Engaging Parents as Partners to Support Early Child Health and Development

WHY DO PARENTS AND PROVIDERS OF PRIMARY CARE AND OTHER CHILD AND FAMILY SERVICES NEED TO PARTNER TO IMPROVE CARE COORDINATION SERVICES FOR YOUNG CHILDREN?

Ensuring and coordinating services that support young children’s healthy development requires strong and effective partnerships between families and health care providers. The effectiveness of each provider recommendation and/or referral depends on effective communication with parents, and parents accepting and implementing the advice. Consequently, providing patient and family education to build care-management skills is a critical characteristic of high performance pediatric care coordination.

A THREE-PART FRAMEWORK FOR BUILDING PARTNERSHIPS WITH PARENTS

The pyramid on page 2 illustrates a three-part framework for engaging parents in supporting healthy child development. It includes engaging with their child, with the services and programs they and their child receive, and with the larger systems and policies that govern those services and programs.
Level 1 — Engaging with their Children: Supporting parents in their parenting role and creating opportunities for them to be involved in decisions about their child’s health and development.

Level 2 — Shaping Services: Creating opportunities for parents to actively shape services so that they are parent-centered and approachable.

Level 3 — Shaping Systems: Supporting parents’ efforts to shape state policies and systems that promote children’s healthy development and to advise states in their efforts to develop broader systemic improvements.

The remainder of this brief describes each level of engagement, explains why each is critical to efforts to improve care coordination and services for young children, and gives examples of how states engaged in these initiatives can incorporate parent partnerships into their work.

Level 1: Parents Effectively Engaged with their Children

What is it?
The foundation for partnering with parents is enhancing their engagement in their child’s health and development. Parents can be supported in a number of health-related functions including:

- Involvement in decision-making about their child’s health care—e.g. choosing and accessing services for their child, expressing needs and perspectives during care visits
- Engagement in activities that help to promote child health and development—e.g. reading and playing with their child, preparing healthy meals, modeling positive health behaviors
- Knowledge and awareness of their child’s needs—e.g. understanding child development, communication with their child, understanding how to motivate their child
- Ability to reflect on and understand their ability to influence and promote their child’s health and development

Why is it important?
At the heart of a parent’s ability to positively impact their child’s health and development is their relationship with their child.

- If parents understand where their children are developmentally, are sensitive to the children’s needs, and are tuned in when problems arise, the parents can be more effective partners in helping ensure that children get the services they need. Parents also will have the ability to communicate more effectively about their children’s health and development issues.
- Understanding the link between children’s health and their physical, social and emotional development, and the importance of intervening with problems as early as possible, can help parents understand the need to follow up on provider referrals.
- Evolving research shows that very simple aspects of parenting—how often a parent holds or touches an infant, the amount of eye contact and affirmative responses parents give, and the level of conflict within the household—can have a profound impact on a child’s health and development.
- It is often a parent’s connection to their child that motivates them to try to improve the services and systems their child needs.

How to go about it
Primary care and other child and family service provider settings can support parents’ engagement with their child by:

- Supporting parents as active decision makers in care planning including setting aside time to explain any health and developmental concerns to them, assuring parents understand the information provided, being clear about decisions that need to be made and connecting them to other resources they can use to inform their decision.
- Modeling important skills; providing interactive anticipatory guidance; having tip sheets and information available that explain different health or development issues and provide ideas, actions and at-home activities that parents can take to support their children.
- Structuring the waiting room to ensure that there is a play space and toys that encourage parent and child interaction; for example, have children’s books and ideas for activities that parents can do with their kids while waiting.
Engaging Parents as Partners to Support Early Child Health and Development

- Providing space and resources for support groups for parents of children with similar health and development issues.
- Training staff members how to reach out to parents, talk with a parent about difficult issues, and communicate effectively with parents.\textsuperscript{2}
- Distributing and providing assistance with parent-administered developmental, behavioral and other health screening tools.

State policymakers can support efforts to assist primary care providers in engaging parents through a variety of mechanisms, including:

- Clarifying existing or establishing new policies, changing claims processing systems or managed care contracts, and updating provider handbooks to recommend or require the use of parent-administered developmental, behavioral, and other health screening tools.
- Providing incentives for providers to engage parents in their practices, such as reimbursement for using parent-administered screening tools.
- Using and reimbursing local health department staff for providing materials and in-service staff training to health care providers, aimed at assisting families in the appropriate use of children's health services under the EPSDT benefit.
- Supporting efforts to help engage parents, through mechanisms such as parent and community cafés, described on page 3.

**Level 2: Parents Shaping Services**

**What is it?**

Parents who are engaged consumers actively participate in the programs that serve them and their children. There are many ways this can manifest itself. In addition to active participation in program services (preparing questions in advance, arriving on time, engaging with staff, taking part in decision making about services, following up on referrals and giving feedback to the service provider even when it has not been solicited), they also belong to the larger community within the program by:

- Volunteering within the program—or otherwise contributing by donating resources and/or time
- Participating in social events and other activities that bring together program participants
- Participating in advisory or leadership boards or other decision-making structures within the program

- Helping advocate for the program
- Mentoring or providing support to other program participants

Clearly not every parent will participate in each of these ways. For most parents, it is sufficient if they are actively engaged in the ways described in the first point. Providers and program administrators alike can promote multiple opportunities for improving consumer engagement, including creating a culture where parental involvement is reinforced as a shared value across program participants.

**Why is it important?**

- Partnering with parents improves service delivery. Parents who are engaged are more likely to provide accurate information and discuss sensitive issues that can help inform service planning. They are more likely to follow advice and complete referrals. They are also more likely to engage with services in a genuine way, heightening the impact of the intervention.
- Creating opportunities for parents to serve in leadership and decision-making roles at the program level and providing regular and structured input helps ensure that the program has useful and accurate information about what timing, structure, and type of services families would be most likely to use, and can identify barriers to effective care.
- Engaging parents as partners can also have positive benefits for them as well as for their children. Headstart has numerous examples of the transformative impact of participating in parent leadership councils. Similarly, success breeds success. Parents who feel more confident about themselves as a result of actively partnering with their child's service providers can transfer that sense of effectiveness to other venues.

**How to go about it**

**Explain why:** To help parents feel valued as partners in shaping the delivery of services and supports that children receive, providers must dedicate time to explain developmental concerns, why any proposed services are important, and how the services will help the parent promote their child's health and development. Other programs have used parents as ambassadors to explain from their own experience why a developmental delay is important to address early and how the service has affected their own lives.

**Present choices:** Make sure that there are multiple options for parents to engage with programs that are part of their child's care plan. Choices allow parents to identify ways to participate that fit their schedules, interests and skills.
Engaging Parents as Partners to Support Early Child Health and Development

Parent Cafés and Community Cafés: Example of Level 1

Strengthening Families is a national initiative that engages programs working directly with children and families in building five, research-based, protective factors that have been found to be linked to the reduction of child abuse and neglect and children's optimal development. Parent and Community Cafés are an important tool used in many Strengthening Families states for directly engaging parents in building protective factors for themselves and their families. Adapted from the World Café, Parent Cafés and Community Cafés are structured small group conversations that bring parents together to discuss issues that are important to them.

Parents are invited to join conversations at Café Tables set up to host an intimate conversation. A casual café environment is created by limiting the participants to six to eight to a table and including food, tablecloths, flowers and other accessories to create an informal nature for the conversation. A parent leader trained in hosting café conversations leads each table. Carefully crafted questions guide the conversation. Each group spends a short period on a particular question and then joins a new table for a second question. Table hosts convey the key points from the previous group’s conversation to help each conversation build on the previous discussion. Generally a total of three inter-related questions are used.

In many cases, cafés are offered in series instead of a one-time event. Café series provide an opportunity for parents to build relationships over time, and to engage in thinking in a deeper and ongoing way about a particular issue.

A number of states have used the café process to engage a broad range of parent leaders who have been trained as café hosts, but also manage and lead the larger café process in the state.

Why Cafés are Effective Tools for Parent Engagement:

The intimacy of the conversation and parent leadership help create a level of candor that might not be achieved in a standard focus group or other feedback or input process.

The careful structuring of the questions and the iterative nature of the conversation in which groups reflect on previous group discussion help to create a structure for synthesizing knowledge across individual experience.

The infrastructure that has been developed around cafés in states has been an important tool for developing parent leadership at the state level. Parents that have been trained as Café hosts feel that they have an area of expertise and a skill base that gives them confidence in leadership roles. The very act of hosting conversations with other parents helps to create a knowledge base for café hosts that is much broader than their own individual experience. This makes them valuable contributors in planning processes.

How ABCD Sites can use Parent Cafés

Arkansas has developed guidelines for Community Cafés that describe Cafés, their purpose, what the state agency will provide, and responsibilities of Café hosts. The Arkansas ABCD project plans to adapt its Community Café model to conduct Cafés in its ABCD pilot sites. The Cafés in these sites will focus on developmental screening, referrals, follow up and linkages to community services.

At this level of parent engagement, the focus is on enhancing the parent’s role in supporting the health and development of their child. The following questions would help in understanding how parents view their own role regarding their child’s health and development and what parents feel they need (both in terms of barriers to overcome and in terms of resources in their community) to more effectively support their child’s development. These questions could help inform thinking about what linkages are needed to support parents as active agents in their child’s healthy development.

Questions that may be considered in designing a Café about care coordination and linkages to services include:

- What does healthy development mean for you and your child?
- What stands in your way in terms of supporting your child’s healthy development?
- What do you do on a day-to-day basis to keep your child healthy?
- How could your community be more supportive of healthy child development?

Resources to Learn More:

To learn more about World Cafés: http://theworldcafe.com/
To learn more about Parent Cafés: http://www.strengtheningfamiliesillinois.org/index.php/line/category/parent_cafe/
To learn more about Community Cafés: https://www.msu.edu/user/nactpf/initiative_parents-2.htm
Create a culture of engagement: Voice the desire and expectation that parents be engaged. Early and frequent communication about the value and options for consumer engagement is critical. Celebrating parent contributions publicly helps to send the message that parents are valued contributors. Parents are often the best ambassadors for a practice or program. Encourage parents to reach out to others and provide them with opportunities and tools to describe the options and benefits of engagement.

State policymakers can support efforts to engage parents in shaping services in a variety of ways, including:

- Requiring that practices that serve as medical homes develop parent advisory committees or include family members on practice leadership teams.
- Linking practices to Family-to-Family Health Information and Education Centers.³
- Supporting parent practice consultants through efforts such as Rhode Island’s Pediatric Practice Enhancement Project (PPEP), described below.

**Level 3: Parents Shaping Policies and Systems**

**What is it?**

Parents can play a leadership role in shaping systems and initiatives that are broader than the day-to-day services in which they and their families participate. They may serve on a statewide leadership team for a particular initiative, actively engage in a parent or consumer advocacy group or provide testimony in hearings or other deliberations on policies that affect children and families. At this level, parents are asked to extend their involvement beyond their own personal experience to represent the interests of a much broader constituency, thus informing and shaping important policy improvements relevant to their child’s care.

**Why is it important?**

Engaging those most affected in decision-making about policies and systems is crucial for ensuring that services and systems are responsive to the needs of families and structured in a way that will truly support families. Too often decisions about families are made without family representation. The well worn phrase, “Nothing about me without me” applies.

---

**Rhode Island’s Pediatric Practice Enhancement Project (PPEP): Example of Level 2**

Rhode Island’s Pediatric Practice Enhancement Project (PPEP) is a partnership between the Rhode Island Department of Health and Department of Human Services, the state’s chapter of the American Academy of Pediatrics, the Rhode Island Parent Information Network/Family Voices, and the Neighborhood Health Plan of Rhode Island. It places and supports specially trained parent consultants in pediatric primary and specialty care practices that serve large numbers of children with special health care needs and their families.

Parent consultants help physicians provide comprehensive medical homes, which support both families and practitioners. They link families with community resources, help providers and families get specialty services and identify systems barriers to coordinated care. Each parent consultant works 20 hours per week in a participating medical practice. When a provider learns or suspects that a patient has needs beyond the medical scope of the practice, the family is referred to the parent consultant. The parent consultant talks with the family regarding the family’s concerns and develops a plan to address the family’s needs. These needs could include resource identification; community referrals for social, developmental or mental health services; links with the education system; eligibility or application assistance for health insurance, nutrition, or housing services; navigation across services; and peer-to-peer support. Parent consultants call families to confirm that they make appointments and ensure they know what to expect when they arrive for a service. Families are served regardless of insurance status. Parent consultants also educate practice staff about state and community-based programs and services.

A 2008–2009 evaluation suggests that PPEP may result in more early interactions with the health care system, preventing costly interactions later. On average, PPEP children had fewer outpatient visits, emergency visits, and hospital stays when compared to the same children prior to PPEP; and PPEP children had more outpatient visits and less hospital stays when compared to a control group. PPEP children have less costly health care than both control groups and slightly more emergency room visits, but fewer hospital stays.¹ As a result of these cost savings, the Department of Health is working with health plans that want to become Medicaid providers to pay for peer navigators as a cost reduction strategy, providing a source of sustainability for PEEP.

Parental involvement helps identify barriers and strategies and is likely to result in overall system improvements.

**How to go about it**

States are engaged in a variety of strategies designed to engage parents as leaders. Parents are members of many state policymaking advisory boards, including Medicaid Medical Care Advisory Committees, Maternal and Child Health advisory councils, and Early Intervention Interagency Coordinating Councils. They also have opportunities to review and comment on proposed rules and to lobby state legislatures. However, they face many challenges, including dedicating time and resources to follow all of the intricacies of state policies and policymaking. For example, Strengthening Families began by mandating that states engage parent leaders on their statewide leadership teams. In an initial two-year state pilot the program found that states struggled to attract and retain parents within their state level leadership teams. Most states had high turnover in the parent representative positions. The parent leadership efforts are robust in a minority of states. Illinois, New Jersey and Washington have each pioneered a sophisticated infrastructure for supporting parent leadership at multiple levels. The strategies these states have developed are now transforming how other states are approaching the work. Lessons from these states include:

- **Draw from the other levels of the pyramid.** Leadership at the state or initiative level cannot be divorced from engagement in the other levels discussed in this brief. States with robust leadership efforts draw from a cadre of leaders that are being developed through their parent café efforts, leadership training institutes, or through structured efforts to attract leaders from operating programs.

- **Invite parent leaders who have experiences that connect them to and give them insight into the experiences of a broad range of parents.** When parent leaders are connected to a broader effort, they can bring a specific expertise that is grounded not only in their own experiences but also in their conversations and experiences with other parents. For example, in states that attracted leaders through their parent café or community café process, café hosts can speak not only from their own experience but from lessons learned through structured dialogues with other parent leaders. The role of parent leaders is not to represent their own experience within state leadership teams, but rather to represent the experiences of the broader networks of parents that are affected by the issue. Similarly, parents that participate in statewide advocacy groups, parent support networks, or parent-led organizations often are engaged in structured activities that allow them to hear from and represent the voices of a broad range of parents.

- **Don’t only invite parents to share their own story.** While sharing a personal story can be powerful within the context of state policymaking, asking parents in leadership positions to “tell their story,” can also create a challeng-

---

**COLORADO MEDICAL HOMES INITIATIVE: EXAMPLE OF LEVEL 3**

Colorado’s Medical Home Initiative is a joint effort of Colorado’s Department of Public Health and Environment, the Department of Health Care Policy and Financing and community stakeholders to ensure that, as required by law, every Colorado child enrolled in Medicaid or the CHP+ have access to a medical home by 2010. Colorado, being part of the NICHQ Medical Home project, has continued to expect parent involvement in all aspects of the program. Colorado Medicaid has hired parents to complete the Medical Home Indices with practices and parents to measure the extent of compliance with medical home principles and parent satisfaction. They have also been hired to be the front line staff for technical assistance to practices. Families are integral to the medical home concept as leaders and partners within the community as well.

Family Voices Colorado provides information for health care providers and families; referral resources; advocacy support; training; and systems change support. Family Voices Colorado was involved in the development and manages a certification process for primary care providers based on the Medical Home Index. The group also engages in family leadership development and makes family navigators available to assist families in negotiating the medical home system.

The Colorado Family Leadership Task Force is dedicated to assuring that the Colorado Medical Home Initiative is culturally responsive and family-centered. By engaging the expertise of family leaders from across Colorado, the task force ensures that a family perspective is considered at all levels of medical home implementation. The task force is committed to developing strong family leaders who participate in policy and systems change efforts to assure children’s health care quality. This task force currently is working on the development of a Family Leadership registry and exploring leadership curricula that promote strong civic engagement.
Rhode Islanders become their own best advocates in providing information, support, and training to help all hire, train, and supervise the parent consultants. RIPIN Information Network, which includes Family Voices, to view the barriers identified through the PPEP database. The department contracts with the Rhode Island Parent Leadership organizations such as Family Voices and Voices for America's Children, and programs of the Family-to-Family Health Information and Education Centers, and Center for Study of Social Policy provide resources on which to draw.

**Putting the Pieces Together: Parent Partnerships in Rhode Island**

The Pediatric Practice Enhancement Project (PPEP), described earlier, is a Medical Home initiative of the RI Department of Health and a project implemented by the Rhode Island Parent Information Network (RIPIN). Parent consultants complete project paperwork, which is entered into a data system developed and maintained by the Rhode Island Department of Health. The Department of Health administers PPEP and is responsible for the project's financial management, data and evaluation, and communication with participating physicians and practices. Staff at the department generate periodic reports and present the information to each PPEP site quarterly so physicians and staff can learn how many of their patients and families have been served, major issues and concerns, and whether problems were resolved. The PPEP database helps identify system-wide barriers facing families trying to obtain appropriate care for their children. The Family Voices leadership team functions as the PPEP steering committee and includes representatives of state agencies (human services, education, and health) and community stakeholders. The leadership team meets monthly to review the barriers identified through the PPEP database.

The department contracts with the Rhode Island Parent Information Network, which includes Family Voices, to hire, train, and supervise the parent consultants. RIPIN provides information, support, and training to help all Rhode Islanders become their own best advocates in school, health care, care, and other settings. RIPIN has cultivated and supported its Peer-to-Peer Support Model for a variety of settings and topic areas. For example:

- The Rhode Island State Parent Training and Information Center and Parent Information Resource Center has Family Involvement Specialists and Family/School Liaisons who take calls from parents, families, and professionals and provides technical assistance to schools on a wide variety of topics.
- All Early Intervention sites include at least one parent on their team, who is hired and supported by RIPIN.
- Family Voices within RIPIN provides healthcare information, family to family health information and support, and leadership development related to health insurance and policy issues for families of children with special healthcare needs.
- RIPIN's Statewide Resource Center is staffed by multiple programs to holistically address the complex needs of families seeking support.

RIPIN provides empowering experiences so parents can advocate for their own children; learn to help other parents and families; shape services systems; and have a voice in policy. RIPIN's architecture and the state's broad commitment to parent leadership have helped make PEPP a success as a medical home initiative that provides enhancement services in a high quality and cost effective manner.
services and policies that are developed with parent input to facilitate parent engagement. Creating opportunities for input both at the program and system level can help all stakeholders jointly design strategies that are truly effective at meeting parents’ needs and most likely to further promote healthy child development.

Rhode Island’s Pediatric Practice Enhancement Project (PEPP) described earlier provides an example of a state initiative that supports the three types of parent partnerships, and the synergy created in doing so. Parents who are involved in PEPP are engaged with their children, as parent consultants to practices, and in informing state policymaking. The infrastructure created to support parent leadership supports not only PEPP, but also a multifaceted parent engagement, as described on page 7.

RECOMMENDATIONS

State policymakers can support efforts at all three levels of the framework for parent engagement.

Level 1: Assist primary care providers in engaging parents:

- Clarify policies to recommend or require the use of parent-administered developmental, behavioral, and other health screening tools;
- Provide incentives for providers to engage parents in their practices, such as reimbursement for using parent-administered screening tools;
- Use and reimburse local health department staff to provide materials and in-service staff training; and
- Support efforts to help engage parents, through mechanisms such as parent and community cafés.

Level 2: Support efforts to engage parents in shaping services:

- Support parent advisory committees or parents on practice leadership teams;
- Link practices to Family-to-Family Health Information and Education Centers and leadership training opportunities; and
- Support parent practice consultants.

Level 3: Support efforts to engage parents in policy and systems changes:

- Enact family-centered policies, including medical home initiatives;
- Call on parent leadership organizations to help identify parents for state policymaking advisory boards; and
- Include within medical home initiatives strategies that encourage practices to be child and family centered, such as parent satisfaction measures, support for parent leadership development, and parent compensation for involvement.

Finally, states can create intentional strategic mechanisms to build on and support each level of engagement by:

- Drawing from and connecting each level of parent engagement;
- Inviting parents to represent the experience of broad networks of parents; and
- Creating a broad infrastructure to support parent leadership through training, support and opportunities to interact with other parent leaders; and resources to resolve the demands that leadership involvement makes on their work and family lives to be effective partners in state or initiative-wide efforts.

ABOUT THE ABCD PROGRAM

Since 2000, the National Academy for State Health Policy (NASHP) has administered the Assuring Better Child Health and Development (ABCD) program. From 2000-2003 and 2003-2006 NASHP administered two 3-year, multi-state learning collaboratives to develop and test Medicaid-based models for improving the delivery of early child development services to low-income children and their families by strengthening primary health care services and systems. A total of eight states participated in the collaboratives. From 2007-2008 NASHP administered the ABCD Screening Academy. Nineteen states, Puerto Rico and the District of Columbia participated. With NASHP support they worked to develop and implement policy improvements designed to promote, support, and spread the use of a standardized developmental screening tool as part of regular well-child care. Screening Academy members also supported selected primary care practices’ efforts to incorporate standardized developmental screening tools into regular well child care—and continue to work to spread those improvements to other practices within their state. In 2009 NASHP initiated ABCD III, which includes a multi-state learning collaborative of five states designed to develop and test sustainable models for improving care coordination and linkages between pediatric primary care providers and other providers who support children’s healthy development.

ABCD Resource Center: http://www.nashp.org/abcd-welcome
**ABOUT STRENGTHENING FAMILIES**

The information in this policy brief is grounded in the experience of Strengthening Families, a national initiative that engages programs working directly with children and families in building five, research-based, protective factors that have been found to be linked to the reduction of child abuse and neglect and children’s optimal development. Currently over half of all states are part of the Strengthening Families National Network. Strengthening Families parent engagement strategies have focused on multiple levels:

- Helping programs on the ground shift program structure and worker practice to make them more welcoming environments for parents.
- Convening thousands of parent-to-parent conversations regarding the protective factors and why they are important in parents’ lives.
- Supporting parent engagement in the self-assessment and decision-making structure at the program level.
- Emphasizing parent engagement and partnership in work with state level leadership teams.

Over the past nine years Strengthening Families has learned a lot—some about what works to build authentic parent engagement, and some about what doesn’t work.

**Strengthening Families:** [http://www.strengtheningfamilies.net/](http://www.strengtheningfamilies.net/)

---

**ENDNOTES**


2. Strengthening Families has created a self-assessment tool that programs can use to assess their program structure and day-to-day practice and make small but significant changes in practice. This self-assessment tool can be downloaded at [www.strengtheningfamilies.net](http://www.strengtheningfamilies.net) and is appropriate across child and family serving settings. Brazelton Touchpoints provides training, technical assistance, and consultation to early childhood educators, early interventionists, and health care and social service providers to create strong partnerships with families of young children and change the way families are served. [http://www.touchpoints.org/index.html](http://www.touchpoints.org/index.html). Retrieved May 26, 2010

3. Family-to-Family Health Information and Education Centers (F2F HICs) are family-led organizations that seek to ensure that families of children with special needs have access to adequate information about health care and community resources in order to make informed decisions. The U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal Child Health Bureau (MCHB) provides the primary funding support. Family Voices provides training and technical assistance to F2F HICs. [http://www.familyvoices.org/info/fc/lpp/f2fhic.php](http://www.familyvoices.org/info/fc/lpp/f2fhic.php). Retrieved May 26, 2010


---

**About the National Academy for State Health Policy:**
The National Academy for State Health Policy (NASHP) is an independent academy of state health policy makers working together to identify emerging issues, develop policy solutions, and improve state health policy and practice. As a non-profit, non-partisan organization dedicated to helping states achieve excellence in health policy and practice, NASHP provides a forum on critical health issues across branches and agencies of state government. NASHP resources are available at: [www.nashp.org](http://www.nashp.org).

**Acknowledgements**
The authors greatly appreciate input and review of draft materials by Deborah Garneau, Office of Special Health Care Needs, Rhode Island Department of Health; Martha Hiett, Division of Child Care and Early Childhood Education, Arkansas Department of Human Services; Megan Marx, Family-to-Family Health Information Network, Family Voices Colorado; Gina Robinson, Colorado Department of Healthcare Policy; and Lisa Schaffran, Rhode Island Parent Information Network.

We also thank Jennifer May and Larry Hinkle, National Academy for State Health Policy, and the Commonwealth Fund, particularly Dr. Ed Schor, Vice President for State High Performance Health Systems, for his suggestions and guidance. Any errors or omissions are those of the authors.

**Citation:**