### THE ISAAC COMMUNICATOR

March 2019

# Message from the ISAAC President

#### Meredith Allan

All the ISAAC family will be saddened to hear of the recent passing of two former members of the ISAAC Executive – Pegi Young and Sarah Lever. Both Pegi and Sarah have left the AAC community an incredible legacy. Tributes to them are on page 3.

I remember Pegi's personal encouragement to me as a new Chair of ISAAC's People Who Use AAC Committee (under a previous structure). Her vision, through The Bridge School Teacher-in-Residence scholarships, has seen many people in the world enhance and expand the use of AAC.

I remember Sarah, as LEAD Chair, facilitating a forum of People who use AAC at the ISAAC 2006 conference in Dusseldorf. She was also behind the idea of AAC Awareness Month. Little did we realize then how the idea would burst onto the world. Over the years I had many laughs with Sarah's mother, Anne, during conference break times.

On December 20<sup>th</sup> of last year, in the Australian state where I live, we saw the release of a report by the Office of the Disability Services Commissioner that reviewed disability service provision for people who died 2016-18. This report was about people with disability and the deaths of those in state care for the previous two years. In its findings, three things were highlighted:

- choking and aspiration pneumonia risk.
- pain or distress, and
- poor disability service practice.



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The report reflects previous findings in the United Kingdom and other states in Australia. The link to the report is https://www.odsc.vic.gov.au/abuseprevention/review-of-disability-serviceprovision/

In Geelong, a city about an hour from Melbourne, a group of parents and support people meet every four weeks to discuss their children's needs and AAC strategies they use.



Our words are worth waiting for."

Here is a list they came up with at the end of last year:

- Visual/object/association/preparing the environment
- Model
- Expect a response •
- Prepare
- Waiting
- Verbal prompt
- Respond
- Give them device
- Interpret clarify
- Feedback
- Open-ended guestions
- Communication Partners

The group did well. It is surprising that this list could almost be used for a lifetime. How often as we grow older does a communication partner ask a question but doesn't wait for a response, or answers for you? Our words are worth waiting for.

Meredith Allan **ISAAC** President Click here to read these articles in translation

### From the **Executive Director**

#### **Franklin Smith**

Welcome to the March 2019 edition of The ISAAC Communicator (formerly ISAAC E-News). We are thrilled to introduce our new "look" and rebranded guarterly communication.

The ISAAC International office continues its work on behalf of the membership around the world and is pleased to advise on the following initiatives: ISAAC Membership Renewal 2019, Conference 2020, ISAAC International Partnerships, ISAAC International Financial Audit 2018, and Webinars.

#### **ISAAC Membership Renewal 2019**

It's membership renewal time! If you are one of our valued Chapter members, please respond to your Chapter in a timely fashion to ensure that your membership is renewed for 2019.

For 2019 and 2020, the ISAAC Executive Board approved the continuation of a "no additional cost" subscription to ISAAC's scientific journal, AAC, for all Institutional and Corporate members.

**\*\*NEW for 2019\*\*** In order to better meet the needs of our Chapters (current or future) in developing countries (as defined by the World Bank), the ISAAC Executive Board authorized the creation of a new group of Chapter membership rates specifically for these Chapters.

Read the full article here



### In Memoriam < 🔍



#### Sarah Lever 1975-2018

All of us at ISAAC were saddened by the passing of Sarah Lever, 43, of Charlotte, North Carolina, suddenly on December 29, 2018. A strong supporter of ISAAC and a member of the ISAAC Executive Board from 2007 - 2010, she traveled the world advocating for the rights of people who use AAC on behalf of ISAAC. Sarah was awarded the Sherri Johnson/ISAAC Conference Consumer Travel Scholarship in 2002, 2004, and 2006.

During her volunteer years with ISAAC, Sarah worked on a number of leadership resources for people who use AAC to encourage participation on volunteer boards and committees. In the fall of 2018, she renewed her commitment to ISAAC by working with Lateef McLeod, VP for LEAD, on International AAC Awareness Month 2018. She planned to work on upcoming LEAD committee initiatives, including supplying the Dare to LEAD Mentorship Program with the leadership materials that she compiled with colleague Martin Pistorius.

Sarah graduated with a college degree in Internet Technologies. She was a weekly volunteer at Clear Creek Nursing and Rehabilitation Center, assisting in the care of people with Alzheimer's, including her mother. As her family describes her, "Sarah had a huge heart and simply loved people."

For more details about Sarah, her life and accomplishments, please click here

#### Pegi Young 1952 - 2019

The Bridge School family was saddened when, on January 1, 2019, Pegi Young lost a long and courageous battle with cancer.

Pegi was the guiding force behind the creation of The Bridge School,



founded in 1986 as an educational program serving children with severe physical and speech impairments. Pegi's charge to The Bridge School staff was to challenge the prevailing attitude of programs that had extremely low expectations for their children, to offer hope to parents, and to develop an environment where children with severe physical and speech impairments had the opportunity to develop their potential and demonstrate their ability to communicate, participate in and contribute to society.

Pegi's unselfish efforts in the support of the education of children with severe speech and physical disabilities changed the lives of children and their families around the world. Neil and Pegi Young were the driving force behind the The Bridge School Concert from 1986 To 2016, which raised the necessary funds to support the school.

For the full text of this article, with a full account of Pegi's accomplishments and well-deserved recognition, please click here



#### **Resources**



#### **AAC Journal & RERC on AAC**

Over the past few decades, significant advances in AAC have changed many lives. The Editors of the AAC journal worked with the <u>RERC on AAC</u> to create a special issue summarizing the 2018 State of the Science in AAC conference, and to make the articles freely available for a limited period of time. Click the links below for the full text of each article:

Light, J., McNaughton, D., Beukelman, D., Fager, S. K., Fried-Oken, M., Jakobs, T., & Jakobs, E. (2019). Challenges and opportunities in augmentative and alternative communication: Research and technology development to enhance communication and participation for individuals with complex communication needs. Augmentative and Alternative Communication, 1-12. https://doi.org/10.1080/07434618.2018.1556



Infographic reprinted courtesy of Kelsey Mandak, Ph.D.

Light, J., McNaughton, D., & Caron, J. (2019). New and emerging AAC technology supports for children with complex communication needs and their communication partners:

#### **AAC Current Issue**

Follow @AACjourn on Twitter!



State of the science and future research directions. Augmentative and Alternative Communication, 1-16. https://doi.org/10.1080/07434618.2018.1557251

Faker, S.K., Fried-Oken, M., Jakobs, T., & Beukelman, D. R. (2019). New and emerging access technologies for adults with complex communication needs and severe motor impairments: State of the science. Augmentative and Alternative Communication, 1-13. https://doi.org/10.1080/07434618.2018.1556730

Light, J., Wilkinson, K. M., Thiessen, A., Beukelman, D. R., & Fager, S. K. (2019). Designing effective AAC displays for individuals with developmental or acquired disabilities: State of the science and future research directions. Augmentative and Alternative Communication, 1-14. https://doi.org/10.1080/07434618.2018.1558283

McNaughton, D., Light, J., Beukelman, D. R., Klein, C., Nieder, D., & Nazareth, G. (2019). Building capacity in AAC: A person-centred approach to supporting participation by people with complex communication needs. Augmentative and Alternative Communication, 1-13. https://doi.org/10.1080/07434618.2018.1556731



#### Resources +



#### **AAC for Caregivers**

Sarah Yong and Deborah Yong of the Specialised Assistive Technology Centre, SPD Singapore, are excited to share with us their new online resource, the AAC for Caregivers Manual. The manual and official post can be found here

The AAC for Caregivers Manual covers eight strategies in AAC that can be downloaded and used as a manual or as separate handouts when training caregivers or professionals working with individuals who use AAC.

For more information about SPD's AAC for *Caregivers* training program, please email Deborah or Sarah at atc@spd.org.sg.

This resource was made possible by the AAC Lightning Pitch cash prize at ISAAC Conference 2018, awarded to Deborah Yong and sponsored by ISAAC International and Deakin University. The authors greatly appreciate this support.

#### **Communication Disabilities Access Canada**

**Communication Disabilities Access Canada** (CDAC) is a Canada-wide non-profit organization that focuses on social justice and accessibility for people who have communication disabilities.

For an update on CDAC's current activities, click here

CDAC also shared this article, Communication is Key, on effective communication in health care interactions, particularly for monitoring Medical Assistance in Dying (MAiD). The article, by Barbara Collier, Anne Abbott, and Hazel Self, was published as one of a series of guest blogs by Vulnerable Persons Standard (VPS) advisors in Ontario, Canada.

For more information contact info@vps-npv.ca





Effective communication is the foundation for all healthcare interactions."

#### **CSWN Newsletter**

The ISAAC CSWN Newsletter is published twice each year. It offers practical information to those interested in AAC and assistive technology in areas of the world where these fields are still emerging. Its aims are to present new ideas that are easily adaptable across settings. Watch for our next issue in July 2019!

Past editions are posted on the ISAAC website



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### **Events**



#### **Global Challenges in Assistive Technology**

An opportunity to meet with international experts in the world's oldest university town, Bologna, Italy, August 27-30

The AAATE 2019 conference will address issues related to technology and disability: technological developments in the field of AT, including ambient assisted living (AAL), smart environments, and the Internet of Things (IoT) applications; social assistive robotics; digital and connected health; virtual and augmented reality.



Also addressed will be the need to provide wider access to AT on a global scale"

Also addressed will be the ethical implications of these new possibilities, data privacy, and self-determination of users with disabilities and older adults; innovations in AT for cognitive, sensory, and motor disabilities; the impact of societal changes that make assistive technology ever more relevant and needed; and the need to provide wider access to AT on a global scale.

For the full text of this article, with AAATE conference highlights, please click here

#### News about ATAAC 2019

*The 4<sup>th</sup> Annual International Assistive Technology and AAC conference, Zagreb, Croatia, October 15-17* 

Leading AT and AAC experts and manufacturers will be presenting information, research, and products, and sharing experiences and valuable advice on working with children and persons with communication support needs.

The <u>ATAAC 2019</u> conference can be attended in person or watched online.

Watch online access lasts for two weeks from the first day of the conference, ensuring you enough time to focus on eac h and every lecture.

All lectures in languages other than English will be simultaneously translated into English.

More information can be found on the ATAAC 2019 website, and regular updates can be found on the <u>ATAAC Facebook</u> and <u>Instagram</u> profile.



ISAAC Calendar of Events View on the ISAAC website



## Chapter News <<< 🕑



#### **Communication Matters**

Communication Matters has been successful in receiving funding from The National Lottery Community Fund (formerly Big Lottery) for developing and supporting mentoring for people who use AAC and other young people with disabilities.

This 5-year project will be delivered in partnership with Creativity in Practice and will be offering Level 1 and Level 2 gualifications in Mentoring as well as supporting the development of two mentoring schemes. This is a fantastic opportunity!

Stay tuned for more news and updates. In the meantime if you are interested in either of these qualifications or in finding out more please contact admin@communicationmatters.org.uk

#### CM2019 – Call for Papers

You are invited to contribute to the Communication Matters CM2019 International AAC Conference (8-10 September, University of Leeds)

The deadline for abstract submissions is April 26, 2019.

CM is using a new online submission program this year – further information on how to submit your abstract here

#### **ISAAC-Francophone**

In search of training or information about AAC? Where to start? How and with what approach? Which method to use? ISAAC-Francophone's Catalogue des formations provides communication approaches and tools for people with communication disabilities.. It is designed to be accessible and useful to all: families and professionals, regardless of their qualification.

#### Available online in French only





#### **Rett til kommunikasjon! Right to Communication!** ISAAC Norway Conference April 8-10, 2019

For more information, click here



Country visits listed here



#### **Chapters**



- ISAAC-Australia www.isaacaustralia.com
- ISAAC-Brazil <u>www.isaac.org.br</u>
- ISAAC-Canada www.isaac-canada.org
- ISAAC-Denmark <u>www.isaac.dk</u>
- ISAAC-FSC <u>www.isaac-fr.org</u>
- ISAAC-India <u>www.isaac.org.in</u>
- ISAAC-Israel <u>www.isaac.org.il</u>
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- ISAAC-NF <u>www.isaac-nf.nl</u>
- ISAAC-Norway <u>www.isaac.no</u>
- ISAAC-Poland <u>facebook</u>
- ISAAC-Sweden <u>www.isaac-sverige.se</u>
- ISAAC-Taiwan <u>www.twsaac.blogspot.com</u>
- ISAAC-UK <u>www.communicationmatters.org.uk</u>
- ISAAC-US <u>www.ussaac.org</u>

#### **Contact Us**

Do you have a question or comment? Please feel free to send an email to feedback@isaac-online.org

#### 2019 ISAAC Membership Directory Call for Advertisers

Advertise in the 2019 ISAAC Membership Directory to reach a dedicated group of consumers, professionals, organizations, and corporations. 2019 Rate Card and Order Form are posted here

SPECIAL OFFER! For all paid ads placed, we will credit back your ad purchase (up to a maximum of \$600), when you book your Conference 2020 booth space by November 30th, 2019. For details, contact Tony Needer tony@isaac-online.org Conference 2020 Exhibitor Sales Specialist.

#### **Membership Renewals**

ISAAC membership runs from January 1 to December 31. To be included in our annual Membership Directory please renew your ISAAC membership By March 31st!





#### Our Vision & Mission

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 & Social Council.

#### **Sharing is Caring**

ISAAC Chapters and members worldwide are invited to submit items of interest from your country or region. News, AAC practice tips, research, personal essays, in article format or as a link to online articles or resources, will be reviewed and made available on the ISAAC website as appropriate. Please send articles and photos to Nola Millin.

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#### The ISAAC Communicator

Published four times each year. Comments on this issue are welcome. Please contact <u>Heather Stonehouse</u>.

#### **Executive Board**

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#### **Stay Connected**

Keep informed about ISAAC news & in touch with the AAC community on our social media!



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