Heading off to College

Preparing for the transition from high school to post-secondary education is a tremendous milestone for anyone. For those with CdLS, as well as their family members, this transition may come with unexpected challenges. It may also be very rewarding and gratifying experience. Emily (pictured left), a 20-year-old from Alabama, who has finished her first semester in college in December, also has CdLS. Her mother, Sandra, shared her experiences preparing Emily for college and Emily’s experiences during the first months in school.

Preparing for Emily’s transition:

Exploring college choices was part of Emily’s Individualized Education Plan (IEP) transition services goals. Emily initially wanted to attend a larger school, further from home, but we encouraged her to visit other schools. I felt she needed to be in a smaller environment to succeed. Emily ultimately decided where to attend. In most other ways, it was just like preparing my other daughter for college: lots of college visits, applications essays, entrance testing, etc.

Emily had to take the American College Testing (ACT) Exam test three times before she scored high enough for admittance. She scored enough on her first test for conditional acceptance (which meant fewer class hours, monitoring, etc.), but she was determined to score high enough for unconditional acceptance.

About Emily’s resources:

The university Emily is attending has a disability support office, which has been a great resource. We met with the coordinator at one of Emily’s first visits and kept in touch with her throughout the process. I let Emily handle all of the discussions with their office (though I was there if needed) because I thought it was important for Emily to take ownership of this process. She currently receives extra time for test taking, can take tests in their office, and receives study notes taken by a school-provided note taker.

We started early in Emily’s education preparing her to advocate for herself, so she’s really good about that. When transition services started at age 14, we made sure Emily knew what her IEP said and prompted her to use her accommodations, but we tried not to let her use her IEP as a crutch. Emily has always been driven by an intrinsic desire to succeed with as little help as possible.

All public universities and many private schools have some form of disability support. As parents, we don’t have many rights once our kids enter college because
they are considered adults, so it’s important for the kids to know where to go for help, and to be comfortable accessing that help when needed.

**About the transition:**

The most difficult part of this transition for me was letting go of the control I’ve always had. Emily had participated in week-long youth camps held at college campuses away from home. These helped prepare her for college life, but she said leaving home was the most difficult part for her. Though she did have some difficulty passing the ACT testing requirements, she could’ve gone to a junior college first if she had not scored high enough.

**About Emily’s first semester:**

Emily is majoring in education and wants to be a special education teacher. I’m a teacher, her aunt is a teacher, and her grandmother was a teacher, so it made sense to Emily.

She loves kids and relates well to children with special needs. Emily says she likes that her classes only last one semester, so she isn’t stuck in any one class for too long.”

She mostly likes her classes, but did feel a little overwhelmed during finals. She loves the social aspect, but is having a little trouble adjusting to fewer academic supports (such as having projects broken down into incremental due dates). She joined Phi Lambda, which is a social club (similar to a sorority). She’s also a member of W.IN.G.S. (Women in Godly Service), which is a group of female students that participate in church-sponsored youth events.

**Advice:**

My biggest advice for those thinking about college: start saving now! Emily doesn’t qualify for Social Security Income (SSI) because she’s so mildly affected, so we are funding it on our own. Also, start early working toward independence if you hope for your child to be independent. In college, students get accommodations but not modifications, so start removing modifications from your child’s IEP early in high school. A good school system will help you do this as part of their transition efforts, but parents need to be aware of this, and understand that it’s designed to help prepare students for higher education.