

## **Sarah Goes to College**

### **\*Part 2**

**Sarah**

Sarah speaks:

The day before I moved to college, my mom asked if I was nervous. “No,” I told her, “I’m excited. Some people say that college was the best years of their life.” In late September, I moved to Seattle Pacific University, a 3000-student Christian college in downtown Seattle, Washington.

I am taking 12 credits in fall quarter. Spanish and Freshman Seminar are each 5 credits. Intermediate Spanish is a lot of review since I took Spanish for 5 years in public school. Freshman Seminar requires writing a short paper every week. Learning to write at a college level is a challenge! These classes meet one after another from 8:00 to 10:50 a.m. MWF. Freshman Seminar was scheduled to meet in a building that has stairs at the entrance and is far away from where my Spanish class meets, so the Disabled Student Services (DSS) office moved my Freshman Seminar to a room down the hall from my Spanish classroom. My third class is Women’s Choir. It is a 2 credit class which meets TTH in the afternoon. Fall quarter has gone well and I plan to take 15 credits during winter quarter.

I live in a 5-story dormitory called Emerson Hall. The dorm is 3 years old and it has many nice features like a laundry room, gym, elevator, underground parking, suites with bathrooms, and a kitchen and lounge on each floor. There are four floors for women students and one for men.

The Residence Life program organizes social opportunities for students who live on campus. Each dormitory floor has a Peer Advisor and a Student Ministries Coordinator. My floor-mates eat dinner together in the dining hall every Thursday. We have a floor discussion group that meets once a week, where we share our life stories. We drew names for “secret sisters”. In the evenings, I join several girls to watch TV in the lounge. Everyone make an effort to include me as much as possible.

The University has done a lot to make living on campus possible for me. It remodeled my dorm room, which has a roll-in shower and a drive-in closet. There is space for my wheelchair and equipment, and two single beds, for my attendant and me. My room is on the first floor for easy access and emergency exit. It has a height-adjustable desk, and I drive my wheelchair underneath it to work at my computer. The Department of Vocational Rehabilitation (DVR) purchased my computer, a Gateway with a CD/DVD drive, plus computer adaptations that help me study. These adaptations include a cordless mini-keyboard, mini-trackball mouse, and Kurzweil 3000, which is reading, writing and learning software that lets me read textbook pages on the monitor, highlight text, and extract notes. The computer can read the text to me with Kurzweil, even in Spanish. I also have a combination scanner/printer and handheld iPAC computer that downloads to the desktop.

I open my room door by swiping my ID card across the keyless entry pad. The barcode unlocks the door and it swings open. There’s a switch on the wall which I push with my wheelchair to open the door from inside the room. My attendants each have an

ID card they use to unlock the outside door of the dorm and my room door when they come to work. There is an underground parking place reserved for my attendant.

I have an attendant with me all the time. My daytime attendant, Linda, is paid by DVR. She works 43 hours per week. Two attendants, Nabila and Kelly, work alternate nights Monday through Thursday; they are paid by the Community Options Program Entry System (COPES), a state program that provides personal care. I have one volunteer attendant who comes on Tuesday mornings.

I met Linda the day before classes started. The first week I felt uncomfortable with her because she laughed all the time and I felt like she was laughing at me. Maybe she was nervous. Finally we had a private talk and she told me not to worry about hurting her feelings, but to let her know what I wanted and what bothered me. She wanted us to have a good working relationship. Once I was honest, I have gotten used to working with Linda and our relationship has improved.

My overnight attendant Nabila works for a home health care agency and has been taking care of me since last spring. Kelly was one of my aides in high school. She is an Independent Provider and I am her only client. Kelly has a different job during the day and the hours she works for me depend on her work schedule at her day job. Once a week, she has to leave at 6:30 a.m. so I have to get up at 5:30 and be dressed at 6:30 when Linda arrives. I have to remember to go to bed early the night before or I fall asleep in class! Some evenings, Kelly comes at 7:30, two hours after Linda leaves. My dad is a professor at SPU, and he stays with me until Kelly arrives. We eat dinner together.

I am happy to say there has not been a single time when my attendant has not shown up for work. A few times, an attendant has told me ahead of time that she can't come, and I have been able to rearrange the other attendants' hours or find a classmate or my dad to help me. Dad meets me at 5 p.m. on Fridays and I come home for the weekends. Sometimes I come to campus over the weekend with my dad or mom.

There are some physical accommodations and procedures for students who have disabilities at Seattle Pacific University. There are automatic buttons to open the doors, as well as elevators in most of the campus buildings. The Mailing Services Dept. collects the mail from my student mailbox and I pick it up at the desk. When I couldn't find food I could eat for lunch, I met with the food service director. I suggested some soft, protein-rich foods I enjoy, and they added tuna fish and egg salad to the lunch buffet. Also, I can register early for classes each quarter. This gives the DSS office time to scan my textbooks and change room assignments, as it did fall quarter. Early registration allows me to get into the classes I want before they are filled.

There were bound to be some unexpected challenges in my move to college. The first week, I wrote a paper on my iPac handheld computer, and when I tried to download it onto my computer, the computer didn't recognize it, so I couldn't print it. I called DVR for technical support, but the paper had to be retyped so I could turn it in on time. Thanks, Dad!

Another challenge is getting enough sleep. I enjoy watching TV with my floor-mates until 11:00, and I go to bed at midnight. The problem is that I have an 8 a.m. class: I was falling asleep in class. I've been taking a nap on weekend afternoons and going to bed earlier on the night before my 8:00 class.

Once, my wheelchair broke down. I used my uncomfortable old manual chair while my mom took my Permobil power wheelchair in for repair. It took 10 days, three

service calls, and an overnight delivery of parts, not to mention patience and perseverance from everyone, before the wheelchair was fixed. I was able to stay at college and didn't even miss any classes.

I love college. I'm learning and making friends. I'm also gaining important life skills like working with attendants, supervising my personal care, keeping track of my belongings, and managing my schedule. Living away from home is great. I'm having the time of my life.

Marilyn speaks:

“We are at the edge of the waterfall, about to go over. Last night Sarah's dad dreamt about falling over the brink. I dreamt that Sarah was attacked and nobody advocated for her when I wasn't there.” This was my journal entry the morning my daughter, Sarah, attended her first college class at Seattle Pacific University.

The day Sarah moved into the dorm, I accompanied her to the US Bank to buy quarters to use in the washing machine. I was transported back to last February when Sarah opened her checking account. We chose US Bank because it had this branch location on the campus. The efforts of eight months ago made this transaction easy. Opening her bank account was one of dozens of preparations Sarah made to get ready for college.

Sarah spent the nights at home that weekend. She returned to campus Sunday evening to attend her residence hall meeting, and stayed overnight with her long-time respite worker, Somer. The next morning, Somer wrote this email: “I just got home from staying with Sarah, and we had a really good night. I think she was nervous because she was up at 3:00, and again at 4:00 and 5:00. All the meetings went well. Sarah was quite the social butterfly going around introducing herself to people and talking it up with everyone. I stayed in the background and let her do her thing. We didn't get into bed till almost midnight. It was hard this morning leaving her as she went off. I almost started crying because I am so proud of her. I still don't believe she is old enough to be in college. You and Rick should be so proud.”

Sarah's dad, Rick Steele, is a professor in the School of Theology at Seattle Pacific University. When he introduced himself to his students on the first day of class, Rick told them he is the parent of a freshman. A student raised her hand and asked, “Are you Sarah Steele's father? Sarah is on my floor. At the meeting last night, she volunteered you to be in the Emerson Hall Film Festival!” When Rick related this exchange, he added dryly, “Imagine my joy.” But he was smiling.

Sarah called me after the first day of classes. As I hung up, I said, “Talk to you soon.” Sarah responded, “Well....maybe.”

Making it possible for Sarah to move to college is the most gratifying thing I have ever done for her. Seeing her custom-remodeled dorm room, watching university staff welcome her, working with a team of providers -- Social Security, Medicaid, Independent Living Center, and Department of Vocational Rehabilitation -- is immensely fulfilling. But it is a huge transition. Our parental roles have shifted. Rick is more involved in Sarah's daily routine. He drives the wheelchair van so he is available if Sarah needs transportation, and he stays on campus until Sarah's overnight attendant arrives. Sarah calls Rick when she needs help with her computer or wheelchair, or has questions about

university procedures. Our schedule at home is different, too. Weekdays are quieter and evenings are more leisurely, but the weekends are busier than ever. Sarah is tired when she comes home on Friday nights. She brings dirty laundry, a grocery list, and homework. I spend the weekend helping her get ready for the next week.

As Sarah said, there have been some challenges. I notified Social Security when Sarah moved to campus and SSI did a re-evaluation of Sarah's eligibility. SSI ruled that room and board costs more than a person who depends solely on SSI income can afford. Paradoxically, Sarah's monthly SSI check has been reduced by \$200. This is a penalty she will have to pay in order to live in the dorm.

Another challenge was the venue of the fall choir concert in the sanctuary of the campus church, Seattle First Free Methodist. The chancel has three short steps, an insurmountable obstacle for Sarah's power wheelchair. A university staff member built a ramp, and, on the night of the concert, I went with Sarah to try it out. It is a bulky contraption made from rough 2x4s, in sharp contrast to the polished oak woodwork in the sanctuary. I suggested that someone stand beside Sarah, to make sure the wheelchair didn't fall off the planks. After Sarah tested it, the ramp was dismantled and stored under the front pew until it was Sarah's choir's turn to perform.

During the concert, the men's choir filed in procession down the center aisle and up the three steps to the chancel. After their performance, the singers recessed, except for four tenors in tuxedos. The young men assembled the ramp and stood beside it while Sarah drove down the center aisle, up the ramp, and onto the chancel. I could scarcely keep myself from applauding. It was a metaphor for the graceful approach the University has taken to meeting Sarah's needs.

There is a postscript to this story: The sanctuary was remodeled last summer, and the architect was in the audience at the concert. He volunteered to design a permanent ramp.

The next concert was a Music Department Christmas extravaganza held at Benaroya Hall, home of the Seattle Symphony. Sarah sang Mendelssohn and Gounod with 200 fellow students. To see her on the stage of one of the finest concert halls in the world, before an audience of thousands, was stunning. We couldn't have imagined this kind of achievement 18 years ago, when Sarah was diagnosed with FOP.

Is all this effort worth it? Not everyone would say it is. I talked to my doctor about our work to help Sarah live at college. He responded, "Wouldn't it be easier just to let Sarah live at home?" After the University DSS Coordinator took an inventory of Sarah's needs, she said, "Do you think Sarah could commute?"

Making it possible for Sarah to go to college and live on campus takes tremendous effort from a host of people, including Sarah. We think it is worth it. Sarah is gaining freedom, independence, and higher education. Being able to attend college will raise her expectations of what she can do in life. As her dad said, "This is the best thing that ever happened to Sarah, and she knows it!"

\*Part One is in the first edition of *Working Together for Successful Transition: Washington State Adolescent Transition Resource Notebook*