

Caring for Families Following the Birth of a Child With Handicaps

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DR. MINDY SMITH (*Assistant Professor, Department of Family Practice*): We will be discussing the issues surrounding the birth, acceptance, and subsequent care of a child with handicaps within the family. The importance of early and continued physician-parent communication and mobilization of community and school resources will be reviewed with an emphasis on anticipatory guidance and the use of family and individual counseling. The burdens faced by parents of handicapped children will be presented along with suggestions for a more active and constructive role for the primary care physician in assisting the family in coping with the many and varied problems encountered.

CASE PRESENTATION

Joey is a 6-year-old boy delivered at 28 to 29 weeks' gestation by primary cesarean section for fetal distress. Mrs. K. developed polyhydramnios early in her pregnancy and had undergone numerous therapeutic amniocenteses, which culminated in premature onset of labor and early emergency delivery. Joey had a right hemispheric intracranial hemorrhage associated with birth asphyxia. He spent approximately 3 months in the neonatal intensive care unit, during which time his hospital course was complicated by sepsis, hyperbilirubinemia, and apnea.

Joey has severe mental retardation, cerebral palsy, and left retrolental fibroplasia (grade IV). He developed a seizure disorder over the subsequent year following his birth. He currently has one to two seizures per month and is reasonably well controlled on carbamazepine. He also takes diazepam to control his spasticity. He receives special education services and is otherwise cared for at home by his parents Mr. and Mrs. K.

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Joey and both parents first visited me in March 1987 to have me temporarily assume Joey's medical care. His father had lost his job, and Joey's medical coverage was now under his mother's work policy. His parents were very concerned about Joey's gradual deterioration in function. They were also considering the possibility of placing him outside their home in the future because they lacked supportive resources to help them continue caring for him at home. Both parents were markedly distressed and in separate interviews reported severe marital discord, multiple stresses, and substance abuse. Both parents were involved in individual counseling.

JAMES COYNE (*Clinical Psychologist, Department of Family Practice*): Mr. and Mrs. K. are unusually articulate in discussing what it has been like to care for their child at home. We can anticipate that what they will tell us will bring to light important issues concerning communications between physicians and families, the burden that the family assumes in attempting to care for such a child, and the limitations of both informal support (family and friends) and existing services.

PHYSICIAN-PARENT COMMUNICATION

MR. K. (Father): My wife was found to have polyhydramnios between her 4th and 5th month of pregnancy. When the physicians finally diagnosed this through sonography, the doctors said, "You can terminate this pregnancy or we can attempt to drain the fluid off whenever it becomes necessary." At that time we were about 5 months along, and Joey was kicking. We didn't want to terminate the pregnancy. When we told them we wanted to continue the pregnancy, the doctors looked at us like we were idiots. They seemed to say, "You don't know what's right for you, but if you people want to go ahead with this, OK." They weren't really concerned with helping us to achieve the best possible outcome. We had to go in every 10 to 14 days and have a liter of fluid drained off through a spinal tap needle. A different person would do the tap each time, and the procedure was done when it was convenient

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for the doctor, not necessarily when it was best for the case. I think this contributed to Joey's prematurity.

DR. THOMAS SCHWENK (*Associate Professor and Interim Chairman, Department of Family Practice*): You said a recommendation was made to terminate your pregnancy. I'm wondering whether it was possible to make that kind of decision given the information that you had?

MRS. K. (*Mother*): Well, the things that the doctors stressed were physical. There might be very expensive surgery. Either they did not stress the reality of what it would be like to have a child with severe handicaps, or if they did, it did not sink in with me. I didn't have any experiences that would lead me to understand what to expect. As it turns out, his physical handicaps are much less a problem for me than the mental ones.

After Joey was born he was taken to intensive care. The physician told me about Joey's right hemispheric intracranial hemorrhage as I stood next to the washbasin outside the neonatal intensive care unit with my landlady. I would no longer visit Joey alone after that. We were terrified for a long time because we did not know what was happening. We found that dealing with a lot of specialists is very difficult. We had little pieces of Joey taken care of by different specialties. If problems arose, it wouldn't be an individual doctor who was called in, it would be the neurology service or the endocrinology service. It wasn't until sometime after Joey came home that we found a pediatrician who was a great help to us in coordinating his care.

When Joey was born, it was very traumatic. I had a lot of feelings of guilt, too. When Joey was born, we were invited to join a study in which a number of infants were given phenobarbital on a prophylactic basis to prevent intracranial bleeding. We figured that the phenobarbital might have some retardation effect, so I said no. I wanted to keep Joey as alert as possible to give him every chance he had. I'm wondering whether Joey's bleeding was related to not giving the phenobarbital? You have to remember there is nobody to interpret all this information for a parent. There was no ombudsman to sit there and take us by the hand and say "this is what it means" in layman's terms.

DR. ROBERT VERMAIRE (*Clinical Instructor, Department of Family Practice*): You mentioned that after Joey's care was coordinated by a specific person, things improved. Do you feel that there is a role for the primary care physician in the Intensive Care Unit?

MR. K.: Absolutely.

MRS. K.: I didn't know family practice or anything like it existed. Our own pediatrician made all the difference in the world dealing with the other services. In the past six years, we have never seen the same neurologist twice, and that causes us to have real fears and concerns.

MOBILIZATION OF RESOURCES

DR. COYNE: It sounds as though there were many professionals involved, but ultimately it came down to the two of you. You were both pretty much alone. What kinds of

challenges were posed to you once Joey came home?

MRS. K.: We found that after we got him home, we would come back to the walk-in clinic weekly because we were so concerned with his health. He went home with seven medications. We put a schedule on the wall so that at 3 o'clock in the morning we would know which medications to give him. He threw up frequently, so we would have to figure out whether to give him his dose of medicine again and how much. He cried almost constantly. There wasn't much that we could do about his crying except to drive him around. This made it hard to communicate with each other.

Having Joey at home was very stressful. The uncertainty was really hard on me. I don't think the doctors wanted to diagnose the cerebral palsy until he was 1 year old. I think that they didn't say the word because they wanted to leave us with hope. The school system also works that way. They put him in the "least restrictive environment." We started out in the health-impaired program, which was very nice, but he failed everything. He couldn't do the tasks, so it was constantly depressing. Finally, his condition was diagnosed, and he was sent to the right program. I saw it coming, but it was as though he'd failed a major test. I would have preferred that he be started out in a more restrictive program and be moved to a less restrictive one as he was able. I understand why they don't want to do that, but it's really hard to cope with more disappointments.

DR. SMITH: A recent article about handicapped children noted the importance, particularly for parents, of having their children's disability diagnosed as early as possible so that intervention programs can be started.¹ A child with cerebral palsy, particularly severe cerebral palsy, should be so identified by 6 months of age to begin an infant stimulation program. This early diagnosis gives the parents some realistic expectations in addition to constructive things that they can do at home to help with their child's development. Screening and counseling families about a child's disability are major problem areas for physicians. In another study, only 50% of pediatricians and 20% of family physicians reported routinely screening for developmental problems, and only 3% to 6% of family physician respondents had utilized infant stimulation or peer-support services.²

DR. COYNE: Suppose a baby was just leaving the hospital now and the parents and family found themselves in a similar situation. What kind of advice would you have for the family that might help them to anticipate things that they will need to know?

MR. K.: Get in touch with your local Association for Retarded Citizens (ARC). Absolutely. Find out about respite care; otherwise, you're going to burn out being there 24 hours a day with your child.

DR. SMITH: How long did it take you to make contact with the agency?

MRS. K.: Not until Joey was 3 or 4 years old. For respite care, which is through a separate agency, there was a waiting list, too. It is a small program. I don't think we

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knew about respite care until after Joey was 1 year old. We saw a lot of people who gave us little bits of information. Drawing this information together was a problem. The home health care nurse got us hooked into the school system, but another parent got us into the respite system. There are a lot of services out there, but it's hard to find a centralized source. Maybe the people at ARC might have acted as an information center, but we were holding out, hoping not to have to deal with retardation. They were actually very helpful in a lot of other ways.

DR. CARYL HEATON (*Instructor, Department of Family Practice*): Another agency that can function as a resource coordinator is Crippled Children Services. This federally funded program provides care for the multiply handicapped child. They also have a program to match medically "fragile" children with case managers before the initial hospital discharge. This program is called the Specialized Home Care Program. In Michigan, however, it is new and was not in place 5 years ago. The case managers in either program help the family complete applications with the appropriate agencies for immediate financial and medical support. Eligibility for Crippled Children Services is determined by medical need, and any physician can submit a Medical Eligibility Request Form through the local public health department. Once the child qualifies, the Local Services Program will assign a public health nurse to be the child's case manager. While this particular program may not exist in all states, it is very likely that a similar program does.

ANTICIPATORY GUIDANCE

DR. SMITH: How did you get through that period of time? Particularly in those first 3 months, did you use family or were you leaning on each other, feeling isolated from friends or family?

MRS. K.: Well, here comes the hard truth. It alienated our families somewhat. My family wanted to be helpful but didn't know what to do. My husband's family withdrew as things got worse and weren't getting better. We turned to each other and to alcohol and drugs. That's how we coped. I would urge people who come home with a child like this to get counseling right away. We saw social workers, and we had a nurse who visited us at home, but what we really needed was counseling, grief counseling. I think it may have been suggested by the hospital social worker, but so many things were being suggested by so many people that the amount of information was overwhelming. I think that some written materials would have been helpful. I know we asked for more information on epilepsy, but we found that more often we were told, "Don't worry about all this." I think they were trying to normalize things as much as possible, but the effect was to leave us with no recourse and feeling as though information was withheld.

DR. MARGARET DAVIES (*Assistant Professor, Department of Family Practice*): Following up on a comment you made a moment ago, how would grief counseling have

helped you handle a live child?

MR. K.: There is grief over the loss of the normal healthy child we would like to have had; that child is dead. Instead we have this child that has severe difficulties.

MRS. K.: Friends tried to be supportive. One friend once told me that Joey was hard to look at because his eyes were so badly crossed. Friends did try to help, but they didn't know what to do either. We isolated ourselves a lot. Also, having to quit my job was really traumatic for me. I tried working three-quarter time at a job that really needed more attention.

DR. SMITH: Do you have fears about having other people involved with Joey?

MR. K.: It's hard to let anybody else take care of him. I felt guilty and ambivalent, wanting to take care of him all the time and then wanting to get away from him, but not having adequate support systems in place. I could get out of the house, but my wife would have to stay. We both couldn't get out at the same time, and even if we could, we had to get past wondering whether Joey was going to be OK.

MRS. K.: It was Joey who kept us together as well as tore us apart. I couldn't conceive of either one of us dealing with him alone.

DR. COYNE: At this rather personal level, how would you prepare a couple for this sort of thing?

MR. K.: Get them into counseling. Any relationship has its areas of conflict, and it's really hard to negotiate when a child presenting such challenging needs comes into the family.

DR. HEATON: I'd like to summarize some of the very important points Mr. and Mrs. K. have been making in terms of the role of the family physician. First, the family physician should encourage the use of support groups early and, if needed, repeatedly. We've heard that lots of advice and suggestions are made, but contact with a parent support group is perhaps the most important advice that can be given. This is one aspect of community-oriented primary care. We need to know our community and its resources. In this county, the ARC is very well organized and active. In another county it might be the United Cerebral Palsy Association. Crippled Children Services is also starting a statewide parent support group. Even if the diagnosis of mental retardation or other developmental disability is not made, the ARC can be helpful for any disabled child because they know the system.

As family physicians, we also need to be available to our families to interpret information provided from multiple specialists. We should anticipate grief and suggest counseling early. As Mr. K. has described, there is a great feeling of loss over the child that might have been, even in the midst of overwhelming time and energy commitments to the child that is. We can also anticipate signs of stress and burnout, the most serious of which is substance abuse. Iatrogenic substance abuse is not uncommon. As physicians, we can be most helpful to families by encouraging counseling and such programs as respite care, not by condoning refuge in minor tranquilizers or alcohol.

Finally, many parents need permission to leave their child in the care of others. Respite care, for example, gives the family a chance to focus more attention on each other. As all of these suggestions need to be reinforced periodically, the continuing relationship that we have with patients puts us in an ideal position to help. To assist in this process, written instructions, names, and telephone numbers can be valuable to the parents, who might not think to ask or are too overwhelmed to remember.

THE BURDEN ON FAMILIES

DR. SMITH: What kinds of things are you coping with now and what are your plans for the future?

MRS. K.: We've been looking for foster placement. Originally I was thinking that I just can't deal with Joey. For one thing he is getting physically large. He's thin because of the cerebral palsy, which is an advantage, but he has a kind of spasticity. When I pick him up, he pushes against me. I have to kind of fold him up to get him through a doorway, and it's getting harder and harder to take care of him. I'm going to be going into long-term substance abuse treatment, so we're trying very hard to place Joey in foster care for at least 3 months of the time I'm gone to give my husband a chance also to normalize himself. Joey reacted remarkably well to a week-long foster placement. He seems able to deal with it, but he's also getting a lot more interested in keeping us around. We're seeing more affection and attachment than before, and as I get better, I find it easier to cope with him. One of the issues we are facing now is whether we will seek long-term foster placement or whether we will be able to find a school, if we can afford one, since there is no longer any public residential treatment.

DR. SMITH: I was wondering about finances. To what extent are you receiving financial assistance for Joey?

MR. K.: In 1984, the state started a new program called Family Support Subsidy, which sent us family support checks for \$225 a month to help pay to keep him at home. At the time we didn't realize that Michigan was in the process of shutting down all of its state institutions for persons with developmental disabilities. While the legislature and the governor may be very proud of having saved some money, I think there's been a big decrease in the amount of service being provided. Persons with developmental disabilities, when they turn 18 years old, can qualify for Supplemental Security Income (SSI) and can often move into group homes, but we've got a child that needs to be in foster care right now, and these homes are very hard to find and even harder to finance. It's a real drain on me to work for a living during the day and then to come home and deal with Joey. I want to be able to do things around the house, but at the same time I feel I've got to be preparing a program for Joey, to provide him with the next activity.

DR. SMITH: Access to financial assistance can be con-

fusing for families who may not realize that such resources exist or where they can be located within the different federal or state agencies. While it is often best to identify potential sources of financial support through the local ARC and Crippled Children Services, four major resources can be considered in meeting the complex needs of families with handicapped children. The Family Support Subsidy Program, administered through local community mental health programs, provides monthly support for children who qualify for special education programs for autistic, severely mentally impaired, or severely multiply impaired (including significant cognitive delays). Funding of approximately \$256 a month can be provided to families based on a school assessment by a multidisciplinary evaluation team.

Supplemental Security Income is available to families with little or no income or resources. Eligibility for SSI is defined as total and permanent disability that prevents a person from performing substantial gainful activities. The child's "job" in this case is growth and development. While family income criteria must be met in cases where children are minors, at the age of 18 years only the adult child's sources of income are considered. In addition, minor children placed outside the home are also considered independent households and are therefore usually eligible for SSI.

Social Security Disability Income (SSDI) may be available to any family in which one member, usually a parent, who has been in the work force retires, dies, or becomes disabled. In such cases, dependent children and sometimes spouses can receive SSDI also. Finally, financial resources in the form of money for respite care (maximum 100 hours per year) and money for transportation, meals, and lodging during the hospitalization of a handicapped child can be sought through Crippled Children Services. Also available through this program is supplemental insurance for children with physical disabilities, which can cover all medical expenses including medications and durable equipment related specifically to that condition. Children for whom this insurance is being sought must meet both diagnostic criteria (cerebral palsy and seizure disorders are included) and financial needs. For children with severe medical and behavioral needs who may not qualify for this insurance program, Medicaid or mental health waivers exist, which can place a child on Medicaid insurance regardless of family income.

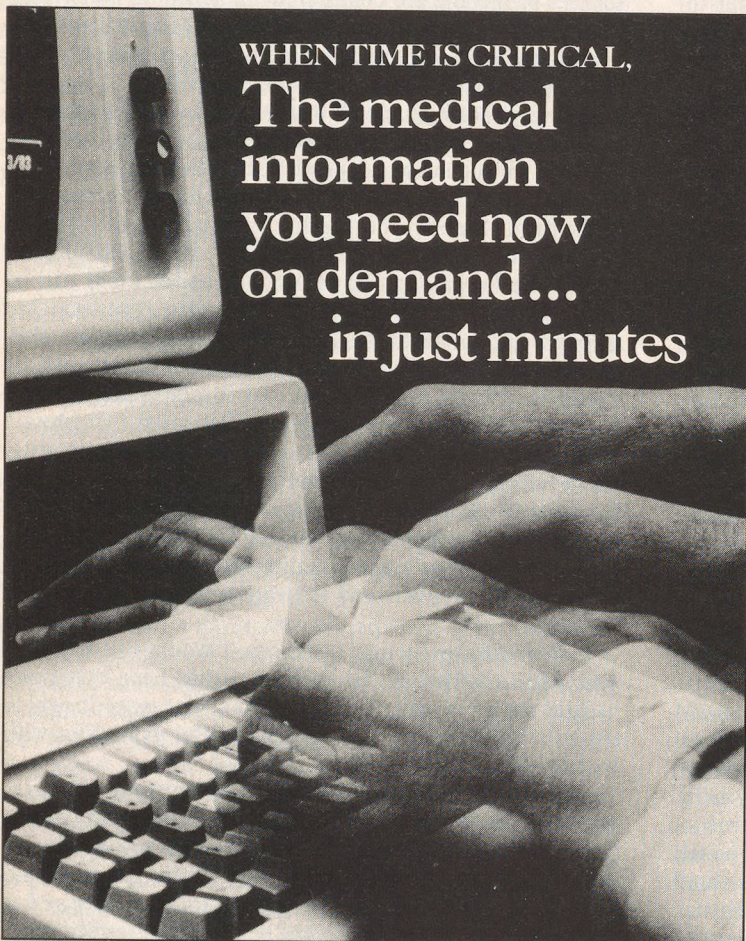
If there are no further questions, I would like to thank both Mr. and Mrs. K. for coming. It has been extremely helpful for us to meet with you to explore ways in which we, as family physicians, might be helpful to families with handicapped children.

DR. COYNE: In working with families like the K.s, it is not simply a matter of a physician communicating clearly, but rather one of ascertaining what parents are hearing or comprehending, given the stress they are facing. It would have been beneficial for the couple to have received a strong message that they would benefit from family counseling, so as to equip them better for the kind of collaboration that would be required of them.

DR. SMITH: Family physicians have important roles in providing anticipatory guidance, early diagnosis and appropriate referrals, and coordination of care, and in removing a little of the fear and isolation through consistent and supportive care.

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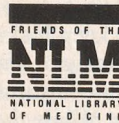


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