



**Communication Access Across the Health Care Continuum  
SECOND FRIDAY FORUM  
Minutes April 10, 2020**

**Who's here? Anybody new?** We had participants from the U.S., Canada & Germany join the PPC Forum discussion. See attached list of participants. New participants included Matt Berwick, Sarah Marshall, India Ochs and Birgit Hennig. We used Zoom, which worked very well. NOTE to all: Please review what your “blurb” says about you (List of Participants) and send update.

**Open Forum (issues, information sharing, announcements, requests for resources, upcoming conference presentations, program updates, questions).** Discussions began immediately re: issues being faced due to covid-19 virus. **PLEASE NOTE. THE GROUP DECIDED WE SHOULD MEET IN MAY. NEXT MEETING IS SCHEDULED FOR MAY 15<sup>TH</sup> AT NOON ET.** We will send agenda AND Zoom invite.

**Communication Rights Issues.**

1. **Barbara Collier** raised concerns in Canada re: lack of effective communication strategies are in place. Additional concerns were raised by **June Kailes** and others. These included issues related to:
  - a. Triage plans in hospitals. Triage with SLPs/AAC clinicians in local communities. Concerns that patients without communication access may be discriminated against when patients are triaged
  - b. Need for people with communication (or potential communication) issues to have a plan BEFORE they enter the hospital. See attached link from June. [Preparing for Hospitalization During COVID-19 Pandemic: A Checklist for People with Disabilities](#) 4/2020. *During the COVID-19 pandemic you should do everything you can to stay out of a hospital, but if you have no choice, BE PREPARED for business not as usual! The normal hospital standards of practice may not be followed due to limited staff, many more patients than usual, and not enough equipment and supplies. It may be much more difficult to ensure your right to medical care is honored.*
    - Prepare in advance
    - Know rights, policies ahead of time
    - Make a plan that includes a “go bag” with documents to take with you, including specifics about communication.
2. Why isn't communication being considered an essential service?
  - a. Barbara noted that no AAC clinicians were asked to be involved in webinar for disability community.

- b. Sarah Marshall indicated some of her colleagues are “redeployed” and not supporting patients.
  - c. Limited, if any, consideration that people who can speak “today” may not be able to “speak” tomorrow. Suggesting that ER, ICU, personnel need to consider what they will do when that happens.
  - d. Familiar communication partners are not available because they are not being allowed in the hospitals
  - e. SIGNAGE? “Just because I can’t talk, doesn’t mean I can’t communicate” ALERT providers that there are alternative ways to communicate
  - f. This is a fast “evolving situation”. Often frenetic.
  - g. Traditional “Standards of care” may not be effect.
  - h. Birgit noted that many patients are deeply sedated in neurorehab AND without assistance from relatives and others who can interpret their non-verbal signals. She noted trying to support patients using phones.
  - i. We also discussed that nursing homes and conjugate living environments are also settings in dire need of help with communication access, as many residents are isolated.
3. **India Ochs** shared materials on the *Communication First* website. Definitely check them out! <https://communicationfirst.org/covid-19/> . In English, Spanish. A toolkit that (1) explains your communication rights; (2) provides tips on advocating for them, and (3) has an accommodation request form you can bring to the hospital. <https://communicationfirst.org/covid-19/covid-19-guidance/#.XotFJxbKnco.facebook>. Guidance on COVID-19 Patient Visitation Policies. From Massachusetts Attorney General Rights of Disabled Persons to Accommodations During COVID-19 Crisis (April 27, 2020),

### Discussion Led By COVID-19 PPC Task Force

4. **Website.** The PPC Forum Task Forces shared information including the following

- a. Need for Decision making boards.

Participants discussed issues related to medical decision-making boards, palliative care and DNR situations. A subgroup of the PPC Task force are beginning to work on this.

- b. Case examples. In process.
- c. More languages. Getting requests.
- d. Resources. Lots coming in and we’re trying to share these under resource section

The screenshot shows the Communication First website with a blue header. The main content area has a red background with the text "FREE communication tools for patients with COVID-19". Below this, there is a grid of icons representing various communication tools. To the right of the grid, there is a table with headers "YES", "NO", "DON'T KNOW", and "LATER". Below the grid, there is a section titled "COVID-19 Supporting Communication with Patients who have COVID-19" with links to "FREE English Tools", "FREE Bilingual Tools", "Case Examples", "Tips for Bedside Communication & Materials Preparation", "Additional Resources", and "The PPC Taskforce".

**Note:** All Task Force members are volunteers. See website for complete list. USSAAC’s Disaster Relief fund is providing support for translations and the PPC Task Force efforts re: covid-19 project on PPC website.

**5. Informatics.** From website early and later April...thanks to Jessica Gormley. See below.

| Informatics – PPC COVID-19 |            |           |
|----------------------------|------------|-----------|
|                            | Since 3/21 | Since 4/3 |
| Users                      | 28,378     |           |
| Pageviews                  | 89,924     |           |
| Downloads                  | ?          | 8,593     |
| Countries                  | 125        |           |

Also, many PPC Task Force members are sharing, publishing on Facebook, Twitter, Instagram and writing articles for NY Times, submitting proposals to the 2020 ASHA Conference, giving a Webinar for ISAAC....April 29<sup>th</sup> @ 7 p.m. ET (it'll be recorded and archived)

A huge shout out for this very busy Task Force. Also, thanks to all the PPC Forum members who are helping, participating in this call and making a difference in your own areas and countries.

Please go to RESOURCES to learn about their work.

<https://www.patientprovidercommunication.org/covid-19-additional-resources.htm>.

**6. Languages.** Materials on the site are now translated into multiple languages (certified medical interpreters). **Richard Hurtig** took the lead on these efforts.

**7. White Paper.** On hold for the moment.

**8. Hot off the Press.** New article in *Geriatric Nursing* with a shout out to the group's work and website available online. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7152917/>

**NEXT MEETING: FRIDAY, MAY 15, 2020 NOON EDT**

#### **April PARTICIPANTS**

##### **\*PPC Taskforce**

**\*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, Co-Chair USSAAC's Disaster Relief Committee. Currently focusing on issues related to emergency/disaster response and 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.

**Megan Case** – Ohio State Medical Center Wexner; OP AT Center. Works to expand services from minute patient enters, ICU, acute, and throughout.

**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 from Germany – Scientific Associate Department of Pedagogy and Didactics for Impairment of Intellectual Development, The University of Oldenburg AAC specialist in hospital rehab and ICU; neurorehab

**\*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 spin off 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.

**\*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.** A speech-language pathologist. Clinical Coordinator, Inpatient Augmentative Communication Program, Department of Otolaryngology and Communication Enhancement, Boston Children's Hospital,

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

**India Ochs** – **Attorney and Social Justice Advocate**, Compliance Officer, [U.S. Department of State](#). Disability Rights activist. Chair of the Board, Communication First

**\*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.

**Jane Quarles.** Speech-language pathologist at St. Louis Children's Hospital in Missouri. Initiated/leading hospital – wide program introducing AAC and AT supports as part of Shared Leadership team to improve care of patients. Developer of communication board and video published with Attainment Company (collaboration with Joni Nygard).

**Amy Sontag.** 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.