

Good morning everyone. My name is Miles Forma.

Before I make my presentation, I would like to thank the International Communication Project and the government of Australia, for inviting me to speak at this event. It is an honor and a privilege to be here.

Imagine you are in a severe car accident. You wake up in a hospital and you can't move or talk. But you can understand and think. Now imagine being with other people who are having conversations with each other but you can't participate in their conversation. You feel isolated and alone.

Because I am non-speaking, Augmentative and Alternative Communication, or AAC, is a really important and a central part of my life. Because of AAC, I am able to communicate what I am thinking to other people and can have meaningful relationships in my life.

Now let me tell you something about who I am. 32 years ago I was born right here in New York City. I was born with a physical

disability called cerebral palsy which has impaired my ability to walk and talk. But having cerebral palsy has not affected my ability to think.

My parents are not wealthy people. But when I was two years old my entire family moved to Budapest Hungary so that I could attend a specialized school for children with motor disorders, called the Peto Institute. My father's profession allowed him to make a living while we were there.

We returned to the United States when I was seven years old. In elementary school I primarily used a manual board to communicate, pointing to symbols and letters to make sentences. Some of my earliest memories include moments where I was faced with adversity and I had to persevere.

Sometimes in school I would get really frustrated with teachers because they didn't understand me and sometimes the teachers would get frustrated with me because of my inability to communicate effectively. My

early teachers even gave up on trying to teach me to read.

Before I went to a residential high school in New Hampshire I was rarely using my AAC device in school because the speech therapists at my old schools did not have experience using AAC technology or training on how my device worked and how to integrate it into my classes.

Having access to AAC technology is very important, but having well trained speech and language pathologists is crucial to a non speaking person's successful use of their AAC devices. Even in the United States, where all children have a right to a free and appropriate education, this is not always the case.

Growing up with a physical disability is hard, especially if you are non speaking. There are many people who live with physical disabilities who may not be as intelligent as I am. But any person who cannot speak, no matter what their intellectual abilities, needs and has a right to have some way to communicate.

I am fortunate because I have had access to AAC for more than twenty years. Today I am talking to you using an AAC device called a Tobii Dynavox I 12+. When my Tobii/ Dynavox is not accessible to me I feel lost because I have no voice. If I didn't have my AAC device to communicate with, I think I would go insane.

When you have a disability and are not able to speak, people often make incorrect assumptions about you. I feel very strongly about this. I have had many experiences in my life where people who don't really understand what having a physical disability is about, assumed that because I am a non speaking person and sit in a wheelchair that I am not intelligent. This is obviously wrong.

As I've said, having AAC has given me a voice. I can participate much more fully in society—in life. With my voice I can advocate for myself and for other people. When I was a teenager, I saw the movie Hotel Rwanda and was so upset I wanted to do something. So at my high school, with the help of an assistive technology specialist,

I organized a fundraiser for the orphans of the Rwandan genocide and after that fundraisers for the refugees of the Darfur region of Sudan. I could not have done this work without my AAC device.

There are people in Africa, Asia and Europe who do not have the advantage of using Augmentative and Alternative Communication devices because in their countries there are no speech pathologists or funds to teach people how to work with a non-speaking person. For instance, I learned that in Swaziland, South Africa one six-year old girl, who was really intelligent, never had an opportunity to speak until a volunteer speech language pathologist put her in an appropriate sitting position for the very first time in her life.

The child immediately began imitating speech! The volunteer organization had only offered to assist the family in getting the girl a wheelchair... but there was little attention paid to her capability for learning to communicate. That is cruel!

In contrast, when I was two years old, I had my first communication book. It was rectangular shaped. It had picture symbols for yes, no, I'm hungry, I'm thirsty, I need to go to the bathroom and can I have a peanut butter and banana sandwich. Apparently at that age I could not stop eating peanut butter and banana sandwiches!

But on a more serious note. Wherever they live, when capable children are left with no way to communicate, they will feel alone and depressed. Because without a way to effectively communicate they are being isolated from their families, their schools and any opportunities in their life.

Today the International Communication Project is urging policymakers to recognize not only that communication is a basic human right but also the impact that communication disabilities have on people's lives and the importance of providing resources that empower them to live their lives to the fullest. I couldn't agree more; that is a message that must be heard.

Thank you.

