

# Advising Parents of Severely Atypical Children

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The family physician is often the primary source of continuing guidance for the parents of autistic, schizophrenic, or brain-damaged children. It is essential to anticipate problems in such areas as use of medication, early education, reactions of siblings, and stresses within the lives of the parents. The family physician can help parents find the resources to cope with the multitude of problems confronting them and their children.

The family physician is often the first professional to identify those severely handicapped youngsters diagnosed as schizophrenic, autistic, brain-damaged, or retarded. Typically, such problems become evident to the physician when these children fail to follow developmental norms, exhibit bizarre behaviors, and, as time goes on, fall farther and farther behind their peers.<sup>1,2</sup> Most family physicians, when they recognize symptoms this severe, refer to their colleagues in psychiatry and neurology for diagnostic and therapeutic opinions. These consultants, although helpful, may not be available to offer the continuing guidance needed by parents of such youngsters over the years.<sup>3,4</sup> This article addresses the issues confronting the family physician counseling these parents.

## Using Medication

*Case #1.* Sally, a four-year-old diagnosed childhood schizophrenic, had been placed on thioridazine by a psychiatrist to control hyperactivity. Several months later she was enrolled in a school program that employed behavior modification procedures to teach self-control. It was quickly observed that Sally's "hyperactivity" virtually disappeared in the carefully structured classroom situation provided by the school and she became a cooperative and attentive student. A home visit by school staff revealed that her parents were highly inconsistent in their management of Sally. They were aided by the home visitor in developing greater structure at home, but had difficulty overcoming the belief that all children, even Sally, need "freedom of expression." Whenever the mother became weary of the effort required to help Sally, she would urge that the child's dosage of thioridazine be increased.

*Case #2.* Donald was seen once by a pediatric neurologist who noted that the four-year-old exhibited a high activity level. In his recommendation

to the referring physician, the neurologist suggested a trial of haloperidol for hyperactivity. Fortunately, before placing the child on medication, the family physician obtained information from the school and from the parents which indicated that this was a highly cooperative and responsive child. He had been very active at the neurologist's office because it was late in the day and he had been kept in the unfamiliar waiting room for a prolonged period of time.

*Comment.* Once a youngster has been diagnosed as clearly deviant in development, it is essential that therapeutic intervention begin as quickly as possible. Some children require medication to control such symptoms as seizures or hyperactivity. There is little need to debate the point that phenobarbital, diphenylhydantoin, and other drugs may provide effective control of seizure activity.<sup>5</sup> The use of thioridazine, haloperidol, methylphenidate, and other medications for the control of "hyperactivity" is less clear-cut. Although these drugs are effective for some youngsters, they may be contraindicated for some and have little impact upon others.<sup>6,7,8</sup> Prescribing medication is the easy response to the behavioral problems of the severely disturbed child. Unfortunately, in many instances, medication has little impact upon the child's behavior, increases his hyperactivity, or makes him so stuporous that he is unresponsive. While a test trial with medication may be warranted, it should not continue without clear evidence of behavior improvement. Some children, as noted in Case #1, respond better to the structure of a behavior modification program than to medication.<sup>9</sup>

## "Prescribing" Special Training

*Case #3.* Stanley, a four-year-old

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boy diagnosed hyperlexic, was notable for his precocious reading abilities which contrasted with his markedly limited speech and social skills. Stanley's parents, more sophisticated than many, recognized that their son required special educational experiences as quickly as possible. They contacted their local school board to request early admission to a program for children with language deficits. The board, initially reluctant to spend tuition money on a four-year-old, was ultimately persuaded that their investment in his early years might produce a significant savings in later childhood.

*Comment.* Unlike the normal youngster, the severely disturbed child cannot afford to wait until school age to begin his education. Very young children with developmental deficits may benefit from stimulation programs which attempt to capitalize on the child's strong points and teach him to compensate for his weaknesses.<sup>10,11</sup>

Most urban communities have special facilities for the preschool youngster with severe learning problems. These programs may be sponsored by a community mental health center, by a parents' association for retarded, brain-injured, or autistic children, or by the school district. Some nursery schools and Sunday schools may be willing to accept a few children who would not normally fit into their classes. A university day care center is an especially good choice in this regard.

Some school systems will assume responsibility for a child's education before the age of five years. As suggested in Case #3, many educators recognize that children with severe learning problems need intensive help beginning at an early age. Parents who have to deal with less enlightened school systems will need to become aggressive advocates for their children. The family physician can play a useful role of support and encouragement in this endeavor.

It is often helpful if parents can identify and suggest to the school system a specific program suitable for their child. Help in finding such programs can be obtained from mental health experts, including psychiatrists, psychologists, special educators, and social workers, as well as from parents of children with similar problems. Contact with other parents who share similar problems is important.<sup>12,13</sup> In

urban areas there are active chapters of such groups as the National Society for Autistic Children, the Association for Children with Learning Disabilities, the National Association for Mentally Retarded Children, the March of Dimes, and the Easter Seal Society. These groups offer their members such services as lectures, summer camps, day care programs, and political activism for the welfare of the children. The family physician can encourage parents to join these groups where they may find the personal and political resources they need. In rural areas where fewer resources are available the physician might bring parents into contact with one another to form their own group.

### Providing For Other Children

*Case #4.* Richard was an 11-year-old brain-damaged child who functioned roughly at the four-year level. A shy, awkward child, he often appeared as though he had just been chastised. Richard's parents spoke to their family physician about their concern that their 13-year-old daughter was embarrassed to bring her friends home because they would see her brother. The parents wondered whether Richard's presence in the home was disturbing the daughter's normal development. The physician noted that the parents were themselves embarrassed by their son's appearance and hesitated to take him with them to public places for fear of the reaction of others.

*Case #5.* Mr. and Mrs. G. were close to ideal as the parents of a trainable, retarded nine-year-old daughter. They were affectionate, relaxed, and able to demand good performance without pushing too hard. Their 11-year-old daughter, much like her parents, was comfortable with her sister's handicap and patiently helpful. Nonetheless, it was a sobering moment for Mr. and Mrs. G. when their older daughter inquired with very real concern if she would always have to take care of her sister when she became an adult.

*Comment.* The presence of a severely handicapped child causes pressures upon other family members.<sup>14</sup> Brothers and sisters, whether older or younger, are bound to be affected by the handicapped child.<sup>15</sup> In some families the problems of the handicapped child may dominate the house-

hold, with siblings feeling predictable jealousy. This issue should be dealt with directly. Children should be provided a full explanation of their sibling's problem. They must be given a fair share of their parents' attention and helped to express jealous or angry feelings about the sibling.

As illustrated in Case #4, children often respond to their handicapped sibling in a manner reflecting parental attitude. Parents who are at ease with a child's handicap will probably find that the siblings are also comfortable. The child who fears to invite other children home lest they see the sibling is often a child whose parents are trying to hide the reality of a handicap. If parents are unable to help their children come to terms with the meaning of a sibling's handicap, it might be appropriate to advise professional counseling for the child as well as the parents.

### The Lives of the Parents

*Case #6.* Mr. and Mrs. B. have two daughters aged six years and four years. The older was diagnosed as brain-damaged at four years of age and two years later they learned that the younger girl had a similar disability. At this point, Mr. B. elected to have a vasectomy to insure that they would have no additional children.

*Comment.* People may worry about children yet to be born as well as the ones they already have. Parents who planned to have several children may hesitate after learning that one of their children has a severe handicap. This concern about hereditary disorders is understandable. The family physician might anticipate this problem and raise the question with the parents so that appropriate genetic counseling can be provided.<sup>16</sup> One of the critical factors in this situation would be honest discussion between husband and wife. Problems with sexual response are not uncommon when one or both parents are fearful about the birth of another child but have not discussed the problem openly.

Having a handicapped child must not preclude living one's own life.<sup>14</sup> Parents who focus their lives around a child, normal or handicapped, are usually not as effective as people who lead more diverse lives. Handicapped children take time, but they do not require every hour of every day. The child should have contact with people

other than his family. A good baby sitter can be an invaluable asset to the family with a handicapped child. The family physician might be able to help parents by identifying sitters who have been helpful to other families in similar situations.

The presence of a handicapped child may create painful pressures on a marriage. The parents' guilt about the child, resentment toward the spouse for failing to give emotional support, sexual problems arising from fear of having another defective child, a sense of being trapped by a child whose needs far exceed what most parents are expected to give: all can weigh heavily upon a couple. If the family physician's guidance is not enough, these problems may respond to counseling by a psychotherapist who can help the couple understand the pressures and develop more effective ways of coping with their difficulties.

### Discussion

Family physicians, because of their prolonged contact with parents and children, are in a unique position to provide parents with guidance when

confronted with the variety of issues created by the challenge of raising a severely handicapped child. It is inevitable over the years that problems involving medical care, monitoring of drugs, the family structure, the education of the handicapped child, and the relationship between the child and his parents will be brought to the family physician.

The era in which we said to parents, "You have an autistic (retarded, schizophrenic) child. There is nothing we can do for him. Take him home and love him" has passed. We know today that it is never too early to start providing the handicapped child with the education he requires. Love is part of the answer. A comprehensive treatment program is the other.

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