

Becoming an Effective Advocate for Your Child

At Hands & Voices, our mantra is “*What works for your child is what makes the choice right.*” As a parent, you know your child best and will therefore be your child’s most important advocate until he’s old enough and informed enough to speak up for himself. You know your child’s strengths and challenges, and you can help identify and push for the resources your child needs to succeed. Because every child and situation is different, advocacy can take many different forms and approaches. Here are some tips to help you effectively advocate for your child.

1. Keep a paper trail.

Make sure to keep copies of all report cards, progress reports, evaluations, educational assessments, medical records, homework samples and other documents. They can provide insights into your child’s learning issues and how much progress he’s making. Take notes at important meetings and keep copies in a file. See the *Keeping Track* section of this toolkit to help organize records.

2. Study up.

Read and attend workshops. Get insights from parents whose children have similar issues. This way you’ll be familiar with challenges you may face and what resources are available to you.

3. Build relationships.

Get to know your child’s support team (including medical professionals, teachers, counsellors, etc.). Building relationships with these people will help keep the lines of communication more open. There’s less of a chance of misunderstanding if everyone knows each other. See the article *Relationship Building is the Place to Start* following this article for more information.

4. Ask questions.

It's important to work with the school, but don't be afraid to ask for clarification, request further testing or question the school's decision regarding services. It's a good idea to submit in writing any requests or questions. Keep copies of these requests that include the date you sent them. It might also be helpful to keep a log of whom you spoke to and when. See the article *Questions to Consider Asking Your Support Team* in this toolkit for suggestions.

5. Stay calm.

Remember that the teachers and other school staff members involved are there to help, even if you disagree with them. The process will go more smoothly if you listen and keep an open mind. Make a list of the topics you want to cover in important meetings. Take deep breaths. Consider bringing a friend or relative who can take notes for you and help keep you steady.

6. Remember that you're in control.

Parents should never feel pressured by school staff to make a decision. Ultimately, you're in the driver's seat. So while it's important to be receptive to the school staff's thoughts, don't agree to something you think goes against what's best for your child.

7. Know the law.

Learn about your child's rights. See the *Disability Rights in Alberta* article in this toolkit for more information. Your child might have the right to extra time on tests and other accommodations or modifications. Keep informed about your school's legal obligations to provide your child evaluations and other services. You can also bring a parent advocate with you to important meetings.

8. Talk to your child.

Understanding what your child is experiencing in school is essential to advocating for his needs. For example, the 30 minutes he's supposed to spend each week with a speech therapist might only be 20 minutes because the therapist keeps showing up late. Asking your child detailed questions will also help him understand what he needs. This will help him advocate for himself when he's older.

9. Know the lingo.

Find out whether the speech therapist and other service providers are "pushing in" (working with your child in the classroom) or "pulling out" (taking your child to a separate location). This is important because your child may say he didn't go to speech that day, but it could be that the speech teacher pushed into the classroom.

10. Attend meetings regularly.

Individual program planning (IPP) meetings and parent-teacher conferences are obviously good opportunities to get an update on your child's progress, but there are also other times. When teachers host a publishing party so kids can showcase their work, this is a good time to see what's been going on in the classroom. PTA meetings may provide insight into curriculum changes. The PTA can also help push for weekend test prep and other resources that could help your child.

Also, remember not to be too hard on yourself or your child. A lifelong journey lies ahead and lessons will be learned along the way, contributing to the richness of that journey!

Geri Coleman Tucker is a freelance writer and editor and a former deputy managing editor for USA Today. She also writes the Asperger Ascent blog. Tucker, a graduate of Kenyon College, is based in the Washington, DC, area.

-Adapted from [Geri C. Tucker, Ten Ways to be an Effective Advocate for Your Child](#)

Relationship Building is the Place to Start

Adapted from Andrea Marwah

"I'm going to get what my child needs no matter what the cost."

Ever feel or say a statement like this? Ever feel so frustrated with your school district that you're ready to scream? I'm sure we all have. Even those of us who appear to have seamless Individual Program Plans (IPPs) and workable teams feel this way from time to time.

What we should consider, however, is the ramifications of this and similar "Let's go to war" statements. What is the actual cost of being a very forceful parent? And going to war assumes an enemy. Usually, members of teams *want to help*. We need to remember this and try our best to work together. Sometimes working together is complicated because the 'systems' we work within limit what we can do. More rarely is a specific challenge or delay due to an individual not wanting to try their best to help.

An IPP team needs to be open minded, flexible, and respectful. They should be knowledgeable, certainly. How do we build these relationships with school personnel and how will it mold our child's journey through school? We all know the saying "the squeaky wheel gets the grease." This is true, right? But we should also consider that after a while, the squeaky wheel just goes unnoticed and becomes more and more "damaged." The same goes with your relationship with a school. Once that relationship is damaged, it takes many years to repair, if it is even salvageable.



See the *Getting Ready for Kindergarten* document in this toolkit for information on IPPs.

So, what can we do to make sure we create and maintain a positive parent/school relationship?

Many things come to mind but first and foremost we need to be respectful and understanding. It's easy to get angry and blow up in the face of adversity. The problem isn't in the act of "blowing up." The problem is that many professionals discount the highly emotional or angry parent. We can go in and throw an "adult" temper tantrum to get what we want but then every time thereafter you will have to fight harder for what you need for your child. And you may be causing emotional harm to those you are fighting against, who may actually be limited by challenges in the system or policy and may not be deserving of your anger.

One main goal of successful advocacy is to teach our children how to stand up for their own needs

We also need to remember that our children are watching us. One main goal of successful advocacy is to teach our children how to stand up for their own needs in a respectful way, and to work toward greater societal inclusion.

We therefore want to model more reasoned, respectful, collaborative actions.

So, here are a few easy steps to maintaining a healthy parent/school relationship.

1. Work with your team.

If you wish to be considered a respected team member, you need to respect the other members. This doesn't mean you have to always agree with what is said, but it does mean one should show respect for expertise.

2. Always be prepared for any school meeting or conversation.

The more prepared you are, the higher the chance your team will accept you as a knowledgeable team participant.



3. Don't lose your cool.

There is nothing more detrimental than the impact of an adult temper tantrum. Screaming, demeaning, and demanding are never a good idea.

Always cool off before speaking with school personnel.

4. Always cool off before speaking with school personnel.

In order to make sure that you won't lose your cool, allow yourself a cooling off period. Don't immediately go in with assumptions that you must fight or argue; it's more effective to have your well thought out rationale ready but only use it if necessary – listen first!

5. Find ways that you can turn a negative situation into a positive one.

Come to meetings or conversations with ideas that work. Sometimes school personnel may just be stumped as to what to do. As a parent, you may be pointing out a need that is not presently being addressed. All the better if you have suggestions for how to address this need.

6. Consider ways to create positive relationships with the team outside the meeting.

Do they see you only once a year? Even if you can't volunteer or support the school, you can thank a teacher or a therapist for an especially good experience or troubleshooting for your child.

7. Last but certainly not least, let go of your assumptions.

Every team meeting is a fresh meeting. Past history may lead you to take an offensive strategy, ready to fight or advocate at every turn. Sometimes, people will surprise you. Maybe a solution has already been worked through. Enter every conversation and meeting with a positive assumption that people are there to help, rather than hinder, your efforts to support your child.

We are equal members of the IPP team. That right doesn't make us the leader of the team; it makes us an equal participant. How we come prepared to problem-solve at the meeting shows us as the experts on our own children. The others around the table are experts in their specialty. They are also constrained by forces beyond them (financial, political). Allow them their expertise, disagree in a respectful way and your child will benefit. Don't be that parent that the school dreads to see coming through the front door. It may work once but you will end up working harder and longer for everything your child needs from that point forward. Be a good model for your child.

Andrea Marwa is the Director of the Illinois chapter of Hands & Voices. Reprinted from the Hands & Voices Communicator.

Advocating for Your Child at School

By Julie Clements-Flatt

What is the most effective way to advocate for your child at school?

Always work with the teacher(s). The classroom teacher is one of (if not the) most important person affecting your child's education. Most teachers welcome the involvement of parents and want to hear your ideas.

Engage in regular communication with the school on an ongoing basis. Here are some tips to make sure you are doing so in a valuable and constructive way:

- Write out a list of what you want to discuss.
- Express appreciation for the good things.
- Be specific about any problems as they relate to your child.
- Approach in a positive, non-threatening way.
- Keep the focus on your child.
- Volunteer your time and talents.
- When making requests or suggestions, be specific.
- Attend all meetings and conferences.
- Ask your child's team members to explain things to you when you don't understand.

From my experience, meetings can be difficult. Sometimes we can feel intimidated in a room full of professionals. The parent can feel like the odd man out. Here are some good tips to follow:

- Always come prepared (bring previous reports, have questions ready, and read any new reports and the IPP prior to the meeting).
- Know your rights.
- Always take your partner with you. Other options: a friend or Hands & Voices parent.
- Leave other children at home (this allows you to focus).
- Keep your emotions in check. It's okay to ask for a break if you need one.
- If required, ask ahead of time for an interpreter.
- Follow-up afterwards.

You may wonder - why would I bring someone with me to the meeting for support? In meetings, it is very easy to become emotional. A support person can keep us on track. They may hear things that we don't hear, or pick up on things such as body language that we may be missing. My husband and I went through a very difficult few years at one of our daughter's schools. If I thought I was going to lose control during the meeting, I gave my husband a non-verbal signal. It worked beautifully. He would take over for me, or suggest we end the meeting and reconvene, or just lighten the mood. The teamwork was a beautiful thing.

When negotiating with the school, as parents, we need to have a realistic plan. Firstly, it is important to know *what your child really needs*. These would be non-negotiable items. For example, a non-negotiable item for our family was that the teacher would use an FM/DM system.

Second would be *what you want* for your child (but may be willing to compromise on as part of the negotiation).

Lastly, *what would be nice, but you would be willing to give up*. Make yourself a list, using these **three headings** to keep yourself on track. Your goal is to come out with all of the "really needs" items.

Having experienced the absolute worst a school system can offer, to now experiencing literally the best - and everything in between - I can't stress enough the importance of good relationships. These relationships will not only be with the classroom staff, but other personnel at the school (such as the administration and office staff) and other professionals (such as educational audiologists, interpreters, and speech-language pathologists).

Take the high road by always being polite and courteous rather than rude or nasty. This will pay off in the end and is an important part of building relationships. You don't want to be "that parent."

Below are some do's and don'ts of relationship building. You may wonder - who is she to tell me about relationship building? I can honestly tell you that my husband and I have both exhibited every behaviour on this list. We know what we know by learning from our mistakes! I can assure you that behaviours on the do list bring much more favourable results than the don't list!

The Do's and the Don'ts when Advocating for your Child

DO	DON'T
Be courteous	Be emotional
Build relationships	Be unreasonable
Focus on your child	Lose your focus
Prioritize	Make it personal
Be positive	Expect the worst
Be prepared	Threaten

Remember, we are all human. We are advocating for our most precious children and therefore, emotions and frustrations will come into play. When you make a mistake, admit it, apologize if necessary, and move on. Get back to the do list. It gets easier with practice.

Documentation is another key piece in advocating for your child. Ask that items you feel strongly about be documented in the meeting notes. Ask for a summary, if possible, before you leave the meeting. Take your own notes. If you have an important verbal communication outside of a meeting, note it somewhere with the date, so that you can refer to it later.

Maintain a binder at home with all your child's reports, correspondences, and your own notes. Often you will be asked for a report from another agency or previous IPPs (Individual Program Plans). The binder will save you a lot of time and stress. It also gives you credibility with professionals when you have everything you need at your fingertips. Recently, I added a list of phone numbers to the binder, including medical numbers. This way, if anything happened to me, all the information is in one place. The entire family knows where the binder is.

In closing: "Children are great imitators. So give them something great to imitate."

Julie Clements-Flatt was the founding president of Alberta Hands & Voices. Her daughter is a teenager who is Deaf, and has a rare genetic disorder called Pfeiffer Syndrome. Sammi was profoundly deafened by meningitis at the age of three. The entire family is dedicated to Sammi and advocating for her and other DHH families.

Encouraging Your Child to Self-Advocate

Claire Blatchford, the author of “101 Ways to Encourage Self-Advocacy,” wrote:

I remember often feeling “at sea” when at school. If home was the harbour, school was the ocean. Sometimes the sailing was easy enough; I could watch carefully, read lips, figure out what was expected, and go along with it all. Other times I felt clueless, stressed out, and quite alone. When feeling this way I’d bluff or retreat. In short, I was much less likely to speak up for myself.

Furthermore, every time I bluffed or retreated, these tendencies were reinforced. The more I retreated, the harder it became to advocate. I could begin to imagine this or that teacher didn’t like me or considered me a pain, giving me more reason not to step forward.

As a parent, you can’t be there at school, but there is a fair amount you *can* do to help your child find her sea legs and voice.

Self-advocacy is the ability to effectively communicate, convey, negotiate, or assert one’s own interests, desires, needs, goals, and rights. In other words, self-advocacy occurs when children who are Deaf or Hard of Hearing can explain to teachers, classmates, bosses and co-workers the nature of their hearing loss, their language skills and the accommodations they require in order to effectively do their work, participate in conversations, and get involved in other activities.

Children are never too young to start on the path to becoming strong self-advocates. One component of educational instruction often overlooked is **supporting the positive development of a child’s self-advocacy skills** both at home *and* at school. A child who can learn to self-advocate early on is better prepared for future independence at school, at home, and in the community.

Self-advocacy skills develop over time with practice and guidance. Children need opportunities to practice their skills in a range of settings and with various people.

Three educational activities to gain self-advocacy knowledge and skills include **explicit instruction**, setting up **role playing** opportunities and **structuring occasions to practice**.

1. Explicit Instruction.

Archer and Hughes (2011) suggest three processes (*I do; we do; you do*) to show students what they are expected to learn, to give them opportunities to practice the skill under conditions that promote high levels of success and to provide an opportunity to demonstrate that they can perform the skill independently.

The **I do** stage: The teacher models or demonstrates the skills.

The **we do** stage: The teacher and the student practice skills together (provides guided practice).

The **you do** stage: The student demonstrates the skills unaccompanied (provides unprompted practice).

2. Role Play.

Prior to situations that require students to use self-advocacy skills, parents, educators and students talk through scenarios and use role-play to practice the appropriate skills. Examples include acting through situations that involve school (e.g., battery dying in hearing device) or transitions (e.g., choosing classes that support a long term career goal).

3. Structuring Practice Opportunities.

Students can also practice using self-advocacy knowledge and skills during their IPP meetings. A four-level incremental approach for student involvement in IPP meetings, adapted from Mason, McGahee-Kovac and Johnson (2004), allows students to address levels of opportunity as well as progress through levels in accordance to their age, capability and opportunities of practice:

Level 1: Students introduce everyone at the meeting to each other.

Level 2: Students present their goals for the future.

Level 3: Students explain their disability, share individual strengths and challenges and explain beneficial accommodations.

Level 4: Students lead and close the meeting.

If you're unsure about your child's 'self-advocacy' progress, there are several resources available for you to reference. Following this section is a checklist of several areas that can be used in kindergarten to grade 12 educational settings for Deaf and Hard of Hearing students. A copy can also be found here:

<http://handsandvoices.org/pdf/SAInventory.pdf>

Another valuable resource with self-advocacy guides, checklists, games, information and materials is on the *Supporting Success for Children with Hearing Loss* site at:

<http://successforkidswithhearingloss.com/self-advocacy>

You may also want to review the article, *Self-Advocacy for Deaf and Hard of Hearing Students* from Hands & Voices, which includes more information on age-appropriate skills and expectations at:

<http://www.handsandvoices.org/needs/advocacy.htm>

Texas Hands & Voices also offers of an extensive checklist of advocacy skills for Hard of Hearing students here:

http://www.txhandsandvoices.org/txhv/files/8213/9144/6548/advocacy_skills_for_hard_of_hearing.pdf

101 Ways to Encourage Self-Advocacy

Claire Blatchford, the author of a booklet titled, “101 Ways to Encourage Self-Advocacy,” is an adult with hearing loss. In the book’s introduction, she said:

“My mother often urged me as a deaf child to speak up when I didn’t hear something, but we never talked together about the different ways I could ask for help. Coaching of this sort was not a part of the mindset of those times. Today, however, real thought is being given to what it means to be a successful self-advocate.”

Even as adults, self-advocacy continues to demand self-acceptance, self-awareness, and self-confidence. Blatchford emphasizes how important you are, as a parent. Can your child see you advocate for yourself, when you need to?

Blatchford, who worked as a teacher for many years, has noticed **that if the leap required to self-advocate is too big, we may not jump at all**. Her sequence from simple to more complex ways to advocate is helpful. For example:

“Continue to encourage your child to be up front about her hearing loss with the bus driver, school receptionist, teacher, classmates, cafeteria workers, and other adults she comes into contact with at school. Help her practice the language to use for clarification of her needs and preferences. For example, “Please look at me so I can see your face when you are talking to me.” Practicing the language of hearing loss should also extend to talking about technology, if your child wears hearing aids, cochlear implants, or an FM system. Calling equipment by their right names is part of becoming more knowledgeable. So instead of “ears,” call them hearing aids; instead of “bionic ear,” call it a cochlear implant; instead of “thing,” call it an FM transmitter.

This booklet is written with school-aged children in mind, but can easily be extended into teens, twenties, and beyond. It is available from Clarke

Mainstream Services (www.clarkeschools.org). Alberta Hands & Voices also has two copies in the lending library.

In Conclusion

Children who are Deaf or Hard of Hearing benefit from developing and mastering self-advocacy skills. Self-advocacy skill development will allow children to become more successful in their daily interactions and in getting their needs met.

Parents and educators can support students in developing self-advocacy knowledge and skills by:

- educating them on their needs, rights, and responsibilities
- assisting them in understanding a problem or a challenge and selecting strategies to try
- providing them with opportunities to practice strategies to problem solve, get needs met, or progress toward goals
- involving them in planning for the future

Many families have found that there is a big difference between self-advocating at home and self-advocating at school. Keep in mind that during transitions, such as to a new school or a new grade, your child may be less likely to advocate for himself. One year, the environment may be sympathetic to him, the next year much less so. This is all part of the growth process.

Adapted from:

[-Lucker and Becker, Fostering Skills in Self-Advocacy: A Key to Access in School and Beyond](#)

[-Students with Cochlear Implants: Guidelines for Educational Planning from Laurent Clerc National Deaf Education Center, Gallaudet University](#)