



Communication Access Across the Health Care Continuum SECOND FRIDAY FORUM MINUTES May 15, 2020

1. **Who's here? Anybody new?** See list of 21 participants below. NOTE: Please update your information. Apologies for errors and/or leaving out important information
2. **First timers.** We welcomed several new participants today and they shared some information. **Alvin Loh** is a physician in Canada that specializes in developmental disability areas. He is involved in teaching MDs and nurses and also engaged in advocacy efforts. Dr. Loh will do a presentation for us at our June meeting. **Barbara Collier** pointed out that he has a Pain Scale tool for people with significant cognitive challenges. **Rachel Santiago** indicated that she needed it "NOW". It is attached to this email. **Marcia Walsh-Aziz** is a SLP/Professor from Denver at Metropolitan State University of Denver. She is teaching a course for SLPs that is cross referenced for first responders. **Andrea Barton-Hulsey** is a SLP/Professor at the University of Florida and active on USSAAC's Disaster Relief Committee. She described a grant request developed with **Amy Sontag, Mary Beth Happ** and another colleague that focuses on covid-19 and issues faced by people with developmental disabilities. Other members of USSAAC's DRC on the call today were **Carole Zangari** and **Amy Sontag** (HP & SB not exactly first timers). Also noted was a proposal submitted to ASHA 2020 in November
3. **Open Forum (issues, information sharing, announcements, requests for resources, upcoming conferences, program updates, questions).**
Barbara noted that our Covid-19 materials are visually oriented so patient may have difficulty. Of note is that on the back of each board is an auditory scanning version. We also discussed having a set of recurring questions (e.g., Guided guessing), "here are things I might want to know" and also where to locate key information about how patient communicates and ideas to start with....on the door, behind the bed, etc. **Richard Hurtig** pointed out ... we do not yet have "evidence" to clarify a preferred location. **Matt Berwick** noted that this is NOT just a HIPAA-related issue, but relates specifically to patient safety. **Rachel Santiago** talked about bedside scripts. Also of concern is lack of access to appropriate caregivers and impact on patient outcomes. **Lois Turner** shared a really nice bedside information sheet. A picture of it is attached to these minutes.
Several people noted information just published by Communication First....go to https://communicationfirst.org/is-your-hospital-visitor-policy-discriminatory/?fbclid=IwAR047-iUhkllQKx9hfn2IZcaPOmQImMC9avxm_pCsaZDBM6FsaA57FmyU8#.Xr4W0vphwb4.facebook
And note that their EVALUATION FRAMEWORK FOR HOSPITAL VISITOR POLICIES Issued: May 15, 2020 is attached. **June Kailes** asked for individual hospital policies. Does anyone have access? Please share if you do. **Birgit** indicated she also has examples of "care plans" she can share. **Andrea** pointed us to a 7 minute PBS video that focuses on issues related to the disparities and policy/practice realities that threaten the lives and well-being of people with disabilities. There is a need for persistent advocacy. Check it out. [Pandemic means Americans with disabilities are not getting services they need.](#) This is NOT new, of course, but it is happening and we need to fight to change these practices.

Barbara shared a story <https://torontosun.com/news/local-news/levy-hospital-bans-disabled-patient-from-using-ipad-calling-it-surveillance-tool>. This is raising many issues re: patients using an iPad (for example) to communicate with family who are not permitted in hospitals.

4. COVID-19 Task Force Update

Content/Reach/Next Steps. **Jessica Gormley** briefly reported the infomatics on visits to the PPC website.

Over 108,000 with 33,000 unique from 133 countries and 13,000 downloads. **Carole Zangari** asked about whether Jessica could get information from the “back end”I think this might tell us where people are learning about the site?

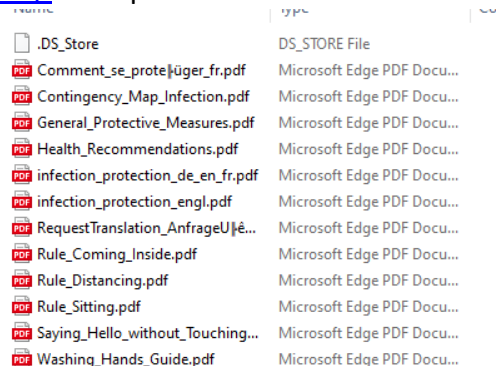
Rachel Santiago announced that the new Comprehension Boards are posted and **Sarah Marshall** indicated that boards developed for service attendants are about to be finished. She thanked **Barbara** for her input.

Richard Hurtig reported status of language boards. Six additional languages are now being prepared.

Currently available? Arabic, Bulgarian, Chinese-Simplified, Chinese-Traditional, French, German, Hebrew, Italian, Portuguese (Continental). Soon to be available: Korean, Vietnamese, Haitian Creole, Tagalog, Karen and Russian

Birgit Hennig shared a link that provides access to multiple infectious disease – related boards in *How to protect yourself from germs and viruses* in English, French, German. Go to <https://www.metacom-symbole.de/en/refugees.html>

Then click on [infection_protection.zip](#) A snapshot of what’s inside follows:



Carole also sent a link to similar types of resources <http://bit.ly/2IS7Mst>

5. PPC Website redesign underway. **Sarah B.** briefly talked about website redesign, joined by **Jessica** and **Rachel**. We are just getting started. If anyone has ideas, please share. We will plan some time at our next meeting to show and discuss. **June** pointed out it’s hard to discuss a site and also pointed about that currently it is all about “now” and it should also be about PPC “tomorrow”. More to come.

Harvey thanked everyone for their participation and we signed off until next month.

Stay safe, be well and in touch. S&H

NEXT MEETING: FRIDAY, JUNE 12, 2020 NOON ET

May 15, 2020 PARTICIPANTS (please send corrections!)

- Tami Altschuler. Clinical Specialist, Patient-Provider Communication at NYU Langone Medical Center. Focuses on patient provider communication. Innovator who has spread use of communication supports from ICUs to implementation hospital wide.
- Matt Berwick. Program Manager, University of Pittsburgh Medical Center (UPMC) Disabilities Resource Center works to ensure healthcare is accessible to everyone with a disability, providing accommodations to patients, as well as guidance and education to staff.
- Sarah Blackstone. “Retired” speech-language pathologist. Co-leader PPC Forum, USSAAC’s Disaster Relief Committee. Currently focusing on issues related to emergency/disaster response, importance of effective communication throughout the disaster cycle and communication access for people with speech and language challenges across contexts. PI of research project on Cortical Visual Impairment and CFO - CA-Office of Emergency Services grant for Monterey County.
- Andrea Barton-Hulsey. Assistant professor at Florida State University. Her research has focused on characterizing the linguistic skills of children with intellectual and developmental disabilities (IDD), She is an active member of USSAAC’s Disaster Relief Committee
- Megan Case. SLP at Ohio State Medical Center Wexner; OP AT Center. She is working to expand AAC/AT services from the minute patient enters, ICU, acute, and throughout the Center.
- Barbara Collier. Speech-language pathologist, Executive Director, Communication Disabilities Access Canada, ISAAC Fellow. Interested in communication access barriers/issues/rights for people with speech and language disorders. Spearheaded Canadian program in training for “communication intermediaries” and other initiatives at provincial and federal levels.
- Jessica Gormley. Assistant Professor, Speech-Language Pathology | Munroe-Meyer Institute University of Nebraska Medical Center, She has worked clinically with individuals who rely on AAC and is interested in the impact on children’s development of speech and language when hospitalized for extensive time periods.
- Mary Beth Happ. A nurse who has conducted research in area of PPC for many years. Currently the Associate Dean of Research and Innovation; Distinguished Professor of Critical Care Research; Director, Center of Excellence in Critical and Complex Care, College of Nursing at Ohio State University.
- Birgit Hennig. Specializes in AAC and is a Scientific Associate in the Department of Pedagogy and Didactics for Impairment of Intellectual Development at the University of Oldenburg in German. She works in the departments of neurological intensive care, early revalidation and palliative care.
- Adrienne Henkel. A nurse and researcher at Universität zu Lübeck Institut für Sozialmedizin und Epidemiologie in Germany. She has studied communication issues in ICUs and nursing homes (and more!).
- Richard Hurtig. Professor (ret.) in the Department of Communication Sciences & Disorders at the University of Iowa where he directed the University of Iowa Assistive Devices Laboratory. Currently, he is the President & CSO at Voxello Inc., which is a spinoff company now conducting clinical trials with a tongue-operated device. He resides in Philadelphia.

June Kailes. Consultant and disability rights advocate. One of original national leaders in the Independent Living Movement, an Adjunct Associate Professor and the Associate Director of the Center for Disability and the Health Policy at Western University of Health Sciences, Pomona, California. She trains healthcare institutions, businesses, universities, state associations, government entities, centers for independent living and other not-for-profit organizations.

Alvin Loh. Developmental Pediatrician, Medical Chief of Staff, Surrey Place; Assistant Professor, University of Toronto. Medical Lead in the FASD Clinic and Co-Lead of Behavior Medical Assessment Clinic at Surrey Place. Research in etiology of Autism Spectrum Disorder and regression. Chair, volunteer advocacy group for children and adults with neurodevelopmental disorders

Sarah Marshall. SLP working in the Communication Aids and Systems Clinic (CASC) and the Neuromotor Development Clinic. Leads inpatient coverage team at University of Wisconsin Hospitals and Clinics (UWHC) and American Family Children's Hospital (AFCH).

Rachel Santiago. Speech-language pathologist, Clinical Coordinator, Inpatient Augmentative Communication Program, Department of Otolaryngology and Communication Enhancement, Boston Children's Hospital

Joni Nygard. AAC specialist who previously worked in clinical settings. She serves as Vice President AAC Resources and Services and Aging Resources for Attainment Company,

Harvey Pressman. President, Central Coast Children's Foundation, Inc. (CCCCF) with outreach outside the U.S., Central and Eastern Europe and Africa. Co-leader PPC Friday Forum and USSAAC's AAC Disaster Relief Committee. Project Director of LISTOS California, a grant awarded by CA-Office of Emergency Services for Monterey County.

Meredith Sager. SLP who works at Boston Children's Hospital and is interested in implementing effective PPC protocols and access solutions for patients and families.

Amy Sontag. SLP, Clinical Faculty in the Department of Speech and Hearing Sciences at The Ohio State University, Ohio State Medical Center in Columbus, OH. Member: USSAAC Disaster Relief Committee

Lois Turner. Program Manager at CAYA (Communication Assistance for Youth & Adults), a provincial resource program providing ACC services, based out of Vancouver, BC. Lois is President of ISAAC Canada.

Marcia Walsh-Aziz. SLP at Metropolitan State University of Denver, Marcia is launching a pilot course (cross-listed with Fire and Emergency Response Administration program). The course will center on how health and human service providers (including first responders) can serve people with diverse communication needs.

Carole Zangari. SLP, Professor at Nova southeastern University in Florida and co-founder of PrAACtical AAC. If you have never visited her blog, you should. <https://praacticalaac.org/>