



**Communication Access Across the
Health Care Continuum
SECOND FRIDAY FORUM
MINUTES
June 12, 2020**



1. **Who's here? Anybody new?** See list of participants. We welcomed several new participants. **Stacy Harpell** joined us from CAYA in Vancouver and **Julie Evans** from Alberta Health Services Edmonton. Also, **Deanna Hughes** joined us from Chapman University. Because today's agenda was so full, we decided to have these folks tell us much about themselves at the end of the meeting (and then ran out of time). Next time!
2. **Open Forum (issues, information sharing, announcements, requests for resources, upcoming conference presentations, program updates, questions).**
 - a. **Support persons for people with disabilities:** Policy shifts re: hospitals visitation. **Barbara Collier** sent a note. "British Columbia lifted its "no visitor" protocol. Many of us are advocating for other provinces to do the same." **Stacy Harpell** in Vancouver and **Julie Evans** in Edmonton also commented. Julie noted that policies permitting support persons often vary by Health authority. **June Kailes** reported information
 - Office of Civil Rights in Connecticut. "Resolves Complaints after State of Connecticut and Private Hospital Safeguard the Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19." This case was fought on behalf of a woman with aphasia who was unable to communicate. <https://www.centerforpublicrep.org/wp-content/uploads/FINAL-Disability-Group-Press-Release-on-CT-OCR-Resolution-060920.pdf>
 - Connecticut Governor wrote. "As vulnerable populations around the state continue to be disproportionally affected by the COVID-19 pandemic... resolution allows a support person to accompany and advocate for individuals with disabilities into our hospitals. <https://www.hhs.gov/about/news/2020/06/09/ocr-resolves-complaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html>
 - Other Resources.
Preparing for Hospitalization During COVID-19 Pandemic: A Checklist for People with Disabilities Edition 2.0, 2020 <http://www.jik.com/pubs/Hospitalhave2go.pdf>
You should do everything you can to stay out of a hospital, but if you have no choice, these tips help you prepare for what you may face. It will NOT be business as usual.
ADA Compliance with Visitations in Healthcare Facilities: Coronavirus Pandemic Guidance for Advocates Edition 1, 2020 <http://www.jik.com/pubs/Covid-visitations.pdf>
Offers tips for advocating for visitations and working with healthcare facilities and state governments during current pandemic crisis about how to ensure healthcare facilities comply with Americans with Disabilities Act.
 - b. **Advocating for equal justice, access and inclusion. Taking action against prejudice, racism, and inequality.**

We discussed what the PPC Forum could/should do. Consensus about ensuring that the website, materials we publish /present/etc. represent and honor the diversity of all individuals. **Action?** Please send Rachel Santiago Rachel.Santiago@childrens.harvard.edu any ideas and materials you have. We need to represent ALL people on the PPC website, Facebook, etc. Joni Nygard offered to reach out to manufacturers to see if they could provide photos. Check out Communication First <https://communicationfirst.org/communicationfirst-stands-in-solidarity-with-all-those-impacted-by-racial-injustice/>

- 3. White Paper Update.** Jessica Gormley explained that the PPC White Paper is meant to help clinicians and researchers and students get access to key information about PPC. This project aims to update resources. We've asked for input from Forum members along the way. The paper is due July 13 and will be reviewed by the *Assistive Technology Outcomes & Benefits Journal*. Jessica, **Rachel Santiago** and **Tami Altschuler** have taken the lead. "Thank you" from us all.

And. Richard Hurtig mentioned an article he is finalizing over the weekend (also co-authored by members of the PPC Task Force). BUSY weekend??

- 4. Alvin Loh: The DISDAT (Disability Distress Assessment Tool) tool in the Behaviour Medical Assessment Clinic.** Slides are attached.

Alvin provided important information about ways to help identify the meaning of behaviors for each individual. Slides are attached. Discussion that followed pointed out the tool helped others recognize the diversity of behaviors and of meaning being expressed (e.g., wanting to engage, distress, pain, etc.). And, how often professionals may misjudge the reason for a behavior....so this tool goes well beyond a pain scale. Research based. Thank you Alvin for sharing. (More info about the tool @ https://prc.coh.org/PainNOA/Dis%20DAT_B.pdf)

- 5. Request from Megan Morris. Re: latest communication apps available on iPads/iPhones---to Disability ADA Coordinators at hospitals and health systems.**

Sarah Marshall will follow up. Several pointed out that it's NOT about "what apps are available", it's about what app might meet an individual's needs. Megan sends her appreciation and they'll connect. Also, we want to reach out to Megan as she is working on issues that relate to health care inequities, etc.

- 6. NIDCD Research (an NIH institute) on the Impact of COVID-19 on Mission Specific Sensory and Communication Disorders.**

Worsening of communicative function because of physical distancing, sheltering in place, and wearing of protective personal equipment during mitigation of this infectious pandemic (interventions for the diagnosis, prevention, or treatment of communication disorders by supporting well designed and well-executed clinical trials.) SBIR?

Given that we were running out of time, this discussion was delayed until more specific

information is available. Several are interested. We will have another meeting to focus on this initiative. Harvey pointed out to Joni that SBIRs might be part of the monies available.

7. Web site update. Jessica showed example of how content will be organized. According to the web designer, we should be seeing something in the next week or so. Harvey also asked for iinfomatics. VERY impressive.

Users (since 3/21). Unique people who visited the site – 36,739

Views (since 3/21). Pages visited -- 119,482

Location. 142 countries

Downloads (since April 15) – 15,962

We adjourned the meeting and invited anyone who wanted to/were able to stay on to discuss next agenda item.

8. Update: COVID-19 Task Force: For those who could stay on.....

The focus of the Task Force has “pivoted” to determining the effectiveness of the covid-19 resources provided AND identify resources not yet available.

Rachel and Tami are considering replicating the national survey they did in 2019? re: SLPs/AAC at bedside to explore whether attitudes/practices had changed.

Also, we discussed need to disseminate a covid-19 specific survey re: PPC web site to large numbers of people. Time to start thinking about content that would be good to capture and let us know your thoughts.

NEXT MEETING: FRIDAY, AUGUST 14, 2020 NOON ET

June 12, 2020 PARTICIPANTS

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.

Tina Caswell. SLP is a Clinical Assistant Professor at Ithaca College and the VP of Vice President of New York State Speech-Language Hearing Association (NYSSLHA). She is an active member of USSAAC's Disaster Relief Committee.

Julie Evans. Senior Practice Lead, Speech Language Pathology and Audiology at Alberta Health Services. Working on a province-wide initiative with a focus on communication access for adults in acute care settings.

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.

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.

Deanna Hughes has been a practicing speech-language pathologist (SLP) for more than twenty years, working in a variety of clinical settings. Currently, she serves as an Assistant Professor in Communication Sciences and Disorder at Chapman University.

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. Speech-language pathologist 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.

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

Marcia Walsh-Aziz. Speech-language pathologist at Metropolitan State University of Denver in SLH Sciences Dept. Currently. Currently, designing an interdisciplinary course related to accessibility to communication between patients and providers, as well as first responders during times of crisis (specifically focusing on COVID but general issues as well). Specializes in language development of children with hearing loss.