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Special thanks to Advisor Erica Dente for her editorial assistance with the E-Newsletter.
The Year in Review: Patient and Family Engagement Breaking the Mold at BIDMC

Caroline Moore, Program Leader, Patient and Family Engagement, BIDMC

Every October, each hospital across the state is required by law to submit an annual report about its Patient and Family Advisory Council. In 2015, to facilitate this task, Health Care for All provided hospitals with a link to an electronic survey, designed to capture the typical data points related to patient and family advisory councils. My attempts to complete this survey were both immensely confusing and enormously gratifying, as I eventually came to the conclusion that there was no possibly way to adequately condense the impressive and far-reaching contributions of BIDMC’s advisors into this one-size-fits all template.

BIDMC has not one, but five advisory councils: the NICU Advisory Council (established in 2006), the ICU PFAC (established in 2008), the Hospital-Wide PFAC (established in 2010), the Universal Access Advisory Council (established in 2010), and the Healthcare Associates Advisory Council (established in 2013). While Advisory Councils have historically made up the foundation of patient engagement at BIDMC, there has been an evolution in the ways in which advisors have been making an impact at the medical center over the years.

Despite the fact that we have five active councils (many hospitals have just one, per their legal requirement) doing a great deal of work, in 2015, participation in advisory council meetings made up just 13% of all BIDMC advisor activities. Many of our advisory council members, along with approximately seventy other active advisors, also participated in a variety of other opportunities, everything from participating on hospital committees (making up 50 % of 2015’s advisor activities), to participating in a variety of short-term activities (37% of advisor activities). These included assisting with staff trainings and presentations; providing video testimonials; participating in focus groups; organizing a patient safety event, advising on research projects; testing websites; interviewing job applicants, and providing e-mail feedback on a variety of topics –staff uniforms, architecture, marketing materials, and much, much more.

BIDMC is so fortunate to have such a committed team of patient and family advisors giving so generously of their time – over 1,000 advisor hours volunteered by this year by 93 advisors. To read more about the ways in which BIDMC’s advisors “broke the mold” this year, go to our website to read the 2015 Annual Report: www.BIDMC.org/PFAC.
Advisor Sound-Off: Reflections about Advising in 2015

Q: What has Advising meant to you in 2015?

- Volunteering as a Patient and Family Advisor has given me an opportunity to make a difference at BIDMC. The committee on which I serve has welcomed me, been interested and willing to listen to my opinions and experiences, and has valued my input. This makes me feel that, by helping to fulfill the mission and goals of the committee, I am contributing to the betterment of the hospital itself.
  – Joyce Black

- In 2015, I was happy for the opportunity to participate in live speaking events for two separate groups of doctors and pharmacists this past year. The live exchange of stories and ideas goes a long way to improving communication. Keep them coming! - Paul Daigneault

- I have enjoyed feeling like I belong to an organization that sees its patients and their families first as human beings. Being able to share experiences, both negative and positive, to make improvements, even in the smallest of ways, just makes me feel good. My involvement also helps me stay connected to my mom since she passed. Being a Patient Family Advisor continues to help me heal my broken heart so I can remain strong enough to help others who may be going through something similar. And, isn't that what life is all about? – Jackie Giannakoulis

- I feel my strengths and interests are well-matched to the advisor opportunities offered to me. I feel appreciated and valued, and I get to use my brain on worthwhile projects, which are all rewarding for a semi-retired person (or anyone else, of course). – Peggy Hooper

- I am so grateful to be given the opportunity to represent the vulnerable. How we treat the sick is a reflection of our humanity.
  – Sari Edelstein
“Ethics is Everyone”
By Advisor Betsy Lowe

On Tuesday, June 2, 2015 the Ethics Advisory Committee along with the Stephen B. Kay Leadership Academy hosted the second annual “Ethics is Everyone” poster presentation. The day started with a reception in the Leventhal Conference Room where attendees were welcomed by Lachlan Forrow, MD, Director Ethics and Palliative Care Programs, and Nancy Formella, Chief Operating Officer. Guests were able to mingle while enjoying breakfast and viewing posters that illustrated ways in which staff go “above and beyond” in their everyday work here at BIDMC. The reception also featured a video in which staff from various departments, including Service Response, Maintenance, Motor Services, Food Services and Ambassadors, describe steps they took to keep the medical center operating this past winter. Following the reception, the posters were moved to the lobby of the Shapiro Clinical Center and were on display for the remainder of the day. The video can be accessed by clicking on (or typing into your browser) the link below: http://bcove.me/vi43f1jg.

Disability Etiquette: Interacting with People with Disabilities in the Healthcare Environment
By Advisor Sandy Alissa Novack

This article is reprinted with permission from Disability Issues newsletter, Spring 2015 issue, Vol. 35, No. 2.

Etiquette concerns are especially serious in a medical setting. We are often at our most vulnerable when we are stressed, ill, and baring our bodies as well as our souls to medical staff. Ray Glazier, principal of disAbility Research Associates (www.disabilityresearch.org) and Disability Issues editorial board member, reports "There are about 726,000 adults in Massachusetts with disabilities, or more than 11% of the general population. This means that every ninth person with whom you have contact with is likely to have some form of disability." The percentage of people presenting with some form of disability will continue to rise higher in many healthcare settings; creating a greater need for medical providers to be trained
in disabilities and issues of disability etiquette. For a solid foundation of general disability etiquette, the United Spinal Association publishes a guide that covers more than spinal disabilities. It includes etiquette for interacting with people who have speech disabilities, learning disabilities, multiple chemical sensitivities, and more. To download a free PDF or purchase printed guides, visit [www.UnitedSpinal.org](http://www.UnitedSpinal.org).

Leana Wen published an article with NPR, *Doctors’ Ignorance Stands in the Way of Care for the Disabled* (May 17, 2014). The article points out, "less than 20% of medical schools teach their students how to talk with patients with disabilities about their needs" and "More than half of medical school deans report that their students are not competent to treat people with disabilities". Alyce Lanoue, a local retired nurse who is visually impaired, says her daughter is enrolled in a nursing program where addressing disabilities in a medical evaluation is not discussed. Her daughter makes it a point to frequently bring up disability related issues during class discussions. Too often the patient with a disability needs to take on the role of trainer. The good news is that medical providers are often eager to learn and do better.

At Beth Israel Deaconess Medical Center-Boston (BIDMC), more assistance for hospital staff is on the horizon. Health professionals are developing an all-staff training module on disability awareness as well as suggested scripting for handling a range of issues. Sample tips will include:

"Human First": See the person, not just the disability.

- When speaking or writing, mention the person first. 'Patient who is using a wheelchair', not 'wheelchair patient'.

- Ask, do not assume, if and what a patient may need.

- If a patient tells you what they need, believe it, use it, and act on it.

Additional etiquette that is specific to the healthcare environment include:

- Adjust your pace so that someone with a disability is not left behind when you run on ahead to the exam room. Walk beside the person with a disability, or slightly ahead of him or her, if you are leading the way to a room.

- Physicians need to be aware that radiological tests involving x-rays machines, MRI, mammograms, etc. are one of the least accessible areas of health care today. Doctors should pause and think, as well as seek consultation, about the person with a disability they want to refer to radiology before making a referral. Sample issues for radiological tests include:
• Weight-bearing x-rays of feet may not be possible if a person with a disability cannot climb stairs to reach the equipment and if the equipment can not be lowered to the person's feet.

• A full mammogram may not be possible if the person with a disability cannot move their body into the necessary positions.

The following individuals share some disability related experiences and advice:

• Elizabeth Dean Clower, a public health physician who uses a wheelchair, believes doctors should consider scheduling longer length appointments for some patients with disabilities who may have complex needs and require more time for a comprehensive exam. Patients can also plan ahead and ask their doctor to talk with the front desk about scheduling a longer appointment for their next visit. This respects the time and needs of both the patient and physician.

• Katie McGuinness accompanies her 94-year-old father to all his medical appointments. She states some medical providers direct the conversation to her rather than to the patient, her father. She encourages medical professional to always look at and talk to the patient.

• Karen Schneiderman, a Senior Advocate at the Boston Center for Independent Living, states that people with disabilities sometimes are afraid to say they need something disability related for their medical care; or they fear there could be repercussions for speaking up. She also says some people may not want to ask for help out of concern they would be laughed at or ridiculed.

Of course, it works both ways. Did it ever occur to you that some of the staff at your medical office may have fears of their own? One healthcare worker recently asked me a question she had been wondering about, and knows others without disabilities would like an answer to, but are afraid to ask. Her question is, if you enter a restroom with multiple stalls, and all except the accessible one are occupied, is it acceptable to use it if you are not a person with a disability? She has observed ladies who are waiting their turn, lower their eyes in disapproval when someone, seemingly without a disability, enters or leaves the accessible stall. She knows that disabilities are not always visually obvious and these stalls are not exclusively reserved for disabled individuals; sometimes people without a disability may need the extra room or accessories of an accessible stall. Even knowing all this, it's confusing to know what to do. She is glad I am interested in opening up the topic of disability etiquette because she knows that she and others without disabilities welcome some guidance on all kinds of disability etiquette matters.
Elana Premack Sandler, former Project Leader of Patient and Family Engagement at BIDMC, says, "I think a common stumbling block for providers and other medical office staff is not knowing what may be okay to ask. Most people want to be respectful and think that not directly addressing a disability is the best way to do that." Elena also shared, "It would be helpful to know from people with disabilities; what is the best way to ask? What are you comfortable sharing?" She acknowledges it's important to respect that everyone's comfort zone is a bit different.

Elana also says she has heard from family members who coordinate the care of their loved ones with cognitive disabilities that it's important for a provider to talk about what they are about to do so the patient is not taken by surprise. For example, "I'm going to stand behind you and adjust this so I can get a better x-ray", or "I'm going to raise the bed now." Elana adds, "I think these ways of communicating are respectful to all patients and honor that a person's body is his or her own."

Sandy Alissa Novack, MBA, LICSW, ACSW, CSW-G is a Social Worker and a Patient and Family Advisor on the Beth Israel Deaconess Medical Center's Universal Access Advisory Council.

Welcome, New Advisory Council Members!

Hospital-Wide PFAC:
Delores Bryant, Billy Duffey, Dorothy McCabe, and Matt Robert

Universal Access Advisory Council:
Stacey Batista, Nathacha Louis, and Stacey Whiteman

ICU PFAC:
Billy Duffey, Joyce Midttun, and Dawn Piccolo
“Above and Beyond” Honoree, Naromie Caidor

Congratulations to Naromie Caidor, a member of the Environmental Services team who works on Farr 6. Naromi’s love for her work shines through in her daily interactions with patients. She greets them with warmth, cheer, and humor, and they look forward to seeing her. Laughter can often be heard flowing out of rooms in which Naromie is cleaning. Recently during rounds, a patient and the patient’s spouse stated that Naromie has been the highlight of her stay at BIDMC, and that Naromie’s kindness has helped her to heal.

Naromie started working at BIDMC almost 28 years ago, after moving here from Haiti. She is grateful to BIDMC for providing her with English language lessons when she first began working here, and for giving her a good job so that her three children (16, 14, and 12 at the time) could eventually join her in America. Naromie’s fourth child was born at BIDMC. All of her children have graduated from college now, and Naromie says that she was able to give her children an excellent education, thanks to a job at BIDMC of which she is extremely proud, a job that gives her a great deal of joy and satisfaction.

Service Tips of the Month

Members of the Ambulatory Service Excellence Steering Committee, in their continual efforts to improve the patient experience in ambulatory (outpatient) clinics, have started to broadcast a monthly “Service Tip of the Month” to all ambulatory employees. Caroline Moore requested ideas for tips from Patient and Family Advisors, and our advisors did not disappoint – sending over thirty different tips. Patient and Family Advisors Joyce Black and Peggy Hooper are members of the Service Excellence Steering Committee and were two of the contributors. Below is the “tip of the month” email that was delivered to the inboxes of over 2000 BIDMC staff members in October. Thank you, Advisors!

Make a personal connection

When you are speaking with a patient or visitor, be sure to make eye contact! It’s the first step in establishing that friendly greeting, and helps the patient feel welcome. So be sure to look up from your computer as soon as someone approaches. It’s a better start to the conversation for both of you.
Patient and Family Advisor
Fall Photo Gallery

"Dunstable", Ellen Rothman

Mal Malme

"Mary O'Malley Waterfront Park", Joyce Black

"Wellfleet", Michael Altman

"Napa Valley Vineyard", Tobie Atlas

Susan Feinberg