## Fluency as a Second Language

#### **Keynote presentation by Jaan Pill**

**CAPS** Conference

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Good morning. I really appreciate the opportunity to speak with you this morning, in this beautiful city of Calgary.

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I've given out some handouts this morning, including a yellow piece of paper. That paper will be used for an activity later this morning.

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Over the past 14 years, I have been involved in the starting up of a number of selfhelp associations for people who stutter, in Canada and elsewhere.

If someone had told me in 1987, 14 years ago, that I would soon be starting out on one of the major adventures of my life, I would not have believed them.

If someone had given me a list 14 years ago and said, "This is what I expect you to get done by the year 2001," I would have said, "The list is too long and there's no way that I could ever find enough time to even get close to finishing all of these tasks."

I think the reason that it all worked out so well for me was because I had no idea what I was getting into.

I became involved in the self-help movement entirely by accident. In 1987, I attended a treatment program in Edmonton where I learned to speak in a new way, after many decades of moderate to severe stuttering. In effect, I learned a new language. I like to say that I learned fluency skills as a second language. After I had learned these fluency skills, I began to make presentations to large groups of people.

This was something that I had [almost] never been able to do before. But I found it hard to adjust, psychologically, to the fact that I was finally able to do a good job at public speaking. To help myself make the adjustment to this new level of fluency, I decided that I needed to compare notes about such things with other people who stutter.

In order to meet other people who stutter, I formed a self-help group in Toronto. After that, I worked with other people to start a national self-help association, namely the Canadian Association for People Who Stutter, or CAPS. As well, I also began volunteer work at the international level on behalf of people who stutter.

Along the way, I've learned a few things. Today I want to share with you some of what I have learned.

#### What have I learned?

What have I learned? I've learned the following seven things that I want to share with you today. Briefly, they are:

- 1. Many of our most important projects are too big for one or two people to do on their own.
- 2. In a successful group, each member has a strong sense of ownership of the group.
- 3. It's good to plan ahead, so that a group will continue to grow long after the founder of the group has moved on to other things.
- 4. A data-oriented approach to gathering information can help us to reach our goals.
- 5. You and I will agree about some things, and disagree about others.
- 6. We need to take care in how we define things, so we can be sure that we're talking about the same things.
- 7. It's great to see growth and renewal of any kind.

These are things that I'll talk about today.

I would note that the reflections that I share today do not necessarily represent the views any of the associations, including CAPS, that I have worked with as a volunteer. These are my personal reflections. [Additional note: CAPS was renamed in the years following this 2001 talk. It is now known as the Canadian Stuttering Association (CSA).]

## **Volunteer projects**

Here's a quick summary of my volunteer work over the past 14 years.

- In September 1988, I founded a self-help group that became known as the Stuttering Association of Toronto, or SAT.
- In the summer of 1990, I delivered a series of lectures in Estonia about Western approaches to the treatment of stuttering. These presentations led to the formation of the Estonian Stuttering Association.
- In August 1991, I assisted in the founding of CAPS. I served as CAPS coordinator for many years.
- At an early stage in development of the International Fluency Association, I served as chair of the IFA's Support Groups and Consumer Affairs Committee.
- In 1995, I assisted in the founding of the International Stuttering Association.
- Until recently, I served as chair of the ISA Outreach Working Group, which seeks
  to establish contacts with people who stutter in parts of the world where ISA is not
  yet represented.

## **Development of CAPS**

**Banff 1991 photo:** Given that it's been 10 years since the founding of CAPS, now is a good time for us to look back at the first Canadian national conference for people who stutter, which was held in Banff, Alberta in August 1991.

This group of people decided, at a series of meetings in Banff, to form a national selfhelp association, which became known as CAPS.

In this photo we see both Einer Boberg of Edmonton, and Marie Poulos of Ottawa, two of the strong supporters of the self-help movement who are no longer with us.

Among other people who have passed away since 1991 are Laurent Bouchard of Montreal, founder of ABC, l'association des bègues du Canada as well as Fred Gingell, a former member of the Legislative Assembly in British Columbia.

Einer, Marie, Laurent, and Fred, among others, have contributed tremendously, during their lifetimes, to the well-being of people who stutter in Canada and elsewhere. Those of us who knew them will always remember their contributions.

It's been 10 years since the founding of CAPS, but the planning began 12 years ago.

**Einer Boberg:** By early in 1989, members of SAT, the Stuttering Association of Toronto, were talking about staging a national conference for people who stutter. In the spring of 1989, Einer Boberg established contact between SAT and the Alberta Stuttering Association, and proposed that the two groups would work together to plan such a conference. In July 1989, members of the two groups met in Edmonton and the planning was under way.

**Lyn Kelly,** who was living in Edmonton at the time, served as chair of the Banff 1991 organizing committee. She played a key role in the organizing of the conference.

**Larry Stone,** who was also living in Edmonton, worked closely with Lyn Kelly. Lyn and Larry were among the key players in getting that conference off the ground.

**Jim Rowlett** of Edmonton is a long-time member of the Alberta Stutterers Association. He also played a key role during the planning process.

**Rick Randall** of Toronto attended the first planning meeting in Edmonton in July 1989. As a market research professional, he also helped to design the pre-conference survey that we sent out to find out if there was enough interest to justify the staging of such a conference.

**Michael Niven** of Calgary was one of the organizers of the meetings in Banff in 1991 that led to the founding of CAPS.

Michael has been involved with CAPS from the very start. He has also been a key player in the organizing of CAPS 2001, which is taking place 10 years since the founding of CAPS in Banff.

**Peter Wyant** of Regina organized one of the three workshops that led to the formation of CAPS. He also assisted tremendously with the writing of the CAPS constitution. One of today's handouts gives you some background about key concepts at the core of the CAPS constitution.

**Allan Chapman,** who moved from Winnipeg to Victoria about 12 years ago, was the third person responsible for organizing of the Banff workshops that led to the founding of CAPS.

**Arun Khanna** of Mississauga, Ontario is one more person I want to mention. He was the master of ceremonies for the open mike session at the Banff conference.

He also raised well over \$70,000, up to about 1997, for the Stuttering Association of Toronto. Much of that money has gone toward the organizing of CAPS conferences, especially in 1995 and 1997. That money helped us get used to the idea of staging conferences at first-class hotels at the centres of Canadian cities.

I've limited my comments this morning to some of the key players who were actively involved starting around 1989. Many other people have played key leadership roles starting at that time.

For example, Willard Mohr of Calgary, who had earlier lived in Ontario, is among the other people who helped out with the Banff 1991 conference. I also want to mention Ron Day of Belleville, Ontario, who has been a most enthusiastic supporter of CAPS conferences right from the start.

We also need to look to the future. I want to bring your attention to the workshop that David Block, the CAPS coordinator, is presenting on Saturday, looking at where CAPS will be heading in the years ahead. Please do attend that workshop if you can.

### Speech therapy

In order to share what I have learned, I want to start by telling you about my own encounters with speech therapy, and how I became involved with the self-help movement.

I was born in Stockholm, Sweden. My parents are from Estonia, across the Baltic Sea from Sweden.

I began to stutter when I was about 6 years old. When I was 5, my family moved to Montreal. Later I lived in Vancouver, and now I live in Toronto.

When I was in elementary school in Montreal, I received once-a-week therapy for stuttering, but it did not help me very much. By the time I was 15, when I stuttered I would often experience complete stoppages of speech. The "h" sound was especially difficult for me. Sometimes I would struggle in silence – for maybe 30 seconds, possibly more – trying to say hello to someone on the phone. At times, I would not be able to get out any sound at all, and I would hang just up the phone.

At other times I could speak quite well, although there was still a sensation that I was using a lot of effort to get the words out, and I often substituted words.

In my early twenties, I had treatment for stuttering at a hospital in Montreal. This was a once-a-week program based on the work of Charles Van Riper. In this therapy, I did not learn much about changing how I spoke. But I did learn to actively seek out speech opportunities instead of always avoiding them. That was a step in the right direction.

Many people have spoken about the impact of stuttering. I would say that, during the first four decades of my life, the impact was pretty severe.

#### **PFSP and CSP**

Twenty-five years ago, at the age of 30, I attended a three-week program in Toronto, the Precision Fluency Shaping Program, also known as the PFSP program.

This program helped me more than anything that I had encountered before. In fact, I was talking fluently when I walked out of the clinic at the end of the three-week program in Toronto.

But a week or two after that program, I was speaking with a friend on the phone. All at once, the fluency skills that I had just learned seemed to fly out the window.

After that relapse, after that loss of fluency skills, I did not speak as fluently as I had been speaking during the last week of the clinic. But in the years that followed, I did not stutter as severely as I had been doing prior to the clinic.

Eleven years later, in 1987, I read an article in the Toronto Star about a stuttering treatment program in Edmonton.

This program was developed by Einer Boberg and Deborah Kully at the Institute for Stuttering Treatment and Research.

In July 1987, I flew to Edmonton to attend the three-week program. At that time I was 41 years old. That was 14 years ago. I'm now 55 years old.

In some ways the Edmonton program was similar to the one that I had attended in Toronto 25 years ago, but there were also differences.

Both programs seek to teach people to speak in a new way. It's like learning fluency skills as a second language. I think of myself as a language student. I'm learning, and constantly refining, my ability to use fluency as a second language.

In my experience, as I've explained in a couple of journal articles, the Edmonton program taught these skills in a way that produced a more natural sounding way of speaking than did the program in Toronto. One of my journal articles is mentioned in the handout.

Some people will tell you that they'd rather stutter in the way that they've always stuttered, rather than speak in a droning pattern. I think they have a valid point. There's no reason why a fluency-shaping program should make you sound like a robot.

Without getting into a technical discussion, I would like to list some of the elements of the fluency skills that I learned in Edmonton in 1987. Some of the terms may have changed since then, but these are the ones that I learned:

- Easy breathing
- Smooth blending of syllables / Continuous airflow
- Light touches / Soft contacts on consonants
- Gentle starts / Easy onset of voicing
- Prolongation of vowel sounds

#### **Transfer and Maintenance**

After I completed the treatment program in Edmonton, I worked for many years on the transfer and maintenance of my fluency skills. It's like learning a language. After you learn it, you need to use it. Otherwise you forget it.

By "transfer," I'm referring to the application of fluency skills in situations where I had experienced difficulties in speaking in the past. By "maintenance," I'm referring to the process of consistently applying fluency skills in everyday situations, over a long period of time.

I had experienced a relapse soon after completing a previous fluency skills program, in Toronto. When I arrived in Edmonton, I was eager to learn everything I possibly could about how to maintain my skills after I had completed the three-week program.

Back in Toronto, I would spend 10 minutes, twice a day, practising my fluency skills. Each day I practised for a total of 20 minutes. If I missed my two daily practice sessions on a given day, I would do four practice sessions the next day. In that way I always averaged two practice sessions per day.

For four years and four months, I kept up this practice schedule. After that, I continued to practise regularly for several more years, but I no longer practised every day.

In Toronto, I would also spend time each week doing transfers. Some of these would be recorded transfers. I would record myself while speaking on the phone, or when making a presentation. Later I would play back the recording, and grade my performance in applying a number of fluency skills. In the Edmonton program, a transfer is not complete until it has been analyzed.

What did I analyze?

In a typical transfer exercise, I might record 2 minutes of a phone call to a friend. I would then rate myself on a number of things, such as:

- Rate (R)
- Onset of voicing (O)
- Consonants: Lightness of touch (C)
- Blending of syllables (B)
- Volume (V)
- Eye contact (E)
- The naturalness of my speech pattern (N)
- And whether or not I stuttered, and if I stuttered, whether or not I cancelled that is,
   whether I went back and said it correctly

Some of my transfers would be unrecorded ones. I would make notes about a conversation that I had with someone, and I would later grade myself on how well I had applied my speech skills.

I also worked extensively on self-talk related to speaking situations. Self-talk refers to things that we tell ourselves during the course of a day. I learned to systematically alter my self-talk. That is, I would first identify what cognitive therapists call "automatic negative thoughts." After that, I would think up "alternative thoughts" that I would use to replace the automatic negative thoughts.

For example, if I had a recurring negative thought about an upcoming speaking situation, I would take an index card and draw a line down the middle of it. On one side, I would write the automatic negative thought – which might be: "Why did I ever agree to make this presentation?"

Then on the other side of the line I would write an alternative positive thought such as: "This upcoming presentation offers me a wonderful opportunity to see how close I can get to speaking at 220 syllables per minute." In time I learned to alter self-talk without using an index card. Altering self-talk has been a central feature of my transfer and maintenance program.

As a result of this work, I have been able to maintain my fluency skills at a high level during the past 14 years.

When I have described my transfer and maintenance program, some people have said, "I would never have the time to do what you have done in maintaining your skills." I agree. Not everyone has the time or motivation to work at maintaining their fluency skills after a program such as the one in Edmonton.

But for me, uncontrolled stuttering had involved even more work, and effort, so I don't mind having to work at maintaining my fluency skills.

But I want to underline the fact that what worked well for me will not necessarily work well for others. About 20 percent of people who take a program such as the one I took do not do well in maintaining their gains after the treatment program.

Some graduates of treatment programs may be trying as hard as the next person to maintain their skills – but they are not as successful, and this may be because of how their brains are wired. Their lack of progress may have a neurological basis. Other forms of treatment may offer more promise for the 20 percent of people who get limited long-term benefit from attempting to learn fluency skills as a second language.

#### **SAT and CAPS**

After the Edmonton clinic, I began making presentations to large groups of people. I wanted to do lots of public speaking, because it was something that I had avoided in the past. When I was making these presentations, I would be speaking fluently, but a voice inside would be saying, "You're not supposed to be able to do this. You're supposed to be falling flat on your face." This inner voice really bothered me.

In order to deal with this, I felt I needed to talk with other people who stutter.

Because I wanted to compare notes with other people who stutter, in September 1988, I formed a self-help group, the Stuttering Association of Toronto. About a year later, a speech-language pathologist named Tony Churchill came to speak to our group. I asked him how I should deal with this inner voice that kept on bothering me. He said I have to get used to the fact there have been some changes in my life. From that time on, I have not been bothered by that inner voice.

My involvement with Stuttering Association of Toronto led to my involvement in the staging of the Banff conference in August 1991.

#### IFA and ISA

About the time that I was first becoming involved with the organizing of CAPS, I also became involved with the work of the International Fluency Association, and with the International Stuttering Association. For a start, I became chair of the IFA Support Groups and Consumer Affairs Committee. In that role, I established contacts with most of the major national self-help associations that existed at that time. Later I also became involved in the founding of the International Stuttering Association.

As I look back on these things, I think of seven things that I have learned.

1. Many of our most important projects are too big for one or two people to do on their own. Most of our major projects require the collaboration of a large number of people, from many backgrounds.

An example of a project that really benefits from collaboration is the International Project on Attitudes Toward Stuttering, or IPATS, initiated by Ken St. Louis of Morgantown, West Virginia.

I strongly support this project, which seeks to answer questions such as:

- Are there differences in how stuttering is perceived in countries around the world?
- Are listeners more at ease with people who stutter in some countries than others?
- How can we measure the results of efforts to increase awareness about stuttering, in different countries in the world?

It's really important, I think, to consider that last question: How can we measure the results of our efforts? How do we know if the results of our public education efforts actually work? It's not easy to find the answer, but Ken St. Louis has made a good start by bringing attention to this question.

#### 2. In a successful group, each member has a strong sense of ownership of the group.

When I started the Stuttering Association of Toronto, I led the first several meetings. After that, I asked if other people would take turns leading two or three meetings in a row. When we made that switch, one of the SAT members said to me, "Now that you're starting to step back, the other members are starting to take on real ownership of the group."

When CAPS was formed, I did everything I could to encourage as many people who stutter as possible to feel a strong sense of ownership of the association. That meant making sure that the ideas of as many people as possible were taken into account at each stage in development of CAPS

When ISA was formed, I did everything I could to encourage member associations of ISA to feel a strong sense of ownership of ISA.

# 3. It's good to plan ahead, so that a group will continue to grow long after the founder of the group has moved on to other things.

When I began the SAT group in Toronto, someone told me that self-help groups often disappear when the founder of the group burns out or moves away. As a result of this advice, from the very start I planned things in such a way that a new leader would be prepared to take over once I wanted to move on to other things.

Similarly, when CAPS was formed, I served as coordinator for many years. When my time in office was up, another person, David Block of Montreal, took my place as coordinator.

## 4. A data-oriented approach to gathering information can help us to reach our goals.

In the case if IPATS, the project aims to gather data about attitudes related to stuttering. The data is being gathered using methods that are rigorous and scientifically valid.

I want to do a survey that Ken St. Louis did at the World Congress of People Who Stutter in Ghent, Belgium in July of this year.

This is how the survey goes. We handed out some little pieces of paper. Could we have the lights back on, please.

For the next two minutes, I'd like you to circle a number. Don't write your name on it. There are no right or wrong answers. You will not give the paper to anyone at the end. And record your first answer or opinion.

Here are the animals. Please note the snake and spider are not deadly, or poisonous. They're just ordinary snakes.

Hold up your hand if you need a sheet of paper.

When you're finished, compare your results with 2 or 3 people next to you. Just look at what you put down and compare.

Now, I want you to raise your hand according to which animal you've rated the highest. Raise your hand if you've rated the cat the highest.

Bird

Snake

Dog

Spider

Now raise your hand according to which animal you've rated the lowest.

Cat

Bird

Snake

Dog

Spider

From the looks of it, we have different impressions of different animals.

Sometimes are responses are based on personal experiences, and sometimes they're based on cultural values.

Now, instead of being concerned about stuttering, suppose I were interested mainly in snakes and spiders. Spider (hold up spider). Snake (hold up snake). What I want to do, is I want to stop or reduce unnecessary killing of snakes and spiders. And to do that, I need to change or improve public attitudes toward these animals.

How would I go about it? One way, among others, is to have a public education campaign, talking about all the wonderful things that snakes and spiders do, with the hope of reducing negative attitudes that people hold about these animals.

Could I have a show of hands for people who hate snakes or spiders? Good, thank you. Now, can I have a show of hands, how many people in this category would change their feelings about snakes and spiders in response to a public education campaign about these animals?

Would that be effective? How would we know for sure?

Who here really hates snakes? I mean, really, really hates them? Who hear really, really hates spiders?

We don't know whether educating people about stuttering will change their attitudes. Who knows, it may be as hard to change attitudes about stuttering, as it is to change attitudes about snakes and spiders. The IPATS project aims to find that out.

One of the suggestions that Ken St. Louis wants to share, based on what he has learned so far in the IPATS project, is that in our public education efforts we should focus more on what people should do when talking with a person who stutters, rather than information on cause, prevalence, and other interesting facts about stuttering.

Here is an example of advice about what to do when talking with a person who stutters:

**Patience and pacing.** Never finish a person's sentence. Also, use a relaxed pace in your own speech, but never so slow as to sound unnatural.

**Body language.** Use natural eye contact and facial gestures to show you're listening.

No advice. Avoid remarks like "slow down" or "take a deep breath."

Ken's second suggestion is to tell, and share, our own stories. Thomas Klassen, a CAPS member from Toronto, has been assisting Ken St. Louis in his IPATS research. Thomas is now teaching at York University. In his own research, Thomas has reported on a study where he asked non-stutterers to rate an individual who stuttered, whom they knew personally. This is the only study Ken knows of that did not find the typical stereotypes about being weak, nervous, shy, etc.

Ken suspects that one of the best ways to change attitudes might be for non-stutterers to have personal contact with people like us. We can increase such personal contact by telling our stories to self-help group members, family members, school classmates, newsletter readers, community organizations, places of worship, as well as through the media including the Internet. We've been doing many of these things over the past decade and more. These are things we can focus on even more in the future.

Ken has also finished a book of stories of people who stutter. It's a great book. I highly recommend it.

#### 5. You and I will agree about some things and disagree about others.

CAPS has a statement in its constitution that talks about offering an impartial forum for the sharing of information. The relevant section says that CAPS aims:

to offer an impartial forum and clearinghouse for the sharing of information among Association members and with the general public regarding treatment programs, research, and any other relevant matters, and to desist from endorsing any particular treatment method

I like to think that this policy, the policy of offering an open forum, is one that most of us can agree about.

On the other hand, quite a few people will likely disagree quite strongly with some of the ideas that I have expressed about the value of learning fluency skills.

There is no reason why all of us should agree on a topic such as fluency skills. What is more important is that we agree about the need to provide for an open forum where people are free to express a wide range of views about how to deal with stuttering.

It's especially valuable, as well, when we can disagree about such things in a manner that is respectful and cordial.

## 6. We need to take care in how we define things, so we can be sure that we're talking about the same things.

When we're talking about fluency skills programs, or fluency-shaping programs, it's really helpful if we define what we're talking about.

For example, some fluency-shaping programs such as the Comprehensive Stuttering Program produce a relatively natural sounding speech pattern. Other programs tend to produce a speech pattern that makes some people end up talking like robots.

So before we talk about fluency-shaping programs, it's useful if we first make it clear what kind of program we're talking about. In the same way that not all cars are alike, not all fluency-shaping programs are alike.

When we're talking about cars, it's useful if we know whether we're talking about a Model T Ford or a Mercedes-Benz that was manufactured this year. In the same way, when talking about the teaching of fluency skills, it's useful if we make it clear which program we're talking about.

#### 7. It's great to see growth and renewal of any kind.

I find it highly significant that the Comprehensive Stuttering Program, the treatment program that I attended in 1987, has been consistently updated, with each passing year, in response to clinical experience, feedback from clients, and worldwide research.

Over the years, I have modified my maintenance program, adding new things that have been developed at the clinic.

When it comes to my own speech, I'm always learning new things.

The concept of growth and renewal is the most powerful concept that I have encountered over the past 14 years.

### Conclusion

By way of summarizing, here are seven things that I have learned over the past while.

- 1. Collaboration. Many of our most important projects are too big for one or two people to do on their own.
- 2. Ownership. In a successful group, each member has a strong sense of ownership of the group.
- 3. Leadership succession. It's good to plan ahead, so that a group will continue to grow long after the founder of the group has moved on to other things.
- 4. Data-oriented approach. A data-oriented approach to gathering information can help us to reach our goals.
- 5. Agreement and disagreement. You and I will agree about some things, and disagree about others.
- 6. Clear definitions. We need to take care in how we define things, so we can be sure that we're talking about the same things.
- 7. Growth and renewal. It's great to see growth and renewal of any kind.