

*Time for another newsletter from the Augmentative Communication World Network (ACWN).*

*This month the newsletter contains information and resources for parents of children for whom augmentative communication has been recommended. Most parents and children use some augmentative communication modes (often without realizing it) before a more formal communication system is suggested; an event that usually gives rise to many questions. “Won’t this interfere with learning to talk?” “Doesn’t this take a lot of time?” The following resources contain many answers to parent’s question, along with videos of children, even toddlers and preschoolers, who are developing language, communicating, learning, and becoming confident students, friends, and family members.*

**Communication Matters** is a UK national charitable organisation of members concerned with the application of [augmentative and alternative communication](#) (AAC) for people with complex communication needs. **Focus On...** is a set of seven introductory topics related to augmentative and alternative communication written and published in a clear and easy-to-understand style by *Communication Matters*. The seven leaflets: *What is AAC; Using Symbols for Communication; Let Your Hands Do The Talking; What can I say? First Steps; Speaking with someone who uses AAC; Communicating with Patients who have Speech/Language Difficulties, Accessing Communication Aids and Computers* are available in PDF and printed forms, and as individual PowerPoint presentations. [http://www.communicationmatters.org.uk/Publications/Focus\\_On/focus\\_on.html](http://www.communicationmatters.org.uk/Publications/Focus_On/focus_on.html)

ISAAC members are free to translate the **Focus on...** leaflets into their national language providing the following wording appears in the translated material: ‘Originally published in English by **Communication Matters / ISAAC-UK**’. Please contact [admin@communicationmatters.org.uk](mailto:admin@communicationmatters.org.uk) for a copy of the master artwork for translation.

### **Central Coast Children’s Foundation (CCCF), USA.**

It is important that responsible clinicians master the evidence that demystifies the myths that surround AAC. It is also important that they help fearful parents and uninformed professionals understand the compelling reasons for early action, giving current examples of enlightened early intervention practice in AAC. In an effort to make such evidence and resources readily accessible to busy practitioners, a comprehensive article written by Harvey Pressman, is available via the **Central Coast Children’s Foundation’s web site**.

<http://www.centralcoastchildrensfoundation.org/myths.htm>

This article is also available in Spanish:

<http://www.centralcoastchildrensfoundation.org/smyths.htm>

## **The University of Washington, USA.**

This university site has information to dispel myths and misunderstandings about assistive technology (AT) and augmentative and alternative communication (AAC), and the many beliefs that create barriers for AAC & AT users of all ages. [http://depts.washington.edu/enables/myths/myths\\_intro.htm](http://depts.washington.edu/enables/myths/myths_intro.htm)

Another section introduces the topic further and tackles myths head on by presenting stories that help to dispel and reduce barriers to the introduction of AAC. [http://depts.washington.edu/enables/myths/myths\\_aac\\_intervention.htm](http://depts.washington.edu/enables/myths/myths_aac_intervention.htm)

The **Enables** web site also discusses myths that surround AAC in relation to toddlers and preschoolers and provides videos of young children learning switch control, taking turns, using eye gaze and making requests for toys and music. [http://depts.washington.edu/enables/myths/myths\\_aac\\_inter\\_infants.htm](http://depts.washington.edu/enables/myths/myths_aac_inter_infants.htm)

The **AAC Institute, USA.** This internet resource that supports parents and other family members as they share the excitement, wonder, and joy of seeing children communicate using AAC interventions. Parents with children who rely on AAC often find themselves in isolated situations and feel disconnected from other families. The **AAC Institute** offers parents a way to share their experiences. <http://www.aac institute.org/Resources/ParentsCorner/intro.html>

## **A Parent's View.**

Robin Hurd is the parent of four children and a Parent Support Liaison with the **AAC Institute**. Robin is known internationally for her dedication to augmentative communication and to her family. **The Autism Life** presents an interview with Robin in which she describes her children's use of augmentative communication. <http://www.theautismlife.com/interviews/robin.hurd.augmentative.communication.interview/>

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## **The Indiana Resource Centre for Autism, USA.**

An article for parents of children with Autism Spectrum Disorders, 'When Your Child is Diagnosed With An Autism Spectrum Disorder', is available in Spanish. You will find: Cuando su hijo es diagnosticado con un trastorno del espectro autista: Un recurso para las familias cuyo niño ha sido recién diagnosticado. <http://www.iidc.indiana.edu:80/irca/fspanish.html>

## **Novita Children's Services, Australia.**

**Novita** is celebrating seventy years of caring for children with disabilities. What a great achievement! Novita's web site describes parents, carers and family members as the 'magic ingredient' in the life of a child with disability! These individuals often make it possible for the child to achieve extraordinary things despite their disability. Novita's web page '**Living with disability - parents and carers**' provides excellent resources for mothers, fathers and many other carers. <http://www.novita.org.au/Content.aspx?p=8>

**The Childhood Apraxia of Speech Association of North America's (CASANA)** mission is to strengthen the support systems in the lives of children with apraxia, so that each child has the best opportunity to develop speech. [www.apraxia-kids.org](http://www.apraxia-kids.org)

This site also offers information for parents of children who may find AAC useful following a diagnosis of apraxia. See the **Family Start Guide**. <http://www.apraxia-kids.org/site/apps/nlnet/content.aspx?c=chKMI0PIIsE&b=839037&ct=837215>

The **Apraxia Kids** web site states: 'Often when someone raises the idea of using sign language for a child with apraxia, parents may experience confusion and even fear. After all, "The child can hear just fine! Why would we use sign language for a hearing child?" Or "But won't using the sign mean my child won't need to talk? Won't it keep him/her from speaking?" Conversely, some parents report that their child's speech language pathologist has told them that the child will rely on sign and thus not learn to speak. The reference below refutes many of myths about signing by providing an article on the use of signing as a suitable communication mode. <http://www.apraxia-kids.org/site/c.chKMI0PIIsE/b.980831/apps/s/content.asp?ct=464165>

*During the past two months, two AAC resource books for teachers in special education have been sent to me from either side of the world. **Supporting communication through AAC (Alternative and Augmentative Communication)** comes from **Ingfield Manor School/Scope** in the United Kingdom and **Disability Resource Handbook for Teachers** is from the **Society for the Physically Disabled, Singapore**. A big Thank You to these organizations and all the authors for these resources.*

**Supporting Communication Through AAC (Alternative and Augmentative Communication)** contains 12 modules. It aims to help parents, teachers and professionals to support individuals who may benefit from using AAC. The modules are available to download from this page as Pdfs. <http://www.scope.org.uk/education/aac.php>**Module 1: Introduction to AAC** [pdf 30k]

[Module 2: Frequently Asked Questions](#) [pdf 30k]

[Module 3: The Nuts and Bolts of AAC](#) [pdf 2Mb]

[Module 4: Games and Activities](#) [pdf 1Mb]

[Module 5: Accessing Equipment, Books and Charts](#) [pdf 800k]

[Module 6: Software](#) [pdf 1.6Mb]

[Module 7: Children within the Foundation Stage](#) [pdf 800k]

[Module 8: Lifelong Learning \(section 1\)](#) [pdf 500k]

[Module 8: Lifelong Learning \(section 2\)](#) [pdf 800k]

[Module 8: Lifelong Learning \(section 3\)](#) [pdf 500k]

[Module 8: Lifelong Learning \(section appendix\)](#) [pdf 80k]

[Module 9: Children and Adults with Profound and Multiple Learning Difficulties](#) [pdf 300k]

[Module 10: One School's Approach](#) [pdf 5Mb]

An insight into how the development of the communication skills of children who attend [Ingfield Manor School](#) <http://www.scope.org.uk/education/ingfield.php> has been addressed. Their school curriculum and the structure of the communication books used are discussed and illustrated in detail.

[Module 11: One County's Approach to Supporting AAC in Mainstream Schools](#) [pdf 30k]

[Module 12: Contacts, Web Resources and Discussion Groups](#) [pdf 30k]

**A Disability Resource Book for Teachers: How to Integrate Students with Physical Disabilities into Mainstream Schools.** There are seven chapters in this book, which aims to help teachers meet the challenges of integration. It reflects the experiences faced by teachers and other professionals when children with complex communication needs were integrated into mainstream schools in Singapore.

1. Inclusive Education.
2. Understanding Disabilities.
3. Assistive Technology.
4. Accessibility.
5. Integrating with People with Disabilities.
6. Challenges.
7. Community

Resources. [http://www.spd.org.sg/form/SPD\\_Disability\\_Resource\\_Handbook\\_for\\_Teachers.pdf](http://www.spd.org.sg/form/SPD_Disability_Resource_Handbook_for_Teachers.pdf)

### **Follow-up to our June 2009 Newsletter - Communication Displays.**

*If you are looking for information on AAC that would interest siblings, here's the book for you. Very simply written and with lighthearted illustrations I think it's a real find!*

**'Using Words, Photos and Symbols'** has been developed as part of a project funded by **Surrey Children's Fund, UK**. The book, which is a free download, covers using symbols & photos as well as sections on speech, signing, and objects to communicate. The book goes well with our August newsletter since it was designed to give families tips on making useful communication tools for their children. A series of templates and training handbooks come with the booklet. To download (it is a large file) click on the title

page. <http://www.communicationpeople.co.uk/Downloads/Using%20words%20photos%20and%20symbols.pdf>

### **Following up to our recent Literacy references:**

*The following sites offer further support add to our collection.*

### **Free books from SET-BC, Canada.**

<http://www.setbc.org/setbc/accessiblebooks/freebooksforyou.html>

## **CELL: Centre for Early Literacy Learning: Practice Guides Especially for Practitioners**

These guides can be used by early childhood educators, child care providers, early interventionists, and other early childhood practitioners for promoting infants', toddlers', and preschoolers' literacy learning using interest-based and highly engaging activities.

<http://earlyliteracylearning.org/pgpracts.php>

### **News from Malawi.**

*Here is a wonderful story from Victor Musowa in Malawi. His story gave me a great opportunity to check my AAC cupboard for materials that would be useful for his programme. If you would like to support Victor or make a donation toward his internet costs please contact him directly at [abigvic@yahoo.com](mailto:abigvic@yahoo.com) for the best way to make mailing arrangements.*

**SHORT STORY.** Grace Salanje was born on the 24/05/98 in a small village near Blantyre city. She was diagnosed CP at five years. Mom reports that she had prolonged labor and Grace did not cry at birth. Due to difficulties accessing hospital services, Grace stayed home with no therapy until five years old when she started attending therapy at the main referral hospital in Blantyre (Queen Elizabeth Central Hospital) once a month. As years passed Mom noticed more challenges for Grace, ranging from communication, gross motor control and difficulty performing activities of daily living. Grace was identified by our team through a community leader who came to ask if we could go to see her. On the 10/11/08 I and the occupational therapist went to Grace's village where we assessed her and together with the Mom we made up a list of priorities to work on. The assessment summary was ***Cerebral Palsy, Athetoid, with involuntary movements more to the left side of the body. Needs maximum support to sit and stand. Difficulty coordinating phonation with very low Maximum Phonation Time, and lots of associated facial movements during speech attempts. Good receptive language and comprehension.*** While there we learned that Grace's Mom was divorced because of her disability as Dad believed that it was Mom who has contributed to Grace's condition. Some of the priority goals included Mobility, Sitting aid, School, and communication. A therapy plan for Grace to attend our rehabilitation centre once a week was made and in January, 2009, we managed to enroll her at a public school. Looking at her difficulty in sitting, a wooden chair was made by a local carpenter and given to her to use at school. The class teacher came to a workshop at our rehabilitation centre where, among other things, she participated in working with communication boards and how to make them using Boardmaker. Together with the Mom we started working on plans to make a communication board for Grace. Mom and the teacher made a lot of drafts of things to be included in the communication board and I worked on putting their plans into a communication board using a computer at the internet café in the city. This took us more than three months to come up with the first set of boards, as the computers at the internet café are shared among a lot of people and you can only use them for a specific allocated time. In April this year our rehabilitation centre paid a local wheelchair technician to make a wheelchair for Grace, The process of making the wheelchair has taken us three months and with a lot of adjustments we now have what we have been waiting for, as Grace's Mom doesn't need to carry a 26kg (57 pound) girl on her back to school as she has been doing the past 6 months. With this new wheelchair and tray we are now able to put the communication board on the tray for easy accessibility. Grace and Mom are very motivated now and at one time Grace's mom said **"Now there is hope in my Daughter"**. Grace comes for therapy twice a month as she can not manage once a week due to transport problem and she is the only bread winner, taking care

of 6 other siblings. There will be more updates in the next story; I will not be able to send pictures as the internet is very slow and expensive.

### **Conference News from Singapore by Marta Aragon**

*Marta Aragon and Tynesha Hingst from the The Augmentative and Alternative Communication Centre (AACC) with the Developmental Disabilities Resource Centre of Calgary, Alberta, Canada (DDRC) attended the International Association for the Scientific Study of Intellectual Disabilities (IASSID) 2<sup>nd</sup> PACIFIC ASIA CONGRESS, June 24 - 27, 2009 in Singapore.*

**DDRC** is a non profit organization with the mission to promote awareness and support communities to include persons with developmental disabilities thereby strengthening communities for all citizens. **The AACC at DDRC** is dedicated to providing comprehensive augmentative and alternative communication (**AAC**) supports exclusively to adults with developmental disabilities and strives to create understanding and awareness in the general community of the true capabilities and potential learning of people with disabilities through augmentative and alternative communication solutions.

**IASSID** is an international and interdisciplinary scientific **Non-Governmental Organisation (NGO)** with official relations with the **World Health Organization (WHO)**. **IASSID** promotes worldwide research and exchange of information on intellectual disabilities and is the first and only world-wide group dedicated to the scientific study of intellectual disability. **IASSID** is committed to enhancing the quality of life, health and well-being of people with intellectual disability and their families through scientific research and the application of research in both policy and everyday practice.

We found that there were strong connections between **IASSID's** commitment, **DDRC's** mission and vision and the **AACC's** primary purpose that we felt compelled to attend this conference. Through the greatly appreciated financial and professional support of **DDRC**, we were able to travel to Singapore to present and participate in this international congress. Conference streams included: Quality of life, behavior support, aging, early intervention, transition and post-school outcomes, physical health, education-learning

disabilities, policy and practice, mental health, families/relationships and augmentative and alternative communication.

Our presentation was titled **Learning to Successfully Implement Augmentative and Alternative Communication Solutions within a Framework of Community Inclusion for Adults with Developmental Disabilities**. We discussed the need for *socially-oriented* AAC intervention by focusing on the concepts of functionality versus diagnosis, goals and strategies, social vulnerability. We also stressed the great importance of social network participation and motivation. Currently, the **AACC** is working hard to develop an AAC Intervention Guide with a strong orientation toward social networks and an approach that will cover every step from assessment through to follow up.

We strongly believe that the field of augmentative and alternative communication can offer tremendous contributions to all of the topics presented at the IASSID congress and can be instrumental in enhancing quality of life, health and well-being of individuals with intellectual/cognitive disabilities and the community in general.

Given **IASSID's** mission we would encourage a larger representation of the AAC field within future conferences. In a 4 day conference with 9 simultaneous rooms offering presentations, only one and a half day and one room was dedicated to AAC. While Australia had a very strong presence in the AAC stream there is a great need for more individuals involved in AAC to participate in order to promote an understanding of how our field can benefit such traditionally neglected populations as individuals with intellectual/cognitive disabilities. We were very satisfied to find that the majority of presenters focused on the achievement of **quality of life** for populations with intellectual/cognitive disabilities - the ultimate purpose of all interventions, including AAC interventions. We at the **AACC** are proud to recognize our work and the work of our colleagues in the field who are striving to provide this population with a higher quality of life through AAC solutions.

*For more information regarding Marta and Tynesha's presentation at the IASSID 2nd Asia Pacific Congress or to share ideas/suggestions, please do not hesitate to contact them at [martaaragon@shaw.ca](mailto:martaaragon@shaw.ca) or [martaa@ddrcc.com](mailto:martaa@ddrcc.com)*

*Once again many thanks to Harvey for sharing these web sites.*

**Harvey's Place:**

Communication Therapy International is an organisation working with people with communication disabilities around the world. The organisations newsletter, edited by Mary Wickenden, UK, is available on-line. The following www reference focuses on Africa. <http://commtherapyint.com/cti-news-letter.pdf>

**Sparadrap.** This web site (in French) is an interesting example of a way to use the Internet to communicate to young patients in a way that can help improve patient care. Here is a description of the site prepared by a member of our staff. <http://www.sparadrap.org/>

**dotSUB** is a browser based tool enabling subtitling of videos on the web into and from any language. There is nothing to buy and nothing to download. Recognizing the potential of global communication powered by the Internet, the founders of dotSUB created a web-based tool that enables video to be accessed in an open, collaborative, "wiki" type environment. The dotSUB tool gives anyone the ability to translate video content into multiple languages via subtitles rendered over the bottom of the video. <http://dotsub.com>

*I hope you will find useful references in this issue of the Augmentative Communication World Network Newsletter. Your comments and stories are always welcome. I look forward to hearing from you and adding your views to our next edition – October 2009. With best wishes.*  
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