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Sugar-coaters and Straight Talkers: Communicating About Developmental Delays in Primary Care

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Abstract

OBJECTIVES—The goals were to investigate parents' and early intervention (EI) specialists' beliefs and experiences regarding discussing child development in primary care and to identify communication barriers and opportunities.

METHODS—Focus groups were held with (1) mothers of young children with typical development, (2) mothers of young children who received EI services, and (3) EI specialists. Seven groups ($N = 46$ participants) were conducted in the greater Cleveland, Ohio, area. Meetings were audio-recorded, transcribed, coded, and analyzed, to identify themes.

RESULTS—Most mothers reported a preference for a nonalarmist style of communication when developmental delays are suspected. In contrast, some mothers preferred a more direct style, including the use of labels to help them understand their child's development. The importance of preparation to accept information about developmental delays emerged as a theme in all groups. Elements contributing to preparedness included information about expected developmental skills, suggestions for promoting skills, and a specific time frame for follow-up evaluation. Mothers of children with disabilities perceived that early reassurance of normalcy by providers in response to their concerns led to self-doubt and increased difficulty accepting the diagnosis.

CONCLUSIONS—Mothers and EI specialists have clear ideas about factors that promote or impede communication regarding child development. This information can inform primary care providers' approaches to monitoring and screening the development of young children and to communicating with parents regarding suspected developmental delays.

Keywords

child development; developmental concerns; communication; primary care

WHAT'S KNOWN ON THIS SUBJECT

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Revised recommendations on developmental surveillance and screening in the medical home mean that providers will increasingly need to communicate with parents about developmental concerns. Little information exists to guide providers in communicating with parents regarding this complex topic.

WHAT THIS STUDY ADDS

This study provides new information and recommendations on conceptualizing communication between parents, primary care providers, and EI specialists regarding child development and developmental concerns.

Systematic developmental screening of children historically has not been implemented in most primary care practices.^{1,2} Revised recommendations for developmental screening from the American Academy of Pediatrics make it likely that screenings will be used increasingly.^{3,4} Developmental surveillance and screening have the potential to facilitate discussions regarding developmental concerns, leading to earlier detection of developmental delays.⁵ Parents' developmental concerns are predictive of actual developmental problems,^{6,7} and early discussions likely determine whether children with suspected delays are referred promptly for evaluation and treatment. Although surveys identified time and costs as principal barriers to screening,^{1,2} other potentially important factors include parents' beliefs regarding communication about child development and the complexity of communication about developmental concerns. Effective communication contributes to the education of all parents in a practice, improving satisfaction with care.⁸

Few studies have examined initial communication regarding developmental concerns in primary care or parent-provider communication regarding suspected developmental delays before an exact diagnosis is known.^{6,7,9,10} Although, in theory, parents can contact early intervention (EI) services directly for an evaluation, primary care providers act as de facto gatekeepers because parents often are unaware of the existence of these services. Although a significant body of literature on communicating difficult news to patients and parents exists, it mainly addresses disclosure of diagnoses.¹¹⁻¹⁵ In developmental/behavioral pediatrics, the focus is on disclosure of diagnoses in subspecialty or inpatient settings.¹⁶⁻²⁵ Applicability to communication regarding suspected developmental delays in primary care likely is limited.

Qualitative methods are especially helpful for furthering understanding of beliefs regarding complex topics that have undergone little study.^{26,27} In primary care, qualitative methods have been used to examine related topics, including maternal disclosure of parenting stress and depressive symptoms²⁸ and perceptions of providers as sources of parenting advice.²⁹

We sought to understand the communication needs, beliefs, and experiences of key stakeholders (parents and EI providers) regarding child development and the initial identification of developmental delays in primary care. The objectives of this study were to identify and to understand new barriers and opportunities for this communication, to address a gap in the literature.

METHODS

Focus Groups

Focus groups were conducted to explore beliefs, opinions, and experiences regarding communication between parents, EI specialists, and primary care providers about child development and suspected developmental delays. A focus group is a planned discussion designed to elicit perceptions regarding an identified area of interest, in a nonthreatening environment.³⁰

A structured list of questions and follow-up probes was developed to address (1) the ways in which parents raise developmental questions and concerns and (2) beliefs, experiences, and recommendations regarding communication with primary care providers about child development and developmental concerns (Table 1). Two researchers in psychology, 1 researcher in family medicine, and 4 early childhood education professionals reviewed the questions for content and clarity.

Participants

Separate focus groups were held with 3 types of participants, that is, (1) mothers of children who were receiving/had received EI services (EI parents), (2) mothers of children <5 years of age who had not received EI services (non-EI parents), and (3) EI specialists. Non-EI parent groups were included to represent the perspective of most parents. Semistructured interviews were conducted with primary care providers, and results will be summarized in a separate report. Other authors have used an approach involving separate groups with multiple stakeholders to study an issue in primary care.³¹

Two community-based EI agencies distributed informational flyers to recruit EI parents. Non-EI parents were recruited through flyers posted at a parent education center, a public library system, an urban university hospital-based pediatric practice, and a suburban pediatric practice. EI specialists were recruited from 2 EI agencies in Cuyahoga County, Ohio. Meetings were held in community settings in the Cleveland, Ohio, area.

Seven focus groups were conducted between May 2004 and January 2005, including 2 with each type of participant and an additional non-EI parent group because of low attendance (Table 2). Each participant took part in one 90-minute meeting and received token compensation (\$25).

Informed consent was obtained. The institutional review boards of the University Hospitals of Cleveland and Boston Medical Center approved this study.

Data Collection

Participants completed a demographic information form. Focus groups were conducted by an experienced facilitator (Ms Mercer). Dr Sices and a research assistant were present at each meeting. Meetings were audio-recorded, and written notes were taken.

Data Analysis

Audio recordings were transcribed and analyzed by using a combined approach of initial immersion/crystallization (reading full transcripts and listening to recordings to obtain an overall sense of themes) and later text editing to identify themes.^{32,33} Three team members coded each transcript independently by using codes based on core topics, met to discuss coding, and resolved discrepancies through consensus. Data were organized by using NVivo 2 software (QSR International, Doncaster, Victoria, Australia).

RESULTS

Themes

Emerging themes focused on ways in which parents and providers initially raise developmental concerns and factors that influence parent-provider communication regarding development and early developmental concerns.

Communication of Developmental Concerns

Discussion of Child Development and Raising of Concerns—Parents in non-EI groups reported that they would raise developmental concerns by asking providers, “Should she be doing this by now?,” rather than stating a concern explicitly. Although some mothers in EI groups recalled mentioning an initial concern directly to the provider, others recalled commenting that their child was not performing certain skills.

Several non-EI mothers thought that they would monitor developmental concerns for several months before raising them at a regular check-up. Although some mothers in both EI groups reported that they had raised a concern as soon as it arose, others acknowledged that fear or denial might make a parent wait. EI specialists thought that how providers ask questions affects the quality of parent responses, “I think that when you’re in that rushed setting in a doctor’s office, if someone comes in and says, ‘Is your child doing this?,’ you kind of know what the answer is supposed to be, so the parents will just say, ‘Yeah, yeah, they are doing that.’”

Recommendations for Explaining Suspected Delays

“Sugar-coaters”: Non-EI parents preferred a nonalarmist style of communication and appreciated providers who acted as partners in addressing concerns. One parent offered recommended wording, “I really think that most children are doing this by now.”

Although participants in EI parent groups also considered it important not to alarm parents, they emphasized the importance of communicating the need to take action, “It seems like he might be behind, but keep an eye on this. . . . Why don’t you read this? And call me back in a couple of weeks and let me know that this isn’t getting any better,” or “[Your child’s] development may be behind; let’s do further testing.” One parent noted, “You don’t have to scare the parent, but just by saying ‘Let’s be safe, let’s do the speech screening. . . . You may be pleasantly surprised, it may be nothing.’”

“Straight Talkers”: Several EI parents recommended a more-direct approach, “getting it out in the open right away . . . and going from there.” One parent stated, “Don’t sugar-coat it. That’s not going to help me 10 years down the road if you try to sweet talk your way through this. Be honest, be straightforward.”

Disclosure of Potential Delays

EI parents and EI specialists emphasized the importance of preparing to hear about developmental delays. One parent explained, “I liked how [the pediatrician] didn’t want to alarm me at first . . . I had time to prepare myself, ‘Okay, when you go in, in 2 months, let’s see what goes on.’ Well, I saw that regression still occurring so I knew . . . I was going to hear something. It was nice to have that preparation and it didn’t just hit me like a wall.” EI specialists agreed that “sometimes the families are not ready” to hear about a delay and questioned the need for services.

EI parents reported that positive experiences during initial discussions about developmental delay fostered acceptance of the diagnosis. The parent of a child later diagnosed as having cerebral palsy reported that her provider “asked all of the right questions and when I said, ‘No, he’s not,’ he was pretty calm, which made me calm. Then he said, ‘It’s probably nothing, but let’s go further with this.’” Another recalled that the provider effectively addressed her concerns about language development; after reviewing a checklist at 15 months, he said, “I don’t want to say anything; I want to see him at his 18-month appointment and we’ll see what happens.” At 18 months, with evidence of continued delay, he said, “I think there’s a lot of red flags. I think there’s a problem; I’m not going to say exactly. I suspect perhaps autism or some sort of developmental delay.” Her child received a diagnosis within a few months.

Barriers to Communication

Blame and Denial—Themes related to blame emerged in a number of groups. In one non-EI parent group with lower-income mothers, several mothers expressed concern about being blamed for their child's delay. When providers reviewed developmental milestones, some mothers feared that they would "consider you neglecting your kid when they [the child] don't know something"; therefore, the mothers answered yes even if their child was not demonstrating the skill. These parents worried that providers would suspect neglect and might report them to child protective services if their child exhibited delay.

Blame emerged as a theme in both EI parent groups. A mother commented on her experience discussing her child's development with the provider, "I think it would have been better to do it together as a team as opposed to him making me feel like it was my fault . . . that [my child] wasn't progressing the way he should have been."

Importance of Being Heard—A number of EI parents reported that providers responded to developmental concerns in supportive ways, providing written information, referrals to specialists, information about EI and other resources, and care coordination. Provider characteristics appreciated by mothers included compassion, open-mindedness, and the ability to "follow [the parent's] lead." One mother recalled the provider saying, "Well, I don't know; we would have to figure this out together," and she appreciated that honesty. Another felt "blessed with a pediatrician . . . [who] took our concerns extremely seriously."

Conversely, a number of EI parents reported difficulty getting providers to acknowledge and to act on their concerns, "Some things just didn't add up to me and, yes, I brought them up right away, but I wasn't always taken real serious about it." A mother of a child later diagnosed as having autism reported, "I had to yell at the doctor one day and say, 'My daughter is not talking anymore. Are you telling me that's OK? You write this down and tell me that it's normal.'" This theme was echoed by EI specialists, "If [the parent has] been to a pediatrician who said, 'Oh, he'll outgrow it,' and we just sit there and listen, sometimes that's the best thing we can do. . . . Just that they're taken seriously."

"Watch and Wait" and False Reassurance—Certain EI parents thought that they had been reassured improperly after raising developmental concerns, with explanations such as, "He's just a boy. . . . If he's not talking by 2 we'll worry about it" and "She'll outgrow it. . . . Give her another year." EI specialists similarly reported, "You get the parents who say, 'I brought this up to my pediatrician, and he said there is nothing to worry about.' . . . The parent feels exasperated by the time I'm there because they have tried to bring attention [to the problem]."

Concerns about the timeliness of physicians' responses to expression of concern emerged in both EI parent groups, "I think our first pediatrician just took too long." Although non-EI parents stated that they would worry if providers raised developmental concerns, they would not blame them if the child was not found to have delays in further evaluations. Participants in both EI specialist groups also said that parents are relieved in these situations and do not discredit providers.

Missed Opportunities to Collaborate on Communication

Participants in both EI parent groups highlighted the importance of direct communication between primary care providers, specialists, and therapists, to avoid giving parents conflicting assessments. EI specialists noted that parents often received conflicting messages, asking, "Why didn't the pediatrician tell me this?" or "Why are you telling me this, and they haven't

noticed this?" EI specialists expressed frustration that the "communication triangle" between themselves, parents, and providers caused some parents to refuse EI services.

EI specialists thought that communication with providers was strained by differences in assessments of children and in the status of the 2 professions, "I think probably I've seen more handicapped children than some of the typical pediatricians have. And so you always walk this fine line between do I call this doctor and say, 'Maybe you should think about doing x, y, z,' and then offending him or her." EI specialists thought that certain parents had difficulty communicating developmental concerns to providers. Knowing this, they coached parents with "key words." One specialist coached the mother of a child she strongly suspected had spastic quadriplegia and was dismayed when the parent reported back, "Well, the doctor said she's moving and we just need to give it a little more time."

EI specialists identified opportunities to improve communication, including established relationships between EI specialists and nurses in some practices and hospital-based EI social workers at some institutions. Participants provided insights and specific recommendations for facilitating effective communication regarding developmental concerns (Table 3).

DISCUSSION

As primary care providers implement developmental screening in response to revised American Academy of Pediatrics guidelines³ to monitor children's development and to promote early identification of developmental delays, understanding the perspectives of parents and EI specialists can facilitate communication with families in this complex area of practice. Results and recommendations (Table 3) may be useful for conceptualizing this communication.

Although some parents reported that they would communicate developmental concerns directly to providers, most described indirect methods, such as mentioning skills the child was not yet demonstrating or asking about expected skills for age. This finding is corroborated by a recent study that analyzed audio-recorded visits in primary care.¹⁰ Although parents may think they have communicated a developmental concern, the level of concern may not be recognized by providers. It is important that providers recognize that parental expressions of concern may be stated subtly, indirectly, or briefly. A related theme that emerged was the perception of not being heard. Previous studies indicated that providers' failure to acknowledge or to address patient concerns is unfortunately widespread.³⁴⁻³⁶

These findings reinforce the value of eliciting parents' developmental concerns in a systematic way,⁶ for example, by using a validated measure such as the Parents' Evaluation of Developmental Status.^{10,37} Although parents theoretically can contact EI services directly, they may not be aware of the services, depending on providers for this information. Respect for providers' opinions also means that, even when they are aware of resources, parents may not access them without the provider's recommendation.

Parental preferences for direct (straight talk) versus indirect (sugar-coating) communication approaches seemed to be related to preparation to hear about suspected delays. Some parents needed weeks to months to prepare to hear such news, beyond the brief "warning shot/forecasting" recommended for medical encounters.³⁸ Nonalarmist wording by providers, maintaining optimism and acknowledging that the child's development might not be delayed, was recommended. Parents also recommended providing information regarding what to observe, possible next steps for further evaluation, and a plan to check in with the provider within a short time.

Other parents cautioned against sugarcoating and favored a direct approach, emphasizing the importance of straight talk. By inquiring systematically about parents' developmental concerns, providers can obtain information regarding parents' readiness to hear about suspected developmental delays and can tailor communication to the level of preparation.

Negative communication experiences included parents' feeling blamed by providers for the child's developmental delay. In 1 group, mothers reported that they might respond in the affirmative to questions regarding developmental milestones even when their child was not yet demonstrating a skill, out of concern that lack of attainment would be seen as evidence of neglect. Dumont-Mathieu et al²⁹ reported similar findings from focus groups with parents from ethnocultural minority groups; parents raised concerns that asking pediatricians for parenting advice might be seen as evidence of inadequate parenting skills, and they expressed fear that pediatricians' mandatory reporting role could lead them to refer the family to child protection authorities. Therefore, in practices serving families from communities affected disproportionately by negative interactions with child protective services, providers' review of developmental milestones might be counterproductive if messages regarding parents' lack of culpability for a child's failure to attain milestones are not included systematically. This provides another argument for caution in the routine use of milestone information elicited by providers in decision-making regarding children's developmental status.³⁹

For sensitive topics, self-completed questionnaires may be more effective at producing disclosure than in-person interviews.⁴⁰ Emphasizing the importance of parental input by using parent-completed screening questionnaires distributed routinely to all parents in the practice and informing parents that providers expect to hear concerns may help address this issue.

Communication through parents, rather than directly between professionals, was noted to be problematic. In some cases, medical providers and EI specialists gave parents different messages regarding the child's development, leading to feelings of ambivalence, confusion, or even mistrust. Direct communication between primary care providers and EI specialists and having families return to the primary care provider to discuss the EI evaluation could help to address this concern.

This study has limitations. It represents the experiences of participants in one community and may have limited generalizability to other communities in the United States. EI parents' children were 7 years of age, on average, and their experiences may not reflect the experiences of parents of younger children who are currently entering EI. Focus groups with 3 types of participants (parents with or without children in EI and EI specialists) provided a comprehensive view of the issue in a single community, but it is possible that we did not reach saturation of themes with this approach.

Further research is needed to determine the generalizability of these results. In particular, work is needed to determine parent and child factors that predict preferences for more- or less-direct provider communication styles regarding developmental concerns. Provider awareness of the complex issues related to communication regarding child development can help improve parent-provider communication in this complex area of practice.

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ABBREVIATION

EI, early intervention.

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TABLE 1
Examples of Questions Used in Focus Group Meetings

	Parent Groups	EI Specialist Groups
Sources of information	Who has been most helpful in helping you to learn about your child's development? How has your child's doctor been helpful to you in terms of understanding your child's development?	Where do parents usually get information about child development? How often are parents the ones to have a concern about their child's development when they are presenting for an EI assessment?
Communication with physicians	If the doctor thinks that a child's development might be somewhat behind, is it better to bring it up with the parent right away, or is it better to wait and make sure that there is really a problem? If a child's development is behind what is expected for age, what words or explanations would help a parent to understand what is going on?	What do parents tell you about the role their child's physician has played in identifying a developmental delay or problem? What words or explanations help parents to understand a child's development when there is a delay? How does communication between EI specialists/educators and doctors happen?
Evaluation	If a child's development seems to be behind, what would help a parent decide to get an evaluation or testing and to get treatment services?	What helps parents decide to get an evaluation or testing and to get treatment services? What are the important factors that determine whether families will come for services after the initial EI assessment?

TABLE 2

Demographic Characteristics of Focus Group Participants

	Parents			EI		EI Specialists	
	Non-EI		Group 3	EI		Group 1	Group 2
	Group 1	Group 2		Group 1	Group 2		
No. of participants	6	2	3	7	11	9	8
Participant characteristics							
Age, mean $\pm$ SD, y	23 $\pm$ 4	36 $\pm$ 8	39 $\pm$ 2	43 $\pm$ 6	40 $\pm$ 8	43 $\pm$ 10	48 $\pm$ 5
Female, <i>n</i>	6	2	3	7	11	9	8
Non-Hispanic, <i>n</i>	5	2	3	7	11	9	8
Race, <i>n</i>							
Black	3	1	1	3	0	1	4
White	2	1	2	4	9	7	4
Other/ >1 race	1	0	0	0	2	1	0
Married, <i>n</i>	3	1	3	3	10	NA	NA
Education, <i>n</i>							
High school/general equivalency diploma or less	4	0	0	0	4	NA	NA
Some college, technical school, or associate degree	2	1	1	4	5		
4-y college or graduate school	0	1	2	3	2		
Family characteristics							
No. of children, mean $\pm$ SD	2.7 $\pm$ 1.0	3.0 $\pm$ 2.8	1.3 $\pm$ 0.6	2.6 $\pm$ 1.0	2.1 $\pm$ 1.0	NA	NA
Age of youngest child, mean $\pm$ SD, y	2.4 $\pm$ 1.5	2.2 $\pm$ 1.2	1.4 $\pm$ 1.4	5.7 $\pm$ 2.4	7.7 $\pm$ 4.0	NA	NA
Age of child in EI, mean $\pm$ SD, y	NA	NA	NA	7.5 $\pm$ 1.7	8.5 $\pm$ 4.7	NA	NA
Child had check-up in past 12 mo, <i>n</i>	6	2	3	7	10	NA	NA
EI specialists' training							
Professional training, <i>n</i>	NA	NA	NA	NA	NA		
Early childhood education						2	7
Elementary education						0	2
Special education						0	4
Social work						6	0
Other						1	1

	Parents			EI		EI Specialists	
	Non-EI		Group 3	Group 1	Group 2	Group 1	Group 2
	Group 1	Group 2					
Time working in field, mean $\pm$ SD, y	NA	NA	NA	NA	NA	13 $\pm$ 9	21 $\pm$ 3
Characteristics of EI clients/workplace							
Type of community where work, <i>n</i>	NA	NA	NA	NA	NA		
Urban, low income						1	1
Suburban						8	2
Both						0	5
No. of children evaluated per week, mean $\pm$ SD	NA	NA	NA	NA	NA	9 $\pm$ 1	10 $\pm$ 4
Qualifying category for service, estimate $\pm$ SD, %	NA	NA	NA	NA	NA		
Suspected/established delays						83 $\pm$ 8	75 $\pm$ 16
Environmental factors						14 $\pm$ 11	22 $\pm$ 18
Other						3 $\pm$ 7	3 $\pm$ 9
NA indicates not applicable.							

TABLE 3

Summary of Themes and Recommendations

Theme	Issue	Recommendations for Primary Care Providers
Raising concerns: parental expression of developmental concerns may be subtly stated	Parents may raise developmental concerns in subtle or indirect ways that may not be recognized by providers as actual concerns (for example, the parent may ask, "Should she be doing this by now?")	Recognize that significant parental concern may be stated not as concern but as subtle questions about skills and milestones; systematically inquire about parents' developmental concerns
Preparation: parents' readiness to hear about suspected delays is key to accepting information	Parents differ in their preferences for providers' communication styles regarding developmental concerns (less direct ["sugar-coaters"]; "I liked how [the pediatrician] didn't want to alarm me at first.... I had time to prepare myself"; more direct ["straight talkers"]; "Don't sugar-coat it. That's not going to help me 10 years down the road if you try to sweet talk your way through this. Be honest, be straightforward"); preparation to hear about concerns may depend on parents' level of awareness or preparation; parents may not be aware of developmental delays and may need time to prepare themselves to hear or to accept this information	Elicit and consider parents' level of awareness of developmental concerns in planning initial communication regarding suspected developmental delays; use nonalarmist style to communicate about possible developmental delays (preference of sugar-coaters, who may not yet be aware); be direct (but gentle) and avoid sugar-coating news about suspected delays (preference of straight talkers, who likely are already aware); when developmental delay is suspected, prepare parents by giving them emerging skills to look for in their child and to discuss at follow-up visits
Barriers/opportunities in communication Importance of being heard/being taken seriously	Some parents think their developmental concerns were not heard or taken seriously by the primary care provider ("[The pediatrician] was listening, but she wasn't hearing everything that I was saying"); false reassurance reduces trust in the provider when a delay is later diagnosed ("She'll grow out of it... Give it another year")	Communicate to parents that providers expect to hear concerns; explicitly acknowledge the importance of parents' concerns, to ensure parents feel they have been heard
Worry that child's lack of skills will be seen as evidence of parental neglect	Some parents worry that providers will view children's lack of skill attainment as evidence of parental neglect and may answer yes to milestones questions when child is not yet performing the skill ("They would consider you neglecting your kid when they [the child] don't know something")	Use review of milestones with caution; some parents may think their child's lack of skill attainment can be cause for referral for parental neglect; consider routine use of parent-completed questionnaires to elicit information about development and to give parents the message that they are not being targeted
Feeling blamed for child's delay	Parents may feel blamed by providers for their child's developmental delay ("I think it would have been better to do it together as a team as opposed to him making me feel like it was my fault... that [my child] wasn't progressing the way he should have been")	Anticipate that parents may feel blamed or accountable for developmental delays and address this concern directly
Feeling supported and part of team with provider	Parents who reported positive experiences in initial discussions of developmental delays in primary care cited rapport with the provider, the provider's openness, and feeling they were working with the provider as part of a team; primary care providers help parents understand and accept developmental problems in their child by providing information, referrals, and care coordination	Providers can contribute to parents' adjustment when developmental delays are suspected by providing access to information and referrals (including EI services); parents appreciate having primary care providers stay involved once the child is referred, providing care coordination while involving parents as members of the team
Communication triangle: parent acts as communication channel between providers and EI specialists	Parents may hear different messages from primary care providers and EI specialists about the child's developmental status; this can lead to confusion and mistrust (for example, the parent may ask the EI provider, "Why didn't the pediatrician tell me this?")	Facilitate communication by establishing direct links between EI services and practices (eg, through a designated nurse/staff person in the practice or through other models such as hospital-based social workers)