

# Advocating for the Advocate

## How to make advocacy easier, more effective, and more sustainable

Highlights from keynote presentation by Birgitta von Krosigk, Dialogica

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### Gathering to learn, connect, and build

If you're a parent or guardian advocating for a school-aged child or children with special needs, you've come to the right place. This Advocacy Conference provides plenty of opportunities to learn, connect, and build.

You will **learn** about:

- legal, political, and health perspectives around special education, from these presenters:
  - Lindsay Waddell, who will speak about Education as a Human Right
  - Jodie Wickens, who will speak about Access to Education in British Columbia
  - Theresa Grech, who will speak about Inclusive Education and Mental Health Effects
- the history of what's happened earlier, and lessons for the future (no need to reinvent the wheel!)
- where to find resources
- vocabulary – to have your voice heard it helps to speak the school system “language”, or at least understand how it is commonly used
- tools, tips and techniques about negotiation, Individual Education Plans (IEPs), and self care

You will have an opportunity to **connect**:

- share some of your stories, and listen to the stories of others
  - think of a success story to share with others
  - if you're new to this, think of a question you'd like to ask another parent

- reconnect with old friends, and try to get to know some new people
  - find someone from the same school district, neighbourhood, or school. Sharing a geographical location can make it easier to help each other out, and to stay up to date with local developments
  - find someone from a different school district. This can also be very helpful, since different districts have different ways of doing things
  - invite someone to try “peer coaching” with you. You can create your own ground rules (how often you’ll chat, how you much time you will each have taking turns being the person sharing and the person listening, what your goals are, and so on). The main idea is to create a reflecting space, where you take turns listening to each other and then ask questions based on what you’ve heard the other person say (as opposed using their comments as a way to launch into your own story)

You will have an opportunity to **build**:

- A conference such as this doesn’t happen by chance. It happens because people give a lot of their time, knowledge, and talents. When you’re the parent or guardian of a child with special needs, you and your child “pass through” the system. Twelve or thirteen years can feel long at times, but in the context of the whole system, it is a short period of time. Rather than reinventing the wheel, build on the foundations created by those who have passed through before you, so that you also contribute to a more equitable education system for those who will follow after you. Even if it is something small, it all adds up!

I’m honoured to be invited to share this day with you, and excited by the prospect of learning new things. Each of today’s topics could form a day-long conference on its own, so take in as much as you can, and know that knowledge is power and that you can always keep learning.

I’d now like to share some observations I hope you will find helpful in your advocacy journey:

1. Doing the Limbo – Managing Roles, Positions, and Stances
2. Working with Stories and Understanding Genres
3. Advocacy 2.0 – Taking Advocacy to the Next Level

## **1. Doing the Limbo – Managing Roles, Positions, and Stances**

Before becoming a parent or a caregiver, how many of you set out to be a school system advocate? My guess is: not that many. Being a parent, guardian, or a caregiver of a child with special needs brings with it many tasks and responsibilities over and above the traditional parental/caregiving ones.

Depending on the age of the child, and the special needs, these can include being a researcher, educator, trainer, coach, counsellor, nutritionist, mediator, accountant, financial planner, project manager, and human resource director.

Now that your child is going to school, you’re expected to be an advocate as well. Add to this whatever employment roles you may also have, and maybe your role as caregiver an adult relative of friend. With

only 24 hours in the day, and at least some need for sleep, how can you juggle all of this without continuously building up stress? Or, to use the limbo reference, how low can you go before you fall down?

One way to manage the juggling act is by looking closer at what these roles are and how they interact. Let's say you have a child with special needs, and there is an upcoming IEP meeting at his school that you need to prepare for, and then attend. You're also the soccer coach for your daughter's team, and the season is in full swing. You work full time as a manager of 20 people, and your boss expects you to implement a new performance review system. You also have to take your mother to her medical appointments because she no longer drives. In this simple example, you are simultaneously playing the role of PARENT, EMPLOYEE, and CHILD.

According to **role theory**, each of these roles have different parts we're expected to play or perform. The early versions of role theory emphasized **role overload** (not enough time or energy to meet the expectations of each role), **role conflict** (the expectations of different roles contradict each other – a conflict *between* roles), and **role strain** (difficulty combining the tasks associated with one status).

In our scenario, attending the IEP meeting during office hours means you're not working on the performance review system. This is an example of role conflict (PARENT | EMPLOYEE). Driving to the soccer games means you have less time to prepare for the IEP. This is an example of role strain (PARENT | PARENT). Not surprisingly, these are usually seen as having a negative impact on your life.

However, having multiple roles and tasks can also have a positive impact. Instead of thinking of energy as a *limited* resource, it may in fact be a *renewable* resource. Energy gained while performing tasks in one role may "spill over" into another role, or skills learned in one role may be useful in another role (**role enhancement**).

In our scenario, being outside on the soccer field may give you fresh air, a bit of exercise, and perhaps a few laughs, which makes it easier to review the IEP draft later that night. Or you may be chatting with another parent, who as it turns out, wouldn't mind driving your mother a few times a month. And as a manager at work, you've had to learn how to negotiate effectively, and you use that skill during the IEP meeting.

We can also unbundle the parental roles within the school system. In one study<sup>1</sup>, researchers found that the parents they interviewed performed four distinct roles when engaging with education professionals.

As **negotiators**, the parents prepared for, and attended meetings, and built up rationales for requests around placement, services, and individual assistance for their children.

As **monitors**, the parents checked the quality and content of the educational program on an ongoing basis. This could be formal (IEP meetings, parent-teacher conferences), or informal (communication notebooks, monitoring changes in the children's behaviour).

As **supporters**, the parents encouraged or assisted the teachers, for example by giving positive feedback on recent changes, or by preparing classroom materials.

Finally, as **advocates**, the parents engaged with other parents to promote system-wide changes.

The parents combined roles, or shifted between roles, depending on the circumstances. Motivated by the children's needs, the choice of strategy often depended on the level of trust between parents and education professionals.

So give yourself credit for all the work you do, and notice how practice can make you more flexible. Don't be afraid to look for short cuts (perform fewer tasks, or to a different standard?), or to ask for help from partners, relatives or colleagues (**role sharing**).

Similar to roles, **positions** are also defined in relational terms. However, positions tend to be more dynamic, and can change many times in a single conversation. In short, when we talk or interact with others, we position each other, whether we are aware of it or not. According to positioning theory, when Person A positions Person B, B can either accept, reject, or modify the offered position. In turn, Person B then positions A, and the process continues.

For example, a school principal may "position" a parent as a novice who doesn't understand how the special education system works. The parent can accept this position, and ask for an explanation. Or, the parent can reject it, and refer to their 5 year experience with an older child, preferably while using special education vocabulary to demonstrate knowledge. Or, the parent can modify it, by positioning themselves as an expert on their own special needs child, and noting that the system is there to ensure equal access to education for all children.

People also position themselves. For example, have you ever said, or heard, "I'm just a mum"? As shown earlier, no one is just *one* thing, with one lonely role to play. And by adding "just" in front of mum, you've placed yourself in a less powerful position: "there is no need to pay attention to my views, I'm just a mum". How would it be to instead say: "as a mum, I am an expert in ..."?

In addition to roles and positions, there are **stances**. A stance can be both a body posture and an attitude. You may be one of the 34 million or so people who have seen Amy Cuddy's Ted Talk on How Your Body Language Shapes Who You Are. Her research on body language shows that simply by changing our body position we can change other people's perceptions about us, and even our own body chemistry. (If you haven't seen the Ted Talk yet, check it out, and try taking up the power stance before your next school meeting!).

In terms of attitude, take a moment to also set your intention for your advocacy, both in the short term and in the long term. This does not mean that your intention will always yield desired results, but it can give you a focus and a sense of purpose, which can in turn inspire confidence in others, or even trigger a joint inquiry into how to better support your special needs child.

## 2. Working with Stories and Understanding Genres

Have you ever been in a situation where it seems like you're talking to a wall – there is little or no response? Or how about the feeling that you're talking about your child, and the school officials are talking about some other child, who shares some characteristics with your child, but who still seems to be someone different?

If you have had experiences like this, or something similar, it could be because "parents and school professionals have different frames of reference for understanding the needs of the child". According to researchers Bacon and Causton-Theorharis (2013)<sup>ii</sup>, schools and districts have a bureaucratic and hierarchical frame of reference, where standardization of practice and professional roles and expertise are highly valued. This is often combined with a focus on the child's deficits, the use of specialized vocabulary, and an emphasis on curriculum. Policy is there to be interpreted according to the local context. Knowing the system, and its players (e.g., union, government, etc) is critical.

On the other side, parents usually bring detailed and deep knowledge of their unique child and their special needs. Parents tend to focus on abilities rather than deficits, and policy is there to be applied, equally across the board. Social development and curriculum are both seen as important. Parents are usually new to the system.

With these different frames of reference, the two sides usually tell different stories, without really listening to what the other is trying to say, and without much learning and understanding.

A parent may say that the child is doing well at home with appropriate supports. Inconsistencies between home and school lead to regression, lost opportunities, a lack of access to education. Independent research support the home approach. The child could do well with individualized support and competent and trained special education assistants. The school receives funding for this child. There is a legal right to meaningful consultation.

School officials may say that the school provides excellent professional services, from within the school and from the district. The teacher is in charge of the classroom, and the special education assistant is there to ensure the health and safety of the special needs students in the class, not to provide instruction for individual, and specific, students. The budget is allocated to the whole school, and is not tied to specific students. Teachers do consult, but parents do not have a right to make decisions.

Understanding how these stories develop out of different frames of reference will enable you to become a better advocate. Learn the vocabulary, and insert yourself – and your child – into the school’s story. Get attention by asking questions that fit within the school’s plot line. Before launching too far into your own story, check whether they are still with you. Invite common problem solving and joint authorship.

### **3. Advocacy 2.0 – Taking Advocacy to the Next Level**

Even if you are successful in co-authoring a new story, it can be a challenge to keep working hard, by yourself, over a number of years. Advocacy 2.0 may help, and the good news is that this conference offers many opportunities to develop the 4 “Cs”:

- Community
- Collective action
- Collaboration
- Communication

Lasting change requires system change. Even the most successful parent advocate may not be able to achieve results beyond their own particular child, in a particular classroom, in a particular grade. Therefore it is very important to develop community both in a literal and in a figurative sense. Collective action is one way to share resources and to spread knowledge. Collaboration both among parents, and between parents and education professionals, can make for better decision making and better student outcomes. And communication is the way things get done. Learning how schools communicate, and how to communicate effectively with them, is very important.

This conference is Advocacy 2.0 in a very real sense. I hope you will do lots of learning, sharing and building together!

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<sup>ii</sup> Stoner, J.B. & M.E. Angell (2006). Parent perspectives on role engagement: An investigation of parents of children with ASD and their self-reported roles with education professionals. *Focus on Autism and other Developmental Disabilities*, 21(3), 177-189

<sup>ii</sup> Bacon, J.K. & J. Causton-Theoharis (2013). "It should be teamwork": a critical investigation of school practices and parent advocacy in special education. *International Journal of Inclusive Education*, 17(7), 682-689.