Case Study 1-2

Finding Resources: Case Management With Childhood Chronic Illness

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Finding resources for families is one of the most important functions for social workers. This case study describes the social worker's effort to find resources for a family with a very sick child.

Questions

1. What were the social worker's goals in this case?
2. What resources were identified for this family?
3. How could the family have been helped to better use the resources that were available?
4. Why were resources critical to the success of this case?

Today, Jeffrey asked me to have lunch with him. It's been so long since a guy asked me to lunch that I was startled for a moment, but then I accepted, especially since I was kind of down and Jeffrey is a bright 12-year-old with cystic fibrosis who has spent the past week in the hospital where I am a pediatric social worker. Every day he has been stopping by my office to borrow the Game Boy or ask for candy, and today he said, "So, do you eat lunch?"

"Yes, I do."

"Do you like to eat here in the hospital cafeteria?"

"Usually that's all I have time for."
"I have a cafeteria pass. I've been eating in the cafeteria."
"I saw you there yesterday with your grandmother."
"When are you going to eat lunch today?"
"When I finish these phone calls."
"Would you like to eat with me, in the cafeteria?"

How could I say no? So we went to lunch, and he forgot to bring his medicines that he has to take before every meal to help with his digestion. I had to call his nurse, who said she would give the medicines to me if I came back to the floor for them. So I climbed the stairs, got the medicines, and rushed back to the cafeteria, collected Jeffrey from a table he had chosen that had no seats left for me, and we sat down to lunch.

During our conversation, he asked, "So what do you do?" And I tried to explain to a 12-year-old my job of hospital social worker, which coincidentally had earlier that week involved having a letter sent to his school asking that he be encouraged to remember to take his medicines every day before lunch. I briefly explained how, in addition to working with upset families, dealing with crisis situations, and contracting with children to take their medicines, I help people get things they need, solve problems, and find resources. And Jeffrey looked at me seriously and said, "That's easy. You have an easy job. You just help people get stuff."

I didn't mention the long hours of overtime for which I do not get paid, or the doctors who ask me to do the impossible for their patients and then fail to call me back when I page them, or seeing the sad eyes of parents whose babies die. And I didn't mention how the long hours are worth it when the doctors tell me I'm awesome, or when a child who was near death in our pediatric intensive care unit walks back into the hospital for a visit and gives me a hug. So just for you, Jeffrey—though you may not understand it all—because you asked and because the job sounds so easy, here's a story about what I do to help people "get stuff."

Late in the work day, I usually check with the inpatient units to see if there are any last-minute problems before I leave for the day. On this particular day about eight months ago, I went to the infant and toddler unit about 4:30 p.m. One of the pediatric doctors approached me and said, "Sometimes you seem to be able to work miracles with patients, and we have a family coming in that sure could use one. They are, to put it mildly, a social disaster. The patient is a 7-month-old baby boy who needs a liver transplant. The family has just moved to town to place the baby on the transplant list and wait for a liver. We think Child Protective Services (CPS) is involved with the family for noncompliance with medical care. The baby is very sick, the father is unsupportive, and the mother is not with it. If they can't get their act together, the baby will have to be taken away from them in order to qualify for the transplant. We were hoping you could help us out."

The next morning, I met the family. One of my colleagues, the social worker for the liver transplant team, had completed a psychosocial assessment, and she gave me a copy. Her job was to assess the family and recommend whether they met the criteria to be placed on the transplant list. In this case, the family was intact and consisted of

the parents, Joe and Rosa, and their four children. In addition to the baby, Nathan, they had three girls aged 5, 7, and 9. Joe worked construction and Rosa took care of the children. Joe's family lived in a city about two hours away. Joe and Rosa had recently left that city to be closer to the hospital for the liver transplant. They had a small two-bedroom apartment and one old car. One of baby Nathan's problems was "failure to thrive," meaning that his height and weight were below the fifth percentile for his age. The transplant team's assessment was that Nathan needed to improve his nutritional status and gain weight before he would be eligible for the transplant. I decided my job was to do what I could to help the family meet those criteria.

I spent a lot of time that morning talking to Rosa about her problems in caring for Nathan. She explained, "This is so hard. I have to do it all myself. Joe doesn't help. Nathan cries all day to be held. I have three other children to take care of. I have to cook, clean, wash clothes, shop, and carry Nathan around all day. Joe comes home at night and wants to know what I did all day. Why is the apartment so dirty? Why isn't dinner ready? Joe's family lives 2 hours away, but no one will come and help. They didn't even help when we lived there. Everyone thinks I should be able to do this on my own. But I am just so tired."

Then I talked to Joe, who said, "I have to work in order to make money to provide a home and food for my family. If I don't work, I don't get paid. Then where do we live, what do we eat? I work hard all day, sometimes 10 to 12 hours. I come home, the apartment is dirty, there's nothing to eat, the baby is crying. My wife should be able to take care of the home while I work. I'm so tired when I get home."

After talking to them, I realized this was a story I hear all the time from families of chronically ill children. Caring for a child with complicated medical needs takes so much time and energy that there can be little left for the basic necessities of life. Caring for a sick child places added stress on a family, especially when that family is already stressed from inadequate resources, poor finances, and isolation. The problem is even worse for a single parent. How does a single parent work and meet the health needs of the child? How does a single parent find a childcare worker who can administer medication, perform treatments, recognize emergency situations, and not cost more than the parent earns at work?

In talking with parents of chronically ill children, I have often brought up the subject of counseling. Rosa gave the common response to this suggestion: "I've had counseling. The counselor says, 'Tell me all your problems.' So I do. Then the counselor says, 'Now don't you feel better?' Well, I don't. I don't need to talk about my problems, I need to do something about them. I don't need someone to talk to, I need someone to hold this baby so I can cook dinner." Rosa's experience with her chronically ill child is similar to that of parents with other disabled children (King & Meyer, 2006). Moersch (1978) observes:

> Parents need the understanding of professionals, but they also need concrete services to help them in managing and living with the . . . child. Some parents . . . have reported that they always had plenty of people to talk with them about their feelings . . . but it was very hard to find someone who could tell them what to do with feeding, toileting, or behavior problems.

It is even harder to find someone to help do those things with the child.

A social worker is in a unique position to help the family find whatever resources are available to help the family cope. In working with chronically ill children and their families, the use of social work does not change the course of the disease, but it does help families address the cumulative impact of the challenges they face. A central role for the social worker is in linking services to the needs of the child and family—with a focus on not just the child but the entire family facing the crisis.

My first task was to assess the family's current resources. They had a place to live, the baby had the state's healthcare insurance, the father had a job, and the baby was receiving Supplemental Security Income ($484 per month), which is available to families caring for a chronically ill, disabled child. In their hometown, the state's health insurance plan had assigned a case manager to the family to help with resources. After meeting this overwhelmed family, however, that case manager had called Child Protective Services (CPS). The CPS worker concluded that the family was doing the best they could under the circumstances. CPS offered the mother a parent aide, but then the family moved to our city and CPS closed the case. The family was very angry at the insurance case worker. I usually try not to get CPS involved when a family is apparently doing their best with what they have. In these situations, I involve CPS only as a last resort when all else has failed. Calling CPS, as this case illustrates, risks alienating the family from the healthcare team. Joe asked for a new case worker from the insurance company.

After investigating all of the above, I assessed that the following services might be available to this family:

- A local children's shelter provides volunteer parent aides to visit families who are at risk once a week. I called this service, and they were willing to move Nathan's family to the top of the waiting list and assign a parent aide immediately.
- Being diagnosed as "failure to thrive" placed the baby at risk of developmental delay and made him eligible for Department of Developmental Disabilities (DDD) services. These services include home visits by a developmental specialist, case management, and respite care in the home. I made a referral and asked them to expedite the intake procedure.
- The state provides long-term care benefits to patients with chronic illness and disability. These benefits include home nursing, physical therapy, occupational therapy, and respite services. I started the application process.
- When parents are in the hospital with a sick child and spend most of their day with that child, they often have to eat in our hospital cafeteria. This expense can add up over time. I give families a meal ticket to eat in our cafeteria when they have no money, are from out of town, and sometimes when I just can't think of anything else I can do for them. I gave Nathan's parents a meal ticket for lunch in the cafeteria about once a week.

The baby was discharged home. I thought the family now had some concrete resources to help them meet their child's healthcare needs. However, things did not turn out as I had planned. Rosa contacted the parent aide program and decided that because the aide would only come out and talk to her and not hold the baby while she cooked, she did not need this service. Rosa failed to return the calls of the DDD intake worker and never set up an appointment. Rosa tried to keep her appointment with the

long-term care office but got lost on the way and never found the office. Joe lost his job and had to go on unemployment. Nathan missed two doctor appointments because Rosa forgot one and didn't have transportation for the other.

The baby was then readmitted to the hospital, still losing weight, and started on tube feedings through his nose into his stomach. The doctors were now very concerned about the family's ability to cope with these tube feedings at home. I began to worry about the family's ability to properly care for the baby. Families can be overwhelmed, but they still must find a way to meet the needs of the child, or that child may be in danger.

The medical team wanted to consider other placement options for Nathan outside of his home. There was discussion of a CPS referral. The team agreed that the baby needed a placement where he could receive the appropriate medical care and gain weight. However, in this situation, as in many, the child was so bonded to his parents that removing him from his home would possibly do more harm than good. As well as medical care, Nathan needed his family's love to get him through a major transplant surgery. In addition, we had a good relationship with this family, and I did not want to jeopardize that relationship by making a CPS referral. As sometimes happens when I am faced with the decision of whether to call CPS or not, I began to think I should have become a nurse instead of a social worker, but then I consoled myself with the idea that as a social worker I get to work with families and patients, but I don't have to deal with bodily fluids.

We decided to hold a meeting with the family and the involved physicians and social agencies. We drew up a contract with the family. We set weekly doctor appointments for the same day and time each week, alternating one week with the pediatrician, the next with the specialist. We set down in the contract exactly what was expected of the parents in caring for their son. I listed the set doctor appointments and phone numbers to call in case of emergency. I listed instructions on how to get transportation to appointments by calling the insurance plan 24 hours in advance. I gave Rosa a calendar with her appointments written on it. I gave her a notebook with paper and pencil to list her questions for the doctors. I included all instructions in this notebook, along with the contract and the calendar. I also included food logs to list exactly what she fed Nathan each day.

I set up Home Health to come out daily to check the tube feedings, weigh the baby, and look at the food logs. I convinced the insurance company to use our hospital's home health agency, even though the insurance did not contract with them, so that Nathan would be seen by one of our pediatric nurses instead of an agency nurse who might not have the appropriate pediatric experience. I had DDD do their intake at the hospital with Rosa. I had the long-term care worker do a home intake so Rosa did not have to drive to their office. I gave Rosa a copy of Nathan's medical records to give to the long-term care worker and expedite the process.

The baby was again discharged. Rosa lost the medical records and could not master tube feedings. She could not reinsert the tube herself when it came out. Instead of calling for help when the tube came out, she would wait for the nurse to show up the next day to reinsert the tube. As a result, Nathan missed valuable feeding time. The baby was readmitted, still not gaining weight.

This time, with the parents' permission, I gave the medical records to the DDD intake worker. Then, since Joe was still out of work, we encouraged him to become more active in his son's care. So Joe slowly became Nathan's primary caregiver. Because he was out of work and spending so much time at the hospital, Joe began to ask for a meal ticket every day. And to encourage Joe to continue to participate in Nathan's care, I gave him one. I began to see Joe and Nathan on a daily basis then, as Joe would wheel his baby down to my office in a wagon to get his lunch ticket and while Joe sang he would move Nathan's arms to make the baby do the Macarena. Rosa visited too. Because Joe was now caring for Nathan, Rosa began to talk about going to work to support the family. Together we explored her options for employment. We discussed her providing respite care for disabled children in her own home. We discussed her becoming a patient care technician at the hospital. We discussed her returning to school to improve her secretarial skills. Then one day Rosa asked about how to become a court interpreter. She was bilingual in English and Spanish and thought this was a job she could do. I made several phone calls, found a training program that offered financial aid, and gave her this information with my encouragement.

It was time for Nathan to go home again, but now he was being fed through a tube directly into his bloodstream instead of through his nose into his stomach as before. I talked to Joe about an out-of-home placement for Nathan. There is a house in our town that provides care for children with complicated medical needs. I encouraged Joe to consider this option so Nathan would gain weight and get his liver transplant. Joe was furious that I would suggest a "nursing home" for his son. Joe insisted that, with proper training, he and Rosa could learn to adequately care for their son. So the doctor and I decided to try to place Nathan at a special care unit at another hospital. The unit could provide intensive discharge training for the family and assess the family's ability to care for the baby themselves. But Nathan's insurance did not have a contract with that hospital. We had to call the insurance plan and try to convince them that Nathan needed to be transferred to the other facility. They said no. We called again. We wrote a letter. The doctor called the medical director of the insurance plan and finally the insurance agreed. Nathan and Joe went to the special care unit, and Nathan was discharged to his home within a month.

Two weeks after this discharge from the special care unit, the home health agency called to say that Rosa had been discussing future plans with her home health nurse. Rosa planned to enroll in the court interpreter program, get a job, and then divorce Joe. The agency also reported that Nathan's sisters were not attending school. Everyone was in a panic over this information. If Joe and Rosa were having marital problems and getting a divorce, it would jeopardize Nathan's chances for getting a transplant. Someone had to talk to the family about getting counseling and sending the girls back to school. I thought about trying to get the hospital to authorize a social work visit at Nathan's home, since I do not usually provide this service, but then the baby developed an infection and was readmitted to the hospital. Rosa assured me she would send her daughters back to school. Joe began to approach me about meal tickets again. However, I had used so many that we were running out of funds, and all I had to offer him were $1 discount coupons. He scoffed at them: "What can I get with this? Soup? I need more than that. Look, I'm down to my last $20. Oh well, it's better than nothing. Want to see Nathan do the Macarena?"

Shortly after this, Joe found a job and went back to work with a better understanding of how difficult and time-consuming Nathan's care could be. The family asked me to help them find a bigger apartment. They had contacted a local agency that helped families of Mexican heritage with housing. I wrote a letter about how Joe and Rosa were working together to care for their child and needed a bigger place to live. The agency gave them a subsidized, three-bedroom apartment. Joe and Rosa moved into their new place and stopped talking about divorce.

Then a DDD case manager called me and said she had been assigned to the family but could not find them. I asked her to come by the hospital to see the family and get their new address and phone number. This case manager helped with the long-term care application, and Rosa finally got DDD services, long-term care services, and someone to provide respite and hold Nathan while she cooked. Nathan was discharged, and we did not see them again for a long time.

One day their doctor, the same one who initially approached me about the family, stopped me in the hall and said, "You know, Nathan is a real success story. His family really turned around and is taking great care of him. He's gaining weight, he's on the transplant list, and now all he needs is a liver. You really are a miracle worker."

I think to myself, "Sure, I am a miracle worker and this job is great when a child gets well and walks back in to give me a hug, but sometimes it is not so great." Remember, all the psychosocial intervention that I can offer cannot change the course of a chronic disease.

Nathan was readmitted to the hospital for the last time about a month ago. He was so jaundiced from his liver disease that he looked as if he could glow in the dark. The doctors decided to keep him in the hospital until a liver became available for him so that he would be at the top of the list. Then Nathan got an infection and began to decline and was transferred into intensive care.

At this point, everyone realized that Nathan was dying—everyone except his mother. I went to see her after the transplant doctor talked to her about the baby being taken off the transplant list.

Rosa said to me, "The doctor told me that Nathan is going to die, but I don't believe him. I know God will save my baby. He will get over this infection and then get stronger and then get his transplant."

I couldn't argue with her. I remember hearing a mother of a seriously ill child telling another mother one day, "You have to be strong for your child. You have to believe that he will be okay. It's the only way you can get through it. You have to believe he will get better or you simply can't deal with it."

So I said to Rosa, "You understand that your son is very sick and that what he needs now is a miracle?" She nodded, and I said, "Well, we all hope you get it."

Sometimes facing a child's death is just too hard for parents, and they need to have hope until the very end to get through it. Because I was at a loss this time for what to do, I gave them a meal ticket. Joe said to me, "So my son has to get this sick in order for me to get a decent meal around here."

Soon afterward, Nathan developed another infection. The doctors talked to the family again about the lack of hope in this situation. They explained to the family that the baby

was being kept alive now by machines and drugs that were only postponing his death. Faced with this information, the parents decided to disconnect the machines and stop the drugs. When I went in to see Rosa, she said to me, "How will I get through this? I've never felt love like this for anyone. How can I let him go? What will I do with his new shoes?"

So I called Nathan's doctor, and he came and knelt down beside Rosa and gently explained exactly how the staff would disconnect life support and what would happen. We encouraged her and Joe to hold their baby and sing to him. When the staff was ready to disconnect Nathan from the machines, Rosa looked to me and said, "Am I going to be okay?"

I don't usually give advice, but I nodded and said, "Yes, you are going to be okay. I know you can get through this for your baby."

So the staff turned off the monitors and the machines and the medications, and we left Rosa and Joe holding Nathan and singing to him as he died peacefully in his parents' arms.

Afterward, I went back in. The nurse was taking the baby from Rosa to place him back on the bed, but he was still hooked up to tubes and wires and difficult for the nurse to manage. She looked to me and said, "I need help, take him." So I held out my arms and took the body of the baby from the nurse and felt something cold and wet on my hands and realized that as a nurse she was wearing gloves that protected her from bodily fluids, but as a social worker I was not. We put Nathan back on the bed, and his mother washed him and dressed him in an outfit from home and put on his new shoes. We gave her a quilt to wrap him in. We took pictures for the family. We made a set of Nathan's handprints. While Rosa stayed with Nathan, I spent some time with Joe and discussed funeral options and grief counseling for the family. Then at the family's request, I told Nathan's sisters that their brother had died.

Finally, the family packed up Nathan's belongings and came by my office to say goodbye. Nathan's youngest sister was holding a bear. "Watch," she said, and she pressed the bear's paw and the bear sang "Hey, Macarena." That's when I cried.

So, Jeffrey, as you can see, I can help people get stuff. In fact, sometimes it seems that I can do miracles. But you are right, that is the easy part. I can get an insurance company to buy a $20,000 piece of equipment for a patient; I can get a pilot to fly a child to doctor appointments monthly for free; I can get a stressed, single mother 8 hours a day of attendant care for her child so the mother can work. But I can't do the hard part, as Joe reminded me one day when I asked what he needed, if he wanted to talk. He said, "I need for my child to not be sick anymore. I need for him to live. Talking about it won't make him better. But I could use one of those lunch tickets."

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