Saved by CART

By Kelly Klapstein

When she was 16 years old, our daughter, who was Hard of Hearing, suddenly lost her remaining hearing and became Deaf. It happened during summer break, in mid-July, and we were shocked and heartbroken. Up until that fateful day, Serena had attended public school, and was mainstreamed with no assistance or intervention. With her hearing aids, she was participating fully in the hearing world.

Learning ASL overnight or attending the School for the Deaf was not an option that we considered. Removing her from her familiar world of school and friends would only cause more stress and anxiety. Our immediate application for a cochlear implant involved about a year of waiting before surgery and activation.

After countless hours searching online for answers and making phone calls, I connected with the Edmonton Chapter of the Canadian Hard of Hearing Association (CHHA). The President, Cindy Gordon, asked me if I knew about CART and told me it could help our daughter if she decided to stay in her current high school. I had never heard of CART before, so Cindy put me in touch with the President of the Alberta Shorthand Reporters Association (ASRA), Linda Halworth. Little did I know that this would turn out to be the answer for which we were looking.

I quickly learned all about CART. CART stands for Communication Access Realtime Translation. With CART, you can see a translation that is being created in realtime on a computer screen. The translation is created by a shorthand writer. But I still could not really understand how it worked, and if it would help our daughter in the classroom. With Linda's assistance, I organized a meeting with all the teachers, administration and support staff for a demonstration of CART in the school board room.

It was now the beginning of September, and I was feeling desperate because the Voice to Text software program (DragonSpeak) the school was using in the classroom was failing miserably. Our daughter was trying to read the translations on her laptop while the teacher spoke into a microphone. The accuracy was only 30% correct, if that. I could see her weariness and exhaustion at the end of the day. She would fall into silence at the dinner table, looking and feeling more and more isolated.

The CART demonstration changed our lives. We were astonished with how quickly the typing and captioning worked, and for once, Serena could follow the entire discussion. Everyone who spoke was recorded fluidly and in real time. I almost cried with relief at that moment, knowing that our daughter would be able to continue her education in her high school with her friends and favourite teachers. The trauma of losing her hearing lessened that day.

The only remaining hurdle, of course, was funding. The fee was to be $100/hour. However, we were very fortunate when the school board decided to fund her entire Grade 11 year for CART services. We also were very lucky to have an excellent CART provider who worked well with our daughter. Within a couple of weeks, there was a marked difference in our daughter's energy level and attitude, and she was starting to participate in discussions in class again.

Although Serena's marks were lower than usual at the end of the school year, she successfully completed all of her classes, played on sports teams and was active in student council. Even without CART outside the classroom, her confidence was bolstered when her lip reading became extremely proficient, and a new set of high-powered hearing aids gave her some sound so she could interpret speech better with the lip reading. Her school life was enjoyable and rewarding, thanks to CART.

However, before the year ended, we were called into a meeting to discuss the future of the CART service for her Grade 12 year and were told that the board would not fully fund CART the following year. Our Learning Coach in the high school was assigned to request additional funding for our daughter as a

Complex Case through Alberta Education and the Regional Collaborative Service Delivery (RCSD).

The RCSD is intended to provide a regional model for support to schools and community partners to meet the needs of children and youth (ECS to Grade 12), as well as to families who have children and youth with complex needs (birth to 20). It is also intended to strengthen the capacity of service providers to collaboratively respond to those needs.

After many hours of filling out forms and making phone calls, the high school Learning Coach and I met with a panel from the RCSD and had a 'roundtable' meeting where we presented our Complex Case. Our audiologist from the Glenrose Hospital also joined the meeting via a telephone conference call, which was very helpful. It was very important that we had the support from the health care field, who supplied valuable information to the panel. It was a stressful meeting with a lot of serious questions, and about a month later, we learned that we were approved for partial funding. Happily, our daughter would finish her final high school year with full CART services.

As I write this, our daughter is writing Diplomas exams and is halfway through Grade 12. She had cochlear implant surgery, and her CI was activated in early September of her grade 12 year. Through the miracle of technology, she can now hear and is improving as time goes on. She still uses CART in all of her classes to fully support her hearing and learning experience. She plans on continuing on to university, hopefully at the University of Alberta, where she will receive full support as a Deaf student in terms of CART services from the Alberta Government.

When I learned that CART services are fully funded for all students in post-secondary university and college programs, I felt dismayed that the students in high school did not have this funding. I believe CART should be provided for students in Grades 7–12, not only high school. They should not have to struggle with limited support of FM/DM systems and Education Assistants alone, when technology like CART exists and can benefit students in the classroom in a

significant way. Perhaps advocacy for CART services in secondary schools should be pressed upon the government and Alberta Education to ensure that all of our children can be successful students.

Without a parent's efforts in advocating for the child's rights to attain special services in school, nothing will change, and our Deaf and Hard of Hearing children will be overlooked and fall behind. Throughout this experience, I learned that I have to speak up and be assertive about getting the assistance and funding my daughter requires. Even my daughter's teachers in high school have wondered what would have happened if I hadn't insisted on CART in her classrooms. Being informed, joining advocacy groups and searching for answers is an integral part of our journey with our children.