

“Mind the Gap”

by Deb D’Luna

“Mind the gap.” The gap between school and adult services is a yawning crevasse without a clear bridge, no matter how many transition forms the school staff complete.

In California, a student with disabilities ages out of eligibility for special education services at age 22. To parents and family, this fact comes as no surprise, yet after 22 years, it’s easy to become reliant on the partnership of special education teachers, staff and administrators. At home, parents must constantly cope with the special needs of a disabled child. During weekdays, the time spent at school is not only intellectually challenging and nourishing for the special needs child, but that time is precious for the parents and caregivers as well. Those are the hours when someone else is responsible, someone else is scheduling the day, the hour, the moment, and providing multiple opportunities to grow in independence and understanding of the world.

Certain as death, age 22 looms ahead as an endpoint. But, like other inevitable ends, the end of special education services is hard to embrace, to imagine, to appreciate, and to really plan for. ‘Transition’ is a special education euphemism that educators use to describe a lengthy time period at the end of school age eligibility. ‘Transition’ evokes images of a smooth progression, a knowable pathway from here to there; in a perfect world, during Transition, things would be ironed out and made ready in anticipation of the last fateful day of school. We call it ‘Aging Out’ because the unvarnished reality is that the reason a student must exit school is age. This phase is actually a frightening and worrisome period before you are in it; families, who are always and everyday the caregivers and decision makers, are suddenly more than ever in the thick of it and alone without that familiar partner and sometimes-adversary, SCHOOL.

In our case, this end occurred with the winter break. As a result, the end for Alexis was confused and muddled by the usual hubbub; the last days before the holiday in a special education classroom are always exhaustingly frenetic. December 18, 2009 came and went and it is doubtful whether Alexis understood that, as she stepped out of the classroom for the last time, she was saying goodbye to friends and staff permanently.

Much as we had anticipated and prepared for this event, we were completely overburdened by the task ahead. Alexis had a resume of work experience developed and supported by the school district staff. With the one-on-one support of her signing aide, (in the field of the Deaf-Blindness, a position called an Intervenor) Alexis had worked at Walmart, Trader Joe’s, LaQuinta Inn and Irvine Valley College. Her Intervenor communicated with the employer and first modified,

then led Alexis through tasks enabling her to be successful: folding towels, photocopying and shredding, sorting and shelving energy bars or frozen foods and even tidying up the rugs and cleaning supply section at Walmart. We felt really confident about Alexis' ability to carry on being a useful participant in a work setting somewhere. We had been told to open a file with the Department of Rehabilitation, talk to Regional Center, get in touch with our school district's Transition Specialist, visit Adult Day and Supported Employment Agencies.

For several months beforehand, we visited, we met, we interfaced. We had been told that adult services are completely unlike anything we had experienced in education. This proved to be a vast understatement. For one thing, in education, a free and appropriate placement is mandated. The focus is on the student's needs and how these needs can be met and remediated. The child's needs are explored, dissected and diced into tiny increments so that goals can be written in measurable benchmarks and then worked on.

In adult services, the focus is on the individual's strengths and abilities because a placement in the world of adult services is at the discretion of the agency. The adult service agency determines whether the individual is a 'fit' with the program, its current clients and the sensibilities of the staff. In plain speech, beyond safety and basic human dignity, very little is mandated in adult services.

For example, we were astonished to learn that sign language interpretation is pretty much non-existent in the working world of the developmentally disabled. One massive agency in Orange County said that they don't provide interpreters or even minimally signing aides, but rely on writing notes to their developmentally disabled deaf clients when communication is necessary. (We were left wondering what kind of information would be deemed important enough for a note. It was sad to think of her cluelessly waiting for a note.) This enormous agency would not even consider our request that they seek a signing job coach that could be shared among Alexis and other deaf or non-deaf clients; they stated that there are plenty of other clients waiting for a placement who do not need such specialized support and flatly refused to discuss the issue further.

We soon realized that our daughter's needs were our dirty little secret; it was her abilities, limited though they were, that we showcased. During exploratory visits, we made our own assessments of whether Alexis could fit in with the program as we observed it. Alexis herself seemed to realize this and eagerly tried to perform whatever task was underway during our observation visits even plunging her hand into dirty dishwater and scrubbing a pan on a visit to a cafeteria work site. We became highly conscious of not making demands or of being seen as difficult.

Although Alexis has always been our exclusive responsibility, the burden felt particularly heavy because, after the holiday period, her days and nights were spent with the two of us trying to keep her busy and content. While we searched for a day program, Alexis was at loose ends, all day every day. It was clear that she was lonely and bored; she became increasingly agitated and dismayed by her empty days. Whatever our worries and concerns, Alexis was the least

emotionally prepared for the end of her school days and appeared to feel rejected, despondent and in grief over the loss.

With the economy in the doldrums, work opportunities were rare and many reliably trained and physically fit individuals with developmental disabilities were out of work. Surely these proven work horses would find positions before Alexis when things did pick up. We did not want her roaming the malls and parks. There seemed to be nothing of an educational nature. Our Regional Center Service Coordinator kept giving us suggestions but each visit showed that either the environment was too noisy for her with hearing aids, or the tasks too mindlessly repetitive or physically too challenging, until at one meeting our Service Coordinator said we should look at Hope University in Anaheim. Hope University is a fine and performing arts infused adult day program whose motto is: "Train the talent, diminish the disability."

We visited the facility – Kim showed us around, Alexis picked up a bell and rang it. Minako welcomed her to join in the music therapy sing along and Alexis was already in her element. Hope had her for a 3-day assessment and then, after 4 months we got news that there was a spot for Alexis at Hope for a 90 day provisional placement. That was 17 months ago. Each day since has been life-transforming for Alexis and for us. Alexis is not a musical or artistic savant (as are some of the students at Hope), but she has talent and passion in both areas that is being trained. All her life, she has had a love of music; she attended to music and perked up when nothing else could reach her, but her passion for art had been completely un-explored. Her drawings have been a revelation to us and a peak into her mind's eye. Through their patience and encouragement, the Hope University staff adds meaning to each moment of every day.

Weekdays, when Alexis gets home, we ask, "How was Hope, Alexis?" She says "Good," then pauses a moment to think and adds, "I had a wonderful, wonderful, wonderful day at Hope University today." That's a routine we have loved getting used to.

Alexis is now nearly 24. Two years ago, she aged out of special education services in Irvine Unified School District.