

## **The Elusive Skill of Self Advocacy**

**By Penny S.**

Most of my days are spent trying to help my son remember where he may have left his gym uniform, putting out other behaviour related fires, coaching his sister not to respond to his attempts to ‘troll her,’ fielding calls or responding to emails from teachers, monitoring the time limits on my son’s videogames, putting food in front of him to eat despite his lack of appetite from the meds and ....oh, yes, ensuring that we maintain consistent pressure as advocates in the school to help ensure his success. Would I want him to take some of that off my plate and set up meetings with his teachers, write down his homework and remember to bring his assignments home? You bet I would!

My son is currently in Grade 11 at a school board in the GTA. Over the past year, there has been a distinct move by the administration; teachers and his other support workers to encourage him begin to develop the skills to ‘self-advocate.’ Magically, somehow.

Last semester, tossing him out of the proverbial nest resulted in two failed courses and bare passes in the others. “Guess he wasn’t ready,” was a typical response. You think? Or was he set up to fail from the start?

What is Self-Advocacy?

I looked up a definition of self-advocacy as even I wasn’t sure about what it meant.

**“Self-advocacy is understanding your strengths and needs, identifying your personal goals, knowing your legal rights and responsibilities, and communicating these to others.”**

*Author’s note: I don’t usually do sibling comparisons, but I am also witness to his sibling who was somehow born with these abilities or absorbed them by osmosis. She has been able to use these skills very successfully in her everyday life and her career of –so far- academic success. So the question as a parent is always: how can I help explain, model or teach these skills if they are not ingrained?*

The concept and process of self-advocacy has been borrowed and refined by the adult disability community over the past 10 to 15 years. The approach acknowledges that in the past, service and healthcare providers, parents, and the legal system more often than not provided service without

actually listening to the individual themselves. There is the assumption that by teaching self-advocacy skills to younger age groups that they will be more effective in ensuring their earlier success in a sometimes unforgiving environment (i.e. high school) and beyond.

Within this approach of coaching the skills of self-advocacy is a list of steps, stages or items that might include: Understanding His Learning Problems, Practicing Communication, Meeting with Teachers, Defining Successful Strategies for Yourself and Knowing His Rights and Actively Participating.

Although these are critical skills to learn, I believe schools have an assumption about the level of maturity and receptiveness to this process of those kids that just don't 'get it' when they are supposed to.

It only works if your kid is motivated, organized, has great communication skills, a good memory and can be dragged off the video game long enough to pay attention.

In reality, some of the skills inventory are offered either through the curriculum, for example in family studies or for students who are required to take a GLE or GLS course (otherwise known as Learning Strategies). In many of these courses, students are offered the chance, year after year, to complete some form of a learning style or preference questionnaire. As with many ADHD students, my son, year after year, showed strengths in oral communication and was identified as a kinetic or experiential learner. I always found it ironic (as did my son when he began to see a pattern) that the school would offer repeated opportunities to help the students identify their strengths as a learner, yet were unable to provide the kind of accommodations to truly meet those needs (for example scribing his test or exam answers). The whole model of high school is still based on the concept of one-way information from teacher to students in a sit down and listen model of delivery.

### **Asking for an Accommodation**

This is the approach most often suggested to our teens when they are in need of help in school. I recall so many instances in IPRC meetings (as well as ADHD our son also has learning disabilities that qualify him for extra support services) and parent interviews where we were assured that all he needed to do was ask and he would receive the support he required at the time (ability to work in the resource room, more time for an assignment, a 'walk around').

My own experience as a teenager (and as a parent in the middle of raising two at the moment), is that the LAST thing any teenager wants is to be is DIFFERENT. Our kids with ADHD are super sensitive to the feeling of already being different, but with an invisible disability you can often 'pass' as normal. The last thing my kid is going to do is further differentiate himself, especially in front of his peer group. His response instead is to either 'check out' or get discouraged, or else (more often) act out his embarrassment.

My son was often confused and would become frustrated when he would make the request, for example, to relocate to the resource room and was denied. "But I asked Miss, just like I was supposed to and she said, 'No!'" He feels it is unfair, but from the teacher's perspective the question was asked at an inappropriate time. Had she not been at the beginning of a chaotic class she may have said "Yes, you can after I review the reading from yesterday with the whole class and show a short movie, and call down to see if Mr. K has any space in the room, then you can leave and complete the worksheet in the resource room." How do you teach this skill?

The skills involved with self-advocacy are the ones that our kids struggle with most. Remember that the core symptoms of ADHD are:

- Misinterpreting instructions
- Unable to pay attention to details
- Completing work without being reminded
- Difficulty organizing belongings and work and Losing things
- Difficulty starting things
- Forgetting normal routines

Not to mention the overlay of an often sullen and moody teen, the curse of procrastination and impaired executive functioning, about which the CADDAC website has this to say:

"Executive functioning skills enable us to: identify a problem, find solutions, organize ourselves, regulate our behaviour and emotions, control our attention levels and resist distractions. Working memory, an important part of executive functioning, is a skill that allows us to keep information in the brain and work with it at the same time. Working memory directly impacts reading comprehension, written expression, math skills and the ability to pay attention and resist distraction. Students with ADHD also frequently process information coming in and going out at a slower speed. Children with deficits in these areas, are frequently mislabeled as being unmotivated, defiant, and lazy."

Sounds like an accident waiting to happen. Our kids are going to get it later than others and it will mean that if our advice is still worth anything (and some days I've been told that it is not), we will need to understand how best to support our teens as they transition into a world that will have expectations about their abilities based on their ages alone.

For now, I will continue to email his teachers until he is ready to take it on himself, with no judgement. While I was thinking about writing this column about self-advocacy this week I watched a perfect example in action on public transit. One morning last week an older lady got on an extremely crowded subway car a few stops after mine. As she entered the car she explained in a loud voice that she would require a seat for the trip and while she was getting settled she would also need to have someone hold her takeout coffee. Someone immediately got up and vacated a seat for her while someone else held her coffee. She sat down, got settled and then reached for her coffee with a smile and a thank you to all. The rest of us looked on with a mix of curiosity, jealousy & that distinctly uncomfortable feeling we Canadians get when someone has not only the nerve to speak loudly to strangers, let alone ask for something for themselves. I could hear us all asking ourselves if we would have the courage to be able to so easily ask for help and support in that same way. I know for certain that I couldn't. Why does the school system expect that our kids are experts?

There are not tons of resources out there about this issue, but here are a few online resources that I came across. Please let CADDAC know if you come across any others.

[http://canlearnsociety.ca/wp-content/uploads/2013/03/LC\\_Self-Advocacy\\_N2.pdf](http://canlearnsociety.ca/wp-content/uploads/2013/03/LC_Self-Advocacy_N2.pdf)

[http://education.alberta.ca/media/513297/unlock\\_8.pdf](http://education.alberta.ca/media/513297/unlock_8.pdf)

[www.greatschools.org/special-education/health/797-self-advocacy-teenager-with-ld.gs?page=2](http://www.greatschools.org/special-education/health/797-self-advocacy-teenager-with-ld.gs?page=2)

<http://www.ldonline.org/article/32728/>

