On Being the "Bad" Mother of an Autistic Child

Jane Taylor McDonnell

I remember I was standing with a young teacher on the playground of a London nursery school, watching my son Paul, then three. He had already been given every medical and psychological test known at the time but was not yet diagnosed as autistic.

"He doesn't look anyone in the eye, does he?" the teacher remarked.

"No, well . . ." I began. "But he does with me . . . most of the time." Why did I bristle at this comment? Partly it was because I thought it was so unfair. His father and I had always known Paul to be an affectionate, alert, intelligent child; his was a happy temperament, we had always thought, an "easy" child, but not too easy. He was healthy, well grown, loved us and his wonderful college babysitters, was passionately interested in his books and demanded to be read to for hours each day. Furthermore, he had always been appropriate in the expression of his feelings (sadness, joy, frustration, fear).

But now in London these things were beginning to seem less important than the fact that he was having so much trouble speaking and was obviously getting more and more frustrated as a result. Slowly, a deepening anxiety was crowding out our earlier feelings of pride and joy in this wonderfully "original" child. I was almost desperate to get some kind of diagnosis for Paul and some help for his delays in learning, and I was especially vulnerable now to any implied criticism.

I thought of all this, as we watched Paul together, this teacher and I. And then she asked: "How many hours do you spend in the library every day?"

I was startled—then stunned and angry. When Paul was enrolled in

the school at the beginning of the fall, I had offered some information about all of us. We were an academic family, living for a year in London. I taught women's studies and my husband taught English at the same college. I was writing a book (trying to), and spent three or four hours in the London Library every day reading Victorian novels written by women: Harriet Martineau, Margaret Oliphant, Lady Blessington.

This teacher's questions had now gone beyond friendly interest; they seemed intrusive and unwarranted. They also seemed to be of a piece with other questions and comments made by the headmistress. Everyone in the school appeared to be preoccupied with the fact that I was leaving my child in a nursery school as I went off to a library to research a book, and with the fact that the child's father or a babysitter sometimes dropped him off at the school or picked him up after his three hours there. Did they think that because I was an English teacher, I was putting undue pressure on my child to speak, or that because I spent several hours a day in the library, I was neglecting my child?

Could I have been imagining all this? Imagining also the pursed lip, the head turned aside, the glance away from me to Paul, then uneasily back to me again? But I knew they never asked these same questions of Paul's father.

It was true, on the other hand, that Paul had several odd behaviors at this time. He was fascinated with a couple of little balls colored blue and green, part of a construction set, which he recognized as similar to two large marbles he had lost a few months before. His high-pitched delight at rediscovering "boo bah, bee bah" (blue ball, green ball) did seem to be out of all proportion to any possible importance they might have to any normal child.

Paul's other nursery school fascination was with the toilets. As soon as he arrived in school each day, he ran off to the bathrooms and started flushing each of the little toilets. He then hung his head almost down into the bowl as he listened to the sounds of the rushing water, perhaps checking for minute differences in pitch and motion. This, needless to say, was considered extremely odd behavior by all the teachers at the school.

His quirks made me anxious and confused. I wanted to defend him, to let these teachers know how wonderful he really was. At the same time I couldn't deny his developmental delays or pretend that he was learning in the same way other children did. I had a whole set of contradictory feelings about myself as well. I wanted to be reassured that I was doing a
great job, but at the same time I wanted my doubts and fears for him to be acknowledged. I wanted it both ways.

But more than anything else, of course, I wanted to be recognized as a good mother. And as a good mother, I wanted to be acknowledged as smart and well informed about children, as well as self-aware, kind, generous, energetic, resourceful, relaxed, and funny! I wanted desperately to believe that all my years in graduate school and in the classroom teaching had prepared me to be a better mother, not a crippled one. I did not want to think that the sensitivity and awareness developed through literature was in any way different from that used directly with people. In my great plans for myself it was all supposed to be of one piece: raising children, writing books, and teaching students. I wanted my life to be full of all these riches, and I had always been deeply resentful of any attempts to make women choose between children and work.

So now, in this London nursery school, I felt that my deepest self was being attacked. I thought of the time when the headmistress suggested I talk to the mother of a little boy who was deaf. “She’s such a sensible Mum,” she had pointed out to me. “She has really devoted herself to that child.” This mother had spent the first three months at the nursery school with her child. She came every morning with him and stayed the whole time, I was told, “until he was completely used to the school.”

I resisted the headmistress and the other teachers in the school, but still the nagging doubts were there, the tiny pinpricks of poisonous anxiety. And in the meantime, Paul was getting worse, much worse, in his school behavior, becoming more and more wild. I tried sitting with him in the circle of the children on the floor as they sang songs or played clapping games. He twisted sharply away from them now, something he had not done before. If another child approached, he simply ran away. More and more he was locked into his obsessions: flushing toilets, arranging little colored balls, flicking light switches, searching for a screwdriver to take things apart.

Six months before this, we had gone to Paul’s pediatrician in Minneapolis and asked that he be tested because of his speech delay. The doctor had been alarmed. Here was a beautiful, healthy child who seemed so normal in every way—except for a puzzling lack of speech and a certain withdrawal from human contact.

The doctor suggested that I read Dibs in Search of Self, the story of a bright but speechless child who had been rejected by his surgeon mother, and who had withdrawn into his own little world until a loving teacher rescued him. I had already read the book and was stunned by the doctor’s suggestion that there was a message for me in those pages. The book had suggested that mothers (otherwise well-meaning, intelligent, kind women) had the power to deprive their children of a sense of self, to destroy them at their very core, to kill their “souls,” as people a generation or two ago might have put it. It attributed an awesome power to the mother, and it was a power to harm, but not to heal. It seemed that professional help was called for in restoring children to a healthy sense of self.

My reading of Dibs had led me to other books about disturbed children, and I had discovered that the worst mother in twentieth-century psychological literature is quite possibly the mother of the autistic or schizophrenic child. These two conditions, now widely accepted as neurological (autism) or biochemical (schizophrenia) in origin, were once conflated, and both were thought to be psychogenic, caused by bad mothers. Possibly the most extreme case made against such mothers, but also one of the most widely read and highly influential, was Bruno Bettelheim’s The Empty Fortress: Infantile Autism and the Birth of the Self, where the author argued that autism was caused by the cruelly rejecting mother. This mother, in fact, was similar—in her complete disregard for the welfare and even the humanity of her child—to the SS guards of concentration camps. Here is a passage from the beginning of the book:

In the German concentration camps I witnessed with utter disbelief the nonreacting of certain prisoners to this most cruel experience. I did not know and would not have believed that I would observe similar behavior in the most benign of therapeutic environments [Bettelheim’s Orthogenic School in Chicago], because of what children had experienced in the past [at home with their mothers].

Bettelheim, who had himself suffered imprisonment in Dachau and Buchenwald, goes on to draw a sustained analogy between the behaviors of the kind of prisoner who became mentally ill under those conditions and the well-known behaviors of the autistic child. He notes that the prisoners often expressed a sense of rage at any change in their immediate environment, just as autistic children rigidly insist on sameness. Mutism in the prisoner and in the autistic child are both traced to pervasive feelings of helplessness and hopelessness, in the child’s case to the mother’s withdrawal of the breast. The prisoner’s “nearly continuous daydreaming was a close parallel to the self-stimulation of autistic children.
The purpose, in each case, was to blot out recognition of an immediate threatening reality. Both often show a strange insensitivity to pain. Both carry their bodies in a similar way and often have a shuffling gait. They might both be emotionally depleted to the point of "catatonia," "melancholic depression," complete "loss of memory," or "disregard of reality." Gaze avoidance is similar in both the autistic child and the prisoner. Bettelheim argues that "the averted gaze of autistic children, their looking vaguely in the distance without seeming to see, and their concentration on things close at hand when there is nothing to see but their own twiddling fingers... is essentially the same phenomenon as the prisoner's averted gaze... Both behaviors result from the conviction that it is not safe to let others see one observing."

Finally, even the mental skills which autistic children often show are discredited, labeled as essentially disturbed behavior. "If another parallel were needed, the often remarked-upon autistic repetition of 'empty' rote learning, lists of names or dates, and the like seems to include some of the same reasons why prisoners favored similar activities: to prove to themselves that they had not lost their minds... even though they could not use (them) to better their fate."

Bettelheim concludes this introductory passage to The Empty Fortress by disavowing any further analogy between the SS guards and mothers of autistic children, but he does so in a very surprising way:

Here I wish to stress again the essential difference between the plight of these prisoners and the conditions that lead to autism and schizophrenia in children: namely that the children never had a chance to develop much of a personality. Thus, to develop childhood schizophrenia it is enough that the infant be convinced that his life is run by insensitive, irrational powers that have absolute control of his life and death.

In other words, the only real difference between the SS guard and the mother of the autistic child is that the mother gets to the child much earlier in life. She is in the unique position of being able to damage him (I say "him" because autism is much more common in boys than in girls) before he has even had a chance to develop a personality. Some prisoners, as Bettelheim well knew, were able to resist the destructive forces on their personalities and to carry on later in life, after liberation, with a traumatized, but essentially intact, mind and spirit. The autistic child never will have such a chance.

One of the most interesting things about Bettelheim's argument is that the autistic child's behavior is taken as proof of etiology; in other words, the fact that autistic children show some of the same behaviors as traumatized concentration camp prisoners suggests that they have been hurt by comparable circumstances in their own lives. And these circumstances, according to his argument, have to have been created by their parents, specifically by their mothers.

Now, three decades after Bettelheim's book was published, this analogy between autistic children and the inmates of concentration camps, between SS guards and the mothers of autistic children, seems preposterous. But we must remember also that Bettelheim's is only the most extreme statement of a view still widely held. Many other writers were convinced that autism was psychogenic, and introductory textbooks used in college psychology classes still sometimes repeat this view. Leo Kanner, who first used the term autistic to describe these children, also claimed that they were treated to "coldness, obsessiveness, and a mechanical type of attention" by their mothers. He argues that the children's "withdrawal seems to be an act of turning away from such a situation." These women he called "refrigerator mothers," a term that stuck and came to be repeated for many years after he first used it.

But perhaps more important than these egregious examples of mother-blaming in the professional literature is the "trickle-down" effect of such views on both the general populace and, even more, on public school teachers, social workers, family doctors and pediatricians, school psychologists, and the like—the people who are most likely to have contact with autistic children and their parents. It seemed pretty obvious to me that Paul's teachers in London, as well as his doctor in the United States, had been trained to view this kind of disability as psychogenic in nature, and specifically as caused by some flaw in the mother.

Such notions have been very resistant to change, in spite of the fact that autism is now widely understood as a neurologically based developmental disorder that affects not just the rate at which skills are learned but also the way in which they are learned. Overwhelming evidence now exists for sensory dysfunction in autism, and it is interesting to see how an alternative explanation to Bettelheim's is now emerging for each of the behaviors he interpreted as caused by trauma similar to that experienced in the concentration camps. Now we know that autistic children have disturbances in one or all of the senses: sight (accounting for the famous gaze avoidance, the use of peripheral vision, and such strange fixations as
the “twiddling” fingers Bettelheim mentions); hearing (hypersensitivity, especially to loud or abrasive noises, which accounts for much of their withdrawal); taste and smell (possibly explaining the eating oddities and the “anorexia” that Bettelheim believed to be a self-imposed starvation to escape a threatening world); touch (the “tactile defensiveness” which a baby may show when picked up and cuddled by a parent and which many psychologists cited as the child’s learned response to a mother’s ambivalence); and proprioception or the sense of the body in space (toe walking or shuffling gait).

Difficulty in coordinating shifts of attention (for example from a person’s voice to his or her face and eyes) and in integrating information from several senses at once are now recognized as neurologically based, rather than a defense against a rejecting mother. This probably accounts for the autistic person’s problems with complex and rapid social interactions, as well as for the child’s sharply focused learning—the rote learning that Bettelheim named as neurotic. Finally, and more importantly, a problem with regulation of the nervous system and the enormous stress which autistic people typically feel causes their withdrawal, tantrums, or self-stimulation, all ways of reacting to or blocking out an overload of sense impressions.

Why were professionals so ready to blame mothers for a childhood disorder such as autism? I think there are several reasons, and I have elsewhere offered possible answers to this question. For one thing, because these children often “look” so normal and frequently have very good health, many experts on autism have resisted looking for an organic or medical explanation. And of course there has been a general tendency of twentieth-century environmentalists, as well as Freudians, to trace aberrant behavior in children back to parents.

There is another possible reason for this readiness to blame mothers for a child’s autism, however, and that is the frustration that many well-intentioned professionals feel when confronted by these children, who so often seem not to get better even with heroic efforts at treatment. Eric Schopler, himself one of the leading professionals in the field of autism, has written persuasively of the temptation to scapegoat parents. Among the reasons given are the professionals’ own “confusion and lack of knowledge” about the causes and optimum treatment of autism, their fear and anxiety, and the projection onto the child of their own guilt at not being able adequately to treat him:

The clinician confronted with an autistic child has the additional burden of coping with the child’s difficult interpersonal behavior. The child may be negativistic and irritable. . . . This interpersonal avoidance and disorganization is often communicated to the clinician. He feels . . . insignificant to the child. The resulting sense of helplessness in the adult is not easily expressed against the child, and considerable pressure develops to explain the child’s impossible behavior in terms of his parents.13

Schopler also suggests that “feelings of inferiority may lead to scapegoating . . . and when the progress in treatment is uneven, the clinician’s role as an authoritative expert is seriously threatened.”16 “Conformity” may be another reason for blaming parents. “When the predominant orientation of a clinic is the psychoanalytic framework, then the emphasis on parental pathology for explaining children’s difficulties is a shared belief among the staff.”17 And finally, when there are so many possible causes of the child’s behavior to consider (perceptual and sensory dysfunction, dietary and metabolic problems, neurological involvement, genetic flaws, as well as the possibility of traumatic experiences), simplification is a real temptation, since it “provides for economy and energy in directing aggression.”18

In addition, Schopler identifies ways in which parents can play into the hands of scapegoating professionals. I would suggest that what he says about “parents” applies particularly to mothers. Mothers are already “embarrassed by their child’s peculiarities,” and as targets of blame they have “little possibility for retaliation because the scapegoater is stronger . . . in terms of prestige.” The mother is already so used to being attacked that her resulting demoralization makes it harder for her to fight back. And finally, “the victim is accessible.” “In their desperate search for help,” and after exhausting all other possible avenues of help, parents may seek out a diagnosis from the very professionals who are likely to offer psychogenic explanations of their child’s disorder.19

So what does all of this add up to? If the subtle hints dropped in the London nursery school constituted the only time I encountered blame as a mother, or if the frustration of an otherwise kindly pediatrician who suggested I read a book about a cured child was the only time someone suggested my child was withdrawing because I had rejected him—then probably not much. But this kind of blame, which was usually indirect and often appeared as much in what was not said as in what was said, happened over and over as Paul was growing up. It’s true I was especially
sensitive, all the more so because I was relatively well informed, relatively well-read in the literature. But one more event, which happened when Paul was in middle school, deserves mention. It shows again how widespread this belief in the psychogenesis of autism was, and it happened not so many years ago.

Paul was not happy in his neighborhood middle school, and a couple of concerned teachers, as well as a friend who was an activist on behalf of children, suggested that we visit schools in Minneapolis, some forty miles away from our home. One of these schools looked particularly promising. It had been set up to address the problems of children with various learning disabilities. It boasted very small classes, dedicated teachers, and a lot of attention paid to the individual learning styles of children. The teachers obviously worked very hard and seemed to have been very successful in building self-esteem among these children, who quickly learned to take a lot of responsibility for their own education.

For all these reasons, this school seemed perfect for Paul. Even though he had the diagnosis of autism, his learning difficulties as well as his remarkable strengths (as shown on test scores and in other ways) seemed to qualify him as an obvious fit for their program. After touring the school and becoming more and more convinced it was the right place for Paul, we sat down for the interview with the principal. I felt very hopeful that at last Paul could get a really superior education and one suited to his particular learning style.

The principal, however, listened to us for about forty-five seconds. As soon as he heard that Paul was diagnosed with “high functioning autism,” he stopped us.

“I can’t take him,” he said.

We were stunned and wanted to know why not.

“He’s autistic,” he continued. “And I am one of those people who really does believe that autism is caused in the home. It’s psychological in origin. That means we simply can’t do anything for him here.”

And with that, he closed the interview.

NOTES

6. Bettelheim, 64.
9. Bettelheim, 68.
15. Schopler, 238.
17. Schopler, 239.
18. Schopler, 239.
19. Schopler, 240