicle for improving the quality of care for CSHCN. While these States have structured their programs somewhat differently, most caregivers, providers, and State staff agree that peer support for caregivers of a child with special health care needs can be valuable to the families and the providers. States have also learned that peer support caregivers themselves lead a complex life. To be effective, they need comprehensive training on their roles and responsibilities, a clear understanding of the time commitment required, and access to a support system.

The experiences of the four States profiled in this *Highlight* suggest that implementing a peer support program can be challenging, especially with regard to financing and reimbursement. Additional research is needed not only on the options for financing peer support, but also on the effectiveness of different approaches to delivering this support.

### Implications

States interested in developing or expanding peer support programs for caregivers of CSHCN may want to consider the following lessons learned by the CHIPRA quality demonstration States:

- Carefully defining the peer support caregiver’s roles and responsibilities, and clearly communicating them along with realistic expectations of the time commitment required.
- Seeking input from caregivers, family advocacy groups, and providers when developing a program.
- Recruiting and selecting caregivers who have cared for a child with special health care needs, are in a period of relative stability in their own lives and in their children’s lives, and are committed to supporting others.
- Giving caregivers ongoing training and resources that they can draw on when providing support to other caregivers.
- Developing a support system for caregivers who provide support to other caregivers.
- Establishing a certification process or using an existing one through which caregivers can become eligible for Medicaid reimbursement.
- Exploring options for formal, sustainable reimbursement—such as State Plan Amendments and waivers for home and community-based services—for caregiver peer support services.
- Addressing concerns expressed by health care providers and other organizations so that they feel comfortable integrating peer support into their care models.

## Endnotes

1. We use the term “national evaluation” to distinguish our work from the activities of evaluators who, under contract to many of the grantees, are assessing the implementation and outcomes of State-level projects. The word “national” should not be interpreted to mean that our findings are representative of the United States as a whole.
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9. Care management entities provide wraparound services for children and youth with complex behavioral health needs. For more information on care management entities in Maryland and Georgia, visit <http://www.ahrq.gov/chipra/demoeval/>.
10. The Georgia Certified Caregiver Peer Specialists curriculum draws on the National Federation of Families Caregiver Support Provider curriculum. Information on this curriculum is available at <http://www.ffcmh.org/>.
11. The Medical Home Portal is available at <http://www.medicalhomeportal.org/>.

## LEARN MORE

Supplemental material for this **Evaluation Highlight**, which includes a side-by-side comparison of key features of the caregiver peer support program in the four States, is available at <http://www.ahrq.gov/policymakers/chipra/demoeval/resources/supplhighlight07.html>

Additional information about the national evaluation and the CHIPRA quality demonstration is available at <http://www.ahrq.gov/chipra/demoeval/>.

Use the tabs and information boxes on the Web page to:

- Find out about the 52 projects being implemented in the 18 CHIPRA quality demonstration States.
- Get an overview of the projects in each of the five CHIPRA quality demonstration grant categories.
- View reports that the national evaluation team and the State-specific evaluation teams have produced on specific evaluation topics and questions.
- Learn more about the national evaluation, including its objectives, evaluation design, and methods.
- Sign up for email updates from the national evaluation team.

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