Diagnosing Developmental Problems in Children: Parents and Professionals Negotiate Bad News

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Objective: To examine how parents and professionals engage in a process of negotiation over what labels to use and what developmental meaning to ascribe to those labels when imparting a diagnosis of mental disability to parents of young children.

Method: We performed a sociolinguistic analysis of 10 feedback sessions with parents whose children had been diagnosed by a clinical team as developmentally disabled.

Results: Professionals shied away from explicit use of labels; they preferred to describe children's deficits with rate descriptors (e.g., "slow"). Parties to the sessions see-sawed between optimistic and pessimistic statements. That is, when parents seemed despairing, professionals would try to hold out hope; when parents were unrealistic, professionals gave more blunt statements. Parents who received the most ambiguous interpretations seemed left with diagnostic questions still unanswered; those who received more forthright information appeared better able to move on to issues of prognosis.

Conclusions: Diagnoses of developmental disabilities are jointly constructed by parents and professionals. We recommend larger and more controlled studies on the relationship between negotiation and labeling in diagnostic feedback interviews and the impact of these processes on parental satisfaction and adaptation.

Key words: mental disability; delay; retardation; diagnosis; labels; interpretation; negotiation; parents and professionals.

Communicating bad news about children to parents who are unprepared for it is a complex and harsh task. The news giver is likely to cherish two incompatible values: a desire to be candid, clear, and thorough (Adams, 1982; Doernberg, 1982; McDonald, Carson, Palmer, & Slay, 1982; Morgan, 1973; Shea, 1984) and the wish to avoid hurting parents unduly. By the same token, the news receiver wants both to hear the truth (Gayton & Walker, 1974; Gilmore & Oates, 1977; Lynch & Staloch, 1988; Pueschel & Murphy, 1976; Quine & Pahl, 1986), yet is likely to resist it. These conflicts are magnified when the news is very bad, the diagnosis is uncertain, and the explanatory labels are ambiguous (meaning one thing to a professional and another to a parent). All these features are associated with the early identification of mental retardation, particularly when its cause is unknown. Imparting this diagnosis, therefore, presents grave difficulties to both the giver and receiver of information. The confusion and ambivalence over what to say to parents is reflected in the professional literature. Some experts caution "tellers" to avoid labels such as "mental retardation" (Behrman & Vaughan, 1987); others advise them to use IQ levels (Shea, 1984) and labels (Doernberg, 1982; Shea, 1984).

Given such conflicting pressures, it is hardly sur-
prising that interpretive interviews often go poorly. Families are dissatisfied with the feedback they receive and frequently do not believe that professionals have fully disclosed the facts (Featherstone, 1980; Isbell, 1979; Quine & Pahl, 1986; Schwartz, 1970). The dissatisfaction may partially be explained by parental defensiveness against “hearing” bad news, but previous studies suggest that professionals may retreat from their own standards of full candor. Svarstad and Lipton (1977), for example, found that professionals provided parents with a frank diagnostic category and/or specification of the child’s intelligence (using IQ or mental age) in only half the cases of the predominantly school-age children they studied.

To reach an accord with parents that is both honest and palatable, professionals must delicately balance bad news with hope. They must use techniques of discourse that blunt the impact and alleviate the despair occasioned by bad news, while not unduly obscuring reality. To resolve this inevitable ambivalence, informers make use of several strategies. We have identified two intrinsic to the content of feedback communication and one intrinsic to the process of communication.

First, professionals use euphemisms to soften and mask the truth. Terms such as “developmental delay,” “slow,” and “immature” are less direct, concrete, graphic, and offensive than the term “mental retardation.” “Retardation,” a term that now seems harsh, was initially a euphemism (Bialer, 1977). It suggests slowed-down mental processes—not imperfect or insufficient ones—and hints at the possibility of catch-up in a condition that is usually chronic. As time and familiarity have eroded the masking power of the term “retarded,” it increasingly has become subsumed by the even more euphemistic term, “developmental delay” or “developmental disability.”

Second, professionals cover their own uncertainty, discomfort, and wish to mitigate the truth by hedging (Frader, Bosk, & Prince, 1980; Solomons, 1969). Language that is indirect, vague, and uncertain serves both to manage professional uncertainty and to minimize the impact of the diagnosis. Hedges used to approximate a condition—“sort of,” “kind of,” “a little bit”—help shrink the distance between normative expectations and the abnormal condition of the child (Prince, Frader, & Bosk, 1980). Hedges that limit an assertion by attributing it to personal judgment—“I think,” “the results lead me to believe,” “it seemed”—express possibility or probability, rather than certainty.

Third, professionals can preserve parental self-esteem and allay distress through a process of negotiation. The concept of negotiation describes the socially constructed nature of encounters in which participants are able to forge a mutual understanding through language. Thus, the meaning of the encounter and the understanding of the information the parents maintain are interactionally and not individually based. The encounter is seen as a bargaining process in which each participant must adjust his or her line of action in terms of what they can expect to attain under the circumstances and in accord with how the others are developing their lines of action. The content of the information is not static and discrete, but fluid and continuous, subject to modulation, change, and adjustment to accommodate such contextual features as goodness of fit between the child and the diagnostic category and parents’ emotional needs. By fine-tuning the diagnostic feedback as conversation progresses, professionals and parents can keep the interpretation circulating around a mutually acceptable set-point.

Increasingly, it is recognized that participants in any encounter are likely to construct their communication jointly (Sacks, Schegloff, & Jefferson, 1974; Schegloff, 1968; Schegloff & Sacks, 1973) and that every aspect of a diagnosis—the label to be applied to the child, the words that explicate the child’s condition, and the likely outcome of the condition—can be negotiated (Fisher & Todd, 1983; Frankel, 1984; Maynard, 1989; West, 1984). Professionals in clinical settings have deliberately used negotiation for defining medical realities in the context of a doctor-patient discussion (Anderson & Helm, 1979; Frankel, 1984) and for designing treatment plans (Eisenthal, Emory, Lazare, & Udin, 1977; Fisher, 1983; Freeling, 1983).

This study of 10 feedback interviews focuses on the topic of negotiation; specifically, how professionals and parents of preschool children negotiate diagnoses of mental retardation and manage levels of optimism and pessimism. These were the specific questions we sought to address. What is the nature of the negotiations? How are parental reactions of optimism and pessimism responded to by professionals? How do parents react to the blurring of diagnostic information?
Method

Sociolinguistic Analysis

The present study used a sociolinguistic method to investigate what transpires between the participants in a diagnostic feedback session. Just as sociolinguists study the way language is used in normal social life (Hymes, 1980), we wanted to track the natural use of language in parent-professional interactions. An enumeration of the dialogue interview-by-interview brings idiosyncratic aspects of each case to the fore, rather than relegate variation to “white noise,” as often occurs when data are compressed into categories and manipulated statistically. It is a good method for inductive reasoning—inferring a rule from observation of particular instances, for hypothesis generating, rather than hypothesis proving. The object is to derive, from a set of particular circumstances, possible organizing principles and regularities that underlie apparent variability (Stubbs, 1983).

Important to a case-by-case analysis of language is the assumption that the same word (e.g., developmental disability) may have different meanings under different circumstances and that the particular meaning is lost if one artificially removes the word from its communicative context. Professionals may reach the identical diagnostic conclusion in two children, but the words they use and the interpretation they give will vary depending upon the parents’ response to their language. Only by tracing the back-and-forth conversational turns one can understand the meanings being exchanged.

This method is admittedly subjective, for it is based on the interpretive judgments of the investigator. The reliability of these judgments rests on the familiarity of the investigator with the field and a deep immersion in the data, what has been referred to as “connoisseurship” (Eisner, 1985). The subjectivity, however, does not detract from the empiricism of the approach. To be acceptable, the arguments must be plausible and the data open to review by others. Validity is achieved by subjecting the principles extracted from the corpus to confirmation with other data sets. As multiple sources converge, confidence in the conclusions increases.

Prior studies of feedback sessions have tended to use after-the-fact methodologies (e.g., questionnaires and interviews). Characteristically the investigator preselects a set of operationally defined verbal behaviors, determines their frequencies, and correlates them with one another or with other outcome variables. Though these studies have yielded important findings—particularly regarding the dissatisfaction of parents—they are insensitive to the shifting interactive dynamics that occur over the course of a session. When the phenomenological field is segmented according to the researcher’s constructs, the circumstances under which something is said are not factored into the findings. Meaning is determined by external criteria rather than by contextual clues. For example, using cumulative frequency to indicate the strength of a construct, a researcher may conclude that someone who offers six friendly statements is more affiliative than is one who offers two. But it may be that a consideration of the context reveals the person with the lower frequency to have been more earnest and sincere. Both embedded and disembedded methodologies have important complementary roles to play in this intricate area (as argued persuasively by Roter & Frankel, 1992).

Participants

The research took place in a diagnostic unit for preschool children that is part of a large eastern children’s hospital affiliated with a major medical school. Children suspected of developmental delays were referred to a multidisciplinary team by pediatricians for an extensive evaluation that included an investigation of medical, social and psychological aspects of the referral problem. The diagnostic process usually included pediatric and neurological examinations, as well as psychological testing and evaluation. Parents returned to the clinic at the conclusion of the evaluation to receive findings and recommendations. Eleven professionals—three doctoral-level psychologists, one master’s level psychology intern, two social workers, and five pediatricians—participated in the feedback sessions on 10 children. In nine of the 10 sessions both parents were present.

Of the 11 professionals participating in the study, a psychologist, always present at the feedback session, was designated as the primary discloser of the diagnosis of mental disability. The other professionals were sometimes, but not always, included in the disclosure conference. In the 10 interviews the number of professional participants ranged from one to four. The “secondary” professionals provided
The 10 children ranged in age from 2 years 1 month to 4 years 10 months and an IQ (as measured by the 1969 Bayley Scales of Infant Development or the 1972 Stanford-Binet) from 50 to 70 (the cut-off for mental retardation used by the hospital following the American Association of Mental Deficiency; Grossman, 1982). The admittedly very small sample is characteristic of studies that employ sociolinguistic analysis where intensive phrase-by-phrase analysis is carried out. (Maynard, 1989; West, 1984). Data for this study consisted of over 10 hours of audiotaped encounters between professionals and parents. Most of the subjects came from two-parent families with a steady history of employment. However, one single-parent family was included, as well as one family with a parent who was recently unemployed and looking for a job. For a full description of the subjects see Table I.

The sample in no sense “representative” of preschoolers with mental retardation, nor even of children seen in diagnostic clinics. Although efforts were made to control for variability in the children’s diagnoses by limiting their age and IQ ranges, there was considerable heterogeneity to the group. One child (with an IQ of 70), for example, was diagnosed as borderline, and two were diagnosed as autistic with developmental delay. A further distortion was introduced by the fact that the sample was susceptible to the effects of self-selection and volunteerism. The three psychologists who participated in the study stipulated in advance that they be given discretion to select the parents from whom permission for audiotaping would be sought. For many families, the psychologists determined, audiotaping would compromise the effectiveness of their feedback session. All families asked to participate agreed to do so. The high degree of sample selectivity, heterogeneity, and small numbers makes this investigation one of hypothesis formulation rather than hypothesis testing.

**Procedures**

Families were told that the purpose of the study was to examine “how professionals communicate Information to parents” and were asked to sign a release so the feedback sessions could be audiotaped. The 10 tapes were then transcribed in full detail, including dysfluencies, self-repairs, false starts, pauses, and overtalking (though not inflection, emphasis, and tone). Altogether, the tapes yielded 707 pages of transcription! By chance, the group of children could be separated into five children who were given the mental retardation (MR) label and five who were not. This split permitted us to look at the effect of the MR label on the feedback session discourse.

The analysis of the negotiation of labels proceeded by review of each tape for professional/parental interactions around what to call the child. The labels used included these specific terms: “mental retardation,” “autism,” “pervasive developmental disorder,” “developmental disability,” “auditory perceptual problem,” “developmental delay,” “hyperactivity,” “learning disability,” “attention deficit disorder,” (and combinations of the above). To be included as a negotiated transaction, the interaction had to include the use of a label, turning taking of at least two sequences between the professional and the parents, and the aim of clarifying, modifying, expanding, or otherwise altering the original linguistic marker for the child’s mental disability.

In addition to negotiations around the label,
Parents and professionals also negotiated levels of optimism and pessimism. Tagging statements as optimistic or pessimistic was difficult because utterances that appear optimistic or pessimistic in a particular context may not appear so when extracted from their context. Furthermore, the manifest content of a statement is not always congruent with the implicit message of the statement. Complicating the coding further was the fact that a response to an optimistic utterance may come several turns after the initial statement.

For the purposes of this study, an utterance was defined as pessimistic if it (a) acknowledged a loss of expectations or narrowed hope for the child; (b) framed the event as immutable, permanent, or with little expectation of change; (c) identified negative aspects of the situation; (d) conveyed doubt about the parents' ability to cope or manage the situation; or (e) expressed negative affect, such as feelings of loss, grief, or sadness. A statement was defined as optimistic if it (a) emphasized the child's capabilities and functioning; (b) delineated the situation as subject to modification; (c) marked positive aspects of their situation; (d) conveyed the belief that there were available resources to cope with the difficulties; or (e) expressed positive affect, such as feelings of relief, determination, freedom from anxiety, and clarity.

The 10 transcripts were reviewed for talk that reflected optimism or pessimism. From the 10 transcripts, 88 discourse events were identified as having such content. The number of events per protocol was distributed with a low of 4, a high of 15, a median of 9.5, and a mean of 8.8. Even though 15 exchanges represents a very small proportion of an hour session, these were the moments during which answers to parents' fundamental question—"What is wrong with my child"?—were constructed. A discourse event was defined as any type of utterance or group of utterances that possessed optimistic or pessimistic content (according to the above criteria) and that were connected by their temporal proximity to each other. For the purpose of counting the shifts in optimism/pessimism, the 88 discourse events were then broken down further into 156 episodes that reflected adjacent turns, or, on rare occasion, the single optimistic or pessimistic utterance. Because of the ambiguity in the construct of optimism/pessimism, we subjected our analysis of this variable to a reliability check.

From the corpus of 88 discourse events, 35 were selected randomly for presentation to three independent judges to determine reliability shifts in levels of optimism and pessimism. Portions of the transcript preceding and following the material for coding were included for context. Agreement on ratings of optimistic, pessimistic, or neutral ranged from 72% to 84%. Agreement on shifts in the level of optimism and pessimism, as identified by at least two judges, occurred in 30 of the 35 cases (as determined by the first author), or 86% of the time.

We investigated the effects of blurring labels by looking at the questions parents asked throughout the conference and particularly in the last 10 and 5 minutes of the session. As a time-limited experience, the diagnostic disclosure conference had a "closing" phase of which participants were aware. The content and timing of parents' last-minute questions represented the parents' "place" vis-à-vis the informational transactions at the endpoint of the encounter.

Results

Negotiating Labels

The professionals' habit of blurring diagnostic information invited parents to join in a struggle over the appropriate designation. Professionals used labels sparingly. They were much more likely to refer to the children's deficits through rate descriptors (e.g., "slow," "delayed," "immature," "like a younger child"), vague references (e.g., "major concern," "problem," "cause for worry"), and aspects (e.g., "motor skill," "type of play," "brain function," "something not right"). Of the references to mental handicap, only 12% were classified as labels, whereas 26%, 33%, and 29% were classified as rate, vague, and aspects, respectively. The group labeled mentally retarded had a lower IQ (mean: 54, range: 51–57) than did the group not so labeled (mean IQ: 66.7, range: 59–70).

We found negotiation over the diagnostic label in 8 of the 10 tapes. In the other two tapes parents bargained (a form of negotiation) over prognosis. Parents of the five children who were labeled as MR all negotiated around the issue of severity. Parents of the three children who did not receive an MR label negotiated around the larger diagnostic category. In the remaining two tapes (both of children not labeled MR), parents appeared to accept the professional's presentation, but tried to ameliorate its impact by asking if they could expect any changes
in the future. Bargaining took the form of circumscribing the terminology and limiting its impact, as seen in the following examples (the first two are children labeled as MR, the third is a child without an MR label):

Professional: This degree of delay means that he's _mentally retarded._
Father: Is there anything that can be done for him?
Professional: There are always things that can be done. [Mother weeps]
Mother: But, he's not _severely retarded_?
Professional: No.
Father: More _moderate._
Psychologist: Our best guess is that he will continue to be _slow_ and probably in the _mildly retarded range_—which would mean that he would be—let's call him "educable."

Initially, the mother found the diagnosis of MR emotionally wrenching. Upon regaining her composure, however, she actively engaged in a cognitive adjustment of the diagnostic label to make it less overwhelming: "But, he's not severely retarded?" Through her proactive efforts this mother was able to establish her son's inclusion in the "mildly" retarded category and thereby limit her sense of loss. In fact, the child at 2 years 9 months had an IQ of 54, a score that places him on the borderline between "mild" and "moderate."

Through persistent questioning designed to improve the diagnostic outlook, parents may succeed in getting professionals to moderate their own statements, as in the following discussion of a child also 2 years, 9 months with an IQ of 51, a score that places him in the "moderate," rather than the "mild," category.

Professional: So, he's really performing kind of at half his age. Which is a very significant delay, which ah, as you say, _retarded_ is an another word for slow. And yes, we would call him _retarded._ That's how he's functioning now.
Father: I mean but he's _trainable?_
Professional: We certainly think he's _trainable._ What's hard to do is to make predictions as to, you know, where he's going to be. . . . This is where he is now. Ahm, we think he will certainly continue to develop and build new skills. . . . Some people think "Well, he's _retarded_. That's it." Meaning—that says everything about it and he's never going to change. And it's not. That isn't what we mean. We mean exactly what you say.

Father: _Mild?_
Professional: _Slow._
Father: Did you say it's _mild_ or ?
Professional: _Well._
Father: She said it was significant.
Professional: In the _mild to moderate range_. It's—
Father: I think it—He'll probably end up _mild_. Again, it's really hard to tell but but probably, he's right now next to the border between _mild_ and _moderate._

Sometimes the negotiating process resulted in the parents and professional self-consciously agreeing to select one label and discard another. The following child was diagnosed as developmentally delayed with autism:

Mother: I think I'm gonna label it as a developmental delay cause I know if—
Father: Anybody hears that—
Mother: You know—
Professional: Listen, if you're comfortable with that—
Mother: I know inside that he has _autistic_ tendencies. I know that has to be corrected.
Father: And it's nothing to be ashamed of.
Mother: Yeah, but you know parents. You know.

This excerpt demonstrates that parents, in their search for a comfortable label, may factor into their choice the probable reaction of family members and friends. They must integrate the new diagnostic knowledge into the entire fabric of their lives. Setting on an acceptable label prepares them to do so.

**Negotiating Optimism and Pessimism**

Each of the 88 discourse events was diagrammed in detail to determine who initiated optimistic or pes-
Table II. Reversals Among Participants in Optimistic-Pessimistic Statements

<table>
<thead>
<tr>
<th>Participants</th>
<th>Pessimistic followed by optimistic statement</th>
<th>Optimistic followed by pessimistic statement</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Across roles</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent statement followed by professional statement</td>
<td>22</td>
<td>19</td>
<td>41</td>
</tr>
<tr>
<td>Professional statement followed by parent statement</td>
<td>7</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Within roles</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional statement followed by professional statement</td>
<td>12</td>
<td>13</td>
<td>25</td>
</tr>
<tr>
<td>Parent statement followed by parent statement</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>44</td>
<td>42</td>
<td>86</td>
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</tbody>
</table>

Table III. Reiterations Among Participants in Optimistic-Pessimistic Statements

<table>
<thead>
<tr>
<th>Participants</th>
<th>Pessimistic followed by pessimistic statement</th>
<th>Optimistic followed by optimistic statement</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Across roles</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent statement followed by professional statement</td>
<td>2</td>
<td>17</td>
<td>19</td>
</tr>
<tr>
<td>Professional statement followed by parent statement</td>
<td>2</td>
<td>12</td>
<td>14</td>
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<tr>
<td>Within roles</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional statement followed by professional statement</td>
<td>2</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Parent statement followed by parent statement</td>
<td>3</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
<td>40</td>
<td>49</td>
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Optimistic utterances, who responded to them, how they responded, or whether a participant shifted between optimism and pessimism within his or her turn at talk. This yielded 156 episodes for analysis. The data were organized into two groups: reversals (when, in a two-statement sequence, the second statement opposed the first) and reiterations (when, in a two-statement sequence, the second statement echoed the first).

The negotiation of optimism and pessimism was evident in all the tapes to some degree in one form or another. Tables II and III illustrate the greater tendency of participants in the feedback sessions to reverse the direction of a prior statement—from optimistic to pessimistic or pessimistic to optimistic—or confirm an optimistic one, than to reiterate a prior pessimistic statement. Only 9 times, out of 135 statements, were pessimistic statements confirmed. The $\chi^2$ derived from a two-by-two table (pessimism and optimism followed by optimism and pessimism) was significant at $p < .05$. Moreover, professionals reversed previous parent and other professional statements more than parents reversed professional or parent statements. Indeed, professionals were almost three times as likely to shift directions as were parents, but were just as likely to reverse optimistic as pessimistic statements. Parents, too, though showing a much lower frequency of directional reversals, were equally likely to shift from an optimistic to a pessimistic statement as the reverse. The $\chi^2$ derived from a two-by-two table (professional and parent reversed by parent and professional) was significant at $p < .05$. These findings are contrary to the consensus in discourse analysis that parties to a conversation strive for agreement and will go to great lengths to avoid disagreement (Goody, 1978).

Reversals
Reversals illustrate the acute ambivalence of the parties who want to be realistic yet preserve hope. When professionals were euphemistic, parents had a need to "flush out" their true position; when they were blunt, parents had a need to soften the assault. In the following example the parents were pushing for the truth against the professional's optimism:

Professional: First of all I don't think this is a serious impairment in the sense of what you saw at Easter Seal.

Mother: Yeah.

Professional: We're talking about a child who's going to be, if at the worst, going to be slow in school.

Mother: Yeah.

Professional: —learning, but is going to be socially appropriate.

Mother: Right.

Professional: And so we're talking about her school career primarily.
Mother: Right.
Professional: And whether she’s going to need special help in school.
Mother: Right. Okay.
Father: And she’ll never outgrow this, is that what you mean?
Professional: I, I’m not saying that. I, I have some concerns that we’re seeing the first evidence of something that might persist in one form or another.

In this exchange, the father, by taking an extremely pessimistic posture, pressures the professional to admit the diagnosis is more serious than she had previously indicated, though she resists a full embrace of his stark pessimism.

In the following episode a parent tries to elicit more optimism from the professional. We get a glimpse of the poignant struggle that parents and professionals go through as they strive to get at the truth while preserving hope and self-esteem.

Father: Is there a chance Johnny’s gonna outgrow that minor, minor retardation now?
Professional: There’s—there’s always a chance. Our best experience is that when he’s at the level where he is, he will continue to be retarded.
Father: Is that like sometimes like when kids are learning things, it seems like they learn a little bit of about it, then it seems like there’s a breakthrough and—
Professional: There is—yeah our—our exp—we would like to express at this time—I think of a—the pessimistic view that is is wh—that he will stay retarded. I think you’re gonna see changes and you’re gonna wonder whether it’s catch-up. You’re gonna see changes just in uh—a—as things are expected. And if—I think there’s always a sense of, of hope and of change, but I—I think—My opinion is that—that he will stay slow.

However much the professional wanted to side with the parent’s optimism in this case (the child’s IQ was 54), he simply could not accede. In the end he substituted the word “slow” for retarded, but otherwise held his ground. That staking out this negative position was painful can be seen in the dysfluencies, bumbles, and hedging.

Reiterations
The wishes of the participants to affirm their mutual support with one another was also seen in their frequent expression of agreement. Agreement, or reiteration, serves as conversational glue that offers participants a semblance of solidarity and collaboration. Agreement also enhances “face” because it sustains the impression that participants wish to create and wards off potential embarrassment or humiliation. In a feedback context, agreement is also a means of repairing the assault to the parents’ public esteem. This “boosting” function is supported by the finding that professionals and parents were much more likely to reiterate optimistic than pessimistic statements (See Table III). Collaboration is sufficiently important to both parties that the professional sometimes strains to find a source of agreement, despite more heartfelt disagreement, as in this case of a 32-month-old boy who was diagnosed with autism and developmental delay.

Mother: I have more confidence. I think he’s going to be fine. I really—
Professional: Yeah. It’s nice that there are the strengths that he has in his development.

Under the urgency of the parents’ wishes, professionals, at times, will extend their sympathetic bonding by escalating their responses with increasing intensity. To counter the assault to the parents’ self-esteem, they flood the parents with affirmation, as in the following example:

Father: And I guess really at this point I have to hold on to that [He will catch up].
Professional: Sure.
Father: I really—
Professional: Absolutely—
Father: Have no other choice. You know.
Professional: You have to—Oh sure. You have to have that hope.

The reiteration of pessimism can also be an expression of solidarity. Note that in the following exchange comraderie is enhanced by the use of the same words:
Parents and Professionals Negotiate Bad News

Mother: It's exhausting me. Why didn't anybody tell me it would be this heavy. Ah! Parenting is hard. Ugh.


What these illustrations make clear is that the pendulum between hope and despair swings widely during a feedback conference and where it rests is only a temporary state. Professionals in these sessions strive to be optimistic and make pessimistic statements only to offset parental statements that blatantly minimize or deny the findings.

**Parent Confusion in Relation to Blurred Labels**

The question naturally arises, would parents have to struggle less for comprehension and acceptance had professionals been more direct? While obscuring the label often gave parents the opportunity to come to terms gradually with their child's disability, might it have left them more confused as well? Parental questions around the diagnosis and prognosis were used as markers of confusion.

The distribution of parental questions during the last 10 minutes of the conference shows distinctively different patterns between the groups that did and did not receive the MR label. Parents who did not receive the MR label, as compared to those who did, indicated confusion by asking more questions about the diagnosis (7 questions versus 1) and fewer about the prognosis (2 versus 11), thereby suggesting that the label perhaps facilitated some understanding of the diagnostic category. The following examples illustrate the different levels of understanding.

The mother of Sarah, a 3-year, 7-month-old child diagnosed as borderline (no MR label), asked the following questions two minutes before the end of the conference: "Oh . . . I know one thing I wanted to ask you . . . Ahm . . . you hear so much today about learning disabilities . . . Does she fall under any kind of category of that?" The question suggests that Sarah's mother did not fully comprehend the basic nature of the category and criteria for inclusion in the borderline diagnosis and still requires clarification of a category.

Parents in the non-MR group often indirectly revealed their limited understanding of the implications of the professionals' words. In the feedback session for Mary, a 3-year, 6-month-old child functioning at a mental age of 2 years, 6 months (no MR label), the mother had been told that Mary had "delayed behavior" and "developmental lags." Thirty-two minutes into the conference, she asked, "Yes, I realize there's lags . . . But what does that mean? What do lags mean . . . to parents?" Here again the mother shows confusion regarding the essential diagnosis.

However, when parents were presented with a recognizable diagnostic entity like "mental retardation," they seemed to be able to proceed with questions concerning the child's future level of functioning, that is, his prognosis. One father asked, "Is there a chance for him to catch up . . .?" and later, again, "But you really really right now don't know which way he's going to go. If he can catch up or—."

Parents, sensing the closure of the conference, appear to feel more urgency to get their most pressing informational needs met. Those who already had a clear sense of the diagnosis, as was the case in the MR labeled group, addressed their concerns regarding prognosis. However, parents who continued to have an ambiguous or vague sense of the diagnosis (the unlabeled non-MR group), were intent on clarification of the diagnostic category before the session ended. They could not address potential concerns about the prognosis. Often, the very questions themselves revealed parental confusion about the nature and extent of their child's diagnosis.

**Discussion**

In this nonrandom sample of 10 feedback sessions, in which the task was to impart a diagnosis of developmental problems to parents of preschool children, we found support for the proposition that interpretations are forged through the interaction of participants and are not "given" by professionals to parents. As in previous studies (Svarstad & Lipton, 1977), we also found that professionals shy away from direct assertions that a child is mentally retarded. Their vagueness leaves a large contested territory over which both parties can lay claims and counterclaims. By the conclusion of the feedback interview, parents leave with information that has been heavily reworked and reformulated. Although much has been said in the literature about the asymmetrical power of professionals (McIntosh, 1974; Waitzkin & Stoeckle, 1976), we found that
professionals were constrained to adjust their behavior to the other side's "place" vis-à-vis the news. Adjusting what is said to accommodate the distance between a professional's and a parent's point of view, modifying the label to conform to parental wishes, and modulating levels of optimism and pessimism are ways in which the professionals limited their authority over the transaction.

The negotiations around pessimism and optimism, as we have seen, see-sawed in both directions, but there was a preponderance of reversals on the part of professionals. We suggest this stems from the compelling desire of the professionals to move parents from their extreme positions—both pessimistic and optimistic—to one that more closely approximates the child's reality. At the same time that professionals are nudging the parents toward reality, they are also, by negotiating optimism and pessimism, trying to limit the injury, rally the parents' spirits, and affiliate themselves sympathetically with the parents. Thus, the negotiation around pessimism/optimism serves two purposes: it presses the diagnosis and prognosis forward, while it keeps parents at a level of tolerable comfort.

The interpretation of MR in a young child presents extremely difficult problems. Professionals steer away from using the term because of genuine uncertainty (Booth, 1978; Goodman & Cecil, 1987), because of its grievous impact (Behrman & Vaughan, 1987), and because it is subject to wide misunderstanding (Boyle, 1975; Ley, 1982; Meehan, 1985; Schuy, 1983). Parents are likely to have prototypical images of a mentally retarded person and these images usually are at the lower end of what professionals recognize as a continuum of retardation (Goodman & Cecil, 1987). Professionals tend to solve the double bind—using the proper term poses the risk of misrepresentation, avoiding the label poses the risk of sustaining parental naivete—by restricting their use of the MR label to children at the lower end of the scale (around IQ 50 or below) who fit the prototype (Goodman & Cecil, 1987) or to children whose condition is clear, such as Down's syndrome (Gilmore & Oates, 1977; Lynch & Staloch, 1988; Quine & Pahl, 1986; Quine & Rutter, 1994; Shiono & Kadowaki, 1979; Svarstad & Lipton, 1977). But parents may not welcome the avoidance of labels; they are frequently dissatisfied with delays and evasiveness in diagnostic feedback sessions (Abramson, Gravink, Abramson, & Sommers, 1977; Quine & Pahl, 1986; Quine & Rutter, 1994).

This is a genuine dilemma. Even though research suggests that "IQ" is quite stable in children with MR from the early preschool years, and that the likelihood of children once diagnosed as retarded remaining so is approximately 75% to 80% (Goodman, 1990; Goodman & Cameron, 1978), one never can be certain in an individual case. Erring on the side of optimism, rather than pessimism, is the clear choice, particularly when one anticipates a refinement of judgment through further evaluations over multiple years. On the other hand, ambiguous labels may make it difficult for parents to discover what professionals are saying, and for them to organize their own responses. In particular, the term "developmental delay," without clarification, is likely to suggest the probability of "catch-up." Withholding a label "to protect" parents may not do justice to their need for complete information and for responsible planning. Parental confusion may inhibit acceptance of and accommodation to their child's needs.

It may be helpful for professionals preparing to tell parents bad news to invite a process of negotiation over the label, that is, to view negotiation as a strategy of choice, an opportunity for initial family adjustment. Renaming and refining a condition gives parents some sense of mastery and control, as well as a "face" with which to manage themselves in public under their new circumstances. Putting the label on the table tentatively, without making it a final judgment, allows parents to resist or consider a known target.

We recognize the preliminary and restricted nature of these findings derived from a particular hospital culture and the professional routines established in response to that culture. Whether the suggested interpretations are applicable to other settings or to diagnostic teams requires further inquiry through systematic controlled hypothesis testing with larger and more representative samples. The two large questions from this study are whether the "sting" is removed from labels when they are subjected to a negotiating process and whether such opportunities are helpful to parents.

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References


Frankel, R. M. (1984). From sentence to sequence: Understanding the medical encounter through microinteractional analysis. Discourse Process, 7 (Special Issue: Physicians and patients in social interaction: Medical encounters as a discourse process), 135-170.


Isbell, L. (1979). He looked the way a baby should look. In T. Dougan, L. Isbell, & P. Vyas (Eds.), We have been there (pp. 19-24). Nashville, TN: Abingdon Press.


Svarstad, B. L., & Lipton, H. L. (1977). Informing parents about mental retardation: A study of professional communication and parent acceptance. Social Science and Medicine, 11, 645-651.
