

It's My Life: Why Person-Centered Care Is More Than Just Talk

India Ochs & Susan Fager
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Learner Objectives

1. Participants will be able to describe three methods for supporting person-centered care in AAC.
2. Participants will be able to identify three key challenges to providing/receiving person-centered care in AAC.
3. Participants will be able to describe how individuals who use AAC and their families can secure proper and effective communication to advocate for themselves.

The right to communicate is not just part of disability laws, but a fundamental human right. The ability to communicate impacts quality of life at all levels (home, work, education, medical, and community). We also all have the basic human right to receive person-centered care. Many challenges exist to ensure adequate, person-centered care for individuals who use augmentative and alternative communication (AAC). People who use AAC represent a diverse group of individuals that have a wide range of diagnoses, life experiences, and varying support systems, along with different needs for AAC. Educators, medical staff, caregivers and other professionals who interact with people who use AAC play an important role in supporting the person but may not have the training/experience and/or resources necessary, or use outdated intervention models. This presentation will discuss the critical need for person-centered care for individuals who use AAC, describe individuals' legal rights with regards to communication, and provide examples of how to facilitate person-centered care through different settings. Discussion will include how to prepare individuals who use AAC and their families to advocate for, and proactively support, their communication needs.

Presenters:

India Ochs is a mother, attorney, author, sports fanatic, and hardcore fan of Star Wars, Robin Hood, musicals, and Robert Kennedy, from Annapolis, MD. An experienced public speaker and agitator, she has been involved in human rights, social policy, and educational advocacy for more than 35 years. Co-author of two published books (Stop the Violence Against People with Disabilities!: An International Resource (2014) and Becoming an Exceptional AAC Leader: Inspiration from 15 Augmentative and Alternative Communication Champions (2021)), India's writings have appeared in professional journals, magazines, newspapers, and social media outlets.

Susan Fager is the Director of the Communication Center in the Institute for Rehabilitation Science and Engineering at Madonna Rehabilitation Hospital. Dr. Fager specializes in augmentative and alternative communication/assistive technology (AAC/AT) for adults with acquired and degenerative neurologic conditions. She has numerous publications in AAC/AT and research grants funded through NIDILRR, NIH, and NSF. Her research has focused on the

evaluation of new and emerging assistive technologies for individuals with severe physical impairments.

References/Resources:

Blackstone, S.W., Beukelman, D.R., & Yorkston, K.M. (Eds.). (2015). *Patient-Provider Communication: Roles for Speech-Language Pathologists and Other Health Care Professionals*. Plural Publishing.

Fager, S., Gormley, J., & Sorenson, T. (2021). Access to AAC for individuals with acquired conditions: Challenges and solutions in early recovery. In B Ogletree (Ed), *AAC Challenges and Solutions: Improving Everyday Service Delivery (First Edition)*. San Diego, CA: Plural Publishing.

Guest Blog: Communication Barriers Faced by AAC Users in Accessing Health Care (2021)
<https://communicationfirst.org/guest-blog-communication-barriers-faced-by-aac-users-in-accessing-health-care/>

OCR MedStar Hospital Visitor Policy Complaint Resolved (2021)

<https://communicationfirst.org/ocr-medstar-hospital-visitor-policy-complaint-resolved/>

<https://www.patientprovidercommunication.org/>

<https://www.patientprovidercommunication.org/research-and-presentations/video-presentations/>