



Communication Access Across the Health Care Continuum FRIDAY FORUM Minutes - February 14, 2020

1. Who's here? We welcomed many new forum members. Please see list below. Welcomes go to **Stacey Harpel** from CAYA in Vanouwer, and **Camille Stewart** from Children's Hospital in Denver and **Meredith Sager** from Children's Hospital in Boston. All are speech-language pathologists in hospital settings working with individuals who benefit from using AAC approaches. Also we welcomed **Dr. Rebecca Koszalinski**, a professor of nursing who was joining us from the University of Tennessee in Knoxville. Others we welcomed include **Sarah Gendreau**, **Stephanie Scibilia** from Mass General Hospital and **Dr. Megan Morris** from Colorado University. They had agreed to tell us more about themselves and their work later in the call.

NOTE to ALL: Please send updates to your information to include in minutes and/or published on the PPC website, <https://www.patientprovidercommunication.org/participants.htm>

2. Open Forum (issues, information sharing, announcements, requests for resources, upcoming conference presentations, program updates, questions).

June Kailes shared the ongoing effort in California of advocates to shape policy/practices related to Power Outages. The group is specifically addressing questions such as "What is the role of health-care (clinics, hospitals, practitioners, health plans) in preparing people for power outages?" as well as collecting data on the impact on specific populations and success of specific solutions.

Harvey Pressman noted our activities in Monterey County as part of the CA State-wide effort to increase disaster preparedness for vulnerable populations....*Listos California Campaign*.

We congratulated **Lois Turner** from CAYA on becoming the CAYA Manager and wished **Jeff Riley** a happy retirement.

3. White Paper Progress report. Rachel and Tami reported that progress is being made. Jessica Gormley was unable to join the call, but they expect they will have a workable draft completed in April. Asked to clarify the purpose of the White Paper, they noted it is an effort to make it easy for clinicians, policy makers, administrators etc. to "find information that can advance advocacy efforts of stakeholders in facilities who want to improve access to communication across health care settings.

4. Introducing and welcoming two "movers and shakers" to the PPC Forum. **Sarah and Stephanie** are leaders in PPC at Mass General Hospital in the Department of Speech, Language, and Swallowing Disorders. They developed an *Acute Care AAC Program for Adult*

Inpatients. Together they told the story, which they had presented during the ASHA Convention, in November 2019. [You can access their slides on PPC website under presentations or click the link <https://www.patientprovidercommunication.org/files/GendreauScibiliaASHA2019EnvisioningandCreatingAcuteCareAACProgramforAdultInpatients.pdf>]. They described Mass General as a large 1000 bed hospital with 8 ICUs. As speech-language pathologists they were very aware of the need to support people with significant communication challenges related to speech/voice/language/cognition/sensory/and medical interventions. To develop a program, they described breaking it down into 3 phases: I. Conceptual; II. Access and Care and III. Roll Out and Refine. They faced many issues during each phase and noted they are working on expanding the program across the hospital. They noted that identifying “champions” and finding key resources is enabling them to spearhead and expand their efforts. They promised to keep us updated. You can find more details in their presentation.

June had two questions. She had consulted for MGH in 2010 and made several recommendations and wondered whether they had been implemented. Specifically, she recommended (1) improving how call buttons worked (specifically making sure they worked so all patients had access and nurses knew if a patient might not be able to respond) and (2) ensuring that key assessments about needs and care, including communication needs were upfront in a patient’s medical record. **Sarah** and **Stephanie** noted that (1) call button issues had improved, BUT more needed to be done. (2) They are working on ways to identify communication needs upfront in EMR of patients.

Megan Morris is a speech-language pathologist/researcher who, along the way, got interested in Disability Law and Policy and also has a degree in Public Health. Megan is currently on the faculty in the Department of Family Medicine in the School of Medicine at the University of Colorado. Her research focuses on disparities in health care and health systems, including issues such as documentation, disability initiatives, biases among medical students/practitioners and the impact on communication access issues on patients. She has 3 grants, which we discussed very briefly. You can read about her in an ASHA Leader article (March 2019), which we’ve attached for your “educational use.” *Adults with Communication Disabilities Face Health Care Obstacles*. Megan’s funding comes from the PCORI (Patient-Outcomes Research Institute) and the National Institutes of Health. Briefly and see links below:

1. *Learning Collaborative to Address Disability Equity in Healthcare (LEADERS)* (2019-2021) aims to develop a learning collaborative of key stakeholders (patients with disabilities, and their caregivers; researchers; disability accessibility coordinators) <https://www.pcori.org/research-results/2019/learning-collaborative-address-disability-equity-healthcare-leaders>
2. *Improving Communication and Healthcare Outcomes for Patients with Communication Disabilities: The INTERACT Trial*. (2019-2023). This study compares two evidence-base interventions to increase primary care providers’ use of communication strategies with patients who have communication disorders to determine patient preferences and effectiveness of interventions and impact on outcomes. <https://www.pcori.org/research-results/2019/improving-communication-and-healthcare-outcomes-patients-communication>
3. *Disparities in Patient-Centered Communication Experienced by Patients with Communication Disabilities*. 2018-2021. This study investigates whether medical students use less patient-

centered communication with patients who have communication disabilities and whether they have implicit and explicit disability biases. The purpose is to inform medical education trainings in order to create effective interventions and improve communication are a necessary step to elimination of health care disparities experienced by patients with CD.

https://hsrproject.nlm.nih.gov/view_hsrproj_record/20191219

Harvey Pressman asked about the use of medical passports and **Megan** said they are included as part of training strategies. **Mary Beth Happ** asked Megan about her accessing funding from PCORI. Megan suggested being able to use/compare evidence-based interventions was a positive for PCORI. June asked about preparation before “visits” and progress in “flagging” electronic medical records EMR, asking where to locate critical information. All agreed ongoing training is essential. **Stephanie** also stated that building relationships as key components of PPC-related program initiatives.

Sarah pointed out that in 2009 when the PPC Forum first met, we could never have had this conversation and none of this was “happening” so progress is being made and it is because of people on the call today and others who get invited and receive the minutes that progress has been remarkable at least in some places. Thanks to our presenters, participants and all who support efforts that improve communication access for people with communication challenges across health settings.

5. Other Updates: Conferences, Articles, Programs, Ideas?

We ran out of time and will be inviting Megan, Stephanie and Sarah back so we have a better opportunity to do a “deeper dive” into the issues and discuss them more broadly.

6. Bibliography: We’re happy to share any article/link or post on the PPC website.

Stransky, ML & Morris, MA. (2019). Adults with Communication Disabilities Face Health Care Obstacles. *The ASHA Leader*. **Attached.**

Blackstone, SW; Ruschke, K; Wilson-Stronks, A; Lee, C. (2011). Converging Communication Vulnerabilities in Health Care: An Emerging Role for Speech-Language Pathologists and Audiologists. *Perspectives on Communication Disorders and Sciences in Culturally and Linguistically Diverse Populations*, 18, 3- 11.

https://www.patientprovidercommunication.org/article_19.htm

Gendreau, S. & Scibilia, S. (2019). Envisioning and Creating an Acute Care AAC Program for Adult In patients. Presentation at 2019 ASHA Convention.

<https://www.patientprovidercommunication.org/files/GendreauScibiliaASHA2019EnvisioningandCreatinganAcuteCareAACProgramforAdultInpatients.pdf>.

List of content related presentations at 2018 ASHA Convention can be found at <https://www.patientprovidercommunication.org/presentations.htm>

NEXT Meeting: April 10, 2020, Noon Eastern

FEBRUARY 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.

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.

Sarah Gendreau. Speech-language pathologist at Mass General Hospital in Boston where she is an inpatient clinician serving adult patients. She specializes in the assessment and treatment of swallowing, cognitive linguistic, and communication disorders impacting medical, surgical, and neurological patient populations. She graduated from the MGH Institute of Health Professions in 2014 and completed her clinical fellowship at Greenbriar HealthCare Nursing Facility in Nashua, NH.

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.

Stacey Harpel. Client Services Manager at CAYA (Communication Assistance for Youth & Adults), a provincial resource program providing ACC services to adults 19 and older in the province of British Columbia, based out of Vancouver, BC. Lois is currently the President of ISAAC Canada.

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.

Rebecca Koszalinski. Rebecca is an assistant professor of Nursing in the College of Nursing at the University of Tennessee – Knoxville. Her research focuses on how technology can be used to improve patient outcomes. She is working with the University of Tennessee Research Foundation to move the Speak for Myself app she developed closer to commercialization.

Megan Morris. Megan is a well-established researcher, speech-language pathologist with a degree in Public Health working in areas concerned with addressing the wide-spread health-care disparities experienced by patients with communication challenges. She is currently an Assistant Professor, Department of Family Medicine, School of Medicine University of Colorado.

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,

which sells products that serve as tools for advancing communication in healthcare settings.

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. Facilitates sharing and/or combining resources to disseminate good ideas about removing communication barriers in health care settings. He is also Project Director of LISTOS California, a grant awarded by CA-Office of Emergency Services for Monterey County.

Meredith Sager. Speech-language pathologist. Working with in-patients to address communication access issues within Augmentative Communication Program, Boston Children's Hospital.

Rachel Santiago. Speech-Language Pathologist and Coordinator, Inpatient Augmentative Communication Program at Boston Children's Hospital

Stephanie Scibilia. Speech Language Pathologist at Mass General Hospital in Boston. Work on the inpatient team at Massachusetts General Hospital with general medicine, neurology and oncology patients including those on intensive care units, collaborating closely with numerous providers to treat patients with complex conditions. Prior to MGH, she worked at Kessler Institute for Rehabilitation in West Orange, NJ. Throughout her career she has been passionate about serving patients who have Alternative and Augmentative Communication needs.

Camille Stewart. A bi-lingual speech-language pathologist from Denver's Children's Hospital. She is working with patients who are unable to access their speech.

Lois Turner. Manager of CAYA (Communication Assistance for Youth and Adults) in Vancouver, BC.

Canada. CAYA is a provincial resource program that provides augmentative/alternative communication services to adults 19 and older whose speech does not meet their daily needs and who reside in the province of British Columbia. Lois is also President of ISAAC-Canada.