

THE VIEW FROM "THE COUCH"

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A MAGAZINE article on Dr. Bettelheim's (1967) latest book was shown to me, since my son was once an "empty fortress". The reporter's first paragraph was as biting as a Wisconsin blizzard. "For the withdrawn and psychotic child, the yellow door (of the Orthogenic School) is their first experience with warmth and brightness." (1967, p. 70-71.)

Dr. Bettelheim's own words proved to be no more comforting. "The precipitating factor in infantile autism is the parent's wish that his child should not exist." (p. 125.)

I am willing to take Dr. Bettelheim's word that he has seen parents who wish that their child should not exist, or mothers like the one who told him that she "thought of him (her son) as a thing rather than a person" (p. 138), but in the 7 years that I have been active in a parent group for emotionally disturbed children, I have met no such parent. The parents in our organization are no different from the parents of normal children. In fact, with the exception of the cases where the disturbed child is an only child, they are the parents of normal children too. And their side of the story should be heard. Behaviour disorders are symptoms, and there may be a variety of causes. A's headache may be due to eyestrain, B's to a difficult boss, C's to a brain tumor.

My case study is necessarily limited to one, because it is only my own story that I know intimately.

To us, Peter our first born, was an unfolding miracle. He was our chance to see the world through a fresh pair of eyes, a reality to the oneness of our marriage, our vote of confidence in the future. But most of all he was himself, a new personality to be cherished.

He was a golden child, so handsome he might have been a girl. So agile—he scared his grandmothers green when he jumped from chair to couch to coffee table. And smart! We delighted in telling how he had outwitted us when he was so young that he could do little more than scoot around on his fat bottom. He loved to pull the plug from our old-fashioned bathtub and watch the water swirl down the drain. In order to bathe him before we lost all the water, we turned him to face the other end of the tub. After a few puzzled moments, he turned himself around and triumphantly pulled the plug. We bought a rubber mat to cover it, but again he quickly located the plug.

Peter nursed eagerly, sat and walked at the expected ages. Yet some of his behaviour made us vaguely uneasy. He never put anything in his mouth. Not his fingers nor his toys—nothing. This seemed like an odd complaint to my germ-

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conscious friends, but my husband and I had grown up in large families and looked at the germ theory with some scepticism.

More troubling was the fact that Peter didn't look at us, or smile, and wouldn't play the games that seemed as much a part of babyhood as diapers. While he didn't cry, he rarely laughed, and when he did, it was at things that didn't seem funny to us. He didn't cuddle, but sat upright in my lap, even when I rocked him. But children differ and we were content to let Peter be himself. We thought it hilarious when my brother, visiting us when Peter was 8 months old, observed that "that kid has no social instincts, whatsoever". Although Peter was a first child, he was not isolated. I frequently put him in his playpen in front of the house, where the school children stopped to play with him as they passed. He ignored them too.

It was Kitty, a personality kid, born 2 years later, whose responsiveness emphasized the degree of Peter's difference. When I went into her room for the late feeding, her little head bobbed up and she greeted me with a smile that reached from her head to her toes. And the realization of that difference chilled me more than the wintry bedroom.

Peter's babbling had not turned into speech by the time he was three. His play was solitary and repetitious. He tore paper into long thin strips, bushelbaskets of it every day. He spun the lids from my canning jars and became upset if we tried to divert him. Only rarely could I catch his eye, and then saw his focus change from me to the reflection in my glasses. It was like trying to pick up mercury with chopsticks.

His adventures into our suburban neighbourhood had been unhappy. He had disregarded the universal rule that sand is to be kept in sand-boxes, and the children themselves had punished him. He walked around a sad and solitary figure, always carrying a toy aeroplane, a toy he never played with. At that time, I had not heard the word that was to dominate our lives, to hover over every conversation, to sit through every meal beside us. That word was autism.

I took my worries to our pediatrician, as I had earlier, when my complaints were too nebulous for him to take seriously. He did a few rough tests, and said that he didn't think Peter was retarded, but that he might be deaf. Deafness could account for his inattention, lack of speech and unhappiness. True, Peter paid no attention to what we said, but he could locate an aeroplane before we were aware of its approach. And he could pick out any note on the piano that my husband played on his violin. Perhaps his deafness was in a high range, which would make speech unintelligible, even though he could hear sound. So we took Peter to an otologist, who too thought Peter might be deaf. He cleaned Peter's ears first and this frightened him so that it was impossible to check his hearing. We were told to bring him back in 6 months when the otologist would try again.

Fortunately, friends introduced us to the Tracy Course—correspondence lessons designed to help parents prepare their deaf children for speech reading. We learned that lip reading is too limited a term. Although it was soon apparent that Peter had no hearing loss, we found the Tracy lessons a godsend. For the first time, I could make sustained contact with Peter. We matched colours, pictures and objects and cross-matched them. We blew feathers to each other across a table. We made faces together in the mirror—at least I made faces. I crouched down to Peter's level so he

couldn't ignore me. We incorporated the neighbourhood children into games. They were delighted with the attention, but keeping Peter in a patterned game was like keeping a butterfly in a straight line.

On Christmas Day, after 4 months of using the Tracy materials, Peter now 3½ years old, talked for the first time. Peter was watching as my husband and a guest played a game that involved moving a button over the points of a star with the count of 1-2-3. While the adults were studying the next move, Peter picked up the button and moved it saying, "One, two, three". It was a Merry Christmas, indeed!

We also went to the university speech clinic where the students studied, taught and tested Peter. They excluded retardation, deafness and aphasia. The director referred me to a psychiatrist.

There was no doubt in her mind. "He has a childhood psychosis. A normal child would be exploring all the corners of my office." Peter was lying on the floor, staring unconcernedly into space. "It is only in the last 25 years that we have realized that these children are not retarded." Then she added consolingly, "At least, the prognosis isn't as hopeless as it used to be".

I was aghast and unbelieving, but only at first. The material the psychiatrist gave me to read was a description of Peter. What could possibly have caused a psychosis in our baby?

The only advice the psychiatrist gave me was to get Peter with other children. But he had been with other children. Our neighbourhood bulged with the post-war baby crop.

We sought help at the child guidance centre, and were assured by their approach. "We don't believe in labels. Let's just say that he is a child in trouble and we will try to help both of you."

I told my psychiatric social worker about Peter but her questions were directed to me.

How did I get along with my parents, siblings, the people at work? As well as most people, I thought.

Had I wanted the baby? Yes, I had gone through sterility studies to get pregnant.

Why had I wanted a baby? Why? I had never reasoned it out. They are a part of life, just like food, sunshine, friends and marriage.

How did I get along with my husband? Very well. She snapped to attention. "Why?" she asked, "Are you afraid to quarrel with him?" Well—we were both in our thirties. We had no serious problems and could laugh at our small differences. Years of separation by the war had made us treasure the ordinary joys of life.

How could I expect Peter to be warm when I was so cold to him? How could I be anything but cold after years of trying to warm up this icy child of mine? Even with your own son, friendship is a two-way street. We hadn't rejected Peter, he had rejected us. Even rejection was too strong a word. Peter accepted us as he did the furniture, as tools to get what he wanted. He simply didn't recognize us as people. Proving this was as difficult as proving which came first, the chicken or the egg.

I asked the psychiatric social worker for suggestions, but she had none to offer. What I did was not so important as how I felt about it. What could I read that would help me understand Peter? She could suggest no reading nor would she advise it. I sounded like a school teacher already. My use of the Tracy course was

held up as an example of my intellectual approach to motherhood. My questions as to the cause of Peter's trouble, she evaded—an eloquent answer, indeed!

I alternated between being overwhelmed with guilt, and feeling resentful at being treated like a child who couldn't face an unpleasant truth. If I could have felt that it was true, that we had been cold and dominating, or cold and indifferent parents, I think I could have faced that fact. At least I would have had something concrete to work with. Anything would have been better than that nameless, formless faceless fear. My self-confidence was fast disappearing. I was less and less able to cope with the problems each day brought. The psychiatrist said he wasn't able to reach Peter. We could see no improvement in him, so I stopped the sessions.

But today, I wonder how anyone could have expected that young, unhappy, childless divorcee who was my psychiatric social worker to help me.

Friends told us about a psychiatrist with another theory. He turned out to be a vast man with vast self-confidence, who put considerable starch into our backs. He gave us techniques which did make Peter less dependent. But after a year or so, we realized that he didn't have the whole answer either.

We consulted a neurologist next, because Peter's teacher had seen him in what might have been a seizure. We recalled too, that over a 2-yr period, Peter had stopped his play once or twice a day, saying, "Lost, lost", had lain down and slept, usually for just a couple of minutes, occasionally for 15 minutes and several times for an hour. This was unusual behaviour in a child who didn't seem to need much sleep. The neurologist thought Peter might be having frequent mild seizures which he compared to turning a light on and off in his brain, giving him a distorted picture of the world. Under medication, Peter's electroencephalogram became normal and his social behaviour improved so much that his teacher said that Peter seemed to have joined the human race. But the improvement did not last.

We felt that we had exhausted the local resources when we had a chance to consult Dr. Leo Kanner of Johns Hopkins Hospital. He said that Peter was autistic, but he added that an autistic child who talks as early as Peter did, might be able to lead a normal life, if he could get enough help. He recommended the Woods Schools at Langhorne, Pennsylvania.

Peter presented us with a challenge we couldn't ignore. He had learned to read with a minimum of help. His ability in arithmetic amazed us—he had worked out all the prime numbers to a thousand after hearing them referred to casually. He talked more now, no longer repeating tonelessly what we said. And he had straightened out his pronouns. But he had little spontaneous conversation. He had a disconcerting way of cutting through the social niceties to the pure logic of a situation. One time he asked a well-nourished aunt if she weren't too fat for dessert. Another time, after hearing a radio announcer's claims, he asked, "What does he mean, better tobacco? My science book says that the active ingredient in tobacco is nicotine and it is a poison." We tried to explain to him that nothing is so dear to us ordinary mortals as our bad habits.

Although indifferent to people, he was not afraid of them. He would go up to strangers, ask them how old they were, how much did they weigh and how much money did they have in the bank—much to the embarrassment of his parents.

How would the separation affect Peter? Wouldn't he really have cause to feel

rejected? And our daughter? Wouldn't she worry that she too might be sent away if she didn't behave? As a nurse, I could arrange my working hours during the time she would be in school, so she would not be left alone.

A residential treatment centre would be expensive, since everyone from the cleaning ladies up would have to have special training. It would take most of my husband's salary, but we thought we could manage if I went back to work. How could we live with ourselves if we didn't try? So we took our slim, handsome son to a school a thousand miles from home and left him with strangers. How desolate we felt, even though assured by my brother and his wife, who lived nearby, that they would fill in for us.

Peter spent 9 years at the Woods Schools, coming home for holidays and summers. The improvement came so gradually that we sometimes wondered if it were worth the effort needed to keep him there. But there were no satisfactory alternatives. Each year when we brought him home, we were filled with plans, high resolve, and optimism. And each fall we sent him back with a sense of failure, sadness and relief. For the job was too big for us. We underwrote psychotherapy, field trips, music lessons and orthodontia. We did not miss the luxuries we might otherwise have had, but we were saddened to see our bubbling extrovert daughter turn into a quiet, withdrawn child in the shadow of Peter's illness, and the changes it made in our lives.

For Peter too, life has been very hard. As a small boy, he had expressed his unhappiness by saying dejectedly, "out-of-tune" or "all mixed up". My mother used to say of us on our off days that we had gotten out of the wrong side of bed. Peter got out of the wrong side of bed every day and life was heart-breakingly difficult for him. When he was about 12 years old, he asked me, "What is wrong with me? I feel like a freak."

What could I say? If I said he was like everyone else, wouldn't that put the burden of his difficulties on him? If I told him that we all differ, that would be an evasion and he would know it.

How does the parent of any handicapped child explain that he has an extra burden to carry through life? It takes most of us adults a lifetime to develop a philosophy or religious outlook that enables us to live with the inequalities and suffering we see around us. And when the suffering is in your own child, you never really do accept it.

I'm not qualified to discuss the programme at the Woods Schools. It apparently gave Peter the help he needed. We, too, found support instead of blame. Peter has made a marginal adjustment, but a "near-miracle" nevertheless, according to his psychiatrist.

Peter chose his own vocation. He tunes pianos, giving them the same devotion that many teenage boys give to their cars. At present he needs help with transportation and arrangements. He does his own book-keeping. He is happy in his work and happy to be home again. We have found a programme for him, where young adults with a history of emotional difficulties meet for recreation and group therapy. I'm sure this is a factor in his continuing improvement.

So, Peter's is a success story. But couldn't this have been accomplished without so much damage to us?

Parents come to the guidance clinic with their hopes and self-confidence shattered.

Wouldn't it be possible for the counsellor to say, "We realize you have been having a hard time. Raising children is never easy and sometimes it is very hard. No parent is perfect and you must not expect yourselves to be. Neither are the circumstances of our lives perfect. Don't waste your energy in regrets and guilt. We will examine the past only so that we can improve our approach to the future.

"Often we don't know why children are troubled. Often we think that they have just learned poor patterns of behaviour. In some cases there may be brain or biochemical abnormality. Perhaps there is a combination of causes. Whatever is the reason, our job is to teach the child better ways to behave. We will try to help you understand your child and yourselves better. Perhaps we can improve your child's adjustment to the world and your adjustment to each other."

Wouldn't it be possible to talk on a personal, friendly basis to parents? When you, the counsellor sit across the desk from us, pencil in hand, unresponsive, neither praising nor condemning, not even laughing at our jokes, you set up a barrier we can't bridge. You don't really get to know us. This is not the atmosphere in which we parents can tell you what is in our hearts.

One of the boobytraps of counselling is the professional language. Not the frankly technical word, but the common word, used in a special sense. At one time, I told of some puzzling behaviour and ended, "How do you treat a child like that?" My counsellor asked me why I thought I should treat my own child. If I could have identified the shift in the meaning of the word "treat" at that time, it wouldn't have mattered. Instead, I only felt confused, discouraged, and somehow guilty.

Another problem is how to interpret the parental behaviour. Parents adapt themselves to the personality of the child, often unconsciously. What may seem like oddities in the parent may be just such an adaptation. My counsellor didn't bother to conceal the scorn in her voice when she asked me why I didn't talk like a normal person. She overheard me asking my unhappy son, "What are the words?", a phrase I had chanced on which Peter answered when he didn't answer the usual question, "What is the trouble?" A mis-shapen key that works is a big improvement over no key at all.

Working in a nursery, I have been impressed with the fact that the infinite variety in people is already obvious in the newborn. I recall vividly one child who cried constantly, even after feeding. You would have thought we had poisoned him, as his screams dominated the nursery. I asked the pediatrician about him, some months after he had gone home. "Well, you know", he drawled, "the parents are rather nervous people." It seemed obvious to me that the baby had inherited his nervous system from his parents, he had not become irritable from living with them. That type of inheritance is not questioned when the mother of a baby with a small appetite tells you that neither she nor her husband eats very much.

I never doubted the good intentions of the people who counselled me. But counselling is in its infancy and methods and attitudes can be improved. We all make well-intentioned mistakes. In our nurseries we used to give oxygen freely to premature babies. We no longer do since we have learned that it may cause blindness.

Parents want to be treated as partners in the job of helping their troubled children. It takes courage for us to come to you, admitting failure in this, the most

important job of our lives. We have read in the newspapers that there are no problem children, only problem parents. And we are worried sick. What will become of this child if we can't get help now? We need your support. We need understanding of our child. We need techniques—you can't express love for a child in a vacuum, and an autistic child's unresponsiveness does leave his parents in a vacuum. Let us not belittle parents, their observations, their abilities. Whoever else works with our children, we are their principal contacts with the world.

Perhaps I am beating a dead horse, but other parents tell me that my experience with guidance is not unique. It has taken me a long time to find the courage to speak out. We parents have much to learn from you and we want to learn it. But if you are going to teach us, you should know how we feel.

SUMMARY

The charge that the parent of an autistic child wishes "that his child should not exist" is not borne out by my experience or by what I have seen in other parents of emotionally disturbed children whom I know.

Guidance counsellors can help parents by giving them support, understanding of their child's deviant behaviour, and by giving them techniques for dealing with it, all in an atmosphere of friendly cooperation.

REFERENCES

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