## HEALTH POLICY AMBASSADORS OF UAB PROPOSAL FOR THE ALABAMA LONG-TERM CARE OMBUDSMAN PROGRAM



# EXECUTIVE SUMMARY



Long term care (LTC) facilities provide full-time medical care, lifestyle activities, and support to residents who cannot otherwise support themselves. Challenges facing LTC facilities include a general lack of awareness among residents and families regarding their rights and how to report violations of their rights to the LTC ombudsman program. In this proposal, we comment on the lack of resident rights education and self advocacy, the underutilization of the volunteer program, and the unlcear reporting process. We propose actionable ways to:



Effective implementation should be done through a stepwise approach that allows for a smooth transition and ample focus on each solution. Surveys, reporting rates, and family council and volunteer metrics can be used for evaluation and redirection. The goal of these proposed changes is to demonstrate productive improvements in the system to promote increased satisfaction amongst residents and their families.

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## **HEALTH POLICY** AMBASSADOR PROGRAM

#### UAB LISTER HILL CENTER FOR HEALTH POLICY





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The Health Policy Ambassadors Program at UAB was established in 2020 to connect students interested in advocating for policy change with community partners. Ambassadors meet regularly with their community partners to identify a policy issue and create an product to stimulate change. Our team worked with Disability Rights & Resources to explore a variety of issues that impact people with disabilities. This partnership led us to research issues with long term care in Alabama, specifically uncertainty around the reporting process for abuse and other infringements on residents' rights. To further our own understanding of this issue, we connected with Mrs. Sheree Head, Long-Term Care Ombudsman Coordinator for Jefferson County. Our conversations with Mrs. Head resulted in this proposal to streamline the United Way Area Agency on Aging's approach to ensuring residents know their rights and how to report cases of abuse.

#### **BACKGROUND** HISTORY OF THE LTC OMBUDSMAN PROGRAM

Long-term care facilities were established in 1935 with the passing of the Social Security Act (SSA),<sup>1</sup> which in turn created the Old Age Assistance program to disburse funds for the care of the elderly. However, this program was not allowed to financially support public nursing home residents; thus, this sparked a rise in private LTC facilities. In the 1950s and 1960s, new legislation increased funding to public facilities, but studies still showed that 50-60% of residents were reliant on public assistance or welfare. Furthermore, the 1956 Commission on Chronic Illness noted the poor quality of care and substandard services provided at these facilities. Licensure varied by state, and there were no standard procedures set by the SSA.<sup>2</sup> In 1963, the Special Committee on Aging began holding hearings for nursing home issues and found significant variation in standards and enforcement.<sup>3</sup> The Nursing Home Standards of care to improve quality and safety.<sup>2</sup>

In 1965, Medicare and Medicaid expanded federal funding and allowed for more skilled services to be provided in these facilities.<sup>2</sup> The US Department of Health, Education, and Welfare was authorized to set standards of care for nursing facilities,<sup>1</sup> but several reports in the 1960s and 1970s revealed persistent abuse, neglect, and substandard conditions in these facilities. During the White House Conference on Aging in 1971, President Nixon condemned nursing home conditions and promised to end funding to facilities that did not meet standards.<sup>2</sup> Dr. Arthur S. Flemming, who was the Counselor on Aging to President Nixon, formed the idea of the ombudsman program as an attempt to improve quality of care and to respond to complaints made by or on behalf of residents.<sup>4</sup> In 1971, the Supplemental Appropriations Act funded ombudsman projects in nursing homes. A couple years later, the Nursing Home Ombudsman Program was transferred to the Administration on Aging (AoA), and in 1977 a training program was established for state ombudsman programs funded by AoA<sup>2</sup>. The state ombudsman program continues to act as the leader of advocacy for resident rights and regulations in LTC facilities today.

#### **BACKGROUND** ALABAMA'S LTC OMBUDSMAN PROGRAM

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Alabama is home to over 800,000 people over the age of 6551, representing nearly 16% of our state's population.<sup>5</sup> As the baby boom generation approaches their senior years, this number is projected to grow to over 1.4 million by 2040.<sup>6</sup> Additionally, nearly 1 in 3 people in the state have one or more disabilities according to the CDC.<sup>7</sup> Older people and people with disabilities may have chronic conditions that make activities of day-to-day life difficult, urging them to rely on LTC services for critical health and personal needs.

These Alabamians have a right to quality long term service options to live as safely and independently as possible. To accomplish this, the Alabama Department of Senior Services (ADSS) has made great strides in implementing a combination of state and federally funded programs that holistically promote the health of the elderly and people with disabilities. The vast range of the programs within the ADSS is shown in **Figure 1**. Many of these programs are designed to promote independent living, a form of care offering those struggling with daily activities a way to remain living at home with supplemental help. However, if independent living becomes too difficult for a person and their family to support, they may need to reside in LTC facilities that can offer intensive and constant care.



**Figure 1: Programs under the ADSS.** The ADSS works with the Area Agencies on Aging to lead 13 high-impact programs addressing four core areas: community education, financial security, legal protection, and health support services. Among these 13 programs is the Alabama Long-Term Care Ombudsman Program, highlighted in purple.

As Alabama's aging population increases demand for such facilities, the state must be careful to protect residents' rights to live free of abuse and neglect. Nearly 1 in 4 people in nursing homes will experience some form of physical, emotional, sexual, or physical abuse from staff, other residents, or family members.<sup>8</sup> Under the Alabama Act 85-657 of 1985. Alabama's Long-Term Care Ombudsman Program (ALTCOP) was established as an ADSS federally-funded program whose primary purpose is to respond to reports of such instances of abuse or neglect that may occur within any of the state's LTC facilities.

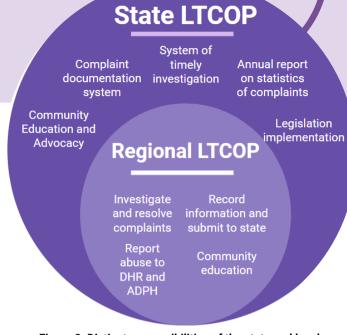


Figure 2: Distinct responsibilities of the state and local ombudsman programs. State is responsible for infrastructure, while the regional programs directly handle complaints.

The program also actively works to prevent abuse from occurring by performing community outreach on resident and family rights and resources, advocating for necessary change within Alabama LTC facilities, and lobbying for residents' rights before local, state, and federal governments.

The ALTCOP oversees the thirteen regional Area Agencies on Aging (AAA) that individually operate local ombudsman programs. At the state level, the program's main responsibility is to maintain the infrastructure for receiving and handling complaints. As depicted in **Figure 2**, the state must understand new and existing legislation pertaining to the LTC ombudsman program and translate it into effective intake, documentation, and resolution systems to handle complaints of abuse. It must also track the effectiveness of the program by compiling statistics of complaints and resolutions and reporting to public agencies.

At the regional level, there are thirteen ombudsman programs that directly investigate complaints and address systemic issues. To gain a better understanding of the roles of the regional ombudsman, we connected with Sheree Head, a Long Term Care Ombudsman Coordinator with the United Way Area Agency on Aging (UWAAA), which oversees the program in Jefferson County. Ms. Head and others on her team respond to complaints and advocate for patients' rights, helping to navigate a myriad of patient-centered resources.

### **AREAS FOR IMPROVEMENT** A. RESIDENT RIGHTS OUTREACH



Many residents in LTC facilities remain unaware of their rights despite the outreach efforts of the county ombudsmen. This may be traced back to there is a lack of sufficient education. This need must be met in order to encourage and empower residents to advocate for themselves. Facilities typically distribute informative pamphlets during intake, but there is no organized process that explains the policies and procedures at these facilities to the residents. This means residents are receiving the information but may very well not be internalizing it because they may not actually look at or remember the materials given. Thus, residents and their families often remain unaware of their rights and the numerous resources that are available to them. Without this vital information, they lack the capacity and power to be effective in bringing up complaints on issues affecting their lives. Furthermore, residents and their families may be unclear on the expectations and roles of LTC facilities in their overall care. With inaccurate expectations, there can be a discrepancy with the reality of the services LTC facilities can provide. Another factor that negatively impacts the ability to advocate is the lack of access to avenues of advocacy. If these resources are not made available to residents, they may not be able to navigate the proper channels to achieve their goals or to improve their livelihoods in these facilities.

### **AREAS FOR IMPROVEMENT** B. FACILITATING SELF-ADVOCACY

Family councils are community-led organizations that often provide an avenue for advocacy for residents and their families. These organizations are typically housed within the LTC facility and are made up of family members of residents who want to make improvements in these facilities. They act in residents' best interests, airing grievances or proposing activities. They discuss policies in the facility and propose changes that may help the residents of those facilities, while simultaneously providing support to the families. Family councils also give new families a space to learn about the resources available to them that they may not have known about otherwise. Such resources include the ombudsman program, the rights and expectations of residents in these facilities, and the reporting process for any abuses they may encounter.

Despite the utility of such councils, they are not active at all locations. Residents don't always have access to the information that allows them to form such programs. When family councils exist, they are reliant upon the families that start them up to remain motivated and active within these groups. Because of turnover, this is not always possible. Furthermore, the establishment of family councils at the LTC facilities can create tension within the facilities due to the potential of policy changes stemming from grievances that are brought up. For these reasons, family councils, though they are useful, may not be known to be an option for residents at LTC facilities.



#### **AREAS FOR IMPROVEMENT** C. STRENTHENING VOLUNTEER PROGRAM

During to the COVID-19 pandemic, the volunteers in Jefferson County are assigned to a single facility and are currently limited to writing letters to residents via the Pen Pal program. The volunteers normally also perform friendly visits, and Jefferson County anticipates beginning a phone-a-resident program as another means of communicating with residents. As such, the program offers volunteers opportunities to build trusting relationships with residents across the county, especially when UWAAA staff themselves are limited to visiting facilities once every couple of months. Through building rapport, volunteers are often entrusted with the experiences and opinions of residents and can better report on the day-to-day workings of a facility while maintaining an active ombudsman presence. They may even receive reports of abuse or neglect, which they may pass on to the regional ombudsmen.

Given the potential utility of volunteers, recruitment needs to be prioritized, especially as pandemic precautions are lifted. Low numbers may dampen the overall impact the volunteer program could have on serving Jefferson County residents. Information for joining the volunteer program is posted in the UWAAA website, directing people to call the 1-800-AGE-LINE hotline, which directs all inquiries relating to the ombudsman program for the state. United Way of Central Alabama maintains a database of volunteer opportunities. However, there are currently no listings that allow people to sign up with the LTC ombudsman program. Additionally, high-traffic volunteer opportunity websites show that the ombudsman program previously had opportunities posted that are no longer available. This may be due to the limited role that volunteers could serve in the pandemic, but as restrictions subside in the coming months, bolstering recruitment online and in-person may serve as a vital way to strengthen the program. Prospective volunteers are required to complete a 2 day training that fully prepares them to take on the role of a trusted confidant among residents in LTC facilities. However, this training could be elevated to train volunteers to take an active role in directing residents and families with minor complaints towards resolving them at the lowest level possible such as family and resident councils. Ombudsman Coordinators often receive complaints they cannot officially investigate but still wish to advocate for better conditions. As mentioned previously, family councils are one of the best ways to lobby for change at the facility level but are highly underutilized. By training volunteers to assist residents and families to build and maintain these councils, they may lessen the burden on the ombudsman program while promoting the selfadvocacy of those receiving long term care.



### **AREAS FOR IMPROVEMENT** D. COMPLAINT INVESTIGATION PROCESS

The ombudsmen program takes complaints through in person quarterly visits to the long term care facilities, through the Alabama Ageline phone hotline, or by contacting the local ombudsman via phone or email. AAA staff then screen the complaint to ensure they have jurisdiction over it and begin the investigation process. This includes contacting the complainant and their family, interviewing facility personnel and witnesses, assembling the facts of the case, and communicating the progress of the case. Once a case has been fully constructed, the complaint may be brought to the long term care provider in writing and resolved, with ongoing monitoring of any changes arising from the resolution.



However, both Ombudsman Coordinators and residents alike face unnecessary layers of complexity on their respective sides of the complaint process, which may keep residents in abusive or neglectful conditions for too long. For instance, Ms. Head noted that the program is sometimes inundated with complaints that the program is not legally allowed to handle. This includes complaints relating to financial exploitation and resident-on-resident violence, both of which fall under the scope of Alabama law enforcement and Alabama Department of Human Resources. Redirecting these cases takes valuable time away from actionable investigations.

#### **AREAS FOR IMPROVEMENT** D. COMPLAINT INVESTIGATION PROCESS

Additionally, once such complaints are transferred to the appropriate agency, Ombudsman Coordinators rarely learn the outcomes of the cases. However, because these cases occur in LTC facilities, the Coordinators need to track the progress and resolutions of the cases so that they may evaluate the quality of the facilities within their jurisdiction.

For residents, it can be unclear when one should file a complaint and how they should do so. Although the ombudsman program maintains a presence in the facilities via quarterly visits and visible posters throughout the facility, complainants may not remember this information. Thus, they may opt to search on the Internet, where residents and their families are greeted with a confusing crossroads on where to submit complaints. Several Alabama agencies offer avenues for submission including the Alabama Department of Public Health and their Elder Care Hotline, Alabama Ageline hotline, and, of course, the websites for the state and regional ombudsman programs. These results are often coupled with many law firms advertising compensation for abuse, which may detract from cases being handled appropriately. Thus, residents' first obstacle is finding the right agency.

Once a resident or a family member finds a regional LTC ombudsman page, there is little information regarding how to file a complaint, what qualifies as a complaint, what the entire reporting process will be if one is filed, and the protections against retaliation if one is filed. There is also not a standardized way of submitting a complaint, as the websites vary from directly contacting the ombudsman program staff to submitting entire case details in an intake form. For the state ombudsman program, there is no contact information available except for the Alabama Ageline hotline. The inconsistent complaint submission process severely weakens the program's online presence, preventing people from submitting valid cases of abuse and neglect.

### **PROPOSED CHANGES** A. INFORMATIONAL WEBINAR

To expand education and selfadvocacy, residents and their families must be informed about the policies, procedures, and opportunities at LTC facilities. Though there can be challenges with effectively delivering this information, the impact of the COVID-19 pandemic has opened up new options in this regard. Creating standardized. an hour-long, informational webinar can aid in disseminating this information. It would be presented live to allow for questions, and a recording would be made available. This webinar can address multiple factors that could lead to improved resident education and advocacy, including the following:



- Roles and responsibilities of LTC facilities
- Overview of the Ombudsman program and its roles and responsibilities
- Resources for residents and their families
- Overview of reporting process and response
- Goals of family councils and how to establish them





#### **PROPOSED CHANGES** A. INFORMATIONAL WEBINAR

The design of such a webinar thus improves resident education and manages family expectations. Furthermore, it explores an option through which resident advocacy can be implemented. Family councils can be essential in allowing residents

and/or their families to promote changes for their welfare, whether that is considering activities or care. Because there is a knowledge gap concerning family councils, this webinar could provide both education and a valuable avenue for residents and their families to achieve change. The specific information about family councils should include the following:

- Roles of family councils
- Structure of these groups
- Process of establishing family councils
- Examples of accomplishments of other family councils in the state
- Logistics (ie meeting time, place, frequency, etc)

Though the webinar will be formally presented quarterly, there may be new residents who enter LTC facilities at a time that does not align well with those presentations. The recordings can provide consistent information but residents and their families would not have the same opportunity to ask questions or raise concerns. To address this consequence, semi-annual town halls can create transparency within the LTC system and permit further opportunities for clarification and information for those seeking it. Ultimately, the format of these webinars maintains the goals of both informing and empowering residents and their families so that they can make the best decisions for their own unique situations.

#### **PROPOSED CHANGES** B. FAMILY COUNCIL INFORMATIONAL MATERIALS

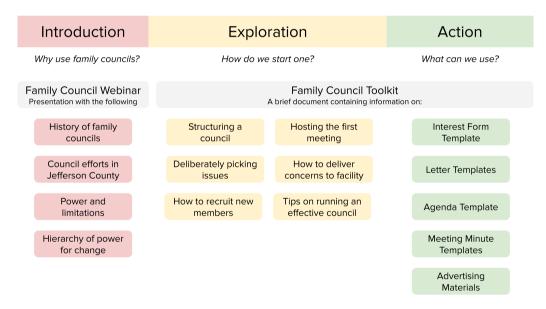
Family councils provide a valuable resource for residents and their families and should be utilized to bridge the gaps seen in long term care. The existing pamphlets on the Ombudsman program and family councils are educational and easy to read; however, an additional flyer should be created to advertise the webinars described above. Because the webinar is recorded, a QR code that accesses the link to the webinar should also be included in the flyer to allow people to peruse it should they wish to do so. An example of a flyer mockup is provided in **Appendix A**. These flyers should be given at intake, left in resident rooms, and passed out by volunteers.

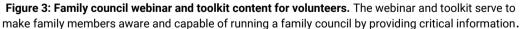
Additionally, posters should hang in areas with high resident and family traffic to advertise the existence of this webinar in a similar way to the pamphlet. Posters should have less comprehensive information but should still elucidate the main points addressed in the webinar. They should offer the opportunity to register for a live virtual option with a Q&A session or to view the pre-recorded version through the QR code. A poster mock up is included in **Appendix B**. These posters should be easily visible in dining areas, activity rooms, front doors, and other areas that residents and their families frequent. In this way, residents and families are exposed to informational materials that could lead them to the webinar, and ultimately, to the creation of family councils.



#### **PROPOSED CHANGES** B. FAMILY COUNCIL INFORMATIONAL MATERIALS

Along with raising awareness of the existence of family councils, the Jefferson County ombudsman program should offer an online toolkit for interested family members to learn to create their own council. Many state LTC ombudsman programs already maintain their own toolkits because they serve as an easily accessible and central resource explaining what it takes to start a council. This toolkit would be a brief document that outlines critical information as outlined in yellow in **Figure 3**. Examples of such a document is provided as **Appendix C**. The very end of the document should include contact information on how to get in touch with a volunteer or an ombudsman to answer any further questions or provide assistance.





The flyers and posters disseminated within long term care facilities and through the program's online presence will serve to raise awareness of family councils as an option to resolve issues at the lowest, and often quickest, level possible. The toolkit further empowers family members to take matters into their own hands with minimal guidance from an ombudsman. Together, these materials will help the ombudsman program broaden advocacy efforts while freeing up resources to address the most pressing issues in the county.

#### **PROPOSED CHANGES** C. VOLUNTEER PROGRAM REVITALIZATION

As pandemic restrictions are lifted, developing a robust volunteer program will provide the manpower to identify critical community issues and advocate for residents' rights. Previous duties of the volunteers such as regular visits with residents should be reinstated when it is safe to do so, and the new phone-afriend program will offer an excellent new way to foster relationships with residents.

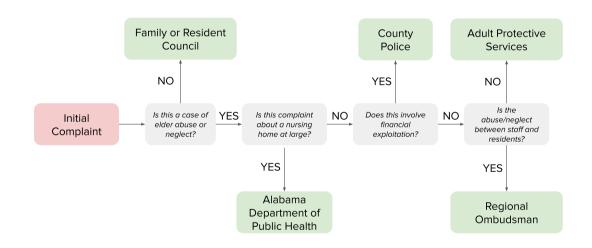
State LTCOP policy also encourages volunteers to support AAA staff with issue advocacy and community outreach. Volunteers with Jefferson County could accomplish this by becoming trained advocates to help raise awareness of family and resident councils as one of the first steps people can take to address issues at the facility level. In order to step into this role, volunteers would first need to be trained to understand the purpose and power of family councils. Volunteers already undergo onboarding training; a specific session focused on family councils could be incorporated into this process. An initial introduction to family councils would parallel the content of the webinar discussed above. Although webinars are excellent for introducing knowledge, volunteers need to become more familiar with the program if they are to act as advocates for establishing these councils. To this end, volunteers should be urged to attend at least one family council meeting occurring within Jefferson County. Volunteers should then be trained how to redirect prospective council members to the toolkit and answer questions that people may have about it.

By broadening the scope of the volunteer program, the demand for volunteers will increase. Thankfully, there are many ways that the AAA staff may recruit across the county. Firstly, the LTCOP should increase its online presence on volunteer recruiting platforms such as United Way's own database and the nonprofit VolunteerMatch. The program would also benefit from advertising its opportunities by partnering with Bham Now, a local news company that often shares opportunities in the Jefferson County region. Finally, the Ombudsman program should leverage its connection with UAB to recruit UAB students, staff, and faculty through BlazerPulse, its own volunteer opportunity database, and by directly recruiting through Pre-Med Advising and in-person tabling events.

#### **PROPOSED CHANGES** D. COMPLAINT PROCESS CENTRALIZATION

As stated above, redirecting cases to the appropriate agency and tracking outcomes of all abuse and neglect cases occurring in long-term care is highly challenging. We also acknowledge that this is an issue that Jefferson County is uniquely able to handle due to Ms. Head's prior connections with DHR and the police force, but this is not the case in other local ombudsman programs. To this end, we recommend some changes at the state level within ADSS and ALTCOP to aid regional ombudsman programs in their efforts.

The ADSS should augment their hotline, 1-800-AGE-LINE, to train responders to properly redirect cases to the appropriate agency based on a standard flowchart of criteria. The preliminary criteria could be as follows (Figure 4):



**Figure 4: Case redirection flowchart.** Training ADSS hotline coordinators to redirect cases to the appropriate agency and logging them into a central case database will help build a comprehensive, statewide picture of abuse and neglect.



#### **PROPOSED CHANGES** D. COMPLAINT PROCESS CENTRALIZATION

Once reports are redirected, though, it is still important for the ombudsman program to know the outcomes of cases such that they may understand what is occurring in long-term care facilities within their jurisdiction. All cases should be registered onto a single database managed by ADSS and updated with case notes as it progresses by having investigators prompted periodically to update the case status. The case status should be labeled according to the stage of the investigation and its final outcome: intake, active investigation, or resolved, and include notes at every stage. The organization or agency that is investigating the case and the AAA region that they fall under should also be on the case listing. If certain facilities or staff members are implicated in a case, this should also be registered under their names. Such a database would also provide useful metrics to ADSS by providing a comprehensive picture on the state of all elder abuse and neglect in the state.

The ALTCOP would also benefit from unifying all of their resources into one comprehensive public-facing website in order to tackle the biggest issues faced by the ombudsman coordinators, residents, and families. The website should prominently feature a way for people to find their local ombudsman by listing the ombudsman coordinators for each Alabama county as well as the ADSS hotline. Then, the website should detail what residents' and family rights are by law and the responsibilities of the ombudsman program. A refined graphic resembling the flowchart in Figure 4 included on the site would help people navigate their way through resolving their issue at the lowest level possible. Support services for residents and families such as the family council webinar and toolkit should be made available. Finally, the site should feature a way for volunteers to sign up directly with their local ombudsman program.

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#### IMPLEMENTATION AND EVALUATION

То effectively implement these solutions. recommend we that UWAAA begin with the solutions that require the least manpower. This proposal has been structured such that the easiest solutions are provided first. For the family council webinar, a brief presentation and script for key points should be prepared, an annual schedule for when the quarterly

webinars will occur should be established, and the webinar and the schedule should be advertised heavily via any United Way social media and by ombudsmen when visiting facilities. Similarly, the family council informational materials and toolkit will primarily require a large upfront effort to design the materials, but once they are designed, ombudsmen and volunteers can together disseminate these materials easily,

Revitalizing the volunteer program and the statewide changes of case investigation and ombudsman program information centralization are more ambitious projects and will require more time. The current training curriculum should be modified to reflect this new focus on family councils gradually as the county becomes more equipped to handle a larger volunteer force. Statewide change for the case database and website would likely require the support of multiple counties; as such, the interest of other counties and of the state ombudsman should be gauged before proceeding further. If there is interest, drafts of designs should be made in conjunction with a web developer as well as research into what residents and families would find most useful.

Ultimately, the goal of all of these proposed solutions are to raise awareness of how to self-advocate and resolve issues in the most efficient manner possible. The best metrics for evaluating interest in family councils are to track the number of new family councils

#### **IMPLEMENTATION AND EVALUATION**

that are created and the membership within all family councils across the county. To measure the effectiveness of these councils, interviews should be conducted with committees from the family councils to understand what issues they have been addressing and what changes, if any, have come from speaking with the facilities. Views on the family council webinar can also gauge interest within the county. Post-webinar surveys can assess the value of the webinar's content and explore what other information families and residents request.

The volunteer program could be evaluated by tracking the number of volunteers and the average duration of service, and the amount of referrals made to the family council materials. Volunteer satisfaction should also be measured by organizing conversations to assess whether they feel they are making an impact and what further support they could need. This can be quantified with satisfaction surveys on a semi-annual basis. Finally, the database and website are potentially a wealth of data. Website traffic shows the reach of the ombudsman program. Case numbers and types could assess the state of abuse and neglect both holistically and at the facility level, and changes over time offer insight into how facilities may be improving.

## CONCLUSION

The Health Policy Ambassadors of UAB are grateful for the opportunity to learn from and to assist the efforts of the United Way Area Agency on Aging. The sheer work Ombudsman the Program Coordinators accomplish to serve residents in facilities across the county is both impressive and vital to preserving Alabamians' health and safety. Through our conversations, we have identified key issues and were inspired to create varied solutions that the Coordinators could choose to implement. It is our hope that these may ignite new greater resident and family autonomy in issue advocacy and relieve some of the challenges Coordinators face throughout the complaint process.

#### **THANK YOU!**

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## **APPENDIX A**



## **APPENDIX B**



## APPENDICES C & D

Please visit the link to see an example of a toolkit.

<u>Please visit this like to see an example of a centralized ombudsman website.</u>