

Self Directed Supports: We're a Family Again



The decision to put our daughter into placement did not come easily. For seventeen years, since her adoption as an infant through Family Services, we had struggled to support Jessica at home and to meet her special needs: vision limitations, speech and developmental delays, the moderate MR that was probably a result of the birth mother's prenatal drug use. By far the biggest challenge was her behavior: severe temper tantrums almost from the time that she could move her little body...the "terrible twos" that she never seemed to outgrow. We did our best to find answers, taking her to specialists, having her analyzed and evaluated and assessed; I even went back to school to refresh my psychology degree with an updated course in behavior modification in an effort to figure out what to do about the behaviors, but solutions were not to be found.

While Jessie was younger and smaller, we were able to contain her so that we could go some places and do some traveling with her. As she became older, she grew more intensely jealous of any attention shown to her three brothers and increasingly intolerant of changes to her routines. Then came puberty and the behaviors turned into outright aggression. We finally took her to a psychiatrist who diagnosed mental illness and prescribed medications, but even that brought only partial relief. We found ourselves prisoners in our own home, constantly working to shape Jessica's environment so that nothing provoked her behaviors, which translated into going nowhere and doing nothing except what Jessica was comfortable in doing. She had to move out, but we felt like we were losing her... surrendering her to others who could support her more successfully than we had been able to do.

Jessie spent the next six years placed in ISLs, Individualized Supported Living arrangements, where she shared three different apartments with three different roommates, none of whom she chose herself and none of whom particularly liked her—we were happy whenever they simply maintained a peaceful coexistence. She was served by an often changing stream of staff who did their best to support her in the life outlined for her in her individual plan. We spoke to her almost daily by phone, and tried to have her visit us regularly in our home until staff informed us that the home visits just seemed to make her more difficult to support when she returned to the placement. We tried visits to her in her apartment, but always felt uncomfortable there, as if we were intruding on the other roommate and staff, so those visits occurred seldom and only for very brief periods. We just never seemed to develop a clear, comfortable, natural relationship with the agency, the staff, the Regional Office and our daughter, and the fact that I worked for the Division of Developmental Disabilities didn't make things any easier. Just what was our role as Jessica's parents and guardians? How much should we be involved in her life? Were we advocating or interfering? Should we just trust her to the wisdom and expertise of the provider agency and Regional Office staff who had to deal with her every day? Her problem behaviors were steadily getting worse and nobody seemed to know what to do. Who could tell us what was best for Jess?

When Jessie was younger, I had taken great pains to make sure that those who worked with my daughter ...the doctors, the teachers, the specialists... understood that **I was the expert on my daughter.**

Whatever degrees and specialties they may have possessed, I expected them to respect my knowledge of Jessica and what worked for her. I wasn't feeling like the expert anymore. Year by year, the distance was growing between us and Jessica, and we didn't know what to do about it. Maybe it was inevitable that Jess would have a life without us. Maybe that was what was best for her.

For her part, Jess seemed to be caught in the middle, as if she had two sets of parents that she had to please at the same time. When we asked her questions about her supports and activities with her staff in the ISL, she often became defensive and anxious, as if worried that she would be in trouble for talking to us about her staff or her activities. When she found a lead staff that was stable and caring, she became almost pathologically dependent upon that person and couldn't stand to be away from the woman for any length of time, even to spend time with us. Meanwhile, she seemed to be having more and more episodes of aggression, several of which ended up in psychiatric hospitalizations. We couldn't take her anywhere with us because we couldn't get along with her for any length of time; she even had to be excluded from her older brother's wedding because we feared her behavior would ruin it for everyone.

The Regional Office and provider agency were supportive, adding double staffing and supported employment to her budget, bringing in a specialist to write a positive behavior support plan and training her staff in PBS, but nothing seemed to work for long. When Jessie wound up being arrested and facing assault charges after a particularly violent attack on her staff and roommate, we knew something had to change.

Fortunately some new faces and new ideas appeared in the Division about this time. I remember sitting in a meeting with the new Self Directed Supports director, listening to her explain the principles of Self Determination and how important it was for people with disabilities to have freedom of choice in their lives, opportunities to fulfill respected and valued roles in their communities, the chance to give back to others and not feel constantly dependent upon others for assistance. I knew all of these issues had been important to my husband throughout his life as a visually impaired chemist—how hard he had fought to be “allowed” to take chemistry courses in the beginning, and how difficult it had been to convince a university that he could pursue a doctorate in the field and, later, to teach at the university level. But I had never thought about these things being equally important for Jessica, probably because of her cognitive limitations and her mental illness. I had only seen her in terms of her needs and her problems; I hadn't given much thought to what she could offer others or whether she was tired of having people tell her what to do. Could more freedom and choices and respect from others really make a difference in the quality of Jessica's life?

A few weeks later, I found myself in another meeting with our Division's new behavioral consultant, who reminded us that people who have truly happy, fulfilling lives seldom have problem behaviors. Again, I thought of Jessica...during her years in placement, we had addressed a number of organic reasons for Jessica's undesirable behaviors, through medications for her anxiety and impulse control disorders and through medical treatment for her hormonal imbalances, and we had filled her hours with a wide variety of activities, but her aggressive behaviors were nonetheless increasing. Was she trying to tell us that this life we had all planned for her wasn't making her happy or meeting her needs?

It was time to talk to Jessica about what she really wanted, what her dreams looked like, what she wished for with all of her heart as she was falling asleep at night. At first, she didn't trust us when we started asking her about what she wanted to happen in her life. She was uncomfortable with changes and she hated disappointments. She was cautious and guarded in her answers, as if fearing we were setting her up to hope for something that she could never have. But we kept asking and pretty soon we began to get the answers.

Jessica wanted to be part of our family again. She didn't want to move in with us—she knew that “grown up” kids lived in their own homes like her older brother, but she wanted to live close to us and see us more often. She wanted to go places with us again, to ball games and shopping trips and visits to family in neighboring states. She wanted to have her own home, with no roommate to fight with her and “push her buttons”, even if it meant she might have to be alone sometimes. She wanted to go to college or maybe work at the college (Truman) where her dad taught. She wanted to make new friends and spend time with old friends. She wanted to have a dog of her own, and a basketball goal where she could shoot baskets with her friends when they came over. She wanted young happy people for staff, who could “do stuff” with her and “teach her stuff,” and not get mad or impatient with her if she didn't do “stuff” right. She wanted a boyfriend. And she didn't want people telling her what to do all the time, especially when she could do it herself.



The light dawned. I wasn't the expert on Jessica any more, but neither was the provider agency or the lead staff or the Regional Office. JESSICA had become the expert on Jessica, and nobody had been listening to her.

We were ready to give Self Directed Supports a chance. Dave and I went house hunting in our neighborhood, a small established 1960s addition adjacent to the university, heavily populated by students and retired people...nice and safe and familiar, the neighborhood where Jessie grew up and where she said she wanted to live. The first trip around the block turned up a tiny well-kept two bedroom ranch “For Sale By Owner,” with a big fenced-in back yard. We walked in and knew immediately it was Jessie's house—the built-in doggie door was the icing on the cake—another one of Jessie's dreams that just might come true. We bought the house and prepared to become our daughter's landlords.

Next came staff. We had thought we had all summer to find staff, but a trip to a new psychiatrist with Jess resulted in a disastrous change to her medications that produced another major behavioral episode and hospitalization. The provider agency was done supporting her—we had less than three weeks to prepare her home and her staff before her discharge from the hospital. Thank heavens for college kids, with their boundless energy, unflagging optimism and unflinching need to pick up an extra buck or two! We were able to recruit seven students who were already working with kids with disabilities in a local summer program to work part time shifts with Jess. Paperwork was filled out, additional training was completed, shifts were scheduled, Jessie's belongings were moved. On June 23, 2009 at 4:00 pm, Jessica walked through the front door of her new home and her new life.

That evening, for the first time ever, Jessica' family gathered together at HER home, sitting around on the living room floor, playing "Sorry" and eating pizza, laughing and talking and just being a family again. *This is how it is supposed to feel*, I was thinking. *This is how it is supposed to be*.

Two months later, things are still feeling the way they are supposed to feel, for us and, by her own account, for Jessica. Our twenty-five-year-old daughter sleeps every night alone in her home after



turning on her burglar alarms and plugging in her cell phone next to her bed, knowing Mom is on speed dial just two minutes away. Weekday mornings she gets herself up before seven to let in the morning helper who makes sure she gets a ride to work on time. Jessica showers, dresses, fixes her hair and takes her own medications from a prefilled planner, fixes and eats her own breakfast, packs her own lunch. ("I can do it myself," she says when her staff, trying to be useful, offers to help with styling Jessica's hair.) After work (which is still supported employment at this point, but stay tuned) Jessica is picked up by another "teacher," one of those happy energetic college kids, who assists her with her evening activities: housekeeping chores, cooking, exercising and, of course, her active social calendar.

Weekends Jessie may sleep in or walk over to our house for breakfast with her brothers before going grocery shopping with me, or she may have staff coming in to assist with the meal planning and laundry. She calls every Sunday morning to make sure the family is up and getting ready for early church, because she doesn't like to be late. In her spare time she visits with the neighbors, talks to her friends on her cell phone, sits down at the computer to read an email from Aunt Glenda in Topeka or checks out the latest news on the Ben Barnes fan club web site. When people stop in to visit, including family and staff, they ring the doorbell and wait for Jessica to open the door, because it is HER door and HER home. She takes great pride in her little house and is not a bit shy about telling her careless brother to get his shoes off of HER couch. The satisfaction in her tone makes it clear that she loves being the one with some authority. Finally!

Has Jessica's behavior changed? Dramatically! She still gets angry at times, but she no longer seems to need to lash out at others physically when she becomes upset. She can go to her own room where no one is allowed to enter without her permission. There, she seems to be able to calm down and process the situation at her own speed and, when she is ready, she moves on with life. She's gone along with the family on several weekend trips with absolutely NO undesirable behaviors—not once did she argue with her two younger (now teenage) brothers...a miraculous accomplishment for any mortal human sister. Never have we enjoyed spending time with Jessica as much as we do now!

Does Jessica always do everything she is supposed to do? No, but neither do you or I—be honest! Now and then there is a day when the bed doesn't get made or the dishes don't get done until she feels like doing them, but she does eventually get to them. She is learning about the food pyramid and how to eat a healthy diet, and she is quite conscientious about daily exercise and taking her vitamins. Most days run like clockwork; she knows when she wakes up on Tuesday morning that she follows her Tuesday schedule, and that's what she does...because SHE chooses to do so.

Will all of Jessica's dreams come true? Maybe not all of them, but we are certainly off to a good start. Her dreams are already changing--after a week of caring for a new puppy, she decided that maybe being a pet owner wasn't all it was cracked up to be. After talking to her staff about all the homework suffered by college students, she's decided getting a job at the university would be preferable to getting a degree there. She takes walks on campus, making friends, checking out the kinds of jobs people do there, and asking her dad to put in a good word for her in the right places. Regarding the prospects for a boyfriend, she's not talking to the parents on that one, but she has been to several group activities with a certain young male coworker, the mention of whose name brings a bright red glow to her cheeks.

Does Jessica's success mean that self directed supports are for everyone? Each person has to make that decision for him- or herself. I can only tell you that it was the right choice for Jessica, and maybe her story will encourage others to consider the program as a possibility. If you are a parent or guardian, don't forget to **listen** to the person whose life is at stake...perhaps, like Jessica, they have hopes and dreams that they are waiting for someone to hear.

If you do choose to self direct, realize that self directing isn't easy. Sometimes Dave and I feel like we are working second jobs. The program both requires and *allows* us to be very involved in Jessica's life: hiring, training and supervising staff, reviewing and approving time sheets, filling out paperwork, making sure all of her medical and other needs are met, stepping in when staff can't work, etc. It necessitates a major investment of our time, energy and resources, but there are plenty of people to help us: Jessica's employees and support broker, our service coordinator and the self directed supports coordinator at the Regional Office, plus all the family, friends and neighbors who are a part of Jessica's life once more. I'm sure we'll face plenty of challenges in the future—life is like that. The important thing is that we'll be facing those challenges together...we're a family again.



Jess' New Home