

# NJSHAPE

March 2019



New Jersey Society for Healthcare Advocacy and the Patient Experience

## President's Pen

Dear Members:

"Accept assurances of my affectionate esteem and high respect." If these words were good enough for Thomas Jefferson to use when closing his correspondence to friends and colleagues, than, I think they are appropriate for me to also use as I end my term serving as your President of New Jersey Society for Health Care Advocacy and the Patient Experience (NJSHAPE.) It has been a true honor to work with all you. When I think of your passion, professionalism and power to always do what is right in serving our patients and families, I am truly humbled by your collective experience. The term "grace under fire," comes to mind when I think of the countless examples of stories we shared in taking the "HEAT" and finding the solutions that help empower our patients. Our role is to serve, through listening; empathizing; teaching; clarifying; moving obstacles; and bringing a voice to voiceless, all so we can improve the patient experience. It's hard work, but most rewarding when you know your presence has helped to calm fears and provide answers in what often is a patient's most critical hour of need.

### In This Issue

- Discrimination based on Gender Identity or Expression?
- Section 1557
- Ability to accommodate the Deaf and Hard of Hearing
- Describing patient experience
- Role of Patient Advocate
- March meeting

Our role may not have anything to do with ordering or dispensing medication or tests, but the help we provide is no less impactful. Bravo, to your patience, your understanding and the wisdom you share. You are all a great asset to your hospitals. It has been my honor and pleasure to serve you. But now it is time to pass on the leadership to our very capable friend and colleague Kim Santana from Cooper Hospital. Over the past few years, we have benefited from Kim's creativity and energy. She has contributed with finding great speakers for meetings and fun activities to elevate our conferences. She is one of those Patient Advocates that also holds multiple roles; Director of Patient Experience, Volunteer Director and Pastoral Care Director. They say, if you want to get something done, give it to a busy person, well, thank you Kim for ALSO accepting the nomination from our members as our new President of NJSHAPE! Looking forward to great meetings ahead!!



Sincerely,

*Teresa Lawlor*

Patient Relations Manager  
Virtua Hospital Marlton  
NJSHAPE Past President 2016- 2018





## Does New Jersey Law Protect People from Discrimination Based on Gender Identity or Expression?

Yes. The New Jersey Law Against Discrimination (LAD) prohibits discrimination based on gender identity or expression. This means that it is against the law for you to be harassed or denied rights and privileges extended to others because of your gender identity or expression or your transgender status. These protections apply to a broad range of people, including but not limited to people who express or present to the public a gender that does not match their birth certificate, people who change some or all of their sex characteristics through hormones and/or surgery, and people who are transitioning.

### What Kinds of Discrimination are Prohibited by New Jersey Law?

New Jersey law protects you against discrimination in four primary areas:

#### 1. Employment

It is unlawful for any employer or labor organization to discriminate against an employee or applicant based on gender identity or gender expression. This means it is unlawful to discriminate when making employment decisions, including:

- Deciding whether to interview or hire an applicant;
- Deciding whether to promote, transfer or discharge an employee;
- Setting job assignments, pay levels, employee benefits or other terms, conditions or privileges of employment.

Where an employer requires employees to follow reasonable dress or grooming standards, employees must be permitted to follow the standards that apply to their gender identity. It is also unlawful to permit workplace harassment based on transgender status, or actual or perceived gender identity or expression.

#### 2. Public Accommodations

Discrimination and harassment are prohibited in places and organizations that are open to some segment of the public, including but not limited to stores, restaurants, hotels, theaters, sports facilities, hair-cutting establishments, medical offices, govern-

ment offices and most schools. This means, for example, it is unlawful to discriminate based on gender identity or expression in admitting and serving patrons, or in assigning rooms, tables or other services and facilities. (Exception: schools operated by a bona fide religious institution are exempt from the LAD.)

#### 3. Business and Financial Transactions

It is unlawful to refuse to do business with any person because of gender identity or expression. This includes buying, selling, leasing, financing, contracting, trading, or providing goods, services or information. It is also unlawful to discriminate based on gender identity or expression in financial transactions, such as loans, mortgages, extensions of credit and financial assistance.

#### 4. Housing and Real Estate

You are protected from discrimination and harassment in the purchase or rental of a house, apartment, office or other commercial property because of gender identity or expression. (Exception: The LAD does not apply to rental of a single residential unit in a two-family dwelling, where the owner lives in the other unit, or renting a room or rooms in a single family dwelling that is the owner's residence.)

### Harassment/Full and Equal Access:

Harassment and making statements or taking action that show that a person is unwelcome because of gender identity/expression, or making it more difficult for a person to do a job, engage in a business transaction, use a public accommodation or have full and equal access to housing or real estate because of gender identity/expression can also violate the LAD.

**Use of Restrooms and Locker Rooms:** Individuals are permitted to use restrooms and locker rooms corresponding to their identified gender or expression. Refusal to allow an individual to use the restroom or locker room consistent with his or her gender identity or expression would be unlawful under the LAD.

## Reprisal:

The LAD also prohibits reprisal or retaliation because an individual made a good faith complaint about discrimination or harassment based on gender identity or expression, or assisted someone else in making such a complaint.

## What Can I Do About Harassment or Discrimination Based on Gender Identity or Expression?

The LAD provides two ways to seek relief:

- **Administrative remedy:** You can file an administrative complaint with the New Jersey Division on Civil Rights (DCR) within 180 days of the act of discrimination. After a complaint is filed, DCR investigates the allegations. If an investigation shows enough evidence to support the complaint, and the complaint cannot be settled, a hearing will be held in the Office of Administrative Law. After that hearing, the DCR Director will issue a final decision as to whether unlawful discrimination has been proven. If discrimination has been proven, the decision will order appropriate remedies.
- **Judicial remedy:** As an alternative, you can file a complaint in the Superior Court of New Jersey, with or without the assistance of an attorney; this type of complaint must be filed within two years from the act of discrimination.
- **Relief available:** The Division on Civil Rights or the Superior Court may order equitable relief, back pay, compensatory damages and attorney fees. The Superior Court may also award punitive damages. In addition, the Division on Civil Rights may impose civil penalties to be paid to the State government.



**NJ Office of the Attorney General**

**CIVIL RIGHTS**

To file a complaint with the Division on Civil Rights, contact or visit the office nearest you:

**Northern Regional Office:**

31 Clinton Street, Newark, NJ 07102  
Phone: (973) 648-2700 • Fax: (973) 648-4406

**Central Regional Office:**

140 East Front Street / P.O. Box 090  
Trenton, NJ 08625-0090  
Phone: (609) 292-4605 • Fax: (609) 984-3812

**Southern Regional Office:**

5 Executive Campus, Suite 107  
Cherry Hill, NJ 08002  
Phone: (856) 486-4080 • Fax: (856) 486-2255

**South Shore Regional Office:**

1325 Boardwalk, Tennessee Avenue & Boardwalk  
Atlantic City, NJ 08401  
Phone: (609) 441-3100 Fax: (609) 441-3578

Visit our web site at [www.NJCivilRights.gov](http://www.NJCivilRights.gov)



## Quick Reference: 155J and Language Access

For more details on educational accommodations, see [page 155J](#).

The U.S. Department of Health and Human Services (HHS) recently issued a new policy on how health care providers should comply with Title III of the Americans with Disabilities Act (ADA), which requires health care providers to make their services accessible to people with limited English proficiency (LEP). The full text of the regulation can be found at [www.access.gpo.gov/nara/pubs/ADA/title3.html](#).

A complete list of all other applicable accommodations can be found at [www.hhs.gov/office-of-equity-practice/ada-compliance-for-health-care-providers](#).



## 1 POST: *Notice of Denial/Exception and Appeal*

155J requires providers to send a notice of nondiscrimination and explain their compliance strategy. Language assistance available in the state/province's top 10 languages. Find out how 155J language is affecting your organization. [Download 155J that supports justice](#) available to be engaged. If you still have any issues, please contact our support team at [1-800-458-3232](#) or [support@justiceforall.org](#).



## 2 ELIMINATE *qualified exceptions*

Written 155J requires qualified providers to **eliminate** the use of:

1. **Written tests** (written-based) for employment or admission to a program.
2. **Tests** (oral and written) for the program unless the provider -- provides the test either in multiple languages or the test is necessary for the program's purpose.
3. **Written tests** unless necessary to a part of the individual's course, program or responsibility and the test is necessary for the program's purpose.
  - Includes all reading and understanding both spoken English and all other oral or written language including translation services/interpreter services and interpretation and
  - It also includes accuracy and frequency communication directly with individuals with oral English proficiency in their primary language.

Typical testing forms with written tests include: admission, employment, and graduation.

### Self-testing/Testing

Self-testing/Testing is used to identify students and measure their skills in reading, listening, and speaking. It is used to measure and improve skills. Testing includes:

**Language Proficiency Assessments** designed to measure the ability of individuals to communicate effectively in a language. It is used to measure the individual's ability to communicate in a language. [Download 155J Assessment Checklist](#)

- Writing** - Written tests of the individual's writing skills - oral/written and written.
- Reading** - Ability to read and understand written - oral/written and written.
- Listening** - Oral/written tests of the individual's listening skills - oral/written and written.
- Speaking** - Oral/written tests of the individual's speaking skills - oral/written and written.

**Cultural Appropriateness and Sensitivity** - Focus on cultural differences in health care settings and ensure that the provider is sensitive to the individual's needs.

- Language** - Ability to provide the information and help in finding a way to help in the right direction.



**Interpreting Health Assessments** is evidence (knowledge of medical vocabulary and ability to accurately convert messages from one language to another in a clinical context, including:

1. Interpretation from English into the target language
2. Interpretation from the target language into English
3. Working in devices in both languages

Any self-referential, self-proclaimed qualified or interested individual has the responsibility to determine if using their services may be in another's best interest. While the self-nominate self-developer, self-nominators who wish to provide care through a non-English language should be informed and advised to determine if they are qualified through practice.

### 3 PROVIDE self-referential, self-proclaimed, self-developer, self-nominate, self-developer, self-nominate

Section 1117 requires that providers take reasonable steps to provide meaningful access to self-identified individuals with limited English proficiency (LEP) to be served or that to be instructed in the emergency department and providers to the best of their professional judgment, training, practice, and available resources to assist individuals who cannot function, understand or communicate in English.

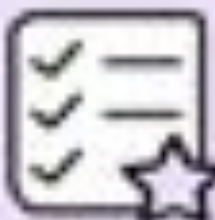
Providers may find it important to self-identify themselves for all possible languages, to more fully help/assist/assistants. "Are you able to understand and speak English now?" [Language self-identification questionnaire](#) for patients with oral/written/visual/auditory or physical disabilities in multiple languages.



### 4 CONFIRM that remote interpretation options are fully functional

Section 1117 requires the use of qualified interpreters and video interpreters to help providers deliver emergency services to the LEP patient – with the caveat that video interpretation may not be the quality standard for the LEP community. The American with Disabilities Act:

1. The video interpreter video and audio use is dedicated/high quality, wide bandwidth video connection is available on-line that delivers high quality video images that deliver picture, high contrast, clarity or glare-free, or image person communication.
2. A clearly defined image that is large enough to display the interpreter's face, arms, hands, and fingers, and the same going in the other direction, arms, hands, and fingers, regardless of the display position.
3. A clear audio connection of voice.
4. Adequate training in use of the technology and other technical knowledge so that they are qualified and efficient in an emergency for 1117.



### 5 TRAIN self-referential, self-proclaimed, self-developer, self-nominate, self-developer, self-nominate

Section 1117 gives all individuals a specific level of action against healthcare providers that let us take reasonable steps to provide meaningful access. This is determined from this or at the LEP rights for the emergency use of language services which allowed from and that we have access to be reasonable. However, has not yet made individual systems to use for distribution. Self-identified individuals the provider's communication of self-identified and be self-referential to ensure an emergency quickly and efficiently.



Healthcare providers with limited English proficiency (LEP) are not allowed to use video interpretation services. For emergency services, providers should use the service. [www.hhs.gov/asep/1117](#)

#### Notes:

1. The following are the providers:

2. The following are the providers of services in English:

3. The following are the providers of services in English:

4. The following are the providers:

5. The following are the providers:

6. The following are the providers:

# Awareness Improves Health Providers' Ability to Accommodate the Deaf and Hard of Hearing



Access to healthcare services is of paramount importance to all those in need. For people with varying degrees of hearing loss the estimated \$15.5 billion in the United States, ensuring health providers offer secondary to ensuring the well, and perceived communication barrier of hearing quality healthcare.

For patients who are deaf or hard of hearing, only in the doctor or hospital are determined to an international society who doesn't speak the host language but it is need of doctor to use language the patient difficulty when through sign communication with others. And even if the patient can't read, he likely will understand only part, if any, of what is written back to him. This presents an opportunity of not dangerous access to anyone involved.

While it's true that a deaf patient society is not limited to a short session, it is a chronic dilemma. For many existing medical care is so demanding that they delay appointments or avoid going to the doctor at all because of communication barriers. The Americans with Disabilities Act (ADA) of 1990 has paved the way for people with disabilities to provide a more equal and services on an equal basis with individuals without disabilities. For the effectiveness and method of accommodation can be used among the health care providers. Communication, for the deaf, will just about "hearing" but also about understanding and meaning of a message and having the option and ability to interact with a caregiver successfully.

Generally speaking, providers make telephone calls to comply with the ADA. However, the care range of disabilities among the population of patients correct presents particular difficulty in the practical application of accommodations. The ADA, a process recognizing a unique barrier for people with disabilities, has presented no small of challenges for hospitals and physicians and the issue of how best to accommodate individuals with specific accommodations, only to encounter less effective, creative strategies.

By [Author Name], [Author Title], [Author Organization]

The ADA requires that services only must provide accommodations based upon the needs of the patient with the disability. Although facilities may use staff who are fluent in a foreign language for non-English speaking people, all facilities are required to employ qualified sign language interpreters or other appropriate accommodations for those who are deaf or hard of hearing.

Given the nature of most accommodations opportunities for some medical diagnosis, a variety of auditory aids can facilitate effective communication with a deaf or hard of hearing patient. For example, a sign method can be presented using the system. In the majority of cases with accommodations what remains a patient might need before the work into the office the prompt a provider to know every potential remedy is having identifiable. The same of most facilities special accommodations for the hearing impaired.

## NEW DIRECTIVES

Revisiting the information is crucial because changes required under the ADA's 2010 standards, which became effective in March of this year, are enhancing the practical side with new directives. For example, including sign language in the

The biggest...  
needed in the...  
United States...  
against a doctor...  
for failure to...  
provide a...  
sign language...  
interpreter was...  
banned about 11...  
New Jersey in...  
October 2008





...and, based on the findings and experiences, the data that the authors had about quality of care, they must be principal and intentionally assessed against 17% of public and private care in the community, all of the following activities will include and help to offer services, which learning issues must be supported and supported by each of participants, and such initiatives must be included on or in the communication approach with public data.

They provided plenty of time to understand their progress or not in the process of doing so. A number of these two members present evidence of the learning experience that might otherwise have been staff assigned, and it seems possible to get it done in provide resources to properly implementing this case. The largest work in the United States against a doctor for failure to provide a sign language interpreter was handed down in New Jersey in October 2016. In this case, the jury awarded \$100,000 and attorney fees to a deaf patient of a dermatologist. The patient sued the physician for failing to provide an American Sign Language (ASL) interpreter despite repeated requests over the course of 10 visits. As a result, she was diagnosed with



particular individuals without the opportunity to participate and fully understand the treatment plan because the health care professional has not, through verbal alternatives in the therapy. The physician agreed to work on effective treatment and patient understanding. The next session was a strong message to doctors across the country that the ADA is recognized and enforced.

#### ADDITIONAL INFORMATION AND RESOURCES

Visit our website to help providers expand the practice. The New Jersey Department of Human Services Director of the Deaf and Hard of Hearing (DHH) is the single state agency responsible for monitoring up-to-date and current the resources on hearing loss. This includes the Communication Access Federal Project, which monitors sites of qualified sign language interpreters, real-time caption providers and remote hearing devices in order to ensure people who are deaf and hard of hearing with communication needs. The DHH also conducts educational activities and training sessions to enhance the ability of hearing loss and hearing aid/wearing devices. The Director can also act a distributor for providers to complete basic ADA information.

An article compiled by the DHH will address a few members of the Deaf and Hearing community. "Thought Issues of Deaf and Hearing and Low-Deafness Hearing" offers helpful accommodations for facilities and how hearing and communicating correctly with hearing loss. The publication will be available shortly at [www.nj.gov/dhs](http://www.nj.gov/dhs).

In addition, state and private organizations have published the Department of Language Learning Programs and Assessment Unit in 2007, the U.S. Department of Health and Human Services (DHH) Office of Minority Health published the report "A Patient-Centered Guide to Implementing Language Access Services in Healthcare Organizations" which can be accessed at <http://www.hhs.gov/healthcare/2007/04/04/070401a.html>.

Additionally, the New Jersey Hospital Association is currently revising guidelines for hospitals under governmentally issued models, which reflects considerations similar to the listed for hospitals/facilities. That guide will soon be available at [www.njha.com/resources/facilities/2007/04/04/070401a.html](http://www.njha.com/resources/facilities/2007/04/04/070401a.html).

Further information on the ADA regulations and changes is that by needs of patients with hearing loss can be found on the DHH web page [www.nj.gov/dhs](http://www.nj.gov/dhs).

Also, a list of certified ADA interpreters and captioning providers may be found at [www.nj.gov/dhs](http://www.nj.gov/dhs) under "ADA Information". And a copy of the state sign language interpreter is available at [www.nj.gov/dhs](http://www.nj.gov/dhs).

#### DEFINITION OF A QUALIFIED SIGN LANGUAGE INTERPRETER

An effective route to fill in and secure providers of the ADA 2010 rules, provides direct services for the following to patients who may be deaf or hearing impaired:

- The ADA defines a qualified interpreter as someone who can interpret effectively, accurately and impartially both receptively and expressively using appropriate specialized vocabulary.
- Specialized interpreters are those who have received some of specialized, formal training in facilities representative of those that employ individuals.
- A qualified sign language interpreter will bridge the gap between English-speaking healthcare providers and patients or guardians who use American Sign Language (ASL) as their primary mode of communication. However, many individuals who have hearing loss may not know sign language, so it is important for healthcare facilities to have multiple approaches available.
- Providers who are professionally qualified may make and use captioning, communication devices or text reader methods such as email or text messaging. When health care providers (HCP) are unable to use the facility's system, which interpreter services are provided locally or through national services are determined by other means. DHH telecommunication lines and a hearing device in a doctor's office.

The approximately 200,000 people with hearing loss in the country rely on their healthcare providers to supply qualified sign language interpreters or other effective means of communication. The New Jersey Department of Human Services Director of the Deaf and Hard of Hearing has very resources to help you accomplish this objective.

specific video, <http://www.nj.gov/dhs> of the Commissioner of Human Services Department of Human Services. **17**



# Describing Patient Experience





## Patient Advocate: A Critical Role in Patient Experience

**Kate Clarke**

Manager, Patient Relations/Inspector Services  
Centene Health

**Kim Pedersen**

Administrative Director, Patient Relations  
Marney Rehabilitation Hospital

**Carol Samakonia, MPA**

Vice President

CHS/CHL Patient Experience/Call Center Director

Introduction by

Jason A. Wolf, PhD

President

The Berg Institute

THE BERG  
INSTITUTE

Improving the Patient Experience

## THE DEBYE INSTITUTE

The Debye Institute is the global community of practice and premier thought leader on engineering leadership development in healthcare. The Institute serves as a premier resource for shared information and peer-to-peer problem-solving, a dynamic Institute of leading voices and has also acted as an interactive resource of leaders and practitioners. The Institute is unique in providing the premier engineering leadership development resources focused on providing the patient experience leading to success of healthcare business and patient.

The Institute offers the premier experience of the world of engineering leadership development in healthcare. The Institute provides peer-to-peer problem-solving and peer-to-peer problem-solving.

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## Introduction

In 2014, The Royal Institute formally welcomed members of the former Society for Healthcare Consumer Advocacy to its Institute community and the new Patient Advocate Community. The society represented a strong and rich heritage based on the rights of the very patient experience movement we are seeing flourish today. Patient advocates were the seeds of that growth and had their essential bloom in the rapidly changing care of change that was able to grow following its foundation from the early 1970s to today.

As healthcare has become a system that has in many ways shifted to new norms, in looking to the future it brings and the challenges it presents over the past volume of issues it can teach us how to face the journey of the patient advocate and their contributions over the years. As a role that has been able to accept responsibility for ensuring the voice of the patient is heard and also being the training used by patients to ensure their own or someone else's in patients, patient advocates in their work have been able to conduct a form of patient experience today – that of what matters and we must be willing to act on that.

This paper, authored by former insightful healthcare leaders and patient advocates themselves, helps us to both understand the practice and reinforce the value for the role of patient advocate has and will continue to play in healthcare. Regardless of the actual title, positioning in an organization, or their resources provided, patient advocates have remained true to a certain set of principles and a shared value that has been driving its maintaining beliefs of focus in healthcare care delivery. They also have played a continuous role in many ways. For as patient advocates employed by healthcare organizations with a commitment to ensuring patient voice is heard, they do not represent the organization as which they are employed, by design and strategy. Some might say that what needs to be said, I do not think many would argue, in some cases it has. But I think we will find in the voices of these leaders and the

sharing of ideas based on 40 years of what was learned presented in this paper that it is possible for new medicine to be born.

It is also important we also truly realize the evolution in this very term "patient advocate" that in this paper we do not address professional patient advocates. These individuals that independently created to create the individual coaching and support a patient and to that level of support without work. It they brought the complexities of healthcare today. We too are not talking about the 20th iteration of the title "patient" advocate, the emphasis on patient, an ever-increasing number of individuals who as patients or family members themselves have used the important work of patients directly to ensure they are heard and respected in the healthcare conversation. We have a comprehensive paper on the voice of patients and families who take the care – voice of patients and families, progress in improving Patient Experience – also available via the Neurosciences.

In the paper's 10th anniversary, intent, insight and ideas for action and all shared. Most importantly an ethical embrace the shared voice of patient advocacy into the broader healthcare and the very human community. This paper provides a vision to set our eye back, but also to take the next steps ahead. The critical role of patient advocate is something we will always need in healthcare, and why this might matter you might struggle to believe a patient experience is more an element to an expanding experience however, I believe it is not continuous, that this is a moment where patient advocates will again help form the conversation for healthcare for the next 40 years to come and beyond. No words matter the patient advocate reminds us of that each and every day. Not of that, I hope there will become greater.

Jackie A. Wolf, PhD  
President  
The Royal Institute

The field of patient advocacy was not one that suddenly surfaced as a new career path or the latest trending "buzz phrase." Patient advocacy developed slowly over time, fueled by the needs of the patients and families in a changing and challenging healthcare climate. This paper will explore the history of patient advocacy, how it has evolved over time and its relevance to the Patient Experience.

## History of the Profession of Patient Advocacy

Advocacy has a rich historic tradition, when you look back at its derivative-bureaucracy. The Ming Dynasty in the 14th century has the first mention of a government ombudsman – "one who acts on behalf of another." Another historical model is the Citizen Advice Bureau organized in Great Britain during World War II to provide displaced people with information and referral services. The idea of helping and advocating for others when they cannot has always been a part of history, but it wasn't until the 1970's that formalized patient advocacy program development emerged in healthcare.

To better understand the development of the patient advocate role, we need to look at the evolution and changes of the healthcare industry itself. In the early 1960's, healthcare for the most part had become big, institutionalized and impersonal. The patient was often uninformed and the doctor-patient relationship was not often a priority. Healthcare had gone from the days of physician house calls, to where the trusting relationship between the patient and physician fell victim to the size and growing complexity of the delivery system. The necessity for healthcare professionals to be looking at the full range of the patients' needs became secondary to the new medical possibilities and technologies available.

Advancements in technology created rising ethical issues and very real patient fears. Discussions were now centered on topics such as chemotherapy, dialysis, transplants and resuscitation. At this time, more technicians were introduced to the patient experience, creating even more distance between the physician and the patient. Patients and families began to feel and react to the unfamiliarity of intensive care units, intimidating machinery, multiple healthcare providers and a confusing array of rules and regulations. Due to the rapidly increasing complexity of the system and because patients lacked technical and medical knowledge and did not feel informed, they were not in a position to be part of decision making regarding their own healthcare treatment and services.

In the mid 1960's our country was embracing individual rights such as civil rights, women's rights and student's rights, which collectively raised the autonomy of the individual as never before. Social issues were framed as the individual versus the institution, who was portrayed as powerful and insensitive. Healthcare, as one of the largest and most powerful institutions, had the ability to impact the rights of many. The climate was ripe for the formation of a patient advocacy model.

In the early 1970's, hospitals began to recognize the need for a liaison between patients and hospitals. Ruth Ravich, who worked at Mount Sinai Hospital in New York, was one person who saw the need and began to bring people together to promote the profession. In April 1970, a daylong seminar entitled "Establishing Effective Patient Relations Programs in Hospitals" began discussion of ways to establish formal advocacy programs.

In March 1971, 140 healthcare professional met in Philadelphia to continue the discussion of the importance of the patient representative role. The concept of the role was to "intervene on behalf of the patients who are falling through the cracks of a fragmented system and make the system more responsive, provide information, consultation, referral and advocacy for patients' social and healthcare concerns."<sup>1</sup>

Additionally, these patient representatives would help staff with challenging patient and family situations, investigate trending problems, suggest solutions, educate staff, patients and the community about patients' rights and responsibilities and bring patients' perceptions to the attention of management. "In a world of specialists, patient representatives would be the generalists- a humanizing, personalizing force in a technological environment."<sup>2</sup>

A year later, the Association of Patient Service Representatives was formed and soon thereafter was accepted for charter membership in the American Hospital Association (AHA). In 1972 AHA surveyed its institutional members and found there were 1,000 hospitals with patient representative programs. In 1973, the model of Patient Bill of Rights was established (see Pop Out Box Below). In 1980, Sarah Lawrence College began a graduate program in healthcare advocacy

1. *In the name of the patient. The patient advocates role in a healthcare facility*, The Beryl Institute, Revised 2014, p. 7.

2. *Ibid.*, p. 7.



The Association of Public Health Administrators grew and flourished over the years, contributing to work in advancing in the name of the patient, as well as supporting student administrators everywhere through networking and education. In 1999, the National Society of Public Health Administrators changed its name to the Society to Healthcare Executive Administrators (SHEA) to reflect the changing nature of healthcare work and the broad and encompassing nature of the work in SHAs, the organization included over 100 years of educating in the name of the patient.

The patient advocacy field and need for Patient Representative Programs was getting significant attention from healthcare facilities and the Institute of Medicine (IOM) survey "Commitment to Patient Representatives: AHA and Patient Representative Groups are the Supercommunity Care Program Model." 80% of patient representatives want to have management such as the Chief Executive Officer, the President or Executive Administrator. 70% of the members said 12 units of healthcare experience. 40% of which had been 2-12 units of experience. Out this line of development, the patient advocacy representative has advanced from knowledge base into the setting of business, business, or Health's Agency.<sup>14</sup>

Patient advocacy professionals have emerged from varied backgrounds including nursing, social workers, social workers, education and training and to name a few. The common theme was the immediate responsibility with the brought to the table.

In 1980, the organization took a decision to align themselves with the busy medical, health student in the growing health care experience movement, and eventually found themselves connected to The American College of Health Executives (ACHE) of The American College of Health Executives of the patient advocate. It became clear that this role was being expanded in talking and creating an educational aspect experience. It was also clear that the communication needed to continue and connect with other the needed through patient and to continue to have a positive impact on the patient experience.

In connecting the role needed, as the patient's rights, we are able to get another level of healthcare. Patients are increasingly less inclined to view their care and services when, often in the individual setting or patient advocate. Also with the increasing complexity of organizational structures in healthcare today, patient advocates are often an important understanding and getting people through the structure of their organization, which works from a business model, structure and flow of business model.

The health care system has the objective of the law that

Since the original medical law focuses a lot of rights, the American Hospital Association has created the law into a document called The Patient Care Representative. Encouraging the ability Patients' Right's Rights. The care recipient becomes a health system participant that should have a right to bring their concerns into the system in their rights and responsibilities.

The patient's ability to communicate in their health care system being a model law.

- 1. High quality medical care
- 2. A clear and safe environment
- 3. Information in your care
- 4. Protection of your privacy
- 5. Help when using the system
- 6. Help with care billing issues

Source: American Hospital Association (AHA) [www.aha.org/advocacy/advocacy/patientrepresentative.php](http://www.aha.org/advocacy/advocacy/patientrepresentative.php) (accessed 12/12/14)



## Understanding the Patient Advocate Professional Role

There are many roles and titles for patient advocates. They are often referred to as patient navigators, patient leaders, advocates and of course patient advocates. In addition to their backgrounds, the main role is typically the role of being an advocate and representing patients. The patient advocate usually fits into a range of the competencies roles in a healthcare organization.

1. Patient advocate
2. Information sharing
3. Initiating change agent
4. Partner in collaboration between the community and the organization
5. Cross-cultural awareness

Additionally, they are trained in education, direct consultation, and education, community outreach, organizing patient family advisory councils, engagement for international systems, including coordination of living and transportation, discharge planning, assistance in visits to provide emotional support, and and social services for patients with special needs to compliance with the Americans with Disabilities Act, sign language, advance directives and end management for end of life patient care/families.

Many different types of organizations are patient advocates although the amount of the focus of their role and the broader support of patient and family needs. They are also engaged in these organizations because many administrators believe that patient advocates is the primary beneficiary in each of these scenarios. Many patient advocates who take on added responsibility also look at the patients necessary to carry them out either as leaders or a part of an organization's overall patient experience/health.

Some of the fundamental areas of focus for patient advocates were looking at prevention, providing patients to actively participate in their own healthcare decisions, Patient advocates manage their responsibility to advance the interest, to represent an

- Educating patients and providers that patients' quality
- Mediating disputes among patients, families and staff
- Investigating complaints on behalf of patients, bringing them out of the center of conflict
- Monitoring and ensuring adherence practices with patients and their families

The skills and knowledge base of the patient advocate in many ways are core skills of the Patient/Insurance Professional in general. In the patient advocate role a strong role in the broader work of patient experience. It

The Patient Advocate Role is knowledge is a continuous learning process involving the knowledge and skills to be able to help patient experience better. The role involves that the patient participating in the development of the role of knowledge sharing in a health care setting. It is a process that involves both offering and receiving information, providing and being an effective patient experience leader. The role is being a part of patient experience, either to help them and provide a clear foundation of knowledge that supports the patient and provides the foundation of patient and family needs. It is a role.

The Patient Advocate Role is a **continuous learning** process involving the patient and the provider in a health care setting. The Patient Advocate Role is a continuous learning process involving the patient and the provider in a health care setting. The Patient Advocate Role is a continuous learning process involving the patient and the provider in a health care setting.



is important to not just understand the skills and knowledge that are necessary to teach. Skills such as feedback, coaching, influencing, motivational, self-directed and collaborative with activities for course writing in the United States are key, including the role of the patient advocate. More often it is a subject or the best teacher's own way, structure, format (personal style of teaching).

In addition to that, there are other skills with a knowledge base that the subject advanced that require in order to accomplish their work effectively. For example, it is important to have knowledge about patient rights and regulatory standards as well as understanding of the classroom and classroom process and how to manage using them, to lead a class.

**TABLE 1. Federal standards in class**

The standards are regularly checked for use by higher education departments in teaching and continuing education in healthcare education.

Content/Content: (includes) if healthcare services within organizational administration, staff, and patients.

**Practice Description:**

1. Develop a course outline for instruction concerning patients' rights and responsibilities, advance directives, and other issues.
2. Develop, manage and update patient guidelines concerning the quality of care and services by providing a formal grievance procedure to the organization.
3. Conduct the effort to collect, analyze and evaluate course evaluation data. Offer feedback to faculty/clinical management to address the patient's needs.
4. Monitor an understanding of the organization's mission, values, procedures and services to ensure a patient position of concern.
5. Provide instruction to patient needs and expectations and work to educate staff and patients concerning their care.
6. Conduct continuity awareness with educational programs for rights of patients. Develop educational and promotional materials on patient rights and related issues.
7. Coordinate implementation of regulatory standards, such as the Joint Commission, along with state and federal laws pertaining to patients' rights, advance directives, the Affordable Care Act, and related issues.
8. Provide education and/or consultation to

institutions that affect patient needs and needs for patient rights.

9. Participate with other members as advised in appearance.
10. Participate in continuing, state and national professional education.
11. Promote continuity, support and sign for all patients as standards for the development and expansion.
12. Refer patients to appropriate services and resources.
13. Develop policies and procedures for the development and expansion.
14. Perform other tasks as advised in appearance.

**Practice Description:**

Minimum education: Bachelor's degree in an allied health profession or a health-related profession.

Minimum field of expertise: Some practice in a health-related field.

Required continuing training: Hospital management, medical training, conflict resolution, case management, organizational administration, administrative management.

Preferred experience: At least one (1) year experience in a health-related field.

Other skills: Analytical problem solving, excellent oral and written communication skills.

## The Advocate's Role in the Changing Healthcare Environment

The advocate's role in today's changing healthcare environment continues to evolve. With a heightened awareness of the importance of a superior patient experience, many initiatives are currently underway in hospitals to make improvements. The patient advocate role is a combination of these efforts. The interests of the industry come from the advocate, comprehensive feedback, should be a vital component of any initiative to improve the patient experience. When patient satisfaction scores are below the desired level, the patient advocate's role is to identify the gaps for quality improvement that have driven that score or patient satisfaction.

It is also important that the patient advocate remains an essential component working with the roles of patient and family advocates if the organization they work for. This unique role allows the patient advocate to take action in support of the patient when there is concern with the actions of the organization. In contrast, the organization also needs to be inclusive of the patient advocate when the patient experience is at risk.

In some cases, the role of the advocate has traditionally been more reactive in responding to complaints. They were looking for ways to correct complaints as they brought forward. As patient change is healthcare, the role has moved to focus on a more proactive approach in order to have a more effective outcome. The insight into the level of handling is without direct and proactive when they resolve a feeling that the staff struggle to addressing complaints in an appropriate way. Thus the patient advocate who addresses the service recovery program to the organization.

From a regulatory perspective, the patient advocate is often responsible for oversight of the organization's compliance with patient rights, administration of the language services program, management of the complaint and grievance processes and identification of improvement opportunities through the analysis of data gathered within the process of addressing complaints and grievances.

In many organizations today, there is also a role for the patient advocate in the Strategic Management plan. This role may be the patient advocate managing the through a family planning for resources and working to ensure that whether at that facility or through the Care centers. One is the role of organizational and leadership skills that are essential to ensure that the patient advocate can effectively plan and execute.

In part of the changing environment, we are also seeing a consolidation occurring in the healthcare industry. Many healthcare organizations are going after patients in their advanced medical care patients. Some services in the community of care, such as small emergency, surgery, rehabilitation (some short-term or specialty). Patient advocates may find themselves working as part of a team with representatives from organizations within the same system or affiliate. Having shared and information. Patient advocates are now having conversations, processes and information from a variety of organizational settings across of healthcare system communication with the management of your local organization. Thus advocates have become critical and patients given that have a critical interest in handling customer feedback, but why and how skills in "working the system" or beyond their team.

The patient advocate is vital in handling operations and billing concerns and conflicts, including a coordinated review of information in customer's rights and responsibilities and serving as a contact point when financial concerns and service involvement and financial is concerned.



### The Patient Advocate as a Leader

In the role of the patient advocate has evolved, so has the number of individuals working in these positions in various settings worldwide. Organizations have been created and organizations exist to provide advocates to traverse the role of the patient advocate that will ensure quality and patient satisfaction.

Today, as laws evolved and new resources are available, it is important to call attention and challenge their healthcare experience. Additionally, research and the science they are now being provided to an individual is defined, established, and used in Healthcare Conditions of Participation and other measures. Organizational health and learning that staff, teaching or health care, are direct feedback from patients and families, and families (as well as being patient) aimed at improving the patient experience.

With this in mind, it is important for the patient advocate to lead a unit and initiative while leading the facility in their organization where discussion about patient satisfaction, data, and strategic goals are being discussed. Patient advocates receive this information to organizations to strategic goals and continuously work toward improving patient satisfaction, patient experience, and quality outcomes. The patient advocate can contribute information and patient family feedback that will help address current developments in the organization.

The patient advocate helps ensure the organization as a whole (laws, regulations, accreditation) and as possible with in the role of the patient being discussed about various facility changes, administrative things, processes and patient engagement, etc. The leadership role of patient advocates has now evolved as they ensure that the role of patient experience leader is organization or are vital part of the patient experience efforts organizations are undertaking. The influence is the patient advocate, individual as well as considered critical leaders in their respective organizations.

### Angela from the

Interview from the interview, the role is being... (text is blurry)

As a patient advocate, I am called on daily to help patients and families. I was called on by family for many, for years, and they are comfortable with providing questions and taking care of patients. I had to ask, but I was then a company with the organization... (text is blurry)

Let me see how this happened with some. We have and growth has been... (text is blurry)

There was a... (text is blurry)

By being... (text is blurry)

The bottom line is that patient advocates must both act as and be considered critical leaders in their respective organizations.

## The Importance of the Patient Advocate Role

The patient advocate through their actions supports the needs, interests and values of their organization, from an individual with an accident and disability care claim, to knowledge and advice, patient family advocacy groups. They help patients and families understand their rights and responsibilities and assist them in navigating the healthcare system.

Patient advocates also have a strong understanding of organizational policy, trends and opportunities to make a positive impact on the patient experience. They are crucial in addressing their organization's focus on creating a more customer culture and based on understanding and connection to strategic priorities of value for business success of today's changing healthcare marketplace.

The patient advocate collaborates with all levels of care and teams, accountability and ownership group across experience. They are able to identify, manage the existing cultural bias and obstacles and barriers, offering and teaching on the skills and techniques to promote needs, values, ideas, and provide better delivery.

In recognizing the importance for value of the patient advocate role, it is critical that healthcare organizations have patient advocates quickly accessible to the patient care, require that the advocate act as a part of the entire patient experience effort. A true advocate is the only one of who or truly chosen to work in healthcare – being care of the patient. The advocate's role is to help the patient's voice be heard.

In other words, it is the patient advocate, this level of education very important that they should understand that because of their, a patient was treated and is being the subject and recipient. Many advocates can read from areas for patient questions that usually asking how they could be advocating for them if they are not in the hospital. And through the work, advocates have come up with creative solutions to fix, including that the organization looks about the patient's needs and handling needs both to affect areas that fit to heart.

To support this and promote the value of the patient advocate in healthcare as the core and profession has increased and grown, patient advocates have stepped and adhered to a professional code of ethics to maintain a focus and return true to the values and values of the work (Figure 3).

Figure 3. Professional Code of Ethics

Members of the Patient Advocacy Community of the healthcare who serve as patient advocates are committed to ensuring their professional relationship is grounded with the following principles:

- Patient advocates have a primary responsibility to the patient.
- Patient advocates are fair, objective and acting within the scope of their professional practice.
- Patient advocates have an obligation to protect patients of their rights and responsibilities and advocate on their behalf.
- Patient advocates provide the autonomy and dignity of each individual and act to prevent discrimination.

- 1. Patient advocates protect and promote the confidentiality of their clients and release patients to the level of their confidentiality.
- 2. Patient advocates function for integrity of the profession by identifying, promoting, and sharing knowledge to set standards for professional practice.
- 3. Patient advocates are committed to ensuring education to maintain professional excellence.
- 4. Patient advocates commit to contribution of their practice. They do not engage in commercial practices. This disclosure does not include professionally related activities such as sales, consulting, recruiting and training.

### Considerations for Action

Encouraging the best policy providers to use any instruments that have gained traction over the last few decades, better solutions can most well placed and will fundamentally remain in relevance today. The paper is not intended to provide a retrospective or review, but also to enable a call to action for why there is a need to develop a national patient advocacy for the next 10 years to come.

It belongs to the future and moving towards better ways, an effort where practitioners are moving toward efficiency.

- 1. To those functioning in patient experience leadership roles, it is important to identify if there is a better patient advocacy program across organizations in health.
- 2. If a formal patient advocacy program is not in place, explore the potential for developing one and staff to create clear and defined policies and procedures for a patient advocacy program including:
  - Processes for the patient's rights and responsibilities.
  - Letting patients, families know who to contact if they have concerns.
  - Developing a system to track and track patient concerns.
  - Having patient family feedback is based on the feedback tool.
  - Supporting your organization in understanding how to manage and address concerns and handle that feedback, based on patient contribution.
- 3. If an entity has a formal patient advocacy program, take the appropriate steps to manage its success by:
  - Identifying if your patient advocacy is the leader of patient concern experience efforts at a site, department or the national experience that can ensure that concerns are sought in other units.
  - Encouraging the patient advocacy to be conversations about strategy, having shared goals, monitoring and engaging patient care, including it essential to maintain a patient advocacy model to flourish.
  - Making use of the patient advocacy tool as appropriate resources or connections with an patient experience, patient safety, clinical quality, etc.

- Engaging the patient advocacy in creating culture that helps the work of patient care teams.
- Using the patient advocacy as a key training tool for patient care, including asking, "What are the key things you are teaching about patient care to our staff members?"

The role of the patient advocacy is a very complex and central one and can truly make a difference for people throughout their healthcare journey. The information from these functioning models to the patient is often the most important affecting our change. It takes a person and has courage to stand up to what is right and speak to someone's heart with honesty. It respects what is essential and for doing the right thing, even if it means being the loud a lot. There is a patient focus as a patient advocate role, it starts including that voice is being heard. It means taking the experience under to that extent, but then also learning from the voice to make improvements in the organization. This work has been a career spent in healthcare for over 40 years, and will continue to do so for many years to come.



### **Authors' Note**

We are grateful to members of the Patient Access Community (PAC) at The Royal Institute as the site from which we collect evidence. Initially, we began collecting the building the foundation for the platform for many years to come. Through the PAC, we provide key resources for our patients, family members, including educational materials, patient and the information, such as in the form of the Patient. We also conduct a direct clinical dialogue and covering of issues with the patient services letters available to members. Additionally, members are available to help your organization in its patient advocacy journey.

We are grateful to members that resources will be of value to our growing community, we see this great work as the first in a series of patient advocacy front initiatives include the PAC, patient access, PACAP, data management, patient rights education and engagement, trials, and innovation (the PAC), regulatory communications, consumer target and more.

We also acknowledge that in our integration with The Royal Institute we are not alone as a breadth of information and a commitment, focused and collaborative faculty of dedicated and compassionate professionals, who we know will help forward on what we believe is the right way to help work - through the voice of the patient's story.

## About the Authors



**Kelly Hynes**  
Manager, Patient Experience/Consumer Services  
Columbia Health

After receiving her PhD in Public Health in 2016, Kelly manages the Patient Experience and Consumer Services Department at Northwestern Medicine - Oakley, Oak Park and Orem Hospitals, located in the Western Suburbs of Chicago. Having begun her career as a nurse, Kelly is working with consumers and providers alike to ensure the healthcare system is patient centered, accessible and easy to use. Kelly is also a leader in the industry, having worked in various roles of patient advocacy and consulting, and supporting other patient advocates in her industry.



**Kim Peterson**  
Administrative Director, Patient Services  
Marquette International Hospital

Kim Peterson has spent 25 years in the healthcare industry including the acute care, ambulatory, hospital setting, medical clinic, outpatient, corporate, home health and healthcare consulting. Kim decided the need for a patient advocacy program at Marquette and led the design and implementation of the program. Kim is the chair of the Patient Experience Leadership Committee, Patient Experience Advisory Board, Committee on Patient Experience and Innovation. Kim is a member of the Quality and Patient Safety Committee and a member of the Senior Leadership Team at Marquette. Kim has presented at The Joint Venture Conference and co-authored an article for the Joint Venture Patient Satisfaction journal on Marquette's "Streamline & Discharge" initiative that was critical in streamlining patient admission across the organization. Kim continues to create resources, manage and oversee a staff of managing clinical systems and facilities, oversee recovery team building, key work, and other team resources to the success of the nursing unit or business recovery scenarios.



**Carol Satchell, MBA**  
Vice President  
Consumer Experience/Consumer Services Group

Carol is a seasoned healthcare leader with a passion and commitment to enhancing the patient experience. She and her team work with organizations to create an optimal patient experience through a strategic approach that includes explicit commitment and accountability, staff engagement, system efficiency, continuous process management and innovation, strategic effort, setting an example through 100% Satisfaction score 24 hours of treatment from admission, access to services and resources, easy, when you need it, and the design, creation and implementation of feedback loops to service recovery, multi-channel and HCAHPS, and the development of their patient experience program and service excellence and patient advocacy departments.

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HOPE Sheds Light is a 501(c)(3) non-profit  
organization.

**Finding HOPE** meets on the second and fourth Tuesday of every month from 12pm to 3pm in the Sanctuary at Holy Cross Church located at 1200 Singer Avenue in Troy, MI.

The meetings are more targeted to address drug and alcohol use and how to manage recovery with your guest speakers who provide education on addiction and recovery. The discussions followed by a small group session that is facilitated by individuals and family members, ensuring a strong recovery plan. The group provides opportunity for connection and to share through struggles from each other.

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The meetings are open to anyone struggling with addiction (i.e., loved ones or friends of those with addiction issues), as well as those seeking recovery for themselves. It is a place to go to those that you're not alone and that there is a support system available.

[HOPEShedsLight.org](http://HOPEShedsLight.org)



## NJSHAPE March Meeting

DATE **Friday, March 22, 2019**

TIME **9:00 a.m. to 3:00 p.m.**

PROGRAM **The Complexities of Managing Combined Behavior Health and Medical Issues by Patricia Smith**

**PFAC Workshop and Discussion**

LOCATION **New Jersey Hospital Association Conference Center**  
760 Alexander Road, Princeton, NJ 08543  
(609) 275-4000

RSVP **Helene O'Leary ([Helene.O'Leary@atlanticare.org](mailto:Helene.O'Leary@atlanticare.org))**  
AtlantiCare Regional Medical Center  
Customer Relations, 1925 Pacific Avenue, Atlantic City, NJ 08401  
Tel: (609) 441-8193

### *Book Recommended by our Speaker*

#### **To Weep for a Stranger: Compassion Fatigue in Caregiving** by Patricia Smith

Compassion fatigue plagues caregivers worldwide. When providing care to others without incorporating authentic, sustainable self-care practices into our daily lives, destructive symptoms surface. Isolation, emotional outbursts, substance abuse and reoccurring nightmares are just a few of the symptoms that can distress the life of a caregiver. With awareness and knowledge, compassion fatigue can be recognized and managed. **To Weep for a Stranger: Compassion Fatigue in Caregiving** is the first step in learning more about this emotional and physical pain-filled syndrome and how to break free from the bonds that restrict compassionate, dedicated caregivers from living a happy, healthy life. Included in this book is the definition of compassion fatigue, its symptoms and causes, and standards of self-care. Also, you'll find information for those new to the helping professions and a special section for family caregivers.



Compassion fatigue plagues caregivers worldwide. When providing care to others without incorporating authentic, sustainable self-care practices into our daily lives, destructive symptoms surface. Isolation, emotional outbursts, substance abuse and reoccur...

