

PARENTS SPEAK OUT

Melody Shares How Parent to Parent Made a Difference for Her and Her Daughter

Here are some excerpts from an interview with a parent who is a participant in a Parent-to-Parent Program.

Melody is a 30-year-old single mother who has a cognitive disability. She also has a 12-year-old daughter, Jessie. Jessie is a beautiful young lady with a great smile and big, beautiful brown eyes. She loves to be held and cuddled. She has several physical and cognitive disabilities, as well as hearing and sight impairment.

Beach Center on Disability
Making a Sustainable Difference in Quality of Life



Melody talks about her hopes for Jessie's future.

"I want Jessie to be loved and wanted by other people. I want people who live in our neighborhood to feel comfortable around her and talk to her. I want them to help her out if she ever needs help . . . I want Jessie to be as happy as possible and to know people love and care about her, no matter how old she is."

Some of that hope infuses itself into their day-to-day life.

"Jessie and I just moved into our very first apartment together, so I don't have the support like I used to. That will take a little while to get used to. But we do have a lot of friends and some family who support us . . . I need to stay really organized, though, so I don't forget to do the things that Jessie needs, like making sure she gets fed on her schedule."

"The biggest struggle I had in the beginning is figuring out how to take care of her by myself, since her daddy's never really been in the picture. That was hard. Jessie's had to have a bunch of surgeries and each time she gets one I have to learn what I have to do differently to help her. It wasn't easy to learn about feeding tubes and how to keep things clean so she wouldn't get any infections. It was and still is a lot of work to get her to all of her doctor appointments, especially since someone else has to drive us there."

In the beginning, Jessie lived with another caring family for a few years while Melody tried to figure out what she needed to do in order to raise her.

"I really wanted to get her back and I knew I could learn the things she needed me to. Nurses and therapists helped me a lot to figure things out and teach me. By the time I got Jessie back, I learned a lot about cerebral palsy, seizures, and being mentally retarded."

But, despite the help from professionals, Melody felt very alone.

"Every time I wanted to talk to my friends about Jessie, they didn't seem to understand. Their kids were all normal, so they couldn't really help me with things I needed to talk about."

"I wish I could have known how different it was going to be to raise Jessie than other kids. I wish I had someone to talk to in the very beginning. I think just having someone to talk to who has a kid like Jessie would have been a big help to me. I needed someone who could understand my needs and Jessie's."

Then, about the time Jessie turned 7, they a visiting nurse told Melody about Special Kids Network and Parent to Parent.

"I called them to see if there was another mom out there who had a kid like Jessie. I couldn't believe it when a mom called me. Even though her daughter is really different in other ways from Jessie, she seemed to understand right away what I was going through and how to help me. I couldn't believe how much she knew already. I think the first thing she really helped me with was to figure out what I had to do to get a lift to lift Jessie into the bathtub and bed."

"It really meant a lot to me when she went with me to visit the doctor who was going to talk to me about Jessie maybe needing a hip surgery. She helped me understand what he was saying and helped me ask him other questions I wanted to know. Then, I really appreciate that she stayed with me in the waiting room until Jessie got out of surgery and that she visited us a lot while we were still in the hospital."

Melody and her Parent to Parent match easily became friends. They still talk weekly.

“It’s really nice to keep talking to her so that if I do have a problem which comes up I know I can always ask her about it. We’ve been friends now for about five years.”

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Beach Center on Disability

The University of Kansas

1200 Sunnyside Avenue, 3111 Haworth Hall • Lawrence, Kansas 66045

Telephone: 785.864.7600 • TTY: 785.864.3434

www.beachcenter.org

