Message from the President

Dear ISAAC Members:

As you may have heard in the global media or from the ISAAC website news, Martin Pistorius, a talented young man who uses AAC (and is a past recipient of the ISAAC President's Award), recently had an extensive promotional tour for his book, “Ghost Boy: The Miraculous Escape of a Misdiagnosed Boy Trapped Inside His Own Body.” Martin’s story is a poignant reminder to us all of the isolation and dehumanization faced by people with severe communication barriers. Indeed stories and situations like Martin’s are precisely what motivates and inspires ISAAC members to do all they can to ensure that everyone’s voice is heard.

At the same time Martin’s book was receiving worldwide attention, a feature-length film about the life of Dr. Stephen Hawking, “The Theory of Everything,” was receiving wide acclaim and winning many awards, including the Oscar for Best Actor for Eddie Redmayne, who portrayed Hawking in the movie.

Both of these works have gone a long way towards capturing and holding the attention of wider society on the enormous challenges faced by people with severe communication barriers. Yet in many countries across the world, we see governments and institutions either ignoring the desperate conditions of people without independent or functional communication, or chipping away at gains achieved over the past decades by reducing funding, services, and resources. How is it that so much popular sentiment and attention can be given to the plight of people without functional communication and at the same time so many decision makers in government and institutions continue to ignore, or indeed slash, funding and resources for basic communication supports?

Perhaps it is a matter of perspective….

Stories of individuals like Martin Pistorius and Stephen Hawking are gripping tales of individual survival against incredible challenges. They are stories that move us as human beings and tweak our awareness of
the fragility of our own lives. As stories they are excellent examples of how, with the right supports and resources, individuals can overcome enormous odds to survive, thrive, and contribute precious gifts to our human family. But to decision makers, these stories of individuals are the granular level of the human condition, they are the trees in the forest and, while truly moving, they are not enough to sway people or groups of people making decisions on behalf of millions of people.

As ISAAC members it is our chosen passion and responsibility to inform politicians and bureaucrats of the wider impact of communication disabilities. Through scientific inquiry, research, and social action we must strive to continue to produce the other side of the story of augmentative communication, the side that addresses the impact of communication disability upon the entire population. We know from past research, the actual population of people who could benefit from AAC supports is comparatively low (Bloomberg and Johnson in their 1990 study pegged it at 0.12% of the population), but we also know this is a population with high need and that each of these individuals is, or should be, connected with a family of people who care about them, families who carry a heavy load and deserve the help of the community. We know from recent and past popular books and movies that some of these individuals can make precious contributions to our society and our collective future, if only they are given a chance to communicate.

How many other people are trapped as “ghost people” unable to participate and realize their potential? This is the bigger picture that we must strive to bring to life through our science and research, a bigger picture that will motivate people in positions of power to make the decisions, to allocate the funds and resources, that will ultimately benefit potentially millions of people who languish as “ghost people.” The micro view of AAC is vital to understanding many aspects of our science, and our improved knowledge of behaviour, language, and technology has enabled great strides forward in developing innovations in AAC for individuals. But let us not ignore the urgent need for a renewed macro view.
encompassing wider demographic research and impact studies on human development on a societal level. It is through this research and information that we fill in the rest of the story with politicians and bureaucrats and move the giant machinery of government to deliver the funding and resources that break the chains of isolation for people who use (or could use) AAC.

Finally, amongst all of the modern accounts of people who have struggled to make their voices heard, I am continually inspired by the 19th century American statesman, Daniel Webster, who offered this view: “If all my possessions were taken from me with one exception, I would choose to keep the power of communication, for by it I would soon regain all the rest.”

Let’s do all we can to ensure everyone has the chance to communicate and obtain their place in our world.

Best wishes to you all,
Jeff

Jeff Riley
ISAAC President 2012-2015


The ISAAC International office continues its work on behalf of the membership around the world, and is thrilled to advise on the following initiatives:

**Conference 2016**

The ISAAC International website has new material posted relating to next year’s conference in Toronto. Click here and you will be directed to the Conference 2016 homepage, where you will see information and links about our Conference 2016 Co-Chairs, Call for Papers, Visitor Information about Toronto, and discounted airfares to Toronto through our Conference sponsor, the Star Alliance Network. Check back regularly, as we expect to be releasing more information about the Call for Papers in the coming weeks.

ISAAC International will once again be making use of our online software tools to assist in the management of Conference 2016. Our online paper submission software will allow for the quick and efficient submission of paper proposals for the Conference. When it comes time for conference registration, we will continue to also

...continued on page 4
use our online conference registration and payment system. These two pieces of ISAAC International infrastructure are key in allowing us to more efficiently and effectively manage our biennial conferences.

2015 Membership Renewal
The start of each new year means another membership cycle. We are getting ready for production of the 2015 Membership Directory, and will need each Chapter to report on its 2015 membership no later than April 30th, 2015. Chapter reports should be submitted directly to ISAAC’s Membership Co-ordinator, Teraiz El-Deir, by email to isaac@isaac-online.org.

Conference 2018
ISAAC International has received three excellent and strong Letters of Interest from groups wanting to host ISAAC Conference 2018 which, as previously announced, will be focusing on the Asia-Pacific region. The ISAAC Executive Board is in the process of reviewing these submissions.

Ongoing ISAAC International Initiatives
ISAAC International continues to look for ways of getting the most from each membership dollar. We have recently concluded an agreement with our current landlord that will allow ISAAC International to stay in our current office space, for up to an additional 5 years. This will mean that ISAAC International will be paying the same amount of rent for our current space in 2022, as it was back in 2012, with no increases!

Now that we have completed our very successful website migration, we are now investigating options for self-hosting the ISAAC International administration server. In addition to providing opportunities for Chapters to take advantage of this information technology infrastructure, self-hosting of our server will open additional opportunities to rationalize and streamline our operations.

2014 Financial Audit
ISAAC International is now conducting its 2014 financial audit, and official audit statements should be available for member review in the April / May timeframe. Please check the Members Only area at that time, which is where the financial statements will be posted. You can also check prior year statements in the Members Only area, or also at the websites of the Canada Revenue Agency and Internal Revenue Service.

As always, I welcome your thoughts and feedback. Please do not hesitate to contact me directly, at franklin@isaac-online.org, should you require any further information or assistance.

Regards and thanks,
Franklin Smith
In Memoriam

**ROBERT JEAN — 1945-2015**

Author-Speaker, User of Communication Device, ISAAC Member since 1999

On January 23, just a few hours after his release from hospital, Robert Jean passed away peacefully at home at the age of 69. He was the son of Paul E. Jean and Marcelle Plouffe and a founding member of the Quebec Cerebral Palsy Association (1950), for which he was named Governor for Life (1971).

In spite of a cerebral motor deficiency that prevented him from using his arms and legs and also left him unable to speak, Robert was unstoppable. Age, a severe scoliosis, asthma, dysphagia, bronchitis, pneumonia, not to mention skin cancer, failed to stop him from realizing his dreams and carrying out his mission.


Author of an autobiography, “Des Yeux Pour le Dire” (2001), published in English under the title “My Eyes are My Voice” (2014), Robert was an active member of the “Association Québécoise de Voile Adaptée,” an adapted sailing program, and of “Ex Aequo,” a disability rights movement. Selected as a medal-bearer for the Rick Hansen 25th Anniversary Relay (2011), he contributed to making a difference and changing mentalities.

Through presentations to a wide audience, including students, healthcare workers and community groups (2002-2014); the publication of articles in newspapers and specialized journals; and guest appearances on television, radio and the web (www.robertjean.net), he worked to enlighten the public and dispel prejudices.

An active member of ISAAC, Robert took part in and delivered speeches at national and international conventions in Canada, the US, Switzerland, and Spain.

...continued on page 6
In Memoriam continued

Our sadness is deep, but there are no words strong enough to describe the pride we all feel for having known you, dear Robert. “True beauty is the reflection of happy people who, tirelessly, spread happiness around them.” Several among us can attest to the brightness in your eyes and your exceptional determination. You proudly shared your message which urged us all to take action and to excel. You were both so small and so big, so fragile and so strong.

Your achievements will remain forever a source of inspiration.

Marc St. Cyr’s Tribute to Robert Jean is also available in French: Hommage à Robert Jean

ROBERT (BOB) MCNAUGHTON — 1922 - 2015

It is with great sadness that we announce the recent passing of Bob McNaughton, husband of Shirley McNaughton, and father of David and Kevin. Shirley was one of ISAAC’s founding members and also the founder of Blissymbolics Communication International. David is well known in the AAC field through his work with Janice Light at Penn State University, both of whom are Co-editors of the Augmentative and Alternative Communication (AAC) journal. Kevin worked as a seating orthotist for many years and now teaches teenage students with autism. The following is an excerpt from the text published here:

“In retirement, both (Bob) and Shirley had many happy experiences with friends at Village by the Arboretum in Guelph, and lived two winters on the Moon River, Bala. They returned to Toronto in October 2012 and gained many welcoming and caring friends in the Don Mills community and at Donway Covenant United Church.

Bob always enjoyed meeting and talking with people. His family and long-time friends were very special to him.... He was always ready to make new friends and explore new places when he accompanied Shirley on her travels related to Bliss…. He will be greatly missed and most lovingly remembered.”

A Celebration of Life will be held on Saturday, April 4, 2015, at Mount Pleasant Visitation Centre, Toronto. Memorial donations may be made to Blissymbolics Communication Institute - Canada, % Katherine Seybold, Treasurer, 296 Glencairn Ave. Toronto, Ontario M5N 1T9, Canada.
In Memoriam — “She Did It Her Way”

Anne Warrick died on November 17, 2014. She led a full life, filled with quiet accomplishments in augmentative communication circles around the world.

Anne was a pioneer in the AAC field, a catalyst for the development of AAC in Poland and India, an ISAAC Fellow, the author of the first book in ISAAC’s series on AAC (Communication Without Speech, 1995), an early adapter of Blissymbols for children with cerebral palsy, a champion for AAC in developing areas of the world, the founder and first editor of the Augmentative Communication World Network (ACWN) Newsletter. And she was so much more: a steadfast friend, a willing volunteer, an amazing colleague, and an all-around wonderful lady. Anne’s ISAAC Series book has been translated into Spanish, Simplified Chinese and Traditional Chinese, still available at: https://www.isaac-online.org/english/publications/.

Anne’s proper English upbringing and consistent lady-like behaviour provided cover for a quick and sometimes mischievous wit and an adventurous streak that took her around the world in support of children and adults with communication impairments. She was also a great wife to Ed, an always supportive mother to Scott, Bill and Deborah, and a valued and valuable grandmother to Dylan, Emily and Vanessa.

Anne’s long career included stints as a speech-language pathologist at Ottawa Children’s Treatment Centre, Ottawa, Ontario, Canada, and the Ontario Children’s Treatment Centre in Toronto, Ontario, Canada (now Holland Bloorview Kids Rehabilitation Hospital). She also served as an international AAC consultant for ISAAC. Anne was known as “Anne Auntie” to the children at the Indian Institute for Cerebral Palsy in Kolkata, India, and DIDI (sister) to all the staff. She was the “guru” of AAC in India and travelled widely in the country conducting workshops to create awareness about augmentative communication. But even more than her skilled professional input, Anne brought into the AAC field the “magic” of communication access.

Anne left this world she served so well in the same way she lived in it: peacefully and on her own terms. Her wish for us, in the words of a favorite poem, was that we “smile, open our eyes, love and go on.”

Contributed by Anne’s many friends from around the world
Chapter News

ISAAC BRAZIL
Please visit the new ISAAC Brazil website (www.isaac.org.br), for information about the organization and updates on their upcoming conference:

JUNE 9 – 12, 2015
VI Congresso Brasileiro de Comunicação Alternativa
UNICAMP - Universidade Estadual de Campinas
São Paulo, Brazil

ISAAC DENMARK
ISAAC Denmark’s annual National Conference was held on March 16-17, with presenters from Norway, Sweden and Denmark. According to Chapter President, Birgitte Brandt, “Being a small Chapter we looked forward to two exciting days with 150 delegates; a group of AAC users met on one of the days. To strengthen Scandinavian collaboration we always invite two members of the ISAAC Board in Norway and Sweden to our conferences; as well, we are invited to their national conferences. ISAAC members in both countries can attend the conference at membership price.”

USSAAC (ISAAC USA)
Andrea Barton-Hulsey, Georgia State University, has been awarded the 2014 New Century Scholars Doctoral Scholarship from ASHA.

ISAAC TAIWAN
ISAAC Taiwan has invited Professor Rowland M. Charity from Oregon Health & Science University to visit Taiwan. Two conferences will be held in Chung Shan Medical University, Taichung City, Taiwan:

2015/5/30 Assessment and Intervention for Children with Complex Communication Needs
2015/5/31 ICF/ICF-CY in Communication Disorders

Information is available here or by contacting ISAAC Taiwan at twsac@gmail.com.

COMMUNICATION MATTERS (ISAAC UK)
ISAAC UK (Communication Matters) is pleased to announce its new team. Patrick Poon, who has dedicated over 10 years to the charity, has recently retired, and Emily Campbell takes over as full-time administrator. The new manager working in support of the Trustees is Dr. Hilary Gardner, a speech and language therapist and senior lecturer in Human Communication Sciences at University of Sheffield, UK.

The Trustees have made some key decisions based on staff changes. The organization’s administrative hub has been relocated to the University of Leeds campus in the vibrant City of Leeds (in the north of England). The University has been the location of the annual conference for several years now and staff have been incredibly welcoming. They have excellent facilities and accessibility for the large number of delegates using wheelchairs, and AAC. Hilary Gardner says, “Please feel free to drop in at any time if you are ever in the city. Our new website is was launched this month as well: exciting times!”

Communication Matters ISAAC UK,
Leeds Innovation Centre 103 Clarendon Rd, Leeds LS2 9DF.
General: Tel & Fax 0845 456 8211 d/o 0113 384 5675
International: Tel & Fax +44 131 467 7487
Reg. Charity No. 327500, Reg. Company in England & Wales No. 01965474
**AAC Around the World**

**ISAAC on Social Media**

- For information and insight on parenting a child who uses AAC, watch “Learning Journey,” a TEDx Talk by Kim Anderson (ISAAC member since 2005); she is the mother of Katrin Anderson, who uses AAC.

  From the video description: “Kim Anderson has extensive experience in international education. Kim lives in Hong Kong with her husband and two teenage girls. Her youngest, due to major complications at birth, is significantly (physically) compromised… (but) her cognitive abilities function well.”

- ISAAC Australia recently published a great blog post by Lisa Lehmann, “Lisa Reflects on the ISAAC 2014 Conference in Lisbon, Portugal.”

- Click here to view and “like” ISAAC International on Facebook!

- The ISAAC BUILD AAC Facebook page, curated by Petra Autnam Dillmann of Namibia, is an excellent forum for sharing news of interest to people in emerging AAC countries.

**CDAC News**

As of April 2015, CDAC welcomes Nora Rothschild as the CAN Ontario Coordinator for Communication Disabilities Access Canada (CDAC). Nora has extensive experience as an AAC clinician and has recently retired from her clinical practices at Children’s Treatment Network of Simcoe York and Holland Bloorview Kids Rehabilitation Hospital.

For more about CDAC, see the article beginning on page 10 by Barbara Collier, CDAC Executive Director.

**“A Journey of Discovery to the Last Frontier”**

Fiona Given of Australia is the winner of the 2014 ISAAC Outstanding Consumer Lecture Award. Fiona’s presentation, "A Journey of Discovery to the Last Frontier: Discovering an Adventure in Antarctica," is now available online. Please click here to access the PDF version through the ISAAC website, or click here to access the PowerPoint presentation directly (PDF, 6 MB).

**BUILD News**

Dot Fraser and Aldona Mysakowska Adamczyk, BUILD Subcommittee for Europe, have reported that the next Eastern and Central European AAC Conference (ECEAAC) will take place in Moldova in October 2015. Details to follow in the June issue of ISAAC E-News.

**ACWN Newsletter Submissions Welcome!**

Augmentative Communication World Network (ACWN) Newsletter welcomes articles with news from emerging AAC nations that you either live in or support. Please contact ACWN Newsletter editor Dot Fraser.
Accessibility Includes Communication

Like many other countries that ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), Canada is now obligated to ensure inclusion and equal access to goods and services for all people who have disabilities, including people who have communication disabilities. As part of that process, accessibility and human rights legislation is currently evolving on a provincial level across Canada. These laws obligate businesses and organizations to create access to employment, physical accommodations, transportation, customer service, and information and communication.

Some disability groups are clearly benefiting from this legislation. For example, people with mobility disabilities have ramps to get into buildings, door openers and curb cuts; people who have sensory disabilities can have documents in alternate formats and people who are Deaf can request sign language interpreting services. However, many people with communication disabilities that are not primarily caused by hearing loss continue to experience inequitable access to goods, services and opportunities because their accessibility requirements are not well understood, inadequately represented in existing regulations and frequently omitted from accessibility guidelines (Collier, McGhie Richmond, & Self, H. 2010). Without strong, consistent and inclusive messaging, the accessibility needs of people with communication disabilities will continue to be omitted within this legislation. This omission impacts people with communication disabilities because there are no clear expectations or guidelines that tell businesses and services what they should do to make their services communication accessible. This is especially significant in situations where communication is critical such as healthcare, education, emergency, police, legal and justice services. People with communication disabilities can experience serious consequences because many of these services are inaccessible to them.

In 2010, Communication Disabilities Access Canada (CDAC) conducted a national survey to find out what accessibility means for people who have different types of communication disabilities, including people who use AAC (Collier, Blackstone, & Taylor, 2012). Based on that research, we define communication access as what businesses and organizations can do so that people can:

- understand what is being said
- have their messages accurately understood by others

…continued on page 11
Accessibility Includes Communication  continued

- use their preferred communication methods such as speech, gestures, writing, pointing to objects or pictures, spelling words, typing on a communication device or human assistance
- communicate over the telephone or use text or email
- communicate at meetings and public events
- receive written information in ways they understand and can use
- sign documents, take notes and complete forms in ways that are accessible to them

While people who have communication disabilities have individual communication access requirements, there are a number of general accessibility accommodations that businesses and organizations can do to improve communication access to their services.

Communication Access Now
Communication Access Now (CAN) is a Canadian project to increase awareness of communication access for people with communication disabilities. On a systemic level, we are educating legislators and accessibility committees on the generic principles and components for communication access, how these can be inserted into emerging policies and how they apply within different contexts. On a community level, we are providing education and resources to businesses, organizations and essential services on ways to improve access for people with communication disabilities. On an individual level, we are sharing resources to support people with communication disabilities to learn about their communication accessibility rights and how to negotiate these when getting services.

Get Involved
As countries begin to develop their accessibility policies, it is time to put communication into accessibility legislation. We can all play a role in this. Here are some suggestions, based on what we are currently doing in Canada:

- Check our website, blog and social media for communication access resources that you can use.
- Find out what is happening in terms of the implementation of UNCRPD or other accessibility laws in your country or area.
- Connect with legislators, policy makers and accessibility advisors and tell them access includes communication and is more than alternate formats and sign language services.

...continued on page 12
Accessibility Includes Communication  continued

• Keep your message consistent and inclusive of all communication disabilities when discussing communication access. One person’s accommodations may be another person’s barriers.
• Explain the difference between clinical services, communication devices and communication access which is about social justice, human rights and what society need to do to make services accessible to everyone.
• Explain the barriers that people may experience within a specific sector before suggesting solutions.
• Share the communication access symbol and tip sheets.
• Support people with communication disabilities in learning about their communication access rights and in negotiating their accessibility needs.

CDAC Resources

To assist you in doing this, we have developed a number of online resources that you can use. These include:

Toolkit for people with communication disabilities containing a video, information about communication access rights, vocabulary to negotiate access accommodations, a communication access card and tips for handling situations where access rights are ignored.

Toolkit for clinicians and advocates containing PowerPoint presentations, videos and tips for educating others about communication access.

Symbols you can use to promote communication access, including the one CAN uses, what it means and how to use it.

E-learning modules and audits for businesses and organizations to learn how to make their services accessible.

Barriers and suggestions for key sectors that have been identified by people with communication disabilities.

Videos about communication access rights.

Access to Justice

As always we welcome your feedback and ideas.

www.communication-access.org
www.cdacanada.com
Email: cdac@bell.net
Letter from Sarah Yong, ISAAC BUILD Committee Chair

ISAAC BUILD was formed with the aim of supporting emerging AAC countries in their efforts to increase AAC awareness and utilization. Promoting and implementing AAC is often a challenge in these countries due to lack of financial or infrastructural resources.

We are seeking ISAAC Chapters who may be interested in collaborating with/supporting emerging AAC countries or regions. We believe that such partnerships would be meaningful and beneficial for both Chapters and BUILD. Some possible ways that Chapters could help include, but are not necessarily limited to:

- Sponsoring membership of individuals from emerging countries;
- Developing/sharing resource materials;
- Providing training in an emerging country/region;
- Sponsoring emerging countries on the ISAAC Five & Five Program.

Chapters who are interested can either contact Sarah Yong, BUILD Chair, or Janice Murray, Chair of the ISAAC Council. We will connect you to the appropriate individuals and will be happy to provide more information. We look forward to collaborating with you in this exciting work!

Representatives from BUILD countries shared information and resources at ISAAC 2014 in Lisbon, Portugal
17th Biennial Conference of ISAAC
August 6 - 13, 2016
Toronto, Ontario, Canada

We are pleased to introduce our ISAAC Conference 2016 Co-Chairs, Shelley Deegan, Tracy Hunt and Tracy Shepherd. You can find their profiles on our website here.

AAIDD Annual Meeting
June 1 - 4, 2015
Louisville, Kentucky, USA

AAIDD’s 139th Annual Meeting, Making a Difference Through Research, Practice, and Policy, offers a full roster of informative and inspiring plenary sessions, cutting edge concurrent sessions, posters addressing emerging issues, and in-depth pre- and post-conference meetings on a number of important topics.

See the full schedule of events, find a hotel, and register by clicking here.

For more information, American Association on Intellectual and Developmental Disabilities (AAIDD)
501 3rd Street, NW, Suite 200
Washington, D.C. 20001
Telephone: 202-387-1968
Fax: 202-387-2193

ISAAC Conference 2016 Travel
Star Alliance will be the Official Airline Network for ISAAC Conference 2016, to be held in Toronto, Canada. Discounts on flights will be available to ISAAC 2016 delegates. Please check the ISAAC website for more information as details become available.

For more event listings, please click here to view the Calendar of Upcoming Events on ISAAC’s website.
HAVE YOU RENEWED YOUR ISAAC MEMBERSHIP FOR 2015?

If you are currently a member of ISAAC, you can renew your membership through your national or regional Chapter. Please do so by March 31st in order to ensure that your name is included in the ISAAC Membership Directory 2015.

Members of ISAAC International and ISAAC Canada may renew their membership online.

THANK YOU!

ISAAC Chapters

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New AAC Journal — March 2015
Vol. 30 No. 4
View Table of Contents here.
ISAAC’s Vision is that AAC will be recognized, valued and used throughout the world.

ISAAC’s Mission is to promote the best possible communication for people with complex communication needs.

ISAAC is a Non-Governmental Organization in consultative status with the United Nations Economic and Social Council (ECOSOC).

Contact Us

Executive Board 2014-2016

Jeffrey K. Riley
President, Canada
(up to September 2015)

Gregor Renner
President-Elect, Germany
(up to September 2015)

Janice Murray
Chair of the Council, UK

Aldona Mysakowska Adamczyk
Chair-Elect of the Council, Poland

India Ochs
VP without Portfolio, USA

Tracy Shepherd
VP-Conference Planning, Canada

Vic Valentic
Leadership Chair for People who use AAC, Canada

Sarah Yong
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Franklin Smith, Executive Director

Teraiz El-Deir, Membership Coordinator

Heather Stonehouse, Manager – Communications

Nola Millin, Editor, ISAAC Website

Janice Light, Ph.D., and David McNaughton, Ph.D., Co-editors, AAC

AAC Editorial Office, Jackie Brown, Editorial Assistant