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The Forest or the Trees?

"Gross global brain damage with severe mental retardation." What more was there to say? "Gross global brain damage with severe mental retardation." The summary words of Dr. Wilmington's diagnosis rang through my ears like a death knell for Melanie. I was devastated and disbelieving. They could not be right, for her intelligence communicated itself to me at every turn. They could not be right because she had learned too quickly all the things I had tried to teach her. They could not be right because her eyes told me they were wrong. They could not, please God, be right because if they were, she would live a life so limited as to be almost useless. They could not be right because she was *my child!*

How does a mother tread the fine line between what she sees and what she wants to see in her child? Where are the strengths and where are the weaknesses of the objective view of the outsider, as compared with the subjective view of the mother?

I believe that the mother's advantage is that of intimacy, which allows her a depth of perception unavailable to an outsider. I knew, for example, that Melanie's difficulty in focusing her eyes often made her appear to be turning away from people when she was in fact trying to look at them. With the advantage of intimacy, I knew also that the little squeal that others might interpret as a cry was Melanie's version of a laugh. I knew that flared nostrils followed by a little yawn meant that she was emptying her bladder.

But the mother's intimacy may also be a disadvantage. That intimacy made it impossible for me to see Melanie for the first time—to see her in her totality as a functioning individual who exists in the present and who compares in any given way to other individuals.

Such intimate knowledge of my child, and in this I am no different from other mothers, made it difficult for me to see her objectively at any point in time. How easy it is for a stranger to say of a child, "This child is spoilt and throws tantrums," "This child is cooperative," "This child is bright," "This child is retarded." Easy because a stranger meets the child on a given occasion and forms an overall impression—an impression that may be valid but is one dimensional.

The mother, knowing every stage that has contributed to the present entity, sees at once the present, past, and hopeful future and, in genuine confusion, replies, "Ah! Do you think so? Well, but, you see . . ." Like the seasoned hunter, she cannot see the forest for the trees; she knows by touch each contour of the land but has no aerial view.

To me, it did not matter that from an aerial view the parts of Melanie's personal jigsaw puzzle did not integrate to form an impressive overall picture. What I knew was each part, by detail of color, shape, and texture. What the objective observers seemed to be looking for was the overall impression—the gestalt presented by Melanie's ill-fitting and poorly coordinated parts.

They observed, for example, that her comprehension of language appeared to be way ahead of all other areas of her development. Indeed, they made a point of commenting on this incongruity between her receptive language and her overall functioning. But they simply could not accept that such a mismatch could be true and attributed her comprehension to intensive repetitive drill on my part and consequent rote learning by Melanie. By *rote learning*, they meant learning that can only be applied within the narrow limits in which the lesson took place. In rote learning, there is no ability to transfer knowledge or apply it in new situations because it is learning that is mechanical rather than creative in nature, and is largely limited to the context in which it was first acquired. According to this view, Melanie's comprehension of language was, in the psychologist's words, a not very meaningful "splinter development."

What effect did this devastating judgment by these professionals have upon me and my view of Melanie?

I wish I could say that their words were only barely influential, that I knew I could retain my own opinion in spite of theirs. But I cannot. In spite of my own experience and observations, I was vastly influenced and depressed by these pronouncements. I think, in the long run, after my initial shock and astonishment, I gradually worked my way to a feeling something like this: I was not convinced that they were right that Melanie had so little potential for intellectual development. But I decided to face the fact that obviously she *functioned* as someone with severe disabilities regardless of what potential she might possess; and after all, how can one consider or describe potential in isolation from a person's performance? The fact was she performed at the level of a person with severe developmental disabilities.

But the corollary to this of course would be, what then? Should I alter my expectations and thus, probably, my efforts and objectives to be more in tune with this terrible diagnosis? I believe that I could not help altering my expectations to some extent. I pride myself on being a realist who manages to cope reasonably well with crises because I take care to prepare myself by accepting whatever appears to be factual. I think I have considerable faith in my own judgment under normal circumstances, but I also have great respect for experience and training. It would have been very difficult for me to maintain my optimism without some encouragement from professional quarters.

Fortunately, I did receive *some* encouragement. Sarah, Melanie's most admiring therapist, was convinced that her colleagues were wrong. She insisted, with no reservations, that Melanie behaved like an intelligent child severely affected by

athetoid cerebral palsy, affecting all her muscular coordination including facial expression and speech. She lectured me severely on allowing myself to be influenced in my approach and insisted that I must aim as high as possible for Melanie and at all times expect comprehension. She reminded me of Dr. Karen Pape's explanation of how difficult it would be for whatever intelligence Melanie might have to break through the barriers of severe brain stem and cerebellar damage, and we regretted that Dr. Pape was away in England at that time.

Like Dr. Challenor and my friend Pat at Blythedale Hospital the year before, Sarah recommended Bobath physical therapy as the most important treatment for Melanie, an approach in which a child is repeatedly put through all the normal developmental patterns of movement in the correct sequence in an attempt to diminish the abnormal reflexes of the child with cerebral palsy and to teach the child to exercise conscious control over her muscles. I doubted very much that I would find such a therapist in Trinidad but was determined to continue practicing what principles I had already learned from the OCCC staff and from Sarah.

I have said that I was depressed and discouraged by the assessment that June. Yet I knew that I could never choose to do less than my best for Melanie. Her welfare and development had become the object of my life, and my own satisfaction and sense of personal well-being were now inextricably bound to hers. If I could work successfully with her, accepting her limitations but providing every possible opportunity for her development, then I would be successful in my own eyes and could live happily with myself and with her.