

PPC Forum Meeting Minutes

May 17, 2024

Our upcoming forum meetings will take place on:

July 19
September 20
November 15

Updates - “Improving Health Outcomes through Effective Communication grant project” (funded by Ability Central):

- **Save the following dates/times for upcoming free webinars on supporting communication access in healthcare encounters:**
 - **Thursday, September 26 at 11 am Pacific, 12 noon Mountain, 1 pm Central, 2 pm Eastern**
 - **Thursday, October 24 at 11 am Pacific, 12 noon Mountain, 1 pm Central, 2 pm Eastern**
 - **Monday, November 18 at 11 am Pacific, 12 noon Mountain, 1 pm Central, 2 pm Eastern**

Attendees:

- We had 29 attendees join the meeting across four countries! Thank you to all who joined!
 - Shira Havousha
 - Helen Paterson
 - Rachel Santiago
 - Tami Altschuler
 - Maryjan Fiala
 - Sarah Blackstone
 - Harvey Pressman
 - Lois Turner
 - Megan Juring
 - Anita Aron
 - Grace Gahan
 - Joni Nygard
 - Meredith Sager
 - Krista Kramer
 - Juliette MacCrate
 - Gail Goldstein
 - Mary Beth Happ
 - Jessica Eng



- Shaylin Sluzalis
- Germán Parodi
- Cissy Cheng
- Peggy Ellertsen
- Toni Iacolucci
- Jack Weber
- Christine Hurtibise
- Randi Seargent
- Audrey Hall
- Whitney Cobas
- Jessica Gormley

Joni Nygard Presentation: CPR+AED Basics Kit

- Demonstrated the development and contents of the CPR+AED Basics Kit to prepare people with disabilities to pass the written and practical tests for CPR and AED use (needed in many employment contexts)
- The kit was developed with Cincinnati Children's Hospital Project SEARCH group
- Information about the kit can be found using the following links:
 - <https://www.cincinnatichildrens.org/news/release/2023/cpr-toolkit>
 - <https://scienceblog.cincinnatichildrens.org/cpr-aed-learning-game-launched-to-improve-accessibility-to-certification/>
 - <https://www.attainmentcompany.com/cpr-aed-basics>
- Contact Joni Nygard at joni@attainmentcompany.com for more information about the development and to learn more about the kit!
- The kit contains:
 - "Perla Saves the Day" story
 - Game board
 - Manikin boards to simulate the pressure need to complete CPR (infant, child, adults)
 - Sorting cards
 - Game is on an app and interactive book as well

Discussion:

- Rachel commented that it was a neat resource to have people with different learning abilities be prepared for aging caregivers (and employment as well) and be equipped with health education and self-advocacy skills
- Harvey commented this aligns with potential interests in disaster preparedness and supporting young people's interests in the health professions
- Sarah inquired about the accessibility for vision and hearing and Spanish - Joni will investigate and share full requirements
- Toni asked if the app fully captioned as it may be useful for getting some practice for people who are hard of hearing - Joni will investigate and share full requirements

Patient-Provider Communication



Communication is the joint establishment of meaning

- Tami mentioned that Narcan administration is now being included in the CPR courses, might be interesting to see how the developers are preparing for that

Future of AAC Research Summit Recap

- Some members of the PPC Form attended and commented on major takeaways related to the importance of needing more AAC research in healthcare contexts. Many attendees were interested in receiving a summary or watching the video recordings, especially of the experiences of people who use AAC
- Videos of presentations shown at the summit will be posted on the following websites:
 - RERC on AAC: <https://rerc-aac.psu.edu/>
 - Communication First: <https://communicationfirst.org/>
- Discussion of one impactful lived experience account by Alice Wong in the hospital. You can learn more about her work on: <https://disabilityvisibilityproject.com/about/>
- Comments:
 - Rachel commented that system infrastructure at every level needs to change: training, medical record systems to route accommodation needs to the right people, and so much more
 - Gail shared her "My Pain Alert" resource and commented that pain management vocabulary is not taught in schools such as medical schools.
 - Randi mentioned the importance of finding ways to ensure that accommodations are flagged in the Electronic Health Record