ANNUAL REPORT
FEDERAL FISCAL YEAR 2018
New Jersey Office of the State Long-Term Care Ombudsman
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A Message from the State Long-Term Care Ombudsman

Dear Fellow New Jerseyan:

I am pleased to present the 2018 Annual Report of the New Jersey Office of the Long-Term Care Ombudsman Program. This Annual Report describes the types of allegations of abuse, neglect and exploitation that are investigated by our highly experienced and dedicated staff, outlines the important contributions of our dedicated Volunteer Advocates, and demonstrates the increasing demand for LTCO advocacy and investigation services.

In addition, this Annual Report outlines some of the key policy and legislative issues being addressed by the LTCO including: efforts to provide better advocacy for members of the LGBTQ community who live in long-term care communities; the impact of New Jersey's Medical Aid in Dying Act on long-term care residents; the adverse effects of regulatory roll-backs at the federal level; the need for additional protections for individuals living in Assisted Living residences who transition to Medicaid (or who spend down their life savings), and our ongoing efforts, through the I Choose Home NJ program, to identify and expand housing resources for individuals wishing to transition from a nursing home into the community.

I am particularly pleased to showcase one of our wonderful Volunteer Advocates, Frank Flaherty, who epitomizes the dedication and selflessness exhibited by our more than 220 Volunteer Advocates. They truly are an amazing group. And we need more of them! If you or someone you know is interested in making a huge difference in the lives of residents of long-term care facilities in New Jersey, don't hesitate to call our Statewide Volunteer Advocate Coordinator Deirdre Mraw at 609-826-5053.

People who live in long-term care communities in New Jersey have rights. They deserve dignity, respect, excellent care and the best possible quality of life. It is the abiding purpose of the New Jersey Office of the Long-Term Care Ombudsman to ensure that these rights are real and meaningful for long-term care residents in our state.

Sincerely,

Laurie Facciarossa-Brewer
State Long-Term Care Ombudsman
The New Jersey Office of the Long-Term Care Ombudsman (LTCO) is part of a national resident-focused, person-centered advocacy program. The LTCO is an independent advocate for older individuals receiving long-term care. Representatives of the Office work with individual residents to help them address challenges they face; in addition, the NJLTCO seeks opportunities to bring about change on local, state, and federal levels and by advocating for policy and legislative initiatives and participating in activities that support the Office’s core mission to advance the rights, the dignity and the self-determination of elderly individuals living in long-term care.

The LTCO operates four programs:

1. **Investigations and Advocacy**: The primary function of the LTCO is to advocate for residents of long-term care facilities who are over age 60 by investigating and resolving complaints made by or on behalf of those residents.

2. **Volunteer Advocate Program**: The LTCO is aided in its mission by a cadre of highly-trained Volunteer Advocates who are assigned to nursing facilities throughout the state. These volunteers are an extension of the Office and are trained to observe the quality of services provided by long-term care communities and advocate for long-term care residents' rights. (See page 11)

3. **I Choose Home NJ**: The LTCO has partnered with the NJ Department of Human Services to promote the state's federally-funded Money Follows the Person program, called I Choose Home NJ (ICHNJ). Under ICHNJ, assistance is provided to nursing home residents of any age who wish to transition back to the community with the services and supports they need. (See page 15)

4. **Regional Ethics Committees**: The LTCO also oversees the operation of several Regional Ethics Committees that provide assistance to consumers, families and long-term care facilities when confronted with difficult medical decisions in a long-term care environment. (See page 19)
Under federal law and state law, the Ombudsman’s office: accepts confidential complaints from any source and/or anonymously via phone, fax, in writing and by email; investigates those complaints and either resolves and/or refers the problem to a regulatory or law enforcement entity for further action; conducts public or private hearings and can subpoena documents or personal testimony; has unrestricted access to elderly residents of long-term care facilities and their records; and works with resident councils to empower residents to advocate for themselves.

Once a case is opened and assigned, the Investigator/Advocate makes an unannounced visit to the facility, visits with the resident to obtain consent to proceed, conducts a complete review of the facts, obtains records and interviews the resident, staff and other relevant witnesses.

The primary function of the investigation is to resolve the problem at the direction of the resident and to the satisfaction of the resident and to ensure that the resident is safe and that their rights and dignity are being upheld.

If the Investigator/Advocate verifies or suspects that the resident has been the victim of abuse, neglect or exploitation, the Investigator/Advocate will formally refer his/her findings to a regulatory or law enforcement entity for possible further investigation and action.
In FFY 2018, the LTCO:

FIELDED 7,783 calls made to the LTCO toll-free intake line (1-877-582-6995). In addition, approximately 500 complaints were received by email and/or fax.

INITIATED 3,316 investigations and closed out 2,903 investigations involving 5,599 separate complaints.

RESOLVED or partially resolved 95 percent of these complaints to the satisfaction of the resident.

CONSULTED with 6,031 individuals seeking information on a wide variety of topics including: residents’ rights, LTCO services, care concerns and involuntary discharge.

PROVIDED information to 5,324 facility staff on a range of topics including: compliance with Peggy’s Law (see page 22), emergency transfer requirements, involuntary discharge, mandatory reporting and residents’ rights.

ATTENDED 589 resident council meetings.

CONDUCTED or attended 208 training sessions for facility staff.

PROVIDED information and input to state surveyors in 111 facilities.

ENGAGED the community during 120 community education sessions.

Of the 2,903 investigations involving 5,599 separate complaints that were closed during FFY 2018, complaints that relate to residents’ rights comprised the largest percentage.
The LTCO also has jurisdiction in 4 Adult Family Care homes, 14 Assisted Living Programs, and 28 Social Daycare facilities.

<table>
<thead>
<tr>
<th>FACILITY TYPE</th>
<th>CATEGORY</th>
<th># OF UNITS</th>
<th># OF BEDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>LONG-TERM CARE</strong></td>
<td>Skilled Nursing Home</td>
<td>386</td>
<td>51,506</td>
</tr>
<tr>
<td><strong>BOARDING AND CARE</strong></td>
<td>Assisted Living Residence</td>
<td>212</td>
<td>19,680</td>
</tr>
<tr>
<td></td>
<td>Residential Dementia Care</td>
<td>28</td>
<td>486</td>
</tr>
<tr>
<td></td>
<td>Residential Health Care</td>
<td>88</td>
<td>1,587</td>
</tr>
<tr>
<td></td>
<td>Boarding Homes</td>
<td>85</td>
<td>1,225</td>
</tr>
<tr>
<td></td>
<td>Freestanding RHCF</td>
<td>74</td>
<td>1,118</td>
</tr>
<tr>
<td></td>
<td>Comp. Personal Care Home</td>
<td>30</td>
<td>2,537</td>
</tr>
<tr>
<td></td>
<td><strong>TOTAL</strong></td>
<td>517</td>
<td><strong>26,633</strong></td>
</tr>
<tr>
<td><strong>OTHER</strong></td>
<td>Adult Day Health Care Services</td>
<td>122</td>
<td>11,692</td>
</tr>
<tr>
<td></td>
<td>Independent Living of CCRC</td>
<td>28</td>
<td>7,683</td>
</tr>
<tr>
<td></td>
<td>Developmental Center</td>
<td>5</td>
<td>1,429</td>
</tr>
<tr>
<td></td>
<td>Specialty Hospital</td>
<td>14</td>
<td>777</td>
</tr>
<tr>
<td></td>
<td>Comprehensive Rehabilitation</td>
<td>13</td>
<td>968</td>
</tr>
<tr>
<td></td>
<td>Psychiatric Hospital</td>
<td>12</td>
<td>1,307</td>
</tr>
<tr>
<td></td>
<td><strong>TOTAL</strong></td>
<td>194</td>
<td><strong>23,856</strong></td>
</tr>
<tr>
<td><strong>GRAND TOTAL</strong></td>
<td></td>
<td><strong>1,097</strong></td>
<td><strong>101,995</strong></td>
</tr>
</tbody>
</table>

Federal Fiscal Year 2018 Spending

State Funds: $1,481,066

Federal Funds: $1,038,928

Total: $2,519,994

State Fiscal Year 2018/19 Appropriation

State Funds: $1,752,000

Federal Funds: $1,149,000

Total: $2,901,000
<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage of Total</th>
<th>Specific Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Residents’ Rights</td>
<td>36%</td>
<td>Physical and Verbal Abuse, Access to Information, Resident to Resident Physical or Sexual Abuse, Transfer, Discharge, Discharge/Eviction, Loss of Property, Choice, Exercise of Rights, Privacy, Financial, Staff Attitude, Language Barrier</td>
</tr>
<tr>
<td>Resident Care</td>
<td>35%</td>
<td>Care Planning, Personal Hygiene, Symptoms Unattended, Wandering, Chemical and/or Physical Restraints, Toileting</td>
</tr>
<tr>
<td>Complaints Against Others (Not Against the Facility)</td>
<td>13%</td>
<td>Certification/Licensing Agency, State Medicaid Agency, System/Others, Financial Exploitation, Family Conflict, Guardianship Issues, Abuse/Neglect by Family Members</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>10%</td>
<td>Resident Conflict, Activities, Food Services, Weight Loss, Fluid Availability, Infection Control</td>
</tr>
<tr>
<td>Facility Administration</td>
<td>5%</td>
<td>Abuse Investigation, Inappropriate Policies, Shortage of Staff</td>
</tr>
<tr>
<td>Complaints about Services in Other Settings</td>
<td>1%</td>
<td>Complaints about Services in Settings Other Than Facilities or by Outside Provider in Facilities (Home Care, Hospital or Hospice)</td>
</tr>
</tbody>
</table>
CASES OPENED (FEDERAL FISCAL YEAR) NORS
(National Ombudsman Reporting System)

- 2014: 2212
- 2015: 2308
- 2016: 2718
- 2017: 2581
- 2018: 3316

CASES OPENED (FEDERAL FISCAL YEAR)
Ombudsmanager-LTCO Case Management System

- 2014: 2318
- 2015: 2607
- 2016: 3237
- 2017: 2995
- 2018: 3399
CASE TRENDS

CASES OPENED (STATE FISCAL YEAR)

<table>
<thead>
<tr>
<th>Year</th>
<th>Cases Opened</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>2301</td>
</tr>
<tr>
<td>2015</td>
<td>2605</td>
</tr>
<tr>
<td>2016</td>
<td>3144</td>
</tr>
<tr>
<td>2017</td>
<td>2986</td>
</tr>
<tr>
<td>2018</td>
<td>3348</td>
</tr>
</tbody>
</table>

CALLS TO INTAKE LINE (FEDERAL FISCAL YEAR)

<table>
<thead>
<tr>
<th>Year</th>
<th>Calls</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>5873</td>
</tr>
<tr>
<td>2015</td>
<td>6688</td>
</tr>
<tr>
<td>2016</td>
<td>7390</td>
</tr>
<tr>
<td>2017</td>
<td>7550</td>
</tr>
<tr>
<td>2018</td>
<td>7783</td>
</tr>
</tbody>
</table>
When problems are identified in a nursing facility, the Volunteer Advocate can play a crucial role in resolving issues of quality of care and quality of life.

Volunteer Advocates deal with issues such as: staff responsiveness; food and nutrition; hygiene problems; lack of activities; and missing personal belongings. Volunteers are trained to identify and intervene when residents are not being treated with courtesy, consideration and respect – all basic civil rights. Serious complaints of abuse, neglect and exploitation are referred to the Office of the Long-Term Care Ombudsman for investigation.

Deirdre Mraw, State Volunteer Program Coordinator, manages the Volunteer Advocate Program at the state level while five Regional Volunteer Program Coordinators manage the program at the regional/county level:

**Sue Rosenkranz (Region I)**
Essex, Hudson, Morris & Union

**Clara Krever (Region II)**
Bergen, Passaic, Sussex & Warren

**Beth Mané (Region III)**
Middlesex, Mercer, Somerset, Hunterdon & Monmouth

**Janet Khanlian (Region IV)**
Burlington, Cumberland, Camden, Gloucester & Salem

**Sharon Brenner-Cadalzo (Region V)**
Ocean, Atlantic & Cape May

The Regional Coordinators are responsible for training and managing approximately 220 advocates located throughout the state.
New Advocate Training

Volunteers must complete a 32-hour training program to become a certified Volunteer Advocate. The training curriculum was developed by UMDNJ-School of Medicine and Rutgers School of Social Work and is modeled after the National Ombudsman Resource Center curriculum. The training program and training manual were recently updated to reflect industry changes, trends, and new federal nursing home regulations. Intensive classroom instruction and additional on-site orientation is conducted by the Regional Advocate Volunteer Program Coordinator.

Training topics include:
- Overview of the Volunteer Advocate Program
- Demographics of the Elderly Population
- Normal & Abnormal Conditions of Aging
- Medication and the Elderly
- Communication Skills
- The Long-Term Care Setting
- Social, Financial, Legal, and Ethical Issues in Long-Term Care Facilities
- Residents’ Rights
- Elder Abuse, Neglect, and Exploitation
- The Office of the Long-Term Care Ombudsman Complaint Process
- Visiting a Long-Term Care Facility

Continuing Education for Advocates

Ongoing training of the Volunteer Advocates is essential to the success of the Program. After receiving the initial 32 hours of training, Volunteer Advocates increase their learning of the long-term care setting by attending quarterly regional meetings or annual state conferences.

Training curricula and methods are constantly being revised and re-evaluated to provide current information to our team of advocates. Content experts in the field of geriatrics, disability services, visual impairments, cultural diversity, LTC assessment and licensing, activities, person centered care, and residents’ rights, have been presented to our volunteers and staff.
Volunteer Advocate Profile: Francis (Frank) Flaherty

“The best way to find yourself is to lose yourself in the service of others.” — Mahatma Gandhi

Volunteer Advocates are a reflection of the broader community. They come from all walks of life and every age group. Some Volunteer Advocates become interested in working with elderly residents as a result of their own personal experiences with aging family members. Others are retirees seeking a meaningful and rewarding way to use the skills they acquired during their working lives to benefit the larger community.

Meet Advocate Francis (Frank) Flaherty. As a retired educator, Frank joined the LTCO team of volunteers after hearing a radio advertisement. “Mom always taught my brother and me, that ‘it is better to give than receive’ and I have always tried to live up to that.”

After completing training, Frank was assigned to Brookhaven Health Care Center in East Orange, NJ. With approximately 120 residents, Frank visits a minimum of four hours a week – frequently more – listening to the resident’s concerns and troubleshooting problems with the facility administration.

When Frank first began to visit Brookhaven, he observed residents in wheelchairs staring at the floor, never glancing up. He decided that he needed a way to connect with these residents. So, on those days when Frank visits Brookhaven, he makes a point to wear colorful, flamboyant socks. Now when the residents see “Socks” (a nickname given by some residents), they know that Frank has arrived.

“You can advocate for a resident, who in some cases, has nobody else. No one visits them. No one helps them with problems they may face within the nursing home. In this position, I have a tremendous amount of responsibility and I can make a lasting impact and meaningful difference in the lives of these residents – a friendly smile, extension of a hand, listening to their concerns, or sometimes just a conversation about the color of my socks that day.”

Frank’s role as a Volunteer Advocate varies.
“One day when the facility was having their Resident Council meeting, the Resident Council President informed a family member that it was a closed meeting and she would have to leave. Later, that same relative asked the purpose of the meeting. After I explained, she inquired as to why family members couldn’t attend. I explained that family members had their own vehicle – Family Council. This family member asked if ‘we’ could start a Family Council. After speaking with the Administrator of Brookhaven, he welcomed the idea. With some sage advice from the Social Worker, we started.”

“As you can see, I enjoy immensely my volunteering. First and foremost is the mission of LTCO. RESIDENTS come first and the rest is gravy.”

Also, in late 2018, when the parent company that owned Brookhaven was having financial problems in other states, Frank was tasked by the LTCO Chief of Staff to make regular visits to the facility and to report back if he identified any deterioration of service there. Frank’s reports were shared with the state regulators who were also monitoring the facility. Frank kept in regular touch with the facility management and with residents and reported back no problems during that transition period.

According to 2018 NORS data:

<table>
<thead>
<tr>
<th>1:1 Resident Interaction: 92,474</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Volunteer Hours to the Program: 38,720</td>
</tr>
<tr>
<td>Trained Advocates: 220</td>
</tr>
<tr>
<td>Percent of Nursing Homes Covered in NJ: 57%</td>
</tr>
</tbody>
</table>

The success of the Office of the Long-Term Care Ombudsman Volunteer Advocate Program is predicated on the dedication and devotion of our citizens who willingly give back to their communities, and their ability to effectively resolve issues on behalf of the population we serve.
### Advocacy and Outreach

The LTCO has played a key role in the I Choose Home NJ program (also known as Money Follows the Person) since 2012. I Choose Home NJ helps people living in nursing homes and developmental centers to move back to the community with Medicaid supports and services they need to live fully integrated lives. In the process, it generates savings that the State must use towards more home and community-based services for more New Jerseyans to age in place. The LTCO works closely with NJ Department of Human Services and the Centers for Medicare & Medicaid Services (CMS) to carry out this important work. Since 2008, the I Choose Home NJ team has successfully transitioned nearly 3,000 people from institutions back into home and community-based settings for a savings of over $30 million.

#### 2008 - 2018

<table>
<thead>
<tr>
<th>Category</th>
<th>2008</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older Adults</td>
<td>996</td>
<td>129</td>
</tr>
<tr>
<td>Intellectual/Developmental</td>
<td>968</td>
<td>65</td>
</tr>
<tr>
<td>Disabilities—</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adults w/ Physical Disabilities</td>
<td>977</td>
<td>141</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>2941</strong></td>
<td><strong>335</strong></td>
</tr>
</tbody>
</table>

#### 2018

- Older Adults: 129
- Intellectual/Developmental Disabilities: 65
- Adults w/ Physical Disabilities: 141
- **Total:** 335

The LTCO staff act as the advocacy and outreach arm of the program for the nursing home population, spreading the I Choose Home NJ message that “A Nursing Home May Not Be the Only Option” and advocating strongly for nursing home residents who want to move out. Because I Choose Home NJ Outreach and Advocacy Coordinators are also Ombudsman’s staff, they have the authority to freely enter nursing homes, to speak confidentially with all residents and (with their permission) review their records, to question staff about activities, and to provide education to nursing home staff as needed. This unique role allows Outreach and Advocacy Coordinators to more effectively identify residents who want to move out, to fiercely advocate for them with all relevant parties, and to help resolve any barriers or issues that may arise.

In addition to identifying and supporting program participants, the LTCO educates nursing home staff, community health care providers, caregivers, families, and the general public about the program. We have exhibited and given presentations about I Choose Home NJ at over 300 venues and have advertised throughout the state via television and radio commercials, commuter rail ads, newspapers, diner placemats, church bulletins, Facebook, and many other platforms. There is now greater awareness statewide about this population/program.
LTCO’s Program Benchmarks

2018 Program benchmarks required that LTCO staff:

**CONTACT** every nursing facility in the State at least one time per calendar year.

**VISIT** 25% of all nursing facilities annually to provide in-services for staff and/or residents and to search for ICHNJ candidates.

**ADVOCATE** for individuals who have been found MFP-eligible but who are in need of housing.

**ATTEND** community events directed at I Choose Home NJ populations, including but not limited to, elder/disability expos and fairs, senior days, faith-based events, etc.

**SPEAK / PRESENT** to community and professional events, conferences, and institutions of higher learning (including social work, nursing, etc.)

**INCREASE** consumer contacts made through the I Choose Home NJ hotline phone number, email inquiries, and website visits by 15% per year.

**MEET** with at least 15 targeted individuals or entities to advance housing opportunities for ICHNJ-eligible individuals.

*The I Choose Home NJ team has consistently met or exceeded these benchmarks.*
Helping to Identify and to Create Affordable and Accessible Housing

Since 2014, the LTCO has filled the Statewide Housing Coordinator role for I Choose Home NJ, a role that has greatly expanded. The statewide lack of affordable, accessible housing continues to be the primary barrier to I Choose Home NJ nursing home transitions. As such, the Statewide Housing Coordinator acts to identify and create more affordable housing opportunities for people coming out of nursing homes, and to help people maintain housing stability after they move. Examples of housing advocacy include alerting nursing home social workers to local affordable housing opportunities, meeting with housing developers to explore possible collaboration, training managed care organizations to secure housing for their Medicaid members, and working with participants to overcome challenging issues after transition (threats of eviction, housing voucher problems, budgeting, etc.).

The Statewide Housing Coordinator role has also been at the leading edge of policy changes related to housing for NJ Medicaid populations. From 2015-2016, the LTCO participated in a housing/Medicaid Innovation Accelerator Program (IAP) hosted by the Centers for Medicare & Medicaid Services (CMS), to bridge high-level Medicaid and housing policy makers in New Jersey. This process became a springboard to more closely connect Medicaid and housing services and has resulted in concrete policy changes for the MLTSS (Managed Long-Term Supports and Services) population, including our nursing home transition population. For example, the I Choose Home NJ team advocated strongly for Medicaid contract language to require all managed care entities providing MLTSS to have experienced Housing Specialists to help find housing for those members. That language is now included in the NJ Medicaid contract and the LTCO, through its Statewide Housing Coordinator, hosts the managed care Housing Specialists quarterly to provide additional housing training and share best practices. The LTCO also receives and reviews quarterly reports from the Housing Specialists about their progress towards housing nursing home members, including high level progress toward managed care organization housing development in New Jersey.

The most exciting examples of recent housing-related work are I Choose Home NJ’s increasing access to housing vouchers through local Housing Authorities and the continued development of the Money Follows the Person Housing Partnership Program (MFPHPP). The Statewide Housing Coordinator has initiated partnerships pursuant to HUD notices to secure housing vouchers in some of our most needed municipalities, especially in the Northeast corridor. Several individuals moved out in 2019 as a result of these voucher opportunities. The MFPHPP, a collaboration between the NJ Department of Human Services and NJ Housing Mortgage Finance Agency to give developers loan money to build affordable housing for people waiting to leaving nursing homes, continues to grow. The LTCO staff was central to the development and implementation of this program, which launched in December 2015 and now provides a pool of $6.2 million of capital loan money to developers in exchange for 80 affordable, accessible apartments. The first of these one-bedroom units was completed and occupied in 2017 and we anticipate dozens more coming online over the next 1-2 years.
“My best friend is home.” When Bernie had to go into a nursing home after his stroke, his wife Micki of 50+ years always hoped he would be able to come back home to live with her. Four years later, that hope was almost gone. When Jen McMahon of the I Choose Home NJ program met Bernie and Micki at the nursing home one Saturday morning and told them that he may be able to go back home with Medicaid supports, Micki says “it was like an angel came down from the sky. We didn’t know that option even existed.” For nearly two years, the I Choose Home NJ team – including Jen and her colleague Kathleen Filippone – advocated strongly for Bernie’s right to move out and connected him to every possible Medicaid service he would need to be safe and comfortable in the community. Finally, this September, Bernie came home to Micki. They are thrilled. Bernie now receives in-home care from trusted home health aides. Of his care, Micki observes that “he gets a lot more attention here than in the nursing home because the aide is only attending to him.” Of Bernie’s coming back home, Micki says, “I felt so lonely and on edge when Bernie was in the nursing home. Now I have my best friend and protector back with me. We are just so happy.” When asked how he feels about being home, Bernie raises his fist and exclaims, “GRRRREAT!”
Difficult Decisions

As individuals grow older and struggle with advanced illness and frailty, they, their families, and their care providers will likely be faced with difficult decisions about their care and treatment.

Decisions can include whether to provide or remove particular treatments, such as dialysis or artificial nutrition, adjust medications, or refer to palliative care or hospice.

For individuals in long-term care communities, the Office of the Ombudsman provides support and ensures that decision-making is resident-focused and consistent with ethical and legal standards.

One way the LTCO does that is through Regional Ethics Committees (RECs). RECs provide an impartial, comprehensive evaluation and assessment of the situation and offer non-binding recommendations to the individuals involved.

RECs provide much-needed education, conflict resolution and ethical guidance to facilities and families when difficult decisions need to be made.

NJ Supreme Court Case Law

- In re Quinlan, 70 N.J. 10 (1976)
- In re Conroy, 98 N.J. 321 (1985)
- In re Peter, 108 N.J. 365 (1987)

Ethical Decisions at End-of-Life Ombudsman Process

As with all of the Ombudsman’s work, the primary focus of the process is to ensure that the resident’s wishes are respected. The Office works with the resident, his or her family and friends, and facility staff to identify the resident’s wishes, wherever possible.

In addition to exploring the resident’s wishes, the Office also gathers clinical information regarding the resident’s cognition, condition, and prognosis, to ensure that legal standards for withholding/withdrawal treatment are met.

Regional Ethics Committees (RECs)

- Multi-disciplinary teams, including social workers, nurses, clergy, and hospice workers
- Established to serve as a resource to residents and health care professionals of LTCF’S who face ethical dilemmas:
  - Treatment decisions
  - Health care conflicts
  - Withholding/withdrawing Life Sustaining Treatment
  - Quality of life issues
- Consultation not required and recommendations not legally binding, but can often resolve ethical dilemmas as close to the bedside as possible.
Ensuring that the newly-enacted right of terminally ill New Jerseyans to a dignified death is a real and accessible option for residents in long-term care facilities.

The Medical Aid in Dying Act (MAID), passed April 2019, allows certain terminally ill New Jerseyans to request, obtain and self-administer medication to end their lives. Prior to its enactment, the LTCO met with multiple stakeholder and policymaking groups and provided feedback about the importance of protections for long-term care residents who wish to avail themselves of this important new right. The LTCO continues to provide input to Department of Health regulations to ensure they contemplate the unique needs of LTC residents in implementation and enforcement.

Strengthening education and advocacy to stop discrimination against LGBTQ residents in long-term care.

Proposed legislation S3484/A5075 would ensure much-needed training and enforcement in long-term care facilities around the rights of LGBTQ individuals residing there. Sadly, older adults are going back in the closet when entering LTC facilities, rightly fearful that staff and other residents will not accept or treat them with dignity. Although the LTCO historically has received very few of these complaints, we believe that this is due primarily to a lack of awareness by LTC residents and their families about their rights and available advocacy. We anticipate these complaints accelerating with the passage of this legislation.

In preparation, the LTCO is at the forefront of this issue - convening LGBTQ senior advocates to understand how the current legislation can be strengthened and working with legislative staff to do so, and training all LTCO staff and 200+ Volunteer Advocates on awareness and advocacy for LGBTQ residents. We are strongly committed to ensuring a safe and welcoming environment for LGBTQ LTC residents throughout the state and have committed to making this one of our focus areas in coming months/years.

Responding to federal rule changes that are damaging to New Jersey’s most vulnerable elders.

The past year has seen federal rule changes that are detrimental to the health, dignity and safety of the long-term care population, particularly to some of its most marginalized residents, including LGBTQ and immigrant seniors.

The Public Charge Rule, announced in late 2018 and published in August 2019, greatly expands the category of immigrants who immigration officials can consider a “public charge” and who therefore can be denied when they seek to adjust their immigration status. It added crucial health and housing benefits (Medicaid, SNAP, Medicare Part D assistance, and Section 8) to the list of public benefits that will be counted against the
person seeking immigration relief. It also makes immigrants over 61, who have limited English proficiency, and/or are dependent on care from others some of the most likely to be deemed a “public charge.” This punitive, discriminatory, and highly political change is already forcing immigrant seniors to choose between seeking benefits they need to maintain their health and dignity, and being able to better their immigration status in the future. As such, the LTCO submitted comments to the announced rule change strongly condemning it and now, with its publication, will continue seek opportunities to oppose its implementation.

Similarly, the proposed changes to the Health Care Rights Law (Section 1557 of the ACA), announced in May 2019, would eliminate or limit legal protections in the provision of healthcare for Limited English Proficient (LEP) individuals, LGBTQ persons, persons with disabilities and chronic conditions, and individuals whose identities intersect across multiple protected classes. The LTCO sees all too often that these forms of healthcare discrimination are real and ongoing and that the most robust legal protections are needed to guard against them. The LTCO will continue to monitor the status of this proposed rulemaking to oppose its adoption.

**Working to create more housing opportunities for long-term care residents who need community placement.**

Since 2014, the LTCO has worked at the highest levels of state government to raise the profile of and opportunities for nursing home residents who need housing in the community. The lack of affordable and accessible housing continues to be the greatest barrier to moving people in nursing homes back into the community. The specifics of this work is described in greater detail in the I Choose Home NJ section (see page 15). The LTCO will continue to work with the managed care organizations (MCOs), not only to ensure they have housing knowledge and expertise to find housing for the nursing home population, but to push at higher levels for MCOs to invest in affordable and accessible housing in New Jersey as they are doing in other states. The LTCO will also continue to advocate that more housing-related services and supports be included in any Medicaid Waiver renewal processes and that the MCO Medicaid contract continues to require the MCOs to engage in meaningful housing activities.
Continuing to educate the public and long-term care facilities about Peggy’s Law implementation.

Peggy’s Law, passed in 2017, requires nursing homes to contact local law enforcement, in addition to contacting the LTCO and Department of Health, when nursing home staff suspect that a resident was abused, neglected or exploited. It also shortened the reporting window for these suspected crimes/violations. To date, the LTCO has provided educational materials to all long-term care facilities and trainings at dozens of facilities on the subject. 2018-19 also saw an uptick in complaints from and collaboration with law enforcement entities. When we encounter facilities who fail to report, we conduct facility-wide education to make all staff aware of their responsibilities under Peggy’s Law. The LTCO will continue to closely monitor facility compliance with these changes.

Ensuring that residents of assisted living residences (ALRs) who spend their money in the facility are not evicted when they transition to Medicaid.

This issue, that residents who have spent hundreds of thousands of dollars at these facilities, are suddenly no longer “guaranteed” a Medicaid bed when they run out of money and transition to Medicaid, continues to occur. This is due to a lack of regulatory authority over ALRs generally, nebulous admission practices where promises are often made but not committed to writing, and a lack of education and empowerment on the part of consumers. The LTCO handles these matters on case-by-case basis but will begin pushing for more systemic solutions, including legislative/regulatory action and a consumer education campaign.

Participating in the World Elder Abuse Awareness Day

Each year World Elder Abuse Awareness Day (WEAAD) is commemorated to raise awareness about the estimated 5 million older adults who are abused, neglected, or exploited. Older Americans lose an estimated $2.6 billion or more annually due to elder financial abuse and exploitation.

A call-to-action event was held at the Richard J. Hughes Justice Complex on Friday, June 15, 2018. The 2018 theme, “Building Strong Support for Elders,” brought forth the significance of elder abuse as a public health and human rights issue.

NJ’s World Elder Abuse Awareness Day event featured a host of wonderful speakers including Lt. Governor Sheila Oliver and LTCO’s own Field Investigator Fred Paugh pictured with LTC Ombudsman Laurie Brewer and Outreach Coordinator Kisha Saffron.
The Ombudsman for the LTCO has been designated the State Long-Term Care Ombudsman pursuant to and in accordance with the provisions of 42 U.S.C. §§ 3058g et seq. The LTCO is responsible for securing, preserving, and promoting the health, safety, and welfare of New Jersey's elderly population, through investigations of abuse, neglect, and exploitation; legislative and regulatory advocacy; policy work; and education and outreach.

The LTCO is considered “in but not of” the NJ Department of the Treasury. However, the Ombudsperson is considered independent of any supervision or control by the NJ Department of Treasury. As per state law, the Ombudsperson is directly appointed by the Governor.
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