What Do Families Want From Well-Child Care? 
Including Parents in the Rethinking Discussion

WHAT’S KNOWN ON THIS SUBJECT: Schor called on pediatricians to rethink well-child care. Gaps exist between traditional well-child care and contemporary needs and pressures. A key, but largely missing, perspective in the rethinking of discussions has been that of parents.

WHAT THIS STUDY ADDS: In this qualitative study, we asked parents to address several core issues including why they attend well-child care visits, the aspects of care they find most valuable, and what changes could enhance the well-child experience.

abstract

OBJECTIVE: The content and systems surrounding well-child care have received increasing attention, and some propose that it is time to rethink both the delivery structure and central themes of well-child visits. A key, but largely missing perspective in these discussions has been that of parents, whose experiences and expectations are central to developing approaches responsive to family needs. In this study, we asked parents to address several core issues: why they attend well-child visits; aspects of well-child care that they find most valuable; and changes that could enhance the well-child care experience.

METHODS: Twenty focus groups with parents (n = 131 [91% mothers]) were conducted by using a semistructured interview guide. Verbatim transcripts were coded for key words, concepts, and recurrent themes.

RESULTS: Primary reasons for visit attendance included reassurance (child and parent) and an opportunity to discuss parent priorities. Families valued an ongoing relationship with 1 clinician who was child-focused and respected parental expertise, but continuity of provider was not an option for all participants. Suggestions for enhancement included improved promotion of well-child care, greater emphasis on development and behavior, and expanded options for information exchange.

CONCLUSIONS: As the consumers of care, it is critical to understand parents’ needs and desires as changes to the content and process of well-child care are considered. Taking into account the multifaceted perspectives of families suggests both challenges and opportunities for the rethinking discussion. Pediatrics 2009;124:858–865

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KEY WORDS
well-child care, parents, pediatric primary care, health supervision, preventive care, developmental care, family-centered care

ABBREVIATION
AAP—American Academy of Pediatrics

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The content and systems surrounding well-child care have received increasing attention. In the past decade, numerous studies have addressed the growing number of anticipatory guidance topics, disparities in access, and discrepancies in quality. The new Bright Futures guidelines provide the pathway for many advancements, but as the history of well-child care shows, pediatrics will continue to strive for additional improvement. Much of the preventive care schedule has been linked to childhood immunizations, creating concern that, in the public eye, visits for infants and toddlers may be synonymous with “baby shots.” By contrast, professionals have viewed these visits as a critical vehicle to address expanded health and prevention needs. These needs reflect important issues, but have also outstripped the time and resources available to address them. Given the growing list of health supervision recommendations, how can priorities be set? Many argue that it is time to rethink the delivery structure and central themes of well-child visits.

A key, but largely missing, perspective in the rethinking well-child care discussion has been that of parents; their experiences and expectations are critical to developing approaches responsive to family needs. If we consider changes in the content and delivery of preventive health care to better meet the needs of families, it is imperative to include the consumers of that care, namely parents, in the conversation.

Past studies examining preventive care from the parent perspective have been largely quantitative and focused on information needs, satisfaction with care, and provision of services. Few studies have collected in-depth information about why parents attend visits and how they value aspects of well-child care. In this study, with diverse focus groups of parents, we addressed several core questions: Why do parents currently attend well-child visits? What aspects of visits do they find most valuable? What changes, from a parent perspective, would enhance the well-child care experience?

METHODS

Participants

We conducted 20 focus groups with parents between September 2005 and July 2006 to address experiences with and views on well-child visits. In most groups (n = 12), parents with children of similar ages (0–2, 3–5, and 6–12 years) were combined to facilitate discussion of age-related health supervision needs. Twelve sessions were held in the Chicago region, with recruitment targeted to various urban and suburban areas to draw participants of diverse economic and racial/ethnic backgrounds. Three of the Chicago-area groups were held with American Academy of Pediatrics (AAP) employees. Eight sessions were held in the Albuquerque, New Mexico (5 groups), and San Diego, California (3 groups), areas. The AAP institutional review board approved the study protocol.

We recruited parents by flyers distributed in local schools, libraries, health centers, churches, and day care centers rather than through physician offices to ensure participants with a broad range of pediatric providers. As part of the screening process, parents were told that the purpose of the focus group was to “...learn more about parents’ thoughts and feelings about the health care children receive when they are well and ways that pediatric health care might be improved.”

Data Collection

Participants in 16 groups (n = 101) completed a background questionnaire before the session (on-site coordinators for 4 groups [30 parents] outside of Chicago were not able to predetermine background questionnaires). One of the authors (Ms Radecki) moderated all sessions by using a semistructured protocol to guide discussion (Table 1). During each session, parents were first asked about their current experiences with well-child care and then were asked to discuss ways to improve visits. Two concepts suggested in the rethinking well-child care discussion (themed
visits and group well-child care) were introduced to parents to obtain feedback. Participants were also asked to offer their own ideas for improvement. Focus groups lasted 40 to 90 minutes; each session was audiorecorded and later transcribed. All groups were conducted in English, however 1 (San Diego, CA) session included several non-English-speaking Hispanic participants, and 2 translators were present to translate questions and answers. Parents (excluding AAP employees) received $25 for participation.

**Data Analysis**

Verbatim transcripts were created for each focus group and independently read and coded by Ms Radecki and Ms Frintner. We used the discussion guide as the basis of analyses, allowing themes to emerge within each of the key question areas. As new or unique content arose, new codes were created. All transcripts were reviewed for common themes and ideas consistent across groups following elements of the grounded theory approach of qualitative data analysis. Dr Olson reviewed a subset of transcripts. Atlas.ti (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) was used to organize transcripts and facilitate electronic coding. Coding discrepancies between the authors were minimal and resolved through discussion, which included review of coded material with similar content.

**RESULTS**

**Sample Characteristics**

Most (91%) participants were mothers and ranged in age from 20 to 57 years (see Table 2). The sample varied by race/ethnicity (27% black, 19% Hispanic), income (46% had an annual income of <$30,000), and child insurance status (42% public).

| TABLE 2 Selected Demographic Characteristics of Parent Focus-Group Participants (N = 101) |
|----------------------------------------|------------------|-----------|
| Respondent relationship to child      | % (n)            |
| Mother                                | 90.8 (119)       |
| Father                                | 6.1 (8)          |
| Other                                 | 3.1 (4)          |
| Respondent race                       |                  |
| Black                                 | 26.7 (27)        |
| Asian                                 | 2.0 (2)          |
| White                                 | 58.4 (59)        |
| Other                                 | 7.9 (8)          |
| Missing                               | 5.0 (5)          |
| Respondent is Hispanic                | 18.8 (19)        |
| Respondent marital status             |                  |
| Married                               | 68.3 (69)        |
| Divorced                              | 6.9 (7)          |
| Widowed                               | 1.0 (1)          |
| Single                                | 22.8 (23)        |
| Missing                               | 1.0 (1)          |
| Respondent highest level of education completed |                |
| High school graduate or less          | 19.8 (20)        |
| Some college                          | 25.7 (26)        |
| 2-y college or technical school graduate | 10.9 (11)       |
| 4-y college or more                   | 42.6 (43)        |
| Missing                               | 1.0 (1)          |
| Child sees 1 particular person for well-child care | 92.1 (93)       |
| Type of clinician usually seen for well-child care |            |
| Pediatrician                          | 85.1 (88)        |
| Family practitioner                   | 6.9 (7)          |
| Pediatric nurse practitioner          | 15.8 (16)        |
| Physician’s assistant                 | 5.0 (5)          |
| Other                                 | 2.0 (2)          |
| Annual household income               |                  |
| Less than $30,000                     | 45.7 (37)        |
| $30,000 or higher                     | 49.4 (40)        |
| Missing                               | 4.9 (4)          |
| Child health insurance                |                  |
| Yes                                   | 93.8 (76)        |
| No                                    | 2.5 (2)          |
| Missing                               | 3.7 (3)          |
| Child main source of health insurance |                  |
| Private                               | 45.7 (37)        |
| Public                                | 42.0 (34)        |
| Other                                 | 6.2 (5)          |
| Missing                               | 6.2 (5)          |

Focus-group participants by location, n

- AAP staff (child ages 0–2 y) 7
- AAP staff (child ages 3–5 y) 7
- AAP staff (child ages 6–12 y) 6
- Chicago suburbs: higher SES (child ages 0–2 y) 7
- Chicago suburbs: higher SES (child ages 3–5 y) 5
- Chicago suburbs: higher SES (child ages 6–12 y) 9
- Chicago suburbs: lower SES (child ages 0–2 y) 6
- Chicago suburbs: lower SES (child ages 3–5 y) 4
- Chicago suburbs: lower SES (child ages 6–12 y) 2
- Chicago (child ages 0–2 y) 9
- Chicago (child ages 3–5 y) 4
- Chicago (child ages 6–12 y) 8
- San Diego military families (child ages 0–12 y) 8
- San Diego families with special health care needs (child ages 0–12 y) 9
- San Diego health clinic 8
- Albuquerque (child ages 0–12 y) 6
- Albuquerque (child ages 0–5 y) 9
- Albuquerque (child ages 0–5 y) 6
- Albuquerque families with special health care needs (child ages 0–12 y) 2
- Albuquerque health clinic 9

Demographic questionnaires were unavailable for 30 participants. SES indicates socioeconomic status. *Question not asked of AAP employee focus-group participants (n = 20).
Focus-Group Findings

Major themes are reported below, supported by quotes from parents. Brackets following quotations indicate the general location and child age range for each speaker’s focus-group session.

Primary Reasons for Attending Well-Child Care Visits

When asked why they attend well-child care, parents reported traditional activities often associated with these visits (eg, immunizations, school physicals) as well as several other reasons for seeking care, clustered into 2 key areas: (1) reassurance; and (2) opportunity to discuss priorities.

Reassurance

In each group, participants talked about the importance of reassurance during well-child visits, wanting feedback to confirm that their child was growing and developing normally. The need for assurance was often mentioned by parents of infants and toddlers.

“...you go in for certain illness, you don’t have the time to grapple with the developmental questions. So at the well-child care visit you get to explore some other issues that aren’t exactly the most pertinent things, but they’re more developmentally and looking more holistically at the child.” [San Diego, mixed ages]

Parents viewed well-child visits as an occasion to ask their own questions and gain information about their child’s health and development. Parents were most interested in content that reflected their personal concerns.

“I want to come in and talk about my own topics and not have time taken up by other things. I don’t want the doctor talking about sleeping habits if my kid is sleeping fine... it might throw me off track for what I really want to talk about.” [Chicago suburbs, 0–2 years]

However, comments also indicated that some parents may be hesitant to ask and want the physician to initiate discussions. Some may be uncomfortable initiating topics, whereas others may be uncertain about what is appropriate to ask.

“There are multiple reasons why physician-parent conversations can be developmentally appropriate. One reason is that pediatricians are trained to ask and want the physician to initiate...”

Key Elements of the Physician-Parent-Child Relationship

Three key elements of the physician-parent-child relationship that mattered to parents were: (1) emphasis on the child; (2) respect for parental expertise; and (3) affect and body language.

Emphasis on the Child

Parents felt strongly that the ideal visit is child-focused—the clinician speaking directly with the child and interacting in a caring manner. Several
parents noted that early visits establish the foundation for positive feelings about health care as the child grows.

“... your doctor addresses the child ... asks the child how the child’s doing. Even if the child can’t talk, the child understands.” [Albuquerque, mixed ages]

“Some of the things he does that I really, really like is that he talks to my son. He asks the questions of my son ... he makes stuff fun ... he does little bird whistles and things like that.” [Chicago suburbs, 3–5 years]

Respect for Parental Expertise

A concern shared by many parents was a perceived lack of respect by clinicians for parents’ expertise regarding their own children.

“... they just really need to acknowledge that you’re the expert on your child. Just talk to us as if we are our child’s expert ... If they were just honest with you and included you in the whole process, that’s important too.” [Albuquerque, mixed ages]

Affect and Body Language

Many parents commented on the importance of the physician “knowing” their child(ren) and recognizing that they were more than a chart number or dollar sign.

“He knows my son, he’s been with him since he was born. He knows us ... so it’s just real important that we have a relationship, I guess that’s what I would call it. It’s not just we’re going to get services, we have a relationship with him.” [Chicago suburbs, 3–5 years]

Physicians’ demeanor and body language was also important to a number of parents. Suggested improvements included better eye contact and more personalized attention.

“They should pay attention. They’re so busy looking at the folder trying to get a grip on what’s on the folder, but they’re not establishing any kind of a relationship with the human beings that are right in front of them.” [Chicago suburbs, 0–2 years]

“... after he’s done looking at my child, look at me, where he has eye contact as opposed to just writing ... I wanna know that I have his undivided attention and that if I ask one extra question it’s not going to burden him.” [San Diego, mixed ages]

Suggestions for Enhancing Well-Child Care

Beyond current experiences, we asked parents to envision how well-child care might be enhanced. Alternate approaches to preventive care proposed in the rethinking debate (themed and group visits) generally received limited support. Parents were concerned about privacy, comparisons between children, intrusion on individual time with the physician, and practicalities such as scheduling (group visits), or lack of fit with their child’s current priorities (themed visits). Parents’ suggestions for improvements clustered in 3 areas: (1) better social marketing about the value of well-child care; (2) increased emphasis on development and behavior; and (3) enhanced information exchange.

Improved Well-Child Care Marketing

Parents reported lack of knowledge about the visit schedule, especially for older children.

“... you tend to go for kindergarten. You need that physical. Then I think it’s what? Fifth grade they have to go again? I’m not sure ... I remember saying to my doctor after that kindergarten checkup, ‘Well should I come back every year now and why? My insurance says each child is covered for a 1-year well checkup and he said, ‘It’s really up to you.’” [Chicago suburbs, 6–12 years]

“Once they get to be a little bit older, I should know the schedule but I don’t. Who reminds you that they should see the doctor once a year or whatever it is once they’re in school?” [AAP employees, 6–12 years]

Other parents were unsure about the need for well-child visits, particularly for children in seemingly good health.

“If my kid’s okay, and all I’m doing is bringing them in to get them measured and weighed and make sure they’re aiming at the Cheerios, why do I need to see a doctor? ... I always laugh when I see the sign, ‘Well Infant Clinic.’ Why do I want to bring my well child to the clinic? ... I grew up, I don’t remember seeing a doctor unless I was sick.” [San Diego, mixed ages]

As the frequency of appointments decreased, parents also lamented a lack of notifications or reminders regarding the next visit.

“... my dentist sends me a postcard, it seems that the doctor would at least from a marketing point of view would be sending me information... They don’t do that.” [Chicago suburbs, 3–5 years]

Increased Emphasis on Development and Behavior

Regardless of the age of their child, parents expressed interest in well-child care more focused on development and behavior.

“Our daughter was a thumb sucker and, ooh, ‘til she was 6 or so ... that was one thing that I would’ve never fathomed bringing up to the doctor. We actually ended up going to a thumb doctor ... that was the best $155 bucks I ever spent ... it worked out fantastic, but that was something I probably never would have thought of just talking to my pediatrician about.” [San Diego, mixed ages]

“I guess I’d like them to just be as equally concerned with ... emotional and mental well being as the physical because a lot of that affects the physical ... having resources ... Where do I go? Who do I talk to? What do I do? Give me an explanation. Tell me what to do, practical things ... not just physically but emotionally too.” [Albuquerque, mixed ages]

Enhanced Information Exchange

A recurring theme across groups was parents’ desire for increased information about healthy growth and development. Parents suggested several ways to make information exchanges more family-friendly by using opportunities both before and after visits as well as technology and community resources (see Table 3 for specific suggestions). For example, parents suggested previsit materials, such as checklists, to facilitate better use of limited time with the physician. They also endorsed seminars led by pediatricians and workshops to educate families on issues regarding child health and parenting. Better linkages with community resources were also sought, because parents frequently
<table>
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<th>Focus</th>
<th>Suggestion</th>
<th>Parent Comments</th>
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<tr>
<td>Previsit</td>
<td>Checklists: A &quot;preview of coming attractions,&quot; helps parents prepare for the visit and know what to expect.</td>
<td>So if they could . . . just give you some printouts or something ahead of time so you know what to look forward to and different types of questions you may want to ask. So if I had that list of questions ahead of time, I’d be more prepared for the visit. [A checklist] also puts that seed in your head for the next 3 or so months. So if you see your child doing something you say, “Oh yeah, I’m supposed to be looking at that,” or the pediatrician said that might happen . . . you’re waiting out in the waiting room while he’s with other people and then you get taken to a room and then you wait in the room some more. . . . as you’re in the waiting room, they can give you like some information that you can read for the few minutes or however long, kind of like this is what we’re going to go over during the visit or this is where your child should be. . . . after your visit, he would actually either e-mail you or send you in the mail a printout of a description of what happened in the visit, things to look for; reminders . . . I think if our pediatricians would do that and maybe give you a summary of here’s what we talked about in our meeting, here’s some things to look forward to or things you can try, that would be really nice.</td>
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<td>Office setting</td>
<td>More efficient use of wait times: Parents are sensitive to long waiting times, especially in multiple places (eg, waiting room and exam room). Use wait times as an opportunity to provide information.</td>
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<td>Postvisit</td>
<td>Visit summaries: Parents would like a recap of important visit information.</td>
<td>. . . after your visit, he would actually either e-mail you or send you in the mail a printout of a description of what happened in the visit, things to look for; reminders . . . I think if our pediatricians would do that and maybe give you a summary of here’s what we talked about in our meeting, here’s some things to look forward to or things you can try, that would be really nice. If you took the children out of that equation, if the doctor’s office offered up a seminar where you could come in the second Saturday of every month . . . and have a little mini discussion group . . . I think with the doctor in a group one-on-one would be good and everybody could discuss the issues and all parents are sitting there . . . sometimes you don’t feel bad because someone else is going through it too, it helps you too.</td>
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<td>Workshops</td>
<td>Parents sought optional learning activities about child health and development, outside the traditional office visit and without children present.</td>
<td>I’ve been looking for parenting classes and I can’t find them . . . They have parenting classes but they’re for how to take care of a newborn child, how to breastfeed them, take care of their umbilical cord, but they don’t have any parenting classes . . .</td>
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<td>Communication</td>
<td>E-mail: Parents sought opportunities to share/obtain information outside the traditional office visit.</td>
<td>. . . I can’t tell you how many times a simple e-mail question and a simple e-mail answer would have sufficed, instead of you having to wait for the certain hours that they answer the phone and I can talk to a nurse. . . . it’s really hard because where I work, it’s like a cube situation and I don’t really want to be discussing my child’s medical stuff in an area where every single person that I work with can hear . . . I like the idea of getting an e-mail. . . . It’s very difficult, but who has time to check the source? Maybe if the doctor could provide a list of websites . . . But it would be nice to leave with some resources and some books or websites. . . . if my doctor sent out kind of what ParentCenter[.com] did, it came from their office instead, even though I’m sure it would be mostly the same information, it would have had a higher priority if it came from them. I think it would be good business from their point of view. . . . seeing the pediatric nurse practitioner has made a big difference for the well-child care . . . I just feel that there’s a lot more attention, a lot more questions asked . . . she asked me so many questions that I never would have thought of her asking me but I thought were so vital . . . potty training . . . when I have questions like that, honestly, I ask my son’s day care teachers, because they deal with it . . . questions like that I feel more comfortable asking them because they are dealing with it on a daily basis. . . . the benefit that I have is that I’m involved with the WIC program, so they are very good at talking to me about my child’s eating habits, how many servings of vegetables he should be eating . . .</td>
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<td>Information referrals</td>
<td>Parents are concerned about the credibility of various resources and look to the pediatrician for referrals to trusted information sources.</td>
<td>. . . if my doctor sent out kind of what ParentCenter[.com] did, it came from their office instead, even though I’m sure it would be mostly the same information, it would have had a higher priority if it came from them. I think it would be good business from their point of view. . . . seeing the pediatric nurse practitioner has made a big difference for the well-child care . . . I just feel that there’s a lot more attention, a lot more questions asked . . . she asked me so many questions that I never would have thought of her asking me but I thought were so vital . . . potty training . . . when I have questions like that, honestly, I ask my son’s day care teachers, because they deal with it . . . questions like that I feel more comfortable asking them because they are dealing with it on a daily basis. . . . the benefit that I have is that I’m involved with the WIC program, so they are very good at talking to me about my child’s eating habits, how many servings of vegetables he should be eating . . .</td>
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<tr>
<td>Community connections</td>
<td>Parents do not expect pediatricians to be their sole source of information regarding child health and development and welcome assistance from other community resources.</td>
<td>. . . if my doctor sent out kind of what ParentCenter[.com] did, it came from their office instead, even though I’m sure it would be mostly the same information, it would have had a higher priority if it came from them. I think it would be good business from their point of view. . . . seeing the pediatric nurse practitioner has made a big difference for the well-child care . . . I just feel that there’s a lot more attention, a lot more questions asked . . . she asked me so many questions that I never would have thought of her asking me but I thought were so vital . . . potty training . . . when I have questions like that, honestly, I ask my son’s day care teachers, because they deal with it . . . questions like that I feel more comfortable asking them because they are dealing with it on a daily basis. . . . the benefit that I have is that I’m involved with the WIC program, so they are very good at talking to me about my child’s eating habits, how many servings of vegetables he should be eating . . .</td>
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noted a disconnect between community organizations (e.g., Supplemental Nutrition Program for Women, Infants, and Children, child care providers, schools) and the pediatric practice.

**DISCUSSION**

This study explored issues surrounding rethinking well-child care through the eyes of parents. We found that families of diverse backgrounds value well-child care beyond immunizations and school physicals, viewing visits as opportunities to gain reassurance about their child and their parenting. Quantitative studies of well-child visits have tended to focus on counting topics covered and services received, but in these open-ended discussions about what they value, parents emphasized a desire to address their individual concerns, preferably with a clinician they know and who respects their knowledge about their child. Parents sought greater attention to developmental and behavioral issues, and suggested several ways to enhance the delivery of preventive care, such as previsit checklists, workshops, and increased e-mail availability.

Qualitative data provides the richness of detail needed to understand how parents think about preventive care and points to concerns that professionals might not have given priority. Focus groups allow a depth of description not possible in quantitative surveys. There are, however, limitations as participants were self-selected and may represent parents more interested and involved in health care than nonparticipants. From these parents we cannot generalize to all US families. Although we conducted sessions in multiple locations and attempted to diversify our sessions, sample size precludes subgroup analyses by race, ethnicity, or socioeconomic status. We are also unable to address the similarities and unique concerns of families of children with special health care needs.

The complexity of opinions raised by participants, however, points to important challenges and opportunities in the rethinking debate. One conundrum identified by our results is that of balancing individual family priorities with the education and guidance pediatricians are expected to cover in a typical well-child visit. We also observed ambivalence on the part of parents as to what topics are under the purview of the pediatrician and when a parent versus physician should initiate discussion.

The changing face of pediatrics also presents challenges to continuity of care. Although preferred by most parents and endorsed by health care professionals, an ongoing relationship with 1 provider may not always be possible, especially for uninsured children whose parents are less likely to report a usual person for well-child care. In addition, the increase in pediatricians engaged in part-time practice and the move toward a team approach to pediatric care where more children may be seen by several practitioners within a practice may make it more difficult for families to see 1 physician on a consistent basis. If the profession adopts a model where continuity is defined more by place than person, what are the implications for patients and professionals? Are there innovative ways to capture the perceived benefits that continuity with 1 clinician provides?

Findings from these focus groups support the work of Bergman et al in their efforts to identify the elements of a high-performing system of well-child care. They note that a one-size-fits-all approach to well-child care is not optimal and cannot best serve the needs of children and families. Those sentiments were reiterated by our parents in their desire for attention to individualized concerns and needs, increased use of technology such as e-mail to facilitate quicker and easier access to care, as well as an approach to preventive care that connects to multiple stakeholders in the community.

Encouraging indications that parents and pediatricians may share ideas and expectations about the future of well-child care are evidenced by new focus-group findings with clinicians. Tanner et al found that pediatricians echoed the importance of ongoing relationships with families, endorsed individualized care and the key role of parents in priority-setting, and emphasized the value of visits more attuned to development and behavior. These areas of common interest may serve as building blocks to move forward the rethinking discussion in a way that is embraced by families and pediatricians.

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