

Learning About Preparing for Future Medical Encounters

If you are someone who wants to be better prepared to communicate successfully with health-care providers, or someone who wants to be better able to help others prepare to communicate more successfully with health-care providers, you have lots of ways to learn more. There are videos you can watch, checklists you can access, articles you can read, communication boards you can download from the Internet, free apps you can use and books you can browse.

In this special section of the PPC website, we have tried to make these tasks easier for you, by providing you with a “one-stop shopping center” through which you can access, and learn from, all these kinds of resources. Taken together, these materials can easily constitute a quick “mini-course” on this topic. They may also help empower you to provide easy ways for others you are helping to access resources that will help them navigate the rocky shoals of patient-provider communication.

We have tried to provide you in this one document with lots of easy to access resources that can help make it easier to helping others, including rationales for making the case to others, useful resources, videos to watch or share with others, smartphone and tablet health communication apps, bibliographic annotations that can lead you to sources to learn more from, and a comprehensive follow-up bibliography that might help you deepen your expertise in this important area.

In the next section, we lay out the rationale for professionals to be much more proactive in preparing the people they work with for future medical encounters.

Preparing People with Communication Difficulties for Future Medical Encounters

Many professionals with expertise in communication don't work in health care, but are employed in schools, clinics, universities, and/or have private practices. It is important to consider the role that these individuals, (as well as future generations of communication professionals), might play in addressing the communication access barriers their clients are likely to experience across health care settings.

No one is in a better position to help people with communication difficulties prepare for the medical encounters they will face than the communication specialists and family members/caretakers who know and care about them. For example, speech therapists who work in schools, agencies, clinics, and private practices can take a lead by asking relevant questions, encouraging family members to think about how their loved ones will communicate during medical encounters, and connecting clients and their family members with information and resources. Other team members (e.g., personal care assistants, doctors, rehabilitation counsellors, occupational and physical therapists) can also encourage their clients who need communication enhancements (and their family members) to prepare for the communication obstacles they are likely to face during future medical encounters. Multiple resources are

now available to help those with communication difficulties become better prepared.

Different scenarios require different solutions. For example, solutions that work with family members and friends at home are often very different from the communication enhancement techniques and technologies someone might choose to use at school, at work, in a restaurant, at a doctor's office, or during a hospitalization. In fact, the supports people require within health care settings are diverse and situation-specific. This means that individuals with communication difficulties must prepare for both predictable medical encounters, such as a pre-scheduled outpatient visit, as well as less frequent and/or unpredictable emergency/disaster scenarios.



Given the complexity and multiplicity of variables involved, a communication specialist or an educator might be reluctant to add “preparing my clients with complex communication needs for future medical encounters” to their long list of client/student goals. And, while adding a section on patient provider communication to a graduate student syllabus might not yet appeal to some professors, others are already paving the way. It is not necessary to re-create materials that already exist or to devise new therapy programs. Many materials are available for professionals, educators, and consumers.

Personal information/medical passport. Everyone (children and adults) should carry personal identification and basic medical information with them at all times. Communication enhancement specialists can encourage family members/caregivers to help people with complex communication needs collect this information and put it

on an ID card, cellphone/tablet, USB stick, or medic alert bracelet. This information should exclude anything that might compromise a person's identity (*e.g.*, social security number, insurance identification numbers, bank account numbers, etc.). These should include multiple copies in multiple formats, to ensure the information is always accessible (*i.e.*, a medical bracelet can be worn; a USB stick or a medical information card can be carried in a wallet, backpack, or purse).

Medical passports should include (a) the individual's personal identification (name, address, phone, emergency-only contact information); (b) medical information (*e.g.*, allergies, diagnoses such as problems with speech, hearing, understanding, and remembering); (c) blood type; (d) a list of current medications (including names, dosages); (e) type of insurance; and (f) a list of doctors and their contact information. People with complex communication needs might also include a brief description of communication preferences (*e.g.*, written phrases or symbols to represent messages such as "Here's how I indicate yes/no/something else"; "I am/am not literate", "I use an SGD or communication board, hearing aids," etc.). A quick online search using search terms "medical passport", "medical identification", or "medical identification card" will yield multiple examples.

Information/instructions about care needs and special equipment.

Individuals with communication difficulties should also have information available that describes their unique needs in some detail in case of an emergency or disaster scenario, or in preparation for an inpatient admission. This information can be stored on a personal computer so it is readily accessible, easily updated, and can be printed

out. Copies can be kept in a backpack, on a USB stick, in a fanny pack, in a wheel chair or walker bag, or a *grab-and-go* bag.

The “grab-and-go bag” is meant to be a packed collection of critical materials, and should include a personalized health-related communication board/display, as well as a list of assistive technologies/specialized communication equipment used (*e.g.*, Speech Generating Device, paper displays, walker, hearing aids, glasses) and where they are kept. It might also be useful to include instructions for maintaining equipment (recharging batteries, safe storage procedures); descriptions of preferred communication strategies (*e.g.*, eye gaze, yes/no response, assisted scanning strategy); and protocols for eating, drinking, sleeping, transferring, walking, skin breakdowns, and communicating. Considerations related to privacy and a list of those who can provide additional information (*e.g.*, therapists, family members, doctors, and friends) should also be included, along with copies of important legal documents such as durable power of attorney and advance care directives.

Preparation for outpatient appointments. Many medical encounters occur during pre-scheduled and time-limited outpatient appointments. These visits may include a trip to the doctor or dentist for a routine checkup, a visit to an urgent care clinic to treat a minor accident or illness, or periodic visits to a physical or occupational therapist, speech/language therapist, audiologist, and so on. Although the nature of outpatient appointments varies, they share certain characteristics, which makes it possible for families to plan in advance

Learning how to communicate effectively before, during, and after outpatient appointments can help individuals with communication challenges to develop health literacy skills as well as increase the chances that their medical and therapeutic needs will be met. Speech therapists and others who work with adults and children are well positioned to encourage clients and their families/caregivers to think about the individual's communication strengths and challenges, and their ability to participate in activities such as (a) making an appointment (phone, email, text); (b) filling out forms; (c) identifying and preparing concerns in advance (e.g., a list of pre-prepared questions); and (d) identifying ways to ask questions, discuss issues, take notes/record a session to ensure recommendations and next steps are understood and jointly agreed to .

Preparing for stays in medical facilities. Whenever someone with communication difficulties is admitted to an acute care hospital, rehabilitation hospital, long-term care facility, nursing home, or hospice facility, communication challenges rapidly increase in both quantity and complexity. Consider, for example, the number of conversations and interactions that are likely to take place in a given day with nurses, doctors, therapists, hospital staff, housekeeping personnel, dietary personnel, other patients, and family members. Consider, too, that the communication needs of patients in different settings are diverse and will change significantly over time. Whether the length of stay is a few days (e.g., in an intensive care unit or hospital ward) or several years (e.g., in a nursing home or an assisted living or long-term care facility), once acute medical issues are managed, most individuals want to talk about topics that reflect their

unique personality and interests like a favorite sports team, TV show, or movie; family gossip; *etc.*

In non-acute inpatient facilities, interactions between patients and staff often become more personalized, as relationships are formed, and as family members return to their own lives and are unable to visit as often. Communication enhancement approaches are often needed both to support face-to-face communication (enabling people to remain engaged in the day-to-day life at their facility), as well as to support communication with family members and friends across distances through email, phone, text, videoconferencing, and social media.

Some of the communication challenges and transitions that will arise in medical facilities can be anticipated in advance. Speech-language pathologists, doctors, and physical and occupational therapists who work with people with complex communication needs can encourage their clients and family members to prepare for an admission that is scheduled in advance; it may also be helpful to contact their colleagues at the facility to offer assistance in the admission planning process. Questions that people with known communication challenges and their family members should consider asking facility staff include the following:

- Does the facility have a policy *re:* the provision of communication access for people with speech and language impairments?**
- Who are my/ my family member's communication partners likely to be (*e.g.*, providers, care staff, family members, housekeeping, dietary?)**

- Will staff be trained so they know how to communicate with me and/or my family members?
- How will I/my family member be supported in communicating basic needs reliably and successfully: eating, drinking, sleeping, toileting, skin care, hygiene?
- Will the I / my family member have access to my personal communication enhancement tools?
- How will I/ my family member activate a nurse call system?
- Will I/ my family member have signage in the room that explains how I/ my family member communicates?
- How will safety concerns be addressed (*e.g.*, infection control, privacy, storage of equipment, *etc.*)?
- What is the knowledge and attitude of the facility's administration and nursing staff regarding augmentative communication and other forms of communication enhancement?
- Will professionals with expertise in AAC be available if needed?

The stakes are especially high if some of these future medical encounters go awry, so it is obviously important to elevate quickly the priority of providing this kind of communication support.

In the next section, we address some of the objections professionals may have to “expanding” their practice to include preparing people for future medical encounters.

PREPARING FOR COMMUNICATION IN FUTURE MEDICAL ENCOUNTERS: IT'S NOT MY JOB?

Many professionals who work with children and adults with communication impairments and vulnerabilities work outside of health care settings, in schools, independent living centers, vocational training settings, *etc.* The clients they work with almost inevitably confront more frequent medical encounters, emergency room visits and hospitalizations than the general public. When those people experience *these* kinds of medical encounters, they also face a



disproportionately large number of communication barriers and breakdowns, which interfere significantly with effective medical treatment. Curiously, not many of these professionals yet acknowledge not only that it is their responsibility to help their clients, but that it's an essential support to the health, education and welfare of the people they help care for.

Fortunately, those professionals who *do* want to help prepare clients for these often crucially important medical and often frequent encounters have available a wide variety of materials that can help their clients prevent communication breakdowns in the doctor's office, the hospital emergency room, the ICU, at bedside in the hospital, at hospital discharge, and in the many other health care settings in which their clients find themselves communication vulnerable, *etc.*

It makes sense, then, that the speech language pathologists, the special needs teacher, the vocational specialists and all those other helpers that work outside of health care settings take some responsibility to help the people they work with navigate future medical encounters more successfully. And there is no need to reinvent any wheels. There already exist lots of ways people have already developed to provide simple tools and strategies that help in these situations: medical communication passports, lists of questions to make sure you get answers to, strategic advice to people with disabilities about dental visits, clinic visits, apps for the iPad, *etc., etc.*

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"More and more patients are going to the Internet for medical advice. To keep my practice going, I changed my name to Dr. Google."

But many professionals who work with people with communication disabilities are unaware of how they can help, and how the skills, tools and strategies they have at hand can be of invaluable assistance to clients who will find themselves in communicatively perilous healthcare situations down the road. Isn't it time for professionals who work outside healthcare settings to acknowledge that it is their responsibility to be more helpful in this area, and to learn more about the strategies and tools that their clients will need during future

medical encounters?



"The Doctor will see you now. Here's your medical jargon dictionary."

While many professionals work with children and adults who have a communication impairment, or communication difficulties secondary to

language or cultural issues, *outside* of healthcare situations (e.g., in schools, independent living centers, vocational training settings, community agencies, *etc.*), their clients typically experience more frequent medical encounters, emergency room visits and hospitalizations than the general public. This means they are at risk for confronting a disproportionately large number of communication barriers and breakdowns over time. This can, and often does, interfere with effective medical treatment.

The next section will describe resources that suggest the many practical ways that professionals who work outside the health care system can help their clients (and families) be better prepared for these inevitably difficult transactions. It will also provide guidance on how to access the practical strategies and materials that are known to be useful to people with communication vulnerabilities during healthcare encounters.

Access to Medical Care Training Package

The World Institute on Disability has created a training package on access to medical care for those with disabilities. This package includes an annotated list of 40 publications divided by themes such as health access and long-term services, international development and disability, and women with disabilities. The package also contains two videos, each accompanied by a training guide. One video and training guide focuses on people with developmental disabilities and the other focuses on people with physical disabilities.

Both sets of videos and guides are designed to train medical providers, families, and individuals with disability to achieve accessible, appropriate care in compliance with U.S. disability law. Both videos use interviews with disabled individuals, family members and a range of health care providers to help achieve this purpose. Finally, this package includes a training tools packet that contains a workshop design and reference material. The workshop design focuses on access and communication in addressing healthcare disparities for people with

disabilities. The workshop design also addresses culturally competent care and compliance with U.S. disability law. The workshop design can be used in conjunction with the two videos.

The publications list ([view here](#)) and training tools packet ([download here](#)) are available for free on the website. Most other publications are available for free download on the website, while some are available for purchase. Each video, with its accompanying report, costs \$100 (\$108.75 for California residents) plus \$4 shipping and handling. Purchasing both videos, with their reports, together costs \$150 plus shipping and handling. ([Order here](#)).

Financial aid is available for those with disabilities or special circumstances.

[Publications list: <http://wid.org/publications> ; Training tools packet: <http://wid.org/publicationswid.org/publications/access-to-medical-care-training-tools-for-health-care-providers-disabled-patients-and-advocates-on-culturally-competent-care-and-compliance-with-disability-law/> ; Order form: http://wid.org/publications/downloads/publications_order_form.doc/view]

Webinar Slides: Standards of Care for Adults with Intellectual and Developmental Disabilities, by Sarah Ailey, Diana Umali and Christine Uyen

This webinar presentation uses a case study of a patient with an intellectual and developmental disability (IDD). It demonstrates effective ways to communicate with patients with IDD, and the need for appropriate standards of care. It provides a detailed model for a nursing care plan to enhance communication for patients with IDD. The goal of the plan is that "the patient's communication skills will be assessed and maximized to facilitate nursing communication with the patient." It calls for ongoing assessment of the patient in four areas: 1) Receptive Communication, 2) Expressive Communication, 3) Use of Alternative Communication Methods and 4) Nonverbal Communication, and includes useful references.

Click here: http://aadmd.org/sites/default/files/Sarah_Ailey_2-16-12_webinar-slides.pdf

Scope: About Disability

A visit to the doctor can be a trying experience for any child. This website gives tips that have been contributed by other parents, care takers and professionals in order to make your visit go smoothly. If you don't see the answer to your question, it also has a forum on which to post questions and access to experts.



<https://community.scope.org.uk/tips/medical-appointments>

CONDITION HELP



The Children's Hospital of Pittsburgh has a unique patient safety program, Condition Help, that seeks to improve communication between families and caregivers. If families of patients at the hospital feel their child's immediate health may be endangered and/or their concerns are not being addressed, they

can call a hotline to have their child evaluated by a different medical team. The medical team consists of a physician, nurse administrator and patient representative, who are available 24/7. After receiving a call, the team comes to the child's room within minutes. This project has empowered families, and has reduced errors. (For more information on results of the project, check out the News Release below.)

News Release: <http://www.chp.edu/CHP/061808>

Condition Help:

http://www.chp.edu/cs/Satellite?c=eHA_Content_C&cid=1189459525424&pagename=CH

P%2FeHA_Content_C%2FCHP%2FTemplate%2FCHP_Layout_04_Content_Page_Template

Children's Hospital of Pittsburgh: <http://www.chp.edu/CHP/Home>

Working with Doctors: A Parent's Guide to Navigating the Health System

Created to help parents become effective advocates for their children in the health care system. It focuses on communication skills with medical professionals, maintaining records, and other important issues. See Translations for Hmong and Spanish.



An individual copy is \$8 and 10+ copies are \$6 each. **Order at:**
<http://www.pacer.org/publications/health.asp>

In the next section, we describe videos that professionals can both learn from and share with clients and students. They also provide first-hand accounts of the many things that can go wrong in health care communication exchanges, which can prove useful in convincing colleagues and family members of the value of making a prior effort to be ready for communication barriers that almost inevitably rear their ugly heads.

Videos

Vision Statements, NHS Education for Scotland



These "Vision Statements" include 10 videos of individuals with communication disabilities sharing their personal experiences with communication in a variety of settings, and suggest what is most important to remember about

communication. Each video includes links to further resources that can be used

to improve communication. The 10 video topics are: 1) Booking Appointments, Contacts and Attracting Attention, 2) Time, 3) Knowledge of Communication Tools, 4) Communication Support and Health, 5) Information, 6) Staff Attitude, 7) Patient at the Centre, 8) Physical Environment, 9) Patient Feedback and 10) Signage.

<http://www.nes.scot.nhs.uk/education-and-training/by-discipline/allied-health-professions/resources,-publications-and-useful-links/making-communication-even-better/vision-statements.aspx>

Disability Rights Stories

The Disability Rights Education Defense Fund (DREDF) has produced *Healthcare Stories*. *Healthcare Stories* are downloadable videos, each interviewing a person with a variety of disabilities from around the United States. Interviewees speak



candidly about their experiences accessing healthcare and describe specific “stories,” pointing out issues that interfere with quality healthcare.

The twelve videos last about 15 minutes each. DREDF plans to add more stories from people with

developmental disabilities. Their goal is that *Healthcare Stories* help disability advocates, health advocates, and others launch discussion and actions that address persistent barriers to healthcare and suggest important solutions that will improve healthcare for people with disabilities.

<http://www.dredf.org/healthcare-stories/>

Serving People Who are Deaf in Hospitals



The experience of deaf and hard of hearing individuals in a hospital setting is often confusing and frightening. Without the ability to communicate, a patient can be left in the dark regarding his or her own care. This need not be the case.

With proper communication services, the hospital experience can be positive instead of terrifying.

http://www.youtube.com/watch?v=N2pwdKqSV7c&feature=youtube_gdata_player



Partner Assisted Auditory Scanning

This video demonstrates a non-electronic communication technique for people with ALS and other conditions that make speech difficult because of limited movement.

Partner assisted auditory scanning allows an individual to select letters

of the alphabet without speaking or pointing, to spell words and to use common abbreviations. Individuals only need to signal yes using whatever gesture is easiest for them, such as blinking or glancing in a certain direction. Partner assisted auditory scanning requires no physical materials--just two people using a simple chart. <http://www.youtube.com/watch?v=pLb6-Oi3uR0>.

NexTalk for Deaf and Hard of Hearing Patients

Baton Rouge General Hospital has employed an exciting resource for its deaf and hard of hearing patients called NexTalk. NexTalk takes the form of a mobile video conferencing unit that enables off site interpreters to provide interpretation services at anytime. The units also allow patients to communicate with friends and family through video conferencing during their hospitalization. To learn more click the below link:



http://www.youtube.com/watch?v=U0bjx01GEAM&feature=youtube_gdata_player

All over the world, more and more people are acquiring affordable smartphones and tablets, for a wide variety of uses. These uses don't very often include getting ready for medical communication breakdowns, but they can be quite readily equipped to help deal with this problem. The following section describes a small sampling of the available resources, with an emphasis on those that can be accessed at no cost. This represents just the tip of the iceberg of such resources, which are being added to on an almost weekly basis.

Smartphone and Tablet Communication Apps

SmallTalk Pain Scale (<http://itunes.apple.com/us/app/smalltalk-pain-scale/id403058256?mt=8>)

- What is it? This app contains a series of images and pain descriptions that let the user communicate the type and level of pain. It is designed for people with aphasia, apraxia and dysarthria.
- How much is it? Free
- Platforms: iPhone, iPod Touch, iPad. Requires



iOS 7.0 or later.

- Reviews: Some reviews mentioned that this app does not allow for sentence construction, or any editing. However, it does allow for a great deal of specificity by offering vocabulary for “body parts, positional words, and pain-related adjectives (dull, sharp, aching, radiating, etc.).”

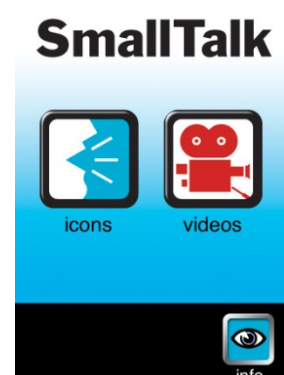
Verbally (<http://itunes.apple.com/us/app/verbally/id418671377?mt=8#>)

- What is it? A text-to-speech app intended especially for people with AAC needs. Users type the phrase that they wish to convey, and *Verbally* speaks it. The app allows users to choose from several male and female voices and three different keyboard layouts. For ease of use, the app has a word predictor and two core grids – one for words and one for phrases. There is no need for an internet connection to use it, either.
- How much is it? Free
- Platforms: iPad. Requires iOS 4.0 or later.
- Reviews: Verbally has received good reviews. Though the voices could be improved, the app’s “purpose and functionality make it so valuable.”



SmallTalk Aphasia : Female

(<https://itunes.apple.com/us/app/smalltalk-aphasia-female/id310102858?mt=8>)



Male: (<https://itunes.apple.com/us/app/smalltalk-aphasia-male/id403064267?mt=8>)

- What is it? This app contains phrases and images to help people who have difficulty speaking. Users select the word or phrase, then let the app “speak.” The categories include doctor’s appointments and emergencies. Users can personalize the vocabulary as well. There is also a mouth-positioning feature that helps the user practice speaking at his or her own pace.
- How much is it? Free
- Platforms: iPhone, iPod Touch, iPad. Requires iOS 7.0 or later.
- Reviews: Users call this app “a real find for folks with communication challenges.” Although the vocabulary is “limited,” and there is no gender option, reviewers agree that the app is easy to use and facilitates communication for those with special needs.

Talk Assist (<http://itunes.apple.com/us/app/talk-assist/id329338159?mt=8#>)

- What is it? A text-to-speech app that allows users to “speak” by typing a message and then having it read aloud. The phrases may be saved, and a bookmark feature lets users store favorite phrases for frequent use.



mubaloo
developing smartphone applications
for your business

www.mubaloo.com

- How much is it? Free
- Platforms: iPhone, iPod Touch, iPad. Requires iOS 3.0 or later.
- Reviews: Reviews say that Talk Assist has a “simple” interface and is overall a good app. However, users would like to see an option for a female voice. Another user wrote that Speak It (which costs \$1.99, see below) is a better app despite the slightly higher cost.

Healthcare Communication App (<http://appcrawlr.com/android/healthcare-communication-app>)

- What is it? The Healthcare Communication App (HCA) uses text-to-speech technology and artfully-drawn picture icons. The patient taps an icon indicating a want or a need and HCA speaks it for them.
- How much is it? \$49.00
- Platforms: ipad, Android
- Reviews: Reviews say that, “healthcare communication app enhances communication between patients and caregivers.”



The following annotated bibliographic references will help acquaint you with the vast literature that exists, albeit it in widely scattered places, to support both the importance of paying attention to the communication barriers and breakdowns that so commonly occur and the existence of tools and strategies that can help circumvent the barriers and alleviate the breakdowns.

Annotated Bibliography

1. Long, Andrew, Anne Hesketh, and Audrey Brown. (2009, May 29). “Communication Outcome after Stroke: A New Measure of the Carer’s Perspective,” *Clinical Rehabilitation*, 23: 846-856. Available at: <http://cre.sagepub.com/content/23/9/846>

Researchers have noted the psychological strains on the caregiver of a person who has suffered a stroke; little study has been done specifically on communication, however. Many people who have



"Enough acupuncture-
get me a couple of aspirin."

a stroke develop a communication problem, and the caregiver also must cope with the new communication challenges. To better understand these effects, researchers used the Carer Communication Outcome after Stroke (COAST) scale. The scale measured the level of communication after the stroke and how this affected the caregiver's quality of life. The results confirmed that communication barriers do affect caregivers, suggesting that **programs focusing on caregiver support should include communication as well as psychological needs.**

2. Morris, M., Dudgeon, B., & Yorkston, K. (n.d.). A qualitative study of adult AAC users' experiences communicating with medical providers. *Disability and Rehabilitation: Assistive Technology*, 8(6), 2013, 472-481.

Patients with communication disabilities face multiple barriers to communicating with medical care providers. To explore these barriers, researchers conducted a series of face-to-face interviews and an online focus group with **participants who use augmentative and alternative communication systems and methods.** **Participants described multiple frustrations in communicating with medical care providers. Themes that arose included: planning and preparing for the appointment, time barriers, inappropriate assumptions, relationship building and establishing rapport, medical decision making and implementing the plan.**

3. Hemsley, B., Kuek, M., Bastock, K., Scarinci, N., & Davidson, B. (2013). Parents and children with cerebral palsy discuss communication needs in hospital. *Developmental Neurorehabilitation*, 363-374. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/24228709>

The aim of this study was to understand the communication needs and experiences of parents and children with cerebral palsy (CP) and complex communication needs (CCN) in hospital. Focus groups with 10 parents and interviews with seven children with CP and CCN were analyzed for content themes. **Results demonstrated that children often want to communicate directly with hospital staff to: gain attention, answer yes/no, convey basic physical needs, give and receive information, control their environment and participate in preferred activities.** Barriers to communication included lack of access to augmentative and alternative communication (AAC), staff preferring to

communicate with parents and lack of time to communicate. Results highlight strategies for successful communication, **the role of the parents in supporting communication** and provision of AAC systems for children in hospital. Policy and practice implications in the preparation of children with CP and CCN for communication in hospital are discussed.

4. Cortes, Dharma E., Norah Mulvaney-Day, Lisa Fortuna, Sarah Reinfeld, and Margarita Alegria. (2009). "Patient-Provider Communication: Understanding the Role of Patient Activation for Latinos in Mental Health Treatment," *Health Educational Behavior*, 36: 138-154. Available at: <http://heb.sagepub.com/content/36/1/138>

Patients can take a more proactive role in decisions about their health care by asking questions about their treatment options. Yet, asking the right questions is more successful when patients know how to formulate questions and to get the information that they need. Many patients do not have these skills, but could acquire them through education and training. **The Right Question Project-Mental Health (RQP-MH) approach devised a model for training these skills, working with a mostly-Hispanic population.** Participants underwent training, held interviews to gauge how they incorporated the information. The researchers noted that the participants were more inclined to ask questions about their care than before. While more research needs to be done over a longer period of time, this method suggests one way in which patients could be trained to take a more active role in decision-making.



5. Beukelman, David, Susan Fager, and Amy Nordness. (2011). "Communication Support for People with ALS," *Neurology Research International*, 2011. Available at: <http://www.hindawi.com/journals/nri/2011/714693/>

People with amyotrophic lateral sclerosis (ALS) almost always suffer a motor speech disorder at some point during the disease's course. When this occurs, the

ability to speak naturally rapidly decreases, and there is often little time to implement an effective augmentative and alternative communication (AAC) program. This article stresses the importance of early intervention and raises awareness of the long-term AAC support that can help people with ALS. AAC support takes many forms, from touch-screens to eye-tracking systems; patients with ALS typically use them until the end of their lives. Thus, **it is essential to accurately and quickly develop a support program suited for the patient's needs.**

6. Rayner, H., & Marshall, J. (2003). Training volunteers as conversation partners for people with aphasia. *International Journal of Language & Communication Disorders*, 38(2), 149-164.

One of the most disabling consequences of aphasia is the way it excludes the person from conversation. Exclusion can lead to confusion and misunderstanding during medical encounters. This study evaluated the possible solution of **training the conversational partners of aphasic people**. Questionnaires given before and after the training documented significant improvements in the scores of conversational partners. There were comparable gains in the participation of the aphasic subjects, which again occurred after training. The study demonstrates that a short training course can change the knowledge and practice of experienced conversational partners. This can lead to a better health care experience for those with aphasia.

7. Blackstone, S. & Collier, B. (2008, September). Communication assistants: Human supports for communication access. *Augmentative Communication News*, 20 (3), 7-13.

As sign language interpreters help the deaf, communication assistants should be in place to help people with complex communication needs (CCN). If a person uses assistive technology to communicate, it often requires a third party to help explain communication methods to new contacts who may be unfamiliar with them. Today, this job usually defaults to family and friends, as professionals are unavailable in most areas of the world. In their article, Blackstone and Collier

present the future of augmentative communication through discussion of a few cases where human supports have been offered for people with CCN.

8. Blackstone, S. & Pressman, H. (accepted, 2016?). Patient Communication in Health Care Settings: Missed Opportunities? *Augmentative and Alternative Communication Journal*.

Augmentative and Alternative Communication (AAC) methods that exist today are not being used to their full potential. Practitioners need to come together to guarantee patient outcomes, safety and engagement through the planning and implementation of AAC methods during encounters with healthcare professionals. Furthermore, medical institutions must prepare future generations of health providers for the use of these methods long before they experience them in a hospital setting. This article explores improvements of current uses of AAC and extension of AAC methods to other groups facing communication barriers.

9. Hemsley, B., Lee, S., Munro, K., Seeda, N. , Bastock, K., & Davidson, B. (2014). Supporting communication for children with cerebral palsy in hospital: Views of community and hospital staff. *Developmental Neurorehabilitation*, 17(3), 156-166. doi:10.3109/17518423.2012.741149

Health professionals and hospital nurses are very active in supporting physical needs of children with cerebral palsy (CP), but the needs of these children go beyond just hospital equipment, movement and eating to augmentative and alternative communication (AAC) needs. A study of 49 health professionals and hospital nurses found that they did not report active roles supporting communication methods for CP patients in the hospital with complex communication needs (CCN), and blamed environmental barriers in the hospital. In her article, Hemsley compiles the views and suggestions from her study to tell how to create a more communicatively accessible hospital for future encounters with children with CP and CCN.

10. Morris, M. (2011). Patient-Provider Communication: Perspectives of Individuals with Significant Communication Disabilities. *UNIVERSITY OF*

WASHINGTON, 3485523, 128 pages

<http://gradworks.umi.com/34/85/3485523.html>

Who better to ask for suggestions to improve patient-provider communication than the patients themselves? Morris conducted a study in which 12 adults with disabilities reported on their satisfaction in communicating with medical providers. While results from her study showed that these adults were generally satisfied, they reported frustration in key areas. Her PhD dissertation, which compiles the patients' responses to her study, looks at patient-provider communication through a new lens.

10 . Patak, L., Wilson-Stronks, A., Costello, J., Kleinpell, R., Henneman, E., Person, C., & Happ, M. (2009). Improving Patient-Provider Communication: A Call to Action. *Journal of Nursing Administration*, 39(9), 372-376.

Patients have the right to effective patient-provider communication. Methods used today, such as ad hoc interpreters, yes/no questions and non-verbal communication, are not adequate and often times frustrating. Effective communication methods can only be established through monitoring and evaluating methods used by care providers on a case-to-case basis. This article lays out a procedure for assessment and improvement of patient-provider communication in care centers.

The above references represent but few of the many sources of information and evidence that sustain the notions that (1) communication barriers in health care settings represent a serious and immediate threat to the provision of adequate health care to people with a wide variety of communication difficulties, (2) relatively few patients get access to the communication supports they need, (3) there are a host of infrequently utilized resources that such patients could be armed with to help prevent communication breakdowns and (4) professionals who do provide help in this area can make a significant difference. The following section adds to the wealth of resources available to those who want to know more.

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