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Low-Income Parents' Views on the Redesign of Well-Child Care

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Abstract

OBJECTIVE—To examine the perspectives of low-income parents on redesigning well-child care (WCC) for children aged 0 to 3 years, focusing on possible changes in 3 major domains: providers, locations, and formats.

METHODS—Eight focus groups (4 English and 4 Spanish) were conducted with 56 parents of children aged 6 months to 5 years, recruited through a federally qualified health center. Discussions were recorded, transcribed, and analyzed by using the constant comparative method of qualitative analysis.

RESULTS—Parents were mostly mothers (91%), nonwhite (64% Latino, 16% black), and <30 years of age (66%) and had an annual household income of <\$35 000 (96%). Parents reported substantial problems with WCC, focusing largely on limited provider access (especially with respect to scheduling and transportation) and inadequate behavioral/developmental services. Most parents endorsed nonphysician providers and alternative locations and formats as desirable adjuncts to usual physician-provided, clinic-based WCC. Nonphysician providers were viewed as potentially more expert in behavioral/developmental issues than physicians and more attentive to parent-provider relationships. Some alternative locations for care (especially home and day care visits) were viewed as creating essential context for providers and dramatically improving family convenience. Alternative locations whose sole advantage was convenience (eg, retail-based clinics), however, were viewed more skeptically. Among alternative formats, group visits in particular were seen as empowering, turning parents into informal providers through mutual sharing of behavioral/developmental advice and experiences.

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CONCLUSIONS—Low-income parents of young children identified major inadequacies in their WCC experiences. To address these problems, they endorsed a number of innovative reforms that merit additional investigation for feasibility and effectiveness.

Keywords

well-child care; delivery of care; preventive services; medical home; family-centered care

Well-child care (WCC), the foundation of US child health care services, encompasses an array of preventive services. Most WCC guidelines include detailed recommendations for physical examination, anticipatory guidance, developmental/behavioral screening, psychosocial screening, laboratory screening, and immunizations.^{1,2} Many parents, however, do not have their psychosocial, developmental, and behavioral concerns of their child addressed^{3–5}; many children do not receive screening for developmental delay⁶; and many pediatricians do not have the time, training, or financial incentives to provide recommended preventive services.^{7,8} These deficiencies are often more pronounced for low-income and minority families^{3,5,6,9–11}; black and Latino parents are more likely to report unmet preventive needs and less likely to be up-to-date on WCC and to report satisfaction with visits than white parents.^{5,11–14}

Various WCC innovations have been proposed; some suggest reforms within the constraints of the current system,^{15,16} whereas others emphasize alternatives such as nonphysician providers,¹⁷ and alternative locations¹⁸ and visit formats.^{19,20} In a national survey, pediatricians suggested that a WCC system less reliant on physicians and face-to-face office visits would be a more effective and efficient way to provide care.²¹

Despite growing momentum for WCC redesign, little research has been conducted in this area. A recent study, *Re-thinking Well-Child Care*, presents an in-depth qualitative analysis of why parents attend well-visits, their value for parents, and possible ways to enhance WCC. The study does not, however, examine in detail parents' perspectives on alternative systems of WCC delivery.²² To our knowledge, no published studies describe parents' perspectives on redesigning WCC. Moreover, low-income and minority parents may have unique concerns; new WCC models might need to be tailored for these and other specific populations.

This study's objective was to describe the perspectives of low-income, ethnically and linguistically diverse parents on the redesign of WCC to children 0 to 3 years of age. Our aims were to assess parents' views on and acceptance of nontraditional ways of receiving WCC services, including delivery by nonphysician providers, in locations such as retail stores or day care centers, and by using non-face-to-face formats including telephone or e-mail.

METHODS

Because the content and focus of WCC varies considerably by child age, our analysis focuses on WCC from 0 to 3 years of age. WCC visits in the first 3 years of life are similar

in content and structure; this time period also represents the most time-intensive years for WCC.^{1,2}

Eligibility and Recruitment

Our sample consisted of parents from 3 clinics of a multi-site federally qualified health center covering a large geographic area in Los Angeles, California. We used 2 methods for recruitment: (1) waiting-room and reception advertisements; and (2) mailings to 350 households (parents of all clinic patients ages 6 months through 3 years). Interested parents were directed to contact the clinic or study coordinator. Parents received information about the study's purpose, time commitment, and eligibility criteria. When more than 1 parent expressed interest, we requested the parent most involved in well-visits.

Eligible parents spoke English or Spanish and had a child 6 months to 5 years of age. This age range was chosen to capture perspectives of a variety of parents, from those just beginning WCC for children 0 to 3 years of age to those who had completed it. This study was approved by the University of California, Los Angeles Office for Protection of Research Subjects. We obtained informed consent from all participants.

Focus Groups

Seventy-five parents were scheduled in advance for 8 focus groups; 56 participated. Four groups were conducted in English and 4 in Spanish; between 5 and 9 parents, a trained moderator, and a note-taker participated in each group. Because focus groups generally include between 4 and 12 participants, and experts recommend that researchers conduct 3 to 4 groups per category of individuals,^{23–25} our target enrollment was 48 (4 groups in each language $\times$ 2 languages $\times$ 6 parents per group).

Focus groups were held in a conference room at each clinic (February 2008 to April 2008) on a Saturday morning. Child care was provided for the 75- to 90-minute discussion. The first author conducted English-language groups; an experienced, bilingual moderator conducted Spanish-language groups. Immediately before each group, parents completed a brief questionnaire of demographic information. Participants received a cash incentive (\$75).

Focus groups were guided by a semi-structured discussion protocol developed by the study team and on the basis of a literature review of WCC redesign. The discussion began with an icebreaker, followed by a discussion of parents' WCC and related experiences. We asked parents about using other providers, locations, or formats to provide WCC services; we probed with detailed descriptions of alternatives proposed in the literature (ie, group visits, retail-based clinics).^{16–18,20,21} Parent interaction and open discussion of diverse views were explicitly and implicitly encouraged. The full discussion guide is included in the Appendix.

Qualitative Analysis

All sessions were digitally recorded, transcribed, and imported into qualitative data management software. Spanish-language groups were transcribed into Spanish and translated into English for analysis. All transcriptions were independently verified by an

additional bilingual research assistant for accuracy of translation and transcription. Two experienced qualitative coders and 2 authors (Drs Coker and Chen) read samples of text and created codes for key points within the text. Through an iterative process, these codes were developed into a codebook. The 2 coders then independently and consecutively coded the transcripts, discussing discrepancies and modifying the codebook with TC. To measure consistency between coders, we calculated a Cohen's κ^{26} by using a randomly selected sample (33%) of quotes from each of the major themes. κ scores ranged from 0.83 to 1.00, suggesting excellent consistency.^{27,28}

Next, the research team performed thematic analysis of the 563 unique quotations that dealt with 4 WCC themes identified from the literature review: (1) problems with current WCC; and the use of (2) nonphysician providers, (3) alternative locations, and (4) alternative formats for WCC services. The team then identified the most salient subthemes; these were the specific concepts and ideas that emerged from the quotes within each major theme, and were discussed by 2 parents in at least 6 of the groups. The analysis was based in grounded theory and performed by using the constant comparative method of qualitative analysis.^{29,30} Because we aimed for thematic representation, we present not only consensus, but also key dissenting views to give a more accurate impression of agreement and disagreement among participants.^{31,32}

RESULTS

Participants

Table 1 describes participant characteristics. Fifty-one mothers and 5 fathers participated in 8 focus groups; the age of the index child was between 6 months and 5 years, and nearly all parents reported a household income of <\$35 000.

Each major theme and its subthemes are discussed below. Tables 2 through 5 provide additional quotes that illustrate each subtheme.

Current WCC: Limited Access, Poor Behavioral/Developmental Services

Although a few parents reported positive WCC experiences, many more reported problems with care; these were captured by 2 subthemes that were similar across English- and Spanish-language groups. For the subtheme of limited provider access (Table 2), parents described: (1) difficulty communicating with their physicians outside of scheduled visits (“They don’t have an actual line that I can just call to ask the question. They make me actually bring her in and then I got to wait. That’s for a simple question.”); (2) problems accessing the clinic/office because of transportation problems (“The person inside the clinic doesn’t know how many buses you took to get to that appointment.”); and (3) inadequate time with physicians during visits (“Because doctors rush you out.”), leading to poor communication and rapport (“The doctors don’t want to listen ... they just want you to hear what they got to say.”). For the second subtheme, inadequate behavioral/developmental services (Table 2), many parents were dissatisfied with the level of behavioral/developmental services provided. They thought that providers spent little time, if any,

addressing their behavioral/developmental concerns about issues such as temper tantrums and discipline (“We need to know how to deal with tantrums.”).

Alternative Providers: Better Counseling, Better Relationships

Two subthemes regarding the use of nonphysician providers emerged. First (Table 3), parents emphasized that counseling/guidance services (anticipatory guidance, behavioral screening, and psychosocial screening) could be improved by using, as adjuncts or replacements, nonmedical professionals (eg, counselors, social workers, psychologists) who might be more qualified to provide these services (“This person is going to focus more on your child's behavior; she's going to actually sit down and talk and find out what's really going on.”). Second (Table 3), parents thought that nonphysicians may be more attentive to parents' needs and to the importance of the parent-provider relationship. They reported that having a provider who listened, addressed their specific needs, and built a continuous and respectful relationship with them was more important than having a physician. Many parents felt that their doctors lacked these qualities and reported finding them more often in their nurses (“The nurses will ask me what's going on; they listen, ask questions, you know, they're just more involved.”).

Parents suggested a wide range of providers including registered nurses, counselors, psychologists, physician assistants, and early childhood educators. A few parents, however, thought that the physician should provide all services (“I just feel way more comfortable if the doctor checked everything.”).

Parents in the Spanish-language groups discussed nonphysicians more often as adjuncts than as substitutes for the physician, whereas parents in the English-language groups generally favored the reverse. Although nonphysicians were regarded in the Spanish-language groups as important additions and as possibly more attentive to parents' needs, these parents wanted physicians involved in every aspect of WCC; in the English-language groups, parents preferred physicians for some services (physical examination) and nonphysicians for others (behavioral screening).

Alternative Locations: More Convenience, More Context

There were 2 subthemes for alternative locations, and they were similar across the English- and Spanish-language groups. The first subtheme dealt with the convenience and context provided by visits at home and at day care centers and preschools (Table 4). Home visits were strongly endorsed by parents; many commented on the convenience, especially those with transportation problems. Some parents shared positive experiences with newborn home visits by nurses (“The nurse could see what you have at home and what you don't have.”). Others thought that home visits would allow the provider to personalize WCC services to their specific needs (“At home, the doctor can also kind of scope out what's going on.”).

Parents were also enthusiastic about well-visits at day care centers and preschools. Although none personally received care in these locations, many thought that these locations would be convenient and would have the benefit of occurring at a place where many of the behavioral concerns could be addressed with the involvement of teachers (“That's probably where your

child will be spending a lot of time, so that maybe if you're my son's teacher, you could see the behavioral problems.”).

The second subtheme addressed the use of retail-based clinics as alternative locations for WCC services. Although no parent had used a retail-based clinic for their child, some had heard about them. Many thought they were conveniently located. However, they were not seen as a viable option for the provision of comprehensive WCC services; parents thought that they should only provide care for minor concerns (Table 4). Although many parents were happy to receive some WCC services by a physician assistant or nurse in other locations, they did not want to do so at retail stores. There was a lack of trust of nonphysician providers in these locations; some parents described uncertainty about the qualifications of nonphysician staff employed by stores (“I would be more concerned where they get their education from.”).

Finally, there were a few parents who wanted to receive all of their WCC services at 1 traditional location, either a clinic or doctor's office (“I think that the visits would be better at the clinic or hospital; the doctor would have more of his tools to use.”).

Alternative Formats: More Empowerment, More Options

Two subthemes emerged for alternative formats. Group visits were universally endorsed in both English- and Spanish-language groups and were seen as empowering to parents (Table 5). They were enthusiastic about having visits with groups of parents with similarly aged children, led by a physician or nurse. They saw these group visits as an opportunity to learn from other parents (“That way you learn from other moms.”) and build a support group of peers (“You end up with people that you can bounce things off in the middle of the night.”). Some parents shared positive experiences they had with prenatal and parent support groups; they saw similar benefits to group WCC.

Although a few parents preferred the traditional face-to-face, one-on-one format for all WCC services (“You'll do whatever's available to you, but it's always better face-to-face.”), most wanted to have the option of receiving some services outside of typical encounters (Table 5). These options included e-mail, telephone, text-messaging, Internet blogs, and Web sites. Some parents already used Web sites that gave them personalized information about their child's development. One parent described how her doctor could use text-messaging to answer her questions (“While she's waiting on this other patient to go into this room, she can send me a message right here. A quick, fast text-message.”). Other parents reported that a lack of Internet access or privacy concerns would prevent them from using the Internet to communicate with their providers. Parents in both language groups endorsed the availability of e-mail/Internet communication, but in the Spanish-language groups, there was somewhat less enthusiasm. Spanish-language parents did not describe experiences using health-related Web sites, and more often discussed Internet access as a problem (“I don't even have a computer.”).

DISCUSSION

Through focus groups, low-income parents identified fundamental inadequacies in the WCC system and endorsed a wide variety of potential reforms with respect to providers, locations, and formats. The changes in WCC endorsed by these parents reinforce key principles of the medical home³³: care that is comprehensive (eg, use of nonphysicians as adjuncts for behavioral/developmental services), family-centered (eg, home visits), and accessible (eg, multiple parent-provider communication options including e-mail, telephone, and Internet).

Our data suggest that incorporating nonphysician providers into WCC delivery may be acceptable and even preferable for many parents. Although studies have shown that the quality of adult preventive care provided by nurses is at least as good as care provided by physicians in several domains,^{34,35} few studies have been conducted in pediatric populations. One study published almost 35 years ago found no differences in the adequacy of WCC in the first 2 years of life provided by nurse practitioners (NPs) versus pediatricians.³⁶ Other studies have examined provider counseling and guidance; 1 reported that NPs were more likely than physicians to counsel on firearm injury,³⁷ and another found that nonphysicians were less likely to discuss nutrition and safety than pediatricians.³⁸ Although parents in our focus groups cited NPs as possible providers, more often other less commonly used providers such as counselors and psychologists were described as useful WCC providers. Hence, more detailed inquiry on the effectiveness of nonphysician providers (beyond NPs) is critical.

Even parents who did not generally favor the use of nonphysicians still described a need for nonphysician providers for behavioral screening/counseling, which they reported as inadequate in their current WCC. One program that attempts to address these needs using nonphysicians, Healthy Steps, incorporates a behavior/development specialist into visits to provide expanded behavioral/developmental services to families during the first 3 years of their child's life. In a controlled trial of the intervention, modest improvements in intervention group parenting behaviors were reported at age 5 follow-up.^{17,39} A major concern for dissemination of Healthy Steps has been reimbursement. Some practices attempt to circumvent this problem by replacing physician time with behavior/development specialist time, thus allowing physicians to perform more reimbursable visits.⁴⁰ It is unlikely, however, that this model could become widely applicable without substantial advances in reimbursement flexibility.

WCC delivery in locations outside of the clinic/office (daycares, preschools, and at home) was strongly endorsed by parents. These changes would likely require significant organizational redesign; for example, clinics and practices might need to develop robust off-site capabilities involving work-force expansion, institutional financial agreements, and adjustments to patient panels and catchment areas. Practices and clinics also face the challenge of coordination of WCC services across different locations. Despite the challenges of providing WCC services in alternative locations, there are several advantages, including an increased focus on family-centered care, accessibility, and convenience; these advantages must be weighed against the costs of practice redesign that such changes would require.

Another concern is that all of these changes could cause WCC to become too fragmented: by using various providers in different locations, some parents could lose what may have previously functioned as a medical home for their child. Child health systems in several other industrialized countries (Australia, England, France, Japan, Netherlands, and Sweden) routinely separate WCC services among multiple providers and have varying levels of coordination among providers.⁴¹ It is unclear, however, to what degree those models may be applicable in the United States. Parents addressed this concern in their discussions by emphasizing that their various providers should be part of a coordinated WCC team for their child. Parents did not want to use locations that were not part of or in communication with this comprehensive WCC team; this concern was best expressed in the discussions of retail-based clinics.

Parents endorsed several alternative formats for care. They wanted various provider-parent communication options available to them (e-mail, telephone, text-messaging), which poses practical challenges for clinics and providers. As parents mentioned, confidentiality is a serious concern. Moreover, because of the time and infrastructure involved, reimbursement systems would have to support each format, and each format would also require ongoing development and maintenance by physicians and other staff. Various reimbursement mechanisms have been proposed for non-face-to-face encounters; for example, a mixed-reimbursement model that adds a fixed per-patient-yearly payment in addition to current fee-for-service payments could provide compensation for these largely unreimbursed services.⁴²

Group visits were strongly endorsed by parents. Group visits have been discussed in the literature for over 30 years; a group of parent-child dyads requiring the same age-specific visit are seen as a group and discuss parenting, anticipatory guidance, and behavioral/developmental issues. Either before or after the visit, each child is examined and immunized.^{20,43} Several studies examining group WCC suggest that it is at least as effective as individual WCC and more efficient in disseminating information to parents.^{19,44–47} Drawbacks to group visits include scheduling, space, and reimbursement issues,²⁰ however, a major advantage is the emphasis on family-centeredness of care.⁴⁸ In addition, providers generally spend more time discussing anticipatory guidance topics in group visits compared with individual visits.^{45,49} Given the overwhelmingly positive response parents gave for group visits, additional study into systems that could support these visits is justified.

Our findings must be interpreted within the context of this study's limitations. First, focus group participants were limited to low-income parents at federally qualified health center clinics in Los Angeles. By focusing on a population of urban, low-income parents, we identified problems and possible solutions for WCC that may not be identified in other populations. These parent perspectives may be very different from those of higher-income parents because of socioeconomic disparities that exist within WCC for access, quality, use, unmet needs, and overall parental satisfaction.^{5,11,12,14,50,51} Second, we focused on WCC for infants and preschool-aged children; we did not address WCC for older children and adolescents. Third, our purposive sampling limits our ability to draw definitive conclusions; our findings should be confirmed with more systematically representative studies, both qualitative and quantitative. Finally, parents' suggestions must be balanced against considerations of feasibility and costs, which were not explored in this analysis.

Nevertheless, these findings represent the first published data describing an in-depth view of parents' perspectives on WCC redesign. As clinicians, researchers, and policy makers consider ways to reform or radically redesign our WCC system, the perspectives of parents will be critical in designing a system that meets the needs of families. Many deficiencies in WCC are more pronounced among low-income populations; hence, redesign efforts should pay special attention to their perspectives. The parents in our focus groups identified several major inadequacies in their WCC experiences, but also endorsed a number of possible reforms to address these problems that merit additional investigation for feasibility and effectiveness.

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Appendix

APPENDIX

Focus Group Discussion Guide: A New Model for the Delivery of Well-Child Care to Infants and Young Children—Parents' Perspectives

Topic #1: Understanding/Knowledge of Well-Child Visits

During a baby's first 3 years of life, most doctors recommend that a baby have several doctor visits. [Babies or toddlers] get weighed, examined, and often get shots at these visits. Parents may get information on taking care of their infant or toddler during these visits. We call these "well-child visits."

(1) Who has recently gone for one of these well-child visits? What are some of the different things that happened during these visits? [Write down the items that the group gives on a dry erase board or large piece of paper taped to the wall]

(2) [If the group does not name any nonmedical items, such as checking for development, helping with parenting issues, etc, ask]: What about other things like checking to make sure your infant is developing normally or helping with parenting issues like [Age-appropriate topics: feeding, dealing with tantrums, toilet training]

(a) [Probe] Are there more examples of these types of services that your [baby/child] might get at these visits?

(3) [Go back to the list and categorize the responses with the group]. We are going to be talking about the best ways to receive all of these services. In order to make our discussion easier, I am going to ask you to help me put these into groups; these groups are all part of "well-child care" [Categorize each by using a separate sheet of poster paper to rewrite them in categories, with the title of the category on top, then explain each, giving age-appropriate examples]:

Physical examination and growth,

Shots, lab and blood tests,

Developmental screening, which is checking to see if the [baby or child] is developing normally. This means learning how to do things like [age-appropriate milestones by age group] when most [babies or children] do.

Providing information and answering questions on child-rearing issues. These include things like infant feeding and sleeping, toilet training, discipline, and car seat safety. We'll call this category "Child-Rearing Information"

[Only include for 12-month and older group] Discussion of any child behavioral problems or concerns that you might have (like how to deal with tantrums). We'll call this category "Child Behavior"

Discussion of any other nonmedical concerns that the family may have, like helping the parent deal with changes in the family. We'll call this category "Family Concerns"

Providing care for babies or children when they get sick. We'll call this category "Sick Visits"

Providing care at night/weekends; you may need to call if your child is sick or you have an urgent question: We'll call this "After-Hours Access"

(a) [Probe] Are there other issues that you think should be included that don't fit into one of these categories? [If there are, try to fit into one of the above categories; if they don't logically fit, then make another "Miscellaneous" category]

(b) Do you think that each of these categories should be covered in well-child visits? [Probe for specific categories] Why or why not?

(4) Parents should receive all of these services during their well-child visits. Today we are going to be talking about these visits for your child, the categories of services in the visits, and what the best ways are for parents to receive these services for their [infant or child].

(5) This way of providing well-child visits (doctor provides most services with some help from nurses or other staff) can be considered a "system" or a way of providing care. The usual system or way of providing care might work better for some of the categories more than others. We're now going to think about other ways of providing care, or other "systems" that might work better for parents like yourselves.

Topic #2: Alternative Systems of Care—Providers

There are some other ways of providing services that I'd like to get your opinion on.

(1) Usually, a doctor gives the well-child visit and has some help from nurses and other office/clinic staff for giving shots, doing lab tests, and taking the [child or baby's] measurements. Has this been similar to your well-child visit experiences? [Probe] Or how were your visits different?

(2) Are there other types of professionals or people that could do some or any of these services or answer your questions? [Give child-rearing, family concerns, sick visits, after hours, and child behavior, as examples]

(3) [Probe] Is it important to you is it that a doctor (and not another person, like a nurse or a nonmedical person in the clinic or doctor office) be the person to provide any particular service? Why?

(4) [Probe] For services not important to be performed by a doctor: Why? Is it because the doctors are not the best people to provide these services? Is it because the doctor does not have enough time to do those services during the visit? Is it because you don't get to see the doctor each time? Are the doctors qualified to give you help on nonmedical issues? Why or why not?

(5) What would you think about an office/clinic where the doctor did the physical exam only and another staff member did the other services, like talking with you about how your baby is developing?

(a) [Probe]: What would be the good and bad of providing well-child care in this way? What about your relationship with the doctor, would that be different? Is that important to you?

(b) [Probe] How would it change your relationship with your child's doctor and the clinic or staff? Would you be more or less likely to call with a question or a problem? Would you be more or less likely to ask questions about child-rearing, family concerns, [Behavioral problems, if > 12-month group], and other concerns you might have? Do you think the quality of the information you would get on child-rearing issues would be the same? Better or worse? Why?

Topic #3: Alternative Systems of Care—Timing and Locations

(1) Do you know how often doctors want you to bring your infant or child in for a well visit? [Get responses before going on] Right now parents go to the doctor for visits at 2 months of age, 4 months, 6 months, 8 months, 12 months, 15 months, 18 months, 24 months, and 36 months. [Write on board] Do you think this is too often, not often enough, or just right?

(a) [Probe] Why not more/less often?

(b) [Probe] Which categories do you think that your children should receive more or less often?

(2) Are there other places that you can think of where you might like these well-child care services to be given? How would you feel about getting these services in these other places?

(3) [Probe if few responses] What about at grocery stores or discount superstores like Target or Wal-Mart? What about at daycare centers or schools? At home visits? At places in your neighborhoods, like community centers or churches.

(a) [Probe] There are now some clinics in stores across the country like Wal-Mart and Target where you can see a nurse for regular healthcare things like getting shots or blood tests for your child. You could even get a physical exam there. These are usually just walk-in clinics, or places where you don't need an appointment. You are seen by nurses or doctor assistants, but if needed, they can give prescriptions too. Have you heard of these clinics? Have you seen them at your local store? Some names are Redi-Clinic, MinuteClinic, and TakeCare Clinic. Would you be interested in using these clinics for your child? Why or why not?

(b) [Probe] Can you think of any reasons why you would not want to use these clinics for your child?

(c) [Probe] What sounds good to you about these clinics? What about them does not sound good?

(d) [If someone has gone to one of these retail-based clinics, they can share their experience]

(4) Are there some types of services that are better at locations outside of the doctor's office or clinic? Which are these and why?

(a) [Probe] How would you feel about getting some of these services in places outside of the doctor's office or a clinic? [If it hasn't come up in earlier discussion, then ask]: Why? What would be some of the problems of having some of these types of services given to you at these other places? What are some of the good things about doing things this way?

Topic #4: Alternative Systems of Care-Format

(1) Some of these types of services, like child-rearing, child behavior, and family concerns are really more about giving information and answering questions. They don't include examining your child or giving any shots or lab tests.

(a) Can you think of some other ways that doctors or nurses could give you this health information without you going in for a visit to the doctor's office or clinic?

(b) What are some of these? [Probe, if no examples given] What about by phone, e-mail, or by the Internet? Would any of these ways work better for you? Are there other ways you can think of?

(c) [Probe] What would make these different ways of getting care better than having them in the doctors' office or clinic? What would be worse about these different ways? How would you feel about getting this information by phone? by e-mail? other ways?

(2) [If not brought up]: What would you think of getting these services in a group with other parents who have children of the same age and need similar information? Would you like to receive information and ask questions in this way? Would this be better or worse than talking to just the doctor or nurse on your own?

(a) [Probe] What would you like about "group visits" like these?

(b) [Probe] What would you not like about "group visits" like these?

Topic #5: Cultural Concerns

Let's go back and talk a little more about the types of services that fit into these categories [Indicate and say each type by referring to its poster]: Child-Rearing Information and Questions, Child Behavior Concerns, and Family Concerns.

(1) Does the race or ethnic group of the doctor make a difference to you when you get information about these things from the doctor? [Probe] Do you think it would change the type of information you would get or the answers to your questions that would be given? Does it make you more or less likely to ask questions about things like behavior and discipline?

(2) What about language? When you speak a different language than the doctor or nurse, does this make a difference? How? Why?

The protocol explains the general topics that will be covered during the focus groups and provides examples of the types of open-ended questions that we plan to ask. However, we will follow the lead of participants and will pursue topics if they are raised in the group as being important.

ABBREVIATIONS

WCC	well-child care
NP	nurse practitioner

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WHAT'S KNOWN ON THIS SUBJECT

Several studies have proposed ways to redesign the structure and delivery of WCC. However, no published studies have examined parents' perspectives on these possible changes to care.

WHAT THIS STUDY ADDS

We examined the perspectives of low-income parents on how WCC might be redesigned, focusing on possible changes to providers, locations, and formats. Parents endorsed a number of innovative reforms that merit further investigation for feasibility and effectiveness.

TABLE 1**Focus Group Participant Characteristics**

Participant Characteristics (N = 56)	% (n)
Parents' gender	
Female	91 (51)
Male	9 (5)
Parents' race/ethnicity	
Latino	64 (36)
Non-Latino black	16 (9)
Non-Latino white	5 (3)
Non-Latino Asian	7 (4)
Other	7 (4)
Parents' age	
18–23 y	25 (13)
24–29 y	42 (22)
30–35 y	17 (9)
36–45 y	17 (9)
Index children's age	
6–12 mo	32 (18)
12–36 mo	48 (27)
3–5 y	20 (11)
Parent household education	
Less than high school	37 (19)
High school/GED	25 (13)
Some college	31 (16)
4-y college degree	8 (4)
Household income	
Less than \$20 000	58 (28)
\$20 000–\$34 999	38 (18)
\$35 000–\$69 999	2 (1)
\$70 000–\$99 999	2 (1)

Missing data: $n = 3$ for parent age, $n = 4$ for education, and $n = 8$ for income.

TABLE 2

Problems With WCC Experienced by Parents: Sample Quotes (298 Total Quotes)

2a. Limited provider access: little capacity for doctor-parent communication outside of scheduled visits.

"[When I have a concern] I'll make another appointment. They always ask, well, she's not due for her physical. I'll be like, well, I have some concerns that I would like to talk to the doctor."

"Yeah, I just can't talk to the doctor. I have to call the appointment line, and they're like, well this is 'Appointments' so you can't talk. So I've been having to switch doctors."

"But they don't give information by phone, if you tell them how your baby is, they tell you that you need to bring him."

2a. Limited provider access: lack of reliable transportation.

"And if you don't have enough money for the bus, you have to lose the appointment or find a ride."

"There were times when I was late, because I had to take 2 buses to arrive; and those buses take a while to get there."

"I had to lose 2 appointments a year ago when I was pregnant, because I had to take the bus and they wouldn't see me; I had to make an appointment for the following week."

2a. Limited provider access: limited time during visits, leading to poor provider-parent communication and rapport building at visits.

"And then when she [the doctor] came in, she just said 'Hi', okay. 'And this is Christopher,'^a duh. And then I'm like, okay, and then she gave him a shot, and said okay, we're giving him shots and then she just left. I didn't see her at all. I'm like, I can't even know who you are, you know, you're touching my child and I don't even know you."

"We were at the doctor down the street. And we would be there [waiting at the doctor's office] forever. And then when we got to the back, it was like rush you in, rush you out. It wasn't address nothing ... it was like, okay, he's fine. He got all his shots, okay bye. But since I been [at another clinic] it's like, I mean when I walk in the door, they already know us, because I been coming here for like 3 years ... They say, 'Oh hi, how's the kids?' You know, if I come alone, 'Where's the other son?' They on it!"

"Because the doctors are trying to rush to see another patient. But if you sit there with them and you say, okay well I've noticed this, I've read this, and I've noticed that it doesn't work for my child, that's going to force him [the doctor] to either use what's up here [points to her head] or go in that little book that they carry or go to the computer and look something up."

2b. Inadequate behavioral/developmental services.

"The ... thing that is missing is counseling, to know how to treat them and control their temper tantrums without getting frustrated, calm them down."

"But the family concerns and the child-rearing, stuff like that is not really addressed. I have to ask for that to be addressed, it's not something that's a given, you know."

"The doctor does not have time to explain everything when she is seeing the child. If she says 2 to 3 words, it's a lot."

^a Name changed to protect privacy

TABLE 3

The Use of Nonphysician Providers for WCC Services: Sample Quotes (117 Total Quotes)

3a. Providers: physicians should serve as the main providers for WCC, but nonphysicians should be used as adjuncts for services outside of the physical exam.

“I think only a doctor or a specialist can diagnose and give medications to help your child. Anyone else can give you information on how to care for your child ... but for me, the doctor gives you medicines, tells you when the next vaccine will be, can diagnose an illness your child might have—but anyone else can give you advice on how to rear your child.”

“I think it'll be easier, because actually, it'll be more broken down. So instead of you just seeing this one person who really don't know nothing and who really don't really care ... it would be more like a group working on your child instead of just this one person who really don't have time for all these patients, but they just trying to make time, you know what I mean?”

“Well what if they have a psychologist in the clinic for those kind of needs? That would be very helpful.”

3b. Providers: nonphysician providers may be better qualified to provide many of the counseling, guidance, and behavioral/developmental services.

“Well, I think sometimes you need to talk to a counselor, because sometimes you don't know what to do to control tantrums. When you're on the street ... and they start with their tantrums ... I think we need advice from a counselor.”

“I say someone else besides the doctor for the child behavior, family concerns, the child rearing. I would definitely refer to a psychologist to see if I am messing up somewhere.”

“I think it would help a child, like, let's say for example me and my husband are going through a divorce ... maybe somebody else besides the doctor that I could go to, talk to them about maybe how this divorce is affecting my children ... I think that would help, or even like development, I mean yeah, doctors should talk to you about that, but maybe it would help also to have let's say somebody else.”

A: “I would say that a person capable of doing it, not a doctor but someone like ... ”

B: “A psychologist or something like that.”

3c. Providers: nonphysician providers may be more attentive to parents' needs, and to the importance of a continuous and respectful provider-parent relationship.

“The nurse takes the time to find out what's really going on with my two kids and she might do the same to everybody else, but at least I feel important, because she actually knows what's going on with my kids. I can relate to her more than I do the doctor, because she actually remembers ... she's more involved.”

“They [doctors] don't want to listen, they just want to tell you what's wrong, and if you don't agree with them, [they say], Well I'm trying to help you and you just' ... I'm like, look, I can't be here.”

“But, I don't know, sometimes I think I talk to the nurses more than I do the doctor You know? Like they talk to you more and the doctor just comes and you know, checks the baby and you know, writes the prescription, you know, and they're gone. So other past experiences, that's what I've had.”

“Well, for me, I think ... the nurses ... like, they all come and they all know my son. And they ask different questions, yeah? ... But I think it's better that each one of them takes their time to actually ask those questions, because they create a better bond with my child.”

“So long as there is a provider that takes the time to check, who cares if it's the doctor or the nurse?”

TABLE 4

The Use of Alternative Locations for WCC Services: Sample Quotes (82 Total Quotes)

4a. Locations: home visits and visits through daycare centers and preschools offer the important context that providers need for the provision of patient- and family-centered care; they also offer a great convenience to families over in-office or clinic visits.

Home visits

“Yeah, you could show them [the providers], ‘My child sleeps in my bed right there. Is this okay, because my bed is so high.’ Then, you could go in the kitchen and show him, ‘This is what I feed her, is this alright?’ You know, you could show them what you’re talking about.”

“Home visits would be good when we talk about development ... because the child’s at home, in their comfort zone.”

“And ... she came to my home, and I was just like, they’re really going to come to my house? Like, wow. I mean, yeah, I think it was very helpful. Especially being a first-time mother.”

“But you know, that would be a good thing, because it helps that parent in their own environment.”

Daycare centers and schools

“I also say that outside [of the clinic]. Yes, because schools have psychologists and all that. If the child has problems, then they ask if there are problems at home, because sometimes that is the problem and it affects the child.”

“If the daycare had a nurse or something like that, somebody to do some of the services instead of me having to take off work, everything could get taken care of right there. Give her the shots and check on her. The daycare tells you when she’s not sleeping, if she didn’t eat today ... they know everything. So that would be way convenient.”

4b. Locations: there was a lack of trust for providers located in retail stores and superstores; although convenient, they were not seen as a viable option for the provision of comprehensive WCC services.

“If you’re there already shopping and you know your child has a cold, and you want to just check, that’s fine. But I prefer to see just maybe one doctor, and that doctor knows my child and knows everything, as opposed to going maybe to different places.”

“I think if you had a simple question, maybe a simple concern, you could go ... I mean something that’s not really going to mess with their health or anything ... just to see how safe they are or if you like them or not. They can help you with the simple things, because the doctors can’t always do everything, because obviously they’re busy.”

“Stores are accessible, because you’re always there every week.”

TABLE 5

The Use of Alternative Formats for WCC Services: Sample Quotes (83 Total Quotes)

5a. Formats: group visits were highly endorsed and seen as empowering to parents, allowing them to serve as informal providers through the sharing of behavioral/developmental advice and experiences, as well as offering social support to other parents.

"When you're in a group of people, you can feed off each other, give ideas and suggestions from other people."

"Just like set a time, like say from like 11 AM to 1 PM; say we all have 10-month-olds and the first hour for the exam and the next hour is for discussion for child rearing and the child behavior. With the kids being looked after."

"The lady here at the clinic gave me those groups when I was pregnant with my child; I came to a prenatal group. They give advice about that, and they give a number to call about any case of domestic violence. Because it doesn't necessarily have to be only about punches, but also violence can be verbal."

"I joined Mom's Club of Oakdale^a and there are a lot of moms. You know, we can talk about anything ... we want to know, 'Oh how about if my kid becomes 2 years old what they do, started talking yet.' You know, a little bit like comparison. Just want to know exactly what my child—is 1-year-old—what they do. Like other moms have."

"Kaiser has something like that, there are support groups for parents of newborn babies, because there is much pressure and sometimes the mother is a beginner."

5b. Formats: phone, e-mail, and Internet are options that should be available to the parent as convenient and timely ways to communicate with providers outside of a visit. However, there were also concerns regarding access and privacy for e-mail and Internet communication.

"WebMD. I love it. I mean, like I said, the 1-year-old ... he started throwing temper tantrums. He would literally fall back, pow! Bang his head, and just keep banging. The lady said [by e-mail], 'You know why he's doing that? As long as you keep paying him attention and you're like, please don't, he's going to keep doing it.' She said, 'Just turn your back.' I was like, you crazy! She said 'Just try it, I promise you, it will stop.' You know, this is e-mail. [I tried it with the next tantrum], and I just turned around and literally walked away. And he was like, what are you doing? Where you going? I'm throwing a tantrum here. And I'm like, I'm just not going to pay no attention. And I mean, it stopped. It really stopped."

"I get that [BabyCenter.com], and I signed up and so they'll e-mail me once a week. ... One thing I liked about it that actually no one else has told me this: is the guidelines. It gave me a good guideline as far as his crawling and when to be concerned. Whereas the doctor's like, 'Oh, don't worry, he'll do it.' It just gives you a good feeling. I think being a mother I think it gives you more better understanding, a better feeling, more secure feeling."

"I would set up a blog for the doctors ... at least 3 doctors each week, Monday, Wednesday, or Friday. They'll go on the Internet at a certain time and ... blog. The community would know which doctors are going in there at a certain time and they can discuss whatever they have to discuss. It would be like a message board where you can ask questions and comment. Like a discussion group, but it's on the Internet ... but you'd have to coincide that [the blog] with computer Internet classes, because everyone isn't Internet savvy."

"Everyone's totally different, so I think if you just ... ask me, you know, would I like for someone to come or would I like someone to call? It's up to the individual. Give me the option."

"Because people steal information nowadays and confidential information could be stolen. It is very important for me that other people don't see my medical information."

^a Name changed to protect privacy