



Collaborations between Long-Term Care Ombudsmen and Protection & Advocacy Agencies

A Report written by

**National Disability Rights Network,
National Long-Term Care Ombudsman Resource Center, and
National Association of State Long-Term Care Ombudsman Programs**

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Introduction

Both the Protection and Advocacy (P&A) and the Long-Term Care Ombudsman (LTCO) statutes require the systems to collaborate in coordination of services¹. This is especially important in this time of limited resources, yet growing population of seniors, many of whom have disabilities. Collaboration between the two systems will maximize the amount of important services that reach people with disabilities and the elderly, enhancing the effectiveness of both the P&A and LTCO systems.

However, the knowledge on the extent, barriers, and best practices of the collaboration between the P&As and LTCOs is anecdotal at best. That is why the National Disability Rights Network (NDRN), the membership and technical assistance provider to the P&A Network, along with the National Long-Term Care Ombudsman Resource Center (NORC), the technical assistance provider to the LTCO network, and the National Association of State Long-Term Care Ombudsman Programs (NASOP), the LTCO membership association, conducted research to gather information on P&A and LTCO collaboration. We appreciate the support of the Administration on Intellectual and Developmental Disabilities (AIDD) in the gathering of this data and the writing of this report. We look forward to working with the AIDD and the Administration on Aging to implement the recommendations in this report, thus strengthening the services provided by both the P&As and the LTCO.

Descriptions of Programs and Organizations

Protection and Advocacy System

The Protection and Advocacy (P&A) System comprises a nationwide network of congressionally mandated, legally based disability rights agencies. A P&A agency exists in every state and territory. There is also a Native American P&A in the four corners region of the Southwest. Collectively, the network is the largest provider of legally based advocacy services to people with disabilities in the United States.

P&A agencies have the authority to provide legal representation and other advocacy services, under all federal and state laws, to all people with disabilities in all settings. P&As have broad access rights to institutions and community settings for purposes of investigating cases of abuse and neglect. All P&As maintain a presence in large and small, public and private facilities that care for people with disabilities, where they monitor, investigate and attempt to remedy adverse conditions. P&As also devote considerable resources to ensuring full access to inclusive educational programs, financial entitlements, healthcare, accessible housing and productive employment opportunities.

¹ 42 USC § 15043 (a) (2) (D) (ii) and 42 U.S.C. 3058g (h) (6)

The Long-Term Care Ombudsman Program

Required by the Older Americans Act, every state has a Long-Term Care Ombudsman Program (LTCOP) that empowers residents, addresses complaints, and advocates for improvements in the long-term care system. Long-Term Care Ombudsmen are advocates for residents of nursing homes, board and care homes, and assisted living facilities. Ombudsmen provide information about how to find a facility and what to do to get quality care. They are trained to resolve problems and assist with complaints at the resident's direction.

The ombudsman program is administered by the Administration on Aging (AoA). The network has 8,712 volunteers certified to handle complaints and 1,180 paid staff. Most state ombudsman programs are housed in their State Unit on Aging. Nationally, in 2012 the ombudsman program investigated over 193,000 complaints on behalf of 126,000 individuals and provided more than 300,000 consultations to individuals².

National Disability Rights Network

The National Disability Rights Network (NDRN) is the non-profit, voluntary membership association for the P&A and Client Assistance Program (CAP) agencies. NDRN's mission is to promote the integrity and capacity of the P&A/CAP national network and to advocate for the enactment and vigorous enforcement of laws protecting civil and human rights of people with disabilities. NDRN provides training and technical assistance to the P&A/CAP network through the Training and Advocacy Support Center (TASC). TASC provides assistance on a broad range of topics including legal, fiscal, governance, leadership, communications and organizational development of the P&A/CAP system. TASC is a federal interagency project of the Administration on Intellectual and Developmental Disabilities (AIDD), the Substance Abuse Mental Health Services Administration (SAMHSA), the Rehabilitation Services Administration (RSA), the Social Security Administration (SSA), and the Health Resources Services Administration (HRSA).

National Long-Term Care Ombudsman Resource Center

The National Long-Term Care Ombudsman Resource Center (NORC) provides support, technical assistance, and training to the 53 State Long-Term Care Ombudsman Programs and their statewide networks of almost 600 regional and local programs. The Center's objectives are to enhance the skills, knowledge and management capacity of the State programs to enable them to handle residents' complaints and represent resident interests (individual and systemic advocacy). Funded by the AoA, the Center is operated by Consumer Voice, National Consumer Voice for Quality Long-Term Care, in cooperation with the National Association of States United for Aging and Disabilities (NASUAD).

² 2012 National Ombudsman Reporting System (NORS) data

National Association of State Long-Term Care Ombudsman Programs

The National Association of State Long-Term Care Ombudsman Programs (NASOP) is a nonprofit organization composed of State Long-Term Care Ombudsmen representing their state programs. NASOP's objectives are to advocate for a stronger Long-Term Care Ombudsman Program and enhance its effectiveness to serve consumers and their families, develop and implement professional education, training, and support programs for Long-Term Care Ombudsmen, facilitate information and best practices exchange between Long-Term Care Ombudsman programs, collaborate with consumer and advocacy organizations, governmental bodies, and health care providers, and promote the interests of long-term care residents before national level policymakers, including federal agencies and Congress, and before national aging and health organizations.

Status of Current Collaboration

In an effort to learn more about LTCO and P&A collaboration at both the state and local levels, NORC and NDRN collected information from their respective networks; NDRN from the 57 P&A agencies, and NORC from both the State Long-Term Care Ombudsmen (SLTCO) and Local Long-Term Care Ombudsmen (LLTCO). The SLTCO often focus more broadly on systems issues, while the LLTCO generally focus on individual advocacy. Therefore, separate requests were sent to each to gain both perspectives.

Our requests were designed to assess each program's understanding of the role and responsibilities of the other, the level of engagement between them, and the formal or informal mechanisms for collaboration and/or sharing information with each other. All recipients were also asked to comment on specific instances in which they collaborated, including on the education of state or federal policymakers and cross trainings. A sampling of these comments is included in the Examples of Effective Collaborations section below.

Summary of P&A Information

While 85% of the P&As had some level of engagement with the State LTCO in their state or territory, much less (47%) had some level of engagement with the regional / local LTCO. Engagement between the P&As and LTCO included: referrals between the agencies, joint trainings and briefings, working collaboratively to transition individuals out of a nursing home into the community, and systemic work to educate policymakers on long-term care issues at both the state and federal level.

This dichotomy also existed in the P&A's knowledge of each system. 68% of the P&As felt very or extremely knowledgeable of the state LTCO, while only 39% of the P&As felt very or extremely knowledgeable of the regional / local LTCO. In fact, in the additional written responses, some P&As were not sure if they had regional or local LTCOs in their state or territory.

Additionally, the information collected showed that a majority of the P&As were working with LTCO in a number of ways. In 2012 and 2013, 61% of the P&As collaborated with the LTCO (either state or regional / local) to educate state or federal policymakers. About the same percentage of P&As had a formal or informal mechanism for information sharing and referrals regarding the needs or complaints of persons with disabilities focused on long-term care services and supports. Ultimately, most of those mechanisms are informal as approximately 11% of the P&As had a formal mechanism with the State LTCO, while only about 7% of the P&As had a formal mechanism with the regional / local LTCO.

Finally, while a majority of P&As and LTCOs are collaborating, only 39% of the P&As have attended, sponsored, or jointly trained at a conference or training.

Summary of State Long-Term Care Ombudsman Responses

50% of SLTCO reported ongoing engagement with P&As, 27% reported some engagement and 23% reported minimal engagement. SLTCO report collaborations including: jointly serving on various committees, collaboration on cases, meetings on budget priorities within the LTCOP for people under the age of 60 in managed care, legislative advocacy, client referrals, and work groups to address systemic issues. 48% of SLTCO report collaborating with P&As to educate state or federal policymakers, and 33% have attended trainings and conferences with the P&As. 54% have a current formal or informal mechanism for information sharing and referral regarding the needs and complaints of persons with disabilities focused on long-term care services and supports.

In terms of their overall understanding of the roles and responsibilities of the P&As, 45% felt they had some to minimal understanding and 55% felt they were very to extremely knowledgeable. The most critical responsibilities of the P&As from the perspective of the SLTCOs included: providing legal assistance and representation for people with disabilities, monitoring of representative payees for people who live in nursing facilities, providing strategic advocacy and education services to persons with disabilities, and addressing systemic issues.

Summary of Local Long-Term Care Ombudsman Responses

Overall, 50% of the LLTCO reported having some to ongoing engagement with P&As in 2012-2013. The LLTCOs reported interactions with P&As to include: assisting a resident in transitioning from the nursing home setting to the community; making case referrals when there may be a role for the P&A; jointly participating on work groups; seeking legal assistance when a case falls under the scope of P&A; system advocacy efforts; and addressing discriminatory admission policies at nursing facilities. 36% of LLTCO reported attending trainings or conferences with P&As, and 8% of LLTCO

reported that P&A representatives sit on their advisory boards. Additionally, 25% of LLTCOs have collaborated with P&As to educate state and federal lawmakers, and 25% reported having a formal mechanism (i.e. memorandum of understanding or agreement) with a P&A.

In terms of LLTCO understanding of the roles and responsibilities of the P&As, 28% reported zero to minimal understanding, 31% reported some understanding, and 41% felt very to extremely knowledgeable. The majority of respondents understood the role of the P&As to predominantly be to offer legal assistance and expertise to residents with disabilities. Other roles / responsibilities LLTCO believe to be held by P&As included systemic advocacy efforts, investigating complaints in long-term care settings, bringing in consultants to review facility practices, and providing information on disability rights and services.

Summary of Common Responses Concerning P&As

Several LLTCOs noted it was their understanding that the P&A in their state only served residents/clients who are under the age of 59, while others thought the P&As served individuals of all ages. Like the LLTCOs, the SLTCOs understanding of the scope of clients served by P&As seemed to vary state by state, with some saying they only served individuals aged 18-59, some 59 and younger, some serving all ages, etc.

There was also a general lack of name recognition of the P&A agency in a state on the part of the LLTCO. Several confused the P&A with Adult Protective Services (APS), or did not recognize the Disability Rights Network name to be the same as Protection & Advocacy, and therefore completed the questionnaire from that perspective. This lack of name recognition, and confusion between P&A and APS, occurred at the SLTCO too, but not as frequently as with the LLTCO responses.

Barriers to Collaboration

While some of the following barriers can be seen in our discussion of the status of current collaboration section, this section of the report will discuss in more detail the information we received from our respective networks concerning barriers to collaboration between the P&As and the LTTCO.

Barriers To Collaboration Seen By P&As

One barrier to collaboration cited by the P&As a number of times was a concern around the independence of the LTTCO given the fact that some programs are located inside state government. As organizations mandated to be independent from state government, some P&As were concerned that the location of the LTTCO in state government could create conflicts in the goals between the organizations restricting the ability to collaborate.

Another barrier that was cited by a number of P&As was the impact of limitations on the sharing of information between the P&As and the LTCOs. These limitations were seen to restrict the effective collaboration between the P&As and the LTCOs to address the needs of the elderly and persons with disabilities accessing long-term services and supports. It was also felt that this limitation hampered the ability of P&As to investigate abuse and neglect allegations due to delays in receiving information.

A third barrier for those that knew of their regional or local LTCO was a concern that the local LTCO and volunteers did not have an adequate amount of training to provide the services and advocacy needed by individuals seeking help with a long-term care problems. This belief has kept some P&As from working with the local LTCO or volunteers.

Finally, a lack of knowledge by the P&As about the regional / local LTCOs is keeping the P&As from effectively collaborating with them.

Barriers to Collaboration Seen By LTCOs

One identified barrier mentioned frequently at both the state and local levels was a general confusion around the types of cases that can be referred to the P&As. Some LTCOs reported that the P&As did not seem to be systematic in the way they handle referrals, and find the types of cases that P&As will investigate to be limited in scope. One State Ombudsman commented in particular that ombudsmen often encounter frustrations in trying to successfully refer individuals to the P&A, due largely to the intake protocol and criteria for accepting cases, which is not always clear to the local ombudsmen.

A second barrier mentioned was P&A misunderstandings of the statutory restrictions on the LTCO's ability to share information. Some LTCOs reported having confrontations with P&As around this issue as LTCOs can and will only disclose identities and share records when they have consent from the resident or legal representative.

Lastly, as was touched on before, there was confusion (more so at the regional/local level) as to what the Protection and Advocacy agency was called in the state. Several questionnaire respondents confused P&A with APS, and one local ombudsman mentioned that the P&A in her area changed its name recently which led to some confusion when referring new clients.

Examples of Effective Collaborations between the LTCO and P&As

Despite the barriers, the information received from the P&As and the LTCO yielded numerous examples of successful collaboration between the two networks. This was particularly true around training and systems advocacy. Some examples of effective collaboration are:

- At the local level, one LLTCO and the P&A have formed a community healthcare consortium, which has been responsible for the passage of several laws increasing consumer protections.
- One P&A meets regularly with the SLTCO to coordinate a legislative agenda in advance of the legislative session. During the past two years, they have worked successfully together on adult family home reform, guardianship, and other issues.
- P&A staff attended a LTCO team meeting to train the ombudsman staff on the roles and responsibilities of the P&As.
- In one state the LTCO and P&A worked together to advocate for individuals who wanted to leave their nursing facility and begin receiving services in their home and community.
- In one state, the SLTCO, Office of Ombudsman for Mental Health and Disabilities, the P&A, and other advocacy organizations meet and collaborate on systemic issues on the leadership level as well as individual case work on the regional level.
- One P&A partnered with a cross discipline group (including the LTCO) to look at financial exploitation of the elderly and people with disabilities. This work resulted in the development of a brochure regarding financial exploitation of the elderly and people with disabilities as well as legislation being passed that allows banks to sooner inform the state Fraud Unit of financial exploitation.
- One SLTCO reported working with the P&A on legislative initiatives which have resulted in strengthening the Vulnerable Adult law, Power of Attorney legislation, and felony neglect and guardianship laws.
- One P&A helped to train LTCO volunteers, cross-referred cases/callers, and worked together to address several policy issues through direct collaboration and broader advocacy coalitions.
- One P&A offers an annual symposium in which at least one representative of the LTCOP attends and presents.

Recommendations

Based on the information we have received from the P&As and LTCO, NDRN, NORC, and NASOP make the following recommendations for future actions to create, strengthen, and deepen collaborations between the P&As and LTCO:

1. The Administration on Community Living (ACL) should fund and support NDRN, NORC, and NASOP to work with their members to promote collaboration.
2. NASOP, NORC, and NDRN will create opportunities for cross-training at the national level through conferences, webinars, or conference calls to increase the exposure and recognition between the two programs.
3. P&As and LTCOP should be encouraged to develop Memoranda of Agreement or Understanding to detail the roles and responsibilities of each entity when working on cases, how the two can effectively and efficiently share information, establish referral processes, and explore avenues for cross-training.
4. To ensure the greatest benefit for the consumer of long-term care services, P&As and LTCOs should have regular meetings to discuss the cases and issues each are handling and how the agencies can better collaborate to address these cases and issues.
5. P&As and LTCO should be encouraged to create opportunities for cross training in order to increase knowledge of the other agency.
6. LTCOs and P&As at the state and local levels should continue to seek out opportunities to work together on systemic issues through jointly participating in legislative coalitions, training conferences, Olmstead Councils, testifying before legislatures, etc.
7. NORC, NDRN, and NASOP should explore ways to increase collaboration to better educate their respective members on the roles and responsibilities of the LTCO and P&As.
8. ACL should review federal statutory provisions for the P&A and LTCO and work with NDRN, NORC, and NASOP on ways that P&As and LTCOs can seek resident/legal representative consent to disclose to each other, especially for unrepresented individuals who cannot provide consent.