

PARTNERING WITH PARENTS TO PROMOTE THE HEALTHY DEVELOPMENT OF YOUNG CHILDREN ENROLLED IN MEDICAID

RESULTS FROM A SURVEY ASSESSING THE QUALITY OF PREVENTIVE AND DEVELOPMENTAL SERVICES FOR YOUNG CHILDREN ENROLLED IN MEDICAID IN THREE STATES

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EXECUTIVE SUMMARY

A child's environment and experiences in the first years of life have lasting effects, even through adulthood. Brain development, social development, physical well-being, readiness for school, and, ultimately, a child's success in life are all linked to these critical first years of life.¹ For children to flourish, families and their communities must work together to support the achievement of the cognitive, social, emotional, behavioral, and physical milestones essential to the healthy development of children.²

Among the most important partners for parents of young children are physicians and other health care providers. Guidelines recommend that children see a pediatric clinician approximately 12 times during the first three years of life for routine, well-child care services.^{3,4} Given the frequent contact that most parents have with their child's health care providers, pediatric clinicians are in a unique position to ensure that children get the healthy start they deserve.

This report summarizes findings from the Foundation for Accountability's (FACCT's) Promoting Healthy Development Survey-PLUS (PHDS-PLUS), a survey of parents of children under age 4 who were covered by Medicaid.⁵ For this report, responses from a core sample of 1,900 parents (approximately 630 per state) were analyzed. The PHDS-PLUS provides a wealth of information about the provision and quality of preventive and developmental services to low-income children insured through Medicaid. These services include:

- anticipatory guidance and parental education;
- assessment of parental health and well-being and safety within the family;
- assessment of parental concerns and follow-up with children identified as being at risk for developmental, behavioral, or social delays; and
- family-centered care that promotes trust and partnerships with parents.

The survey also examines issues surrounding the health of young children and their parents and family health behaviors and routines. The survey was administered in three states participating in The Commonwealth Fund's Assuring Better Child Health and Development (ABCD) program: North Carolina, Vermont, and Washington.^{6,7,8,9} The ABCD program supports selected state Medicaid agencies' efforts to improve preventive and developmental services for young children and their families.^{10,11}

Key Findings

Among this population of low-income families with a young child under age 4 covered by Medicaid, key findings include:

- A significant number of children are at risk for developmental, behavioral, and/or social delays. Two of five parents reported at least one concern about their child's social, emotional, behavioral, and/or cognitive development (40%). The concerns of approximately one of five parents were significant enough to indicate that their child is at high or moderate risk for behavioral, developmental, or social delays based on the Parents' Evaluation of Developmental Status (19%) (Chart ES-1).¹²
- Few children receive recommended comprehensive preventive and developmental services. Only about one of five children received preventive and developmental services that met a basic threshold of quality across each of the seven aspects of care assessed (23%). Among the range of preventive and developmental services the American Academy of Pediatricians recommends pediatric clinicians provide, pediatric clinicians were least likely to provide a basic level of assessment on the psychosocial well-being and safety within the family (49%) (Chart ES-2). These findings are not surprising given that earlier studies have shown significant gaps between the preventive and developmental services that are both recommended and needed and what is actually provided.^{13,14,15,16,17}
- Parents have concerns that are not addressed by pediatric clinicians. Two of five parents reported that their child's pediatric clinician did not routinely ask whether they had concerns about their child's development and well-being. Less than half of parents who reported potentially serious concerns also reported getting the information they needed to address these concerns (46%). More than three times as many parents who were asked by pediatric clinicians about their concerns reported that they got the information they needed, compared with those who were not asked (66% vs. 20%) (Chart ES-3).
- Having a personal pediatric clinician or nurse makes a difference. Nearly one of five children lacked a personal pediatric clinician or nurse who knew the child well (17%). Children with a personal pediatric clinician or nurse were one-and-a-half times more likely to receive a basic level of comprehensive care than children without a personal pediatric clinician or nurse (24% vs. 16%). Parents of children who had a personal pediatric clinician or nurse were nearly one-and-a-half times more likely than parents of children without a personal pediatric clinician or nurse were nearly one-and-a-half times more likely than parents of children without a personal pediatric clinician or nurse were nearly one-and-a-half times more likely than parents of children without a personal pediatric clinician or nurse to report receiving family-centered care (74% vs. 51%). Parents

of children with a personal pediatric clinician were also one-and-a-half times more likely to report being asked about their own health and the health of their family, compared with children without a personal pediatric clinician or nurse (30% vs. 20%) (Chart ES-4).

Other Important Findings

- One of 10 children did not get needed care or got delayed care (10%). In half these cases, this downfall was due to a lack of pediatric clinician appointments that would not disrupt parents' ability to meet work responsibilities.
- One of seven parents of children with special health care needs reported problems paying for that care despite having Medicaid coverage for their child (14%).
- Nearly one of three parents reported problems paying for their own health care needs (30%).
- Children at risk for developmental or behavioral delay were about half as likely as other children to receive comprehensive services than those not at risk for such problems (14% vs. 25%).
- Only one of five parents of young children received information or counseling on basic parent education and counseling topics that the American Academy of Pediatrics recommends be routinely discussed, such as reading to children, nutrition, injury prevention, and child behavior and communication.¹⁸
- More than two-thirds of parents not receiving anticipatory guidance in key areas wished their child's pediatric clinician discussed specific issues that were not addressed (67%). Topics of greatest interest were injury prevention, child communication and behavior, and the achievement of developmental milestones such as toilet training.
- Half of mothers who reported symptoms of depression were never asked about their mental and emotional well-being (50%).
- Parents who reported family-centered care were nearly twice as likely to receive anticipatory guidance and parental education (67% vs. 38%).

Implications for State Medicaid Agencies

Results from the PHDS-PLUS reveal areas where state Medicaid agencies can improve the health of low-income young children enrolled in Medicaid. While recent expansions in insurance coverage for children are critical, findings suggest that this coverage is not sufficient to ensure that children receive even a basic level of preventive and developmental services. Implications of this finding for state Medicaid agencies include:

- State Medicaid agencies need policies to monitor and improve quality. Preventive and developmental services are the most basic aspects of health care for all children. State Medicaid agencies need to routinely monitor health care quality for children, set performance expectations for health plans and pediatric clinicians, and work with these plans and clinicians in efforts to improve care.
- States can influence key factors that support quality care. Promoting quality preventive and developmental services for young children enrolled in Medicaid may require state Medicaid agencies to evaluate and consider changes in:
 - the availability and distribution of pediatric clinicians and community-based developmental services;
 - reimbursement policies and the use of performance incentives for health plans and pediatric clinicians; and
 - strategies to inform parents about a child's need for preventive and developmental services and how to learn about and play a role in ensuring high-quality care for their children.
- States should work for more transparency and accountability to consumers. This conclusion is echoed by the emerging national consensus that measuring and reporting on health care quality to the public must be a priority in order to improve health and health care delivery in the United States.^{19,20}

Implications for Pediatric Clinicians

These conclusions indicate that pediatric clinicians should form stronger partnerships with parents to learn about parental concerns and assess children's development and well-being. The study also suggests that pediatric clinicians are not meeting needs in educating and referring parents to services that could improve their ability to care for their children, as well as help them address other issues that directly affect their children, such as maternal depression, smoking, or alcohol abuse in the home. To better equip them, clinicians need practice-based techniques, methods, and information about:

- what topics are important for the education and counseling of parents;
- how to ask parents about their concerns and follow up with information and support to prevent or address problems;
- how to assess a young child's development; and
- where and how to refer parents for help that is beyond clinicians' ability to provide.

Finally, results of this study demonstrate the value of surveying parents about the quality of health care their child receives and the richness of information that can be obtained through the methodology used in this survey (see Appendix). The information is essential to understanding the degree to which health care is meeting the needs of children and whether efforts to improve the quality of care are making a difference. Findings emphasize that parent-reported assessments of preventive and developmental services for young children provide valid and valuable information to guide efforts to improve the quality of their health care.



Chart ES-2. Few Children Enrolled in Medicaid Receive Comprehensive Preventive and Developmental Services







PARTNERING WITH PARENTS TO PROMOTE THE HEALTHY DEVELOPMENT OF YOUNG CHILDREN ENROLLED IN MEDICAID

INTRODUCTION

A child's environment and experiences in the first years of life have lasting effects. Brain development, social development, physical well-being, readiness for school, and, ultimately, a child's success in life are all linked to these critical first years of life.²¹ For children to flourish, families and communities must work together to support the achievement of the cognitive, social, emotional, behavioral, and physical milestones essential to the healthy development of children.

Parents have many concerns about their children's health and development, and they need and want information and support to help their children thrive.²² Some evidence from recent national surveys indicates that parents are not getting the information they need.^{23,24,25} Among the most important partners for parents of young children are physicians and other health care providers. Guidelines recommend that children see a pediatric clinician approximately 12 times in the first three years of life for routine, well-child care services.²⁶ Given the frequent contact that most parents have with their child's health care providers, pediatric clinicians are in a unique position to ensure that children get the healthy start they deserve.

Previous studies indicate that parents want to talk with their child's pediatric clinicians about a range of topics such as feeding and nutrition, sleep, injury prevention, learning, communication, discipline, and toilet training.^{27,28,29,30} In fact, in one recent national survey conducted by The Commonwealth Fund, parents indicated that they would pay more for health services that provided more support in these areas.³¹ Many parents also want guidance on what might be considered more sensitive issues such as smoking, alcohol and drug use, depression and mental health, family violence, and gun safety.^{32,33,34} Yet studies confirm that significant gaps persist between the preventive and developmental services that are both recommended and needed and what is actually being provided.^{35,36,37,38,39}

Studies also show that education and counseling provided by pediatric clinicians can be effective in enhancing parental behaviors that promote the healthy development of children in areas such as language development,^{40,41,42} injury prevention,^{43,44,45} safety,^{46,47,48} feeding and nutrition,^{49,50} discipline and parent-child interactions,^{51,52,53,54} sleeping,^{55,56,57} and toilet training.⁵⁸ When pediatric clinicians and other health care providers address

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parental concerns and needs for information and also pay attention to the health of the family in which children live and grow, many benefits can result:

- parental knowledge, skill, and confidence in parenting abilities can be improved, and the inherent stress and worry of parenting can be reduced;
- a child's strengths and well-being can be nurtured, and problems with a child's development can be detected early or avoided altogether;^{59,60} and
- families can be linked to valuable services and resources in their community, and home and community conditions that support the health and development of children can be encouraged.^{61,62,63}

The health care system, and pediatric clinicians in particular, should take an active role in promoting the healthy development of children. A number of recent initiatives and programs have focused on improving the quality of children's health care, including The Commonwealth Fund's Assuring Better Child Health and Development (ABCD) program.^{64,65} This program supports selected state Medicaid programs to improve the quality of developmental services available for young children.

This report summarizes findings from the Foundation for Accountability's (FACCT's) Promoting Healthy Development Survey-PLUS (PHDS-PLUS), a survey of parents of children under age 4 who were covered by Medicaid.⁶⁶ For this report, responses from a core sample of 1,900 parents (approximately 630 per state) were analyzed. The survey asked parents about the health of their young children and family and to what extent their child's needs for preventive and developmental services were being met by the health care system. Collecting information directly from parents is extremely important. Recent studies have clearly documented that pediatric clinicians often underestimate concerns about parenting and the developmental status of children, as well as the presence of other risks to the health of the child.^{67,68,69,70,71,72,73}

I. HEALTH STATUS OF LOW-INCOME CHILDREN AND THEIR PARENTS

When assessing preventive and developmental care for young children, it is important to get a full picture of the health characteristics of the child and family. The PHDS-PLUS examines three distinct aspects of a child's health:

- overall health status of the child;⁷⁴
- whether adult/parent respondent has concerns about their child's development and behavior that indicate the child is at risk for a developmental/behavioral delay using the Parents' Evaluation of Developmental Status questionnaire;⁷⁵ and
- whether the child has a chronic physical, mental, or behavioral health problem that requires special health services and/or results in a functioning problem for the child, using the Children with Special Health Care Needs Screener.⁷⁶

Questions focusing on the health of the adult/parent respondent include:

- a single item asking about general health status;⁷⁷
- two items asking about work days lost due to mental or physical health problems;⁷⁸ and
- three items to identify mothers at high risk for depression.⁷⁹

Key Findings

While the survey found that the overall health status was excellent or very good for most young children enrolled in Medicaid, many experienced health problems and had special health care needs. Many parents had concerns about their child's learning, development, and behavior, and a significant number of children were at risk for behavioral, developmental, or social delays.

While most low-income children were healthy, many experienced health problems.

• Eight of 10 young children had "excellent" or "very good" health status according to parents' reports (80%) (Chart 1-A). Parents of infants (0 to 18 months) were somewhat more likely to report "excellent" or "very good" health status when compared with parents of children ages 19 to 48 months.

- One of eight (12%) children was born with a low birth weight and/or prematurely. These children had poorer health status compared with children with a normal birth weight and gestation.
- About one of eight children (12%) under four years old had a chronic condition or other special health care need likely to require ongoing, comprehensive, and coordinated health care services.
- One of five children (19%) was at high or moderate risk for behavioral, developmental, or social delays based on the Parents' Evaluation of Developmental Status (Chart 1-B).

Parents were concerned about their children's development.

- Two of five parents (40%) raised at least one concern about their child's social, emotional, behavioral, and cognitive development (Chart 1-C).
- One of five parents (20%) said that they were concerned about their child's language development (Chart 1-D).
- More than one of five parents of children 10 months or older were concerned about how their child behaved (22%), and 19 percent were concerned about how their child got along with others.
- Nearly one of five parents (17%) of children 19 months or older reported concerns about their child's pre-school and learning skills.

Many parents of low-income young children experienced health problems.

- Only three of five parents (60%) reported "excellent" or "very good" health status.
- Only 48 percent of parents with less than a high school level of education reported "excellent" or "very good" health status, compared with 61 percent of parents with a high school or greater level of education (Chart 1-E).
- Sixteen percent of parents noted "seven or more" poor physical health days in the past 30 days. This compares with 12 percent in the general U.S. population of women under age 45.⁸⁰

• One of five (19%) mothers experienced symptoms of depression. Mothers ages 18 to 24 and those with children with special health care needs were more likely to report symptoms of depression compared with other mothers (Chart 1-F).













II. CHILDREN'S ACCESS TO AND UTILIZATION OF HEALTH CARE SERVICES

In assessing the quality of care received by young children covered by Medicaid, it is important to consider the pattern of health care service utilization and reported problems in getting care. PHDS-PLUS items that ask the adult/parent respondents about the child's access to and use of health care services include:

- questions about the target child's use of the health care system (e.g., number, type, and settings of health care visits) and whether they have or had problems getting their child needed health care;^{81,82}
- questions about problems accessing the health care system (e.g., care not received or delayed care), the reason for the lack of or delay in care, and the effect of lack of or delay in care on the parent/child;
- questions about whether adult/parent respondents have or had difficulty paying for health care services for themselves or their child;⁸³ and
- questions relating to whether their child has a regular pediatric clinician and received a developmental assessment and whether their child's care was coordinated as needed.⁸⁴

Key Findings

Nearly all children included in the survey had visited a pediatric clinician or other health care provider in the last year. However, a significant proportion of children lacked a personal pediatric clinician or nurse, had problems in accessing the health care system, and had a high rate of emergency room use. Many parents reported having trouble paying for a child's health supplies as well as for their own health care.

Children enrolled in Medicaid routinely used health care services.

- Nearly all children (99%) had visited a pediatric clinician's office or clinic in the past year. Thirty percent of the children had visited a pediatric clinician one to three times in the past year and 70 percent had visited a pediatric clinician four or more times (Chart 2-A).
- One of three children (33%) had visited an emergency room at least once in the past year, and 9 percent had at least one overnight hospital stay according to

parents. Children with special health care needs were two times more likely than others to visit the emergency room or have an overnight hospital stay.

• Most parents (77%) reported that their child's personal pediatric clinician was a pediatrician. Seventeen percent of parents reported that their young child's personal health care provider was a family practice physician, and 3 percent reported that the provider was a nurse practitioner (Chart 2-B).

Health care access problems persisted for some children.

- Nearly one of five children (17%) lacked a personal pediatric clinician or nurse who knew the child well (Chart 2-C).
- One of 10 children did not get needed care or care was delayed. In half those cases, the problem was a lack of available appointments with pediatric clinicians or other health care providers. More than half of parents reported that this lack of availability had an impact on their ability to meet work and other daily responsibilities (Charts 2-D and 2-E).
- Twice as many parents of children with chronic conditions and other special health care needs reported problems paying for their child's health care needs compared with parents whose children did not have special health care needs (14% vs. 7%) (Chart 2-F).

Parents had trouble paying for their child's basic needs and their own health care.

- Two of five parents experienced "a lot" or "some" trouble paying for much-needed supplies for their children, such as diapers, formula, food, clothing, and shoes.
- Nearly one of three parents had "a lot" or "some" trouble paying for their own health care.

Nearly all Medicaid families were assisted by the Women, Infants, and Children (WIC) Program.

• Nearly nine of 10 parents (86%) reported assistance through the WIC Program.

Few parents were offered or referred to parenting or health education classes.

- Only one of 10 parents (10%) reported being referred to any parenting or health education program or class. A similar number (11%) reported actually attending a parenting class after the birth of their child.
- Of parents who were referred to a parenting or health education program or class, 29 percent had attended a program or class focused on child development. The other parents had attended a program or class about parenting skills (19%), breastfeeding (11%), or some other subject (37%).













III. OVERALL ASSESSMENT OF PREVENTIVE AND DEVELOPMENTAL HEALTH CARE FOR LOW-INCOME YOUNG CHIDLREN

The PHDS-PLUS assesses the level and quality of comprehensive preventive and developmental care that the American Academy of Pediatrics and the federal Maternal and Child Health Bureau recommend pediatric clinicians should provide for children under age 4. Specifically, the PHDS-PLUS measures the following seven aspects of recommended care:

- provision of age-appropriate anticipatory guidance and parental education;
- assessment of psychosocial issues and safety in the family;
- assessment of smoking, alcohol, and substance abuse in the family;
- provision of written and other health information to parents;
- family-centered care (communication and partnership with pediatric clinicians);
- provision of follow-up care for children at high or moderate risk for developmental/behavioral or social delays; and
- helpfulness of care provided.

Calculation of Quality Measures

Survey items for topics listed above are used to construct composite quality measures. These measures are calculated by combining response across relevant items within a topic area, such as anticipatory guidance or psychosocial assessment of the family. Throughout this report we present "threshold" scores for the composite quality measures. These threshold scores are calculated as summarized in Table 1 below.

Quality Measure Scoring Algorithm for Threshold Measure		
Anticipatory guidance and parental education	Proportion of respondents reporting "yes" to discussing 80 percent or more of a core subset of topics that the American Academy of Pediatrics recommends pediatric clinicians discuss with parents (10–12 topics included per age group).	
Psychosocial assessment of the parent and family	Proportion of respondents reporting "yes" to discussing at least two of three psychosocial assessment topics that the American Academy of Pediatrics recommends pediatric clinicians discuss with parents, including parent depression and moods, safety and guns in the home, and availability of emotional support for parent.	
Assessment of smoking and alcohol and drug misuse in the home	Proportion of respondents reporting "yes" to being asked about smoking in the home and alcohol and drug misuse in the home.	
Follow-up for children at-risk for developmental, behavioral, or social delays	Proportion of respondents whose child is identified as being at risk for delay using the Parents' Evaluation of Developmental Status that report receiving some form of follow-up care.	
Health information	Proportion of respondents reporting "yes" to having received some type of written, audio, video, or other form of information they can take home on each of three topics: child development, child safety and injury prevention, and child's physical health and well-being.	
Family-centered care	Proportion of respondents reporting, on average across five topics, that care received from their child's pediatric clinician is "usually or always" family-centered.	
Helpfulness of care	Proportion of respondents reporting, on average, that the care received from their child's pediatric clinician is "helpful or very helpful" in building their knowledge about child behavior and child safety and injury prevention and confidence as a parent. This topic also includes getting needed information in a timely way and helping parents meet their own needs while caring for their child.	

Table 1. Scoring Algorithm for Threshold Measures of Quality

Key Findings

Low-income children covered by Medicaid received certain elements of preventive and developmental care to varying degrees. Only one of five children, however, received all aspects of care assessed by the PHDS-PLUS. This means that many parents had concerns about their child's well-being and questions about parenting that went unrecognized and unaddressed by the child's pediatric clinician. Variations in the quality of care were observed across many child and parent characteristics such as age, race, health and marital status, and whether a child has a regular pediatric clinician. The variations presented in this report remain after controlling for potentially confounding variables. Few children received comprehensive preventive and developmental care.

- About one of five children (23%) received preventive and developmental services that met a basic threshold of quality across the seven aspects of care assessed in the survey. The highest levels of preventive care services provided by pediatric clinicians were reported in the areas of assessment of smoking and alcohol and drug use in the family. The lowest levels were reported in the area of psychosocial assessment of well-being and safety within the family (Chart 3-A).
- Aspects of care varied according to child and parent characteristics. For example, toddlers were consistently less likely than infants or older youngsters to receive comprehensive services (Chart 3-B). This variation in quality remained in multivariate and logistic regression analyses controlling for factors such as child, family, and health care system characteristics.
- About half as many children at risk for developmental or behavioral problems received comprehensive services compared with those not at risk for such problems (14% vs. 25%) (Chart 3-C).
- Children with a personal pediatric clinician or nurse were one-and-a-half times more likely to receive comprehensive care compared with children without a personal pediatric clinician or nurse (24% vs. 16%).
- Parents with a high school education or less were significantly more likely to receive a basic level of assessment for psychosocial issues, safety, smoking, and substance abuse in the family compared with parents who reported higher levels of education (Chart 3-D).

Many parents' concerns about their child's development were not addressed.

- Two of five parents (40%) said they were never asked by their child's pediatric clinician whether they had concerns about their child's development and wellbeing. This was true regardless of how many concerns a parent had (Chart 3-E).
- More than half of parents (54%) with concerns about their child's development did not get the information they needed to address these concerns, especially those related to their child's behavior and communication (Chart 3-F).
- Parents who were asked by pediatric clinicians about their concerns were three times as likely to get the information they needed compared with parents who were not asked (66% vs. 20%).

Children at risk for developmental, behavioral, or social delays may not be getting appropriate follow-up care to track and address these issues.

• For two of five children (40%) at risk for developmental, behavioral, or social delays, no follow-up steps to track and/or assess possible problems were reported by parents (Chart 3-G).

Although many young children received care from multiple pediatric clinicians, that care was often not coordinated.

- One of four parents (24%) reported that their child received care from more than one kind of health care provider or used more than one kind of health care service.
- Nearly two of five parents (38%) of children receiving care from more than one provider reported that no one from their child's pediatric clinician's office or clinic helped them to coordinate their child's care (Chart 3-H).
















IV. PROVISION OF ANTICIPATORY GUIDANCE AND PARENT EDUCATION

The PHDS-PLUS includes age-specific items that ask about the anticipatory guidance and parental education topics pediatric clinicians may have discussed with them in the last 12 months. It is recommended that these topics be discussed routinely within a 12-month time period and focus on the following issues:

- physical care and well-being, such as nutrition, placing young children on their back to sleep, and bedtime routines;
- developmental care and well-being, such as how the child gets along with others, night waking and fussing, language development, toilet training, and the importance of reading to the child; and
- injury prevention, such as how to make the house and car safe for the child.

Key Findings

Parents were consistently more likely to report that their child's pediatric clinician discussed issues related to injury prevention and physical care than issues related to their child's communication, behavior, and development. Parents who did receive anticipatory guidance and parental education reported fewer concerns about their child's development and were also more likely to report engaging in positive parenting behaviors compared with parents who did not receive guidance and education.

Parents needed and wanted more information about their child's well-being.

- Only one of five parents of young children had received information or counseling on each of the essential parent education and counseling topics covered in the survey that the American Academy of Pediatrics recommends be routinely discussed,^{2,3,4} such as reading to children, nutrition, injury prevention, and child behavior and communication.
- Two of three parents who reported that their child's pediatric clinician did not talk with them about one or more key topics indicated that they wished they had received information about these topics. This was especially true for topics related to injury prevention, child communication and behavior, and the achievement of developmental milestones such as toilet training.

Pediatric clinicians consistently emphasized some aspects of a child's health and development over others, with some variation by age of child.

- Pediatric clinicians were more likely to address issues related to the physical care of the child (46%) and injury prevention (52%) than to address topics related to the child's development, behavior, and social growth (35%) (Chart 4-A).
- Among the anticipatory guidance topics, parents of infants nine months old or younger reported that pediatric clinicians were most likely to talk about putting a child to sleep on his or her back (95%) and car safety (93%) and less likely to discuss what a child is able to understand (71%) and how to avoid burns to the child (63%).
- For parents of children ages 10 to 18 months, pediatric clinicians were most likely to focus on nutrition (92%) and car safety (91%) and less likely to focus on establishing bed/naptime routines (68%) and discipline techniques (56%).
- For parents with children ages 19 to 48 months, pediatric clinicians were most likely to discuss issues related to food and feeding (87%) and car seat safety (85%) and less likely to discuss discipline techniques (61%) and toilet training (56%).

Parents of infants age nine months and younger wanted more information about their child's development, learning, and behavior.

- Three of five parents (60%) of children nine months old or younger whose pediatric clinician did not discuss what their child was able to understand reported that they wished they had discussed this with their child's pediatric clinician (Chart 4-E).
- Nearly half of parents of children nine months old or younger (48%) whose pediatric clinician did not discuss the importance of reading or showing a picture book to their child reported that they wished they had discussed this with their child's pediatric clinician.
- Nearly half of parents of children nine months old or younger (47%) whose pediatric clinician did not discuss what behaviors parents can expect to see in their child reported that they wished they had discussed this with their child's pediatric clinician.

Parents of children ages 10 to 18 months old said they would like more information on safety, sleeping habits, and nutrition.

- Three of five parents of children ages 10 to 18 months old (59%) whose pediatric clinician did not discuss treatment of poisoning (using syrup of Ipecac) with parents reported that they wished they had discussed this with their child's pediatric clinician (Chart 4-F).
- Nearly two of five parents of children ages 10 to 18 months old (38%) whose pediatric clinician did not discuss night waking and fussing with parents reported that they wished they had discussed this with their child's pediatric clinician.
- Three of five parents of children ages 10 to 18 months old (60%) whose pediatric clinician did not discuss vitamins and foods the child should eat reported that they wished they had discussed this with their child's pediatric clinician.

Parents of children ages 19 to 48 months old wished they had more opportunity to discuss issues of safety and learning with their pediatric clinician.

- More than half of parents of children ages 19 to 48 months (54%) whose pediatric clinician did not discuss treatment of poisoning (using syrup of Ipecac) reported that they wished they had discussed this with their child's pediatric clinician (Chart 4-G).
- Nearly half of parents of children ages 19 to 48 months (45%) whose pediatric clinician did not discuss the words and phrases their child uses and understands reported that they wished they had discussed this with their child's pediatric clinician.
- Two of five parents of children ages 19 to 48 months (40%) whose pediatric clinician did not discuss ways to teach their child about dangerous situations reported that they wished they had discussed this with their child's pediatric clinician.

Parents who received recommended anticipatory guidance and parental education reported more benefits and fewer concerns about their child's growth and development.

- Parents whose pediatric clinician talked with them about how their child behaves were significantly less likely to report concerns about their child's behavior compared with parents who reported no such discussions with their pediatric providers (21% vs. 27%) (Chart 4-H).
- Parents whose pediatric clinician talked with them about how their child gets along with others were significantly less likely to report concerns about their child's social skills than parents who reported no such discussions with their pediatric provider (18% vs. 25%).
- More than twice as many parents who discussed their child's behavior with their pediatric clinician reported that care they received was helpful in understanding their child's behavior as compared with parents who did not discuss these issues with pediatric clinicians (48% vs. 21%).

Parents who reported receiving recommended anticipatory guidance and parental education also reported more positive parenting behaviors.

- Over one-and-a-half times as many mothers of children ages nine months or younger who reported breastfeeding their baby also reported that their child's pediatric clinician had discussed breastfeeding with them compared with mothers who did not report breastfeeding their child (67% vs. 41%) (Chart 4-I).
- Nearly twice as many parents of children age nine months or younger who lowered the temperature on their hot water heater reported that their child's pediatric clinician had discussed burn prevention with them, compared with parents who did not report adjusting the water temperature (68% vs. 37%).
- Nearly twice as many parents of children ages 10 to 18 months who keep syrup of Ipecac in their home reported that their child's pediatric clinician had discussed treatment of poisoning with them, compared with parents who did not report keeping syrup of Ipecac in their home (82% vs. 44%).







Chart 4-D. Provision of Anticipatory Guidance and Parental Education About Injury Prevention Varies by Age **Proportion of parents reporting** discussion with pediatric clinician ■ 9 months or younger □ 10–18 months □ 19–48 months 80 60 54 60 47 46 Percent 41 37 40 7 20 4 5 0 **Talked about some Talked about none Talked about all** of the topics of the topics of the topics Note: See Appendix for a complete list of the individual survey items included for each topical focus. Source: FACCT's 2001 PHDS-PLUS.



Chart 4-F. Parents Want to Discuss Topics Not Addressed by Pediatric Clinicians: Children 10–18 Months Old









V. ASSESSMENT OF PARENTAL WELL-BEING AND SAFETY WITHIN THE FAMILY

The stability of parents and homes are major determinants of the health and well-being of young children. National guidelines recommend that pediatric clinicians assess the wellbeing of parents and safety within the family. PHDS-PLUS includes questions about whether the child's pediatric clinician assessed the parent and family for the following:

- depression and emotional health of the parent;
- source of social and emotional support for parents;
- firearms in the home;
- smoking in the household; and
- alcohol and other substance abuse in the household.

Key Findings

Pediatric clinicians did not usually assess the mental and emotional well-being of parents. Smoking in the home was the most common issue to be assessed regarding the health of the family environment. Based on findings from this study, it does not appear that low rates of assessment are due to targeting those most at risk. Parents with symptoms of depression or who are at greater risk for the misuse of alcohol were not more likely to report being asked about these topics by pediatric clinicians.

Few parents were asked about their own health or family well-being.

- Less than one of three parents (28%) reported that their child's pediatric clinician talked with them about topics relating to their own well-being and safety, such as depression and moods, social and emotional support, and the presence of firearms in the home (Chart 5-A).
- Half of parents (50%) reported that their child's pediatric clinician did not talk with them about whether they experienced symptoms of depression.
- Four of 10 parents (42%) reported that their child's pediatric clinician did not talk with them about whether they had someone to turn to for emotional support.
- Six of 10 parents (59%) reported that their child's pediatric clinician did not talk with them about whether they had firearms in the home.

• Parents of children with a personal pediatric clinician or nurse were one-and-a-half times more likely to report being asked about their own health and the health of their family compared with children without a personal pediatric clinician or nurse (30% vs. 20%) (Chart 5-B).

Parents experiencing depression were often not identified by pediatric clinicians.

• Half of mothers (50%) who experienced symptoms of depression in the past year said that they were not asked about their mental and emotional well-being by their child's pediatric clinician during this time (Chart 5-C).

Assessment of smoking, alcohol, and drug use occurred inconsistently.

- Almost seven out of 10 parents (69%) were asked about smoking and alcohol and drug use in the home. However, of those who were not asked about all three behaviors, three times as many parents were only asked about smoking (30% not asked about alcohol or drugs vs. 10% not asked about smoking) (Chart 5-D).
- Pediatric clinicians were more likely to ask racial minorities than whites about smoking, alcohol, and drug use (74% vs. 65%) despite lack of evidence that these issues are more likely to occur among racial minorities (Chart 5-E).











VI. PARENTS' EXPERIENCES WITH PEDIATRIC CLINICIANS

One of the most important factors for ensuring that parents get the information and support they need to promote the healthy development of their children is a positive, family-centered partnership with their child's pediatric clinician. Items in PHDS-PLUS that focus on the degree to which the care provided is family-centered include how often the child's pediatric clinicians do the following:

- take time to understand the specific needs of the child;
- respect the parents as the experts about their child;
- build the parents' confidence;
- ask about how the parent is feeling as a parent; and
- take time to understand the parents and the child's family and how the parents prefer to raise their child.

Key Findings

Although most parents reported that pediatric clinicians respected them as the expert about their child and took time to understand their particular needs, breakdowns in communication between many parents and clinicians still occurred. Only half of parents noted that pediatric clinicians usually or always performed all aspects of family-centered care. When clinicians did attend to and provide information for parents as part of familycentered care, their overtures were generally very well received. Parents who reported positive experiences of care and communication with their pediatric clinicians were much more likely to report receiving preventive and developmental care.

Many parents did not experience care as being family-centered.

- Only half of parents (53%) reported that their child's pediatric clinician "usually or always" provided family-centered care in each of five areas (Chart 6-A).
- A greater number of parents whose children have a personal pediatric clinician reported receiving family-centered care compared with parents whose children do not have a regular pediatric clinician.
- Parents of children with high or moderate risk for developmental delays were less likely to receive family-centered care than parents with low or no risk for such delays.

Family-centered care is associated with provision of services:

• Parents who reported that care was family-centered were nearly twice as likely to report receiving anticipatory guidance and parental education (71% vs. 46%) (Chart 6-C).

Parent information and counseling were helpful to parents.

- Nine of 10 parents (90%) who received counseling and information from their child's pediatric clinician reported that these were "very helpful" or "helpful" to them in building their knowledge and confidence as a parent in one or more areas, including:
 - > understanding their child's behavior;
 - > protecting their child from injuries;
 - > getting timely information about issues they are facing with their child; and
 - > helping them learn to meet their own needs while caring for their child.

Helpfulness of information and counseling can be improved.

• One of four parents reported that information and counseling provided by their child's pediatric clinician were "not at all" or only "somewhat helpful" in understanding their child's behavior (25%) or protecting their child from injuries (27%) (Chart 6-D).

More attention needs to be given to the well-being of parents.

- More than one of three parents (36%) reported that their child's pediatric clinician never or rarely asked them how they were doing as parents (Chart 6B).
- One of three parents (33%) reported that their child's pediatric clinician was not helpful or only somewhat helpful in helping them to meet their own needs while taking care of their child (Chart 6-D).









CONCLUSIONS AND IMPLICATIONS

Findings from the PHDS-PLUS reveal significant opportunities for improving the health of young children. Results show that while many parents and children receive some recommended preventive and developmental services, few receive the kind of comprehensive services that national guidelines and research literature suggest they need. Several conclusions may be drawn based on the results summarized in this report:

- Parents have significant concerns about the development and health of their children that are not addressed by pediatric clinicians.
- Health care access problems persist for many young children, despite Medicaid coverage.
- Few children receive comprehensive preventive and developmental services, and care is often worse for those whose parents have the greatest number and most serious concerns about their child's development and health.
- Higher quality care is provided to children with a personal pediatric clinician or nurse who knows the child well—a finding that underscores the importance of continuity of care.
- Parents need and want more information about parenting their children.
- Educating parents makes a difference in their behaviors and confidence.
- In addition to the child, more attention needs to be given to the health of the parent and family. This is especially true for mothers who report symptoms of depression and/or who have children with chronic conditions and other special health care needs. Health care coverage for parents is essential.
- For many parents, care is neither family-centered nor responsive to their personal needs and concerns.

Implications for Pediatric Clinicians

These conclusions indicate that pediatric clinicians can improve care by forming stronger partnerships with parents, learning about parental concerns, and assessing a child's development and well-being. This study also suggests that there are gaps in educating and referring parents to services that could improve their parenting skills and help them address other issues that directly affect their children, such as maternal depression and smoking or alcohol abuse in the home. To do so, clinicians need techniques, practice-based methods, and information about:

- what topics are important for the education and counseling of parents;
- how to ask parents about their concerns and provide information and support to prevent or address problems;
- how to assess a young child's development; and
- where and how to refer children and parents for help that is beyond the clinicians' ability to provide.

Implications for State Medicaid Agencies

Results from the PHDS-PLUS reveal important areas where state Medicaid agencies can improve the health of low-income young children enrolled in Medicaid. While recent expansions in insurance coverage for children are critical, findings suggest that insurance coverage is not sufficient to ensure that children receive even a basic level of comprehensive preventive and developmental services. Implications of these findings for state Medicaid agencies indicate that:

- State Medicaid agencies need policies to monitor and improve quality. Preventive and developmental services are the foundation of health care for all children. Results of this study suggest that state Medicaid agencies need to monitor health care quality in this area and take steps to set performance expectations for health plans and pediatric clinicians. Agencies also need to work with clinicians in efforts to improve care.
- States can influence key factors that support quality care. Promoting quality preventive and developmental services for young children in Medicaid may require state Medicaid agencies to evaluate and consider changes in:
 - the availability and distribution of pediatric clinicians and community-based developmental services;
 - reimbursement policies and the use of performance incentives for health plans and pediatric clinicians;
 - strategies to inform parents about a child's need for preventive and developmental services and how parents can learn about and play a role in ensuring high-quality care for their children; and

- > assuring continuous health insurance coverage for children and their families.
- States should work for better transparency and accountability to consumers. This conclusion is echoed by the emerging national consensus that measuring and reporting on health care quality to the public must be a priority if we are to improve health and health care delivery in the United States.^{85,86}

Everyone has a role to play in promoting the healthy development of young children. Improvements in care require a comprehensive strategy that involves state purchasers and policymakers, families, pediatric clinicians, and the health care system, as well as communities and society at large. At every level, information is essential to change. Results of this study demonstrate the value of surveying parents about the quality of health care their child receives and the richness of information that can be obtained through this type of methodology. Such information is essential to understanding the degree to which health care is meeting the needs of children and whether efforts to improve the quality of care make a difference.

APPENDIX. SURVEY METHODOLOGY

Overview of the Survey

The Promoting Healthy Development Survey-PLUS (PHDS-PLUS) was administered by a single third-party survey vendor to parents of children under age 4 in three state Medicaid programs. The PHDS-PLUS is a 128-item telephone/interviewer-administered survey developed under the rubric of the Child and Adolescent Health Measurement Initiative, which is coordinated by the Foundation for Accountability (FACCT). The survey takes approximately 15 to 20 minutes to administer by telephone.

The PHDS-PLUS is derived largely from the self-administered Promoting Healthy Development Survey (PHDS) (78% of PHDS-PLUS is in the PHDS). Among the items addressing these topics are those on parental health status from the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance Survey,⁸⁷ a three-item screen for depressive symptoms,⁸⁸ and a screen to identify children with special health care needs.⁸⁹ Each of the three states participating in this study also included an additional five to 10 items that asked adult/parent respondents about topics of particular interest to each state's ABCD program implementation efforts.

The PHDS-PLUS includes survey items related to the following topics:

- child and adult/parent respondent sociodemographic information;
- child and adult/parent respondent health status and health risks;
- access to and use of health services;
- parent/family activities and behaviors;
- provision by pediatric clinicians of anticipatory guidance and parental education;
- assessment by pediatric clinicians of psychosocial issues and safety in the family;
- assessment by pediatric clinicians of smoking, alcohol, and substance abuse in the family;
- provision of written and other health information to parents;
- whether care provided by pediatric clinicians is family-centered;
- provision by pediatric clinicians of follow-up for children at risk for developmental/behavioral problems; and

• helpfulness of education and counseling provided by pediatric clinicians.

The FACCT website (www.facct.org) provides a mapping of PHDS-PLUS items to each of these topics as well as additional information about the development and testing of these survey items.

Calculation of Quality Measures

Survey items for topics five through 11 listed above were used to construct composite quality measures. These measures were calculated by combining responses across relevant items within a topic area, such as anticipatory guidance or psychosocial assessment of the family. Throughout this report, we present threshold scores for the composite quality measures. These scores are calculated as summarized in Table 1 on page 16.

Identification of Children for Purposes of Survey Administration

Two samples of families with young children were drawn in each state. The first was a random sample of child Medicaid clients, stratified by age (one-fourth were 3 to 9 months old, one-fourth were 10 to 18 months old, and half were 19 to 48 months old) and by length of enrollment in Medicaid (80% met a 12-month continuous enrollment requirement). In addition to this core random sample, unique samples of children were drawn in each state to address specific questions of interest to that state (total sample size = 6,000). In one state, this unique sample was made up of an additional random sample in order to increase the sample size. In the other two states, children were stratified by geographic location and/or race/ethnicity affiliation prior to sampling. Findings from the combined core samples across the three states participating in this study are presented in this report (N = 1903).

Survey Administration

Prior to survey administration, adult/parent respondents received a letter from their state Medicaid agency that described the survey project and explained that the survey was about the health care of a specific child within their family (the target child). Throughout survey administration, the interviewer referred to the child by his or her first name so that it was clear that the respondent should respond to the survey questions relative only to the target child. The parent or guardian in the household that best knew the child's health and his or her medical care history was asked to complete the survey. Up to 20 attempts were made to reach parents of child Medicaid clients by telephone. Overall, 64.7 percent of the families included in the starting sample were successfully contacted and 94.6 percent of those contacted consented to complete the survey.

Study Limitations

Three state Medicaid programs participated in this study. While these states were diverse in terms of racial/ethnic make-up and other factors, findings presented here are not intended to provide a picture of health and health care quality for all young children with Medicaid coverage in America.

Generalizing findings to all children with Medicaid coverage may be further limited due to the fact that the sample for the PHDS-PLUS was composed largely of children continuously enrolled in Medicaid for at least 12 months. Such children may be more likely than those who have limited or episodic enrollment to have a regular provider as well as a more established relationship with health care providers. As such, they may be more likely to receive needed care, and the content and quality of that care may also differ. In addition, only families enrolled in Medicaid for which telephone numbers were available were included in this study. If families without recorded telephone numbers differ from those with recorded phone numbers, unknown biases may result.

Earlier studies show that findings from a telephone administration of the PHDS may yield more positive assessments of the health care system than a mailed administration. This is not surprising considering evidence in the literature showing a consistent, positive, optimistic biasing effect when telephone administration is used.

Overall, we expected both the mode and sampling biases to lead to somewhat optimistic assessments of the health promotion and developmental services provided to the entire Medicaid population in each state.

Finally, it is also important to remember that this survey was conducted only in English and therefore results do not represent the experiences of non-English-speaking families and children.

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