Taking a Closer Look at Residents' Rights

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Residents' Rights are safeguarded by the 1987 federal Nursing Home Reform Law. This law requires each nursing home to "promote and protect the rights of every resident" placing high prominence on each resident's dignity and self-determination. Nursing homes are mandated to meet these federal requirements if they participate and receive funding from Medicare or Medicaid. In addition, several states have Residents' Rights clearly written into state law and/or regulations for nursing homes, licensed assisted living, adult care homes, and other board and care facilities. Any resident living in a long-term skilled nursing setting is guaranteed the exact same rights as an individual living in the local community. As Activity Professionals, it is vitally important to know that the 1987 Nursing Home Reform Law requires nursing homes to care for all residents in a manner that promotes and enhances their *Quality of Life* ensuring dignity, personal choice, and self-determination. Additionally, all nursing homes are required "to provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care that... is initially prepared, with participation, to the extent practicable, of the resident, the resident's family, or legal representative." (The National Long-Term Care Ombudsman Resource Center)

A fellow Activity Professional from Australia recently shared with our NAAP Board, via an international conference call, a different twist on a popular phrase we oftentimes say in the United States; namely, "Think outside the box." Australians say, "Think outside the square."

The meaning of these four simple words remains the same in both cultures, but more importantly there is a valuable 'learning lesson' for all of us to delve into and reflect upon with specific regards to Residents' Rights. Today's resident is indeed much different than the resident admitted into our nursing homes twenty, thirty, or even forty years ago. One significant difference is that these individuals enter their 'new homes' already knowing their rights. And, they expect these rights to be honored and respected at all times.

Thus, the 'new call' for Activity Professionals is to:

- 1). Think outside the square.
- 2). Expand your knowledge base beyond the square's *four lines*.
- 3). Understand and preserve each of the Residents' Rights (listed at the end of this article).
- 4). Learn specific strategies to help resolve problems and concerns.
- 5). Know exactly how to get the right help and assistance if and when issues arise.
- 6). Always ensure the resident's best Quality of Life possible!

Through my research, I happened upon a powerful real-life story that could happen at any one of our communities. The story follows: Two friends of mine, Vera and Zayda, had been together for 58 years. When Vera's Alzheimer's became too much, Zayda moved her to an assisted living facility. Zayda could barely trust family or neighbors with the truth, let alone strangers, so she and Vera became "sisters." Much later, after Vera's death, Zayda needed to move into an assisted living facility herself.

She had many, many photos of the love of her life, but dared not display them in her new home.

The other residents would talk about husbands, children and grandchildren, but she felt too vulnerable to tell the truth. Zayda was in hiding and terribly isolated.

~ Nina L., Carlsbad, CA

(LGBT Older Adults in Long-Term Care Facilities: Stories from the Field. www.lgbtlongtermcare.org)

Residents have the right to be free from abuse by any individual, including other residents. As Activity Professionals, our residents' self-esteem, dignity, sexual, cultural and religious affiliations, personal leisure interests and daily pursuits are all important life-choices that we are committed to recognize, respect and help fulfil. Any type of mistreatment including verbal, sexual, mental and physical abuse, neglect and financial exploitation must be dealt with proactively and immediately. The above-cited story of Vera and Zayda is definitely another learning lesson for us. Think about your next large group 'Activity Reminisce' and discussions and conversations that residents and other staff members could possibly share before, during and after the session. It is incumbent upon you, the Activity Professional, to be prepared with the appropriate *actions and reactions* for everyone to see and hear. You are and will always be the Quality of Life role model for your residents! They count on you to uphold the highest ethical standards with integrity, diligence and a positive attitude.

Members of the National Association of Activity Professionals' Regulations Committee have willingly shared their personal views regarding Residents' Rights and how these federally mandated rights directly impact their department, activity programming and residents they serve.

Lucy Emmil, Director of Resident Engagement in Louisville, Kentucky:

I was so happy when CMS decided to review and revise the former Residents' Rights Interpretive Guidelines to accommodate culture change in facilities. Our programs are designed to promote opportunities for choice, self-determination and accommodation of any special needs the resident may have. Sometimes, I found corporate standards or the home's marketing director or administrator driving the activity calendars, instead of the Activity Director and residents making choices. I saw cut and paste type activities from one month to another on calendars, with activities our residents did not want to do or even worse possibly could not do just to meet corporate standards. In addition, many times I witnessed residents being brought to activities to meet a "quota" on how many were attending instead of focusing on the true purpose of the program of actively participating. Sometimes, I saw residents being taken out of an activity they were enjoying because either nursing or therapy wanted to do their treatment. Once CMS got behind some of our resident rights however, we were able to empower our residents to make the choices and suggestions they wanted to see in their activity programs. These rights helped us as Activity Professionals to advocate for our residents. We became better able to provide programs our residents wanted as well as help eliminate the "numbers game." The self-determination right (§483.15-Quality of Life) gave residents the right to make choices about their daily routines and preferences including the right to choose self-directed activity programming. As an Activity Director of over 35 years, I can tell you bingo will not be on my list of things I want to pursue. Most likely, I will want to enjoy quiet, self-directed activities in my room or other place of my choosing. I will want to stay up late and sleep in, skip breakfast and just have coffee when I wake up and get my showers sometime before lunch. As I am aging, I find I am older than some of the residents living with us in the nursing home.

I think, "How many years before I might have to come live in a facility and make it my new home? Would I want to live in an environment that provides care but not "caring" about me as a person?" I think not. This has prompted me to be even more of an advocate for Residents' Rights, as I want to be able to live my life as I prefer and continue to ensure the residents I care for have this very same opportunity.

Catherine E. Sabatini, Special Care Activities Director, Bethany Health Care Center, Sisters of Saint Joseph, Boston, Massachusetts:

Honoring Residents' Rights as an Activity Professional in a Dementia Care Unit is of the utmost importance. Training is required annually to all who work and volunteer on this special unit. Every Activity Professional must be an integral part of the unit's training team and be able to provide team members with specific strategies that address meaningful moments, personcentered care, and techniques that help staff know how not to allow the diagnosis overshadow the person's Quality of Live (§483.15 - Quality of Life). Each resident has specific strengths and contributions at all stages of his/her life. The Activity Professional should encourage staff to help residents pursue their hopes and dreams no matter how large or small and one of the best ways for this to happen is to encourage the resident to express personal preferences and make choices daily! The following questions/statements should be addressed with your colleagues, so they can acquire a full understanding of what meaningful moments are and how these moments affect Residents' Rights:

- When does the resident seem the happiest?
- o Does the resident start an activity without formal directions?
- What type of physical problems and/or concerns does the resident have?
- o Emphasize the resident's moments and not the accomplishments.
- o Increase their spirits by offering them tasks that will boost their sense of pride.

- Use lifelong occupation to restore self-esteem.
- o Remember that their capabilities and enjoyment may change within the period of the day.
- Adjust the personal programming to each individual as their needs change with the disease.

Finally, it is essential that Activity Professionals work side-by-side with their city's Long-Term Care Ombudsman Program. Any individual may contact his/her local or state ombudsman for information and assistance making sure that Residents' Rights are honored and respected. Many states also have citizen advocacy groups that champion this cause. Further information may be acquired by contacting the National Citizens' Coalition for Nursing Home Reform. Their email and website are included for your convenience: email: nccnhr@nccnhr.org and website: www.nccnhr.org. Another informative website can be found at: www.theconsumervoice.org. This website, The National Consumer Voice for Quality Long-Term Care, offers long-term care consumers, family members and advocates valuable tools for providing Quality of Life services to our residents and highlights Residents' Rights throughout the year.

The 1987 Nursing Home Reform Law is shared for your convenience and accessibility:

The Right to Be Fully Informed of

- ✓ Available services and detailed charges for each service
- ✓ Facility rules and regulations, including a written copy of resident rights
- ✓ Address and telephone number of the State Ombudsman and state survey agency
- ✓ State survey reports and the nursing home's Plan of Correction
- ✓ Advance plans of a change in rooms and/or roommates
- ✓ Assistance if a sensory impairment exists
- ✓ Residents have a right to receive any and all information in a language they understand

Right to Complain

- ✓ Present grievances to any staff member, without fear of reprisal and with prompt efforts by the facility to resolve those grievances
- ✓ To complain to the Ombudsman program
- ✓ To file a complaint with the state survey and certification agency

Right to Participate in One's Own Care

- ✓ Receive adequate and appropriate care
- ✓ Be informed of all changes in medical condition
- ✓ Participate in their own assessment, Care Plan, treatment, and discharge
- ✓ Refuse medication and treatment
- ✓ Refuse chemical and physical restraints
- ✓ Review personal medical record
- ✓ Be free from charge for services covered by Medicaid or Medicare

Right to Privacy and Confidentiality

- ✓ Private and unrestricted communication with any person of their choice
- ✓ During treatment and care of one's personal needs
- ✓ Regarding medical, personal, or financial affairs

Rights During Transfers and Discharges

- ✓ Remain in the nursing facility unless a transfer or discharge:
- ✓ (a) is necessary to meet the resident's welfare;
- ✓ (b) is appropriate because the resident's health has improved and s/he no longer requires nursing home care;
- ✓ (c) is needed to protect the health and safety of other residents or staff;
- ✓ (d) is required because the resident has failed, after reasonable notice, to pay the facility charge for an item or service provided at the resident's request
- ✓ Receive thirty-day notice of transfer or discharge which includes the reason, effective date, location to which the resident is transferred or discharged, the right to appeal, and the name, address, and telephone number of the state long-term care ombudsman
- ✓ Safe transfer or discharge through sufficient preparation by the nursing home

Right to Dignity, Respect, and Freedom

- ✓ To be treated with consideration, respect, and dignity
- ✓ To be free from mental and physical abuse, corporal punishment, involuntary seclusion, and physical and chemical restraints
- ✓ To self-determination
- ✓ Security of possessions

Right to Visits

- ✓ By a resident's personal physician and representatives from the state survey agency and ombudsman programs
- ✓ By relatives, friends, and others of the residents' choosing
- ✓ By organizations or individuals providing health, social, legal, or other services
- ✓ Residents have the right to refuse visitors

Right to Make Independent Choices

- ✓ Make personal decisions, such as what to wear and how to spend free time
- ✓ Reasonable accommodation of one's needs and preferences
- ✓ Choose a physician
- ✓ Participate in community activities, both inside and outside the nursing home
- ✓ Organize and participate in a Resident Council
- ✓ Manage one's own financial affairs

This closing line from reggae singer, songwriter, musician and guitarist Bob Marley sends a compelling message to all as we respond to each resident's call:

"Get up, stand up, Stand up for your rights

Get up, stand up, Don't give up the fight."

~ Bob Marley

Once again, a very special thank you to the following National Association of Activity Professionals' Regulations Committee members for their significant and valuable contributions and input to this article.

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