



CHILD DEVELOPMENT AND MEDICAID:  
ATTITUDES OF MOTHERS WITH YOUNG CHILDREN  
ENROLLED IN MEDICAID

*A Report on Focus Group Findings in  
North Carolina, Utah, Vermont, and Washington*

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March 2001

Support for this research was provided by The Commonwealth Fund. The views presented here are those of the authors and should not be attributed to The Commonwealth Fund or its directors, officers, or staff, or to members of the Task Force.

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## PREFACE

The Commonwealth Fund established the Assuring Better Child Health and Development (ABCD) Program in 1998 to strengthen the capacity of the health care system, and the Medicaid program in particular, to provide low-income families with services geared toward early childhood development. As part of the ABCD program, the Fund awarded a grant to the National Academy for State Health Policy (NASHP) to help state Medicaid agencies deliver these services effectively. Based on their proposals, four states—North Carolina, Utah, Vermont, and Washington—were selected to join a consortium and receive grants for testing ways to improve the delivery and financing of developmental services.

A major objective of the ABCD program is to improve the health and development of low-income children and support policies and programs that help parents properly nurture their infant or toddler's healthy development. Since children receive and access care through parents, it is important first to understand what parents know and how they feel about child developmental services. To aid the consortium states and others in developing programs that take into account parents' experiences and attitudes, the Fund supported Lake Snell Perry & Associates to conduct focus groups with mothers who have very young children enrolled in the Medicaid program. Two groups were held in each of the four states. The following topics were discussed: mothers' opinions of their current pediatric providers and the quality of doctor–parent communication, current barriers to coordination of health care services, preferred ways of receiving information about parenting, concerns about their child's development, and reactions to the types of services and models tested by the ABCD states.

We hope these findings will help states promote the healthy development of low-income children will be interested in the findings contained in this report. Parents offer their advice on how to design and disseminate educational materials, from targeting information to young mothers or first-time mothers, to using culturally appropriate language, to explaining why the information provided is important. They also provide valuable insights for doctors about how to improve their communication skills. Indeed, many of the problems regarding parent–physician interaction are not limited to low-income patients but are relevant to families regardless of socioeconomic status. For policymakers, there are recommendations about how to notify mothers about services and provide them with information. Focus group findings also suggest specific areas where state Medicaid programs can play an active role in supporting early child development.

While the mothers who participated in this study helped to highlight ways in which services could be improved with respect to child development, many of their overall comments about Medicaid and their access to health care were quite positive. Participants said they value the care their children receive and appreciate the opportunities the program provides. Their feedback thus confirms the importance of building on state Medicaid programs in efforts to promote early child development.

We thank Susan Kannel and Michael Perry from Lake Snell Perry & Associates for coordinating and moderating the focus groups; Ana Rivera and Maria Yvonne Rivera for moderating the Seattle and Charlotte Spanish-language focus groups, respectively; our state project directors for their assistance with identifying parents and planning the focus groups; and Melinda Abrams of The Commonwealth Fund and Deb Curtis of the National Academy for State Health Policy for their guidance and input on the project and the report. Most of all, we extend our appreciation to the 76 mothers who agreed to participate in the focus groups and share their experiences with us.

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## EXECUTIVE SUMMARY

Despite robust economic growth in the United States over the past several years, nearly one-quarter (22%) of young children age 5 and under live in families with incomes at or below the poverty level (about \$17,000 for a family of four). Poverty places children at risk for an array of health and developmental problems. Children of low-income families are less likely to have access to health care, and their parents are less likely to engage in activities that can help foster their child's healthy development.

Health-related developmental services, such as home visits, structured developmental assessments, and parent education, have been shown to reduce unnecessary emergency room visits and increase the frequency with which parents read aloud to their young children, better preparing them for education. For low-income families, Medicaid and other health care programs can play an important role in ensuring that families with young children receive care needed for early childhood growth and development.

In the summer and fall of 2000, The Commonwealth Fund commissioned Lake Snell Perry & Associates to conduct eight focus groups with mothers of very young children enrolled in Medicaid. Two groups were held in each of the four states currently receiving grants from the Fund to improve delivery of Medicaid services related to early child development: North Carolina, Utah, Vermont, and Washington. The focus groups were intended to expand understanding of what mothers know about child development, how they perceive the developmental services provided by Medicaid, and what their interactions with pediatricians and other clinicians have been like. Each participating state also added questions designed to inform the design of its Fund-sponsored project.

The findings from these focus groups should be of use not only to the four states, but also to policymakers, Medicaid program directors, pediatricians, and others in any state or locality that is contemplating changes aimed at improving the health and well-being of infants and toddlers living in low-income households.

### FINDINGS

For many families, Medicaid is helping to provide access to good pediatric care. Focus group mothers in North Carolina, Utah, Vermont, and Washington view Medicaid as an important program and are thankful for the free health coverage it provides. These mothers reported that their children have access to preventive and well-child care—used particularly for immunizations. Most said they had a regular place to take their children for health care and were satisfied with that care. However, discussions with these mothers also

highlight gaps in care. Families that do not have a regular pediatrician are less satisfied with the care their child receives than those who have been able to establish a relationship with a doctor.

Although many of the mothers participating in the focus groups said they have adequate access to information about child development, a significant number face barriers to receiving this kind of information. These are mothers who do not have a regular pediatrician whom they trust—one who will engage them in a discussion about their child's development. Often, they have an incomplete understanding of development issues: many believe, for example, that regular immunizations are all the well-child care their child needs. Some of the focus group mothers feel that their doctor does not spend enough time with them. Some also noted that they are asked to complete questionnaires about their child's development without receiving any explanation of how they are used to guide their child's care.

Among those mothers who say they have adequate access to child development information, there were some who expressed dissatisfaction with the way it is presented to them. When the doctor simply tells them what to do—without listening to their views and showing respect for their child-rearing expertise—these mothers find it difficult to accept and follow instructions. In addition, some of the child development information supplied by Medicaid and individual doctors is not culturally appropriate to its intended recipients. Spanish-speaking mothers, in particular, cited a lack of competently translated written materials. They also complained that there are not enough Spanish-speaking clinicians or proficient translators.

### Reaching Parents with Information

The mothers in this study offered helpful advice about how best to provide them with childhood development information. Following are some of their suggestions.

Provide information appropriate to the mother's age, parenting experience, language, and cultural background. Mothers want advice and programs that are targeted to their particular experience, living situation, and needs. They say that a one-size-fits-all approach will not work. First-time mothers, for example, need more information than more experienced mothers—teen mothers will have different concerns than older mothers. Participants also want information on child development to reflect parents' ethnic, religious, language, and socioeconomic background.

Do not tell parents what to do without explaining why. Parents want to know why health care providers make the recommendations they do about child development.

Do not forget mothers' well-being. Some mothers want their providers and Medicaid to show concern for their own health and well-being, since raising a small child can be both physically and emotionally demanding.

Include fathers and other family members, too. The focus group mothers pointed out that all the advice and information about infant care is directed solely at them. They want fathers to learn about child development, too. Grandparents and other family members who are involved in caregiving should also be informed.

Make materials easily accessible—and avoid information overload. The child development information produced by Medicaid should be simple, to the point, and organized in a way that makes it easy for busy mothers to find the information they need quickly. Furthermore, parenting programs should be held at convenient times and in nearby locations, possibly with babysitting services provided.

Create easy-to-access educational tools such as videos and charts, and use the Internet. Many mothers recommended that the Medicaid program develop instructional videotapes about child development, which they could watch and review at their leisure in their own home. A few mothers also suggested that Medicaid develop charts, posters, and refrigerator magnets that could serve as a daily reference for their child's development. A number of mothers mentioned they would prefer to access child development information through the Internet.

Provide opportunities for interaction with other mothers. Many expressed interest in the idea of attending discussion groups with other mothers to talk about child development issues. They believe they can gain practical information and pick up tips by talking with mothers like themselves.

Offer a home-visiting program that is responsive to mothers' needs. Mothers support the concept of learning about their child's development through visits from nurses or other trained professionals, but they want to make sure the program is "mother-friendly." They would like the program staff to:

- Work with mothers to set the timing of the first visit. Some prefer waiting a few weeks before being contacted; others need help sooner.
- Not call so frequently to check in with mothers—once is enough.
- Show respect for mothers' expertise and opinions during the home visits.
- Make it clear from the start that visiting nurses are not there to “spy” on mothers or make judgments about them.

Pediatricians should continue to be the main source of information about child development, but they could improve their interaction with mothers. Many mothers said they prefer to learn about child development through their pediatrician. However, some think the following changes in their practices would be helpful:

- Allow parents to spend more time discussing development issues during appointments.
- Raise development issues with parents, because they do not always know what questions to ask.
- Be respectful of parents' views on child-rearing during visits.
- Engage parents in discussions about child development, rather than just relying on standard questionnaires.

## IMPLICATIONS FOR MEDICAID

This research points to ways in which state Medicaid programs can address the issues and challenges raised by mothers. Possible steps include:

- Helping mothers of Medicaid-enrolled children form relationships with their pediatricians, whom they believe are the best source of information about child development. An important component of this help is reducing lapses in health insurance coverage, to help ensure continuity of care.
- Extending Medicaid benefits so that mothers can receive services and support for a longer period after the birth of their child. Services should



address maternal health problems that may interfere with the ability of mothers to care for their infant. Medicaid should also facilitate opportunities for learning about child development.

- Offering more nurse home visiting programs and placing child development experts in doctor's offices—which mothers say they like and would use.
- Creating an awareness campaign to educate mothers about the benefits of comprehensive well-child care and encourage them to take their child to the pediatrician regularly.
- Raising awareness among pediatricians and other clinicians about their central role in informing mothers about child development, and offering ideas as to how they can provide this information effectively.
- Identifying potential linkages with other programs serving low-income families with young children, such as the Women, Infants, and Children (WIC) program.
- Designing child development programs to reflect differences in mothers' age, parenting experience, cultural background, and language.
- Establishing standards for interpreters so that non-English-speaking mothers can feel confident that the information they receive is accurate.

## I. INTRODUCTION

Although child poverty rates in the United States have improved since 1993, one of five children age 5 and younger (22%) is poor and 42 percent live in families that are at 185 percent of the federal poverty level or below.<sup>1</sup> Young children constitute the poorest age group.<sup>2</sup>

Poverty can increase children's risk of an array of health and developmental problems. Poor children are more likely to have had a low birth weight and to have been overweight as toddlers. They are more likely to suffer from lead poisoning, experience developmental delay, have a learning disability, and suffer from emotional or behavioral problems.<sup>3</sup> Low-income children are also less likely to have access to health care, and their parents are less likely to engage in activities that foster healthy development—from breast-feeding to reading aloud everyday.

Recent evidence indicates that poverty in the earliest years of life may have a more powerful and lasting influence on a child's subsequent health and achievement than does poverty at any other time in childhood. While most poor children are resilient and grow up to be productive adults, some do not. Without intervention, poverty-related differences among young children just beginning school often persist over time.<sup>4</sup>

Pediatric clinicians are in a good position to help parents understand the dynamic process by which children grow and learn and to foster a child's healthy development. Health-related developmental services, such as home visits, structured developmental assessments and parent education, have been shown to reduce unnecessary emergency room visits, increase the number of breast-feeding attempts by new mothers and increase the rate of reading to young children per week.

Serving one-quarter of all U.S. children age 6 and under and 61 percent of poor children ages 1 to 6, state Medicaid programs provide critical support for young children and their

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<sup>1</sup> The federal poverty level for a family of four is set at \$17,050; 185 percent of poverty is about \$31,500. See National Research Council and Institute of Medicine, *From Neurons to Neighborhoods: The Science of Early Childhood Development*, Jack P. Shonkoff and Deborah A. Phillips (eds.), Board on Children, Youth, and Families, Commission on Behavioral and Social Sciences and Education (Washington, D.C.: National Academy Press, 2000).

<sup>2</sup> Bennett, 1999 (National Center for Children and Poverty).

<sup>3</sup> Greg Duncan and Jeanne Brooks-Gunn, "Family Poverty, Welfare Reform, and Child Development," *Child Development* 71 (January/February 2000): 188–196.

<sup>4</sup> *From Neurons to Neighborhoods*, 2000.

families.<sup>5</sup> Medicaid covers comprehensive preventive services that are designed to enhance children's growth and development.

To learn more about the experiences and opinions of mothers who have used Medicaid's child developmental services, The Commonwealth Fund commissioned Lake Snell Perry & Associates to conduct eight focus groups with mothers who have children age 4 or younger enrolled in Medicaid. The focus groups were conducted in June and September 2000 in four states—North Carolina, Utah, Vermont, and Washington. With Fund support, these same states are currently testing new ways to strengthen the capacity of their Medicaid program to deliver child developmental services.

Participating mothers were asked the same core set of questions in all four states. Additional questions were individually tailored to reflect each state's particular interests and child developmental efforts. Table 1 lists focus group characteristics.

*Author's Note:* This study is based on qualitative research. To be conclusive, the findings would need to be tested and quantified through a telephone survey or similar research method. These findings do, however, offer useful insight into mothers' views about child developmental services.

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<sup>5</sup> Paul Fronstin, "Sources of Health Insurance and Characteristics of the Uninsured: Analysis of the March 1999 Current Population Survey," EBRI Issue Brief, No. 217 (January 2000).

**TABLE 1: PARTICIPANT PROFILE**

Group No.	State	Date	Ethnic Composition	Age of Target Child	About Participants
1	Vermont	6/9/00	White	12 months or younger	Mothers with a child enrolled in Medicaid who refused home visits from the Healthy Babies Program, either initially or after one or two visits.
2					
3	Utah	6/28/00	Mostly White (One Hispanic)	18 months or younger	Mothers with a child enrolled in Medicaid who reported that the child did not have any disabilities or serious or chronic illnesses.*
4					
5	Washington	9/19/00	White	4 years or younger	Mothers with a child enrolled in Medicaid who reported that the child did not have any disabilities or serious or chronic illnesses.
6			Spanish-speaking Hispanic		
7	North Carolina	9/27/00	Spanish-speaking Hispanic	2 years or younger	Mothers with a child enrolled in Medicaid who have used one of three local pediatric practices for at least 6 months (or since their child's birth); also, mothers who reported that their enrolled child did not have any disabilities or serious or chronic illnesses.
8			Mixed African-American and White		

\* Recognizing that children who have physical and mental disabilities, or chronic illnesses, have specific needs and pose diverse challenges for Medicaid, this study did not seek to address these issues.

## II. FINDINGS

### MOTHERS' PERCEPTIONS OF THEIR CHILD'S HEALTH CARE

The mothers who participated in this study said that their Medicaid-enrolled child has access to preventive and well-child care through the program. While most reported they are satisfied with this care and have a strong relationship with their child's pediatrician, there were a number who seemed less than satisfied. Generally, these are mothers who said they do not have a regular pediatrician to watch over their child's health care, but instead must see whichever doctor is available when they take their child in for an office visit. Some mothers also explained they are frustrated with the long waits to see the doctor or to make appointments. Once they see the doctor, they complain of being rushed and not having enough time.

There were also signs that some mothers may not be taking advantage of the well-child care that is available to them. For example, some mothers acknowledge that they occasionally miss or delay well-child appointments or scheduled immunizations because they are busy or forget about the appointment. Some mothers also said that while they make sure their child receives scheduled immunizations, they are less concerned about missed well-child care visits. They feel their child is covered because he or she was immunized.

Mothers also expressed both positive and negative opinions about Medicaid. While they are generally satisfied with the program's coverage and thankful for their child's free health care, they are frustrated with Medicaid's bureaucracy and sometimes feel looked down upon because their child is enrolled in the program.

Most mothers said their child has access to all the necessary preventive and well-child care a young child needs.

Focus group mothers initially painted a positive picture of access to preventive and well-child care through Medicaid. They said they take their children in for immunizations, and most reported bringing them in for regularly scheduled well-child checkups. Most also follow a recommended schedule of well-child checkups for their baby during the first year or two. As one Vermont mother explained, "[They have

checkups] at two weeks, two months, six months, and then a year. I think that is how they do it.”

Most mothers also said they receive help in their efforts to keep up with scheduled immunizations and checkups. Some report their health care provider encourages them to schedule the next appointment at the end of each well-child visit. Others receive a postcard reminder or a telephone call in the days leading up to each appointment. Some of these reminders come from the doctor’s office, while others are sent by the state child health program.

Most mothers reported that their child has a regular pediatrician who manages the care. For about half the mothers, this is a private pediatric practice. The other half brings their child to a clinic or health department. Almost all have a place to go for care after normal office hours; few seem to rely on the emergency room, except in dire circumstances.

Most mothers reported that they are satisfied with their child’s care, though some are less than satisfied—whether because of long waits to see the doctor or the amount of time the doctor spends with them during office visits.

For the most part, the mothers who participated in the focus groups are pleased with the health care services their child receives. Many said that their child is cared for by competent and knowledgeable health care providers. Those who have been able to form a relationship with a particular doctor are especially likely to be pleased with their child’s care. Many mothers also said that their child’s doctor spends enough time with them and answers their questions during well-child visits. “[My child’s doctor] really spends time with you and she wants to find out even things affecting the kid at home other than the child’s health,” one North Carolina mother explained. “Sometimes I almost feel like she’s wasting other people’s time. I’ll be like, ‘Oh well, we’ve taken so much of your time,’ and she says, ‘Don’t worry about it, I just want to make sure that you are okay’.” Other mothers share similarly positive stories about their child’s providers.

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*“I do feel sometimes that he is kind of in a hurry to get to his other patients. I try to ask him all the questions before he leaves and he will ask if there is something else, but he’s got one foot out the door and one foot in.”*

*Washington mother*

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A few mothers, however, feel they do not have enough time with their child's doctor. They claimed that appointments are rushed and the doctor seems distracted or impatient. This complaint was raised more often with regard to sick visits, for which the regular doctor is sometimes less available.

In addition, those mothers who have not found a regular doctor for their child said they were not fully satisfied with their child's care. They would prefer to have a relationship with just one pediatrician, one who knows their child and is familiar with his or her medical history. The reasons for not having a regular doctor vary. A small number do not seem to realize the benefits of having one doctor with whom they and their child can develop a relationship. To them, a doctor is consulted only in times of illness.

Others said they did not know they could have just one regular physician. One mother in a Utah focus group explained that she saw a different doctor each time she took her baby to their clinic. "They haven't asked me [if I wanted a regular doctor]. I get to see whoever's there. I mean, it's really close to my house. That's why it's so convenient. I've taken her there for her shots, but they never asked me [to choose a primary provider]." A few other mothers said they do not have a regular doctor because of the high turnover in their child's health plan; as soon as they finally establish a relationship with a doctor, that doctor leaves the practice. Such turnover is unsettling, said these mothers, because they feel that no one is watching over their child's care. A few mothers also reported that they have been unable to find the right provider for their child, despite switching many times.

Some dissatisfied mothers talked about the long time it takes to schedule a well-child visit. They said they must spend too much time in waiting and examining rooms with their child—even with an appointment—before they get to see the doctor. Some mothers believe the problem is that their child's doctor has too many patients and overbooks appointments. The result, they said, is that it can take weeks or even months to schedule an appointment. One North Carolina mother described her experience:

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*"Since [my son] was five months old, I've seen at least six or seven different doctors."*

*North Carolina  
mother*

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*"They keep me a long time waiting to be seen, and then I spend half an hour [in the exam room] waiting for the doctor to arrive. If the appointment is at 1:30 you're done at 3:30."*

*Spanish-speaking  
North Carolina  
mother*

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I haven't been back to the doctor since [my child] was nine months old. I had to make an appointment, but I can't get in until November, so I'm still waiting. And I've been in between doctors, too, because [my child's doctor] retired, so I haven't actually been talked to by anybody since my daughter was like five months old.

Some focus group members joked about not being able to schedule the six-month checkup until their child was nine months old. Even after they make an appointment, some mothers said they have to wait in the doctor's office for a long time. A few mothers, frustrated by the long waits, end up missing well-child appointments.

Not having a regular pediatrician also means that some mothers miss out on opportunities to learn more about their child's development. Comments of focus group participants suggest that mothers are less likely to ask a doctor health care questions or discuss their child's development if they are seeing a different doctor at each visit. Participants said that a certain level of comfort and familiarity is needed for these discussions to take place.

Even though well-child care is available through Medicaid, some mothers are not taking advantage of it.

Some of the mothers explained that they live busy lives and sometimes forget about or skip scheduled well-child visits and immunizations. They noted that their child's apparent good health lulls them into thinking that a delayed or missed doctor visit or immunization will not harm their child. One Washington mother said of her situation: "I kept skipping [my children's doctor's appointments] because I kept forgetting. I think I've got them up-to-date now. I think two of them need their shots, [though]."

In some cases, mothers may be delaying well-child care because they do not fully understand the benefits of preventive care. While these mothers know their provider recommends regular well-child visits and scheduled immunizations, they may not understand why such care is important and what consequences missed appointments and immunizations can bring. It became apparent during the focus group

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*"It's been nine months since I've taken my son to the doctor because he has all the vaccines he needs. The nutritionist [at WIC] told me to take him in for a checkup."*

*Spanish-speaking  
Washington mother*

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sessions that some of the mothers believe immunizations are the only preventive health care their child really needs. Well-child visits, they feel, are not necessary as long as their child is kept up-to-date with the recommended shots.

An illustration of this thinking comes from one of the Washington focus groups. Some of the mothers told of bringing their child to the local WIC center for health care, since these centers provide immunizations for children and also weigh and measure them. For many of these mothers, these limited services constitute the majority of the well-child care their son or daughter receives. Only if the WIC nurse tells them of any problem or concern do mothers take their baby or toddler to a doctor for a more thorough exam. “I only take him for his vaccines because he never gets coughs or diarrhea—nothing,” said one mother. Because they confuse immunizations with comprehensive well-child care, some mothers unknowingly miss out on developmental information and services that could benefit their young children.

Most mothers have a positive view of Medicaid’s coverage but dislike the program’s cumbersome bureaucracy and the sometimes condescending treatment they receive from enrollment workers, doctors, and office staff.

Most mothers appreciate all the health care services that Medicaid covers, and that this care is provided at little or no cost to them. As a Utah mother commented, “[Medicaid] is a lot better than getting insurance through your job because you have copays [with employer coverage], and then sometimes it does not cover [a service you need]. Then you have to pay the rest of the bill, and it is very stressful.” Other study participants noted that Medicaid covers not just basic health care for their child, but also a broad range of specialist services. A number of mothers asserted that they and their child receive better personal treatment through Medicaid than they would through private insurance. One mother was particularly effusive in her praise:

I wasn’t poor with my first daughter, but I’m broke with this one. I’m getting more help, more love, more concern and support than I ever thought was possible. If I could take it back and have [my older daughter] get

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*“When my son was born, there were some doctors that would be rude to you or wouldn’t give you the care you deserved because you are on Medicaid. They say ‘Oh, you’re on Medicaid’ and kind of roll their eyes and treat you different.”*

*Utah mother*

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the kind of care that [my younger daughter] is getting, [I would]. It is just phenomenal.

Yet some mothers point out that there are problems with Medicaid. They complain about Medicaid's bureaucracy and difficulties with billing—for example, mistakenly receiving bills for services covered by Medicaid. Others mentioned trouble with prescription coverage: some have not been able to obtain medication recommended by the doctor because Medicaid does not cover it. Some mothers also said that Medicaid's eligibility rules are confusing and the enrollment process too complicated.

Finally, some mothers do not like the way they are treated by Medicaid enrollment workers, providers, and providers' staffs. These mothers feel they and their child are sometimes treated like second-class citizens because they have Medicaid. Mostly they complained of an enrollment worker, doctor, or staff person who "talked down to them" or treated them brusquely.

#### MOTHERS' KNOWLEDGE OF CHILD DEVELOPMENT

The focus groups revealed that many mothers know quite a lot about child development issues, particularly about the basics of physical and mental development. They are engaged on this subject, ask their pediatrician a lot of questions, and talk to family and friends frequently about their child's development. Many mothers said they want to learn more about development from providers and are open to new ideas and parenting techniques.

But comments made during the focus group discussions show that, in fact, some mothers do not always follow expert advice. While they acknowledge that their decisions may sometimes conflict with what doctors or others advise, ultimately they feel they know best as the mother. A lack of information may be behind why some mothers ignore their doctor's recommendations regarding development. Some mothers said their providers do not always properly explain the advice they give or the possible consequences of not following it. As a result, mothers may be making independent decisions for their child without knowing the risks.

The manner in which doctors and others relay their advice to parents appears to play a key role as well. Some mothers explained that they tend to “shut down” when they perceive that the provider is talking down to them or simply “telling them what to do.” They also are less open to hearing advice if they feel the doctor is ignoring their experience with and knowledge of their own child. Presenting child development information in the right way—by showing respect for what the mother knows, by facilitating a give-and-take discussion, and by providing explanations and reasons for the advice rendered—can sometimes determine whether a mother will comply with her doctor’s recommendations.

Mothers pay close attention to their child’s development; indeed, many seem to know child development basics and are eager to learn more.

Nearly all mothers in the study said they celebrate their child’s everyday advances and victories and are on the lookout for any potential problems. They care deeply about their son or daughter’s development, and many claimed they are aggressive about obtaining information on the topic. Most said they talk with their child’s doctor about development issues. Moreover, these mothers share their knowledge and ideas with, and ask questions of, friends and family members. Some read parenting magazines and pamphlets about child development. Even those who do not know a lot about the topic insist they want to learn more, because they feel that promoting their child’s development is part of being a good parent.

Mothers’ concern with child development was evidenced by some of the comments made during the focus group sessions. “My daughter is 13 months old and is still afraid of walking,” said one mother. “Some of my friends say that she should be walking already.” Another mother commented, “My five-year-old is still wetting the bed. I think lately he is doing better, but my six-year-old didn’t do that. I’m like, ‘Why is that happening to him?’” Still another mother voiced concern over her child’s temperament:

When [my daughter] started day care, she was really shy and quiet. At home she is okay; but [not at day care].

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*“Time spent with the parents teaching them, showing them different things [is very important to a child’s development]. Being a single mother, sometimes you don’t have that time so they don’t develop, I don’t think, as well as other children.”*

*Vermont mother*

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Other kids were really hyper, even though they were all the same age. I asked the doctor and he said it is just her way.

Notably, during the focus group sessions mothers tended to share information, ask each other questions, give advice, and recommend resources to help with answering development-related questions.

Not only are mothers interested in child development, they seem to know a lot about the topic, too. Almost all said they know the basics about child development, including physical and intellectual milestones and where their own child should be developmentally. A number of mothers defined development broadly to include emotional and social growth as well. Most mothers said they are aware of the conditions that affect child development, such as environmental, genetic, and health factors. They also understand the vital role they play as parents. As one Utah mother explained:

[Lots of things parents do] affect how babies develop, [like] having other kids around, physically working with them ... talking, touching, feeling, showing them books, reading to them. Other stuff [affects their development too], like how you took care of yourself when you were pregnant.

Some mothers, however, are not always open to advice on child development issues, sometimes preferring to rely on their own instinct—even if it conflicts with experts' recommendations. When it comes to their child's development, some mothers say they do not always follow what their doctor and child health experts say. Focus group mothers provided examples of decisions they have made that might be frowned upon by their provider. One mother, for example, said she puts her baby to sleep on his stomach even though she knows doctors recommend infants be placed on their backs. She explained:

I have a 16-year-old. When she was an infant, they wanted you to lay [your baby] on his stomach. Now, 15 years later, they want you to lay him on his back or on

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*“Who’s to say what’s right and what’s wrong? If that’s what [a mother] wants for her child... .”*

*Vermont mother*

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his side. How can they say this is good and this is bad and now 15 years later, it's reversed? I just don't understand that. They say it is about SIDS, but I just don't believe that. I mean, if the kid wants to sleep on his stomach, let him sleep on his stomach.

Mothers make similar comments when it comes to disciplining their child, preferring their own approach to what experts may say.

According to many of the mothers, one of the primary reasons they do not heed some of the advice is that the prevailing standards for child development seem to change every few years upon the release of new research findings. Certain practices mothers have been using because they were once recommended—such as putting the baby to sleep on its stomach—suddenly are considered wrong. Many mothers said they are confused by this changing advice. They choose to stick to what they feel is right.

Some mothers also said they ignore expert advice when they do not understand it. A number of mothers spoke of instances when a doctor told them to “just do this” without providing any explanation. They admitted that they had skipped well-child visits or delayed scheduled immunizations because they did not understand why they should be getting this care. “I took [my child] to the doctor because he had a fever,” explained a Spanish-speaking mother from Washington, who said she does not take her young child to the doctor for checkups. “Aside from that, I've only taken him for his vaccines.” Another mother admitted to smoking during her pregnancy, even though her physician told her not to.

In some cases, the mother may not fully understand the risks of skipping checkups, even though she knows her decision goes against the doctor's advice. In other cases (such as smoking or drinking while pregnant), the mother may be engaging in risky behavior despite her awareness that doing so could cause the baby harm.

When information on child development is presented in the “wrong way,” mothers are less likely to absorb it or act on it. Many mothers seemed confident in their ability to decide what is best for their child and to guide their child's development. Sometimes, they

feel the advice that clinicians give can come across as “preachy” or intrusive. Specifically, many mothers dislike it when doctors or nurses talk down to them, or make them feel ignorant. Said one Vermont mother:

I think people are offended when they don't know things. They don't want to admit to themselves that they don't know how to do something. You sort of have to be convinced that you don't know something, that you have to be taught something.

The above quote captures one of the key challenges in sharing child development information with mothers: no mother wants to be told she is uninformed when it comes to her own child. Another mother added to this observation:

[They need to respect that] you are an intelligent person who can form your own opinions and make logical decisions for your child. I mean, they have a lot of great advice, but as a mother, you are the one raising the child, and you need to find a decision that you are comfortable with.

Focus group members said they want doctors and nurses to be sensitive to their expertise as mothers—and to show more respect when talking to them about child development. These mothers stressed their desire for give-and-take during visits, not lectures. They would like suggestions, choices, practical ideas, and helpful hints. In particular, mothers want explanations for the recommendations that are given. If information were presented in these ways, most mothers said they would discuss a broad range of developmental issues with their child's doctor or nurse.

#### INTERACTION WITH PEDIATRICIANS AND NURSES

Many mothers in the focus groups reported that they have thorough and wide-ranging discussions with the pediatrician about their child's development. Some mothers, however, said that their interactions are less than satisfactory. These mothers describe having narrowly focused

conversations that go no further than the standard questionnaire they normally complete prior to the appointment. Others commented that the doctor simply tells them what to look for with their child, rather than engaging them in a meaningful two-way dialogue.

Mothers, however, may place limits of their own on interactions with providers. For example, some focus group mothers said they are uncomfortable discussing discipline with their pediatrician, who they fear will judge them or tell them their method is wrong. Some mothers mentioned that they prefer the advice of family and friends over the advice of providers when it comes to “social issues” and their child’s development.

Home visits received mixed reactions. In Vermont, where the focus groups consisted of mothers who had turned down a home visit from a nurse, a few mothers said they resist receiving advice about child development from nurses—as opposed to a pediatrician. They also voiced displeasure about how they were approached by the nurses doing the home visit.<sup>6</sup> In Utah, where Medicaid home visiting programs do not yet exist, mothers were much more receptive to the idea. They think nurse home visits would be an effective and convenient way to learn about their child’s development.

Most mothers said they freely discuss their child’s development with the pediatrician, though some complained that their discussions about development are too basic and narrowly focused—if they take place at all.

Most mothers said they have discussed their baby’s development with a health care professional, at least on some level. Doctors generally ask parents about age-appropriate benchmarks—such as visual tracking, rolling over, sitting up, crawling, and talking—during appointments. Beyond these basic benchmarks, many mothers also reported having discussions about diet, routine, and sleeping schedules. A few mothers said that their child’s doctor also makes more extensive inquiries into

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<sup>6</sup> The Vermont mothers were purposely recruited to learn why they turned down home visits by a nurse that were sponsored by the Medicaid program, which means they are a biased sample. In this regard, they do not represent how other mothers with a young child enrolled in Medicaid may feel about the state’s visiting nurse program.

other areas, such as their own health and well-being, their living arrangement, and their parenting style. A Vermont mother said, “On one of the first visits, they asked a lot of different questions about the living arrangements, any smoking in the house—things like that.”

In addition, most mothers said their child’s doctor welcomes their questions about child development, especially during well-child visits. Some mothers mentioned that they are very assertive and organized about this: they make a list of questions to ask prior to each visit and methodically go over every one with the doctor. As one mother from North Carolina explained, “I go with a list of questions, and if he talks about what is on my list, I check it. After he’s done explaining everything, if he doesn’t touch the topic I had in mind, I ask questions about it.” A mother from Utah said:

I get right in there [with questions about things like] reading and the sun screen; I ask before I am told. I am assuming that she would [answer me] because she is very generous with her responses, and she asks personal things and she really gets into it. She is really a nice woman.

Others are less organized and aggressive, but still manage to ask many questions during their appointments.

A few mothers, however, said they do not ask many questions. They explained that they feel rushed by their child’s doctor and do not believe he or she would welcome their questions. Others do not know what to ask; they just assume the doctor would tell them if something was important.

Some focus group mothers said discussions about development are limited to a set of predetermined questions from a questionnaire they complete before the visit. Sometimes they fill out the form prior to the visit and do not even review it with the doctor. As one Vermont mother commented, “They give me this little form where they find out how advanced your child is. ‘Is he rolling over? Does he look for

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*“They have a check list. That’s all I’ve ever been asked. They go through and ask, “Do they do this? Do they do that?” They ask you the questions and check it off. In my experience, that’s it and then you’re done.”*

*North Carolina  
mother*

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things when you take them away from him?’ Then they just take [the form]. They don’t ask me [about it].”

Other mothers said the doctor simply tells them what to do. In the words of a North Carolina mother:

I have [asked the doctor questions but], I haven’t had real good responses. I get to ask questions, but I kind of get told what do to. It’s not like a conversation. It’s not like building a relationship. It’s kind of like they say to me, “Well, you’re a mom, a first-time mom, so you really don’t know anything, so let me tell you.”

These are not the kinds of interactions most mothers want when it comes to discussing child development issues with their provider. As the focus groups made abundantly clear, mothers want to be treated with respect. They want doctors to engage them in a real conversation—not just give instructions.

In some cases, the mothers themselves place limits on their discussions with pediatricians, particularly with regard to disciplining their child.

Discipline is a hot-button issue for many mothers, and it certainly produced a great deal of emotion and passion during focus group discussions. Some mothers said they do not welcome doctors’ advice on how to discipline their child, feeling it is outside their realm of expertise and an invasion of privacy. When the pediatrician raises the topic, some mothers said they feel like they are being judged on their method of discipline and their parenting skills.

Many mothers prefer to follow their own instincts, or to consult with their mother or friends—but not the provider. “[About] that kind of stuff [like discipline], I tend to talk to my parents or relatives or friends who have children,” explained a North Carolina mother. “I think everybody has a sense of what they want. I don’t think there is anything a doctor can do to help you with that because they are not in your life every day.” Some mothers said that while they know that discipline

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*“[I don’t like when they give advice about] stuff that is not medical ... you should spank, you shouldn’t spank ... .”  
You know, there’s a lot of gray area and there’s a lot of different people to go to [for advice] on that.”*

*Vermont mother*

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might relate to a child's development, they are simply unwilling to discuss the topic with a doctor.

A few mothers also mentioned they become uncomfortable when discussions with providers touch on issues they consider to be "social" rather than "medical"—and therefore outside the provider's expertise. Examples they gave included discussions about parenting style, the child's sleeping schedule or behavior, and the parents' living arrangement. On such matters, these mothers said they prefer to follow their own judgment or to seek the advice of family and friends.

While a few of the Vermont mothers are ambivalent about, or even resistant to, receiving advice from home-visiting nurses, mothers in Utah—where there is not yet a Medicaid home-visiting program—are more receptive to the idea.

A number of Vermont mothers raised practical objections to home-visiting nurse programs. Some mothers complained that nurses contact them as soon as they come home from the hospital, without giving them enough time to adjust to motherhood and to see what help they need. Others said that during this period, they often already have the help of a family member. In that case, a phone call or visit at a later time (when the family member is no longer available to help) would be more beneficial.

Other Vermont mothers commented that some of the home-visiting nurses are very insistent, making numerous phone calls to set up visits even after they are told that visits are not wanted. As one of these mothers explained, "For a while they were calling me like every day or every other day asking, 'Do you need a visiting nurse?' After a while, I would be like, 'Okay, I'll be here, fine.' And I just wouldn't answer the door because they wouldn't stop calling me." A few mothers who accepted an initial home visit said they felt that the nurses were "bossy" and too intent on telling the mothers what to do, rather than asking mothers for their opinions or answering questions. According to one mother:

[The nurses] need to keep their opinions in. I wanted to do half nursing and half formula ... but her opinion was

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*"They [Medicaid] want to go to your house and see what the conditions are at your house. They push that very much. I didn't need anybody, I didn't want anybody, and they were trying to push that [nurse's visit]."*

*Vermont mother*

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that she did not want me to do that. For her to tell me I couldn't do that was totally wrong. So, they should tell you what is best, but they have to give you options [too].

A few mothers are suspicious of the state-sponsored home-visiting programs. They wonder if the nurses are sent to report on them and their qualifications to remain in the Medicaid program. Indeed, a few mothers said they felt they were being spied on. Other mothers perceived that the home-visiting nurses were judging them—their parenting style, their lifestyle—and did not like this feeling.

Some of the Vermont mothers also told the focus group that they question nurses' qualifications to provide advice on child development. It seems that while these mothers trust the input of their doctors on the topic, they are wary of nurses' input because they "do not know as much as a doctor about the topic." Indeed, some mothers want to know if the home-visiting nurse is a mother herself before taking any advice.

Yet Vermont mothers also expressed some positive feelings about the home-visiting program. Many said they want to learn more about their child's development and are open to hearing new information and ideas. If nurses had contacted them at a later time, they noted—instead of within the first few days of their return home from the hospital—they would have been more open to accepting the visit. Also, a few Vermont mothers who received an initial home visit maintained that they might have agreed to additional visits if only the nurse had been less bossy and more sensitive and respectful.

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*"Especially if it is their first-time baby, any little extra, even if it is five minutes [is helpful]."*

*Utah mother*

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Because Utah's Medicaid program does not yet have a home-visiting service for new mothers, the mothers in those focus groups had much less real-life experience to help them judge the effectiveness of the service. Nevertheless, they did express interest in it. Utah mothers said they are open to home visits from nurses and learning about child development issues. "That would be nice," was one mother's response. Such a program, several noted, would be a convenient way to get this information because, as one mother said, "You can't get out a lot."

Participants in the Utah groups said they like the idea of being able to discuss development topics privately with a nurse. Said one mother, "Sometimes people have an easier time when it is just one-on-one rather than in front of a whole group. And breast-feeding, that is a hard thing to learn in front of a group of people." Utah mothers thought of other subjects that they would like to have asked a visiting nurse about when they first returned home with their newborn. One mother told this story:

Well, I remember when I brought my son home, he hadn't had a wet diaper or bowel movement. That is when I called the nurse and they said, "You better get him in here." And you know, he was jaundiced. Stuff like that, because you don't know. He's Mexican, so I didn't know if he was just darker or yellow. I just thought, "He has a nice skin color."

#### CULTURAL COMPETENCY

The mothers of Medicaid-enrolled children who participated in this study, especially the Hispanic mothers, talked about the importance of having developmental services designed for families of different cultural backgrounds. In the words of one Spanish-speaking mother from Washington, "[There need to be] programs that are sensitive toward cultural differences."

Poorly trained interpreters and inadequate access to Spanish-speaking providers and translated written materials were problems that figured prominently in focus group sessions with Hispanic mothers. But other issues related to culture emerged across all eight focus groups: the family's role in decision-making, distrust of the U.S. medical system, religious beliefs and discipline, perceptions of a healthy weight for an infant, diet and attitudes toward nutrition, and sleeping habits. Some mothers in this study asserted that these issues affect how they interact with providers on child development. Insights provided by these mothers show that a better understanding of culture, religious beliefs, and language could make efforts to educate mothers about child development more effective.

Many Hispanic mothers said that the interpreters provided are often not skilled enough; they want greater access to Spanish-speaking providers, as well as more translated information on child development.

Hispanic mothers in the study stated their preference for Spanish-speaking providers. When they are forced to rely on interpreters, these mothers said they have less confidence in the information they receive. When interpreters are used, some Hispanic mothers worry they are missing important information about their child's health, or that the interpreter may be holding back. As one mother said:

Interpreters are not one hundred percent trustworthy. I had an interpreter at the University of Washington when I had my baby, even though I did not really need her. She was very unprofessional. She was reading and talking on the phone. It was a lack of respect.

In addition to better-trained interpreters, these mothers would like more access to Spanish-speaking providers. A number of mothers said they see a Spanish-speaking doctor but often cannot make appointments for sick visits—only for well-child care. Others explained that their clinic does not have enough Spanish-speaking providers, so they must use interpreters.

Spanish-speaking mothers also said they want more child development information in Spanish. "When I was pregnant, they gave me many books about how to do everything, like breast-feeding," said one woman. "I'd like it to be the same now, to get more books [on other issues]." Other mothers in the focus groups mentioned that they would like more opportunities to learn about child development. "I think they should give us talks every once in a while [about] ... how to take care of children during their growth," suggested a Spanish-speaking mother from North Carolina. "One every six months, so that it can give us new ideas, since we never stop learning."

Focus group members called for greater sensitivity on the part of providers and the Medicaid program to the cultural, religious, and economic differences among mothers of enrolled children.

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*"I would ask that everything possible would be done in order for us Hispanic women to receive information. A lot of women don't get information; many of them just stay home. You could mail pamphlets, invite them to talks, motivate them."*

*Spanish-speaking  
Washington mother*

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Awareness of cultural and other differences emerged as a concern not only in the focus groups with Hispanic mothers, but in other focus groups as well (many of which were ethnically mixed). A number of mothers offered examples of times when doctors and the Medicaid program itself failed to take into account their cultural, religious, or socioeconomic background, which can influence how a parent cares for her child.

One Hispanic mother from North Carolina told her focus group, “I always wanted to ask them about my daughter’s flat feet. It’s not very important in this country, but it is in mine. I think I asked a doctor about it once, but he ignored me.” Many of the Spanish-speaking mothers talked about how they want their babies to be “nice and chubby,” but that their pediatricians tell them this is unhealthy. Another mother, an immigrant from Nigeria, explained that her pediatrician instructed her to feed her baby bland food. But she protested that her son is African, and thus likes spicy food.

Many mothers described specific influences in their lives that have contributed to their views on child development—influences that providers and Medicaid do not always understand. For example, many Hispanic mothers spoke of how they make decisions jointly with their family members and of relying heavily on the advice of parents and siblings when it comes their child’s health care. Some young African-American mothers said their mothers play a primary role in helping them make decisions about their young child’s health. Utah focus group mothers, many of whom are married, perceive that much of the information they receive from Medicaid is directed toward single mothers because it does not mention fathers or other family members. A mother in Washington, meanwhile, explained that her Christian beliefs shape her approach to discipline. She referred repeatedly to her use of “biblical discipline” with her young child.

Some immigrant families are simply not comfortable with the U.S. health care system. One Mexican-American mother said her family does not trust health care in this country. She explained:

I called my family in Guadalajara before I took my daughter to the hospital to have her heart checked out. They told me, "Take her, but don't let them do anything." I called my mother to ask her what I should do. She said that if it is this or that, then bring her to Guadalajara, don't do anything [in the U.S.].

Economic factors can also have a major impact on access to care. A number of low-income mothers, for example, mentioned the problems they have securing transportation to the pediatrician's office. These limitations often dictate where they can go for health care services; sometimes, lack of adequate transportation causes them to miss appointments altogether. "Transportation is a problem a lot of times," a North Carolina mother explained. "When my son turned two, I knew that he needed his shots. I had to take him [to the nearest clinic] because I didn't have a car."

The examples above illustrate some of the many factors that shape how mothers raise their children and make decisions about health care. Comments of focus group participants suggest that doctors and Medicaid do not always understand the wide range of factors that influence how mothers raise and care for their children, and why they sometimes conflict with "expert" advice. Many feel there needs to be greater awareness of and sensitivity toward differences among families in the Medicaid program so that child-rearing advice is as effective and relevant as possible.

#### REACHING OUT TO MOTHERS

This study has amply shown that mothers with young children enrolled in Medicaid care a lot of about their sons' and daughters' development and want to learn more. They want informative discussions with their providers; they want to bounce ideas off friends and family; they want guidelines and practical information; and they want to be good parents by enhancing their child's development. Mothers will use child development information if it is provided in a helpful and nonthreatening way, and if it takes into account their own personal knowledge and expertise.

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*"WIC was trying to tell me how to change a diaper [for my infant]. I had a two-year-old already and they were showing me how to change a diaper."*

*Vermont mother*

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Provide information appropriate to the mother's age, experience, language, and culture.

Mothers said they want advice and programs that are targeted to their own experience, situation, and needs. A one-size-fits-all approach, they noted, will not work. More experienced mothers, for example, do not need the same information as first-time mothers. A Utah mother explained:

This was my third child and they're like, "Oh you have to take the breast-feeding class." I'm like, wait a minute. I have two other children besides this one. Why do I need to take another breast-feeding class? I've taken it twice already. Give me something I haven't had.

Experienced mothers said they want information presented in a way that recognizes their prior experience. If a review of the basics—like breast-feeding—is important, they need to be convinced of this. Teen mothers, as well as older mothers, may have different concerns. "A 16-year-old mom is different from a 30-year-old mom," noted one young mother. "You just have to have somebody there for teen moms [to help them with everything], while the older moms just need somebody that they can actually relate to."

Spanish-speaking mothers recommended that information directed at them be translated into Spanish. Mothers also want information on child development to reflect their diverse ethnic, religious, and socioeconomic backgrounds, since these factors influence their approach to child-rearing.

Give reasons and explanations—mothers want to know "why" — and show respect for mothers' experience and opinions.

Instead of just telling them what the experts recommend, mothers said they want and need health care providers to explain—in lay terms—why they make the recommendations they do about child development. Mothers explained that this approach communicates respect for what they know about their own child, and is more likely to have an influence on their thinking. A mother in a Vermont focus group illustrated this point:



My [home-visiting] nurse told me not to give my daughter a pacifier, but I felt she needed it. I mean, she's always sitting there [making a sucking sound]. So I gave her a pacifier. The nurse just told me not to do that. She told me how to take care of my child. She did not say, "I don't think you should give her the pacifier because of these reasons." It was more, "Don't give her the pacifier."

Many mothers said they want their providers to treat their opinions with respect, since they know their child better than anyone else. Teenage mothers, in particular, feel they are patronized by doctors and other health professionals. They become reluctant to take advice from people whom they feel are talking down to them.

Do not forget about the mother's well-being.

Some mothers mentioned that they would appreciate it if their doctor would ask about their own health and well-being. They would also like advice on how to ease the pressures of raising a small child.

Include fathers and other family members, too.

Some mothers pointed out that all the advice and information about infant care is directed solely at them. As one mother explained, "I think it's funny how much things are geared to the mom. Everything that comes to our house about our kids has my name on it. It feels weird, since I'm married." A Utah mother added, "I think it would be great [to include fathers more] because a lot of times the father of my son is not really welcome to come. And that makes me not want to go at all." Many mothers whose baby's fathers are involved in raising the child want them to learn about child development, too. For young mothers living at home, it might also make sense to involve grandmothers, who often serve as young mothers' biggest source of advice and support as well as primary caregivers.

Make materials easily accessible—and avoid information overload.

Some of the focus group women were single working mothers, and many said they are often overwhelmed by the demands of raising a

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*"They should not just ask about how your baby is doing, but how you are doing too, because [taking care of a new] baby is hard."*

*Utah mother*

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young child. Often they feel inundated with health care information from Medicaid and from their provider, and admit they do not always read it. Some receive the same information over and over again.

All informational materials, they suggested, should be simple and to the point—perhaps one or two pages on specific topics geared to their child’s age and gender. Materials should be organized in a way that makes it easy for busy mothers to find the information they need quickly. Mothers in the study said that having a folder or some other method of organizing pamphlets for future reference would help them make better use of the information.

Participants also said that home visits should be brief and scheduled at convenient times. Doctors’ visits should involve as little waiting time as possible. In addition, mothers recommended that parenting programs be held at convenient times and at nearby locations, possibly with babysitting services provided. They stress that all efforts to reach them should take into account their need for fast, flexible options to participate.

Create easy-to-access educational tools such as videos and charts, and use the Internet.

Many mothers recommended that the Medicaid program develop instructional videotapes about child development—similar to the ones about breast-feeding and other topics that they viewed in the hospital after giving birth. Mothers could then watch these tapes at their leisure in their own home. A few also suggested that Medicaid develop attractive charts, posters, and refrigerator magnets that mothers could hang up in their home for use as a daily reference on child development. They suggest that these tools lay out all the developmental benchmarks. Although many mothers said they know much of this information already, they believe it would be helpful to have it consolidated on one poster or chart.

Finally, a number of the mothers mentioned that they currently use the Internet to gather information on various topics. The Internet, they said, could also be a useful way of conveying information to mothers

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*“They send me the charts that say, ‘These are the shots they need to have on certain months’ and all that kind of stuff. I think they send the same thing over and over. They send it too many times. I’ve seen too many of those letters.”*

*Vermont mother*

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about child development, especially since it allows them to do their research at any time.

Provide opportunities for peer-to-peer interaction.

Many participants expressed interest in attending discussion groups with other mothers to talk about child development issues. They believe they can learn from each other and gain practical suggestions from talking with mothers like themselves. Indeed, throughout the focus groups, mothers spoke of their friends and peers as being a major source of advice and guidance when they have questions about their child's development. They recommended a forum such as the focus groups, one where mothers could share their ideas and experiences and perhaps ask questions of a developmental specialist. However, some mothers noted that it may be difficult to attract mothers, since they are already too busy and may not be able to find (or afford) a babysitter. As a possible solution, someone suggested that child care or activities for kids be made available at the forum.

Offer a home-visiting program that is responsive to mothers' needs.

In general, the focus group mothers support the concept of learning about child development through nurse visits, but they want to make sure the program meets certain conditions. Utah mothers in particular expressed enthusiasm for a proposed home-visiting program, while some Vermont mothers believed the program in their state needed some changes. They would like the program staff to:

- *Work with mothers to identify the best time for the initial visit.* Some mothers said they have less need for advice and support right after delivery because they have family and friends around to help. After this initial period, however, mothers say they are more open to help from visiting nurses. Other mothers may want and benefit from earlier contact, however.
- *Limit phone calls.* Vermont mothers complained most about the frequent phone calls they receive from home-visiting program staff asking if they would like a visit.

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*"They are so pushy, they could not respect what I said. Well, I don't want them coming to my house. It didn't make me feel comfortable. I didn't know who in the world was coming over. I [already] had plenty of help."*

*Vermont mother*

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These mothers said that in the first few days they were home with their newborn, they only wanted rest and quiet. They recommended only one phone call—and then leaving it to mothers to call back if they want a nurse to visit.

- *Respect mothers' expertise and take the time to explain advice.* Some Vermont mothers asserted that the visiting nurses acted in a bossy manner and often told mothers *what* to do, rather than explain *why* they should do it. To counter this impression, nurses should make a special effort to listen to the mother's opinions, seek her input, and give positive feedback whenever possible.
- *Make it clear that they are not there to spy on mothers or pass judgment.* Some of the Vermont mothers said they question the motivations of visiting nurses. They wonder if nurses are spying on them on behalf of the Medicaid program. To alleviate this concern, some suggested that nurses explain up front that they are there only to answer mothers' questions about their child and to give helpful ideas and suggestions.

Continue to use pediatricians as the main source of information about child development, but encourage them to make some changes in how they interact with mothers.

Many mothers in the study agreed that talking with their pediatrician is the preferred way of learning about their child's development. They trust information from the doctor the most, particularly if they already have a positive relationship with him or her. Nevertheless, some mothers think that their interactions with pediatricians on child development issues could be improved.

First, they would like to be able to spend more time with their child's doctor during appointments to discuss these issues. Mothers also want doctors to raise specific topics themselves, since mothers do not always know what questions to ask. Some said they want doctors to know that they are more likely to follow advice if they are shown respect, asked

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*"I have [asked the doctor questions but] I haven't had real good responses. I get to ask questions, but I kind of get told what do to. It's not like a conversation. It's not like building a relationship."*

*North Carolina  
mother*

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about their own ideas, and treated as equals. Finally, mothers do not want interaction limited to standard questionnaires about their child's development; they want the opportunity to raise their own issues and concerns.

### III. POLICY IMPLICATIONS

The findings from these eight focus groups have implications for state Medicaid programs. Many mothers who participated believe they have access to preventive care for their young child and adequate information about child development, but a significant number perceive their access as limited. The latter are mothers who do not have a regular pediatrician whom they trust, one who engages them in discussion about their child's development. These mothers have gaps in their knowledge of development—they think that regular immunizations are all the care their child needs. They feel that pediatricians do not spend enough time with them.

Even mothers who have access to information on child development are not completely satisfied. Some have providers who “tell them what to do” rather than ask questions and treat their opinions with respect. There also appear to be shortcomings in “cultural competency”—that is, some child development information does not account for the diversity of parenting practices and the needs of people of different cultural and socioeconomic backgrounds. Language, as well, poses a challenge for some Spanish-speaking mothers, who complained of a lack of translated information. They also cite problems accessing Spanish-speaking providers and proficient translators.

State Medicaid programs can help address the challenges mothers raised in the focus groups by:

- Helping mothers of Medicaid-enrolled children form relationships with their pediatricians. Central to this is assuring continuity of health insurance coverage as well as health care services.
- Extending the period for Medicaid coverage so that mothers are eligible for benefits for a longer time following the birth of their child. Doing so would facilitate treatment of maternal illnesses that may interfere with infant care, and would provide more opportunities to educate mothers about infant and toddler development.
- Offering more home-visiting programs and placing child development experts in doctors' offices.

- Creating a media campaign to make mothers aware of the benefits of comprehensive well-child care and motivate them to see their pediatrician regularly.
- Raising awareness among pediatricians and other clinicians as to their central role in educating mothers about child development, and offering ideas about how they can provide this information effectively.
- Identifying potential linkages with other programs serving low-income families with young children, such as WIC.
- Tailoring child development programs so that they reflect differences in mothers' age, experience, culture, language, religious beliefs, and economic status.
- Emphasizing cultural competency and addressing language barriers to account for the diversity of the Medicaid population and the different ways that mothers approach child-rearing.
- Establishing standards for interpreters so that non-English-speaking mothers can have confidence in the information they receive.

## IV. METHODOLOGY

In the summer and fall of 2000, Lake Snell Perry & Associates conducted eight focus groups to learn how mothers with young children enrolled in Medicaid viewed child development issues. Two groups were held in each of four states—North Carolina, Utah, Vermont, and Washington—that are receiving grants from The Commonwealth Fund as part of its ABCD initiative to build state Medicaid agencies' capacity to deliver developmental services.

Focus group participants were recruited from lists of young children enrolled in Medicaid. These lists were provided by each state's Medicaid office. Groups were held in focus group facilities chosen according to their proximity to low-income and minority neighborhoods and their experience in recruiting residents of these communities. Moderators from Lake Snell Perry conducted the focus groups and analyzed the results with the help of the National Academy for State Health Policy and The Commonwealth Fund.

Each group was composed of eight to 12 mothers of children under age 4 who were enrolled in Medicaid. The number of participants with work experience in the medical or child care fields was limited. In every state but Vermont, efforts were made to exclude mothers of children with serious or chronic illnesses, or developmental delays or problems, on the grounds that their experiences with the medical community—as well as the special health care needs of their child—would be different from those of other mothers. Despite having incorporated this criterion into the screener, there were one or two mothers in each state whose children did have some chronic illness or developmental problem.

Beyond these basic criteria, group composition differed slightly in the various sites based on the programmatic objectives of the states. The specific group compositions are:

- Burlington, Vermont. Two groups were conducted on June 9, 2000. Both groups were composed of mothers with children 12 months of age or younger who, according to state records, had refused the home visits offered by Medicaid's Healthy Babies program. In actuality, about a third of the mothers had received home visits most likely, but not necessarily, through the Healthy Babies program. Those mothers who had home visits had discontinued them after one or two initial visits. Although no racial group was excluded in the screening process, all participants were white, which was expected given the state's racial makeup.



- Salt Lake City, Utah. Two groups were conducted on June 28, 2000. Both groups were composed of mothers with children 18 months of age or younger who reported in the screening process that none of their children had any serious or chronic illness or developmental disabilities. Although no group was excluded in the screening process, almost all participants were white, though each group had one Hispanic participant.
- Seattle, Washington. Two groups were conducted on September 19, 2000. Both groups were composed of mothers with children age 4 or younger who reported in the screening process that none of their children had any serious or chronic illness or developmental disabilities. The first group was with white mothers; the second group was with Hispanic mothers and was conducted in Spanish.
- Greensboro, North Carolina. Two groups were conducted on September 27, 2000. Both groups were composed of mothers who had used one of three local pediatric practices for at least six months (or since their child's birth). Both groups comprised mothers with children under age 3 who reported that none of their children had any serious or chronic illness or developmental disabilities. The first group was with Hispanic mothers and was conducted in Spanish; the second group was mixed, with white and African-American mothers.

In each state, the participating mothers were asked a core set of questions, as well as some questions individually tailored by the state consortium members. In Vermont, questions were asked about the Healthy Babies program and about home-visiting programs in general. A home-visiting program was also discussed in Utah, where Medicaid is currently considering such a program. In Washington, additional questions were added about how best to reach mothers with information and assistance about child development. In North Carolina, participants were asked about their experience with the specific health care facility they had been using for their child's health care.

## RELATED PUBLICATIONS

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#444 *Creating a Seamless Health Insurance System for New York's Children* (February 2001). Melinda Dutton, Kimberley Chin, and Cheryl Hunter-Grant, Children's Defense Fund–New York. New York has recently brought Medicaid and Child Health Plus together, making the two programs more compatible. This paper takes a comprehensive look at both these programs in order to identify areas of continued programmatic disparity and explore ways to bridge differences.

#439 *Patterns of Insurance Coverage Within Families with Children* (January/February 2001). Karla L. Hanson. *Health Affairs*, vol. 20, no. 1. Using the 1996 Medical Expenditure Panel Survey, this article examines patterns of health insurance within families with children, determining that 3.2 million families are uninsured and another 4.5 million families are only partially insured.

*Child Development Services in Medicaid Managed Care Organizations: What Does It Take?* (July 2000). Carolyn Berry, Pamela Butler, Linda Perloff, and Peter Budetti. *Pediatrics*, vol. 106, no. 7. Copies are available from American Academy of Pediatrics, 141 Northwest Point Blvd., Elk Grove Village, IL 60007-1098, Phone: 888-227-1773, Fax: 847-434-8000, E-mail: [journals@aap.org](mailto:journals@aap.org).

*Building State Medicaid Capacity to Provide Child Development Services: An Overview of the Initiative* (March 2000). Deborah Curtis and Helen Pelletier, National Academy for State Health Policy. Copies are available from the National Academy for State Health Policy, 50 Monument Square, Suite 502, Portland, ME 04101, Tel: 207-874-6524, Fax: 207-874-6527, E-mail: [info@nashp.org](mailto:info@nashp.org), Website: [www.nashp.org](http://www.nashp.org).

#367 *Assuring the Healthy Development of Young Children: Opportunities for States* (February 2000). Peter Budetti, Carolyn Berry, Pamela Butler, Karen Scott Collins, and Melinda Abrams. This issue brief examines opportunities for states to enhance the provision of health-related developmental services to children in low-income families, particularly by emphasizing the importance of preventive developmental services in primary, pediatric practices.

#326 *Financing Children's Health Care Needs in the Next Century*, Cathy Schoen and Catherine DesRoches; *Opportunities to Improve Health Care for Low-Income Adolescents*, Karen Scott Collins and Melinda Abrams; *Medicaid's Impact on Access to and Utilization of Health Care Services Among Racial and Ethnic Minority Children*, Allyson G. Hall; *Health Care Coverage and Access for Children in an Urban State: the New York Perspective* James R. Tallon, Jr., and David R. Sandman; and *Child Development and Pediatrics for the 21st Century: The Healthy Steps Approach*, Kathryn Taaffe McLearn, Barry S. Zuckerman, Steven Parker, Michele Yellowitz, and Margot Kaplan-Sanoff (December 1998). *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, vol. 75, no. 4. These articles were originally presented at the fourth annual Margaret E. Mahoney Symposium on the State of the Nation's Health.

#305 *Insuring the Children of New York City's Low-Income Families: Focus Group Findings on Barriers to Enrollment in Medicaid and Child Health Plus* (December 1998). Peter Feld, Courtney Matlock, and

David R. Sandman. This qualitative study sheds light on why a large majority of New York City children who are eligible for Medicaid and New York State's Child Health Plus (CHP) program remain uninsured, even as the state is set to expand coverage to many more low-income families. The report reveals that parents face serious obstacles to getting their children on Medicaid and keeping them on, and have minimal awareness of CHP.

#304 *Improving the Delivery and Financing of Developmental Services for Low-Income Young Children* (November 1998). Karen Scott Collins, Kathryn Taaffe McLearn, Melinda Abrams, and Brian Biles. This issue brief examines the effects of inadequate health care services on the development of young children, and discusses efforts at the federal and state level to improve access and developmental outcomes for young children in low-income families. It also introduces the Fund's new Assuring Better Child Health and Development Program.

#275 *Covering Uninsured Children and Their Parents: Estimated Costs and Number of Newly Insured* (July 1998). Kenneth E. Thorpe and Curtis S. Florence, Tulane University. The authors examine the likely impact of the Child Health Insurance Program (CHIP), demonstrating how it should help reverse the decline in health insurance coverage for children, but may leave many of their parents uninsured.

#267 *Listening to Parents: A National Survey of Parents with Young Children* (March 1998). Kathryn Taaffe Young, Karen Davis, Cathy Schoen, and Steven Parker. *Archives of Pediatrics and Adolescent Medicine*, vol. 152, no. 3. This article reviews the methods, results, and implications for pediatricians of *The Commonwealth Fund Survey of Parents with Young Children*, which was released in August 1996.