



Augmentative Communication World Network Newsletter

June 2014

Editor: Dorothy Fraser

Associates: Sarah Blackstone & Harvey Pressman

www.centralcoastchildrensfoundation.org

Welcome to the June, 2014, edition of our Augmentative Communication World Network newsletter. As an introduction to this newsletter we have included references that affect all of us as we strive to achieve inclusive societies.

The United Nations Convention on the Rights of Disabled People (the Convention) is a statement of the human rights of all disabled people and covers all areas of life. Governments must report on how they will promote, protect and monitor its implementation.

Articles 9 and 21 are especially important as they require disabled people to have access to information and communication in different forms. These Articles set out disabled people's right to find out and give information and to say what they want, the same as everyone else.

View in Easy Read at:

www.equalityhumanrights.com/uploaded_files/publications/uncrpd_guide_easyread.Pdf

Understanding the United Nations Convention on the Rights of Persons with Disabilities

<http://www.handicapinternational.fr/fileadmin/documents/publications/HICRPDManual.pdf>

A Handbook on the Human Rights of Persons with Disabilities

Editor's note: the following quote from the manual is of special interest to me because of my connections with Serbia: *"The manual was first drafted for a training of NGOs and DPOs in Belgrade, Serbia in September 2007"*

We hope you enjoy reading the updates and news we have received from around the world.

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<http://www.centralcoastchildrensfoundation.org/home/augmentative-communication-world-network/acwn-newsletters>.

[Editors' Note: AAC By the Bay: *It's rare that participants at a single conference get to learn about even one or two groundbreaking new ideas in their field. It's quite amazing when they are introduced to four or five in the course of a few days.*

It's even rarer that a conference breaks new ground in terms of expanding access to its ideas to a larger and more varied community. It's simply amazing when people from three different continents get to participate actively in the same conference presentations at the same time.

The Bridge School's AAC By the Bay 2014 Conference managed to combine both amazing feats. For example, participants heard, usually for the first time, about:

- (1) how to make AAC tools and strategies far more relevant for far more people in healthcare settings,*
- (2) how to integrate awareness and knowledge of cortical visual impairment into daily classroom practice for the many children with AAC needs and severe motor impairment who also have (previously undetected) cortical visual impairments,*
- (3) how new ways to provide hands-free, upright mobility for children with severe physical impairments that usually confine them to wheelchairs and/or stationary seats or standers can give them better access to the academic curriculum and impact every aspect of their lives (including their health).*
- (4) how schools can provide, even for preschoolers with severe physical impairments who rely on AAC, a comprehensive approach to literacy, including a strong emphasis on writing.*

The conference matched new ways of thinking about AAC with novel ways of reaching a broader audience. In addition to the in-person audience in San Jose, California, groups gathered in Mexico City, in Russia, in Canada and in thirteen locations within the United States to see and hear the presentations, ask questions of the presenters, and learn about ideas that at other times might take years to migrate to their regions. Through the magic of Cisco technology, people in these other areas were enabled to feel an integral part of the action.

We asked Dr. Vicki Casella, Executive Director of the Bridge School to provide us with an overview of AAC By the Bay. Here is her report.

We will never be thankful enough to Sarah for her support through the International Collaboration Program and to Christine for her teaching and the difference she is making in the lives of our children and their families.

TALKING ABOUT EMOTIONS USING CULTURALLY SENSITIVE AAC

By

Ji Young Na, Pennsylvania State University, State College, PA, USA



I speak five different languages. I am a Korean native speaker, I study and teach in English, I am a certified Japanese speaker, and I can speak both Korean and American Sign Languages. Speaking five different languages is wonderful because I can communicate with more people around the world. However, I always keep in mind one very important thing when I speak any language. That is “CULTURE.” I need to be ready to speak not only using a linguistically appropriate language (e.g., Korean or English), but also a culturally appropriate language (e.g., Korean or American cultures). For example, in Korea, a recipient may graciously refuse three times before accepting someone’s gift. Saying “No, thank you”, when accepting the gift is culturally appropriate.

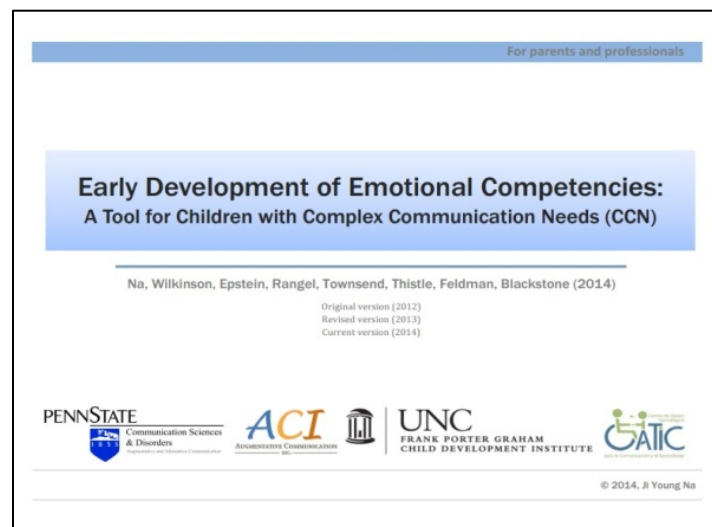
This is true for individuals who use AAC as well. Their AAC systems should have not only linguistically appropriate language, but also culturally appropriate language. Culturally sensitive language is especially important when they talk about emotion because it is well known fact that emotion is culturally grounded for each individual. For example, culturally inappropriate emotion symbols or phrases might not be used by the individual and/or accepted by his/her conversational partners, depending upon the cultural community.

We have developed an assessment tool for Early Development of Emotional Competencies (EDEC) in children with complex communication needs (CCN). The EDEC tool allows

families/clinicians to become more aware of the need for language that enables a child to engage in culturally-appropriate conversations about emotions and emotional situations. It is not a tool developed to diagnose or prescribe; it is not intended to change the behavior of a family. Rather, the EDEC tool is a way to better support the types of communication about emotions that are valued in that family. Using the EDEC, one can gather information that is useful to family members, teachers, and clinicians so teams can better support children with CCN to develop the emotional competencies needed to function effectively and participate actively in their families, schools and communities. The EDEC tool is appropriate for young children (birth-10 years) with CCN, who have very limited speech and language skills secondary to cerebral palsy, Down syndrome, and other conditions. It was not developed for use with children on the autism spectrum.

In order to provide a culturally appropriate assessment tool and to increase awareness about culturally sensitive emotion language in AAC, the EDEC tool is intended for use across different languages. Currently, we have translations in Danish, English, Korean and Spanish. A German version is expected to be ready in the summer of 2014; versions in Dutch and French will be available in the future.

Photos of the EDEC tool

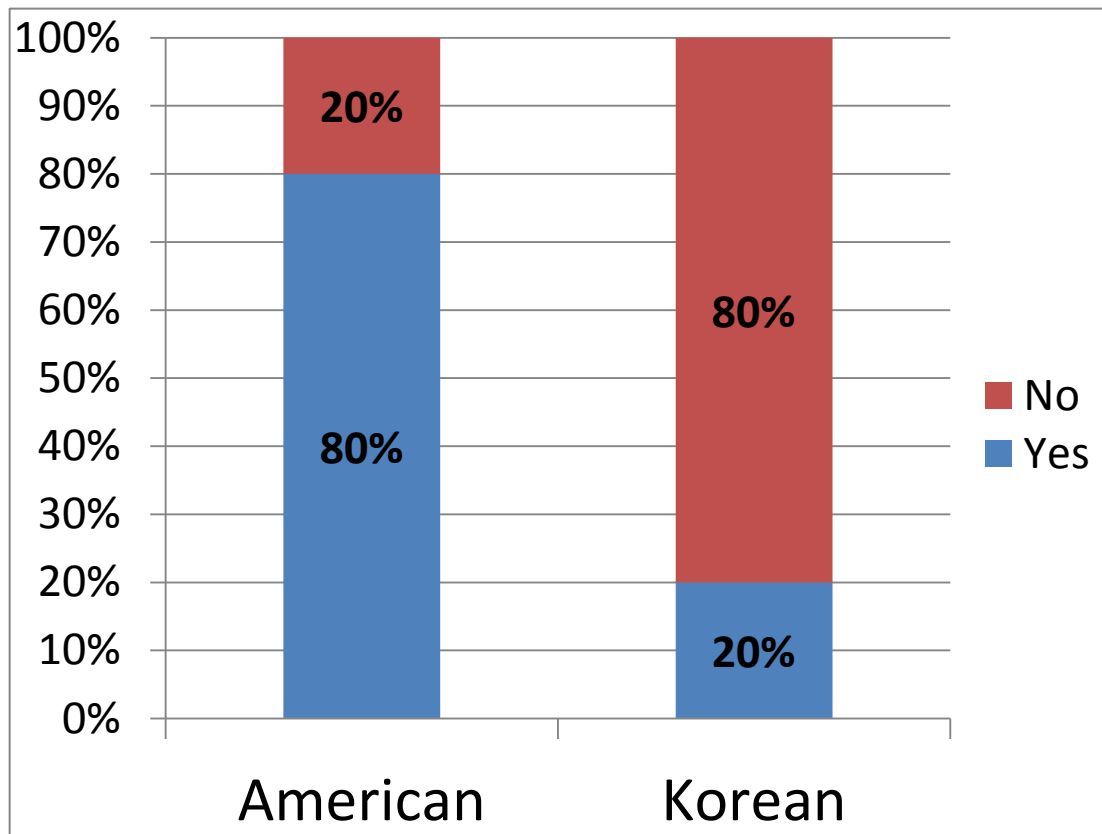


I recently conducted a pilot study using the EDEC tool, which revealed systematic cultural influences on mother-child conversation about emotions. Twenty American and Korean mothers with typically developing children participated in this cross-cultural validation of the EDEC tool.

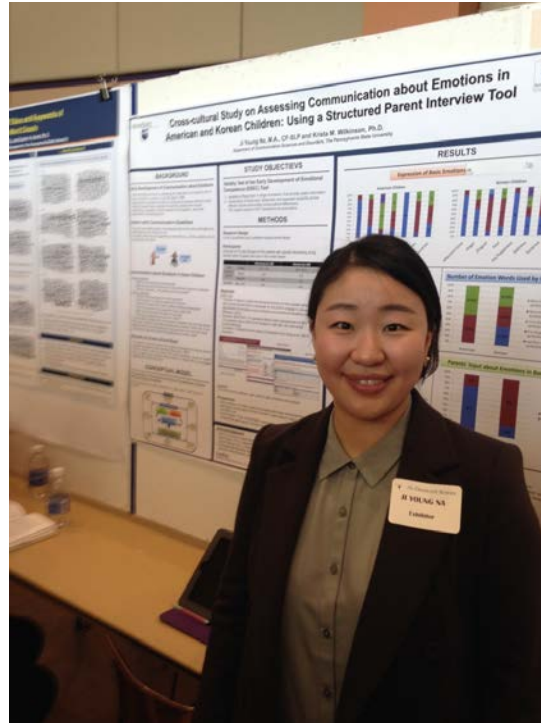
I found a range of answers within each cultural group, as well as systematic variability across different cultural communities. The most dramatic cultural difference was that American mothers (80%) were far more likely to encourage emotion-related conversation during book reading activity than Korean parents (20%). However, both cultural groups reported the same reasons as to “why they do not encourage an emotion-related conversation during book reading activity”. Those who answered “No” for the question (*i.e.*, 20% of Americans and 80% of Koreans), said their children were “old enough” to interpret the character’s emotions by themselves, and thus, did not need any parental supports. In other words, mothers from these two cultures report having an overall different mother-child conversational style, however, they expressed the same rationale for their decisions. Further data analysis of this pilot study will contribute to a better understanding of cultural and linguistic differences in emotional development in American and Korean children.

Results of the Pilot Study with the EDEC tool

Parents' Input about



The team that has worked on developing the EDEC tool feels it is critical that individuals who use AAC have ways to communicate their own and others' feelings using culturally appropriate emotion language. We are exploring ways to support the development of emotional competence in these young children. We can begin by supporting families and professionals to have a better awareness about the need for individuals with CCN to have access to emotion language in their AAC systems, beyond happy, sad, angry, so they can have meaningful conversations about their feelings, opinions, interests, and beliefs, as well as their wants and needs.



**Ji Young at the Graduate Exhibition at Penn State, April, 2014.
Poster Session.**

{This study was funded by the federal grant from the U.S. Department of Education (H325D110008). It was completed in collaboration with Dr. Krista Wilkinson. The partial results of this study were presented at the 2014 Graduate Exhibition at Penn State. If you would like more information about this study, please contact Ji Young Na (jzn129@psu.edu) or visit: <http://aac.psu.edu/?p=2051>.}

AAC IN GHANA

[Editor's Note: *One of the most practical and effective efforts to introduce and adapt augmentative communication tools and strategies to the cultural and economic realities of an emerging nation is taking place in the schools for children with special needs in Ghana. Supported by regular visits from teams of Columbia University faculty and graduate students over the past several years, teachers from these schools have gathered together in Ghana for an annual AAC weekend retreat.*