

October 2019

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Recommended Citation

Baxter, D. (2019). An Open Letter to Those who Counsel Parents of the Handicapped. *JADARA*, 10(4). Retrieved from <https://repository.wcsu.edu/jadara/vol10/iss4/5>

AN OPEN LETTER TO THOSE WHO COUNSEL PARENTS OF THE HANDICAPPED

Dorothy Baxter

Dear Counselor:

Shortly after sunrise, on October 25, 1953, my third child and second daughter, Laura Diane, was born. It was an easy and uncomplicated birth, and Laurie was a "perfect" baby, a chubby 8 lbs. 10 oz., with large violet eyes and a crown of pale blond peach fuzz. Eagerly awaiting the news of her birth were Daddy, a teacher in a small New English college, big sister Susie, almost four, big brother Jeff, two and a half, and an assortment of fond relatives in Connecticut and New York. Jeff was sure to be particularly pleased, since he was the only one who had known positively that the new baby would be a girl! Just a month previously, he had put his ear to my tummy and solemnly pronounced, "Her's walking round in there. Her say, 'hi, Deffie.'"

After a brief look at my new daughter, long enough to marvel at her tiny perfection and sweetness, I was wheeled back to my room. A thoughtful nurse brought me a cup of coffee and I lay back against the propped pillows, sipping coffee and looking out the bedside window at the colorful remnants of the sunrise, awaiting my husband's visit. I knew even before he arrived that he would be as happy as I. Of the two of us, he was the worrier throughout each pregnancy. Somehow he was never quite able to believe that everything would be all right with the baby until it arrived. Just a few weeks earlier, a close friend of ours had been delivered of her third child. The baby had been born hideously deformed and had lived just a few hours. We had not talked about it much, except to express our sympathy and sorrow, but I knew that he had been doubly concerned ever since, and must even at that moment be experiencing a tremendous sense of relief and joy.

Mrs. Baxter is the mother of a deaf woman.

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Yes, truly, at that moment “my cup runneth over.” There have been many happy times in my life since, but I cannot remember any with any more clarity than that morning, now more than twenty-two years ago.

The next three months raced by. Halloween, Thanksgiving, the first snowfall, the annual party at Susie’s nursery school, and the excitement of Christmas. It was the first Christmas in which Susie and Jeff were really old enough to participate and we had the added fun of an unexpected visit from my father and step-mother. One of my favorite snapshots from that Christmas day is a picture of my father holding baby Laurie on his lap, with Jeff and Susie cuddled close at either side. Another is of me holding Laurie. She is on my lap, facing me, and we are smiling at one another.

At her three month check-up Laurie weighed in at just under 15 lbs. She was a happy, contented baby who ate and slept well, laughed and cooed delightedly and responsively, and who could almost, but not quite, turn over by herself. I was not as good about keeping up her baby book as I had been with the first two, but whenever I did make an entry I could see that, developmentally, she was a good two or three weeks ahead of her brother and sister at the same age. I can remember leaving the doctor’s office that day feeling like a very successful young woman. I had a happy husband, three bright and beautiful children, and a life very much like the one I had fantasized for myself when I was in my early teens. What more could I possibly want?

Just two weeks later, Laurie’s little life and world, and with it mine, fell completely and totally apart. Like Humpty Dumpty, the perfect egg smashed, and not all the king’s horses or all the king’s men were ever able to put it totally together again. Even to this day, the vibrations from that crash continue to affect all of Laurie’s family, including two more sisters and another brother who were at that time still unborn. Laurie, of course, was the one most cruelly hurt.

At three and a half months of age, Laurie lay on an ice filled mattress in the pediatric unit of the state’s leading hospital, fighting a temperature that kept climbing over 105 and a raging meningitis of such rare type that it took experts six weeks to diagnose. She finally came home from the hospital at seven months, weighing less than 11 lbs. She had survived two craniotomies to remove a sub-dural membrane that had formed over her brain as well as a massive sub-dural hematoma that had developed between operations, and a salmonella meningitis, a form of meningitis so rare that her doctor could only find 120 recorded cases, all of which had been fatal. Once a plump and rosy baby, she looked like a victim of a concentration camp. It took literally hours of patient rocking and cuddling to coax a bit of a smile from her. But she had survived, a miracle of such proportions that we were all pathetically grateful. At that moment I thought all that was needed was lots of tender, loving care, and soon my beautiful baby would be strong and well and the nightmare of her illness would be forever behind us.

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What I didn't know, but would find out bit by bit over the coming years, was that Laurie had been left deaf, epileptic, brain-damaged, and potentially so scarred emotionally that by the time she was twenty-one she would have a full-blown psychotic episode that indicated schizophrenia and possible life-time institutionalization. Thankfully, that horror has to date been avoided. For the last year she has been receiving Mellaril, vitamins, and once-a-week therapy from a dedicated and talented psychologist who is himself hard-of-hearing. She is in job-training at Goodwill Industries, and so far her progress has been good enough to allow for hope that within the next year or two she will be able to evolve a reasonably happy and self-sufficient life.

Those years from then to now could fill a book, and perhaps someday I will write it all down as well as I can remember it. Laurie's life has been extremely hard for her, and I feel strongly that someone should attempt to articulate for her all that she cannot. However, that is not my purpose in this piece. Here I want to be selfish enough to talk about *me* and how I have been affected by what has happened to Laurie. More specifically, I want to talk to all of you who will perhaps someday find yourselves in the position of having to counsel parents of children with problems similar to Laurie's.

Over the years, I have met many of you—doctors, teachers, psychologists, social workers, etc.—and each of you has had a far more profound effect on me than you probably realized. I took all of your words to heart, since you were the “experts” and presumably knew far more than I. Some of your advice and counsel was excellent, and for that I am and always was profoundly grateful. Those of you who were empathic, who admitted you didn't have all the answers, who helped me to find other sources of help, you know who you are. I came back to you again and again, and together we searched for answers. Even though we weren't always able to find them. I knew how much you cared and how hard you, too, were trying.

It is to some of the rest of you that I address this, those of you who evidenced what I have come to think of as tunnel vision. Wrapped up in your own special areas, you never troubled to look at the larger picture. I know what I am going to say will strike some of you as unnecessarily harsh and highly subjective. I *am* going to speak subjectively. I freely admit that even before I begin. I have spent many hours this last year looking back over Laurie's life and the part I have played in it. Our lives have become so intertwined that in ways we might be called “Laurieandme” as though we had become one person instead of two. I realize that I must assume ultimate responsibility for the way I reacted to Laurie's multiple problems, but I am equally aware that if you had taken the time and trouble to find out more about me and my particular emotional make-up and coping mechanisms, some of our problems might have been avoided.

For example, do you remember, Mrs. A., when my husband and I first visited your school? Recommended as one of the finest oral schools for the

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deaf in the country, we were reluctantly convinced that it was in Laurie's best interest to send her to school as a residential pupil by her third birthday. Instead of probing long enough to discover that I was still agonizing over what part, if any, I might have played in Laurie's illness (Had her bottles been sterile enough? Was any of her baby food spoiled?), or letting me verbalize about how hard it had been to have her in the hospital for so long, or getting me to admit that in some ways I wanted to send her to school so that I wouldn't have to be watching her every minute and could have some relaxed time with my other children, instead of finding out anything about where I was at that point, you took a very brief history, concentrating on her deafness, and then proceeded to "sell" me your school. You paraded out three of your prize pupils, girls whose speech was so good and whose lip-reading abilities were so developed that it would be hard for the average person to know they were deaf. The inference was clear: Send Laurie here and in just a few years it will hardly matter that she is deaf. And so we enrolled her.

And you, Miss B. You were the counselor on Laurie's floor. You were the one who insisted I cut Laurie's curls because it was "too hard" to comb her hair each morning. You also spent a lot of time telling me how important it was that Laurie know how much she was missed at home so she wouldn't feel rejected. Your motives were good, because unfortunately there were and still are many handicapped children who get so much abuse at home that they prefer school to home. But you didn't seem at all aware of how much I resented having someone else "mother" my child all week, or of how hard it was to send her away every Monday, or of the twinges of guilt I felt when I relaxed after each strenuous weekend with her. Very mixed emotions on my part, and I admit now that I didn't show them. Instead I bent over backward to be a "good" mother and hopefully win the school's approval for the way I dutifully followed each instruction.

And you, Dr. C. You were the first neurologist to examine Laurie. She was sent to you by the school psychologist after I had told him of the difficult time I had handling Laurie's compulsiveness and contrariness. After you examined her, and before you had an EEG done, you gave me a stern lecture to the effect that you couldn't see much wrong and that it was evident that I had "spoiled" her. Later, after the results of the EEG were back, you did have the grace to call and tender an apology of sorts. You said the EEG showed great abnormalities, and that it was thanks to the astuteness of the school psychologist that it was done, because on the basis of the evidence you would never have ordered it. You ordered medication, and it did help somewhat, but I had a hard time handling your initial reaction. Should I now be glad that Laurie did, indeed, have neurological problems that affected her behavior, and it wasn't because I had been a poor mother and "spoiled" her?

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And the next year, when we decided it would be better to have Laurie live at home and attend a closer school as a day pupil, even though it was not an "oral" school. Do you remember me, Dr. D.? You were the psychologist at the new school. Before the fall term started, Laurie had attended the neighborhood summer play school with her younger sister. She kept bringing home pictures of herself that she had drawn while the others were listening to the record player at quiet time. In every picture, Laurie had no arms. This concerned me, and I asked to meet you as soon as school started and told you about the pictures. You said you would see Laurie and would report back to me. Do you remember what you told me? I can't quote you exactly at this late date, but I remember the gist of what you said vividly. You said that when the child draws herself, she is really drawing the mother, and the lack of arms indicated that Laurie did not see me as loving her. You didn't ask me anything about myself or my feelings. You never suggested that it was a topic we might explore further. It apparently never occurred to you that the drawings might, just might, indicate some of Laurie's intense reaction to her oral training, where hands and sign language were a severe "no-no", even though a natural form of expression for the deaf. I had been told time and time again that I should never let her attempt to sign because then she wouldn't work hard enough at being oral. All my brief exposure to you did, Dr. D., was cause me to introspect even further, and to feel extremely guilty every time I had a negative or hostile feeling toward Laurie. My other children could on occasion, scream "I hate you" or "You don't love me" and it didn't bother me, because they knew and I knew that we had a strong, loving relationship. But you were a psychologist, one of those mysterious people with the ability to "know" what people really thought. If you said Laurie didn't think I loved her, and if sometimes I didn't feel very loving, then it must be that my negative feelings were damaging her and I had better quash them.

And, so I quashed them. I went conscientiously to every parents' meeting at the school. I read everything I could about deafness. I tried very hard to explain everything to Laurie, not wanting her to feel left out or confused about what was happening around her. I had been her first teacher, back when she was only 20 months old and she was enrolled in the John Tracy Correspondence course for deaf children. We had worked together several hours every day for the year before she started school, and so far as was possible, I tried to be aware whenever talking to her of the tremendous handicap of deafness. By the time she was nine or ten, I had done such a "good" job of it that I had become her major link with the hearing world. She could read my lips almost perfectly, and whenever she was confused about anything or wanted to communicate something to someone else who wasn't able to understand her, she turned to me as a translator.

During those pre-puberty years, it worried me that Laurie was not anywhere near as outgoing as her deaf classmates. I had tried enrolling her in

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Girl Scouts and a bowling club, and encouraged her classmates to visit frequently. She was not interested, and wouldn't participate in any school activities, except very reluctantly, preferring to cling to me.

Do you remember the day, Mrs. H., when I visited Laurie's classroom so that I could get some idea for myself of how she was functioning? You had been her teacher for two years, and you had been complaining that she wasn't "working to capacity" and wouldn't make friends with the others. You had a picture on the board, a telephone company ad showing a night-time scene in a deserted parking lot. A woman's car was obviously disabled with the hood up, and the woman was standing in a lighted phone booth, obviously making a call for help. The children had made up a story about the picture, up to the point of the phone call. Each child in the class went to the board to write his own last sentence to the story. All of the children except Laurie wrote something to the effect that the man from the garage came and fixed the lady's car. Laurie wrote, "The lady could never get out of the phone booth."

Laurie's sentence didn't seem to shock you, but it terrified me. The next day I started making inquiries about where she could get some help. The school psychologist had no time for her, and the best we could do was a local psychiatrist who had done some work with the deaf. For almost eight months I took Laurie to his office once a week. The fee was very high, and with five other children to look after, the time spent each Saturday became a burden on the whole family. But if it helped, we felt it more than worth it. Do you remember us, Dr. J.? You saw my husband and me once, and saw me for a few minutes alone on another visit. I tried to tell you that my husband still couldn't even talk about Laurie's deafness, and never went with me to any of the school meetings, etc., and that I was feeling exhausted by it all. Your answer was just a vague directive to me to the effect I should "relax" and, to my knowledge, for the next eight months you sat in your office for an hour each week and listened to Laurie recite a poem she had memorized about a turtle. Maybe more took place, I don't know, but that is all I ever learned about it. Nothing changed in Laurie's life at school or at home, except that she seemed to be more isolated from others, more clinging, and more "crazy." Finally we dropped the "therapy" and you seemed perfectly happy with our decision.

And you, Mrs. R. Do you remember the summer when Laurie was 12 and we decided to send her to your camp for a month? A former teacher of the deaf, you ran the only camp we knew of for deaf children. You had a reputation for running a fine camp, and we packed Laurie up and sent her off with high hopes that she would have a rewarding experience. Some of her classmates were also going, and Laurie seemed at first to be enthusiastic. Do you remember the visiting day two weeks later? Laurie met us in tears and begged us to take her home. She said the cabin was too dark at night, she had fallen out of bed one night after wetting the bed, and that the other

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children had hit her and laughed at her. You became very defensive when we asked if the children were alone at night. You said they managed fine and that a guard checked them several times during the night. Laurie was just babyish and poorly adjusted. And so we took her home with us.

It was only a few weeks later that I was awakened during the night by strange noises from Laurie's room and found her having a grand mal seizure. She convulsed repeatedly during the night while we made frantic calls to the pediatrician. A year earlier, the neurologist had discontinued her medication, reasoning that she had never had an observable seizure and it probably wasn't doing her much good anyway. Belatedly, we realized that she must have had a seizure at the camp, and of course it had frightened the other children as well as Laurie. Because they were all deaf, and no adult had been around, no one really had known what had happened.

It was six months before the seizures were under control. I had started back to college a year before, hoping to continue my education and fill my head with something besides Dr. Spock, the PTA, and the problems of deafness. Now I had to quit school and concentrate on Laurie's new problem. She would have to come first. I resented it bitterly, but I never dared say so. It had been the first time in 16 years that I had been doing something solely for myself. Looking back, I guess I felt as though I was being punished for being so "selfish."

The next five years were all pretty much alike, as far as Laurie's experiences were concerned. We moved to another state and enrolled her in another residential oral school. She didn't want to go, but the younger children needed far more of me than I was able to give when Laurie was home. Do you remember her, Mrs. Y.? Every time we spoke you complained that Laurie would never do anything with the other girls. You told me that I had probably over-protected her and I should urge her to be more social. Didn't you ever believe me when I told you how hard I was trying? Somehow I don't think you ever began to understand until you had tried for a year, finally giving up in despair when Laurie flatly refused to attend the school dance. The night of the prom, Laurie stood outside the gym in her bathrobe, looking in at the others all dressed in party clothes and having a fine time. I think that was probably the first time you sensed the sadness and despair and feelings of failure that I had been carrying for so long.

Well, dear counselor, the above doesn't begin to cover it, but I hope that you have gained something from what I have said. The next time you are faced with a handicapped child and his or her family, don't be so ready to make judgments. If the child has only one visible handicap, don't automatically assume that that is all you have to deal with. If a parent comes across as very verbal and competent, don't assume that they have everything under control, or that they are cold and unfeeling. Listen for the little clues that tell you that the intellectualizing is their way of handling feelings that are too painful to surface easily. Don't be easily misled if the child is

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pretty and has a winning smile and seems very docile in your presence. Listen, really listen, to what the parents tell you about the child at home. And, perhaps most importantly of all, help parents to admit to feelings of grief, and shame, and anger, and tiredness, and despair. If you do that, you will not only help parents to seek the fulfillment of their own personal lives, but you will have helped immeasurably to make the child's personal burden much lighter.