

What Do I Say to Parents WHEN I AM WORRIED ABOUT THEIR CHILD?

BY JUDITH S. BLOCH, ACSW

With the passage of the Individuals with Disabilities Education Act (IDEA, 1997) by Congress, early childhood educators are expected to identify children with suspected disabilities so they can access evaluations and benefit from the entitlement for services created. Many methods and materials have been produced to help staff deal with the responsibility of recognizing children with possible disability and assist in the screening of children for developmental delays, but how do you talk to parents? Preschool administrators and staff have repeatedly

asked for help in approaching family members to discuss a suspected behavior problem, especially of children who may be emotionally disturbed, autistic, or ADHD (Bloch, 1999). How can this important task be done without alienating a parent or heightening their anxiety? If we revisit our understanding of family life and the psychodynamics of parenting, we can become better prepared to deal with this sensitive and important task.

TALKING WITH PARENTS

The manner in which the "informing" process with parents is handled is an important test of the integrity of the educational program or center (Donahue, Falk, & Provet, 2000). Ideally, staff are prepared and trained procedures are in place before anyone has to talk to parents. Four stakeholders are included: the troubled child, the parents, the teacher, and the administration. For the purposes of this article, we will focus on the staff-parents communication when suspected delays are identified.

THE PARENTAL DILEMMA

Becoming a parent elicits a variety of needs and expectations, the most common of which is the desire to expand one's circle of loved ones—to love and be loved. Virginia Satir (1967) discusses this eloquently in her book *Conjoint Family*

Therapy. For fathers, parenting may mean an assertion of manhood; for mothers, a biological imperative. Some see parenthood as a second chance, an opportunity to satisfy their own unfulfilled childhood needs or to realize thwarted adult ambitions. Still others expect that parenthood will become a means of providing protection and care for themselves in their old age. We choose parenthood for many different reasons, but the plan is for a healthy, happy child; the event is a time for celebration. With conception and adoption, parenthood brings aspirations for the family, dreams of love, security, and achievement.

Self-esteem and image, parental expectations, and dreams are threatened by the presence of a child's impairment. The pain and disappointment that is generated, especially at the very first phase when parents have a beginning awareness of the possibility of disability, may precipitate a crisis. Keep in mind that families do not move with tranquility from one which includes well children to one which includes a child with a disability. Reacting to the "real" can be problematic. There is an internal and natural resistance to the unwelcome change of status. The staff's appreciation of the parental fear of a label, or a classification, or even the suggestion of a disability will affect the nature of the dialogue. Confirmation of a disability has a significant impact on the family and



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requires adaptive change for all its members. This process can be slow and difficult.

THE STAFF'S DILEMMA AND RESPONSIBILITY

From birth to age six, children's brains are especially responsive to experiential influence. Research on the brain has produced impressive evidence that supports the value of an early start, especially for children with disabilities or for children at risk (Dodge & Heroman, 1999; Shore, 1997). Parents are likely to become distressed at a later date if early warning signs and risk factors are ignored, their children fail to make anticipated maturational gains, or when their children have not received entitlements. A growing public awareness of federal legislation and entitlements and an understanding of the importance of early remediation and its potential provide compelling reasons for early care systems to get services started.

TWO STORIES

In an article in *Sh'ma* (Artson, 1999), a parent tells his story:

"When our son Jacob was about two-years-old, he began to pull away, to slide into another world, behind some wall that we could not penetrate. We constructed a delusion to fool ourselves into thinking that nothing was wrong, that our boy was just developing differently from his twin sister. The horror was so vast that we willingly agreed with the popular pabulum that people offered us: We need to let him grow to be who he is without labeling him. We repeated this desperate, misguided mantra until we could no longer honestly say it; until the reality was so pressing that it shredded out denial..."

Another parent (Gartenberg, 1999) described her son Moriel, 12, as severely disabled by autism and said, "When Mori was two years old, his disability began to make itself known, crashing down on us like a meteor through the roof. In the five

years that followed, as we struggled with his loss of language and his strange, out-of-control behavior, my husband and I lurched and stumbled about in sorrow, exhaustion, and anger."

OTHER PARENTAL REACTIONS

In many instances, parental reactions to the birth (or later identification) of a child with a disability is similar to reactions described in DSM-III-R (Diagnostic and Statistical Manual of Mental Disorders, 1987, Third Edition, Revised): "The essential feature of this (Post-Traumatic Stress) disorder is the development of characteristic symptoms following a psychologically distressing event that is outside the range of usual human experience. The stressor producing this syndrome would be markedly distressing to almost anyone, and is usually experienced with intense fear, terror, and helplessness. The most common traumata involve either a serious threat to one's life or physical integrity; a serious threat or harm to one's children, spouse, or other close relatives and friends; sudden destruction of one's home or community." The parental reactions that professionals observed sometimes led them to conclude that these parents were irrational, dysfunctional, or part of the problem.

Typically, parental reactions at the first staff identification meeting fall into three categories (although parental responses are in reality much more complex and varied). They can be described as:

- Relieved to hear their own fears voiced; they are in basic agreement that something is wrong.
- Puzzled, unsure, frightened, but also concerned. Is the worrisome behavior a stage, part of temperament, can be outgrown, or a sign of a problem?
- In denial; possibly angry; disagree with your observations; or assert that their child has no difficulties at home, only in your center.

Do

- Accept the importance of parental input; elicit their perspective
- Remain sensitive to parental feelings: fear, anger, denial
- Focus on a child's observable behaviors; highlight strengths as well as problems
- Stress the value of an early educational start; offer hope
- Expect that the exchange with parents may take time
- Maintain confidentiality with parent

Do Not

- Focus on etiology (causes)
- Focus on diagnosis
- Focus on prognosis
- Become defensive
- Propose a solution

ESTABLISHING AN ALLIANCE

An understanding of the volatility of parental feelings combined with the pressing need to acknowledge the problem in order to help the child benefit from the "window of opportunity" may cause a staff hesitation to begin to assess a child and consult parents. Some early childhood educators may even feel unprepared to take on this task. And, understandably. The education and training of child care staff is varied. The literature points to a broad range of backgrounds for teachers; some with a high school education and little or no experience with young children, and others qualified as certified teachers with a college or graduate school education (Vail, Tschntz, & Bevil, 1997; Butera, 1996; Young, Marsland, & Zigler, 1997). Even when teachers are certified, their training may not have included any preparatory work to help them deal with parents. Untrained staff, unavailable consultation or supervision, limited experience, and time constraints, are all barriers to overcome and legitimate issues to be addressed.

Many directors will need to assess their staff's level of skill, their experiences and their attitude towards parents before

scheduling any meetings. In some instances, it may be necessary for the director to take on this responsibility. An expansion of the staff's repertoire of skills through training and supervision may be necessary before they can initiate a productive dialogue. Dunst (1988) contends that dealing with parents is "a craft that can be learned and perfected." He states further that the "heart of the process for enabling and empowering families is the relationship established between the help seeker and help giver." He lists six staff attributes necessary in order for them to be able to promote the ability of families to meet their needs. These are:

- 1) effective communication
- 2) honesty
- 3) understanding of families' concerns
- 4) emphasis on solutions (not causes)
- 5) actions
- 6) confidentiality

As a result of the experiences at Variety Pre-Schooler's Workshop (VPSW), two other major ingredients could be added to the mixture if we are to establish trust these are great listening skills and time. Staff reactions to parent input are an important part of any exchange. They may hinder or facilitate an outcome that leads to an evaluation for the child, if appropriate. This first step is critical because later decisions regarding classification, placement, and services in the least restrictive environment setting all follow.

MOTHER BLAMING

Unfortunately, "mother blaming," an established pattern in the 1950's and 60's, (Bailey, 1994; Bloch, 1997; Caplan & Hall-McCorquodale, 1985a, 1985b) is a view that persists in many circles. Such an attitude interferes with the alliance that needs to be established with parents. Even new findings such as etiology, especially as related to children with ADHD (Barkley, 1999), autism and Pervasive Developmental Disorders (PDD) (U.S. Surgeon General,

1999), have not reversed all of those earlier attitudes. Today, we also know that neurological and biochemical disabilities can create or certainly contribute to serious behavior management problems. "The cause of emotional and behavioral problems is unquestionably complex...I do not believe, nor want to imply, that if an individual child has a mental problem, it must have been caused by the failure of adults to provide for that child" (Bryans, 1999, p. 484). Federal legislation (IDEA) and its language reflects this understanding with regulations that promote collaboration and propose that evaluations focus on the child's behavior and classification and not on etiology.

It will help to remember that during this period of early identification even strong, intact families may appear disorganized and chaotic. Staff cannot assume that the anxiety and occasional marital differences observed at initial meetings are responsible for creating the child's difficulties. In fact, it may be quite the reverse. Frankel (1963) said that it is appropriate to react in inappropriate ways to inappropriate experiences.

A BEGINNING APPROACH

The set of core skills and the method that is proposed in this paper emerged from extensive experience with a helping and facilitating process at Variety Pre-Schooler's Workshop (VPSW). The proposed approach can be adapted to fit into the context of the work at the center or preschool.

It is useful and significant to distinguish between two types of initial contacts: One requested by a parent, and the other by the staff. In the first instance, it is probably best to be a good listener. Find a comfortable, private room where there will be no interruptions of any kind, not even for a minute or two, or for a phone call. Leave enough time, preferably an hour (if possible), for the discussion. After the informal greetings to help put someone at ease and get started, let them tell you what prompted their request.

Parental concerns should be taken seriously; their observations are usually reliable and valid (Dinnebeil & Rule, 1994). In a report from Howlin and Moore (1997) describing the experiences of almost 1300 families with children with autism, it was concluded that parents in the United Kingdom had an early sense of the problem (by the age of 18 months) and sought help from the doctor when the child was two years of age. However, the report indicated that a diagnosis was not made until the child was six, losing the advantage of early diagnosis and educational intervention.

In the next scenario, the meeting initiated by the staff, the beginning can be somewhat different. In this instance, staff need to state at the onset, in as neutral a way as possible, the purpose of the discussion. For example, "I asked you to come in so we can talk about Jimmy, and how he is doing at school and at home." It would be best to stop after this introductory remark and give the parent a chance to respond. If this is not productive, an inquiry about parental perspectives may move the discussion along (i.e., "How do you think Jimmy is doing?"). Again, try to be a good listener. Resist the temptation to introduce the problem too soon or to expand in detail. This could turn the session into a monologue and discourage the participation that is needed. Parents will usually have a great deal to tell us if we are ready to listen. Sometimes this is easier said than done.

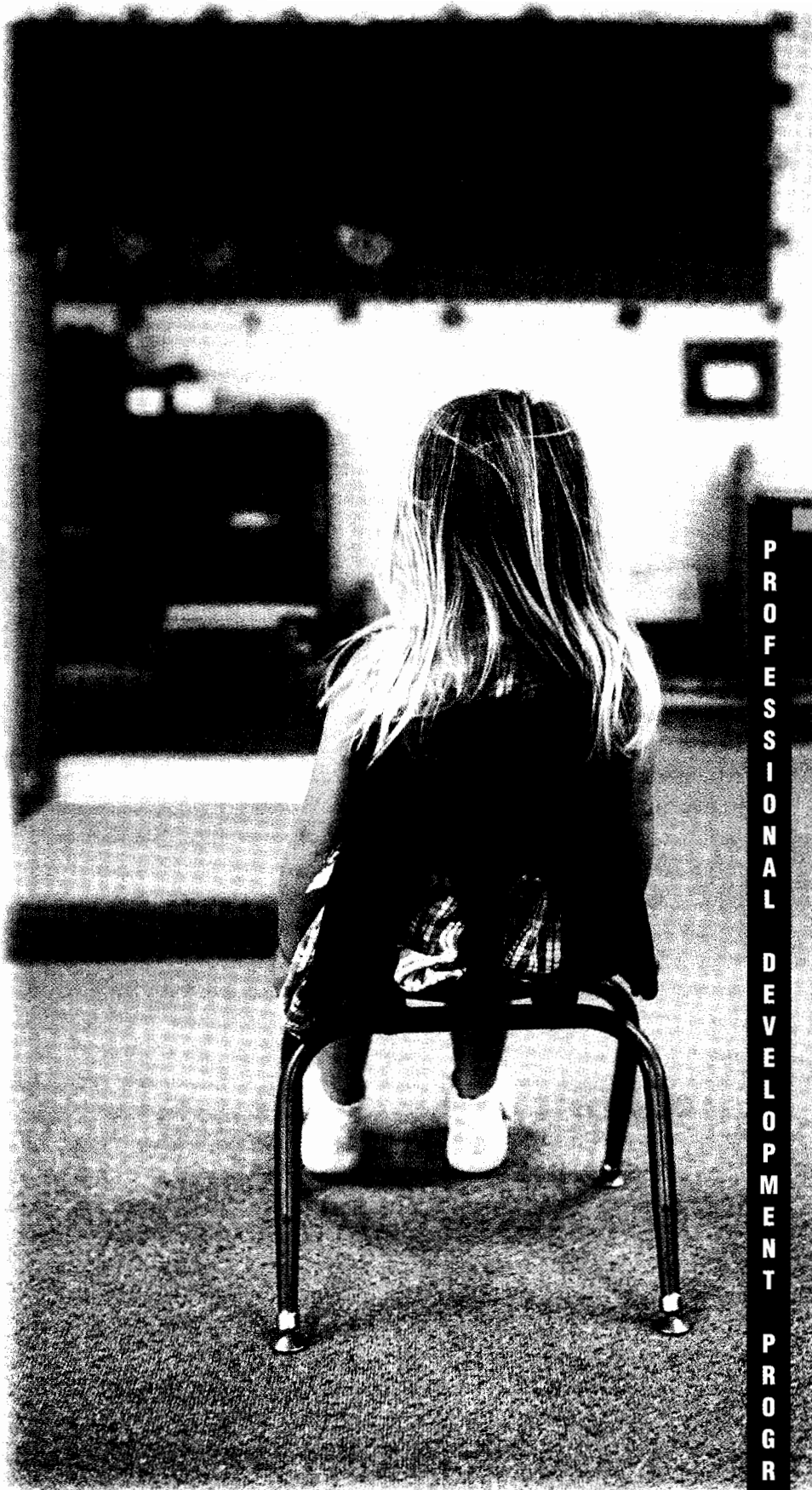
INCLUDING PARENTS IN ASSESSMENT

Including parents in the assessment process, according to Bredekamp and Copple (1997), increases the accuracy of the data collected and paves the way for involvement in their child's education. It is also one of the best ways to get a good picture of the child's performance in multiple settings. Sharing responsibility for screening recognizes the usefulness and value of parental judgment, reaches for it and

includes it in arriving at decisions. The process produces meaningful information, is consensus building, and will facilitate later decisions.

In both instances, a discussion initiated by either parent or staff, *The Five P's* (Parent/Professional Preschool Performance Profile) System may be used. It asks both parents and teachers, separately and independently, to observe and rate the child in the home and center. In this approach, parents share responsibility for the preliminary screening with the teacher. After discussing the areas of concern, i.e., language development or social skills, the full *Five P's*, or a specific domain (i.e., language) may be used by both primary caregivers to rate the child on observed performance in the child's two major natural settings: home and center. Use of this system will lead to the identification of a child's strengths and gaps or delays in achieving milestones anticipated at specific ages. The rating system (Yes, Sometimes, No) is easy to learn and use. Parents can be trained to observe and rate their child interacting with play materials and others over an extended period of time and in a wide range of activities. Rating judgments are then shared and compared, producing information for further planning.

Frequently, parents will respond to concerns about language. Talking, in particular, is a major milestone, and a child's performance is more easily compared to other children of that age. A child of two usually has a vocabulary of at least 50 words (Paul & Fountain, 1999). As a teacher, ask parents, "Tommy does not use words to communicate, to tell me what he wants. Does this happen at home, too?" The discussion should produce increasing clarity about the child's disability and with it, the parental perception and reaction. If needed, the teachers could suggest that they, along with the parents, continue to look at the child's use of language in an expanded way; preparing ratings on the language scales.



The Language Development domain consists of three scales: Communicative Competence (the social use of language); Receptive Language (what a child under-

stands); and Expressive Language (the child's speech, vocabulary, and sentence structure). These three scales would be very important to use for a child who does not use language to communicate.

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If a child has problems responding to the teacher, playing with others, or joining group activities, the Social Development Scale is also useful. The Social Development domain consists of three scales: Emerging Self (how a child develops a sense of who he is); Relationships to Adults (how a child relates to significant adults); and Relationships to Children (how a child interacts with his peers).

The teacher's use of the Classroom Adjustment Scale will give parents a picture of their child's performance at the center—how he or she responds to such tasks as identifying classmates, participating in individual and/or group activities initiated and sustained by the teacher, concentrating on a task for five to 10 minutes without being distracted by surrounding activities or noises, and tolerating familiar transitions from one activity to another in the classroom.

The proposed collaborative process usually increases the parents' understanding of milestones and age-appropriate behavior. It also takes into account the possibility that the child may behave differently in different settings. Parents may recognize the child's emerging skills before they are observed in the classroom or center.

Since access to the evaluation entitlement and other services are voluntary, parents cannot and should not be coerced into participation. Staff, of course, may take the initiative and assume responsibility for screening and providing information, if requested by parents. Even if every effort to elicit parental cooperation is made, some may elect to discontinue this process. Others may proceed at an excruciatingly slow pace; challenging professional views and values.

CONCLUSION

Training and preparing staff in early care facilities to deal with parents of children with possible disabilities is a timely issue. Not only because we know there is a large population of unidentified and unserved infants, toddlers, and preschoolers (especially from disadvantaged sectors and in foster care), but also because IDEA has created entitlements that address these needs. The documented effectiveness of early identification and intervention are compelling reasons to inform and empower parents to act on their behalf. The general considerations and underlying philosophy of an approach with a potential to reach and engage more parents has been outlined. It recognizes that in any approach to families, sensitivity to their individual characteristics as well as their culture, priorities, and concerns is the best way to begin the work and to establish the trust that is necessary for collaboration.

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lished in 1966, VPSW was one of the first preschools on the eastern seaboard to identify and educate youngsters with serious learning, language, and/or behavior problems.

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Early Childhood programs servicing children 18-65 months needed to participate in VPSW's national normalization study of *The Five P's* by Judith S. Bloch. FREE materials. Teacher stipends. Parent gifts. For more information, please contact Janice Friedman by phone at 800-933-8779, Ext.126; by fax at (516) 921-8130; or e-mail at jfvpsw@aol.com.