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ONE MEDICAL HOME AND ONE SCHOOL MAKE A DIFFERENCE FOR A FAMILY

November 12, 2009 by Jo Lynne Lyon

Note: This article, written by a mother of a child with special health care needs living in Cache County, Utah, first appeared in the Champions for Inclusive Communities’ November 3 newsletter. It is part of a series focused on the experiences of individual families as they work to obtain community-based services for their children with special health care needs.

The experience in the hospital last year when my 9-year-old daughter was first diagnosed and treated with diabetes was very overwhelming. We left feeling unprepared and lacked confidence to deal with her treatment. Luckily, our family doctor — our medical home — helped us through this initial scary phase. He helps coordinate my daughter’s care with her endocrinologist to ensure she stays healthy. He is very good at communicating with my child, and he keeps in regular contact with us.

I also had an interesting experience with the school system not long after my daughter’s diagnosis. I left a message with her school saying that my 9-year-old child had been hospitalized and diagnosed with diabetes and asked if we could meet to discuss possible assistance for her. A staff member later left me a message, essentially saying there was nothing they could do. I knew that the school district should provide a health plan for children who require assistance because I have worked with children from the Up to Three program and have been an advocate for families in our school district. I called the secretary back and asked her if my daughter was the first child with diabetes to attend the school. She said that in the past there had been a couple of children, but their mothers came with them to school to help. When I explained that I would talk to the school district’s nurse, her tone changed and she wanted to excuse herself for not providing me with the information I needed concerning a health plan and further assistance for my daughter. She also asked me not to involve the school district’s nurse.

My point is that I know I could have eventually received the support and health plan I needed for my daughter in that first school, but I could never change people’s attitudes towards parents and children with special needs. My daughter was already dealing with a life-changing event – an incurable disease, paired with the stress over not fitting in or being liked. I did not want to add eye-rolling, non-empathetic behaviors that would make her feel like a “chore” to anyone.

I decided to home school her for few months, but it did not work so well because I still was working, both away from and at home, making all the meals, cleaning, doing laundry, learning about diabetes, grieving, and helping other members of my family deal with the situation. I was tired! I could not leave my job because we needed the health insurance. So I prayed for help and was directed to Summit Elementary School.

My daughter and I were just visiting Summit one day when a lovely woman, who was so sweet and friendly, stopped in front of my daughter, shook her hand, looked into her eyes, smiled, and said “hello sweetheart.” My daughter said hello back and smiled and the lady hugged her. This sweet lady, the school secretary, asked both of us if we were interested in enrolling in Summit. I explained that I home school and that I was just looking and maybe signing up for a math class or a gym class. I explained that my daughter has diabetes Type 1 (very different from Type 2 diabetes). She said “me too” and showed her insulin pump to us. Then she added that in fourth grade there is a little boy with the same diagnosis whose teacher was well trained and had taught other children like my little one before. This little boy’s mother also teaches fifth grade at Summit and knows all about the condition. She has even done shots for other children.

Within two days my daughter was enrolled full time in Summit Elementary. Soon after, we had a meeting with the district nurse (who was well prepared for our family health plan), the school principal, her teacher-to-be (who is excellent), and the fifth grade teacher and mother who was and is an angel. This woman took the time to share a tear with me, she read a book called “Taking Diabetes to School” to my daughter’s classmates, she helped her feel welcome, and she also gave her a backpack equipped to care her insulin supplies along with a Teddy bear name Ruffles who has diabetes. My girl loves her bear and gives him shots. She comforts him and reassures him at night.

All of this has been so helpful. Everyone I have seen at Summit seems to be happy and seems to love their job. In the hallways, children are greeted and noticed by teachers and the two super secretaries keep good track of her blood readings. Summit Elementary gave us the support we needed.