

TALKING WITH PARENTS WHEN CONCERNS ARISE

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Marta cared for six children in her home. Rashad, now nearly eight months old, was enrolled by his parents Maurice and Rosa when he was six months old. Rashad was their first child. Marta began to be concerned about Rashad's development. Rashad was a very happy, contented baby. However, he seemed almost too content to Marta. He would stay on a blanket either on his back or his stomach for hours without fussing. He could roll over, but hadn't shown much interest in moving by himself. When Marta asked Maurice or Rosa how things were going, they seemed very thankful for such a "good" baby. Marta wondered if she should say anything about her worries. Maybe Rashad was just a "good" baby.

Sarali attended ABC Child Care Center. She was nearly three years old and had been at the center for one year. Emily, her teacher, had just taken a class at the local community college about child development. During the class, she found herself thinking about Sarali who was always in need of adult attention. Sarali often was in the middle of things when other children were hurt or upset. Emily wondered what it was about Sarali that made her stand out. Her parents, Juan and Maria, had two older children and were always rushed during drop-off or pick-up. They certainly didn't seem worried. Why was she?

As a child care provider, you are often the first one to notice a child who learns or communicates differently than other children in your care. If your careful observation and efforts to work effectively with a particular child do not seem to be meeting the child's needs, it is time to look for help to foster belonging and appropriately support this child in your program. This help can come from the family, but more expertise may be needed, such as from the child's pediatrician or health care provider, a therapist or another

specialist. When you recommend to the family that they seek help in this way, or if you get their permission to seek such help yourself, you are "making a referral." It is easiest if the parent or family member makes the referral, as they will have the information needed and can get the process started more quickly. In order for you to make a referral, you will need to talk to the parents of the child first. They must give their written permission (consent) before you seek other assistance.

Sometimes parents will notice the developmental differences on their own. Although comparing one child with another is a disservice to both, it often helps parents to have a broader view than they may have if their experience is limited to their own child. One mother of a baby who was born with a heart defect entered an infant/toddler program that had a parent observation component. She was shocked when she saw the difference in development between her son and the other children his age. Because of his fragile condition and several surgeries, his early experiences had been very different from other children his age in this program. This mother didn't need the caregiver to recommend a referral. She went immediately to the heart specialist and the pediatrician and asked for help with her son's developmental needs. She understood that when specialists are worried about saving a baby's life, their concerns about overall development go on hold sometimes. With the help of the caregiver and a developmental specialist, the child moved from being seen primarily as a heart patient to being a developing toddler.

That case was unusual because the parent didn't need a referral. She already had specialists to help her and ultimately the child care program as well. If the concern you have is for a child who isn't already defined as a child with special needs, you may not know how the parents will react when you share your concerns.

How do you decide when to have a formal conference to talk to parents about your concerns? If you have spent some time focusing on the child and clarifying your concerns, you can ask the parents to schedule an uninterrupted time for you to talk with them. If you

have worked to establish a good relationship with the parents, you probably have been talking to them all along, so you know if the issues you are worried about are unique to your setting or if the parents have noticed the same at home. You may know that the parents are concerned as well, and that their concerns are the same as yours. You may also know if they have not expressed any worries and can take that into account in planning a conference.

Certainly if there have been regular small conversations, the conference itself won't come as a surprise to the parents. Nevertheless, if you decide that the time has come to get some outside help by making a referral, this conference may take on deeper significance than the usual parent-caregiver conference or the casual conversations you've been having with the parents and/or other family members.

PREPARING FOR A FORMAL CONFERENCE

Prepare for the conference by making careful observations of the child. Observation of the child over time will give you information about specific behaviors that illustrate the concern. It will help you clarify a general concern (Rashad seems too easygoing; Sarali is always in the middle of trouble.) with specific examples of behavior (Rashad stays in one position for up to 30 minutes and doesn't change positions on his own; Sarali has trouble sitting at the table during snack time and often hits children.). Note when and where those behaviors occur and under what circumstances. Also, with focused observation, you may get some insights into what is contributing to the behavior. See if changing the environment or your approach affects the behavior. Keep

track of all the details of what you have tried and what happened. This record can contain important information to share with the parents.

Remember it is only appropriate for you to discuss what you have observed about *specific behaviors*. Avoid the urge to label or diagnose. Sometimes parents have noticed that their child's development is different from most

children and they come to the conference feeling relief that someone has noticed. They may come anticipating that they will get the help and support they need. Other times, parents may be unaware of differences or unable to see them. Parents may have different expectations due to culture or experience. If parents haven't noticed anything, it may be a different situation.

Observations of Rashad

Marta thought about Rashad and what other infants his age were like. Marta decided to focus on Rashad's movement. She would make notes with the time and position in which Rashad was. She noticed that Rashad would stay in the position in which he started for at least 30 minutes. Rashad only rolled over from his back to his stomach one time in the three days Marta was keeping track. He did roll from his back to his side. Marta also noticed that Rashad spent time watching the other children and looking at toys, but rarely picked up toys or other objects that were in his reach. Marta came to realize that she had been changing Rashad's position without realizing it several times a day.

Observations of Sarali

When Emily asked her aide Tim about Sarali, he said Sarali "behaved badly and bothered other children" but Emily knew that would not be helpful to her parents. Emily decided to watch Sarali carefully so that she could give specifics. Emily noticed that Sarali had a harder time sitting still than other children and didn't cope well with transitions. She counted the times Sarali got up during snack and was able to give the actual figures of two times on Monday, Tuesday and Wednesday, five times on Thursday and one time on Friday. Emily could describe the behavior that indicated Sarali doesn't cope when there is a change. When it's time to come inside or to go down for a nap, she ran away from the teacher and grabbed toys from the shelf. When playing with more than one other child, Emily observed and recorded five incidents of hitting other children during the past week. She also noticed that Sarali had fewer words and phrases than other almost-three year olds.

CAREGIVER RESPONSES

One thing to keep in mind is that YOU may have an emotional response to the possibility of a child having a delay or difference in development. Noticing a difference in development can make you sad, nervous, upset, or anxious to get help. Your own emotional response will impact the way you share the information with the family. If Marta's only exposure to children with motor delays had come from seeing children with Muscular Dystrophy on the television, she might be very sad and even scared about the potential for this disability in Rashad. If you are a person concerned about children growing up to be independent individuals, the idea that a child has a special need that might get in the way of that goal may seem tragic to you. On the other hand, if your background stressed interdependence more than independence, you may consider a child with a special need a gift, not a liability. The family may have entirely different feelings. For example, if Emily is anxious to get speech and language help for Sarali, Emily may not be able to listen fully to the parent's perspective, and may be especially discouraged if Sarali's family does not share her concern.

Caregivers need to take the time to uncover their own emotional responses before meeting with the family. It may be helpful to talk with a colleague or the director about your own feelings. Sharing about the situation should not contain specific information about the family unless the listener is part of the staff. The discussion also needs to occur in a private location, not a restaurant or crowded staff room. Knowing what your feelings are can help you anticipate what

reactions you may have when sharing the information. For example, you may be surprised if the family agrees with your observations, yet is not very worried. Or, you may be especially frustrated if the family wants more time to observe on their own when you are sure that the child needs help. Once you realize your potential emotional reaction, you will be better able to keep it "out of the way" when conducting the conference. You may also be better prepared for the variety of ways that each family member may react.

When thinking about your feelings about your concerns for the child, the implications of those concerns, and about the family's response, keep in mind the positive feelings that you have for the child and all of the strengths that you've seen in the child. Regardless of your concerns, the child is still the wonderful being who is the focus of her family's love and your care.

CONDUCTING THE CONFERENCE

In the meeting itself, do what you can to make the parents feel comfortable and at ease as much as possible. Choose a seating arrangement that brings you together instead of separating you. Sitting behind a desk, for example, can make a psychological as well as a physical barrier between you and the parents or other family members. A warmer, friendlier arrangement may work better. Provide for privacy. This meeting is between you and the parents, not the business of the secretary or the rest of the staff. If you are a family child care provider you may need to meet outside of regular hours of care. Set aside enough time so that the meeting isn't rushed and you can talk things through. If this is the first such meeting

the parents have had, they need to feel that you care and that they can trust you.

If you and the family members do not speak the same language, careful thought must be given to interpretation during the conference. This conversation generally has an emotional component, and therefore appropriate interpretation is critical. When sharing information about a child's development, it is likely that some of the words and nuances in phrasing will be challenging for inexperienced interpreters to translate. Additionally, some parents may understand another language, such as English, yet not be able to fully understand and participate in a conversation about their child. A family may use someone (such as another family member or older child) for routine interpretation; however, they might not feel comfortable putting that person in the position of interpreting for this conference. You may need to explore other community resources.

Start the conference by gathering information from the family about how they see their child. Ask open-ended questions. Truly listen and show an interest in all that they say. Give them a chance to talk without interruption. You'll learn more about the family and the child and may be able to identify concerns that you have in common with the family.

When it is your turn to share, start with what is going well. Sharing positive qualities that you've observed lets the family know that you're paying close attention to their child and that you care about their child. Both listening to the family and sharing positive things about the child helps the family to know that

you are partners in meeting the needs of their child.

Ask about how the child behaves at home. If the family differs in their view of the child, be open to their perspective. Asking how the child behaves at home gives you information for comparison of your observations. You may also discover that there are different expectations due to the family's culture or values. When done respectfully, this communication can lead to a better exchange of ideas and ultimately be of most help to the child.

Before you share your concerns with the family, ask if they have any concerns that they haven't already indicated. Specifically asking the family if they have concerns that they haven't mentioned before gives the family another opportunity to voice their own observations or concerns and may provide information that supports what you've seen.

As you begin to talk about your concerns, let the family know that you are sharing your concerns to support their child's development and to get some ideas for how to best meet their child's needs. Be sure you communicate what you want to say clearly, without judgment and with concrete examples. It is especially important that you share your observations without labeling or diagnosing. DO NOT suggest that a child has a specific diagnosis (such as attention deficit disorder). Most child care providers are not qualified to provide such a diagnosis and doing so often gets in the way of the next steps in the referral process. On the other hand, your specific observations and

descriptions of what is happening will be very helpful to any specialists who become involved.

SUPPORTING THE FAMILY WHO WANTS TO ACCESS RESOURCES

If the family is also concerned or agrees with your observations, you can move to a discussion of possible next steps. Support the family in getting help. Their biggest fear is often that you will reject their child or them if extra help is needed. Let them know that you are there to support their child and to incorporate any new ideas. You should have information ready about services within your program, local early intervention services, special education services, and other resources. By sharing your concrete observations, you will be able to help the family clarify their questions about their child and what the referral will accomplish.

When ready to refer to the early intervention program, local school district, or pediatrician/healthcare provider, let the family take the lead. Since many families will want to take action, be prepared to talk with them about resources for obtaining further assessment and/or possible services. This is the point at which you are “making a referral.” It is generally appropriate to refer the family to their pediatrician at the same time you refer them to the local early intervention/special education resources.

Calling resource agencies ahead of time to gather general information can be very helpful. However, you cannot guarantee eligibility or services from another agency to a family. Rather, describe what might happen after the referral and what the possible outcomes might be based on what you’ve learned

from the agency. You can also let the family know that you can be a source of information to the referral agency. Parents must give permission for you to talk about their child with referral sources, so you will want to carefully respect the family’s confidentiality and be sure that you have clear, written consent.

When the family wants to access other resources, being aware of potential barriers can be very helpful. Some barriers include issues of insurance, spoken language, cultural practices, transportation, and discomfort, or previous negative experiences with authority figures such as teachers or doctors. It is not uncommon for a child care provider to help the families obtain services their child needs by setting the process in motion for them. Be careful not to do too much for the family, however. Rather than feeling responsible for overcoming the barrier, you can focus on supporting the family as they encounter a barrier. For example, a family can make the call to the referral source from your office, with you there to provide support and clarification if needed. Finding ways for the family to meet their child’s needs will serve the family and their child best in the long run.

WHEN THE FAMILY CHOOSES NOT TO ACCESS RESOURCES

If the parents don’t understand what your concerns are, think they are not important, or disagree with your observation, they may be upset if you suggest that a referral is necessary. It’s even possible that your observations will shock or anger them. In this case, sensitively supporting the parents’ feelings is called for without getting caught up in them. When infants and

toddlers are distressed, caregivers accept the feelings and empathize with the child. Parents need the same approach from caregivers. You are not a therapist, but some of the listening skills of a therapist can serve you well. For example, if the parents get angry, your immediate response may be to get defensive and argue your case. If you get caught up in your own feelings, you are less available to give parents the support they need at a time when they are vulnerable. Understanding that anger or blame are common responses for people in pain helps you accept the feelings without taking them personally. You may feel an urge to come back with your own feelings, but this is the time to focus on those of the parents and listen to what they have to say without minimizing their upset feelings or trying to talk them out of the feelings. Share with the parents that you see further assessment as a positive move and that both of you have the child's best interests at heart even if you don't see eye-to-eye at the moment.

Sometimes the family may not choose to access resources when you first share your concerns or they may be open to information, yet not take action immediately. Rather than label them as being "in denial" or something else, remember that everyone moves at a different pace and accepts information differently. The family's emotional response will affect what they are able to hear and understand. Processing and integrating this information will take varying amounts of time. The reality that life will have to change—that their child may be different than other children—is very hard for some families to hear. Unless behavior or other issues, such as medical urgency, will prevent you from caring for the child without assistance,

allow the family to proceed on their own time line. Be prepared to support them in understanding what you have shared, repeating the information whenever necessary. Let them know that there is resource information available whenever they want it. If you find that your own judgment or emotions about this interfere with your ability to respect the family as the decision-maker, seek support for yourself and don't be afraid to suggest that the family discuss this with someone else as well. If you believe that not seeking help is an issue of neglect, then you do have an obligation to be clear with the family and make an appropriate referral to a child protective agency yourself. Referrals to child protective agencies do not require parent consent.

RESOURCES FOR FAMILIES

Health and medical service systems

In many cases, it is appropriate to have a family talk about their concerns with their primary health care provider. Some issues faced by children with disabilities or other special needs are medical in nature and will require careful follow-up by a health care provider. Some health care providers specialize in working with children with special needs, while others have limited knowledge of the assessment and service issues. Parents and providers must be proactive to assure a good match between child and primary health care provider. It is often a good idea for the referral to be made to the special education/early intervention service system at the same time as the referral to the health care provider because the referral process takes time and referring only to one system (such as health care) may delay the entry to the other (such as early intervention). Remember, referrals are best made

directly by the family. If a provider makes a referral, the family must have provided clear permission.

Local special education/ early intervention service systems

Local special education and early intervention service systems are required by law to engage in “Child Find.” In other words, there is supposed to be an active and ongoing effort on the part of the specialist system to identify children who may be eligible for services. Some areas may provide free screenings at local child care settings, while others may send outreach materials to child care and medical agencies. Not all children with differences in their development will qualify for services from special education or early intervention. This is determined after appropriate screening and assessment. This assessment is provided to families free of charge, as are most special education services. After referral, the special education or early intervention agency has 45 calendar days (50 for children over three) to complete the assessment, determine eligibility, and hold a meeting to plan for services if needed. Again, referrals are best made directly by the family.

Once a referral is received, representatives of those agencies will talk with the family and may schedule an assessment to see if the child qualifies for services. Knowing the best contact name and number in your local districts can be of great help to the family. Each state is required to have a *Central Directory of Services* for early intervention services. There are legal timelines for responding to parent requests for consideration of early intervention or special education services. Parents may also put their

request in writing if they are having difficulty getting a response. Parents must give written permission for the child to be tested and receive early intervention or special education. All services are confidential and many are provided at no cost to the family. Even if a child is not found eligible for early intervention or special education services, the team providing the assessment may have suggestions for ways to support the child’s growth and development. Additionally, they will be able to give guidelines for monitoring the child’s progress as the child becomes older, in case the family or you become concerned.

If the child referred is found eligible and begins to receive services, the child can benefit from your working with the specialists on his or her team. They can become consultants to you and the family. The open and ongoing communication you have established with the family will serve you well as you continue to exchange information and support the child.

The sooner concerns about a child’s development or behavior are identified, the better the chance to provide effective help that may be important to the child’s future development. You, as a care provider, are in a unique position to work with families to identify concerns and take advantage of the opportunity to access services and supports early. Together you and the family provide the love and support for the child to become all that she or he can be!